

# Introduction

*Robert Fine and Jack Levison*

## A THIRD-GRADE EPIPHANY

I (Bob) recall my daughter's third-grade Bring-Your-Father-to-School day. One after another, students grasped their fathers' hands, shuffled to the front of the classroom, and explained what this or that father did for a living. "This is my dad. He's a doctor. He fixes broken bones," said one little boy, holding the hand of an orthopedist. "This is my father. He builds houses," said another, grasping the thick hand of his father. "This is my father. He's a surgeon. He fixes people's hearts," said one daughter while holding a thoracic surgeon's hand, which, on any other day, would deftly maneuver tools to replace a broken valve or bypass a clogged artery.

My daughter nervously grabbed my hand as we strolled to the front of the class. "This is my daddy. He helps people die." The children stared dumbfounded. My medical colleagues, the orthopedist and thoracic surgeon, let out unguarded chuckles. "Sweetheart," I said, "I think your class might understand better if we say I treat pain in patients who are really, really, really sick." I looked to the teacher for guidance and, seeing none, told the class, "And sometimes, kids, the patients I treat are so sick that they die. I am very sad when that happens."

Palliative care specialists do not set broken bones or bypass clogged arteries. Rather, they lessen all sorts of pain, including the total pain, the *total*

*suffering*, of those facing the most serious of illnesses. They do not, like so many medical specialists, organize their labor around various organs of the body. Neurology for the brain. Hepatology for the liver. Nephrology for the kidneys. Cardiology for the heart. Ophthalmology for the eyes. Orthopedics for the bones. Pediatrics for the young. Geriatrics for the old. But palliative care? What does the palliativist do, if not to rescue, not to cure?

#### A FLEDGLING DISCIPLINE

In 1543, Bartholemew Traheron, who would hold posts as member of Parliament, dean of Chichester Cathedral, and canon at Windsor Castle, translated into English *Practica in arte chirurgica copiosa*, a massive nine-volume surgical compendium by Giovanni da Vigo, the official surgeon of Pope Julius II. In a single line, Traheron, translating Vigo's observations on the treatment of a canker—what we would today call an ulcerated mass—captured a distinction that has propelled and plagued the art and science of medicine for centuries: “We wyll speake of his cure aswel eradicatyue as palliatyue.” Too often in modern times, we are asked if the goal of medicine is eradication or palliation. Cure or comfort. Might this be a false dichotomy? Might not the goal of medicine, as Giovanni da Vigo, half a millennium ago, suggested, be both curative and palliative?

Though the distinction is old, the discipline of palliative care is new. Specialty certification in hospice and palliative medicine was not offered by the American Board of Medical Specialties and the Accreditation Council for Graduate Medical Education until 2006—though the gestation period began more than half a century earlier. Many pioneers, some of whom are authors in this book, nurtured this new discipline, starting with Dame Cecily Saunders, the English social worker, nurse, and physician who spearheaded the modern hospice movement, and Balfour Mount, the Canadian urologic cancer surgeon most often credited with founding the palliative care movement.<sup>1</sup>

Unfortunately and too often, the terms “palliative care” and “hospice” are confused with each other, leading at times to patient harm, especially when physicians and patients delay referral to palliative care because they believe it is identical with hospice. To avoid this confusion, it is best to think first of supportive palliative care, which ideally serves the sickest 5 to 10 percent of the population in any given year. This sort of care, measured in a span of months

to years, should be offered *early*, alongside efforts to slow down, cause remission of, or even eradicate and thus cure the primary disease.

Supportive palliative care can benefit patients by relieving complex suffering—not only physical symptoms like pain or nausea, but emotional symptoms like depression or anxiety, the social suffering of the patient’s family, and even spiritual distress. But, as a growing body of literature suggests, early supportive palliative care can also improve survival, at least among metastatic cancer patients.<sup>2</sup> The benefits of *early* palliative care are so compelling that the American Society of Clinical Oncology recommends such services within eight weeks of the diagnosis of metastatic, stage IV, cancer.<sup>3</sup>

The second and more familiar type of palliative care is known as hospice care. Hospice, which first arrived in the United States in 1975, serves especially the dying, who make up less than 1 percent of the population in any given year. Sometimes hospice begins only hours or days prior to death, but typically it spans a time frame of weeks to a few months. With a few exceptions, hospice, unlike supportive palliative care, does not begin until a patient and physician conclude that further attempts to slow the progression of disease are neither possible nor desirable.

