

ETHICAL
PRACTICE
IN GRIEF
COUNSELING

LOUIS A. GAMINO
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Ethical Practice in Grief Counseling

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Foreword

When I began my practice in clinical psychology in 1968, my annual professional liability insurance was \$70. Forty years later, it has escalated to 30 times that amount, *with annual increases*. Some of this increase is the result of inflation and the rising cost of health care. Some of the increase is the result of society's litigious bent. Some reflects the increasing technology used in the field of mental health. Counseling over the Internet was nonexistent 40 years ago because there was no Internet. In this book, Louis Gamino and Hal Ritter present the whole gamut of areas where thanatologists and grief counselors may face ethical dilemmas and concerns, many of which they may not have thought of before now.

One complex area where ethics intersects thanatological practice is the "right to die." Giving dying persons a choice in their final months of life has been an important discussion over the past 4 decades. Some years ago, I worked with the Concern for Dying group in New York where we crafted a living will. This document and other advanced directives have given dying patients much more autonomy over end-of-life choices. However, as medical technology develops, some of these choices are not as clear-cut as some would want us to believe. The emergence of hospice during this same time period, with its focus on palliative care, makes some of these choices clearer and easier to manage.

Another area of ethical controversy in thanatology is physician-assisted suicide. I served as a consultant to the American Psychological Association when it tried to come up with a formal position on this issue. Discussions in this area can obviously generate a lot of heat. Because depression and pain management can be factors in the choice to die, patients may change their minds, making this a very murky area. I remember consulting with the staff at Massachusetts General Hospital when an elderly man repeatedly shouted that he did not want his gangrenous leg removed. He wanted to die. During my suicide evaluation of him, he told me the same thing. Ultimately, his leg was removed. When

I spoke with him later, he denied saying that he wanted to die and was very happy to be alive.

Gamino and Ritter make the case that grief counselors and those working with patients and families in end-of-life care need to explore their own mortality before letting this affect their ethical decisions. I couldn't agree more. Back in the early 1970s, many physicians were not doing a stellar job with end-of-life care because they saw the death of a patient as a failure. Unfortunately, many physicians still operate with that mindset. Dr. Ned Cassem and I created an elective course for second-year medical students at Harvard where students could meet with dying patients and their families and hone their skills for working with this population. An important objective of this course was to help these students explore their own mortality—how it might influence their motivation for entering medicine and how it might affect their work with dying patients. The class was well attended and I later published the exercises in a book, *Personal Death Awareness* (1976). A related area of ethical concern is grief counselors who have not worked through a loss in their own life, which can cloud their judgment when working with bereaved clients. Thanatologists, death educators, and grief counselors are well advised to consider whether they have the requisite “death competence” described by Gamino and Ritter that is so crucial when working with the dying and the bereaved.

With the increase in disasters, both man-made and natural, there is a tendency for grief counselors to want to rush in and help. However well-intended their motivation, without adequate training all kinds of ethical problems can emerge. I had just moved from Boston to California when a commercial jet collided with a smaller plane, killing all on board and raining debris on one particular community. I decided that I needed to help with this disaster and just showed up on the scene. I was an experienced grief counselor trained in stress debriefing, but I was not part of a formal response team. This limited my helpfulness and opened me to possible ethical violations. I recognized this and soon exited. I took home one important lesson about disasters—know the community where you are trying to work. This was a largely Latino community and many of the behaviors around grief and loss were clearly different from those I knew so well from practicing in Boston. People working disasters need to understand the community in terms of class, religion, and ethnicity if they are to be effective with their interventions. Gamino and Ritter outline carefully how grief counselors can and should respond to community disasters, including being part of a response team such as the Red

Cross. Critical incident stress debriefing should be the approach of first responders; grief counseling may not be needed early in a disaster and may not be appropriate for everyone. Good intentions are not enough. Incidentally, the media often confuses stress debriefing with grief counseling and calls *any* intervention after a disaster “grief counseling.” We need to help educate them.

An alluring area of work for some grief counselors is the arena of forensic and legal testimony, often because the fees for service are high. I am frequently asked by lawyers to be an expert witness for cases on which they are working involving death and loss. I try to steer away from the forensic area because the research data is often soft and can be refuted by crafty lawyers who get chuckles from making the counselor look inept. However, there are times when grief counselors must become involved in legal action to which their own clients are party. This is quite a different situation from testifying as an expert consultant. Gamino and Ritter provide excellent guidelines for how to handle this necessary type of legal involvement and how to navigate through the ethical dilemmas presented by giving testimony in a court of law.

The ethical areas that thanatologists and grief counselors need to consider are many and varied, including legal responsibility for patient records, conflicting dual relationships, informed consent, patient confidentiality, Internet counseling, moving or closing a practice, and infraction reporting. Gamino and Ritter do an excellent job of providing timely advice and helpful suggestions for how professionals can manage ethical dilemmas that arise from the practice of grief counseling. The authors present a model for ethical decision making—the Five P Model—that will lead grief counselors through five distinct areas that need to be addressed when faced with *any* ethical decision.

Like the old Baptist hymn says, “What more can be said to you than has been given?” This book is comprehensive and the case studies flesh out the concepts, making the book interesting and readable. Even the most experienced grief counselors need to read this book as it will shine a light on some of our practices that we may never have considered. For me it was conversations with clients between the counseling room and the outside door. Does a discussion about my Boston Celtics in that space constitute the dual relationship of patient and friend? Interesting.

Finally, it is heartening to me to realize how our profession of thanatology has matured over the last 4 decades. We have well-known volumes on the technique and practice of grief counseling. We have our own code of ethics through the Association for Death Education and

Counseling. Now, Gamino and Ritter have provided an invaluable resource on ethics for professionals who certainly will struggle with ethical dilemmas while practicing grief counseling in a contemporary environment. I think it shows the maturity of our field when we ask ourselves not only how to do effective clinical work but also how to practice with the highest ethical standards.

*J. William Worden, PhD, ABPP
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Preface

During graduate school at the University of Kansas in the 1970s, the clinical psychology program's intramural basketball team was named "Ethics." This moniker derived from the introductory course on assessment in which the professor continually emphasized the importance of ethics in clinical practice, long before ethics courses were required in graduate curricula. Prior to one game, a player from the opposing team questioned the meaning of that nickname, "What is 'ethics'?" Psychology teammates shared a good laugh at the rival's expense, musing over how someone could be ethical without even knowing what the word meant.

Grief counselors and those working with the dying and the bereaved know that ethics in practice is no laughing matter. Concern with what is the right and proper course of action in death-related dilemmas cannot simply be relegated to philosophers, medical ethicists, licensing boards, or ethics committees. Grief counselors must know the principles and standards that govern their work domain and, ideally, operate from a proven system of values and morals.

Unfortunately, even conscientious mental health providers, beleaguered by the prospect of satisfying their annual ethics requirement for licensure, may perceive a disconnect between what constitutes good ethical practice and the enterprise of therapeutically effective counseling. In reality, no such disconnect exists. It is our contention and a major theme of this book that *sound ethical practice is good counseling practice, and good counseling practice requires sound ethical practice.*

Busy grief counselors focused on client care may be tempted to reduce the notion of sound ethical practice to a solely defensive posture, that is, practice that is free of ethical error or missteps that lead to professional liability, risk management concerns, ethics committee investigations, or a malpractice insurance nightmare. However, such a mindset dangerously overlooks the nexus between ethics and practice that is

crucial to provision of efficacious counseling. Instead, we propose that sound ethical practice is integral to intervening effectively.

What is unique to ethics in grief counseling? A specialized domain of ethical challenges can arise when counselors grapple with issues pertaining to dying, death, and bereavement. It is the authors' aim to provide, in a comprehensive text, a compilation of these major areas of ethical concern and to address them with a level of specificity beyond that typically found in generic texts on ethics in medicine or mental health. In addition, the Code of Ethics adopted by the Association for Death Education and Counseling (ADEC, 2006; Appendix A), an interdisciplinary thanatology organization, will be invoked as a *domain-specific* standard of care for dilemmas related to dying, death, and bereavement that can be used adjunctively with *discipline-specific* ethics codes that govern various professional groups. (Please note, in this book we cite repeatedly the current ADEC Code of Ethics. Therefore, we have omitted referencing the date of publication in all but this initial citation because to do so would be tedious and unnecessarily redundant.)

