

Cultural scripts for a good death in Japan and the United States: similarities and differences

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Abstract

Japan and the United States are both post-industrial societies, characterised by distinct trajectories of dying. Both contain multiple “cultural scripts” of the good death. Seale (*Constructing Death: the Sociology of Dying and Bereavement*, Cambridge University Press, Cambridge, 1998) has identified at least four “cultural scripts”, or ways to die well, that are found in contemporary anglophone countries: modern medicine, revivalism, an anti-revivalist script and a religious script. Although these scripts can also be found in Japan, different historical experiences and religious traditions provide a context in which their content and interpretation sometimes differ from those of the anglophone countries. To understand ordinary people’s ideas about dying well and dying poorly, we must recognise not only that post-industrial society offers multiple scripts and varying interpretive frameworks, but also that people actively select from among them in making decisions and explaining their views. Moreover, ideas and metaphors may be based on multiple scripts simultaneously or may offer different interpretations for different social contexts. Based on ethnographic fieldwork in both countries, this paper explores the metaphors that ordinary patients and caregivers draw upon as they use, modify, combine or ignore these cultural scripts of dying. Ideas about choice, time, place and personhood, elements of a good death that were derived inductively from interviews, are described. These Japanese and American data suggest somewhat different concerns and assumptions about human life and the relation of the person to the wider social world, but indicate similar concerns about the process of medicalised dying and the creation of meaning for those involved. While cultural differences do exist, they cannot be explained by reference to ‘an American’ and ‘a Japanese’ way to die. Rather, the process of creating and maintaining cultural scripts requires the active participation of ordinary people as they in turn respond to the constraints of post-industrial technology, institutions, demographics and notions of self.

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Introduction

Japan and the United States are both post-industrial societies characterised by late capitalism, advanced technology, and high levels of consumerism. To varying degrees, their citizens are engaged in what Giddens (1991, p. 244) has called “the reflexive project of the self”, the “process whereby self-identity is constituted by the reflexive ordering of self-narratives”. They assume that human choice influences, if not determines, how a

person lives his or her life. Such societies also have distinct trajectories of dying which differ from those of earlier eras and less industrialised nations. A person is more likely to die in old age than in childhood, and death is more likely to occur following chronic illness than from infectious disease. Death most often takes place in hospitals in these societies, attended by “experts” and medical machines (Seale, 2000). Care of the dying has been commodified, with decision-making often related to questions of financial arrangements. Yet it has come to be assumed that there is now an element of choice in how one dies. These trajectories of dying in both the US and Japan frame the experience of the

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living, and contribute to values, ideas, and interpretations as to what constitutes a good or bad death.

In keeping with the pluralism of post-industrial societies, both Japan and the US contain multiple notions of the good death. Sociologist Clive Seale speaks of multiple “cultural scripts”, narratives that contain cultural representations of death in meta-stories of dying. These messages are conveyed through society by various means, including official discourse, broadcast media presentations, and personal testimonials. They may be articulated by “experts” in various fields, or communicated in social interaction and the rituals of daily life.

The model of cultural scripts of dying retains a key role for human agency. The ability of people to utilise particular scripts depends in part on circumstances beyond an individual’s control, such as a palliative care script being limited to those with cancer or AIDS. Elements of social structure such as social class, age, and gender may also influence an individual’s access to particular scripts. However, Seale (1998, p. 68) stresses that scripts are not *determinative*, but rather should be considered “as raw materials that are strategically (though not always consciously) used in particular situations”. People choose from among cultural scripts to deal with their particular circumstances.

Scripts of good death are thus parts of the larger cultures in which they exist, stories and concepts from which people choose in order to select, interpret, and justify behaviour surrounding the process of dying. Although Japanese and Americans assume vast cultural differences between the two societies, the *types* of scripts Seale describes can be found in Japan as well as in anglophone countries, as will be described below. The similarities result from technology, dying trajectories, and notions of self that are common to post-industrial cultures. How then should we conceive of the differences that exist? This paper argues that what we call cultural differences have to do as much with the ways that people draw upon the scripts to interpret their experiences with dying, illness, and death as with the scripts themselves. Seymour (1999) points to the way that different expectations and experiences with medical technology create various interpretations of the “natural death” script in British intensive care settings. When such differences are patterned and have expression in language and metaphor, we can consider these as cultural differences, but from a more nuanced perspective than by trying to identify “an American” or “a Japanese” ideal of the good death.

Although the various cultural scripts provide a vocabulary with which to discuss end-of-life issues and structure a set of institutional options from which choices are made in post-industrial societies, they can also be misleading if taken as statements of actual behaviour. Advocates and experts voice ideals that,

particularly when we consider dying cross-culturally, are confused by outsiders with the ways that people think and act. Ordinary people rarely perceive that there is a single correct script to be followed. Rather, they recognise multiple answers to the existential and ethical issues at the end of life, and using cultural metaphors, draw from a number of scripts simultaneously or consecutively. After introducing Japanese and American versions of common cultural scripts of dying, I present this alternative perspective, exploring metaphors that ordinary patients and caregivers draw upon as they use, modify, combine, or ignore these cultural scripts of dying. I will focus particularly on the values and dilemmas they identify concerning common elements of a good death: choice, time, place, and personhood. I conclude that while cultural differences may indeed exist, the process of creating and maintaining cultural scripts requires the active participation of ordinary people as they in turn respond to the constraints of post-industrial technology, institutions, demographics, and notions of self.

Methodology

My data are drawn from participant-observation studies of end-of-life decisions in the United States and Japan in the 1990s. The American fieldwork was conducted in English for 1 month in 1992 and 6 months in 1993 in a large, independent, tertiary care hospital in a mid-western American city. The hospital had no religious affiliation. Time was spent observing rounds, conferences, and patient care and interviewing patients and staff in several intensive care units, regular wards, and in the departments of Bioethics and of Palliative Care. In addition, 102 patients and/or family members were interviewed at the time of admission to this hospital concerning their ideas about advance directives, and of these, 19 were interviewed again in greater depth later in the hospitalisation.

The Japanese data were collected over a 7-month period in 1996 through observation and interviews in three hospitals of different types (a private university hospital, a national specialty hospital, and a hospice and paediatric units of a Christian hospital) and in home visits with home nurses and/or physicians. In addition to observing rounds, family conferences, staff conferences, and patient care situations, I interviewed 41 physicians, 14 nurses, 9 volunteers, 34 seriously ill patients, 23 family caregivers, and 21 other professionals such as social workers, bioethicists, and medical journalists. Interviews and discussions in Japan were conducted in Japanese. In both fieldwork settings, notes were taken during and immediately after the interview or observations, and daily field journals were kept. When appropriate, some of the formal Japanese interviews (mainly

those with medical staff) were tape recorded and later transcribed by a native speaker.

The analysis in this paper is based on reading in the bioethics, sociological, and other academic literature in both countries, on material from the popular media, especially newspaper articles, and on an inductively derived set of key concepts that commonly arose in interviews and observations.

Cultural scripts of dying

US, Britain, Australia

In his work on death and bereavement, Seale has identified four cultural scripts of dying found in anglophone countries: modern medicine, revivalism, an anti-revivalist script, and religious scripts. The script of modern medicine resulted from social as well as technological change from that of earlier eras. Aries (1974, 1981) has demonstrated that ideas about a good death in western culture are historically contingent. The circumstances and meaning of dying associated with modernity include an increase in affectivity, smaller family units, the privatising of the experience, secularisation, and the oversight of death by physicians. Other researchers in sociology and anthropology have followed the insights of Aries, describing other scripts of dying with attention to the specificity of time and place.¹

Walter (1994) has developed a concept of “revivalism”, a newer script that arose in contrast to the modern, medicalised death. Building on Aries’ distinction between “traditional” and “modern” ways of dying, he adds that in modern society there are no longer shared norms as to how to die and how to mourn. A newer, “neo-modern” script of dying “revives” death from its “hidden” place in the hospital and its denial in public discourse. In this neo-modern or revivalist script, death is prolonged, it is brought from the realm of private experience into the public realm, and it relies on the authority of the self as active decision-maker (Walter, 1994, pp. 50–51).

Walter further identifies two versions of this neo-modern script. The first is psychologised dying, as found especially in the hospice and palliative care models of dying well. As Seale (1998, pp. 5–6) describes it,

Patient-centered medicine encourages confessional moments in which bonds of trust are negotiated and patients are cast as inner adventurers. Care of the self is seen primarily as an individual project in Western, or at least anglophone medico-psychological discourse... This transforms the experience of dying into an opportunity for growth.

Walter (1994, pp. 40–41) also recognises a post-modern version of the revivalist script. Public and private are conflated in this approach, and the dying person assumes full autonomy, supported by an ideology of radical individualism and by romantic and consumerist trends of post-modern society.

