

Living, Dying, Death,
and Bereavement
(Volume One)

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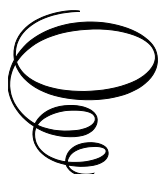
*Conversations with
Thanatologists*

By

David E. Balk

Foreword by Paul C. Rosenblatt

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Living, Dying, Death, and Bereavement (Volume One):
Conversations with Thanatologists

By David E. Balk

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This book is dedicated to Mary Ann Balk and to Janet Renee Balk, my wife and my daughter, in thankfulness for and appreciation of their savvy, grit, love, support, courage, help, intelligence, senses of humor, commitment to achieving social justice, and fervent outspokenness about equality. Each has core values and beliefs by which she leads her life. My heart smiles when each enters a room where I am.

Also this book is dedicated to the administrators, faculty, and staff of Brooklyn College, particularly to the faculty and staff of the Department of Health and Nutrition Sciences, who made welcome during 15 productive years at CUNY a wandering thanatologist from the wilds of the American Midwest. I appreciate the trust and friendship you offered.

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FOREWORD

This book features life histories, gathered by David Balk, from 37 leaders in the field of death, dying, and bereavement (thanatology). The book is a treasure with many different potential uses.

For qualitative researchers, the life stories are a resource for exploring a wide range of issues in the lives of thanatologists, the field of thanatology, what people include in their life stories, and the interview process. I can imagine these life stories fueling projects in such research areas as the psychological and social aspects of occupational choice and personal development, the sociology of occupations, the sociology of developing disciplines, the history of death, dying, and bereavement as topics for academic study and professional training, thanatology as it relates to the culture(s) in which it developed, and gender as it relates to interviewee lives and the development of thanatology.

The interviews are valuable resources for learning about the field of death, dying, and bereavement—its complexity, its social networks, the influential ideas, and the different and sometimes opposed lines of thinking. The people interviewed offer insights into themselves, the academic and professional disciplines in which they have worked, and the society they live in as they talk about how they became involved in a field that focuses on death, dying, and bereavement.

The interviews are a unique resource for learning about each of the 37 people. Included in that are their constructions of their personal histories, their stories about themselves, things they have accomplished as thanatologists (including research, writing, teaching, work with the dying and their families, mentoring, program development, grief counseling, grief therapy, editing, and popularizing), what they make of those accomplishments, and what they hope to accomplish in the future.

I know many of the 37 people interviewed, have read and cited publications by, I think, 26 of them in my own writings, and listened to talks by many of them. But as much as I know these people, I learned things about every one of them by reading the interviews, and for me that was sweet, interesting, informative, and sometimes emotionally touching. It is a book about good,

interesting people who have lived good, interesting lives, and have done important things.

The life stories Balk elicited from the interviewees are filled with engaging, moving, remarkable, fascinating stories. I think each of the 37 life stories is worthwhile reading and reflecting on its own. But I also think there are some striking things that a number of the life stories have in common. Others may read these life stories differently than I, but one thing I think that is in stories and that is striking to me is how often in the lives of the interviewees, one event, one person saying or doing one thing, one opportunity, one random choice, or one coincidence led an interviewee into thanatology and into projects that have done great good and made an enormous difference in the lives of others. Another thing that is striking is how these people have not gone it alone, but have been richly connected to others. Thanatology leadership and good works involve inspiration by others, collaboration with others, help from others, and help given to others. And as part of that, quite a few of the 37 interviewees talk about others of the interviewees.

As Balk points out in his introduction, there are many leaders in the field who were not interviewed (and I include David Balk among those leaders who were not interviewed). So I do not think of this as a book that offers life stories of close to all the leaders in the field, but if one learns the life story material from the 37 people interviewed by Balk one would know a great deal about the field. So I see this book as a valuable educational resource for students of thanatology. Of course the interviews only touch on what they touch on, so if one were interested in becoming more expert on the life of Colin Murray Parkes, Thomas Attig, Sister Frances Dominica, or Charles A. Corr (I used a random number table in choosing these four), one would have to go well beyond the interviews of them in this book. But still the 37 interviews in this lovely book provide quite an education in the field of thanatology.

Paul C. Rosenblatt
Professor Emeritus
University of Minnesota
July 3, 2020

VOLUME ONE

CHAPTER ONE¹

INTRODUCTION

About This Book in General

Thanatologists share their life stories in this book. The persons telling these stories have chosen careers that concentrate on dying, death, and bereavement. Many have been with individuals as they were dying; many others have been with individuals coping with a loved one's death. All have made significant contributions increasing our understanding of dying, death, and bereavement. These thanatologists' lives offer rich glimpses into the history of thanatology over the past 75 plus years.

“Thanatology” is a difficult, unfamiliar word for many persons. “What is thanatology?” they will ask. “It is the study of dying, death, and bereavement,” they will learn. Avoidance is a common response when learning the meaning of the word. Another response, less common, is to express interest to learn more. The conversations presented in this book, from persons whose very lives and professional careers focus on dying, death, and bereavement, address the desire to learn more.

