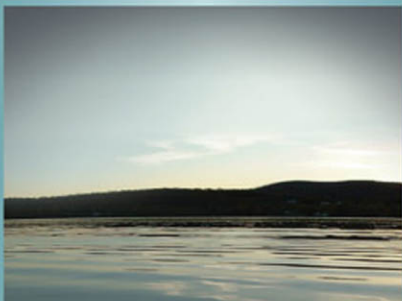


DANAI PAPADATOU



IN THE FACE
OF
DEATH

PROFESSIONALS WHO CARE
FOR THE DYING AND THE BEREAVED

SPRINGER  PUBLISHING COMPANY

In the Face of Death

*Professionals Who Care for the
Dying and the Bereaved*

DANAI PAPADATOU, PhD

 **SPRINGER PUBLISHING COMPANY**
NEW YORK

Danai Papadatou, PhD, is a professor of clinical psychology at the Faculty of Nursing of the University of Athens. Her clinical experience, research interests, and publications focus mostly on issues related to pediatric palliative care, bereavement support, and health care providers' responses to the death of their patients. Her work is known internationally through her publications, presentations at scientific meetings, and active involvement in international work groups and societies. She has organized several conferences and symposia and, along with her father Costas Papadatos, organized in 1989 the First International Conference on Children and Death and subsequently edited the book *Children and Death* (1991). She has received an award from Children's Hospice International (1989), and the Death Educator Award from the Association for Death Education and Counseling (2001). She had the honor to serve from 1999 to 2004 as chair of the International Work Group on Death, Dying, and Bereavement, an organization of leaders in the field of thanatology.

Dr. Papadatou is also the founder and president of a Greek non-profit organization ("Merimna"), which provides services to children and families who are coping with illness and death experiences, offers training to professionals who support seriously ill and bereaved children and adolescents, organizes psychosocial interventions in disaster situations, and sensitizes the Greek public on issues related to death and dying.

Copyright © 2009 Springer Publishing Company, LLC

All rights reserved.

No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior permission of the publisher or authorization through payment of the appropriate fees to the Copyright Clearance Center, Inc., 222 Rosewood Drive, Danvers, MA 01923, 978-750-8400, fax 978-646-8600, info@copyright.com or on the web at www.copyright.com.

Springer Publishing Company, LLC
11 West 42nd Street
New York, NY 10036
www.springerpub.com

Acquisitions Editor: Sheri W. Sussman
Production Editor: Julia Rosen
Cover design: Mimi Flow
Composition: Apex CoVantage

09 10 11 / 5 4 3 2 1

Library of Congress Cataloging-in-Publication Data

Papadatou, Danai.

In the face of death: professionals who care for the dying and the bereaved/
Danai Papadatou.

p. cm.

Includes bibliographical references and index.

ISBN 978-0-8261-0256-0 (alk. paper)

1. Terminal care. 2. Bereavement. 3. Grief therapy. I. Title.

R726.8.P35 2009

616'.029—dc22

2008050933

Printed in the United States of America by Hamilton Printing Company.

The author and the publisher of this Work have made every effort to use sources believed to be reliable to provide information that is accurate and compatible with the standards generally accepted at the time of publication. The author and publisher shall not be liable for any special, consequential, or exemplary damages resulting, in whole or in part, from the readers' use of, or reliance on, the information contained in this book.

The publisher has no responsibility for the persistence or accuracy of URLs for external or third-party Internet Web sites referred to in this publication and does not guarantee that any content on such Web sites is, or will remain, accurate or appropriate.

Contents

Foreword xi

Preface xiii

Acknowledgments xix

SECTION I: THE CARING RELATIONSHIP 1

1 Society, Science, and Death 3

The Medical Model of Care 5

The Biopsychosocial and Holistic Model of Care 6

The Relationship-Centered Approach to Care 9

2 A Relationship of Care 21

Partners in Care 22

The Attachment Bond 24

Request for Services in Death Situations 25

The Person's Attachment Behaviors 28

The Professional's Caregiving Behaviors 32

Bond Affirmation Through Belonging 35

3 Distinct Features of the Helping Relationship 39

Exposure to Death and Mortality Awareness 40

Inevitability of Suffering Versus Potential for Growth 47

Experience of an Altered Sense of Time 50

Involvement in the Caregiving Relationship 54

4 The Accompanying Process 61

The Myth 61

From Myth to Reality: Assuming a Companionship Role 67

Condition 1: Establishing an Appropriate Frame 70

Condition 2: Being Fully Present 79

Condition 3: Being Vulnerable Enough 92

*Condition 4: Developing a Holding Environment for Ourselves
and Co-Workers* 103

Working in Private Practice 105

When the Care Provider Is Seriously Ill or Dying 108

The End of Accompaniment 110

SECTION II: THE CARE PROVIDER IN DEATH SITUATIONS 113

5 The Wounded Healer 115

From Myth to Reality: The Suffering of the Care Provider 117

Aspects of Care Providers' Suffering 120

Grief: A Healthy Response to Death Situations 128

6 A Model for Professionals' Grieving Process 131

*Proposition 1: Professionals Who Experience the Death of a Person as a
Personal Loss Are Likely to Grieve* 134

*Proposition 2: Grieving Involves a Fluctuation Between Experiencing
and Avoiding Loss and Grief* 139

*Proposition 3: Through Grieving, Meanings Are Attributed to Death,
Dying, and Caregiving* 146

*Proposition 4: Personal Meanings Are Affected by Meanings That Are
Shared by Co-workers, and Vice Versa* 155

*Proposition 5: Grief Overload and Grief Complications Occur When
There Is No Fluctuation Between Experiencing and
Avoiding Loss and Grief* 159

Proposition 6: Grief Offers Opportunities for Personal Growth 163

*Proposition 7: The Professional's Grieving Process is Affected by
Several Interacting Variables* 167

7 The Rewards of Caregiving 175

Obstacles to Rewarding Experiences 178

Conditions That Promote Rewarding Experiences 179

The Wisdom of the Wounded Healer 186

SECTION III: THE TEAM IN THE FACE OF DEATH 189

8 Caregiving Organizations and Death 191

Suffering in the Workplace 193

The Organization's Myths and Ideals	196
The Organization's Primary Tasks and Mode of Functioning	198

9 Team Functioning in Death Situations 203

<i>Principle 1: Team Functioning Is Affected by the Organization's Culture</i>	206
<i>Principle 2: Team Rules Determine How Professionals Should Care for Dying and Bereaved People and Cope With Suffering</i>	209
<i>Principle 3: There Are No Functional or Dysfunctional Teams—Only Teams That Use Functional and Dysfunctional Patterns to Cope With Loss, Death, and Suffering</i>	217
<i>Principle 4: The Chronic Use of Dysfunctional Patterns Renders a Team Vulnerable to Various Types of Disorganization</i>	230
<i>Principle 5: Crises Are Inevitable; They Hold the Potential for Team Disorganization as Well as Team Growth</i>	236
<i>Principle 6: All Teams Have the Potential to Function With Competence</i>	242
<i>Principle 7: Interprofessional Collaboration Is an Unfolding Process That Is Reflective of a Team's Development and Growth</i>	256
<i>Principle 8: Resilience Is Enhanced by the Team's Ability to Cope Effectively With Suffering, and to Creatively Use Its Resources to Foster Change and Growth</i>	260

