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## Introduction: Issues at the End of Life

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Until recent decades, death and the dying process were largely a matter of private decisions made within specific religious and cultural frameworks. Increasingly, however, questions of how societies make decisions about the ending of life have become a matter of public policy and of ethical debate. Advances in medicine have the capacity to extend life indefinitely, but often with poor quality and escalating dependence on medical technologies. Demographically, the aging populations in most developed countries and the increasing incidence of AIDS and other chronic diseases in developing countries promise to complicate end-of-life decision making in the coming decades. As a growing proportion of societal resources are concentrated at the end of people's lives, the ethical and policy issues are bound to intensify. Thus, the more we can understand and debate the issues now, the better the chance we will have of dealing with their mounting consequences for all countries.

The literature on treatment of terminal patients, euthanasia, brain death, and other issues related to dying has expanded significantly in recent decades (for example, see Webb et al. 1997; Olick 2001; Wijdicks 2001). There remains, however, a paucity of publications on how these issues are handled across countries. Furthermore, the few cross-national studies that have been published usually include only several countries, particularly Western ones (e.g., Sass et al. 1998). This book brings together policy experts from a wide array of countries in all regions of the world to examine how these countries are coping with end-of-life issues. How are the issues defined? What is the level of debate? How are terminally ill patients treated by their respective health care systems? In light of demographic patterns, increasingly scarce health care resources,

and an expanding array of lifesaving technologies, decisions affecting the end of life are becoming problematic matters of public and thus scholarly concern in most countries.

### **Issues Surrounding End-of-Life Decision Making**

There are numerous multidimensional issues that together define the context of policy making on end-of-life issues. Although most attention in the West has focused on the elderly as terminal patients, in some countries the major focus might be on younger adult AIDS patients or on children dying from malnutrition or infectious diseases. Another important category of cases, although much smaller in number, consists of critically ill or extremely low birth-weight babies. In each of these categories, the responses to the problems they present can vary significantly across countries. Basic questions relate to what institutional services exist for care of the terminally ill; how, where, and by whom these patients are treated; how aggressive and costly the treatment regime is (e.g., the availability of intensive care units); who makes the final decisions as to level of care given; and who pays the escalating costs of dying.

More specific questions relate to the availability of medical specialists and adequate pain management, palliative care, and hospice services. The World Health Organization defines palliative care as

the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families. (World Health Organization 2002: 1)

According to the Center to Advance Palliative Care, a national initiative supported by the Robert Wood Johnson Foundation at Mount Sinai School of Medicine in New York, hospice care is an organized program for delivering palliative care. Hospice care may be provided in either a facility or the home, but the basic concept is one of comprehensive care for the dying. Although the physical facilities may be very extensive or quite minimal, according to the American Academy of Family Physicians (2003) it should include control of pain and other symptoms, psychosocial support for both the patient and family, medical services commen-

surate with the needs of the patient, and specially trained personnel with expertise in care of the dying and their families. What types of hospices operate and what level of palliative care and pain management are accessible to the dying in different countries?

Conversely, what, if any, boundaries or cutoff points exist for aggressive treatment of a particular category of patient, whether an extremely premature infant, an end-stage AIDS patient, or a terminally ill elderly patient? Also, where do individuals generally die? In intensive care units, hospital wards, nursing homes, hospices, or at home? Moreover, who funds this care and who ultimately makes the life-ending decision in cases where the patient is unable to so? Doctors, the family, ethics committees, the government, or some or all of these?

Accompanying the medical dimensions of policy making for the end of life are the social and legal aspects. In some Western countries, considerable emphasis in recent decades has been directed toward empowerment of the patient or patient autonomy. A wide variety of legal mechanisms have been created toward this end. Prominent among these advance directives are the living will and the durable power of attorney. The goal of advance directives is to return to the individual the ability to control the dying process, primarily by refusing life-extending interventions. However, they also contain a resource allocation dimension and in virtually all cases are designed to specify limits on continued treatment and expenditures; they are not a demand for extended intervention.

