

IS THERE A DUTY TO DIE?

and Other Essays in Bioethics

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9. Nat Hentoff, "Duty to Die?" *The Washington Post*, May 31, 1997.

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Introduction

I found myself watching the families. I was a college teacher trained as a philosopher, and now I was charged with the task of trying to turn myself into a bioethicist. I was unfamiliar with hospitals and uncomfortable in them. The medical jargon baffled me. I had no clinical eye to tell how the patient was doing. The new and largely undefined role added to my discomfort. I knew that I was supposed to help doctors with the ethical aspects of their decisions, but I couldn't even understand their conversations about those decisions.

The attention of the physicians and medical students I accompanied on teaching rounds was focused on the patient, and especially on the patient's illness. They talked mainly about the clinical variables that might provide the keys to restoring health, or at least combating the effects of incurable illness. The activities of other health care professionals—nurses, therapists, technicians—also centered on the patient.

Most of the time, doctors and hospital staff do not pay much attention to the patients' families. Yet even to my untrained eye, it was evident that a serious illness or death represents a profound crisis for everyone in the family. Death and dying are often much more difficult for the survivors than for the dying patient. Family members also sometimes suffer more than the patient from the patient's debilitating or chronic illness. Families are torn apart by disagreements over treatment options, and I could easily imagine those rifts echoing through the family for decades—"I'm still not speaking to Joe after what he did to Mom." I saw families struggling to cope with the consequences of decisions doctors and patients made—decisions that would often seriously compromise the lives of the patient's loved ones, sometimes even without substantial benefit to the patient.

This focus on the patient usually means that the discharge of a patient is thought of as the end of the story—she is gone, no longer a patient here, no longer in our care. A discharged patient is a success, a happy ending to the story. But a discharge is seldom the end of the story. Especially not now, when patients are frequently discharged still battling chronic illnesses rather than cured. Although a loved one in the hospital might once have been a brief disruption of family life, today the ramifications of decisions made in the hospital more frequently continue to unfold long afterward in the life of a family, sometimes for decades. Even when the patient dies, that is still not the end of the story. The death of a loved one and the *way* she died may rearrange the life of a family for a year or more. Indeed, a death in the family can haunt family members for the rest of their lives.

Hospitals—and most hospital physicians—are not very good at dealing with family crises or responding to the needs of those who love and care for the patient. Family members are “visitors,” not patients, so the staff often does not feel responsible for caring for them. The brief conversations physicians have with “the family” are generally social courtesies that serve only to inform family members about how the patient is doing medically. Sometimes these brief encounters are too compressed and not honest enough to ever be informative. Families are normally silenced—they are not consulted except when the patient is incapable of speaking for herself. Even then, family members are asked only what the patient would have wanted—never what they themselves want. What this illness or the treatment of it will mean for their lives is considered irrelevant.

I asked the hospital chaplain one day whether he knew of families that had been seriously damaged by what had been done in the hospital. “Sure,” he replied, “lots of them.” Then I asked whether he knew of families that had been made whole, stronger, or healthier by what was done in the hospital. He thought for awhile, “I can’t think of any,” he said. “None come to mind.” This, too, may be a result of the focus on the patient and on the disease of the patient.

When I left the hospital, I would return to my office to try to get myself up to speed in the literature of bioethics. I was surprised to find that families were also ignored and silenced by those writing in bioethics. The routine dismissal of the interests of the family I had witnessed in the hospital is sanctioned and promoted in the literature of bioethics.

Bioethicists almost unanimously advocate a “patient-centered

ethics," an ethics that claims that only *the patient's* interests and values are to be considered in medical treatment decisions. That makes sense when only the patient is (significantly) affected by a medical treatment decision. But that's often not the case. Why, then, are the rest of the family's interests not to enter at all into the moral equation, and certainly not if they conflict with what's best for the patient? How can it be ethical to consider only what's best for one—the patient—when decisions are made that will dramatically alter the lives of all members of a family?

I wondered whether anyone else was watching the families and thinking about what doctors and hospitals are doing to them.¹ I knew that sometimes the practice of medicine is ethically better than our theories of medical ethics. Some physicians, especially primary care physicians in rural areas, pay close attention to the impact of treatment options on their patients' families. Here is one doctor's account of how health care decisions were made 50 years ago in rural Nebraska:

The entire family used to gather around grandmother's bed and discuss whether to send grandma to the hospital or Junior to college. If she was able, grandma herself would sometimes participate in this discussion. I can see nothing demeaning or degrading to grandma in such discussions.