Both revivalist scripts emphasise individual control and choice, with the “emotional accompaniment” of caring others to preserve social bonds, although the caring others may be psychological and spiritual professionals rather than family and neighbours. Dying provides opportunities for personal growth, and for the construction of self that Giddens (1991) describes as a post-modern project. Although the majority of deaths still take place in hospitals or other institutions supporting medicalised dying under the authority of physicians and other health professionals, elements of revivalist, especially psychologised scripts have been incorporated into these contexts. Revivalist styles of dying, however, are available only in certain circumstances. Because of the revivalist emphasis on bringing the private experience into public discourse, an “open awareness” (Glazer & Strauss, 1965) of a prolonged process of dying is essential. Thus, this script is primarily limited to patients who have cancer or AIDS. The ability or desire to participate in the open awareness, the acceptance of “care workers”, and the radical individualist style of decision-making may depend on education, social class, age, and gender (Seale, 1998).

In recent years, the apparent consensus of a neo-modern or revivalist ideal of what constitutes a “good death” has been shattered by heated controversies in many countries about euthanasia and physician-assisted suicide. People on both sides of these debates share common revivalist assumptions about the need to alleviate suffering and the desire of individuals to autonomously control the process of their dying (Hart, Sainsbury, & Short, 1998; Seale, 1997). With the US Supreme Court decision on physician-assisted suicide in 1999, the US has at least temporarily resolved the debate from a legal and institutional perspective in favour of the palliative care version of the revivalist script, in contrast to the Netherlands, which in 2001 legitimated voluntary active euthanasia, giving it equal legal standing to the palliative care model.

The third of Seale’s cultural scripts is that of resistance to the revivalist approach. This script of resistance was exhibited by those of his respondents who

¹In the sociological literature, see, for example (Charmaz, Howarth, & Kellehear, 1997; Bradbury, 1996; Clark, 1993; Fitzpatrick, 1997; Hays, Gold, Flint, & Winer, 1999; Kastenbaum, 1979; Schroepfer, 1999; Smith and Maher, 1993; Young and Cullen, 1996; Firth, 1996). In anthropology, see Counts and Counts, 1985; Dracklé, 1999; Goldey, 1983; Hockey, 1990; Kalish, 1980; Namihira, 1996; Platt and Persico, 1992; Sasaki, 1996).

preferred a “closed awareness” of dying (such as not knowing their diagnosis and/or prognosis) and those who rejected the services of hospice nurses, social workers, or other professional supporters, frequently opposing the psychologising of dying and mourning which they represent. Seale sees this script as a “relic” of former times, one which has little reference to popular culture in Britain, and one which may be associated with people of lower educational and income levels, or as Seale (2001, pers. comm., July 19) suggests, “those who are not well-schooled in the kind of reflexively self-aware projects of identity that Giddens describes”. In this sense, resistance to revivalism is a script without mainstream cultural legitimacy.

On the other hand, recent scholarship which takes a critical look at hospice philosophy and practice offers new legitimacy without necessarily providing an alternative model for dying. The motivations of the authors range from the desire to reform and improve hospice care to the wish to challenge the perceived hegemonic portrayal of hospice as *the* way to a dignified, caring death. These authors note inconsistencies in hospice ideology, contradictions between hospice philosophy and practice, the ambivalence of many Americans to hospice or palliative care, and the effects of health care financing on end-of-life care (Ackerman, 1997; Barnard, 2000; Barnard, Towers, Boston, & Lambrinidou, 2000; Hart et al., 1998; Leich, 2000; Seymour, 2000; Walter, 1994).

Seale (2000) also notes the coexistence of religious or spiritual scripts for dying in anglophone countries, and this may be especially vigorous in the US. Religion or spirituality may serve as an alternative script, but it is also a meta-script that is interwoven into all of the other scripts: pastoral care “experts” operating within the hospital setting, the Christian basis of hospice (Long & Chihara, 2000; Ackerman, 1997), and the opposition of some organised religious groups to euthanasia. In addition, the recent flood of interest² in spirituality in illness/dying in the US suggests the reinvention of traditional religious scripts in the service of resistance to currently popular models of secular dying, whether in a hospital, home, or hospice.

Japan

Medicalisation of the life course has been a trend in Japan in the last half of the 20th century. Biomedicine,

²I am thinking here of the established work of organisations such as the Park Ridge Center and the Temple Foundation, but also of descriptions of various grant programs for research and medical education, for example at <http://grants.nih.gov/grants.oer.htm> or at <http://www.gwish.org>. It is interesting to consider the use of the “scientific method” to justify the importance of religion or spirituality in American society.

gradually introduced from Europe from the 17th century, was made the official medical system in 1875 when all physicians (including those practising East Asian herbal medicine) were required to pass an examination in biomedicine to obtain a medical license. In the 1960s and 1970s, Japanese biomedicine became increasingly oriented towards high technology diagnosis and treatment, and more hospital-centred. A national health insurance system and catastrophic medical coverage has meant that hospital care is readily available with little regard to cost. Birth and death moved from being family centred events in the home to professionally synchronised occasions in the hospital (Kashiwagi, 1995, 1997). When I conducted my fieldwork in the mid-1990s, the use of high tech medicine, even for terminally ill patients, was the standard of care, and physicians continued to be trained to save lives at all costs.

But there has also been decreased trust in physicians, and the witnessing of suffering when the illnesses of family members are protracted but incurable. We might consider that the revivalist alternative in Japan began with the euthanasia movement. The Euthanasia Society of Japan was officially founded in 1976, but it has roots going back through its founder to the birth control movement of the 1920s, the Eugenic Protection Act of 1946, and the Society for Reforming Funerals and similar groups in the 1960s and 1970s (Oki, 1992). In the 1980s, the Euthanasia Society shifted its focus towards “passive euthanasia” and the advocacy of living wills, and in 1983 changed its name to the Japan Society for Dying with Dignity. Public interest in questions of informed consent, disclosure of diagnosis, withholding of treatment, and euthanasia expanded in the 1980s and 1990s with increased media attention (especially at the time of the Shōwa Emperor’s terminal illness in the late 1980s), consumerist pressure (see Leflar, 1996 on citizens movements for access to medical records), and changes in government policy to encourage informed consent for treatment and thus disclosure of diagnosis and prognosis.

Hospice care was also introduced into Japan from Britain in the 1970s. The earliest hospices were established at two Christian hospitals. By the late 1980s, the national government had begun to encourage programs for the treatment of terminally ill patients, leading to the development of more than 50 licensed hospice or palliative care in-patient facilities by the late 1990s (Long & Chihara, 2000). As in Britain and the US, the media often portray hospice and euthanasia as being in opposition, yet both approaches are based on assumptions about individual control and rejection of medicalised dying.

A major difference, however, between the revivalist approach in Japan and in the US is the political context, in which revivalism in Japan is experienced as “foreign”. The euthanasia movement, from its founding, has

associated itself with international right-to-die movements. The English term “informed consent” is widely used instead of its official Japanese translation. The translation (literally, “explanation and assent”) is itself controversial because some claim that it does not effectively capture the nuances of individual rights (Asai & Kobayashi, 1996; Morikawa, 1995; Ôgyû, 1995; Sugita, 1995; Leflar, 1996). Hospice, in the minds of many Japanese, is Christian, with its emphasis on psychological support, the autonomous patient as the centre of the decision-making process, and other “non-Japanese” themes. Disclosure of diagnosis, euthanasia, and other practices are argued to be “modern”, and some writers even accuse the Japanese public of being “confused” or ignorant when they are unaware of the modern approach (see Hoshino, 1993).

Resistance to the revivalist script thus takes a somewhat different form in Japan than that described by Seale for Britain. Certainly, there continue to be many people who prefer to not be told their diagnosis directly, and even more who attempt to protect family members from bad news (Long, 1999). But such attitudes are not merely “relics” of traditional values, but become part of a polarising discourse about the relation between Japanese and “western” cultures. To disagree with the rights-oriented phrasing of the arguments for full disclosure would expose one to claims of paternalism and of violating human rights. Rather, those advocating a script of resistance talk about “East Asian bioethics” and “Japanese sensibilities”, while the “progressive” advocates of the revivalist script speak of “international” (that is, “American” or “Euroamerican”) standards and practices (Kitahara, 1996; Sakamoto, 1996).

Not surprisingly, religious and spiritual discourses on dying based on Japanese religious ideas also take a somewhat different shape than those in the US, where Christian assumptions frame the discussion. The great majority of Japanese do not claim any particular religious faith, rarely participate in religious rituals, and have at most a nominal affiliation with a Buddhist temple for the purpose of performing death and memorial rituals. Although their worldview is primarily secular, Buddhism, Confucianism, and Shinto have contributed ideas about a continued existence after death as an ancestor, Buddha, or spirit, beings which are not neatly distinguished by their theological origin. In the eclectic folk version of these understandings, these spiritual beings retain their personal identities and continue to be part of the social world of their families after death, generally benevolently. Even if unarticulated, most Japanese combine this vaguely defined “Japanese” sense of life-after-death with heavy doses of secular science (Becker, 1990; Fan, 1999; Grossberg, 1999; Harvey, 2000; Hui, 1999; Lo, 1999; Lock, 1997; Lock & Honde, 1990; Maruyama, 1999; Morioka, 1999;

Namihira, 1996; Ohnuki-Tierney, 1984, 1994; Smith, 1974, 1999).