The palliativist’s job, whether working in supportive palliative care or in hospice, is not principally to diagnose and treat *disease*, but rather to diagnose and treat the *suffering*, the dis-ease, that inevitably falls on the shoulders of those who face serious illness. The meaning of the noun “diagnosis” is related to the Greek verb *diagnōskein*, to decide, to determine, to distinguish. Diagnosis of disease relies on the hard sciences and is an essential, indispensable tool, but not the sole or even sufficient tool for the care of the whole person. A second sort of diagnosis, the diagnosis of human suffering, is also necessary. Paul Kalanithi, a neurosurgeon who died of cancer at the age of thirty-seven, embraces this distinction in his memoir, *When Breath Becomes Air*: “Science may provide the most useful way to organize empirical, reproducible data, but its power to do so is predicated on its inability to grasp the most central aspects of human life: hope, fear, love, hate, beauty, envy, honor, weakness, striving, suffering, virtue.”<sup>4</sup> If the diagnosis of disease is an effort to ensure *that* we live, the diagnosis of suffering through palliative care is an effort to enrich *how* we live, especially in the shadow of death.

No single definition of palliative care, therefore, will do. No sterile job description will suffice. Because not all disease can be cured, nor all pain eradicated with a laser, scalpel, radiation beam, chemical, genetic, or other

biological manipulation, palliative care experts coordinate, collaborate, and cooperate in multidisciplinary teams to palliate, to cloak, to relieve total pain. Palliative care is, in essence, the diagnosis and management of suffering, the *total* suffering of physical, social, emotional, and spiritual pain. Palliativists care for the most seriously ill among us. Story after story in this volume attests to the complex, multidisciplinary, global, and occasionally heroic effort to manage that total suffering.

#### AN ANCIENT STORY OF PAIN

A preoccupation with pain is nothing new. It goes back to the beginning—as far back as Genesis, in the Bible’s opening story. The intimacy of a potter-God’s lips pressed against a freshly formed human figure, poised to blow breath within, brings the promise of unending love. This is wildly exciting if somewhat awkward. Yet even before that first kiss of life, we are alerted to the underside of creation: Adam—human—is dust from the ground. The new life, full and rich and pulsing with potential, is blown into someone who, in short measure, will be condemned to return to the earth, ashes to ashes, dust to dust.

But not before he—and she—knows the story of pain. They will know physical pain, these first two, but not in an antiseptic sort of way, not neatly diagnosed and dispensed with. The curses of everyman and everywoman—they are not yet named as individuals, so their story is *our* story—are expressed by the resonant Hebrew word *itsavon* (*iššābôn*). The man and woman, both, will know *itsavon*. The woman will experience *itsavon* when she is in labor. The man, too, will experience *itsavon* when he labors in the field. Man and woman both labor, both know *itsavon*, he to wrest fruit from the soil and she to wrest fruit from the womb—both, in antiquity, doubtful and difficult ventures.<sup>5</sup>

In the Bible’s opening scene, then, there is no divvying up of pain. The broad-shouldered first word for the *man’s* pain fuses sweat and toil and grief and loss and hurt with, in the vagaries of antiquity, occasional healthy harvest; the same word for the *woman’s* pain fuses sweat and toil and grief and loss and hurt with, in the vagaries of antiquity, occasional joy and life and healthy birth. The scholars who transposed the Hebrew into Greek in ancient Alexandria seem to have understood the density of this first word for pain. They translated the Hebrew words for pain in this story with the Greek words *lupē*, grief, and *stenagmos*, groan. The man would know pain, but not only in

his weary back and blistered palms. The woman's pain would transcend the breaching of a cervix. Life, the very first story tells us, is destined to be rife with grief, raw with groans.

