Contributions of Qualitative Research

There's More to Dying than Death: Qualitative Research on the End-of-Life

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Since human death is often regarded as one of the most individual and biological events, the broad field of death and dying forms a counterintuitive – and therefore attractive – case to establish the intellectual legitimacy of social science generally and qualitative health research in particular. Emile Durkheim (1979) argued that every society produces its own suicide rate dependent on how people are integrated and regulated to establish that the seemingly isolated fact of taking one's life has deep societal origins that could be discovered. More recently, several scholars have tested the obduracy of their theories with society's attitudes towards death and dying in times of war and peace.

Qualitative research also aspired to acquire formal legitimacy through an ambitious study of death and dying. In 1958, researchers declared the study of death and dying neglected and barren, but this situation changed in the early 1960s when Anselm Strauss and Barney Glaser (1970) conducted a study of interactions between dying patients and health care providers in six San Francisco Bay area hospitals. The study was groundbreaking for substantive and methodological reasons. Especially, the notion of awareness contexts captured the zeitgeist that institutionalized dying led to widespread alienation and isolation. At a time where patients received euphemisms, embellishments, or lies about the severity or exact

nature of their diagnosis and prognosis, Glaser and Strauss (1965) documented that terminally ill patients often went to great lengths to figure out their status to be confronted by a wall of silence of health care providers and complicit family members. Their analysis, along with Kübler-Ross (1969) influential writings on the five stages of grief, galvanized a social movement aimed at humanizing contemporary dying that took the form of various hospice and palliative care initiatives. Besides crystallizing late modern unease with the medicalization of the dying process, the books *Awareness of Dying*, *Time for Dying*, and the case-study *Anguish* foreshadowed the emergence of the influential labelling theory, produced a collection of concepts that became part of the intellectual canon, prompted change in how terminal patients were informed about the prognosis of their disease, and constituted a prime example of the application of a systematic qualitative methodology.

In conjunction with their study of dying in hospitals, Strauss and Glaser wrote a methodological manifesto that articulated the principles of grounded theory as a general approach to conducting qualitative research in a period where quantitative research took centre stage, much theorizing was not grounded in empirical research, and some qualitative research lacked clearly defined standards. They proposed that sociologists build theory from the ground up through systematic conceptualization and constant comparisons with similar and distinct research areas. Theories grounded in substantive areas could then lead, through further abstraction, to formal theories of social life. In the heydays of Parsonian and Mertonian functionalist theorizing, the boom in social survey research, and C. Wright Mill's empirically weak writings, the book became a research standard; in the traditional sense of a powerful rallying point for an alternative social science.

Thus, also for qualitative research the area of death and dying formed a dare: if Strauss and Glaser could refine qualitative methodology in what looked at first sight a hostile domain, then they had proven the method's merits beyond doubt. Once launched in the area of death and dying, grounded theory became established as a generic qualitative research methodology with an especially strong presence in health research (see Bryant and Charmaz, 2007). At the same time, a full range of qualitative methods from discourse analysis, historical research, focus group research, in-depth interviewing, and especially ethnography dominated the study of death and dying for the next decades.

In the remainder of this chapter, I will review the rich qualitative studies of institutionalized dying since Strauss and Glaser, focusing on the medical staff's management of lingering, slow dying trajectories and on the much smaller literature of managing unexpected death and explaining suspicious and violent death. I will also sketch a research agenda that explores the forms of contemporary death and dying that are rarely qualitatively investigated, in part because of the focus on studying institutions, expected deaths, and using qualitative methods. First, I will explain why death and dying forms such a good match with qualitative research methods. I argue that this has less to do with Strauss and Glaser's foray in this field than with the broader cultural consensus about what is wrong with contemporary dying.

THE FIT BETWEEN QUALITATIVE RESEARCH AND DEATH AND DYING

Did Strauss and Glaser (1970) initiate a decade – long research tradition of studying death qualitatively or were they also products of their time? Strauss and Glaser's prolific endeavours constitute the most explicit linkage between qualitative methods and the field of death and dying and they are often regarded as founders of this field. Yet, while they were doing their study, other social scientists also employed qualitative methods to study dying in hospitals and the topic was on the mind of many others in ways that made qualitative methods a good fit. Strauss and Glaser may thus have reflected the spirits of the times rather than initiated the research of decades to come. Indeed, the original merger of qualitative research and the topic of death and dying may be less a consequence of the pioneering study of Strauss and Glaser than the result of what can be called a broad post-Second World War humanist focus of the death and dying scholarship.