10 The Good-Enough Team 269

Team Narratives of Traumas and Achievements	271
Leaders in Good-Enough Teams	275
Supervisors and Consultants	278
Toward a Community of Support	281

11 The Challenges of Educating Health Care Professionals 285

<i>Challenge 1: Develop a Philosophy of Teaching That Promotes Relational Learning and Reflective Practice</i>	287
<i>Challenge 2: Develop Curricula That Include Goals, Learning Objectives, and Methods of Teaching That Focus on Relationships With the Dying, the Bereaved, and Co-Workers</i>	288
<i>Challenge 3: Integrate Current Knowledge Into Educational Programs and Supervised Clinical Applications</i>	290
<i>Challenge 4: Evaluate Training Outcomes as Well as the Context and Process by Which Learning Occurs</i>	291
<i>Challenge 5: Integrate Formal and Informal Learning Activities Into the Work Context</i>	293

Epilogue 297

Appendix: Brief Description of Bowlby's Theory on Attachment 301

References 305

Index 321

Foreword

*Doctor, Doctor, shall I die?
Yes, my child, and so shall I.*

Skipping Rhyme, circa 1894

This old rhyme encapsulates the painful reality that underlies this remarkable book. We are all in the same boat, and the main difference between the dying patient and the doctor is that the patient will probably die before the doctor.

Life-threatening illnesses, such as cancer, invade families and societies as well as patients. We are all changed by them. “Send not to learn for whom the bell tolls/it tolls for thee (John Donne).” The implication is that, if we are to be of help, we must include death’s influence on all of the relationships that surround and are affected by it.

Much of the literature in recent years about palliative care (the care of the dying) and bereavement care (the care of the bereaved) has the patient and the bereaved individual as the objects of study. In this book, Danai Papadatou does something quite different. She draws on her considerable experience of working with nurses, doctors, and other members of the caring professions along with wide reading and her own systematic research to explain how death affects the caregivers, both as individuals and teams, and how this then affects their care of people facing death or the death of those they love. From this analysis she draws out an approach of relational care—care based on an understanding of relationships—that should be essential reading for these professions.

Although she makes use of sophisticated educational, psychological, and sociological knowledge, Papadatou writes in an engaging and non-technical language, managing to convey complex ideas in a manner that is accessible to all.

As a psychiatrist with a special interest in people’s attachments to each other and the consequences when those attachments are severed

by death, I found Papadatou's extension of this field of study to include the caring team both enlightening and personally challenging. I suspect that I am not the only reader who will realize that our own needs sometimes conflict with those of our patients. But we are never too old to learn, and it is reassuring to find that we do not have to be 'perfect' but simply 'good enough.' As an author, teacher, psychologist, and friend, Danai Papadatou is certainly good enough for me.

Colin Murray Parkes OBE, MD, FRCPsych

Preface

Thousands of years ago, during the fifth century B.C., Hippocrates described medicine as a practice and an art. The Hippocratic Corpus, his collected writings as well as those of his students, states that the healer who exercises his skill and knowledge for the benefit of the sick may experience suffering in the process. Hippocrates perceived and described the healer's suffering as integral to the care of the ill person:

There are some arts which to those that possess them are painful, but to those that use them are helpful, a common good to laymen, but to those that practice them grievous. Of such arts there is one which the Greeks call medicine. For the medical man sees terrible sights, touches unpleasant things, and the misfortunes of others bring a harvest of sorrows that are peculiarly his; yet the sick—of means of this art—get rid themselves of the worst of evils: disease, suffering, pain and death. (Jones, 1923, p. 227)

Twenty-five centuries later, even with advances in medicine and nursing, suffering among health care professionals is largely disenfranchised and neglected despite its integral role in their work. There is a widespread belief that suffering is not supposed to happen to experts. It happens only to people who are ill, dying, or bereaved and these are the people who receive help to enable them to cope with and alleviate it. The suffering of care providers has been ignored, mostly because they prefer to suppress it or keep it private. The privatization of their pain prevents them from openly acknowledging their anxiety, anger, sadness, guilt, fear, disgust, and grief, which remains hidden, along with the sense of helplessness, hopelessness, meaninglessness, or confusion that is experienced at times. However, by dismissing and denying suffering, they concurrently close their eyes, shut their ears, and turn their back on any person, family, or situation that triggers disturbing thoughts, feelings, or responses.

Most studies on burnout suggest that one of the most stressful situations that health care providers experience on the job is death. Recent

studies of trauma workers who are empathically engaged with people who are traumatized by death, abuse, and disasters suggest that professionals are vulnerable to vicarious traumatization and compassion fatigue. This may be true. But are compassion stress, traumatic disorders, and burnout all we experience in the face of death, or is there a wider and more complex process that occurs in illness, dying, and bereavement situations? Should we focus on understanding our intrapsychic and idiosyncratic responses, or should we expand our perspective and explore how we develop relationships with dying and bereaved people, what we bring into these relationships, how we affect them, and how we are affected in return? Do we suffer? Can suffering be totally eliminated in the face of human loss and death? Can it be changed or transformed?

“You will get used to death,” the medical director of a pediatric oncology unit told me compassionately when he saw me crying over the death of my first young patient. I realized over the years that one can never get used to death. Nor can one ever become immune to human pain and suffering without paying a high price. Occasionally, we get used to the sight of death or to listening to stories of trauma. It is natural. Unfortunately, some get used to a sense of futility (“What’s the point?”), hopelessness (“There is nothing we can offer”), or despair and learn to avoid relationships with dying and bereaved people in order to protect themselves.

When our personal suffering remains untapped, unexplored, and hidden, our relationships with individuals, families, and colleagues are deeply affected. This happens because suffering does not occur in a vacuum. It stems from relationships; it develops within relationships and affects them in positive or negative ways. Yet it is within relationships that suffering can also be alleviated and/or transformed. By shedding light upon our own responses in the face of serious illness, dying, and death, we bring them out of the darkness, understand them, and seek alternative ways to accept them, own them, cope, and occasionally change them. It is with such a goal that this book was written. It aims to explore the experiences of care providers who care for seriously ill, dying, or bereaved children, adolescents, or adults, and to offer a framework in which their responses can be understood, addressed, and transformed. Based upon theory, research findings, and clinical illustrations, this book intends to trigger readers’ thinking and hopefully elicit reflection and debate among colleagues.