For whom is this book written? This volume is designed for grief counselors, mental health clinicians, death educators, health care providers, hospice workers, clergy, those in the funeral and aftercare industry, and anyone concerned with how to better educate and care for the dying and the bereaved. We anticipate that our readers share as their common denominator a dedication to working with death-related problems and issues, rather than sharing the same professional affiliation or training. It is our contention that ethical challenges inevitably arise in everyday practice and that the information in this volume can facilitate a seamless blending of sound ethical decision making with effective practice of grief counseling.

In the interest of disclosing personal biases, it is important for readers to know that both authors of this book hold life values grounded in our respective religious belief systems. Louis Gamino is a lifelong practicing Roman Catholic, and Hal Ritter is an ordained minister of the Southern Baptist Convention. Each of us considers our spiritual values inseparable from the conduct of our lives, both personal and professional. We find the "spirit of the law" embodied in our faith traditions to harmonize quite well with the secular professional codes upon which the reasoning in this text is based. Our Five P Model for ethical decision making maintains fidelity to those secular codes of ethics that inform our professional judgment. It is not based on religious beliefs. Instead,

we conceptualize faith beliefs to be a dimension of the grief counselor *as human agent* when determining a specific course of action in response to an ethical dilemma. All codes of ethics call for integrity in deportment and decision making, and for us, integrity is grounded in a Christian value system.

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Louis Gamino

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This book could not have been finished in a timely manner without the benefit of my “mini-sabbatical” supported by a private gift from my father’s estate. I am indebted to both of my parents for making this possible. In the end, I offer humble thanks for the magnanimous love of my wife, Marla Ann, and my children, Gabriel, Claire, and Dominic, who generously shared the kitchen table, the family computer, and their Saturday mornings to make it possible for me to write this book.

Hal Ritter

Any writing project takes time and understanding by those who are not involved in the project. I really express appreciation to my wife, Michaela Ritter, who was a constant encouragement, but who also expressed unlimited understanding and patience. I appreciate her patience for all the times she had to attend various functions by herself, because of my writing schedule.

I also express my appreciation to the various teachers and professors of ethics who taught me academically and also mentored me in the decision-making process. In addition, I appreciate the many clients and patients with whom I have worked as a counselor and therapist. They have taught me many aspects of the decision-making process, for a client's work is primarily that of making decisions that have the possibility of significant life changes. After all, therapy really is a decision-making process, sometimes more ethically significant than others. Some decisions are morally neutral and are based more on circumstances and preferences. However, some decisions are highly significant morally, particularly regarding issues that must be resolved for the forward movement of life. My clients and patients who have engaged in these significant moral decisions have trusted me to share that journey into wholeness with them.

*LAG & RHR, Jr.
October 13, 2008
Temple, Texas*

1

Introduction

Most health care practitioners, mental health providers, and human services workers have a connotative understanding of what is meant by ethical practice. Strictly defined, ethics is the discipline dealing with what is good and bad and with moral duty and obligation, particularly the principles of conduct governing an individual or group. Ethical practice of grief counseling means helping clients and their families while operating from an internalized code of conduct and adhering to the highest level of professional standards and mores. To do so, grief counselors must start from a position of personal integrity and responsibility and then be aware of and follow ethics codes, statutory regulations, and case law that pertain to their realm of practice.

DEFINITIONS

In the popular press, *grief counseling* is an umbrella term typically employed to describe activities such as providing comfort or consolation to those suffering losses from illness, accidents, violence, natural disasters, terrorism, or war. Grief counselors may be credited with possessing special knowledge or ability to help mourners that goes beyond customary social responses of extending sympathy, offering support, providing

companionship, or participating in religious rituals. However, exactly what constitutes this expertise or how grief counselors apply their special skills often remains unclear to the general public.

Depictions of grief counselors in the popular press are not always favorable. For example, one pundit drew an editorial cartoon depicting grief counselors as carrion birds ready to descend and feed from the misery of aggrieved survivors following a fatal school shooting. Thus in popular literature, not only is there ambiguity associated with the concept of grief counseling, but also there may be polarized opinions about its necessity or usefulness. All of this contributes to fuzziness about what is meant by grief counseling.

One of the landmark texts for professionals in the field, William Worden's (2009) *Grief Counseling and Grief Therapy*, distinguishes between *grief counseling* (e.g., psycho-education, supportive listening, normalizing bereavement-related symptoms) for those with uncomplicated bereavement and *grief therapy* for individuals whose grieving is complicated, such as prolonged, delayed, exaggerated, or masked. The latter is thought to require more sophisticated clinical acumen and advanced therapeutic techniques on the part of the provider. However, Worden's distinction may be lost on lay persons or even blurred by professionals who use the terms grief counseling and grief therapy interchangeably.

Because the purpose of this text is to provide professionals working with issues of dying, death, and bereavement a comprehensive handbook for navigating ethical dilemmas that may arise in the course of their work, we embrace a broad definition of grief counseling and eschew fine-grained distinctions based on the level of clinical expertise applied. In this text, the term grief counseling refers to any professional endeavor aimed at relieving personal suffering (e.g., emotional, psychological, physical, spiritual) brought about by the experiences of dying, death, and bereavement. Thus, grief counseling may include a wide spectrum of grief-related services including education, counseling, therapy, consultation, support, and advocacy provided in a variety of locations such as clinics, offices, hospitals, nursing homes, private homes, pastoral settings, funeral homes, schools, or work settings.

Because this book is devoted to domain-specific ethical problems, we use the term *grief counselor* in an umbrella fashion to refer to practitioners licensed in any of several professional disciplines. Thus, grief counselors may be psychologists, social workers, counselors, marriage and family therapists, nurses, physicians, clergy, or funeral directors. Even unlicensed volunteers or paraprofessionals who have received focal

training in bereavement support may face some of the ethical dilemmas addressed in this text and therefore can benefit from its content.

Finally, for the sake of clarity and readability, we use the terms *client* and *clients* to refer to those individuals who are the recipients of grief counseling services. The designation of client is intended to be inclusive of those seen in traditional counseling practices as well as others: patients of physicians, nurses, or clinical psychologists; congregants in pastoral settings; customers in funeral home settings; and, when applicable, students and trainees in educational environments. The only exceptions made to this general rule are in discussions specific to hospitals or hospices, where the term *patient* is used by convention.

CASE EXAMPLES

Throughout the text, we include numerous case examples to underscore the commonplace nature of ethical dilemmas in the everyday practice of grief counseling and to illustrate the complexity that many of these situations entail. Some of the cases are purely fictional. Others were inspired by case material conveyed to us by colleagues around the country or from our own case files. In each instance, the circumstances and details of the case have been deliberately altered and reworked so as to remove any potentially identifying information. Our goal is to preserve the authenticity of the case examples for teaching purposes while at the same time to protect the privacy of the original parties involved. In no instances have cases been described verbatim without such modifications. With these precautions in place, any perceived similarity between case examples in this text and instances known to readers are most likely a function of the ubiquity of ethical dilemmas in counseling.

BLIND SPOTS

All grief counselors are subject to blind spots. Even the most ethically conscientious grief counselor can get in a hurry, skip an important step, make an erroneous assumption, overlook a conflict of interest, neglect to consider a consequence, or rationalize an action as good for the client when it is really the counselor's own interests that are being served. The best defense against blind spots is to keep constantly in mind that everyone, *even you*, can fall prey to a blind spot.

