EDITED BY
RENEE S. KATZ AND
THERESE A. JOHNSON

ROUTLEDGE

SECOND EDITION

WHEN PROFESSIONALS WEEP

Emotional and Countertransference Responses in Palliative and End-of-Life Care

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When Professionals Weep

When Professionals Weep speaks to the humbling and often transformational moments that clinicians experience in their careers as caregivers and healers—moments when it is often hard to separate the influence of our own emotional responses and world-views from the patient's or family's. *When Professionals Weep* addresses these poignant moments—when the professional's personal experiences with trauma, illness, death, and loss can subtly, often stealthily, surface and affect the helping process. This edition, like the first, both validates clinicians' experiences and also helps them process and productively address compassion fatigue, burnout, and secondary traumatic stress.

New material in the second edition includes increased emphasis on the burgeoning fields of hospice and palliative care, organizational countertransference, mindfulness, and compassionate practice. It includes thought-provoking cases, self-assessments, and exercises that can be used on an individual, dyadic, or group basis. This volume is an invaluable handbook for practitioners in the fields of medicine, mental health, social work, nursing, chaplaincy, the allied health sciences, psychology, and psychiatry.

Renee S. Katz, PhD, FT, is a licensed psychologist, board-certified diplomate in clinical social work, and fellow in thanatology. A clinician, author, and trainer, she has worked with the dying, the bereaved, and those living with serious illness for more than 30 years.

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When Professionals Weep

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Second Edition

Edited by
Renee S. Katz and Therese A. Johnson

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With deep gratitude and respect to all our clients and patients who have taught us how it is to live courageously in uncertainty

and

In loving memory of Moya Duplica, Bonnie Genevay, Jerome Katz, Susan Spring, and W. D. Spring, each of whom added richness to this shared endeavor

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Series Editor's Foreword

In the 10 years since Renee S. Katz and Therese A. Johnson published their first edition of *When Professionals Weep*, I have found myself recommending it to colleagues and students scores or perhaps hundreds of times. This passionate advocacy stems not simply from my respect for the editors, significant as that may be. Rather, it comes from my genuine conviction that a braver, more intelligent, and more personal discussion of countertransference—that furtive awareness that our personal trigger points are being touched in a given interaction with a patient or client—has never been written in any area of specialization in the helping professions.

That a book of such courage, perspicacity, and honesty now *has* been written—not once but twice—in the daunting context of death and dying is a minor miracle. And yet, it may be this very context, where existential concerns rise up ineluctably for both helping professionals and those they hope to serve, that compels attention to the emotional entanglement of both parties as they meet at the edge of the abyss. As each chapter in this volume vividly conveys, such situations have the power to either inform or subvert our clinical care in hospice or hospital, in private practice or palliative care, and in connection with dying that is tragically premature or sadly overdue. For this compelling reason, the myriad ways in which countertransference can "hook" helpers and prompt both unwarranted heroism and helplessness deserves a close and candid analysis. And once again, Katz and Johnson provide just this, extending, updating, and deepening a discourse they did much to open a decade before.

What struck me as I perused the pages that follow was not so much the range and scope of this volume—as impressive as that is—but rather the clarity and coherence of the basic message that was intoned in a different key in each of the 20 thoughtful and well-written chapters: the very experiences and motivations that move us to engage this work with the dying or bereaved have the power to undermine it. The likelihood of this outcome increases in proportion to our unconsciousness of the ambiguous emotional interplay that serves as the subtext of every clinical conversation and every end-of-life consultation with our patients, our clients, and ourselves. Self-knowledge, though indispensable, is inevitably incomplete and is acquired through hard work across a professional lifetime. Ironically, perhaps, wisdom arises more from a humble encounter with our failures than with our successes.

This, at least, is my own partial distillation from the book's cornucopia of thoughtful reflections, principles, and especially clinical case studies that drew me into the ethical labyrinth presented by dying or grieving people whose lives and losses often mirror our

own. These same accounts in turn challenged me to reflect on my personal attitudes, values, experiences, and actions in similar circumstances—real, feared, or imagined. In this way author after author seemed to invite me into a dialogue of such depth that each functioned nearly as an episode of personal therapy, professional consultation, or spiritual direction. Read receptively, the following essays have the power not only to illuminate a vital topic at the core of our encounter with death and loss but also to shed light on the manner in which our professional actions and decisions can be overdetermined by our unacknowledged vulnerabilities and defenses.

In summary, the editors of and contributors to *When Professionals Weep* invite you to read the myriad authentic explorations of countertransference in their work and in so doing to "read" more deeply your own as well. I, for one, feel richly repaid for having accepted that invitation.

Robert A. Neimeyer, PhD
November 2015

Foreword

Sigmund Freud was brilliant. Yet like most pioneers, this was evident in the areas he explored and the questions he asked more than the conclusions he sometimes drew. Certainly Freud's brilliance was evident in his work on transference and countertransference. Freud was insightful in recognizing the unconscious forces that surround the therapeutic relationship. Yet while Freud believed the examination of transference was an essential element in therapy, he strongly cautioned about countertransference as a severe challenge to the therapist's objectivity—even competence.

Yet this opprobrium on countertransference can deny our humanity—especially in palliative and end-of-life care. It cautions us to be objective and personally uninvolved while offering compassionate care—a largely futile task.

I was 23 years old when I first began working in this field as a student chaplain in a pediatric oncology setting. It was at Sloan-Kettering, a major cancer research hospital. At that time a diagnosis of leukemia was a virtual death sentence. Many children with that disease were treated at Sloan-Kettering in hopes that some experimental therapy would extend their lives beyond the expected 18 to 36 months. One of my patients was an eight-year-old boy named Johnny Mandala. Even in the hospital environment, Johnny maintained a mischievous mien. We often got calls from a deli across the street that some little boy was throwing finger paint or water on unwary pedestrians on First Avenue (obviously less fun if you were one of those pedestrians). With death all around, Johnny seemed so full of life. He was loved and spoiled by staff—including me. On the last day of my service in the Clinical Pastoral Education (CPE) Program, the staff held a small party. Johnny felt bad that he did not have a gift for me, so he slipped off his hospital wristband, so he could give me something so that I would remember him. The other gifts I received from staff were used or discarded over time. The candy was soon consumed, the scarf reluctantly tossed after good use. Yet after more than 40 years, I still treasure the wristband.

And yes, when Johnny died, I wept.

Over the years, there would be other clients among the dying and bereaved that would touch my heart in very special ways. The incredible value of Renee S. Katz and Therese A. Johnson's *When Professionals Weep: Emotional and Countertransference Responses in Palliative and End-of-Life Care* is that they acknowledge and recognize the validity of such responses. It is normal, they assert, especially in crisis situations like serious illness and end-of-life care, to have feelings and reactions. It is natural and inevitable.

Katz and Johnson recognize, though, that countertransference may not always be positive. Like Freud, they acknowledge that sometimes the professional's own issues may get in the way of good care. I have a classic example that I use in class. Years ago, I was working with a foster care agency as a consultant. One task that I was assigned involved a social worker in the Independent Care Unit. In foster care, there can be three goals for children placed. In the best situations, the goal is reunification with the family. If this is not possible, a second goal might be to free the child for adoption. In both goals, the desire is to provide a sense of permanence for the child. There is a third goal—used exclusively with adolescents if neither goal is viable. This is independent living. Here the child is expected to remain in care until he or she reaches maturity.

Naturally, these goals define treatment. If the goal is reunification, maintaining parental contact is essential. If the goal is adoption, parental rights are likely to be terminated. In independent living, however, the goal is that the child should be empowered to make choices—one of those choices is the contact he or she would like to retain with the biological parent.

Now here was the problem. The particular social worker, whom we will call Anthony, was an ex-priest. He had been transferred by his order to serve a church in Bronx, New York, that still had Italian-language services. He had left his own mother in Italy. While here, he fell in love with a parishioner and obtained peaceful release from his vows, so he could marry. He used his vacations to see his mom—winter without his wife and children, summer with the family.

He had abandonment issues—he had abandoned his aging mother, his mother country, and his mother church. Unconsciously he would not let the children under his care abandon their mothers. In each session, he would ask the children if they had contact with their mothers—and berate them if they had not. His clients—both foster children and foster families—were livid as the children left him upset. Only by confronting his own issues was he able to see how his countertransference was negatively affecting his work.

Katz and Johnson are sensitive to all the nuances of countertransference. They recognize and acknowledge that while feelings toward clients are natural and inevitable—human—we need to be aware of them and continually assess how they are affecting our care. Countertransference is normal, but the old caution still remains—we need to be clear of these feelings, and there is danger when we care more than the client.

Acknowledging the normalcy of our reactions also allows us, as individuals and organizations, to recognize the issue of moral distress—or the reactions of staff to seriously ill and dying patients. Some patients' illnesses and deaths affect us more than others'—perhaps by the nature of the patient's life or the way that the patient died. Here we can then offer support such as debriefings or ethical grand rounds to allow staff to ventilate their emotions, reactions, and concerns. Perhaps this will hasten the move away from the individualistic ethos that surrounds contemporary ethics to a more ecological model that acknowledges that the decisions we make in palliative and end-of-life care affect others—family and intimate networks, including those who offer care. Perhaps another needed principle of bioethics is a relational one that understands the connections that are an essential aspect of our humanity.

In the final analysis, this may be the essential contribution of Renee S. Katz and Therese A. Johnson's *When Professionals Weep: Emotional and Countertransference Responses*

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in Palliative and End-of-Life Care. This incredible work has the power to liberate professionals to recognize that their humanity is the essence of their care, while they consciously stay aware of the necessary limits inherent in caring.

Kenneth J. Doka, PhD
Professor, the College of New Rochelle
Senior Consultant, the Hospice Foundation of America

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Preface

In the preface to our first edition of *When Professionals Weep*, we spoke to the nature of the perplexing, cunning, and often provocative phenomenon called countertransference. We wrote:

> For the better part of a year we wrestled with our own defenses and self-protective mechanisms which inevitably surfaced in our writing. As much as each of us was eager to examine our personal-professional interactions, we found that we had significant blind-spots that we could not see at first. In fact, several of us unconsciously found ourselves distancing from the countertransference material—by glossing over it, by focusing on technical details of the issue or population about which we were writing, by moving into academic and research-oriented subject matter, by over-quoting the "experts," and by intellectualizing our experiences.
>
> *This* is countertransference. In telling our stories, we relived our experiences, but with the proverbial lens of hindsight. We had nowhere to hide from the discomfort of admitting our foibles, our mistakes, the depth of our feelings, or the voracity of our attachments.

Ten years later, here we are again, having been challenged by all the subtle and not-so-subtle levels of countertransference that resurfaced and informed the writing of these chapters. To be sure, countertransference is "alive," still challenging, still surprising, and still laying bare the most vulnerable of psychic spaces within us.

Perhaps we should not be surprised at the truth of such fundamental processes. Countertransference is a natural phenomenon. It begins with emotional reactions that arise within ourselves as a result of our interactions with others—patients, families, staff, and colleagues—and, as we point out in this volume, with institutions and organizations. Neuropsychologists note that emotions are simply physiological responses to the environment: inevitable, natural, and designed to evoke responses and actions. It is these responses, if driven by forces beyond our conscious awareness (our countertransference), that can either help or hinder our efforts to provide compassionate, effective care. Discerning those forces that are driving our feelings and behaviors takes effort. Awareness of countertransference requires focus and conscientious intentionality aimed at unearthing what we might otherwise cover up or ignore.

As editors and clinicians who have for decades worked with serious illness, end-of-life care, grief, and bereavement, we continue to see the long-lasting consequences of unconscious and unacknowledged countertransference in the lives of professionals,

patients, and families. We listen to the anguish of the hospice nurse whose patient chose to end his life by gunshot; we help the widower grieve his wife's denied wish to die peacefully at home rather than hooked up to tubes and machines in the Intensive Care Unit; and daily, we process individuals' feelings of powerlessness with their diseases and with the providers and systems designed to treat them.

Although the fact of countertransference has not changed, the face of countertransference possibility *has*. Since the publication of the first edition of *When Professionals Weep*, there have been considerable changes in the health-care environment: new methodologies, new technologies, and new ways of prolonging life, not to mention myriad treatments for diseases that at one time carried imminent death sentences. Our strong, research-oriented milieu holds out promises of the next-best study or protocol or intervention that could biologically sustain life. Additionally, a patient's right to self-determination in health care is taking its place at the forefront of medical, social, and legal venues. Individuals feel freer to question their physicians as "experts" and to turn to specialists, programs, studies, friends, and of course, the ubiquitous Internet—all of which will dish up the medical opinion du jour on everything from diagnosis and treatment to alternative therapies and prognoses.

To reflect the landscape of these changes, we have updated and added chapters along the continuum of care. Sharmon Figenshaw, in Chapter 5, identifies the personal-professional stumbling blocks that arise in identifying and responding to patients' desires and directives in palliative and end-of-life care settings. Terry Altilio and Bridget Sumser, in Chapter 11, speak to the gifts and challenges of new palliative specialty programs and to the virtues and vices that arise in teams charged with providing comfort care in a milieu that can be unwelcoming, at best. We discuss clinician heartaches, difficulties, and dilemmas when receiving requests for medical aid in dying, and we explore the oft-controversial policies at systemic and organizational levels that complicate the picture of personal countertransference, moving many providers into a complex vortex of competing expectations among patients, families, employers, and themselves. Finally, Katherine Knowlton and Renee S. Katz (Chapter 16) utilize insights from current research to bring us additional methods with which to examine, address, and utilize countertransference awareness, including mindfulness practice and Balint interdisciplinary process groups. These new additions accompany other updated chapters, all of which address this cauldron of countertransference potentiates. Exercises and reflections are woven throughout, giving the reader the opportunity to explore—either privately or with others—the deeply complex world of personal-professional intersections in palliative and end-of-life care.

In the end, to paraphrase T.S. Eliot, we return to the beginning—to ourselves, to our open hearts, and to our capacities to meet each new insight with curiosity and tenderness. And, to that end, we encourage you to read the poignant piece in Chapter 20 written by our beloved friend, colleague, and fellow author, Stu Farber, who died last year from acute myelogenous leukemia (AML). As a palliative care physician, university professor, and mentor to countless palliative and end-of-life care providers, Stu embodied the principles embedded in this edition. Stu also struggled with many of these issues as a patient, yet he transcended the struggle by holding true to what he valued most in life. His bright light has lit the way. Thank you, Stu. And thank you, reader, for your commitment and openness to engaging with one of the most challenging aspects of our work, our countertransference.

Therese A. Johnson and Renee S. Katz

Part I

Introduction

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1 When Our Personal Selves Influence Our Professional Work

An Introduction to Emotions and Countertransference in Palliative and End-of-Life Care

Renee S. Katz

As helping professionals working in palliative and end-of-life care, we are deeply affected by loss, heartbreak, and tribulation in our personal as well as professional lives. In fact, many of us have chosen to work in palliative and end-of-life care as a result of our own experiences with dying, trauma, and loss. Whether we are physicians, chaplains, nurses, social workers, psychologists, physical therapists, or occupational therapists, we have certain values and ethics, sociocultural influences, personal life histories and memories, and preconceived notions and assumptions that we inescapably bring to our work (Katz & Genevay, 2002).

The "C" Word

When we invited our contributing authors to write about their experiences and the subtle ways in which they can get "hooked" when providing palliative and end-of-life care, we discovered an abundance of preconceived notions and biases about the "C" word (countertransference). The authors were concerned that countertransference implied a distant, impersonal, even sterile work style. They pictured caricatures of stereotypical Freudian psychoanalysts using academic and theoretical intellectualization to avoid being truly present, truly genuine, or truly human. We had to challenge the authors to look beyond the stereotype of the distant, tabula rasa analyst and understand that the "C" word is every bit as relevant to health-care professionals working with patients and families living with serious illness or the threat of death as it is to psychoanalytic psychotherapists. We had to make the case that countertransference is a concept that actually beckons helpers to look at their humanness in the face of serious illness, dying, death, and bereavement rather than avoiding it.

It is true that the concept of countertransference was initially described by Freud as an unconscious process involving the arousal of the analyst's unresolved conflicts and problems (Freud, 1910). In Freud's classical definition, countertransference was regarded as an obstacle to treatment, a blind spot that the analyst had to overcome to work effectively (Freud, 1912). Over the years, however, the definition of countertransference extended to include the totality of feelings experienced by the clinician toward the patient—whether conscious or unconscious or whether prompted by the client's dynamics or by issues or events in the clinician's own life (Beitman, 1983; Kernberg, 1965; Langs, 1983; Shubs, 2008). Countertransference is now regarded as a natural, appropriate, and inevitable emotional response (Gabbard, 1999; Maroda, 2004; Racker, 1968), and "a crucial source

of information about the patient" (Gabbard, 1995, p. 475). Working with countertransference is regarded as a positive and important therapeutic tool, "an indispensable instrument" (Gill, 1994, p. 102) in our work. It is the basis for empathy, compassion, and a deeper understanding of both the patient's and the clinician's own processes (Beitman, 1983; Heimann, 1950; Little, 1951; Shubs, 2008; Wishnie, 2005).

Sandler, Dare, and Holder (1973), Dunkel and Hatfield (1986), and others have delineated the necessity of examining countertransference dynamics in interactions beyond strict psychoanalytic or psychotherapeutic treatment. We, too, believe that countertransference is part and parcel of all helping relationships, as we shall see in the writings that follow.

Countertransference in the Context of Palliative and End-of-Life Care

In palliative and end-of-life care, professionals of all disciplines and levels of experience are subject to powerful reactions to their work. These responses are far more diverse than simply "compassion fatigue" or "vicarious traumatization." Some of these responses originate in the helper, some "belong" to the patient (but are knowingly or unknowingly incorporated by the empathic helping professional), and some belong to that 'alchemy,' that 'space' that takes its own place in the poignant relationship between helper and patient. The context of critical illness, death, and dying brings these responses into an altogether unique realm of thought and practice. Countertransference responses can be complex and often enormously subtle in their manifestations. They inevitably affect every interaction, every theoretical discussion, every diagnostic workup, and every treatment plan.

Whether we are psychologists in private offices struggling to sustain an empathic environment for those who suffer profound loss and deep trauma, whether we are physicians wrestling with those words that will dim the hope in our patient's eyes, whether we are clergy or hospice social workers painstakingly striving to help patients make meaning at the end of life, whether we are administrators and teachers of clinical and residency programs working hard to prepare and support those in the trenches—*all* of us require an understanding of this subtle yet complex process that impacts our work every day.

For example, do you recognize any of the following scenarios?

> The Midwest doctor who has sworn an oath to do everything possible to sustain life—how does he 'help' an elderly Chinese woman whose family culture does not permit her to 'know' of her imminent death and the lack of further curative treatments?
>
> The conservative Catholic social worker whose father committed suicide when she was 12—how does she 'help' a family in its decision to stop all antibiotics and tube feedings for their 45-year-old father who is now brain dead?
>
> The young psychiatrist who simply prescribes psychotropic medication for the elderly Jewish patient who can't stop scrubbing his arms—how does he 'help' when he has missed the chart note explaining that this man survived the Holocaust by burying dead bodies in Auschwitz?

We believe that understanding countertransference processes is invaluable in all therapeutic relationships, and working with patients and families living with serious illness or facing the end of life is no exception. Thus, in the chapters that follow, we use the term *countertransference* as an "abbreviation" for the totality of our responses to our work—emotional, cognitive, and behavioral—whether prompted by our patients, by the dynamics incumbent to our helping relationships, or by our own inevitable life experiences.

The Dovetailing of the Personal and the Professional

Our real, often intense reactions to work in palliative and end-of-life care tell us that there is a personal-professional interface between our own life developmental tasks and our professional interactions (Genevay & Katz, 1990). Yet, how many of us take the time to reflect on the convergence of our personal lives and those of the patients and families with whom we work? How many of us have been trained to stop, breathe, and reflect on the dynamics that may be affecting us in this profoundly privileged work? Can we be sure that we are making the 'right' decisions on behalf of our patients if we have not examined the multiple facets that impact our thinking, feeling, and behavior in this very personal work?

Personal work? No, this is professional work, one might argue. In fact, in the pages that follow, we propose that our professional work with seriously ill, dying, and bereaved patients is *extremely* personal in nature, that we are profoundly influenced by our patients and their families as much as they are impacted and influenced by us, and that our emotional responses *do* impact the clinical moment—whether we want them to or not, whether we are aware or not, whether we can *admit* it or not.

And, therein lies the rub. With medical training that emphasizes physical symptom relief, treatment, and cure, health-care providers have borne the expectation and the responsibility of effecting therapeutic outcomes based on their evaluations of the patient, on the technical science, and on the "facts" as they know them. Yet, providers are often taken aback: the facts don't add up. How can that be?

Attending to the whole of the patient-clinician experience may provide a vehicle for understanding this phenomenon. With the advent of quantum physics, the definition of an entity, of an experience, and even of a unit has changed. Scientific explorations of objectivity and subjectivity have revealed fascinating new discoveries about what has long been understood as the "gestalt"—the whole that is greater than the sum of its parts. These findings demand that we face the truth, that we, as 'experts,' cannot responsibly divorce ourselves from this whole—nor from the alchemical reaction that occurs when two individuals engage with each other at what is, perhaps, the most vulnerable time in a human being's existence, living with serious illness and the threat of death. Patients, their subjective experience of their own illnesses, their families, and their worlds—everything, in fact—is irrevocably changed with our entry into the helping relationship. Taking responsibility to examine and explore how we influence the individual and the individual's processes and outcomes, how the patient influences us, as well as taking stock of the ways in which these impact our professional actions, is long overdue in the literature on palliative and end-of-life care.

Thus, in this volume, we scrutinize *ourselves* in *our* part of the dyad. We examine what we bring to the therapeutic relationship and, conversely, the ways in which it impacts us.

The authors have taken great risks in inviting us into their therapeutic realms. They disclose uncomfortable, even embarrassing, moments, actions, and outcomes of their work; they reveal interactions diagnoses, treatment recommendations, and the like, which upon their later reflection were not as objective and helpful as they would have liked to have believed. And, paradoxically, the authors reveal that some of these same 'failures' were, in fact, exactly what the patient needed!

In so admitting our professional foibles (influenced by our personal life histories, experiences, and cultural overlays), we hope to encourage other professionals working in palliative and end-of-life care to confront and examine their own denial, fear, helplessness, and anger related to death and loss as well as their need to control, cure, save, and 'do good.' In the pages that follow, we examine dynamics such as how practitioners both over-help and under-help patients and families; how personal feelings, cultural and religious biases, and prior life experiences can contribute to inappropriate diagnosis, referrals, and interventions; and why treatment is prolonged with some patients and terminated prematurely with others. We invite helping professionals to examine their inherent assumptions about a 'good death,' about resilience and hope when, in fact, the meanings attributed to these words become so relative and so differently understood by the patients, families, and communities with whom we work.

The Courage to Be Honest

It is our belief that if we have the courage to identify and confront the totality of our responses in palliative and end-of-life care, we can use them to inform and enrich our work. If we do not, we may find ourselves entangled in potentially damaging situations. It is our hope that examination of these complex personal and professional interactions will be requisite training for each and every person working with seriously ill, dying, or bereaved patients. And for those of us already deeply immersed in this work, we trust that this volume will serve as a guide to unraveling and understanding our own responses to this profoundly nuanced and deeply personal work. In so doing, we grow both personally and professionally.

Note: Case vignettes are used for illustration throughout the volume, but identifying data has been changed to protect the confidentiality of the patients and health-care workers.

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Part II

Special Issues in Palliative and End-of-Life Care

Introduction to Special Issues in Palliative and End-of-Life Care

Serious illness and the ending of a life is a process unlike any other. It has the capacity to burn away all but the most essential and primal of human needs. As caregivers, we often feel inadequate and powerless as we face the physical and psychic pain and anguish of our ill and dying patients. Being present to the suffering of another human being can drive us to heights of altruism, compassion, and advocacy or sink us to depths of cowardice, denial, and fear. In this section's opening chapter, Arbore captures the essence of how our own human need to feel that we have done "right" is as inescapable as the dying person's need to have some measure of control, comfort, and, above all, meaning.

Addressing spirituality in palliative and end-of-life care in Chapter 3, Reverend Wendleton gives voice to the chaplain's impossible task of being fully present with people in their moments of fear and existential emptiness, and Reverend Bowman gently encourages all clinicians to become comfortable in moments of spiritual need. "Giving space" to the spiritual meaning unique to each dying person and their surrounding loved ones is a humbling responsibility.

Figenshaw argues for perspective in advance care planning in Chapter 5: the perspective of the practitioner whose medical expertise must be conveyed in clear layman's terms and the patient's, whose expertise on the subject of his or her own life and goals must be understood, respected, and honored.

Finally, this Special Issues section describes the dance of parallel process: the supervisor and the supervisee replicating the dance steps of the supervisee and the patient. Ten Tusscher, in Chapter 4, eloquently describes the multiple levels of countertransference inherent in our clinical work, foreshadowing the work of her colleagues in Section III of this volume, who address the multiple levels of countertransference press at the organizational level, as well.

Note: There are excellent opportunities at the end of several chapters to deepen your understanding of your personal-professional intersections. Please refer to the chapter tables and Countertransference Tool Box.

2 Suffering and the Caring Professional

Patrick Arbore, Renee S. Katz, and Therese A. Johnson

> The sting of illness and death is the spectre of broken relationships and the loss of the world. Over and against this threat stand the efforts of caregivers and companions to embrace the sufferer and continuously reaffirm his or her capacity for relationship.
>
> (Barnard, 1995, p. 24)

Every day thousands of professionals (physicians, nurses, social workers, psychologists, counselors, clergy, nursing assistants, in-home supportive services workers, physical therapists, volunteers, and many others) provide skilled and compassionate care to those who are suffering and in need, negotiating a delicate interplay of their own unspoken needs and expectations with those of their patients. The professional, though he or she cares about the patient, may resist getting close enough to recognize, understand, and share in the patient's suffering.

Charon (1996) calls this phenomenon parallel suffering, where the suffering of the patient and the suffering of the professional are kept separate. Unfortunately, by distancing from the patient's suffering, the clinician loses opportunities not only to strengthen the patient's ability to fight for hope (e.g., hope that the patient will be able to endure physical, emotional, or spiritual pain) but also to help the patient make meaning of his or her struggle. When this happens, sick and dying people are left isolated and alone in their pain and suffering.

The Etiology of Suffering

There are many reasons why people suffer with serious and terminal illness. DeBellis et al. (1986) proposed these reasons: pain, loss, disability, failure to achieve relief from symptoms, the complexity of treatment, the effects of disease on families and friends, unfavorable prognoses, and the expense of treatment. Cassell (1976) adds that suffering springs from the person's perception that they are disintegrating. The perception of loss of physical, cognitive, and spiritual integrity and the impending destruction of identity as a whole, healthy person triggers the suffering.

Suffering is extended, according to Byock (1997), when physical pain is ignored, when a person's emotional pain is not understood, or when pain is dismissed as inevitable. Although physical pain initially begins as a protective mechanism for the body, alerting the conscious mind to tissues being damaged, it transforms into a villain immediately

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after sounding its life-saving alarm. The transition from pain to suffering occurs when the pain is accompanied by emotional, social, or spiritual distress and feels overwhelming and out of control.

The relationship between pain and suffering is complex; if left unrecognized and unaddressed, neither one will be alleviated. In an attempt to reduce pain, medical practitioners may not notice the extent of the patient's emotional suffering and thus target their interventions exclusively to the physical pain. However, complete cessation of physical pain cannot be achieved without concurrently addressing emotional or psychosocial pain, that is, suffering.

Mayling

> Mayling, a Chinese woman who had been diagnosed with stomach cancer 17 years earlier, taught Patrick a great deal about suffering. She had bouts of intense physical pain that were being treated by a palliative care nurse specialist. When Patrick saw her, Mayling reported that her physical pain was being treated with a variety of medications. Yet, Mayling still seemed to be suffering: "I can't even sit. Is this a way to live? Is this what people call quality of life? I don't see any meaning, so why go on? There is no logic, no explanation, no understanding. I cannot find an answer. I have stopped looking for one. I don't think human knowledge has an answer for me. I am lonely. Fighting this disease is a solitary experience now. Regardless of how many people are around me, I am still the only one who has to experience the pain and live with the fear."

Patrick learned that Mayling was worried about what would happen to her husband when she died. Her suffering was certainly related to her physical pain, but it also was caused by the real, human dilemmas that surfaced in the process of her living and dying. As a helping professional, Patrick needed to be very skillful in exploring and addressing the psychosocial issues that were causing distress in Mayling's life. To attend only to her physical distress would have been a huge oversight, resulting in a less-than-helpful outcome. When Patrick called Mayling's palliative care team for additional pain medications, he secretly hoped the medication would be an "easy answer." In fact, it would not have been the answer at all but rather a way to alleviate Patrick's own uncomfortable, helpless feelings. It would have been a displacement of his own anxiety into a concrete, "practical" attempt to alleviate Mayling's suffering.

The Role of the Helping Professional

Offering Support to Decrease a Sense of Isolation

Working with seriously ill and dying patients and families requires that we look at our internal resources regarding our ability to work with those who suffer. To help patients re-perceive their pain so that they can become more comfortable, we must offer support that comes from the truth of our being (Dass & Gorman, 1985). That is, we must lean in and offer assistance that comes from a genuine and empathic place in ourselves.

It is difficult to be present and willing to accompany those who suffer through their pain. Many helpers, in an attempt to feel safe in their feelings, retreat from the pain of

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their clients, by becoming "professional" or "objective." This often manifests as distancing or aloofness. It can be especially hard to "stay close" when the sufferer weeps—in fact, when *we* weep. There is a tendency to want to comfort the individual by stopping his or her tears. Yalom (2002) suggests that the helper may wish to encourage sufferers to go deeper into their pain by inviting them to share their thoughts about the tears, not in an aggressive way but in a gentle way that allows them to experience compassion for themselves and what they are enduring.

> When Mayling was tearful and despairing, Patrick leaned in. "I sense such despair. What are you mourning right now?" Through her tears, Mayling responded. "I never imagined that my life could turn out like this. I used to be proud of myself, the way I managed the pain. But now the pain seems beyond me. I have absolutely no control over what I can do. Everything is about my body and how it can handle food or medications or pain."
>
> Patrick realized that he needed to support Mayling in mourning this loss of identity as a strong woman who had control. He recognized that Mayling was mourning the fact that the whole focus of her life had become the management of her symptoms at the expense of all joys, other efforts, and interests. To determine how he could best support her in her mourning, Patrick first examined his own responses: he needed to see her as someone who was not "just" a series of symptoms but was someone with a full life apart from her illness. So, he asked her about her life—how she came to the United States, how she met her husband, what she had learned, and what her life passions were.

Barnard (1995) notes that if we can allow our patients to give voice to lament, we

> can intercept and work on . . . [their] suffering within the framework of communication. The hopelessness of certain forms of suffering—whether this is grounded in conditions that are at present petrified or whether it is unalterable—can be endured where the pain can still be articulated. (p. 26)

> To help Mayling give voice to her lament, Patrick asked her to describe the pain, where it originated, how it changed. He validated the ineffectual use of language to describe certain experiences and encouraged use of metaphors, images, and analogies. Mayling responded: "The tumors are pushing against the liver. I feel bloated all the time. The tumors are pushing the ribs! You can see the ribs have actually shifted (points to her ribcage). I really have no idea where my heart is sitting right now. All my major organs are being pushed by a whole belly full of tumors. I look like a freak. It's so scary to be trapped in this body. I feel like a prisoner already sentenced to death; I am just waiting for it. And this waiting is tiring."

If we can encourage narrative and storytelling about pain and suffering, we will often help bring the trauma of the experience into consciousness. We then have the opportunity to help the patient review and reconstruct the trauma until it is robbed of some of its power. Mayling's stomach cancer caused enormous pain, and the protruding tumors

embarrassed her. By inviting Mayling to talk about her body, her illness, and her experience, Patrick made it possible for Mayling to better integrate this trauma into her life experience.

As caregiving professionals, we must encourage our patients to give voice to their suffering and then be ready to accompany them *into* their pain. If we can bear witness to the suffering, we can diminish their sense of aloneness, at least for a while. We must be willing to explore the circumstances and extent of our patients' losses, and perhaps most importantly, if we can tolerate it, we must be present to the depth of their anguish and despair. Perhaps, then, we can be present when the patient begins those early forays into the search for meaning.

Being Versus Doing

"Being" with suffering clients rather than "doing" something for or to them is challenging not only for the newer clinician but for the seasoned professional as well. Knowing *how* to respond to the suffering of others, especially when it is out of usual and familiar practices or even counter to what others are doing, can be unnerving.

> William, a man in his 90s, was nearing death. The student intern assigned to see William became visibly agitated as she sat in his hospital room. The student manifested her nervousness by glancing at her watch, shaking her foot, shuffling papers, and frowning. Although awake, William was too tired to speak above a whisper. He acknowledged her presence and smiled weakly. After about 20 minutes, William fell asleep. No longer able to contain her discomfort, the student raced for the door.
>
> As she walked down the bright hallway toward the elevator, the student reviewed her brief encounter with William. She felt angry and resentful. "There was nothing I could do," she thought. "He could barely talk, and he probably didn't care whether I was there or not. I don't think we should bother people like William who are sick, frail, and dying. What good did my visit do? He probably won't even remember I was there! What difference did it make to be with him? I was useless."

Even the most experienced among us can feel awkward and helpless, especially in settings such as the nursing home. Our biases and stereotypes of these facilities can significantly impair our abilities to be present and to see the individual needs of each patient. We feel angry that people have to die this way. We feel uncomfortable with the tubes and monitors recording vital signs. How hard it is for us to be with people for whom we can offer only our presence.

> One hospice social worker related how terrible she felt as she walked down the hall of a nursing home and heard one woman wail, again and again, "Help me, please; someone help me!" Members of the nursing staff walked by, engaged in various duties, and did not respond. Upon questioning, one nurse condescendingly replied, "She's demented!"

This is an example of countertransference, unexamined, unconscious, and ignored. Who will step up and ask the questions: Why does having dementia negate the suffering? And why would we ignore someone who has dementia? Where are such beliefs created? Perhaps we avoid asking these questions out of fear, out of guilt, or simply out of denial.

If we can remember that our presence and the sharing of our basic humanity can be a healing experience for our patients, we can often sustain ourselves during those challenging situations. Being aware of our countertransference, which may manifest as feelings of nervousness, anxiety, or anger, will help us stay connected with those who suffer. By viewing countertransference as a tool, rather than an obstacle, we become better helpers to those for whom we care.

Helping to Establish Meaning

One of the ways in which we can help people cope with their distress and suffering is to encourage them to tell their stories. Stories are a way of organizing and interpreting experiences. They can be vehicles for helping individuals find meaning in their condition—to "make" meaning in the context of suffering (Neimeyer, 2001). For example, it is not unusual to hear as a result of their illness: "I am forever grateful that this stroke taught me to treasure not work, not material things, but my family, my relationships, my 'living in the now!' " As helpers we hear stories of victory not necessarily in terms of a physical cure but in terms of reconciling one's relationships or one's personal sense of disintegration.

Mayling's and many other sufferers' quests for meaning are evidenced in the persistence of their questions: "Why?" "Why me?" "Why is this happening to me?" The meaning attributed to suffering is highly subjective and fluid. In the case of Mayling, there is her own personal suffering, the suffering of her husband, the suffering of the oncologist, the medical social worker, the chore worker, the members of the palliative care team, friends, family, and Patrick himself. Each member of the team must eventually settle on his or her own meanings as the result of witnessing Mayling's or *any* patients' pain and suffering.

In working with those who suffer and are in despair, it is important, however, not to push the issue of higher meaning. As one bereaved individual once declared, "I hope you aren't one of those helpers who want me to be grateful for the suicide death of my husband because I'm not going there." As helpers we must allow the person's natural curiosity, instincts, and energy to surface the issue of higher meaning. To facilitate the search for meaning, we can invite suffering patients to share their own interpretations of their experiences. As we listen to their comments, we may want to ask ourselves what their statements tell us about their views of the world, of God, of their families, and of their professional helpers:

> Mayling's husband would occasionally question her about why she wanted to continue living. This questioning troubled Mayling. She said, "I'm scared. I don't want to offend God. My religion does not permit me to kill myself. But if there is a God, he is blind, deaf, and dumb. He has forsaken me. I don't even know how to tell you how much it hurts to live like this. This is not a life anymore. This is hell."

Mayling's case demonstrates the suffering that takes place when people experience threats to their identity or the potential destruction of important aspects of their selves.

Mayling's religion was important to her. Her belief in God was an integral part of her life experience. Questioning this relationship added to her fears.

Suffering individuals often provide "hints" as to where the malaise lies. While the malignant tumors destroyed Mayling's stomach, her relationship with God was infected as well. Although professional helpers may not experience the same interest or background in the religion or spiritual beliefs of our clients, it is important to stay present and open to their discussions about God, spirit, and the divine. Patrick, in working with Mayling, silently acknowledged their different experiences of a "higher power." What he connected to, however, was the passionate way in which Mayling spoke about her relationship with God. Although he did not share her view, Patrick could support her passion for this relationship. Helping Mayling reconnect with her faith in God brought her a sense of comfort that the palliative medication did not afford her.

Listening and Empathizing

> False reassurance. Evasion and denial. Avoidance and flight. Blaming the victim . . . The assumption that the control of pain and other physical symptoms is equal to the elimination of suffering. These are among the most common strategies, within medicine and within the culture as a whole, for walling off suffering. Each is an enemy . . . either because it distorts the patient's experience or because it seals that experience off from us completely. . . . Why do we do this? . . . We want to protect ourselves from being overwhelmed by feelings of our own mortality; from stress and burnout.
>
> (Barnard, 1995, p. 25)

Armed with education, skills, and techniques, we must be careful not to stay just in our *heads*. Rather, we must open our *hearts* to the suffering of others. When working with distressed individuals, we are exposed to their guilt, shame, rage, anguish, trauma, loneliness, hopelessness, and ambivalence. We also witness stories of defeat and victimization. If the helper is afraid to "go there"—that is, to begin a conversation about how the individual views his or her illness—the helper may unconsciously give the message that he or she is afraid and overwhelmed or that the patient's story is not important. The result is a missed opportunity to normalize the often conflicting antecedents and consequences of suffering. For example, a veteran may never tell you the depth of his or her pain, believing that it is a "just" consequence for the killing in which he or she participated during war. Colluding with this silence, while perhaps "comfortable" for the helper, detracts from the opportunity to explore a myriad of feelings and beliefs, past and present. Neither the helper nor the sufferer grows through this type of avoidance.

Rather, the helper must reach out through empathy—that is, the helping professional must work to intuitively reach a compassionate understanding of the patient's experience. An important component of empathy is intimacy (Shamasundar, 1999). Intimacy evolves through the development of closeness as the helper accepts the mood and state of being of the sufferer. Intimacy can shift the nature of a conversation from one that is trivial to one that is meaningful as well as therapeutic. One of the hazards of intimate conversations, however, is that feelings are ignited in us as we get close to the agony of those we are helping. The deeper the empathic sensitivity and the deeper the desire to know and help, the stronger the potential for professional stress (Shamasundar, 1999). In Patrick's desire to understand what Mayling was experiencing, he had to step into her world. In that

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intimate relationship he found Mayling's mental, emotional, spiritual, and physical worlds absolutely terrifying. To distinguish his own feelings and reactions from those of Mayling, Patrick had to monitor and reflect on his feelings, their antecedents, and their associations.

Exploring Psychosocial Aspects of Pain

Pain arises from physical, emotional, social, and spiritual arenas. Thus, we must assess each of these arenas and then identify a plan to alleviate or mitigate the pain as well as accompanying feelings and practical needs.

When personal needs perceived to be vital to maintaining quality of life are hindered or no longer available, patients experience frustration, hopelessness, and psychological pain. When the pain is perceived as unbearable, intolerable, or unacceptable, suicide ideation can surface. Statements such as "I won't put up with this pain" or "I think I deserve a merciful ending" are common indicators that suicide thoughts are formulating. It is extremely difficult for helpers to respond adequately to comments such as: "Why go on?" "If there was a God, he would have taken me long ago rather than leaving me in such pain." "Everywhere I look, I see only reason for despair."

Barnard (1995, p. 26) notes that the "fear of our own undoing in confrontation with chaos and disintegration is at the core . . ." of our discomfort with suffering and despair. This fear is intensified when we hear that our patient's pain is so unbearable that death seems a better alternative. Listening to suicidal thoughts may compel the helper to: (a) interrupt the person's story and attempt to strongly influence him or her not to talk about dying or death; (b) attempt to falsely reassure him or her; or (c) attempt to move to a "solution" without understanding the true meaning of the pain. The outcome of these approaches leaves the sufferer alone with his or her self-destructive thoughts—isolated rather than connected with the helper.

> "Do you know how disgusting it is to see your body falling apart in bits and pieces?" demanded Mayling. "It's not right. I'm scared. No loving words exist that can calm the fear in my heart. All I know is this continuous torture. There is no end. Just give me an end . . . just give me an end."
>
> Patrick's gut lurched when he heard those words. Mayling was thinking about death as an escape from pain and suffering. Patrick wondered if she was asking something of him that he couldn't do. What wasn't he providing to ease some of her suffering? Patrick wrestled with these questions, knowing that they arose from his desire to see her suffering end, for her sake as well as his own. He became overwhelmed with a sense of powerlessness, helplessness, and professional, as well as personal, self-doubt.

How many of us hear words like Mayling's and simply do not know what to do in response because we hurt and ache when we sense the degree of suffering and the depth of despair?

Psychological pain—hopelessness, helplessness, and a sense of being worthless—is often the center of self-destructive thoughts and behaviors. Decreasing emotional pain by meeting basic psychosocial needs can prove to be life-saving (Shneidman, 1985). Reducing the level of suffering just a little bit can support the patients' capacity for working through the painful situation in which they find themselves. Often, the process of

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assessing and articulating their needs can, in and of itself, produce a feeling of control in the patient, thereby reducing the sense of chaos and oppression, which lead to despair.

Countertransference Responses to Suffering

Suffering is part of the human condition. Every person suffers at some point in his or her life; the helping professional is no exception. We develop beliefs about suffering through our personal experiences with it; through the loss, pain, and suffering of our friends, families, clients, and patients; and as a result of the influence of our cultural backgrounds and spiritual philosophies. Grappling with the notion of suffering often comes as a result of our work and our desire to help.

As helping professionals who are regularly exposed to loss, pain, and suffering, we must be vigilant about understanding and attending to our countertransference feelings so that we do not find ourselves inadvertently acting them out. The most common countertransference issues that can unconsciously manifest in our work with suffering individuals include the following:

- *Helplessness*—To avoid this uncomfortable feeling, helpers may psychologically distance themselves from the person who is suffering by becoming either over- or under-involved. Thinking about other matters when involved with a patient, clock-watching, and contriving reasons why a patient really doesn't need help are all ways that unconscious countertransference feelings of helplessness can seep into the therapeutic relationship.
- *Shame and Embarrassment*—Watching the physical or psychological disintegration of those for whom we care may trigger feelings of shame and embarrassment that may result in the helper "looking the other way"—literally and figuratively not being able to directly "see" the suffering. This often occurs because of our fears of our own inevitable dying and our perceptions of the indignities in these processes.
- *Denial and the Wish for It to Go Away*—Helpers may convince themselves that talking about the pain will contribute to, rather than alleviate, the individual's distress. Additionally, the helper may "misunderstand" the sufferer in an unconscious attempt to make the problem "go away." For example, the sufferer may say, "I feel so alone because of this illness; no one in the family wants to be with me." The helper, in trying to put a lid on his or her own anxiety, might find him- or herself trying to placate or gloss over the reality of the patient's experience. A common response is to attempt to "fix" the problem—"Of *course* your family wants to be with you!"—or to provide misguided advice: "People would talk to you if you didn't focus on your pain so much. You need to talk to your family about what is going on in *their* lives."
- *Anger and Hostility*—If helpers are unaware of their own anger, whether at the disease itself, at their inability to help, or because of their frustrations (personal and professional), anger can get displaced into the helping situation. Labeling is an example of displaced anger. For instance, labeling someone a "drug seeker" may be the helper's attempt to assuage his or her own helplessness and inability to control the patient's pain. Anger can also seep out in the form of ridicule—"You don't really mean that you're in that much pain, do you?"—or sarcasm—"Isn't this the reason why you take the pain pills?"

- *Sorrow*—Whereas our tears can often create empathic bonds with our patients, there are times when, in our own deep sorrow, we cannot maintain a connection with the sufferer because we are too involved in our own suffering. When suffering patients become aware of our distress, they may feel abandoned or guilty that their experiences have upset us. Patients may unconsciously reverse roles in an attempt to comfort the helper, or they may change the subject to relieve the helper's discomfort.
- *Restlessness*—If helpers feel anxious to make things right, to alleviate pain, or to do a "good job," they may impose their own agendas, such as pushing clients to find something of value in their experiences. Not recognizing these countertransference responses may result in a pacing problem, where the helper's agenda takes precedence over the needs of the person who suffers.

Utilizing Countertransference to Enhance Our Work

If we feel scattered, confused, agitated, despairing, frightened, or angry before or during our patient care, we must examine the etiology of these feelings: are these my own uncomfortable feelings, or am I responding to something the patient is experiencing? We can then decide on a course of action: we can choose to let the sufferer know that we are experiencing certain feelings so that we can explore them together, or we may choose to share them with a colleague or supervisor at another time. This choice is dependent on a number of factors: (a) will the information be informative, clarifying, or beneficial in any way to the client; (b) will the disclosure shift the focus from the patient to the helper; (c) is there a potential for harm to the patient, family, self, or therapeutic relationship if the professional discloses; and (d) is the timing right? Often, the best option is simply to let our feelings inform us of what the sufferer is experiencing and, without self-disclosure, "wonder" aloud if perhaps the patient is feeling angry, helpless, confused, or some other way.

Summary

Suffering often begins in a diagnosis of a medical illness, in the news of the death of a beloved family member or friend, or in the awareness of our own dying or some other disastrous experience. As helping professionals, if we fear pain and anguish, and if we ignore feelings that are evidence of our own parallel suffering, we run the risk of denying these very feelings in our patients. This leads to isolation and further despair and cuts off any possibility for positive change.

By admitting to our countertransference responses, we open the opportunity to both recognize our collective humanness and to increase our compassion in the face of suffering. If we can take time to invest in our own healing, we will be more able to sustain our abilities to "be" with the experience of suffering rather than feeling compelled to "do." Staying close, being present, witnessing, and acknowledging our patients' suffering are the first steps to empowering them to recognize and hold on to glimmers of hope and change in their own inimitable ways.

In sum, our work in palliative and end-of-life care exposes us to the most painful experiences of the human condition. Being present to suffering on a daily basis places huge demands upon our psyches, our souls, and our very beings. We must remain fully present to suffering and at the same time know our limits. At times we will be able to nourish freely the hungry soul of a sufferer. Occasionally, we may calm the anxious state

of the person who is dying. We may even reduce the unbearable pain in a person who suffers as a result of self-destructive ideas.

Yet, there will be times when there is nothing we can do for a suffering person. All we may be capable of is *being* with the person in his or her pain, attending to the quality of our own consciousness. If we cannot *do* something for the sufferer, we are called upon to "dwell in whatever truth and understanding we have come to which is beyond suffering" (Dass & Gorman, 1985, p. 44). It is here that true compassion arises. And, as Dass and Gorman (1985) so eloquently note, "Hearts that have known pain [can] meet in mutual recognition and trust" (p. 44).

In the end, to paraphrase Barnard, the promise of 'being' with suffering in palliative and end-of-life care is twofold: to provide assurance to our patients that they are not alone in their suffering, and "to create a psychological and spiritual space within which change and growth are possible" (Barnard, 1995, p. 24). If we can stay present and stay connected, we can provide opportunities for our patients to grow in their abilities to respond with courage and creativity to threats against their very existence (Barnard, 1995). We can provide a milieu in which patients can express not just grief, fear, and desolation but confidence, joy, and even triumph.

COUNTERTRANSFERENCE TOOL BOX:

In the Face of Pain: Countertransference and Suffering

Renee S. Katz

Mary, a 69-year-old post-mastectomy patient, had successfully battled recurrent breast cancer for 20 years. When she discovered another lump in her breast that was found to be malignant, she returned to her local cancer center for additional chemotherapy and radiation. With the onslaught of the new regimen, Mary became increasingly weak and debilitated. She would arrive at the center hunched over and would slowly and painstakingly drag herself to her "station."

One afternoon, Mary wearily confided in Sarah, her nurse of many years: "It's too much," she whispered. "The nausea, the pain . . . it's excruciating." Then, turning away, she wept silently. "I'm just so tired. This is no way to live. Mary, I'm done. I'm not coming back."

As her nurse and as someone who has developed a deep affection for Mary through all the years you've worked together, what might your ***initial*** *impulse be?*

___ Convince her that this pain is temporary. "Just give it a chance."
___ Tear up and cry.
___ Analyze aloud the possible reasons for her distress.
___ "Discuss"/push the medical necessity of the chemo/radiation regimen (aka, "guilt trip" her into continuing treatment).
___ Shut down emotionally. Become quiet.
___ Other:

If you checked any of the above boxes, read the corresponding paragraph. Ask yourself if any of these thoughts resonate with your experience:

Convince her that this pain is temporary. "Just give it a chance."

We often develop significant, intimate relationships with our patients as we accompany them through the ups and downs of their lives and their illnesses. In long-term relationships like these, it is not uncommon to find ourselves in "cheerleading" mode—helping our patients find hope during difficult moments, providing emotional support through the vicissitudes of serious illness, and literally rejoicing when remission is attained. Cheerleading can make it difficult to "hear" our patients' pain—emotional, physical, psychosocial, and spiritual. Our desires to "hold on" to our patients by denying the severity of their illnesses can hold us hostage to unrealistic expectations and can set us up unconsciously to minimize their suffering. In fact, many clinicians move to aggressive "pain management" techniques when patients express a desire to 'give up,' believing that somehow controlling the physical pain will eliminate the patient's emotional suffering. In reality, this is often the way clinicians attempt to control their *own* anguish and suffering in the face of imminent death.

Tear up and cry.

Professionals working in palliative and end-of-life care are often deeply touched by loss in their personal and professional lives. In fact, many of us have chosen this work as a result of our own experiences with dying, trauma, and bereavement. It is critical in this work to keep up with our personal as well as professional losses. Otherwise, we may experience bereavement overload and feel discouraged, demoralized, even "swallowed up" by our patient's hopelessness and pain. It is at these times that we can find ourselves "lost" in our own sorrow and unable to support our patients in *theirs*.

The relevant question is: will your tears create a natural sense of empathy, or will the patient feel the need to comfort you?

Analyze aloud the possible reasons for her distress.

The sting of loss and the unbearable suffering of our patients may resonate with our own, unresolved losses. We may not feel we can bear the loss of one more patient or the death of this particular patient. If we have "stuffed" our feelings of grief and, perhaps, told ourselves we're "just fine," we may find ourselves cutting off further conversation about pain and loss with our patients. To avoid dealing with our patients' emotional needs to grieve, to process their losses and to make meaning of their suffering, we may unconsciously distance ourselves from the pain and grief through intellectual and analytical discourse. This form of intellectual distancing serves to protect the clinician's heart by allowing the clinician to stay in his or her head. When

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this occurs, we deprive our patients of the emotional space necessary for exploring their own losses and for doing the healing and restorative work necessary to put their houses in order.

"Discuss"/push the medical necessity of the treatment (aka, "guilt trip" her).

Medical professionals trained to cure may find themselves at odds with the type of care needed when "cure" is no longer the patient's goal. "Pushing" a patient to accept a treatment protocol is often a way professionals ward off their own uncomfortable feelings of guilt, shame, and failure. When these feelings become unbearable, we may unconsciously displace our own guilt onto the patient by "guilt tripping" them into treatment.

Many practitioners spend lifetimes overachieving and becoming "authorities" in their particular fields. These pursuits are often our attempts to assuage deep feelings of insecurity and inadequacy. When we place ourselves in the position of omniscient "experts," we may be at higher risk for unfairly pressuring our patients because we may interpret their refusal of treatment as "giving up" and as questioning *our* authority. In reality, however, it is the professional's need for power and control that must be questioned under these circumstances.

Shut down emotionally. Become quiet.

When suffering and pain fill the affective reservoir of the helping relationship, the professional may shut down emotionally in an attempt to "wall off" the suffering and escape the excruciating feelings brought forth in the clinical situation. The risk is that a mutual "turning away" can happen between patient and professional. The professional may avoid talk of the issues at hand (and may even rationalize this as a way to "protect" the patient from further pain), while the patient, sensing the helper's emotional withdrawal, may attempt to avoid burdening the helper by changing the subject or glossing over his or her true distress. As such, a valuable opportunity to process the multitude of feelings, desires, and needs is lost. Patients, feeling emotionally abandoned and invalidated, are left alone in their pain, while simultaneously, clinicians suffer silently with theirs.

* * * * *

Being in the presence of unremitting pain and suffering can be overwhelming, unsettling, and deeply moving. Clinicians must carefully monitor their responses, or in an attempt to avoid despair and self-doubt, they may find themselves reacting to patients in ways that disrupt the therapeutic relationship. Unchecked distancing or anxiety on the part of the clinician deprives patients of the opportunity to mourn and come to terms with their lives—past and present. It also deprives the clinician of the opportunity to mourn his or her own losses in the face of serious illness or death.

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It is critical for clinicians to keep up with the grief of their losses—both personal and professional. Only when we are comfortable grieving our own losses and confronting our personal closeness to and distance from death can we adequately help our patients give voice to the profound grief and suffering in their own lives. "Give sorrow words," instructed Shakespeare. Sometimes, this is easier said than done.

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3 Risking Connection

Spirituality in Palliative and End-of-Life Care

David H. Wendleton, Ted Bowman,
Therese A. Johnson, and Renee S. Katz

Introduction

For those of us charged with the care of the spirit (clergy, chaplains, and all those who integrate the spiritual into their practices), serious illness and impending death often create a desire to engage, comfort, and create safe space for "the work of meaning-making and dying." For the dying person, the "work" is often about exploring the meaning of one's life, preparing for the demise of one's body, and depending on belief, coming to terms with the transition or annihilation of the spirit. For the seriously ill patient, as well as for the dying person and his or her family, this work is also about legacy: what traces of meaning will be left in the hearts and actions of others?

As spiritual caregivers in this context, our work can feel more urgent, more "important," even critical. It can feel larger than simply addressing the perceived concerns of those for whom we care. It can feel like a yearning that emanates from deep within our being. In fact, we often hear spiritual counselors declare that this work is not just a job but a 'calling.' We warn that when our work becomes simply a means to pay the bills, we should look for something else to do with our lives. Given this great responsibility and the wish to respond to the needs of the dying and those living with life-limiting illness, spiritual caregivers may find it difficult to resist delivering the answer, the fix, the understanding, or the determined insight into the deeper meaning of our connectedness to this world.

Countertransference "Hooks" in Providing Spiritual Care

Subtle pressures, both internal and external, can contribute to our exaggerated expectations of what we can and should be able to do as "caregivers of the soul." Our responses to these pressures, whether conscious or unconscious, whether emanating from within us or from within our patients, whether the result of organizational or systemic pressures (see Altilio and Sumser in Chapter 11 for more on organizational countertransference), hold the potential for danger and for opportunity.

Recognizing the "Forest From the Trees"

Spiritual care is not synonymous with religious practice. This necessary differentiation is a constant point of tension for those of us in practice as pastoral counselors and

chaplains. What is the difference between spirituality and religion? How does the difference manifest itself in providing care to our patients and clients?

Stanworth (2004) describes spirituality as "the interpretative story and ensuing values of an experience that can be regarded as both human and ultimate" (p. xvi). It "is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski et al., 2009, p. 887). When we provide spiritual care to our patients and families, we are serving to help them connect or reconnect to life—"to things, practices, ideas and principles that are at their core of being—the breath of their life" (Lunn, 2003, p. 154).

A major concern for the spiritual care provider lies in clarifying the differences between religion and spirituality, for him- or herself and for the patient. If we are not clear about our own beliefs, we may give a false sense of sharing the same religious beliefs and practices as our patients. We may presume to understand a particular religious stance or theological belief and respond to patients based on our own assumptions. This can cause us to overreact or lose focus. For example,

> Ann was a 65-year-old woman who was dying of cancer. Her principal spiritual dilemma was her fear that in the afterlife, she would not see her daughter, Emily, who had died of suicide 15 years prior. As a Catholic, she reasoned that if the church does not allow burial of those who die by suicide alongside those who die naturally, perhaps Emily would also be excluded from heaven.
>
> This fear was expressed to a volunteer from the Catholic ministries who attended to parishioners in the hospital by giving communion and joining in prayer. As fate would have it, this volunteer had experienced the loss of a family member through suicide, and she immediately moved to both reassure Ann that she would see her daughter in heaven and to debate the Church doctrine of burial. Ann quickly changed the subject by asking if the volunteer could call the nurse for her noontime medication. The volunteer, having some recognition of her missstep, called the chaplain and explained what had occurred. The following day, Ann was able to address her fears with the chaplain, and in response to gentle questions, she was able to express her long-held sadness and guilt surrounding her daughter's death. She began to mourn her daughter and the years spent yearning for one more embrace. When the chaplain left her room, Ann was more at peace despite the lack of answers to her religious dilemma; somehow her spirit had been eased in the mourning of her losses.

As this case illustrates, if we cannot engage a patient around their belief system because of our reaction to their beliefs, we have allowed countertransference to adversely impact our care. We must clearly focus on creating opportunities for patients to speak to the deeply held religious beliefs that shape and guide their spirits, and we must stay clear of any pressure to make our patients' beliefs fit certain schemas in our minds. If we can be open to hearing *all* the meanings attributed to our patients' beliefs, then we have a great opportunity to explore the ways in which these meanings can be used to help them address difficult existential questions and challenges as they confront life-threatening illness, dying, and death.

The God Complex

As spiritual caregivers, we may find ourselves believing that we *ought* to bring an experience that is different from that which any other helping professional can provide our patients. This self-imposed belief can reflect our own insecurities about what others expect of us and about what we expect of ourselves. We wonder, "Shouldn't we have more to offer than other professionals because we have a relationship with the holy or because we practice the disciplines of the religious? Isn't it realistic for patients to expect the spiritual care provider to have more meaningful answers to the questions of essence when they are suffering with serious illness or are distressed near the end of life?"

Often patients or family members harbor underlying expectations that clergy can bring them healing—physical, emotional, and spiritual. They may make assumptions about what the chaplain believes or doesn't believe. Many desire to receive "answers" from God's representative. What may seem to be a simple request for prayer often holds multiple levels of meaning. It is very easy to make the mistake of "performing" based upon an assumption of the patient or of the patient's family. How easy it is to forget our true roles and succumb to patient, family, and staff notions of what we are "supposed" to do. These role expectations may be voiced directly or communicated implicitly with requests or even a simple look, as Claudia illustrates next.

> Claudia worked as a social worker in a busy county hospital emergency room. She would always introduce Dave, the chaplain on call, to the family and then declare, "I'm sure the chaplain would love to have a prayer with you!" Despite many direct conversations in which Dave asked her not to set him up and establish his agenda with the family, she continued her declarations. Other staff members seemed to carry a belief that Dave's role was to sit with the patient and family and make sure that important issues were addressed. Dave often wondered *whose* important issues really needed to be addressed.

External expectations about our roles, along with our own fears that we may not measure up, make it easy to take on an assigned role rather than providing spiritual care in a way that honors the patient's and family's needs. If we feel compelled to lead with our roles and not ourselves, we are not truly invested in the care of the other. Rather, we may find ourselves immersed in our own sense of superiority and "specialness." If we can move beyond expectations related to our "holiness," we can invest in the care of the other and be present as fellow sojourners. We can stay *human* and use the many tools we bring from our spiritual work and training to be present first as a person and then as a provider.