The first section of the book, “The Caring Relationship,” adopts a primarily interpersonal perspective by focusing on the relationship

between the person who is dying or grieving and the care provider. Its main purpose is to describe the nature of services that are provided at the end of life and through bereavement according to the medical and biopsychosocial model of care, and propose as an alternative *a relationship-centered approach to care*. This approach acknowledges the reciprocal influence between care seekers and care providers, each of whom brings his or her own unique set of experiences, values, and perspectives to the caring relationship. Special emphasis is placed on the dynamics involved, and on the characteristics that render this relationship distinct from other helping relationships. The Greek myth of the labyrinth and the ferocious minotaur that Theseus succeeded in killing with the help of Ariadne's love and wisdom is used to illustrate the unique aspects and conditions that facilitate an accompanying process through the dark and unfamiliar paths of dying and bereavement.

The second section, "The Care Provider in Death Situations," adopts an intrapsychic approach and addresses our personal responses to death. Another Greek myth, that of the wounded healer, is used to illustrate how the ability to care is enhanced when we learn to recognize and accept our suffering as part of being human and empathic in our relations with others. Suffering is discussed in relation to the concepts of burnout, compassion fatigue, and vicarious traumatization, while a new framework is offered for understanding some of our healthy responses in the face of death. A model for the grieving process of health professionals based on the findings of studies that I conducted with my colleagues in Greece and Hong Kong is presented, and its seven basic propositions are analyzed. Physicians' and nurses' accounts illustrate aspects of their grief that are affected by personal, interpersonal, and social variables. Special consideration is given to the difficulties and grief complications that some professionals experience, as well as to conditions that promote rewarding experiences and enhance personal growth.

Finally, the third section, "The Team in the Face of Death," adopts a systemic perspective and focuses on the organizational context within which care services are offered. Attention is given to how a team organizes itself and develops functional and/or dysfunctional patterns in order to cope with loss and death. Eight principles illuminate how teams cope with death encounters at a systemic level. Special consideration is given to dysfunctional patterns as well as to the risk of team disorganization when such patterns are perpetuated over time. Three key conditions that enhance team functioning and resilience in death situations are analyzed: (1) commitment to goals, tasks, and co-workers, (2) establishment

of a holding environment that allows team members to contain, reflect on, and transform suffering, and (3) open teamwork that enables professionals to move beyond the team's boundaries and—through meaningful collaborations—offer interdisciplinary services that benefit dying and bereaved people as well as themselves. This section ends with an invitation to review our philosophy, goals, and methods of teaching palliative and bereavement care in order to adopt a relational approach that promotes learning through relationships among students, instructors, patients, families, and practitioners. Five challenges are discussed, innovative approaches as to the methods of teaching are presented, and special emphasis is placed on how best to prepare students and young practitioners to accompany dying and bereaved people and cope with loss and death issues in their professional and personal lives.

I have tried to avoid using the impersonal word *patient* as much as possible, because I believe that we care primarily for *people* in death situations, who are assigned the role of patients. Whenever the word is used, it is not with the intent of undermining my respect for each individual's uniqueness.

My thinking and writing have been influenced by several theoretical approaches, rather than by a single psychological school of thought. My European studies in psychodynamic theories and my American post-graduate education in humanistic psychology and a systemic approach to care have been integrated in my clinical practice, which was enriched by the recent contributions of phenomenology to the health care field. Influential in my work with dying and bereaved people have been the works of John Bowlby on human bonds and separation; of Alfred Adler on self-determination and social belonging; of my teacher and mentor Oscar Christensen on families; of Eric Cassell, Kay Toombs, and Arthur Frank on the phenomenology of illness; and of René Kaës on institutions. A source of incredible learning has also been my relationships with individuals, families, and colleagues with whom I have shared death experiences. They enabled me to explore unknown territories and expand my horizons of understanding. The content of this book derives from three major sources: my clinical experience in pediatric palliative and bereavement care, my academic experience in the education of health care professionals, and my research on care providers who are repeatedly exposed to death encounters.

The book is addressed to professionals who work in caregiving organizations (e.g., hospitals, hospices, home care programs, bereavement centers) or in private practice. This includes nurses, physicians,

psychologists, social workers, chaplains, palliative care specialists, bereavement counselors, and other health care specialists who provide services to seriously ill people and support families through the illness, dying, and bereavement process. It is also intended for trainees as well as for educators who design courses or seminars on death and dying, on health psychology, on communication skills, and on stress management and staff support. Health managers can also benefit from understanding the complexity of employees' and teams' responses and of the necessity of building appropriate structures to support care providers in their caregiving role. In addition, the book can be of value to researchers who wish to design qualitative studies and advance our knowledge of a critical topic that deserves deeper exploration and consideration. Even though it is written for professionals, I believe that it can also apply to volunteers who accompany families through dying and bereavement.

Over the past decades, clinicians, researchers, and educators have emphasized the importance of humanizing the care of sick and dying people who are institutionalized and of bereaved individuals, who have been negatively affected by the growth of a grief industry that pathologizes bereavement. It is my belief that in order to ensure the humanization of care, we need to humanize the role we assume in death situations instead of idealizing it or projecting onto it powers and qualities we do not possess. Of all living experiences, death reminds us that we are all finite and mortal. But death also invites us to value life, invest it with meaning, and honor it.

The process of writing this book has been filled with emotional, cognitive, and spiritual challenges as well as with personal transformations. I relived the deaths of several children I have accompanied through the end of life, as well as the bereavements of many families. I reflected on the quality of services we provide and read and reread the transcripts of colleagues who confided in me their most intimate thoughts and work-related experiences in the context of my research studies.

This book is a small token of my deep gratitude to all the children, adolescents, and adults whom I have been privileged to accompany in death situations. Through their suffering and personal growth, they taught me about living and valuing the present moment while striving to contribute to the creation of a better and more human world for all.

Acknowledgments

Throughout the journey of writing this book several people have been very supportive, and I am indebted to them. Robert Kastenbaum was most encouraging of my decision to undertake and commit myself to this challenging endeavor. Barbara Sourkes, my dearest colleague and friend, was always available to read the manuscript at critical stages of its development, discuss key issues, and offer constructive feedback. She has been a valuable companion and an excellent critic. I am also deeply thankful to Colin Parkes, Chuck Corr, and Scott Long, who read a few chapters, offered constructive feedback, and enabled me to clarify some of my thinking. My appreciation also extends to Kelly Moraiti and Eleni Kotrozou for their assistance with the organizational details of the manuscript, as well as to Thanassis Goudzivelakis and Eleni Kotsani, two nurses, who gave me permission to use their drawings in this book. Some of the content in chapters four and six also appear in the Oxford Textbook of Palliative Care of Children (2006) with permission from the author.