The salience of thanatology is obvious when we consider several topics: the aging demographics of most countries, the leading causes of death and the realities of how most persons die, the growth of hospice and of efforts within medicine to insure that a good death becomes the norm of medical practice, the push for public health to be more substantively involved in end of life issues, genocidal wars in the Middle East and in Africa, the world-wide devastation caused by the COVID-19 pandemic, the constant lethal assaults on Black males and females in the United States, knowledge that bereavement and grief are more prevalent on college campuses than many outsiders realize, and increases in the number of countries and states permitting physician-assisted suicide.

¹ Charles A. Corr read an earlier version of this chapter and provided helpful feedback.

Thanatology is a multi-disciplinary endeavor. Persons from several disciplines contribute to the field. Among these disciplines are philosophy, anthropology, art, medicine, literature, psychology, theology, education, anthropology, gerontology, family science, nursing, social work, history, psychiatry, religious studies, and sociology. With such rich, well-established disciplinary sources, thanatology ironically has not gained identity as an academic discipline within higher education. There are but a few colleges that offer undergraduate or graduate degrees or advanced certificates in thanatology: Brooklyn College of the City University of New York, King's University College of Western University in London, Ontario, Marian University in Wisconsin, and Hood College in Maryland. The National Center for Death Education at Mount Ida College in Newton, Massachusetts, offered thanatology workshops and advanced certificates until the University of Massachusetts absorbed the college in 2018. Perhaps the difficulties of filling thanatology's multiple disciplinary requirements provide insight into why thanatology has not gained recognition as an academic discipline. Another explanation could be rooted in the prevalent denial of death across cultures and societies. It is implausible to argue that thanatology lacks validity for scholarly study in any of the disciplines mentioned above.

Several disciplines that contribute to thanatology are represented in this book. Specifically, participants have disciplinary training in psychology, religious studies, art, literature, history, social work, nursing, theology, education, psychiatry, sociology, philosophy, and anthropology. Some participants have training in two or more disciplines.

Impetus to Produce This Book

The impetus to produce this book is fivefold. Here is what I mean.

Impetus One. Several major contributors to thanatology have died and thus are forever beyond our learning their personal reflections on thanatology and on their lives: a list of some of these persons includes John Bowlby, Erich Lindemann, Catherine Sanders, Richard Kalish, Ron Barrett, Jack Morgan, Catherine Johnson, Elisabeth Kübler-Ross, Ernest Becker, Robert Kastenbaum, Hannelore Wass, Avery Weisman, Cicely Saunders, and Herman Feifel.² Many of the main figures who have contributed to

² While I was in the midst of conducting interviews, Phyllis Silverman died. She had agreed to take part, but simply had not the energy at the end to do so. Within six months of my interviewing Robert Fulton, he died.

thanatology are now in their late 60s if not older. While their writings have shaped our current thinking, we know little about what shaped them and, if we wait too long, we will be unable to talk with them. The message was clear: “Seize the day.”

Impetus Two. Thanatology is alive because its roots extend into the past and nourish the present. An impetus for this project is my concern that the history of thanatology is being relegated to the sidelines. An indicator of the spread of this indifference to the past is the growing prejudice for publications that are 5 years old or less.

How to make clear my position without being dismissed as a know-nothing troglodyte opposed to gains in knowledge and blind to the evolution of ideas? Maybe I’m just an old fogey wedded to the past and opposed to change. On the other hand, perhaps there is value in what pioneer thanatologists produced, and we need to know and use those valued contributions. But then, if there is value in the past, how to make clear my concern that thanatology’s history be valued and used without overstating the case?

I value the work of ongoing, up-to-date scholarship. With my colleagues at the various universities where I have taught, I consider suspect syllabi for courses, let’s say, on adolescent development or on astronomy or on palliative care or on nutrition or on bereavement, with no current scholarship highlighted. Obviously, we need new studies from inquiring minds that extend our knowledge and question our assumptions and findings. While I am concerned over a loss of historical perspective in thanatology, at the same time I highly prize advances in knowledge; it is not an either/or proposition. We need both to be grounded in past scholarship and open to new findings. Who would gainsay the vital contributions to our field from the recent forays into neuroscience (Kosminsky and Jordan, 2016a)? Who would question the recent efforts to make a good death an expected outcome and other efforts to increase sensitivity within medical schools to the humanities and the arts (Bertman, 2015; Institute of Medicine, 2015)? Who seriously would dismiss the ongoing examination of continuing bonds (Klass and Steffen, 2018)? Who doubts the importance of recent scholarship identifying issues that bereaved college students face (Cupit, Servaty-Seib, Parikh, Walker, et. al., 2016; Servaty-Seib and Fajgenbaum 2015; Varga, 2017)? On the other hand, valuing, for instance, the latest bereavement scholarship and ignoring contributions from the history of bereavement research implies that what Freud (1917/1957), Lindemann (1944), or Bowlby (1969-1980) wrote about bereavement is

simply unimportant when compared to a journal article or book published recently. The wisdom of classics becomes lost when they are unexamined due to gaps in our learning rooted in overemphasizing recent publication dates. While I suspect that some readers by now are dismissing my argument as a strawman, or even a hollow man argument, how many have read Lindemann, Bowlby, or Freud? How many consider it unimportant to read them?