Religious scripts may also be articulated by religious leaders, some of whom serve as commentators on social issues in the media. Leaders of organised religions in Japan express a variety of positions on contemporary issues of dying, as LaFleur (1992) discusses for abortion and as Tanida (2000) found when he surveyed religious leaders about euthanasia. Committed practitioners of the “new religions”, in which religious beliefs and practices have a direct impact on their adherents’ daily lives, probably come closest to the explicit knowledge and desire to follow a spiritual script that incorporates a sense of meaning in death.

Thus, the Japanese versions of the four scripts identified by Seale as characterising anglophone countries (medicalised dying, revivalism, resistance, and religious/spiritual) exhibit some differences from those of the US, for example, less emphasis on psychologising in the revivalist script, the global contextualisation of resistance to revivalism, and an emphasis on ancestors in Japanese spiritualism. Yet the differences between the US and Japan are not so much in whether or not these scripts exist, but rather in how they are differentially used. Their political use in Japan has been suggested in my discussion of resistance, and is supported by interpretations by North American scholars of Japanese resistance to brain death (Feldman, 1996; Lock, 1997). Elements of established scripts are also adopted by individuals as they attempt to make sense of their experience, both in contrasting their identity with that of an exotic other and in speaking of their own dying or that of intimates.

Cultural scripts and national identity

All of these scripts are known through their expression by advocates and “experts”. Medical professionals, media, educators, government officials, and religious leaders profess and advocate the “right” way.³ These professional expressions are not the only versions of cultural scripts of dying, yet they are often the ones that are picked up by foreign journalists or scholars attempting to “diversify” bioethics cross-culturally, but they provide a limited picture of end-of-life decisions in that society. I will offer two examples of how this results in cultural stereotyping: some American writers’ views of dying in Japan and Japanese informants’ impressions of the US way to die. These stereotypes about dying, of course, do not exist in isolation. As Edwin Reischauer (1988, pp. 128–129) noted, Americans have perceived Japan as a nation of group-dependent warriors, while

³That is, they see the scripts as proscriptive models rather than, as Seale does, as cultural options.

the Japanese have focused on the elements of American culture that point to the rugged individualism supposedly exemplified by cowboys of the wild west.

American writers have expressed the notion that the Asian approach is one of acceptance of a “nature” that is inclusive of human activity.⁴ Nature, which partakes in salvation and is a means by which humans may achieve it, is considered central to Japanese religiosity (Shaner, 1989; LaFleur, 1989). In contrast, “westerners” attempt to control or dominate nature. In this dichotomy, Japanese see their own dying and that of others as a continuation of a natural process, while Americans and Europeans fight against death in an attempt to conquer it. Alternatively, Americans might associate a Japanese style of dying with the calm stoicism of the samurai who faces death with honour. In her book, *Graceful exits: How great beings die*, author Sushila Blackman (1997) focuses on this image of a Buddhist ideal of a calm death as she relates stories about the deaths of famous Asian sages, monks, and priests.

Just as Americans have focused on spiritual definitions of death in Japan and generalised those to an entire population, terminal illness and death in the US are often stereotyped in Japan in terms of a Christian worldview. During my fieldwork in Japan, several people with vastly different educational levels made comments to me such as, “In Japan, we don’t believe in the idea of Heaven like Christians do, so death is much more frightening for us”. They seemed to hold an image of Americans who, bluntly told that they are dying, remain unflustered, committed to fighting their disease until the end, calmly writing out living wills, and then dying in dignity, alone, in peace, knowing that they will be reunited with their God in Heaven. Those who are attracted to a revivalist script turn to its well-known Christian advocates, such as the Jesuit Alfons Deeken, a leader in the death education movement, and Kashiwagi Tetsuo, a physician and a major spokesperson for hospice. Both give frequent and well-attended public lectures and classes, and write books and articles that apparently sell well. Deeken’s message is that,

At the foundation of Christian belief is the faith that death is not merely the end of bodily life, but is the gate to eternal life. The hope of resurrection and the expectation to meet loved ones again in Heaven give great courage and consolation in the course of suffering in the face of death (Deeken, 1996, author’s translation).

It appears that to many Japanese, Christians somehow have the answer.⁵ During my fieldwork, nurses at

⁴This notion is traced by Morris-Suzuki (1991, p. 81) to the work in the 1960s of Lynn White, a historian of technology.

⁵It was also pointed out to me that Christian funerals are much simpler and cheaper and are thus a draw for potential

several hospitals expressed their feelings that they lacked the skills and knowledge to provide the psychological and spiritual support required by the revivalist script but which they seemed to assume Americans automatically had by virtue of their Christian upbringing.

Reischauer (1988, pp. 128–129) points out that the reality of daily lives in both countries reveals much less difference than the cultural stereotypes of romanticised “otherness” suggest. Recognising that multiple cultural scripts coexist in both the American and Japanese contexts, it is more useful to come to an understanding of cultural differences *and* similarities by first examining the ways in which ordinary people draw from multiple scripts as they talk about death. In the following sections, I will examine the ways that Japanese and Americans spoke of good and bad deaths regarding four topics: the assumption that death somehow contains an element of choice; the timing of an ideal death; the place of death, in particular noting the metaphor of “home”; and persons, that is the relation of the dying person to the larger social world.⁶

The use of cultural scripts to make sense of dying

To gain a better sense of how non-experts draw upon cultural scripts rather than blindly follow them, this section will explore the ways that people talk about dying. Just as there are common scripts, there are also common elements in discussions of dying in Japan and the US. My interviews suggest that in a general way, Americans and Japanese share some common notions of a good death: (1) a dying that is peaceful; (2) the basis of such a peaceful death is that the last stage of life is pain-free; (3) that a good death is one in which the dying person is surrounded by caring family; (4) a recognition of a continuity from living through dying; (5) a belief that death was, or should be, a personalised experience appropriate to that person’s values and life conditions; and (6) strong concern that one not become a burden on family, reflecting and creating an ambivalence about the social nature of dying. These are often discussed in terms of choice, timing, place, and person that accompany the process of dying well or poorly.

(footnote continued)

converts. It reminds me of the Americans I heard in the late 1960s talking about cremation here as being more “natural”. In contrast to the positive view of a “Christian” approach to death and dying, Ei (1994, p. 72) notes that if he compares the deaths of Buddha and Christ, he prefers the peaceful passing of Buddha to Jesus’s painful death on the cross. At the Annual Meeting of the Japanese Society for Bioethics, I heard several speakers make rash generalisations about the beliefs and approaches to bioethics of Christians, Jews, Moslems, and Africans.

⁶These topics were inductively derived from content analysis of field notes and interview transcripts.

American dilemmas and metaphors

Choice. The revivalist script features the notion of choice in dying, and the Americans I spoke with frequently voiced their views in terms of choice. However, *whose* choice it was varied not only from one person to another but also from one context to another. For example, drawing upon a religious script in expressing her views on living wills, a woman whose husband had just been admitted to the hospital for cardiac surgery explained, “That [a living will] does what God should decide. The living will throws the decision back to people, but that is God’s will. It’s a preliminary to euthanasia, that’s what I think.” But other people expressed a belief that God and the doctors work together, combining spiritual and medicalised scripts. For example, when I asked about the role of prayer in coping with her illness, Pat Klecha,⁷ a woman seriously ill with pulmonary hypertension, replied:

I would pray to God that I would be the miracle patient, that they would find a perfect match for the transplant, that I would have no complications and live a long time... God is good to me. He answers my prayers... I know that God sent me to Dr. Taylor and Dr. Brose.

In another instance, spiritual and medicalised scripts were utilised sequentially. A man in his 20s whose wife was dying had been asked by her doctors about discontinuing her treatment. The physician consulted a staff bioethicist and a conference with the physician, the husband, and the bioethicist was arranged. The husband asked and responded to questions fully within the context of a scientific worldview. Yet when the physician left and discussion continued with the Catholic bioethicist, the young man immediately began to speak about God and his Roman Catholic beliefs. This was the most dramatic example that I saw, but it was not unusual to hear people “code switch” in this way, drawing upon multiple scripts and worldviews.