I wish to express my gratitude to Sheri W. Sussman, editorial vice president at Springer Publishing Company, who played a key role as the acquisitions editor of this book, and who has supported me with her encouragement, understanding, and persistence. Finally, I offer my heartfelt thanks and endless love to my daughter Alexia for being so understanding of my desire to write this book and so eager to celebrate its completion.

The Caring Relationship

SECTION
I

1

Society, Science, and Death

It is widely assumed that Western societies are death denying. This assumption has been reinforced by the seminal work of the French historian Ariès (1974, 1981), who studied the representations and management of death in Europe from the early Middle Ages through modern times. Ariès described how death, which was initially “tamed” and perceived as a familiar event in the lives of people who were frequently exposed to it, progressively came to be an alien experience, cut off from the rest of life, and denied as a result of historical and social developments. He argued that modern society’s denial of death is reflected in the prevailing attitudes toward dying individuals, who are put away in health care institutions, and toward bereaved people, whose grief is expected to occur in private. Perceived as a threat to social order, death became a taboo topic that is excluded from social discourse.

Ariès’ thesis on the denial of death is questioned by some sociologists, who offer an alternative interpretation. They claim that modern secular societies “face up” to the reality of death by organizing themselves in order to actively cope with the irreversible disruption of social bonds caused by death (Albery, Elliot, & Elliot, 1993; Parsons, 1978; Seale, 1998). According to Kastenbaum (1977), each society develops a death system that more or less formally and explicitly comprises a system of symbols, meanings, and practices assigned to specific people with

defined roles (e.g., health care providers, funeral directors, lawyers) and designated locations (e.g., health care institutions, cemeteries, funeral homes). Academic, legal, religious, and health care institutions define which death is “acceptable” and which is “unacceptable” and hide certain aspects of dying and bereavement while rendering others public (Seale, 1998). In most Western societies, for example, academic institutions propose a scientific body of knowledge that guides professionals in how to perceive, control, and manage death and how to care for the dying and the bereaved; legal institutions create laws that specify which deaths are socially acceptable (e.g., war-related deaths, death by capital punishment, or euthanasia) and which are not and should be controlled or sanctioned (e.g., death by murder, suicide); religious institutions offer systems of beliefs that explain death and create rituals to help people cope with mortality and suffering; and the media shapes representations of death through the display of certain images (e.g., of violent deaths caused by accidents, disasters, terrorist attacks), the avoidance of others (e.g., slow, lingering deaths), the use of specific words and phrases (e.g., “war casualties”), or the creation of narratives about death events. Thus, every society has its own unique death system that shapes and affects death-related experiences.

Western secular societies, which have attempted to hide—rather than deny—death during the last century, are currently confronted with a new reality. Disasters, terrorist acts and threats, and war events are introduced directly or indirectly—through the media—into our daily lives. They do not happen only to others living in foreign lands. These out-of-the-ordinary experiences can happen to anybody. We are repeatedly reminded that we live in a world that is not safe. Tight controls and warnings about our safety in airports, at big gatherings, even in schools; alerts about hurricanes, floods, and fires; or the practice of safety procedures in the case of earthquakes and human-induced disasters are a few examples that highlight the uncertainty of our existence. Concurrently, extraordinary achievements by the biomedical sciences create new hopes. Cloning, stem cell research, organ transplantation, and spectacular pharmaceutical developments that prolong or attempt to create life raise new ethical dilemmas and concerns regarding the limits of our living existence.

In this era, life-and-death issues are increasingly brought out in the open. Attracted and threatened by them, secular societies are challenged to address these issues. People who are sick, dying, and bereaved are affected by these conflicting pulls as well as by the new ethical dilemmas that determine their trajectory through dying and bereavement.

Concurrently, we, the care providers, are challenged to offer services in ways that are acceptable and meaningful to them as well as to us, and to society. We are incited to review the models of care that guide our actions and orient our clinical practice and eventually revise, expand, and/or change them. With this goal in view, I will briefly examine two prevailing models that affect our approach to the care of dying and bereaved people: the medical model of care and the biopsychosocial or holistic model of care. Each offers a context that defines caregiving and consequently affects death experiences for those who seek services and those who provide them.

THE MEDICAL MODEL OF CARE

The medical model is concerned with the assessment and treatment of sick bodies, diseases, and mental health conditions. These are perceived as independent of the person who suffers. They are assessed, objectively measured, classified, labeled, and treated. Dying and bereavement, which are natural processes, are perceived as dysfunctional conditions to be controlled by science. More precisely, dying is medicalized through the management of physical symptoms located in a dysfunctional body that hosts a life-threatening disease, while bereavement is pathologized and viewed as atypical. In both situations, care aims to restore health and resolve grief through a return to “normalcy,” which was disrupted by illness or the loss of a loved person.

The medical model of care sets as its primary goal the “solution of a riddle” rather than the care of a person (Nuland, 1994). The riddle in dying is posed by the life-threatening nature of the disease, and in bereavement, by the intensity and duration of grief symptoms. Solving the riddle comprises the identification of a correct assessment or diagnosis, an appropriate treatment or intervention, and an accurate prognosis as to the possibility of health recovery or grief resolution.

The care provider assumes a role of “expert” in the solution of the riddle, while the dying or bereaved person is turned into a case to be solved. A relationship between the professional and the person is developed via a body that hosts the disease or via a psyche that hosts an atypical mental health condition. Their relationship is governed by strict rules and expectations that protect both participants from becoming emotionally involved. They cooperate against a *dis-ease* or *dis-order* caused by illness, death, and suffering and become adversaries when their goals are not achieved.

A heroic script is assigned to “experts,” who assume the responsibility of all decisions and treatments, while a victim script is assigned to dying and bereaved people, who conform to orders, rules, and regulations. These heroic versus victimizing scripts are perpetuated with the consent of both individuals seeking services and practitioners who abide by the values of a medical model that promotes an illusion of control over death and over suffering. When interventions fail to control death and suffering, dying and bereaved people are either subjected to futile treatments and therapies that compromise the quality of life or abandoned by clinicians, who, in turn, are rejected and accused by those who showed trust in their “expertise.” Care providers who are not successful in restoring health or resolving grief are left to cope with a sense of failure, helplessness, and despair over the pursuit of unrealistic goals.

While the medical model has never been able to fully control death, it has succeeded in *owning* death by defining it in scientific and biological terms. Consider death certificates. All define death as a bodily event that is measurable, objective, and located in a dysfunctional body. It is never recorded as a natural event due to old age, or as a psychological event caused by the decision to end one’s life, or as a social event triggered by the suffering of a broken heart or bereavement. Death is presented and understood *only* in biological terms, and it is presented as such to the dying as well as to bereaved people.