Novices in the field are most vulnerable to blind spots because of inexperience. In their eagerness to do a good job, please clients, and cultivate a practice, beginners may act in well-intended ways that have unintended ethical consequences. What starts out as a good-faith attempt to help becomes an ethical misstep when complications arise. For example, there was the beginning counselor who saw a client individually for bereavement-related issues and then agreed to include the client's spouse in some of the sessions in order to facilitate how the spouse could better support the grieving client. When serious marital conflict erupted in the process, the original client became disillusioned and no longer wanted conjoint meetings. However, the counselor was unclear about who was the client at that point—the original client or the couple? Even though the spouse withdrew, the bereaved client felt alienated and distrustful about continuing with the counselor, who was perceived to have mixed allegiances. Because those boundaries were not clear, the original client ended up dropping out of treatment. This is a good illustration of why working with a mentor early in one's career can provide an invaluable form of check and balance against potential blind spots. As risk managers are quick to point out, avoiding a problem in the first place is one of the best strategies for minimizing liability.

Experienced grief counselors are more vulnerable to the blind spot of thinking of themselves as ethically infallible. With good training, considerable practice experience, a favorable reputation, admiration from peers, and a waiting list of clients wanting to be scheduled, one can be lulled into a false sense of ethical security. Believing that nothing untoward will occur in such a successful professional practice is dangerous thinking. Even at the top of one's game or at the height of one's profession, grief counselors can still fall prey to a blind spot.

Consider the situation of the highly esteemed grief counselor who helped a young couple after the devastating loss of their first child following an unanticipated birth complication. So appreciative and grateful was the couple for the grief counselor's deft assistance during their travail that, when they had a healthy second baby, they asked the grief counselor to be one of the godparents at their infant's christening. The honor conveyed by the couple's request temporarily blinded the grief counselor to the untenable role conflicts inherent in their proposal, and the invitation was initially accepted. After reflection and discussion with a colleague, the grief counselor realized that the contradictions posed by a simultaneous professional and personal relationship were ethically inadvisable, and the invitation was subsequently declined.

This shows why not only novices but also experienced grief counselors need to make arrangements for regular consultation with a trusted colleague who can function as an extra pair of eyes and ears to help detect when something might go awry or when an ethical problem is brewing. Many practicing grief counselors meet their ongoing consultation needs using the professional buddy system. That is, they meet periodically for lunch or coffee with a colleague who is not afraid to respond candidly to their questions and doubts. Often, it is a reciprocal relationship wherein they do the same for their colleague. Such an arrangement can keep even the most prestigious grief counselor humble and help ensure that one's therapeutic relationships with clients are not jeopardized by unanticipated or unrecognized ethical violations.

HOW TO USE THIS BOOK

Whether readers are psychologists, social workers, counselors, marriage and family therapists, nurses, physicians, clergy, or funeral directors, all must first faithfully follow their *discipline-specific* codes of ethics and professional standards. In this book, we build on those guidelines by implementing the *domain-specific* ethical standards of the Association for Death Education and Counseling (ADEC), which are designed to inform and guide professionals encountering ethical dilemmas when death and bereavement are the therapeutic focus. This recommendation is consistent with current trends in the field of ethics wherein scholarly literature addressing specific problems in ethics constitutes one of many resources to be consulted when faced with a particular dilemma (Welfel, 2006).

In Chapter 2, we outline our customized process for ethical decision making in care of the dying and the bereaved, the Five P Model, and follow that with an exposition of the concept of death competence for grief counselors in Chapter 3. Chapters 4 and 5 cover consent and confidentiality, respectively, topics important to all mental health providers but which present some special challenges to grief counselors. Then, in subsequent chapters, we address major content areas specific to the enterprise of grief counseling: end-of-life dilemmas (Chapter 6); multiple relationships in thanatology (Chapter 7); ethnic, cultural, and spiritual considerations (Chapter 8); Internet counseling (Chapter 9); ethical controversies in grief counseling (Chapter 10); potential pitfalls of public service (Chapter 11); grief counselor as expert witness (Chapter 12); and moving or closing a professional practice (Chapter 13). The text concludes

with Chapter 14 on reporting a colleague or facing a complaint. Having identified the areas of ethics most salient for those working with the dying and the bereaved, we seek to model how discipline-specific and domain-specific ethics codes, used together, contribute to a stance of professional accountability and a timely resolution of ethical problems.

Of course, no book can provide an answer for every occasion. We strive to offer clear guidelines for how to resolve ethical dilemmas in grief counseling given the enormously complex contextual variables that often surround these cases. Readers of preliminary drafts of our book have responded uniformly that the text was thought-provoking and informative, leading them to consider carefully how they would apply its concepts in their own work settings with their unique circumstances. This is precisely our goal—to inform an active, vital, creative, and thoughtful response on the part of grief counselors to the ethical challenges they face everyday. For us, the end result should be a response characterized by uncompromising professional integrity that incorporates thorough knowledge of ethical principles, standards, and precedents together with sensitivity to and compassion for the suffering person.

2

Ethical Decision Making: The Five P Model

Various traditions and models exist for ethical decision making in health care. Although no single model can claim status as the ultimate key to solving every dilemma, every ethically conscious health care professional needs to be familiar with at least one working model to apply when confronted with an ethical dilemma. The ethics code of the American Counseling Association (ACA, 2005a) states succinctly this obligation.

When counselors are faced with ethical dilemmas that are difficult to resolve, they are expected to engage in a carefully considered ethical decision-making process. . . . While there is no specific ethical decision-making model that is most effective, counselors are expected to be familiar with a credible model of decision-making that can bear public scrutiny and its application. (ACA Code of Ethics, Purpose)

In this chapter, we first review some of the major streams of thought in the field of health care ethics in order to provide a conceptual context for introducing our customized model of ethical decision making. The Five P Model, which adapts and extends the pioneering work of Helen Perlman (1957), is specifically crafted to provide a practical approach for the thoughtful consideration and resolution of the everyday ethical challenges faced by mental health practitioners. We employ the Five P

Model throughout this text and encourage grief counselors to consider it as the credible model they adopt personally.

THEORIES FOR ETHICAL DECISION MAKING

A good theory offers several advantages to the decision maker. First, it provides a methodology for organizing diverse data into a coherent whole. Second, a good theory will provide a user-friendly process for actually making a decision, without resorting to some vague abstraction. In this regard, most ethical theories define the ultimate goal as decision making. Finally, a good theory provides the decision maker with a clear understanding of why the decision is being made, that is, a rationale for the decision. Thus, a good theory can help prevent the cart-before-the-horse phenomenon in ethical reasoning—reaching a conclusion about an ethical matter according to some tacit process and then searching for an ethical principle or law to justify the conclusion (cf. Haidt, 2001). Kitchener (1984) proposed that ethical theory helps the decision maker move beyond immediate, intuitive judgments and actions to a critical-evaluative level of reasoning that incorporates professional codes of ethics and moral principles in a reflective process suitable for addressing novel or complex dilemmas.

Now we review five basic theories for ethical decision making: virtue ethics, rule deontological ethics, principle ethics, utilitarian ethics, and feminist ethics.

Virtue Ethics

Virtue ethics, sometimes called character ethics, is a process of decision making based not only on information but also on one's personal integrity. Virtue ethics is focused on the individual making the decision, as well as the primary group to which one belongs. Tracing its origins back to the Greek philosopher Aristotle, virtue ethics has also enjoyed a contemporary revival (Pellegrino & Thomasma, 1993). The virtue ethics approach asks the question, "Who is a virtuous person?" In other words, how is the person's identity and integrity evident in the decision being made?

What if a grief counselor is asked by a family to falsify information conveyed to the client? In one case, for example, the client's spouse

cautioned the counselor before test results were delivered, “We only want *hopeful* information.” Unfortunately, the test results clearly indicated a worsening of the client’s condition. The counselor’s response was, “You need *accurate* information in order to know exactly what you’re dealing with so you can prepare adequately.” In effect, the counselor was saying, “I cannot lie to the client. My personal integrity does not allow me to lie. What kind of person will people think I am if they know I will lie to another person? And what kind of grief counselor will people think I am if they know I will lie to a client?” In this case, withholding bad news is the equivalent of lying, and the counselor believes that lying compromises personal integrity.