I imagine an oncology specialist, a suicidologist, or a palliative medicine specialist nodding yes: to them it is not important to have read Lindemann, Bowlby, or Freud.³ I acknowledge that historical classics very likely differ across the fields of thanatology. The foundations of the fields of dying and of death are not writings on bereavement. However, there are roots in the past that are as important to the fields of dying and of death as the writings of Freud, Lindemann, and Bowlby are to the field of bereavement: for instance, from the twentieth century, Bluebond-Langner (1978), Glaser and Strauss (1965, 1968), and Nuland (1994) to the field of dying, and Aries (1975, 1981), Becker, (1973), and Feifel (1959) to the field of death. Clearly, works from other centuries offer valuable reflections for thanatologists, for instance, 2400-year-old philosophical dialogues of Plato (1871), 440-year-old essays from Montaigne (1580/1979), 357-year-old poetry from John Donne (1663/1956), and 135-year-old literature from Tolstoy (1886/2015). Does Shakespeare ever go out of date or lose connections with living and dying and grieving?

One result of ignoring the past is relying solely on second-hand accounts of seminal scholarship from another generation. Another result of ignoring the past is a vulnerability to reinventing the wheel. On a few occasions, I have heard “new ideas” being trumpeted without the trumpeter’s faintest recognition that earlier scholars presented these ideas a generation or more ago. Consider efforts to sensitize physicians and medical school students to psychosocial issues at the end of life and to bring the humanities into the medical school curriculum. One would expect current work in this area to be informed by Bertman (1999), Weisman (1972; Weisman and Worden, 1977a), Worden (Sobel and Worden, 1982; Worden and Proctor, 1976), and Cassem and Stewart (1975). Consider the constructs “self-concept” and “self-disclosure.” A solid use of these constructs in contemporary thanatology would examine earlier scholarship, perhaps from such figures as Allport (1961), Fulton (1965), Jourard (1971), Larson and Chastain

³ However, working with suicide loss survivors would lead one to the bereavement literature and the trauma literature.

(1990), Offer (1969), and Super (1963); whether those specific scholars' works are consulted, a current researcher would look for how the ideas of "self-concept" and "self-disclosure" have developed and been used over time, not just examine their appearance within the past 5 years.

The persons interviewed in this book are part of the living history of thanatology. Learning their life stories brings the history of thanatology front and center and provides examples of how the past influences us and them and thanatologists yet to arrive on the scene.

Impetus Three. In-depth conversations with leading contributors to thanatology offer unique perspectives on the history of the field, assessments of colleagues' contributions, appraisal of influential ideas, and considerations on what the field needs to be doing. We learn what led individuals to become interested in issues of dying, death, and bereavement. We learn what obstacles some persons faced. We also may gain a holistic appreciation for these persons as they share not only what they have done (are doing) in thanatology but also what else motivates them; what, as it were, fascinates them about life and what they do when not engaged in thanatology. In short, these oral histories provide a series of inspiring life stories from persons who have influenced thanatology.

Impetus Four. Stories have enduring interest across cultures. Storytelling is a principal source of meaning making that is being used increasingly as a research tool (Lewis, 2011) and as an intervention within grief counseling (Neimeyer, 2012a, 2012b, 2019). Joseph Campbell (1949) persuasively presented the power of stories to convey and uncover meaning in human existence. Rollo May (1953) embraced literature for its unsurpassed value in disclosing matters central to humanity. This fundamental aspect of storytelling—disclosing meaning through empathic understanding (Dilthey, 1894/2010; Polanyi, 1958)—becomes elaborated in the case study method, the responsive evaluation approach, and alternative means of communicating information professed by Robert Stake (1986, 1995, 2010; Stake and Balk, 1982) at the University of Illinois at Urbana-Champaign. Stake notes (a) that humans learn primarily through observation--consider Bandura's social learning model (Bandura, 1977)--and (b) that rich observational details in research reports enable people to make naturalistic generalizations (Stake, 1980; Stake and Trumbull, 1982).⁴ In summary, stories grab people's

⁴ Naturalistic generalizations are formed by comparing and contrasting details and descriptions in a story and finding applications to other situations with which the person is familiar. Reading about struggles a thanatologist had with being

attention, offer rich insight and understanding about questions that impinge on human existence, and promote naturalistic generalizations. I started this project with explicit assumptions that life stories gained from thanatologists would be meaningful for more than a small group of persons and would lead to naturalistic generalizations.

