

1 *What the social and behavioural studies say about dying*

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In the popular mind, the serious study of the dying experience is often traced to Elizabeth Kübler-Ross's best-selling work *On Death and Dying* (1969). Nevertheless, important academic work by sociologists Barney Glaser, Anselm Strauss, Renee Fox, or physician John Hinton among others, had in fact pioneered this field well before the appearance of the best-selling psychiatrist. Although the study of dying is very much a post-1945 research development with important theoretical and empirical gains made in the 1960s, the field has continued to struggle to attract researchers over the years.

Certainly the growing concerns over aged care and hospice care have brought their share of interest in the dying experience but much of the research effort has focused on carers' experiences and views, social, psychological or medical problems of dying, and health service delivery issues. Specific research on dying as a particular form of social life and experience that goes beyond, yet providing context to illness and its associations, receives far less attention even today. Yet that wider experience is important to understand.

Assumptions or implicitly held views about dying drive diverse policies and lobbies about care – from euthanasia, hospice and palliative care to other policies about aged care or the legal or medical determination of death. These assumptions are also commonly the basis of other profession-based theories about the limits to counselling, psychotherapy or spiritual and pastoral interventions. Many of our assumptions about the dying experience are just that – common assumptions characterized by little empirical support. Other assumptions are actually derived empirically but from highly selective sources and traditions of social literature about the dying experience. The aim of this opening chapter is to critically review the major literature studying dying conduct and to identify and make explicit their different theoretical insights, limitations and future possibilities.

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I believe that it is self-evidently important that clinicians, academics and policy-makers are explicit about the model of dying that is at the centre of their particular advocacy, course of action or arguments. To date, most literature from these occupational areas has *not* demonstrated this kind of frankness, leading some to believe that a certain consensus exists about the social experience of dying. As I will argue in this review, no such consensus about the dying experience exists.

The review is organized around seven themes that directly emerge from the empirical literature on dying behaviour. I characterize them according to their theoretical emphasis and do not for a moment argue that they are immune from overlap or social complexity, often rehearsed even by the authors themselves. I acknowledge that dying from cancer, or elderly dying in nursing homes, is mediated by social determinants such as gender, class or education for example. Dying behaviour often reflects the different lifestyles and values of the person at the centre of that conduct. The elderly for example, like all dying people, are not a homogenous group (Wass et al. 1978–9; Mearns 1981). Notwithstanding these qualifications, a systematic review of the literature about dying conduct nonetheless suggests seven reoccurring insights. These consist of theories about dying as agency, linearity, oscillation, disengagement, disintegration, disenfranchisement and transformation.

The theme of agency: dying as personal control

By far the most common view of dying is that dying people are in control of their fate, that they are active players in the last scenes of their lives. This is a major theme in the literature on suicide, making explicit the role of agency in determining not only the mode of dying but also its timing (Durkheim 1952; Alvarez 1970; Sagan 1987). Suicidal behaviour appears to be strongly associated with the aged and particularly with social influences such as modernization (Makinen 2002), affluence (Andersson and Moniruzzaman 2004), individualism (Sourvinou-Inwood 1981) and social fragmentation, dependency and alienation (Seale and Addington-Hall 1994, 1995). But studies of illness dying display no less emphasis on personal control than do studies of suicide.

In terminal illness, the most common phrase disguising the idea of agency is the ‘good death’, a signature term that describes a series

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of individual actions that portrays dying persons as controllers of their affairs. As Houlbrooke (1998: 184–219) describes it for many Europeans: on feeling that one will die soon one makes a will, dividing the estate fairly, making some provision for the poor, accepts visits from priests and doctors, says one's prayers and goodbyes and dies surrounded by friends and family at home and in bed. Such descriptions of the good death are replete in the literature from early Europe (Sussman et al. 1970; Boase 1972; Souvinou-Inwood 1981; McManners 1985; Jalland 1996), in European populations of more recent times (Fox 1959; Hinton 1967; Kalish 1970; Saum 1975; Jaffe and Jaffe 1977; Kastenbaum 1979; Marshall 1980; Kellehear 1990; Young and Cullen 1996; McNamara 2001; Kaufman 2005) and in some non-European populations (Counts 1976; Lifton 1979).

Away from studies that have emphasized preparations initiated by the dying are other studies also emphasizing the control exerted by the dying but referring to their abilities to maintain identity (Matthews 1976, 1979). Planning for their demise, informal willing, organizing others for a life beyond the dying person's lifespan and card-carrying with medical and social information are illustrations of this identity maintenance, particularly by older women. Active negotiations with physicians and other healthcare workers, the use of advanced directives or the pursuit of advanced technological interventions are also well-described signs of agency and control while dying (Kaufman 2005). Other researchers emphasize the more informal ability of the dying to conduct 'impression management' to manipulate medical and nursing staff to gain favours, attention or maintain positive relationships with hospital staff (Weisman and Hackett 1965; Watson 1976; Hinton 1971).

