Unequal Before Death

Unequal Before Death

Edited by

Christina Staudt and Marcelline Block

This volume is published with the generous support of
The Schoff Fund of the University Seminars at Columbia University

CAMBRIDGE
SCHOLARS
PUBLISHING

Unequal Before Death,
Edited by Christina Staudt and Marcelline Block

This book first published 2012

Cambridge Scholars Publishing

12 Back Chapman Street, Newcastle upon Tyne, NE6 2XX, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

Cover image: Eugène Delacroix, *Hamlet and Horatio in the Cemetery*, 1839.
Oil on canvas, 81 x 65 cm. Louvre, Paris, France. Réunion des Musées Nationaux/Art Resource, NY.

In William Shakespeare's *Hamlet* (Act V, scene 1), two clowns digging a grave for Ophelia, who had drowned, debate whether she is deserving of a Christian burial. Did she or did she not commit suicide? The answer would determine the manner in which her corpse is laid to rest. As Hamlet and Horatio arrive at the cemetery, the first gravedigger/clown exhumes a skull, revealed to be that of Yorick, formerly the king's jester, thus prompting Hamlet to recall, "Alas, poor Yorick! I knew him…a fellow of infinite jest, of most excellent fancy. He hath bore me on his back a thousand times, and now how abhorr'd in my imagination it is!" Delacroix's painting captures the moment of discovery of Yorick's skull. Delacroix started, in 1834, to make a series of sixteen lithographs illustrating *Hamlet*, one of which, "Hamlet and Horatio Before the Grave Diggers" (1843) is of the same scene depicted in the 1839 oil painting reproduced on the cover of *Unequal Before Death*.

ISBN (10): 1-4438-3792-X, ISBN (13): 978-1-4438-3792-7

To Our Mothers

TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

ACKNOWLEDGMENTS

An anthology is a collaborative effort. Our respect and gratitude go first and foremost to the thoughtful, knowledgeable scholars and writers who have contributed chapters to this volume. We have enjoyed working with them and have learnt a great deal from the insights they share in this book.

Additionally, several of the authors are Members and Associates of the Columbia University Seminar on Death, which sponsored the second biennial Austin H. Kutscher Memorial conference, with the eponymous title Unequal Before Death, in March 2010. This book is based on earlier versions of the papers presented at that conference. We wish to thank the conference committee for coordinating the forum with so much enthusiasm and dedication. Michael Bartalos, who was then a co-chair of the Seminar on Death, Tom Caffrey, Nathan Ionescu, Kevin Keith, Jerry Nessel, John Kiernan, Maureen Landry-O’Reilly, Jerry Piven, Sherry Schachter, Lesley Sharp and Margaret Souza selected papers of the highest quality, organized panels facilitating the exchange of ideas, and coordinated sessions with grace and sharp intellect. Our warm appreciation also goes to the conference coordinator, Pamela Guardia, who handled the logistics with much efficiency.

We extend our gratitude to Columbia University Seminars for their intellectual and financial assistance and are especially grateful for the encouragement and guidance of its past and current Directors, Robert Belknap and Robert Pollack, as well as for the unfailingly cheerful help and support of Alice Newton, its associate director. Our deepest appreciation goes to the generous financial support from the Schoff Fund of the University Seminars at Columbia University, which contributed resources to bring this volume to fruition. We are most indebted to Elan Lipson for his wonderful design work on the images in the book as well as his stunning cover design.

We are truly grateful to Carol Koulikourdi, Amanda Millar and Soucin Yip-Sou at Cambridge Scholars Publishing for their invaluable and extraordinary assistance, support and guidance every step of the way in seeing this book published.

Finally, we thank our colleagues and students for the stimulation they bring us and for their reinforcement of our belief that addressing issues around the end of life is worthy of time and energy. For the patience and

good humor they exhibit as we labor through late nights and for the sustenance of all kinds they constantly provide us, we are deeply indebted to our families and close friends.

Christina Staudt and Marcelline Block, Editors
New York City, February 15, 2012

INTRODUCTION: THE GREAT “EQUALIZER”?

CHRISTINA STAUDT

Death has been deemed the “great equalizer,” but each journey towards our shared, ultimate fate is unique. The length of our lives, our trajectories to the end, the quality of our last days, how our deaths are perceived by others, and the handling of our remains are governed by nature and a host of man-made agencies.

Our genetic make-up predisposes our body to a path of deterioration that is modified by our natural and social environments. Ethnicity, gender, and age have constituent roles in shaping our lives and how they end, as do family and group belonging. Acquired economic and social assets—wealth and income, education and occupation, as well as social status—furnish diverse resources. Our cultural and religious affiliations mold our attitudes toward death and dying and combine with our psyches to influence how we experience and prepare for the last period of our lives. Where we live influences our access to care and support systems, as well as our risk of deprivation and disaster. Our homelands’ histories, their legal systems and socio-political regimes, the media, and other power centers regulate the relative importance of these elements and construct advantaged or disadvantaged individuals and groups. The favored ones receive access to affordable healthcare and are empowered with knowledge and support. The less fortunate lose on those fronts, have shorter life spans and are, additionally, burdened by a disproportionately high risk of dying by violent, traumatic causes, in personal conflicts, wars, and natural disasters.