Influential philosophers, psychoanalyst, historians, and social scientists have argued that mortality forms the ultimate limit in modern societies, because it constitutes the defeat of reason, since reason cannot conceive of the reality of death and conquer mortality. Elias (1985) summarizes, 'it is not actually death, but the knowledge of death, that creates problems for human beings'. Mortality awareness conjures an existential ambivalence in individual and social life generating defence mechanisms. In premodern Europe, Aries (1977) situated a 'tamed death' as cultural coping mechanism; death was tame in the European Middle Ages not because of domestication but because it 'was never wild before'. Death simply *was*, it could be bewailed or regretted but not manipulated. In this fatalistic perspective, the 'dance macabre' gripped rich and poor, young and old alike; religious authorities explained death as a predetermined egalitarian part of cruel human fate. In the wake of the philosophy of Enlightenment with its emphasis on mastery of nature and contingency, life expectancy might have increased but mortality remained ultimately indifferent to instrumental human efforts. A medical, legal, and – later – therapeutic ethos gradually replaced religion as moral authority. In the realm of death and dying medicine prevailed.

While questioning the inevitability of death, modernity added anguish to it: security of small victories over some acute, devastating diseases enhanced insecurity in light of the ultimate demise. One much publicized reaction in modern societies to this frontier of reason is *seclusion and professional management*: hide death in institutions, disavowing its existence through spatial and social segregation under supervision of medically trained experts. Secondly, while mortality itself cannot be avoided, individual *causes of death* can be *determined*, and then manipulated and postponed. Bauman (1992) characterizes this frantic search for pertinent causes while losing sight of the ultimate futility of the endeavour as the 'analytical deconstruction' of mortality in which 'fighting the causes of dying turns into the meaning of life'. Mortality was deconstructed in autopsies to be tabulated in public health instruments such as the International Classification of Disease, which in turn form the basis of epidemiological health policies.

The result of those twin modern death brokering strategies is simultaneously a professionalization of the dying process and an 'excessive preoccupation with the risk of death' in daily life leading to a society organized around risk.

The broad consensus in intellectual circles that modernity gave rise to a frantic search to postpone death and ignore the dying formed a good fit for qualitative research explorations. Health scientists became interested in how exactly death was managed in institutions and what alternatives were possible. The research agenda of much of the past four decades was to retrieve the experience of death and dying and taking care of the terminally ill in hospitals and nursing homes. When hospices materialized, health scientists studied how these new institutions fulfilled their missions to break the mould of institutionalized dying. These experiences were not only difficult to capture in surveys but also the notion of standardized research instruments went against the grain of the broader focus on retrieving socially contextualized experiences. In addition, the concentration of the dying and their caregivers in institutions made observations and in-depth interviews logistically feasible. Consequently, death and dying is a rare research area in medicine where qualitative studies are well established.

QUALITATIVE STUDIES OF DEATH AND DYING

In Western societies, about 75 percent of people die in institutions, mainly hospitals and nursing homes. The proportion of people dying in the United States from chronic illnesses in acute care hospitals has been declining between 1989 and 2001 from 62.3 percent to 49.5 percent. Over that same period, the percentage of deaths in nursing homes increased from 19.2 percent to 23.2 percent, and the percentage of people dying at a place they considered home increased from 15.9 percent to 23.4 percent.[1] People who die suddenly may paradoxically also die in hospitals, even if they collapse in public places or at home: when bystanders or relatives alert emergency services patients will be transported to emergency departments where the death will be verified and certified. Deaths thus are centralized in institutions for diverse reasons.