Such is a sliver of ancient literature, offering not a clinical diagnosis, as important as that is, but a story to be told, heard, and told back again. A story of pain, of grief, of groaning. A mirror, even, of our own pain a trillion heartbeats later. Siddhartha Mukherjee, in his memoir *The Emperor of All Maladies: A Biography of Cancer*, tells us that “medicine . . . begins with storytelling. . . . Patients tell stories to describe illness; doctors tell stories to understand it. Science tells its own story to explain diseases.”<sup>6</sup> The Bible—some of humankind's most ancient literature—begins by telling the story of pain. Relentless and inexorable and all-encompassing. *Total* pain. The first story—and it's meant to be told and heard this way—of *our* pain.

#### A STORY YET UNFOLDING

I (Jack) moved to Southern Methodist University in 2015 to teach Hebrew Bible, what Christians call the Old Testament. I arrived with modest financial support from the International Catacomb Society perhaps to do something a little different from my prior work. With a history of searing headaches, I resolved to expand our understanding of pain by connecting ancient texts on pain and suffering with modern medical practitioners, whose responsibility it is to palliate pain, especially near the end of life. I was introduced to the palliative care and clinical ethics specialist Bob Fine, who just happened to live down the street from my office. Over several hours of exhilarating front porch conversations, it became obvious, at least to the two of us, that the biblical antiquities professor and the palliativist and ethicist had much to learn from each other about pain and suffering.

Encouraged by the camaraderie I experienced with Bob, I began to gather a small coterie of scholars of antiquity and modern medical practitioners. They were an improbable cluster, by any measure, yet together we met, physicians and scholars, to wrest insight for palliative care from ancient texts on pain. Among them were Joe Calandrino and Joe Fins, both of whom have contributed creative essays to this book; Richard Payne, to whose memory this book is dedicated; and, of course, Bob Fine. We met informally twice in New York City, thanks to the hospitality of Brooke Holmes, Goheen Professor of Classics at Princeton University.

About the same time, a group from Perkins School of Theology at Southern Methodist University visited the Houston Methodist Research Institute. There I met Mauro Ferrari, CEO of the Institute. A few years later, in 2018, Mauro told me that something unprecedented was about to happen. The Roman Catholic Church's Pontifical Academy for Life was planning to hold a conference for the first time on American soil, in collaboration with Houston Methodist Research Institute and the department of palliative, rehabilitation, and integrative medicine at the University of Texas MD Anderson Cancer Center. The foundation of this unprecedented symposium, Palliative Care and Spirituality for Life, would be the Marialuisa Lectureship for Life, the history of which Mauro has chronicled in an appendix to this volume.

I introduced Mauro to Bob Fine, and both of us attended this stunning symposium. I could not help but notice the remarkable lineup of speakers, so I met immediately with Mauro to discuss publication. The speakers, I knew, represented an array of luminaries in the field. So, shortly after the symposium ended, Bob, whom I had asked to coedit the volume, and I gathered contributors, adding one or two who had not attended the symposium, and set about to produce this volume. Like the symposium, this volume is unique, defying any single category and scrambling tidy parameters.

#### A VOLUME WITH MANY PERSPECTIVES

The first part of this volume, "Palliative Care: Personal Memoirs," consists of personal histories of palliative care from the perspective of some of its pioneers: Eduardo Bruera, Constance Dahlin, Neil MacDonald, and Declan Walsh. Nowhere else is the primal challenge and unfolding promise of palliative care documented so personally and professionally. Nowhere else are so many varied stories of those who forged a new discipline, from the days of Dame Cecily Saunders, recorded. As editors, we have made a good faith effort to preserve the unique, even idiosyncratic, voices in this section. Dahlin's essay represents a professional history of palliative care from the perspective of nursing. Bruera, MacDonald, and Walsh offer various personal reflections on the emergence of palliative care, with an eye to the institutional and personal challenges early proponents faced. These are unique and influential voices. For these alone, the volume would be worth reading.