Examples of inequalities that affect people in different settings are plentiful: In the United States, the death penalty is more likely to be meted out to African-Americans than to people of other races; patients in urban not-for-profit hospices receive more palliation than those in rural for-profit hospices; homosexual partners are denied the right to a common burial plot. In developing nations, people are more likely to die of environmental causes, pandemics, and preventable diseases than in industrialized nations and within many so-called “poor” nations, the gap between the haves and the have-nots can be a chasm.

*

This book addresses inequalities surrounding death from the perspective of experts in a range of humanistic and social science disciplines. The majority of the chapters are revised versions of papers presented at a conference, entitled “Unequal Before Death,” organized by the Columbia University Seminar on Death in March 2010 and attended by professionals in academia, healthcare and the not-for-profit sector. The purpose of this collection is to bring attention to the many inequalities affecting the end of life experience and to encourage collaborative research and action that can improve the experience of the dying and those around them.

This volume does not question the truism of death as the ultimate equalizer but rather, seeks to explore the many ways in which the final journey is not equal. My aim in this introductory chapter is to frame the theme of inequality and death by reviewing a number of disparities that influence life spans and shape the range of experiences at the end of life for the dying and those around them. In the process, I point out how the individual chapters of this collection, which all offer closer examinations of specific inequalities, fit into the framework, and I bring attention to pertinent issues of inequality that may be implicit in some of the chapters but are not directly addressed.

The first section of this Introduction—“The Outlines of Inequality and Death”—homes in on the complex theme and provides an overview of some relevant concepts. The following five sections center on different, constructed inequalities, which with some exceptions all fit under the rubric of “social determinants” 1) “Identity Based Disparities,” notably age, race/ethnicity, gender/sex, and sexual orientation, but also demographically (often) more ambiguous identities, such as religion and cultural groupings; 2) “‘Class’ Based Inequalities,” rooted in income, education, status, resource distribution, and social environment; 3) “Geographic Inequalities,” including rural vs. urban areas and developed vs. developing countries and their shifting boundaries; 4) “Ethical and Legal Environment,” as relevant to the shaping of unequal experiences at death; and 5) “Psycho-Social Inequalities,” touching on differences of individual disposition and personal relationships. The chapters of this book are sequentially ordered so that they correlate with this outline.

The segmentation is intended to make the theme more intelligible, not to suggest that the subject of inequality and death can be delimited into discreet sections. Overlapping factors account for many of the inequities in morbidity and mortality among population groups. Access to care and death by violence and injury, especially, are conditioned on and consequences of several types of inequality. Access issues are here discussed under several applicable section headings; comments on violent death are incorporated under "Geographic Inequalities," since location is one of the greatest determinants of such demise.

The Outlines of Inequality and Death

For most of history, when the elderly and sick, infants and birthing mothers died at home, death was perceived as an integral part of life;[1] while equality in the face of death was assumed, life's conditions among the living were highly unequal. Among scholars, death and the conundrum of mortality have been addressed for as long as we have recorded evidence.[2] "Equality" as a concept describing a relationship among individuals or groups of people, was given its contemporary meaning when it entered the philosophical vocabulary with renewed force during the Enlightenment (e.g. Locke, *Second Treatise* 1690). The idea of equality has since enjoyed a privileged place in public discourse, and the debate continues on its appropriate integration into social systems.

That death comes to all regardless of moral conduct or social status has been repeated in different contexts and media throughout time: In America in the 19th century, the newly invented Colt-45 revolver was dubbed "the great equalizer" because, presumably, it gave everyone the same odds in a shoot-out.[3] Pictorial representations of *Death Dances* show people of

---

[1] In the Western world in the 20th century, the common practice of placing the elderly and dying in separate care facilities and hospitals removed death from public view and polite conversation. The publication of Elisabeth Kübler-Ross' *On Death and Dying* in 1969 began the re-introduction of the topic into the public domain. For a survey of the literature on death since mid-20h century, see Staudt 2009a.

[2] For a compact account of Western thought on death since antiquity, see Choron 1963.

[3] "In the late 1800s, the proliferation of the Colt 45 revolver eventually tamed the lawless American West by allowing even the weak and socially disenfranchised, who lacked the traditional instruments of power and influence, to assert their will and defend themselves against those endowed with land, position, and political

different classes meeting the same fate, as for example in Hans Holbein the Younger's famous rendition of 1538 and in Alfred Rethel's politicized version (published after the European socialist uprisings of 1848). Sacred and secular texts articulate the theme:

> All share a common destiny-
> the righteous and the wicked, the good and the bad, the clean and the unclean, those who offer sacrifices and those who do not…. For the living know that they will die….
>
> *Ecclesiastes,* circa 2nd c. BC

> For maggots
> Your fat king and your lean beggar is
> But variable service—two dishes but to one table
> That's the end.
>
> William Shakespeare, *Hamlet*, circa 1600

