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How We Die Now

*Americans Aging and Dying  
in the Twenty-First Century*

In the spring of 2002, I met Sarah, a hospice nurse caring for my grandmother, Phyllis Walsh, during one of the last days of her life. Grandma Phyllis was in her seventies when cancer infested her body. After several months of caring for her at home, Grandpa, my mom, my sister, and I were relieved when Grandma Phyllis qualified for hospice care. In the quiet and peaceful hospice wing of the hospital near her home in the Twin Cities, we were able to enjoy Grandma's final days rather than scramble to try to care for her at home. At home, we had scrambled to adapt to her changing needs, struggled to lift and clean her pained body, and failed too often to protect her pride and privacy. We loved her, but we were out of our element and sometimes over our heads trying to care for her. In hospice, we could leave the skilled part of her care to the nurses and focus on making the most of our remaining time together. I even had the privilege of witnessing Grandpa and Grandma saying good-bye to each other. When Phyllis started to move into the final stages of death, the members of our extended

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family were able to gather and talk to her and among ourselves, knowing that her physical needs were being addressed by the remarkable nurses who worked in the hospice wing.

During those final days, we practically lived on the hospice wing, and it was then that I witnessed Sarah doing her amazing work. During one eight-hour shift, I observed Sarah touch and turn bodies, raise beds, massage limbs, chart physical changes, measure pain, treat symptoms, and dress wounds. In addition to offering the physical strength, stamina, and medical knowledge that she clearly possessed, Sarah took care of the emotional and spiritual needs of her patients and their families. She acted as a mediator for members of a family who had not spoken to one another for over a decade, discussed with a granddaughter of one of her patients whether or not angels existed, and encouraged an elderly man to let his wife “go” now. As someone who studies work and identity, I was mesmerized by how demanding, multifaceted, and important Sarah’s labor was. The intellectual, physical, spiritual, and emotional work that Sarah did in those eight hours was, to my mind, beyond the realm of remuneration. How would you prepare a worker to be thrown suddenly into a pivotal moment in the history of a family? How would you train someone to be responsible for teaching about death at the moment of dying? These are some of the questions that inspired this study.

As a hospice nurse, Sarah received special training in palliative care and helping others die. Unlike Sarah, most individuals who grapple with the changes of old age are *not* trained to do so, including home health workers, nurse’s aides in nursing homes, family care providers, and even many doctors, who often learn how to help others navigate the end of life through trial and error. Trained or not, these workers help others die, and in the process they learn about their patients and themselves, and about living and dying.

As an ethnographer of labor, I investigate why workers are attracted to their work, what they learn from their work, and what sustains and challenges them. I wrote this book because I wanted to know what the “Sarahs” of the world knew: I wanted to know more about aging and dying and to be comfortable in that knowledge. I wanted mortality to be less hidden, more familiar. I interviewed and observed many “Sarahs”—true end-of-life experts—for this book. I recount their stories here to inform and inspire the rest of us, who find ourselves navigating a changing landscape of old age and death for which we have no training and little preparation to encounter.

### Demography Is Destiny

In 2011, the United States lurched over the starting line of a seismic demographic shift that scholars refer to as global aging (Angel and Angel 1997; Kiernan 2006). Many of the readers of this book will witness the peak of this change during their lifetimes. Consider this snapshot of how dramatically the balance between youth and old age will change. In the year 2000, just over a decade ago, the number of centenarians—people over the age of one hundred—in the whole world was 180,000. In one decade, that number has more than doubled, having grown to 450,000. By 2050, that number is expected to increase even more rapidly to an estimated 3.2 million humans over one hundred years of age (Fishman 2010: 8). This substantial rise in the number of centenarians is just one of the demographic puzzle pieces that will significantly change cultures around the world in the coming decades. Some demographers tell us that by 2050 older people will outnumber children for the first time in human history (United Nations 2008). This transition began in the United States in 2011, when the first of the baby

boomers<sup>1</sup> turned sixty-five years of age, moving the United States ever closer to a society in which old age and death are more common than birth and childhood.

