About fifteen years ago, my close American friend Judy died of breast cancer. A woman in her thirties, a mother of two young girls, she wanted to live. She received conventional treatment and pursued experimental therapies, even traveling to another city for an early bone marrow transplant. Sadly, none of the treatments were successful. Over the next few months, she spoke to me about hope, and she expressed her acceptance of death, asking only that she “die with dignity” in her own home.

The last time I saw her, the morning of the day she died, Judy was lying sedated on a hospital bed in the intensive care unit, hooked up to a ventilator and to a variety of tubes and monitors. What had happened? She had expressed her wishes so clearly, had a loving family, and expert medical care. My first reaction to seeing her body on the hospital bed, moving only with the ventilator, was anger that her wishes were not being honored.

Years later I heard another side of the story. In that version, Judy’s husband and parents had decided together to have her hospitalized; they recognized that she was dying but were unwilling to let it happen at home in front of her three- and eight-year-old children. Her husband and parents also needed to know for themselves that they had not given up on her when there might still be some way to prolong her life so that she could have more time with her family. My friend herself would certainly
have agreed with the values of protecting children and continuing to hope.

My initial response was perhaps an overly simple application of the bioethical principle of autonomy. This was my first lesson in the realm of dying about the gap between a voiced cultural ideal and lived experience. Long before I became familiar with the terminology of bioethics, I shared in its assumptions about the priority of the individual’s choices and the value of being aware of a terminal prognosis and thus able to talk about one’s death with close family and friends. The explanations I heard later helped me to become more aware in my own society of what as an anthropologist I already recognized for Japan: that real-life decisions are not limited to the application of explicit cultural rules or moral principles but rather are tied up with a cacophony of multiple, sometimes conflicting values and interpersonal relationships. End-of-life decisions are not unique in this regard; it is only that their consequences are more profound than many other decisions in our daily lives.

CULTURE AND DYING

Like Judy, Mrs. Aizawa was a woman in her mid-thirties who was dying. She, too, was a woman who wanted to live for her children’s sake. I met her in a specialty hospital where she was being treated for a life-threatening condition called pulmonary hypertension, in which the pressure in the arteries feeding into the lung is dangerously high while the blood pressure in the rest of the body is normal. The usual treatments for hypertension would lower her blood pressure too much before the lung pressure could be brought to safe levels; in this hospital she received special medications and oxygen. A month after I first spoke with her, Mrs. Aizawa was feeling better and receiving patient education about how to live at home with a portable oxygen tank. The last time I saw her she told me that she had already missed her children’s Cultural Day activities at school and was anxious to get back to her home, several hours away, to return to family life. But about a week later she suddenly and unexpectedly relapsed and died in spite of a desperate attempt on the part of the medical staff to save her life.

Does culture matter? Death was, of course, not a choice for either Mrs. Aizawa or Judy. Both women spent their final days on ventilators in intensive care units. Yet the way they died had to do with choice, not the autonomous decision of an individual patient but decisions resulting from a
social process of negotiation of meanings. Although in neither case could the women’s ideals, based on cultural assumptions about life and self, be fully achieved, these ideals nonetheless helped to shape their final days. The narratives of Mrs. Aizawa’s dying by those involved in caring for her suggested a process that was very “Japanese.” In contrast to my American friend Judy who “accepted” her death, Mrs. Aizawa never “gave up” on life or on her responsibilities as a mother to her children. Mrs. Aizawa appeared to have had little input into the decisions made about her final treatments but instead entrusted those decisions to the medical staff and to her husband and in-laws. And in their roles as caregivers and medical professionals, they decided to try everything to maintain her life, even if it risked a less-than-peaceful dying, a decision that seemed consistent with Mrs. Aizawa’s own preferences.