Other people were more concerned with which *humans* were making the decisions about dying. In discussions about advance directives, people frequently contrasted the physicians making the decision to discontinue treatment with the patients’ right to decide for themselves (medicalised versus revivalist scripts). Others noted that family members might make decisions. One

⁷At the time of my interview with her, I asked Ms. Klecha if she preferred that I use a pseudonym or her own name in writing about her story. She replied that she wanted to be who she was, and complained that one of her physicians had written about her but that she was merely a nameless case of a disease for which he would get career credit. She thus asked that I identify her by name in my writing. In this paper, all other names of patients and staff I interviewed are pseudonyms.

perspective expresses the revivalist view that a responsible person takes charge: “My husband saw his father on life support, and didn’t like watching. He doesn’t want to put his family through that”. On the other hand, an emphasis on family may reflect resistance to the revivalist script, as expressed by an American patient:

It’s up to the next of kin to be able to decide in extreme cases if life support should be continued or not. When it comes down to it, if it’s a case where I’m a vegetable, the doctor informs my wife and tells her the complete story. Then she should have the right to decide.

The “rights” phrasing and the desire for the wife to decide rather than insisting on individual autonomy (for example, the use of a living will), might appear inconsistent to advocates of a “pure” script. Resistance was expressed less ambiguously by a man in his 30s:

Interviewer, probing: Do you think it’s a good idea to have these things written out in advance, or it is better to take things as they come?

Respondent: Better to take things as they come.

One thing that strikes me, however, is that the American discourse seems to concern whether dying is a decision of humans or God, individuals or families or doctors. This focus, however, serves to mask the great influence of insurance companies and health maintenance organisations on treatment decisions. The 2001 debate in the United States over a Patient’s Bill of Rights may be the first step in drawing national attention to this, and may alter the frame of the American discourse on decision-making.

Timing. The criterion for the appropriate time for dying for many Americans was not chronological age but “hopelessness”. If a patient was young but was expected to never recover to live a meaningful, conscious life, even a child might be allowed to die if “hopeless”. On the other hand, both the staff and the lay people at the American hospital where I observed expected that everything would be done to save the life of someone who might recover to some degree of independent functioning, even if the patient was very old. Rather than chronological age, people spoke of “dying before their time”, or “I don’t want to keep going when my time is up”, perhaps indirect references to a religious script.⁸ A more direct religious context was provided by a 45-year-old woman accompanying a friend being

⁸A survey by Seale and Addington-Hall (1995) in Britain found that controlling for age, dependency, and level of pain and distress, spouses were more likely than other relatives or acquaintances to think it would have been better for the person to have lived longer rather than to have died earlier than he or she had.

admitted to this hospital: “I wouldn’t want no life support. I can’t see lingering on if you’re suffering and there’s no chance”.

Yet the idea of “dying before one’s time” was combined with a medicalised script in the following excerpt from an interview of a 50-year-old candidate for liver transplant and his wife, in which the idea serves as a challenge to medical assumptions:

Patient: No one wants to die before their time, and we don’t know when that time is... It’s overwhelming to me now. A lot goes through your mind. But when it’s [a transplant] or die, the decision becomes easier...

Wife: I’m concerned with the time of death—not hurrying someone else’s death to save my life.

I often asked people what was meant by a “natural death”, a key metaphor of the revivalist script, which was almost always viewed positively. Responses frequently made reference to timing. Such a death means not prolonging life when there is no hope, and in particular, not “lingering”.

Place. “Going home” is an important metaphor which carries multiple meanings. Some patients and families who spoke in religious terms described death itself as a “going home to God” as well as “going to a better place”. Home in the revivalist script also represents a contrast to a medicalised dying in the hospital.⁹ I believe that home remains an ideal for many Americans when they think about their own dying, as expressed by a healthy woman, probably in her 70s, during an elder class I once addressed. After I had spoken about Japanese images of dying at home, she raised her hand and asked, “Isn’t that what we all want? To be in our own home with our family around and to just put our head down on our kitchen table?”

Yet changes in American society have altered this ideal in a number of significant ways. For some very ill elderly patients, “home” may be a nursing home rather than a place where family members share their lives. The increased proportion of middle aged women working outside of the home creates additional burdens on family members which dying patients might wish to avoid; many people spoke of not wanting to burden family with their “lingering”, whether those burdens be financial or emotional. And finally, when patients are sent home to die, the concern may be less for their peace or dignity as for cost-savings for third-party payers. [Leich \(2000, pp. 208–209\)](#) offers a critique of home hospice nursing as

...undermin[ing] patient autonomy...when conflicts arise over exactly how and where patients wish to die. Patients’ and caregivers’ attempts to control the care patients get, including their decisions about whether or not to use hospital care, can place them at odds with home hospice organizations, whose goals increasingly include limiting patients’ use of inpatient care.

The ideal of dying at home may be difficult to achieve, but sometimes the wishes of medical staff, insurer, and family align to make it possible. Mr. Caprio was a man in his 70s who had suffered several strokes and clearly expressed his desire to go home. The attending physician and family agreed. About a week after his discharge from the hospital, I asked his doctor if he knew how Mr. Caprio was doing. He replied, obviously fostering Mr. Caprio’s choice, “He’s at home now, and seems more comfortable. I went out there yesterday. He is getting home care; [the therapists] are doing a good job. He sleeps most of the time, but wakes up, waves at his family. He told his wife he’d see her in heaven. The family has really rallied around”. This image suggests the revivalist ideal. Yet in some cases such as that of Mr. Caprio, it is difficult to reconcile the revivalist interpretation of striving and personal growth while family provides support, with the sense that what is significant here is precisely the sense of continuity and definition of self as part of a larger social body which is quite distinct from the emphasis on the discrete physical body of medicalised dying or the individual psychological self of revivalism.

In other cases, resistance (especially on the part of the family who are expected to “rally around”, sometimes for an extended period of time) and practical concerns combine to alter the meaning of “home”. In one situation I observed, Mr. Lincoln had life-threatening complications due to surgery at a tertiary care hospital about 70 miles from his home. His elderly wife felt somewhat responsible in that she had encouraged him to have the surgery, which he had initially resisted, and thus was now pushing for his going home to die. However, home care was insufficient for Mr. Lincoln’s condition, and in any case, he was unconscious. The intensive care unit’s head physician was convinced that he would make no further improvement, and was thus concerned about whether Mr. Lincoln’s insurance would continue to cover his care there. A compromise was reached that Mr. Lincoln would be “moving toward home”. What this meant was that he would be transferred to a hospital in his hometown.

Persons. The most salient issue for Americans concerning the social world was the very definition of personhood, for once someone was no longer a person, many saw no point in continuing to keep their body functioning with the aid of technology. As in the above

⁹ At the time of this research, the proportion of deaths in the United States which took place in hospitals was 77.0% (US Department of Health and Human Services, 1996, vol. 2, p. 374).

discussions about choice, time, and place, the topic of personhood also exhibited references to multiple scripts, sometimes by the same speaker. “Vegetables” and “machines” were the metaphors through which Americans frequently spoke about personhood.

The lack of concern for the person, as opposed to the body, is revivalism’s critique of medicalised dying. But when is a body no longer a person? The following excerpts from interviews illustrate the revivalist type of response:

I don’t want to be a vegetable—that’s not living.

If I’m a vegetable, forget it. Don’t put me on a machine. I wouldn’t know what I’m doing anyway. I won’t recognise anyone.

Either you’re a human being or you’re not, and if machines take over you’re not human any more.

These statements indicate concern for rationality, sociability, and control that are the assumptions of the revivalist approach to dying. People drew the line in different places and times. One person said she did not want to be a vegetable for more than a week; another for 6 months. For some, the ability to eat, toilet oneself, and live in one’s own house was critical to defining oneself as a functioning human being; for others like Mr. Caprio [whose dying at home was discussed above], being able to interact with family defined personhood despite being hooked up to various equipment and receiving professional care. Many of the Americans spoke of not wanting to become a burden on loved ones, suggesting that independence rather than dependence is the basis for social relationships.

In speaking about vegetables and machines, however, people utilised multiple scripts. One female patient suggested that God is on the side of natural death. “God’ll make the decision when we go—and there won’t be no machines”. A more subtle incorporation of a spiritual approach was voiced by a 62-year-old man, who contrasted being a “vegetable” and being human, utilising the spiritual metaphor of the soul:

If I was in a state of [being a] vegetable, I wouldn’t desire to continue if I had the choice. If I’m in a coma, don’t pull the plug, or if it’s a stroke, because you don’t know. But if I’m brain dead, then it’s worthless. If the brain is dead then the soul is gone.

In contrast, some people with whom I spoke, including religious fundamentalists of Christian, Moslem, and Jewish backgrounds completely rejected the goal of human control. They found it unacceptable to stop aggressive treatment, since death is something only God decides; to turn off a ventilator or to not treat pneumonia when drugs are available is defined as murder. If machines had been invented and medicines

discovered by humans, it was God’s will that they be used for good, and saving a life is an unquestionable “good”. Faith, prayer, and religious music were sometimes included, along with lack of pain and the comfort of family and friends, as elements of dying well. While this is clearly a religious script, cases I observed in which “medical futility” was an issue were not infrequently voiced by the family of the patient in these terms. I suggest that this therefore represents not only an alternative script, but also a script of resistance to both the acceptance of the physician’s ultimate authority *and* to the revivalist script which places human control and psychological introspection at its core.