When I heard this story, I was struck by the moral sensitivity and wisdom displayed—here, in practice, was an ethic attuned to the inseparability of the lives of the members of families and to the implications of treatment decisions for the patient's loved ones. But it was hard to imagine such conversations in a modern hospital, or physicians participating willingly in them. And I could find nothing in either the traditional ethics of medicine or contemporary bioethics that would explain or justify such discussions and decisions.

A patient-centered ethics is, I sensed, fundamentally at odds with the ethics of families.² In a family, the working assumption is that any major decision will inevitably affect the lives of all members of the family. So the interests and well-being of all members of the family must be considered and weighed in making *any* major decision. In a family, no one's interests are irrelevant, and no one's interests are to trump the rest. No one—except for a very short period of time—should be the exclusive focus of the efforts of an entire family. Because lives within a family are deeply intertwined, there will inevitably be complex trade-offs and careful attempts to juggle or har-

monize the different interests of everyone. Attempts at compromise, as well as sacrifices, are needed all around. Loyalty to the rest is required of all. Finally, everyone in the family must be allowed to speak, not only of what she herself has at stake in a decision, but also about her vision of what would be best for the entire family. What each has to say must be heard; it must help shape any final decision.

What happened? How could the impact of medical treatment on the patient's loved ones and families have been overlooked and ignored or dismissed as morally irrelevant? How could families be so routinely silenced?

What I suspect happened is this. When philosophers and theologians became bioethicists and started going into hospitals, they succumbed to the focus on the patient and the health-related concerns of the hospital. They saw themselves as developing an ethics for doctors and began this task with an ethical analysis of the doctor-patient relationship. Focusing on this relationship, it was easy to fall into the unspoken assumption that the doctor and patient are the only two people in the picture, hence the only people who belong in the moral equation. In fact, the families often were not part of the picture—they were usually not present when decisions were made, and patient confidentiality could be invoked to make sure they would not be present. They were clearly peripheral to the focus of the hospital; they could be ignored, they *were* ignored. Bioethicists could also fall quite naturally into thinking of discharge as the end of “the case,” and if discharge is the end of the matter, families may appear not to have all that much at stake in treatment decisions.

So bioethicists fell into thinking in terms of the ethics of a dyad, the doctor and the patient. The ethics of this dyad seemed straightforward: The doctor is to serve the interests of the patient. The central issue then became: Who defines the interests of the patient? Bioethicists saw rampant paternalism in the doctor-patient relationship, with doctors making far too many decisions for patients. So they sought to empower patients by helping them recover the right to define their own interests, goals, and values and make treatment decisions on the basis of their own perceptions of what is best for them. “Let the patient decide” became the slogan of bioethics, patient autonomy its watchword. “Whose life is it, anyway?” bioethicists asked rhetorically, as if the lives of family members were separable and treatment decisions would affect no one but the patient.

This patient-centered bioethics fell neatly into line with the offi-

cial ethics of traditional medicine. The Hippocratic oath states, "Whatever house I enter, I will enter for the benefit of the sick." Moreover, doctors, nurses, and other health professionals are all trained to think of themselves as advocates for their patients. So bioethicists could say to health professionals, "Retain your patient-centered ethics and your patient advocacy. You are right to serve the interests of your patient exclusively. Only recognize that the patient is normally more knowledgeable about her own interests than we are."

That is a simple, manageable message. A patient-centered ethics also greatly simplified the task of bioethicists. All the new moral problems of medicine are much easier if only the patient's interests are considered relevant.

In the last 10 years or so, the powerful "cost-containment" movement in medicine has forced the expansion of the doctor-patient dyad into a triad that now includes the interests of "third-party payers." Since someone must pay for all this health care, bioethicists and physicians have reluctantly admitted that the interests of the payers—employers, insurance companies, the government, HMOs—are morally relevant. Just how considerations of cost to third-party payers are to be considered in the ethics of health care is currently *the* question of bioethics.