The Desire to Be Loved

If we are unaware of our own personal needs around self-esteem and self-worth, we can easily find ourselves interpreting our job descriptions in ways that meet our own needs for adoration and affirmation. On a number of occasions Dave found himself in this position and realized it was connected to his early need to "be a good boy." He began to ask himself, "How does this manifest itself in my spiritual care?"

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> Early in Dave's work he would find himself coming to the hospital at all hours of the day and night. He would spend many, many hours with family members—unknowingly seeking affirmation from them and from staff members, looking for confirmation that he was "the best" for always being there. Dave would find himself lingering (often hovering) amidst the patient and family in the hopes of becoming known as the "best chaplain we have ever had." These encounters were very seductive and fed his desire to please and to be accepted by the team. Of course, a great deal of his response to these encounters was also driven by fear. Would he do the right thing? Would he be judged as not being good enough? Would he lose respect and integrity?

Fear, whether real or perceived, is a powerful motivator. The question is motivation for what? And for whom? While it may feel great to receive feedback that we are amazing people providing wonderful care, we must continually evaluate our needs for recognition and admiration so that they do not get in the way of providing authentic spiritual care. Our motivation in doing this work must be to assist our patients to discover their own resources and plot their own courses. The greatest gift we can give our patients is to companion them on their journeys and help them discover new and fulfilling ways of engaging in their own spiritual work.

The Quick Fix

The push for a "quick fix" can impact issues of boundary setting, professional competence, and the balance of appropriate emotional and spiritual connection. The following vignette illustrates one such interaction:

> Mary, lying on a gurney parked outside the operating room, was refusing to go forward with her open heart surgery. The nursing staff called Jonathan, the chaplain, and asked that he come down right away and convince Mary to go through with the scheduled surgery. Jonathan arrived at Mary's bedside ready to do the job. His strategy was to help her see how much she had to live for. Thus began their dialogue:
>
> *Jonathan*: "But, you have so much to live for!"
> *Mary*: "Like what?"
> *Jonathan*: "Well, what about your husband?"
> *Mary*: "He's having an affair with my son's wife."
> *Jonathan*: "Well, what about your children?"
> *Mary*: "I haven't talked to them in 25 years."
>
> And on and on this went until Jonathan "got it." Finally, he said, "It sounds like you really don't have anything to live for." To which Mary replied, "That's what I've been trying to tell you for the past 45 minutes!"
>
> Jonathan took his leave. He realized that in his attempt to provide the "quick fix," he had, essentially, bowed to the nursing staff's needs, not to Mary's. This certainly was not his idea of good, patient-centered work.

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How is it that we can be so vulnerable to moving into "fix it" mode? Most of us have entered into this work because we want to make a difference. We want to create experiences that bring healing, insight, reconciliation, and even hope, particularly at these critical times of transition. Often, we have been drawn to this work because we have experienced firsthand the benefits and challenges of our own losses. When we look back on our experiences, we may realize that working with those facing death is our way of "mastering" emotional conflicts about our own losses. We may unconsciously want to make sure that others do not make the same mistakes. We may want to protect our patients from experiencing the hurt, pain, and suffering that we experienced. But, the desire to smooth the way creates an unnecessary burden for the professional and distracts the patient from focusing on his or her own work. Often, that "work" is about the patient's personal struggle with the "dark night of the soul," that is, the struggle with questions about meaning, values, things held dear, or contributors to their current existential emptiness.

If we inadvertently find ourselves avoiding difficult or uncomfortable spiritual crises, or if we notice that we are feeling the urge to "make nice" or deliver a "quick fix," we must ask, "What is driving this sense of urgency? Is there something about the current situation that is making me feel uncomfortable? Touching me personally? Am I perhaps being reminded of personal struggles in my own 'dark nights'?" At such times, it is useful to engage a trusted colleague or colleagues to help identify the source of our discomfort and to "move us along" so that we can do our work with the best interests of the patient in mind.

Delivering "The Answer"

When an individual receives a diagnosis of serious or life-limiting illness, the quintessential spiritual process of exploring meaning and purpose takes on an urgency all its own. The spiritual caregiver must consider his or her position in relationship to the questions of the essence of life and living, death and dying: what is the meaning of health and illness? What is the nature of the human person? What is the meaning of bodily life? What is the meaning of death? How do we respond to those who are separated from hope? What is the relationship between pain and fear, care and healing? What is the role, if any, of faith?

This does not mean that the care provider must have answers to these questions, but he or she must be willing to wrestle with such questions. Richard Groves (2002) identifies four primary spiritual arenas associated with spiritual pain: meaning, relatedness, hope, and forgiveness. To empathize with and understand the source of spiritual pain, the caregiver must reflect upon tragic, often incomprehensible suffering and sorrow and the corresponding dilemmas in finding meaning in suffering. He or she must understand the dynamics associated with relatedness—that is, the ways in which the processes of disease and life-changing illness can impact relationships with others, with ourselves, and with God or the transcendent. The care provider must examine what hope means and how these meanings can change in the course of the dying trajectory. For instance, initially a patient might hope for a positive prognosis. As their disease progresses, they may express the hope to see a loved one get married. Later, as the patient is dying, hope may manifest as the desire for a pain-free death.

Finally, the spiritual care provider must be able to wrestle with questions of forgiveness. What does forgiveness mean? Who determines the legitimacy and the need for forgiveness: the care provider or the client? What power delivers it? Is it a requisite act for a dying person to "save his or her soul"? For those of us who have not struggled with these questions in our own lives, we may feel intimidated when we sit with the patient and the family. In our discomfort we may quickly move to provide an "answer." When we do this, we lose the opportunity to understand *their* experience and needs. This can lead to a superficial "feel-good" experience with insignificant depth for the patient.

A classic example is the way in which the tool of prayer can be used to exit a conversation versus engage in it. When Dave is asked to provide a prayer for a patient, he takes the request seriously and sees it as an invitation to help the patient open him- or herself to the sacred. Rather than delivering "the answer" (i.e., a rote, formulaic, "feel-good" prayer), Dave asks what the patient would like to include in the prayer. This allows the patient to talk about what holds value and meaning for him or her and thus helps the patient connect to the sacred as they see it.

Generally, we caring professionals want to say or do something that will lighten the load or lift the spiritual burden. We may even find ourselves believing that the most current palliative or end-of-life intervention will be the perfect salve. While we may want to create outcomes full of happy endings, we must be able to stay present and compassionately "hold" the hard reality and seemingly unanswerable questions. If we deliver "the answer" without embracing these questions, spiritual care cannot be effective. In the words of Parker Palmer (1998, p. 150),

> If we want to support each other's inner lives, we must remember a simple truth: the human soul does not want to be fixed, it wants simply to be seen and heard. If we want to see and hear a person's soul, there is another truth we must remember: the soul is like a wild animal—tough, resilient, and yet shy. When we go crashing through the woods shouting for it to come out so we can help it, the soul will stay in hiding. But if we are willing to sit quietly and wait for a while, the soul may show itself.

When patients are in need of spiritual care, it is the person who is comfortable with the "unknown," with the angst associated with difficult and challenging life events, and with the struggle for making meaning in suffering, who will be perceived as most helpful. To develop the capacity to sit with the discomfort, we must attempt to understand why it is difficult for us to tolerate the unknown. We must *listen* instead of direct. As Rilke (1993) declares, "Live the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answer" (p. 35).

Father Knows Best, or Whose Agenda Is It?

Training, continuing education classes, and years of experience in the field increase our comfort with and knowledge of what we can realistically do to help our patients and families living with critical or life-limiting illness. When we are further along in our careers, we can let go of earlier needs to "hover," to be "loved," or to make ourselves

"indispensable." Instead, we can truly focus on being present with patients, families, and staff members—on their terms when *they* need it.

However, there are times when we may also find ourselves presuming to know best what the patient *should* do or what the patient *should* need. Lorna, a hospital chaplain, illustrates:

> Early one morning, Lorna was paged by the son of an elderly patient. He wanted a prayer of healing for his 90-year-old, dying mother. Lorna knew that this 90-year-old woman had no chance of recovering, so such a request really seemed unrealistic. She did not want to provide a sense of false hope, and she secretly wanted to "help" the son accept the fact that his mother's death was imminent. Lorna used her good chaplaincy skills to try to achieve her goal: rather than directly impose her beliefs and try to persuade the son to accept reality, she asked him about the meaning of "healing." He stated that he wanted a prayer for physical healing. Lorna suggested that there were many forms of healing and that death might also be embraced as an ultimate healing experience. She was not sure how convinced he was. Yet, she did offer a prayer that voiced the son's wishes and at the same time maintained *her* integrity (i.e., not providing false hope or colluding with his denial about the reality of his mother's approaching death). Feeling confident that they had moved to a place of compromise and understanding, Lorna was surprised when she was paged as she was leaving the nursing unit. The nurse making the page stated that the son with whom Lorna had just spent so much time was wondering if there was another chaplain he might speak to! Here, Lorna thought she was so insightful and aware—but, in fact, in her need to be right, she presumed to know what the son needed. In fact, she didn't "know best"; he did. If Lorna had been able to respect the son's way of facing the difficult reality of his mother's death, perhaps she could truly have been of help. Instead, the person she truly had helped was *herself*. She helped herself maintain her "I know best" position.

When we find ourselves thinking that we know best, we have lost any potential for supportive care. Spiritual caregivers must acknowledge that there are encounters where we feel afraid, confused, and out of control. To deny these feelings only leads to a false sense of security wherein our personal agendas become the foremost component in the relationship. If we can tolerate fear and ambiguity, we can be open to opportunities to hear clearly the needs and desires of the patient. In so doing, we can move deeply into the patient's experience so that we can respond to *their* agenda, not ours. Accepting the patient's agenda can move the relationship to a transforming and respectful place that allows the patient to do his or her own deep spiritual work. Struggling with the questions of meaning associated with life, dying, and death is the work that touches the spirit and soul of our humanity.

When the Countertransference "Works"

There are many times when a patient or family situation significantly impacts us because it resonates with something deep inside us. These feelings and emotional

responses can be used in ways that benefit our work—provided that we are open to "hearing" them. To wit, here is an encounter that Dave had with a young family facing terminal illness:

> A young husband and father had been battling leukemia for over two years when he arrived in the critical care unit of our hospital. He, along with his wife and two children, had traveled a great distance from a neighboring state and had arrived in critical care because of complications associated with his treatment. Dave met the patient and his family early in the hospitalization and immediately recognized many parallels in their lives. The children in the family were a son who was 11 and a daughter who was 8. Dave's daughters were the same age. Immediately he thought about how he, as a father, would want to be treated if he were in this situation and how he would want to care for his children if he were facing imminent death. The patient was going to die during this hospitalization. Had the patient and his wife talked with the children about his death? Were the children included in significant ways with his illness and his dying? How protected, included, or responsible did they feel? Fortunately for Dave as the spiritual caregiver, these were, in fact, the patient's concerns. The patient's hope and desire was to have some quality time to share and engage those he loved, especially his children.
>
> Speaking to the patient's wife in the hallway Dave asked if the children understood that their dad was dying or if they had been asked about what they did understand. She indicated that while the children had lived for two years with the illness, the parents had never set aside time to speak directly to them about the issues of death. Dave suggested that while no one knew her children better than she, if dying was going to be addressed with the children, now was the time. She agreed. Thankfully she, too, had been wrestling with just how she might engage the subject of death and felt that the children would benefit from direct and honest dialogue. The mother asked that Dave go with her to speak with her children. As is often the case, the children understood a great deal about what was happening. After well over an hour of tears and sharing of stories, Dave asked the children: "Do you have anything you want to ask me?" The son looked at him and said, "Why don't you adults talk like this in front of my dad?" With one thoughtful question, this wise 11-year-old took this intervention far and beyond what Dave had ever imagined. He wanted to engage his father in conversation and "bring along" the adults, whether they were frightened or not! Dave managed to say something to the effect that adults are often fearful of saying the wrong thing or causing someone to feel sad. Then he added, "If you want to talk to your dad about his dying and how you feel, we adults will be okay."
>
> The little boy stretched out his hand to Dave and asked if he would go with him. Dave had the sense that this honest emotion would be healing to the patient and family. Nevertheless, Dave felt uncomfortable as they approached the father's room. He wondered how the dad would receive this direct and clear communication. They stepped into the room. The young boy moved to the other side of his dad's bed, while Dave stood by the door. The

> son declared almost immediately, "Dad, I know you are dying." His dad said, "Yes I am." Turning back the blankets on the bed, the father invited his son to join him and snuggle. The son wasn't finished. He turned to his dad and began to tell him what he was going to miss when he died: camping trips, baseball games, hunting and fishing, long walks, football tosses, and simply "hanging out." The father then turned to his son and spoke of what he would miss: the first date, high school graduation, football games, his son's marriage, and his first grandchild. Later that night while many family members gathered around his bed telling stories and reminiscing, the father slipped into a coma and died.
>
> This family hoped to see the circle "completed," and they did—with understanding, clarity, and a sense of closure. Their values matched Dave's values, and he felt fortunate to share them with this young son, his father, and his family.

When patient and care provider are in agreement about core beliefs as well as desired outcomes and ways to achieve them, the "work" bears great potential for healing, and the encounter can truly be sacred.

Spiritual Care and the Non-Chaplain Provider

Spirituality is now routinely included in the arc of palliative or holistic care (Lattanzi-Licht, 1998, pp. 39–40). Finding a sense of comfort with addressing or simply being present for a patient's spiritual crises or profound moments of meaning making are opportunities that present for all members of the care team. Often a patient or family member has a special relationship with a particular member of their team, whether physician, nursing assistant, or social worker. At times, it is these medical professionals, not chaplains, who are present for those oft-unpredictable sacred moments in living with dying. Spirituality and making meaning of struggle, suffering, pain, and loss is a keenly personal experience that all clinicians must be willing to explore with their patients and families.

> To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity. I see no reason or need for my doctor to love me—nor would I expect him to suffer with me. I wouldn't demand a lot of my doctor's time: I just wish he would brood on my situation for perhaps five minutes, that he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.
>
> (Broyard, 1992, pp. 43–44)

How do we become comfortable with providing a presence that allows for spiritual work and construction of meaning to occur? To become comfortable with exploring another's reality of suffering, loss, doubt, and fear, we have to first develop a level of self-awareness that will allow us to actually put our own beliefs and fears aside and help

us to enter our patient's world. In addition to the countertransference hooks outlined earlier in this chapter, Pargament (2007) has identified unconscious or unchecked perceptions that clinicians can bring to spiritual care experiences and that can result in potential countertransference reactions. The following Countertransference Tool Box delineates some of these perceptions, along with suggested exercises that might assist clinicians and organizations in recognizing and addressing these perceptions in themselves. Exploratory, open-ended questions that clinicians find useful in these moments of spiritual opportunity are listed in Table 3.1.

COUNTERTRANSFERENCE TOOL BOX:

Countertransference Hooks in Spiritual Attunement

Adapted from Pargament (2007)

Spiritual bias: the tendency to hold stereotyped views of religion and spirituality

Exercise or Practice:

1. Write a brief synopsis of the spiritual and religious beliefs of your family of origin. Next, journal about how your beliefs and perspectives have changed to their current states. To what do you attribute those changes?
2. In a group consult or interdisciplinary team meeting, share cases that exemplify dilemmas concerning religious practices or beliefs that address suffering, dying, belief, or nonbelief in the afterlife.

Spiritual myopia: difficulty seeing the spiritual dimensions of problems and solutions; the tendency to see spirituality from a global, undifferentiated perspective

Exercise or Practice:

Practice charting your subjective assessment of the patient's current spiritual and emotional concerns each time you document physical issues.

Spiritual timidity: the fear of addressing spirituality based on the belief that spirituality should be separated from treatment

Exercise or Practice:

Use the documentation you have created in this exercise to formulate potential hypotheses regarding dilemmas the patient might be experiencing. Discuss these in team meetings or in supervision. Confirm with the patient and/or family.

Spiritual enthusiasm: the tendency to see spirituality as the root of all problems or the source of all solutions

Exercise or Practice:

List all the statements, pronouncements, or advice you felt were particularly offensive or insensitive after a loss that you yourself experienced; for example "God never gives us more than we can handle." What feelings were evoked in you in response?

Spiritual cockiness: overestimation of the practitioner's own level of competence in spiritually integrated care based on his or her spirituality

Exercise or Practice:

Cockiness is bred when end-of-life workers act as if they *must* say something. Skilled end-of-life care often demands silent caring. Practice silence or use a simple touch when responding to a patient's expression of grief or other strong emotion. Note any internal reactions you have.

Intolerance of ambiguity: the desire for definitive, simple solutions to complex problems. Caregivers want to say or do something that will lighten the load or lift the burden or to practice an end-of-life principle to aid someone in "dying well." An ambiguous loss is one that is unclear, often with no desired resolution, or it could be a loss with conflicting feelings and thoughts. The intersection of ambiguity and caring can lead even the most competent and sophisticated of clinicians down the street to countertransference.

Exercise or Practice:

Rather than offer solutions, engage in a "Ministry of Presence." This entails being attuned with patients and families through eye contact and mirroring of expressions. Rather than interrupt the patient or family member, use facilitative responses like nodding or saying, "Uh-huh."

Build empathy through use of reflection: "So I am hearing that . . ." "sounds like . . ." "that would have made me . . ." Build a sense of solidarity that decreases the patient's sense of aloneness through "I wish" statements: "I wish things were different. . . . I wish I had some better news. . . . I wish we had a medicine to turn things around, but I will work with you to . . ."

Conclusion

At times of critical illness and near the end of life, we strive to provide spiritual care that enables patients and families to voice their fears, questions, and personal spiritual struggles. We work to encourage them to declare what is true for them, and we pursue

Table 3.1 Exploratory Questions

To recognize and acknowledge the spiritual dimension
Is there anything you'd like me to know about your spiritual life in the midst of this? *I know that spirituality can be important to our health. What does spirituality mean to you?* *Tell me more.* *What meaning does that hold for you?* *What matters the most to you in life?* *What spiritual practices do you engage in?* *Has your illness changed your view of life?*
To assess coping
This is hard. How are you holding up? *How have you been managing this? Does your family cope with it similarly or differently?* *What helps you cope? What are your sources of strength and hope?* *Where do you turn in times of stress?* *Who truly understands your situation?* *For what are you deeply grateful?* *When have you felt most deeply and fully alive?* *What causes you despair or suffering?* *What are you afraid of right now?* *You seem to be managing well, but this has to be difficult. What's the hardest part?* *What is the most challenging or of greatest concern?* *Who or what do you worry about the most?*

Adapted from Bowman, 1994; Nichols & Hunt, 2011; Pargament, 2007; Schaffer & Norlander, 2009.

opportunities to accompany them on the quest for understanding the greater and deeper questions of our existence.

As professionals engaged in palliative and end-of-life care, it is particularly important that we understand the experiences, values, and beliefs that lay the foundation for our own tentative answers to these questions. If we do not, we may find ourselves caught up in the desire to deliver "the answer," the fix, the insight, the understanding, or the "feel-good" experience. We may even assume that it is our *role* to do so.

Awareness is the key to separating our own needs, beliefs, and projections from those of our patients. We must constantly question our motivations, understandings, and temptations to "do good." Only by being clear about which needs belong to the patient and which to us can we provide care that allows patients and families to wrestle with their own relationships to the spirit on *their* terms, not ours. Only then can we truly *be* with our patients as they attempt to make meaning at these critical junctures of their lives.

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4 Client, Clinician, and Supervisor

The Dance of Parallel Process

Tessa ten Tusscher

Clinical supervision provides a wonderful venue to learn from the transference and countertransference issues between the client and helping professional. Being one step removed from the immediate clinical situation, the clinician and supervisor can take time to reflect on what is happening in the client's care, how the therapeutic relationship evokes feelings in the receiver of care (transference) and provider of care (countertransference), and how to understand the dynamic between the recipient of care and the caregiver.

Psychodynamic treatment is largely based on bringing to consciousness the patient's unconscious material that he or she transfers onto the therapist. The therapeutic relationship becomes the vehicle through which these thoughts and feelings become conscious and thus allow for a working through of previously undigested material. The clinician and patient enter into a highly complex and nuanced dance, wherein both parties use their feelings, associations, and thoughts about each other to facilitate change. On a broader scale, it can be argued that all professional caregiving involves a similarly nuanced dance where the receiver of care and the provider of care have both a conscious relationship and an unconscious one. Supervision serves, at least in part, to help the clinician focus on *his or her* responses to the client's material, to bring these responses into consciousness, and to be able to use the responses to help the client.

Clinical supervision mirrors many aspects of the therapeutic relationship. Both are helping processes, both involve the use of the self as the agent of change, both are intimate relationships, and the task of both is to provide a container to reflect on thoughts and feelings. The supervisory relationship, then, is replete with transference and countertransference reactions between the clinician and the supervisor.

However, there is another layer of complexity as the material discussed in supervision is largely that of the client. So, the supervisor, in addition to his or her countertransference responses to the clinician, has emotional responses to the client's material *and* to the clinician who brought it in. The clinician holds both positions—countertransference to the client's material and transference reactions to the supervisor.

These sets of relationships, and the emotions inherent to them, set the stage for supervision and provide some clues to where supervision can thrive and where it can flounder.

Analysis of parallel process is a useful way to tease out these complex sets of responses. Initially perceived by Harold Searles (1955), "*Parallel process is the means through which the relationship between the patient and the therapist is reflected in the relationship between the therapist and the supervisor*" (p. 135). This psychodynamic concept, while simple on the surface, provides a vehicle for discussing the unconscious reactions between the clinician and supervisor. It also offers the supervisor some clues about how

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to understand and interpret the supervisory relationship to facilitate the best outcome for both clinician and client.

Parallel process originally was conceived as an “upward bound phenomenon” with its energy emerging from the therapist’s emotional responses to the patient’s material. Searles (1955) argued that the emotions felt by the supervisor are a reflection of those felt by the therapist toward his or her patient. Thus, the job of the supervisor is to use his or her responses to the clinician as information about the client. Joanna serves to illustrate.

Joanna

I supervised Joanna, who was typically a very empathic and insightful student. During the course of our work, she changed from being very curious about Derek, her older male client, to discussing him in a superficial and disinterested manner. I found that my thinking also became concrete and decided that Joanna’s disinterest resulted from a general malaise that stemmed from it being winter and from the fact that Joanna had been struggling with an ongoing, low-grade virus.

> For three weeks, Joanna presented the material about Derek’s upcoming surgery for a brain mass with minimal affect, focusing on the details of the surgery and on case management issues that would arise as a result of the hospitalization. I found myself becoming very worried about Joanna’s health, noticing that she appeared tired and worn-out. On my insistence, we talked about the need for Joanna to take care of herself and speculated that she might benefit from a week off from work and a consult with her physician. Joanna appeared to agree with my concern but did not make any moves to cancel clients or to schedule a break. Finally, I realized that we were engaged in a parallel process: Joanna was thinking about case management for Derek, while I was trying to manage Joanna by sending her to her doctor and recommending a week off from training. We had not been discussing Derek’s fear of the upcoming surgery or the fact that his sister had previously been hospitalized for a seemingly simple procedure and never recovered. We were identifying with Derek’s unspoken fear, colluding with his defense against knowing just how frightened he was, and we were not helping him or Joanna process these fears.
>
> Supervision then focused on this absence and on Joanna’s anxiety about Derek’s future. Joanna disclosed that she had witnessed her grandmother’s decline after a hospitalization and that she had been dreaming of her grandmother during the past few weeks but had not connected the dreams to her patient. Once Joanna made the connection, she was free to find ways to help Derek talk about the terror he was feeling and his conviction that he would never recover his mobility.

Interestingly, Joanna began to look stronger and less tired to me, and the supervision paralleled the therapy by resuming its more psychological focus. This example shows us how the client’s material (the surgery) as manifested in the client-clinician relationship (Joanna and Derek’s unspoken worry about the surgery) became replicated in the supervision (my worry about Joanna’s illness). Only after the replication became conscious could we more effectively help the client.

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Various schools of psychodynamic thought conceive of countertransference in divergent ways. On one end, traditional Freudian theory views countertransference as an unconscious reaction to the client's material that is grounded in the clinician's own history. The professional should protect the client from her countertransference by taking it to her own therapy to work through. From this perspective, the clinician reviews her emotional responses to the client's material, looks for where she has a strong emotional reaction to something that the client is talking about, and uses her own therapy to understand what is being evoked in her. For example, when I noticed that Joanna was feeling disengaged from Derek, she worked in therapy to make the connection to her fear and grief over her grandmother's decline and then worked on these concerns, so she could be open to hearing about Derek's fears.

Contemporary relational theorists view countertransference as clinicians' emotional responses to the clients' material that provide valuable clues to the clients' unconscious worlds. From this perspective, Joanna views her disengagement as a possible clue that Derek is disengaging from his fears of the surgery. The fear is being kept unconscious by being projected onto Joanna.

Similarly, there are divergent ideas about the utility of parallel process in supervision. Some view it as an occasional occurrence that, once identified in supervision, is best handled in the clinician's own therapy. This view sees the clinician's task as being the "clean slate" onto which the client projects his or her material. The therapist must do everything he or she can to keep the slate clean from his or her own material and, when experiencing countertransference (as identified through parallel process reactions in supervision), should work through these feelings and not impose his or her material onto the client. Here, my role as Joanna's supervisor is to point to her disengagement, listen for her connection to her grandmother, and encourage her to work this out in her own therapy so that she can be emotionally available to her client.

Relational theory views parallel process as an inherent part of the therapy dynamic that should form a core part of supervision, allowing the clinician and supervisor to learn about the dance between the client and the therapist through the supervisory relationship. This two-person model (Joanna and Derek as co-participants in their therapeutic relationship) views parallel process as more of a two-dyad/three-person paradigm among client, clinician/supervisee and supervisor. (Derek and Joanna and I all participate in the relationship—Joanna and Derek in therapy and Joanna and I in supervision.) From this perspective, any or all of the three people can create or enact a parallel process. It is not necessarily an "upward bound model" that starts with the patient's material but can emanate from any of the players in the two dyads. This renders the client vulnerable to the unconscious material of the clinician and/or the supervisor.

Parallel Process and the Fear of Death

The relational model of parallel process is particularly helpful when thinking about the types of issues that develop when working with emotionally charged end-of-life and palliative care issues. Clinicians who have a calling to work in this arena are likely to have had experiences of death or illness that steered them into wanting to work with clients at this stage in their lives. When these motivations, conflicts, and beliefs remain unconscious, they can get enacted, and the client can become the unwilling recipient of the unresolved issues of the helping professional and/or his or her supervisor. It is crucial

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that clinicians take responsibility for uncovering their unconscious material and that they remain eternally curious about their own motivations, drives, anxieties, and stumbling blocks. Fear of death can lead to dramatic enactments—both in the therapeutic relationship and in the supervisory one.

Mary

Mary was working with Ida, an 86-year-old eastern European woman who was struggling with depression in large part in response to having Parkinson's disease. Mary saw Ida every week in Ida's home in a comfortable, subsidized apartment in San Francisco, California. Ida was not married and had lived a slightly bohemian lifestyle. She had not focused on making money, preferring to spend her energy on fighting for social justice. Ida was an intellectual woman who loved to read and discuss literature, politics, and psychology. Mary and Ida formed a close bond, and Mary developed a positive, somewhat idealizing, countertransference toward Ida. They shared similar social values, and both were passionate about political activism. Mary described looking forward to their sessions and confessed that she felt like she was "visiting a favorite aunt." In the course of their work, Ida became less depressed, expressed gratitude for Mary's interest in her life, and developed a more optimistic attitude toward her health. Both Mary and Ida desperately wanted Ida to remain healthy enough to live at home, and both quietly shared a dread that she might become too frail to do so. In supervision, Mary and I touched upon this fear but did not pursue it in any depth. We all remained blind to Ida's failing health and clung to the fantasy that Ida's Parkinson's was stable. We also ignored Ida's meager financial situation. One day, Mary visited Ida only to discover that she was terribly ill, running a fever, delirious, incontinent, and unable to move her limbs. Ida quickly was taken to the hospital and eventually stabilized, but she did not return to her usual functioning. Ida was discharged to a nursing home for long-term care.

In supervision, Mary was bereft. She cried and talked of wanting to take Ida home with her. Mary became very critical of the staff at the nursing home. In supervision, she railed against the perceived poor and inequitable medical care, threatened to contact the ombudsman, and developed an adversarial relationship with the attending physician. Sessions with Ida were spent complaining about the facility. Ida and Mary were joined in helpless rage at Ida's situation. Process notes revealed that Mary's rage was not helping Ida; rather, it was *fueling* her discomfort and depression. Ida began to withdraw into herself and became more and more passive. In supervision, when I commented that some of Mary's rage might be toward Ida for being ill and frail, rather than from the incompetence of the nursing staff, Mary bristled and lectured me on the plight of low-income elders in San Francisco. I found myself becoming irritated with Mary and her political barrage.

After a period of several weeks, Mary's attitude changed. She started to talk about Ida in a more remote and distanced manner, focusing on Ida's cognitive decline and speculating on whether Ida could still benefit from therapy. Mary recommended that we order some cognitive testing. She seemed to be

asking for permission to stop treating Ida and to extricate herself from the pain of the weekly sessions. Uncharacteristically, she also canceled two supervision appointments, and our time together began to feel adversarial. I felt that I was not adequately meeting Mary's needs and felt stymied about how to help her tolerate her sense of helplessness. When Ida came up in supervision, my (unspoken) wish was that she would disappear. I was feeling helpless toward Mary, and Mary was feeling helpless toward Ida. I began to think that Mary and Ida had hit an impasse and that, perhaps, treatment should stop. I was aware of feeling that my supervision was feeling blocked but could not put my finger on what was going wrong. Mary and I started to collude in abandoning Ida and justified it in terms of our inability to help her.

Finally, Mary complained to me that our supervision was feeling unsupportive and that she experienced me as distant and cold. She wondered if I wanted to get rid of her as a supervisee. We began to talk about our supervision, and I told her about my sense of helplessness in getting Mary to address her angry feelings toward Ida and my annoyance at her rigid insistence that the problem was political rather than psychological. Through this discussion, we were able to piece together the feelings of rage, helplessness, and grief that Mary felt about Ida's illness and about how terrified and alone she had felt when she discovered Ida in her apartment. Mary's grief felt intolerable. She was angry with Ida for making her feel so sad, and she was angry with me for referring Ida to her in the first place. By allowing room for this grief in supervision, we opened discussion of the sense of helplessness that Mary had been holding for Ida and the feelings of helplessness that I had been feeling toward Mary. Becoming conscious of these processes allowed Mary to return to her role as Ida's therapist rather than being stuck in the role of a niece who could not save her favorite aunt. It also allowed me to return to being a more useful supervisor who no longer wished that Mary or Ida would disappear. In this enactment, we were perilously close to deserting Ida and to labeling her as "unfixable" or "no longer appropriate for treatment" because of our feelings of helplessness about Ida's decline in health and because of our introjections of Ida's helplessness, hopelessness, and rage.

Parallel Process and Dementia

Clients who have dementia present particular challenges to clinicians. While the client struggles with increasing memory and other cognitive losses, the clinician is challenged to form a therapeutic relationship that cannot rely on memory and is not cognitively mediated. A clinician finds it very difficult to remain engaged with a person who cannot remember his or her name from week to week or who repeats the same story with no knowledge of the repetition. They frequently distance themselves from the clients and can act out their worries through treating the clients differently (often less respectfully) than those clients who are cognitively intact.

When supervising clinicians who work with people with dementia, I am frequently struck by the difficulty that they have in thinking deeply about their clients and how difficult it can be for them to remain interested in their clients' internal experiences. Clinicians, who are typically curious about their cognitively intact clients and who come

to supervision with ideas about transference/countertransference and rich case formulations, often have marked difficulty thinking conceptually about their clients with dementia. I have noticed a shift in energy that occurs when discussion moves from a cognitively intact client to one with dementia. Often a feeling of deadness enters the room as the client's material is presented in a superficial and concrete manner. The clinician might recount a session using phrases like "then she went to her usual repetition about . . ." or, "she was talking about her painful shoulder but then reverted to the usual mantra, 'Worse things happen at sea; let bygones be bygones.'" Or, the clinician may complain that "nothing much happened in the session—it was the usual catalog of phrases that she always uses." These are the same clinicians who will excitedly bring in a cognitively intact patient's dream, treasuring it as a symbolic view into the client's unconscious! Somehow, the fantasies of the demented person are less enticing than those of the non-demented one. The difficulty that clinicians have in being interested in the meaning beneath the "worse things happen at sea" metaphor mirrors the clients' difficulties extrapolating their thoughts.

Countertransference reactions often include intellectual numbing, distancing, difficulty concentrating, a sense of dread, and a strong desire to get away from the patient. In supervision, this can manifest in rationalizing why the client cannot be helped, resistance to exploring the client's unconscious material, and discomfort with embracing a client-centered approach to treatment. Clinicians often display a remarkable lack of empathy, finding it more tolerable to be sympathetic and to pity the client than to imagine life from the demented client's perspective.

These difficulties are understandable. As professional caregivers, we rely on our intellect to be able to do our work. We are constantly thinking, wondering, planning thoughtful interventions, and challenging ourselves to think about cognitively difficult things. We are absolutely dependent on our minds to do our work. Coming face-to-face with dementia pushes not only our personal buttons but also the limits of our professional identities.

These countertransference reactions can be paralleled in supervision if the supervisor colludes with the clinician's anxiety and allows the discussion to remain deadened and distant. Supervisors who can address their own horror at losing their mental competence and who can talk about the terror they experience—about losing a sense of self, losing the ability to hold onto memories and experience, or regressing to a state of dependence—are more able to help their supervisees stay present for their demented patients. This is not an easy task. Many of us become overwhelmed when thinking about the losses inherent to dementia. We easily collapse into a non-curious and nonanalytic space. This collapse may well be a projective identification of the client's collapse and of his or her loss of analytic skills.

To experience this difficulty, try to write detailed process notes from an hour spent with somebody with moderate-stage Alzheimer's disease. My experience is that this is an extremely hard task in part because the session may not be very verbal but relies on nonverbal or very simple verbal communications. It is difficult to capture the nuances of the session as both client and clinician struggle to connect separate and discrete thoughts and the client continuously loses the thread of the conversation. Small changes in eye contact, the client's posture, or a momentary grimace are also hard to capture. Even more difficult are the clinician's and client's emotional responses throughout the hour.

Professionals working with clients with dementia become highly sensitive to their clients' nonverbal communications, the moments that feel alive and engaged and those that feel numbed or deadened, and subtle shifts in affect that indicate the difference between feeling safe and attended to rather than frightened and done to.

Some people, after trying this exercise, report that they feel "spacey" and that they cannot remember the connections between one thread and another. They report that they "think" they felt something but were not sure or that the experience is like trying to piece together a complicated dream, where they have an overall sense of the dream and its meaning but experience great difficulty explaining how the discrete parts fit together. My sense is that this describes the experiences for many of our clients with dementia and that the attentive clinician introjects these dreamlike feelings. By struggling with the client to understand and by tolerating not knowing, the clinician creates space for the client to experience his or her life in a different way. However, when the clinician shuts herself off from the struggle and can no longer tolerate not understanding, she adds another layer to the dementia process and leaves the client alone with the experience.

As the supervisor, I often have felt a similar inability to think about the session, catching myself drifting off or having to exert an inordinate amount of effort to stay focused and think about the patient. The sensation is unpleasant and, while it gives us great and powerful information about the client's experience, is one that I want to get away from. One can see how the clinician and supervisor could collude to protect themselves from knowing about their demented client's internal worlds by resorting to overly concrete discussions or by deciding that they should "not waste" supervision time on such a "low-functioning" client.

Jocelyn

> Jocelyn was a student whom I worked with who grappled with this problem for two years. A remarkably able clinician, she pushed herself to stay focused and interested in Anna, her client with dementia. In large part she was also able to keep Anna's material alive in supervision, and we did not allow ourselves to avoid transference/countertransference and parallel process issues as they arose. Toward the end of the two-year treatment, as Jocelyn was completing her training, we worked hard on the termination process. Each week for the last three months, Jocelyn would bring up termination. On each occasion, Anna appeared surprised by the reminder, experiencing it as a new event. However, Anna's associations to the news were not static and included stories about her (deceased) husband, accounts of other losses, associations that were indicative of jealousy and rage, and a couple of instances when Anna confused herself with Jocelyn and talked about moving on with her life and starting a career. Equally, her affect changed from week to week. She displayed anger, sadness, indifference, longing, and some acceptance. In short, Anna's associations and emotions were as rich and as complex as any other client's, even though she did not remember them from one week to the next.
>
> In supervision, Jocelyn and I became fascinated by Anna, and she suddenly became very alive for us. I think that we were trying to hold onto Anna's experiences, in part, because Jocelyn was having a difficult time leaving Anna and,

in part, because we could not bear to think that the relationship would end with no shared memory of the experience between Anna and Jocelyn.

We were rewarded. On the last session, when Jocelyn went into Anna's room, Anna started the session saying, "This is our last time together. I don't like it." And she started to cry.

Parallel Process and Intergenerational Therapy

Younger, inexperienced clinicians often talk of the feelings that are evoked when working with a client who is the same age as their parent or grandparent. Younger clinicians' expectations of what their older clients "should" be feeling are largely based on fantasy as the clinician has not reached the developmental milestone of his or her older adult client and has no experiential basis upon which to base expectations. Many of these fantasies are founded on the clinicians' relationships with their own parents and grandparents. Younger professionals frequently hold the expectation that all older adults are focused on death and dying (likely a manifestation of their own worries about death and/or the loss of their parent). Less frequently do they think that issues of sexuality, relationships, and childhood trauma will be topics of concern. This mismatch of beliefs can result in the clinician not being able to hear what is important to the client and in the clinician resisting bringing these taboo topics to supervision.

I remember treating an older religious man (somewhere in his mid-80s) as a beginning therapist while being supervised by a retired male psychoanalyst. The patient was very concerned about his sexual functioning, reporting that he had erectile dysfunction and telling me in detail of the various treatments that he had undertaken to improve his functioning. He also felt guilty that he had a strong desire for sex. His material embarrassed me. I thought of this man as being the same age as my grandfather and felt that his discussions with me were inappropriate. I was also angry with him for making me feel uncomfortable and somewhat prudish. My countertransference was one of a granddaughter being forced to listen to the sexual urges of her grandfather. In the treatment, I continuously reframed his comments into a wish for a close, loving relationship and would not hear the libidinous content. In some ways, I verbally castrated him by transforming his wish for sex into a neutered nonsexual wish for love.

Out of embarrassment, I avoided bringing this client into supervision for several weeks, and when I did, I conveyed my discomfort by pathologizing the patient, describing him as being obsessively concerned about his penis as a defense against his rage at aging. I hoped that my supervisor would agree with me and that somehow we could stop the patient from talking about his penis. I wanted my supervisor to take on the role of a parent and protect me from this inappropriate sex talk from my grandfather. In both the clinical and supervisory relationships, I cast myself as the child and lost my role as the adult therapist.

I was surprised and initially angry that my supervisor did not collude with this fantasy but pushed me into confronting my own prejudices about sexuality and older adults and my unconscious belief that there was something pathological with older adults wanting vital and sexual experiences. I came to see that my discomfort also was triggered from the client's erotic transference to me, which I experienced as inappropriate and akin to that of a pedophile, forgetting that I was in my mid-30s at the time.

In this example, the agent of the parallel process was the clinician in her countertransference to the patient and transference to the supervisor. It would have been very easy to continue to pathologize the patient as a defense against my discomfort and thereby make him feel even guiltier for his sexual feelings.

Parallel Process in Organizations

Much of the literature on parallel process has been confined to the world of psychodynamic psychotherapy and, as such, can seem like a rarefied and esoteric concept. But, as Frawley-O'Dea and Sarnat (2000) point out, parallel processes are basic components of everyday relational life. For example, the "kick the dog" phenomenon is the mechanism where insults in one humiliating or enraging relationship are transferred to another.

I worked in an outpatient psychiatric clinic for a number of years. Typical of many such clinics, our patients were very chaotic and disturbed, and our budget was very small. Our management was grappling constantly with the challenge of providing services to more and more people with less and less money. Each year, the budget would be cut, and city hall would insist that the agency take on more patients. It felt like living in a classic double bind. The agency's contract rendered them impotent to negotiate a better arrangement. The leadership of the clinic felt betrayed by local politicians and often was criticized for overspending or for not treating enough patients. Unfortunately, a key leader in the clinic managed her sense of impotence and rage by insisting on ever more elaborate documentation to "prove medical necessity." At one point, the paperwork requirements were so complex that she produced a 140-page manual on how to chart and instituted monthly mandatory staff trainings.

Line staff were increasingly disgruntled and felt that their clinical work was not valued and that the clinic had become a bureaucratic nightmare. At one point, a well-respected clinician was disciplined for inadequate documentation, almost resulting in a strike. Morale was very low, and despite the trainings, the paperwork was never satisfactory. Here, the impotence felt by the leader, as she struggled to provide services and to gain respect from city hall, was transferred to her staff through the creation of impossibly complex and ever-growing charting requirements. Interestingly, the line staff felt the same resentment toward the leader that she felt toward city hall. It was also interesting, if sad, that the result was that fewer patients were seen and the clinic stumbled into a quagmire.

However, not all parallel processes are negative. Many of us have had the experience of culture change that can accompany a change in staff or management. I had the opportunity to observe this while consulting with a skilled nursing facility that specialized in Alzheimer's care. This facility faced many common problems. The staff were underpaid and, often, under-trained. A lot of the care was rather impersonal, with staff displaying little knowledge about their patients' lives, wishes, or interests. Similarly, management was somewhat distant, providing little beyond the minimum staff trainings and no encouragement to develop social or mentoring relationships. A new director of nursing was appointed who was resourceful and passionate about her work. She instituted several changes including weekly clinical conferences for all staff, a staff recognition award, and monthly social events. In addition, she took it upon herself to learn about her staff's families and personal interests. These changes in supervision led to a significant shift in

patient care. Certified nursing assistants (CNAs) started to show more interest in their patients and the level of personalized care improved. The nursing director's interest in the lives of her staff and encouragement of their development was paralleled in the staff's increased interest in their patients.

Conclusion

This chapter has discussed the role of parallel process in the supervision of clinicians working with clients at the later stages of life. Parallel process is a powerful three-person dance that, when made conscious, can offer a host of insights into the client's treatment and, when it remains unconscious, can make the treatment run amok. Analysis of parallel process is a variant of the analysis of transference and countertransference, focusing on the supervisory relationship rather than the therapeutic one.

Loss Self-Awareness Test

A Values Clarification Tool

Renee S. Katz and Bonnie Genevay

Type of Loss	*Least* (Anxious, Sad, Helpless)				*Most*
1. *Watching my body waste away*	*1*	*2*	*3*	*4*	*5*
2. *Losing bladder and bowel control*	*1*	*2*	*3*	*4*	*5*
3. *Losing my ability to speak*	*1*	*2*	*3*	*4*	*5*
4. *Losing the ability to enjoy my favorite activity (e.g., be in nature, listen to classical music, etc.)*	*1*	*2*	*3*	*4*	*5*
5. *Losing my ability to function independently*	*1*	*2*	*3*	*4*	*5*
6. *"Losing my mind" (e.g., severe memory loss)*	*1*	*2*	*3*	*4*	*5*
7. *Losing those features that make me feel attractive*	*1*	*2*	*3*	*4*	*5*
8. *Losing the ability to leave my bed*	*1*	*2*	*3*	*4*	*5*
9. *Losing the ability to care for or nurture my loved ones (e.g., children, parents, partner, pets, etc.)*	*1*	*2*	*3*	*4*	*5*
10. *Unremitting pain or discomfort that makes it impossible to focus on anything else*	*1*	*2*	*3*	*4*	*5*
11. *Losing my ability to make a contribution to the world*	*1*	*2*	*3*	*4*	*5*
12. *Losing my ability to enjoy food and eating*	*1*	*2*	*3*	*4*	*5*
13. *Losing sexual function*	*1*	*2*	*3*	*4*	*5*
14. *Losing the ability to work in my chosen profession or field*	*1*	*2*	*3*	*4*	*5*
15. *Losing my raison d'être*	*1*	*2*	*3*	*4*	*5*
16. *Dying alone*	*1*	*2*	*3*	*4*	*5*

Circle the number that best represents your response to each loss from *Least* (anxious, sad, helpless) to *Most*.

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Treatment of people near the end of their lives evokes strong feelings in the clinician and supervisor. Fear of death, grief, confrontation with our own mortality, witnessing a person "disappear" into ill health or fade away into dementia, and feeling our impotence to stave off death pull us toward identifying with the client and becoming confused between our material and theirs.

Analysis of the supervisory relationship can reveal the emotional reactions of all the players—client, clinician, and supervisor. To be effective, it requires both the clinician and supervisor to commit to rigorous self-reflection. This, in and of itself, supports the client's therapeutic work, moving it from a dyadic to a triadic relationship. Bette Midler once asked, "Aren't two heads better than one?" Now, we suggest that three are better than two.

"Making the unconscious conscious" can be a valuable therapeutic tool. However, we all resist this process and, despite our best intentions, fight to keep our deepest anxieties buried. The supervisory relationship allows us to revisit the unspoken aspects of the therapeutic relationship and to explore its unconscious enactments.

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5 Compassionate Decision Making Near the End of Life

Sharmon Figenshaw

Introduction

Advances in medical technology have created a situation in which the lines between rescue and life-saving measures and the prolongation of suffering before death are frequently blurred (Rogne & McCune, 2011). Providers of medical care are trained to use life-saving measures to their fullest extent, but too often that training does not include a moral or ethical examination of right use. Physicians and others frequently come away from their training with an unexamined compulsion to use whatever means they have available to save lives.

Notable authors (Gawande, 2014; Morhaim, 2012) are reaching out to us at the societal level to consciously explore our values; to imagine scenarios of acute, chronic, and serious illness; and to highlight the necessity of conveying our wishes through conversation and documentation. Protecting patients from unwanted treatments by allowing people to have a say in medical scenarios is the legal framework of advance directives such as a health-care directive or durable power of attorney for health care. These documents provide individuals with the opportunity to name the parameters of care they would, or would not, want to receive in life-threatening medical situations. These directives can be filled out without medical guidance and are often done in conjunction with other legal paperwork such as wills and estate planning.

Despite the growing encouragement to complete advance directives, the reality remains that less than one-third of Americans has completed these documents (Morhaim, 2012; Morhaim & Pollack, 2013; American Public Health Association, 2012). Thus, many people get sick and seek help in our hospitals and other medical settings without any prior thought, or at least no documentation of their thoughts, regarding the care they want.

When people become sick, the process of eliciting advance directives is more likely to involve guidance from the medical team as the consequences of those decisions are more imminent. As our ability to extend life increases, it is imperative that medical practitioners know how to relate the medical realities of patients' conditions to patients in ways that allow patients and families to understand the implications, so they can choose care that is consistent with their values and goals. This is best accomplished when patients and practitioners each share their perspectives and expertise: the practitioner as the expert on how the medical situation will affect the patient's life, the patient as the expert on his or her own life and what constitutes a meaningful life for him or her. Both of these

perspectives are needed to develop a medical plan that accounts for a possible future in which life-extending measures might be considered.

Without an investigation of each professional's personal values related to decisions about end-of-life care, the default position, "do everything," all too frequently dictates the flow of medical care. Who will think to ask "Is this what you want?" *before* the patient is perched precariously at the threshold of potentially invasive life-extending interventions?

The situations in this chapter illuminate not only the need for eliciting the patient's definition of a meaningful life but also how as clinicians we so strongly, and often unbeknownst to us, influence these discussions and decisions. What words do we use or fail to use? What values do we subtly, or not so subtly, communicate as we help families envision and prepare for unknown events in an uncertain future?

Medical Training and Practice: Setting the Foundation for Countertransference

Countertransference in health-care providers can arise from any number of professional and personal factors. Medical personnel may have unexamined feelings about their desires to be the heroes of a story as they use every means to extend and save lives. They may have stories in their own lives with loved ones whom they wanted to help but couldn't, or they may have limited skills or fears about being in the presence of strong emotions that can arise when their patients face serious illness and death. They may have strong values from their training or personal lives that make it hard for them not to use every means possible to extend life. In addition, physicians are increasingly experiencing burnout (Schanafelt et al., 2012), which certainly can affect how much energy the practitioner is able to invest in the relationship with a patient. Studies indicate that clinicians who experience multiple losses through patient deaths gradually withdraw from close support and relationships with future patients (Zamanzadeh et al., 2014).

One of the deepest, least-examined sources of countertransference for physicians and health-care providers stems from a deep assumption, an agreement if you will, throughout medical training that death is the enemy. Generally, medical clinicians learn to value only one measure of success: life. That is, "I must prescribe or employ the correct treatment, or my patient could die." These earnest health-care professionals know that there are gradations, nuances, and personal interpretations of quality of life, but they carry inside the message of a powerful training. Hundreds of lectures, seminars, rounds, and textbooks address disease. And they do so predictably: etiology, diagnosis, and treatment—for cure, whenever possible.

Yet, when people are seriously ill, longer life is not their main hope. In fact, 'living as long as possible' is number 9 out of 10 things people cite as being important to them at the end of life. Not being a burden, being free of pain, being home with loved ones, being able to say good-bye are all of higher importance to patients facing the end of life than the length of time they have left to live (Steinhauser et al., 2000).

Rarely, however, does medical training address these priorities or go on to describe the lived experience of those who are not or cannot be cured. By avoiding teaching clinicians to address the reality that many diseases are not cured, the entire institution of

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medicine perpetuates a powerful message: "giving up" (which is often the way in which comfort care is interpreted) is *not* an option. If treatments do not "solve" the problem, the result is simply unacceptable or, more conveniently, someone else's problem. If we are not in touch with this very deeply ingrained aspect of our training, it easily can creep into our interactions with patients and families.

How we culturally and medically act out this assumption, that survival is the only good option, is one of the greatest countertransference hooks influencing medical practitioners today. Throughout the health-care system, from the emergency department to the critical care unit to the primary care office, all are vulnerable to strong, unexamined feelings and assumptions. (See Countertransference Tool Box.)

Emergency Department: Countertransference With Intensity

Certain areas of the hospital are crucibles of intensity. Emergency departments (EDs) and intensive care units (ICUs) are fraught with medical crises involving life-and-death situations. It is in these arenas of medical care that conversations about advance directives are most needed. Otherwise, we risk providing care that does not respect the patient's wishes and, worse, may introduce harm and burden to the patient and family.

Countertransference is hard to escape for ED physicians. The threat of people dying on their watch is an ever-present reality. Not only does their training emphasize saving and extending lives, but "keep death away" is the unconscious press. As ED staff meet each new patient, they are already thinking through the list of diagnoses and possible outcomes. Medical personnel must first stabilize the patient, then decide if the patient will require hospitalization, and if yes, determine if the patient will need advanced life support, consultations, or other urgent interventions.

With rapid triage and medical skills in high gear, how do busy physicians stop long enough to have a conversation with, or to even think about, what their patients would desire for themselves if their functional capacities were to be threatened? What activities would their patients need to return to to consider all this medical effort "worth it" to them?

During emergencies, professionals with a bias toward maximum medical interventions meet patients and families in crisis—when projections and vulnerabilities are heightened. As these forces dovetail in the ED, a potent crucible of countertransference is created. For instance, physicians who work in EDs can feel frustrated when people come for help but then don't accept the treatments they offer. "Why do people come here if they don't want us to treat them or save their lives? Don't they know that's what we *do*?" These assumptions, and the ensuing frustration, are at the heart of the countertransference dilemma in the ED and the ICU. What underlies this lament is this: "I am trained to save lives. If people don't want everything I am trained to do, if I can't use that training, I feel helpless. I simply don't know what to do then." Medical practitioners are not a group of people that tolerates feeling helpless very well.

In fact, people come to hospitals, to clinics, and to doctors because their own knowledge and resources are limited in the face of illness. They or their loved ones are suffering, and they are unprepared or underprepared to manage the pain and suffering (no less their own emotional pain). Patients and their families often hope the disease process or medical problem can be "fixed" with medical treatments aimed at cure. But many patients present with unfixable problems; they don't know what to do, but they do know

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they cannot bear the suffering. Both patients and families see our medical institutions as places of comfort and help when they feel helpless and overwhelmed.

Clinicians who work in the high-intensity areas of the hospital are trained to act quickly and automatically to provide life-saving medical interventions. They know they need to ask the important question, "What would this patient want?" But, too often, the question "spills" like this: "Would you want us to do everything possible to save your life?" Most people heartily reply, "Of course!" That is, "of course" until they learn that life-saving measures may lead to a life on machines, in a skilled nursing facility, or without the capacity to regain their prior abilities. Then the answer for many people, especially elders living with chronic illness, changes to "No" or "Not if I can't go home, or drive my car, or play with my grandkids, or function independently."

Patients and families are asked to make these decisions when they are in crisis in an overwhelming, busy medical environment, which for many is as different a place as a foreign country. They understand only a fraction of what is being said but don't want to "look stupid." Mostly, patients and families trust that the medical team, the doctor, knows the "right" thing to do to help their loved ones. When patients and families say that they "want everything done," often this simply means "do everything you can to help my loved one feel better." They assume that any care we offer *will* help and that it will make the suffering go away.

If we are not aware of our countertransference, we unconsciously may presume to know what patients and families understand and what they want based on our own projections and assumptions. We can, for instance, find ourselves using language that is vastly different from the ways families understand it. In a study of physician-patient communication, results showed that even when physicians believe they are using common, easy-to-understand language, patients, and even nurses, still perceive the language used to be largely medical (Bourhis, Roth, & MacQueen, 1989; Hadlow & Pitts, 1991). Clinicians use terms like "Full Code" not realizing that many people do not know to what this refers. For patients and families, the word "full" sounds good, like something they should choose if they want the best care. If we are unaware of this phenomenon, we unconsciously may ask questions in a way that actually leads to the answer *we* are wanting, one that may allow us to *do* something (aka proceed with our best medical skills). In our haste to do good, we simply may not ask questions that help patients examine what is important to *them*, not what is important to us.

Hank and Elizabeth

> The palliative care team got a call from a physician in the ED to see Elizabeth, an 82-year-old woman who had been brought to the ED by her husband, Hank. "She has stage 4 colon cancer," the physician explained, "but he wants her to be Full Code. Maybe you could come talk to him." (I neglected to ask the physician exactly what words he used in the conversation with the man, partly my countertransference fear that I might offend him!)
>
> When I arrived, I found Hank at Elizabeth's side. Elizabeth, extremely thin and gaunt, was lying on a gurney, turned on her side—curled up as much as the narrow bed would allow. I asked Hank what he understood about Elizabeth's condition. "She has cancer and I can't get her to eat. She is getting so weak that I can hardly get her up."

> I asked what he was hoping for in bringing her to the hospital. “That you will help her! She needs more care than I can give her. I hope you can, you know, take care of her.” Sensing that Hank had brought Elizabeth for comfort care, not life-prolonging care, but given the fact that the ED physician had said that Hank wanted her to be Full Code, I felt I needed to be very clear about determining Elizabeth’s code status. (Notice how the pressure to get a medical determination of “code status” created a strong countertransference response in me!)
>
> “We will do our best to take care of her,” I said gently. “But we need to know what kind of care you’d like for Elizabeth. For example, if she gets so sick that you think she might die, would you want us to use breathing tubes and machines to help her breathe or to prolong her life, even try to bring her back if her heart stops? We call that Full Code.”
>
> “Hell no,” Hank protested. “I think she is dying! I can’t see what good it would do to make this go on longer! I don’t know what that is, Full Code. I just said yes to what the doctor offered because I wanted him to help her. Please! Give her everything you can, so she won’t suffer.”

In this example, I brought my own countertransference to my interactions with Hank and Elizabeth. I brought the personal conviction that people who are beyond cure should be offered comfort care, not simply life-prolonging care. During my conversation, I had to make sure I allowed space to hear what Hank’s version of caring for Elizabeth meant. I easily could have made the mistake of projecting *my* sense of what she needed if I had assumed, without checking it out, that Hank wanted only comfort care.

The Intensive Care Unit: Countertransference as a Team

Patients in the ICU inherently are experiencing life-threatening situations, often undergoing multiple procedures and life-saving or life-prolonging treatments. Families facing serious illness are thrown, often quite suddenly, into this world of medical jargon and procedures at a time when their loved ones are so sick that they cannot take part in their care, are often on machines that require full sedation, and are frequently experiencing some level of confusion. Suddenly, the patient is a collection of body systems and body parts, each with its own specialist. The myriad of specialists on the medical team express their individual opinions about medical goals and possibilities specific to their particular specialty areas, often without ever addressing how the patient is doing overall or whether the likely outcomes will match the patient’s and family’s goals.

Families are in shock, dazed and often confused by information that can seem contradictory and inconsistent. “The dialysis doctor said the labs are better today.” “The cardiologist said the medications are working.” “The nurses said Mom hasn’t made any progress.” With death the ever-present threat, physicians and other members of the medical team distance themselves from this reality by focusing on whatever body parts they specialize in treating, looking for any improvement to share with families who are hungry to hear good news, anything that gives them hope for their loved one’s recovery. There is a strong current of countertransference in physicians who fear that something they do, or fail to do, could tip the precarious balance of life toward death. There also can be a strong desire to be appreciated by the family, and sharing good news is one way to cultivate their gratitude.

Often, even when there is acknowledgment that patient values and quality of life should guide the use of medical technology, practitioners can't help but struggle with the question of uncertainty. Advance directives, even when they exist, are often limited in their ability to speak to actual situations. Standard phrases involve "determination of terminal illness" (often by two or more doctors) or "permanent vegetative states." But the medical facts of a person's situation rarely fit neatly into those criteria. More often, outcomes are uncertain and fraught with ambiguity. One neurologist, in response to questions about whether her patient would ever recover from the significant brain damage, stated the dilemma succinctly: "I can never say 'never.' . . . We just don't understand the human brain well enough to ever be sure that there isn't a small chance of some recovery." These types of responses can leave families frustrated and lacking guidance at a time when they are trying to make difficult decisions about life-extending care. The family needs answers to essential quality-of-life questions: what is the possibility of recovery? How much is "some" recovery? What is possible in one, two, or six months if we commit to a course of tube feeding or other aggressive support? Too often, these questions simply cannot be answered definitively.

Atul Gawande (2014) presents the dilemma eloquently: "In [cases of unstoppable medical conditions], death is certain, but the timing isn't. . . . How do you attend to the . . . concerns of the dying when medicine has made it almost impossible to be sure who the dying even are?" (pp. 156–157).

Naturally, the doctor wants to believe that the medical care they prescribe will provide the best possible outcome for their patient. Yet, at the same time, the chances of that "best outcome" can be minimal, with far greater likelihood that the patient will not progress to a full or acceptable level of recovery. Unconscious discomfort or anxieties about such ambiguous outcomes become part of the clinician's countertransference. Because of their own discomfort or, perhaps, because of their fear of disappointing the patient or of having to "hold" the patient's or family's upset, physicians may address only the small chance of "best" recovery without ever exploring what is truly important to the patient.

This desire to hope for the best or to act as if recovery has a higher chance than is realistic can be acted out by the entire ICU team. (See Chapter 20 in this volume.) For instance, whereas ICU team members may intellectually know that the medical care they are providing is futile, they can easily be seduced into the "heroic" work of attempting to bring someone back from, quite literally, the brink of death.