> The glories of our blood and state
> Are shadows, not substantial things;
> Death lays his icy hand on Kings;
> Scepter and crown
> Must tumble down
> And in the dust be equal made
> With the poor crooked scythe and spade.
>
> James Shirley, *Death the Leveller*, 1646

> …death, the great equalizer, always restores to its possessors the rights of mind….
>
> Susanna Moodie, *Life in the Clearings versus the Bush*, 1853

> Maybe death is the great equalizer, the one big thing that can finally make strangers shed a tear for one another.
>
> Mitch Albom, *Tuesdays with Morrie*, 1997

The phrase "Unequal Before Death" has (at least) two meanings: unequal *in advance of* death, i.e. during life, and unequal *in the face of* death, i.e. at the end of life; and it raises questions such as "unequal to whom?" "unequal in what way?" and "unequal by whose measure?" When referencing inequalities during life, we are primarily concerned with socially constructed stratification. Stratifications based on innate ("natural") qualities exist and are apparent, for example in the differing abilities of

---

status. The revolver thus earned itself the moniker 'the Peacemaker,' or more aptly 'the Great Equalizer.'" Kartchner 2004, 169.

children and adults, but many (if not most or all) differences attributed to race, gender and other groupings prove, after examination, to be socially constructed. Society produces hierarchies of “class” and status based on fluctuating and complicated economic and moral value systems.

How we interpret “equality” and “inequality” depends, to a certain extent, upon whose theoretical shoulders we stand. Marx, Weber, Gramsci, Durkheim, Parsons, Davis and Moore, Dahrendorf, Carchedi, Poulantzas, and Wright all offer variations on the theme of social stratification.[4] But regardless of whose definition we adhere to, the stratification of people has shown to have mortal impact. Recently, Sandro Galea et al (2011) demonstrated that poverty, low education level and other social disadvantages accounted for 4.5% of all deaths in the United States in the year 2000. Research presented by Nancy Krieger (2011) and others suggest that this may be a gross underestimation of socially attributable mortality: “In our 2008 study…,which analyzed the fall and rise of US socioeconomic inequities in premature mortality between 1960 and 2002…,we reported that the percent…of adult US premature deaths (before age 65) that would not have occurred had everyone had the same age-specific rates of mortality as adults living in the top quintile income counties in 2000 equaled 25%.”

In the United States, analyses of health inequalities, whether conducted by United States Department of Health and Human Services or by private research organizations, are commonly referred to as “health disparities.” The choice of the word “disparities” in lieu of “inequalities” shows how a subtle ideological bias can direct a discussion on health differences. “Inequality” hints at a subtext of injustice, whereas “disparity” indicates difference without a fairness value.

Because of differences in value judgment and methodology, comparisons of inequalities between countries are difficult. Amartya Sen has synthesized perhaps the most useful way of measuring health and mortality inequalities in a global context, enabling comparisons among nations with vastly differing socio-cultural and economic premises. Combining social and economic, philosophical, and practical considerations he has posited a formula that centers on “capabilities” valued by the individual, creating a model for discussions on inequalities that is useful both across and within cultures and regions (Sen 1992). Nevertheless, even Sen’s comprehensive and nuanced formula leaves ambiguities for the theorist.[5]

---

[4] For a useful summary, see Bottomore 1991.

[5] For a review and discussion of Sen’s model, see Archard 1995.

Our understanding of the concept of inequality is, notably, a matter of personal ideology and the socio-political and cultural environments that have shaped us. The editors of this book do not propose a universal definition of inequality. Each individual author in this anthology is explicit about his or her own definitions as is needed for his or her purposes and implies by the treatment of the chosen topic how the concept of inequality should be understood within the context of that chapter. All of the authors can be assumed to bring a personal value system to their writing. The variety of perspectives and approaches offers the reader a nuanced and rich picture of what inequality can mean for individuals, and groups of individuals, at the end of life.

*

Human beings are not identical. We can expect to be unequal in the face of death, just as we were unequal in life. In describing the death of an individual, age and cause are commonly cited in obituaries and news articles, e.g. “Jane Doe, age 65, succumbed after a long battle with breast cancer” or “John Doe, age 45, was found dead by asphyxiation in his apartment.”[6] These terse statements hide lifelong narratives. When we approach the threshold that separates the living from the dead, we will have been uniquely shaped by biology and circumstance. With a singular DNA, which may or may not have contributed to a substantial degree to the timing and cause of our demise, each one of us is a product of our natural, social, political, cultural and economic environment. We possess personal, social and financial resources that empower us to differing degrees. The space we occupy (socially and geographically) and the identity we were born into and acquire grant us—or not—knowledge and connections, access to medical care and other essential resources, as well as expose us to varying risks of disease, injury and violent death. The odds of survival into old age vary immensely among population groups and regions within the United States and around the world.