Concentrating their research efforts in these places where deaths occur, social and health scientists have been struck by how health professionals work towards ideals of culturally appropriate dying but often fall short of achieving humanistic deaths. In an earlier review of the literature on which the following section is based, I distinguished several of the iterations of culturally appropriate deaths: death without dying, natural deaths, resuscitated deaths, and good deaths.[2]

The deaths without dying occur when patients have been kept in, what Strauss and Glaser called 'closed awareness'. Patients remain uninformed about the seriousness of their diagnosis and prognosis. This situation is less common in the United States as it was in the sixties, but it still occurs regularly in countries with a more paternalistic medical profession such as Italy, Belgium, or Israel. In the United States, 'bad news' is now routinely communicated to terminal patients,

giving rise to the opposite situation of 'truth dumping', where a clinician informs patients and relatives of the worst-case scenario but offers little follow-up on how this information has been processed. Patients are more likely to be kept in the dark of their pending death if they die from non-oncological conditions. If such a patient dies, the staff may not be surprised, but relatives may be shocked. This death still corresponds to the ideal of slipping away in one's sleep. Anspach and Kaufman have documented that these deaths may occur for organizational reasons, because a consensus among health care providers is only necessary to withdraw or withhold care; as long as at least one key member of the medical team wants to continue with therapy, the treatment paradigm will prevail. Health care providers may also be reluctant to breach a terminal prognosis, because they fear creating a self-fulfilling prophecy.

In her recent study of dying in hospitals using ethnographic methods, anthropologist Sharon Kaufman (2005) noted that 'what is natural is negotiable'. She and others have found that 'natural deaths' are tightly scripted and organized in hospital settings, especially intensive care units where between 15 and 35 percent of hospital deaths occur. The staff actively harnesses drugs and medical technologies to mimic a gradually declining 'natural' dying trajectory by a piecemeal withdrawal of therapies. Because most patients are comatose in intensive care units and admittance signifies life-threatening conditions, there is little emphasis on the patients' death acceptance. Still, assent of relatives to withdraw and withhold care is crucial in US intensive care units where relatives have legally supported proxy decision making powers and the actual time and manner of death is often determined in difficult ethics conferences between clinicians and relatives. The staff's 'orchestration' of the death as an inevitable transitory process with a measured balance of action and nonaction involves matching their interventions with the expectations of relatives, including actively shaping those expectations when relatives are 'unrealistic', showering them with technical information, presenting ready-made decisions, relieving guilt feelings, and 'psychologizing' them when they resist staff. Staff also invites relatives to be present at the moment of active dying, quietly say their goodbyes, and keep physical contact. In addition, the staff's decisions to withdraw care are measured in such a way that they obliterate the impression that the staff 'killed' the patient but that the death was preordained by the terminal disease, lowering the possibility of litigation.

The specific meaning of sudden unexpected deaths is now offered by resuscitation techniques, turning a sudden death into a stretched standardized dying process, leading to the paradoxical situation of the resuscitated death. In light of the remarkably low survival rates of resuscitative efforts inside and outside hospitals, several social observers have noted that resuscitation procedures soften the abruptness of sudden death. With relatives waiting in separate counselling rooms, physicians 'stage' information, gradually informing relatives about the worsening situation, occasionally even stretching the reviving effort to facilitate informing relatives or running 'slow codes' to give the impression that life-saving

efforts took place even if the staff did not believe in them. In some hospitals, relatives are invited to attend the tail end of the reviving effort and say their good-byes. The emphasis on restoring ventilation and circulation during resuscitative efforts frames the sudden death as a cardiac failure, offering a readymade 'cause' of death. Because resuscitative efforts ultimately aim to save lives, the ideal of the resuscitated death reassures relatives and clinicians that the death was pain-less, unpreventable, and quick with everything medically possible done. Research also shows that advance directives are not always able to stop the resuscitative momentum, particularly when clinicians see an opportunity for successful treat-ment. Relatives seem to have residual impact when care providers have determined that too much uncertainty prevents a clear medical course of action.

The hospice and palliative care movement reacted to the alienating image of technology mediated hospital deaths. Critics of modern dying remained divided whether the site of dying, the technologies surrounding death, or a combination of both were the fundamental cause of dehumanization. Hospice care and palliative care advocates did not necessarily renounce institutional settings or technolo-gies, but they aimed to develop a care setting focused on holistic terminal care, including the spiritual, religious and social needs of the dying. Many social observers have noted that during the past decades hospice has lost its alternative, holistic edge with institutionalization while hospice workers have 'routinized' the good death into 'a socially approved form of dying and death with powerfully prescribed and normalized behaviors and choices'. Hospice care has been insti-tutionalized around the highly specific 'ideology' of the 'good' death. The good death involves aggressive symptom management, and attention to the religious, social, psychological needs of the dying and their loved ones to achieve the nor-mative goal of accepting impending death. As such, the good death constitutes a historical continuation of the *Ars Moriendi* that links the devastation of the Black Death in the Middle Ages to the mass casualties of the Civil War period into the present.