This apparent cultural difference becomes less sharp when we consider how Mrs. Aizawa might have answered years earlier, before she became ill, the question of how she would want to die, before death was acknowledged as a possibility. I suspect that like many Japanese I interviewed, dying peacefully at home surrounded by family would have been an important ideal. But in the reality of illness and dying, other compelling values were called into play. She and her caregivers drew upon alternative definitions of dying well, based on the high-tech setting and the social relationships surrounding her when she died. What seemed so “American” about my friend Judy’s approach was not only the ideal of dying at home, but also the ideal that she could talk openly about her preferences and expect that her “dignity” would be respected. Yet in the reality of her dying, family and professional medical staff redefined the ICU image of horror into a symbol of hope and love, and making the hospital a place where dying was “good” because her children were protected and her adult loved ones were with her.

Thus to understand the cultural differences in the ways these women died, we cannot rely on oppositional contrasts of Japanese and American culture. For both women, their final days were shaped by the participants’ active decisions made from among a range of choices available to them. To explain their deaths by drawing up a list of cultural characteristics neglects diversity within societies and denies agency to the humans who continually create as well as conform (or not conform) to cultural expectations. As I will describe in Chapter 6, aspects of Mrs. Aizawa’s dying are grounded in “Japanese culture,” behaviors, explanations, and a medical
insurance system that are unlikely to be found in the experiences of most Americans. Yet the specific decisions about how she died were also based on the unique constellation of her experiences: her age cohort and its place in history, her gender, her social roles, her family’s socioeconomic status, and her interpersonal relationships. A superficial look might suggest that decisions were made for her, a perception that corresponds to a stereotype of Japanese medical and familial paternalism. A closer examination shows that she died according to a cultural ideal—“dying her own way”—that could be achieved paradoxically only because Mrs. Aizawa, like my American friend, was her “self” only as she was embedded in social relationships. In both situations, the dying women and the people around them engaged in a process of negotiation of the means and meaning of death by drawing upon multiple concepts that constitute the “vocabulary” for a good death in these societies. All these factors—the technology, the social relationships, and the various ideas and meanings—are essential to understanding the relationship between the culture and the biology of dying.

CULTURE AND CHOICE

In an anthropological understanding of culture, all of human life is experienced through the lens of learned meanings and social experiences. Choice is related to culture in two ways. First, cultures vary in the extent to which choice is emphasized in ideology. Second, cultures differ in the sets of options from which people choose, and in the meanings and sanctions associated with each option.

In all societies, people make choices in their daily lives about many things, including moral questions about whether or not to follow rules or customary practices and how to behave toward others. The types of choices people make over time help define what kind of people they are within the social worlds they inhabit. Yet societies vary in their interpretations of what it means to choose and the importance of that process. The ideologies of postindustrial societies—that is, socioeconomic systems based on high-tech communication and service work—stress the need to make choices to create a desired “self.” In both the United States and Japan, people believe they have a wide range of choices in how they live their lives and are socialized to perceive that their choices define their public selves. Decisions thus become a means of expressing who we are or want to be in society. Our Enlightenment intellectual heritage, which insists on our separateness and autonomy, and our capitalist culture,
which “sells” an image of self through consumptive decisions, are elements of this focus on choice. Positioned by structural characteristics such as race, class, and gender that we cannot usually choose, we are expected, in our postindustrial ideologies, to create narratives of individuality ordered and enacted in interaction with others.

The belief that people have choices is not always such an important component of ideology. In societies where people struggle to provide a consistent food supply for their families, there may not exist a strong sense that life presents a series of options; and some ideologies suggest that individuals with little power have no right to make choices. In contrast, most of us who have grown up in middle-class or affluent homes in postindustrial societies probably assume that choices are a “natural” part of living as a human being. We may note great technological developments that appear to offer us almost unlimited choice as consumers: cars and washing machines in past decades, and now computers, $15 watches, designer clothes, DVD players, and SUVs. Perhaps we also recognize the increasing choices we have regarding where to live, what type of occupation we will pursue, who (and whether) to marry, what brand of laptop is best for our needs, and what television show we will watch at 8:30. Historical change has brought us new options and this heightened sense of choice. We may be responsive to pressure from family and friends, but we generally consider ourselves free to select from among the alternatives as individuals. American egalitarian ideology avoids confronting the larger social structural context; although this ideology encourages us to consider and even reject constraints such as those of gender and race, we often do not recognize constraints on our choices imposed by our political-economic system, social structure, interpersonal relationships, and cultural symbols and metaphors.