Sometimes, dying people are viewed as active contributors to the social and even physical life of others as they volunteer for experimental medical research that will not necessarily benefit them but others who come after them (Fox 1959; Parsons et al. 1974). Even physical stamina and control are emphasized by some studies. The physician Witzel (1975), in his medical investigation of 360 dying people, for example, emphasizes how the majority of the dying maintain their consciousness and social relations until quite late in the course of their dying.

Agency theories of dying commonly portray dying people as individuals in control of their destiny. Most of the empirical support

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for this idea usually comes from historical studies of dying among the middle classes – whether from Souvinou-Inwood’s aristocratic descriptions of dying in Ancient Greece, McManner’s study in the Enlightenment, or Jalland’s study in the Victorian period (although, see Young and Cullen 1996, and Strange 2005, for important exceptions). In any case, contemporary social studies of people dying in modern hospitals are portraits of dying under modern healthcare and are therefore consistently reports of dying from degenerative diseases associated with affluence and long life expectancy – cancer, heart disease or neurological decline such as motor neuron disease or dementia. Whether these are medical studies from authors such as Hinton or Witzel, or sociological studies from authors such as Fox, Glaser and Strauss, or Seale, the overwhelming majority of the empirical support for this image of dying comes from regional circumstances of comparative affluence. These are also the backgrounds of most of the writers and researchers, and this may also partly explain the descriptive bias or selective vision in much of the narrative from these studies and commentary.

Nevertheless, studies of dying that emphasize control tell us how the dying reciprocate their social obligations in life right to the very end. Dying people prepare for death often by getting their social and legal affairs in order before they die. They use professional people such as priests, lawyers or doctors to help ease their passage. The deliberations of these dying people reinforce and reproduce the ideological interests of the day – they do not ignore a lifetime’s investment in work, family or religion. Rather, dying people reinforce their importance to themselves and their networks by affirming their relevance right up to the very end of life. Theories of agency locate these activities, obligations and responsibilities in a dying person who is usually conscious enough and has time enough to execute them.

The theme of linearity: dying as a journey

Among anthropologists and sociologists, the idea of dying as a journey is an old one that can be traced to an early study by Van Gennep (1969). Van Gennep’s classic work on the rites that people undergo during the life course is one of the earliest works to highlight the fact that the life course is not biologically determined but rather socially constructed by the community. Puberty rites, for example, are not

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based on the physical appearance of sexual maturity but on a desire to separate initiates from the asexual world and to integrate them into the sexual one. The criteria for initiation are often based on a diversity of social determinants, age or gender for example. Van Gennep theorizes that individuals in the community underwent a series of rites that both separated them from some experiences and groups (children, single adults or warriors, for example) and incorporated them into others (adulthood, married people or as elders, for example). These rites were characterized as rites of separation, transition or liminality, and incorporation.

In the original work, Van Gennep devotes only one chapter (Chapter 8) to death, and most of that chapter addresses funerals. Van Gennep (1969: 146) notes that in matters to do with death, rites of transition and incorporation dominated. He fails to realize that a principal reason why rites of separation appeared to be less apparent may have to do with the fact that most of these probably occur during dying itself. In the 1960s, sociologists Glaser and Strauss took it upon themselves to conduct these observations of dying as a 'trajectory' (1968: 6) or 'status passage' (1971: 8). These phrases were based on Glaser and Strauss's view of hospital dying as a journey that involved family and hospital staff making a time-related series of assessments about the dying person's behaviour during their final illness.

Assessment of the dying person's physical and psychological decline, the occasional reversibility of that decline, or the duration and pace of that decline, among other factors, were important to chart for family and staff because these indicated what each party should do in relation to dying. Dying became a process and series of 'critical junctures' that others could employ to help them determine what to do next. In other words, viewing dying as a narrow passageway that leads individuals from 'living person' to 'dead person' was an important social device for care management by family and healthcare staff. In this way, theorizing dying as linearity – moving from point 'A' to end-point 'Z' becomes an interactive assessment by carers to note aspects of dying that were important *to them rather than the dying person*. In this way, the concept of status passage inherits its community concerns and priorities from the earlier anthropological idea of rite of passage.