As with the ideal of the natural death, staffs negotiate the 'good' death through active management of both the physical condition of the patient and the actions and expectations of the dying and their relatives. Hospice workers aggressively treat thirst, bed sores, constipation, and pain – even if the pain management with morphine might depress breathing (the 'double effect') – in order to keep the dying patient comfortable, but draw the line at curative interventions, including prescribing antibiotics for infections. While some critics have charged that pain management has overshadowed the psychodynamic and religious acceptance of death, relatives and the dying patient still have to 'assent' to the ideology of hos-pice care aimed at a particular kind of good death. Thus, for example, while hospice workers might take pride in facilitating the smoking habit of a dying patient, relatives are instructed not to call an ambulance in a crisis and possibly negating the cost savings of hospice care. Even the sequence of saying goodbyes is optimized in hospice care. When the stage of active dying or 'death watch' occurs, the hospice worker takes the relatives in to say their goodbyes, and leaves

the dying person with a close 'confidant'. With such tight management of expectations and dying trajectories, patients might request to die but hospice care workers, largely for religious reasons, oppose hastening death. Instead, hospice workers offer comfort care as the alternative to assisted suicide. Yet some patients might not respond to such care.

Contemporary institutional death management involves attending to the physiological aspects of dying with medical technologies in order to preserve life, to allow dying to occur uninterruptedly, or to hasten death but without being held accountable for the actual death. Most qualitative research has reiterated how medical personnel do not simply take their clues from relatives but manage the expectations of relatives and patients in an attempt to align them with a medically acceptable notion of dying, even if this involves not informing relatives to avoid giving up 'hope'. Dying ideals depend on the anticipation of the death, the length of dying, the disease process, available resources, and to a limited extent on the activism of relatives. The contemporary normative ideals fuelling the actions of medical experts are aimed at rendering dying meaningful for an intimate social network of relatives and care providers without disturbing institutional routines.

Social and health scientists have detailed how the staff often fails to obtain an ideal death. Among the barriers are staff-related factors such as opposing opinions among clinicians, diagnostic and prognostic uncertainty and ambivalence, staff shortages, staff apathy, diverse staff cultures, and medical errors. Other barriers include patients refusing to die, wanting to die, or dying too quickly, relatives abandoning the dying or refusing to let go, and divided families or relatives intending to speed up dying. Finally, researchers noted budget cuts, failing technologies, apparently divine interventions, lack of resources, and other unforeseen contingencies. The deaths that clearly deviate from the ideals might provoke anger, embarrassment, expense, suspicions of medical error and iatrogenics, and possible litigation if the relatives feel wronged. If relatives disengage, the staff might get away with an approximation of acceptable deaths.

EXPLAINING DEATH AND IMMORTALITY

Besides institutionalized dying, the other emphasis in modern societies is the push to explain death in order to avoid premature death and extend the lifecourse. Here, among the domains of action of interest to qualitative social and health scientists are deducing causes of death through autopsies, organ and tissue transplantation, and, outside the strict medical field, immortality in cell line development.

The number of autopsies, once the hard-fought hallmark of scientific medicine for centuries, has been steadily waning. Autopsies used to be the defining socialization moment in medical education, but they have been gradually replaced by virtual autopsies and other computer-aided teaching tools. In hospitals, autopsies used to be the final arbiter of clinical acumen but asking for the 'post' has declined

due to the surge of imaging technologies, reluctance of relatives to assent to autopsies, cost consciousness due to the rise of managed care, fear of litigation if therapeutic mistakes are discovered, new instruments of quality control, changes in the medical curriculum, and shifts in the discipline of pathology. The death knell came in 1971 when the Joint Commission on the Accreditation of Hospitals eliminated autopsy requirement for hospital accreditation. An autopsy rate of 41 percent in 1961 had declined from 5 percent to 10 percent by the mid-1990s. The main place where the autopsy thrives is in forensic medicine where pathologists conduct a postmortem investigation to identify the deceased and determine the cause and manner of death, including homicide and suicide.