But through all this, the family is still left out of consideration. Strangely, only monetary costs—not human costs—are considered morally relevant to medical treatment decisions, and then only the monetary costs to an employer, the government, an insurer, an HMO, the hospital, or the physician. When the family must pay, the costs—both financial and human—again vanish from the moral equation. Worse yet, costs are increasingly being shifted onto families, as patients are discharged from hospitals "quicker and sicker." This practice substitutes care by family members for professional care, and the financial costs, too, are often shifted onto families. Most families have little ability to pay these costs, and they often "pay" in real sacrifices in the quality of their lives—unrelieved caregiving, social isolation, depleted savings, and lost careers.

If we do not think about families, we may not even fully acknowledge the sacrifices our cost-containment effort imposes on them. We see only that it saves money for employers, insurers, and hospitals; our only concern is that *patients* may not do quite as well with home care.

Seventeen years later, I am still watching the families. The deep conviction that we must not lose sight of patients' families dovetailed

with my interest in thinking about the ethics of personal relationships—love, friendships, relationships, and families—and the essays that make up this volume were born. They record my attempt to work toward a *family-centered* ethics of medicine to replace the patient-centered ethics of traditional medicine and contemporary bioethics. From my perspective, a patient-centered ethics of medicine is morally perverse. A patient-centered bioethics cannot be justified when the rest of the family also has important interests at stake in treatment decisions—indeed, interests often more important than those of the patient. Families and loved ones must not be silenced. Families must not be reduced to “patient-support systems” or to means to the well-being of patients. We must, then, substitute a family-centered bioethics for a patient-centered bioethics. These are the themes that unite these essays.

I do not have a complete family-centered ethics to offer. In particular, I still lack adequate accounts of justice or fairness within a family, and also of how family decisions about medical treatment are to be made. I have not yet been able to write about many of the subtler features of family life. Still, each of these essays represents a journey toward a family-centered ethics of medicine beginning from a different starting point. They are united by the conviction that an ethics of health care must take seriously the fact that major illness is, indeed, “an illness in the family.”

Most of the essays in this volume have been published previously and have not been revised for reprinting here. They are arranged in chronological order. Since all are variations on a theme, the reader is encouraged to read this volume selectively, beginning with the essay that looks most interesting and working out from there. Later essays in this volume do not require familiarity with earlier essays; in writing them, I could not assume an audience that would be familiar with my earlier work. Each essay had to stand by itself, and there is, unavoidably, considerable overlap and repetition among them.

The first essay—“In Search of an Ethics of Personal Relationships”—formulates my discomfort with the clumsy ways philosophers have talked about the ethics of personal relationships because of the impersonal context that philosophers tend to implicitly presuppose when they write about ethics. This essay will be of interest primarily to those concerned with philosophical ethics. “What About the Family?” is my first and most general statement of a family-centered bioethics. It provides perhaps the best general sketch of the project

that unites this book. “The Problem of Proxies with Interests of Their Own” reflects on proxy decisions—decisions made on behalf of patients who cannot speak for themselves. Virtually all bioethicists subscribe to a theory of proxy decisions that is, I argue, badly mistaken. “SUPPORT and the Invisible Family” comments on one small piece of the famous and important SUPPORT study of medical treatment at the end of life. This part of the SUPPORT study, which documents the financial and lifestyle consequences for families resulting from decisions to extend the lives of very seriously ill and dying patients, has received little attention or comment. “Elder Abuse, Ethics, and Context” considers the problem of defining abuse in situations in which the family must provide extensive care for an ill or debilitated family member. Although this essay focuses on care of the elderly, there are important similarities in the analysis of the care—and the abuse—of younger family members. “Dying at the Right Time” discusses a good death and physician-assisted suicide from a perspective in which “a good death” includes more than simply what’s best for the one who is dying. “Autobiography, Biography, and Narrative Ethics” addresses the central issue of who tells the story of an illness—who speaks, and who is silenced. To many, the entire line of thought I have been pursuing will seem to culminate in “Is There a Duty to Die?” A duty to die seems to carry a family-centered ethics all the way to the end of the line, to the most extreme conclusions that can be drawn from it.

A duty to die raises a host of troubling issues. My view that there is a fairly common duty to die is definitely a minority opinion, far from the prevailing wisdom of bioethics. Accordingly, I thought it important to include several different perspectives on this essay. Daniel Callahan, Larry Churchill, and Felicia Cohn and Joanne Lynn graciously agreed to comment on this essay. All have many other things they want to write, and I thank them. I have also reprinted Nat Hentoff’s response from his widely syndicated column in *The Washington Post*. My final essay in this collection is a reply to these commentaries.