> Mabel, a 93-year-old woman, was admitted because she choked on a bite of chicken while out to lunch with her family. Mabel had completed her advance directives and had advised her family to "let me go when it's my time." She had a Physician's Orders for Life-Sustaining Treatment (POLST) form indicating that she did not want to be resuscitated. However, the choking incident was sudden and happened while a waiter was nearby; he immediately started first aid and CPR while Mabel's family called 911. So, despite Mabel's prudent planning, she was resuscitated and brought to the ICU.
>
> When the physician admitted Mabel to the ICU, the family vividly described how this woman lived mostly independently, walked one to two miles a day, and was robust and in great health, exhibiting only mild dementia. The family brought in her POLST and advance directive but agreed with the physician who

> stated, "Now that she's already intubated, let's just keep going; if she's healthy, as you say, she might just come right through this."
>
> The ICU team met daily, repeating the story of this healthy 93-year-old who should be able to get back her former quality of life if the team could just get her through this. Captivated by the story, the heroic persona, the belief that Mabel would wake up and start cracking the jokes her family told them she was famous for, the team continued to mobilize on Mabel's behalf.
>
> At day 10 in the ICU, it was clear things were not going well. It became clear that Mabel's recovery, if any were possible, would not be quick. It would require that she remain on the ventilator for weeks or months, which would require a surgery to have an airway tube moved to her neck and a feeding tube placed. She would then be transferred to a long-term-care facility to see if she could slowly be rehabilitated.
>
> Before opting to have this done, the palliative care team was asked to consult with the family. With careful listening and exploration, they learned that, in fact, it had been more than a year since Mabel had taken her legendary one- to two-mile walks, that the family had been increasingly concerned about Mabel's frequent falls, and that her verbal skills and appetite, including difficulty swallowing foods, showed a clear progression of advancing dementia. The family had, in fact, been watching her progressive decline over the last six months. As much as they had hoped for the best, they all felt bad about prolonging Mabel's medical trauma and putting her through this high-intervention ordeal that she had clearly stated she never wanted.

The countertransference of the ICU team began when they bought into the "image" of this courageous figure, of someone who was defying the norm—someone who, they determined, should be given every chance to survive. The team hoped to give Mabel what the family said she wanted most, for Mabel to return to her beloved home. The team's collusion with the family's unrealistic hopes of attaining this goal became the justification for ignoring her wishes, thus subjecting her to care she never wanted.

These well-meaning staff members were seduced by a heroic story set amidst the heartbreak and suffering experienced by the majority of their ICU patients. Caught up in the narrative they'd constructed, the team put off the palliative care consultation. Here is where, inadvertently, the blinders of countertransference interfered with the opportunity for a conversation that would have revealed the truth of Mabel's prior quality of life along with accurate information about what her wishes would be in the face of these uncertain outcomes. Like the physician who could only focus on the small chance of recovery, Mabel's ICU team took a long time to admit that the outcome might be less than positive, leaving the family to struggle with increased guilt about what they had put Mabel through.

Primary Care: Countertransference With Depth

Primary care clinicians care for patients over their life span. They frequently establish deep, abiding relationships over the decades, coming to know their patients well and caring greatly for them. When these patients are diagnosed with difficult or life-limiting illnesses, clinicians can, and almost certainly will, be emotionally affected. It is no small

task having to face a future in which a serious illness may not be amenable to treatment. Often, unable to bear the thought of the suffering of these beloved patients, clinicians may unconsciously cope by focusing on "hope." By residing in an optimistic place, these devoted practitioners wish to give their patients the best chance at "getting through it" with the least amount of emotional pain and suffering. It is hard for these medical providers to admit, to see, that this actually may be an effort to save themselves from having to witness and to be with pain and suffering.

> Jo, a 69-year-old woman, was diagnosed with Alzheimer's dementia. She and Bob, her husband of 38 years, had been patients of Dr. Smith's for nearly 20 years. It was Dr. Smith, in fact, who had diagnosed Jo's dementia.
>
> Jo and Bob were both highly educated. They believed in having their affairs in order and being prepared. Jo was very clear that she would not want treatment for any life-threatening illness. Jo and Bob discussed this with Dr. Smith, who made sure Jo's wishes were documented in the medical chart and POLST form. The couple explained that they would want to be able to care for Jo at home as long as possible, with the help of paid, in-home help.
>
> Unbeknownst to Bob and Jo, Dr. Smith's wife recently had died of multiple sclerosis. Dr. Smith had been her primary caregiver. In discussing Jo's wishes, Dr. Smith hearkened back to memories of how difficult these very decisions had been in his own situation and how he wished that his wife could have made similar choices. But, most excruciating of all for Dr. Smith was the anguish he experienced in anticipating what lay ahead for Bob. Dr. Smith was powerless to alter the course of Jo's illness. He did not know how to prepare Bob for this; he could still viscerally feel how unprepared he had been. Dr. Smith made a mental note and told himself not to project his own situation on them. After all, Jo and Bob were being realistic and making the preparations they could. Who could do more?
>
> Then, the unexpected happened. Bob suffered a major heart attack during Thanksgiving dinner. Someone called 911 and Bob's heart was restarted. But it had taken a long time. Jo worried that his brain was without oxygen for too long.
>
> Once in the ICU, Jo discovered that after her diagnosis, Bob had amended his advance directives with his attorney. She was shocked to learn that while Bob's advance directives stated that he would not want to live permanently in a vegetative state, Bob *would* want CPR, intubation, medications, and IVs aimed at prolonging his life. The medical staff rightfully interpreted this to mean that he would want aggressive care to be given a chance at surviving a major medical event.
>
> Bob was in the ICU for weeks, on life support, not waking, but also showing strong vital signs and fairly good physiological recovery. The question was whether his brain would recover. Jo felt sure that Bob did not intend to be kept alive given the very small chance of recovery. But her son, Sam, who had arrived to support her, along with the physicians caring for Bob, felt that Bob's directives indicated that he would want this level of care, this chance at recovery. The medical team expressed the feeling that Bob would likely need lifelong care in a facility. Jo was positive that Bob would not have wanted that. She knew that Bob's intention was to be kept alive only if it was likely he could return to being her caregiver.

> Although Jo voiced her assessment of Bob's directives, her dementia was worsening with the stress of the conflict. She found herself left on the sidelines of the decisions being made, with the doctors increasingly talking to and deferring decisions to her son rather than to her.
>
> Over the course of three months, which included two readmissions and multiple pneumonias, Bob finally died in the ICU. After Bob's death Jo found that she was afraid to live into the more advanced stages of her illness. She feared that she could not trust her son Sam to honor her wishes if she got sick. She feared he would keep her alive longer than she would want. She also knew that she would, possibly sooner than later, not have the will or memory to act on her own behalf. One day, Sam called to say he would be over in a few hours to take her to dinner. She got into her car in her enclosed garage, turned on the engine, and rolled down the windows. Jo fell asleep and never woke up.

Stu and Annalu Farber, in Chapter 15, "The Respectful Death Model," write eloquently about the conspiracy of silence. This is not only a phenomenon that happens in the personal relationship between doctor and patient but also within families and other support systems. As in the case of Jo and Bob, Jo was silenced; she felt increasingly isolated as her thoughts became progressively more difficult to express. Bob was silent about changing his advance directives. Perhaps he feared Dr. Smith's judgment about his choices. All the while, Dr. Smith, who wanted nothing but the best for this couple about whom he cared so much and with whom he so overidentified, remained silent in his sadness, unable to really help them prepare for the worst. Without guidance, Bob did not appreciate the importance of keeping their son abreast of their wishes and plans. In all of this silence, Jo was left believing that her end-of-life wishes would not be honored.

Professional-Personal-Professional Intersections

In preparing to write this chapter, I asked some of my most revered colleagues, "How does your personal experience influence you as you work with people who are facing serious illness diagnoses?" One ICU nurse, Carol, told me this story:

> When Carol's dad, a brilliant doctor, called to tell her that he had been diagnosed with terminal colon cancer, she immediately launched into all the things he could do, all the treatments that might be available. . . . She was his smart, ICU-trained daughter, and she would save her dad!
>
> He said, "Carol, I am going to die from this and probably sooner than later. I am okay with that, but you aren't. That is *your* problem, and you need to think about this. That's how you can support me." So she did, and they had many talks.
>
> Months later, when he became very ill and went into kidney failure, the doctors called in specialists and announced plans that involved dialysis for Carol's mother to approve. Although her mom "knew better," the physicians made it sound like they knew what they were doing, so she agreed to the dialysis.
>
> Carol could see that her dad was dying, though no one had said that. She followed the doctors out of the room and politely asked for a minute of their time. She asked the oncologist, "Did you ever have a conversation with my dad about what he wanted or how he envisioned the end of his life?"

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He replied, "Well, no, we hadn't gotten around to talking about it." "Well," she said, "I did. And so did my mom. I really think you need to go back in there and ask her about my dad's wishes as she considers these options."

The physician complied, and indeed, Carol's mom had said yes to the treatments because she hadn't realized, and no one had said, that her dear husband was nearing the end of life. Once she understood what the doctors were saying about his condition, that they could not fix his problems and that the treatments they were proposing would only extend his life temporarily, she knew that was not what he would have wanted. Carol's father was put on comfort care and allowed to die comfortably, free of machines, with his family at his side.

Carol now carries her dad, his straightforward challenge of "that's your problem," and their many talks about how he envisioned his dying with her every day into her work with patients in the ICU. Her dad's story is what reminds her to really stop and ask her patients, "What is this like for you? What do you think is happening? What are you hoping for? What do you want the rest of your life to look like?"

Responsibility and Opportunity

Practitioners working with seriously ill and dying patients face situations daily in which their own feelings toward life and death are stirred up. Whether it is our desire to save or be the hero, whether it is our fear of disappointing others, whether it is our inability to be with suffering or our inability to separate our own values from those of our patients, these responses, if not examined, inevitably will influence the care we provide. They will, inevitably, affect our capacities to hear, understand, and respect the wishes of our patients and families. (See the box for Common Cognitive Misconceptions, Negative Consequences, and Reframing Tasks in Advance Care Planning.)

Common Cognitive Misconceptions, Negative Consequences, and Reframing Tasks in Advance Care Planning

Cognition: A health-care provider who cannot improve a medical condition has nothing to offer.
Consequence: The provider may feel demoralized and avoid the patient or family.
Reframing Task: Consider the gratifying care we can provide when cure is not possible, such as the successes in helping a patient die well.

Cognition: Patients generally do not want to discuss issues related to death and dying.
Consequence: Medical practitioners may displace their anxiety onto the patient and family, depriving them of an important opportunity to have input into their care.
Reframing Task: Rather than make a global assumption, consider what the particular patient needs. Gather data that clarifies what the patient needs, such as "What are your thoughts about your illness? What is the hardest part for you?" Remember that you are providing the patient and family an important opportunity to have input into their care.

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Cognition: Raising issues of advance care planning will take away hope.
Consequence: This narrowly defines hope as "hope to not die," perpetuating the clinician's sense of hopelessness and helplessness during the dying process.
Reframing Task: Redefine other kinds of hope we can offer patients, such as hope for quality living (as they define quality) until they die. This allows advance care planning to provide opportunities for hopeful discussion.

Cognition: Health-care providers must address their own concerns about death to have open discussions with patients about end-of-life issues.
Consequence: The clinician may deprive him- or herself of learning how patients cope with and grow from adversity. The patient will be deprived of a meaningful opportunity to teach the clinician something that will be remembered after the patient dies.
Reframing Task: The clinician might think more about what the patient can teach him or her about dying and coping with adversity rather than what wisdom the clinician should provide to the patient. The clinician might talk to patients from a standpoint of being curious about their experiences with serious illness and dying rather than what he or she thinks that experience should look like.

Cognition: The clinician must always have something to say.
Consequence: This limits the capacity to be in silence and listen.
Reframing Task: The clinician should consider what he or she can offer by listening and what messages the patient or family is conveying during those silences he or she feels the need to fill.

Note: Adapted from Weiner, J. S., & Cole, S. A. (2004). ACare: A communication training program for shared decision making along a life-limiting illness. *Palliative and Supportive Care*. *2*(3), 231–241.

How do we protect our patients, their families, and ourselves from misguided assumptions, interventions, and decisions? We start from a place of curiosity, a place where we put the patient, the family, and their own stories first—a place where the patient leads and we follow—allowing discovery and the capacity to be open to hearing *their* values about what makes life worth living from *their* perspectives, not ours. This requires not just self-awareness and self-examination, but that we make conscious and conscientious efforts in our communication with patients and families living with serious illness and the threat of dying. It requires that we ask more than tell and that we use open-ended questions and judgment-neutral language that allows patients to understand their situations at the same time as it encourages them to express their goals through their own stories of meaning. (See Appendix 1 at the end of this chapter for guidance on advance care discussions.)

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Conclusion

The stories in this chapter remind us that we health-care professionals are human, that we are vulnerable, and that, by the very nature of our deep caring, we are likely to infer and interject a portion of a story of our own making into the stories of our patients. Countertransference is a given. We will bring our experiences and views of life and death into encounters with our patients. If we are not aware of these possible influences on the care we give, we risk making assumptions about the care people want based on our own personal opinions or life experiences. We are vulnerable to imposing our own values into our interactions with patients and families, subtly or overtly, or by omission—by not recognizing when questions need to be asked.

When, instead, we consider that the person whose life is being affected by the illness and treatments is the most important expert in the room; when we proceed by utilizing that expertise to explore the values that they hold dear, those things that give meaning to their lives; and when we use that information in conjunction with other expert input to offer medical interventions that preserve what is meaningful and important to that patient, then we are truly practicing patient-centered care. To do this well, we must be willing to be uncomfortable, endlessly curious, and ever humble in the presence of people who come to us for care and healing.

Appendix 1

The Clinician as Guide: Ten Elements of Good Advance Care Planning Discussion

Element	*Facilitating statement/question*
Clarify Current Experience and Treat Suffering	– How is this illness affecting your life? – What is it like for you to have _______? (e.g., cancer) – What are the hardest things about this illness for you (medically, psychologically, spiritually, and financially)? – What kinds of suffering are you going through? – What are the things that give you the greatest meaning, pleasure, and dignity in your life? How has this illness affected that? – How can we help you now?
Elicit Prior Experience With Life-Limiting Illness and Medical Decision Making (previous losses, medical history, and current illness)	– I see from your medical history that your father died from colon cancer. What was his experience with cancer like? What were the best and worst parts of his medical care? If you would ever be in a similar situation, what would you want us to do for you? What would you want us not to do? – Tell me about medical illnesses or surgical experiences you've had. Were any of those illnesses so serious that you thought you might die? What was your experience like with that illness? How did you feel about how your medical care was handled? – What do you understand about your current medical illness? Where do you see things going? What are your hopes? What are your expectations? Do you ever think about dying?

(*Continued*)

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Element	*Facilitating statement/question*
Listen for an Invitation to Discuss Death and Dying Issues	– You mentioned that you understand this is a serious illness. Tell me more. – You say that you just take things a day at a time. What happens when you think past that? – You said that after you got the diagnosis, you became very scared; what scares you most now? – Where do you see things going with your illness in the future?
Link Medical Decisions With Life Experiences and Loss	– Your friend fought the illness hard to the end and endured many painful side effects of chemotherapy. We're approaching a similar decision now. – You want to live long enough to see your granddaughter graduate college. Do you want us to treat you aggressively at all costs? – It must be so hard to say good-bye to all the people you love. Most people have a hard time letting go. – You have lost so much during your illness. How does this affect how you think about the kinds of medical treatment you would like?
Health Care Proxy Transitions	– Who have you confided in about your medical situation? How well does that person understand your values regarding your treatment? – What would you want your loved one to know that would relieve their burden if they had to make such a decision for you?
Clarify and Summarize	– So you wouldn't want to live like a vegetable? Tell me more about what that means. – You say you wouldn't want to be hooked up to a machine. Is that under any circumstances? – Let me make sure I understand everything you've told me so far.
Share Your Clinical Opinions	– Under these circumstances, chemo would have little chance of extending your life. You also would have less time to spend at home with your loved ones. – Yes, I expect that you will die from this illness. – We would be very surprised if your spouse would regain consciousness or be able to breathe again without the machine's help.
Involvement of Loved Ones	– I'd like to ask the people closest to you to come to our next appointment; is that something you would want?
Discuss Opportunities	– How would you like to spend your remaining time? – What things do you need to say to people you haven't yet?
Negotiate Goals of Care	– Although we believe strongly that placing your husband on a breathing machine won't improve his acute leukemia, we'll agree to try it for several days to see if his pneumonia improves. Will you agree to meet again at that time to reevaluate the treatment plan?

Adapted from Tulsky, J. A., Fischer, G. S., Rose, M. R., & Arnold, R. M. (1998). Opening the black box: How do physicians communicate about advance directives? *Annals of Internal Medicine, 129*, 441–449.

COUNTERTRANSFERENCE TOOL BOX:

Emotional Barriers to Advance Care Planning

Are you having difficulty discussing advance care planning with your patients?

Below are common feelings evoked in health-care providers charged with helping patients with advance care planning.

Circle those emotions being triggered in this particular patient encounter, then check those sentences that may explain some precipitants to your responses.

Anxiety

I'm afraid that a truthful discussion will hurt the patient.
I'm concerned that an advance directive discussion will cause the patient to lose hope.
I don't know how much death I can tolerate without burning out.
I feel out of control in my ability to halt the progression of this illness.
I'm worried that I will guide the discussion based on my own values without knowing what is best for the patient.
I'm afraid that the patient will see my tears, upset, and grief.
I'm uncomfortable with the uncertainty of this prognosis.
I want to avoid a conflict with patient, family, or other clinicians about treatment decisions.

Sadness

I am sad about losing this patient:

a) She or he is a patient with whom I've become close.
b) She or he is someone with whom I identify.

This patient is forcing me to face the following:

a) The inevitability of my own future death.
b) The ways in which I might die.
c) The (future) death of my loved ones.

Frustration and Anger

I feel forced to discuss advance care planning, but I'm not qualified!
This patient is too "needy" or "demanding."
This patient or family member keeps insisting on hope in the face of medical futility.
I don't have enough time to deal with this.
Administration is causing stress: productivity demands, administrative impositions, and so on.

Helplessness

I don't want to believe that I can't cure this disease.
I can't tolerate the uncertainty (e.g., "Doctor, how much time do I have left?").
I can't assuage the grief of the patient and loved ones; I can't make them feel better.
I can't change their experience of pain, fear, or anger.

Shame

I feel I've failed if I can't keep my patient alive.
I've been trained to cure, not heal.
I feel "emotionally incompetent" to handle strong reactions of the patient and loved ones.

Guilt

I wish this would end soon.
I feel like I'm giving up on the patient if I discuss advance directives.
Am I encouraging a do not resuscitate (DNR) or do not intubate (DNI) order for my own convenience?
It's hard to see this patient suffer. I wish she or he could let go and die.

Note: Adapted with permission from: Weiner, J. S., & Cole, S. A. (2004). Three principles to improve clinician communication for advance care planning: Overcoming emotional, cognitive, and skill barriers. *Journal of Palliative Medicine, 7*(6), 817–829.

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Part III

Specific Populations and Settings

The diversity of settings devoted to end-of-life care is as varied as the populations they serve. In light of this array, Lopez, in Chapter 6, illustrates basic principles and common defenses that all professionals must endeavor to understand in working with people of diverse ethnicities, cultures, and developmental life stages. Providers are encouraged to explore their beliefs, biases, and fears, and the ways in which these factors might impact the kinds of care they provide.

Next, Barnhill's Chapter 7 describes scenarios particular to dying in a hospital setting, where the needs of patients, staff, and families intersect to create a confusing yet compelling force on the professional who is asked to serve as "expert." Whether as a nurse, physician, psychologist, social worker, or chaplain, the role of "problem solver" can be experienced in distinctly darker terms, for example, as the executioner or the torturer.

When horror and violence have been perpetrated by the taking of a life through homicide or suicide, Rynearson, Johnson, and Correa, in Chapter 8, caution clinicians to put the emphasis not on the senselessness of the dying but on the stories of the living, thereby allowing survivors a coherent story with which to rebuild life.

The death of a child is experienced as a crime against nature and is rife for professional countertransference. It pulls from us our deepest protective instincts, making it impossible to clearly separate the personal and the professional. This heartbreak is explored in the hospital setting by Doe and Katz in Chapter 9, and as the "ghost" of grief in the therapy room, by Osband in Chapter 10.

Note: There are excellent opportunities at the end of several chapters to deepen your understanding of your personal-professional intersections. Please refer to the chapter tables and Countertransference Tool Box.

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6 The Influence of Culture and Ethnicity on Palliative and End-of-Life Care

Sandra A. Lopez

In our professional world there are often topics that tend to create a certain tension or strain in the room whether it is a classroom presentation, training, dialogue with colleagues, patient case conference, or one-on-one counseling session. These conversations are delicate in nature and may elicit anxiety in some professionals and avoidance and denial in others. Discussions related to life-limiting illness and death, and culture and ethnicity, frequently fall into this delicate basket of uncomfortable professional conversation. In some ways, these topics are similar in that they have an impact on every human being and, thus, cannot be completely avoided as they cut to the core of our personal selves. Issues surrounding serious illness and dying can create feelings of discomfort and may contribute to an experience of disquiet for the helping professional who is in denial about, or who does not wish to face, his or her own mortality. Becoming aware of one's cultural and ethnic values and beliefs also can create concerns about how one fits with self, with others, and in the world. Clearly, the intersection of these two topic areas can create uncomfortably challenging situations for helping professionals.

This chapter illustrates the uniqueness of working in the field of palliative and end-of-life care and the importance of understanding the influence of culture and ethnicity in the helping process. It also explores the potential for countertransference issues, which inevitably accompany the professional's efforts.

Culture, Ethnicity, Serious Illness, and the End of Life

Facing Pain, Loss, and Death

Working in palliative and end-of-life care can be challenging to any helping professional. Palliative care is often about pain and about suffering, mortality, and death. It takes a certain passion, tolerance, and ability to sit with emotional, spiritual, and physical pain to do this work. Bowlby (1980, p. 7) notes:

> The [potential] loss of a loved person is one of the most intensely painful experiences any human being can suffer, and not only is it painful to experience, but also painful to witness, if only because we're so impotent to help.

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Worden (2008), in his book *Grief Counseling and Grief Therapy*, addresses three possible ways in which the helper can be touched by the experience of grief and loss of others. First, the experience of others may mirror important losses that we, personally, have encountered. This on its own is not necessarily an issue; it becomes an issue, however, when the practitioner has not fully resolved his or her grief around these losses. Using myself as an example, during the first years of my mother's diagnosis of Alzheimer's disease, I became fully aware that it would be in neither my best interest nor the best interest of any prospective client, to work with anyone who was experiencing the loss of a loved one's mental capacities. It was too close and too current a life stressor for me to be effective with clients who were mirror images of my own personal struggles. I needed to first grieve the loss of my mother as I knew her before I could face this loss in others.

A second challenge faced by the helping professional working in palliative and end-of-life care occurs when the grief experiences of our patients reflect losses that we may face in the future. A social work practitioner with diabetes who provides medical social work services to a patient whose leg has been amputated due to severe diabetes might face such a challenge.

Third, Worden also discusses our coming to face "existential anxiety." Existential anxiety refers to one's own personal death awareness that may be elicited in the stories of others, especially when the ill, dying, or deceased person has characteristics similar to the helper's, such as gender, age, or ethnicity. For example, when I review the daily newspaper's obituary column, I find myself much more interested in those individuals who share aspects of my physical self. Confronting these deaths forces one to have a greater realization that death, illness, and loss are part of life at any age in any circumstance. The Dalai Lama (2002, p. 29) speaks to death awareness directly:

> It is crucial to be mindful of death—to contemplate that you will not remain long in this life. If you are not aware of death, you will fail to take advantage of this special human life that you have already attained.

Facing serious illness reminds us of the fragility of life and our nearness to death. If we can accept death as a part of life, we can strive to live life to its fullest, to prioritize those values that are important to us, and thereby to more easily prepare for our own eventual demise. If we are conscious of them, these are some of the rewards we reap in working in palliative and end-of-life care.

Understanding Culture and Ethnicity

What is culture? What is ethnicity? There are so many definitions in the growing literature on cultural diversity and multicultural and cultural competency (Devore & Schlesinger, 1999; Green, 1998; Julia, 1996; Lum, 2011; Sue & Sue, 2012). In an effort to simplify the process of understanding culture and ethnicity, the following basic definitions will be utilized: "culture" refers to common elements or characteristics within one's sociological grouping. Normally, we think of cultural groupings as having distinct values, beliefs, behaviors, languages, rituals, customs or traditions, and accepted

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practices for living and dying, partnering, marriage, childbearing, parenting, and family and communal life. "Ethnicity" refers to a common ancestry that some persons may share with one another. Ethnicity can be an integral part of how one defines him- or herself in a given society, or it may be something that one knows on an intellectual level yet has not experienced on a personal practice level. For example, it is quite common for persons to identify as being Swedish, yet they may not know what it means to "be Swedish" in practice. On the other hand, an individual might say they are Italian American and cite particular customs, foods, and rituals that are unique to being Italian American.

It is far more valuable to view culture as being expansive or extensive. Culture can include things such as developmental stage of life, profession, educational level, geographic region of the country, religion, spirituality, sexual orientation, political affiliation, gender, socioeconomic status, and more. This indicates that individuals can affiliate easily with several cultures at once and, depending on where they are in life, or in the life cycle, they may lead with one or two of their distinct cultures. For example, values and beliefs may differ by developmental stage. An adolescent, for instance, would likely place value on far different things than an elder or older person.

It should be noted, then, that the process of identifying cultural affiliations can be challenging for the helping professional. It is human nature to want to categorize, understand, and predict. But the danger of stereotyping lurks if we arbitrarily make assumptions about patients' cultures by virtue of their names, facial features, manner of speech, and presentations. Cultural assumptions often lead to faulty conclusions in that we mistakenly can assume something about a patient that may be far from the truth. If we have a hypothesis, it is helpful to assume nothing and, rather, pursue exploring that hypothesis through gentle inquiry and conversation. Patients and families often will inform us as to what is important to them at any given moment if we open space for it. In fact, it is often thought that practitioners can be far more effective when they reside in a place of cultural humility, making no assumptions about values, beliefs, and practices and, rather, assuming that every encounter is a cross-cultural experience.

Countertransference Potential With Multicultural Issues in End-of-Life Care

In response to a changing society with greater diversity, there has been a notable surge of literature addressing culture, cultural diversity, and cultural competence (Devore & Schlesinger, 1999; Green, 1998; Julia, 1996; Lum, 2011; Sue & Sue, 2012). Although there is a growing body of literature devoted to the understanding of serious illness, grief, loss, and death, there is still a scarcity of literature related to the understanding of culture and ethnicity as it relates directly to these arenas (Braun, Pietsch, & Blanchette, 2000; Irish, Lundquist, & Nelsen, 1993). Combined with the issue of countertransference, we see an even greater dearth of writings.

Mostly, the literature provides strong messages of encouraging practitioners to consider culture as an important part of their work and to develop sensitive interventions or strategies for working across diverse cultures. What is not addressed, however, is the whole arena of how our cultural affiliations may enhance or detract from the work we do

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with our clients across settings. In fact, when I think of the intersection of ethnic-cultural, palliative, end-of-life, and countertransference issues, I am reminded of how a careful exploration of these issues might have helped me with my own struggles as a young social worker:

> It was 1983, and I was assigned to the sixth-floor medical unit in a hospital setting. We had a patient who was in her mid-80s who had suffered a severe stroke. From Mexico, she was here visiting with her daughter when she experienced the stroke. She had no insurance and was brought into the hospital through the emergency room. Mrs. Rodriguez had been hospitalized for one week when Dr. Powell ordered a social service consultation to talk with the family about considering a do not resuscitate order (DNR).
>
> After all these years I can still vividly describe the look of the room, the patient, and the daughter as I visited them that day. Mrs. Rodriguez reminded me of my grandmother: white hair, olive skin, and frail. For some reason I brought more feeling into the room this particular day—not my usual empathy but more than that. I remember feeling both puzzled and angered by Dr. Powell's intent to remove life-sustaining supports from this frail, elderly, Mexican woman. I was angry with Dr. Powell because, in my perception, he showed little emotion or concern about the patient or her family, stressing, rather, the importance of reducing hospital costs for an unnecessary stay for an uninsured patient. I remember thinking that at some level, Dr. Powell might be biased in his treatment of this elderly person. After all, there were other patients on the unit that were in similar shape, yet they were not being counseled about a DNR.
>
> So why this patient—why Mrs. Rodriguez? I can still recall discussing this case with my clinical supervisor. I struggled with carrying out the wishes of Dr. Powell (i.e., to broach the subject of a DNR with the family), recognizing that I had so much feeling about this case. It was the kind of case you regrettably take home and into your sleep. It is the kind of case that is still vividly remembered even after 30 years of social work practice.
>
> During clinical supervision, my supervisor was highly effective in helping me understand the challenges of working with the then-new Medicare guidelines as well as with the financial constraints posed in the hospital system. She spoke to the challenges of interdisciplinary work, such as balancing my professional social work values with those of the physicians, nurses, and other health-care staff.
>
> On a basic level, many essential issues were addressed. What was not addressed, however, was my discontent and struggle with having to discuss a DNR with this particular family. In reexamining this case, and with 25 years behind me as a practicing social worker, I can see how culture and ethnicity were major and significant pieces of this experience. How could they not be? After all, since I was a Mexican American female social worker with a father originally from Monterrey, Mexico, and a mother who identified strongly as Mexican American, culture had played an important part in shaping my

personal and professional identities. My professional interventions had to have been guided in some part by my being of a similar ethnicity as that of the patient. Additionally, value dilemmas can be expected to surface naturally when we accompany terminally ill patients and their families through the process of serious illness and ultimately death. Many times, these values are strongly connected to who we are as professionals or who we are as human beings. Many times they are connected to our cultural and ethnic affiliations.

Exploring My Countertransference Hooks

I grew up in a close-knit family and learned to value interdependence with little or no emphasis on independence. It wasn't until college that I heard any distinct reference to something called individualism or independence. Mutualism, collaboration, and family pride were emphasized and modeled within my Mexican family. Decision making was a part of what we did as a family, with some input and guidance from trusted authority figures on the outside. Catholicism played a large part in influencing our belief that God, not humans, made decisions about end-of-life issues. Thus, when my grandmother was ill in her 80s, I witnessed my family's dedication to her care and to prolonging her life.

How did all of this fit with Mrs. Rodriguez in the hospital setting? Clearly, countertransference was active here. Let's review the characters—Mrs. Rodriguez, a Mexican-born patient visiting her daughter in the United States; her daughter, a more acculturated Mexican female who decided to make her life in the United States yet maintained strong connections with her family in Mexico; and a beginning social worker in her 20s who identified herself as Mexican American and strongly identified with many of the traditional values and beliefs of her Mexican culture. Let's also not forget Dr. Powell, a middle-aged white man extremely knowledgeable and skilled as a medical internist but who was not openly caring and compassionate. Last, consider my seasoned Jewish clinical social work supervisor, who was also knowledgeable, skilled, and supportive. Then, let us recall the era, one in which "sameness" was promoted and pointing out differences related to culture and ethnicity was not highly regarded. The political climate was one that promoted being homogeneous, acculturated, and as "American" as one could be. In reviewing the factors here, it almost seems like "an accident waiting to happen." At the time, however, it obviously was not perceived as such. It is also reflective of the miasma of constantly changing confluences that contribute to the complex health-care arena.

A retrospective, in-depth examination of the countertransference issues reveals my struggle and discontent with the opposing values among Dr. Powell, the family, and me. My cultural and ethnic affiliations as a Mexican American, Catholic, and social worker contributed to the frustration. What is interesting to note is that I can keenly remember my conflict yet have little or no memory of the patient's or daughter's struggle. This to me is an indication of how I had lost sight of their needs and wishes and had become the champion of what *I* thought were their values. While it may be true that I had in some

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sense joined with their values, in reality I did little to learn about what they wished to do. I was motivated by my personal desire to promote my own values and beliefs. In essence, my personal history collided with the clinical situation. I was brought back to vivid memories of a grandmother who was allowed to live and who was loved and cared for until such time that she died. Notably, I wanted this for Mrs. Rodriguez as well, but I wasn't aware enough to notice it, let alone articulate it.

As this case illustrates, countertransference, even when quite overt, may be overlooked. It is not uncommon for helping professionals to have difficulties in separating their worlds from those of their patients. When there is a gnawing discomfort or something we "just can't put our fingers on," a red flag should be raised. Such vague feelings are often signals that we have become "hooked" by something in the clinical milieu. At this point, utilizing supervision and consultation can help the practitioner separate his or her own needs and experiences from those of the patient.

Understanding the Influence of Culture and Ethnicity in Palliative and End-of-Life Care

The possibilities of countertransference are rich and complex, especially given the intersection of serious illness, dying, culture, and ethnicity. Ridley (2005), in broaching the subject of countertransference and culture, encourages helping professionals to confront their issues related to race, culture, and ethnicity. He identifies eight racially related defense mechanisms that, when examined together, provide a valuable framework for exploring our biases and assumptions across cross-cultural helping situations. The framework includes defenses such as color blindness, color consciousness, cultural transference, cultural countertransference, cultural ambivalence, pseudo-transference, overidentification, and identification with the oppressor (Ridley, 2005). The focus here will be on the four defensive dynamics most common in palliative care and end-of-life experiences. These are: color blindness, cultural transference, cultural countertransference, and overidentification.

Color blindness is the illusion that a minority client is no different than a nonminority client (Ridley, 2005). This illusion often stems from three common origins. First, the helper may have learned through childhood and adulthood that we should promote sameness and equality, and therefore, we don't "see" differences. Many helping professionals have been taught this principle by well-intentioned parents and families who wanted to promote fairness for all. Second, the helper may take the approach of color blindness in an effort to not be seen as prejudiced, discriminatory, or racist. Third, discomfort and insecurity about race, culture, and ethnicity may create a tendency to want to avoid any reference to differences.

Cultural transference can be a common experience for some helpers and can be especially frustrating or disturbing to those who are appreciative of cultural differences. Many times, patients have experienced prejudice or discrimination based on culture at the hands of other authority figures or helping professionals. The patient may automatically fall into behaviors reflective of a previous experience

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because the helper represents the "bad guys" of the past. Naturally, the helping process can then become challenged in that this unaddressed conflict can impede the work.

Cultural countertransference is a defense mechanism experienced by the helping professional when working with a particular patient or family. In response to a patient's ethnicity or culture, the professional may be reminded of a previous experience and transfer his or her reactions into the current relationship. As with transference, the impact on the helping process can be significant and create barriers in the therapeutic relationship and, thus, in the ability of the professional to be truly helpful.

Overidentification, the fourth defense mechanism, is related to the emotional connection that a helper may have with a patient of a similar cultural or ethnic background. On the one hand, the fact that the helper can be culturally empathic is an asset to establishing rapport in their relationship. On the other hand, it may create a tendency for the helping professional to overidentify with the patient and make assumptions based on his or her own personal experiences without being able to separate them from those of the patient. When this occurs, the helper is no longer capable of being objective; he or she is trapped within his or her own assumptions, struggles, and conflicts, and thus, true, objective attention cannot be given to the patient's issues.

The presence of any of these aforementioned defense mechanisms is more common than we would like to think. With time constraints, increased caseloads, and need for multitasking, the practitioner is often afforded little, if any, time to reflect on the ways in which these mechanisms might be manifesting in the therapeutic relationship. I have found it helpful to utilize Renee S. Katz's Personal Case Consultation Exercise (see the Countertransference Tool Box). First, I write these four defensive maneuvers on a clean sheet of paper that has been folded into four sections. At the top of each section, I write the defense mechanism and then ask myself: "In what ways might I be influenced by this defense in my current situation? Are there specific attributes of the patient to which I am particularly vulnerable (i.e., which push my buttons)? How are these being manifested? What can I do to 'unhook'?"

Mitigating the Negative Impact of Countertransference

Recognizing that culture and ethnicity can influence the work we do in palliative and end-of-life care, we must stay aware to prevent cultural conflicts, to keep up with our countertransference experiences, and to understand and manage cultural influences.

As emphasized throughout this chapter, it is important to recognize that serious illness and dying, and culture and ethnicity, are topics that can evoke fear, anxiety, discomfort, and tension for the helping professional as well as for the patient and family. The natural response to tension and anxiety may be to avoid such topics, to deny potential reactions, or to minimize or even ignore these reactions. Although it may be argued that it is human nature to respond in such a fashion, we cannot afford to let our patient care suffer; we must acknowledge the delicate nature of these topics and the difficulty in

facing these issues. When we can face our own foibles in this regard, we have a valuable tool with which to effectively harness or manage our reactions and responses. So, just how do we do this?

First, it is important for the practitioner to have completed an examination or exploration of his or her personal issues related to life-limiting illness, dying, and cultural experiences. It is strongly suggested that one complete a thoughtful and in-depth exploration of one's experience with death as well as an inventory of one's experiences with serious illness, disability, grief, and loss. It is imperative to reflect on experiences with death-related losses as well as non-death-related losses, exploring how we have processed our grief reactions and how we have coped with bereavement. Further, we must look at what we have learned from others about coping with serious medical challenges, loss, and grief. This is an ethical imperative. When we examine our own loss histories, we are better prepared to face the losses of others and provide effective interventions to patients and family members.

From the perspective of culture and ethnicity, it is equally important for the helper to have a sense of who they are culturally (Lum, 2011). This requires an in-depth examination of our cultural and ethnic affiliations and a review of our values, beliefs, behaviors, rituals, customs, and traditions that make up our cultural identities. This also requires that we take a careful look at any biases we may have developed. Such self-examination can be challenging and perhaps unnerving because most helping professionals would prefer to think that we are completely free of bias. Such exploration can be especially challenging for those who have lost touch with their cultural and ethnic identifications due to assimilation or oppression or due to the emphasis on identifying with the mainstream culture.

It is important to ask ourselves how our culture perceives death, how grief is expressed, and what help-seeking behaviors and rituals make up our cultural experiences around health, illness, and disability. To some degree, what we learned in our own cultural milieus will influence how we "show up," how we grieve, and how we approach individuals facing serious illness and death. We must constantly examine these intersections. Specifically, to what degree does culture and ethnicity influence how we perceive illness, death, help-seeking behaviors, end-of-life care, family involvement, decision making, and the authority of health-care and helping professionals. For example, crying is encouraged in some cultures and discouraged in others. Help-seeking behaviors are encouraged in some communities, but in others it is never okay or only okay in certain circumstances. In another common example, it is generally known that in American society, health-care systems will be operating from principles and policies that are guided by Western values and thought. One such principle is that of 'patient self-determination,' which guides the provision of education and information to patients so that they can make informed decisions on their own behalf. In some ethnic and cultural groups, this principle does not exist. The emphasis may be more on following the wisdom of the collective family or chosen decision makers, their faith in God or fate, or the physician who is granted the authority to declare whether a patient has the right to have information about his or her anticipated death.

Integrating Culture and Ethnicity Into the Helping Process

The best way to understand the influence of culture and ethnicity is to listen to the subtle verbal and nonverbal messages that are provided to practitioners throughout the helping experience.

The goal in understanding the influence of culture and ethnicity in the helping process is to convey appreciation of and respect for cultural differences. When the helping professional views cultural differences as unacceptable, negative, or frustrating, patients and family members may sense these reactions on the part of the helper. In other cases, culturally and ethnically different patients may have learned that others are intolerant of their cultures, and they may automatically prejudge the caring, compassionate helper.

If we recognize that all of our patients are, in essence, culturally and ethnically different from us, then we can consciously make efforts to really get to "know" others. This starts with considering our own beliefs and assumptions. It means embarking on a lifelong process of self-reflection, self-examination, and self-critique and, from there, utilizing self-awareness to help us inquire respectfully, with curiosity and openness, about the patients and families with whom we work. It also means acknowledging power differentials, being willing to say when we don't know, and actively giving up the role of "expert" to embrace the role of student (Danielson, personal communication, 2015).

Additionally, it is important to process and share our explorations with our professional colleagues. Group supervision and consultation, case conferences, team meetings, and in-services can provide appropriate structure for these kinds of discussions. Tremendous learning can happen when we share ideas and experiences in an authentic, safe, professional environment. Dialogue must allow for complete sharing of perspectives without fear of repercussion or judgment. When the emphasis is on creating a fruitful dialogue rather than changing one's perspective, then rich personal and professional learning can take place. Our patients benefit, and so do we.

Conclusion

The enormity of the tasks, as well as the often exhilarating and spiritual nature of the work in palliative and end-of-life care, is both challenging and rewarding. This work becomes even more complex when we recognize and work with the influence of culture and ethnicity in the helping process. Being sensitive to potential cultural and ethnic differences provides us with an opportunity to be more sensitive to the needs of the patients we serve. For some, this may represent a dramatic shift in paradigm from promoting sameness (an approach adopted during the melting pot era) to appreciating and honoring diversity, a more contemporary way of thinking.

If we fail to acknowledge obvious, as well as subtle, cultural and ethnic influences, we may miss the opportunity to provide appropriate and truly helpful care. We must recognize that the impact of culture and ethnicity in palliative and end-of-life care is a delicate yet highly significant part of our work. If we can honor and embrace the impact that culture has on the helping relationship, we will be privy to a valuable avenue for reaching patients and families and honoring a rich component of their lives.

COUNTERTRANSFERENCE TOOL BOX:

The following self-assessment exercise is presented to help you become aware of the ways in which unconscious biases and defense mechanisms may present in your current work. Choose a current case in your practice that involves a patient or family whose ethnic, cultural, or racial background differs from yours. With this case in mind, jot down the answers to the questions in each Cultural Countertransference Tool Box, and complete your *Personal Case Consultation*, below:

Personal Case Consultation

Renee S. Katz

Color Blindness/Inability to See Differences

In working with minority clients or those of differing racial or ethnic backgrounds, clinicians may find themselves operating under the illusion that minority clients are no different than nonminority clients. This can create the illusion that ethnic, cultural, or racial differences have little if any impact on the work. In thinking about your case, in what ways might you unconsciously be diminishing the importance of race, culture, and ethnicity?

Ethnic and Cultural Transference and Countertransference

As with so many situations in life, practitioners may find themselves unconsciously "bringing" their own prior life experiences into the helping relationship and reacting to current situations through the lens of prior ones. In thinking about your case, in what ways might you be transferring feelings, thoughts, or expectations from prior experiences with race, culture, or ethnicity into your work with this current case?

Overidentification

When practitioners share similar cultural or ethnic backgrounds as their patients, they may bring a particular empathy and rapport to the therapeutic relationship. They may also find themselves overidentifying with these patients and families. This can be particularly problematic when the practitioner inadvertently makes assumptions about perceived similarities in values, desires, and goals. In thinking about your case, in what ways might you be identifying with your patient or family because of similarities in backgrounds?

Cultural Self-Consciousness

Practitioners who identify with the majority culture may feel self-consciousness in their work with minority clients. This can lead to a sense of uneasiness about attending to or acknowledging issues of diversity. Feeling embarrassed or guilty about differences in life experiences (e.g., vis-a-vis oppression, discrimination, socioeconomic status, privilege, and opportunities) is frequently at the bottom of such discomfort. In thinking about your case, how might a sense of embarrassment or shame about your own ethnic, cultural, or racial background be impacting your work?

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7 Torture, Execution, and Abandonment

The Hospitalized Terminally Ill and Countertransference

John W. Barnhill

Introduction

In this chapter, I will focus on the terminal stage of the terminally ill from the point of view of their medical team. Torture, execution, and abandonment may seem unnecessarily harsh terms, but they correspond to the feelings that can be engendered in the treating staff by this population of very ill patients. These countertransference reactions can lead to suboptimal patient care and a recurrently painful work experience. I will address each of these three reactions by using illustrative cases from my work as a psychiatric consultant within a large hospital. In each case, there are accessible therapeutic approaches that allow for a more gratifying experience for both the dying patient and the caretaker.

Case 1: Torture

Background

My psychiatric team was called to help with the care of Mrs. Alexander, a 70-year-old woman in the surgical intensive care unit (SICU). Two months earlier, Mrs. Alexander had been admitted for a relatively simple pneumonia after a lifetime of good health. She had, however, developed a serious blood infection, which resulted in the need for her to be on a ventilator. Strong antibiotics had led to kidney failure, and she had been started on dialysis. She had developed a painful body-wide rash. Long-standing heart disease had worsened, and she had developed a very low cardiac ejection fraction that required powerful—and dangerous—medications to boost her blood pressure. Worse, she had developed a fungal infection of the heart and aorta. Such an infection is treatable only by surgical removal, but surgeons refused to do the surgery because of her tenuous cardiac status, saying that she would inevitably die on the operating table. Throughout this ordeal, Mrs. Alexander remained alert and able to communicate through nods and hand squeezes.

Reason for the Consultation

The medical and surgical team agreed that there was no way that Mrs. Alexander would survive. She was in constant pain, grimacing and moaning whenever she was moved or touched. Unable to move her hand well enough to write, she communicated slowly, but when alone with the doctors and nurses, she clearly and recurrently mouthed, “Kill me.” She appeared to be entirely alert and had experienced no episodes of confusion despite

her many medical problems. When lying quietly and in no acute pain, she appeared to understand the hopelessness of her situation and the implications of withdrawal of life supports, and she consistently asked that they be removed. During visits with her adult children, however, she communicated that she hoped to recover and wanted everything done for her. The psychiatry consultation was called to resolve the patient's indecision.

People who work in the SICU tend to be busy and self-reliant. They are accustomed to complexity and hardship. At least within my hospital, they call relatively few psychiatry consults. In this case, however, the seasoned nurses and physicians felt overwhelmed by the fact that they were causing severe pain in someone who had no hope of recovery. They called the consultation because they felt like torturers.

Initial Fact Finding

Mrs. Alexander was a thin, frail woman surrounded by the bells, tubes, and machines that accompany the sickest people in the modern hospital. Her eyes were remarkably alert and clear, though her skin was mottled and angry—signs of her antibiotic-induced rash. At the slightest touch, she shut her eyes and silently groaned. Via hand squeezes and nods, she communicated that she did not feel depressed, that she would want everything done if she could survive, and that she didn't particularly want to die. If, however, there was no hope of recovery, she would rather die than prolong suffering.

Interviewed separately, Mrs. Alexander's three sons agreed that she had never been depressed or suicidal. They agreed that they had no interest in prolonging needless pain and would agree to withdraw life support if she would assent in their presence. As it was, however, she continued to deny excessive pain whenever anyone in the family was in the room and indicated that she wanted continued medical interventions.

Reconceptualization of the Consultation

When confronted with an unsolvable problem, it is often best to enlarge the issue and broaden the understanding. This can first be done by acquiring information that conforms to George Engel's proposal for a biopsychosocial approach to medicine (Engel, 1977). In this case, the medical team had emphasized the biological aspects of her illness without appreciation of the psychosocial aspects of her ambivalence.

Because the patient was unable to talk or write, much historical data was drawn from her children. Mrs. Alexander had developed a hardscrabble business after having been abandoned by her husband after her third son was born. The sons described how she had been a tough and somewhat arbitrary disciplinarian throughout their childhoods but that they were always proud of her ability to make ends meet. It was exactly this survivor mentality that seemed to be fueling her need to be seen by her children as resilient and as someone who would never give up.

Discussion

The staff called us to help Mrs. Alexander overcome her ambivalence about the termination of life support. Much of their motivation was reasonable and reflected their sincere effort to help reduce suffering. Most of their patients suffer, however, and few

see psychiatrists while in the SICU. In this case, the patient was making them feel bad about *themselves*, bad that they were inflicting severe pain on a helpless patient whose own situation was hopeless.

As one intensive care nurse said, “It is just horrible to inflict pain every time that I adjust her pillow. That would be okay if she was going to get better, but she’s not.” A physician commented, “I really don’t like to spend my time and everyone else’s time on a patient who is never going to make it. It’s not like we’re making her feel better or giving her quality time. It’s futile, hurtful, and wasteful.”

I had my own reactions to this case that were somewhat different than those of the primary medical team. Underpinning many of my reactions was the reality that while I had been a practicing psychiatrist for over a decade, I was relatively new to the field of inpatient consultation. And so, upon hearing about the case, I empathized with the team’s hopelessness. Upon entering the patient’s room, I empathized with everyone’s horror at inducing more pain in this clearly suffering woman. In addition, I was transiently tentative about my ability to use psychodynamics while surrounded by the bells and whistles and advanced technology of the SICU. Not only was I unfamiliar with the science and technology, but I was not a regular member of the SICU team, and so I was an outsider to them. This led me to wonder whether any of my suggestions would be acceptable. The final barrier was the patient’s personality. Her sons had described her as ruthless and tough. While an unflattering characterization, this view of her personality afforded me a means to gain a connection with someone who was, in many ways, distant and unreachable.

The Intervention

Upon entering Mrs. Alexander’s room, I decided to engage this woman with a formulation that combined accuracy with a positive regard. This was complicated by her inability to speak, but she was alert and able to nod and shake her head. I talked about what I’d learned about her life, such as her sons’ pride in her accomplishments and durability. I talked of her difficult medical situation and that no doctor thought she could ever leave the SICU. I mentioned that this wasn’t the first time that she was bucking the tide and that I’d bet that she had been a thorn in people’s sides for as long as she could remember. She smiled and nodded. I elaborated a theory that a lifetime of struggle had left her unprepared to ever give up. And I told her that her sons would see her as resilient regardless of her decision about the life supports. She seemed deeply affected by this discussion and agreed with the formulation. After talking with her sons the next day, she agreed to discontinue the ventilator. This led to a family reunion within the SICU so that grandchildren and other relatives would have a chance to say good-bye.

After the visits, however, the patient made it clear that she could never give up, that she would take her chances with the pain. Her sons shook their collective heads and said that sounded just like her.

My consultation did not lead to termination of life supports, and the patient held on for another 10 days. At the same time, the staff felt significantly reassured after we discussed with them the rationale for her decision. The patient’s life story of struggle put the ongoing pain into perspective, and the nursing and medical staff felt relieved that they were allowing Mrs. Alexander to have a death of her own, even if it was a physically tortured death that none of them would have wished upon their worst enemy.

Case 2: Execution

Background

The psychiatric consultation team was asked by the director of the medical intensive care unit to assess Mrs. Bradford, a 70-year-old woman who was, in some respects, similar to the woman described in the first case. Most of her organs were failing, and she required strongly toxic medications to stay alive. There was no chance that she would survive. Unlike the first woman, however, Mrs. Bradford was completely unconscious. Her dying wishes were being carried out by her husband of 50 years, who was insisting that all possible measures be enacted.

Reason for the Consultation

Ongoing efforts to save the patient seemed futile. The medical staff wanted the psychiatrist to help the husband accept the wife's death and consent to a DNR (Do Not Resuscitate) order.

Initial Fact Finding

As is always the case in talking to a patient's proxy, I wanted to understand the patient's prior wishes as distinct from those of the proxy. She had left no living will or written instructions. In talking to Mr. Bradford, it seemed that he and his wife had talked about termination of life supports twice. One conversation had been precipitated by a comatose woman who had received national attention. Mrs. Bradford had said at the time that she had heard that it was possible to come out of such states and that it would be sad if the plug was pulled prematurely. On another occasion, she had said that she would never want to be on a respirator for years if there was no chance for recovery. Her views were, therefore, contradictory and not especially applicable to her own situation. They had no close friends or children, and Mr. Bradford didn't know of anyone who might have additional information about her views.

Mr. Bradford said that his only reference point was his experience at the front lines of the Korean War, where he had several times watched friends get blown up. The medications that were keeping his wife alive had also caused her to swell immensely. He was particularly horrified by her grotesquely bulging eyes. He was convinced that she could not recover but felt stymied. He wanted to protect her from the pain but worried that the Catholic Church would view the actions as murder or suicide.

Reconceptualization of the Consultation

This impossible situation required additional perspective. As is often the case, we did not have clear evidence about Mrs. Bradford's preferences. Instead, we would have to rely upon Mr. Bradford's best estimate of what she would want in this situation.

Mr. Bradford was primarily concerned about two issues. First, he did not want to disobey Church doctrine. Second, he did not want to give up on her or on his long-held role as her protector.

Discussion

I shared the husband's sense of repulsion and despair: his wife appeared swollen to the point of unrecognizability. It seemed impossible that she could recover. I recognized I was being called to explore the possibility of hastening her death and so could be seen as an executioner. I was, however, comfortable with the judgments of my medical peers, and so I accepted the inevitability of her death. I also agreed with the U.S. legal system, which posits that a termination of life supports would not be "killing her" but rather a valid way to finalize a death that had already been decided.

In working with the husband, I was most concerned with the two issues described in the reconceptualization of the case. I understood his desire not to abandon his wife during her time of greatest need. After meeting with him for a few minutes, however, I felt confident that we could discuss his protectiveness and that I could likely help him understand that he would be most helpful to her by letting go. I was not heavily invested in this point of view and could imagine a conflicting scenario, but my first take on Mr. Bradford was of a practical man who was rapidly accepting the inevitability of his wife's death.

I had more inhibitions about exploring Catholic doctrine. Strong religious belief not only is admirable but has been shown to be very helpful in times of crisis. When I think of making life-and-death decisions in the SICU, however, my own bias is to turn toward ethical principles, the law, and the medical profession rather than the Catholic Church. Further, I wondered how I could enter into a worldview that was distant from my own and that did not seem open to a psychological exploration of the issues.

I was most intrigued, however, by my interaction with the doctors, nurses, and social workers on the unit. In particular, the staff was quite mixed as to the reasonableness of the ongoing treatment and of the psychiatric consultation. Their responses illustrate a theory of group process that can be very helpful in looking at staff response to stressful situations.

Some staff members felt that the husband's decision was well thought out and should be respected without intervention. While this group felt unhappily passive in the face of a hopeless medical situation, they saw no alternative to maintaining their usual standard of care. Some in this group believed that a senior physician—who was on vacation—might be able to turn the situation around, either by devising a treatment strategy or by using his powers of persuasion, but each member of this group felt personally powerless to help the situation.

A second group, which consisted of two medical students, believed that *more* should be done for the patient, not less. Despite several days of hearing a uniformly discouraging prognosis from senior clinicians, the students continued to perform exhaustive literature reviews with the hope of uncovering a hitherto unknown treatment.

A third group eyed the psychiatric consultant with open skepticism. They believed that they did not need an outside consultant, that the situation—while an unhappy one—was essentially their stock in trade. They didn't need a psychiatrist to get involved when the patient, herself, was unconscious. This third group did not express these feelings directly—we work in a collegial hospital—but to each other, and their concerns were uncharacteristically mistrustful in tone. In particular, they believed that the consultation reflected an effort to coerce the husband into doing something that he didn't want to do. At least one staff member wondered if the psychiatry consult was an attempt to

reduce the length of stay by killing off a terminal patient. As is known by most hospital staff, insurance reimbursement for many patients is tied to the length of stay. Assuming a given diagnosis, shorter stays increase hospital profit. It is only a slight exaggeration to say that this latter group believed that the psychiatric consultation was intended to kill off a money-losing patient. One staff member joked that the consultation could—in itself—be considered a case of malpractice. The third group seemed to fall into the mistrustful stance because they didn't want to be seen as killers or executioners.

This situation presents a useful segue into a discussion of group dynamics. It should be first noted that each member of the treating team was quite focused on taking good care of this dying woman, and even though the team can be subdivided into smaller components, the actual care of the woman appeared highly professional. Nevertheless, we can see that one subgroup of the intensive care team felt demoralized. A second felt oddly optimistic and hypomanically energetic. A third felt unusually wary. They seemed to believe that their desire to "execute" the patient would lead to external retribution.

Interestingly, these subgroups conform to the three basic responses that tend to derail the conscious working function of a group. It doesn't matter whether the group is found in a Wall Street boardroom or on a Little League baseball team. Stressed-out groups tend to pursue unconscious agendas that differ from the actual assigned task (Bion, 1961; Rioch, 1970). Further, each of the characteristic responses can be found in individuals who are approaching a stressful situation, not just in the overall group. And is there a group that faces more stress than health-care providers who have chosen service as their life's work and are then confronted with the challenge of ending another person's life?

The first group felt demoralized about Mrs. Bradford. They made jokes that the director of the SICU had left on his vacation to avoid this "impossible" case. They performed ably, but the clear undertone was discouragement and helplessness. I silently hypothesized that they saw the SICU director as powerful, knowledgeable, and patient, but they feared that their neediness had overwhelmed him and led to his abandonment of them in favor of his vacation. We did not discuss this hypothesis—the SICU was not group therapy—but their uncharacteristic helplessness and demoralization was fairly obvious. They hoped for the return of their powerful leader but doubted if even he could make a difference. They resented me, a pale imitation of their regular leader.

The second group used a different constellation of defenses to face their depressive and anxious feelings. They longed for an external solution, but instead of behaving with glum passivity, they acted with manic zeal. In this particular SICU setting, we saw the two medical students pairing up to attack the medical literature. Their optimism was useful to an extent, and it is such hopefulness that can give rise to medical discoveries and maintain group spirit. In this case, however, their pairing allowed them to avoid the sad reality of this patient's future. Further, their relentless optimism lacked reflective insight and was imbued with criticism of other members of their team. This manic response to depressive anxiety is known within the group process literature as the "pairing" or romantic group.

The final group was more explicitly hostile toward the psychiatric consultation. They viewed the decision as being clear. The proxy had refused DNR, so the patient should receive all available treatments. I was struck by this group's certainty in the face of an

impossible situation. They viewed me with thinly veiled hostility and criticism that was both surprising and uncharacteristic. When I mulled over the situation, I hypothesized that this non-reflective view of right and wrong helped them ease their inevitable anxiety. My entrance into the fray allowed them to take their own unacceptable feelings—that the patient be allowed to die—and project them onto me. They then assumed that I would be (and should be) attacked by the legal system for expediting an execution.

These group dynamics can also be seen in each of us. When we face a particularly stressful patient, for example, each of us might experience an oscillating set of reactions. We will likely get our work done, but depending on the situation, we might feel one or all of these reactions. For example, when I saw this patient, I quickly felt hopeless that I could help. I felt buoyed by the enthusiasm of the medical students and felt, transiently, that perhaps there was something that the team had missed. Maybe we could help her survive. And I felt that if I were successful at helping her die without ongoing, horrible pain, then I might be party to illicit manipulation of the grieving husband. In a sense, I identified with each of the three subgroups. I also felt a series of reactions to these initial feelings, reactions that were less than completely charitable. For example, I felt that the demoralized group should try harder, that the medical students were naive, and that the hostile group was paranoid and simpleminded.

The Intervention

As I recognized the characteristic responses within myself, and recognized the characteristic responses within the team, I was able to step back from these regressive, disabling tendencies and do my job. I was not being asked to save the dying woman or to manipulate the husband into doing our bidding. I was not being asked to blindly critique the staff or do group psychotherapy. My job was to address the situation and try to help create a reasonable resolution. Helping create reasonable resolutions seemed far easier than performing medical miracles or doing "wild analysis" on unsuspecting hospital employees.

In talking to the husband, it became clear that he was overwhelmed by his wife's illness. While they had discussed their distaste for hastened death, their discussions had lasted a few moments and taken place many years before. Neither of them had previously seen the inside of a modern SICU. Neither of them had thought through the reality of ongoing, futile, painful medical procedures. And neither of them was as blindly religious as had been initially presented. They viewed themselves as strongly Catholic, but like many American Catholics, their views on a variety of ethical topics were somewhat different from the views endorsed by the Vatican. Because religion tends to be viewed as sacrosanct, the medical team had not explored Mr. Bradford's actual views on the termination of life supports. Instead, they had accepted his initial statement as his final word. Like most patients, the Bradfords had not previously developed their "final word" on the subject but needed encouragement to explore the current options. In discussing the situation with Mr. Bradford, I was reminded that "breaking bad news" may seem overwhelming to everyone concerned. It is often easier to *break down* the bad news into its component parts. For this husband, some of the bad news was that his wife was suddenly going to die. They had not been able to have children. She was his best friend and best ally. He was soon to be alone in the world.