The average number of children born has dropped dramatically as well over the last forty years. For example, in the United States, the average birthrate dropped from 3.1 children in 1975 to 1.9 in 2005, producing a sharp rise in the proportion of Americans over age sixty-five relative to younger Americans (Korczyk 2004). Urbanization, availability of reliable birth control, and the employment of many more women have combined to reduce the number of children born while increasing the total number of people in the workforce. For several decades the proliferation of women in the workplace masked the declining number of available workers; now, as both women and men “age out” of the workforce, the shifting balance between active workers and retirees becomes clear. Take, for example, the case of Spain, which currently has one of the oldest populations in the world. The aging of the population in Spain is also produced by a combination of longer lives and lower fertility rates; however, the pace of elongated lives and declining birthrates is faster and further along than in other European nations. Currently, life expectancy in Spain is 83.8 years for women, the highest in Europe, and 77.2 years for men (“Aging Population in Spain” 2007). Meanwhile, the average birthrate dropped dramatically from 3.0 children in 1975 to just 1.2 children today, one of the lowest birthrates in the world. Demographers predict that these two forces, taken together, will produce a 24 percent decline in the Spanish population by 2050. By that same year, Spain will have the highest percentage of elder people in the world. People sixty-five and older will constitute 37 percent of the population by

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1. Baby boomers are individuals who were born between 1946 and 1965 (Howe and Strauss 1991).

that date, an increase of 117 percent over the current percentage (Bosch 2000).

Nations vary in how they approach the graying of the population. Currently, the vast majority—85 percent—of retired people in Spain reside with family, but institutional care is becoming a more popular alternative (Botsford 2002). This low rate of institutional care is in contrast to that of Norway, for example, “where home care has been available for over 25 years. There, surveys show, old people prefer *not* to have family members provide personal care” (Neysmith and Aronson 1996: 13; italics added). In the United States, the oldest old are the most likely to live in institutionalized care settings such as nursing homes. While not every nation deals with the changing balance of youth and old age in the same way, many will face decisions in the coming decades about how to provide care and support to an elderly cohort that is quickly outnumbering its younger counterparts.

Taken together, the demographic changes in average birth-rate and average life expectancy alter what demographers call the dependency ratio. The dependency ratio is a calculation of the proportion of the working population who can support those who are not in the labor force.

Commonly, the dependency ratio relates to the number of people who are unproductive because of age (under 15 and over 65 years of age), because of infirmity, or because they are involved in an organized activity such as child rearing, to those who are productive, usually employers or employees between the ages of 15 and 65. (Baltes 1996: 13)

The dependency ratio is one way of capturing the shifting balance between youth and old age in a culture. This ratio is a critical measure for social planning because it “indicates the loca-

tions along the age spectrum at which there are more dependents than working producers” (Baltes 1996: 13). The dependency ratio can also help calculate the needed level of contributions for programs like social security, and it can provide a glimpse into the caregiving demands faced on average by a particular generation. For example, in the United States, “some analysts estimate that this situation will worsen: baby boomers probably will put in, on average, 18 years assisting elders as compared to 17 raising their children” (Olson 2003: 56). What will it mean to live in a world in which seventy years of age is more common than ten years of age? What will we need to change about our social infrastructure to accommodate those changes? And, given our longer lives and slower deaths, who should care for us and how? These are just some of the questions that arise as a result of the dramatic demographic changes under way.