Over the past few decades, the dramatic increase of scientific knowledge of life-threatening illnesses as well as of bereavement has contributed to spectacular advances in the care of dying and bereaved people. As a side effect, however, it has also contributed to the pathologization of normal processes such as dying and grieving. Dying and bereavement are therefore de-normalized and often de-humanized as they are transformed into scientific riddles. This pathologization and medicalization have increased the marginalization of people and have served as a form of social control over death and suffering. Care seekers and care providers are, therefore, deprived of the meaningful and personal relationships that often develop in death situations.

THE BIOPSYCHOSOCIAL AND HOLISTIC MODEL OF CARE

In protest of the over-medicalization and dehumanization of care, an alternative model, the biopsychosocial model of care, made its appearance by the end of the 20th century. Charts on the rights of sick people forced

professionals to redefine their goals and values, and George Engel (1977, 1980, 1997) set the foundation of a model that took into account their psychosocial needs. This model adopts a patient-centered approach that deals with individuals rather than diseases and clinical cases. It advocates that each individual be treated as a unique human being and understood in his or her wholeness (Balint, 1969). The concept of wholeness refers to the undivided unity of a person's body and mind, which is in reciprocal interaction with the physical and social environment.

The principles of this holistic model were implemented and further developed by some inspirational health professionals who cared for people at the end of life. Cicely Saunders, Elisabeth Kübler-Ross, Jeanne Quint Benoliel, Florence Wald, Balfour Mount, Ida Martinson, and Colin Murray Parkes were some of the charismatic leaders who contributed to the development of the palliative care approach. This approach was based on a new set of values that humanized the care of dying individuals, who were invited to actively participate in their care, and of families who were supported before and after the patient's death. The message of these pioneers was loud and clear: individuals have the right to have a say in their experiences and the care they receive in the face of death. Dying and bereavement are experiences that belong to *them*, not to professionals.

Thus, focus shifted from professionals, who know what is "best" for others, to individuals and families, who identify what is important to them when life comes to an end (Egan, 1998; Egan & Labyak, 2001). Care providers with different scientific backgrounds and experience adopt an interdisciplinary team approach that addresses physical, psychological, social, and spiritual needs and ensures a dignified death that corresponds to each person's and family's values, desires, and preferences. This approach turned into a social movement that spread around the world. The response was so impressive that within only 30 years, approximately 5,000 hospice, palliative, and bereavement care services were developed in several countries across all the continents (Clark, 2002).

There are four distinct ways in which palliative care differs from the biomedical model and offers an alternative approach to the care of dying and bereaved people:

- 1 Death is defined as a natural, unavoidable life event that causes increased suffering due to the final and irreversible rupture of human bonds. Interventions aim not to fight death when it is imminent, but to ensure dignified conditions for the dying person and to offer support for the bereaved. Focus is shifted from the

prevention and control of death to the experience of living with the awareness and reality of death. Palliative care is introduced when life-threatening disease is diagnosed, and grief counseling is made available to facilitate the family's acceptance and adjustment to loss.

- 2 The person's lived experience and, by extension, his or her biopsychosocial and spiritual needs become the main focus of care. This patient-centered approach is expanded to include significant others. Thus, holism is ensured through a family-centered approach that addresses the needs of family members, who participate in shaping experiences at the end of life and through bereavement. This approach acknowledges the impact of death upon networks of people who are changed forever as a result of loss.
- 3 Teamwork is redefined so as to promote interdisciplinary collaboration among professionals with different expertise, who cooperate with each other instead of compartmentalizing their services. The team's goal is to integrate various services into a comprehensive plan of care that addresses the needs, preferences, and desires of each person and family who is faced with death and bereavement.
- 4 Care providers are encouraged to develop personal relationships with dying and bereaved people and to accompany them in their trajectories. The hazards of caregiving are recognized, and the importance of professionals' support is acknowledged.

The palliative care approach assigns an active role both to professionals, and to dying and grieving individuals, who are expected to develop a partnership toward the achievement of a good death or recovery from loss. In this partnership, a heroic script is usually assigned to terminally ill people, who are expected to display courage by being aware of their dying; by being expressive of their innermost feelings, thoughts, and needs; and by being autonomous in their decisions. In a similar way, the bereaved are expected to openly express their feelings and thoughts, work through their grief, and move toward "restoration," or "resolution."

Open awareness, self-expression, and self-determination are Western values reinforced by the practice of palliative and bereavement care in contemporary secular societies. Studies undertaken in North America,

the United Kingdom, and other European countries confirm a shift in physicians' attitudes toward truth telling and the use of advance directives in the face of death. The person seeking services is expected to lead the journey through dying or grief, while the professional assumes the role of a companion who offers information, guidance, and support. This role is believed to require expertise and involves helping people to come to terms with their mortality; live meaningfully in the face of death; address physical, psychosocial, and spiritual needs; share farewells with loved ones; prepare for the funeral; and be supported through bereavement (Seale, 1998). These activities function as rituals that prepare the dying for death, orient bereaved families toward living, and guide professionals in their interventions. They bring a sentiment of order that enhances control over death, dying, and bereavement.

The palliative care approach reflects modern society's active attempt to face up to the reality of death by introducing dying and bereavement into the midstream of life. It personalizes care by addressing individualized needs and attempts to humanize it by rendering it social. People receive support from the caring communities of home care programs, hospices, and bereavement centers rather than being marginalized or alienated.

THE RELATIONSHIP-CENTERED APPROACH TO CARE

Where do we stand at the dawn of the 21st century? I believe we are at a crossroads. Much has been accomplished within a short period of time, and a great deal remains to be learned. We are challenged to critically review our models of care and evaluate our practices, raise critical questions, and seek answers that will help us to move forward. This process has just begun in both end-of-life and bereavement care (e.g., Fins, Miller, Acres, Bacchett, Huzzard, & Rapkin, 1999; Larson & Hoyt, 2007; Randall & Downie, 2006; Stroebe, Hansson, Stroebe, & Schut, 2007; SUPPORT Investigators, 1995).

Studies conducted in North America with large populations of terminally ill patients indicate that the biomedical model of care is still widely prevalent, while serious obstacles compromise the application of palliative care. In spite of people's preference for a humanized death that occurs at home, the majority continue to die in hospitals and nursing homes, where they are treated as diseases or "cases" to be managed.

The use of life-sustaining interventions remains excessive, and physical pain is largely mismanaged, causing increased suffering among dying patients and their relatives (e.g., Fins et al., 1999; SUPPORT Investigators, 1995). Evidence indicates that palliative services are offered only to limited populations, particularly patients with life-threatening diseases that have a predictable course and outcome, such as cancer and AIDS. Elderly people and patients with chronic conditions for which death cannot be predicted (e.g., chronic heart failure, chronic obstructive airways disease, diabetes) are deprived of psychosocial and spiritual care. Even though they suffer from a terminal condition, they are not viewed as dying, and consequently, their needs are totally neglected. They come in and out of health care institutions until one day they “suddenly” succumb and die as a result of health complications (Field, 1996; Seale, 1996). Finally, limited access to end-of-life care is common among people with minority ethnic backgrounds. The care they do receive is often compromised by professionals’ insensitivity to their cultural beliefs and practices regarding life-and-death issues. As a result, they grow to mistrust the health care system, which they perceive as inconsiderate of their values, needs, and preferences (Krakauer, Crenner, & Fox, 2002).