Because virtue ethics asks, “What is a virtuous person?” it is concerned with evaluating good traits of character. In ethics courses, the question may be asked, “Which traits of character or virtue are important for a grief counselor?” (Pence, 2004). Many believe traits such as wisdom and compassion are important. Although knowledge and skill can be learned, wisdom is seen as necessary for the beneficial application of knowledge, and compassion refers to the character of the provider when applying specialized skills.

Hauerwas (1981) espouses a version of virtue ethics that he calls *character ethics*, based on Aristotle’s theory. For Hauerwas, the ethical question is, “What kind of people will we be for the decisions that we make?” In other words, the ethical decision not only reflects the personal integrity of the decision maker but also shapes the kind of person that decision maker will be in the future. Decision making molds personhood. In addition, Hauerwas views the ethical question in the context of the community to which one belongs. For Hauerwas, it is the Christian community. However, the context can be any applicable community, such as the broader community of thanatologists: death educators, bereavement researchers, and grief counselors. When Hauerwas asks what kind of people “we” will be, he means that the decision shapes both the personhood of the individual and the identity of the community of which one is a member. In other words, individual grief counselors represent not only themselves but also the community of thanatologists of which they are part.

If the question of virtue ethics is applied to a social issue, such as physician-assisted suicide, the answer becomes one that reflects both the character of the person making the decision and the character of the reference group of which one is a member. For example, if a health care organization supports physician-assisted suicide, what does that decision

say about the organization if it also claims to support hospice and progressive palliative care? Is it assisting the dying to live each day until they die, or is it facilitating dying when the terminally ill no longer have quality of life? And who judges the quality of that life?

Families sometimes reflect virtue ethics when they are asked to make end-of-life decisions for a loved one. Various family members may ask, “What does this say about us, as a family, if we terminate care for Mom? Will others say we killed or murdered our mother? I do not like how that feels. That is not what I want to think about this decision.” Others may say, “What does this say about us, as a family, if we unnecessarily prolong Mom’s life, knowing she is in terrible pain?” In either case, the ethical question is about the identity of the family group, as well as those individual, decision-making family members.

Rule Deontological Ethics

Rule ethics is a form of decision making that seeks to know the “correct” rule for the decision being made. Deontological is from the Latin word *deontos*, which means “duty” (Pence, 2004). The ethical issue is one’s “duty” to do “right.” The notion of rule ethics was developed by the 18th century German writer Immanuel Kant (1724/1789). For Kant, why an act is done is more important than its consequences. In this regard, personal motive is an important part of determining the rightness of an ethical decision, so the value of an action is determined by the quality of the intention behind the action.

For example, one may give money to the Hospice Foundation of America (HFA) for purposes of getting a tax deduction. Tax-wise, it may be a smart decision. However, it is not a morally virtuous decision. On the other hand, one may give money to the HFA believing in a duty to help those who are dying and their families. In this case, the decision is morally virtuous. In both examples, giving to the HFA has the same consequences: helping dying people and getting a tax deduction. However, the higher motivation of helping dying patients, rather than just getting a tax deduction, makes one decision more virtuous than the other. An additional principle from Kant is that people have value, and they should never be treated as disposable or as merely the means to some other end or consequence. In other words, the higher ethical principle is that which says that people have worth and dignity.

Kant’s (1724/1789) approach to rules for decision making included his application of a universalizing principle known as the *categorical*

imperative. The categorical imperative insists that any act can be ethical only if it is based on a rational reason or principle that can be recommended as universal law. In other words, it can be proposed for everyone. For example, should people contribute money to the HFA for altruistic reasons? Yes, because helping provide information and resources regarding palliative care and end-of-life decision making is a universal principle for good. What about blackmail as a reason for getting money for the HFA? No, I cannot recommend blackmail as a universal principle because it violates the law as well as human dignity. In other words, supporting the HFA is a sound moral decision. However, to use blackmail or extortion to raise money for the HFA is not morally virtuous because individuals will be devalued and harmed in the process of blackmailing them. In this case, Kant's use of the categorical imperative is a constructive way of helping people think about ethical decisions.

One variation of rule deontological ethics is knowing what one's religious tradition considers to be the right rule to follow. Some will seek out help from sacred texts, from respected fellow faith members, or from clergy to inform their notions of what is right and wrong. Regardless of religious affiliation, a decision maker using rule ethics often seeks out the *right* thing to do in a given situation. Even when the result is a poor outcome, rule ethicists may comment, "Well, it may not have worked out the way we wanted, but at least we know we did the *right* thing." In other words, even though the outcome of the decision was not preferred, there is no second guessing or residual guilt about the decision because the decision makers know they "did the right thing"; that is, they followed the correct rule.

Other variations of rule deontological ethics are company rules or agency policies, state laws, and the regulations of one's profession. Regardless of the origin of the rules that one follows, *most important is the intent to do the right thing*. The assumption is that rules are made to protect individuals and communities. Rules prescribe desirable decisions and proscribe undesirable ones. If the rule says that clients have the right to all aspects of health care information about their individual care, then withholding information about an exam or test result is a violation of the rule. If giving the client the troubling information results in an uncomfortable or distressing emotional response, the person giving the information can still be assured that "at least we know we did the right thing" by giving the information. The person giving the information may say, "I am sorry for the discomfort this has caused, but at least we know you have been told the truth."

Principle or Value Ethics

Many people state they have certain principles that are formative for their lives and foundational for decision making. For some, there is one central principle, such as love, or peace, or life. They will use this organizing principle to consider all the various aspects of any decision, such as “I believe in peace, so I want this to be the most peaceful, or the least violent, decision.” In the case of elective medical procedures, violence may be understood as the infliction of pain from the recommended procedure. Although it is realized that some pain is part of life, the intent of decisions is always for the least amount of pain (i.e., violence) and for the pursuit of peace and tranquility (i.e., pain reduction).

If someone values life, he or she may say that he or she wants everything possible done in order to preserve life. Any discussion of premature termination of life by withholding various mechanical or nutritional supports is seen as devaluing life and leading toward a view of human life as expendable when it is inconvenient. Valuing life often divides families in end-of-life dilemmas. There may be one person or group who says, “Do everything possible to keep Dad alive. That’s what he would want. He always fought for us when we were growing up, and he taught us to believe in life. He’d never agree to giving up. You never know when a new drug will be discovered.” Another person or group may say, “You’re right, Dad always fought hard for us. But the fight is over. Dad is in terrible pain, and there is no hope for him getting any better. Living for him, like this, is not life. We need to let him go and let nature take its course.”

In this example, some of the family believe that any limits to care are the same as “giving up” and may also be a violation of the principle of the value of life, as it has been taught to them by their father. Conversely, others view the merciful end of a painful, medically debilitated life as a better option for one who always affirmed life. They believe that because there is no hope of recovery, their father should be allowed to die by letting nature take its course. Their decision to “let go” is an affirmation of a life well lived. What the previous group views as “prolonging living” is something they view as “prolonging dying.”

Biomedical ethics has embraced the principle or value ethics approach, in large part because of the influential work of Beauchamp and Childress (2008). To guide decision making, they champion four basic ethical principles: *nonmaleficence*, *beneficence*, *autonomy*, and *justice*. Their approach is the subject of a later section of this chapter.

Utilitarian Ethics

Utilitarian ethics, or consequentialism, has a long history, particularly in the United States with its philosophy of pragmatism. Pragmatism says that if a particular procedure or activity works out positively, then it must be the best decision. Utilitarianism is a variation on pragmatism—it says that the best ethical decision is one that brings the greatest good to the greatest number. Philosopher John Stuart Mill (1792/1859) is the one who most clearly developed a theory of utilitarianism, “the greater good for all.”