In summary, when I listened to lay Americans talk about their ideas of good and bad dying, I heard a variety of ideas and values. The differences could rarely be attributed to the usual demographic categories of social analysis, such as gender, race, or religion. Rather, in these open-ended interviews and discussions, people drew upon a range of ideas that are part of the American cultural landscape. Sometimes, they consistently drew from a single script on dying; at other times, they combined elements of several scripts in creative new ways to express themselves, much as humans use language to convey meaning.

Japanese dilemmas and metaphors

Although Japanese patients and family members have similar notions to those of Americans about the good death in general terms, when they spoke about choice, timing, place, and person, their focus was often on different issues and metaphors. Yet like Americans, they drew upon multiple scripts of dying.

Choice. Japanese patients, families, and medical staff rarely described dying in terms of choices as Americans did, perhaps because the revivalist script is less widely known and accepted. Yet there has been a great deal of debate about who the appropriate decision-maker should be, acknowledging some element of choice. Public discourse has centred on topics of medical paternalism and informed consent, especially the question of whether or not to inform a patient of a cancer (and more recently, an Alzheimer’s Disease) diagnosis. In day-to-day life on hospital wards, there has been considerable tension about who should make end-of-life decisions (Long, 1999).

A medicalised script gives decision-making authority to professional experts. This perspective was widely accepted among patients and families, as indicated by the frequency with which I heard, “We have no choice but to trust the doctor”. As a family member put it, “I’m a person with no medical knowledge. They’d ask us if we had questions but I didn’t even know enough to know what to ask”. Physicians were respected for their

specialised knowledge which is expected to help the patient.

Some individuals drew upon the revivalist script in which an individual patient is expected to be an autonomous decision-maker. I spent time shadowing a senior staff physician widely known in the local medical community for his advocacy of patient autonomy regarding disclosure and informed consent, although he was not supportive of the hospice version of the revivalist script. He introduced me to a patient, Mr. Urayama, who had asked to be told directly if the examination and tests turned up bad news. He later became famous within the hospital when he wrote the physician a letter thanking him for the disclosure and for allowing him to make decisions about his treatment. Despite his wife's discomfort with his requests, Mr. Urayama subsequently asked that his chemotherapy be discontinued and that he be transferred to a palliative care ward in another hospital where he died several weeks later.

In contrast to my conversations and interviews in the United States, in Japan, I rarely heard references to God as a decision-maker except by Christians. There were, however, occasional references to a religious or spiritual script. A hospice patient who was not Christian commented, "But when god takes something, he gives something, in a great circle". In another situation, a non-religious physician in his 80s whom I had known for years was describing his poor health, which had required multiple surgeries on his colon. He remarked, after describing the most recent medical treatment, "I guess god wanted me to live for a while longer—must have something in mind for me".

The script that is most controversial because of its continuing ability to offer opposition to both the medical and the revivalist scripts is one which emphasises the role of family as decision-makers. The issue is not one of proxies, but rather of what constitutes good care giving. For many, the assumed responsibilities of a caregiver include maintaining an atmosphere of calm and an attitude of hope. In such a script, disclosure is cruel, and of course without it, the family must make decisions that are what they believe the patient would want, or are in the patient's best interest. A dramatic example of the utilisation of this script was the family of another patient of Mr. Urayama's doctor, the disclosure advocate. The adult children of this 79-year-old woman with terminal pancreatic cancer strongly resisted the physician's intent to tell their mother her diagnosis, claiming,

There's no one who thinks of our mother more than the three of us. I can't imagine that the doctors do. We may be wrong, but we have infinitely more *kokoro* ("heart") in it than they do... It may be rude to say about the doctors who are helping her, but I

don't think the love we have for her can even be compared with their care.

But neither did their rejection of the revivalist script indicate a complete acceptance of a medicalised dying. Rather, they drew from both medical and family scripts, continuing active treatment until the end, but stopping additional testing that created pain or discomfort. All of the patient's children and grandchildren were at her side when she died.

Timing. Unlike Americans who focused on "hopelessness" more than chronological age, Japanese beliefs and practices differentiated the appropriateness of death by age category. It was expected that everything would be done to save the life of a child, including severely disabled newborns. For example, a paediatrician explained,

We talk to the parents about what to do... But somehow we can't say "turn off the ventilator". Because we know once we turn it off they will die, and so it's seen as killing...

In contrast, the death of an elderly person who has lived to fulfil normal adult responsibilities may be sad, but it is accompanied by a sense that it might have been expected. Of course, there is no magic age at which this shift occurs; nonetheless cancer in a woman with unmarried children or a worker prior to retirement elicits different responses to treatment options (including disclosure) than that of a frail elderly widower. As an 80-year-old farmer put it, things are planted in the spring and ripen in the fall. "Since human beings live in nature, I will die when god (*ten no kamisama*) calls me to heaven".

In addition to age, there are other criteria for a good death similar to Americans' fears of "lingering". Both *pokkuri shinu* (to die suddenly) and *rōsui* (a gradual decline in old age eventually leading to death) were mentioned as "ideal deaths" in interviews. They are folk terms and thus might be considered relics of a pre-revivalist age, but both can also be seen as representing "natural" ways to die in opposition to a medically orchestrated process. These terms may also be used as metaphors for a quick, painless death on the one hand, or an extended period for preparing for death on the other, often combined with elements of other scripts. For example, a physician in his 40s worried about both sorts of death, incorporating a medical model.

What would be ideal death? I already worry about a cerebral infarction or becoming demented... What kind of death would be good? In general, having family there, but I don't want to be a burden on people... If you become demented, it's a great burden on those around you...or, if you become a paraplegic and are bedridden, it's a lot of work for

the family and medical costs pile up too. I'd like to avoid that as much as possible.

Another person, a patient with a chronic but not terminal illness, drew on a revivalist script, but used the contrast of sudden death and a prepared death to think through her response when I asked her about her ideal death. She first responded that her ideal death in one sense would be to have it happen quickly so she would not have pain. On the other hand, she would want time to prepare. Maybe an ideal would be to go to a place by the ocean or a lake where she could get ready and take walks by the sea and they would give her morphine for pain.

Several people linked the idea of a relative's slow, gradual death to the process of becoming an ancestor, and there exists a common notion that demented elderly, in their not fully being in this world, are perhaps already god-like.¹⁰ These ideas indicate the existence of portions of spiritual scripts in people's interpretations of the speed of death.

Many other people with whom I spoke raised the positive and negative aspects of dying quickly and of dying gradually. No one suggested that there was one correct answer for everyone, and they drew on the various scripts of medicalised, revivalist, resistance, and spiritual dying as they were relevant to their own thinking.

Place. Where to die is an issue in Japan as well as in the United States. Although there is a strong cultural ideal of dying at home, surrounded by family, the medicalised script holds sway, with 76.8% of deaths occurring in hospitals or in nursing homes in 1994 (Kôseishô Daijin Kanbô Tôkei Jôhôbu, 1996, pp. 1, 127). Patients, and especially families, believe that hospitals offer professional care, the most current knowledge and expertise, and a hope for recovery, even if that hope is very small. Perhaps most importantly, in hospitalising an ill relative, family members can feel that they have done their best as caregivers and will thus be beyond criticism.

A different place is offered by the hospice/palliative care script. In Japan, these services have primarily been centred around in-patient institutions, generally as a separate ward of a hospital with supplementary out-patient and home visit services. In accord with the revivalist approach, all of the hospice and palliative care wards I visited encouraged the presence of family members, provided a kitchen where families could

prepare food, and even offered a traditional style tatami-floored room where families might, if they chose, spend the last days of the patient's life together, sleeping next to each other in the "traditional" manner (Caudill & Plath, 1966). Hospice staff also tried to assist with patients' requests to make visits home for a day, a weekend, or a holiday (*gaihaku*), providing caregiver education to family members, and sometimes even cajoling reluctant family members into having the patient "go home" for what was possibly the final time.

Nonetheless, the ideal of dying at home, surrounded by family and away from machines, remains strong, and can be viewed as a script of resistance. Patients in both hospice and regular wards frequently commented, requested, or pleaded that they wished to go home. A metaphor that is sometimes used is "to die on tatami", the reed-mat flooring of traditional Japanese architecture, upon which futon mattresses and comforters can be spread for sleeping. One man I spoke with told me of the story of his uncle's death. He had been hospitalised and asked to go home to die. His doctors believed he could live another year with hospital care but believed going home would shorten his life. When they asked him why he wanted to go home, he explained that he wanted to be able to stick his foot out of the comforter and feel the tatami. The staff decided to honour his request, his family agreed to care for him, and he lived, resting on tatami, for the remaining 2 months of his life.