We see this continuing obsession with the idea of living and dying as journeys because they always serve the same community functions – when is the right time to leave, go elsewhere or become something

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else? What are the ‘signs’ that we or they should look for in making the decision or decisions about what to do *next* (Gustafson 1972; Lofland 1978; Pollack 1980; and recently Small et al. 2007)? In psychiatry, we have witnessed the staging process of this journey described in emotional terms – people feel certain emotions at different stages of the dying process. These emotions can act as points of orientation for carers to know where the dying person is in the overall process of dying (Kübler-Ross 1969, 1974; Germain 1980). Such stage theories – both social and psychological – have led to the observation that the way people are expected to die and the way they actually do die are commonly divergent (Weisman 1972: 148). If theories of dying that emphasize control represent selective vision of the observers, theories of dying as linearity commonly represent vested interests of carers no less. The dying experience is filtered to the extent that it can, or cannot, tell carers what to do next. Going beyond this criterion is a road less travelled by researchers.

The theme of fluctuation: dying as oscillation

Once the literature on dying moves away from the hospital setting and particularly from an epidemiology of cancer dying towards dying in old age, the picture of dying grows unsteady. Although there is some debate about the association between increased life expectancy and increased quality of life, it is apparent that the prevalence of acute and chronic illness remains related to social determinants (Crimmins 2004: 81). That picture of chronic illness in old age makes the parallel picture of dying in old age an equally fluctuating one (Moss et al. 2003: 160; Lunney et al. 2003).

The pattern of terminal decline in the elderly is one characterized by cycles of health and illness, decline and improvement. Despite the fact that most people who develop cancer are over the age of fifty, most people over that age don’t actually die of cancer (Hall et al. 2002). The majority of the aged die of other chronic conditions such as dementia, heart disease, diabetes or chronic obstructive airway diseases (Moss et al. 2003: 160). The actual cause of death for many of these people is organ failure (kidney, liver or heart) or ‘frailty’ (Lunney et al. 2003). In a major study of 4,000 people over the age of sixty-five, Lunney et al. (2003) found that people with organ failure had a ‘fluctuating’ pattern of dying with cycles of disability and

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improvement. Those with ‘frailty’ experienced poor function over the whole year and were more inclined to have shorter periods of improvement and longer periods of obvious decline.

In both styles of dying, the determination of ‘dying’ is difficult and unpredictable (Lloyd 2004: 238). For aged care staff in nursing homes and other related facilities there is reportedly great ambiguity and conflict over how ‘dying’ is defined let alone identified (Sidell and Komaromy 2003: 51–2). But ageing is not the only form of dying that exhibits a frequent oscillation between decline and improvement. HIV/AIDS also exhibits these kinds of fluctuations. The emergence of effective antivirals to manage but not cure HIV makes the identification of ‘dying’ in this population also extremely difficult and complex. The theories about dying as fluctuation, when combined with the epidemiology of ageing, makes this particular style of dying no small matter. AIDS now affects 40 million people worldwide with some 25 million people already dead from the virus (WHO 2005). The life expectancy of someone with HIV – from first contracting the virus to its progression to AIDS – is approximately ten years (Fleming 2004). Like growing old then, the awareness of dying is gradual, mediated by bouts of serious, increasing but episodic illness and disability.

In theory, the idea of dying as oscillation is able to accommodate a complementary notion of agency, and sometimes it is highly apparent that, in the case of professional people with HIV/AIDS in affluent contexts, they actually are able to display this element of control. In reality, however, most people with HIV/AIDS live and die in poverty in the developing nations of the world, especially in Africa. Consequently, both life and death for people in these economic situations do not exhibit great degrees of agency. For people dying in poverty from malaria or tuberculosis, the presence of control is possible as a traditional partnership exercised with family and community. But the stigma and shame of AIDS dying often leaves such dying people with much less support (Takahashi 1998; Songwathana and Manderson 2001; Liddell et al. 2005).

In the case of the elderly, particularly the large group of elderly in nursing homes and those suffering from dementia, the idea of personal agency soon disappears under the weight of institutionalization and the social consequences of custodial care (Kitwood 1993; Giacalone 2001). However, Small et al. (2007) argue that the idea of journey and agency may not disappear entirely because the

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theoretical debates and empirical investigations about the fate of self in dementia remains contentious and inconclusive (see Small et al. 2007: 120–7).

It is also possible to integrate the idea of ‘dying as journey’ into this current idea of ‘dying as oscillation’ but usually only retrospectively since the so-called journey of ageing and dying is poorly recognized in care institutions (Mackinley 2005), clinical diagnoses (Sullivan 2002; Page and Komaromy 2005) or sometimes even by the aged themselves (Bytheway 1995). In this conceptual way, theories of dying as fluctuation are distinct from those about agency or journey because they represent a style of dying very much shaped and distorted by multiple disease causation, economic marginality and stigma. It may be that the so-called fluctuating or oscillating experience of dying is in fact a direct reflection of the ambivalence of a wider culture towards public displays of economic, aesthetic and bodily decay.

