



End-of-Life Care
and Pragmatic
Decision Making

A Bioethical Perspective

D. Micah Hester

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End-of-Life Care and Pragmatic Decision Making provides a philosophical framework based on a radically empirical attitude toward life and death. D. Micah Hester takes seriously the complexities of experiences, and argues that when making end-of-life decisions, healthcare providers should pay close attention to the narratives of patients and the communities they inhabit so that their dying processes embody their life stories.

Every one of us will die, and the processes we go through will be our own – unique to our own experiences and life stories. Hester argues that it is reasonable to reflect on what kinds of dying processes may be better or worse for us as we move toward our end. Such consideration, however, can raise troubling ethical concerns for patients, families, and healthcare providers. Even after forty years of concerted focus on biomedical ethics, these moral concerns persist in the care of lethally impaired, terminally ill, and injured patients.

Hester discusses three types of end-of-life patient populations – adults with decision-making capacity, adults without capacity, and children (with a specific focus on infants) – to show the implications of pragmatic empiricism and the scope of decision making at the end of life for different types of patients.

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A Bioethical Perspective

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To Caroline: I was never able to touch you when you were alive, but you touched me too deeply to express in words. Our special gain also became our greatest loss, and yet your story lives on with us always.

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Preface

Any experience[, ideal, or concept], however trivial in its first appearance, is capable of assuming an indefinite richness of significance by extending its range of perceived connections. Normal communication with others is the readiest way of effecting this development, for it links up the net results of the experience of the group and even race with the immediate experience of an individual.

John Dewey

On the way
we passed a long row
of elms. She looked at them
awhile out of
the ambulance window and said,

What are all those
fuzzy-looking things out there?
Trees? Well, I'm tired
of them and rolled her head away

William Carlos Williams

Another book about end-of-life issues . . . how can this be? For more than thirty years, bioethics, medical ethics, clinical ethics (whatever you choose to call this field of concern) has been looking at end-of-life issues as paradigmatic of ethically challenging situations in medicine. For that long, at least, articles and books looking into the

many aspects and challenges of end-of-life care have been produced. I cannot truly explain why I have added another text into this array.

And yet it is worth taking just a moment to note that there is always more to say about end-of-life care. We will all die. In fact, everyone who at the time of this writing is my age or older will be dead by the turn of the century. Today, tomorrow, and the next day, some physician will be at the bedside of some patient who is dying, and tomorrow (or maybe the next day) some patient's dying process will pose a challenge to herself or others – whether the challenge is medical, social, personal, psychological, or ethical. And surely somewhere in the United States during the next month, the end-of-life care considerations of a patient will prove ethically challenging to such an extent that it will be brought before a hospital ethics consultant or committee. These are inescapable facts of the world we live in. There truly is more to say, more work to be done. Given these facts, the book you hold does not pretend to have a final say or to produce the last word or even to be comprehensive.

During the preparation of the final manuscript for this book, two books, CG Prado's *Choosing to Die* and Robert Young's *Medically Assisted Death*, were published by Cambridge University Press. These two philosophers (Prado from Canada and Young from Australia) have offered careful and interesting arguments for "rational suicide" and "voluntary active euthanasia," and I recommend them to any reader of this book. While they are more narrowly focused in scope than this book, they both are more detailed in the development of their respective issues. What follows in these pages, then, may best be seen as a survey of how a radically empirical philosophical approach affects our analysis of (and practices surrounding) some specific issues in end-of-life care writ large.

What is equally important to distinguish, however, is the role philosophy plays in this book. In a review of Prado's and Young's books in the *Journal of the American Medical Association*, Ernle Young observed, "Prado's book is a . . . somewhat arcane academic treatise; Young's is a book of relevance to clinicians. . . . Prado's appeal to medical ethics will be appreciated only by the small minority of trained philosophers among them. . . . Young's book, in contrast, is a pragmatic and cogent read for all those [interested in bioethics]" (Young 2008,

1703). Now, whether or not I endorse the reviewer's take on these books, my point in mentioning this contrast between Prado and Young is to explain that the work you are now reading is somewhere in between. The early chapters are explicitly and purposefully philosophical – attempting to explain the conceptual basis that grounds the insights throughout the book. The later chapters turn to more clinically grounded discussions, though not devoid of philosophical text. I admit that I am unapologetic about this, as I believe good medical ethics demands a clear conceptual approach. And I trust that philosophers and clinicians alike will find herein challenging but useful considerations worth taking the time to read. (Of course, those less interested in the theoretical can skim Chapters 2 and 3.)