A second piece of bad news was that he had promised to take care of her, and he felt powerless and upset that he was not reducing her pain and suffering when she most needed his help. While a proxy is supposed to make medical decisions based on the patient's likely preference rather than his own preference, Mrs. Bradford had generally ceded important issues to him. And, with regard to the current situation, he simply didn't know what she would want. He had made many difficult decisions in his life, he told me, but he had generally accumulated enough information to make the decision obvious. In this case, the decision remained obscure. The only way to help her would be to hasten her death, but such an action would put him at odds with his Church. Their faith was the only other thing he could count on. He asked me if the Church would reject him if he followed his heart and allowed her to die. Instead of assuming responsibilities that transcended my own expertise and authority, I referred him to experts. He talked to his longtime priest on the phone. One of our hospital-based priests came to the SICU to see Mrs. Bradford and then met with her husband in a nearby office. I don't know the content of their discussions, but within an hour, Mr. Bradford had signed the DNR order and allowed the staff to back off on some of the medications. His wife soon died. When he left, he was tearful but said he knew he'd made the right decision.

The case of Mrs. Bradford worked out as well as could be expected. She was able to die without prolonging her pain, and her husband was able to walk away without feeling like he was torturing her. I felt a bit like an executioner but did so with the awareness that no alternative was preferable. By breaking down the bad news and looking respectfully at the difficulties, the problem unraveled in a way that seemed to best reflect the wishes of Mr. and Mrs. Bradford. The medical outcome differed from that of Mrs. Alexander, but the process was similar.

Case 3: Abandonment

Background

My psychiatric consultation team was asked to assess the capacity of Dr. Collins, a 51-year-old woman with metastatic ovarian cancer who was repetitively refusing medical interventions. Long divorced, Dr. Collins had one adult child from whom she was estranged. She was a highly successful academic whose papers were known to me. Her only visitor was her personal assistant.

Reason for the Consultation

The patient's irritability and attention to detail was impeding treatment. Each minor medication change and diagnostic test required multiple, lengthy discussions with her physicians. Despite much effort, she frequently refused interventions at the last minute, leading to the question of whether or not she possessed the mental capacity to make such decisions.

The patient had been irritable and unhappy for many months. The psychiatric consultation was called to improve compliance and to minimize "waste" of the staff's time. The staff felt uncharacteristically ready to abandon this patient.

Initial Fact Finding

Dr. Collins was initially wary about a psychiatric consultant and appeared both sad and irritable. She became enthusiastic, however, as she discussed the many failings of the hospital, the staff, the physicians, and the field of psychiatry. In so doing, her affect brightened, and she spoke with speed and logic. She denied self-criticism and suicidality, but she admitted to feeling hopeless. Her self-esteem was tied heavily to her work, and she believed that she had inadequate time to write another book or teach another class. She freely admitted to feeling lonely. She explained that all of her friends and coworkers had decided to go on with their busy lives and that she was annoyed by all of them anyway. She didn't recall exactly why she was fighting with her only relative, her daughter, but she was adamant that it had been the daughter's fault. In discussing past times of crisis, Dr. Collins described buckling down, working hard, and maintaining bantering sarcasm with colleagues.

Reconceptualization of the Consultation

The mental capacity question was straightforward: the patient clearly possessed the cognitive capacity and emotional flexibility to accept and refuse medical interventions. Further, she was careful to refuse procedures, such as blood draws and a chest X-ray, that were of minimal importance to her care. It appeared that Dr. Collins's noncompliance stemmed from her desire to control some vestige of her life, and her irritability and sadness stemmed from the losses associated with terminal illness. Her view of herself had changed, and she saw no way to resume her previous trajectory. Further, her university had long afforded her enough social life so that her personal isolation could be ignored. In the hospital, without students, colleagues, and work, her ineffectual loneliness was profound. Further, she had been mistrustful of people throughout her life, and during times of crisis, she tended to become frankly but transiently regressed and paranoid. Her treatment refusal was related to these psychological processes.

Discussion

When first called to see Dr. Collins, I was unsure that I could be of help. Not only did she lack complaints that could be treated by medications, she was overtly unpleasant to all of the staff. With such patients, battle over control will be bloody, regardless of who wins. Unlike the staff, however, I lacked an agenda of efficiency. I was able to avoid the first countertransference obstacle with Dr. Collins: I wasn't going to get frustrated and angry when she refused to do the bidding of the hospital. This freed us to talk about a wide range of political, personal, and social issues, and this allowed her to show a side of herself that was clever and curious.

I found it easy to banter with her, and I enjoyed hearing her perspective on a variety of issues, including her harsh views of my own profession. In that way, I settled in as an attentive student. At the same time, she needed to see me as her peer and even as her mentor. I noticed that she seemed especially eager for me to be proud of her and to see her professional accomplishments in the best possible light. Interestingly, her assistant mentioned that this eagerness for praise was unusual; she was ordinarily dismissive of such a need.

Therapeutic fit is important, and not all patients work equally well with all therapists. In this case, I was genuinely curious about her life and about her perspectives. With other dying people, I have learned about pre-Holocaust Poland, the electricians' union, and how to spin a bowling ball. These efforts at understanding are important for three related psychodynamic reasons. First, they provide an important mirroring experience for the patient who feels like he or she is falling apart (Kohut, 1977). Second, the creation of a dynamic life narrative can allow the dying patient to regain a sense of cohesion during a time of disintegration (Perry, Cooper, & Michels, 1987). And, just as importantly, the effort to create a life story allows the consultant to maintain a respectful alliance with someone for whom the typical response is abandonment. The way in which we can help the patient create a personal narrative varies widely. In Dr. Collins's case, she and I talked about her having become a single parent, while she was still in graduate school, and how this might have impacted her child-rearing as well as some of her particular research topics. I pursued this information from within a medical, psychoanalytic tradition that is familiar to me (Viederman & Perry, 1980), but there are a variety of ways in which a life story can be told. While beyond the scope of this chapter, the underlying principle is, I think, to retain a respectful, tactful curiosity while pursuing important structural elements in the patient's life. Patients tend to feel quite relieved to talk about their lives, and if they don't want to talk, they generally make this quite clear.

Like most seriously ill patients, Dr. Collins was experiencing a regression that was, in her case, leading to bitter criticism of everyone around her. She had lost the use of her best defenses, which included the ability to critically and playfully look at issues from multiple perspectives, and this had led to the loss of the banter that had held her close to many of the people in her world. Her isolating mistrust created a self-perpetuating spiral of abandonment that was showing no signs of reversing itself.

The Intervention

I explained this theory to Dr. Collins during our second meeting. To try to turn the spiral around, I made two suggestions. First, I asked Dr. Collins to write a 500-word essay on the failings of the hospital. Second, I asked her to call her daughter, explain that she was ill, and apologize for being a difficult parent. Dr. Collins laughingly balked at these requests, but as I left her room, I explained that I'd be back the next day to assess her progress.

I rarely give homework assignments but did so in this case for several reasons. First, Dr. Collins was bored and angry, and the writing assignment was intended to give her a task that could help her use her energy in a potentially positive way. Focused scholarship had been one of her main modes of binding anxiety throughout her life, and I hoped that she would find a writing task to be a means for her to regain perceptive curiosity. I was seeing such curiosity during our sessions, but she was spending most of her days staring at a blank wall and criticizing staff. I was only able to suggest such a thing because we had developed an alliance immediately upon meeting. Without a certain degree of trust, any such suggestions would be ineffective. In addition, suggestions should be tailored to the patient, and this professor-patient seemed a natural fit for a writing assignment.

My suggestion for her to call her daughter was even less typical for me, and I would have backed off that request if the patient had not been receptive. It was my opinion that

Dr. Collins was feeling unduly isolated and had a limited time in which to work out this parent-child conflict. Such a request—while unusual—might kick-start their relationship.

In regard to both assignments, I was taking advantage of an alliance that grew quickly out of a parent-child sort of relationship. Dr. Collins was regressed in the context of her hospitalization and terminal illness. This regression had led primarily to irritable mistrust. In addition, however, in the safety of our relationship, Dr. Collins demonstrated a baseline level of trust that stemmed from the early parent-child interaction. Also called the unobjectionable positive transference, it allowed her to trust me after we had spent only a few minutes together. I think that her trust in me was reciprocated within me by my unusually parental suggestion. Further, it seems possible that I was compelled to attempt a parent-child reconciliation because I was feeling both roles with this woman.

During the ensuing three days, Dr. Collins began work on her essay. She complained about the assignment, but piles of paper grew upon her bed, and she quit being a nuisance to the staff. The medical team was quite pleased with her changed appearance. On Friday, I told her that both assignments were due on Monday. She complained that she couldn't finish the paper and wouldn't apologize to her daughter. I explained that she had a choice, but that if she didn't finish them by Monday, she'd get a failing grade for her hospitalization.

When I returned on Monday, I learned that Dr. Collins had died.

Three weeks after Dr. Collins's death, I received a call from her daughter. She wanted to have a session with me. I hesitated but agreed, adding that I wouldn't be able to reveal what her mother and I had talked about but would be happy to hear what she had to say. When the daughter arrived in my office, I was most struck by the rapid, confident, articulate speech patterns that they shared. Through tears, the daughter explained that her mother had called the day before she had died and had apologized for being mean. Dr. Collins had then far surpassed my homework assignment and had explained that she had been tough on herself and her daughter because she believed that the world was a hard place. She traced this back to her own mother's early death and her husband's abandonment of them when the daughter was a baby. She had believed that she would be a better role model than nurturer and that she was intensely proud of the daughter's accomplishments but even more proud that the daughter had somehow learned to be a kinder version of herself. The mother had then told her daughter that she was just following her shrink's orders and not to take any of it too seriously. The daughter had thought to call me when she found the written homework assignment among her mother's hospital belongings.

I was struck and touched, of course, by the effectiveness of the intervention with Dr. Collins and was reminded that almost all of the actual insight was supplied by the patient. I was reassured that psychodynamics has much to offer in the work with dying patients, especially in terms of helping people put their lives into a cohesive narrative. I was reminded that work with the dying is also for the living. And—by reading a messy homework assignment that focused on suboptimal food—I was reminded that people can be at their very best even when they are in other ways at their very worst.

Conclusion

Feelings of torture, execution, and abandonment are three ways in which health-care workers can react to the dying patient. There are many other ways, and any one staff

member can feel any combination of reactions based both on the patient and on his or her own personal psychology. Given the intensity and sadness that are part of the dying process, disturbingly conflicted reactions are normal and commonplace. Awareness of one's own reactions can be helpful for multiple reasons. Such self-awareness allows us, for example, to take a step back and not get swept away by the currents of subconscious passion that can arise both within us and within the group in which we work. Awareness of possible subconscious group processes allows us to shrug off other people's views of us and do our jobs without internalizing their projections and allowing them to obstruct our work. Most importantly, acceptance of the reality of mixed feelings allows us to provide better service to the patients who need our help. Ironically, then, our awareness of our feelings of torture, execution, and abandonment allow us to provide more humane and kind care to the people who have entrusted us with their lives and their deaths.

COUNTERTRANSFERENCE TOOL BOX:

Attitudes Toward Death

Recall your last three patients who were ill or dying. Using an identifying initial for each, write their initials next to the words that seem to describe their palliative or end-of-life processes. Ask yourself if each particular constellation evoked similar responses in you; how did you react to each different experience? How might your unconscious expectations be influencing your work, your team, and your work environment—either positively or negatively? Compare this list with the Triangles of Countertransference Tool Box in Chapter 19.

_____ ending
_____ pain
_____ flowers
_____ beginning
_____ joy
_____ rejuvenate
_____ uncertainty
_____ nature
_____ warmth
_____ peace
_____ nothingness
_____ clouds
_____ winter
_____ happy
_____ night
_____ stars
_____ away
_____ ominous
_____ suffering
_____ sunshine

_____ calm
_____ good
_____ threatening
_____ soft
_____ evil
_____ beautiful
_____ regretful
_____ sick
_____ bright
_____ cruel
_____ forever
_____ morbid
_____ innocent
_____ darkness
_____ unexpected
_____ remorse
_____ hospital
_____ violence
_____ loneliness
_____ separation

_____ rest
_____ scary
_____ loss
_____ heaven
_____ time
_____ light
_____ gone
_____ final
_____ black
_____ kind
_____ relief
_____ fear
_____ anxiety
_____ sweet
_____ putrid
_____ hymn
_____ music
_____ sacred
_____ closure
_____ other

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8 The Horror and Helplessness of Violent Death

Edward K. Rynearson, Therese A. Johnson, and Fanny Correa

The timeless human fear of dying and death follows a rough chronology—absent in the very young who are unaware of death, denied in the toddler whose awareness is processed magically, avoided in the adolescent whose potential for dying is muffled by the intense drive for vigorous individuality, acknowledged in the young adult, strong and prevailing in the parent who worries how his or her death might impact others, lessened and at times virtually absent in the geriatric who is suffering or disabled.

On what do we base this fear? Our unique, human awareness of death carries us into a quagmire of confusion because sentience and reasoning disintegrate at the moment of dying. What we claim to "know" of death can be no more than presumptive. Cultural, spiritual, and religious beliefs of death may comfort us with the promise of some transcendence beyond dying, if we choose to believe them, but such transcendental paradigms define death through living terminology—a "reunion" or "reintegration" of our spirit or body in something perpetual and coherent. Life and death become complementary—connected in some incomprehensible but vital way—pointing us beyond our fear of disintegrating in the disintegration of death itself.

The fear accompanying our awareness of *violent* death is not cushioned by a complementary transcendence. Violent death narrows and spirals into an awareness of helpless terror—a "black hole" of painful chaos. The fear of violent death is circumscribed to the dying itself, replayed as a vivid, imaginary drama of a killing. Killing is unnatural and reprehensible at any age and in any place, caused by human intent (homicide, suicide, genocide, or terrorism) or negligence (accident) and perpetrated upon someone who was terrorized and helpless as he or she was dying. This is altogether different than dying from something "impersonal"—a disease that follows a longer course and allows the dying individual and surrounding family members time and space to prepare for the inevitability of death.

When someone dies violently, he or she is usually alone and unsupported. Ninety-five percent of violent deaths occur without the presence of family or loved ones (Rynearson, 2001). Some natural deaths—vascular deaths from stroke, myocardial infarction, or ruptured aneurysm—may occur with limitations of time (immediacy) and space (isolation), and while sudden and traumatic for loved ones because of the immediacy and isolation, this form of dying is "natural"—no one is responsible for a killing.

The "Public" Inquisition of Violent Death

After a natural death there is little public recounting of the dying beyond an obituary in the paper and announcement of the memorial service. Respect for the family's need for privacy is paramount.

This is not so with violent death: with violent dying there is an inevitable social outcry and response from police, then the media, the medical examiner, and detectives, and an even longer process of inquiry and judgment if someone is apprehended, tried, and imprisoned. When someone is killed, the surrounding community must intercede, for this is a dying that cannot be seamlessly integrated with time and commemorative death rituals. Killing is so horrific and reprehensible that it must be stopped—so it won't happen to the rest of us. Each medical and legal agency constructs a different version of the killing designed to establish a logical reenactment of the external drama to establish the "who, what, when, where, and why" of the dying. This public processing of the violent death intrudes upon the family's private recounting of the life and death of their loved one. The public inquiry can become a frustrating ordeal for the family members who seek information, justice, and redemption for the killing but, at the same time, need to maintain a nurturing and commemorative memory of the deceased. The public reenactment and retelling of the killing may reinforce terror and helplessness in surviving family members.

Basics of Intervention

The Story

A fundamental way that the mind first tries to accommodate to an overwhelming event is to imagine and then retell it as a story. Constructing a story around an experience of any kind brings order and meaning. A story has a beginning, middle, and end—with characters who share and mutually resolve needs and conflicts—and the story celebrates and endorses social values at the same time. After a violent death, the mind reflexively relives the dying moments of the person as a story, and because there was a caring relationship, it is intolerable to imagine the terror and helplessness. There are few ways that the violent death of a loved one can end with meaning—only an empty absurdity: "this never should have happened."

The reenactment story of the violent death is a primary response, and it recurs as a repetitive thought, flashback, or nightmare for days or weeks after the death, for example, day and night dreams of a body falling from the 40th floor, faceless, but knowing it is your father.

There are also compensatory or secondary stories whose purpose is to make the dying "unhappen." They often occur in combination rather than alone:

(a) Story of remorse—*"I am somehow responsible for the dying. I should have prevented it from happening: I wish that I had died instead."*
(b) Story of retaliation—*"Someone else is responsible for the dying. I am going to find that person and get even."*

(c) Story of rescue—*"I imagine how I could have stopped the dying and saved my loved one."*
(d) Story of reunion—*"I need my loved one here with me, so I can be safe from what's happened."*
(e) Story of protection—*"I can't allow this to happen to anyone else whom I love. I need to keep my loved ones close to me so that I know we are safe."*

These repetitive stories fill the mind during the first days and weeks of traumatic grief. In time, with the support of family and friends and the finality of the funeral and memorial service, the memory of the violent death and its stories fade.

Most people are able to accommodate to this horrific loss by engaging in spontaneous restorative retelling. This is accomplished through meaningful rituals and commemoration of the deceased with friends and family. In spontaneous, restorative retelling, the living memory of the person gains ascendancy and becomes stronger than the memory of his or her dying; for example, *"I remember when she would hum as we washed and dried dishes together."* Each person must find a way to reestablish him- or herself in the life of the person who died, and it is the realignment of the "violent dying" to "our living" that creates a restorative direction in the retelling.

Sometimes the public retelling of the dying by the media, police, and courts is inaccurate, insensitive, and misleading and complicates the private retelling. It is difficult for the friend or family member to finally accommodate to the dying until this public processing of the dying story has been completed. It is more the rule than the exception that families postpone their "giving over to" grief until after the scales of justice have been weighed. Their defenses can finally relax; they can begin to address the rest of their lives without the deceased. With no one left to fight, they are alone with their loss.

Separation and Trauma Distress

Trauma distress and separation distress are concurrent responses to violent death. While the thoughts, feelings, and behaviors of trauma and separation distress are not specific, they are roughly separable into two syndromes, shown in Table 8.1.

Trauma distress is associated with repetitive, intrusive, and enervating thoughts, images, and stories of the intersecting memories of the deceased, the dying, and the self. These include: (a) dysfunctional images of the deceased that contain their terror and helplessness as they were dying, (b) dysfunctional images of the dying that recur as an involuntary witnessing of a disintegratory drama that cannot be controlled, and

Table 8.1

	Trauma Distress	*Separation Distress*
Thoughts	Reenactment	Reunion
Feelings	Fear/Shame	Longing
Behavior	Avoidance	Searching

(c) dysfunctional images of the self that persist as being remorseful, retaliatory, rescuing, and helpless without the deceased or ultimately protective of remaining friends and family members.

Shame is a prominent feeling related with a dysfunctional image of the self and is often seen only after a violent death (as opposed to a natural dying). Shame arises from the stigma still strongly associated with death by suicide or homicide as if the deceased and bereaved are viewed in a *less than* or *deserved of* light. Shame is also an implicit experience in the bereaveds' attempt to come to grips with the magical thought that they could have prevented the death by somehow *knowing* and thereby taking the appropriate action. Understand that this is an experience by families, friends, and possibly professionals who had treated the deceased prior to their death.

Trauma distress takes neuropsychological precedence over separation distress. Because the dysfunctional images and stories are primarily related to the trauma of the dying, supportive strategies to deal with trauma distress are the initial goals of intervention.

Before dealing with separation distress, someone who is highly traumatized by violent death needs to be stabilized. Early intervention must focus on restoring the client's capacity for maintaining a sense of *safety, separateness, and autonomy* from the dying experience. These preverbal capacities comprise *resilience*—and without them the individual is overwhelmed in the dying imagery and stories. Without resilience, their separate individuality dissolves into the nameless swirl of terror and helplessness—as did the deceased.

Resilient Attitudes

As violent death is inherently disintegrative and incoherent, the therapist and patient first establish a safe psychological "space" for the telling and retelling of the compensatory and restorative stories—separated from the dying imagery of the deceased. In addition to the psychological space achieved through the creation of a trusted therapeutic alliance, one way to establish this safety is for the therapist to clarify several working "attitudes":

> *"We need to help you focus less on the dying of your loved one—and more on their living."*
> *"Try not to think your way out of this—you won't find answers to all the whys—we need to help you reconnect with life where you can find some answers."*
> *"Inevitably, you will remain changed by what has happened—nothing can be as certain as it was before."*

This perspective differs from the more familiar model of grief therapy, which recommends a focus upon, and catharsis of, unresolved feelings of mourning and ambivalence about the loss of the loved one. It also differs from the goals of trauma therapies, many of which insist upon graduated exposure to the traumatic event (the violent death of the loved one). In contrast, the early staging of a resilient "attitude" clarifies for the patient and the therapist that the violent death of a loved one places limitations on what can be tolerated: *"You need to define yourself apart from the violent death—you can't stay there."*

This directive by the therapist gives the client permission to seek relief and possible hope and transcendence through the story of the living. (*Note*: there are instances in which clients are so overwhelmed by the trauma imagery that it is necessary to first reduce traumatic distress by utilizing trauma-informed behavioral interventions that de-escalate anxiety and hyperarousal, so stories of the living can be accessed.)

Establishing a tolerance for ambiguity relieves the therapist and patient of the unrealistic goals of "cure" or "recovery." There can be no return of certainty. The aftermath of threatened mortality, suffering, and powerlessness following the violent death of a loved one cannot be resolved. There is no resolution for existential dilemmas such as these.

Coping with the existential dilemma of continuing to live beyond the identification with violent death is ambiguous at best. Thus, the goals of intervention after the violent death of a loved one are necessarily modest and limited to: (a) moderating the separation and trauma distress through sessions that reinforce resilience, stress management, and guided imagery; (b) retelling and revising the role of the patient in the story of the dying often through sessions that focus on the commemoration of the life of the deceased before focusing on the dying imagery; and (c) reestablishing the patient in a vital connection with his or her ongoing life outside of therapy. Resilience is reestablished through the proverbial "putting one foot in front of the other," and as each patient is able to increase his or her tolerance for the activities of living, he or she begins to regain lost perspective.

This is not the time to search out and uncover previous traumas or painful losses. Adjusting to the violent death of a loved one consumes an enormous amount of concentration and energy. Focusing on problems that occurred before the dying puts the survivor at risk of diverging from the essential task of redefining oneself apart from the violent death.[1]

Potential for Countertransference in Traumatic Loss Bereavement

Posttraumatic recollections and emotions can weigh heavily on professionals creating a vulnerability to strong, often unconscious feelings and reactions such as rage, bystander's guilt, dread, horror, and a sense of privileged voyeurism. Some or all of these countertransference responses may be elicited in the helper—whether early responder, medical provider, chaplain, social worker, or therapist.

"Six degrees of separation" is a reference to hypothetical degrees of separating one's self from an event and aptly illustrates the helping professional's position in response to violent death. These degrees of separation determine the potential for an unwitting acting out of countertransference feelings in traumatic loss work. Think of the professionals who are usually involved in a traumatic death: emergency personnel, chaplains and clergy, medical examiners, police, hospital staff, lawyers, victim advocates, counselors, and therapists. Every one of these professionals will have played a different role in the discovery process of the death. Unless they are new to their position, most helping professionals have developed a fairly complex system for coping with the pain, fear, and tragedy of violent death. This system provides for degrees of separation that help the professional to define the victim and family as "them" versus "us," and with this distinction the propensity toward devaluation or negative judgment can either increase or decrease, impacting the quality of service proffered.

The term "degrees of separation" denotes variables that allow for a psychological distancing from the event *and* the victims. These variables include: proximity to the death (present at the death scene or later notified), proximity to the survivors (working directly with or indirectly), tasks or responsibilities, degree of control, past experiences, and identification with victim or survivors. For example, the health-care team's best defense against identifying with the victim is meeting the immediate medical need; the victim becomes a "gunshot wound," not someone's brother. The police, medical examiner, and legal team focus on the investigation and bringing the perpetrators to justice. These professionals utilize the variables of task control and past experiences to defend against the pathos of human vulnerability. They also may use "gallows humor" to minimize the impact of the horror they experience. If their contact with the bereaved is relatively brief and focused on accomplishing their duties, their secondary traumatization and potential for countertransference acting out will be minimal. If there are extenuating circumstances that pierce their professional demeanor, for example, identifying with the victim or with the survivors, "them" changes to "could have been me," and the potential for acting out increases. The likelihood of identifying with the victim and survivors increases with (a) the length or depth of contact with them, (b) the degree to which the personal characteristics of the helper match those of the victim (e.g., same job, age, race, etc.), or (c) the degree to which the professional has personally experienced a similar loss.

Another group of professionals, defined by their task of supporting the survivors through "being," not "doing," comprise another category; these are the chaplains, clergy, and therapists who inform and support the bereaved. Their degrees of separation are fewer as they do not have the concrete task of binding a wound, handing out medication, or solving the crime, all of which can serve as distractions or defenses against feelings of helplessness and identification. There is a greater emphasis on witnessing or helping the survivor tolerate the pain instead of actively controlling the mitigation of it, like a doctor or lawyer would. Their contacts with the death facts, the bereaved, and the subsequent unfolding of the story are often more frequent, lengthy, and multidimensional. This greater degree of interaction and use of self to understand, empathize, and comfort leads to an even greater potential for countertransference as it reduces the possibility for psychological distancing in defending against our basic human terror of being helpless.

In the case illustrations that follow, we describe some of the countertransference reactions unique to violent death. The first two cases address early interventions and their unique countertransference issues: Therese identifies some unfortunate reactions by initial incident responders (emergency personnel) that had disastrous consequences; Fanny details the therapist's struggle with "empathic enmeshment" and the role of the "rescuer." The last case illustrates countertransference in longer-term work.

Addressing Countertransference in Early Interventions

Initial Responders

When initial responders (emergency personnel) are called to the scene of a violent death involving adolescents, the potential for countertransference is significant. We all remember those risks we took as teenagers that we were lucky enough to walk away

from. It is doubly hard for responders who have teen children because they are aware of the potential for risk and harm in a developmental stage that seems to invite it.

> Bob and Tom were two 16-year-old survivors of a recent tragedy in which one of their best friends died from a fall snowboarding in an off-limits area. It was the end of a beautiful sunny day, and they were in search of one more run before heading home. The fresh snow beckoned beyond the boundary line, and the group of three boys ducked under to take advantage of it. Jake, as always, led the way. In less than a heartbeat, it happened: one minute he was a few yards ahead, and before another breath could be taken, he had disappeared. Bob and Tom laughingly started to yell for him, but with no response, their hearts began beating a little faster. They reached the tree line and realized the drop off. There was the snowboard with one foot attached sticking out from the snow. After what seemed hours, but were only minutes, they dug Jake out from beneath the snow, but he was not breathing. They performed CPR until someone in the area heard their calls and came to assist. When ski patrol arrived it was determined that resuscitation was futile. The boys, in shock and with frozen fingers, accompanied the stretcher with their friend's covered body off the mountain. They were met by other emergency personnel and the words, "Well, this should teach you boys a good lesson about skiing out of bounds!" These words, hastily spoken, will forever hauntingly echo in the nightmarish reality of that day's events.
>
> Guilt is one of the predominant emotions experienced by survivors of traumatic death, and logic and reassurance do absolutely nothing to assuage it. When these boys retold their story to me in therapy, my internal reaction was one of strong anger toward the person who had uttered those words. I (TAJ) was able to resist the urge to react from this strong countertransference, and instead of loudly castigating the judgmental responder and instantly casting myself in the "good guy" role, all I allowed them to see was a closing of my eyes and a sigh. After a long silence I spoke to the role of guilt and anger after a traumatic loss. We spoke at length about these difficult feelings, and ultimately our conversation led to identifying how other survivors have used it to fuel something important in a way of legacy, for example, the grassroots start of Mothers Against Drunk Drivers. This reframing, without denial of their truth, would become another thread in the restorative retelling of their story; it allowed them to not end the story there, with the burden of responsibility for a death, but, rather, to create the potential space for retribution and restoration of meaning.

It is important to note when speaking of the potential transformative powers of grief and loss that one does not deny or disaffirm the clients' expressed current experience of their pain. As for my countertransference reaction of deep anger—I have chosen to direct it positively in speaking out in workshops and now in writing of the negative impact of a few hastily spoken words from someone who should not have sat in judgment. I must also acknowledge that I sat in judgment of this responder and, to be truly honest, must admit my own capacity to "open mouth, insert foot."

Rescue and Enmeshment in Therapy

We have discussed the importance of the early staging of a resilient "attitude," which will in turn set the stage for the grief work and the restorative story. Homicide survivors often are trapped in the past and terrified of the future. Even in the first session, the impact of the horror of the story can leave an imprint on the clinician. It is important for the clinician to be able to understand the complex dynamics of this working relationship and be able to monitor his or her own thoughts, reactions, and feelings. The clinician models a resilient stance by tolerating and not "disintegrating" as the story of horror unfolds. If the therapist cannot maintain this fortitude, the client loses his or her belief that stability and sanity can be reestablished.

If you will, draw this picture in your mind's eye: the therapist is the one standing on the beach throwing out the line to the client, who is struggling deep in the breaking waves of the ocean, resisting the undertow that will take him or her too far out for rescue. If the therapist loses his or her footing and is dragged into the ocean, then both are lost. This metaphor describes the uniqueness of working with survivors of violent death. Because of the violence and the human intent involved, larger-than-life forces subsume the world of the survivor. They can be dragged under water by the horror, the incomprehensiveness of the act, the suddenness of the loss, and the implications of "*what if?*" These forces make the role of the "rescuer" almost an inevitable one for the therapist in the beginning of the therapy. For the therapist who works with traumatic loss, what is of greatest import is not the assumption of the role but knowing when to stop pulling on the rope.

In the following case the therapist (Fanny) is pulled into the ocean of the client's horror:

> Mrs. A. came in for services after the recent murder of her 17-year-old son, her mother, and her father. Mrs. A. was deeply traumatized. The reenactment story she told was filled with horrifying images, feelings of remorse, yearning for reunion with her family, and strong urges to retaliate against those who had perpetrated the crime. The focus of our initial work was to stabilize, restore, and redirect the story of the dying. This restorative retelling was abruptly interrupted when she learned from the autopsy report that her son's skull was being held as evidence. It was two months after the homicide; Mrs. A. was distraught, outraged, and horrified. She began having intrusive images of her son's skull sitting on a shelf awaiting trial. She also recalled a conversation that she had with her son at the driver's license office regarding organ donation in which he told her he was "afraid of leaving body parts behind." Feelings of guilt surfaced: "I have failed as a mother. I could not protect my son. I could not even give him a proper burial and honor his wish to be buried whole."
>
> It was at this time that I (FC) began to feel the tug of empathic enmeshment. Wilson and Lindy (1994) describe this countertransference reaction as one in which the trauma therapist overidentifies with the patient and becomes over involved. This eventually can lead to a loss of boundaries. Overidentification with a client can cause the therapist to feel reluctant to probe more deeply into the client's story often because he or she fears causing the client more pain. It

was my identification with Mrs. A.'s despair and helplessness that created in me an urge to rescue, repair the wound, and make things "right." The horrific image of her son as "the headless horseman" became my image. I became completely enmeshed in this client's horror. I recognized that I felt as helpless as she did and I, too, began to second-guess our legal system. As a clinician, I needed to be impartial. Instead, I found myself criticizing and trying to resolve the problem. As a social worker, I felt it was my responsibility to look into the matter and ensure that procedures were in place to prevent this type of incident from occurring again. I remember how angry I felt that no one seemed interested in looking into the details. I doubted my ability to genuinely help this client.

In observing my own sense of helplessness and rage, I became motivated to gather the key players involved in the case. Together, we held a round-table discussion to look into these matters. In a sense, I took on the role that survivors often do in trying to assure this would never happen again. Feelings of anger and guilt emerged for all the providers involved in her case; these countertransference feelings led us to an unusual alignment of advocacy on behalf of this client and the "headless horseman." It was fortunate that all the systems (medical examiner, the prosecutor's office, homicide detective, crime victims compensation, and a community advocate) drawn into this situation worked together with the client toward a solution to this dilemma.

Once the authorities began the process of releasing her son's remains, the focus of therapy was redirected toward healing rituals. That helped me to reestablish my role as the therapist and relinquish the role of case manager or advocate. I once again felt able to empower the client to focus on the story of the living, not the dying, of her son. For this mother, a sense of purpose emerged as she began to create a scrapbook of memories, a catalog of milestones of her son's life from birth to death. When the time came for exhuming the body, a religious ceremony was performed, and the scrapbook and other personal items were placed in the casket. As disturbing as this experience was for this mother, having the opportunity to prepare for the burial empowered her. "I accomplished my responsibility as a mother and buried him whole as I had promised." Having accomplished this task was restorative not only for this mother but also for all of those involved in her case. We were all able to let go of the anger and the guilt that arose with the identification of her horror.

In the way that empathic enmeshment can draw the professional helper into over involvement and, perhaps, into over helping, an opposite countertransference result can arise with equal voracity: empathic distancing. In this common countertransference response, the professional unconsciously distances him- or herself emotionally to escape the agonizing helplessness and horror of the trauma. This type of emotional self-protection can cause "empathic strain" (Wilson & Lindy, 1994) in the helping relationship, depriving the patient of the deep empathy required to do this work (Fischman, 1991). As Luban and Katz (2006) so pointedly describe the first edition of this book, a turning away can occur in a "don't ask; don't tell" response that may be rationalized as an attempt to protect the patient from future hurt. In reality, this is a coping mechanism disguised to protect the *helper* from overwhelming emotions. As a result, the patient may

unconsciously comply by refraining from burdening the clinician with his or her raw, unadulterated experiences.

In addition to these illustrations of countertransference rage, dread, and horror, Luban and Katz (2006) highlight the fact that clinicians also may experience bystander guilt and/or a privileged voyeurism. This is frequently seen with large-scale disasters, genocide, or acts of terrorism and torture that lead to violent deaths. "I feel an immense sense of guilt because I led a happy and protected childhood while these people suffered so much" (Danieli, 1993, p. 542), or, "I feel awful. She died in the Twin Towers, while I was just heading to my office, two blocks away. Why her and not me?"

With privileged voyeurism, the excitement and "glamour" of working with a survivor of trauma or violent death can cause the clinician to dwell excessively on one or more parts of the patient's experience because of his or her own voyeuristic needs, not because of the patient's. This is especially so when a trauma has been sensationalized or become the subject of inordinate amounts of media attention. What was it really like? How did he survive? If we do not keep our personal curiosity and sense of "titillation" in check, we run the risk of abusing our role and relationship, "thereby perpetuating the traumatic rupture, discontinuity and loss" (Danieli, 1993, p. 545).

Termination of Therapy as a Secondary Loss

In working with survivors of violent death, the client's recovery produces the loss of another relationship: that with their therapist. The therapist simultaneously experiences his or her own anticipatory grieving for the loss of such an intense therapeutic relationship. The therapist may have difficulty accepting that his or her role as rescuer or advocate is no longer needed; he or she may continue to worry about the client and his or her quality of life. As a defense mechanism, some therapists may begin to distance themselves as termination approaches. This countertransference manifests itself when the therapeutic sessions become more of a social hour reflecting on current events or topics not relevant to the traumatic grief. This is often the way clinicians deflect from their own deep feelings of loss of intimacy and loss of this particular relationship; it is also indicative of the therapist's basic separation-attachment style.

The client may collude with this avoidance and distancing as they, too, will suffer another lost relationship. This aspect of the therapy can represent a parallel process with the primary loss, and if the therapist is aware, he or she will note that the client is working through this loss in a similar style. Evidence of the client's basic separation-attachment style, as well as the degree of resumed resilience, will be uncovered in the termination phase. For example, some clients may courageously voice their concern about termination, while others may begin distancing themselves gradually. For some clients, their therapist, once seen as a source of support, may now be a reminder of their pain. One can imagine how the therapist feels when he or she is cast in this role: producer of pain, not assuager of it!

Early on in Fanny's work, she was surprised by this distancing and would question her work: "Did I say or do something wrong?" "Why didn't they say good-bye?" As a therapist, it is important to be able to read the signs and overtly name the ambivalence. As clients begin to reestablish their lives outside of therapy, the therapist also should begin

addressing termination. Because of the feelings involved in the loss of a relationship, the clinician must identify the separation distress distinct to the therapy itself. Denial, anger, and mourning are all part of the process of terminating therapy. If this work does not happen, client progress is impeded.

Ending a therapeutic relationship should be a shared experience highlighting the work accomplished and addressing the transition issues to come. For therapists to be able to manage countertransference, it is vital that they have enough self-awareness to admit to the dynamics occurring in the therapeutic relationship (Salston & Figley, 2003). It is important that therapists control their own anxiety, sustain empathy, and always work toward bringing unconscious material into conscious awareness.

The Conscious Use of Countertransference in Traumatic Loss Counseling

As therapists working with survivors of traumatic and natural loss, we have struggled with maintaining the neutral stance so important to the therapeutic processes of mirroring, reflecting, and transference. It felt so wrong somehow to remain "detached" or "neutral" in the face of such horror, distress, and sadness. Therese recalls her own experience of her first therapy session after the traumatic loss of her sister: "I fled from what I perceived as the intellectual, 'professional' detachment of the psychologist who treated my traumatic grief as a pathology. I desperately needed someone who understood that my response was a normal response to an abnormal event." Therapeutic work with people who have suffered a traumatic loss and who are still struggling with both the trauma distress and the separation distress must be done at a level of empathetic, psychoeducational support. The counseling interventions used are these: listening to the stories of reenactment and resilience, acknowledging the client's felt experience, providing a safe environment, maintaining a stance and belief in the client's resilience, and offering a pitifully small amount of knowledge regarding the impact of trauma on an individual's well-being. This is done in a very interactive manner that does not imply "professional" and "patient."

Countertransference is a very useful tool in this kind of support as the therapist's emotional response is used as a tool to understand and explore the client's reenactment narrative. Attending to the countertransference may also be useful in contributing to the restorative narrative. The following interaction illustrates this:

Client: "I watched as he argued with her—she turned and began to walk away, and I saw him reach into his backpack. He pulled out a gun, pointed, cocked the trigger, and shot her. It didn't seem real. All I could think of was my babies at home and that I would be next, so I ran into the building and hid. I didn't even think of calling for help or doing something to stop what happened until later. Maybe it would have ended differently."

Therapist: *(noting her internal response)*: "I stopped breathing when you described him pulling out the gun; I can't believe you were able to act so decisively in such a terror-filled moment. I think I would have been frozen—paralyzed. That is what I feel here, now."

Client: "I just knew I wanted to live."

Therapist: "You chose life."

This client over the next five years "flirted" with death many times by developing an addiction to pain medication.

Grieving traumatic loss may be complicated by characteristics of the client that are antecedent to or a result of the loss, for example, depression, anxiety, and relationship dynamics that existed between deceased and survivor. Other variables within the grieving process itself, such as extreme avoidance or victimization, can also impede mourning. When these are present, not only does therapy include those counseling skills and interventions identified earlier, but it is advisable to provide a more formal application of therapeutic processes that help uncover the unconscious conflicts and defenses that have created the impediment.

Separate from the complications described, determining whether counseling or therapy is called for is often a matter of listening to your countertransference. As your clients relate their experiences, and they describe a response or thought that seems widely divergent from your own, a red flag should go up. At this point it is helpful to determine whether the divergence can be explained by temperamental differences or possible cultural differences or whether the client consciously understands the relation between the experience and response. An example of the latter would be the reciting of a trauma with little or no affect. This incongruity between experience and response could be an indication that there exist unconscious motivations or defenses that need to be gently explored in a psychodynamic framework.

Therese describes her work with Linda to illustrate:

> Linda wanted to understand why she had difficulty maintaining romantic relationships; they always started with a sense that "this was the one," but after a period of time, they inevitably fizzled into unhappiness and conflict. In her initial history she revealed that her father had been killed when she was 11 years old. She talked about how he was murdered by a business associate, and she also spoke of her experience with her parents' divorce three years previous to the homicide. There was a sense that she had mourned these losses and had integrated them into her life. We began to focus on her current experiences with men and would reflect back to these original losses as appropriate.
>
> It was not until I (TAJ) brought this case to my consultation group six months after its initiation that I realized what I had been missing throughout this therapy: the homicide of long ago had never been truly integrated into Linda's sense of self or world view. I discovered this when, in discussing the case, I could not remember any of the details of the homicide. It was with absolute amazement and embarrassment that I came to see that I had unconsciously colluded with my client in accepting the homicide as simply an "unfortunate" loss that resulted in feelings of abandonment and rejection. In my unconscious collusion, I never examined the cauldron of traumatic imagery she had closed herself off to and the resulting lack of accommodation of her father's dying. What also amazes me is that I intellectually "know" how children can grieve only to the degree that their cognitive and emotional development allow them, yet I did not intuit or deduce that she was still using these same inadequate defenses that she employed as a child.

I felt like a fool, but I also deeply appreciated how my countertransference finally spoke to me. It was at this point that we began the process of looking at her defenses and gently uncovered what had been held in check all these years.

Conclusion

The mental, emotional, psychological, and spiritual accommodation to violent death is a complex process that rarely has an ending or conclusion. Helping professionals, whether initial responders, emergency room nurses, or therapists, play important roles no matter where in the process they enter and exit. To be supportive and grounding to the client, the tasks of the clinician are consistent: (a) stabilize and establish safety, (b) educate as to "normal reactions to abnormal events," (c) reestablish a sense of resilience through focus on the "living story," (d) strengthen coping skills, and (e) help establish short- and long-term self-care patterns.

At the same time, the clinician must stay aware of the subtle and not-so-subtle countertransference responses to this work. This is not always as easy as it seems. Often we need our colleagues, consultants, and supervisors to help us (a) explore our feelings, resistances, and countertransference reactions so that we can use them to inform us, not rule us; (b) establish and maintain rigorous plans of self-care to prevent compassion fatigue and burnout; and (c) diversify our practices by working with clients who have not experienced violent death.

If we practice what we preach, we can be a part of this deeply humbling experience. If we can take a role in the survivor's restorative retelling of a traumatic loss, we can be witness to the resilience of the human spirit even in the face of violence, horror, and traumatic death. If we can tolerate our *own* feelings and countertransference responses, we will have the privilege of accompanying our patient in a restoration of meaning and purpose in life beyond violent death.

Note

1 For the interested reader, Rynearson (2001) has developed time-limited (10–20 sessions) interventions with goal-directed agendas for loved ones after violent death.

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9 Professionalism and Our Humanity

Working With Children in Palliative and End-of-Life Care

Jane Doe and Renee S. Katz

Preface

In anticipation of writing this chapter, we eagerly surveyed nurse colleagues, former nursing supervisors, and several inspiring nursing school professors. We spoke to nurses newer to the field as well as to nurses who have been in the profession for many years. We were eager to hear their input and ideas about the ways in which health-care professionals can get emotionally "hooked" and perhaps even provide care based on their emotional responses—not solely based upon patients' needs. "Yes," they all agreed. "Our personal reactions to caring for seriously ill and dying children certainly can impact our work," but "No," not one experienced nurse could give an example of a time when he or she had had such an experience. In fact, they responded that "that simply does not happen with experienced, professional nurses . . . perhaps with younger colleagues in their early years."

* * * * *

It is 10:30 on a Friday morning. We are meeting our colleague, a pediatric intensive care unit (PICU) nurse, to discuss how personal emotional reactions impact her work with dying children. Our colleague arrives, cheerful, eager to talk, and very self-assured. She has been in the field for close to 20 years. She shares with us several moving examples of children that she and her colleagues have worked with, and we wonder aloud about various difficulties that must have surfaced with the staff. "Oh, no, no, no," she explains. "These are very professional nurses. They are passionate about their work, and they make it their business to provide caring, sensitive support to the children and their families. There is no time and no need to 'process' any pain-filled PICU experiences or gut-wrenching deaths."

We ask about the impact of returning to work day after day while burying grief, trauma, or other uncomfortable feelings raised in the course of her work. "Well, a social worker did show up once to discuss a particularly difficult death with us," she admits. "She wanted us to analyze our feelings. We spent two hours talking—but we did no analyzing of feelings. Physiological systems and technical issues of the death? Yes. Feelings? No way." Then, without missing a beat: "Heck! We are a well-greased machine. We're a caring, loving team. We don't *do* touchy-feely!"

And thus began our journey to understand what exactly is so "terrible" about being honest about the impact of this very sacred, very demanding work. By the end of the hour with our colleague, she admitted, "I guess we *do* need to learn to be human."

"No," we replied. "We just need to *admit* that we are human."

Introduction

Nurses and other helping professionals who care for seriously ill and dying children often experience profound, intense feelings about their work (Matzo & Sherman, 2001; Sourkes, 1992; Vachon, 1987). These emotional responses are important: they help us bond with our patients and empathize with their families. They can also "help" us become involved in ways that aren't quite as helpful as we would want to believe (Lattanzi-Licht, 1991).

Yet, pick up almost any standard nursing or allied health sciences textbook; you would be hard-pressed to find even one chapter devoted to examining the ways in which emotional responses might impact the provision of care. Why is this so? One could speculate that perhaps it is a remnant of the time when the allied health professions had to grow up "in the shadow" of the physician-centered medical system—a system whose culture was, for many years, male dominated and very hierarchical. Nurses, medical social workers, physical therapists, and others had to "prove" their value to the physicians with whom they worked. Stoicism, intellectual understanding (at the expense of emotional understanding), clinical excellence, and a "buck up" attitude were, perhaps, ways to prove one's value. Perhaps they were the means to *survive*.

Nevertheless, no matter how professional or how experienced we are, there are times when we are deeply touched by the children for whom we care. In addition to the many countertransference issues that arise in caring for adult patients, two unique issues specifically contribute to the development of countertransference in the pediatric population. First, the death of a child is "off time." No one is prepared for the death of a child; it is out of the natural order of things. It feels unfair because the child has been deprived of living the full life to which we believe he or she is entitled (Rando, 1984). Second, both patient *and* family are typically the foci of care when caring for children and adolescents coping with serious illness or near the end of life: "the agony of the parents, whose very roles of protecting and nurturing their child are usurped by an illness over which they have no control. . . . [These parents] also need a caregiver's help" (Rando, 1984, p. 368). Thus, countertransference responses to either the patient, the family, or both may result.

The purpose of this chapter is to stimulate awareness of the ways in which professionals who care for seriously ill children may bring their own vulnerabilities, assumptions, and emotions into their work and the ways in which these responses undoubtedly impact the clinical situation. Two cases will serve to illustrate.

Tara

> Tara, a 17-year-old girl with leukemia, was wise beyond her years. Tara's mother, Jane, was a single parent who had years of mental health problems and drug and alcohol addictions. Jane and her children moved frequently, living at times in communes and at other times with relatives—and it was at these times

that Tara was admitted to different hospitals in various geographical locations to treat her leukemia.

Ultimately, Tara was admitted to the intensive care unit (ICU) of a regional medical center. She and her mother quickly learned that her leukemia had progressed significantly and the likelihood of Tara surviving this episode was slim at best. In response to this news, Tara's mother disappeared for several hours (in the weeks to come Jane often would leave the hospital when things got tough). It was during this time that Tara's nurse, Andrea, got to know her.

Tara very clearly articulated to Andrea that if it came to it, she was not afraid of dying, that she had a very strong personal faith, and that she knew God would take care of her. Tara told Andrea that she did not want to undergo unnecessary procedures or treatments that would leave her in pain, nor did she want to suffer any longer than was reasonable. However, Tara was willing to undergo a series of chemotherapy treatments to try to put her cancer into remission because she was greatly concerned about who would care for her mother if she didn't.

Chemotherapy left Tara extraordinarily weak, and ultimately the attempt at remission was unsuccessful. Slowly, Tara's kidneys failed, then her lungs and her heart. She survived on continuous dialysis, mechanical ventilation, and intravenous infusions of life-sustaining medications. Throughout her ordeal, Tara acted strong around her mother and would cry silently when alone with her nurse. It seemed that the harder things got for Tara, the more often her mother was absent from her bedside.

A few weeks into Tara's treatment, her older brother, Greg, showed up at the hospital after being released from a stay in jail. With his arrival, a care conference was called for Tara's family. The intensivists, oncologists, a social worker, and nurses were all present and provided a detailed update on Tara's condition. The family was told that further chemotherapy could not be provided to Tara because her organs were failing. She was dying. Greg, who held Tara's power of attorney, told the staff to "do whatever they needed to do to keep her alive" as he believed that Tara would be able to recover. Denial is often the response of loved ones when given the news that a child is doing poorly. Andrea realized that it was part of her job to support Tara and her family as they came to grips with this devastating news.

During Tara's final weeks on the unit, her liver failed and she slipped into a metabolic coma. Andrea remained diligent in her nursing duties and attentive to Tara's multiple needs. It was her impression that due to the unrelenting progress of her leukemia, Tara was in a great deal of bone pain as evidenced by her grimaces, moaning, and tears. "Had we just turned off the dialysis machine, the toxins in her body would have built up, and she would have slipped away," Andrea noted. But Greg insisted that the staff forge on and provide all the life support necessary to keep his sister alive. He was reluctant to allow pain medications to be administered for fear of addiction or a hastening of Tara's death. Andrea felt helpless to provide Tara the peaceful death she felt Tara wanted.

Following a particularly difficult few days caring for Tara, Andrea told her colleague that she was exhausted from caring for Tara in this way that was

> so contrary to her beliefs about what was in the best interests of the patient. She gave her report to the night nurse and left for the evening. Later that night, Tara suffered a cardiac arrest. A full resuscitation was attempted, but it was futile. Tara died a violent death without the presence of her family. Andrea was crushed. She arrived to her next shift irritable and upset—feelings that remained even months after Tara's death.

Andrea felt guilty for letting Tara down and for not advocating for her more strongly when she no longer had a voice to do it herself. She felt guilty for not being firmer with Tara's family and, instead, letting them dictate care that made Andrea feel as if she was torturing Tara. Tara had told her in the beginning that she did not want to suffer, yet every time Andrea had to move Tara or suction her airway, she caused her a great deal of pain. Tara had trusted Andrea to help her; Andrea felt that she broke that trust.

Andrea was also overcome with sadness and helplessness. She was sad that Tara would not have the opportunity to go to a prom, or drive a car, or care for children of her own someday. Andrea was sad that at the end of Tara's life, she felt too "empty" to give any more to this young woman with whom she had shared so many intimate conversations. "Surely Tara must have sensed that," Andrea thought with regret.

Finally, Andrea was angry at Tara's family, not only for choosing care that prolonged Tara's suffering but also for not being present when Tara died. (Tara's mother had disappeared two days before she died, and the staff had been unable to contact her. Her brother was out of the hospital for the night.) She was angry that Tara felt obligated to undergo painful treatment and a futile resuscitation effort for her mother's sake. She was angry at Greg for asking his sister to continue to fight and endure so much pain when the outcome was inevitable, and she was angry at him for refusing pain medications when it was clear that Tara needed them. Andrea was angry at a disease that could not be cured. "After all, aren't we in the business of curing?" she asked.

Andrea's struggles are not unusual. When working with such a vulnerable, seriously ill population, it is easy to identify with both the child and with the parent. Yet, rarely are members of the health-care team given an opportunity to explore the impact of their work on themselves and, reciprocally, to examine the impact of their own emotions on the care they provide to their patients.

In Tara's case, Andrea found herself emotionally involved with Tara in a very maternal, loving way. It was almost as if Tara became her daughter—with Andrea grieving over the lost possibilities of Tara's first prom, of getting a driver's license, of becoming a mother and having children. She found herself trying to protect Tara from feeling that she had to take care of her own "part-time" mom, Jane. In fact, in processing the whole set of events with a colleague, Andrea realized with dismay that she had unconsciously been competing with Jane for Tara's affection. She had inadvertently set about proving that she was the "better" mom. None of this was conscious.

Andrea felt deeply ashamed. She wished she had had the opportunity to identify the role she had slipped into with Tara early on in her care. If she had been aware of her countertransference, Andrea thought, perhaps she might have made a bigger effort to invite Jane to "mother" Tara in the ways Tara most needed at the time. Perhaps she might not have "written her off" as a mother and, instead, she might have been able to coach her to stay present with Tara through her illness and through the dying process. Perhaps

she would not have become over involved to the point that she felt utterly and completely emptied at the end. And what of Tara? Being the sensitive child that she was, had Tara picked up on these dynamics? And if she had, did she feel torn in her allegiances?

In Tara's case, a young patient was provided excellent care in the PICU. Her family received all the support to which they were entitled (e.g., resources, education, care conferences, and attention to their psychological needs). Yet, the subtle, complex feelings evoked in the staff, family members, and system—and in the patient herself—went unrecognized and unprocessed. Perhaps the culture of the PICU does not allow for consideration of countertransference; perhaps high levels of education and experience are emphasized but not the ability to self-reflect; perhaps professionals in this setting fear that if they admit to "personal" involvement, it may be used "against them" to question their decisions or competency? It can be hard to admit that even in a highly professional, top-notch staff, the influence of unrecognized countertransference can be significant.

Alex

> Alex, a two-year-old boy, was admitted from the emergency room to the pediatric intensive care unit (PICU). He had climbed up onto the kitchen counter at the very instant that his mother turned to reach for something from the pantry. In a heartbeat, he was up, but his pocket caught on the stove's hot burner. He toppled, hit a large pot of boiling hot water, and sustained first-degree burns to 80 percent of his body. Alex's parents, a high school teacher and a nurse, kept vigil at his bedside. They frequently expressed their shock and disbelief about the accident and about the extent of the burn injuries to their only child.
>
> The PICU staff identified strongly with this family. Here were two helping professionals, one of whom was a nurse in an adult ICU at another hospital and, as one nurse phrased it, "one of us." The staff quickly labeled them a "nice family," and the nurses became resolutely positive and solicitous in their interactions with them. Alex's mother was quietly invited to use the PICU staff lounge so she could make herself a cup of tea or just relax—a privilege not ordinarily offered to "regular" parents. There, the staff "schmoozed" with her frequently. They were drawn to Alex's mother and yet seemed slightly uncomfortable. They often asked her, in a half-joking manner, not to tell their nurse manager of the privileged treatment she was receiving.
>
> Rochelle became Alex's nurse. She cared for him throughout the many days when Alex had to undergo excruciating hydrotherapy treatments to help his charred skin regenerate without infection. She was with him when he screamed in horror the first time he caught a glimpse of his blackened, scarred face in the mirror, and she continued to care for Alex when he unexpectedly contracted a staph infection that sent his little body into an immediate, deadly decline. When Alex was put on life support, Rochelle and her team quickly moved into "hyper-mode." They worked fervently and tirelessly to get the staph infection under control but to no avail. It became imminently and tragically clear that Alex was not going to make it.
>
> Rochelle was on duty when the physician explained to Alex's parents that the boy was not going to survive. Rochelle was also present when they discussed

withdrawing life support. She watched in awe as the parents solemnly made plans for visitors to come see Alex before he died. Usually it is the staff who begin to bring up end-of-life care to the family. These parents were different. They chose the time that Alex's life support would be discontinued and let the staff know what they wanted.

The family had a clear plan with the attending physician as to how things would progress. Rochelle knew what the plan was but didn't realize how she would feel about it until it was actually put into action. When the family was ready, Rochelle gave Alex a generous dose of antianxiety medication as per the doctor's orders. After that had a chance to work, and again, per doctor's orders, she delivered an unusually large dose of intravenous pain medicine—a dose significantly larger than usual for a child of Alex's weight. Rochelle was deeply troubled by that fact. She knew from the moment she gave the medicine that she would struggle with the type of care she gave to Alex at the end of his short life.

After the discontinuation of Alex's life support, Rochelle left the family alone in the room to be with Alex until he stopped breathing on his own and until his heart stopped beating. Alex died in his mother's arms. He was comfortable and had a peaceful death. After Alex took his last breath his parents said good-bye rather quickly. Rochelle bathed and dressed Alex in an outfit his mom had brought for him. She sat alone and held him for about an hour, then said good-bye to this young boy who was not much older than her own son. "There but for the grace of God go I," she thought. And she was moved to tears.

Rochelle knew intellectually that what was being done medically for Alex was reasonable and humane. She was fully supportive of the end-of-life plan that had been put together with the care team and his parents, that is, until she delivered the medications that kept him comfortable during his death. Although she had followed physician's orders, she felt tremendous guilt. The fully ingrained, professional part of her felt as though she had personally hastened this child's death. When she shared this with a clinical specialist at work, Rochelle was questioned about whether she realized the implications of administering such a large dose of medicine. Rochelle was looking for support. She felt chastised instead.

The following day at work, realizing that her heart was still heavy with grief and that she was still struggling with her feelings surrounding Alex's death, Rochelle asked to care for a patient on a different service. Her request was denied, and she was assigned to another trauma patient. There was no time to grieve and no time to process the guilt with which she desperately needed to come to terms.

In this case, an otherwise healthy child suddenly became a dying child. Facing the traumatic death of a child is particularly excruciating as we are forced to face the fragility of life and the unfairness of what we once thought was the world order; it is simply unnatural for a child to die before his parents. In Alex's case, a whole system became activated around this sudden, traumatic event.

We can speculate that Alex, being the son of another ICU nurse, elicited a great deal of terror in the staff: it was "too close to home." Although the staff treated Alex's

mother as a peer, what was the true impact of this "special" treatment? In the staff's eagerness to treat her as a colleague, who among them cared for her as a *parent* as she struggled with her own shock, bewilderment, and grief? Did she feel pressure to maintain this "one-of-the-gang" relationship with the staff rather than be allowed to grieve openly? And what of Alex's father, who was perceived by the staff as "a nice guy"? Was he given the opportunity to express his anger about the unfairness of the accident, or did he unconsciously collude with the professionals' discomfort and stay in the "nice" role—avoiding expression of his true feelings? In reality, this "extra special" care may have been a defense against the staff's own felt powerlessness to save Alex's life. In a sense, placing Alex's mother into a professional status served to distance the staff from uncomfortable identification with her as a parent.

And, finally, what about Rochelle? She was forced by the demands of the system to bury her feelings. There was no room to address her deeply felt guilt and ambivalence. In fact, when she did take the risk to share the impact of Alex's death with a colleague, she got her hand slapped. Rochelle is part of an institution where there are no built-in systems by which to stay abreast of and process deeply held feelings that are naturally evoked in palliative and end-of-life care. If, for instance, there had been opportunities for peer support, consultation, case conferences, or even a milieu that supported close examination of personal responses in one's professional care, perhaps Rochelle would not have found herself in the position of administering a dose of medication that she did not feel right about. Instead, she was forced to forge on and ignore her discomfort. In this way, the system promoted its ideal of the "consummate professional." But at whose expense?

Professionalism and Our Humanity

As professionals working in palliative and end-of-life care, we value our training, our experience, and our ongoing professional development. Ask any nurse, for instance, and he or she will tell you at length what professionalism means to him or her: diagnoses and care plans, continuing education, evidenced-based practice, activism in professional associations and institutional leadership, implementation of policies and procedures, and provision of outstanding care that is in the best interests of the patient and family.

Where do personal feelings and responses to the work fit in? Most health-care professionals would like to believe that their emotions and beliefs never impact the care they deliver. In fact, if pressed, many would be reluctant to even *look* at their feeling responses, let alone acknowledge that they can affect provision of care; this would not be "professional."

A colleague, in reviewing this chapter, asked in bewilderment: " 'Professional' versus 'human'? Is that what we have done? Have we been seduced into arrogance with our 'knowledge'? Is that why we sit in all humility when finally faced with that which our 'knowledge' cannot pierce, contain, or explain . . . like suffering? And death?"