### The Longevity Dividend

In the twenty-first century, many of us are living longer, dying slower, and, more importantly, dying *differently* than our ancestors. The territories of old age and dying have changed greatly in only a few generations. Many humans born today will live as many as thirty years longer than their ancestors. Around the world, the average life expectancy in 1900 was thirty years of age. By 2000, that average had risen to sixty-four (Fishman 2010: 13). Worldwide, better nutrition and health care combined with technological advances in medical care have extended longevity. As Ted Fishman explains, if you add up all the extra years of life, “today’s 6.7 billion people will enjoy more than 250 billion extra years of life” than if we had been born just a century ago (2010: 13). Through medicinal advancements, new technologies, and lifestyle alterations, Americans born today have a life expect-

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tancy thirty years longer than that of previous generations (United Nations 2008). In the United States, average life expectancy was forty-seven at the turn of the last century, rising to seventy-seven in 2000 (U.S. Bureau of the Census 2010). Some scholars describe this extra time as the “longevity dividend” and the “true wealth of nations” (United Nations 2008).

The longevity dividend is the combined result of two changes: longer lives and slower deaths. At both societal and individual levels, many adjustments will have to be made to accommodate and seize the potential offered by the longevity dividend. If societies prepare and lay claim to the opportunity, the longevity dividend offers the potential for longer, richer, fuller lives. However, the longevity dividend could also be squandered if societies do not anticipate and prepare for the eminent demographic changes by altering social structures and becoming informed about the needs and possibilities that arise from living and working in an aged society.

The first force producing greater longevity is that many fatal diseases have been modified or eliminated by modern medicine. Many diseases that once caused immediate death can now be managed for many additional years of life or even cured altogether. Many more humans have access to safe, abundant, and reliable food, safe sewage removal, and potable drinking water. Medical science has better informed our understanding of how disease is transmitted, and changes in personal hygiene and public health have responded to this new knowledge. Preventive medicine has improved, as has the ability to extend life once a disease has been diagnosed. Taken together, all these changes have added up to longer lives.

The second force shaping longevity is that dying processes in the contemporary era are now incremental as compared to the more sudden deaths most humans experienced in the past

(Kiernan 2006: 7). For example, in the United States, strokes and accidents have been replaced as the top killers. Americans now die from slower, longer diseases, including cancer, heart disease, and Alzheimer's disease (Kiernan 2006: xv). This is not to say that sudden deaths no longer occur from childbirth, car accidents, or heart attacks, but rather it is more common for people to die after a slow decline due to multiple chronic diseases. These shifts have resulted in a dramatic social change: contemporary humans can now see their own death coming. "The change, for a growing number of people every day, is this: dying today is gradual. For the first time in human history, we can anticipate our mortality. We can watch its slow approach. We can look it in the eye" (Kiernan 2006: 12). The prolonged process of dying that now characterizes many end-of-life experiences opens up new opportunities that are easily overlooked because of a lack of preparation.

Our social rituals and the social organization of old age and death have not kept pace with our longer lives and slower deaths. As Dr. Atul Gawande explains, longer lives introduce more time, but that time is often accompanied by uncertainty and even confusion about what differentiates life from death.

For all but our most recent history, dying was typically a brief process. Whether the cause was childhood infection, difficult childbirth, heart attack, or pneumonia, the interval between recognizing that you had a life-threatening ailment and death was often just a matter of days or weeks. These days, for most people, death comes only after long medical struggle with an incurable condition—advanced cancer, progressive organ failure or the multiple debilities of very old age. In all such cases, death is certain, but the timing isn't. So everyone struggles with this uncertainty—with how, and when, to accept that the battle is



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lost. Technology sustains our organs until we are well past the point of awareness and coherence. (Gawande 2010: 38)

Unlike sudden and rapid deaths, which created a short period of dying (sometimes minutes, sometimes weeks or months), the new conditions of dying often result in years of ups and downs, of good days and bad, and of prolonged dying processes for which we do not yet have rituals, best practices, or even the language to describe. Dr. Gawande explains, “In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die” (2010: 40). As such, although prolonged dying offers many possible benefits, as a historically new phenomenon, it also entails confusion and concern.