Some have argued that the notion of utilitarianism developed historically within the United States because of its traditions in Christianity, with its attendant views of charity, love, and caring for others. In other words, utilitarian ethics pull for the majority to receive the greatest benefit or greatest good, with charity toward all, including one’s enemies. Certainly, this is consonant with the democratic system in the United States. Yet one of the limitations of utilitarianism is that the majority may not consider the needs of the minority. With multiple cultures and ethnicities in one society, how does one consider the greatest good for the greatest number?

The greater good for one person or group may be very different from the greater good for another person or group. For some, there is no consideration of the benefit for the larger group. For them, the only consideration is how the decision will benefit some smaller group, such as the elite, or the wealthiest, or the most educated. Alternately, a cultural minority or a religious sect may reject utilitarianism because it excludes or marginalizes its interests (see Chapter 8, “Ethnic, Cultural, and Spiritual Considerations,” for a more detailed discussion of how to honor such individual differences in ethical decision making).

In end-of-life issues, the utilitarian approach first views the needs of the patient. What is good and beneficial for this person? What does the patient view as good? How does the patient view quality of life? If capable of medical decision making, what does the patient want? If there is a medical decision being made for the patient by another person, a surrogate or proxy decision maker, the question remains, “What is best for this patient?” It is not what the surrogate decision maker wants for the patient but what the surrogate understands to be the patient’s wishes. Although some individual family members may want to keep a loved one on life support, that may not be what is best for the patient or what the patient would want. In such end-of-life examples, utilitarian ethics also

ask what is good for the greatest number and how the patient's wants may affect other stakeholders in the decision.

For example, utilitarian ethics often come into play when considering how to allocate scarce medical resources. If the patient with limited life expectancy cannot breathe without a respirator, how long is the patient's choice to continue living supported if there are other critically ill patients with a better chance of recovery who may need that respirator? In the arena of organ transplant, the question arises of who most deserves to receive a preciously limited commodity, such as a cadaver's kidney. The ethic of "the greatest good for the greatest number" may favor giving the kidney to a young adult mother of three minor children whose kidney disease resulted from a congenital birth defect versus an older, single male whose former alcoholism ruined his kidneys.

Feminist Ethics

Feminist philosophy offers a sharp counterpoint to the more traditional ethical theories presented thus far. The feminist perspective prizes relationships as an ethical value (Farley, 1985; Lebacqz, 1985) and seeks to equalize power among people by dismantling social norms and institutions that establish and maintain gendered hierarchies (Donchin, 2004). Feminists posit that most ethical theories have been developed by men, who tend to put a premium on autonomy and individualism. Alternately, Gilligan (1982) put forward caring—managing and maintaining relationships through love, care, and responsibility—as a core ethical value.

Feminists also argue that men have a privileged position in society, which means that men have more power than women, just because of male gender. Especially in Western society, White men tend to have more authority than men of color. The result is that the voices and opinions of others, such as minorities, immigrants, or refugees, are often silenced or marginalized. For this reason, feminists focus on understanding power differentials and their interconnections with gender, race, culture, class, physical ability, sexual orientation, age, religion, and ethnic heritage (Ballou, Hill, & West, 2008; Feminist Therapy Institute, 2000). Eradicating oppression in all its forms, respecting diversity, and advocating for social change when societal or communal attitudes and practices harm an individual's growth potential are core values in feminist ethics.

A good example of how feminist ethics can be applied to ethical decision making in a health care environment is the method proposed by Verkerk et al. (2004). Drawing heavily on Walker's (1998) feminist ethics,

they reject a notion of morality as discrete, codified knowledge. Instead, Verkerk et al. view morality as a fluid, interpersonal, socially constructed reality: “It is a way of expressing who we are, of understanding others, and holding others and ourselves to moral account” (p. 32).

In confronting any ethical dilemma, Verkerk et al. (2004) first ask professionals to reflect on their own individual sensibilities and reactions in a given situation, similar to starting with Kitchener’s (1984) immediate, intuitive response. Then they guide professionals toward understanding that they are part of a clinical practice that involves multiple perspectives and positions, that is, beginning the critical-evaluative process described by Kitchener. Verkerk et al. use a “reflection square” in which one key perspective is considered in each quadrant: the agent’s (i.e., the health care professional’s) core values and beliefs, the agent’s actions, social norms, and consequences of social norms. Their goal is to enhance consensus-building among professionals working together as a team to attain “moral competence: the ability to see what is morally relevant in a situation, knowing the point of view from which one sees it, understanding that others may see it differently, and then, with others, responding well to what one sees” (p. 37). To some, this may sound like the essence of moral relativism. Yet it is based on core feminist values—mutual respect among health care professionals, sensitivity to the perspectives of others, collaborative rather than hierarchical decision making—and provides a working example of how feminist ethics can be applied to ethical decision making.

ETHICS IN MEDICINE

Ethics in the professional fields of counseling and mental health evolved from the larger rubric of medical ethics. The original impetus for ethics in biomedical and behavioral research emerged after World War II and the Nuremberg War Trials. In Nazi Germany, some medical doctors conducted cruel biomedical experiments on concentration camp prisoners, without their permission. The Nuremberg Code of 1947 resulted from the trials and established standards for biomedical ethics (Grodin, 1992). It was followed by other international efforts to guide physicians in ethical conduct of biomedical research involving human subjects, such as the 1964 Declaration of Helsinki, now in its fifth revision (World Medical Association, 2000).

In the United States, the infamous Tuskegee Syphilis Study, initiated in 1932, exploited poor, rural Southern black males to investigate the

long-term effects of the disease and deprived its experimental subjects of the benefits of a cure that was discovered partway through the study, namely, penicillin (Jones, 1981). Public awareness of the study in 1972 brought an outcry for reform (Centers for Disease Control and Prevention, 2008; Tuskegee University, 2008).

In 1974 the U.S. Congress passed the National Research Law (Pub. L. 93-348), which codified into the Federal Register guidelines for protecting human subjects involved in biomedical and behavioral research. These regulations were recently revised (U.S. Department of Health and Human Services, 2005). The original law created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. One of the charges to the commission was to establish guidelines for research at all levels in the United States: What are the boundaries between the routine practice of medicine and biomedical or behavioral research? How is risk–benefit to be assessed when using human subjects? How are human subjects to be selected for research? What is informed consent for the purposes of research on human subjects? (Miser, 2005).

In 1976 the Smithsonian Institution's Belmont Conference convened for an intensive 4-day study of the new guidelines, followed by monthly meetings over the next few years. In 1979 the commission issued its directives as the *Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Three ethical principles, or general prescriptive judgments, relevant to research involving human subjects were identified in the *Belmont Report*: respect for persons, beneficence, and justice. In the original Belmont report, *beneficence* encompassed the tandem concern of “first, do no harm,” or *nonmaleficence* (Miser, 2005).

One result of the establishment of these four ethical principles is that they apply to all health care situations, including physical medicine and mental health care. Whether in biomedical or behavioral research or in clinical care, the concept of informed consent is given great prominence (see Chapter 4, “Consent”). Consent for nontherapeutic research, which generally seeks healthy volunteers for the purpose of gaining knowledge to further medical options and does not directly benefit the participant, has more stringent requirements to be sure the person is fully free to give consent. Children, prisoners, military recruits, and even medical students are morally excluded from all but the most risk-free research on the grounds that their freedom to refuse is limited or compromised (Wheeler, 1996). On the other hand, therapeutic research, which is often experimental in

nature, has a less stringent level of consent because people with end-stage diseases are often willing to accept the potential risks of untried medical interventions when no other treatment options are available.

Biomedical Ethics

Beauchamp and Childress (2008) reformulated the three ethical principles from the *Belmont Report* in slightly different terminology that is in general use today. Respect for persons is now considered under the principle of autonomy. Nonmaleficence and beneficence are now parsed as separate principles. Thus, the four principles they advocate are nonmaleficence, beneficence, autonomy, and justice. Some ethicists will add an additional principle, such as fidelity or professional relationship, but these four are the traditional standard for biomedical ethics. Some professional disciplines have adopted versions of these four, or five, principles as aspirational goals for their members (cf. American Psychological Association, 2002).