* * *

It is our hope that this chapter has stimulated an interest in self-examination and reflection upon these issues. If we can allow ourselves to admit to our foibles, our

vulnerabilities, and the impact of our deep care and concern for our patients, perhaps we will come to understand that humanity and professionalism are not mutually exclusive. Perhaps we will learn just how human we all are at the bedside. And, certainly, there is no shame in that.

Afternote

The reader may wonder how Jane Doe became the first author of this important chapter. Jane Doe is a pseudonym. The nurse who contributed most of the case material and many of the thoughts in this chapter did not feel comfortable having her name published.

Professionals working in palliative and end-of-life care must pause to ask why it is still not safe for nurses to "out" the truth of their human selves. Bartlow (2000, pp. 243–244) notes:

> Most caregivers disguise their own fears and isolation as a 'need for objectivity.' We find it particularly hard to touch the part of ourselves that dies with each patient. Sadly, the caregiver who hides his own fears of mortal loss, her own deepest questions, behind layers of important busyness becomes little more than an empty white coat.

The nurses in this chapter certainly were not "empty white coats." In fact, becoming an "empty white coat" is anathema to most nurses—especially to those working with the pediatric population. Perhaps, then, this chapter can serve both to increase awareness of the culture of nursing that hinders nurses from disclosing their human fears and also to engender support for nurses to discuss openly and come to terms with those fears.

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10 Ghosts in the Consulting Room

Bereavement, Grief, and the Therapist

Bev Osband

Introduction

The man sitting across the room from me is casually dressed in jeans and a carefully pressed plaid shirt. He is in his late 40s. He looks a bit like a cross between a scholar and a farmer with his horn-rimmed glasses and scuffed work boots. He speaks quietly, haltingly, in a way that makes me feel like the words have to push through to get out, as if at any moment his throat might close and the words would be trapped. He tells me,

> My son died . . . in an accident. . . . His car went off the road. . . . There was a downpour after a long dry spell; the road must have been slick. . . . There were no witnesses. . . . They found his car partly hidden in a ditch beneath the underbrush. . . . The police called me at seven in the morning. . . . I was making coffee. . . . I fell over, onto the floor.

The man—I'll call him Jim—swallows hard, and his face flushes. I feel my own throat constrict, my own breath grow shallow, and a dull pain blossoms in my chest as I watch him fight the tears that threaten to come but cannot or will not be seen.

This is what I do for a living. I listen to people who have 'lost' someone they love, people who find that in a split second, their lives have been turned upside down, and they wish with every cell in their bodies to turn back the clock just enough to make the accident, the overdose, the diagnosis—whatever took their beloved child, spouse, partner, or friend—"un-happen."

When I first decided to become a therapist, I talked with my own therapist about the idea of becoming a specialist in working with the bereaved and terminally ill. He hesitated at first, then said something about how, in his experience, all therapy was in some way about loss, though, he added, when a therapist has his or her own experience of a particular kind of loss, it can affect his or her capacity to do the work. He did not tell me that I should not follow my desire to work in the field of grief and loss; rather, he seemed to be warning me about just how hard it might be. Still, I was not sure what he was talking about. It was because of my life experiences that I wanted to do the work. I knew things 'ordinary' people did not know. I was a bereaved person. I felt like I was the 'hardest kind of bereaved person'; I was a bereaved parent. My daughter Jenny had died in a bicycle accident at the age of 13. Who better to work with other bereaved parents, or spouses, or anyone for that matter, than a person who had lost someone they

loved? I knew what it was all about. I wanted to turn my own tragic loss into something meaningful.

As I look back now, from a distance of more than 15 years, I can see just how wise my former therapist was. He never mentioned the word 'countertransference,' though even if he had, I doubt I would have understood what he was talking about at that time. It has only been through the process of working with patients who are also grieving that I have gained some sense of what it means to be mindful of my own issues, to the extent that one can become conscious of what is often unconscious. Of late I have come to think about countertransference as a hook of sorts, something that happens between my patient and me, that is, a phenomenon that has the potential to inform the work we do together or to subvert it. Judith Vida, a psychoanalyst, suggests that countertransference is a "defensive technical word for the analyst's existence," where existence means "something alive and not ignorable, something that is to be embraced and made use of" (personal communication, February 7, 2004). When I work with a bereaved person, I cannot disown my existence and life experience, though I have learned that whereas at times it enables me to empathically relate to my patient, there are also times when it interferes.

The Challenge

I began my new career in 1989 at an agency that provided both hospice- and non-hospice-related bereavement support services. My caseload soon filled with people of all ages and walks of life. What these people had in common was that someone they loved had died and they were grieving. I did not tell them that I was grieving too.

There was a young African American woman whose brother had been killed in a drive-by shooting; a 92-year-old woman whose only surviving child, her 62-year-old son, had been killed in a motorcycle accident; and a gray-haired woman in her early 60s whose 38-year-old daughter had died recently after a long battle with breast cancer. There was a young family: husband, wife, and three children under the age of 10. He had been diagnosed with inoperable metastatic lung cancer, though he never smoked, and was very near death when we first met. And there was a young man with HIV/AIDS, recently diagnosed with Stage IV lymphoma, who just wanted someone to talk to who wasn't a friend or a relative.

Hour after hour they came. Down the long hallway, up the stairs, into my office they came looking for something. I wanted so much to help them, and yet I was looking for something too. I had been a bereaved parent for six years when I began to work as a bereavement counselor. I felt ready to take on this work, and yet over time I came to the awareness that there were things I needed to work through in my own mourning process if I was to be truly available to my patients.

Experience has taught me that having faced the particular kind of death that took my daughter's life, a sudden accident, I may not necessarily be prepared to understand the way a young widow might respond following the long, agonizing death of her husband from lung cancer. I also have grappled with the issue of disclosure. Do I tell Jim, the man whose son died in a motor vehicle accident, that I too am a bereaved parent? What if my patient comes on the referral from a colleague who tells her, "Bev will understand; she lost a child too"?

Finally, as I continue to work through the pain of losing my daughter, I have come to think about her death as belonging to the unfolding of fate: her own, mine, and that of all who knew her. Fate, that force of doom better known to the ancient Greeks than to modern people, is neither an easy nor necessarily a welcome way to think about things that are beyond our control, particularly the death of someone we love.

To reveal or not to reveal my own life experiences, how to respond when a new patient comes in knowing something about my personal life, and the phenomenon of fate—these are just a few of the factors that contribute to what I have come to apprehend as my particular countertransference burden. My patients have taught me a lot about my countertransference, my "hook," and have helped me develop a capacity to work empathically with a whole spectrum of loss-related issues. What follows are some of our stories.

Personal Grief in the Professional Relationship

When I began my practice more than 15 years ago, I knew there were some things I would never do. For one thing, I would never hurry people in their grief process. My own experience as a client taught me that. In the first few months following Jenny's death, I had sought help from someone who represented herself as a specialist in bereavement. Mary was helpful at first, listening as I tried to work through the pain and guilt I felt about the accident that took Jenny's life. She had been riding her bicycle down a hill near her father's house. She went through the stop sign. The pickup could not stop in time. Though the medics came within minutes of the accident and worked heroically to save her life, there was nothing they could do. There was nothing rational about my guilt, but there it was.

After a few months of meeting weekly, Mary became impatient that I was not moving more quickly toward acceptance and resolution of my grief and suggested that I join a women's group she was forming. It became clear at once that this was not a group for women dealing with bereavement but a general 'group therapy' group. Though all of the women were dealing with difficult life issues, for me it felt like too much to ask them to hold the particular pain I brought that had to do with the death of my child. It would be many years before I would realize that I couldn't bear to inflict this particular pain on anyone else because I could not yet deal with my own agony and the enormity of what had happened to my daughter.

Even as I knew I would not hurry people along in their grief and mourning processes, only over time would I come to the awareness that for me, countertransference, my "hooks," often would be about my own grief and loss. This was particularly true with Rita,[1] a young woman, newly widowed, who was one of my first patients.

Rita

> It was not easy to find the rambling brick-and-clapboard ranch house in the half darkness. Twice I drove down the gravel road, and twice I turned around thinking I had made a wrong turn. Then I saw a young girl swinging a lantern and waving, and realized I was in the right place after all. Rita and Ted had built

the house themselves; everything from pouring the foundation to installing the automatic sprinkler system was their handiwork. Yet, it was hard to imagine that the emaciated man lying on the sofa in the den was the same man who had done all that work. Ted, 36 years old, had lung cancer, though he had never smoked. He and Rita, age 35, had been high school sweethearts. They had three children, Michelle, 10, Brian, 7, and Tracy, 3. They decided that though Ted would have preferred to be at home, with three young children, home hospice care was not an option. I was making a home visit to see how they were managing as Ted weakened and as the family began to face the reality that he would die.

There were concerns about the children, how to talk to them about their dad, and there was Rita, facing the enormity of her husband's illness and imminent death. Though I had the sense at this first visit that Ted had little time left, I had no idea just how quickly his life would end.

In the weeks following Ted's death, Rita struggled to keep things going. We met weekly in sessions marked with tears and expressions of fear and anger. Rita wondered how she was ever going to make it on her own. Though financially secure, she felt lost in the house without Ted. The two older children seemed to be managing, but little Tracy was having a hard time. She kept asking when Daddy would be home and insisted on setting a place for him at the table for dinner. When her big sister insisted that Daddy would not be there, Tracy would fall apart and throw a tantrum. Rita told me she sometimes lost her temper and would scream at the children, but on the whole she worked hard to keep things going. I listened and tried to be supportive. It was clear that Rita had friends and family who had lots of opinions about what she should do but no one who just listened and offered support in this difficult time.

Months passed, and Rita seemed to be adjusting. She decided to sell the house and move closer into town. Every nook and cranny of the house she and Ted had built together held too many memories and too much pain. She felt it was time for a change. I was concerned that she was moving too quickly and tried to explore with her the illusion that fleeing the house would mean leaving the nightmare of Ted's illness and death behind, but she was determined.

A tension began to develop in our work together. I had the sense that Rita felt I did not understand her restlessness and need for a new life. She was right; I did not understand. I was concerned about her and about the children but really had little sense of what it was like for her to try to go on without Ted. Rita met someone and started dating. Leaving the children with friends or grandparents, she was often gone for the weekend, returning to find the children squabbling and angry with her for being away. I tried to help Rita understand what was going on with the children, that they had lost their father and now it felt like they were losing their mother too, but more importantly, I tried to help her see that her feelings of restlessness and need to be away from the children were a defense against the pain of her own grief. Rita felt she had grieved enough and wanted to get on with her life. She just wanted to have some fun.

I found myself growing increasingly anxious as I watched Rita, a slim and attractive woman with light brown hair, metamorphose into a thin, tense

woman with frosted platinum hair and hot pink fingernails. She traded the family van for a flashy sports car and talked about the clubs where she had gone dancing. Rita's transformation felt wrong to me. She was a widow, and she was supposed to behave like a widow! I found myself feeling critical, even contemptuous, and then envious, thinking how unfair it was that when a spouse died, one could simply find another, but when a child died, there was no replacement. Where I had once felt compassion for Rita, I came to feel impatience and frustration. At times Rita became defensive, especially when she sensed my criticism, which though not verbalized, must have been apparent in my demeanor and tone of voice.

Rita began to cancel sessions, saying that she was too busy with the children or too tired to drive into the city from the suburbs where she had found a temporary rental house. I felt she was running away, trying to avoid her pain, but I came to understand that it was my contempt and envy that pushed her away. Still, we maintained a connection perhaps because she could sense that despite my being critical at times, I also cared about her and the children.

In my own therapy I found myself sobbing one day as I 'confessed' to envying my patient, even hating her for the seemingly carefree, happy life she had found in the aftermath of her husband's death. Over the next several months Rita continued to come to sessions, a bit less frequently, but still clearly wanting to explore what was happening in her life without Ted. Gradually, I began to notice a subtle shift in the feeling between us. Although we were meeting less regularly, there was a sense of greater openness as she explored the ups and downs of life in her new relationship. As I became more conscious of my negative projections onto Rita, I found myself more open to her unexpressed pain and suffering. I had not experienced the death of a spouse. I did not know, from the perspective of lived experience, what she was going through. I needed her to be my teacher on what for me was an uncharted path.

One day, well into our second year of working together, Rita brought a dream that beautifully reflected both her personal situation and the state of our therapeutic work. She said, "I am on a horse, riding bareback through a strange landscape. I've never been here before, and I don't know where I am or where I am going. I reach into my pocket and pull out a map, but when I unfold it, I realize that it is a blank sheet of paper." Together we explored what this dream meant to Rita. She said that the fear she felt on seeing the blank map in her dream felt a lot like the panic she had experienced the day Ted died and she left the hospital carrying his few belongings to the car. It was as if her entire landscape had transformed into one she had never seen before, and she had no idea which way to turn. We talked about what it feels like to know that we must go on and how frightening it is to explore new landscapes without a map to guide us. I sensed a surge of warmth as we acknowledged, on several levels, the deep meaning of this dream.

C. G. Jung always asked, "Why this dream now?" As I reflected on Rita's dream and the power it held not just for her, but for both of us, I had the sense that the purpose of this dream was to help both of us face the reality that there is no universal map to guide us through our grief and mourning. The close,

> intimate contact with the horse, a strong and vital animal, often symbolic of the life force, puts us in touch with a vitality we long for in the face of death. It is as if the dream was telling us that map or no map, life will go on. Hang on for the ride.

When a patient brings a dream, it is a gift from the psyche, an offering that complements our conscious, waking-life perspective. When we take the dream seriously, we, patient and therapist, are changed by it. In his classic paper, "The Patient as Therapist to His Analyst," Harold Searles (1979) puts forth the notion that our patients heal themselves through healing us. According to Searles, people often come to therapy seeking to accomplish with the therapist what they could not accomplish with a grieving or otherwise disturbed parent, a parent that has been internalized. Searles suggests that as the work of therapy unfolds, it is the patient's success in "treating" the therapist that contributes to his or her own healing of the parent within. As I reflect on my work with Rita, there is a sense of what I have come to call 'mutual healing,' a variant of Searles's idea, more akin to Jung's belief in the mutuality of the therapeutic process. For example, in his essay, "Problems in Modern Psychotherapy," Jung (1929/1966) observed:

> By no device can the treatment be anything other than the product of mutual influence, in which the whole being of the doctor as well as that of the patient plays its part. . . . For two personalities to meet is like mixing two chemical substances: if there is any combination at all, both are transformed. In any effective psychological treatment the doctor is bound to influence the patient; but this influence can only take place if the patient has a reciprocal effect on the doctor. (para. 163)

Mutual Healing

This kind of mutual healing comes in many forms and, I have often found, when we least expect it. In my work with Jim, I discovered the ways in which countertransference can function as an avenue for connection. Not all countertransferential experiences are negatively valenced. There are times when our 'existence in the room' conveys something ineffable, opening an opportunity for the experience and expression of deeply buried feelings.

Jim

> Jim, the man whose son died in an automobile accident, came to therapy reluctantly. It was not his way to lean on others but to be the one on whom others leaned. It was clear from the beginning that he found it excruciating to talk about his grief and generally avoided talking about his son until the last few minutes of the session. As time went on, a pattern developed in our sessions, with Jim recounting the week's events and the difficulties he was having on weekends, time when he and his son would have done things together. Sunday evenings were the worst, he would tell me. It was as if enduring the empty chasm of the weekend left him drained, too tired to sleep, too depressed to face the coming week, empty. Often, at this point, he would pause, and I could see

the change come over him: the flush of pain and the almost visible tightness in his throat. His eyes would redden as the tears hovered, not daring to fall. I knew he was thinking of Brad, but he could barely whisper his name.

During the second spring of our work together, a few weeks short of the third anniversary of Brad's death, Jim arrived as usual, but rather than telling me about his week, he remained uncharacteristically silent. The tightness was there in his throat, and even when he tried, he could barely speak. I felt myself choke up, thinking back to the first few years after Jenny's death when the approach of the anniversary of her death threatened to overwhelm me. Emerging from my reverie, I found myself saying, "It won't be long now before the anniversary of Brad's accident. It's so hard to talk about it . . . to talk about him. Sometimes it feels like it is all a bad dream, and you'll wake up, and he'll be there, but then you realize you are awake, and the nightmare of his death is a reality." Jim shook his head and tried to swallow; a few tears escaped and trickled down his cheeks. We sat there quietly for a long time, each of us thinking about the child we missed so much. Then Jim spoke, "This happened to you too, didn't it?" I felt frozen. I had not told Jim about Jenny's death, and yet he knew. This was his therapy, his hour, not mine. Yet I could not lie, nor could I use the old psychotherapy ruse of turning the question back on Jim: "What are you thinking about?" Rather I chose to answer his question. "Yes, this happened to me too. It was a long time ago, also an accident." Son or daughter, he wanted to know, and how old. "A daughter," I answered. "She was 13." Again there was a long silence, and then I heard, barely audibly, the words, "I'm sorry. . . . I'm so sorry."

From a theoretical perspective there are many ways to understand and explain this experience of mutuality with Jim. For example, from an object relations viewpoint, one would say that my countertransference emanated from Jim, that I "received" his disavowed or too-painful feelings, that I introjected them and could then speak to feelings he could not verbalize, in essence that what I experienced was an example of projective identification (Klein, 1946). The difficulty for me is that such an explanation does not resonate with my experience of being with Jim, in particular because it implies that I am a blank screen, a generic therapist, and neglects the reality that we share the experience of having lost a child. What occurred between Jim and me felt more like what Aron (1996) might call an interaction. As Aron explores the terrain of mutuality in the therapeutic relationship, he develops the idea of interaction because unlike projective identification, which has to do with discrete events, the word "interaction" conveys the sense of continuity and process. It is precisely this sense of continuity and the gradual unfolding of the therapeutic relationship that brought Jim and me to the moment described.

At the time, however, I was concerned after this disclosure that I had perhaps intruded upon Jim's grief with my own, concerned that he might not feel as free to use our time together to explore the terrain of his own mourning or that he would use me as a measuring stick against which to gauge his experience. What became clear over time was that Jim seemed to trust me more with his vulnerability. He never expressed regret for my having disclosed the fact of my daughter's death, nor did he compare himself to me in any overt way. He did what he had been doing before the disclosure. He came to

sessions and struggled to make sense of what is incomprehensible. He talked about how hard it was to sit in the lunchroom and listen to people gripe about their team losing in the play-offs. Most of our sessions ended with Brad, how much he missed him and how hard it was to dream about him and wake to find that it was just a dream. We began to talk about those dreams as visits from Brad, something that brought tears to both of our eyes.

Jim and I have continued to meet for sessions over the years, not regularly. But typically in the spring and again in the fall before Halloween, he will call for an appointment. For Jim, as for many bereaved people, these are times when it seems like the rest of the world is rejoicing, while he feels the familiar dark drag of grief gripping him once again. It may be, too, that Jim knows I will understand something about the pain he still feels, and though we do not talk about my experience of loss, it is nevertheless there to inform our work.

Fate, Guilt, Synchronicity, and Grace

That Jim found himself working with me, and I working with him, is an example of what C. G. Jung would call a synchronicity, the "simultaneous occurrence of two meaningfully but not causally connected events" (1952/1969, p. 441), in essence a parallelism of events in time that have no causal relationship. In my work with patients and in my own efforts to come to terms with my daughter's death, particularly the guilt I claimed, I came to see synchronistic events as evidence of a force I recognized as fate that governs the unfolding of our lives.

I must emphasize that I did not come to this awareness through intellectual efforts, nor did I achieve whatever ephemeral insight I have gained without considerable resistance. I came to this awareness through guilt. In essence, things began to happen to me that challenged me to deal with my feelings of guilt. Specifically, I experienced how working through my own issues affected my countertransference, my "existence in the room," and so influenced the healing process of my patients.

One of the most difficult challenges one faces in dealing with overwhelming loss is the sense of vulnerability such loss engenders. Quite unconsciously, I believe, one of the ways we defend against that vulnerability is by claiming guilt for whatever led to the death of our loved one. In my own experience, for many years, no amount of rational argument or well-meant reassurance could diminish my feelings of guilt. To relinquish the sense of security, however false, that guilt provided meant accepting my own impotence to protect my surviving daughter and others whom I love. Guilt of this sort exacts a toll and at some point becomes paralyzing. Yet, relinquishing it means nothing feels safe, ever. Over time, as I faced this conundrum, I felt the cloak of false security grow thin and tattered, and a sense of dark dread took its place.

What occurred could not have been predicted or prescribed, but a series of dreams and synchronistic events occurred over several years so that gradually the shell that my guilt provided grew brittle and cracked. Bit by bit the awareness grew that whereas bad things certainly did happen, so did good things, and they did so without regard to anything I might do or not do. The stunning nature, the numinosity, of these synchronistic experiences and the power of the dream images took me as if by force, and the feelings

of impotence and vulnerability that once threatened to destroy me transformed and became the freedom to depend upon and defer to something beyond myself.

I recognized that "something" as "fate," a phenomenon better known in ancient times than it is today. Long ago in ancient Greece, the Fates were spinners and weavers: the goddesses Clotho, who spun out the thread of life; Lachesis, who measured it; and Atropos, who cut it off. Today we tend not to think in terms of gods and goddesses but may resonate with the idea of "the thread of life" as a metaphor for the unfolding path a life follows. Through dreams and synchronicities, I came to experience metaphorical threads that link all things in the universe across space and time, and I have come to see Jenny's death in a larger context. That is not to say that I no longer feel anguish at having lost my daughter. I am her mother and still ache with longing to have had the chance to see her grow to adulthood. What has become possible, though, is a sense of greater spaciousness for wondering, for reflecting, and for making meaning.

The first synchronicity occurred on October 30, 1987, four years after Jenny's death. It was my 43rd birthday, and a friend invited me to go for a walk around Green Lake. I did not feel much like celebrating, but a walk on that brisk fall afternoon felt like a welcome distraction. The weather was blustery—sun breaks alternating with rain squalls. About halfway around the lake, as we approached the east side, we saw a rainbow-colored tent in the distance and every now and then caught bits of music carried on the wind. Thinking this was nothing more than a music festival of some sort, I was completely unprepared when we came around the front of the tent, and I looked up and saw Jenny's name in large, red letters appliquéd on the wall of the tent. My heart constricted, and I could not catch my breath. Then I saw a familiar face, Jenny's jazz band teacher, and realized that this was the tent that had been purchased with memorial gifts after her death. Though I knew about the tent, I had never seen it before. Now, on my birthday I was standing under it. As I watched the wind billow through the colorful fabric and heard the music, it was as if Jenny's spirit was saying, "Happy birthday, Mom." Neither I, nor the jazz band teacher, nor my friend who suggested the walk, caused this terribly meaningful event. It was beyond rational explanation; it just happened.

This was a beginning, and yet the darkness persisted. At times I felt bitter and envious of others whose lives seemed untouched by loss and grief. I felt stuck, unable to move through or beyond the day-to-day pain. My dreams, when I recalled them, seemed dark, and even with my dream eyes wide open, I could not penetrate the gloom. I do not recall questioning God's existence at that time, but rather felt that God was hiding. Then, in the summer of 1989, I had the following dream: I am in a hallway with my friend Jean. I know she is dying from ovarian cancer, and I am very sad. I hug her and feel how thin she is. Then I leave and go outside into the street that is shiny and wet with rain. I look into the roadway and see an apple sitting on the pavement. Just then a large black car comes racing down the road and runs over and crushes the apple. I run out and pick it up. When I look at the crushed fruit, I see a golden key giving off a bright, warm light.

As I explored this dream with my therapist, the meaning seemed to unfurl before us. My grief and bitterness were like a cancer that was killing me, slowly devouring me from within. I needed to leave that place of darkness and go out into the world where I witnessed

an accident that destroyed to reveal. The dream shows me that the golden, light-giving key is hidden in the fruit of the tree of the knowledge of good and evil. The almost biblical quality of the dream seemed to tell me that God was not hiding but communicating an essential message that challenged what had become my contingent way of life: I will be good so that nothing bad happens to those who are precious to me.

This was a numinous (a word that literally means "the nod of the divine") dream through which I felt as if something of the divine had become incarnate in me, and although nothing had changed, everything was different. Its profound meaning reverberated through every aspect of my life, including my work with patients. In essence the dream affected my countertransference, my "existence in the room," both consciously and quite likely in ways that were unconscious as well. Where before I had been locked into a worldview that was constricting, I began to feel freer to be and less compelled "to be good" as a condition for protecting those I loved. In my work I felt a greater spaciousness and capacity to embrace the "not knowing" that inevitably comes with the particular kind of therapy that is grief work: the not knowing why and the not knowing when or if or how the pain would ever diminish. I could sit with another's grief, nurturing the unfolding of the process, and not somehow feel compelled to try to do something or to fix it.

Time passed, and my therapeutic work with people who were grieving continued. In addition, I was sometimes asked to give lectures or workshops on death and dying for professionals who would be working in the field. Annually, since 1988, I have given such a class for training physicians' assistants at the University of Washington. In 1996, I was teaching the class as usual. The group was lively, and the discussion far ranging. After the first hour I called for a break and prepared to talk informally with students who had questions or just wanted to chat. That afternoon, a big, burly man approached me and asked if I knew a particular nurse who was an administrator at a nearby hospice. I did know her and inquired as to whether he was involved in hospice work. He said that he was not but was an emergency medical technician, an EMT, and that he drove a Medic One unit based at the hospital with which the hospice was affiliated. He said he had worked with this nurse when she was the supervisor in the emergency room at that hospital. This was the hospital where Jenny was taken after the accident, the place where she died.

In a matter of seconds I felt myself get very hot and then cold. I could feel sweat begin to trickle down my chest and back and was relieved that my long-sleeved dress hid the goose bumps on my arms. I hesitated for an instant and then asked how long he had been an EMT in that area. He answered, "About 20 years or so." Hesitating again, I haltingly told him that my daughter had died in a bicycle accident in that area in August, 1983. His eyes widened and filled with tears as he said, "August 1, corner of . . ." I was stunned and only half heard his words as he told me how he and his partner responded to the call and had tried everything they could to save her life. Overwhelmed, we gave each other a long hug. It had been 13 years, as many years as Jenny had lived, and at that moment, quite synchronistically, as if it were meant to be, I had met the person who had been with her when she died.

Each of these events, and others like them, occurred in a moment in time, moments linked together across time both by their deep personal meaning and by their numinosity. I do not believe it is possible to turn away from such a series of events or to reduce

them to mere coincidence. Rather, I resonate with the words of Russell Lockhart (1987), a Jungian analyst, who writes:

> the fateful quality one feels in synchronistic experience can be revealed even more fully by finding the links between synchronistic experiences. That is, it is hard to see—but not to feel—the significance of any particular synchronistic experience. But if you attend to a series of synchronistic experiences, you will begin to see a pattern to the inner and outer events woven together in time. . . . There you will see the threads of your fate right before your eyes. (p. 97)

These experiences have been pivotal in the evolution of my own grief process. They are a part of my being that I bring to the consulting room, where in subtle ways they contribute to my work with others who are grieving. What I have had to grapple with is the awareness that each of us must find our own experiences of the numinous, our own synchronicities, and our own dreams—phenomena that can guide us if we are available to experience them.

When the face across the room reflects my own, I need to be particularly alert to my desire to be helpful. I have learned by way of experience to recognize a certain feeling of excitement or urgency that comes when I am at risk for disclosing the particulars of my own experience in an effort to mitigate someone else's pain. It is invariably a clue that I need to sit quietly and listen. It often helps at such times to remember something one of my mentors once told me, which is that grief is a process, not a problem to be solved.

Having written about my own discovery of fate, guilt, and synchronicity, I find myself thinking of Grace, a young woman who came to me a few months after her baby died from sudden infant death syndrome (SIDS). A colleague referred her and told her I would understand because I was also a bereaved parent.

Grace

> Grace blamed herself for her baby's death, and many of our early sessions were filled with her efforts to pinpoint the mistakes she had made during her pregnancy or after the baby was born that would explain why the baby had died from SIDS. She had worked too long and been tired when she went into labor. She had needed some anesthesia during the birth and had ended up not being able to do "natural childbirth." She had noticed that the baby had a runny nose but had not taken her to the pediatrician. She had not given up her morning cup of decaf coffee. The list went on. Grace's search for an answer, particularly a concrete explanation for her baby's death, was intense.
>
> Grace wanted to know how my child had died and why. Had I done everything possible to save her life? How old was she? Had she too died from SIDS? Was she sick? Was it an accident? There seemed to be no end to the questions, questions that I deflected, telling Grace that each of us grieves differently and that it was my job to help her find her own path.
>
> At the same time, I found myself wanting to talk to her about fate, guilt, and synchronicity, thinking that perhaps if she could move beyond blaming herself, she might find solace and eventually come to see her loss in a larger context as I had. I was tempted to disclose but recalled my own experiences almost

> 20 years ago with Mary, who had little patience with the course my grief was taking, and I found the capacity to hold my silence.
>
> Gradually, I began to explore with Grace what purpose her guilt served, for example, how and if it figured in her experiences of not knowing why her baby died. She became more aware that in an odd way, feeling guilty seemed to calm her, though only momentarily. Indeed, she likened the feelings of guilt to eating too much refined sugar. There was a sense of some kind of instant gratification, followed by a crash. We could laugh together about her metaphor, and we could feel ever so slight a shift toward recognizing just how seductive guilt feelings can be in the face of having to deal with the pain of not knowing and the overwhelming sense of vulnerability that comes with acknowledging that there are powers greater than ourselves at work. We did not call these powers by name. It would have felt presumptuous for me to call them 'fate' or 'destiny,' or 'the divine.' That would be Grace's prerogative. And yet, I could not help but think these thoughts.

I am not certain whether my countertransference helped or hindered Grace's efforts to work through her grief. At times she was clearly frustrated with me for not telling her how to do "it," but at other times she seemed able to trust that no one, including me, could tell her how to grieve her baby's death. On the one hand she seemed to feel safe with me and grateful for my patience, especially when friends and relatives turned away and could not or would not listen to her talk. On the other hand, I asked myself whether the fact that I was holding in mind the possibility that she might come to see her guilt as a defense against the terror of the unknown and that she might begin to see her baby's death in a larger context of fate was in some way making her process more difficult. I did not know the answer to these questions. I could only let this work unfold and remain open and alert to the risk of missing clues or cues that Grace needed something other than what I was able to offer.

Summary

I find it tremendously challenging to sit with people who come to seek relief from the enormous pain that comes with the death of a loved one. In my practice as a psychotherapist working in the field of bereavement, I feel particularly challenged by the fact of having myself lost a child. Looking back, I have come to accept the reality that my countertransference is a function of both my own bereavement experience and the long process of working through the despair, pain, and guilt that once threatened to destroy me. At times I am quite conscious of its influence; at other times, it is only when things begin to go wrong in the work that I have to wonder at its subversive presence. In such situations, what has been most useful for me is my own therapeutic process, the careful attention to dreams, slips of the tongue, and body sensations.

This chapter offers some examples from my work with bereaved patients that typify the ways in which I have experienced the workings and effects of countertransference in the therapeutic relationship. While I think these stories are instructive, they are meant to be more heuristic than prescriptive. I feel a deep sense of gratitude to all of the bereaved individuals who, over the years, have trusted me with their stories, their feelings, their hopes and despair, and who, often enough, do find their own paths in life after losing someone they love.

COUNTERTRANSFERENCE TOOL BOX:

Self-Assessment in Grief and Loss

Renee S. Katz

Explore the following self-assessment questions. Notice any trends, strong feelings that are stirred up, and memories that are called to mind. With a trusted colleague or supervisor, discuss any insights or thoughts that these questions evoke.

- **The family "rules" about grieving that I grew up with are** (e.g., "be strong," "don't cry," "be a man," "cheer up," "don't whine," "be brave," "don't make anybody else sad or uncomfortable," "stay calm") . . .
- **The ways my grandparents, parents, siblings, and partner cope with grief and loss are . . .**
- **My initial, "knee-jerk" reaction to a major loss is . . .**
- **What works best for me when I am overwhelmed by loss and grief is . . .**
- **One past loss about which I feel particularly sensitive, vulnerable, or raw is . . .**
- **The type or manner of death that I would find most difficult is . . .**
- **Of the important people in my life who are now living, the most difficult death for me would be . . . It would be particularly difficult because . . .**
- **What I need to do now and in the future to keep up with my losses (both personal and professional) so that I can grieve them, let go of them, and stay healthy is . . .**

Note

1 Rita is not my patient's real name. In this case and the others that follow, names and other particulars have been altered to protect the identity of the individual and maintain confidentiality.

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Part IV

Social, Legal, Ethical, and Organizational Influences

> *As we attend to the reactions of our own minds, bodies, and hearts, we work to cultivate curiosity, humility, and open-mindedness to be with another's experience and to actually see and hear each patient, each family member, and each team member with clarity and compassion. Along the way, if our hearts hurt or our minds feel stuck, we may use our feelings, our discomfort, or our empathic responses as clues to discover which confluence of factors—individual, team, or system; conscious or unconscious; internal or external—may arise. Then we bring them to light to be observed, processed, and utilized to enrich our work.*
>
> (Altilio & Sumser, Chapter 11)

Altilio and Sumser describe the complex waters of countertransference in palliative practice, where there are many schools of fish: individual clinicians, patients and families, colleagues and team members, and medical and hospital systems, all influencing the nuanced work we do.

The two chapters that follow address choices near the end of life and the controversial practice of medical aid in dying. Kelly and Varghese, in Chapter 12, address the potential for harm when autonomy is valued at the expense of careful investigation of the meaning behind a request for life-ending medication, and Katz and Johnson (Chapter 13) present additional countertransference hooks that are evident in organizations and in individual providers who receive requests for hastened or medical aid in dying.

Finally, Johnson's chapter on ethics (Chapter 14) attempts to separate the controversy from the process that all clinicians should follow when faced with competing or unexamined ethical issues. Especially in matters of great emotion and strongly held beliefs, a template that helps us navigate toward a conscious and ethically sound plan of action is a welcome lifeboat.

Note: There are excellent opportunities at the end of several chapters to deepen your understanding of your personal-professional intersections. Please refer to the chapter tables and the Countertransference Tool Box.

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11 Prisms of the Heart

The Journey of Palliative Care

Terry Altilio and Bridget Sumser

Ring the bells that still can ring
Forget your perfect offering
There is a crack, a crack in everything
That's how the light gets in
—*Anthem* by Leonard Cohen

"Have you been hurt in your life? I can see it in your eyes. I do not see it in their eyes, only yours." A patient addresses the social worker, one of four palliative clinicians rounding on a new patient recently diagnosed with cancer.

On any given day, in any given setting, there are exchanges that create reflective moments where clinicians are asked to consider how aspects of the self, the other, and their shared context interface and influence responses and reactions. Does this patient's comment signal a transparent moment that reflects the inner sadness of the social worker? Or, perhaps, a nonverbal message of team distress? Is it a clue to the inner life of the patient, diagnostic of his or her own history, fears, or vulnerability?

How do palliative clinicians who come to this specialty with varied histories and disciplines create a shared and safe space where countertransference, whether subjective or diagnostic, becomes a vehicle by which to enhance their insights and practice? Does palliative care practice have unique attributes that enrich or complicate the work of examining countertransference, whether it manifests in the individual, the team, or the system? As individual palliative care social workers and colleagues, we attempt to explore these questions, aware that we each bring our unique histories and intergenerational influences to our work. And, as such, these inevitably will become part of our countertransference responses, whether we are conscious of them or not.

Terry has practiced for 25 years during a time when palliative care in the United States evolved into professional specialties and when programs proliferated nationally and internationally. She did not consciously intend to specialize in palliative care. Bridget is a clinician five years into social work. She consciously chose clinical and academic training in palliative care, responding to what she most aptly describes as a calling born out of personal experiences with advancing illness and the end of life.

Each of our unique personal and professional histories affords several vantage points from which to "unpack" the subjective and objective countertransference responses that

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are ubiquitous to palliative and health-care environments. This chapter is an invitation to step back and consider the joy and challenge of joining clinicians of varied disciplines as we enter the lives of patients and families who are in the process of evolving illness. As we attend to the reactions of our own minds, bodies, and hearts, we work to cultivate curiosity, humility, and open-mindedness to be with another's experience and to actually see and hear each patient, each family member, and each team member with clarity and compassion. Along the way, if our hearts hurt or our minds feel stuck, we may use our feelings, our discomfort, or our empathic responses as clues to discover which confluence of factors—individual, team, or system; conscious or unconscious; internal or external—may arise. Then we bring them to light to be observed, processed, and utilized to enrich our work.

Palliative Care Defined

According to the World Health Organization (n.d.), palliative care is an approach "that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual aspects of care."

To understand countertransference in the context of palliative care, we must attend to several distinguishing factors that shape this particular clinical environment. Palliative care is a medical specialty with essential physician presence. Teams provide services that integrate along the continuum of illness, including the end of life and bereavement. Teams may be described variously as multidisciplinary, interdisciplinary, transdisciplinary, or interprofessional—terms that may provide a clue as to the style and structures of each team's collaborative processes. Generally, palliative care teams act as consultants. In most instances, they serve at the behest of primary teams who may be working to diagnose, treat, or assist patients who are living with life-limiting illness. As such, palliative teams serve not only patients and families but also the clinicians requesting consultation and advice. This dual accountability, along with the styles and structures of team processes, can create unique, subtle, often unconscious landscapes for replicating family systems, thus setting the stage for a multitude of countertransference responses. A narrative example from Terry follows:

> I was raised in an Italian American family, the only daughter and the middle child of three, a position in Italian culture that was replete with expectation. In our family, however, this expectation was fractured by our mother's death after a brief illness. Those were the years when little attention was paid to the emotional needs of children. There were no models or supports for single, widowed fathers who were raised to fill the role of "breadwinner"—while the mothers of their generation fulfilled their roles as homemakers. Over time, and in many ways, this "motherless" band of three children raised themselves without the cultural patterning that was traditionally passed on through the maternal role. Our father's fledgling guidance was tolerated, but all the while, a slew of complex, uncomfortable feelings went unrecognized. We did as all children do: we built defenses that we unconsciously hoped would sustain and protect us.

> Clearly, this history is powerfully linked to my choice of discipline, one that privileges values such as autonomy and self-determination along with advocacy and elevating the voice of the invisible and underserved. Working intimately in the midst of complex patient and institutional narratives, where privileged values differ, has been one of the most challenging and personally nuanced arenas in which countertransference pulls have surfaced. Many personal insights, some profound, some shocking, some overwhelming, have come from my efforts to balance my subjective and objective countertransference responses in the ongoing negotiations across disciplines. In particular, as shifts occur in the locus of leadership and power between colleagues and within clinical scenarios, it is not always clear whether my reactions about perceived medical "parentalism" or my identification with vulnerable patients and families are clouding my capacity for critical thinking and compassion. It can be challenging to separate self from other, to distinguish objective thoughts and feelings from personal and collaborative ones, and to work respectfully across disciplines, often within profound narratives that require clinical and ethical discernment. The ongoing effort to be clear about what is self and what is other has helped lessen my internal (and externalized!) judgment and impatience and now supports, instead, a curiosity and inquiry that has served to deepen my appreciation for colleagues who practice the complex art and science of palliative care.

In addition to the challenge that palliative clinicians face at the interface of family history and inter- and intra-team practice, palliative team members are unique in that they choose to work with patients and families along an uncertain path of critical illness that may potentially lead to death. For example, on any given day, a hospital palliative care team may consult with patients who are newly diagnosed or who have an exacerbation of a chronic serious illness such as chronic obstructive pulmonary disease (COPD). Or, team members may be immersed in complex medical, emotional, ethical, and spiritual work related to decisions about whether to accept or forgo life-sustaining treatments such as dialysis or resuscitation. Team members may provide services to patients and families over an extended period of time and across settings, or they may be called in to address an immediate crisis for several minutes or several hours. It is amidst the instability, uncertainty, and flux of these varied trajectories of illness and opportunity that complicated feelings, thoughts, and values surface. These become all the more complex within the crucible of varied professional roles, personal histories, and the degree to which insight, thoughtfulness, and responsibility for countertransferential responses is valued. The following narrative, which evolved over 30 minutes, provides a glimpse into one aspect of the landscape that frames palliative process, decision making, and action.

> Mrs. Douglas, a 48-year-old married woman, was admitted to the cardiac intensive care unit after a massive heart attack. Mrs. Douglas did not respond to maximum medical interventions and was put on a ventilator. It soon became clear that rather than helping Mrs. Douglas's medical condition, the ventilator appeared only to be prolonging her dying process. A decision was made with her family to withdraw Mrs. Douglas from the ventilator. Believing that Mrs. Douglas would die shortly after, her cardiologist requested assistance from

a palliative physician skilled at medicating for comfort during the process of ventilator withdrawal. The palliative care physician spoke with Mrs. Douglas's husband and with their 15-year-old daughter, Hillary. Hillary, understanding what was about to transpire, requested to be with her mother during the process of withdrawing the ventilator. The palliative care physician did not explore the meaning or the appropriateness of this request with Hillary and her father and did not consult with the palliative interdisciplinary team. Rather, believing it would be too traumatizing, she unilaterally refused the request. The ventilator was removed, while Hillary sat on the floor outside the room and wailed her grief. This helplessness and frustration was echoed by the deafening silence of the palliative team's social workers, whose expertise was not invited nor asserted.

Unfortunately, all this went unexamined at the time, leaving stranded five women whose emotional lives were greatly impacted and, for the moment, were all intertwined.

Looking through a retrospective lens, one can understand the felt powerlessness of the palliative team's social workers, which emanated from a poignant mix of subjective and objective countertransference. Personal and professional histories evoked certain aspects of their countertransference responses, which were compounded by the team's upset and mourning of a missed opportunity, potentially echoing Hillary's own internal experience. The reality of that moment, the clear message that "team" does not necessarily imply equality in power, responsibility, or accountability, weighed heavy in its revelation. It was only with a concerted effort to attend to all the subtleties of their responses that these clinicians were able to move from reactivity to a deeper and richer understanding of the feelings and behaviors of each team member. They could then examine how cultural and generational differences played a significant role in the acting out of each clinician's subjective countertransference.

One social worker was pregnant with her first child. The tsunami of feelings evoked by the precipitous death of this 48-year-old mother was personally traumatizing and overwhelming. Had she been aware of her internal milieu, she might have been able to share these waves of fear with her team, and she might have been able to utilize her colleagues' support and consultation to hold her personal responses separate from her professional judgments. Terry's experience of her mother's precipitous death during adolescence, along with her memories of shock, lack of preparation, but also unanticipated resilience, fueled a strong, empathic identification with Hillary. Profoundly aware of her vulnerability to overidentify with grieving teens, she worked hard to stay conscious of all the dynamics of Hillary's compelling situation, and she extended particular effort to remain conscious of a critical question: "Whose agenda is it?" Finally, the physician who assumed autonomous decision making was a single mother of two teens. How might her current and prior personal and familial experiences, along with the personality styles and developmental issues of her own children, inadvertently influence her swift and immediate decision? In truth, all these dynamics are potential fuel in the cauldron of acted-out countertransference responses. All demand their own examination and unpacking.

The poignancy of this unfolding drama was rife with potential countertransference—both positive and negative. In reality, the actual consequences of the acted-out countertransference will remain unknown to the clinicians who were so intimately involved in the

rapidly unfolding circumstances of that day. To some degree, the traumatic impact of this experience on the team will now become part of the team's countertransference potential as well.

The Unique Contributions of Palliative Care Settings and Interdisciplinary Teams

Hillary's story illustrates some of the often unexplored aspects of palliative care that contribute to countertransference whether in relation to patients and families, fellow professionals, teams, or the systems in which palliative care operates. Frustration, tears, moral distress, transient powerlessness, listening, and learning have been the fertile ground from which the following observations have grown. While we discover and hold accountable the contributions of our unique emotions and history (subjective countertransference), it is important to continue to deconstruct other complex variables that may influence our emotional responses and reactions in our professional work.

Institutional Effects

Interdisciplinary work and relationships are core tenets of palliative care. Thus, the inherent question of "what is mine and what is the other's?" is ever present. Patients and families bring their histories, cultures, emotional needs, and expectations of each discipline into their relationships with their current providers. Similarly, health-care providers have preexisting narratives about our colleagues—previous experiences with doctors, nurses, social workers, chaplains, and other health-care providers—that color our expectations and inform our capacity to be open with one another. The effectiveness of consultation teams presumes the ability of clinicians to attend to countertransference generated not only in their relationships with patients and families but also in their relationships across disciplines and specialties. Palliative care services flow from intimate and intense connections within the "nuclear team" as well as along the continuum of relationships with the "extended team," which may include referring clinicians, community providers, and staff across units and settings. When we take all these perceptions, biases, and expectations, add the ingredients of stress, trauma, and crises, and place these in the "fish bowl" of a hospital system, we have the makings of a potential crucible of countertransference. In this setting, unconscious and interpersonal manifestations of countertransference move from private to public and are influenced by the institution's culture of accountability. It is in this "loaded" environment that palliative care clinicians are expected to think critically and objectively about crucial, often life-and-death decisions. It is under the influence of these multiple systems that they must assess, diagnose, and treat.

One institutional variable that greatly influences patient care is the press that team members experience in response to the intersecting forces of regulation and finance. These financial, often political realities complicate the countertransference. Thus, countertransference potentiates do not reside solely in the realm of relationships with patients, families, or colleagues. Hospital and governmental systems provide their own unique pressures.

For example, in the case of Mrs. Douglas, she was cared for in the cardiac intensive care unit. This setting is infused with covert and overt pressures to justify the length of

stay and the medical necessity of any medical intervention. Team members who unwittingly harbor an internal, percolating mistrust of authority are often vulnerable to strong feelings about these systemic pressures, frequently viewing unpopular decisions with skepticism, if not disdain. Who is really benefiting from, for instance, the decision to withdraw a ventilator—the patient or the system? For Mrs. Douglas, was the expeditious removal of her ventilator and the physician's quick response an inadvertent bowing to financial pressures imposed by the institution? Was there an unconscious social justice concern at play, perhaps emanating from a mandate to protect limited resources? Were there conflicting personal and professional values and codes of ethics within the team? It is likely that all these complex relationships, emotional responses, and institutional pressures did, in part, impact the pace and outcome of decisions made on behalf of Mrs. Douglas and Hillary that day.

In these tenuous, complex situations, team members frequently can feel marginalized in the decision-making process. Rather than deal directly with the health professional responsible for a controversial decision, team members may find themselves displacing their rage and indignation onto the "injustice" of it all. It is not always clear whether upset at systemic pressures and priorities reflects a real, deep-seated concern for vulnerable patients and families or is, rather, a displacement, a way to mask or distract from the myriad of unavoidable, difficult-to-admit feelings that surface in this poignant work. Additionally, raging at "the system" can be significantly less threatening than confronting the physician directly and certainly less heartbreaking than having to sit with the horror and helplessness of the situation.

With Mrs. Douglas and Hillary, had the palliative team observed the multifaceted impact of the countertransference distress, they might have slowed the decision-making process. They might have had the time to weigh all the institutional, personal, and professional responses generated by this heartrending situation. They might have created additional time for the family to integrate the meaning, current and future, of this end-of-life ritual for Hillary. In fact, it might very well have been possible to mediate a presence for Hillary that was responsive to her needs as well as to the physician's concerns.

Interdisciplinary Effects

While decisions around Mrs. Douglas's care were likely impacted by intrapersonal and institutional variables, it is also likely that power imbalances between disciplines, between clinicians, and between patients and families were also at play. Although team members may act as if there is parity among members, the reality of the differences in function, liability, and authority often percolates and silently and unconsciously informs intense discussions and emotions. This power differential is often more exquisitely felt in disciplines such as social work or spiritual care. Frequently overlooked and undervalued in health-care systems, these health-care professionals can experience countertransference responses particular to their roles. They may recognize, exaggerate, or overidentify with patients and families who, while struggling to negotiate these same health-care systems, do so in a significantly disempowered role. Alternatively, these disciplines, in an effort to gain approval or feel secure in their positions, may identify with those whom they perceive as powerful authorities in the system, a defense akin to identifying with

the aggressor. Both responses are worthy of examination so that they do not adversely impact clinical care or institutional goals. It can be extremely challenging to stay aware of these countertransference responses while attempting to meet the needs of patients and families and all the while acknowledging and demonstrating respect for institutional goals, an outcome that impacts the survival of consult services and the large health-care systems in which they reside.

It is curious to ponder whether intra- and inter-team conflict and distress is, at times, the consequence of clashing countertransference reactions that arise not only from emotional etiology and personal history but from discipline-specific values that remain unobserved and unexamined. The interplay of each discipline's professional history, along with their core values, is also at work within palliative care teams. When we think about a core palliative care team—physician, nurse, social worker, and chaplain—each member comes from a different professional context based not only on their training, roles, and responsibilities but also upon the histories of each discipline. The individual foci of our unique disciplines teach us the particulars of how to approach our work and our duties. We are taught, for instance, whether to value personal insight or not, whether to lead with our hearts or our heads, or whether to lead and then listen or listen and then lead. Our medical colleagues, who are taught to be task- and goal-oriented, often lead and then listen, while social workers and chaplains, relying on process, listen and then, if required, lead. Nurses seem to blend aspects of both contexts in their roles as their work is often relationship based and outcome driven.

Another area in which interdisciplinary differences may manifest is in the sphere of goals and priorities of medical care. For instance, the medical profession frequently prioritizes healing the sick, doing no harm, and writing orders to achieve these goals. Nurses frequently prioritize their expertise in care and comfort. Chaplains may privilege faith, ritual, affirmation, and presence, while social workers often value giving voice to the downtrodden, the vulnerable, and those marginalized by society. Social work places much import on autonomy, a value that while congruent with the shift in Western medicine from parentalism to self-determination and shared decision making, can be a potential hotbed of countertransference. Social workers who have historically felt devalued in the health-care arena must take particular care lest they find themselves vigilantly promoting autonomy and self-determination at the expense of the empathy, critical thinking, and discernment necessary in facing significant ethical and moral dilemmas.

These generalizations and hypotheses are offered to help us consider the meaning of our choice of disciplines and the disparate ways these choices may manifest in powerful emotions that are often generated in our efforts to work together in the intense and intimate work that is palliative care. Clearly, each professional is at risk of unknowingly weighing profound decisions through the lens of their particular discipline's perspective. The risk, of course, is that if these unconscious influences are never brought to awareness, they cannot be articulated. If they are not articulated, they cannot be addressed. They risk going underground, thereby precluding any possibility of examination or mediation.

The Persistent Work of Teams—A Rich Resource

Palliative practice, at its most pristine, integrates core principles and depends on skills provided by clinicians of varied disciplines whose aim is to work collaboratively toward

a shared mission. It is not therapy, yet all the involved clinicians do therapeutic work within a relationship of rapport and respect. They enhance the care provided to patients and their families to maximize benefit and mitigate harm. This vision is often based in an integration and respect for patient and family history within the present context. Our interventions have the potential to influence the legacy and future well-being of patients and families well beyond their immediate experience with us. Thus there is an opportunity to maximize benefit and mitigate harm not only in the present but also for the future.

Within this context, team members approach the work through a unique purview where professional training, responsibilities, and personal experience intersect. In essence the palliative care team's work is a cross-cultural endeavor: each discipline has its own culture separate from each individual's emotional, developmental, and personal history. Frequently, cross-cultural misunderstandings can occur within the team because of differences in high- and low-context cultures. Generally, the current practice of Western medicine is provided in a low-context setting. That is, clinicians rely on providing information in an explicit, time-effective mode; the context of the relationship is secondary—often due to the need to negotiate high patient volumes. For many physicians this has been a poignant loss, not only of authority but also of relationship and meaning in their work. Alternatively, high-context perspectives prioritize the relationship, with the efficient relaying of information second. In these settings, information is shared through a relational, perhaps more nuanced communication style.

It is generally assumed that living with serious illness and possible death requires a relational, highly nuanced style (high-context experience). Patients and families frequently look to the physician and other providers not only for information but for a humane understanding of their particular struggle, which is best achieved if there is a relationship of trust. They seek not just information but connection. They desire to be truly "seen" and known. Within a high relational context, patients and families are then freed to begin the careful work of emotional, psychological, and spiritual integration. They safely can turn their attention to the poignant task of making meaning from situations that may seem arbitrary or unfair. One could postulate that if a high relational context had been privileged in the Douglas case, perhaps the pace with which decisions were made would have been examined, and another outcome might have ensued.

The most successful teams encourage collaboration and trust among clinicians and a blending of high- and low-context discipline input to create positive outcomes. Inevitably, however, the dual contexts of those who value process as much as outcome with those who privilege outcome over process result in complicated feelings, assumptions, conflicts, and judgments. Under these circumstances, the team meeting, palliative care's most essential tool, can serve to invite inquiry, curiosity, and compassionate care.

Addressing Countertransference

Palliative care teams work tirelessly to ensure expert-level pain and symptom management and to address psychosocial and spiritual needs of patients and families as they negotiate illness, decision making, and the evolution of serious disease. This requires an intricate weaving of knowledge, emotional intelligence, and communication skills with a capacity to be attentive and responsive in the moment—attentive to what is occurring

externally and internally—for patient, family, *and* helping professional. Hospital-based consultation teams work with a list of patients that changes daily, grows with the addition of new consults, and shrinks consequent to expected or unanticipated losses due to death and discharge. This is a world of triage, constant change, and uncertainty. Team meetings, at their best, offer a safe place wherein clinicians can draw from their

COUNTERTRANSFERENCE TOOL BOX:

Reflective Exercise

Palliative care responds to the needs and well-being of the whole person. This requires the presence of whole clinicians who are able to witness, accompany, and advocate for patients and families while being aware of and tending to their own experiences. Attention to countertransference can begin with small practices built into the work day that help us attend to feelings and reactions as we go.

In acute care settings, palliative care teams may see patients across the life span at vastly different moments in their disease trajectory, from diagnosis through immediate bereavement. Moving from room to room creates opportunities for experiences to blend and emotions to become confused and heightened. Integrating these brief exercises, marking a pause, increases and enhances our awareness throughout the day, directly informing our capacity to identify countertransference issues and responses. We may not have the necessary space to process or reflect entirely at any given time. However, identifying triggering, stimulating, or emotionally challenging experiences in the moment can reduce a stress response that over time makes our feelings more elusive and harder to name.

The following simple suggestions, based in mindfulness practice, require new habits or attribute specific meaning to habits you already have, thus interrupting a practice pattern that in all likelihood may seem quite comfortable. These intentional moments, initiated throughout the day, can increase one's awareness more generally.

- Identify daily tasks that can act as reminders to slow down, allowing you to take stock of where you are in the moment. For example, every time you wash your hands or use hand sanitizer, enter an elevator, turn on your computer, or dial into your voice mail, take two conscious deep breaths, focusing equally on each breath as you inhale and exhale.
- When sitting, be it at your desk, a family meeting, or a team meeting, keep both feet on the floor. Feel the support of the ground under your feet. Check in with your posture. Feel your back supported by the chair. Take a deep breath.
- Take a moment to mark the start or end of your work day. Select work shoes that you leave at your desk. Use the time changing your shoes to notice how you feel. If there is a need there, consider how or if you wish to respond to it.
- Jot a few quick notes before you leave for the day: single words, names, feelings, or moments that you can come back to and review later. Leave the notebook at work.

reservoirs of knowledge, experience, and expertise to build and support a compassionate community for themselves. Meetings can be places where the processes of reflection, deliberation, and inquiry bring to light the emotional and spiritual lives of individual team members as well as the values, assumptions, pressures, and sources of distress that inform the unique disciplines and the collective life of the team (Altilio & Coyle, 2014; Gracia, 2001; Hermsen & Ten Have, 2005). These are the moments of insight and reflection that teams are gifted when they find the courage to share their experience and distress and when they listen for and through their respective biases, emotional responses, and cognitive discomfort. Team meetings built on a foundation of trust and emotional safety actually may serve as an antidote to unbridled countertransference (Edmondson, 2008). This is a gift of great meaning and import. In fact, the integrity and quality of palliative care depends on it.

Conclusion

Palliative care teams work constantly in the wake of what has come before, from the smallest to largest details of what is unfolding in the lives of patients and families and what may unfold in the future. Teams work in the wake of physical, emotional, and existential suffering and in the wake of the many overlapping relationships that surround each patient, all changing in the sea of illness. Each member works in the wake of the changing self, changing roles, changing relationships, and changing decisions. Each clinician negotiates these waters from different backgrounds and training, with shared and unique responsibilities to each patient and family as well as to the institution and health-care system. Individual reactions, thoughts, and feelings; the sense of close connection to what is happening; and that occasional, profound sense of disconnect are paths to the insight and ethical discernment essential to the shared work of palliative care. To step back and consider palliative practice through a prism that separates colors and light creates the possibility that we may hold and appreciate the intimate weaving of self and other. To be in this conversation day after day honors heart, courage, honest reflection, and the care of patients, colleagues, and self alike.

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12 The Seduction of Autonomy

Countertransference and Physician Aid in Dying

Brian Kelly and Francis T. N. Varghese

Introduction

The request for physician aid in dying presents complex social, ethical, cultural, interpersonal, and psychological dilemmas. Current discussions of the issue tend to reduce these complexities to debates about individual rights and legal issues. This narrow view, however, does not take into consideration the interpersonal and social forces that shape the patient's appraisal of his or her illness and that in turn inform his or her personal choice for aid in dying. The doctor-patient relationship is only one such force but is nevertheless critical in influencing how patients perceive their situations, how they attribute meaning to them, and how they make decisions about whether to seek assistance in dying (Varghese & Kelly, 1999).

The most common issues debated vis-à-vis physician-assisted dying generally surround those of rational decision making, ruling out major psychiatric disorders at the time, and determining the patient's competency to make decisions. Far more important, we argue, are the clinical issues: understanding the nature and degree of the patient's suffering, examining the impact of the relationship between health-care staff and patient, as well as exploring the ways in which psychosocial factors influence the patient's decisions (Varghese & Kelly, 1999).

Notably, an empathic gap between doctor and patient can occur based upon gender, class, culture, ethnicity, and age, among other things. Because in most societies the majority of physicians come from particular socioeconomic groups, some disadvantaged groups are rendered particularly vulnerable. The dominant culture's assumption of the overriding ethical status of individual autonomy cannot be overestimated. Nor can it be assumed to hold the same high regard in other sociocultural groups and settings. What is less clearly examined in the controversies about physician-assisted death is the cultural context and meaning of dying, of suffering, of illness, and of disability. Central to the context is the doctor-patient relationship as empirical findings suggest that this relationship has a profound effect on the patient's perception of his or her situation (Varghese & Kelly, 1999). Annas (1993), in fact, postulates that perhaps discussions of hastened death and physician aid in dying "are all symptoms of the problem modern medicine has with dying rather than the solution" (p. 1573).

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Case Study

> Jack is a 38-year-old man with a 10-year history of recurrent melanoma. His face has been significantly disfigured due to extensive surgeries involving removal of part of his nose and cheek. His long-term partner died 12 months ago with complications of HIV dementia. Jack lives alone and sees his family on a regular basis. Jack has been increasingly withdrawn, is having difficulty adhering to chemotherapy treatments, and experiences considerable discomfort with fatigue, nausea, and breathlessness. Jack was referred for psychiatric assessment after taking a deliberate overdose of opioid analgesics. He had called an ambulance after taking the medication when he became fearful that he would die. Prior to his overdose, Jack had phoned his sister, a nurse, who had said, "It's up to you what you do—we know you've been through a lot." Jack reported that he had made an agreement with his primary care physician that if his disease advanced, he wanted a prescription to hasten his dying. His physician agreed to prescribe the medication for this use when the time was right. When the physician was contacted, he concurred with Jack's account. The physician had known the family for many years and had been caring for Jack since his diagnosis with cancer. The physician felt that Jack had been through enough. He explained, "At least there is *something* I can offer him. . . . I think I'd do the same if I was him. He should be allowed to die the way he wants."