In addition to the power of stories to discover and disclose matters significant to humanity, some stories simply are interesting in themselves. Examples include the excellent biographies of Charles Darwin (Browne, 1996, 2003, 2006), William James (Allen, 1970), Alexander Hamilton (Chernow, 2004), and Harry Truman (McCullough, 1992), innumerable novels, the oral histories of community psychologists (Kelly and Song, 2004, 2008), and John Henry Newman's account of the development of his religious ideas (Newman, 1864/1950). The stories thanatologists present in this book not only uncover and disclose matters central to humanity but simply are interesting in themselves.

Impetus Five. The life stories presented in this book convey rich information about personal development and social commitment. Studying personal development and social commitment became centrally important in psychology and education in the 20th century, primarily in the middle decades. Development occurring in stages became a paradigm used to describe and explain personal development and social commitment. The major examples primarily, though not solely, focused on cognitive change over time. Piaget (1954) explained a child's increasingly more complex comprehension of reality in terms of passage through distinct stages: preoperational to formal operations. Kohlberg (1974, 1981) explained moral development in terms of 6 stages of moral reasoning that lead to increasingly sophisticated reasoning about justice; Gilligan (1982, 1993) proposed an alternative, arguing that Kohlberg over-valued justice in place of empathy and caring, and that Kohlberg showed no appreciation for how women reason about moral dilemmas. Fowler (1981), extrapolating from Piaget and Kohlberg, described changes over time in faith consciousness in terms of 7 stages that lead to greater cognitive complexity, compassion, tolerance for ambiguity, and commitment to social justice. Perry (1968) reported how young adults' thinking about reality moved from a dualistic epistemology (absolutist decisions about what is right or wrong) to a committed relativism in which conflicting claims about truth are assessed in terms of evidence and in terms of the convergence of probabilities; Perry

marginalized, for instance, could lead readers to insights about similar experiences in their lives and in the lives of others.

noted that movement from dualism to committed relativism existed in consort with changes in reasoning about ethics. Erikson (1950, 1968) explained identity formation in terms of movement through 8 stages that extend from infancy through old age and lead to either increasingly greater community solidarity or increasingly greater self-absorption. Of course, we know that Kübler-Ross (1969) picked up on using the paradigm of development occurring in stages in her presentation of terminally ill persons' psychosocial responses to learning they were dying; we also know that the stages of dying she proposed are deeply questioned (Corr, 2011, 2018; Doka and Tucci, 2011; Konigsberg, 2011).

The themes of personal development and social commitment have interested me over my life as a student, teacher, administrator, and scholar. I briefly describe below my interest in changes over time in terms of these themes. This interest was an impetus to complete this oral history project. Because of my involvement with thanatologists, I became invested in documenting the rich, inspiring personal development and social commitment that mark their lives. It has become abundantly clear to me that persons' involvement as thanatologists leads to increasing self-understanding à la Erikson and Perry and a concomitant commitment to being citizens of the world. We understand that we are all in this together.

My interest in personal development and social commitment emerged, if inchoately, at least by my undergraduate years and became much more pronounced in my graduate Counseling Psychology studies as I tacked toward writings of Erik Erikson and his notions of identity development over the life-span (Erikson, 1950, 1968; Erikson, Erikson, and Kivnick, 1986), as I was attracted to the career counseling/vocational development system of Donald Super and his linkage of self-concept to career choice (Super, 1963, 1964), and as I became intrigued with Alexander Leighton's (1959) profound writings on culture and community psychiatry. My interest in personal development was stimulated when I found Myra Bluebond-Langner's (1975) dissertation on terminally ill children, later turned into a book (Bluebond-Langner, 1978), on the shelves of the Graduate Library at the University of Illinois at Urbana-Champaign and read it several times. My interest in personal development and social commitment was in play as I worked with researchers at a community mental health center in Phoenix to document the life stories of persons dealing with chronic mental illness (Wignall, 1975). My interest in personal development was part of my reasons to write a dissertation in which I interviewed adolescents bereaved over a sibling's death (Balk, 1981). My interest in personal development and social commitment influenced me when I advised college students and

encouraged them to tell me their short-term and long-term plans and why those plans mattered to them. The writings of William Perry (1968) helped me organize my growing path toward constructivism and my swelling sense that Newman (1864/1950, 1870/1955) correctly linked certitude to converging probabilities. Erikson's and Perry's writings, plus Fowler's model on faith consciousness development, also helped me organize my understanding of the cognitive and psychosocial issues that frame college students' lives. Belief in the importance of personal development and social commitment emerged as my wife and I collaborated on an extensive study of the continuing education needs of Episcopal clergy and in that study transcribed in-depth interviews with many members of Province VIII of the Episcopal Church (Balk and Balk, 1985). Interest in personal development and social commitment manifested when I became aware of and committed to (a) documenting the incidence and prevalence of college student bereavement and (b) engaging universities to organize and deliver relevant help to the students (Balk, 1997, 2001, 2011a). Finally, this interest manifested when as the Chair of the Department of Health and Nutrition Sciences at Brooklyn College I set aside 20-30 minutes at the start of all monthly department meetings for individual faculty members to tell the rest of us one or more projects they were working on.