Thousands of studies have been conducted in an effort to map why some population groups die earlier and have poorer health than others. The root causes of inequalities in lifespan and health outcomes remain difficult

---

[6] Since 1983, US statistical reports do not allow “natural” death or “old age” as causes; everyone is assigned a medical diagnosis or a mortal injury (an accident, homicide or suicide, or an act of nature or war), which is deemed the “cause” of death. For a summary of leading causes of death in the United States, see www.cdc.gov/NCHS/data/nvsr/nvsr58/nvsr58_19.pdf, and chapter one of this book.

to pin down exactly but genetics, age, race/ethnicity, class, geography and, more recently, eco-social environments, are among the most researched areas. Collectively, these factors (excepting age and, usually, genetics) are often referred to as "social determinants." They conspire to influence a range of human life outcomes including mortality. In chapter 1, *Data on Inequalities in Mortality: from Local to Global*, Betty Wolder Levin highlights startling differences in ages and causes of death among different ethnic groups and classes around the world as well as within the United States and the boundaries of New York City. The chapter's charts and tables serve as reference material and background to the subsequent chapters, which delve more deeply into externally constructed mortality differences.

"Identity" Based Discrimination

"Identity" is a fraught and slippery concept with different meaning in different disciplines.[7] In daily speech we use it to refer to biological characteristics—a "blue-eyed boy" as well as to amorphous, ill-defined concepts such as "religious fundamentalists." We have self-described identities, and the same or different identities are imposed on us by others. "Identity" can apply to a unique individual or define a group. It is used here in the most encompassing sense.

Genetics

A substantial amount of scientific and financial resources goes into genetic research aimed at prolonging life and altering our natal genes, barring disease and promoting health. Certain diseases are directly or disproportionately correlated with gender and ethnicity, e.g. prostate cancer in men and Tay-Sachs among Ashkenazi Jews. DNA-mapping of individuals is becoming increasingly common, and carriers of genes that

---

[7] For thorough analyses of identity based data and for references to specific studies beyond the ones mentioned here, see Kant Patel and Mark E. Rushefsky, *Healthcare in America—Separate and Unequal* (2008). In separate sections the authors look at African-Americans, Hispanics, children, the elderly, gender issues, and geography, reviewing health status and outcome, access to care and its quality for each category and attempting to explain the reasons for the disparities. For a thoughtful analysis of the role of ethnicity in health disparities, see also Donald A. Barr, *Health Disparities in the United States–Social Class, Race, Ethnicity and Health* (2008). For a history of "identity" and contemporary theories in sociology and social psychology, see Burke and Stets 2009.

mark them at high risk for disease with expensive treatment protocols are potentially at risk of unequal treatment by those who are responsible for paying the bills, i.e., medical insurance companies. The Patient Protection and Affordable Care Act of 2010 includes a provision on pre-existing conditions that is aimed at eliminating unequal treatment but how this regulation will be handled in practice is yet unknown. That mitigation of genetic disorders will create more equal chances of longevity is generally understood but the research is pursued without much reference to its equalizing effect.

In the pursuit of cures for various diseases, discussions of inequalities occur mostly when one group perceives the funding and effort expended as unfairly or disproportionately favoring another group. Examples include the research to cure lung cancer and HIV/AIDS, both of which have aroused contention because of the role individual choice and behavior can play in contracting these diseases.

DNA is influential in determining a person’s biological propensity for health and longevity, but DNA is not destiny. Genetic factors are combined with the effects of the natural and socio-culturally constructed environment, creating a complex and troublesome set of variables to unpack. Studies on health and mortality inequalities in the United States traditionally have been the territory of economists and sociologists and have been based on identity: ethnicity, gender, and age, following the categories of data collected and reported by the US Department of Health and Human Services, while DNA research has been the purview of medical research and often disease focused.

Age

That people of advanced age and newborn babies are more likely to die than healthy people in their prime may seem a “natural” phenomenon, rather than a manifestation of inequality. However, the substantial extension of the average lifespan and the decrease in infant mortality rates in most industrialized countries during the twentieth century have changed the perception of what constitutes “normal” death rates for infants and “too young to die” at the other end of the age spectrum.

Children are vulnerable everywhere, but among the most blatant inequalities, related to death and dying, are the extremely high infant death rates that remain in some countries despite available inexpensive remedies to save them. Every day 25,000 children under the age of five die from pneumonia, diarrhea, malaria and newborn complications that are easily preventable and rarely lead to death in the developing world (Save the

Children 2010). Substantial improvements in mortality rates for infants and children have been made in some countries. In Botswana the infant mortality rate has decreased from 76 per 1,000 live births in 2001 to 12 per 1,000 live births in 2009, whereas a much smaller improvement has been recorded in neighboring Namibia, from 56 to 45 per 1,000 live births (Save the Children, 2002 and 2010). While the reasons for the difference in success are multifarious, the supposition emerges that inequalities can be erased with sufficient emphasis on the problem and government priorities that favor children's survival and wellbeing.

Because the notion of a dying child is abhorrent and feels "unnatural" in most societies, all available resources tend to be called upon when a crisis strikes but if the family and community are poor, the resources are often tragically insufficient. And even if the children survive—whether in a slum in India or a housing project in New York City—they remain in poverty and are deprived of the proper nutrition and education that could advance their prospects of a decent livelihood as adults; they remain disadvantaged for life and are likely to die younger than their counterparts in more affluent areas.