Jack's case provides an example of the problems underpinning physician-assisted dying in end-of-life care and specifically the significance of the interactions between the clinician and the patient. The case illustrates how countertransference and transference can operate to bring the patient's care to this point. In this chapter we will discuss the impact of Jack's illness on himself, his doctor, and his family. We will examine the interactions between those affected by Jack's illness, and we will use these insights to explore the possible meanings—to the patient, physician, and family—of the request for aid in dying. Jack's desire to end his life on his terms will also be considered with respect to the clinical and interpersonal factors that emerge in the care of a dying patient and the responses evoked in personal and professional caregivers.

The Psychology of the Helping Relationship

Jack's illness is one in which there is a deteriorating course and potential loss of a range of important bodily and mental functions. While this may evoke feelings of sympathy and compassion in health-care workers, other reactions or feelings may also come to the fore—feelings that can be difficult to acknowledge, let alone discuss. These can include feelings of disgust, impotence, helplessness, turning away, even the desire for a compassionate ending.

Thus, inasmuch as communication between patients and health-care providers is critical when considering the request for hastened death (Hamilton et al., 1998), the psychology of the relationship between the helping professional and the patient is, perhaps, most important. Each party brings a range of personal characteristics and expectations to the interaction.

The Clinical Context

The most obvious factors that clinicians bring to the helping relationship are their professional roles and duties, their motivations to relieve distress, as well as their wishes to assist the patient (Kelly, Varghese, & Pelusi, 2003). Helping professionals also are shaped by a set of more personal factors such as their own fears regarding illness and death, their reactions to the intensity of the patient's needs and increasing dependence on them, impressions about the nature of the patient's medical status, as well as responses to individual patient attributes such as age, ethnicity, and background.

The patient brings to the clinical context factors that shape the meaning of his or her illness: problems and symptoms caused by the disease, past personal and family experiences of illness, as well as the ramifications of the multiple losses that accompany the illness. In addition, the patient often struggles with the impact of the disease on his or her sense of self, sense of autonomy, and independence. The emotional implications of an increasing sense of helplessness and growing reliance on others cannot be overestimated.

The clinician's task becomes that of assisting patients to adapt to such changes, including changes in their roles, in their relationships, and in their sense of control. Supporting the patient so that he or she can adjust to these changes without fear, shame, or loss of esteem can be one of the most difficult and challenging tasks for clinicians and for all involved. When a request for aid in dying is added to the mix, the interpersonal dynamics, the transference, and the countertransference become all the more complex.

In fact, the intersubjective nature of countertransference is no better illustrated than in such a situation: on the one hand, a patient's misery, suffering, and perceived self-destructive tendencies may act to engender in the doctor feelings of being overwhelmed or "done" with suffering and a wish that the patient's life *could* end. On the other hand, the patient's wish to die and feelings of worthlessness and being a burden to others may in part be a reflection of what the doctor brings to the therapeutic encounter. In a world where physicians' omnipotent fantasies of saving lives and defying death are thwarted by incurable disease, doctors may find themselves "sickened" by death and deterioration and unable to tolerate the patient's suffering. The need to feel helpful, to be able to restore function, and to be effective is sorely challenged by the dying patient. Being able to 'provide' aid in dying "may become one such response by a doctor to his or her own feelings of futility and failure, but one that is in a form that disguises unacceptable feelings in an attempt to regain a sense of mastery and [control] . . . and that can have dangerous consequences" (Varghese & Kelly, 1999, p. 99). This becomes a particular problem when the anxieties of the patient resonate with the doctor's own vulnerabilities. In such a case, the demands of the patient may not be questioned.

The Impact of Helping Professionals' Responses to Illness

As described, the helping professional's reactions and responses to the patient's medical status are important forces in shaping the patient's experience of his or her illness. What is communicated subtly—or not so subtly—may directly or indirectly impact the patient's psychological responses and perception of the situation. For instance, the feelings of futility and hopelessness often recognized in the patient may be as much the

result of the physician's dilemma as of the patient's. "For some doctors, the patient's wish to die may provoke an unrecognized relief to the frustration, helplessness, and perhaps guilt and responsibility, because their own distress at the failure of their treatment may distort their responses and judgment" (Varghese & Kelly, 1999). Thus, in discussing and exploring patients' needs, clinicians' awareness of their own reactions is fundamental (Hamilton et al., 1998).

In empirical research on this issue, the doctor's inclination toward offering aid in dying was among a set of clinician factors that were significantly associated with the patient's wish to hasten his or her death (Kelly et al., 2004). Whereas autonomy and independence are highly valued by modern medicine, it may be difficult for the clinician to challenge rigid adherence to principles of autonomy in the patient or to confront such uncompromising views in him- or herself. As such, an unconscious collusion may occur in which death is seen as the only solution to the patient's, family's, and doctor's predicament. When the doctor is "seduced" by the allure of individual patient autonomy, aid in dying becomes a means of maintaining the illusion of mastery or control—a way to combat uncertainty. Death may also provide a solution to the sense of shame, guilt, and loss of dignity shared by others, including the family and health-care team. Viewed within this context, discussion about hastened death without the requisite unraveling of the meanings of such a request can be seen as a manifestation or enactment of the problems everyone in this case is having with Jack's death and illness rather than the "solution" to those problems.

The Interpersonal Dynamics

Jack's request for assistance in ending his life cannot be understood outside of the clinical and interpersonal context in which his illness (and treatment) is occurring. We suggest that there is invariably a subtext incorporating the unstated (and perhaps un-statable) hidden needs and responses of all parties involved. This subtext needs to be explored, as with any request a patient makes that suggests the clinician behave in ways that fall outside the expected boundary of the clinical relationship.

A helpful analogy may be to think about the issues that are raised when a patient requests a sexual relationship with the clinician. A request to step outside the boundary of the professional relationship in this way demands that the helping professional examine the layers and perhaps multiple meanings of such a request—to both patient and clinician alike—including any possible role the doctor may have unconsciously played in its development. The context in which a patient requests aid in dying requires examination in the same way (Varghese & Kelly, 1999). The clinician will be unable to do this effectively, however, if he or she is unable to examine his or her own role in shaping the patient's distress and experience of his or her illness (Hamilton et al., 1998; Varghese & Kelly, 1999).

Projective Identification

In the case of a gravely ill or difficult patient, the clinician may experience intense feelings of frustration, helplessness, and anger toward the patient. As much as we may hate to admit to these feelings, they are not uncommon and may, in fact, be unconsciously

detected by the patient as a wish that he or she would die. We know from clinical experience that when a clinician has thoughts that a suicidal patient would be better off dead or wishes that the patient would successfully complete a threatened suicide, these feelings are a very reliable indicator that the patient is, indeed, dangerously suicidal.

This is the nature of projective identification (Varghese & Kelly, 1999). Projective identification refers to the process through which the clinician experiences feelings toward or about the patient that mirror those that the patient is experiencing about him- or herself. Thus, if the patient feels hopeless, angry, or overwhelmed, the clinician experiences these same, identical feelings toward the patient—often unconsciously and often without being aware that these emanate from deep within the patient. Unexamined projective identification can shape the helping professional's clinical actions and responses. This becomes potentially hazardous for patients requesting aid in dying as it simply cements their "stuck" experience without the opportunity for exploration, change, or learning.

Francis describes how projective identification manifested in the case of a patient who was not coping well with her illness:

> The patient was causing all sorts of distress among her treating clinicians because of her demands and verbal attacks on them, especially in accusing them of being incapable of caring for her. Along with her erratic adherence to the treatment protocol, she frequently complained, "I'm sick! Why can't anybody help me here?" It was not uncommon for the staff, out of earshot of the patient, to suggest that her death by suicide would be a relief to all.
>
> One night, the social worker who was involved in the care of the patient experienced a very disturbing dream in which the patient was on a ledge, with arms extended, beseeching the social worker for assistance. In the dream, the social worker calmly walked over and pushed the patient over the ledge. The day after the dream, the patient took a serious, nonfatal overdose of her medication. This experience brought the social worker face-to-face with the fact that his frustration, anger, and even murderous feelings toward the patient (of which he was not fully aware) had been indicative of the patient's deep despair and self-hatred. Her behavior had been so repulsive to the staff that no one, including the social worker, unearthed the true meanings behind her demands and hostility.

Caring for seriously ill and distressed patients places great demands on the clinician's capacity to both monitor his or her reactions and responses to the patient and at the same time be aware of the impact the patient is having on him or her and on others. In a request for hastened dying, we must examine the subtext of the request. Might the patient actually be saying, "I am too much of a burden. . . . My illness is intolerable to you. . . . You are disgusted by me" or "Living with this illness is too scary or awful to discuss."

Countertransference Enactment

Countertransference enactment is a term used to describe the translation of countertransference feelings into actual behaviors toward the patient (Gabbard, 1995; Kelly,

Varghese, & Pelusi, 2003). The enactment of such feelings can serve to contain the medical provider's own, uncomfortable feelings. It also can deter the provider from responding more appropriately to the patient's needs. The provision of aid in dying or initiating discussions about the issue may present a vehicle for such enactment if the distressing issues being faced by both parties are not considered, reflected upon, and discussed. Is providing Jack with medication for his death a compassionate response by his doctor, or is it driven by countertransference enactment? Is this the patient's wish to die or the doctor's desperate enactment of relief?

What does it mean to Jack to secure such a contract or agreement? It may indirectly indicate that there is a point at which death is the solution, a point at which the illness and its complications, or Jack's needs, become intolerable and other trajectories are not worth exploring. If others, especially those caring for the patient, see death as the solution, how does the patient challenge his or her own fears and helplessness?

Jack's primary care physician describes Jack's request as "understandable" and "what he would do" if in the same situation. The inclination to assess the request for aid in dying in terms of "rationality" alone may be a manifestation of countertransference in that the benchmark becomes whether the patient's response is, in the professional's opinion, "understandable" under the circumstances and/or whether the professional's own, personal response is the "correct" one.

Inaccurately putting oneself "in the patient's shoes" to make clinical decisions and evaluations of quality of life leaves the patient vulnerable to the clinician's personal and unrecognized issues concerning death, illness, and disability. Is it not presumptuous for health-care providers to assume that decisions can be based upon what they themselves would wish if they were in a similar situation? This brings the clinical relationship to a new dimension: the wishes of the clinician for the patient are presumed to be identical to those of the patient! Is the clinician experiencing empathy? Or is this countertransference enactment in disguise (Varghese & Kelly, 1999)?

In essence, the potential exists for the patient and doctor to come to share the view that death is the solution to the problems and distress that *both* experience. This is especially so when the patient's view of his or her worth and future resonates with that of the doctor or when patient and doctor share similar fears, frustrations, and disappointments about the illness. When the doctor comes to experience the depth of the patient's hopelessness and demoralization, the prospect of physician-assisted dying may appeal and, indeed, be justified as "realistic." Additionally, the current dominance of autonomy as a principal value in medical decision making may cause a clinician to feel pressured to comply with any apparently reasonable request on the part of the patient.

Alternative Responses to the Request for Hastened Death

The Role of the Therapeutic Frame

Ideally, the therapeutic frame provides a place wherein both patient and doctor safely can explore distressing experiences and feelings. The frame provides a boundary that maintains clear roles and responsibilities for the clinician while at the same time allowing the patient the freedom to discuss his or her fears and needs. When patients feel

safe in the knowledge that it is the doctor's role to try to gain an understanding of their distress rather than to act upon their requests, they may be more forthcoming with their deeply held fears and concerns. When this happens, the therapeutic encounter provides the clinician a space and place to develop insight into the patient's pain, demoralization, and depression, which often underlie desire-to-die statements.

Flexible and sensitive application of clear boundaries is important in the care of the dying and becomes particularly so given the intensity of feelings about death, illness, and its progression that each party experiences. When caring for dying patients, awareness of the boundaries of the professional relationship becomes *more* important rather than less. This awareness enables the clinician to (a) maintain realistic hopefulness; (b) retain a capacity for emotional engagement with the patient without becoming overwhelmed by the experience or responding with detachment; and (c) stay involved without becoming demoralized. The challenge of maintaining empathic involvement with dying patients while at the same time retaining realistic hope about the benefits of care (even if palliative in its goals) requires an emotional presence and involvement without fatigue and disengagement.

For physicians, the focus of their professional and personal self-esteem and sense of purpose can be heavily reliant on perceived success or mastery in the face of a patient's illness. This can become focused on the capacity to cure illness or achieve successful symptom control. These values and motivations can be challenged significantly when we are forced to confront death, bodily deterioration, the limitations of medical interventions, and the increasing intensity of the patient's needs and distress. The clinician, feeling frustrated, guilty, and ineffective, can inadvertently react by becoming over or under-involved in his or her patient's care. He or she may also feel pressured to relax the usual therapeutic boundaries. If physician aid in dying is a way to put an end to misery, we must ask the question: "Whose misery are we talking about?"

Exploring Patient and Family Concerns

Another way of responding to Jack's request for assistance in ending his life would be for the doctor to use the request as an opportunity to explore the concerns underpinning it. Common patient concerns include fears about what support will be available through the dying process; insecurities about the level of commitment on the part of the physician, health-care team, and family; as well as fears of being a burden, dying alone, or dying a painful, undignified death. It is possible that initiation of a discussion of physician aid in dying might reflect an indirect request by Jack for assurance of the doctor's continuity and commitment to his care, irrespective of the disease course.

Could Jack's doctor have responded differently to the request for hastened death? When legislation permits physician-assisted death, the doctor can be vulnerable to seeing the issue solely in terms of competence, rationality, and the exclusion of major psychiatric disorder. This can interfere not only with further thought about alternative responses but also with the exploration of the underlying meaning of the request. A thoughtful response also requires that the doctor appreciate the impact of his or her own reactions and feelings toward the patient.

Depression and Major Psychiatric Disorders

Certainly it is important to consider the possible clinical problems that might trigger a patient's request for aid in dying, such as the presence of severe depression (Block, 2000; Emanuel, 1998). For some, however, the issues may be less about depressive illness and more about the dilemma of adapting to the changes in autonomy, independence, and roles that occur with illness. The request for aid in dying can be a means of expressing the need to maintain control (at almost any price) and sometimes without considering the needs or impact on others, such as family members and loved ones.

Even in the context of major depression, however, the nature of the request for hastened death requires a level of attention to the interpersonal factors previously described. The factors contributing to the patient's level of suffering need to be carefully assessed across the physical, psychological, cultural, and spiritual domains of his or her experience of illness (Emanuel, 1998).

The Social and Interpersonal Contexts

The social context must be considered: the impact on family, the problems of alienation and isolation, the personality and background of the patient, as well as how this request might be interpreted in the context of the patient's attempt to adapt to the demands of the illness. It is also critical to consider the request in terms of the interpersonal interaction—what is the patient really asking of the doctor? What aspects of the clinical interaction might be relevant to understanding how this request arose and how to respond to it?

Fears of the Experience of Dying and of Being a Burden

Often underlying the request for aid in dying are fears and expectations about dying, about the future, and about how others will cope with their increasing needs for care (Back et al., 2002). It is perhaps not surprising that for some patients, it is the anger toward their caregivers, especially their doctors and nurses, for their perceived failings and disappointments that is relevant when the request for physician aid in dying is made. The request can be interpreted to mean "this is the only thing left that you have to offer me." Patient anger and disappointment require sensitive exploration and acknowledgment as they can accompany the experience of progressive illness even amidst expressions of gratitude and positive aspects of care.

In Jack's case it may have helped to explore what his illness and impending death meant for him. Did he fear the loss of independence? Did he fear intractable pain or other debilitating complications? Jack's fear of being more reliant or dependent on the doctor, his need for assurance of commitment to his care despite its complexity, and his feelings about having metastatic melanoma (such as shame, horror, and guilt) must be queried.

Family Concerns

Additionally, the needs of the family and their response to the potential loss of their loved one are important factors here. Families need help in understanding their (often

mixed) feelings about the impending loss of their family member. In this case, the family's sense of helplessness about Jack's illness, as well as the ways that their distress might be being communicated to Jack, are relevant. Additionally, Jack is likely to draw upon his experience of his partner's death to shape his expectations of his own death, but a key difference might be his isolation and lack of intimate support. Jack cared for his partner; does he fear dying alone?

The Conversation

The willingness to talk about dying and being sensitive to when the patient is ready to talk about death are important aspects of communication (Wenrich et al., 2001). A sensitive, biopsychosocial-spiritual approach has the potential to restore a sense of direction, purpose, and meaning to Jack's treatment—for both Jack *and* his physician. Such candid discussions also hold the potential to enhance Jack's feelings of control and to combat demoralization (Kissane, Clarke, & Street, 2001). And, for the physician, greater empathic engagement and understanding of patient needs often can build greater confidence and trust in the helping relationship. This is critical so that understanding and exploration of choices can be possible.

With alternative responses such as those described, it is possible that Jack might have felt more supported and understood by those caring for him. He might have experienced less isolation and found other ways of expressing or dealing with his existential distress, short of seeking aid in dying. He might have had an opportunity to explore the effect of and grief over his partner's death and perhaps come to expect a less despairing death. He might even have had the opportunity to establish a sense of personal meaning about his illness and feel a greater connection to his family, friends, and others. All this might have enhanced Jack's sense of dignity and value (Chochinov, 2002).

Paradoxically, agreeing to support Jack's request for hastened death *without* exploring the underlying concerns limits his choices and potentially erodes his autonomy in that it may reflect the forces of *others'* wishes—not his own. The question is whose suffering is being relieved by his death, and whose needs are determining his actions—his own or those of the people around him? By exploring, rather than acting upon, his request, Jack gains the opportunity to establish his own wishes and choices—unencumbered by the projections, fears, and judgments of others.

Keeping Up With Our Countertransference Reactions

In caring for seriously ill and dying patients and their families, we must constantly monitor our own affective responses to our patients and their particular situations as a means of gaining a better understanding of them (Meier, Back, & Morrison, 2001). Staying aware of over involvement and detachment from patients or their families, as well as tracking the potential effects of personal demoralization, is especially important. Our own values about autonomy and independence, our adverse or prejudicial reactions to illness, and our fears about death for ourselves and others are all factors that must be understood as parts of our countertransference in caring for seriously ill and dying patients.

When the patient requests aid in dying, we must ask ourselves: What does this patient mean with this request? Is there something within me that has contributed to the patient's making such a request? Is the patient responding to *my* needs and issues? What might I have directly or indirectly communicated to the patient that has impacted his or her perception of the illness? Is this request a reflection of the patient's despair, or is it an indication that others (including me) have despaired of the patient or have been perceived by the patient as having such despair? Would the patient's death serve my own needs by removing any reminder of my own impotence?

The reader may be appalled at the suggestion that doctors could feel destructively toward patients to the extent of hate and disgust and that these feelings could influence palliative and end-of-life decisions. Is the danger of countertransference overstated? We contend that, with the exception of physicians who lack the capacity for insight and self-reflection, most doctors would admit that in whatever field or setting, there are patients we like and those we do not. There are patients whose conditions cause us frustration and despair, and there are patients we wish would "just go away." Fortunately, because of our code of ethics, we are obliged to treat all patients with the utmost consideration and to provide them with the best possible treatment—despite our personal interests or feelings. Rather than deny our true feelings and responses, being honest about them and attempting to understand their origins and meanings can lead to a better understanding of the patient's (and our!) suffering.

In developing an appreciation for this aspect of our work, it is important that we have methods to constructively review our treatment of and experiences with patients. We have found it helpful to (a) work in a clinical team where treatment decisions can be challenged; (b) receive professional support for the complex tasks involved in caring for patients facing the end of life; (c) receive advice and consultation from colleagues; and (d) seek out professional supervision that encourages an understanding and constructive discussion of the impact of this kind of work on the clinician.

Conclusion

Although this chapter has discussed factors within the physician-patient relationship that impact decisions about aid in dying and hastened death, these issues are also pertinent to relationships between patients and other health professionals. The broader concerns surrounding hastened death include the limitations of clinician training and skills in care of seriously ill and dying patients, limited access to specialized palliative care services, and the emotional stress experienced by those caring for dying patients.

Decisions about aid in dying present a number of challenges to clinicians. While the issue has been debated on ethical, legal, and moral grounds, the clinical issues and in particular the psychodynamic issues have been given less attention. It is important to place the problem of the request for aid in dying squarely within the clinical context—the context of the emotional, social, spiritual, and existential problems experienced by patients, the interactions and feelings evoked between patients and the professionals caring for them, and the health-care systems in which care of the seriously ill and dying takes place.

The *relationship* between patient and health-care professional is a critical element of the clinical context. It is the vehicle by which discussions around emotionally significant issues occur, and it is the conduit of communication about the development and outcome

of illness. The patient's keen perception—whether conscious or unconscious—of the clinician's ability to be emotionally present and to offer sustained support can shape the patient's perspective of their illness and their future.

Separate from whatever legislation exists, physicians, psychologists, psychiatrists, and others evaluating the request for physician aid in dying must assess not only the patient's experience of the illness but their *own*. Only by examining the dynamics of the patient-professional relationship and the personal, interpersonal, and existential factors that shape that relationship can a true understanding of the request for hastened death be assured. The allure of autonomy is seductive. It is up to us to determine just what this highly valued principle means in light of the *patient's* experience, not our own.

COUNTERTRANSFERENCE TOOL BOX:

Renee S. Katz

Take a moment to read each of the statements below. Write down your immediate, unfiltered response to each statement. Pay attention to your "knee-jerk" reaction to each statement as well as to feelings, thoughts, and impressions that surface after your initial response.

Statement #1:

"For some doctors, the patient's wish to die may provoke an unrecognized [sense of] relief [from the physician's] frustration, helplessness, guilt and responsibility. . . . [The doctor's] own distress at the failure of their treatment may distort their responses and judgment. . . . An unconscious collusion may occur in which death is seen as the only solution to the patient's, the family's and the doctor's predicament. When the doctor is 'seduced' by the allure of individual patient autonomy, aid in dying becomes a means of maintaining the illusion of mastery or control—a way to combat uncertainty. Death may also provide a solution to the sense of shame, guilt, and loss of dignity shared by others, including the family and health care team . . .

The context in which a patient requests aid in dying requires examination. . . . Clinicians will be unable to do this effectively, however, if they are unable to examine their own role in shaping the patients' distress and experience of their illness. . . . Is providing [life-ending] medication . . . a compassionate response by [the] . . . doctor, or is it driven by countertransference enactment? Is this the patient's wish to die or the doctor's wish to kill (Varghese & Kelly, 1999, pp. 43–46)?"

Initial response:

Additional thoughts:

Statement #2:

"Much of the harm to dying patients arises when physicians are unable to step back from their professional goal of saving and prolonging life in order to recognize the exigency of their equally important second duty: to relieve suffering . . .

Where did we take the turn down the unforked, dead-end road that says we must stand by and watch while doctors do something for every medical condition, however much misery it may produce? Why do the sons and daughters of Hippocrates stand silently outside our mothers' rooms peering at flashing numbers while writing orders for more dripping medicines to shore up collapsed veins and souls? Why, before committing their patients to the treacherous rapids of terminal therapy, don't they ask one simple question: 'What do you want?' . . . Dying patients . . . *aren't choosing death over life: they know they're going to die, and they're choosing how and when to do it*" (Preston, 2006, pp. xvii–9, italics added).

Initial response:

Additional thoughts:

* * * * *

Strong initial responses—whether of agreement or disagreement—to either of these statements may indicate that we have considerable preexisting bias in this arena. To bring our fullest consciousness to this aspect of palliative and end-of-life care, which so significantly impacts our patients' opportunities to live and to die "well," caution and self-awareness must be de rigueur.

We must be vigilant about attending to our feelings of despair, fear, and conviction in this oft-moving and tender work. If we avoid these feelings in ourselves, we may unconsciously act them out through over involvement, detachment, projection, or denial.

If we can let ourselves know that our feelings may be evidence of our own parallel suffering, we can use this awareness to stay close, be present, and companion our patients on *their* personal journeys without influencing them with *ours*.

* * * * *

Normative Responses to Desire-to-Die Requests

Shock

For clinicians unfamiliar with hospital and hospice settings, the sight of tubes, monitors, IV poles, and the like can feel foreign and somewhat unnerving. When a patient or family makes a decision to discontinue use of any medical regimen, the helping professional can feel helpless, confused, powerless, and

out of control. A numb, dazed emotional response can be a way of protecting one's psyche from the associated discomfort and overwhelming feelings. When we are emotionally flooded in this way, we may find ourselves immobilized, unsure, and unable to process the information in our*selves*, no less in those with whom we work. This is the time for consultation, peer support, education, and self-assessment.

Anxiety

The context of serious illness, death, and dying forces us to face our own mortality and our beliefs and values about what makes life worth living. When a patient makes a decision to end a treatment or medical intervention, we can find ourselves agitated and alarmed. We may dread having to face these types of decisions on the part of patients and families because we haven't come to terms with our own ambivalent feelings about the meaning of life or the definition of a "good death." Further, if we are not familiar with the laws and mandates relevant to such decisions, our fears about our own involvement in such cases—legally and ethically—can escalate. Our impulse is often to take action—and quickly—to rid ourselves of these uncomfortable feelings. Yet, without careful thought, consultation, and processing with the family, we may inadvertently project our own beliefs onto them or influence them in ways that reflect our own views and biases and not necessarily theirs.

Upset (Sad or Overwhelmed)

Our own grief and sadness can surface when we face serious illness or the impending death of a patient. Perhaps it is the patient with whom we have built a long-standing relationship whose death touches us deeply; perhaps it is a child whose death feels particularly "off time"; perhaps it is an individual who reminds us of someone special in our own lives. Anger, agitation, and deep wellsprings of sorrow can surface in the helping professional. In addition, if the patient's decline or impending death is sudden or traumatic, the professional can experience strong, unprocessed feeling responses simply because they, themselves, are traumatized by the loss and have had little or no time to begin their own grief work and process of saying good-bye.

Ongoing work with significantly ill or dying patients can leave the clinician with feelings of exhaustion and anguish. If we find ourselves flooded by our own deep sadness, we may become immobilized and distracted. As such, we lose the capacity to "be" with the patient to examine and consider the existential questions with which they struggle. In addition, we may find ourselves unable to "hold" psychic space for possibility or for hope.

Anger

As clinicians, we work hard "in the trenches" to help patients improve their sense of well-being, lifestyles, and relationships. When a patient wants to hasten his or her death, despite our best efforts, our egos can take a blow. We

can feel frustrated, angry, resentful, and impotent—and we may feel embarrassed about these feelings, especially if we see ourselves as caring, accepting, and empathic clinicians. If we feel ashamed of our "real" feelings in the face of these difficult struggles, we may find ourselves using defense mechanisms such as displacement of responsibility and intellectual distancing to assuage our bruised egos. Our countertransference can "push" us to blame a patient for his or her emotional plight or to too quickly "turf" or transfer a case. Worse, we may find ourselves "writing off" patients even before we have had the chance to process their experiences. Neither of these actions serves to facilitate positive outcomes—not for our patients *nor* for ourselves!

Compassion

Being present to the depth of our patients' anguish can be heartrending. If we can navigate the slippery shoals of our own histories, life experiences, and anxieties, we will often successfully find compassion and empathy for our patients' pain and struggles. As such, we can be present to comfort and to companion them through their suffering while maintaining the therapeutic frame.

Relief

The anguish of watching difficult, painful, or drawn-out dying processes can take its toll on the helping professional. It can be excruciating to witness the pain and suffering that all too frequently accompany modern-day interventions to extend life. Practitioners may feel a sense of relief when learning that a patient will no longer be subject to the ravages of invasive medical procedures and the suffering incumbent in these. We may also react out of our own beliefs about what constitutes a "good death" or "quality" living. When this happens, the clinician may fail to explore other factors impacting the patient's or family's decisions such as hopelessness, depression, fears of being a burden, religious or spiritual concerns, and other experiences that could be impacting their appraisal of the situation. As practitioners, we must also be aware of the subtle messages we might be sending that might be influencing our patients' and families' perceptions of their situation, the degree of suffering, and the meanings they attribute to it. Are they making decisions to withhold or withdraw treatment to "take care" of us—or them?

Food for Thought

Being in the presence of unremitting pain and suffering can be overwhelming, unsettling, and deeply moving. Clinicians must carefully monitor their responses in palliative and end-of-life care, or in an attempt to avoid despair and self-doubt, they may find themselves reacting to patients in ways that disrupt the therapeutic relationship. Unchecked distancing or anxiety on the part of the clinician deprives patients of the opportunity to mourn and come to terms with their lives—past and present. It also deprives the clinician of the opportunity to mourn his or her own losses in the face of the patient's decline or demise.

Identifying situations that "hook" us, examining uncomfortable feelings, and having the courage to face things we'd rather avoid are crucial to recognizing when countertransference may be impacting our responses to witnessing our patients' suffering.

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13 The Desire to Die

Voices From the Trenches

Renee S. Katz and Therese A. Johnson

Introduction

In Chapter 12 Brian Kelly and Francis T. N. Varghese thoughtfully and cogently have described the seduction of autonomy in requests for medical aid in dying; that is, the often compelling nature of desire-to-die statements in patients' requests for aid in dying. While it is true that physicians and other medical providers frequently want to help, to "save," or to please a patient by honoring a request for aid in dying, it is equally true that many health-care professionals feel an innate discomfort in considering hastened dying or assisted dying. The need to scrutinize our relationships to these competing, equally compelling reactions to desire-to-die requests is critical in our work in palliative and end-of-life care.

Western medicine is experiencing a growing call for self-determination in health-care decision making. The long-held stance that doctors "know best" and that medical interventions should aim to keep patients alive at any cost is being challenged in medical, social, spiritual, and ethical circles nationwide. As the aging baby boomers face critical illness, disability, and death, they are asking the established medical community to honor individual choice regarding when and how to die. They are raising questions about what constitutes a good death, quality living, quality dying, and surviving versus thriving.

A growing number of choices are available to patients who wish to have a say in the timing of their dying. Choices such as voluntarily stopping eating and drinking, stopping artificial nutrition and hydration, or withdrawing active mechanical intervention and ventilation are legal methods by which to hasten the natural dying process (in all 50 states). Additionally, medical aid in dying is available in numerous states. Patients' desires for choices, for options, and for the capacity to have some say and control at perhaps the most poignant time of the life cycle are forcing health-care professionals of all types to more closely examine the intersection of personal, professional, and organizational responses to requests to hastening one's dying process.

Personal, Professional, and Organizational Intersections

Conflicting internal and organizational values that arise amidst these currents of change can create environments that are ripe for countertransference acting out on both subjective and systemic levels. This is evident, for instance, in the hospice movement whose stated mission, to neither aid nor hinder prolonging life but to offer a "good death," was once deemed controversial.

Sheila

> Sheila pursued nursing and fell in love with her work at a local free-standing hospice. She had been working with a young woman in her 40s who entered the center briefly to manage debilitating symptoms of amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease), particularly swallowing issues. The patient and her parents were taught how to operate the equipment for suctioning as well as other skills for keeping secretions at a minimum. Sheila, who was in her mid-30s, had quickly identified with this patient. Recognizing her patient's distress about becoming dependent on her parents again at this stage of her life, Sheila made it a point always to present decision-making questions directly to her patient. Just prior to discharge, believing that she would have the opportunity to see this patient again, Sheila expressed her hope that the next time this patient returned, she would be the nurse on duty. It was shortly thereafter that the patient's mother drew Sheila aside and reported that her daughter had chosen a date in the near future when she would voluntarily stop eating and drinking as well as any artificial nutrition or hydration. Sheila was visibly distressed and could not finish her good-byes to this patient, whose independence she had championed. At team meetings the following week, Sheila continued to question whether she had somehow missed an opportunity to identify and address her patient's fears, discomfort, or distress. Sheila struggled internally, asking herself where she had gone wrong. She worried that she had fallen down on the job: maybe she could have influenced a different outcome.

Hospice and palliative care professionals are proud of their pain and symptom management skills. When patients choose hastened dying or medical aid in dying, some may feel as if their skills were not put to good use. They often believe that if they had been able to do a better job managing their patients' pain or symptoms, their patients would not pursue this option. For some, it can be particularly heartbreaking when one of their highly independent patients chooses to take the medication "early"—even prior to debilitating physical effects. This can be particularly frustrating when a team member believes that a lot more could be done to provide good symptom management. The provider's *own* assessment is that the patient has good quality of living; thus, like Sheila, the provider cannot understand why the patient would choose to end his or her life.

We all have ideas about what constitutes quality living and quality dying. Our personal views and values and our prior experiences with critical illness, disability, and death all inevitably surface, influencing our beliefs about when hastened dying is "justified" or not. It can be difficult to keep our personal expectations separate from our patients' desires. If we are not aware of our own distress and assumptions that we bring to such situations, we may not accurately "hear" or try to understand our patients' perspectives—leaving them, perhaps, without the support they need.

When Organizational Pressures Complicate Personal and Professional Practice

In addition to bringing our professional ethics and values to our work in palliative and end-of-life care, medical providers may consciously or unconsciously respond to

requests for aid in dying in ways that reflect personally held religious, moral, or cultural values that conflict with those of their patients. Unexamined countertransference in this arena can manifest as trying to talk a patient out of his or her beliefs; withholding access to the people, systems, and procedures necessary to pursue aid in dying; or ignoring the request entirely. This occurs in the personal arena of the helping professional as well as in the organizational system. For instance, in hospitals and community clinics that not only ban the provision of medical aid in dying but often restrict even the discussion of these choices by medical personnel and employees, the context in which the professional works may influence the way he or she responds. In many of these situations, what occurs is not an overt denial of information and care but a covert and often confusing instruction on how to effect a hastened death.

George

> George was dying of COPD (Chronic Obstructive Pulmonary Disease). He had sustained a stroke and was terrified that he would have another and "wind up a vegetable," unable to function at all. This was his greatest fear, and it led him to ask his longtime physician about utilizing the death with dignity law in his state. Much to George's dismay, his doctor immediately responded that he did not believe in physician-assisted dying and "fired" George from his practice. Stunned, George consulted with his pulmonologist, Dr. Moor, who agreed that George qualified for the request and sent him for a second opinion from a different physician on his medical team. This physician told George that she did not believe in physician aid in dying. Although his COPD was in the terminal phase, she could not say *with certainty* that George would die in less than six months. She declined signing the form. George called Dr. Moor again in desperation, and a hospitalist was brought in to consult with George. He met with George, reviewed all of George's medication, and said, "Now don't take all these medications together, or you'll fall asleep and not wake up." He assured George that he would find another physician to provide the necessary second opinion. However, before George could meet with another physician to receive a second opinion, he had another minor stroke. After he recovered, George called Dr. Moor to say good-bye, noting that he was afraid that if he had another stroke, he might not be able to thank her for their work together. He did the same for the hospitalist. He then took all his medications. His wife found him nearly dead and called 911. He was transported to the local emergency department, and the hospitalist was called. He instructed the team to refrain from providing further treatment as George had indicated that he wanted to die. The team complied, and George died in the emergency department.

In this case, the personal beliefs of two physicians interfered with their capacities to truly "hear" the needs of their mutual patient. Neither provider was *required* to act in a way that would violate their personal-professional values. If they had had the capacity to hold their personal beliefs separate from George's, these providers might have honored his patient rights and the law such that an appropriate referral could be made to

a different provider—one who might more objectively have worked with George, his concerns, and his request.

Sometimes conflicting personal-professional-organizational beliefs can be the cause of even more tragic outcomes, as in the case of Robert:

Robert

> Robert was a longtime medical social worker. He had worked on the oncology unit of a large hospital for more than 20 years. He took pride in his work, in his ability to help patients and families move closer in their marital and familial relationships near the end of life, in his capacity to assist patients to find meaning in leaving their legacies, and in the skills he utilized to help patients and families facilitate a "good death" for themselves, however they defined and determined "good." Robert's hospital endured many years of financial stress and ultimately was bought by a large, private, religious organization. Employees and community members were assured that nothing would change for the hospital, other than a new name and new management. Staff felt relieved and confident that their working environment would improve under the new leadership.
>
> The hospital's "numbers" improved quickly, but the atmosphere of the hospital did not. Rather, a pall settled over the oncology unit as well as other inpatient units and outpatient clinics. Employees learned that patients' rights to choose to terminate early pregnancies or to choose the option of death with dignity were now prohibited. Not only were these patient rights terminated, but employees and staff were advised that they were not to discuss these options with patients and families even if the topics were raised by the patients themselves. Robert felt his heart sink. The pit in his stomach grew as he experienced the true nature and impact of the new administration's gag order. His social work code of ethics specifically called out a client's right to self-determination and autonomy. According to the ethical code of his profession, Robert's patients were entitled to determine their own health-care decisions, and the social worker's responsibility was to uphold his or her code of ethics by supporting patient choice. Now, when a patient wanted to consider all of his or her end-of-life choices, including utilizing the Death with Dignity Act, Robert had to choose between violating hospital policy, violating the patient's right to informed consent, and violating his professional ethical code.
>
> This excruciating bind was no more apparent than in Robert's work with Charles, a patient dying of brain cancer. Charles had long planned to use the Death with Dignity Act at such time as he felt his tumor would preclude a quality of life that he considered tolerable. He had discussed this with his family early in his illness. With his psychologist, he had worked on examining all the meanings that underpinned his choice, and he had spent considerable time saying good-bye and tying up loose ends to facilitate a smooth transition. Charles's time had come, so he asked his physician for life-ending medication, as allowed under state law. Charles's request was met with silence and stonewalling. Feeling hopeless and helpless that his well-thought-out plans had been stymied,

Charles returned home. He drew himself a warm bath and, within minutes, shot himself.

The shock, dismay, disbelief, and self-doubt generated by this tragic act reverberated with trauma for Charles's family and for all the medical providers who had cared for him.

Regardless of their own personal beliefs, medical professionals working in organizations that do not allow for discussions about the full range of end-of-life choices are held captive to a double bind: they are caught between a system that can punish them for erring on policy and the patient whose well-being they are charged to attend. They face the unenviable choice of either defying their employer by giving the patient requested information or denying the patient the rights to lawful care. What is lost is the opportunity to address the meaning behind the patient's request for fear of retaliation or discipline by the professional's employer. When clinicians' abilities to provide care are compromised, or when they are asked to do things that violate their personal conscience or professional ethics, demoralization, compassion fatigue, and moral distress can ensue.

Opportunities to Find Meaning in Living With Dying

The politics and legalities of death with dignity are grist for another volume entirely. What is eminently clear, however, is that respect for patient autonomy; respect for our own strong, often surprising countertransference reactions; and respect for the psychosocial-spiritual issues which underpin requests for aid in dying must be thoughtfully examined and carefully weighed.

If we are not vigilant, our desire to "do right" effectively may inhibit us from truly hearing the meaning behind the request for aid in dying and may prevent us from providing a professional response and appropriate intervention. Desire-to-die statements should trigger thoughtful, unhurried conversations with our patients and families in which we seek to understand the request without embedding it with our interpretations, assumptions, or projections. Is the request driven by misunderstanding? Fear? Unacknowledged or unaddressed suffering? Physical discomfort that potentially might be relieved with excellent palliative care and pain control? Examining the clinical issues, medical concerns, psychosocial-spiritual struggles, and interpersonal factors involved allows us to be true to the ethics of benevolence and maleficence (see Johnson's Chapter 14). Otherwise, our own alarm, anxiety, or discomfort may propel us into hasty actions and decisions, bypassing the necessary attention to process.

We know from experience and numerous studies that we cannot totally separate our individual contribution of "self" with all its attendant beliefs, fears, and hopes from any one interchange with another human being. We inevitably have an effect on the patients and families we serve, as they do on us. With life-and-death issues, the argument for compassionate care must rest neither on rationality nor upon any one particular value system. Instead, as health-care professionals we must first utilize ethical principles that effect a compassionate and respectful exchange of knowledge and, second, offer services regardless of our personal beliefs, values, or cultural mores. Ethical principles call for a consciousness of intent, but to reach this consciousness, we must be aware of our countertransference. We must explore and be curious about our own agendas in addition to being curious about our patients' experiences and desires.

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A savvy clinical psychologist demonstrates what careful, thoughtful conversation can bring to the fore when a request for aid in dying is met with caring, careful attention and examination.

Myra

Myra, a longtime Oregonian, was in significant pain, dying of ovarian cancer. She was 61 years old, divorced, and a practicing Roman Catholic. Myra had requested the option of death with dignity. Her primary care physician, Dr. Baxter, had voted for the Death with Dignity law in Oregon, but this was the first time that a dear, long-term patient was asking him to write the prescription for life-ending medication. He found himself quite torn about this role. Dr. Baxter believed that Myra had every right to her request, but he struggled with his Hippocratic Oath and his training to use medicine to "save" lives. He feared being judged by his fellow physicians—whether he responded in the affirmative to Myra's request or refused it. Additionally, Dr. Baxter struggled with his own grief about participating in Myra's choice to end her life. He questioned whether he was actually neutral enough to accurately determine Myra's mental capacity to make this decision. Dr. Baxter's discomfort was palpable. He decided to refer Myra to a trusted psychology colleague for evaluation, in part to ease his own distress, ambivalence, and fear.

Myra followed Dr. Baxter's recommendation and immediately set up an appointment for the competency evaluation with Dr. Kate. In her appointment, Myra described her situation and her long-held beliefs about choice at the beginning of life and near the end of life. She discussed the ways in which she had consciously tied up loose ends and left her legacy. She described her personal, political, and religious beliefs. Dr. Kate listened intently, gathering the rich data she needed for her evaluation. As Myra became more comfortable in session, Dr. Kate, knowing that ending one's life is considered a mortal sin in the Catholic Church, inquired of Myra whether she actively followed the Roman Catholic faith. Myra did. Dr. Kate was puzzled. In Catholicism this type of mortal sin was considered the worst kind, condemning the wrongdoer to hell. She inquired further. Myra, turning the tables, then asked Dr. Kate what God thought about aid in dying. "Well," Dr. Kate mused, as God had not told her Himself, she had no way to answer this. The two laughed then talked further about Myra's conception of hell and eternity and how medical aid in dying fit with Myra's beliefs. . . . It didn't. After some discussion, Myra revealed that she had planned to take all the prescribed medications and then, before falling asleep, she would ask God for forgiveness, in a sense hoping to trick God into believing that the assisted death was an accident.

The two talked further. Dr. Kate took time to listen, to query further, and to empathize with Myra's struggles. After some time had passed, Myra became pensive. "I can see that I was hoping to fool God," she remarked. "He's not going to be fooled. Never mind, I don't want the option of using the Death with Dignity law. But I'm not done talking with you." Myra confided in Dr. Kate, describing her fears about dying, pain, loss of dignity, and the loss of her ability to think rationally. Dr. Kate was able to share with her the ways in which

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hospice and palliative care could address and alleviate many of these concerns. Myra's relief and peacefulness was striking. She left the appointment with a sense of serenity and a clear direction for next steps in her journey. Myra died peacefully and naturally while receiving hospice care.

In this case, a thoughtful, discerning physician allowed himself the space to become aware of the many nuances of his countertransference responses. Rather than allow his personal feelings to drive his decision and actions, he consulted. He utilized a trusted colleague to help objectively examine this compelling situation. The psychologist, in turn, did not fall into a hasty determination of competency at the expense of taking time to examine the multiple layers of meaning in this request for life-ending medication. How fortunate for Myra that she had two insightful medical providers who took the time necessary—with her and with themselves—to facilitate an end-of-life experience that honored Myra's deepest held personal, psychological, and spiritual needs.

When it comes to concerns about human life and human death, we owe it to ourselves and to our patients to respect and honor all possibility, all potentiality. We can do this only with awareness and a true commitment to examining our countertransference responses to all that presents.

COUNTERTRANSFERENCE TOOL BOX:

Am I Facing Hastened Death, or Am I Facing Suicide?

Renee S. Katz and Therese A. Johnson

"Why go on?"
"Life isn't worth living."
"I deserve a merciful ending."

Have you had terminally ill patients indicate that they are tired of their suffering or simply tell you they have thoughtfully made a choice to die on their own terms?

What feeling responses did you experience?

Possible Feelings:

__ anger __ guilt __ shock __ fear __ anxiety __ frustration __ hopeless
__ lost __ overwhelmed __ helplessness __ relief __ confusion __ agitation
__ calm __ disappointment __ compassion __ self-doubt __ sorrow
__ irritation __ empathy __ responsible __ repugnance __ futility __ inept
__ vulnerable __ out-of-control __ like a failure __ burdened

Are there other feelings you experienced? Which feelings are most intense for you? What may be contributing to the intensity and types of feelings you experience? Write your answers below:

____
____
____
____
____
____

What types of thoughts and reactions did you experience?

Possible Thoughts:

"Help! I'm in over my head!"
"I don't want to be involved in this."
"I'm afraid of the legal implications."
"Maybe I can talk them out of it."
"I need to do *something!"*
"Can't blame him or her. That's what I would want too."
"I'm not doing a good enough job with this patient."

Did you find yourself experiencing any of the thoughts above? Did you find yourself quickly making a judgment or determination? Write your answers below:

____
____
____
____
____

Which of the following might be influencing your thoughts and reactions?

__ *prior, current, or anticipated personal experiences with death*
__ *prior, current, or anticipated medical or health-care experiences*
__ *religious beliefs*
__ *cultural values*
__ *values or ethics of your profession*
__ *the culture of the agency, clinic, or hospital in which you work*
__ *other*

Countertransference Constellations

At times, patients' vulnerabilities, medical situations, and life experiences resonate with ours. It is at those times that we must be all the more vigilant about the impact of our personal histories, sociocultural influences, religious convictions, and values. If we are not, we risk making false assumptions and premature judgments

without fully exploring the patient's concerns and the layers of meaning inherent in such requests.

Identifying situations that "hook" us, examining uncomfortable feelings, and having the courage to face things we'd rather avoid are crucial to recognizing when countertransference may be impacting our responses to requests for hastened dying.

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14 Futility and Beneficence

Where Ethics and Countertransference Intersect in Palliative and End-of-Life Care

Therese A. Johnson

> One person's good is another's evil. . . . Only critically reflective medical ethics and self-critical individuals of good character can offer some hope for the future.
>
> (Thomasma, 1998)

Personal responsibility and accountability are quietly assumed by millions of health-care workers in the thousands of end-of-life decisions that occur daily in hospitals, hospices, and homes across the nation. Often, it is only in retrospect, when our memories and emotional experiences threaten to overwhelm us, that we ask ourselves the question: Would we have acted the same or differently if we had been truly methodical in pursuing our conscious understanding of the issues? What do we as health-care workers bring to each decision-making point, and what do we carry with us after?

I ask myself that question as the germination of this chapter lies deep within the compost of my own experiences with death. My personal and professional history reflects multiple brushes with chosen death: the suicide of a neighbor, a family member, and a client in addition to the possible hastened deaths of patients and friends. Each of these experiences have given rise to countless bits of countertransference, passive and active, negative and positive, that informed and shaped the experience that followed in the wake of the previous. From the first experience, which introduced the cognitive possibility that life may not be worth living, through each successive experience, my underlying anxiety about what *I* understood and believed deepened. That anxiety inevitably affected the care of others. If I had been more self-critical of the impact of my history on my beliefs and more understanding of how the applications of ethical principles by others have navigated these same struggles, perhaps I would rest easier with my decisions and their outcomes.

My personal odyssey is the microcosm; the macrocosm is the developed world's loss of innocence as demographics and values change and technology allows us to live longer, but not necessarily more fulfilling, lives. This chapter is for the health-care worker in that context, faced with the day-to-day tasks and decisions, minute to monumental, that comprise the care of seriously ill and dying individuals. The hoped-for outcome is that the health-care provider—as she or he climbs into bed after a day in which she or he has participated in the intimate care of any patient—will fall asleep with the confident belief of having *responsibly* navigated the treacherous shoals of determining "what is right" when considering multiple viewpoints. This chapter is dedicated to their efforts to

maintain a sense of equilibrium when faced with the conflicts of ethical principles on a personal and professional level and against the backdrop of societal judgment.

Life-and-Death Decisions

There has been a great deal written on ethical decision making in situations of serious illness and end-of-life care, including models describing the process in clinical settings (Beauchamp & Childress, 2012; Jonsen, Siegler, & Winslade, 2010) and public policy ensuring individual rights (e.g., informed consent, Patient Determination Act, do-not-resuscitate orders, Natural Death Act). In addition to these writings, there are professional position statements and guidelines for ethical practices within specific professions (e.g., medicine, nursing, social work, psychology, etc.) Add to this mix the organization's (hospital, nursing home, and hospice) policies and procedures, and you get a dizzying array of oft-conflicting theories, priorities, and practices. They all attempt to address and protect the needs and rights of the patient, the patient's family, the medical community, the legal community, and the culture in which these are embedded.

What appears to be a missing link in many of these writings is the question: What is the right or best decision for the individual health-care worker? What happens when the worker's ethical values are in opposition to those of the patient or the institution? Is there a natural hierarchy? Do we have an equal opportunity for our needs, beliefs, and rights to be heard and considered, or are these beliefs and rights simply subsumed by the oath we take as caregivers? We need to find ways for health-care workers to feel comfortable ("comfort" does not imply "ease") with the responsibilities of our work, especially during the vulnerable and profound process of dying. There must also be a way of controlling the influence of our personal countertransference, which can negatively impact our understanding and experience of the ethical principles of doing good (beneficence), doing no harm (nonmaleficence), and respecting autonomy.

I propose that we must examine our own beliefs, principles, values, and understanding, *before*, *during*, and *after* providing care that is likely to be a pivotal change point for the patient. Though it is difficult to anticipate and prepare for every eventuality, and though we do not know what we are capable of until we find ourselves involved, we must prepare ourselves to assist another person in his or her choices around dying. And, we must learn to live with the choices we have made or helped another to make.

Toward a Conscious Assessment in Personal, Ethical Decision Making

Many factors in a decision-making process can be unconscious. These unconscious, often unexamined factors are the foundation of our own countertransference. They encompass beliefs, values, and needs that comprise the backdrop for personal, professional, institutional, and societal decisions. Inevitably there will be conflicts between and within each arena.

We can assume that in any hospice center or hospital ICU, there are health-care workers whose personal values (embedded within the context of religious, cultural, and personal experience) are in opposition to the institution's legal and moral mandate to

administer or withdraw life-support measures. Are these health-care workers given the opportunity to examine their personal understandings and allowed to act according to their conscience, or are they subtly or overtly pressured to comply with the institution? Were the care decisions influenced by family, clergy, or others?

In the belief that we owe our patients and ourselves the effort it takes to make an informed decision before we participate in any crucial act of caregiving at the end of life, I propose that we: (a) educate ourselves, (b) examine our motives, and (c) consciously accept our roles and responsibilities in the larger picture.

Education

There are three areas critical to a clinician's understanding of palliative and end-of-life practices. They are, first, ethical principles; second, end-of-life terminology and its shifting meanings; and last, moral and legal controversies in working with seriously ill or dying patients.

Knowledge of Ethical Principles

The principles of beneficence, nonmaleficence, autonomy, mercy, and justice, which are the cornerstone of most ethical guidelines, commonly are not introduced to health-care workers until years after they begin to work in health-care institutions. To provide end-of-life care without an understanding and exploration of the ways in which these principles come into play is to court confusion and misunderstanding. The health-care worker must determine which principles are at stake, which are in conflict, and which take precedence *prior* to justifying a decision to participate in a course of action.

> *Principle 1: Autonomy*. This principle describes the "moral right of individuals to choose and follow one's own plan of life and action" (Jonsen, Siegler, & Winslade, 1998). To act autonomously, one must have liberty, freedom from controlling influences, and agency, the capacity to act intentionally.

Consider this principle in light of all the players within the decision-making matrix: the patient, family members, and caregivers, including medical, psychological, and spiritual clinicians. When do you make your own decisions? Act on your own values? And how do those decisions and values impinge on the rights of others?

Liberty is a concept that poses psychological and philosophical quandaries. For instance, how do we define controlling influences? One controlling influence is our countertransference, which could prejudice the kind of information we give a patient. Another is the information the patient gives us so that an informed treatment option can be presented (e.g., if the patient doesn't tell you he or she is a recovering drug addict, too low an opioid dose may be given to control pain). There are types of controlling influences that actually restrict autonomy and yet are sanctioned, for example, hospitals owned or operated by religious entities that opt out of providing means and information on medical aid in dying.

Consider where countertransference might intersect with the principle of autonomy in the following scenario: Kate was a registered nurse (RN) with a local hospice affiliated with a Catholic hospital; when patients inquired as to the Death with Dignity Act, she would report that she was not allowed to provide that information, but she would leave pens inscribed with the name and phone number of the local chapter of Compassion and Choices as she left the room.

A second consideration is related to "the capacity to act intentionally," which refers to the ability to make competent decisions.[1] When is a person "not competent"? How is capacity defined within the profession and the institution? The person who assesses another person's competency *must* beware of allowing personal judgments and cultural norms to intrude.

> *Principle 2: Beneficence.* This principle describes the duty to assist persons in need and to contribute positively to the patient's welfare (Jonsen et al., 1998).

Simply stated, beneficence means to do good. It is the founding principle in health care. What is difficult to ascertain is *whose* good any one ethical decision should reflect. If there is a conflict, should the welfare of the patient, institution, society, or health-care worker take precedence?

Phillip Kleespies (2004), in speaking of the frequency with which the autonomous choice of the patient conflicts with the physician's wish to do good, contends that

> it is entirely possible, and perhaps best, not to view these principles as competing. Rather, their view is that beneficence provides the primary goal of health care, while autonomy (and other ethical principles) places moral limits on the professional's efforts to pursue this goal. In this framework, no principle in bioethics is preeminent over another, but, in effect, the patient needs to listen to and understand the goals of the physician or healthcare team, while the team must respect the autonomous choices of the competent patient. (pp. 30–31)

Examine this scenario for the ethical and countertransferential intersection: A physician whose mother died from lung cancer refuses to sign an order prescribing oxygen for a COPD patient who still smokes. The doctor mutters to the RN—"She'll just blow herself up if I do!"

> *Principle 3: Nonmaleficence.* This principle describes the duty to refrain from causing harm. What constitutes harm? How do we determine levels of harm (i.e., to the patient, the family, the institution, or the community)?

This ethical principle arises especially in circumstances where the question of futility is explored. Is it ethical for a physician to offer and promote tests and further curative treatments when it is obvious that the disease is no longer curable? A frequent quandary for the individual health-care worker is the request to accept another professional's assessment that prolonging treatment is not harmful. Opponents and proponents of withdrawal of artificial nutrition and hydration both claim harm is being done. If a professional disagrees, what should he or she do? Can the nurse refuse to

participate? Does the social worker feel comfortable in asking for an ethics committee review?

Scenario: The daughter of a dying man asks the nursing staff not to inform him of his impending death as she does not want his stepchildren notified. As the clinician, what do you do?

Principle 4: Mercy. This principle is widely invoked in arguments for (a) assisted death, (b) ending treatments that prolong suffering and a continuation of minimal quality of life, and (c) providing enough pain relief to reduce physical suffering but with the concomitant effect of suppressing respiration.

The construct of intentionality is crucial in the consideration of this principle, as understood by Battin (1994, p. 101):

> Where possible, one ought to relieve the pain or suffering of another person, when it does not contravene that person's wishes, where one can do so without undue costs to oneself, where one will not violate other moral obligations, where the pain or suffering itself is not necessary for the sufferer's attainment of some overriding good, and where the pain or suffering can be relieved without precluding the sufferer's attainment of some overriding good.

As Thomasma (1998, p. 398) further qualifies,

> If one never intends the death of another, but instead intends the relief of suffering, even if the action done causes death or contributes to it . . . then that person has not interiorly or exteriorly taken over the role of God, has not assumed dominion over the life of another human being.

Scenario: You are a nursing assistant in a nursing home and have cared for a patient increasingly disabled by Parkinson's for three years. In the last year he has repeatedly asked not to be treated aggressively. His wife has health care power of attorney as the patient is judged not to have decisional capacity, and she continues to opt for treatment. You are the sole witness to his aspirating a piece of food. What do you do?

Principle 5: Justice. This principle refers to fair, equitable, and appropriate treatment in light of what is due or owed to persons, including equal rights to health-care resources, regardless of geographic location or ability to pay.

Scenario: As the clinical director of a hospice program, you are aware there is only one bed available for inpatient care. Simultaneous requests arrive: the spouse of a woman (who is not imminently dying) has previously donated money to the hospice and is now looking for a one-week respite stay, so he can take a short vacation; a nurse requests the bed for an imminently dying patient whose family cannot provide that type of care. Your decision?

Health-care workers should be encouraged, if not mandated, to pursue education regarding ethical principles and potential dilemmas particular to their organization's population and setting. Education hopefully leads to moral courage in action:

> Taking action requires us to leave our role as passive bystanders (aka enablers) when we learn of questionable or unacceptable behavior, especially when the welfare of others is at stake. We must often teach ourselves how to leave the comfort and safety of "it's not my problem," "someone else will take care of this," "it's probably not as bad as it looks," or "speaking up won't make any difference."
>
> (Pope, 2015, p. 146)

Knowledge of End-of-Life Terminology

Knowing the following terminology may prevent health-care workers from using terms mistakenly and thereby avoid creating confusion for patients and families that can give rise to fear, guilt, and misinformed decisions.

Withholding or Withdrawing Life-Sustaining Therapy/"Letting Die"/"Allowing to Die": This is accepted widely as an ethically justifiable legal practice. It denotes honoring the refusal of treatments that a patient does not desire, that are disproportionately burdensome to the patient, and/or that will not benefit the patient. Examples of such treatment include life-sustaining or life-prolonging therapies such as CPR, mechanical ventilation, artificially provided nutrition and hydration, and antibiotics.

Physician-Assisted Death/Assisted Suicide/Medical Aid in Dying: These terms denote making a means of dying (e.g., providing pills) available to a patient with knowledge of the patient's intention to end his or her life. It is currently legal only in five states. There is a current controversy about the use of the word "suicide" as it is historically a term describing "a self-destructive act that is motivated primarily by emotional distress or psychopathology [and] does not apply to all situations in which a terminally ill person wants to exercise control over the timing and manner of death. The Oregon Death with Dignity Act (1995) states that 'under the Act, ending one's life in accordance with the law does not constitute suicide' " (American Psychological Association, 2000).

Hastened Death: This is an ambiguous term that can be used to define the categories already described as well as the following:

Rule of Double Effect: This is a principle that provides moral justification for a clinical action that has two foreseen effects: one good and one bad. It is often used to justify the administration of opiates and other medications at the end of life that may hasten the patient's death; the action is considered justifiable because the intent is to relieve pain and suffering, which in turn may cause an unintended but foreseen consequence, that is, death.

Mercy Killing/Euthanasia: Someone other than the patient performs an act (e.g., administering a lethal injection) with the intent to end the person's life. This is not legal in the United States with the exception of state death penalty laws.

- *Voluntary active euthanasia*: an act of bringing about the death of a person at his or her request

- *Involuntary active euthanasia*: an act of killing a person who, while competent, opposes being killed
- *Nonvoluntary active euthanasia*: an act of killing a person who is incapable of making an informed request

Constructs of Cessation of Consciousness

Death:

- Cardio Respiratory Criterion: irreversible cessation of circulation and respiration
- Brain Criterion, the Uniform Definition of Death: "an individual who has sustained either (1) irreversible cessation of circulatory and respiratory function, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead." (Jonsen et al., 1998)

Persistent Vegetative State (PVS):

A neurological diagnosis defined as "a sustained, complete loss of self-aware cognition with wake/sleep cycles and other autonomic functions remaining relatively intact. The condition can either follow acute, severe bilateral cerebral damage or develop gradually as the end state of a progressive dementia." Studies show that, when properly diagnosed, recovery of consciousness is almost unprecedented. The majority of these patients will not require respiratory support, but will require artificial nutrition. Since persons in PVS retain some reflex activities, they may have some eye movement, swallowing, grimacing, and papillary adjustment to light.