Limitations of the Book

All research has limitations. Some limitations to this book are evident:

1. Several persons who have made significant contributions to thanatology are not part of my book. Their stories deserve to be told. Should interest in providing oral histories of thanatology advance, perhaps persons not interviewed here will be included in a new project.
2. Certain areas of thanatological focus are either underrepresented or are missing altogether. Attention should be given, for instance, at some point to interviewing bereavement counselors, child life specialists, hospice nurses, persons engaged in organ donation, physicians with specialties in palliative care, researchers specializing in oncology, in neurology, and in immunology, and administrators who run programs focused on end of life.
3. This book primarily includes thanatologists from the United States; there are three from England, one from Greece, two from Canada, one from Israel, and one from Australia. Attention should be given to getting life stories from Asian, African, Middle Eastern,

Australasian, South American, Latin American, Mexican, European, and Canadian thanatologists. It is possible that the International Work Group on Death, Dying, and Bereavement is in position to carry out such an endeavor.

4. I was limited by my fluency in only one language, English. Thanatologists who do not speak English were thus ruled out; the conclusion is obvious for what needs to happen in future studies.
5. The participants in this book are predominantly White and European-American in origin. Again, the conclusion is obvious for what needs to happen in future studies. When obtaining life stories of thanatologists from a diversity of racial/ethnic backgrounds, it will be crucial to heed Paul Rosenblatt's caution as to who should gather such stories.
6. While reading any interview, a person may wish at some point that a different approach had been taken, perhaps that a follow-up question had been asked or a different reply had been offered and thus other information elicited.

The Plan Followed

Initially, I considered identifying equal numbers of persons in, respectively, four categories: scholars, teachers, administrators, clinicians. The plan was to interview 8 or more persons in each of these categories. As examples, Holly Prigerson is a scholar, Illene Cupit is a teacher, Donna Schuurman is an administrator, and Jeffrey Kauffman is a clinician. Yet, no one fits neatly into only one category. While primarily a clinician, Jeffrey Kauffman is also a scholar, Holly Prigerson is a scholar and an administrator, Illene Cupit is a scholar and a teacher and an administrator, and Donna Schuurman is an administrator and a scholar. Most, perhaps all, thanatologists fit into more than one category. For instance, while Robert Neimeyer's contributions to thanatology are primarily scholarly, he is also a teacher and a clinician and in the past few years has taken on administrative duties directing the Portland Institute for Loss and Transition; while David Fajgenbaum is clearly a researcher, his administrative acumen has been paramount in the genesis of both National Students of AMF⁵ and the research consortium studying orphan diseases titled Castleman Disease Collaborative Network. It is easier to identify individuals who are scholars than persons whose contributions stem from their administrative, clinical, or teaching

⁵ Now called "Actively Moving Forward." See <https://heal grief.org/actively-moving-forward/>

leadership. Rather than fill a matrix of four categories, I eventually decided simply to contact persons whom I know and invite them to participate in an oral history of thanatology. Some of the participants' life-long contributions make them pioneers; however, I also contacted individuals who are making significant contributions in early or mid-career. Three persons whom I approached agreed at first to take part, but later changed their minds.⁶ The final sample includes 37 persons: 21 males and 16 females.

Each person who was interviewed responded to a simple e-mail message: "I am conducting oral histories of leading figures in thanatology and hope you are interested in and willing to be part of the project. If so, let me know and I will provide you much more information, including an informed consent document."

The informed consent document made clear the purpose of the project and the procedures. Unlike most research with human participants, oral history identifies who is taking part; that stipulation was made crystal clear to participants. The CUNY IRB approved the study. A small research grant from the PSC-CUNY Research Foundation provided initial funds for the project (TRAD A 47-51).

I drew up a set of interview questions and sent it ahead of time to each person who agreed to be part of the study. That set of questions is reproduced in Table 1. The dates of the interviews are given in Table 2.

The interview questions provided a guide to organize each conversation. The questions are what Stake (1995, 2010) calls "foreshadowing questions," that is, questions that an interviewer considers ought to be asked before the interview begins; in the midst of a specific interview, the interviewer may decide a foreshadowing question should be ignored and something else addressed or realize a question has been answered even though it was not asked. An example of a question that emerged as I did interviews but had not thought to put into the original set is whether the person's thanatological work ever led to feeling marginalized.

Each interview lasted from 90-120 minutes and was recorded using a version of Dragon Speak and then copied to a Word document by means of a program at www.temi.com. A research assistant initially transcribed and cleaned up 8 transcripts, and I completed the remaining 29. In producing

⁶ Two said they had reconsidered because they did not want to revisit and disclose some painful episodes from their lives. One simply said he no longer was willing to take part.

transcripts, I reviewed each conversation and eliminated the “noise” that occurs when persons talk: for instance, I removed “ums,” continual use of “you know,” extensive use of “really,” and other distractions to the flow of a conversation.