In sum, my work here takes on related lines of argument that follow from a particular philosophical attitude – that of radical empiricism. That is, this book is written by someone who wants to explore the implications for end-of-life care should we take on a concern for meeting the many and various textures of lived experience in their individual and social manifestations. If you are not so moved by the implications of a radically empirical attitude, I fear you will give up on the arguments herein within one or two chapters. I would not say that you were wrong to do so; only that it would be so much the worse for me if you did.

However, should you choose to take the journey, my hope is that you will find an account of morally sensitive care for the dying that, while possibly surprising – even infuriating – does, at least at times, help illuminate some truths about our living and dying. Life contains moments of hope and situations of deep tragedy, and what I believe is important for all of us to recognize is that life continues all the way to death – that is, that dying persons still live until their last moments. As such, we need to take seriously what such experiences entail for them, for the communities in which they reside, and for the persons and institutions that care for and about them.

I will let the rest of the book speak for itself, and for me.

As already noted, the subject matter has been covered extensively in the literature, and thus, many excellent pieces of analysis and insight simply have not been considered in this study. I regret that the book

is impoverished all the more because of this. While the book is fashioned as a single, connected statement, it began in bits and pieces, fits and starts. One chapter of my original doctoral dissertation was the genesis of this work, and other journal articles and conference presentations took on related themes that came together in a more intentional and systematic way herein. All has been rethought in light of the general purpose of the book and the continuing flux of information and analysis concerning end-of-life medicine and practice.

I owe my deepest appreciation to a great many people, and though I may leave some important folks out, I want to let you and them know of their direct and indirect contributions to the completion of this work.

First, I must thank Michael Hodges, my dissertation advisor at Vanderbilt. The chapter on end-of-life care was his favorite of the dissertation, and as such, his encouragement in getting me to continue my work on the themes therein was of singular importance. Also, the influence of other graduate teachers, John Lachs and Richard Zaner, are evident throughout the text. I can only hope I have served their tutelage well.

As with much of my work, once again, John J. McDermott played a pivotal role in bringing this text to press. John heard a conference paper of mine, and at a subsequent luncheon suggested to me that coupling that paper with some of my previous publications would make a good book – I hope that I succeeded in creating just such a book. His support and friendship are always a great service to me.

Many people have read portions of this text, whether in early incarnations as journal articles or book chapters, or later as my attempt to complete the book came to a close. I would therefore like to thank the following publishers and publications for kindly granting me permission to draw on previously published writings of mine: Delese Wear, former editor of *Journal of Medical Humanities*, which published my first writing on end-of-life issues, now part of Chapters 3 and 4, and which originally appeared under the title “Progressive Dying: Meaningful Acts of Euthanasia and Assisted Suicides” in *Journal of Medical Humanities*, 1998, Vol. 19, no. 4:279–98; Glenn McGee, editor of the book *Pragmatic Bioethics*, which included two

chapters of mine, one of which is the basis for parts of Chapters 4 and 5, and originally published in *Pragmatic Bioethics*, 2nd edition, Glenn McGee (editor), MIT Press, copyright © 2003, 121–36; Lainie Ross, editor of a special issue of *Theoretical Medicine and Bioethics*, from which an article of mine has become part of Chapter 6, and which originally appeared under the title “There is More to the Story than We Explicitly Acknowledge” in *Theoretical Medicine and Bioethics*, 2007, Vol. 28:357–72; Eve DeVaro Fowler former philosophy acquisitions editor at Rowman & Littlefield, which published my first monograph in bioethics, *Community as Healing*, in which some of the arguments of Chapter 2 were first developed and published: *Community as Healing*, copyright © 2001, Rowman & Littlefield 47–66; Worth Hawes, philosophy acquisitions editor at Wadsworth, which published my co-authored book *On James*, in which much of the “radical empiricism” discussion was first developed and published: *On James*, Talisse, RB, and Hester, DM, copyright © 2004, Wadsworth, a part of Cengage Learning, Inc., reproduced by permission, www.cengage.com/permissions; and anonymous reviewers of the many journal publishers to which I submitted material. Robert Talisse helped me fashion some of the work on James’s radical empiricism (and attempts to keep me honest and reflective as a philosopher), and Chris Hackler read through several of the later chapters. Others who have influenced the work have been colleagues (in no particular order – with many I have forgotten to list, I’m sure) from around the country – Mary Mahowald, Griff Trotter, Toby Schonfeld, Karen Kovach, Alissa Swota, Tomi Kushner, James Medd, Mark Moller, David Mathis, Robert LaGrone, Harold Katner, Richard Ackermann, and the anonymous reviewers of the various versions as this book tried to find its feet. To all of them, my deepest thanks. I owe special thanks to Beatrice Rehl at Cambridge University Press for her encouragement and championing of the book, and to Ronald Cohen, whose editing polished and improved the text.