Dying on tatami might be interpreted literally, as the hospices and palliative care units have in providing a traditional room for patient and family use, or it may be used loosely to represent home and family. In a 1990 national survey by the Ministry of Health and Welfare, over half (53.3%) of the respondents stated that if they had terminal cancer, they would like to have their nursing care at home, as opposed to 28.1%, who selected a hospital and 11.1%, who selected a hospital for the terminally ill (Kôseishô, 1995, p. 41). Entertainer and social commentator Ei Rokusuke comments in his book *Daijô* (1994, p. 86) that "it doesn't matter if death takes place in the hospital or at home—the question is who will care for me when I'm dying. I don't want to die surrounded by medical equipment and technicians in the ICU, but rather by family and friends".

The playing out of this script was described by a Japanese friend, Mrs. Nishimura, in describing the death of her father-in-law.

My father-in-law's death was just *rôsui*.¹¹ He got around fine until the last 10 days of his life. One day he couldn't get up, so we called the doctor and he came over. He told us he'd give him medicines and that I should feed him rice porridge and keep him

¹⁰See, for example, the film *Hanaichimonme*, or the best seller by Ariyoshi Sawako, *Kôkotsu no Hito* (see Ariyoshi, 1984 for English translation). Traphagan (2000) notes, however, that while ancestors are physically dead but socially alive, senile elders are physically alive but socially dead. Both are ambiguous positions in society.

¹¹Gradual decline in old age. That is, he did not die from an identifiable illness.

comfortable... The doctor let us know that the end was coming... Gradually, he became unable to eat at all. The doctor said, "Are you okay? Are you sure you don't want to have us take him into the hospital. We could give him IVs". I said I was okay, it hadn't been that long. And really, he was just lying in bed quietly, so it wasn't so hard. I knew my father-in-law would want to be at home. The doctor agreed that if we could handle it, that would be best. He died at night; I had been watching him and suddenly I was startled with a gurgling kind of breathing. I suddenly realised what that meant, so I quickly called the doctor. He came over right away. It was 3:30 in the morning. After he had been here for about 5 min, he announced the death. He told us the body would stay supple for an hour, so we should wash him and put cotton in his mouth, because of his false teeth, and tie up his chin with a towel so his mouth wouldn't fall open. So we washed him well... with soap and warm water. After we took care of all that, that's when I suddenly got scared... He had become a *hotokesama* [Buddha]. [The body] was a corpse, not a person any more...

As Mrs. Nishimura told the story, the emphasis was on "tradition" as suggested by her description of the post-mortem washing of the body, but the excerpt ends with a reference to a religious script.

Mrs. Nishimura's father-in-law had such a death because of his physical condition and care needs, because of the family's living and financial situations, and because of their commitment to "tradition". Others who desire such a death may have a more difficult time achieving these circumstances. As one physician reflected,

Yes, in Japan, there is something about wanting to die on *tatami*... Most patients here don't say they want to die on *tatami*, but they do say often that they want to be discharged... We respect their wishes, even if we don't think their condition is good... We can't say no to *tatami no ue*; it's tough... We have to at least put them on oxygen. At the end, they'll be bedridden, and it will be a lot of work... In the past, families were large so it was okay. But now to go home to only a child or a husband, or if they're living alone... we look at the patient profile and sometimes it's just impossible.

Dying at home in the revivalist script is based on ideas of the autonomous individual, personal growth, psychologising, and an open awareness. In the image of dying on *tatami*, people can feel more comfortable, be themselves in familiar surroundings, and have more opportunity to spend their last days as they wish. But while the *tatami* image shares some characteristics of the revivalist script, it differs in its focus on the individual as

part of the family, and thus might be considered part of a script of resistance. Whenever I asked about the meaning of the phrase, my informants' comments and explanations without exception began with family. Dying at home represents a connection to not only a currently living family but also to an idealised Japanese past. It also suggests future ties to a social world through becoming an ancestor. Ultimately then, like the revivalist script, dying at home is about self, but it is a different sense of personhood, providing an alternative script to that of the revivalist autonomous individual that combines elements of resistance and of spirituality.

Person. People in both countries expressed concerns about the personhood of the dying. Whereas American discourse on personhood focused on drawing a line between human and non-human (vegetable, machine), the Japanese discourse seemed to be more concerned with connecting the dying person to a wider social world that extends beyond the world of the living (Smith, 1974, 1999; Morioka, 1999). But there were a variety of scripts that I heard as people spoke about personhood and individuality in Japan as well as in the United States.

The medicalised script is based on the scientific understanding that the physical body is the only basis of life, and thus of personhood. Several Japanese people with whom I spoke expressed the view that whatever life they had would end with the death of the body; that with death they would cease to exist as a person. As one patient put it, "People are cremated and the ashes taken home—I think people have some sense of a spirit (*tamashii*) in that. But that's about all. It's the physical sense". A young medical resident, well-schooled in science, expressed his own inability to imagine anything beyond death, and thus wondered how any human could honestly face his or her own death. Japan has one of the most highly educated populations in the world; biomedicine has been the dominant form of health care for more than a century. It is thus not surprising that as they go about their daily lives, most people operate in accord with a scientific worldview.

The revivalist script, however, is of interest to some. The hospice where I observed engaged in practices of the revivalist self: trying to establish what was important to the dying person, and how he or she wanted to spend the final days. This individualising of the treatment of the dying was accepted and welcomed by family members of the hospice patients, who themselves were often engaged in discussions of what the relative would want, bringing in favourite foods, or arranging for visits home. But I believe that part of the comfort on the part of family members with hospice care was its correspondence in several significant ways with scripts of resistance and spirituality.

Since patients often expressed a desire to go home, it is not easy to distinguish which script is being drawn upon without listening carefully to words being used.

Elements of spiritual interpretations of dying were not commonly voiced but were often just below the surface. For example, in Mrs. Nishimura's description of the death of her father-in-law quoted earlier, she used the Buddhist term *hotoke* to express her father-in-law's state of being after death, although she did not appear to mean this in any deeply religious sense. Similarly, the room in a hospital where the deceased's body is taken and family members may wait for the hearse is called a "*reianshitsu*", or a room to rest or calm the spirit. Professional "caring" requires that those who are directly responsible for the patient (physicians, nurses, and possibly others) bow in final greeting as they send off the corpse from the *reianshitsu*. This was routinely done in the hospice where I observed by calling the staff away from their other duties when the hearse arrived, but is also sometimes done at other hospitals as well. Such a ritual indicates respect for the deceased and the family and, with no scientific rationale, connects the dying person with family, both living and dead.

A script of resistance to the centrality of the individual patient forms the basis of the most prominent concern of those affected by someone's dying. The phrase, *shinime ni au*, was used to explain to me what was considered "uniquely Japanese" by some informants, and was also used in discussions between and family and staff (see also Fetters and Danis, in press). It literally means to "meet the dying eye", and thus insists on the presence of others at death, the opposite of *kodoku na shi*, or the lonely death of dying alone. *Shinime ni au* calls for the presence of the attending physician and nurse at whatever hour death occurs; most importantly, it refers to the presence of family, whose arrival will be awaited before death will be allowed to occur (or at least be declared).¹² Interestingly, for a society that historically practised single-child inheritance, *shinime ni au* makes strong claims not only on the inheriting child but on spouse, all children and grandchildren, and siblings along with their spouses. In one case I observed, a woman's expected death was postponed, despite the presence of her husband and elder son, until the younger son could complete the civil service exam he was taking, be notified of his mother's condition, and arrive from a city several hours away.

¹² Despite my Japanese informants' beliefs that this desire is uniquely Japanese, my observations in an American hospital and discussions with American medical staff concur that family presence just prior to death is very important to Americans as well. As in Japan, death is not infrequently postponed until a distant relative can arrive. I have not investigated this thoroughly, but there may be a slight difference in the emphasis on the role of the accompanying relative. Americans talk about wanting to say "goodbye". In Japan, the stronger emphasis is on "being there". The value of parting words from the dying, however, exists in both societies. See also the article by Seale (this issue).

What connects the emphasis on satisfying individual desires, pain management, and the presence of family is the concern for the "peaceful face" of the dying person. The spiritual side of its importance in becoming an ancestor was voiced to me by a patient who was a life-long practitioner of the Buddhist-based "new religion" of Sokagakkai.

It is from your past or your ancestors' past that you become ill. That's why it's important to *jōbutsu* ("die in peace"). Some people become dark when they're dying, so they make their face into a smile, and open their eyes.

Dying peacefully, satisfied, and surrounded by family may create a benevolent ancestor rather than a wandering vengeful spirit in the religious script. But the notion of dying in this way is also a verification of the social bond both for the dying and for the family members who may continue to consider the deceased as part of the family in his or her new role as ancestor.