Related to advance directives are various policy initiatives and debates over the concept of euthanasia, itself loaded with complex and varied meanings both within and across cultures and countries. Some commentators distinguish between passive and active; voluntary and involuntary; and other categories of euthanasia, thus allowing for support of some but not other types (table 1.1). Others argue that such distinctions are artificial and that all forms of euthanasia are morally wrong and thus must be outlawed. Still others argue that the distinctions are of little help and that individuals should not be precluded by law or moral codes from making their own choice as to how and when to die. Although the most vehement opposition to euthanasia tends to center on those cases where the active assistance of a third party is required, the debate over doctor-assisted suicide frequently is deliberately linked with cases involving the

**Table 1.1**  
Categories of euthanasia

	<i>Passive</i> Omission of measure to prolong life	<i>Active</i> Direct inducement of death
<i>Voluntary</i> With patient's express and informed consent.	<i>Passive Voluntary</i> Conscious <i>and</i> rational patient refuses life- prolonging treatment and request is granted.	<i>Active Voluntary</i> Conscious <i>and</i> rational patient requests and is given lethal injection.
<i>Speculative</i> Without express and informed consent (i.e., comatose patient, infant, dementia patient).	<i>Passive Speculative</i> Cessation of life- prolonging treatment for patient unable to give informed consent.	<i>Active Speculative</i> Lethal injection administered to patient unable to give informed consent.
<i>Involuntary</i> Against the express directions of the patient.	<i>Passive Involuntary</i> Cessation of life- prolonging treatment of conscious and rational person against his or her will.	<i>Active Involuntary</i> Lethal injections administered to conscious and rational patient against his or her will.

Source: Blank (1995: 163).

withholding or withdrawing of treatment, thus again clouding the lines between passive and active types of euthanasia. The question remains as to how different countries define and deal with euthanasia.

Another challenging issue is how we define the death of a human being. In response to the development of life-sustaining technologies and the need for organs for transplantation, some countries have moved to a legal definition of death as brain death. There are two critical dimensions to this issue. The first is the conceptual interpretation of what death means in the context of medical technology, since the traditional understanding of death as the irreversible cessation of cardiopulmonary functions can be "clouded by technological means of prolonging those functions in patients" (Weir 1989: 292). The second dimension centers on the appropriate clinical tests to be used to determine that a patient is in fact dead, especially when the patient's life has been prolonged by technological means. Because technologies in both of these areas are

advancing rapidly (in the first instance, life-sustaining technologies and in the second, diagnostic technologies that indicate the presence or absence of specific types of activity in particular regions of the brain), and because of the linkage of brain death to the availability of organs for transplantation, the definition of death has become a contentious issue, and one that is likely to vary from country to country.

A broad array of end-of-life issues, therefore, from how and where the dying are treated, to who makes the decision to withhold or abate treatment or allow physician-assisted suicide, and to how we define and measure death elicit considerable public and professional debate. This is not surprising because decisions on the ending of life are among the most intensely emotional and ethically charged issues. Critical to understanding these issues in a broad sense is the extent to which they are common across nations and cultures or, contrarily, vary from one country to the next.

This book is an attempt to provide a foundation for more in-depth study of the issues by placing end-of-life decision making in a comparative context. Although it is dangerous to uncritically apply policies that appear to work in one country to another country, cross-national research is useful in expanding the range of options open to policy makers and in allowing them to explore the experiences of their counterparts in other jurisdictions in dealing with similar problems. Ovretveit (1998), for instance, argues that travel and information systems are making it both easier and more necessary to understand cultural and national differences. Likewise, Harrop suggests that “by examining policies comparatively, we can discover how countries vary in the policies they adopt, gain insight into why these differences exist, and identify some of the conditions under which policies succeed or fail” (1992: 3).

Comparative studies also give us cross-cultural insights as to what works or does not work in a wide variety of institutional and value contexts. Why do factors that might be viewed as overpowering in one national context, such as the attitudes of the citizens or the medical profession, result in different outcomes elsewhere? According to Immergut, the “comparative perspective shows that some factors are neither as unique nor as critical as they appear, whereas others stand out as truly significant” (Immergut 1992: 9). Ham (1997) adds that an examination

of international experience is useful in demonstrating the difficulties faced by and the wide range of approaches available to policy makers. Given the complexity of these issues, only knowledge of what is happening in many countries can generate the evidence necessary to consider the full array of options.