Whatever the relationship between the wider culture and the dying, it is also true that dying, from the point of view of these studies, is not a continuous physical, psychological or social journey with one overall sense of identity or purpose. Dying, as an identity and as a physical experience, is not always an uninterrupted trajectory of decline. Dying can be, and is often, an intermittent experience determined by the disease process and the social roles and circumstances that prevail in end-of-life situations.

The theme of disengagement: dying as withdrawal

When dying people steadily decline, noticeably and incrementally, sometimes in ageing or in the last few days or hours of life, this process is often characterized as a form of disengagement. These dying people are described by others as withdrawing their attentions from the affairs of the wider world, including family and self-care, appearing to surrender to tiredness, weakness or dependency in general. These theories of disengagement were originally developed to account for patterns of withdrawal by the aged (Cumming and Henry 1961; Damianopoulos 1961), but they have subsequently been incorporated into the more broadly applied idea of ‘social death’ (Sudnow 1967; Kalish 1968, 1972; Humphries 1981).

Fulton (1977) includes family in his idea of ‘disengagement’, arguing that as families disengage from their dying, hospital staff tend

to increasingly engage themselves with the dying either in stepping up their watchfulness over the declining days or hours or in their nursing attentions in the final hours. Kalish (1968, 1972) argues that disengagement is a valid description of what actually happens to many dying people because many of them are simply too old or sick to desire their usual engagement. He argues, as indeed do Cumming and Henry, that activity is *not* the opposite of disengagement but rather engagement. The old and dying may still be active, but this may not represent genuine social or emotional engagement on their part.

Of course, the problem with this view, as with many psychodynamic interpretations of other people's behaviour, is that we cannot easily distinguish between speculation about active conduct that represents 'engagement' and other so-called active conduct that disguises 'disengagement'. In practical terms, this means that we have no idea what proportion of active dying people are 'really' disengaged because they are indistinguishable from other active 'engaged' people.

Other defenders of disengagement theories have argued that disengagement may well be an appropriate response to a cohort or group experience (Marshall 1975). In other words, when everyone is getting married or getting their first jobs there is a widespread feeling that things are 'right' and 'appropriate' for that time of life. In just this way, Marshall (1975: 1140) argues that many residents in nursing homes and aged care facilities feel that dying is an appropriate part of their lives since most of them will share the same fate. This social process of 'legitimation' permits their withdrawal to be viewed as a supported, understood and even a learned response to declining health or severe illness (Blauner 1966: 383). But there have been other less accommodating critics of disengagement theories.

Scoggins (1971) and Hochschild (1975), for example, believe that disengagement is a response to society withdrawing from their sick and elderly. Disengagement theories ignore the social determinants for health (age, sex, class, etc.) that may also apply to other social experiences such as withdrawal. Disengagement may also not be disengagement but re-engagement with other activities, values or concerns. Disengagement may be a superficial and misleading ascription to major changes from one part of life (working, grandparenting, for instance) to another part of one's life more adaptive to frailty (gardening, reading, increased television viewing, as examples).

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Scoggins is particularly critical of disengagement theories, challenging the assumption that withdrawal is both inevitable and satisfying for the dying and their network. Scoggins (1971: 143) argues that the elderly in particular are being rejected as non-functional, inefficient and ugly, and ‘retirement’ is society’s permission to ‘disengage’. Disengagement may be a response to social rejection and segregation (see also Hockey and James 1993).

However, it is difficult to distinguish here the criticism about social response to ageing, by both the aged and the wider society, and what actually happens when people are near death – at any age. Hochschild (1975: 559), a critic of disengagement theories for the aged, readily admits that for dying people, ‘distance from death ... was the one most conducive to social and economic disengagement of a mutual (me–them) kind’. In the context of the current review, it may be no coincidence that the language and ideas of ‘disengagement’, ‘withdrawal’ or ‘surrender’ have been greeted with suspicion, criticism and even rejection over more readily received and preferred notions of dying as ‘agency’ and ‘personal control’.

We cannot fairly separate that critical response from its possible sociological basis. Philosophically and methodologically, we must accept that all studies of dying come from researchers and carers who enjoy basic levels of health, and not from the dying themselves. Furthermore, most of these studies are conducted by members of the Western middle classes – a culture famous for its anxious attachments to personal control and individual autonomy (Lasch 1980; Vidich 1995). A certain degree of withdrawal as a response to serious illness should come as no surprise to anyone, but the ambivalent academic response to that reality makes a balanced assessment of its social conditions contentious. This too should come as no surprise given the cultural character of the research leadership into dying over the past half-century.

From theories of disengagement, we learn that dying may not only be a slow withdrawal of bodily energies but also a slow withdrawal of social engagement and interest as well. Even in societies or personal situations where dying receives optimum support, few dying people can sustain – or seem even to desire to sustain – an active social involvement to their last breath. At some point in the dying process there often comes a time when it is important for the dying person to