In recent decades, how to die has been added to the realm of what we can choose. Death has been medicalized and technologized; our options appear to be expanded by new technology and new institutional structures. A cancer patient, along with her doctors and family, decides whether to continue apparently futile aggressive therapy or to obtain hospice services. As a society we shape these choices by our allocation of financial and human resources. An individual may choose to reject food and water, while our society decides whether to make physician-assisted suicide a legal option. Since both decisions are based on values concerning suicide and autonomy, individual choice and societal choice are in fact
interdependent. Anthropologist Hikaru Suzuki’s work on the commercialization of funerals in Japan points out that both levels must be considered in the context of postindustrialism. Thus, although this book focuses largely on choice at the individual and interpersonal levels it is important to keep in mind the way that conscious societal choices, such as health care policy, constrain the options people can exercise in their daily lives.

The core bioethical principle of autonomy can be readily understood as an American interpretation of the project of constructing selves through choice, a process generally defined by legal and philosophical discourses. These discourses have tended to value the solitary mental process of construction more than the interactive elements of self. But the creation of consistent narratives of self through lifestyle choices is a postindustrial phenomenon broader than the concept of autonomy. Japan is undoubtedly postindustrial, yet has historically not had an ideology of autonomy and egalitarianism but rather one of smooth interpersonal relations. Thus although Japanese society shares in assumptions of choice, at least some Japanese versions of “choice” are not the same. Autonomy is itself an option in Japan, among other culturally legitimate ways of making choices. What might bioethics look like in a postindustrial society that values choice, but where choice does not always mean autonomy? What if autonomous choice is just one possible way to make decisions?

People choose from among differing sets of options that are culturally defined. Whether choice is appropriate in a given situation and by whom choices should be made are cultural rules. Consequences follow from some choices and not others depending on how decisions are interpreted and evaluated by others. Even among different people in the same society, there is variation in what we think ourselves capable of deciding. In contemporary affluent societies, some people may believe they are the decision-makers about all aspects of their lives; others accept small choices, such as what to have for dinner, but attribute major life directions to super-human forces such as God or fate and reject the project of active self-construction described by Giddens. Others believe they are making choices when in reality they have little control over their situation, for example “choosing” to die at home when insurance will no longer cover hospitalization.

Within and among postindustrial societies, there is also variation in whether or not we perceive a specific option as viable (eating squid for
dinner, for example), in choices that are possible in our society but not for us (buying a million dollar house), and in our attitudes toward the various options before us (whether or not to have children, or whether to leave the question to fate). We are aware of some of these perceptions and attitudes; many, however, are not conscious, and we may not realize we hold them until we meet people who do not share them. I never imagined that fish and seaweed were breakfast food, and I had not even heard of miso soup until I went to Japan for the first time as a teenager. Now young Japanese probably think of fish and miso soup for breakfast as an old-fashioned option; for their grandparents it was assumed that this was what you ate if you could afford it. The meaning of the option has changed, as have culturally constructed categories of difference such as social class, age categories, and gender.

Options for how to die are not universally available even when choice is considered appropriate. In the state of Oregon, physician-assisted suicide is a legal option not available in the rest of the country. Hospice care is available for the many Americans who wish to die at home, but the relatively recent development of home hospice in Japan and the strong emphasis on caregivers “doing everything” means that the feasibility and meaning of that choice is different in Japan. But the availability of this option will change as more hospice programs come into being.