Along with the remarkable inheritance of longer lives come the challenges that accompany rapid social change, including worse health, longer illnesses, slower deaths, longer aging, and increased dementia. As Daniel Callahan explains, “Death now principally comes from the chronic and degenerative diseases of aging.” The dying process is also shaped now by what Callahan calls “technological brinkmanship” (1993: 40–47). Brinkmanship is defined as the “art or practice of pushing a dangerous situation or confrontation to the limit of safety especially to force a desired outcome” (Merriam Webster Dictionary Online 2010). Technological brinkmanship is fed by forces in the medical system, including how doctors are trained, the litigiousness of medicine, and the separation of science and ethics. As Janet Shim, Ann Russ, and Sharon Kaufman explain, doctors are trained to assess if a patient meets the criteria for a procedure. If the patient does, then the procedure is encouraged. Physicians are not keen to advise against a procedure because doing so would reveal their estimates about how long a patient has to live, and “who wants to be part of that [possible]

miscalculation?” (2006). Treating illness with procedures takes on an imperative without regard to quality of life. That imperative replaces choice and deliberation. More invasive procedures make additional procedures conceivable, and so the path of endless intervention begins.

Technological brinkmanship prolongs life, but the attendant danger is the lack of quality that might accompany such prolongations. On the positive side, prolonged dying offers the opportunity to wrap up one’s life deliberately, to fulfill final wishes, to say good-bye to loved ones, even to plan one’s own funeral. On the negative side, prolonged dying presents the dying person and his or her family members with historically new options for which there is no clear ethical or social road map. Is prolonging life good regardless of quality? How do we plan younger lives around the ups and downs of older lives? Dying individuals and their family members have to make difficult decisions that can induce uncertainty, confusion, hurt feelings, and shame.

Despite this future toward which we are rushing, many of us approach it seriously underprepared to face death personally or professionally. This book uses the experiences of workers, residents, family members of patients, and administrators at a continuing care retirement community (CCRC) that I call Winthrop House. I use the experience and knowledge of these people to help explore the new conditions of old age and the when and why of how we die now. What could be learned from end-of-life workers about accompanying others toward death? Might we find ourselves better prepared for death, or even better able to live, if we confront what they know? These were the questions with which I began this study. Despite the potential of the longevity dividend, currently our social, economic, and medical systems are mismatched with the conditions of our longer lives and slower deaths. The remainder of the book explains the fears and anxieties that currently lock us

into mismatched approaches and responds to these fears with the knowledge and insights of end-of-life workers. I believe that we can learn from the expertise of individuals whose jobs require them to be flexible, facile, and creative in the face of new social facts.

### Longevity and Inequality

The longevity dividend is not equally distributed. The final chapter of life is shaped by the gender, race, and class-based systems of privilege and oppression that structure the rest of life. First, the longevity dividend is a privilege of the young and the accident of being born in an advanced industrialized country. The youngest generation has the longest life expectancy in almost all nations (with the exception of war-torn nations); however, the life expectancy varies widely *across* nations. As Ted Fishman makes clear, being born into an advanced industrialized nation is the biggest contributor to longevity.

If you look across history, at every culture that ever existed, reviewing all the scientific literature and self-help books, you find only one crack-sure mode of maximum life extension: it is best to be born sometime after the turn of the twentieth century, preferably, though not necessarily, in an affluent, developed country. Nothing else even comes close. (2010: 70)

*Within* nations, life expectancy also varies by race, class, and gender. Each of these factors influences the kind of choices available to elders, the quality of care received, and the likelihood of needing assistance in one's later years. So while the longevity dividend is a shared social phenomenon, individual experiences are influenced by one's social location.

In nineteenth- and twentieth-century American culture, care of the aged and the dying was defined as women's work that women should and usually did provide for free to their blood relatives and their husbands' relatives. In the twenty-first century, caring for dependents continues to be women's work, both paid and unpaid. Care for the aged and dying is not recognized as difficult physical and psychological work that is financially straining, and even spiritually draining. When elder care moves into the public sphere, it remains encoded as women's work, and it is primarily women—particularly women of color—who are poorly paid to care for dependent elders, be it in home health care, nursing homes, or CCRCs (Glenn 2010). In fact, women make up a whopping 77 percent of the adult children providing care to elderly parents, and 60 percent of women will provide private elder care at some point in their lives (Margolies 2004; Olson 2003).