Similar findings reflect the status of pediatric palliative care (for a review, see Liben, Papadatou, & Wolfe, 2008). Most children in Western countries die in hospitals, and some in intensive care units. Despite the fact that home care has been repeatedly found to have beneficial effects upon parents’ and siblings’ adjustment to loss, professionals are reluctant to refer children and adolescents to home care programs or hospice facilities because of their insistence on the use of disease-directed therapy (Fowler, Poehling, Billheimer, Hamilton, Wu, Mulder, & Fran Gould, 2006). Pain and symptoms are mismanaged, causing unnecessary suffering in children (Goldman, Hewitt, Collins, Childs, & Hain, 2006; Wolfe et al., 2000) and in parents, who remain dissatisfied with the quality of care that they and the sick child receive (Contro, Larson, Scofield, Sourkes, & Cohen, 2002, 2004; Meyer, Burns, Griffith, & Truog, 2002).

What about bereavement care? Outcomes regarding the efficacy of bereavement services have been more confusing. Meta-analytic reviews have led to erroneous claims that grief counseling is at best mildly effective, and at worst harmful to the bereaved. This unwarranted pessimism, which is reflected in some literature reviews and in the popular media, has caused some damage to the reputation of grief counseling. A critical review of all available meta-analyses on grief counseling undertaken by Larson and Hoyt (2007) has recently brought to light statistical

limitations that contribute to these erroneous conclusions. Their investigation led them to conclude that there is no empirical evidence that bereaved people are harmed by counseling or that individuals who are “normally” bereaved are at any special risk. It is, therefore, prudent to maintain a cautious optimism as to the empirical findings and conduct more rigorous research on individual and group counseling, which will determine who among the bereaved benefits from what kind of professional help, and when.

Another major issue of concern in the field of bereavement is related to the identification and classification of pathological forms of bereavement. Professionals have been involved in heated debates about the pros and cons of introducing a diagnostic category of pathological grief (potentially to be referred to as traumatic grief or protracted grief) into the *Diagnostic Statistical Manual of Mental Disorders*. The question remains as to who will benefit from such a classification: The bereaved, whose difficulties will be recognized and treated? The professionals, who will use a shared code of communication with regard to grief complications or who will negotiate reimbursement for services? Pharmaceutical industries, which will produce and promote new drugs for profit? Or society, which will find a new way to control undesirable behavior?

There is no doubt that at the dawn of the 21st century, we are faced not only with new challenges with regard to the care of the dying and bereaved, but also with new concerns that affect every person on this planet. Nowadays, we all have to live with the uncertainty that is evoked by natural disasters, by terrorism and nuclear threats, and by the consequences of contemporary biotechnology (e.g., excessive prolongation of life, proliferation of genetically modified organisms in the food chain, genetic manipulation, human cloning). Death is not something that happens only to *others*, but a reality that affects us all. As a result, it cannot be ignored.

Both as individuals and as care providers, we must begin by staring death in the face and confronting our mortality. In so doing, we may realize that such a confrontation is also an awakening experience that can help to not only temper our fear of death but also enrich our lives (Yalom, 2008). Such a realization can assist us in supporting seriously ill and bereaved people to engage in a similar process and come to terms with the reality of death. While some benefit from direct confrontation and open discussions about death, dying, and grief, others do not. Confronting death does not preclude an un verbalized awareness of dying and grieving that helps some individuals to continue viewing

life as “normal” in order to protect their bonds from any threat or impending separation, and to avoid the anxiety that is associated with existential concerns or a narrative reconstruction (Seale, 1998). In our multicultural society, the needs, values, priorities, and preferences of the dying and bereaved vary to such a degree that those of us who provide services to them must possess—besides specialized knowledge and skills—an ability to relate with sensitivity and to create caring communities in which bonds are affirmed and belonging is enhanced in the face of death, loss, and separation.

Recent evidence shows that people’s relationships to care providers constitute a key factor that determines satisfaction with end-of-life and bereavement care (e.g., Contro et al., 2002; Heller & Solomon, 2005; Hickey, 1990; Malacrida et al., 1998; Meyer et al., 2002; Solomon & Browning, 2005; Steinhauser, Christakis, Clipp, McNeilley, McIntyre, & Tulsky, 2000; Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000). Dying and bereaved people report that the primary source of satisfaction regarding the care they receive is related to their relationships with care providers who are caring, humane, and sensitive to their needs. Interestingly, the major source of their distress is associated with unsatisfying relationships with professionals who provide inadequate pain relief, fragmented care, insensitive support, and unclear or no information. It therefore becomes evident that individuals and families expect something from caregiving relationships that is qualitatively distinct from what they actually receive. They ask for more understanding of what they are going through, more genuine concern, more compassion for their suffering, and more humanness.

How do we respond to such requests? Usually by striving to operationalize understanding, compassion, and genuine concern in measurable skills that will permit us to address the psychosocial and spiritual dimensions of a person’s illness or loss experience. These skills are taught in workshops and seminars that offer specific guidelines about how to communicate bad news, how to cope with difficult patients, how to use active listening skills, how to assess spiritual needs or deal with unfinished business, how to use interview guides, and how to provide grief support. The problem with most of these educational approaches is that they train care providers to apply specific skills with people who are expected to fit prescribed guidelines or interventions. Moreover, they create the expectation that if the acquired skills are implemented according to the guidelines (e.g., the SPIKES model of the breaking of bad news¹), then care providers will relate effectively with people in death situations.

Ironically, this educational approach, although holistic in theory, creates a reductionism that objectifies both the individual and his or her dying and bereavement condition that is managed by the use of protocols or a prescribed set of guidelines.

What we, as care providers, tend to forget is that we are an integral aspect of the care process and that we bring into relationships something personal that transcends knowledge and skills. Our goals, needs, and motives for providing services in this field are mistakenly perceived as unimportant and independent of the way we relate to others, while our personal responses to death situations are viewed as subjective and obstructive to caregiving. We act as if quality of care is independent of who we are. In our striving to understand or assist another person, we often times remain dissociated and estranged from ourselves. While this protects us from realizing how we are being affected by the illness or grief experience of others, it also deprives us of the opportunity to be human in our encounters with dying and bereaved people.

It is my firm belief that our holistic approaches to the care of dying and bereaved individuals should expand their scope and pay closer attention to care providers, who affect and are being affected by the people they accompany through dying and bereavement, by the practitioners they collaborate with, and by the community in which they provide their services. A relationship-centered approach, rather than a patient-centered or family-centered approach, may serve as a first step toward a new understanding of care.