Once a conversation was transcribed, it was sent to the person interviewed to see if there were any changes to be made. Eventually, I received permission from each person to use the version of the transcript that he/she approved. In the case of Robert Fulton, such approval came from his son, the executor of his estate, because Bob Fulton died approximately six months after we talked and never did review his transcript. Transcripts that are published are the versions that the persons interviewed agreed could be made public. The informed consent document specified that other versions of the interview, including the recorded conversation, would be deleted once an agreed upon final transcript was produced.

Personal Reflections on the Conversations

When Danai Papadatou asked me to comment on my experience of doing the interviews, I spontaneously said, “My experience more than anything else, as shown again in my interview with you, is that the people I talked with are impassioned about their work. When you get people talking about what they're professionals in and what matters to them, you can just hear it in their voices, the energy and how much it matters to them. That's one of the things and I don't know how that's going to come across in a transcript. I think it might take the skill of like a Fitzgerald or someone to make those words convey the tone you can hear in people's voices about how much these things matter to them.”

The persons interviewed did so with clear interest, many enthusiastically. Of course, it would be a mistake to assume that enthusiasm would be the response of every person invited to take part in such a study. As noted earlier, two persons who initially agreed to take part later changed their minds, indicating they did not want to revisit and disclose to others some painful episodes in their lives; one person agreed and later withdrew his offer to participate, saying he had decided he just did not want to do it. Yet enthusiasm was characteristic of many persons who participated. Some said they felt honored to be among the persons being interviewed, even questioning whether they belonged in a project gathering oral histories from persons who are leaders in the field.

In the midst of conversing with these thanatologists and when reading transcribed interviews, I often felt energized. Being given permission to interview these persons was a unique privilege, and I appreciate how openly they told their stories. It may well be that the offer to take part and talk about matters so central to themselves was a singular attraction for many, perhaps for all of the persons who took part.

These conversations stand by themselves. They contain riches worth mining, and I trust others will see them as a motherlode awaiting their inquiry. I decided to leave interpretation to the reader. I want the conversations to be the focus, not my analysis examining these conversations. Some colleagues disagree with my decision, and one said bluntly that it will all be boring simply to present the conversations. Another colleague noted that formalistic analyses eventually will take place as readers reflect on and examine the rich data in these conversations.

Rather than engaging in formalistic analysis, I have written a brief section containing my thoughts about the project. I present lessons I learned from reading and reflecting on the conversations and from having actively participated in each conversation. I discuss these lessons in terms of (a) Why do thanatology, (b) Leading figures, leading ideas, (c) Influential ideas considered untenable, (d) Ideas that participants wish were taken more seriously, (e) Generativity, (f) Feeling on the margins, and (g) Things learned that were unexpected or out of the ordinary.

Why Do Thanatology

What led these 37 individuals to select thanatology as a professional focus? One thing is certainly clear. No one from an early age said, "I am going to be a thanatologist when I grow up." As many readers may have assumed, a significant loss held singular importance for some. Many of these losses took place in the participants' childhoods, and in two cases before the participant was born. Some persons who mentioned losses due to death significantly formed their development include Robert Fulton, Betty Davies, Nancy Hogan, Mary Alice Varga, Colin Murray Parkes, David Fajgenbaum, Chris Hall, and Bob Neimeyer. In Harold Ivan Smith's case death came in two forms to influence him: a fascination with the work of a local funeral director and the existential danger of death through electrocution risked by his father and other children's fathers who worked for the Louisville Gas and Electric Company. While other experiences also shaped them, losses due to a death had lasting influence on these individuals and sensitized them to issues of dying, death, and bereavement.

Not all the participants traced the origins of their thanatological work to a loss due to a death. Some came to thanatology by serendipity, such as Irwin Sandler whose interest in childhood bereavement following parental death emerged from a large, multi-faceted research program he directed that focused on coping responses to stress; he and his colleagues only began studying bereavement after they worked with families dealing with alcoholism and with divorce. Dennis Klass' extensive scholarly work on parental grief came about because he was invited to help some bereaved parents starting a St. Louis chapter of Compassionate Friends. Helen House, a hospice for children with life-limiting conditions, began in Sister Frances Dominica's act of friendship to help a mother and father who were overwhelmed with caring for their very ill child. Donna Schuurman's lengthy involvement with the Dougy Center and with advocating for bereaved children came about initially because she went for an interview as a volunteer at the suggestion of her husband who thought she'd be interested in the mission and people at the Dougy Center.