Social and health scientists have been suspicious of forensic death investigators' determination of suicide arguing that official suicide statistics tell us more about the way officials construct official statistics than about the phenomenon of suicide. Alternatively, epidemiologists have tried to determine whether official statistics undercount the official suicide rate, agreeing that while underreporting may occur, these statistics are sufficiently approximate for social analysis. Yet, how do forensic investigators relying on autopsies decide that a suicide took place when confronted with a dead body? This issue is complicated by the fact that Western society's understanding of suicide depends on the intent of the deceased to take his or her own life and verbalization of intent disappears at the moment of death. Viewing this occupational dilemma, I conducted an ethnographic study of death classification in a medical examiners' office observing forensic pathologists at work. I concluded that deaths are classified as suicide when they form a tight fit with forensic investigative criteria. Evidence of a suicide only qualifies as such because medical examiners have the legal mandate and the medical skills to retrieve and interpret it. Medical examiners exchange information within an organizational network of key allies in law enforcement to exclude other causes of death and bolster their determinations. Medical examiners have few incentives to boost suicide rates: a suicide is never a default option but needs to be positively proven according to professionally relevant criteria. Trauma to the body inconsistent with suicide or potential lethal, natural disease will be taken seriously as alternative explanations. As a group, medical examiners tend to privilege similar sets of information and investigative procedures, but because of the tremendous variation in organizational networks and occupational resources, variation in death classification is inevitable. The question of suicide underreporting is thus impossible to settle: different professional groups working in a different sociopolitical and organizational environment may draw the boundaries of suicide differently. As long as an external postmortem suicide standard is lacking, the problem of variation between and within geographic jurisdictions will likely continue.

Organ transplantation has traditionally been associated with the redefinition of death. As Giacomini (1997) and Lock (1995) have shown using historical documentary analysis, the notion of brain death – in which a patient's brain has ceased to function but heartbeat and respiration continue with the support of medical

technologies – was introduced to allow organ and tissue transplantation to take place after the development of the ventilator. This conceptual–technological development allowed people previously considered alive to be declared dead. Cross-cultural ethnographic research shows that the implementation of brain death varies. At one end of the continuum, brain death has been routinely accepted in North America where altruistic organ donation dovetails on long-standing traditions of charity. Still, even in North America among both medical specialists and the general public, doubts remain about how dead brain death really is. At the other end of the acceptance continuum is Japan where Lock (1995) relied on ethnographic methods to document a protracted public debate over brain death and where the practice is considered a bioethical issue of major contention. Concern persists in Japan about the vulnerability of organ donors. Even after the practice of brain death received legal status in 1997, a person can only be declared brain dead when they have provided written consent to organ donation and a close relative has co-signed an advance directive. The reluctance to embrace brain death results from scandals in heart transplantation, mistrust of medical specialties, greater focus on family consensus, well-established norms of reciprocal gift-giving, and religious objections. Other countries, such as Mexico, may lack the infrastructure of technologies, personnel, and other resources on which the definition of brain death depends.

Over the last decades, various developments of 'anti-aging' medicine, stem cells, cloning, and genetic technologies have forcefully brought the chimera of immortality back to the forefront. Similar to the once culturally cutting edge transplantation technologies, these new biomedical technologies promise a continued physical presence via biological tissues and genetic materials. Much of this remains still hyperbolic and actual instances of animal and people 'immortality' remain iconographic (e.g., Dolly, the cloned sheep). Still, under the public radar screen in hundreds of laboratories, immortality of the tissue kind may already been achieved. Hannah Landecker (2007) notes that the first widely used human cell line, HeLa, has been present in laboratories since 1951. A researcher took the cells during a biopsy from Henrietta Lacks, a young African American woman, who sought help for intermenstrual bleeding but died eight months after the biopsy with a malignant cervical tumour. Her cells, however, continued growing and dividing, unperturbed by their artificial environment outside the body in laboratories. Research scientists designated the cells as 'immortal'. By reviewing the historical representations of the cells and their body of origin, Landecker shows how the 'human interest' story reflects ambivalence to cell biology as harbinger of immortality.