The basic idea of the relationship-centered approach is that care cannot be perceived or understood independently of the relationships in which it occurs. In these relationships the reciprocal influence between care seekers and care providers—each of whom brings his or her own unique set of experiences, values, and perspectives—is recognized (Beach, Inui, & Relationship-Centered Care Research Network, 2006). Such an approach invites professionals to understand not only the other person, but also the selves they bring to their encounters, as well as the relationship that results from such meetings. We can no longer offer solely specialized knowledge and skills. Expertise in palliative and bereavement care, although important, is not enough. No matter how “expert” we become—or strive to appear—dying and bereaved people remind us that we are human and equal in the face of death. We all die—some sooner, others later. In this field of work, we are all affected by the transience of life, the irreversibility of death, the suffering that loss engenders, and an existential quest for meaning.

To this day, phenomenological and narrative approaches have contributed significantly to our understanding of the dying or grieving person's subjective world. Unfortunately, these approaches have not had the same impact on the exploration of the private worlds of health care professionals. It is only recently that studies began to shed light on the subjective experiences of health care professionals in death-related situations (see chapter 5). Preliminary evidence shows that behind the facade of a false professionalism that promotes rational thinking, objectivity, and detached concern, care providers are affected by death encounters. Their accounts reveal aspects of the professional as a person who suffers but seldom acknowledges it or does something about it. Focusing on oneself (both as a person and a care provider) is imperative, according to the relationship-centered approach. Knowing oneself becomes equally important as knowing the person one is invited to help. Both are necessary for the building of a relationship in which care is offered and received.

To illustrate the reciprocal influence of the person and of the professional, take a moment to look carefully at Escher's 1938 drawing titled *Two Birds* (Illustration 1.1).

In order to see the figures, one must first focus on the white birds, which appear on a shaded background, and then focus on the shaded birds, which appear on a white background. The beauty of the image is neither in the white birds nor in the shaded birds alone, but in their combination.

The relationship-centered approach poses a similar challenge. It requires that we learn to shift the focus of our attention from the person's subjective world (the white bird) to our own subjective world (the shaded bird), and from ourselves back to the person in order to understand what unfolds in an intersubjective space that is shared and is unique to our relationship.

Notice that in Escher's picture, the perfect fit between two birds becomes evident only if these are perceived within a larger context that comprises several birds. In a parallel way, relationship-centered care also requires that we pay attention to significant others who are brought—directly or indirectly—into our dyadic interaction. A dying or bereaved person, for example, brings into the relationship with the care provider his or her personal story, along with a world of family and significant other relations (the white birds). These relationships form the context in which both he or she and significant others experience dying or bereavement, and grow in the face of multiple changes that

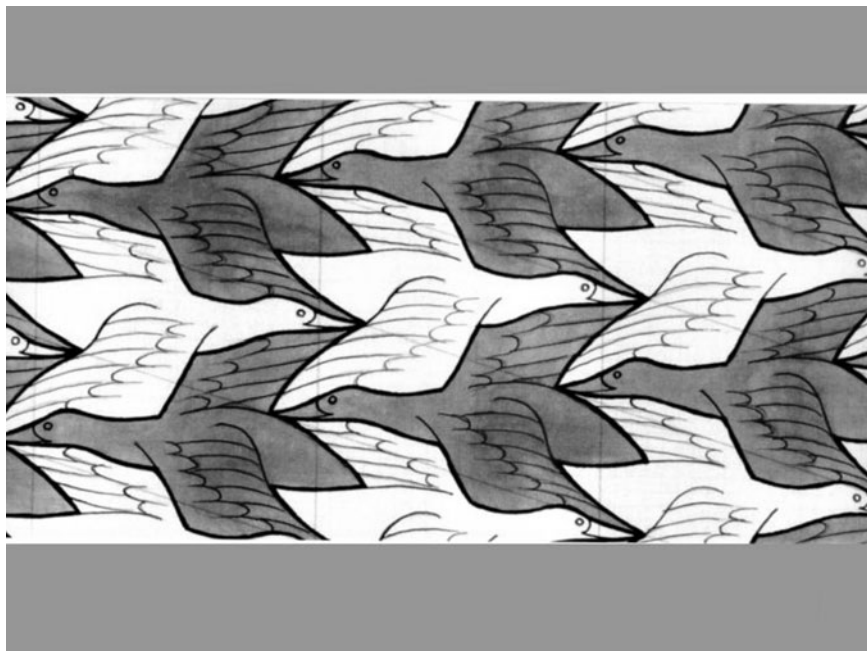


Illustration 1.1. M. C. Escher, 1938

M. C. Escher's "Two Birds" © 2008 The M. C. Escher Company–Holland. All rights reserved. www.mcescher.com

occur within themselves and in their environment. We, on the other hand, bring into our relationship with each person our personal and family histories as well as a network of team and other professional relations that are shaped by the organization's goals, values, and ideals (the shaded birds). These relationships affect the quality of care we provide and determine the stresses and rewards we reap from the process of caregiving. Although each set of birds is facing in a different direction, the observer has the impression that they move together as a result of a perfect fit. Quality care results from a similar fit, which requires a collaboration between people who face a life that is uncertain or dramatically changed as a result of impending death or the death of a loved person, and care providers who face in the direction of a more or less stable life with an anticipated future. The space in which they meet, interact, and coexist is enlarged and enriched as a result of their collaboration.

A relationship-centered approach focuses on whatever transpires when the world of care seekers and the world of care providers meet and interact in a setting of care and community context (Figure 1.1). To

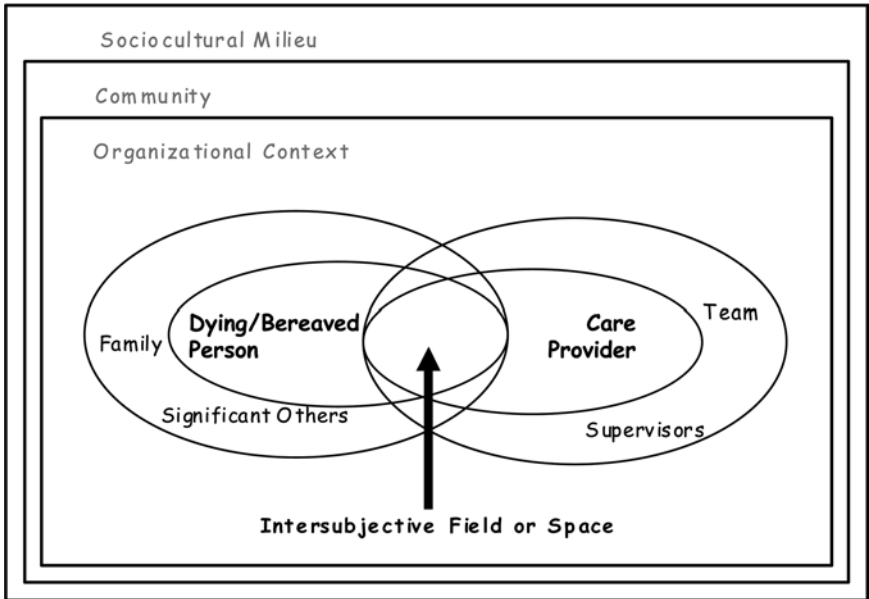


Figure 1.1 The context of the caregiving relationship

better understand the outcomes of such encounters, it is important to consider its basic components. These involve:

- 1 The acknowledgment of the subjective world of the dying or bereaved individual who seeks care
- 2 The acknowledgement of the subjective world of the care provider
- 3 The influence of other key persons (i.e., family members, team members, other colleagues) who are—directly or indirectly—involved in the caregiving or care-receiving process
- 4 The intersubjective space or field that is formed as a result of their encounter
- 5 The organizational or work context in which care is offered and received at the end of life and through bereavement
- 6 The community and sociocultural milieu in which care in life and death situations unfolds

It becomes evident that not only the relationship between a person and a care provider, but their respective relations with family members, significant others, colleagues, co-workers, and supervisors, is important.

These are further affected by the work, community, and sociocultural context in which care is being offered.

When these worlds meet, an *intersubjective field* is developed that belongs neither to the person nor to the professional, but to their relationship, which is embedded and affected by a wider network of relationships. Whatever unfolds in this intersubjective field is brought by the person back to the members of his or her family, who are subsequently affected; in a parallel way, whatever transpires in this intersubjective space is brought by the professional back to the team and organization, whose goals, values, and practices are reinforced, disconfirmed, challenged, or changed.

What is the intersubjective field or space? Stern (2004) defines it as “the domain of feelings, thoughts, knowledge that two (or more) people share about the nature of their current relationship” (p. 243). When the professional and the patient enact prescribed scripts and roles, they remain oblivious to their own and the other’s subjective experiences. In contrast, when they are open to each other, and in touch with themselves, the intersubjective field is enlarged and offers opportunities for change and growth as a result of their interaction. For example, in the presence of an empathic professional, the dying or bereaved person may view and experience him- or herself in a new light. Similarly, in the presence of a grieving individual, the professional may discover aspects of him- or herself that were unknown to him or her but emerge as he or she revisits past experiences of loss. Insights and changes that occur in the intersubjective field are often subtle, implicit, and un verbalized, but nonetheless significant. They provide opportunities for new explorations, new experiences, and new narratives that are co-created in the face of death. They have the potential to render care more human, meaningful, and enriching for those who receive, as well as for those who provide care services.

In fact, the relationship-centered approach is concerned with the development of large networks of relations among people, professionals, teams, and communities that have the potential to be caring, enriching, and rewarding for all parties involved. Such an approach incites organizations to pay closer attention to the relational aspects of caregiving in order to prevent the marginalization and institutionalization of the dying and the bereaved, and to avoid the stigmatization or idealization of professionals who work in the field of thanatology. Not only should individuals and families benefit from reciprocal and caring relationships, but professionals and teams should also experience satisfaction from

collaborating with and supporting each other in the face of death. This renewed focus on relationships aims at rendering dying and bereavement a *social affair* that is shared and experienced as meaningful and humane by those who receive, as well as by those who provide care.

I believe that a shift from a patient- and family-centered approach to a relationship-centered approach requires a thorough and critical review of established ideas and practices, which are often taken as self-evident truth. Whether such a process will lead to new adaptations that will enhance the quality of our services or to a paradigm shift that will involve the reorganization of our knowledge and practices remains to be seen. In any case, a critical review will inevitably involve changes that must occur at multiple levels, three of which, in my opinion, are critical.

At a personal level, it is imperative that we redefine our caregiving role. We are neither practitioners who apply knowledge and skills upon clinical cases nor neutral observers of people's private worlds, which are impacted by death. We are active participants in relationships who affect and are affected by others and by shared experiences. As such, we need to explore our responses to the people we serve, as well as to co-workers with whom we share the caregiving process. An introspective process can be facilitated through appropriate education, supervised clinical practice, and peer review groups, all of which promote self- and team understanding.

At an administrative level, organizations must review their goals and formulate policies that do not thoughtlessly serve their own needs. It is important to create a culture of care that responds both to the needs of individuals and families and to the needs of professionals, who must be held and supported in their work. If the ultimate goal of care is to integrate dying and bereaved people into society rather than isolate and marginalize them, organizations must be responsible for cultivating a web of relationships with other teams, services, and institutions that ensure continuity and quality of care. Relationship-centered care can help organizations become more environmentalized and humane and less impersonal and self-serving.

At an educational level, institutions must offer models of learning that enable students and trainees to develop relationships that are meaningful and rewarding for all participants. An alternative educational approach in palliative care referred to as relational learning (see chapter 11, challenge 2) goes beyond the accumulation of knowledge through didactic lectures in classrooms; it offers a wide repertoire of educational experiences, all of which are situated in direct relationships

with patients, families, peers, and colleagues. New challenges emerge when education introduces opportunities for self-understanding, for interdisciplinary collaboration, and for learning from patients and families, whose wisdom is incorporated into clinical practice. Care cannot change without them, nor can it change if professionals do not develop an ability to reflect on and learn from relationships with them.

Changes in the above domains should not be limited to the modification of our views but should involve a progressive reorganization of our values, beliefs, axioms, theories, and models of care. Giving up long-held assumptions and specific ways of thinking and providing care is a threatening process that creates confusion and insecurity. However, this process opens up opportunities for new knowledge and growth that may result from a renewed relation to ourselves, to the people we serve, and to our colleagues. This is a challenge worth undertaking.

A relationship-centered approach, in my view, offers a fresh look at care that is not perceived as a product to be packaged and sold by professionals, and consumed by people in need. It emphasizes the interpersonal and social nature of care that tempers suffering in the face of death, fosters belonging, and allows growth to occur. Such an approach can enhance and enrich relationships that are relevant to health care through both education and practice (Report of the Pew-Fetzer Task Force on Advancing Psychosocial Health Education, 2000).

NOTE

1. SPIKES is a protocol for delivering unfavorable information to patients about their illness through which clinicians fulfill four key objectives: gathering information from the patient, transmitting unfavorable medical information, providing support, and eliciting the patient's collaboration. This protocol involves the following steps: *setting* up the interview, assessing the patient's *perception*, obtaining the patient's *invitation*, giving *knowledge* and information to the patient, addressing *emotions* with empathic responses, and developing a *strategy* of collaboration and a plan for the future—or SPIKES (Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000).