Marginalized children suffer the most but not all inequalities are poverty based. Children from otherwise comfortable backgrounds may be overlooked and underserved in end-of-life and bereavement contexts (Balk and Corr 2009). Survival rates for the elderly are less correlated with personal and regional affluence than for youth. The discrepancy in older people's mortality rates between rich and poor countries is generally smaller than for younger age groups. Similarly, within the United States, death rates between ethnic groups and groups of different income levels vary most in the 15 to 45 age group. After 65 the differences are small and after age 80 negligible (WHOSIS 2009).

In the United States in1960, more than a third of those over 65 lived in poverty (as it was defined then)[8], and so did just over one quarter of children. The over-65 population has since then become a powerful political block through interest groups, such as the AARP and the Gray Panthers, whereas advocacy groups for children have been less successful (Spriggs 2007). In 2008, less than 10 percent of those over 65 lived below the current poverty line, as contrasted by almost one fifth of all children (US Census Bureau 2011).

Senior citizens are, on the whole, well provided for under the American healthcare system. All citizens over 65 are entitled to Medicare, which is often supplemented by Medicaid, private insurances and/or

---

[8] For the calculation of poverty in 1960, see Fischer, 1997, pp. 6-7.

retirement packages from former employers. The poverty level of the elderly, as a group, is lower than the national average. This relative state of wellbeing does not prevent excessive, existential suffering in particular circumstances.

People over 65 consume a greater portion of the healthcare budget than any other age group in all industrialized countries, and proportionately most in the United States. Given this (dis)proportionately high allocation, the question of resource distribution becomes increasingly urgent. It is a sensitive issue. Nations with universal healthcare have evolved *de facto* rationing systems, often based on age. So for example are organ transplants, dialysis, and certain other procedures and operations, in practice, not encouraged for people over a certain age, even if such regulations are not clearly stated. It is not a matter of equal treatment of all afflicted with, say, kidney failure. Rather than offering organ replacement on a first-come-first-served match basis, the unstated rule is a consideration of return on investment for the nation as a whole, resulting in the person in her productive years receiving the organ, rather than the octogenarian with a much shorter life expectancy. This can be seen as an equitable approach if one argues that everyone has an equal right to achieve old age. In countries without universal healthcare, such as the United States, medical care and procedures are generally not rationed based on age but made available according to ability to pay (oneself or through insurance), a covert form of rationing. Because Americans over the age of 65 have Medicare, they become, as a group, favored over those segments of the population, which have less generous—or no— insurance plans. This fact is likely to be one of the most contentious issues as the United States struggles with reforming its health care system and policies to control costs.

Ethnicity and Race

Ethnic and race-based discrimination has a long and ongoing history in most regions of the world, manifesting itself in targeted groups’ exclusion from specific residential areas, limited employment options, restrictions on movements, and, at worst, forced servitude and slavery. Whether sanctioned, regulated or informal, discrimination reduces resources for the disenfranchised group and results in a sub-standard life and living conditions that contribute to morbidity and early death. In the United States, African-Americans and American Indians and Alaska Natives have shorter life expectancies and suffer from several life-limiting diseases, such as heart disease and diabetes to a greater degree than whites and

Asians, the latter being the group with the greatest longevity. The disparities are most pronounced for males aged 15 to 45.

Race-based health inequalities have been recognized and problematic in the United States for a long time. The Tuskegee Syphilis Experiment (conducted from 1932 to 1972) is an especially horrifying example of extreme unequal treatment: impoverished black males with syphilis were denied available treatment, with a predictably deadly outcome, in the name of mainstream research. On a less dramatic but cumulatively hugely detrimental scale, segregated neighborhoods and outright discrimination during much of America's history caused treatment facilities, care options, and medical specialists available to African-Americans to be separate from, and frequently inferior to, those open to non-minority Americans. One recent report linking unequal treatment to the deaths of thousands of persons of minority heritage shows that the problem of treatment disparities persists to a measurable degree (Limtanakool 2005). According to a detailed county-by-county survey in 1999, the life expectancy for urban black men was 15.4 years shorter than for Asian men. Southern rural black women's life expectancy was 12.8 years shorter than Asian women's (Murray et al 2006). In contrast, white surviving spouses in the United States are more susceptible to morbidity and premature death after widowhood than black widows and widowers, in what is known as "the widow effect" (Elwert and Christakis 2006). Infant mortality among blacks is 2.4 times as high as among whites (Heron et al 2006).

Access to healthcare—variously defined but generally seen to include three steps 1) getting entry into the system, 2) reaching a site where needed services are offered, and 3) developing relationships with providers (HealthyPeople.Gov)—is curtailed for many minorities. A primary reason for reduced access to healthcare has been the lack of financial resources and/or insurance, conditions that affect minority groups to a greater extent than whites.[9] Other reasons for poor access are residence far away from healthcare providers and problems of acculturation and language. In a controlled study, Asian minorities reported fifty percent more difficulty in getting access to care than white respondents (National Healthcare Disparities Report 2009).