Nonmaleficence is based in the oft-repeated principle “first, do no harm” (in Latin, *primum non nocere*). In other words, if nothing can be done to benefit a patient, at least do nothing that will harm the patient. If cure and return to a quality life are not possible, then do not do anything to make the situation worse. The other side of avoiding any harm is the principle of *beneficence*—doing something that will improve the patient’s life, even if it means providing only comfort or palliative care. Beneficence is nicely summarized in the doctor’s adage “Cure sometimes, alleviate [suffering] often, comfort always” (Roberts, 1997, p. 360).

Autonomy is based in the occidental philosophy of valuing the individual, which comes to the West particularly through the writings of Immanuel Kant (1959/1789). Autonomy is based in the notion of respect for the person, where the individual is the determining agent for decision making. The individual has the right to full disclosure of all information regarding treatment options, as well as information regarding the potential consequences of no treatment. Autonomy is not a democratic process, where the majority of the interested parties make the decision. In other words, the family cannot overrule or outvote the desires of the individual patient who is capable of making an independent decision.

The fourth principle in medical ethics is *justice*. Justice means fairness, that is, all patients will be treated fairly and holistically within the bounds of the resources that are available. It does not mean that all patients will be treated the same because the same resources are not available to every person. However, within the context of what resources

are available, treatment should not be limited or withheld based on income, social standing, education, race, gender, ethnicity, disability, or religion. In the field of medicine, the international humanitarian group Doctors Without Borders is a good example of justice in action. These physicians will travel anywhere in the world to provide care, within their ability, regardless of the politics of the geographical area or the politics of the individuals they treat.

Those who include the fifth principle, *fidelity*, believe that being truthful with a patient and maintaining confidentiality are important obligations in any professional relationship. Health care professionals enter into a fiduciary relationship with patients—one with a deep sense of trust embedded in it—that carries with it a qualitatively different level of obligation than would a nonprofessional association. Fidelity means counselors honor the caregiver–client relationship by behaving in a manner worthy of the faith and trust placed in them. Loyalty is another aspect of fidelity—professionals are expected to advocate for clients when appropriate, and they never abandon their clients. Honesty, integrity, trustworthiness, responsibility, and loyalty are all dimensions implied by the principle of fidelity.

Clinical Ethics

Jonsen, Siegler, and Winslade (2004) developed a model specifically for making ethical decisions in clinical medicine. This model, sometimes referred to as the “four box” method, begins by organizing the facts of the case into four discrete categories: medical indications, patient preferences, quality of life, and contextual features. Medical indications include all relevant medical information pertaining to the illness: diagnosis, prognosis, treatment options, and consequences of no treatment. The ethical principles related to medical indications are nonmaleficence and beneficence. Patient preferences consider how the patient with the illness wants to be treated. The ethical principle of autonomy, or respect for the individual as a decision-making agent, is most pertinent. Quality of life can be difficult to determine. After all, who decides what is perceived as quality—the patient, the family, or the staff? The ethical principles most applicable to quality of life determinations include autonomy, nonmaleficence, and beneficence. Contextual features include mediating factors such as religion, economics, family, race, ethnicity, and gender. The prevailing ethical principle here is justice, ensuring that patients are treated well and treated fairly. Because the Jonsen et al. approach is most

applicable for clinical cases in medicine, it is less applicable in counseling and therapy (G. McGee, personal communication, December 2006).

ETHICS OF GRIEF

The ethics of grief allow people to mourn individually. Although many risk factors (Gamino, Sewell, & Easterling, 1998, 2000; Parkes & Weiss, 1983; Rando, 1993; Raphael, 1983) and mediating variables (Worden, 2009) influence mourning, the value and quality of the attachment to the deceased person is a principal determinant of the character and depth of grieving. Although much has been written about stages of grief and tasks of grieving (cf. Neimeyer & Gamino, 2003), evolving conceptual models reify the notion that grieving is very much a personal, subjective process (Neimeyer, 1998). Some have attempted to define normative styles of grieving, such as intuitive versus instrumental grievers (Martin & Doka, 1999; Martin & Wang, 2006), whereas others target pathological variations of grief as absent, delayed, or prolonged (Boelen & Prigerson, 2007; Goldsmith, Morrison, Vanderwerker, & Prigerson, 2008; Rando, 1993; Worden, 2009). From one cultural perspective, Muslim physician Muhammed Ayub observed, “If people do not weep now (for their loss), their organs will weep and produce disease later” (Ritter, Smith, Santibanez, Ayub, & Tayi, 2005, p. 260).

Ethically conscious grief counselors adhere to a position of pluralism wherein the sensibilities, preferences, and traditions of each individual mourner are respected. The ADEC Code of Ethics states this quite clearly in its “Basic Tenets.”

The member takes care to know the student or client. Good education and counseling are based upon an understanding of, and a respect for, the student’s or client’s cultural background, developmental status, perceptions, and other individual differences and needs. (ADEC Code of Ethics, Basic Tenets, 3)

The member strives to present various views of a death-related question, indicating the member’s own values if appropriate, and respecting the student’s or client’s choice among alternatives. (ADEC Code of Ethics, Basic Tenets, 6)

This respect for people’s individuality in grieving and in their decision making reflects the fundamental ethical principle of autonomy. Rigidly

applying a unitary formula or an external standard of how grieving should progress may constitute a violation of the principle of nonmaleficence, “do no harm.”

This is not to say that innovative theory and research have no place in grief counseling. Quite the opposite, they figure prominently for practitioners who stay current in their field. Theory and research can be applied flexibly while still respecting individual differences. For example, we often use Stroebe and Schut’s (1999) dual process model of grieving to illustrate for bereaved clients that oscillating between grief work and going on with life is considered normal and to give permission for that oscillation dynamic to express itself in very individual ways. Similarly, in counseling bereaved parents who wonder why their time trajectory of grief seems so different from those mourning other kinds of losses, we use Klass’s (2001) qualitative study of bereaved parents in support groups to exemplify categorizations that the parentally bereaved *assign themselves* to describe their grief journeys. However, we portray Klass’s findings as a sample, not an invariant template. In each instance, the ultimate goal is to help the struggling griever, which is the ethical principle of beneficence in action.

Sometimes loss brings up old conflicts and animosities within groups, for example, schisms among family members. Grieving may also elicit untapped resources and mobilize latent strengths of which persons were unaware. These crosscurrents are inherent in the nature of grief and thus are to be anticipated in the practice of grief counseling when ethical decisions must be made. Evenhandedly mediating conflicts, promoting fairness in the treatment of the dying or the bereaved, and advocating for open access to resources enacts the ethical principle of justice. The ADEC Code of Ethics endorses this important aspect of ethical practice.

The member serves in an advocacy role to assist the individual or society to cope with death-related issues. The member intervenes to prevent exploitation of the student or client and is obligated: (a) to be available to the student or client; and (b) to educate or counsel regarding rights, responsibilities and options with their possible consequences. (ADEC Code of Ethics, Basic Tenets, 5)

THE FIVE P MODEL

The preceding discussion of ethical theories and time-honored principles of health care ethics is foundational for how grief counselors think

about ethical decision making. In any ethical dilemma, there is the *who*, *what*, *where*, and *how* of the decision. The *who* includes the client and others involved in the decision. The *what* is defining the problem as well as the contextual variables that surround the problem. The *where* entails venue-specific or location-driven aspects to take into account. The *how* refers to the relevant ethical principles employed as well as the actual process that will be followed for making the decision. Unfortunately, some ethical theories seem to address one dimension of decision making more than another, and some theories seem abstract rather than practical. For these reasons, we propose a five-step model for ethical decision making that addresses the *who*, *what*, *where*, and *how* of the decision and that is designed to be especially applicable for ethical dilemmas in grieving and end-of-life situations.