The second part of this volume, “Palliative Care: Pain and Suffering,” contains essays that might be said to have their home in the burgeoning field of medical humanities. The starting point for Joseph Fins’s essay on the nature of time is Tennessee Williams’s *The Glass Menagerie*. Kathryn Kirkland offers a slow and thoughtful reading of Jane Kenyon’s poem “Coats” in an essay directed to pedagogy. And Joseph Calandrino draws intimate and innovative connections between the ancient playwright Sophocles’s *Philoctetes* and the suffering of contemporary patients. Though ranging widely, all three essays in this section are connected by a deft and daring ability to shed light on palliative care through its unlikely association with various bits and pieces of poetry and plays, ancient and modern.

The third part of this volume, “Palliative Care: Essential Issues,” is perhaps its most eclectic. Ethicists Robin Lovin and Daniel Sulmasy explore the question of autonomy through two quite different lenses; the locus of Sulmasy’s essay is a monastery, while Lovin’s focus is various patients, but together they ask the question of what constitutes the good—a thorny inquiry—in the context of pain and suffering. James Cleary and Constantino Benedetti tackle issues related to opioids, though from altogether different perspectives. Benedetti focuses upon an American tragedy, Cleary upon a global crisis. Dominique Monlezun’s essay looks to the future, with an eye toward the impact of artificial intelligence on the evolution of palliative care.

The final section, “Palliative Care: The Caregiver,” contains various primers for those who accompany men and women who suffer. Andrew Achenbaum, starting with Leo Tolstoy’s *The Death of Ivan Ilych*, a book often used to introduce medical students to the phenomena of pain, suffering, and death, offers insights from his own personal journey as a caregiver, providing guidance for others who are or will become caregivers themselves. Stacy Auld, Courtenay Bruce, and Charles Millikan offer an institutional point of view as individuals who have successfully incorporated the spiritual component of care in a nationally renowned hospital. Bettie Hightower offers a grassroots perspective on hospital chaplaincy, while Tullio Proserpio, Elena Pagani Bagliacca, Giovanna Sironi, and Andrea Ferrari tell the story of a remarkable institution in Milan and how chaplains make inroads into the lives of adolescents with cancer. The story of Lucia, who anchors this final essay, is worth telling in any land.

This volume has something to say to a breathtaking array of readers, to any “human merely being” in the face of serious illness, from patients to family

members to physicians, and to any other members of the health care team.<sup>7</sup> Pioneers of the field lead us back in an unvarnished way to the matter of origins. Leading researchers, who are shaping approaches to palliative care for the next generation, offer fresh perspectives on topics as diverse as narrative approaches to medicine, the nature of time, and global challenges to palliative care; these essays span the ages, from Sophocles's *Philoctetes* to the promise of artificial intelligence. Ethicists lead us, through anecdotes and analysis, into a discussion of human flourishing and the challenges of individualism in palliative care. Colleagues from Milan introduce us to innovations in an institute devoted exclusively to adolescents with cancer. The breadth of essays is stunning, but the wealth of experience even more so. This volume offers an extraordinary look at palliative care: its history, told through hard-won experience; its challenges, told in institutional, ethical, and global terms; its spiritual dimensions, told from the perspective of spiritual care providers, both professional and volunteer; and its unfolding perspectives, told in ways both practical and innovative.

## NOTES

1. The recent publication of Balfour Mount's *Ten Thousand Crossroads: The Path as I Remember It* (2020) deserves mention.
2. Temel et al. 2010; Bakitas et al. 2014; Sullivan et al. 2019.
3. Ferrell et al. 2017.
4. Kalanithi 2016, 170.
5. These words can be found in Genesis 3:16–19.
6. Mukherjee 2010, 390.
7. The language of a “human merely being” is borrowed from E. E. Cummings’s “I thank you God for most this amazing.”

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