I also wish to thank both my previous institution, Mercer University School of Medicine, and my current ones, University of Arkansas for Medical Sciences and Arkansas Children’s Hospital, especially Bonnie Taylor, for their support of my professional scholarship. It is also at these two institutions where the majority of my clinical

experience has arisen, and working with the physicians, nurses, and social workers, not to mention, patients and families therein, has enriched my understanding of these issues.

Finally, my family allows me the opportunity to work in the field that I do, taking time away from them to complete such efforts. My love and affection to Kelly, my wife, and to Emily, Joshua, Matthew, and dear Caroline, my children.

. . . And in the end
The love you take
Is equal to the love you make.

Lennon and McCartney,
Abbey Road (1969)

Crito Revisited

Socrates: . . . [K]eep this one truth in mind, that a good man cannot be harmed either in life or death, and that his affairs are not neglected by the gods. . . .

Plato's Apology

Crito: . . . Socrates, I do not think that what you are doing is just, to give up your life when you can save it, and to hasten your fate . . .

Socrates: . . . We must . . . examine whether we should act in this way or not, as not only now but at all times I am the kind of man who listens only to the argument that on reflection seems best to me. I cannot, now that this fate has come upon me, discard the arguments I used; they seem to me much the same. I value and respect the same principles as before . . .

Plato's Crito

In the ancient Greek dialogue, *Crito*, Plato provides a portrait of his mentor, Socrates, only days before his death, and while the death scene itself is left to another dialogue, it is in *Crito* that Socrates explains why he would rather die in prison than live in exile (Plato 1997). The conversation is instructive on many levels, and one aspect that merits greater attention is the extent to which Socrates's cultivated character relates to the decision at hand. In particular, the dialogue raises issues concerning decisions at the end of life, decisions faced (in admittedly much different ways) by a multitude of patients,

patient families, friends, and healthcare providers. In order to bring this out, let us begin, rather than with a simple recounting of the Platonic dialog, with a retelling of the story, updated and transformed from the prison cell to the hospital room.

Mr. S. is in his early seventies. He is a professor of philosophy and a war veteran who has earned commendations for bravery in battle, but is now confined to a bed in a hospital. According to his physicians, his cancer – a myeloma – is terminal, and so he simply awaits his fate. Though staring squarely into the abyss of death, his mind remains clear, even vibrant, and his mood is easily buoyed by visitations from his friends and loved ones.

One morning, Mr. S. awakens to see his friend and oncologist Dr. C., who has come not only to visit but to bring news and a proposition. The news is that Dr. C. has been investigating options, and clearly the hospital has reached the limits of what it can do to keep Mr. S. alive. In light of this, Dr. C. has looked into the possibility of employing alternative therapies at other centers around the world, and he wants to propose to Mr. S. some of these treatments that, while expensive and experimental, offer a small chance of success for extending life. However, being such a longtime and close friend, Dr. C. knows that Mr. S. will not be easily persuaded by some fly-by-night, desperate attempt to spare his life. Instead, Mr. S. will require of Dr. C. a careful accounting of this plan and a justification for following through with its recommended actions. In fact, Dr. C. is prepared to put forth several arguments on behalf of his proposition in the hope that Mr. S. might wish to prolong his life if possible.