A seminal work for us is a social work text by Helen Perlman (1957). In addressing the task of social casework, Perlman defined a four-part problem-solving process, taking into consideration the person, the problem, the place or social context, and the helping process. It is important to note that Perlman was not addressing the idea of ethics or ethical decision making. Nonetheless, her ideas form the nidus of our model. Adapting and extending Perlman's work, we include a fifth element—ethical principles—that transforms her problem-solving process into a decision-making model for ethical reasoning. Thus, our Five P Model can be stated succinctly as follows: “A *person* with a challenging ethical *problem* in a particular contextual *place* applies appropriate ethical *principles* in a deliberate decision-making *process*.” A schematic representation of the Five P Model is presented in Figure 2.1.

The essential elements of the Five P Model for ethical decision making are summarized in Table 2.1.

Person

The first consideration is the person or persons affected by the decision to be made. *Who* is this person? What is the individual's age, educational background, occupational history, and socioeconomic standing? Are there cultural, ethnic, or religious considerations? What kind of interpersonal relationships does the person have in terms of family, friends, and social connections? What experience with loss or losses has the person had? Oates (1982) comments that people's grief, meaning, and recovery are cumulative so that each loss, successively, is a reminder of previous losses. Further, does the person have capacity for decision making? Is

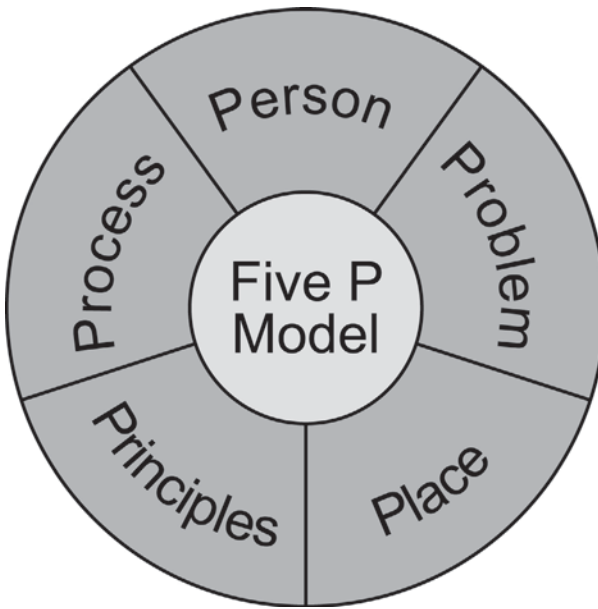


Figure 2.1 Schematic representation of the Five P Model for ethical decision-making

the person's capacity adequate for understanding the subtle nuances and complexities of the ethical issue as it is being formulated?

What decision-making style does the person bring to the process? Some people are more intuitive, believing they just know or feel what the right answer is, and do not question their inner convictions. Deductive decision makers want to first collect data and gather information before deciding. They do not want to overlook a potentially crucial piece of information and prefer to have all the facts to weigh. Then, there are non-decidors who, because of denial or dependency, do not want to take responsibility for decisions that need to be made. In all these things, it is important to have a clear understanding of who is the person in the dilemma.

Problem

The second consideration is the problem. This is the *what* of the decision-making process. What is the specific ethical issue that needs to be resolved? How is the problem understood, and is it properly stated? Is the problem formulated differently by various stakeholders? For example, one person may want to spend the family savings on an elaborate funeral to honor

Table 2.1

FIVE P MODEL FOR ETHICAL DECISION MAKING

“A *person* with a challenging ethical *problem* in a particular contextual *place* applies appropriate ethical *principles* in a deliberate decision-making *process*.”

1. *Person*: Who is this person?

Age. Sex. Education. Work history. Economic background.
Single, married, partnered. Home/family. Friends. Social support.
Ethnicity, culture, religion. Community/civic activities.
Strengths/resources. Personal resilience.
Other personal history (e.g., previous losses, decision-making style).

2. *Problem*: What is the specific ethical challenge to be resolved?

Statement of the problem. What is the ethical dilemma?
Who is formulating the problem? Who else has an interest in the problem?
Is the problem properly stated? Other variables?

3. *Place*: Where is the ethical dilemma manifested?

Physical location. Medical setting: clinic, hospital, hospice, nursing home?
Other: private home, funeral home, place of worship, educational setting?
Public or private place? Are there agency/institutional considerations?

4. *Principles*: What ethical principles are the focus of the problem?

Ethical principles: autonomy, beneficence, nonmaleficence, justice, fidelity.
Ethics of the profession. ADEC Code of Ethics.
State/federal laws. Personal narrative. Religious, ethnic, cultural “rules.”

5. *Process*: How will the decision be made?

How will information be gathered? How will all voices be heard?
Time limitations. Ethical theory. Resolution of the dilemma.

the deceased. However, other family members may want a simple funeral without incurring significant cost. The important factor is to clearly focus the problem and determine what information must be gathered in order to fully understand the decision. Who will provide the information? What resources are available for gathering the information?

It is always important to distinguish the person from the problem. Counseling theories universally encourage a nonjudgmental acceptance of the person apart from the problem (cf. Rogers, 1957). In particular, narrative approaches to counseling emphasize that the person is not the problem, but the problem is the problem (White & Epston, 1990). In other words, the griever may be very upset and distressed, but the ethical dilemma to be faced and the decisions that need to be made must be evaluated with some objectivity and without being overwhelmed by the emotions of the moment.

Place

The third aspect of ethical decision making is consideration for the context of place wherein the ethical dilemma is manifested. This is the *where* of the decision-making process. Where does the ethical issue occur? Is it a private or public place? Often, the determination of place provides some information regarding who is involved in the decision. Is it a public policy matter? Are there agency, institutional, or venue-specific regulations or contingencies involved, or is it an individual or family decision? Does the dilemma locate itself in a medical environment of some kind, such as a hospital or nursing home? In each of these settings, place determines important contextual cues for the decision-making process.

Principles

Which ethical principles operate is the fourth aspect of ethical decision making. This is part of *how* the decision is made. Is the focus one or more of the major ethical principles for decision making—nonmaleficence, beneficence, autonomy, justice, and fidelity? Are there other considerations, such as religious regulations or ethnic sensibilities, customs, or laws? For example, in respecting the rights of the individual according to the principle of autonomy, some people are very careful to be sure that the decision is made by that individual or agent. Those of Anglo-European descent may be more attuned to individual decision making. On the other hand, for some, no decision is made without the input and consideration of those in close relationship to the agent, particularly family members. For many from Hispanic lineage, no decision is truly individual because all live in a relational matrix with other people who are an important part of one's identity and decisions.

For grief counselors, ethical decisions will be based on allegiance to a discipline-specific code of ethics from their respective professional organization as well as on working familiarity with the domain-specific ADEC Code of Ethics.

Process

The final element of decision making is determining the process that will be followed for resolving the issue. This is another aspect of *how* the decision is made. How will the information that has been gathered

be prioritized? What ethical theory and which principles are applicable to the process? If there are several, how will they be prioritized as to which one will carry more decisional weight? Is it to be a democratic decision where the greatest good for the greatest number, such as family members, prevails? How will the minority voices be respected rather than marginalized? Does a rule need to be applied? If two or more provisions of the grief counselor's professional code of ethics appear to give conflicting guidance, how will the discrepancy be resolved? Are there particular legal issues to consider? In other words, a significant part of making the ethical decision is determining what the process will be. Another factor is the temporal aspect of the process. Is it a decision that needs to be made quickly because of some urgency to the problem? Or, is there more time for reflection and contemplation of how the information will be gathered and used? All of these considerations affect the process to be used in ethical decision making.

CASE EXAMPLE

Maria is a 16-year-old Hispanic female who lives at home with her parents and a younger brother. They are a strong Christian family and members of a charismatic church that believes in faith healing. Maria is in the final stages of cancer, currently hospitalized, and in much pain. The medical staff's recommendation is for her to be transferred to hospice care. Maria has been clear about her feelings. Even though she is young, she has been through a lot with radiation and chemotherapy. She now says, "I'm okay. Just let me go."