Conclusion

In his review of ageing and dying trajectories around the world, Seale (2000) raises the question of the appropriateness of the revivalist script of dying (hospice and euthanasia) in non-anglophone countries such as Japan. My data make it clear that although their voices may not be the loudest in the international literature, that script is very much part of contemporary Japanese culture. There exists a growing hospice/palliative care movement, an organisation actively advocating the use of living wills, and widespread public support for decisions to limit aggressive medical treatment at the end of life. Moreover, ordinary people such as Mr. Urayama interpret their circumstances and determine their choices in accordance with a revivalist script that emphasises individual autonomy, personal growth, and the acceptance of death. Not only does Japanese culture incorporate medical and revivalist scripts of death, my data show that there also exist religious scripts and scripts of resistance, though their specific content is not identical to those described by Seale.

Examining these scripts cross-culturally allows us to identify similarities and differences in ideas about the good death. In both countries, many people expressed a desire for a meaningful death that is timely, pain-free, and appropriate to the way they have lived their lives. Patients in both countries express concern for their relationships with significant others, not wanting to become a burden but wishing for a sense of connectedness. In both countries, people voice scientific explanations of death while often maintaining an underlying spiritual sensibility. This seemed more explicit in the

United States than in Japan, whereas family responsibility for care and social continuity was a more dominant theme in Japan. Observations and interviews also suggest a cultural difference concerning the definition of “timeliness”, with Americans often referring to the metaphor of “hope”, and the Japanese utilising criteria related to social roles and age.

Beyond similarities and differences, the data also point to an important gap in both countries between cultural scripts and the ways that ordinary people talk about dying. While experts explain and advocate particular roads to death, many of the common metaphors used by patients and caregivers express common sense understandings of dying that remain outside of articulated scripts, and in a sense transcend them. As people spoke about their various criteria for dying well, they used shared metaphors such as dying on tatami in Japan or becoming a vegetable for Americans. People used these metaphors to think through their own feelings about how to die well, for example, when Japanese contrasted *pokkuri shimu* and *rôsui*, or to explain their views to others, as when Americans spoke of “lingering” or “pulling the plug”. These results caution those who would use the explicit scripts articulated by experts as indicators of culturally specific ideas of a good death.

This ethnographic research also points to a clearer understanding of how scripts function beyond the words of the experts. In post-industrial societies, there is no single way to die, and multiple scripts serve as alternative models for how to die well. As optional approaches, individuals draw upon scripts differentially. As Seale notes, type of disease, educational background, religion, and social class may influence exposure and access to different scripts. Yet the ethnographic data presented here also suggests that scripts are not mutually exclusive. Some elements of dying well are found across a number of scripts, such as the inclusion of “spirituality” in all of the American scripts from hospital pastoral care to the prayers of fellow churchgoers. The Japanese reinterpretation of revivalism according to the symbolic opposition of “Japanese versus foreign” is another way that the boundaries of pure scripts are blurred.

Moreover, as Giddens suggests, individuals in post-industrial societies are engaged in a process of self-construction, and this appears to include a path to death deemed appropriate to the person. Thus, patients and those around them draw upon multiple ideas of good death in order to construct a meaningful death. When a patient explains that “God sent me my doctors”, or a Japanese hospice provides a tatami room for dying patients and their families, they are creatively mixing scripts to find the appropriate way to die, or a meaningful explanation for dying. Recombination of elements of various scripts is one way in which these

models are utilised in Giddens’s post-industrial project. Additionally, there is evidence that people “code switch”, offering differing metaphors and interpretations depending on the context, especially depending on the person to whom they are speaking. To what extent this is unconscious (that is, a culturally assumed “natural” behaviour) and to what extent it is conscious is difficult to determine.¹³

Thus, although this paper demonstrates the existence of parallel scripts of good dying in both the United States and Japan, what is more significant is that examining their expression points to a gap between scripts as proscriptive models for a good death and their interpretive use in daily life. In explicating their personal notions about choice, time, place, and personhood in dying, many people drew from multiple scripts or shifted their frame of reference in different contexts. This cannot be explained as insufficient familiarity with the experts’ scripts, but rather as the sort of creativity all humans exhibit when they create new meanings with culturally given morphology and syntactic structures. By exploring the complex relationship between ordinary people and cultural scripts of dying, it becomes abundantly clear that simple dichotomies of national difference miss the point. In a post-industrial society, people interpret and utilise their ideas in light of their own experience and creatively recombine elements from them, contributing to the maintenance, creation, and reinterpretation of notions of the good death.

References

- Ackerman, F. (1997). Goldilocks and Mrs. Ilych: A critical look at the ‘philosophy of hospice’. *Cambridge Quarterly of Healthcare Ethics*, 6, 314–324.
- Ariès, P. (1974). *Western attitudes toward death: From the middle ages to the present* (P.M. Ranum, Trans.). Baltimore: Johns Hopkins University Press.
- Ariès, P. (1981). *The hour of our death* (H. Weaver, Trans.). London: Allen Lane.
- Ariyoshi, S. (1984). *The twilight years* (M. Tahara, Trans.). Tokyo: Kodansha.
- Asai, A., & Kobayashi, Y. (1996). Infômudo konsento saikô (Reconsidering informed consent). *Nihon Iji Shimpo*, 3751, 98–100.
- Barnard, D. (2000). Policies and practices near the end of life in the US: The ambivalent pursuit of a good death. In S. O. Long (Ed.), *Caring for the elderly in Japan and the US: Practices and policies*. London: Routledge.
- Barnard, D., Towers, A., Boston, P., & Lambrinidou, Y. (2000). *Crossing over: Narratives of palliative care*. Oxford: Oxford University Press.

¹³ This distinction parallels that in linguistic analysis of, on the one hand, the speech of native speakers being grammatically sensible and, on the other, conscious oratory.