Further, some participants explicitly stated they are not primarily thanatologists but rather, in addition to an interest in dying, death, and bereavement, they have a professional career that encompasses other issues, including thanatology. Paul Rosenblatt is a primary example. He has a plethora of interests, including thanatology, and has made significant contributions in marriage and family therapy, the impact of racism, farming as a life, and grief. Irwin Sandler, mentioned above, is very plain that he is a community psychologist, not a thanatologist. Holly Prigerson is a sociologist with extensive focus on the matter of prolonged grief disorder. Myra Bluebond-Langner is an anthropologist both conducting and directing qualitative studies into various end of life policies and practices. Dame Commander Barbara Monroe is a social worker with expertise in probation and in child welfare who initially became involved with St. Christopher's Hospice because working there offered her a shorter commute.

Leading Figures, Leading Ideas

Not surprisingly, many persons interviewed mentioned the same names when asked who were leading figures. Some names are from the past, that is, historical. Names of persons who are, so to speak, out of the past included Sigmund Freud, John Bowlby, Herman Feifel, Ernest Becker, Elisabeth Kübler-Ross, Cicely Saunders, Avery Weisman, and Richard Kalish. It surprised me that Erich Lindemann was mentioned less frequently than I had expected. Another surprise was that a good portion of the persons

interviewed did not mention any name out of the past when answering the question, “Who in your estimation are the major figures that have influenced thanatology?” It may be that the phrase “leading figures” meant to them persons active and alive today. However, for others, the obvious starting point for identifying leading figures is historical with, as Simon Shimshon Rubin said, “the grand trio that’s Freud, Lindemann, and Bowlby.”

Present day persons frequently named were Robert Neimeyer, Colin Murray Parkes, Margaret Stroebe, Bill Worden, Robert Kastenbaum, Robert Fulton, Dennis Klass, Charles Corr, Jack Morgan, Ken Doka, Phyllis Silverman, and Tom Attig. Some persons mentioned Hannelore Wass, some mentioned Holly Prigerson, some mentioned Paul Rosenblatt, some mentioned Jeanne Quint Benoliel, some mentioned David Balk, and some mentioned Therese Rando. Some names mentioned might be considered idiosyncratic to the larger field of thanatology, but clearly these scholars made important contributions: Richard Lazarus, Barney Glaser, Anselm Strauss, Baba Ram Dass, Bonnie Green, Judith Herman, and Ronnie Janoff-Bulman; in addition, some persons who were mentioned--Stephen Levine, Stanislav Grof, Eugenia Waechter, Sandy Marks, Jr., and Ned Cassem--I did not recognize but learned they had made distinct contributions to thanatology.

Leading ideas mentioned were continuing bonds, attachment theory, the dual process model, palliative care, disenfranchised grief, meaning making, and complicated grief. Some persons mentioned the efficacy of grief counseling and discussed the debate over that topic that enveloped thanatology a while back. Some persons mentioned anticipatory grief and others a good death, but I want to point out that the construct anticipatory grief was considered untenable in some quarters and a good death was dismissed as repugnant by one participant. It is noticeable that the leading ideas mentioned have to do primarily with issues of bereavement. That fact may reflect the sample of persons who took part in this project.

Influential Ideas Considered Untenable

The very question posed to the participants, “Are there any ideas that have influenced (or are influencing) thanatology that you consider untenable?”, elicited responses highlighting that some persons are committed relativists (Perry, 1968). That is, truth to them is “field dependent” and relative to historical and cultural contexts (Toulmin, 1958, 1972, 1990). Thus, we have the response of Paul Rosenblatt: “I don’t think in those terms. I think of thanatology or thanatological science or whatever it is we’re doing, I think it as more like a cultural thing and like any cultural thing, it has its own

realities and it has its own meanings and it will be what it will be and it has to be what it has to be.” Bob Wrenn said, “the word ‘untenable’ is a little hard to be absolute about.” Colin Murray Parkes said, “I’m actually a very inclusive person. I try not to block off.” Heather Servaty-Seib noted that academic freedom is important and that she opposes efforts to stifle conversation, and in the same vein, Chris Hall said, “I don’t believe that there’s an idea in and of itself that I find reprehensible or so objectionable that it shouldn’t be part of the conversation.” And Myra Bluebond-Langner simply said, “I wouldn’t use the word ‘untenable.’”

The most frequently mentioned influential idea considered untenable in thanatology was Kübler-Ross’s (1969) 5 stages of dying. Other examples mentioned were “anticipatory grief,” “grief resolution,” and “pathologizing of grief.” Some mentioned “the grief work theory” and—more an act than an idea—incorporating hospice into the hospital system. While “resiliency” has become a construct widely supported, some persons take exception, not only considering it untenable but also actually thinking it harmful because it ignores or dismisses the difficulties of coping with trauma.