---

[9] In 2005, 29% of Native Americans, 34% of Hispanics and 21% of Blacks as compared to 13% of Whites were uninsured in 2005 (Kaiser, 2006, p. 23). These numbers are expected to change when the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act, signed into law by President Barack Obama on March 23 and March 30, 2010, respectively, go into effect, unless the provisions of the Acts are overturned by the US Supreme Court.

Certain healthcare services at the end of life are utilized to a markedly unequal degree by different races. In 2009, Black/African Americans represented 12.9% of the total US population but only 8.7% of hospice patients; people of Hispanic or Latino origin were 15.8 % of the total population but merely 5.6% of hospice patients; and Asian, Hawaiian, Pacific Islanders, 4.6% of the total population, represented only 1% of hospice patients (US Census Bureau, Quick Facts; NHPCO 2010, 7). Fear of exclusion and under-treatment are likely contributing to the disproportionately low use of hospice and palliative care services by African-Americans. That almost twice as many Blacks as other patient groups choose "full code" when death is very near supports this argument (Johnson 2010). The reasons for the "underutilization" of hospice among non-white groups can probably be found in cultural value systems that differ from those articulated by hospice and in a lack of language appropriate information. The intricacies of identity-specific needs in hospice care is explored by James Maurino in chapter 2, *Addressing the Current and Future Needs of Racial, Ethnic, and Sexual Minorities and Care in Hospice Settings*.

Different minority populations have starkly varying rates of death by violence (homicide and suicide) and by injury. So for example, is an African-American 5.7 times as likely to die from assault as a white person, while an Asian-American is half as likely (National Vital Statistics, Table B 2010). While assaults account for less than one percent of all deaths in the United States, almost twenty thousand lives could be saved if the problem could be fully addressed. Suicides occur disproportionately among American Indian/Alaska Native adolescents and young adults (Healthcare Disparities Factsheet "Suicide" 2011).

The legal system has been accused of re-enforcing structural racism, by meting out, in relative terms, more severe sentences, including capital punishment, to non-whites. The American Civil Liberties Union (ACLU) has determined that in Cumberland County, NC, from 2001 to 2011, prosecutors "were over three times as likely to seek the death penalty if the crime involved at least one white victim. Defendants convicted of killing white victims were more than twice as likely to receive the death penalty from the jury as defendants charged with killing victims of color" (http://www.aclu.org/capital-punishment-racial-justice/north-carolina-v-robinson).

Religion and Culture

Different religions subscribe to different ideas about life's conclusion.[10] Ethnic, cultural and religious belonging shape attitudes and practices and accounts for vast disparities in our final experience and the choices we make as we approach death (Braun et al 2000). In chapter 3, *Death in the Service of Life: Individual and Cultural Projections and Practices*, Siamak Movahedi and Glenn Jacobs employ psychoanalytical tools and cultural readings of religious death cults among several Hispanic cultures and show how through ritual, disenfranchised undocumented immigrants find ways to face death that may offer advantages over mainstream American populations.

What may appear as the most obvious common ground, such as the medical definition of "death," is colored by nuances of culture and religion and creates unequal conditions for the dying and their families even within otherwise seemingly homogeneous groups. So, for example, is the question whether "brain death" comports with Jewish law—*halacha*—of controversy among rabbinic authorities (Breitowitz [ND]). In Japan, where death is interpreted as a social event—rather than an individual one —the idea that the end of a life can be declared to have occurred at a specific moment in chronological time is generally rejected, including by many clinicians (Lock 1996).

In the United States, borders between cultural and ethnic patterns are being erased as people originating in different cultures intermarry, live and work in close proximity to each other, and associate in civic activities together. Often today, Americans' end-of-life experiences are more "flavored" by their ethnicity and religion than fundamentally shaped by them. Nevertheless, discrimination occurs, especially when the rights to—or space for—devotional practices and end-of-life rituals are denied, or when ethical codes clash. Such conflicts arise, for example, when the policy of a religiously affiliated facility is at odds with the personal care wishes of a patient. Cases that receive attention in the United States include Roman Catholic hospitals that do not agree to the patient's (or, more commonly, the designated healthcare agent's) request for the withdrawal of artificial nutrition and hydration. Situations surrounding the performance of abortions, including bombings of clinics, are other manifestations of irreconcilable moral values that result in discriminating actions and occasionally death.

---

[10] For an overview of the understanding idea of death and practices surrounding death in major religions, see Kramer 1988 and Bregman 2010.