(Jonsen et al., 1998)

Understanding End-of-Life Controversies

To support caregivers in understanding end-of-life controversies, it behooves health-care organizations to (a) hold regular in-services on the subject, (b) provide clear policies and procedures including clinical pathways for the initiation or termination of any treatment option, (c) provide consultation or supervision support to any professional struggling with a patient care plan, (d) encourage regular interdisciplinary meetings to plan care, and (e) provide ready access to ethics committee consultations or reviews.

The individual practitioner should examine the arguments for any controversial practice in the medical, psychological, religious, social, legal, and philosophical literature. (See, in particular, "The Continuing Challenge of Assisted Death," an article by Mary Ersek, PhD, RN, in the 2004 *Journal of Hospice and Palliative Nursing*, pages 46 to 59, about the use of ethical principles in key arguments for and against assisted death, and the Oregon Nurses Association Assisted Suicide Guidelines in Table 14.1.)

Table 14.1 Oregon Nurses Association Assisted Suicide Guidelines

Nurses who choose to be involved

If as a nurse your own moral and ethical value system allows you to be involved in providing care to a patient who has made the choice to end his or her life, within the provisions of the Death with Dignity Act, the following guidelines will assist you.

You May:

- Provide care and comfort to the patient and family through all stages of the dying process. Teach the patient and family about the process of dying and what they may expect.
- Maintain patient and family confidentiality about the end-of-life decisions they are making.
- Explain the law as it currently exists.
- Discuss and explore with the patient options regarding end-of-life decisions, and provide resource information, or link the patient and family to access the services or resources they are requesting.
- Explore reasons for the patient's request to end his or her life, and make a determination whether the patient is depressed and whether the depression is influencing his or her decision or whether the patient has made a rational decision based on the patient's own fundamental values and beliefs.
- Be present during the patient's self-administration of the medications and during the patient's death to console and counsel the family.
- Be involved in policy development within the health-care facility and/or the community.

You May Not:

- Inject or administer the medication that will lead to the end of the patient's life; this is an act precluded by law.
- Breach confidentiality of patients who are exploring or choosing medical aid in dying.
- Subject your patients or their families to unwarranted judgmental comments or actions because of the patient's choice to explore or select the option of medical aid in dying.
- Abandon or refuse to provide comfort and safety measures to the patient.

Nurses who choose NOT to be involved

If as a nurse your own moral and ethical value system does not allow you to be involved in providing care to a patient who has made the choice to end his or her life, within the provisions of the Death with Dignity Act, the following guidelines will assist you.

You May:

- Provide ongoing and ethically justified end-of-life care.
- Conscientiously object to being involved in delivering care. You are obliged to provide for the patient's safety, avoid abandonment, and withdraw only when assured that alternative sources of care are available to the patient.
- Transfer the responsibility for the patient's care to another provider.
- Maintain confidentiality of the patient, family, and health-care providers continuing to provide care to the patient who has chosen medical aid in dying.
- Be involved in policy development within the health-care setting and/or the community.

You May Not:

- Breach confidentiality of patients who are exploring or choosing medical aid in dying.
- Inject or administer the medication that will lead to the end of the patient's life; this is an act precluded by law.
- Subject your patients or their families to unwarranted judgmental comments or actions because of the patient's choice to explore or select the option of medical aid in dying.
- Subject your peers or other health-care team members to unwarranted judgmental comments or actions because of their decision to continue to provide care to a patient who has chosen medical aid in dying.
- Abandon or refuse to provide comfort and safety measures to the patient.

Reprinted from Oregon Nurses Association. (1998). *Medical aid in dying: ONA provides guidance on nurses' dilemma*. Retrieved from http://www.oregonrn.org

Examining Our Motives and Intentions

Self-Assessment

Examining personal beliefs and values is a subjective process that continues to develop with each new experience. Each time we face a new situation, we must reassess whether because of factual or emotive reasons, a change in attitude or action is warranted. It is difficult to impose a structure on this process, but the default simply is to react from emotion and belief. The worst-case scenario is not even to react from oneself but simply because it is an accepted or mandated practice.

It is critical to give thought to the "what ifs," effectively creating both a subjective and an objective experience. This is crucial especially when working with dying patients. As a hospice social worker I would frequently encourage patients to ask their physicians the hypothetical question, "If it was your mother or daughter, what would you recommend?" This question, with genuine consideration, should force the health-care worker to look beyond accepted practices and social mores and respond with their own truth, which can be very helpful to the patient. Sometimes this truth is, "I don't know." Early in my hospice career I was asked by a patient to provide information on assistance in dying. At this point in my history I had not come to an understanding of what my belief was, so to respect this conflict of personal and professional ethics, I transferred the care of this patient to another social worker who had greater clarity on this issue in his personal and professional role.

It is extremely helpful to use a framework to explore the different threads that entwine to create your unique philosophy and that also influence your issues of countertransference. This framework should comprise the following:

(a) the spiritual or religious background with which you grew up as well as your current practices and beliefs;
(b) your family's beliefs and experiences with dying and death;
(c) your cultural background and how it impacts you;
(d) your personal experience with similar decisions or events;
(e) your professional mandates, laws, and peer opinions; and
(f) your thoughts about the meaning of suffering and death.

Another excellent resource is the Values History Form, developed at the Center for Health Law and Ethics, University of New Mexico School of Law and Ethics, found in the back of the American Hospital Association's book on *Health Care Ethics Committees: The Next Generation (*Ross, Glaser, Rasinski-Gregory, Gibson, & Bayley, 1993).

Patient and Family Assessment

One of the lessons I learned serving on an ethics committee in a suburban hospital was that frequently, the ethical dilemma being presented could have been resolved if a more careful patient and family assessment had occurred. What often appeared to be an impasse between the patient and medical staff's ideas as to appropriate treatment would seem to dissipate upon clarification of the patient and family's understanding of the

disease and treatment processes and especially upon the revelation of their underlying fears. As Figenshaw has identified in Chapter 5 on advance directives, providers often use language that is unknown and confusing to patients and families, thereby creating potential for resistance when in fact there is none. The patient's and family's emotional responses to the disease and dying process are factors that should be assessed regularly so that they can be addressed in beneficial ways by health-care workers (e.g., explaining to the family that forcing hydration and nutrition when their loved one is actively dying creates a burden on internal organs that produces greater suffering).

Patient assessment in end-of-life care focuses on the relief of suffering. As *Education for Physicians on End-of-Life Care* (EPEC) states: "Patients suffer as persons with relationships to others, a past, and an anticipated future. Consequently, assessment must include all of these aspects of a patient's condition and experience" (Emanuel, von Gunten, & Ferris, 1999). The EPEC Project's Whole Patient Assessment Module includes the following components: disease history, physical symptoms, psychological symptoms, decision-making capacity, information sharing, social circumstances, spiritual needs, practical needs, and anticipatory planning for death. An assessment process that addresses these arenas can, in and of itself, be a therapeutic tool that can establish the basis for a trusting relationship between patient and clinician. This relationship is crucial to (a) exploring the patient's beliefs, knowledge, values, and wishes; (b) examining the often hidden anxieties that can increase pain and suffering; (c) helping the patient and family communicate their needs and expectations with each other and the medical team; (d) building faith and trust, so when the need for a difficult decision comes to pass, the patient and/or family believe their best interests are being served; (e) establishing a bond between health-care worker and patient, so empathy is present; and (f) helping the patient and family to not feel alone (see Farber & Farber, Chapter 15). Patient and family assessment is an area rife with countertransference. Thus, we must cross-examine ourselves rigorously to ensure that we do not make assumptions based upon the interests of any one person in the situation. The following vignette demonstrates how an ethical dilemma could have been avoided if a proper patient assessment and self-examination of countertransference reactions had occurred:

> Melinda was a 68-year-old New Yorker transplanted to the West Coast, where her only daughter lived. She was diagnosed with breast cancer, and palliative treatment was recommended. She had a prognosis of less than six months, which qualified her for the hospice program. It was obvious from the beginning that she had a conflictual relationship with her daughter, her only living relative, and many vague reasons were given as to the origin of this conflict. She was living independently in an apartment, but as her disease progressed, her breathing became more compromised, and she had a great deal of difficulty negotiating the outside stairs to her home. It became clear that she would need a different placement for the remainder of her days. I was a fairly new hospice social worker, and I enjoyed this flamboyant, tough-talking East Coaster who obviously had lived a 'colorful' life. I advocated for her admittance into the inpatient hospice unit and for the one residential bed allocated for uncompensated care. She gave up her subsidized housing on my assurances that she could "die in hospice" cared for by the nursing staff. After a month of her living in these new quarters, complaints of her 'inappropriate' behavior began to surface with

> the inpatient staff, and I rushed to her defense. As a patient who was ambulatory as well as alert and oriented, she did not look like a dying person; further, she smoked and drank—a lot more than what was considered acceptable, even in a hospice center that prided itself on patient determination of quality of life. We were quickly embroiled in a battle of whose needs took precedence as the nursing staff soon declared that they could not accept responsibility for her care given her lifestyle. This took place at a time when the Medicare hospice benefit was divided into a maximum of four certification periods, and a physician had to regularly recertify that the patient continued to be eligible based on specific criteria. Melinda did not pass that recertification. It was determined that her prognosis easily could be greater than six months. I was left to pick up the pieces: find emergency, low-income housing without stairs, arrange for Medicare to provide home health care instead of hospice care, and apologize to Melinda and her daughter for not accurately assessing the situation and determining the potential outcomes. In the weeks that followed her removal, the hospice center changed its policy of admittance to the uncompensated care bed and restricted its use to two months at a time. It probably won't surprise you that I continued to visit Melinda on personal time, assisting with the myriad of daily functions with which she had difficulty. She died seven months later.

In this example I was influenced by multiple countertransferential reactions. First, I reacted to the client herself, wishing to "do good" (beneficence) but not reflecting on whether her needs would truly be met by my "rescue." Second, in response to the hospice center's concerns, I quickly became the crusader for my client's rights to determine her own quality of life. My perception that she was being judged because she did not fit an image of a "good patient" thrust me into an adversarial role, and I effectively lost sight of the guiding principle of nonmaleficence. I even believed that the ethical principle of justice had been sullied in the hospice's decision to restrict use of uncompensated funds. It became a battle of righteousness and ego into which I poured residual energy from all my personal losses in life-and-death choices. Countertransference took over, and ethical principles were used simply as something to bolster my argument. Finally, in response to what I considered an unethical decision by the administration (the change of prognosis that made her ineligible for hospice care), and out of guilt for my own part in this fiasco, I lost sight of my own professional boundaries with this patient. Because I so frequently had to struggle with the issues of my responsibility in helping someone live or die well, I have noted a marked tendency to want to be "noble" about accounting for my actions. This is my countertransference hook. I become the judge that "sentences" myself to the consequences. I have no doubt that it is also a way for me to feel in control in a situation that evokes powerlessness.

I believe I could have minimized the ethical dilemma and unconscious countertransference reactions if I had completed a formal, ethical decision-making process early in my care of this patient. I needed to ask: What are the conflicts? What are the goals? What are the options? What are the consequences? These are the basic questions that must be answered to make a quick decision about a specific course of action. The model proposed by Forester-Miller & Davis (1996) for the American Counseling Association is an excellent guide to personal-professional decision making (see Table 14.2), but there are many available online and in books.

Table 14.2 Personal-Professional Decision Making

1. Identify the problem.

   Gather as much information as you can that will illuminate the situation. In doing so, it is important to be as specific and objective as possible. Writing ideas on paper may help you gain clarity. Outline the facts, separating out innuendos, assumptions, hypotheses, or suspicions. There are several questions you can ask yourself: Is it an ethical, legal, professional, or clinical problem? Is it a combination of more than one of these? If a legal question exists, seek legal advice.

   Other questions that it may be useful to ask yourself include these: Is the issue related to me and what I am or am not doing? Is it related to a client and/or patient's significant others and what they are or are not doing? Is it related to the institution or agency and its policies and procedures? If the problem can be resolved by implementing a policy of an institution or agency, you can look to the agency's guidelines. It is good to remember that dilemmas you face are often complex, so a useful guideline is to examine the problem from several perspectives and avoid searching for a simplistic solution.

2. Apply the applicable professional code of ethics.

   After you have clarified the problem, refer to your professional (nursing, counseling, physician, etc.) code of ethics to see if the issue is addressed there. If there is an applicable standard or several standards, and they are specific and clear, following the course of action indicated should lead to a resolution of the problem. To be able to apply the ethical standards, it is essential that you have read them carefully and that you understand their implications.

   If the problem is more complex, and a resolution does not seem apparent, then you probably have a true ethical dilemma and need to proceed with further steps in the ethical decision-making process.

   - Determine the nature and dimensions of the dilemma. There are several avenues to follow to ensure that you have examined the problem in all its various dimensions.
   - Consider the moral principles of autonomy, nonmaleficence, beneficence, justice, and fidelity. Decide which principles apply to the specific situation, and determine which principle takes priority for you in this case. In theory, each principle is of equal value, which means that it is your challenge to determine the priorities when two or more of them are in conflict.
   - Review the relevant professional literature to ensure that you are using the most current professional thinking in reaching a decision.
   - Consult with experienced professional colleagues and/or supervisors. As they review with you the information you have gathered, they may see other issues that are relevant or provide a perspective that you have not considered. They also may be able to identify aspects of the dilemma that you are not viewing objectively.
   - Consult your state or national professional associations to see if they can provide help with the dilemma.

3. Generate potential courses of action.

   Brainstorm as many possible courses of action as possible. Be creative, and consider all options. If possible, enlist the assistance of at least one colleague to help you generate options.

4. Consider the potential consequences of all options, and determine a course of action.

   Considering the information you have gathered and the priorities you have set, evaluate each option, and assess the potential consequences for all the parties involved. Ponder the implications of each course of action for the patient, for others who will be affected, and for yourself as a counselor. Eliminate the options that clearly do not give the desired results or cause even more problematic consequences. Review the remaining options to determine which option or combination of options best fits the situation and addresses the priorities you have identified.

(*Continued*)

5. Evaluate the selected course of action.

   Review the selected course of action to see if it presents any new ethical considerations. Stadler (1986) suggests applying three simple tests to the selected course of action to ensure that it is appropriate. In applying the test of justice, assess your own sense of fairness by determining whether you would treat others the same in this situation. For the test of publicity, ask yourself whether you would want your behavior reported in the press. The test of universality asks you to assess whether you could recommend the same course of action to another clinician in the same situation.

   If the course of action you have selected seems to present new ethical issues, then you'll need to go back to the beginning and reevaluate each step of the process. Perhaps you have chosen the wrong option, or you might have identified the problem incorrectly.

   If you can answer in the affirmative to each of the questions suggested by Stadler (thus passing the tests of justice, publicity, and universality), and you are satisfied that you have selected an appropriate course of action, then you are ready to move on to implementation.

6. Implement the course of action.

   Taking the appropriate action in an ethical dilemma is often difficult. The final step involves strengthening your ego to allow you to carry out your plan. After implementing your course of action, it is good practice to follow up on the situation to assess whether your actions had the anticipated effect and consequences.

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Accepting Our Roles and Responsibilities

When a patient or a patient's family is forced to make critical, life-and-death decisions, how does our role as the professional directly or indirectly affect the course they take? In instances in which we have no input, how do we assume responsibility in complying with decisions the patient or family makes, especially when those decisions run counter to our beliefs and values? Can we provide care even in cases in which we strongly oppose the actions or consequences? These questions are the basis of most ethical dilemmas, personal and professional.

There are no easy answers. There are guidelines, rules, and regulations, not to mention fate and circumstance, that point the way. Our responsibility is to remain conscious of all the forces that determine our actions. If we are not conscious of our beliefs and judgments that give rise to our countertransference, we will unknowingly make or participate in decisions influenced by these biases, often harming our patients and ourselves. As health-care professionals we must rigorously hold up our beliefs to scrutiny, examine their etiology and flaws, and determine for ourselves how we want to act in any given moment—with decisions minute to monumental. With the resulting sense of self-respect and integrity, we can avoid faltering in self-care and in the care we provide others. We owe this to our patients, to their families, and most especially to ourselves.

Note

1 "Capacity" is a medically judged quality; "competence" is a legally judged quality.

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Part V

Implications for Practice

Models to Address Countertransference in Palliative and End-of-Life Care

The previous sections use the ancient medium of narrative and storytelling to teach. As countertransference arises from the intersection of the "self" and the "other," it would have been impossible to convey these understandings in any other way. How one human attends to another in his or her living and in dying is not easily quantified.

In the section that follows, the authors offer helpful strategies to address and preempt the inappropriate acting out of countertransference responses in palliative and end-of-life care. These models are drawn from different life arenas; Farber and Farber's respectful conversations (Chapter 15), Danieli's group exercises (Chapter 18), and many of the individual exercises throughout this volume and in Katz's concluding chapter were the result of hard-won experience in work with seriously ill and dying patients. Katz's chapter on mindfulness (Chapter 17) and Knowlton and Katz's on Balint groups (Chapter 16) reflect specific techniques, along with the rewards of reflecting upon, learning from, and utilizing understandings of countertransference to provide more responsive and more compassionate care to our patients *and* to ourselves.

Professionals across the spectrum of care can use these models to ensure that seriously ill patients, dying patients, or grieving families receive the benefit of our fullest consciousness around issues that impact our abilities to live well until we die.

Do not assume that any of these chapters are solely for physicians or medical personnel, as any nursing assistant or professional volunteer will tell you that often the most momentous of decisions are made while changing a bed.

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15 The Respectful Death Model

Difficult Conversations in Palliative and End-of-Life Care

Annalu Farber and Stu Farber

Introduction

Whether we are psychologists, nurses, physicians, hospice volunteers, consultants, or other healing professionals, there will be times when we get "hooked" by a lack of self-awareness, a particular bias, or a blind reliance on our expert training. As caring professionals, each one of us too often falls into a place of mindlessness. This chapter will focus on the importance of being aware of our interactions and prescriptions, and it will present a model of care rooted in respect, one that acknowledges the power of relationship and that invites us to be mindful, curious, and open to surprise. Mindfulness, attention to the particular knowledge and preferences that the other brings to a relationship, and awareness of our own fears, biases, and beliefs help us to help those we serve (Langer, 1990).

Occasionally, we may find ourselves in a situation with a patient or client that challenges our professional precepts or personal values. Whether defined as transference, countertransference, or professional myopia, something hooks us, and we become immersed in an ethical dilemma or watch our well-intentioned care plan take a nosedive. So we ask: What went wrong? We offer here a model for developing a therapeutic relationship that we believe will be useful in answering this question. It is based on integrating the patient and family story into care planning. We will also share personal stories using pseudonyms to look at four hooks that interfere with providing good care: (1) expert certainty, (2) a patient and professional conspiracy of silence, (3) the fear of uncertainty and a desire for control, and (4) the "myth" in cultural diversity.

The Respectful Death Model is born out of and used in the medical culture, a culture that defines the human experience in a way that often ignores individual knowledge and personal experience. The medical culture rarely allows time for patients and families to conceptualize, let alone express, their values and goals in the overwhelming world of a life-threatening illness. Medical science is center stage from assessment to care planning. There is little language, ritual, or process available to uncover and integrate the patient's story prior to prescribing a course of action. The Respectful Death Model invites professionals to listen *mindfully* to the lived experience of our patients, families, and ourselves as we all struggle with the loss and grief of the end-of-life experience.

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A Respectful Death Model for Care

"Good death" is a term often used to describe the possibilities for growth and awareness at the end of life. One value of the "good death" concept is in acknowledging the inevitability of death. It also provides a model that is open to more positive end-of-life experiences (Byock, 1997). Still, there is an inherently value-laden aspect to the term "good" that implies a right or a wrong way. It begs a judgment, but who is the right party to be that judge? Is it the helping professional with extensive clinical experience who may be watching a patient and family make decisions that are certain to add to their combined suffering? Is it the patient exercising his or her autonomy? Is it the family caregiver who has taken on the courageous and compassionate task of caring for his or her loved one?

These concerns led us to formulate the model of a respectful death. The word "respect" supposes a nonjudgmental relationship between parties and an opportunity to weave expertise, values, and differences into a whole cloth that supports the common values of all parties. Respect guides all participants to explore and create a shared story. The patient, family members, and care professionals begin to share knowledge and work toward a common goal.

Findings in recent studies show that patients, family members, and helping professionals all agree that the presence of a therapeutic relationship is very important to effective outcomes (Farber, Egnew, & Herman-Bertsch, 1999, 2002). Integrating the Respectful Death Model into our practice requires developing a relationship of discovery with patients *and* families. Patients, families, and care professionals report the following components for achieving this level of care:

- *Commitment*: Stressing that the helping professional will care for the patient and family through and beyond death
- *Connection*: Creating a special relationship that allows any topic of importance to the patient and family to be discussed regardless of whether it is medical or not—this aspect of relationship is related to Carl Rogers's concept of unconditional positive regard (Rogers, 1973)
- *Consciousness*: Understanding the patient's and family's personal experience, as well as the helping professional's personal and professional meaning, within the ever-changing context of illness

This model creates a space where all participants—the patient, family members, and caring professionals—are able to enter into a caring relationship and explore optimal outcomes based on the patient's values, experiences, and goals. A full discussion of the Respectful Death Model can be found in *Living With Dying: A Comprehensive Resource for Healthcare Practitioners* (Berzoff & Silverman, 2004).

Being curious about and respectful of our patients' stories can be a precarious step. To embrace this model, we must start by understanding that we, as professionals, have only a piece of the knowledge. We have clinical knowledge and expertise, but we are not experts in the patient's goals, the family's needs, or their community's traditions. As we weave together both our professional expertise and our patient's lived experience, creative patterns surface that allow us to help our patients live the best lives possible based on their values and goals until the end is at hand. Why is this so hard for well-intentioned

professionals? Is it because we no longer have control? Is it because the illusion of predictability is lost? When we accept that others also hold essential knowledge, their contributions must inform the ultimate design of the plan of care. When we are in this alchemy of shared relationship, we are called upon to be open to surprise, attentive to nonmedical considerations, and creative in care planning.

The following stories explore some common challenges in caring and demonstrate how maintaining a respectful relationship with patients and families can reduce the possibility of developing flawed treatment plans. Our stories are told from the perspective of a physician, a hospice volunteer, and consultants to health-care teams.

Expert Certainty

Professionals have knowledge and experience that gives them a powerful perspective to define problems and offer solutions. Additionally, patients and families are usually novices at being seriously ill and in navigating the health-care system. Out of their vulnerability and desire for safety, patients and families often will accept the authority of their professional caregivers with little or no personal introspection or question. Without reflection, professionals often take on this mantle and share in the certainty of "right ways" for patients and families to behave and to accept their diagnoses and prognoses. Leaving the patient perspective and our own biases unexplored may lead to conflict when the "right ways" are at odds with patients' or families' preferences, values, or goals. There remains only the professional foundation for understanding why a family member suddenly becomes intractable or a patient becomes noncompliant.

Falling back on the comfort of what we know, on our professional training and applied experience, is a natural reaction to difficult or complex situations. It is difficult to integrate a concept that is outside the realm of science and professional expertise because it means we must challenge our own certainty. Staying within the realm of our expert knowledge generally reduces our personal discomfort and may enhance the patient's confidence. Annalu's experience with a hospice client exemplifies this problem:

> Edith and her family were clients of our hospice team. She was a talented and dignified lady in her early 90s whose joys in life were her husband of 75 years, Joe, her daughter, Nancy, her granddaughter, Aimee, playing the piano, and reading. She lived with Joe in their lovely home in a rural retirement community. While they were quiet people who didn't like to burden others, they did allow their neighbors to check in on them periodically and to run errands to the pharmacy and grocery store. Edith wanted to live out her life at home with her husband.
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> When Edith lost her eyesight, a hospice volunteer was requested to come to the home to read to her. I took this assignment and soon realized the need to provide respite for Nancy, the primary caregiver, as well. Over time I learned that Edith was quietly but adamantly opposed to going to a nursing home. Nancy and her husband lived modestly, both working full time. Their small home could not accommodate her parents. Further, neither Nancy nor her parents could afford to hire in-home caregivers. Therefore, Nancy came to her parents' home before and after work each day to prepare meals, ensure that

medicines were taken properly, do housekeeping chores, and tend to her parents' various needs.

When I first met the family, two things were clear: one, that Nancy was perpetually tired, and, two that the end of this journey, while unpredictable, was a ways off. Edith and I began our relationship reading books. When Edith would tire, we would talk, reviewing the wonderful stories of Edith's and Joe's lives. Edith's journey was such that I spent several months with the family developing a mutual appreciation and refining the volunteer support offered to meet the family's evolving needs.

Nancy struggled with the physical and emotional drain of caring for her mother while working full time and tending to her own family's needs. The drive time between her work and her parents' home was half an hour each way when traffic was good. Nancy shared with me that she wasn't sure if she would be able to care for her mother at home in her final days, which meant that Edith would need nursing home care at some point. It was easy to see the guilt and self-doubt that burdened Nancy as she explored the space between her love and sense of duty to her mother and the certainty of her own personal limits. What I heard clearly was that Nancy wasn't seeking decision-making help, she was saying, "I want you to know that this is all I can do."

Over the months that Edith was on hospice care, her condition followed a natural course of physical decline. Toward the end, when Edith's care needs quickly spiked beyond what Joe and Nancy could handle, the hospice team recommended that Edith be admitted to the hospital to allow respite for the family and provide time for the team to review her plan of care. During this stay, Nancy told the hospice team that she would not be able to care for her mother at home at the level now required. The hospice social worker and nurse explained the various home support services available and that the only affordable alternative would be a nursing home. They reminded Nancy that her mother's expressed desires were to live out her days at home and avoid going to a nursing home. Nancy remained firm in her conviction that caring for her mother at home in Edith's final days was not something that she could do. So the hospital discharge nurse began to look for long-term care-options.

I visited Edith on the day that she was to be discharged from the hospital. Joe was sitting at Edith's bedside, while Nancy and I talked just outside the door. Nancy was distraught over how she should tell her mother and father that Edith would be going to a nursing home. At that moment the discharge nurse came into the room and announced to all that it was time to go because a cabulance was waiting to take Edith to the Bayview Villa Nursing Care facility. The distress that this announcement caused was palpable. Nancy was embarrassed and guilt stricken, and Edith and Joe were stunned and distraught to receive such big news in this way.

Later that same day I contacted our hospice volunteer coordinator, Aileen, to debrief about what had occurred. I shared my concern for Nancy's emotional turmoil in making the nursing home decision, and what I witnessed as a lack of sensitivity to the family dynamics. Aileen was a great believer in both the importance of teamwork and the unique perspective that volunteers brought to

> the team. She asked me to come to the team meeting that week and share my observations on the events surrounding Edith's discharge, which I did.
>
> The hospice social workers had been involved deeply with Edith's family for several months. During the team meeting I listened as well-trained, caring professionals promoted a predetermined model for a "good death" experience for this family. I heard phrases such as, "if Nancy would only have . . ." or "Nancy just needs to . . ." What was missing was an appreciation for the courageous work that Nancy had performed for almost a year or an acknowledgment that not everyone is emotionally or psychologically able to step up to the hard task of being responsible for a loved one at home in the final days. What these caring people also missed was an appreciation for the special knowledge that I had of Nancy and her family and the fears and distress that she had shared with me. My knowledge was discounted as nonprofessional and therefore not of value.
>
> What was most upsetting for me about this experience was the lack of exploration into what was 'right' for this family as a whole. At the very core of hospice philosophy is the concept that the unit of care is the patient *and* family. In this instance, the hospice team had fallen into that space of privileged expert—knowing 'the right way.' Mindfully listening to the family's story and then creating a supportive environment to facilitate the last chapter of Edith's life within that unique story was missing.

We have since had long conversations about this topic of professional certainty. Through our professional and personal growth, we have come to appreciate that while there may be "good ways to die," they are not everyone's ideal. When one of us says, "This could be so much better if only . . ." the other asks the question, "This could be so much better for whom?" Whose picture of a good end-of-life experience are we trying to achieve—the doctor's, the hospice team's, or the patient and family's? When we start with the patient and family goals and values in mind, then weave in our own professional expertise, we are much more able to reduce conflict and distress for all parties.

The Conspiracy of Silence

The conspiracy of silence between the helping professional and patient is one of the most common hooks that Stu as a physician has experienced and observed in his palliative care consultative practice. In the conspiracy of silence the physician senses either consciously or unconsciously the patient's reticence to talk about the possibility of death and opts not to "go there," believing that he or she is supporting the patient's wishes. The physician is often relieved that he or she doesn't need to have this discussion due to the personal discomfort evoked, and the patient is relieved that the physician is avoiding any talk of mortality. The following story of Stu's experience with his lifelong mentor and friend taught him the value of examining the conspiracy of silence in his own practice and as he teaches others:

> Bill was a teacher, mentor, and close friend since I was 12 years old. Over the years he had been one of the most influential and supportive persons in my life. From middle school to marriage, from birth to death, he was always present to

> help support and guide me through the cycles of my life. When I learned Bill had colon cancer that had spread to his liver, my heart sank. I knew that the prognosis was poor. No matter what treatments he chose, he was likely to die within two years. I hoped to support him, his wife, and their three children, just as he had helped my family and me over our years of friendship. Initially Bill responded well to his treatments, and he continued to live his rich, full life.
>
> One evening Bill and I went out to dinner. As we both enjoyed a well-set table and delightful conversation, I asked how things were going. Bill shared his surprise at how well he was tolerating his chemotherapy and how well he felt. While I was pleased to hear his report, in my heart I continued to worry about his poor prognosis and, barring a miracle, that this honeymoon period would end all too soon. I wondered just how much Bill understood his likely future. So I asked him what he expected in the coming months. Bill was thoughtful for a few moments then replied he hadn't really thought about it. I asked what his oncologist had shared with him. Bill then smiled broadly and said, "Oh, Dr. Blackwell and I share a conspiracy of silence. He knows that I'm not anxious to discuss the future, and I know he is uncomfortable discussing it as well. So, we just don't talk about it."
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> My heart sank once again as I heard Bill's words and realized the increased suffering that would occur for everyone as important medical decisions were made divorced from the most probable context in which they would be lived. But even more powerful was a sudden recognition of just how often I had participated in the "conspiracy of silence" in my professional life as a physician. How seductive it has been for me to use the patient's discomfort as a reason to avoid performing what I now see as my central responsibilities in caring for patients with life-limiting illness. My professional responsibility, no matter how difficult it may be, is to humanely explore with my patient and his or her family what it will mean to them if the best outcome doesn't happen.

The conspiracy of silence is one of the most common hooks for all team members that I observe in my work as a palliative care physician. My colleagues and I want to help our patients feel better. To explore the issues that are frightening or distressful to the patient, family, and me challenges the basic assumptions of the relationship I want to share. What if the patient or family becomes upset about what I am telling them or, worse yet, gets angry with me? Why should I take such a risk and perhaps suffer myself? It's much easier to believe that I'm honoring the patient's choice to avoid a tough topic than to explore my own motivations and fears.

While avoiding the reality of impending mortality is one of the most frequent conspiracies, there are legions of others. Whenever we think we are avoiding discussing an important issue because "it's what the patient wants," we should use that as a trigger to reflect more deeply on the situation. Is it truly the case that the patient doesn't want to discuss this topic? Or is this our way of avoiding our own discomfort and inhibitions? Or, is it some combination of both? On a deeper level, we should ask ourselves this: Is an exploration of the topic with the patient going to improve his or her lived experience? If either answer is yes, then it is our professional responsibility to develop respectful, safe, and creative ways to invite the patient into a shared conversation where we can explore

the topic. We also have the professional responsibility to keep offering an exploration of mortality and other difficult conversations in a respectful way as long as it provides the opportunity for a more optimal outcome consistent with the patient's goals and values.

Fear of Uncertainty and Desire for Control

Medical professional training emphasizes the dangers of uncertainty and loss of control. Uncertainty is presented as the enemy that must be vanquished in every clinical encounter. When living with serious illness, the patient and physician want a controlled environment and a context where precision (the ability to reduce uncertainty) can be maximized. Focusing exclusively on the biomedical model is an extremely successful way of supporting the sense of certainty and control desired by everyone—physician, extended health-care team, patient, and family. For the physician, exploring the diversity of the patient's story is dangerous. Bringing the patient's story into the clinical encounter increases the risk of uncertainty and decreases the sense of control that medical science provides the professional. In reality the only certainty in end-of-life care is that the patient eventually will die. Each individual experience is unpredictable and uncontrollable along the path toward death.

Uncertainty is a given, and control is an illusion. The heavy emphasis on scientific precision professionalizes and routinizes an intensely personal, unknowable, and unpredictable experience. By embracing uncertainty and acknowledging our inability to control the outcome, we allow ourselves to focus our energies creatively and mindfully on the shared values and goals of the patient, family, and physician rather than being limited by biomedical values. An encounter with one of Stu's first patients emphasizes this point:

> Early in my professional development and career, I had the privilege of caring for Barbara. She was an energetic and bright widow in her early 70s. Each quarter I monitored her high blood pressure. She came immaculately groomed and energetically shared stories about her contributions to the many charitable and community organizations she supported. She was one of my first and favorite patients. During one of her visits, Barbara complained of significant low back pain. What I initially thought was a common case of arthritis turned out to be a rare case of connective tissue cancer (sarcoma) involving the major arteries and nerves of her left pelvis. No effective radiation or chemotherapy treatments existed at that time. Given the tumor's extensive growth, the only surgery possible was a complete amputation of a quarter of her pelvis including her left hip and leg. This extremely complicated surgery could only be done many miles away at the regional university medical center. Making the situation even more difficult was the severe pain Barbara experienced in her left leg due to pressure from the cancer on her pelvic nerves. The pain remained severe despite high doses of morphine.
>
> In the midst of this difficult situation, I admitted Barbara to the hospital to control her pain and to explore with Barbara and her family her medical options. As I sat at her bedside on the sixth floor cancer unit with her three sons discussing her medical situation and treatment options, I was amazed at Barbara's courage and peaceful demeanor. I carefully explained the medical

situation to be sure that Barbara and her sons understood that there was no 'cure' for her condition short of surgery at the regional university medical center. Additionally I explained that her nerve pain was extremely difficult to treat, and none of the specialists locally had any suggestions beyond what was already being done. I then invited Barbara and her family to ask questions. When I was sure that they understood the medical situation and treatment options, I asked Barbara what she wanted to do.

Barbara replied with the grace and assuredness she had always displayed that she wasn't interested in going to a distant university medical center for a disfiguring operation or pain control. She wanted to remain in her own community surrounded by her sons. She thanked me for the excellent care I had provided and asked again that I do the best I could to control her pain. I shook her hand, feeling sad but strengthened by her courage and expression of thanks for my caring efforts. I wrote new orders in her chart increasing her morphine dose and making arrangements for her return to the nursing home.

My mind then shifted to the busy day ahead of me as I hurried down six flights of steps toward my car. While crossing the hospital lobby, I heard the paging operator's voice, "Dr. Farber, please call 6J." I stopped, called 6J, and will never forget the nurse's words, "Dr. Farber, could you please come back up and talk to Barbara? She just tried to jump out of the sixth-floor window." As I raced up the steps, my mind was reeling. How had this happened? We had just met, and I had used my best professional skills to make sure Barbara understood her situation and options. What had gone wrong?

Sitting again at Barbara's bedside, I learned in a deep and indelible way what had gone wrong for Barbara. More importantly, I learned from this amazing woman lessons that have transformed me both personally and professionally. With the nurse at my side, I looked into Barbara's eyes and said, "Barbara, I don't think I've been listening very well to what you want to tell me, but you have my full attention now." She smiled, nodded her head, and said, "Dr. Farber, this pain is so terrible. I would rather be dead than continue to live with it. I don't want to go to Seattle to have my pain controlled. I want you to do it here. I know my choice to forgo surgery means I am embracing my death, but to me having a deforming surgery and being unable to be the active person I have always been makes no sense. Can you help me?" As we sat in this intensely intimate and shared space, the appropriate treatment option that had eluded me for Barbara was now simple and obvious. I said, "Barbara, we can start an intravenous morphine drip and keep raising the dose until you are pain free. Given your cancer's involvement into your nerves, it is likely you will need enough morphine that you will be asleep, but I know we can take the pain away."

Barbara smiled at me and said that as long as her children agreed and could be with her, this was exactly what she wanted. We called her sons back and discussed the new plan. They all heartily supported her decision. In a short time Barbara's pain was well controlled, and she was comfortably asleep. Before she fell asleep, she and her sons shared their final good-byes. Three days later she died peacefully having taught me more than I ever could have predicted.

My medical knowledge had limited my ability to know the right way to treat Barbara's condition. She had come from a generation that both respected and would never challenge my professional authority. My attachment to the biomedical approach was born of a fear of uncertainty and a reciprocal need to maintain control. By focusing my energies on providing medical solutions, I felt in control. This provided an illusion of certainty for both Barbara and me. Barbara's totally unexpected attempt to jump out of the hospital window became the portal through which I was able to reframe my medical skills and use them in a way that respectfully supported her and her family at the end of her life.

The Myth in Cultural Diversity

Generally, when we think about cultural diversity, we are aware of people who are very different from us in obvious ways—ethnicity, traditions, nationality, and so on. We are then alert to the fact that there may be some unique belief or value system that should be explored to provide culturally sensitive care to a "culturally diverse" patient and family. Herein lies the myth in cultural diversity. The reality is that each patient-professional encounter is a cross-cultural experience. It is important to respect the deeply held and unique values, traditions, family affiliations, and spiritual foundations in all patients' stories. A subtler challenge of recognizing diversity exists with those whom we judge to be "just like me." The more we perceive a patient or client to be like us, the less likely we are to be curious about their values and preferences, and the less effort we may expend exploring their nontraditional choices. In this case, "nontraditional" refers to those choices that don't fit our preconceived notions of the right way to act. In fact, when a person is quite like us, we are often confused and dismayed when their decisions don't conform to our system of values.

What is wonderfully simple about the Respectful Death Model approach to diversity is that the plan for culturally responsive care comes from the experts—the patient and family. At each meeting, the cultural experience to be explored is that of the patient and family. Therefore, building respectful, listening relationships with patients—eliciting their expertise—naturally leads to a higher level of understanding and better outcomes.

Annalu learned an important lesson about the definition of culture and the myth of "people like me" when she was consulting for a regional cancer center. She had been retained to lead the development of a patient and family workbook (Farber & Farber, 2001) based on qualitative research done with cancer patients and their caregivers. In the pilot phase of the program, she invited current cancer patients to volunteer to test the workbook and then participate in one of several focus groups to share their feedback. Annalu was in full professional business mode as she organized and facilitated the groups. Though not by design, all of the participants in the first group were middle class and Caucasian and ranged in age from 40 to 60. These were people who were outwardly much like her. What she hadn't prepared for was that the first focus group was also a complete immersion into the world of living daily with life-threatening illness. All of the participants had been living with cancer for a significant period of time. About 45 minutes into the discussion, Annalu was struck by the fact that, with the exception of herself, no one else in the room was likely to be alive in a year's time. She was stunned by this recognition and overwhelmed by its accompanying grief. These people were not like her at all. They were living the end of their lives.

Being mindful that cultural diversity is embedded in every client-professional relationship is crucial to providing sound care in culturally sensitive ways. We must remember to assume little and ask the grounding questions that respectfully acknowledge the unique perspectives that each party brings to the discussion. We can ask questions such as these:

- Who would you like involved in your health-care decisions?
- How do you understand your illness?
- What do you think will happen to you in the next weeks? Months?
- What do you fear most?
- What do you hope for?
- Where do you draw your strength in times like this?
- How do you see your future?
- Is there anything else I should know about you and your goals or beliefs?

We should invite every patient or client into a safe space where her or his knowledge is respected and explored. In that space, an exploration of cultural diversity, as it pertains to the situation at hand, will surface naturally, and the potential for cultural conflict will be diminished. A common example of cultural conflict arises when the culture of family-based decision making meets the culture of individual autonomy that is embedded in many Western disciplines. Stu faced this challenging situation upon admitting an 80-year-old Burmese woman with terminal cancer to the nursing home:

> I was about to enter the room with an interpreter and introduce myself to this woman when her son and daughter intercepted me. The son stated in clear English that both he and his sister didn't want me to tell their mother that she had cancer. This request went against all of my Western culture expectations and the stringent rules of autonomy guaranteed to patients in a nursing home by both state and federal regulations. The situation seemed poised to become confrontational.
>
> Before addressing the difficulties raised by their request, I asked the children why they didn't want their mother to know she had cancer. They shared that, in their culture, it was up to them as children to care for their sick mother and make appropriate medical decisions for her. She had enough to do just living with her illness. Additionally, they felt that if she knew she had terminal cancer, she would only get depressed and die sooner.
>
> Considering this information, I asked the children if it was acceptable to talk with their mother and get her perspective on the situation. I promised that during this initial meeting, I would not tell their mother that she had cancer. I set the expectation, however, that after the initial meeting, I would want to discuss this request with them further. They agreed.
>
> So, I met with the patient and asked many questions through the interpreter aimed at clarifying her understanding of her situation. My questions included: How do you see your situation? What do you expect to achieve in the nursing home? What else would you like to know?

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> The patient described her recent surgery and her need to recover and get stronger in the nursing home so that she could go home. At no point did she ask about her diagnosis or ask for further medical information, even though I opened that door for her several times. I asked the patient how she wanted to handle the communication of her medical situation. I explained that some patients like to be told all of the medical facts and make their own decisions. Other patients want their family members to talk with the medical team and make medical decisions for them. Still other patients want something in between these two options. The patient looked directly at her two children and stated quite clearly through the interpreter that she wanted them to make all medical decisions for her. She didn't want to be involved and trusted that her children would share with her anything that she needed to know.
>
> It was with great comfort that I met later with the son and daughter and was able to agree to their request to not tell their mother about her cancer. True autonomy is when a patient and family communicate and make medical decisions in a way that makes sense to them. What the children requested was exactly what the mother wanted. To force her to know that she had terminal cancer would have violated her autonomous decision, and further, it would have caused unneeded suffering for everyone—the patient, the children, and the medical team.

In this scenario, it can be argued that *true autonomy is the patient's choice*. If, for example, the patient and family opt to have medical decisions made by the eldest son or daughter (family-based decision making), the patient's autonomous right to make that choice should be supported even though it pushes against traditional medical culture. Ultimately cultural diversity demands that we listen to and embrace the story of the other in our care planning.

Both exploration and curiosity are essential for drawing out the patient story and providing respectful care. Stu learned this as he cared for Barbara. He had initially failed to include Barbara as the "cultural expert" on her values and what gave meaning to her life. He meticulously and caringly shared with her the details of his medical-cultural perspective but was blind to how she wanted to live each day of her life until she died. Stu sees now that he gave no thought initially to whether the medical treatments he was providing would help Barbara to live a life of meaning and value or one of increased personal suffering. As it turned out, with the best of intentions, his initial recommendations would have offered her a life of unacceptable suffering filled with pain and unendurable loss.

Summary

We as health-care professionals generally are not well prepared by our education to provide palliative and end-of-life care. What we are trained to do is to identify problems and offer solutions from the perspective of our professional training and culture. Working in the intensely intimate and demanding environment of end-of-life care and serious illness, immersed in our professional knowledge, it is difficult to reflect diligently on our own actions, values, and beliefs. Our professional biases make it even more difficult to

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be deeply respectful of the patient and family as people who come to us with life stories filled with values, beliefs, hopes, and fears. Instead, we often see each patient as a problem to be solved.

Alternatively, we can look at each patient and family as coming to us to collaborate on living the best life possible under the difficult circumstances of a life-limiting illness. The patient and family are the experts on their goals and how they want to live each day of their lives. If we as helping professionals strive to understand the essential knowledge in each patient's story, we can then creatively integrate our own professional knowledge and experience. In this way we facilitate each patient and each family in living out their days in ways that are meaningful to them, and we are enriched in the process.

Such an approach requires each of us to courageously establish therapeutic relationships that acknowledge or own vulnerability, uncertainty, and lack of control. We simultaneously are affecting the patient's experience and being affected by the patient's experience. By mindfully opening to and exploring the alchemy of this shared experience, we provide profound learning and growth for our patients, their families, and ourselves.

The Respectful Death Model we have described is founded on these principles:

- Professionals do not have all of the answers.
- Each encounter with a patient and family is a cross-cultural one where the patient and family are also experts, holding the essential knowledge of their values, beliefs, and goals.
- Uncertainty and loss of control are opportunities for creative and collaborative problem solving.
- It is the responsibility of professionals to invite patients and families into discussions on any topic that will support a fuller and more meaningful life consistent with the patient's and family's values and goals.

This model is best approached as a shared relationship that emphasizes respectful exploration of all involved: patient, family, community, and self.

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16 Balint Groups to Address Countertransference and Burnout in Palliative and End-of-Life Care

Katherine Knowlton and Renee S. Katz

Introduction

Caring for patients with serious or terminal illness evokes powerful emotional responses in even the most experienced of health-care providers. These reactions can trigger a cascade of clinical and behavioral responses from grief, irritation, and avoidance to deep affection, idealistic hope, and over involvement. When left unaddressed or unexamined, demoralization, burnout, and boundary crossings can result (Shanafelt et al., 2010).

To prevent this, it is important for clinicians to be aware of both the patient's emotions (Block, 2000; Meier, Back, & Morrison, 2001) and their *own* (Katz & Johnson, 2006; Ofri, 2013). However, health-care professionals are not always cognizant of the emotions and thoughts that can get in the way of their work with critically ill and dying patients and families (Weiner, 2006). These reactions may stem from individual countertransference conflicts and feelings, or they may reflect normative reactions to life-threatening illness and mortality.

Whatever the origin, lack of professional self-awareness can contribute to disconnection from patient, family, *and* self. This disconnection impairs the provider's capacity to be fully present to a plethora of patient feelings and experiences, frequently interfering with the capacity to be present to suffering, let alone to attempt to address or relieve it. Nonmental health clinicians are particularly vulnerable as they often are encouraged to put their feelings aside when working in stressful or emotionally charged situations. Palliative and end-of-life care is no exception (Kearney, Weininger, Vachon, Harrison, & Mount, 2009; Weiner, 2006).

Clinician Know Thyself

In this era of quick fixes, financially driven health-care policies, and high-acuity workloads, there is little room, little time, and little appreciation for the need to stop, take stock, evaluate, and examine ourselves, our patients, their families, and the systems in which we work. Efficiency is valued over process, definitive decisions over options, and evidence-based protocols over patient-identified goals. Little value is placed on the internal emotional needs and conflicts of the health-care provider, and even less attention is paid to their impact on relationships with patients and their families. Without attention to the interpersonal dynamics that inevitably surface in every provider-patient interaction, health-care professionals are left in precarious situations cognitively, emotionally, and clinically (West et al., 2006). In recognition of these difficult dynamics and their impact on patient care, Balint groups were born.

Balint Group Beginnings

The era was World War II—the place, postwar England. The players were primary care physicians swamped with the psychosomatic and psychosocial complications presented by their patients as troops demobilized and the chronic costs of war set in. In witnessing the intense challenges imposed on their medical colleagues at this time, psychoanalysts Michael and Enid Balint (Balint, 1972) developed Balint groups to help primary care physicians deal with the nonmedical aspects of treating people with posttraumatic stress disorder and other problems. The Balints understood that the interpersonal medium often carried the curative aspect of care and, indeed, that some patients might come needing the medicine of the doctor's caring respect (Balint, 1972, p. 116). Accordingly, their case consultation groups were designed to help physicians focus on their doctor-patient relationships. To this end, Balint groups encouraged empathy and understanding of the patient, the physician, and the relationship between the two.

Today Balint groups have evolved to include health-care and mental-health professionals from multiple disciplines (Balint & Norell, 1973). They are in use in more than two dozen countries (www.balintinternational.com), both as training for professionals new to their fields and for ongoing support and development of experienced practitioners. Balint groups support and nurture the kind of searching self-reflection that leads to the self-realization of an empathic and effective clinician, that is, a better clinician (Diaz, Chessman, Johnson, Brock, & Gavin, 2015).

Thus, they are especially well suited to people who work in end-of-life care.

A Balint Group in Action

The following case, taken from a group of international participants, demonstrates what happens in a Balint group.

With the Balint group gathered, one of the group's leaders asked for a case. A palliative care doctor shared the following. He worked as a consultant in a large teaching hospital and was called to help with a dying man when staff were in conflict with the patient's family. The doctor, a tall man of British heritage, entered the hospital room to find the patient, a 24-year-old Asian man diagnosed with late-stage pancreatic cancer, disoriented, physically agitated, and grimacing in pain. Over the course of his brief treatment, the patient had not managed his own care. His mother and father had made all medical decisions throughout his illness and were now in his room forbidding staff from giving him the help they felt they could. A miserable-looking resident and an angry nurse stood outside the room.

Over a couple of hours of careful negotiation with the embattled parents and the dying son, the doctor won permission to order medication to ease the patient's agitation and pain. By the time the doctor's shift ended, the patient was resting much more comfortably. Now, at this international conference two weeks later, this presenting physician had been unable to get the case out of his mind. He did not know why and asked for the group's help.

The group discussed the case by imagining what it was like to be the doctor in this situation, what it was like to be the patient, and what the experience was like for the parents and others in the complex treatment context. They identified the doctor's helplessness,

his sense of being an awkward intruder, and his burdensome awareness of the vulnerabilities and the palpable suffering in everyone he met on the unit that day. They spoke of the son's physical pain and his devotion to his parents. Several people noted that they considered his deference to them culturally normative for an only child of this age and heritage. They speculated that the successful, worldly son might have grown up being the bridge between his old-fashioned émigré parents and the English-speaking city in which they found themselves. They remarked on the reversal of this dependency during his final illness. The group members guessed that the patient knew he was dying but that he had hidden this knowledge from his parents to spare them additional anguish. Finally, the group speculated that the parents felt frantic and helpless and might be fighting misguidedly to protect their son because they found the whole situation so un-trustable, so unacceptable, so unbearable. One group member noted that what dies with an only child may be a whole family, not just a single person. Other members imagined that this tenderhearted doctor felt responsible to several patients in this one consultation: the dying son, the parents, the troubled resident, and maybe even the mis-attuned hospital ward itself.

The doctor listened to all this with interest, taking the freedom given him by the group to pursue his own thoughts and use what was said for his own purposes. In the end he thanked the group, admitted surprise at the complexity of the accurate picture the group members had been able to form, and said he had several new insights about the situation. He told the group that as a result of listening to their processing of the case, he had decided to give a grand rounds on this case to help hospital staff with multicultural sensitivity. He did not explain any specific shift that had occurred during the group work but felt sure he would no longer be haunted by the case. Waelder (cited in Menninger & Holzman, 1973, p. 94) observes that "since we are all partially blind, the best we can do is to support each other so that the vision of one may make up for the myopia of the other." Perhaps, for this physician, the Balint group supported that vision.

Impact on Care

The sources of isolation for people who provide medical and mental health care are many: confidentiality prevents us from talking freely about the most important interchanges that happen in our days; the ways we try to make sense of things may be quite technical, and this has a tendency to isolate us from our feelings. Finally, some of our truly intimate relationships may be with very troubled or unpeaceful people so that their closeness is hard to bear.

Balint groups address all these sources of isolation. Access to peer support influences job satisfaction and the sense that one can sustain meaningful work (Kjeldmand, Hoemstrom, & Rosenqvist, 2004). Reintegration of affects and deepening self-awareness improve the practitioner's use of him- or herself in work settings (Lichtenstein & Lustig, 2006). And the original goal of the Balint group, improving doctor-patient relationships, means that the real human satisfactions of providing care are more available to practitioners. In essence Balint groups address Gabbard's (1999) premise that countertransference "is inevitable and useful as part of an exploration involving two spontaneous and responsive individuals engaged in an intense and emotionally taxing interaction."

Successful Balint groups require good leadership (Johnson et al., 2004) to establish and maintain enough safety to open up emotionally. To this end leaders must instill strong norms of confidentiality and respect. Balint groups are not therapy, so leaders must encourage deep reflection while respecting the limit of focusing on the professional self and not on the personal self. Optimally the groups also require steady membership and good enough frequency, at least once a month, for their 'dose dependent' effects to be felt. They have been known to continue for decades, perhaps the ultimate evidence of their utility (Salinsky & Sackin, 2000). Where there is risk of burnout, such longevity also may attest to their supporting and sustaining healthy careers.

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17 Mindfulness in Palliative and End-of-Life Care

Meeting the Moment Fully

Renee S. Katz

Introduction

In the midst of life, we are in death. In our work with seriously ill and dying patients, we cannot help but be impacted by profound, sometimes subtle, sometimes jarring experiences of struggle, abandonment, desire, and hope. We sit with pain, suffering, joy, and elation—and, at times, moments of awe and transcendence. Our psyches' responses to our biopsychosocial-spiritual experiences in palliative and end-of-life care are often not available to our conscious minds; we frequently cannot access our countertransference responses cognitively by simply thinking about them. It is here, at the edge of cognition, psyche, and soma that our countertransference responses often lie fallow—awaiting the cultivation of our consciousness.

Mindfulness practice is one way to become aware of our countertransference reactions and our resistance to them. When we cultivate our abilities to open to all that arises and deepen our capacities to be present to all manner of experiences that may surface in our work, we can tune into the messages our patients and families are overtly or covertly trying to send. And, we can tune into our own authentic responses.

Mindfulness Past and Present

Although current-day mindfulness practice frequently is attributed to the Buddhist tradition, mindful reflection and contemplative practice have been components of a variety of religious traditions for centuries. Jewish *kabbalah* and *mussar* traditions, Christian monastic centering prayer, and Hindu meditation techniques all have components of contemplative reflection embedded in their practices. Additionally, mindful meditation has been and continues to be a component of ancient practices such as yoga, qigong, and tai chi—all of which are experiencing newfound popularity in our modern world.

Mindfulness-based techniques are being used with diverse populations and settings. Training in mindfulness and in mindfulness-based stress reduction, for instance, has been used successfully to decrease burnout and compassion fatigue in physicians and other health-care workers (Kearney, Weininger, Vachon, Harrison, & Mount, 2009; Shapiro, Brown, & Biegel, 2007), to reduce acute and chronic pain (Bauer-Wu et al., 2014), and to cultivate compassion-based interventions (Seppala, Hutcherson, Nguyen, Doty, & Gross, 2014). Applying and cultivating mindful attention to the examination of

countertransference in palliative and end-of-life care are equally compelling. As Tony Back (personal communication, 2015) astutely notes, "Countertransference is the water we swim in. The value of noticing and naming countertransference is that it puts a spotlight on an everyday phenomenon."

Mindful Attention in Palliative and End-of-Life Care

The authors in this volume have identified countertransference hooks common to our work in palliative and end-of-life care. Our own fears of disability and death, our denial of helplessness, our vulnerabilities to overidentify and move into despair, anger, and overcontrol—all these responses can show up in our work, whether we are aware of them or not. To some degree, these reactions are adaptive, preserving our sense of intactness, helping us maintain hope, and providing a vehicle with which to preserve our professional boundaries. But they also can serve to distance us from the real, felt experiences of our patients and families. Our countertransference can catapult us into making inaccurate assessments and assumptions; it can cause us to push our own agendas and to invest unrealistic amounts of time and energy into our work, perhaps fusing our personal needs with those of our patients.

Ultimately, our unconscious and unaddressed countertransference feelings and reactions can interfere with our capacities for empathy, compassion, emotional availability, and responsiveness to our patients. In the worst case, countertransference responses may inadvertently cause us to make decisions based upon our own beliefs and values or in reaction to experiences in our personal lives, whether past, present, or in the anticipated future.

It is during those moments when we are most vulnerable to the personal unconscious that mindful attention is, perhaps, our most valuable tool. Mindfulness provides us the opportunity to take a breath, ground ourselves, and pause long enough to adequately observe what is happening in ourselves, in our patients, and in the intersubjective relational moment. It allows us to, as Sylvia Boorstein (2007) suggests, "meet the moment fully; meet it as a friend," that is, with compassion, kindness, and an open heart, accepting all that arises without retreating out of discomfort, fear, shame, or guilt.

Mindful attention affords us the possibility of achieving deeper clarity in our work and the capacity to then deliberately *choose* a response rather than acting impulsively. It provides an opportunity to bring the accumulated wisdom of our past experiences to new situations, reining in otherwise unbridled, unconscious reactions. This awareness and attention allows us to establish or reestablish a caring connection to ourselves and to the other, no matter how agitated, activated, or overwhelmed we may be (Boorstein, 2007, p. 12). In essence, mindful awareness provides us an exquisite tool for attunement and re-attunement, moment by moment.

Cultivating Mindful Attention

How do we begin to use mindfulness practice in our work in palliative and end-of-life care? No external action is necessary, and no extra time is required. Diligent effort, concentration, and attention are the internal, silent steps we take to restore our minds to places of balance, ease, clarity, and wisdom. We begin with curiosity, openness, and

an investigative mind-set, allowing space, without judgment, for whatever shows up. We notice our thoughts, our feelings, and our experiences in the body. We meet these experiences with cordial intent so that we can clearly discern what might be being triggered in us—what is ours, what is the patient's, and what belongs to the clinical relationship. Allowing space, welcoming all our responses and omitting none, provides an opportunity to see more clearly the sources of our distress. Then, with these insights in hand, we can assess each experience to determine a right course of action. Mindfulness, as Boorstein (2007, p. 116) frequently reminds us, is a method by which we take our mind to the laundry! It is a process of liberating the mind from the stories it tells itself and the secrets it tries to keep hidden because it is uncomfortable, afraid, or too embarrassed to face them. All unlaundered, unattended responses are potentially problematic: they stealthily can inform or influence our thinking, our behaviors, and our interactions.

"Well," one may ask, "doesn't any self-aware, caring professional naturally do this internal assessment as part of the work?" The answer is: "Well, yes, of course," and, "No, not necessarily." In fact, this book was conceived and produced because professionals from diverse lines of work asked for more information about how to access the deep recesses of our unconscious minds, which are precisely that—unconscious! Not one of us is immune to the vulnerabilities and agitations of our psyche. We simply cannot be mindful at all times or in all the ways we would like to think we are. It takes practice to work with our long-standing mental habits and notice our unconscious jumps to assumption, judgment, defensiveness, myopia, and impulsive action. Halifax (2009) notes that, "just as the body needs to be slowly stretched for greater flexibility, so does the mind need time for training [and practice]" (p. 12). It is for this reason that mindfulness is called a "practice."

Mindfulness in Action: Meeting Each Moment Fully

Methods of mindful practice vary from tradition to tradition and from teacher to teacher. Most involve the development of three basic skills by which to restore the mind to balance and clarity: focused attention and concentration, steady observing (mindfulness per se), and compassionate acceptance (Boorstein, 2007; Halifax, 2009; Pollak, Pedulla, & Siegel, 2014).

Focused attention helps us stay attuned to the present moment; mindful observation enables us to broaden and deepen our awareness of moment-to-moment sensations; and compassion allows us to welcome with friendly acceptance and curiosity all that arises in our experience. These practices help us open to and accept whatever arises in our minds, tolerate whatever affect is present, let go of cognitive frameworks we may wish to bring to the encounter, and sit with the physical, emotional, and spiritual experiences, impulses, stories, and memories that arise. In other words, mindful attention encourages us to befriend difficult thoughts, feelings, and sensations that we might otherwise avoid, deny, or defend against. It moves us toward greater insight. When we can let go of expectation, when we can be in a place of "not knowing," we can be alert and aware in the moment. Mindfulness allows the realities of the moment to inform us and our choices. Only then can we discern the appropriate response, the right action.