Maria's maternal uncle, her mother's brother, is the minister of their church. He actively proclaims evangelism and faith healing. He believes that Jesus is going to perform a miracle of healing for Maria, his niece, who is named for Mary, the mother of Jesus. He admonishes the family not to give up. He tells them they must have faith and believe that God is a healer who advocates for life.

The medical staff is in agreement that comfort care is the only viable option for Maria at this stage of her disease. Maria has indicated her personal preference not to continue suffering, but to *allow natural death* (AND) to take its course. However, Maria's parents have always been swayed by the teachings of their church, as presented to them by Maria's uncle. Therefore, her parents are praying for a miracle and want to do whatever is necessary for Maria to live until such a miracle can occur

“in God’s time.” Curiously, Maria’s younger brother seems to empathize more directly with his sister’s suffering and wants to let her go.

The medical staff wants to help Maria by suspending further medical interventions and by providing palliative pain control and psychosocial support through hospice care. They respect Maria’s position and view her as an incredibly courageous young woman whose wish to die should be honored. However, they also know that Maria, at age 16, is still a minor child, and that her parents have the final say in medical decisions for her. They seek the assistance of a grief counselor with experience in end-of-life decision making to help bring the medical staff, Maria, and her family to consensus, if at all possible.

Person

In the Five P Model, consideration of person is first. In the case example, the protagonist is Maria, a 16-year-old Hispanic female with end-stage cancer. She is a minor child who is unmarried and lives at home with her mother, father, and brother. She is fully cognizant of her condition and the futility of additional treatment. Yet, because she is a dependent minor, her parents still have legal authority for her medical decisions. Culturally, Maria and her family endorse an ethic of solidarity where they do not abandon or leave behind one of their own. Also, they are members of a charismatic Christian church that believes in faith healing. In short, for legal, cultural, and religious reasons, Maria’s wishes cannot be considered independently from those of her family and faith community.

Besides the extensive support of Maria’s family and the expertise of the health care team, the involvement of the grief counselor constitutes an outside resource brought to bear on the ethical dilemma posed by Maria’s situation. In addition, the hospital bioethics committee is available to advise, consult, or mediate.

Problem

The second dimension of the Five P Model is the problem. Here, the ethical problem lies in the fact that the patient, Maria, and the health care team favor hospice care for her terminal cancer, whereas her parents and church family want more aggressive medical treatment to prolong her life while praying for the miracle they seek. Thus, the two sides are deadlocked on how to proceed with Maria’s care. The medical staff does not want to inflict further suffering on Maria—that is, by “prolonging

dying” with use of a respirator and Intensive Care Unit (ICU) technology. Maria’s parents insist on “prolonging living” because they fervently believe that their prayers for a miracle will be rewarded with a dramatic turnaround in her condition; therefore, they cannot “give up.”

A complicating aspect of the ethical problem is the issue of Maria’s capacity for medical decision making. As a mature minor, her preferences generally are given serious consideration, but the final decision still rests with her parents (for a detailed discussion of minors’ capacity for their health care decisions, see Chapter 6 on end-of-life issues).

Place

The place where an ethical problem occurs is the third part of the Five P Model. Maria is currently hospitalized. Transferring to hospice probably means hospice home care. However, prolonging her life probably means the ICU. Location in a hospital setting has significant implications for the outcome of the medical decision. The health care team is in its home court and cannot be compelled to deliver treatments they deem unwise, unduly burdensome, or futile. Although charged to be an advisory body only, the bioethics committee may well have an eye toward preventing the hospital’s liability and could be perceived as “in the pocket” of the medical staff. Their neutrality would have to be clarified.

Likewise, the grief counselor has a staff affiliation at the hospital that allows the counselor to assume a professional role with Maria and her family. Does this affiliation influence the grief counselor’s objectivity? Because the hospital staff requested the counselor’s participation, will the counselor’s efforts be focused on the staff or on Maria and her family, or both, as the recipients of the grief counselor’s expertise? Is it possible for the grief counselor to function as a true ombudsman for conflict resolution with these location-driven parameters? (See Chapter 7, “Multiple Relationships in Thanatology,” for an extended discussion of how to handle such mixed allegiances.)

Principle(s)

Several ethical principles, the fourth aspect of the Five P Model, apply to this case example. Autonomy appears to be the most prominent principle in play. To what extent will Maria’s clearly expressed wishes about her treatment affect the final medical decision? In other words, will her parents afford her some degree of self-determination in choosing

comfort care over continuing treatment? Maria's level of autonomy is incomplete, legally speaking, because of her status as a minor; the autonomous decision really belongs to her parents, and not to her. Pragmatically, her autonomy is also limited by cultural and religious factors that promote inclusion of her natural family and her faith family in decisions about Maria's health care.

The concerns of the medical staff show that the ethical principles of beneficence and nonmaleficence are also in the picture. Their understanding of how to help a dying teenager (i.e., beneficence) is to make her as comfortable as possible by controlling her pain and providing social and emotional support. Nonmaleficence demands that non-curative medical treatments, which induce patient discomfort to administer and create unpleasant side effects afterward, are not pressed upon a vulnerable person with a terminal prognosis. Additionally, Maria should be protected as much as possible from the emotional distress accompanying the disagreement about her treatment.

The ethical principle of justice also figures in this case scenario. The grief counselor may point out that justice demands all voices in the debate be heard and respected. Further, justice includes deliberation about allocating resources. Should an ICU bed be made available for Maria, who is expected to die despite treatment efforts, rather than reserved for someone with an acute illness who has a chance of recovery?

Process

Amid the crosscurrents of these many considerations, determining the process for reaching a decision is the last step of the Five P Model. Although Maria is the patient, several people are involved in the medical decision making for her. The process may have to include all of them. The grief counselor, in concert with the health care team, can provide an invaluable service by meeting with the family members in various stages. For example, an initial meeting may include the minister-uncle along with Maria's parents, brother, and others. However, a subsequent meeting without the uncle may be important for clarifying the parents' position. The brother may figure prominently in the discussion given that he understands closely what Maria wants for herself. His input may counterbalance the uncle's influence. Finally, the counselor may talk with Maria herself about her personal preference and how she understands her parents' thinking in the matter. Such "shuttle diplomacy" can sometimes prepare conflicting parties for a mediated compromise.

In this example, there is a real sense of urgency that the decision must be made without delay. Given that Maria is dying, a course of action needs to be determined for how to handle her physical deterioration. The grief counselor, together with a representative of the medical team (e.g., oncologist, primary care physician, or hospice nurse), may participate in a bedside conversation with Maria to verify her wishes. Also, a similar meeting could include the grief counselor, the doctor, the parents, and Maria in order to finalize a plan. Perhaps some reframing could help the parents accept hospice care for Maria without feeling that they are compromising their religious faith—for example, limiting what medical treatments are pursued does *not* limit what their deity may deign to accomplish for Maria in the way of healing or cure (cf. Jacobs, Burns, & Jacobs, 2008).

SUMMARY

Overall, ethics is about decision making. In making decisions, there are always underlying values represented. Our review of the ethical theories in this chapter is intended to help readers recognize underlying values that they embrace when making ethical decisions. It should be obvious that there is no single perspective or ethical theory that is all-encompassing or always right. Certainly, the tradition of ethics in medicine has much to contribute to our understanding of the foundational principles involved in making well-reasoned, sensitive, and ethically sound decisions in the everyday practice of grief counseling.

Adopting a credible model for ethical decision making is imperative if grief counselors expect to resolve their own ethical dilemmas as well as help facilitate client and family decisions that often have to be made within a very short period of time. The Five P Model is proposed as one such model for ethical decision making that is particularly applicable to dilemmas that arise in grief counseling. It takes into account five elements fundamental to every ethical decision: person, problem, place, principles, and process. Appendix B contains a worksheet modification of Table 2.1 that the authors make available as a tool for ethical decision making with the Five P Model: “A *person* with a challenging ethical *problem* in a particular contextual *place* applies appropriate ethical *principles* in a deliberate decision-making *process*.”