Studying the issues across many country settings can also illuminate the commonalities of problems and variables across countries. Although at some level policy surrounding the end of life might be unique to each country, one cannot ignore the globalization of problems and potential solutions. Immediate transmission of knowledge about new medical technologies through the mass media raises public and professional expectations and demands for access to those innovations. Through the Internet, people can become informed about the newest treatments available elsewhere in the world, and public demands for them can rise accordingly. Citizens can also shop across national boundaries to determine where certain practices, such as doctor-assisted suicide, are legal. Likewise, international medical conferences and journals transfer technologies and knowledge quickly from one side of the globe to the other, thus working to globalize professional standards.

Some observers argue that these global forces reinforce the convergence theory, which posits that as countries industrialize they tend to converge toward the same policy mix (Bennett 1991). The convergence thesis would suggest that end-of-life policies across disparate country environments would have a tendency to become more similar over time as the countries develop economically. Gibson and Means (2000), for example, argue that recent restructuring has led to convergence of the health systems of Australia and the United Kingdom despite quite dissimilar goals and strategic emphases. Based on an examination of trends across industrialized democracies, Chernichovsky (1995) agrees that despite the variety of health care systems, health system reforms have led to the emergence of a universal outline or paradigm for health care financing, organization, and management.

Critics of convergence theories, however, argue that they oversimplify the process of development and underestimate significant divergence across countries (Howlett and Ramish 1995). Convergence, they argue, downplays the importance of country-specific factors other than perhaps

economic development, and most studies that find evidence of convergence do not find it applicable across the board, thus allowing for divergence in other areas. This book does not attempt to test the convergence theory, but its current prominence in the literature dictates that its appropriateness to end-of-life policy be addressed in the concluding chapter.

## Organization of the Book

This book brings together ethical and policy experts from a range of countries in order to examine how end-of-life policies vary across these countries, what country-specific factors influence these policies, and how terminally ill patients are treated by the respective health care systems. As such, it is hoped this volume will fill a void in the literature, which although it is extensive, contains few works that look at a full range of these issues across more than several nations. Even the broader literature on comparative health policy has tended to include only industrialized, primarily Western, countries, thus giving a skewed picture of the problems and context. As a result, the conceptual debates over various health policy issues, including end-of-life decision making, have become largely framed by Western practices and values. The objective here is to expand the prevailing boundaries of comparative study by including countries that represent a wide range of cultural, economic, and ideological dimensions.

The chapters that follow make it clear that ethical issues as framed in affluent countries dominated by a liberal and capitalist value system cannot easily be extrapolated to countries with less individualistic cultures or lacking the economic resources necessary to achieve such ends. Although there is considerable variation across Western nations (and in some cases within them) regarding end-of-life policies, these differences are even starker in this broader sample of countries.

In order to provide a starting point for discussion and facilitate comparative data, chapter contributors were asked, where possible, to address these questions and issues:

1. What are the estimated costs of dying, per person and in aggregate?
2. What proportion of health care costs is expended in the last 6 months of life? The last 3 months of life?

3. What proportion of the population dies in intensive care units, hospitals, hospices, homes?
4. What proportion dies with some form of advance directive? What forms of advance directives are available? Are they binding?
5. What is the level of availability to pain management?
6. What is the mix of high technology and palliative care?
7. What are cutoff points for aggressive care? Who decides? What is the legal definition of death?
8. What government policies, if any, are operative in end-of-life decisions?
9. What policies, if any, are there for assisted suicide or euthanasia?
10. What agents are most responsible for making these decisions (a government agency, the medical community, ethics committees, the family)?
11. What role does age play, if any, in decisions at the end of life?
12. What factors unique to the country (cultural, social, religious, economic, etc.) are critical for understanding end-of-life decision making in that country?