- Becker, C. (1990). Buddhist views of suicide and euthanasia. *Philosophy East and West*, 40, 543–556.
- Blackman, S. (1997). *Graceful exits: How great beings die*. New York: Weatherhill.
- Bradbury, M. (1996). Representations of ‘good’ and ‘bad’ death among deathworkers and the bereaved. In G. Howarth, & P. C. Jupp (Eds.), *Contemporary issues in the sociology of death, dying and disposal*. New York: St. Martin’s Press.
- Caudill, W., & Plath, D. (1966). Who sleeps by whom? Parent–child involvement in urban Japanese families. *Psychiatry*, 29, 344–366.
- Charmaz, K., Howarth, G., & Kellehear, A. (1997). *The unknown country: Death in Australia, Britain, and the USA*. New York: St. Martin’s Press.
- Clark, D. (Ed.). (1993). *The sociology of death: Theory, culture, practice*. Oxford: Blackwell Publishers.
- Counts, D. A. & Counts, D. R. (Eds.). (1985). *Aging and its transformations: Moving toward death in Pacific societies*. Pittsburgh: University of Pittsburgh Press.
- Deeken, A. (1996). Kirisutokyō ni okeru shiseikan (A Christian view of death). Paper presented at the annual meeting of the Nihon Seimei Rinri Gakkai, Tokyo, October 23.
- Dracklé, D. (1999). Living and dying: Images of death and mourning in the Alentejo. *Anthropos*, 94, 121–140.
- Ei, R. (1994). *Daijōjō*. Tokyo: Iwanami Shoten.
- Fan, R. (Ed.). (1999). *Confucian bioethics*. Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Feldman, E. A. (1996). Over my dead body: The enigma and economics of death in Japan. In N. Ikegami, & J. Campbell (Eds.), *Containing health care costs in Japan*. Ann Arbor: University of Michigan Press.
- Fetters, M. D. & Danis, M. (2002). Death with dignity: Perspectives on cardiopulmonary resuscitation in the United States and Japan. In: H. T. Engelhardt Jr. & L. M. Rasmussen (Eds.), *Bioethics and Moral Content: National Traditions of Health Care Morality: Papers Dedicated in Tribute to Kazumasa Hoshino*. Dordrecht: Kluwer Academic Publishers. pp. 145–164.
- Firth, S. (1996). The good death: Attitudes of British Hindus. In G. Howarth, & P. C. Jupp (Eds.), *Contemporary issues in the sociology of death, dying and disposal*. New York: St. Martin’s Press.
- Fitzpatrick, L. (1997). Secular, savage and solitary: Death in Australian painting. In K. Charmaz, G. Howarth, & A. Kellehear (Eds.), *The unknown country: Death in Australia, Britain, and the USA*. New York: St. Martin’s Press.
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Stanford: Stanford University Press.
- Glaser, B., & Strauss, A. (1965). *Awareness of dying*. Chicago: Aldine Publishing Co.
- Goldey, P. (1983). Good death: Personal salvation and community identity. *Journal of the Anthropological Society of Oxford*, 14, 1–16.
- Grossberg, J. B. (1999). Formulating attitudes towards death: A case study of a Japanese Jōdo Shin Buddhist woman. In S. O. Long (Ed.), *Lives in motion: Composing circles of self and community in Japan*. Ithaca: Cornell East Asia Series.
- Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the good death. *Mortality*, 3(1), 65–77.
- Harvey, P. (2000). *An introduction to Buddhist ethics: Foundations, values and issues*. Cambridge: Cambridge University Press.
- Hays, J. C., Gold, D. T., Flint, E. P., & Winer, E. P. (1999). Patient preference for place of death: A qualitative approach. In B. deVries (Ed.), *End of life issues: Interdisciplinary and multidimensional perspectives*. New York: Springer Publishing Co.
- Hockey, J. L. (1990). *Experiences of death: An anthropological account*. Edinburgh: Edinburgh University Press.
- Hoshino, K. (1993). Euthanasia: Current problems in Japan. *Cambridge Quarterly of Healthcare Ethics*, 5(1), 45–47.
- Hui, E. (1999). A Confucian ethics of medical utility. In R. Fan (Ed.), *Confucian bioethics*. Dordrecht: Kluwer Academic Publishers.
- Kalish, R. A. (1980). *Death and dying: Views from many cultures*. Framingdale, NY: Baywood Publishing Co.
- Kashiwagi, T. (1995). *Shi o manabu (Learning about death)*. Tokyo: Yūgaikaku.
- Kashiwagi, T. (1997). Shi o mitoru igaku (Medicine that cares for the dying). *NHK Ningen Daigaku*, January–March. pp. 1–129.
- Kastenbaum, R. (1979). Healthy dying: A paradoxical quest continues. *Journal of Social Issues*, 35, 185–206.
- Kitahara, T. (1996). Tōajia baioeshikkusu kaigi ga shimeshita mono (Characteristics of East Asian bioethics). Paper presented at Nihon Seimei Rinri Gakkai Dai Hakkai Nenji Daikai, Eighth annual meeting of the Japanese Association of Bioethics, Tokyo, October 23.
- Kōseishō. (1995). *Kōsei hakusho (Health and welfare White Paper)*. Tokyo: Kōseishō.
- Kōseishō Daijin Kanbō Tōkei Jōhōbu. (1996). *Jinkō dōtai tōkei, Heisei rokunen (Vital statistics of Japan, 1994)*. Tokyo: Kōseishō.
- LaFleur, W. R. (1989). Saigyō and the Buddhist value of nature. In J. B. Callicott, & R. T. Ames (Eds.), *Nature in Asian traditions of thought: Essays in environmental philosophy*. Albany: SUNY Press.
- LaFleur, W. R. (1992). *Liquid life: Abortion and Buddhism in Japan*. Princeton: Princeton University Press.
- Leflar, R. B. (1996). Informed consent and patients’ rights in Japan. *Houston Law Review*, 33, 1–112.
- Leich, J. (2000). Preventing hospitalization: Home hospice nurses, caregivers, and shifting notions of the good death. *Health, Illness, and Use of Care: The Impact of Social Factors*, 18, 207–228.
- Lo, P. C. (1999). Confucian views on suicide and their implications for euthanasia. In R. Fan (Ed.), *Confucian bioethics*. Dordrecht: Kluwer Academic Publishers.
- Lock, M. (1997). The unnatural as ideology: Contesting brain death in Japan. In P. J. Asquith, & A. Kalland (Eds.), *Japanese images of nature: Cultural perspectives*. Nordic Institute of Asian Studies. Richmond, Surrey, UK: Curzon Press.
- Lock, M., & Honde, C. (1990). Reaching consensus about death: Heart transplants and cultural identity in Japan. In G. Weisz (Ed.), *Social science perspectives on medical ethics*. Philadelphia: University of Pennsylvania Press.
- Long, S. O. (1999). Family surrogacy and cancer disclosure in Japan. *Journal of Palliative Care*, 15, 331–342.
- Long, S. O., & Chihara, S. (2000). Difficult choices: Policy and meaning in Japanese hospice practice. In S. O. Long (Ed.),

- Caring for the elderly in Japan and the US: Practices and policies.* London: Routledge.
- Maruyama, T. C. (1999). *Hospice care and culture: A comparison of the hospice movement in the West and Japan.* Brookfield, VT: Ashgate.
- Morikawa, I. (1995). Patients rights in Japan: Progress and resistance. *Kennedy Institute for Ethics Journal*, 4, 337–343.
- Morioka, K. (1999). Eternal engagements: Solidarity among the living, the dying, and the dead. In S. O. Long (Ed.), *Lives in motion: Composing circles of self and community in Japan* (pp. 243–254). Ithaca: Cornell East Asia Series 106.
- Morris-Suzuki, T. (1991). Concepts of nature and technology in pre-industrial Japan. *East Asian History*, 1, 81–97.
- Namihira, E. (1996). Inochi no bunka jinruigaku. (The cultural anthropology of life). Tokyo: Shincho Sensho.
- Ôgyû, H. (1995). Dôï no rinri (The ethics of consent). *Igaku Tetsugaku, Igaku Rinri*, 13, 132–139.
- Ohnuki-Tierney, E. (1984). *Illness and culture in contemporary Japan.* Cambridge: Cambridge University Press.
- Ohnuki-Tierney, E. (1994). Brain death and organ transplantation. *Current Anthropology*, 35, 233–254.
- Oki, T. (1992). *The living will in the world: Proceedings of the ninth international conference of the World Federation of Right to Die Societies.* Tokyo: Japan Society for Dying with Dignity.
- Platt, L. A. & Persico, V. R. (Eds.). (1992). *Grief in cross-cultural perspective: A casebook.* New York: Garland Publishing Co.
- Reischauer, E. O. (1988). *The Japanese today.* Cambridge: Belknap Press of Harvard University Press.
- Sakamoto, H. (1996). Tôajia seimei rinri gakkai no sôritsu (The establishment of the East Asian Association of Bioethics). *Gakujutsu Geppô*, 49, 741–745.
- Sasaki, S. (1996). “Bad death” and evil forest: Judgment on good or bad death and its logic among the Ejagham, Southwestern Cameroon. *Japanese Journal of Ethnology*, 61(1), 25–27. (English summary of article, “Warui shi” to “jaaku na mori”: Kameruun nansaibu, Ejiagamû shakai ni okeru shi no “zenaku” handan to sono rinri. *Minzokugaku Kenkyû* 61(1), 1–24.)
- Schroepfer, T. (1999). Facilitating perceived control in the dying process. In B. deVries (Ed.), *End of life issues: Interdisciplinary and multidimensional perspectives.* New York: Springer Publishing Co.
- Seale, C. (1997). Social and ethical aspects of euthanasia: A review. *Progress in Palliative Care*, 5, 141–146.
- Seale, C. (1998). *Constructing death: The sociology of dying and bereavement.* Cambridge: Cambridge University Press.
- Seale, C. (2000). Changing patterns of death and dying. *Social Science & Medicine*, 51, 917–930.
- Seale, C., & Addington-Hall, J. (1995). Dying at the best time. *Social Science & Medicine*, 40, 589–595.
- Seymour, J. E. (1999). Revisiting medicalization and “natural” death. *Social Science & Medicine*, 49, 691–704.
- Seymour, J. E. (2000). Negotiating natural death in intensive care. *Social Science & Medicine*, 51(8), 241–252.
- Shaner, D. E. (1989). The Japanese experience of nature. In J. B. Callicott, & R. T. Ames (Eds.), *Nature in Asian traditions of thought: Essays in environmental philosophy.* Albany: SUNY Press.
- Smith, R. J. (1974). *Ancestor worship in contemporary Japan.* Stanford: Stanford University Press.
- Smith, R. J. (1999). The living and the dead in Japanese popular religion. In S. O. Long (Ed.), *Lives in motion: Composing circles of self and community in Japan.* Ithaca: Cornell East Asia Series 106.
- Smith, D. E., & Maher, M. F. (1993). Achieving a healthy death: The dying person’s attitudinal contributions. *The Hospice Journal*, 9, 21–32.
- Sugita, I. (1995). Infômudo konsento to wa nani ka (What is informed consent?). *Igaku Tetsugaku, Igaku Rinri*, 13, 88–104.
- Tanida, N. (2000). Japanese religious organizations’ view on terminal care. *Eubios Journal of Asian and International Bioethics*, 10(2), 34–37.
- Traphagan, J. (2000). *Taming oblivion: Aging bodies and the fear of senility in Japan.* Albany: State University of New York Press.
- US Department of Health and Human Services. (1996). *Vital statistics, 1992.* Hyattsville, MD: US Department of Health and Human Services.
- Walter, T. (1994). *The revival of death.* London: Routledge.
- Young, M., & Cullen, L. (1996). *A good death: Conversations with East Londoners.* London: Routledge.