CONCLUSION

With never-ending existential dilemmas and an unabated sense that modern death falls short of ideals, the way we die remains a rewarding research topic for

qualitative health researchers. An interpretive orientation that reveals how organizational, technological, and broader sociopolitical factors influence dying in various institutionalized settings from either a patient's or a care provider's setting remains a topic that plays to the strengths of qualitative researchers. There is always room for a study of how artificial ventilators or feeding tubes not only save lives but also tend to continuously generate bioethical dilemmas. Research, following the footsteps of Anspach (1993) or Chambliss (1996), will be able to show that the recurrent bioethical quandaries are to some extent dependent on organizational arrangements and only scratch the surface of problematized issues. Bioethical dilemmas are not inherent to feeding tubes or ventilators but these technologies as part of institutionalized hospital practices generate fodder for bioethicists, especially when aging patients with dementia receive feeding tubes.

The strong existential dimension of contemporary dying is both an opportunity for built in drama but it is also somewhat of a limitation in the sense that a study about dying has difficulty being about anything but death. Is it possible to conduct a study of death and dying that addresses the broader political context? Eric Klinenberg's study of the 1995 Chicago heat wave, in spite of well-documented shortcomings, may have achieved such a cross-over. In essence, Klinenberg aims to explain mortality in an urban environment, but he does not produce a study of death: the heat wave victims become a rallying point to examine the workings of city government's crisis management, the role of the media in holding politicians accountable and reporting decisions, the colliding agendas of various neighbourhood stakeholders, and the crumbling of a social welfare infrastructure. Studies about lethal natural disasters caused by tsunamis, earthquakes, or volcano eruptions or research on terrorism, homicide, suicide, or even HIV-AIDS are rarely shelved with the death and dying literature but provide interesting entrance points for a more political and broad sociological perspective of contemporary dying.

Similarly, we can imagine studies in hospices that besides the well-trodden theme of how these settings live up to their promises to humanize the dying experience, address broader political, economical, and sociological themes. Hospice and palliative care, for example, lends itself to approaches sensitive to a professional perspective that examines turf wars as well as the struggle for legitimacy within medical hierarchies and between medicine and the broader general public. The critical observations of hospice's normalization of the good death can then be viewed as a professional challenge for hospice workers.

Another theme that has received less attention in the study of death and dying is the role of money and finances and governmental regulations. Reading the social scientific literature on death and dying, one easily receives the impression that financial resources are nothing but necessary evils that may be mentioned in passing but rarely are explored for how they circumscribe the possibilities of death and dying. This contrasts strongly with the broader writing on the health care field where finances are deeply implicated in access problems, therapeutic choices, and practice variation. In addition, researchers have documented how

finances soar at the end of life, even for the indigent. Yet, social scientists have paid little attention to how, for example, Medicare payment schedules and regulations affect the kinds of care provided at the end of life.

Death and dying in developing countries tends to emphasize reduction of excess mortality rather than the dying experience. Still, there are some notable exceptions. For example, Nancy Scheper-Hughes' (1992) provocative study of infant mortality in Brazil questions taken-for-granted assumptions about mother–child attachment and brings the differential values of human lives at death into perspective. Others have examined cross-cultural differences in terminal illness and death. Here, again, opportunities abound to explore both the dying experience and its political economy.

Finally, the time may be ripe for a comprehensive study of death and dying in the twenty-first century that examines not only where and how people die but also how death avoidance and the aspiration of immortality motivates and organizes other areas of life. Such a study should cover the institutionalized locales where the majority of people die as well as the culturally salient deaths such as homicides and war fatalities. Throughout the literature of death and dying runs a major theme of *ars moriendi*. With the medicalization of death and dying, this good way of dying has been challenged. Yet, the institutionalization of death and dying has been going on for more than a century in Western countries and we may want to examine how changes in technologies, medical practices, and organizations keep affecting how people die now.

NOTES

1 Brown atlas of dying, http://www.chcr.brown.edu/dying/usastatistics.htm, accessed January 3, 2008.

2 I also distinguished 'dignified death' as interpreted by the assisted dying movement but because little qualitative research has been done on these deaths, I will skip this here. See Timmermans (2005) for more information.

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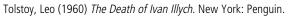
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