The most radical examples of religious intolerance with a deadly outcome in the last decades have been terrorist acts by suicide/homicide bombers. Ethical norms are violated among the majority of religious practitioners when self-destruction and murder are being promoted as a glorious path. The cultural history and individual psychology of the world’s martyrs are complex and nuanced; and the treatment and definition of the concept of martyrdom—broadly defined by Merriam-Webster as “the suffering of death on account of adherence to a cause and especially to one's religious faith”—is conditioned by the perspective of the onlooker/writer (Bowerstock 1995; Boyarin 1999; Castelli 2004; Cook 2007; Jensen 2010). A shared perception about and among martyrs is that they are set apart, that their deaths are not equal to the deaths of others: martyrdom is a means to elevate oneself above others; it offers grandeur and transforms darkness into light, destruction into salvation. In chapter 4, *Death Is Its Own Conquest: the Prestige of Martyrdom in Palestine*, Talat Halman focuses on Palestinian suicide bombers. He demonstrates that these individuals and their supporters do not see death as an “equalizer.” Instead, committing suicide in the name of their cause, is viewed as a vehicle to raising martyrs’ lives (and deaths) above others. Supported by a “culture of suicide,” they seek, and gain, distinctive prestige and fame.

Gender and Sex[11]

Women have a longer life expectancy than men in almost all countries. Exceptions are a few nations in southern Africa, where the rate of maternal mortality is very high, e.g. Namibia and Lesotho. This pervasive female advantage does not change when total life expectancy increases for a regional population. The inequality is presumed to be, in part, genetically based but since male/female discrepancies vary substantially among nations, social and cultural factors are also at play; life style and life goals as well as work conditions, cultural norms and other variable conspire more or less against men in most societies (Vallin 2006).

Because women for so much of history have been the subjugated sex, anti-discriminatory efforts are mostly on behalf of women. Attempts to rectify the historic underrepresentation of women in clinical research has resulted in recent studies bringing attention to how women’s bodies differ

---

[11] “Gender refers to a social construct regarding culture-bound conventions, roles, and behaviours for, as well as relationships between and among, women and men and boys and girls… [S]ex is a biological construct premised upon biological characteristics enabling sexual reproduction” Krieger 2001.

from men's, notably in regard to heart disease (American Heart Association). In *The Politics of Inequality: AIDS, Culture and Power*, the fifth chapter in this collection, Ida Susser examines "the ways in which ideologies of gender and everyday practices of subordination interact with political and economic forces to reproduce inequality" and shows how research and scientific perspectives on AIDS have affected the course of the worldwide AIDS epidemic. Her chapter also addresses discriminatory practices related to the race, class/income and nationality of those infected by AIDS.

In most of the world, gender is not nearly as important a determinant of health and mortality as is household income (Gorman 2006). In industrialized nations, women continue to make strides toward socio-economic parity with men, and systemic unequal treatment that increases the risk of death is less and less common; but in the private, domestic sphere women are at far higher risk of meeting a violent death than men. During the first five years of the millennium, thirty-three percent of female murder victims were killed by a spouse or partner, as contrasted with three percent of male murder victims. Native American and Black women are the most vulnerable. In 2000, the number one killer of African-American women ages 15 to 34 was homicide at the hands of a current or former intimate male partner (Rennison 2003).

The status and survival rate of widows and widowers vary from culture to culture and even from family to family. But across the globe, regardless of economic system, more women survive their husbands with reduced financial security than vice versa. In some developing countries, the situation for widows can be particularly harsh. While "sati"—"a Hindu practice whereby a widow immolates herself on the funeral pyre of her husband"[12]—is no longer legal and a rare practice, Hindu widows' material hardship or expulsion from the home of the former husband may not be (Damon 2007).

Amartya Sen's accounts in the 1980s of the 100 million "missing girls" drew much attention at the time. He highlighted the excessive mortality of girl children in much of Asia and the Middle East, where families, including mothers, regardless of household income and class, provided better food, education and healthcare for their sons than their daughters. The "missing" females were also a result of girl infanticide and abortion of girl fetuses, especially in China during the decades of legal limits on reproduction (Sen 1990). In an updated report using 2003 data, Klasen and Wink (2005) show that the absolute number of "missing" women had

---

[12] http://dictionary.reference.com/browse/sati

increased since the 1980s but that that their share of the total number of women alive had decreased, indicating a reduced level of discrimination; relative survival rates for women in most of South Asia and the Middle East had improved but worsened in China.

A major inequality between women of the developing and the developed world is the rate of maternal death (women dying of pregnancy and childbirth related causes). In spite of substantial improvements between 1990 and 2008 in many countries, notably in North Africa and the Middle East, the situation has deteriorated in several sub-Saharan countries and in Afghanistan, where more than 15% of pregnant women die of pregnancy-related causes, as compared with 0.5-1% in most developed nations (UNICEF). In many developing countries where women are made to marry in their teens, maternal mortality is the number one killer of girls aged 15-19 (Hogan et al 2010). In the United States the maternal mortality rate increased from 1.2% to 1.7% between 1990 and 2008, reflecting increased mortality among poor women (UNICEF).

Because wives generally live longer than husbands, women all over the world find themselves more frequently than men at the bedside of a dying spouse and as the bereaved. All over the world, women are still the primary caregivers in the family and have disproportionate responsibility for the sick and frail and, generally, they are the ones charged with managing the practical aspects of a dying relative, whether of their own family or their husbands.' And the vast majority of those who care for the dying in hospitals and nursing homes are women. Perhaps, it is men who are disadvantaged in this context. Usually more distanced from the dying and numerically less trained to cope, more men than women encounter the dying experience for the first time at their own passing.

