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978-0-521-13073-8 - 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

### *A Bioethical Perspective*

*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.

D. Micah Hester is Associate Director of the Division of Medical Humanities and Associate Professor of Medical Humanities and Pediatrics at the University of Arkansas for Medical Sciences, and is clinical ethicist at Arkansas Children's Hospital. He is the author and editor of eight books and numerous journal articles, and he coordinates the Pediatric Ethics Consortium and the Pediatric Ethics Affinity Group of the American Society for Bioethics and Humanities.

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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,

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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



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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

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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](http://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)