CHOICE AND DYING IN POSTINDUSTRIAL SOCIETIES

Culture encourages the development of certain technologies, establishes a system of conventional meanings, and represents a set of interpersonal consequences for various choices. But postindustrial societies specifically provide multiple technologies, multiple meanings, and variation in the responses of others to an individual’s choice. British sociologist Clive Seale suggests, with regard to dying, that people in Anglophone countries have multiple “cultural scripts” available to them. These provide different narratives of dying well, though they may not have equal status or power. Seale stresses that these scripts are not determinitive, but rather should be considered raw materials that may be strategically—though not always consciously—used in particular situations.” The availability of particular scripts depends in part on circumstances beyond the individual’s control, such as his or her social class, gender, and age; available scripts may be circumscribed by the illness, such as a palliative care script
limited to cancer or AIDS patients. Moreover, individuals respond to death differently and their use of scripts is also based on the choices they make in dealing with their circumstances. James Agee in his 1938 novel *A Death in the Family* portrays how each member of an extended family in Knoxville, Tennessee in the early twentieth century experiences and responds to the death of a man in his late 30s. His wife, young children, deaf mother-in-law, and other relatives attribute a variety of meanings to the automobile accident that caused his death and to the death itself. Individually and collectively, they struggle to redefine the tragedy as a “good death.”

Thus, multiple scripts of good death are embedded in the larger cultural systems. People choose (and are constrained from choosing) from among the concepts and narratives in these scripts to model, interpret, and justify behavior surrounding the process of dying. The types of scripts Seale describes can be found in Japan as well as in Anglophone countries but with variations reflecting differing historical traditions (see Chapter 4). The similarities result from the technology, dying trajectories, and the project of self-identity construction that are common to postindustrial societies, as well as from common human needs and emotions. National differences between the scripts explicated by “experts” from government, media, or academia are only part of what anthropologists mean by cultural difference. They also consider the more equivocal ways ordinary people use a variety of scripts to interpret their experiences with illness, dying, and death. In accordance with the ideal of choice, ordinary people rarely perceive a single correct script to be followed. Rather they recognize 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.

The bioethics literature often exhibits a dependence on expert definitions of a single script to define, for example, “the Japanese view of euthanasia,” failing to recognize the existence of multiple scripts. They also neglect the gap between ideals or rules of how things “should” work on the one hand, and the way ordinary people actually live their lives on the other. Most contemporary scholars who study the clinical bioethical issues discussed in this book have taken the former approach, making normative arguments about how people should decide. My concern is primarily with the latter, with how ordinary people act and think about dying and the new options that have become part of contemporary life. This ethnogra-
phy focuses on issues raised by clinical bioethics, describing rather than prescribing end-of-life decisions in Japan. It examines the ramifications of disclosure, withholding and withdrawal of treatment, organ donation from those who are brain dead, euthanasia, and pain management in Japanese social and medical practice.

Readers might challenge my focus on these bioethical categories as imposing Western concepts onto Japan, but in fact all of these are recognized as “social issues” or “ethical dilemmas” in Japanese writing by academics, clinicians, and the media. Public opinion polls, interviews, and coverage of “events” are framed in these terms in contemporary Japan. This is an example of the globalization process discussed by Arthur Kleinman, in which various scripts have symbolic value by virtue of their association with what is “modern” or “Western.” Since most writing in Japanese bioethics is normative (as it is in the United States), this book attempts to expand the frame of discussion to the broader context of these issues and describes multiple Japanese scripts and the ways they are experienced by ordinary people. I identify alternative interpretations and explanations, show conflicting values, and emphasize the importance of negotiating decisions through social relationships (institutional and interpersonal) to understand the difficulty of real-life decisions and the diversity of responses despite strong hegemonic pressures toward a particular cultural script presented by “experts” as “modern,” “Western,” or “correct.”