According to his own evaluation of the situation, Mr. S. has been careful to cultivate the particular life he has led. He accepts the choices he has made, and most were quite deliberate. He has never been one to cling to life at all costs, and he does not jump at options simply because they are before him. He prefers to be reflective and to consider options in the context of his environment and character. As death approaches, then, he is confronted with the possibility, though perhaps remote, that he can stave off the abyss for awhile. Rhetorically, Dr. C. asks his friend, “Are you not acting ‘cowardly’ by taking the ‘easy way out,’ not fighting to extend your life (‘Where is

your rage against the dying of the light?')? Would it not mean more time with family and friends, and Don't you owe your family at least that much? Would you not be able to bring your unique insights to even more people as you continue to live? Would it not demonstrate a 'manly' defiance at the cruel fate that has befallen you?"

For Mr. S., none of the arguments is persuasive; in fact, Mr. S's responses are quite clear and consistent: His family will understand, and his friends surely should. There is no way of telling whether his unique way of interacting with others will translate outside the community in which it was formed. Why be defiant against a fate that was neither of his own choosing nor of his own making? To "scramble" for life is inconsistent with his approach to life. He has never wanted to be too self-concerned, never feared death, never wanted more than his due, never wanted to be beholden to others. He has always tried to think through problems and choose wisely, not wildly. Though death will surely be an outcome of his choices on these matters, it is a death he is willing to embrace, for it is the most meaningful way for him to live unto death.

How We Die

Life – *living*, really – is the condition in which we all find ourselves, and though there might be a few who vainly argue the opposite, and regardless of the promises of a few geneticists or even some cryogenicists, *that we die* is a fate that most of us realize. However, these two facts taken together often lead to stress and frustration concerning our futures. Death is inevitable, whereas living is actual. Living is what we know; death is obscure. Eventually, though, it is possible to come to grips with one important fact: Even though death is the end point of our living embodiment, dying is a process within embodied living itself – that is, dying is part of our on-going life stories. Should this realization occur, the focus may shift from *that we die* to *how we die*.

Illustrating what she calls the "cinematic" myth of the "Good American Death," Nancy Dubler writes, "[The death scene often] includes the patient: lucid, composed, hungering for blissful release – and the family gathers in grief to mourn the passing of a beloved life. The

murmurs of sad good-byes, the cadence of quiet tears shroud the scene in dignity” (Dubler/Nimmons 1992, 146). Unfortunately for many of us, our deaths will not be the spiritual, peaceful “passing” that we might envision or desire. As physician Sherwin Nuland explains, “To most people, death remains a hidden secret. . . . [T]he belief in the probability of death with dignity is our, and society’s, attempt to deal with the reality of what is all too frequently a series of destructive events that involve by their very nature the disintegration of the dying person’s humanity” (Nuland 1993, xv, xvii). For many, the hope is that they will die surrounded by loved ones (or quietly in the night), slipping away without pain after tying up all loose ends. The reality for the great majority of us, however, is that we will find ourselves ravaged by disease, struck down by illness, or tragically injured; we will be hooked up to machines, ingesting drugs. Nurses and physicians, strangers to us really, will be our most consistent contacts with humanity. Family and friends will find themselves without resort and at a loss to help if for no other reason than that we rarely give a clear account of our desires concerning end-of-life care before it is too late to give any account at all. We would like to think that these situations are at the margins, but if so, the margins are awfully wide and, either way, must not be ignored. Death, as William Gavin has argued, is a complex of historical and cultural as well as biological factors that do not present themselves for tidy packaging (see Gavin 1995; 2003). Crudeness and vagueness, frustration and mutilation are at play as much as scientific, technological precision in diagnosis and prognosis. Loneliness, pain, and bitterness are more common than peace and joy.

Mr. S, then, is a rare person – thoughtful, brave, and consistent in his character, able to move toward death with a calm, careful, considered disposition. In these respects, his case is easily idealized, hardly displaying the confusion, pathos, and tragedy of the hundreds of thousands of patients each year who find themselves confronting issues at the end of life. As such, there is only little we can glean from Mr. S’s situation. Tolstoy’s Ivan Ilych may be closer in sketch to many real-world deaths, with his pains and fears, concerns and insights, and yet his account also marks the death of only one man. What can