Ideas That Participants Wish Were Taken More Seriously

Cross-disciplinary fertilization was one overarching idea mentioned. Given that thanatology depends on many disciplines, a lack of cross-disciplinary fertilization seems paradoxical, if not ironic; however, given the insularity of disciplines within higher education it is immediately apparent why thanatology is not as inter-disciplinary as an ideal world would allow. Greater openness to other cultures was another overarching idea mentioned, as was openness to professional organizations and associations outside of thanatology. Jack Jordan and Paul Rosenblatt and Louis Gamino mentioned traumatology, and Colin Murray Parkes, Jack Jordan, and Phyllis Kosminsky mentioned neurology. A smattering of some of the other ideas participants wished thanatologists took more seriously include spirituality, organ donation, non-death losses, the importance of the family, and collective trauma. Openness to other disciplines than one’s own came up a few times. The bibliography displays the extensive breadth and depth of disciplines used by thanatologists.

Generativity

Erik Erikson (1950, 1968, 1986) used the paradigm of stages of development to describe changes in identity formation across the life span. A core aspect

of his model is increasing investment in community as an individual matures in response to the particular crises present in Erikson's stages of psychosocial development. One sign of maturity is displayed during adulthood in what Erikson termed generativity, that is, a deep interest in promoting the development of a younger generation. We find generativity spread throughout the participants in this oral history project. Clear examples are the mentoring found in the work of Nancy Hogan, Darcy Harris, Illene Cupit, Carla Sofka, Chris Hall, Bob Neimeyer, Bob Wrenn, Paul Rosenblatt, Tashel Bordere, Mary Alice Varga, and Bob Fulton. In reality, I can think of no person interviewed who did not fully, wholeheartedly engage in mentoring.⁷

The very process of creating and maintaining organizations or something else beneficial to persons touched by dying, death, or bereavement is found in every person I interviewed. I will give several examples; those I leave out will be found in the conversations that comprise the coming chapters of this book. Thus, we have Betty Davies' work to develop hospices for children, David Meagher's involvement with Brooklyn College to create academic programs in thanatology, Barbara Monroe's heroic efforts to keep St. Christopher's Hospice functioning, Dale Larson's multi-decade work centered on furthering hospice, and Stephen Connor's international activities to make quality palliative care available to persons in third world countries. Ken Doka produced the formative construct disenfranchised grief, examined gender and grief, supervised several teleconferences, and edited many books for the Hospice Foundation of America. We have Myra Bluebond-Langner's efforts at both Rutgers University and at the Institute of Child Health at University College London to change policy and practice for children with life-limiting and life-threatening illness. We have Jack Jordan who has designed training programs to teach sensitive, efficacious responses when dealing with the trauma of suicide. We have Tashel Bordere's efforts to bring social justice to African-Americans grieving deaths. Illene Cupit and Heather Servaty-Seib have been instrumental in getting their respective institutions to design bereavement leave policies for college students. Simon Shimshon Rubin not only produced the seminal two-track model but has championed ethical reasoning in clinical practice. Chris Hall has been central in providing excellent thanatology education across Australia and in advocating international perspectives. Sandra Bertman has accepted the challenge to bring the arts and humanities into the medical school curriculum. Louis Gamino helped us learn two fundamental

⁷ The same observation applies to Dr. Tracy Wong who directs studies in thanatology at Brooklyn College but who was not interviewed.

questions to identify whether someone will benefit from grief counseling. Robert Neimeyer's multifaceted teaching and clinical work has helped to anchor constructivism into our understanding of bereavement. Colin Murray Parkes worked extensively with victims and perpetrators of genocide in Rwanda. Paul Rosenblatt has worked closely with younger colleagues on many topics. And we have the efforts of the Association for Death Education and Counseling and of the International Work Group on Death, Dying, and Bereavement to educate the wider public about thanatology.

Feeling on the Margins

Thanatology has a taboo aspect about it, and engaging in the field can lead persons to feeling they are marginalized. Some participants in this book readily acknowledged that they had paid such a price. A prime example would be Robert Fulton whose graduate student interests in death and dying had been dismissed by the internationally respected professor whom he hoped would be his dissertation advisor and whose thanatological work as a full Professor in the Department of Sociology at the University of Minnesota was systematically and routinely disregarded during his many years in that institution. Other persons who noted that their efforts in thanatology elicited being marginalized include Dale Larson, David Meagher, Donna Schuurman, and Danai Papadatou. Donna hinted that she did not dislike being on the margins because it gave her a needed perspective to assess things; however, Danai talked of the loneliness that accompanies being on the margins.

Things Learned That Were Unexpected or Out of the Ordinary

People's life plans change, and that truism hardly is unexpected or out of the ordinary. However, some thanatologists' changes in life plans I had not expected. For instance, Bill Worden entered college to be a chemist, Dale Larson to be a physicist, Heather Servaty-Seib and Tom Attig to be mathematicians, Mary Alice Varga to be a pharmacist, and Jack Jordan to be a rhetorician. Difficulties with undergraduate chemistry led one participant to shelve plans for medical school and shortly thereafter discover her passion for social work. One participant all but completed doctoral work in philosophy before changing his life course to immerse himself in psychoanalysis and eventually become a psychoanalytic psychotherapist specializing in loss. I was surprised to learn Darcy Harris sang opera, Chris