Choosing, then, unlike autonomy, is not necessarily an individual mental act creating a clear hierarchy of value priorities such that future decisions become obvious. Rather, it is the process of recombining elements of various cultural scripts, themselves symbolic, that are available in post-industrial societies and then enacting them in relations with others. This process is closer to using language than to constructing a mathematical proof. To speak, we construct meaningful utterances using available sounds and their combinations that are designated as significant in a particular local context. For dying, numerous locally understood elements come together to create the meaning of its process. An example is the preference for the presence of family at a death in an intensive care unit, which draws simultaneously on the scripts of high-tech medicine and the cultural significance of family relationships. Although people can create new combinations of elements from various scripts, there are constraints on that creativity if it is to be meaningful. A shaman might be invited to
invoke spirits in a terminally ill Hmong patient’s hospital room, but bringing in a bridal consultant would make no sense.

Choices are constrained by what is possible in a given environment: in language, by the sounds that a human can make; and in dying, by access to resources and in the institutional arrangements available for specific diseases. Options are also limited by what is recognized. There must be at least a minimally shared system of meanings because language and dying are both social processes. Choices are further influenced by the values attached to particular options and their consequences, for example using a swear word in language or helping a dying person to end his or her life. In other words, decisions made about the end of life must be understood not as “cultural” in the narrow sense of the beliefs espoused by a particular population, but rather, as the totality of the choices people make, choices influenced by social structure and economic relations, by sets of minimally shared meanings, and by relationships. In bioethics, the American emphasis on autonomy masks both the real limits to individual decision making and the wider meaning of choice-in-context in a postindustrial society. The study of dying in Japan refocuses the lens so we see choice as a social process.

**ORDINARY PEOPLE AND BIOETHICAL CHOICES**

What follows is thus both an ethnography of the final days or months of life in Japan, and at the same time, an investigation of the social and cultural nature of end-of-life decisions in one postindustrial society. Both Mrs. Aizawa and my American friend Judy were “ordinary people,” in that they had no particular expertise in medicine or in dying. They were not famous, nor were they trendsetters or opinion leaders. This book is mainly about people like them. In the next chapter I describe how anthropologists pursue cultural analysis, exploring structure, meaning, and social interaction. Choice in Japan, as in other postindustrial societies, concerns consciously creating personhood, but we must also consider how such personhood is constrained and enacted in social context.

The subsequent two chapters introduce the framework in which dying takes place. Chapter 3 outlines the demographics, institutions, and technology of dying in Japan, the country with the world’s longest life expectancies and a distinctly postindustrial pattern of causes of death. Access to advanced medical technology and financing through a univer-
sal medical insurance system impacts decisions about how death occurs. Chapter 4 describes some of the words, metaphors, and sometimes contradictory narratives of dying that ordinary people draw upon in thinking about what constitutes a “good death.”

The following section of the book raises questions familiar to bioethicists. Chapter 5 addresses the question of who makes decisions about a dying patient in Japan, challenging the universality of “Western” interpretations of autonomy through a negotiated definition of “dying one’s own way.” In Japan, the issue of informed consent, as well as disclosure of diagnosis and prognosis, have become matters of public discourse. Yet despite an emerging consensus about the desirability of knowing and deciding for oneself, practices and interpretations of them remain diverse, reflecting varying understandings of the nature of selfhood in Japan.

Chapter 6 explores the use of high-tech treatments at the end of life. Regardless of their own ideas about “dying well,” Japanese physicians are not encouraged to discuss end-of-life decisions with patients and colleagues due to their professional mandate to preserve life at all costs and the structure of Japanese hospitals and medical careers. Ultimately, decisions about withholding and discontinuing treatment suggest that the “goodness” of a death has much to do with the quality of relationships among patient, family, and physicians. Multiple definitions offer a range of meanings from which the interpretations of good or bad dying are created.