In the United States, not only are women the caregivers; they are also the most likely to be the *recipients* of institutional care: women make up 65 percent of all residents in nursing homes (U.S. Bureau of the Census 2009). Because women, regardless of race or class, live longer than men on average and marry people older than themselves on average, they are more likely than men to be widowed. Even if they are still alive, husbands are also less likely than women to care for their spouses at home. As a result of all these tendencies, women are the primary recipients of institutionalized care. Elder women are also more likely to live alone at the end of their lives: among white women aged sixty-five to seventy-five, 33 percent live alone as compared with only 12 percent of white men (Olson 2003: 103). This disparity continues and increases as white men and women age. By the age of eighty-five, a startling 59 percent of white women and 28 percent of white men live alone. White men are more likely to have unpaid care in their homes from wives, daughters, or other female relatives, while white

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women are more likely to find themselves alone and potentially in need of institutional care. Black women are even more likely to be single than white women of the same age, and since older black people are three times as likely to be impoverished and have approximately half the wealth of white people of the same age, black elders are less likely to have a range of choices for addressing their needs in the later years of life (Olson 2003: 133).

In short, white people are more likely to live longer and to have real choices about the conditions of their care in their final years and days. The privileges of being white and the relative disadvantage of being black, Latin American, American Indian, or Asian American accumulate over time. Laura Katz Olson explains how these different experiences take shape over the life course and are incorporated in health outcomes and care regimens. “Minority and other deprived older populations, who have suffered a lifetime of poverty, poor nutrition, and limited access to medical care, tend to have greater mortality, morbidity, disabling conditions, and inferior health status overall than the more advantaged groups” (2003: 9). Rather than being influenced by just the aging process per se, longevity, frailty, and dependency are all shaped by social, economic, cultural, and political contexts.

In the United States, the longevity dividend is largely shaped by structural racism. For example, even our life horizon—average life expectancy—is deeply divided by race. In the United States, current life expectancies for a white woman and a white man are 80.8 and 75.9 years, respectively, while the average life expectancy for a black woman is 77.4 years and for a black man 70.9, a full decade less than for a white woman (Centers for Disease Control and Prevention 2011). Racial minority elders are more invisible, more likely to be poor, and more likely to live with members of their extended family in the final years of life. Amazingly, even pain management varies by racial category. “Physical pain among

the dying remains uncontrolled, often unaddressed, and certain groups of people are at much greater risk than others. In America, you have a greater chance of dying in pain if you don't speak English, and if you are black, Hispanic, poor, elderly, or a woman" (Byock 1997: 242).

Finally, while minority elders are more likely to *need* assistance at the end of their lives, they are less likely to make use of institutional care. Many minority elders express distrust in institutionalized elder care, and in many minority communities, the expectation that younger generations will care for the old is very strong, making family care the obvious choice. Given the long history of systematic institutional neglect and abuse of black Americans—such as the Tuskegee experiments in which black men were intentionally given syphilis, the widespread forced sterilization of black women by doctors, and the failure to study and address ailments that disproportionately affect black communities—black elders have reason to proceed with caution when seeking long-term care (Allott and Robb 1998). Many black families are reluctant to turn over the care of their loved ones to institutional care. Social science research also suggests that minority filial networks are stronger than white ones, in part as a means of surviving and thriving in a racist culture divided by social class. As Olson explains, "For Blacks, Latinos, and Asians, whose values emphasize collectivism, interdependence, and mutual assistance the dependency of frail older people on their family is both expected and accepted as a predictable phase of the life cycle" (2003: 127–128). In short, minority Americans' "preference" for family care likely reflects family values and also potentially exposes disparate access to for-pay services. As the elder boom develops, formal and informal decisions about how to make use of the longevity dividend will determine if inequality continues to characterize the final chapter of our lives.