Sexual Orientation

The range of civil rights accorded, or explicitly denied, homosexuals varies widely among countries and within the United States; in seven countries homosexuality is punishable by death (ILGA 2010). To a great extent, discriminating acts against homosexuals, including murder, correlate with religious fundamentalism, whether Christian or Muslim and occur in countries with legal protection as well as in those without.

In the United States, members of the Gay-Lesbian-Bisexual-Transgendered (GLBT) community, in the thirty-six states which have legal statutes or constitutional amendments prohibiting same-sex marriage or partnerships, experience inequalities with consequences at the end of life that are exclusive to that group. Unless specifically authorized by law, many hospitals and other institutions, where death is likely to occur, do not recognize gay partners as "next of kin," with the result that they are frequently denied rights normally accorded spouses or immediate family members, such as hospital visitation. Likewise, a domestic partner may be denied survivor benefits that would have been given to a heterosexual spouse. Even in otherwise tolerant places, local regulations can be restrictive about gay couples purchasing a family burial plot (Toy 2003); the diagnosis of some cancers may be overlooked for lesbian patients (Brown and Tracy 2008); and the personal and psychologically different needs of gays and lesbians at the end of life may be overlooked by mainstream healthcare providers (Smolinski and Colon 2006).

Nevertheless, many prohibitions and restrictions are being eroded, deliberately to remove discriminatory practices or by virtue of laws that allow more choice for all residents. As of March 2012, same-sex marriage is legal in six states[13] and Washington, D.C., as well as among some Native American tribes in Oregon and Washington; in several other states, including Maryland and Washington, such legislation is pending. Illinois accords same-sex committed partners the same bereavement and funeral leave as married heterosexual couples. The equivalent of a Medical Power of Attorney[14] is available in all fifty states (special circumstances in Louisiana), allowing all individuals the right to select the person they wish to speak for them in case they are incapacitated. Most states today have at least some legal provision giving residents the right to decide their own funeral arrangements or assign an agent to do so and GLBTs can take advantage of such provisions.[15]

'Class' Based Inequalities and Resource Distribution

In trying to determine why some groups live longer and why preventable diseases are more prevalent among some populations, privately funded research teams in America as well as the US government have increasingly moved away from identity criteria, i.e. ethnicity, gender

---

[13] Connecticut, Iowa, Massachusetts, New Hampshire, New York, and Vermont. Maryland and Washington have enacted legislation to begin allowing same-sex marriage in the fall of 2012.

[14] Depending on the State, this legal document is also known as Health Care Proxy, Power of Attorney for Health Care and similar names. It allows someone to designate another person to act in his or her name to make health care decisions if the principal does not have capacity to do so him/herself.

[15] Alabama and Arkansas assign this right only to a "next of kin," defined to exclude a domestic partner.

and age, in favor of other bases.[16] An aggregate perspective, taking into consideration socio-economic status as well as race, has been used by some (e.g. Barr 2008) but a combination of education and income is seen increasingly as the most reliable tool to stratify a population (for models see Gilbert 2002; Thompson and Hickey 2005). Level of education alone, which is relatively easy to determine and mostly non-fluctuating, has also become a convenient shorthand substitute for "class," since, generally speaking, the higher a person's education is, the higher is his income level and job status.

Income and Knowledge

Studies on poverty and health have shown that income can be a determinant of health up to a threshold level, after which the health benefits of additional affluence diminish (Lynch et al 2004a). That said, income level may not directly correlate with health or life expectancy but specific studies concerned with mortality and morbidity differences indicate that people with lower income levels are disproportionately under-treated (Limtanakool 2005) and have substandard access to healthcare which, in turn, often leads to inferior health outcomes; people below the poverty level report difficulties to access healthcare twice as often as those in higher income groups (National Healthcare Disparities Report 2009).

Furthermore, studies that conclude that income is a vague criterion in determining health outcomes are measuring quantitative outcomes, i.e. mortality and morbidity rates. But, quality-of-life factors, which may be difficult to measure objectively, play an important role in determining the end of life experience. Two persons, afflicted by the same terminal disease, receiving the same quality medical treatment, having the same prognosis, and dying after a similar number of days after diagnosis, do not necessarily pass their last days on equal terms. If the two patients have substantially different financial resources to fund complementary health

---

[16] European countries have traditionally addressed health inequalities from a neo-materialistic perspective, using the concept of "class," defined as a combination of income, education and occupation, and, in the case of the UK, asking people to self-identify as belonging to one of five distinct classes. Self-identification is an imprecise tool in the United States: In a survey conducted by the National Election Studies 51% of Americans self-identify as "working class," of which 10% considered themselves "upper working class;" 49% self-identified as "middle class," of which 10% considered themselves "upper middle class" www.electionstudies.org/nesguide/toptable/tab1a_8.htm.