In the end, the emphasis given to each question varied widely across the chapters, as discussed in more detail in chapter 14. The fact that many authors were unable to uncover even rough data on many of these factors, especially on the first four questions, is itself important in demonstrating the variation in the state of end-of-life policy across these countries.

In order to provide a broad range of studies, the countries in table 1.2 were selected. They represent a good mix of economic, religious, and cultural contexts and are about equally from the West and non-West. They range in population size from 6 million in Israel to more than 1 billion each in India and China. There is also substantial variation along economic lines. While European countries, Japan, and the United States all have a per capita gross domestic product (GDP) of over \$20,000, with the United States highest at \$33,900, India and Kenya have less than a tenth of that figure at \$1,800 and \$1,600, respectively. Similarly, while Japan, Taiwan, the Netherlands, and the United States have unemployment rates running under 5 percent, the rate for Kenya is 50 per-



**Table 1.2**  
Countries studied and selected variables

Country	Population (millions)	Gross domestic product per capita (US\$)	Unemploy- ment rate (percent)	Population under 15 years (percent)	Population over 65 years (percent)	Life expectancy at birth (years)	Infant mortality (deaths/ 1,000 births)
Brazil	172	6,150	7.5	29	5	62.9	38.1
China	1,260	3,800	10.0	25	7	71.4	28.9
Germany	83	22,700	10.5	16	16	77.4	4.8
Israel	6	18,300	9.1	28	9	78.6	7.9
India	1,014	1,800	na	34	4	62.5	64.9
Japan	126	23,400	4.7	15	17	80.7	3.9
Kenya	30	1,600	50.0	43	3	48.0	68.7
Netherlands	16	23,100	3.5	18	14	78.3	4.4
Taiwan	22	16,100	2.9	22	8	76.4	7.1
Turkey	66	6,200	7.3	29	6	70.1	49.9
U.K.	59	21,800	6.0	19	16	77.7	5.6
U.S.	275	33,900	4.2	21	13	77.1	6.3

Source: Data from *World Factbook* (2003).

Notes: All numbers are for the year 2000, except GDP and unemployment, which are for 1999. na, not available.

cent. Although these indicators fluctuate from year to year, the relative states of these economies are consistent by country, a factor that is bound to have an impact on the way in which end-of-life decisions are made.

In terms of health, two variables that serve as very rough indicators of the health status of a population are life expectancy at birth and infant mortality rates. Life expectancy is 80.7 years in Japan and over 78 in Israel and the Netherlands. In contrast, life expectancy in Brazil and India is approximately 62 years, and in Kenya it is only 48 years. Likewise, infant mortality rates vary widely, from 3.91 deaths per 1,000 births in Japan to more than 60 per 1,000 births in India and Kenya. Moreover, it might be expected that countries with rapidly aging populations face different pressures than those with relatively young populations. Among our countries again there is wide variation. Countries such as Brazil, Turkey, India, and especially Kenya have extraordinarily high proportions of their populations under age 15, while countries such as Germany, the United Kingdom, and Japan are dealing with large older populations.

Likewise, cultural factors and social values vary across countries, and in some cases are most crucial for end-of-life policy. Values dominant in the West such as individual rights, lifestyle choice, and the dependence on technology to fix all problems, including death, are not universals, despite what much of the bioethics literature assumes (for exceptions, see Alora and Lumitao 2001, and the work of Macer 1998). Moreover, there may be strong cultural and value divisions within a particular country that are important in defining policy. Religious factors are particularly critical dimensions for death-related policies, and in some countries they are the single most important factor. Moreover, social structures can be central to care of the terminally ill and in setting the boundaries of such care. In many countries, extended families and communities still have a central role to play, while in other countries even the nuclear family seems to play a limited role in care giving.

Overall then, the countries represented here offer a wide range of contexts for studying end-of-life policy. We leave it up to the individual authors to describe in more detail the critical cultural, religious, and other factors that affect the end-of-life debate in their respective countries

and return briefly in the concluding chapter to discuss the findings as related to the themes and issues.

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