Mindful practice can be utilized unobtrusively at any time of the day. That is, a mindfulness check-in can be done "on the spot" whenever necessary. As Altilio and Sumser, in Chapter 11, beautifully note, even the act of moving from room to room creates opportunities to employ mindful awareness. Because our emotions can become confused and heightened at any time in our work, integrating even brief mindful awareness exercises can place a momentary pause in our day. This affords us the opportunity to attune to and deepen our awareness, thereby directly informing our capacity to identify countertransference issues and responses. "We may not have the necessary space to process or reflect entirely at any given time. However, identifying triggering, stimulating, or emotionally challenging experiences in the moment can reduce a stress response that over time makes our feelings more elusive and harder to name" (Altilio & Sumser, Chapter 11, this volume).

Pollak et al. (2014) note that the simple act of closing one's eyes and observing the sensations in the core of the body can help individuals access feelings that might otherwise be outside of their conscious awareness. Like other mindfulness-oriented health professionals (see, e.g., Brach, 2003; Hanson, 2013; Neff, 2015), Pollak et al. (2014) might use any number of variations of basic mindfulness practice.

A simple mindful attention instruction might look like this:

1. Invite yourself into the stillness of your body, your mind, and your heart.
2. Breathe to open to a larger sense of spaciousness.
3. Notice the breath as it enters the body and as it leaves, allowing the breath to move at its own pace and rhythm and allowing the body to breathe.
4. Bring to awareness the physical sensations of the breath at this moment.
5. Bring a beginner's mind, being curious and open to this experience.
6. Stay with the breath, welcoming all the experiences of your mind, heart, and body.
7. When you have taken the time you need, allow a moment of transition to turn your attention outward, and return to the moment and situation at hand.

A briefer instruction enjoyed by some professionals is attributed to Thich Nhat Hanh:

1. "Breathing in, I calm my body and mind. Breathing out, I let go."
2. On the inhalation, think: "Dwelling in the present moment."
   On the exhalation, think: "This is the only moment."

Simple practices, such as momentarily closing one's eyes, putting one's hand on one's heart, and noticing the breath can shift our "mind space." Taking slow belly breaths at one's own pace, without words, while attending to the breath or simply counting each breath, is another very basic mindfulness practice that can be used "on the spot." Andrew Weil (n.d.) builds on this practice with instructions for four–seven–eight breathing:

1. Exhale completely through your mouth.
2. Now, close your mouth and inhale through your nose, into the belly, to the count of four.
3. Hold your breath for a count of seven.
4. Breathe out completely through your mouth for a count of eight.
5. Inhale into the belly and repeat the cycle up to a total of four times.

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Some individuals, after grounding with the breath or some other object of focus (e.g., an object in the visual field, something in nature, or a mantra) prefer to use one of Sylvia Boorstein's (2007) meditations to welcome an open spaciousness and acceptance:

1. "May I meet this moment fully; may I meet it as a friend."
2. "Turn off the mind. Light a candle in the heart. Pay attention with compassion."

Sharon Salzberg (2002), utilizing ancient Metta practice, provides the frame of loving-kindness practice, a variation of which might be a grounding in invocations such as the following:

1. May I open my heart with compassion to all that arises.
2. May I welcome all and turn away nothing.
3. May I let go of expectation and accept whatever this experience might be.
4. May I embrace all sensations and experiences with kindness.
5. May I trust in presence.

No matter what variation on a mindfulness theme one chooses, the foundations, goals, and physiological effects are similar. Silence and a non-judging attention to the body, psyche (emotions), mind, and objects of the mind form the foundations of mindful attention (Boorstein, 2007; Halifax, 2009). Silence is the medium in which we cultivate deep concentration, tranquility, and mental stability or equanimity. It helps us steady our minds, bodies, and emotions. When we are in this steady state, we are less prone to reactivity, less quick to judge, and less likely to attach to particular outcomes. We can lean into our mental states rather than distance or detach from them, no matter how uncomfortable, disturbing, or upsetting they might be. Mindful presence allows us to nurture steady compassion and an open, accepting heart for ourselves and others. As such, mindfulness is an antidote to professional burnout and compassion fatigue. It reduces stress, provides opportunities for new insights, and opens infinite, new possibilities in every patient and family encounter.

Mindfulness Practice and Meditation

Mindful attention takes commitment, effort, and patience. We practice imperfectly, with a compassionate, nonjudgmental attitude, so that we can meet each moment fully and as a friend (Boorstein, 2007). This type of tender attention is possible—albeit imperfect at times—even in brief moments of mindful practice, such as those already described. Engaging in more formal, daily mindful practice and meditation involves setting aside a designated time and space outside of our work lives to develop our mindfulness "muscles" and to do the ongoing work of "laundering" our minds. Formal practice provides us a way of becoming intimate with the workings of our minds. It affords us

> a spacious and powerful container in which to cultivate . . . awareness—and we need that kind of concentration, because in being with . . . [seriously ill and dying patients], our mindfulness will be routinely challenged by all kinds of complex conditions: working with families in extreme states of grief, rage, or frustration; working

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> with dying people suffering almost unbearable pain, fear, denial, or isolation; sitting with [patients] . . . in the slow tide of Alzheimer's, or [with] a mother whose son . . . [has] been murdered. Concentrated awareness synchronizes body, speech, and mind, bringing our full attention to the immediate situation without adding anything extra. [This allows us] . . . to show up, simply being present for whatever is offered, whether the underbelly of suffering, the mystery of transcendence, or the truth of the ordinary.
>
> (Halifax, 2009, pp. 11, 62)

This is how we meet our countertransference: fully, deeply, consciously. *This* is how we show up moment by moment.

Conclusion

No matter what form of mindfulness practice we embrace, we are afforded an exquisite opportunity to confront our countertransference responses and face those poignant, often profound experiences of being with serious illness and death. When we can step through our fears, abandon our fixed ideas about outcomes, and simply remain present—to bear witness and to accompany our patients in joy and in suffering in living and in dying—then we can more skillfully and more effectively take compassionate action on their terms, not ours.

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18 A Group Intervention to Process and Examine Countertransference in Palliative and End-of-Life Care

Yael Danieli

Introduction

Countertransference reactions are integral to, ubiquitous, and expected in our professional endeavors. Our work calls on us to confront, with our patients and within ourselves, the extraordinary human experience of dying. This confrontation is profoundly humbling in that at all times these experiences try our view of the world in which we live and challenge the limits of our humanity. The need to cope with and work through countertransference difficulties is imperative for optimal training of *all* members of the health-care team, including physicians, nurses, psychologists, social workers, physical therapists, occupational therapists, and the clergy.

Processing Event Countertransference[1]

The following is an exercise process that I have developed over the last three decades of working with trauma, which has been found helpful in numerous workshops, training institutes, short- and long-term seminars, and consultative and short- and long-term supervisory relationships. While it originally evolved and is still done optimally as a part of a group experience, it also can be done alone to assist the clinician working privately. As one veteran clinician who does it regularly stated, "It is like taking an inner shower when I am at an impasse with . . . [a] patient."

Instructions for Participants

In a group setting, participants are asked to arrange the chairs in a circle. After everyone is seated, without any introductions, the leader gives the following instructions:

> The first phase of the process will be private, totally between you and yourself. Please prepare at least two large pieces of paper and a pen or pencil. Create space for yourself. Please don't talk with each other during this first phase.

1. **Systematic Deep Relaxation:**
   The session starts with 20 to 30 minutes of systematic, deep relaxation, including guided imagery, to help participants focus internally.
   At the end of the relaxation period, the leader instructs: Choose the palliative and end-of-life experience most meaningful to you. Please let yourself focus into it with as much detail as possible.

2. **Imaging:** Draw everything and anything—any image that comes to mind when you focus on the experience you chose. Take your time. We have a lot of time. Take all the time you need.
3. **Word Association:** When you have completed this task, turn the page, and please write down every word that comes to mind when you focus on this experience.
4. **Added Reflection and Affective Associations:** When you finish this, draw a line underneath the words. Please, look through and reflect on the words you wrote. Is there any affect or feeling word that you may have not included? Please add them now.
   Roam freely around your mind, and add any other words that come to mind now.
5. **First Memory of a Serious Illness or End-of-Life Experience:** When was the *first time* you ever encountered this experience?
   What happened? How did it happen?
   What did you hear?
   What was it like for you?
   Who did you hear it from? Or where did you hear it?
   Go back, and explore that situation in your mind with as much detail as you can: What was it like?
   How old were you?
   Where are you in the memory?
   Are you in the kitchen, in the bedroom, living room, in class, in the movies, in the park? Are you watching TV?
   Are you alone or with other people—with your parents, family, or friends?
   What are you feeling? Do you remember any particular physical sensations?
   What are you thinking?

A psychotherapist in the training reported: as a child I remember very vividly that I had been scrounging around and found an old carton of pictures. I discovered that my grandmother had lost a sister and family. I felt terrible, having brought it to everybody's memory. And I knew nothing about it at the time. And everybody, of course, was crying and very upset when I brought down this box and said, "Who are all these people?" I was at my grandparents', and I asked them. I assumed the pictures were from Europe. And I asked them. And the result was everybody was crying. . . . I still feel guilty and sad . . .

Five sessions later, when presenting a case, this therapist realized that his difficulties with asking his patients questions were related to this memory. Working through this memory helped locate one source of his difficulty and enabled him to explore patients' issues more freely.

6. **Choices and Beliefs:** Are you making any *choices* about life, about people, about the world, or about yourself at the time? Are you making decisions like the following?
   "Because this happened . . ."
   "This means that life is . . ."
   ". . . that people are . . ."
   ". . . that the world is . . . "

What are you telling yourself? Are you coming to any conclusions? This is very important. Stay with this.

7. **Continuity and Discontinuity of Self:** Think of yourself today; look at the situation. Are you still holding those choices? Do you still believe what you concluded then? Would you say "this is still me" or "this is not me anymore"? What is the difference? What changed and why?
8. **Sharing With Others:** Have you talked with other people about it? Who did you talk to (both in the past and now)?
   What was their reaction?
   What was your reaction to their reaction?
9. **Secrets: Not Sharing With Others:** Is there anything about this that you haven't told anyone, that you decided is not to be talked about, or that is "unspeakable"? Is there any part of it that you feel is totally your secret that you dealt with all alone and kept to yourself? If there is, please put it into words, such as "I haven't shared it because . . ." or "I am very hesitant to share it because . . ."
   Please mention the particular people with whom you won't share it, and why.
10. **Personal Knowledge of Those Who Are Seriously Ill or Facing Death:** Moving to another aspect of the interpersonal realm, do you personally know individuals who are dying or who have died or their family members? Friends, neighbors, or colleagues?
11. **Self Secrets:** There are secrets we keep from others to protect either ourselves or them, and there are self secrets. Take your time. This is very important. Imagine the situation of the very first time you ever heard anything about the event. Roam inside your mind, like taking a slow stroll. Is there anything about it that you have never talked to yourself about, a secret you have kept from yourself? An area that you have sort of pushed away or kept at arm's length from yourself? Or about which you say to yourself, "I can't handle that"? If this is too painful, try to breathe through it. Why is it the one thing that was too much for you? What haven't you put into words yet that is still lurking in that corner of your mind you have not looked into? You can draw it first, and when you are ready, please put it into words.
12. **Personal Relationship to Death:** What is your *personal* relationship to death? Please write the answers because even the way you write makes a difference. Did your place of birth figure in your relationship and your reactions to death? Does your age figure in your relationship to death?
13. **Identity Dimensions:** How do the following dimensions of your identity figure in the choices you made, and influence your relationship to the experience?
   religious
   spiritual
   ethnic
   family
   cultural
   political
   (socioeconomic) class
   racial
   gender
   health

national
international
identity
You can answer these one by one for both then and now. If there is any dimension that makes sense to you that has not been mentioned, please add it.

14. **Professional Relationship to Palliative and End-of-Life Care:** Let us move to your professional self. What is your professional discipline? How long have you been working in it? What is your professional relationship to either the palliative or end-of-life situation on which you chose to focus? Within your professional practice, have you worked with individuals who are seriously ill? Individuals who are dying? How many?
15. **Therapeutic Orientation:** What therapeutic modality did you employ? Emergency or crisis intervention, short- or long-term? Individual, family, and/or group interventions? Was it on an inpatient or outpatient basis? What modality did (or would) you find most useful, and why (for yourself or others)?
16. **Work Other Than in Palliative and End-of-Life Care:** Has working with individuals and families in palliative and near end-of-life situations been the only area of your work? Please list other periods in the life cycle with which you have worked. Reviewing our work every so often is helpful.
17. **Training in Thanatology:** Have you ever been trained to work with patients and families who have experienced serious illness or are dying—in school or on the job? If so, what have you found to be the crucial elements of your training without which you would not feel prepared to do the job? One professional retorted, "Other than my personal experience, I really had to go by the seat of my pants and not by what I was taught in school."

Understanding the Process

Phase One

This process serves both to begin the group and to map out the issues for the group. The sequence of the first phase of processing the countertransference is from the immediate visual imagery through free associations to the more verbal-cognitive material. It then moves to articulate how the particular case or experience fits within the helping professional's experience, her or his personal and interpersonal development, and the gender, racial, ethnic, religious, cultural, and political realms of her or his life. It begins with one's *private* world and proceeds through the context of one's interpersonal life to one's professional work. As one psychotherapist described it:

> You reexperience your feelings through this. It takes you from the picture, being very concrete . . . like the way your experiences at the end of life occur. You are very shocked and numb, shocked at recognizing your own reactions, their depth and intensity . . . and then gradually words, and then not stopping there but go into feelings that you don't think of and don't have time to think of . . . and, like what happens in the retelling, putting things into words, from the impersonal to the inside. But then it pulls you out, to the professional. It lifts you back into reality, so the therapist is not stuck in it.

Participants in group settings have frequently remarked on the feeling of intimacy that permeates the room even though the first phase of the process takes place in silence, perhaps reflecting the sense that it is opening ourselves to ourselves, which allows for intimacy.

Phase Two

The second phase of the process works best in a group setting. This is the sharing and exploring phase. Clinicians are able to explore and comprehend the consequences of their experiences with serious illness, dying, and death that they have experienced directly or indirectly in their lives. The group modality thus serves to counteract their potential sense of isolation and alienation about working with the dying. As one professional helper described it:

> You are invited for a Saturday-night dinner or a picnic by very well-meaning people who want to connect you with other people whom they think you may like, and somebody introduces you as a person working with the ill and dying, and then you are expected to make small talk. It's like being in a crazy warp. And you are expected to entertain people with your work. You feel the same as you feel after the death of a close person: distant. As a result we ourselves devalue small talk because we feel distant, potentially reproaching banter and relief.
>
> I remember feeling like I had a double life. When with friends Saturday night, I didn't dare to say anything. Carrying this burden, becoming deeper and deeper involved, do you have the right to disturb other people? When dealing with dying people, you begin to think of yourself as possibly an irritant to ordinary folk you interact with: family and colleagues. I recall being referred to in my department as "the Angel of Death" and described as "obsessed" and "overreacting," as if the material emanates from within you and you have to be put in a box, like a freak.

A thanatologist who has worked in palliative and end-of-life care since the early 1970s similarly described being ostracized by his colleagues:

> I existed in between different worlds. . . . There were years of loneliness, pain, searching, and self-questioning. However, one thing was clear: I would never again be a traditional academic . . . or clinician. My life had changed forever, and there was no turning back. . . . Among the things that made a difference was a growing affiliation with others doing this work—which was not only reassuring but validated my commitment . . .
>
> The network of colleagues around the country became a kind of family, trusted friends on whom I could call to sort out my feelings and the impact of the work. . . . I now believe that everyone involved in our field has to be profoundly affected by the work because it impacts the souls of helpers.

Elsewhere, I have suggested that groups have been particularly helpful in compensating for countertransference reactions. Whereas a clinician alone may feel unable to contain or provide a "holding environment" (Winnicott, 1965) for his or her patient's feelings, the group as a unit is able to. While any particularly intense interaction invoked by this work may prove too overwhelming to some people present, others invariably come

forth with a variety of helpful "holding" reactions. Thus, the group functions as an ideal absorptive entity for abreaction and catharsis of emotions, especially negative ones that are otherwise experienced as uncontainable (see Krystal, 1988). Finally, the group modality offers a multiplicity of options for expressing, naming, verbalizing, and modulating feelings. It provides a safe place for exploring fantasies, for imagining, "inviting," and taking on the roles and examining their significance in the identity of the participants. Ultimately, the group encourages and demonstrates mutual support and caring, which enhances self-care. These considerations also apply to therapists working in groups.

This training process assumes that the most meaningful way to tap into our emotional hooks and countertransference in palliative care and near the end of life is to let them emerge, in a systematic way, from the unique nature of the helping professional's experience. She or he can thus better recognize and become familiar with her or his reactions to monitor, learn to understand and contain the reactions, and use the experiences preventively and therapeutically. During the sharing phase, when participants describe the process of selecting and drawing the images, they already have put them into words. For example, one helper related the following:

> When you said, "Draw a picture," I had the same reaction as always—that there was nothing that I could put on a piece of paper that could, for me, convey the overwhelm that is what I associate with, like this amorphous, just dark, overwhelm. And there is nothing that I could pick out, except that I, and then as I was sitting here, thinking, the thing that strikes me, of course, is . . . what I later wrote: the faces of death. It wasn't so much the death but the always staring into the face of death, and always knowing that we're not now but are going to be there in the next two minutes, never mind days, weeks, months.

Aspects of Ongoing Group Supervision

Space does not permit describing the richness of what can be learned in ongoing, prolonged group supervision processes nor giving full narrative examples of the crystallization of countertransference reactions through repeated reviews; the interacting tapestries of, among others, event countertransference and person countertransference; the mutual impact of differing adaptational styles to the emotional responses of therapists and patients (Danieli, 1981); or examination of mutual (counter)transferences among members played out in the group dynamics. One important instance of the latter is the attempted expulsion of the supervisor—the person leading the exercise process, who thus becomes the symbolic agent of the "unacceptable feelings"—by or from the group for "victimizing" them and exposing their vulnerabilities by encouraging them to confront or (re)experience the totality of their affective responses.

The exercise may also arouse ambivalence in participants. Claiming an inability to draw and a preference to "only do the words part" is an obvious example of resistance. One clinician attempting to do the exercise process alone stated:

> Even for people who took a seminar, it's very powerful and assumes a degree of training and sophistication. To do it in one clip is very traumatic. It forces you to meet, confront yourself, your feelings and thoughts, with regard to issues you would rather

> not deal with, that you usually won't do on your own. It's better to do it, part by yourself, and discuss it with another person and then continue with the next part. You have to stop because, even though it's worthwhile, it can also be difficult. It's easier and more productive to do it with somebody else because you have to convey a complete thought to another person. When writing it down you may fudge. It's individual. Some people perhaps can be very honest with themselves writing. But since it's powerful and difficult material, you need another person's support. If you fall, somebody will be there to catch you or stabilize you. If you do it individually, do only as much as you can. Patients are entitled to human rather than ideal therapists. It is very powerful. I will do it when I am ready. . . . Even in a workshop you should be flexible and give people choice—group, pairs, individual—and give them the opportunity to decide what is better for them even if they have to do it over 10 times to meet everything.

The exercise process does not aim to replace ongoing supervisory countertransference work. It does aim to provide a sorely needed focus on and experiential multidimensional framework for processing the impact of this deeply touching work on the patient's and therapist's lives.

The exercise process makes poignantly clear the paramount necessity of carefully nurturing, regulating, and ensuring the development of a self-protective, self-healing, and self-soothing way of being as a professional and a full human being. The importance of self-care and self-soothing is acknowledged in the exercise by building into the process instructional elements such as "take your time . . . take all the time you need" and caring, respectful attention to every element explored.

Invariably group members learn about cultures other than their own. They come to finish unfinished business with their patients and with themselves and to explore their wounds, clean the pus, and heal them. They come to seek answers and to find forgiveness, compassion, and ultimately, understanding and camaraderie. They mobilize creative energy and allow themselves to transform as people to be more authentic in their work and more actualized in their personal lives.

Some Principles of Self-Healing

The following principles are designed to help professionals recognize, contain, and heal emotional and countertransference responses in their work in palliative and end-of-life care.

1) To recognize one's reactions:

   - Develop awareness of somatic signals of distress—one's chart of warning signs of potential countertransference reactions, for example, sleeplessness, headaches, and perspiration.
   - Try to find words to accurately name and articulate one's inner experiences and feelings. As Bettelheim (1984) commented, "What cannot be talked about can also not be put to rest; and if it is not, the wounds continue to fester from generation to generation" (p. 166).

2) To contain one's reactions:
    - Identify one's personal level of comfort to build openness, tolerance, and readiness to hear *anything*.
    - Remembering that every emotion has a beginning, a middle, and an end, learn to attenuate one's fear of being overwhelmed by its intensity and try to feel its full life cycle without resorting to defensive countertransference reactions.
3) To heal and grow:
    - Accept that nothing will ever be the same.
    - When one feels wounded, overwhelmed, or burned out, one should take time to accurately diagnose, soothe, and heal before being "emotionally fit" again to continue to work.
    - Seek consultation or further therapy for previously unexplored areas triggered by patients' stories.
    - Any one of the affective reactions (i.e., grief, mourning, or rage) may interact with old, personal experiences that have not been worked through. Thus, when working on and with countertransference reactions, helping professionals will be able to use their professional work purposefully for their own growth.
    - Establish a network of people to create a holding environment (Winnicott, 1965) within which one can share one's thanatology-related work.
    - Therapists should provide themselves with vocational avenues for creative and relaxing self-expression to regenerate energies.

Being kind to oneself and feeling free to have fun and joy is not a frivolity in this field but a necessity without which one cannot fulfill one's professional obligations or one's professional contract.

Concluding Remarks

Countertransference reactions are integral to our work, ubiquitous, and expected. Working through countertransference difficulties is of pivotal importance to optimize and make meaningful the necessary, heretofore pervasively absent, training of professionals in working in palliative and end-of-life care.

In doing this often deeply moving and privileged work, organizational support and understanding is critical. The cultures of organizations must be altered to make staff support an integral part of this work rather than a short-lived afterthought usually following crises.

Ideally, adequate training in thanatology and in the impact of one's self in this work should be a precondition for working with seriously ill and dying patients. Only by genuinely exploring, processing, and integrating the conscious and unconscious components of their own responses and transcending them can professionals be fully prepared to help patients and families experiencing serious illness or the end of life. Only then will clinicians be prepared to be full partners in the process of healing.

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Note

1 Copyright © Yael Danieli, 1993. Portions of this section appeared previously in Danieli, Y. (1993). Countertransference and trauma: Self healing and training issues. In M. B. Williams & J. F. Sommer, Jr. (Eds.), *Handbook of post-traumatic therapy*. Westport, CT: Greenwood/Praeger; Danieli, Y. (1994). Countertransference, trauma and training. In J. P. Wilson & J. Lindy (Eds.), *Countertransference in the treatment of PTSD*. New York: Guilford.

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Part VI

Conclusion

19 The Journey Inside

Examining Countertransference and Its Implications for Practice in Palliative and End-of-Life Care

Renee S. Katz

Introduction

> Countertransference doesn't announce its arrival; it sneaks in and becomes part of the therapeutic relationship. Although it is certainly preferable to catch it before it manifests, we have to expect that we will most often discover countertransference after it has arrived.
>
> (Cozolino, 2004, p. 165)

And so *we* have arrived. In journeying through the contents of this volume, we have witnessed stories of regret, disillusion, and tragedy. Yet these same tales are also stories of commitment and courage, of caring, and of love. These are the everyday stories of helping professionals working to provide compassionate care to patients and families living with serious illness or in the shadow of death.

Taking the time to journey inside ourselves and examine our countertransference gives us an exquisite opportunity to illuminate these stories. If we can allow ourselves our foibles, vulnerabilities, and mistakes, we can use our countertransference responses to inform our work. When we do, our patients benefit, and so do we. We grow in awareness and in the capacity to open to the 'humanness' of this powerful and profound work.

Undoubtedly, the primary lesson to be learned from this discourse on countertransference reactions is that we simply cannot be totally "objective" in our work. This is because we each bring our own personal contributions to the therapeutic relationship. Our life experiences and sociocultural backgrounds, our beliefs and biases, as well as our desires and fears, influence and inform us. And we inevitably experience our patients' feelings and behaviors through the lens of our subjectivity.

Just as the therapeutic relationship is a collaboration between patient and helper, so, too, is countertransference a jointly created phenomenon (Gabbard, 1999; Safran & Kraus, 2014). In much the same way as an improvisational dance is codetermined by both dancers simultaneously, it is not always clear which parts of our countertransference responses come from whom (Coburn, 2001). To accurately understand what belongs to the patient, the helping professional must first examine the contributions of his or her own psychological vulnerabilities. This requires us to relinquish our omnipotent, perfectionistic, "professional" images and, instead, accept our humanity (Beitman, 1983).

Variations on the Countertransference Theme

In sharing their stories and journeys, the authors have highlighted a number of different types of countertransference reactions—each providing equally important indicators of the convergence of our personal and professional selves. These "variations on a countertransference theme" include objective countertransference, subjective countertransference, and diagnostic countertransference.

Objective Countertransference

Objective countertransference, first described by D. W. Winnicott in 1949, refers to the expected, "normative" reactions we have to a patient's presentation, personality, or behavior. Objective countertransference responses are ones in which the helping professional relates to the patient in the same way(s) that anyone else would. For example, certain patients can be so venomous and nasty that anyone with whom they interact, including the professional helper, responds with hateful feelings. This, Winnicott argues, has less to do with the clinician's own issues than it does with the patient.

In Doe and Katz's chapter (Chapter 9) on dying children, for example, the unfairness, heartbreak, and tragedy of childhood death is experienced by the nurses in ways one would expect any individual to respond when faced with such untimely death. In Rynearson, Johnson, and Correa's chapter (Chapter 8) on violent death, the clinician's experience of shock and horror also demonstrates an expected, "objective" countertransference reaction.

Of note: although this type of countertransference has been referred to as objective countertransference, we can never be certain that our responses are *truly* objective. Even with seemingly obvious, universal reactions, each clinician's response is colored by his or her own internal experiences of the patient. In reality, it is never quite clear where our objective reactions leave off and our subjective ones begin.

Subjective Countertransference

Subjective countertransference (Gorkin, 1987; Wilson & Lindy, 1994) refers to countertransference that is evoked because of the clinician's personal issues, conflicts, history, and experiences. Florence Joseph (1962, p. 34) succinctly describes her subjective countertransference with a dying patient:

> I have more than a suspicion that in my treatment of Alice, despite the sacrifice involved, I was deriving a great deal of gratification. In my own family constellation, as the youngest child in a large group, I grew up feeling that I lacked a responsible role in matters of importance. I had often fantasized being chosen by my parents, my teachers, and my friends as a leader whom others followed with trust and confidence. During Alice's last months, in her time of need, I was, I am certain, the most important person in her life.

In Wendleton, Bowman, Johnson, and Katz's chapter (Chapter 3) on spirituality in palliative and end-of-life care, Reverend Wendleton describes how his early needs to be

a "good boy" were unknowingly reenacted in his need to prove himself to the health-care team and families with whom he worked. In a similar vein, Joanna, in ten Tusscher's chapter (Chapter 4) on parallel process, finds herself 'turning away' emotionally from her patient, Derek, because the severity of his medical decline unconsciously evoked her own, unprocessed terror and grief over her grandmother's failed health.

Indeed, when subjective countertransference is triggered, clinicians may respond in ways that gratify their needs to rescue and be needed or in ways that alleviate their own anxiety or guilt. They may also respond in ways that soothe their own suffering or emotional pain.

Diagnostic Countertransference

Patrick Casement (2002) coined the term "diagnostic countertransference" to describe countertransference responses that give us important clues about our patients' dynamics. Often, when patients experience emotions that feel unbearable or unspeakable, they may try to communicate them to us "by impact" (Casement, 2002). That is, they may stir up feelings in the helper that cannot be communicated in words.

Casement notes that we often are subjected to the unspoken cries of those with whom we work. It is at those times that we must, despite the confusion and pain evoked in us, persevere in our mission to understand because, eventually, the unconscious purpose of those pressures will become apparent. In this sense, countertransference is viewed as an important instrument of research into the patient's unconscious. When we "get" the unconscious purpose of the patient's communication, we can understand them more fully. Further, when the patient feels that someone truly understands and can *tolerate* their most difficult feelings, the therapeutic alliance is strengthened, allowing us to venture more deeply into the work.

I will never forget an experience I had involving a patient's "communication by impact" to me:

> We had just ended a post-mastectomy support group session in which Eileen had usurped much of the group time with lighthearted, distracting chitchat. The other group members were clearly irritated, so I had gently encouraged her to "share the floor." Eileen seemed to take the feedback well, and after the session, my co-therapist and I smugly made a mental note.
>
> When I awoke the next morning, I found that my voice mail had recorded three messages at 4:15 a.m.! I listened carefully, and with each new message, my heart sank, and my body shook with terror and alarm. In the messages, Eileen venomously accused me of "telling on her" to the department head after group, of purposely ignoring and labeling her in a derogatory manner during the session, of being pompous in not consulting her regarding a group topic, which given her profession, she knew significantly more about than any person there. The assault went on and on, and I was shaken to the core.
>
> I found myself rehearsing conversations in my mind in which I defended myself and pointed out all the inaccuracies of her accusations. I called my co-therapist to ask if I truly had been so oblivious.

> All that morning I could not stop the shell-shocked feeling, and upon leaving the house, I had a small car accident. "What the heck is going on?" I asked myself. I felt as if I had PTSD.
>
> And indeed I had! It finally dawned on me that *this*, in fact, was what Eileen was experiencing under all that light chitchat. The mastectomy had left her feeling traumatized and attacked. *She* was walking through her own hellacious war zone, and now, I was in it! *This* was the true meaning of her communication—and she had an urgent, unconscious need to get this across to me.
>
> Unbeknownst to her, Eileen had tapped into one of my own areas of emotional vulnerability: my mother had survived a catastrophic war experience. It was all too familiar.

Melanie Klein (1946/1975) calls this kind of affective communication "projective identification." In her view, the patient exerts interpersonal pressure, coercing the clinician into experiencing the patient's own intolerable affects (Gabbard, 1999). It is this very dynamic that Kelly and Varghese so eloquently describe in their vignette in Chapter 12 about the clinician who dreams that he's pushed his client off a cliff—only to discover her attempted suicide the next morning.

These varying types of countertransference responses remind us that countertransference feelings may be raw, intense, disturbing, and very much within our conscious perceptions. They may also be subtle, insidious, and completely outside of our awareness.

Developing Awareness Through Personal Exploration

Countertransference is always specific to the psyches and unique personalities of the two individuals involved in the therapeutic relationship. Although each mutually influences the other, as practitioners, we bear "the crucial responsibility for containing and maintaining the [professional] boundaries and frame of the work" (Wishnie, 2005, p. 15). We must be both participant and observer, allowing ourselves to be drawn into the patient's experience while simultaneously remaining sufficiently separate, so we can monitor and more objectively understand what is happening (Havens, 1976; Sullivan, 1953). This is easier said than done. Where do we begin?

Acknowledging professional fallibility and accepting our personal vulnerabilities and limitations are critical. Identifying situations that "hook" us and recognizing feelings we have been trained *not* to have are difficult tasks but imperative ones. Thus, Socrates's early injunction to "know thyself" is pertinent. To begin to detect the subtle ways in which our personal issues may be affecting our therapeutic interventions, we must first start with ourselves.

First, we must accept that it is normal, in fact universal, to have strong feelings and reactions in this work. Second, we must take time to reflect on the personal underpinnings of the journey that has brought us to this work. Because our relationships with parents, siblings, partners, and grandparents shape our attitudes and coping styles (Weiner, 1989) as well as our self-concepts and biases (Genevay & Katz, 1990), we must be willing to examine the ways in which we inevitably bring these relationship histories,

perceptions, defenses, and personality styles into our professional roles. We can begin reflecting on our personal-professional journeys by asking ourselves these questions:

- When did I first become interested in working in palliative and end-of-life care? Were there any particular individuals or experiences that stimulated or influenced this interest?
- To which aspects of this work was I particularly drawn? Why?
- How did I envision myself in this work?
- As I look back now, what insights do I have about what motivated me? Family experiences? Ways I felt about myself as a child, including my role(s) in the family? Early or more recent experiences and messages I received about separation, dying, illness, and disability?
- To which questions might I be seeking answers?
- What are the most interesting parts of my job? The most rewarding? The most frustrating?
- What do I experience in ending with my patients and their families? How does an ending due to death feel as compared with an ending for any other reason?
- How did my early family experiences shape who I am now and my choice of profession?
- How would I characterize my relationships with each of my family members?
- How were emotions handled in my family? How was conflict handled?
- To what extent were feelings of guilt, shame, and depression present?
- What biases, religious convictions, ethics, and values existed in my family of origin? Which of these do I carry with me today?
- What do I consider to be the nodal experiences of my life?
- What are my current, significant relationships like? Which parts of these relationships are most rewarding? Most frustrating?
- What current personal, familial, or social stressors am I experiencing? Have I experienced, or do I anticipate, any losses or endings, in my personal life?
- About which parts of my personal life do I feel the most passionate? From which parts of my personal life do I draw support and sustenance?

Conducting a personal inventory of this nature will help us to develop an awareness of our personal vulnerabilities, including those individuals and situations that are most likely to push our buttons or "hook" us emotionally.

When we are in the work environment, we must regularly journey inside ourselves to scrutinize our potential contributions to issues that arise in our patient care. Three specific lines of questioning are helpful:

> First: *Am I behaving in some way that indicates that a personal-professional trigger point has been activated within me?*
>
> For instance, am I experiencing any of the following:
>
> - Forgetting or arriving late to appointments?
> - Losing patience?
> - Feeling sleepy or bored during patient contact?

- Frequently changing the subject, distracting the patient, or "filling in" the silences?
- Intervening beyond the call of duty (over helping)?
- Intervening much less than is usual (under helping) or withdrawing completely?
- Attempting to persuade or "bulldoze" my point of view?
- Arguing with a patient or family?
- Avoiding a particular client or family?
- Glossing over or avoiding particular topics or issues?
- Having the impulse to fake sympathy?
- Falsely reassuring a patient or family about their concerns?
- Comparing tragedies?
- Attempting to go for a "quick fix" (and avoid important process issues)?
- Looking for ways to transfer a patient?
- Wishing a patient or family would disappear or seek services elsewhere?
- "Tuning out" or doing mental errands while with the patient or family?
- Making condescending remarks about the patient or family to other professionals?
- Feeling pushed to "cure" or "fix" a patient—especially when she or he is incurable?
- Bringing home intense feelings or frequent thoughts about the patient or family?
- Labeling clients (e.g., "difficult," "noncompliant," "resistant")?
- Making unnecessary home visits or hospital visits?
- Promising more than I can deliver?
- Minimizing the patient's or family's concerns?
- Suggesting concrete, pragmatic "solutions" to fix emotional problems?
- Experiencing an urge to self-disclose?
- Experiencing an urge to reassure?
- Feeling a need to defend my interventions?
- Repeatedly forgetting my patient's name?

[Adapted with permission from Katz, R., & Genevay, B. (2002). Our patients, our families, ourselves: The impact of the professional's emotional responses on end-of-life care. *American Behavioral Scientist*, *46*(3): 327–339.]

Second: *If I am honest with myself, what feelings are being evoked in me? Which of these feelings are most intense? Most disturbing?*

(See Countertransference Tool Box: Feeling Self-Reflection Survey.)

Third: *If I feel that my countertransference has been triggered, can I utilize the following self-awareness questions to shed light on the dynamics?*

- What particular meaning does this patient or this family hold for me?
- When I think of this patient or family, how do I feel? (Think especially of any uncomfortable feelings or reactions that are unusual for you; consider your responses in the Feeling Self-Reflection Tool Box).

- What were my initial reactions to this patient or family?
- What is it about this patient or family that is hooking me or pushing my buttons? Is it a specific feature? Behavior? Word(s)?
- When I am with this patient or family, what do I find myself doing? (Note any behaviors, activities, and thoughts that are uncomfortable or unusual for you, as in Question 1.)
- In what areas do I feel "stuck," need support, need to ventilate, and/or feel I'm not progressing?
- What personal experiences with serious illness, disability, trauma, grief, loss, or dying (past and present) may be dovetailing with my work at this time?
- What is going on inside this patient or family? Are these same feelings being induced in me? Is the patient or family trying to "reach" me in some way? Why? And why now?
- Are the responses of the patient or family triggering something in me that resonates with other people or situations in my life? If yes, are these parallel issues occurring in my life or in my family members' lives now, or are these issues that I have experienced in the past that are reminiscent of this patient or family unit?
- At which developmental stage of my life do I feel when I am with this patient or family?
- What role am I playing in this particular relationship?
- Where on the continuum of over-involvement versus disengagement am I?
- Am I giving too much of myself to my job? If yes, are my obligations real or self-imposed?
- Can I use my feelings and responses to better understand something about this patient or this family?

[Adapted with permission from Katz, R., & Genevay, B. (2002). Our patients, our families, ourselves: The impact of the professional's emotional responses on end-of-life care. *American Behavioral Scientist*, *46*(3): 327–339.]

And fourth: *Can I identify any organizational, systemic, or social forces influencing my personal-professional responses to this situation?*

When we ask ourselves this question of environmental influence, we can utilize the Triangles of Countertransference diagram along with the Potentiates of Countertransference included in the Countertransference Tool Boxes at the end of this chapter. First we examine the potential sources of countertransference (patient-family, professional-clinician, or organization-system); then we ask ourselves what types of countertransference responses are being elicited (objective, subjective, or diagnostic). We utilize all three avenues of inquiry to help us uncover, examine, and then determine how to best utilize our insights on behalf of our patients, their families, and ourselves.

Our ability to "climb into" our patients' worlds provides us opportunities for both empathy and understanding. At the same time, if we are to truly manage and contain our countertransference responses, we must make it routine practice to examine and understand our personal-professional reactions along with the potential influence of the systems and

organizations in which we work. Using the exercises in this chapter, along with the Countertransference Tool Boxes at the end of this chapter, can provide us with a vehicle for our own "internal supervision" (Casement, 2002). We can then turn to our "internal supervisor" to help us (a) move freely between different ways of considering the patient-helper interaction; (b) observe "live" what is happening in our interactions so that we can reflect on the relationship dynamics, its meanings, and its possibilities; and (c) monitor our own contributions so that we can distinguish what belongs to us, what belongs to the patient, and what these responses might indicate about our interactions (Casement, 2002). The object is not to eliminate countertransference but to follow and understand it so that we can more deeply know our patients without acting out our own issues.

Developing Awareness Through Training, Supervision, and Personal Psychotherapy

Working with our countertransference takes courage. It takes willingness to admit to mistakes we've made and to face things we'd rather avoid—painful memories, hurt and buried feelings, and the unknown, perhaps terrifying terrain of our work. We simply cannot do this work alone. The need for ongoing clinical support and supervision is not to be underestimated. Separate from our own self-scrutiny, it is often our personal therapists, our peers, our trusted colleagues, and supervisors who can identify areas in which we've become hooked. Not even the most experienced clinician is without his or her blind spots and vulnerabilities. Thus, not even the most experienced among us should be working without this safety net.

When should we consider individual psychotherapy and/or additional professional consultation? If, after utilizing the lines of questioning delineated earlier in this chapter, we continue to have difficulties unraveling our countertransference, identifying the basis for it, or "unhooking" from it, we must seriously consider additional assistance. Tables 19.1 and 19.2 provide additional considerations for determining if our unconscious processes are impacting our work.

Short of individual therapy and consultation, professional training is essential. The most effective training allows professionals to consider and connect their own fears of dying, illness, and disability with issues of loss in their families of origin and with their current beliefs about aging, grieving, and resolution of family issues. Training that promotes (a) confrontation of personal and professional fears of failure, (b) analysis of needs for control in the face of loss, (c) facilitation of unresolved grief work, and (d) clarification of beliefs about professional competency and responsibility is key.

Professional training is most beneficial when it combines didactic information with values clarification tasks, exercises to identify personal "risk factors," role plays and practice, demonstrations of approaches to use with patients and families, as well as examples of approaches that are *not* helpful (Genevay & Katz, 1990). The training setting affords the helper a safe environment in which to acknowledge professional fallibilities and limitations. This opportunity alone provides essential modeling and practice for the helping professional. Professional training experiences can be therapeutic for the clinician, offering, for instance, insights and confidence with which to admit to patients and families that there are often no answers to life's deepest and most disturbing questions. This admission in itself is often healing to patients and families who may feel alone with their existential crises and feelings of inadequacy (Katz & Genevay, 1987).

Table 19.1 Consider Additional Professional Consultation If:

- You find you have the impulse to talk to "everyone" about your patient or family.
- You are feeling burned out or less satisfied with your work, or are having thoughts of leaving your profession, or are beginning to question your professional competency.
- You find yourself relishing the role of expert and/or doing a lot of advice giving.
- You are not sure whether an issue has a professional or personal basis or solution.
- You find yourself giving rote or pat answers, delivering a standardized monologue, or relating to patients in "fixed" ways.
- You find that you're treating your patients as 'cases' or 'problems,' sometimes indicated by your referring to them by their diagnoses rather than by their names (e.g., "the total mastectomy in Room 1212").
- Your patients complain about you, or suddenly several patients or team members decide they no longer need your services.
- The line between morals and ethics seems blurred such that you cannot easily delineate between a personal value and the appropriate treatment intervention.
- Colleagues express concern about "how you're doing" at work.

Table 19.2 Consider Pursuing or Returning to Individual Therapy If:

- Your countertransference potential has too many unresolved areas.
- You find yourself "taking patients home" with you, are dreaming about them, or are otherwise preoccupied with them.
- You or someone in your family or friendship circle experiences a recent, major loss or serious, possibly life-threatening illness, death, or near-death experience—or any time your personal and professional lives converge.
- Your work with a particular patient or family evokes a strong or new traumatic memory or opens the wounds of incompletely mourned losses.
- You find yourself feeling indispensable or feeling unusual amounts of resentment, blame, guilt, hopelessness, rage, cynicism, or feelings of failure.
- Your colleagues suggest that you are "not yourself" and wonder if you are getting enough "support."
- Even after professional consultation you cannot seem to "unhook" from your countertransference responses and/or find yourself acting them out.
- Your consultant suggests that personal psychotherapy would be helpful.

Conclusion

Professionals working in palliative and end-of-life care are regularly confronted with the fragility of life and the inevitability of death. We may unknowingly react to patient and family issues in ways that reflect our own biases, emotions, and life experiences—past, present, and anticipated future. When we do so, our professional objectivity is diminished; we risk compromising our abilities to provide accurate diagnosis, appropriate treatment, and compassionate care (Katz & Genevay, 2002).

This book has attempted to address our emotional responses and countertransference feelings in palliative and end-of-life care so that we can help our patients face serious illness, dying, and death with honesty and integrity, with compassion and care. The authors have named their most common countertransference reactions: anger and resentment; inadequacy and failure; powerlessness and lack of control; frustration and guilt; sadness and grief; fears of trauma, emotional pain, loss, dependency, and death; and desires to be needed, loved, and admired. If we ignore, defend against, or distance ourselves from

these emotional reactions, we run the risk of "helping" our patients back into the very problem areas for which they have consulted us (Katz & Genevay, 1987). In addition, we run the risk of "helping" *ourselves* into the trajectory of compassion fatigue and burnout.

Awareness of countertransference responses holds enormous potential. If we can squarely face our feelings and accept responsibility for the ways in which they may contribute to our patient-professional interactions, not only do we help our patients, but we also benefit: we grow in awareness and in our capacities to become more effective health-care providers. We can use the information we have gathered as an empathic bridge to a truly compassionate and therapeutic connection. In so doing, we grow both personally and professionally: we become more insightful, more resilient, and more fully committed individuals and professionals.

It is through this personal-professional connection that we can understand the richness of our patients' experiences. If we have erred, we can make corrections. If we are "picking up" our patients' unprocessed dynamics and emotions, then we have been given an invaluable opportunity to truly communicate our "humanness," our capacity for attachment, and our relatedness in this complex and deeply personal journey.

COUNTERTRANSFERENCE TOOL BOX:

Feeling Self-Reflection Survey

Renee S. Katz

Circle each feeling you are experiencing. Rate each feeling by intensity (1 = mild; 5 = intense), then examine these in light of the third set of questions.

Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Angry	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Defensive	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Manipulated	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Taken advantage of	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Inadequate	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Exhausted	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Dead	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Impatient	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Afraid	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Sad	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Tense	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Helpless	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Numb	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Like a failure	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Like a hero or savior	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Irritated or frustrated	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Disgusted	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Useless	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Resentful	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Out of control	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Disillusioned	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Inept	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Desperate	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Stuck	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Burdened	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Confused	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Intimidated	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Ineffective	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Irrelevant	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Guilty	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Bereft	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Overwhelmed	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Ashamed	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Responsible	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Infallible	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Protective	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Special	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Needy	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Sexy	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Compassion	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Affection or love	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Warmth	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Feeling Evoked in Me	*By the Patient*	*By the Family*	*By the Organization*
Hopeful or optimistic	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Enthralled	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Smug	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Grateful	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Proud	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Stimulated	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Fascinated	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Entertained	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

Adapted with permission from Katz, R., & Genevay, B. (2002). Our patients, our families, ourselves: The impact of the professional's emotional responses on end-of-life care. *American Behavioral Scientist*, *46*(3): 327–339.

COUNTERTRANSFERENCE TOOL BOX:

Triangles of Countertransference

Renee S. Katz

Instructions: When you find yourself in a situation in which you are "hooked," utilize these Triangles of Countertransference to try to discern the dynamics at play.

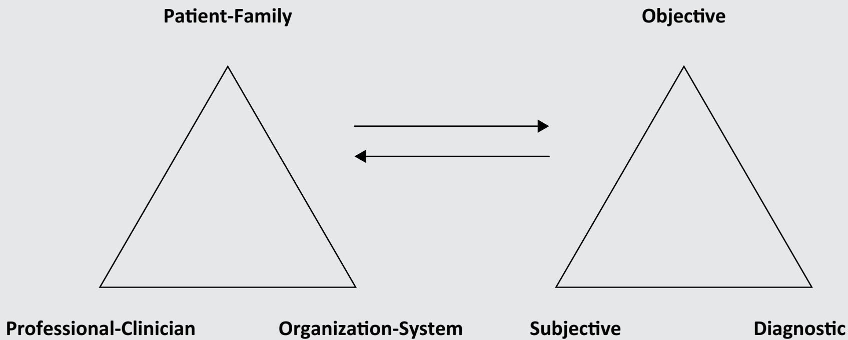
First identify the sources, origins, and "players" in your countertransference arousal utilizing the Potentiates of Countertransference Tool (next tool box). Is your countertransference response being potentiated by issues in the patient or family? In the organization? In yourself? Note these on the triangle on the left.

Next, determine whether the reactions being elicited in you are subjective, objective, or diagnostic (see earlier in this chapter for more information on each of these types of countertransference).

Note these on the triangle on the right.

Process any insights with a trusted colleague, consultant, or supervisor, if possible.

More will likely be revealed!



COUNTERTRANSFERENCE TOOL BOX:

Potentiates of Countertransference

Personal Factors in the Helping Professional:

- Personal beliefs, values, spiritual beliefs, and ideological systems
- Preconceptions and assumptions
- Life experience: current, past, and anticipated
- Personal family dynamics
- Cultural experiences and differences

(*Continued*)

- Degree of training and experience with this population or diagnosis
- Underlying motivation for working in this field
- Theoretical framework or lens
- Personality style
- Personal coping styles and primary defenses
- Multiple losses, stressors, and traumatic events: past, present, and anticipated
- Personal health status of the provider
- Self-care or lack thereof
- Degree of social connection or isolation
- Stage of the life cycle
- Presence and degree of moral distress

Specific Factors in the Patient:

- Who the person "is"
- Nature of the attachment
- Life stage
- Length and trajectory of the illness or dying
- Perception that the pain, suffering, or death is or was preventable
- Sense of injustice or unfairness about the illness or death
- Diagnosis or prognosis or what is or isn't known
- Conflicts with family or difficult family members
- Level of acceptance versus denial
- Resilience
- Multiple psychosocial, health, or emotional problems
- Availability or limitations of resources
- Degree of suffering or trauma
- Degree of trust in the provider
- Personal spiritual connection or lack thereof

Institutional or Organizational Factors:

- Inadequate resources—personnel or funding
- Inadequate or inconsistent training or supervision
- Lack of support (at macro and micro levels)
- Political factors in the organization or team
- Rigidity versus flexibility regarding change in existing organizational structures
- Support and stewardship of teams and individual professionals
- High acuity
- High caseloads
- Stigma versus acceptance of employees who acknowledge distress
- Disenfranchised grief
- Role blurring
- Turf wars
- Role and safety of whistle-blowers
- Conflict in values, mission, or policies

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Part VII

Epilogue

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20 Living Every Minute

Stu Farber

During Halloween 2013, I went to the emergency room with chest pain and shortness of breath. Thus began our odyssey with acute myelogenous leukemia (AML). I say "our" because this journey has emphasized how I live within a network of relationships that includes self, family, community, and colleagues. If I have learned nothing else, it is my interdependence with others that provides love, joy, and peace in my life. Much to my surprise, I chose to undergo eight months of aggressive chemotherapy and at the time was in "cytologic remission." As of January 2015, this is no longer true as my leukemia has relapsed. I have a 24.5 percent chance to be alive in five years or, conversely, a 75.5 percent chance of dying any time before. Of course the reality is I will either be 100 percent alive or 100 percent dead, and no one knows what will happen in advance, which is true not only for me but for everyone.

Four months into our journey, Annalu, my wife and caregiver, also was diagnosed with AML. She chose to undergo the same aggressive chemotherapy. So for four months we were both patients and caregivers simultaneously. It is impossible for us to adequately express our gratitude to the family and friends who swooped in to support us during that "twilight zone" time. Annalu was initially in remission but has since relapsed and is receiving palliative treatments. The reality is that my beloved wife will die within the next year.

I am now her main caregiver and expect to survive her, although one can't be sure. We have learned to live with uncertainty. As her caregiver, we both experience the vicissitudes of her illness, and I witness my own future. We awaken each day expecting the best, accommodating to whatever happens, and to the best of our ability, avoiding the worst. It's no surprise to us: physical suffering is the foundation of the worst, but medicalization of our lives is a close second.

This article is an effort to share what I have learned over the past year both personally and professionally. In this effort, I use poetry to express complicated and often ineffable lessons I have experienced, often at the deepest levels of my being. When you read, I encourage you to reflect on those lines that speak directly to your heart. Explore what is within you that connects strongly to these poems and to my comments. These are the lessons I wish to leave you with.

Two Worlds

My heart is full of good intentions.
I want to help using all I know.
I know a lot you don't know about

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diagnosis, treatment, risks, benefits, statistics.
How can I assure you know enough,
so you can make the right choices?
I protect my heart so I am safe
from making choices,
from sharing your life.

My heart is full of life.
I know a lot you don't know about
love, hope, grief, fear, illness, mortality.
How can I help you know enough about who I am,
so you can help me make the right choices?
So we can share our knowledge and our lives?
~Stuart Farber

The fundamental lesson I have learned as a professional patient is that clinicians and patients and their families inhabit two entirely different worlds. Unfortunately, the medical world is the one that holds dominion. The surging currents of medicine sweep everyone down a river rushing toward life-prolonging treatment as inevitably as the tides follow the moon. The fallacy that I am an autonomous individual who can and should make treatment decisions based on the medical facts provided by my clinicians continues to confront Annalu and I at every medical crisis point. Discussions focus on treatments to prolong life and make invisible the very life we are living. This medical model protects clinicians from having to make tough decisions and having to engage with their patients and families on an intensely personal level.

As I sat in my hospital bed following my second round of intensive consolidation chemo and seven days of neutropenic fever, the infectious disease (ID) attending shared that I likely had a viral infection that my returning white count should take care of. However, there was a small chance I had PCP pneumonia, and if that was the case, then without treatment I would die. The best way to be certain I didn't have the lethal PCP pneumonia was to have a bronchoscopy. He then asked me, "What do you want to do?" I smiled to myself as I considered his question. First, I was in no shape to decide much of anything given how muddled my mind was by both sickness and grief. But the answer arose from within my inner self: "I don't want to do anything that would make me feel worse. I feel a bit better now than when I came into the hospital. I want to wait and see if I continue to improve. There is a very small chance I have PCP pneumonia and a very large chance I have a virus that will get better. If I'm wrong, I am at peace with the consequences, including death." Much to my surprise the ID attending said, "That is the same choice I would make." I was dumbfounded. Every word he shared led me to think he wanted to do a bronchoscopy. I am convinced that almost every patient who participated in the same discussion would opt for a bronchoscopy. How can this be? It is craziness. Yet it is repeatedly our experience. How to integrate these two worlds into one shared world is the critical challenge.

So what have I learned from my new friend leukemia? Personally, I always knew that I was going to die. I just didn't believe it. Now I get it to my core. I am mortal. Knowing I am mortal is a sacred knowledge that makes each moment an awesome gift filled with opportunity for love, joy, and peace. It has transformed how I live my life. If I know I am

mortal, then what is important? It's sharing love and joy within my relationships: with myself, my wife, my family, my grandchildren, my friends, my colleagues, and the community in this very moment we are living.

Professionally, I understand in a deeper way that death is not a medical event. It is a central life cycle event that we will all successfully complete, no matter how much medical care we get or don't get or how healthfully we live or don't live our lives. Death is a process to be lived, not a problem to be solved. Yet literally every clinician Annalu and I have interacted with is more afraid of death than we are; they focus on solving the problems of our illness with little awareness of how we want to live our lives. It is a paradox. The clinician is focusing on "treating" the illness that threatens life, but the "life" of the person who is ill is invisible. It is critical for clinicians to embrace death as a normal part of life, so they can accompany and guide the patients and families they serve through the sacred process of living until death.

The Way It Is

> There's a thread you follow. It goes among
> things that change. But it doesn't change.
> People wonder about what you are pursuing.
> You have to explain about the thread.
> But it is hard for others to see.
> While you hold it, you can't get lost.
> Tragedies happen; people get hurt
> or die; and you suffer and get old.
> Nothing you do can stop time's unfolding.
> You don't ever let go of the thread.
> ~William Stafford

Our experience has starkly taught me just how disconnected my clinicians are from having a curiosity about my thread. There is comfort residing in the abstractions of the biomedical model. My story becomes one of diagnosis (AML), prognosis (bad), and treatment plan (chemo protocol). All this information fits nicely on the Excel spreadsheet that defines my medical story. Why talk with me or even examine my body carefully when the computed tomography (CT) scan or bone marrow biopsy provides better answers for my treatment? With rare exceptions, the clinicians who have treated me have good hearts, and care deeply, but possess little or no knowledge of my thread. My thread is the narrative I use to make sense of my life. It is longitudinal, nonlinear, emotional, and filled with contradictions, and it integrates my life experiences into a coherent whole. It is within the values and meanings of my story that treatment decisions are made. What contributes to meaning and quality is not about living longer but living a life that is consistent with my thread. Without knowing my thread, it is impossible for a clinician to provide respectful care.

To the handful of clinicians who were patient centered (i.e., understood my medical goals), I am eternally grateful. To the four clinicians who understood my thread, I cannot express the depth of my appreciation. This gap existed with every discipline and left me feeling that while well meaning, most providers are mostly nuisances and at times major annoyances in my daily life. Palliative care is a work-around, not a solution. Radical

system change is needed that includes a fundamentally new alliance among patients, families, and professionals.

It is a false choice asking me to choose between life and death, certainty and uncertainty, or hope and fear. The reality is that all these things are happening simultaneously. I have AML that will shorten my life (certainty), but how it will shorten my life is unknown (uncertainty). I know specific consequences of choosing certain medical treatments such as doctor appointments, side effects, and length of treatment time (certainty), but I don't know how the benefits or burdens of these treatments will manifest (uncertainty). My life remains full of hope, joy, and love while simultaneously filled with fear, sadness, and grief. Living in paradox is not a strength of my medical providers. They strive for the clarity and safety the biomedical model provides. Focusing on precision (i.e., the process of limiting uncertainty) to provide the hoped-for hope of extending life leaves everyone unprepared for diminishment, resulting in immense suffering for all.

Annalu and I have found living in paradox allows us to expect the best (sometimes a stretch given my palliative care background), be prepared for how to live if the best doesn't happen, and clearly define the worst, so we can avoid it. Openly discussing the worst has not made it happen but rather the contrary: it has helped us avoid treatments that are inconsistent with our threads. It also has led to difficult discussions for our providers who were stretched to continually prepare for all outcomes (including the worst) throughout our illness. Overall, it has greatly relieved everyone's distress in our uncertain situation.

Ira Byock talks about human beings and human doings. One of the most cherished gifts of my illness is to be "between act and act . . . simply be . . . wonder who I am." In reflection, I more deeply appreciate that as a physician, I was taught to act and defined my worth by my actions. I treasure times of simply "being present" with others in a new way. I also am aware how rare it is for clinicians to simply "be" with me and how "bound" they are to action.

Loss and grief have been inseparable companions for Annalu and me during this past year. Our grief is the natural response to the many losses we have experienced. Grief is neither a problem to be solved nor a disease to be cured. It is a process to be experienced and supported that has added richness and meaning to my life that I did not know were possible. Once again, grief has been one of the many paradoxes that have leavened my life. As a patient, I have been amazed at the distance my providers keep from my grief and, when it is touched, how quickly they are "bound" to "fixing" it. Most of my clinicians are so busy protecting themselves that "being with me" is not possible. The lack of acknowledgment and support of my grief is a profound personal and professional lesson for me.

One of the most meaningful lessons I have learned in the past year is the power of legacy. When I was first diagnosed, I was filled with an anxiety that was physically palpable. Reflecting on my feelings, I realized the major cause of my anxiety was a fear of not being able to share with my family and community how much I love them and what I value in our relationships. It was devastating to imagine all our mutual loving and caring would be lost and forgotten. Over the next frenzied week, I wrote letters to my wife, sons, and grandchildren sharing my love, acknowledging their gifts, and describing my hopes for them. I am an amateur guitar player and singer and recorded songs for them to play at my wake. At the end of that week, my anxiety was greatly calmed. I have continued to

create my legacy in many ways and have found it to be rewarding. I am both sharing the love and wisdom I want with those I care about most to remember as well as opening myself up to provide to them the gifts they want from me. This is something I should have been doing all my life and not as I sit on the brink of mortality.

Creating legacy has left me with a profound sense of completion. The wisdom and caring I have garnered in my life will continue to live in the hearts and spirits of those I love. While I may be physically absent, my legacy will be living actively in relationship to those I care about most. It is my form of mindful immortality. It is the reason I am sharing these words with you, my palliative care community.

Professionally it has deepened my understanding of how important legacy creation is for patients, families, and communities. This hard and rewarding work is difficult to engage. Yet it is deeply rewarding for those who do it and their families. Finding ways to engage patients and families in creating legacy is a sacred opportunity for clinicians. Professionals aren't doing the work but are inviting patients and families into a safe environment where such deeply human connections can be explored and expressed.

Late Fragment

> And did you get what
> you wanted from this life, even so?
> I did.
> And what did you want?
> To call myself beloved, to feel myself
> beloved on the earth.
> ~Raymond Carver

As I gaze into mortality, love sits in the center of my consciousness. Love is the inspiration that creates my courage to move forward as a caregiver to my wife, a patient receiving care, a father accepting support from my children, and a human simultaneously living and inevitably dying in the miracle of this world. As I sit with my medical caregivers, I see fear of failure at the center of their consciousness, with death being the ultimate defeat. These professionals actively, albeit unconsciously, convey that living longer is always preferable to dying, but they fail to appreciate that the most important act is to support living in harmony with a narrative thread. It is another of the many paradoxes that I live within. I leave my insights as a legacy for others to reflect upon and use as they see fit for the benefit of themselves and all those they touch.

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