For several decades leading up to Japan’s Brain Death Law of 1997, the Japanese media prominently debated the notion of brain death and the related practice of vital organ transplantation. Some North American scholars who have followed this debate have emphasized the political-economic causes of earlier Japanese resistance to recognizing brain death; others have focused on concepts of self and social relationships in Japan. Chapter 7 reviews these arguments from the perspective of ordinary people’s ideas and the experience of two patients, an American woman who turned down the opportunity for a transplant and a Japanese man who was, before the Brain Death Law, living on an artificial heart. They teach us the dangers of cultural stereotyping without investigating the availability of resources and the limitations on individual choices.

Postindustrial technology has also provided new options for the end of life. Chapter 8 presents a gamut of ways to deal with a less-than-ideal dying. Hospice, at one end of the continuum, and euthanasia at the other
are both laced with ambivalence. Distinctions taken for granted by bioethicists such as that between euthanasia and physician-assisted suicide are not part of the common discourse on these matters, nor is the concept of hospice widely understood as it is in the English or U.S. contexts. Yet ambiguity provides space for negotiating how to die and for interpreting the deaths of others.

Chapter 9 returns to the question of culture and choice. Japanese today do not have a “Japanese way to die” despite wide consensus on some bioethical issues. New ways to die mean new layers are added to older narratives of dying, from which people construct the meaning of life. Emphasis on “dying one’s own way” is not limited to the hospice approach. Euthanasia, organ donation, and more ordinary decisions about sharing knowledge and discontinuing treatment are ways to negotiate control and meaning for dying patients and for survivors. To understand this process, we need to consider “Japanese” ethical principles and also the constraints of the medical system, the use of new technologies, social relationships, and the meanings of death and of self. Choice implies the existence of alternatives; the social embeddedness of self implies ambivalence about those alternatives.

**WHAT WE LEARN FROM THIS STUDY**

This book uses common bioethical issues to frame an investigation of how contemporary Japanese make choices about dying in an era of expanding options and changing technology, meanings, and social relationships. What can we learn from studying decisions about dying in Japan?

First, we can learn something about Japan, moving beyond stereotypes of samurai slashings and Buddhist meditation as cultural models of dying. As a wealthy postindustrial society, Japan shares in the technology that provides the full range of contemporary options for how to die. Its values incorporate the “reflexive project of self” that Giddens claims is characteristic of postindustrial society, yet differences in the allocation of resources at the societal level have also resulted in consequences for Japanese patients’ and professionals’ choices that differ from those of their North American or northern European counterparts. There are also historically derived differences in the construction and maintenance of social relationships, and in Japanese assumptions and values that lead to differ-
ing interpretations of the various options. By studying Japan we can learn through contrast about ourselves, and this is the second benefit of examining how Japanese act, think, and make decisions in their final days.

In addition, this research helps us grapple with the gap between formal cultural rules and what ordinary people do. In our own society, we may be unaware of unconscious assumptions, and cultural messages may be thought “natural” or “normal.” We tend to judge those whose views differ from our own perspective as alien or wrong. Issues such as euthanasia or abortion quickly become politicized. By stepping out of our own cultural setting and studying another, one which in some ways is quite similar to ours but in which we are not so personally involved, we can begin to recognize complexity and ambiguity, rather than seeing issues as black-and-white. When we confront a critical situation in our own lives, we might want a simple solution, and others may wonder why we can’t make a clear choice. Policy-makers and professionals might prefer clear guidelines and rules that can be implemented unambiguously, but the process of hashing out such policy in a pluralistic society has proven difficult. What we see by looking at Japan is that ambiguity is normal. Ordinary people do not live their lives making simple consistent decisions in all situations. Cultural messages are multiple and conflicting, personal choices have consequences, meanings change, feelings may be ambivalent, and we can rarely stack our values into a consistent set of neatly ordered priorities.

While people are responsive, positively or negatively, to the discourses of experts and the media, cultural change requires the accumulation of experience and decisions before new behavioral patterns can emerge and new interpretations are widely shared. A diversity of views and ambiguity, then, should not be understood as obstacles to the moral life of a society, but rather as the raw material from which people can construct meaningful deaths, and thus meaningful lives.