The afterword contains two sets of less abstractly theoretical reflections. The first is the personal responses of my own family to the essay, “Is There a Duty to Die?” One of the concerns raised by a duty to die is how it would affect the rest of the family. The responses of my family may not be representative, but my family has been living for several years with the awareness that one of their loved

ones seriously believes he might one day have a duty to die. I thank my sons Bill and Jay, and my wife Mary for their reflections on an emotionally difficult subject. The second part of the afterword is a list of responsibilities of those facing the end of life. This list was formulated by a group of seniors, members of the Institute for Continued Learning in Johnson City, Tennessee. I thank them for permission to print this summary of their discussion. I think their list of responsibilities is an excellent starting point for discussion of the various dimensions of a responsible death.

I get by with a little help from my friends. I wish to thank Hilde and Jim Nelson, without whose assistance and advocacy this volume would not exist at all; Amelie Rorty for her support and encouragement at a critical point in my career; the physicians at the East Tennessee State University college of medicine who adopted a philosopher into their midst and patiently taught me something about medicine; my colleagues, mainly in the philosophy department at ETSU, who carefully read many earlier versions of these arguments; and especially my wife, Mary English, who helped me understand more about love, relationships, and family, and then worked with me to capture some of it in the words of these essays.

NOTES

1. The only book by bioethicists I know of that shows evidence of sustained reflection on families and health care is Nelson, Hilde L., and James L. Nelson, *The Patient in the Family*. New York: Routledge, 1995.

2. I have no definition of "family" to offer, but I do not restrict that notion to blood ties or legally sanctioned units. Although ties of blood and bonds of legality create their own set of issues, I am equally concerned about ties of affection and deep friendship. A deep, long-standing friendship is some patients' most important personal relationship; for some, it *is* their family. Nor do I assume that all family relationships are positive, supportive relationships. Ties of blood and marriage can create intensely antagonistic and hostile relationships. I believe that even the interests of a hateful and hostile family member are relevant to the ethics of treatment decisions, although the hostility is also a relevant factor. After all, hostility toward a relative does not make someone morally inconsiderable. Moreover, we dare not assume that the patient is innocent, that the hostility she now faces from her family is entirely unprovoked and unjustified.

In Search of an Ethics of Personal Relationships

Although it's been 10 years, I can still see the student, hands on her hips, as she brought my beautiful lecture on Kant's ethics to a grinding halt: "Is Kant saying," she demanded, "that if I sleep with my boyfriend, I should sleep with him out of a sense of duty?" My response: "And when you're through, you should tell him that you would have done the same for anyone in his situation." What could I say?

We do not search for what we already have. Thus my title commits me to the thesis that we do not yet have an ethics of personal relationships. And that is in fact my view, a view grown out of incidents like this one.

More specifically, I believe that for at least the past 300 years or so, philosophers thinking about ethics have tacitly presupposed a very impersonal context. They have unconsciously assumed a context in which we mean little or nothing to each other and have then asked themselves what principles could be invoked to keep us from trampling each other in the pursuit of our separate and often conflicting interests. Consequently, I contend, what we now study and teach under the rubric of ethics is almost entirely the ethics of impersonal relationships.

Various explanations might be offered as to why philosophers have thought in terms of impersonal relationships. Philosophers have historically been almost exclusively males, and males have generally believed that the public realm where impersonal relationships predominate is much more important and worthy of study than the private and personal dimensions of life. Or perhaps the assumption that we are talking about impersonal relationships reflects the grow-

ing impersonality of modern society or an awareness of the increasing ability given us by our technology to affect the lives of people quite remote from us.

However, even if philosophers were not thinking about personal relationships when developing their ethics, it might seem that an ethics adequate to impersonal relationships should work at least as well in personal contexts. For in personal relationships there would be less temptation to callously ignore or to ride roughshod over each other's interests, owing to the greater meaning each has for the other. Thus it seems reasonable to assume that the principles constituting the ethics of impersonal relationships will work satisfactorily in personal contexts as well.

But this assumption is false. An ethics of personal relationships must, I try to show, be quite different from the ethics of impersonal relationships. Traditional ethics is, at best, significantly incomplete, only a small part of the story of the ethics of personal relationships. Often it is much worse: basically misguided or wrong-headed and thus inapplicable in the context of personal relationships. In fact, much of traditional ethics urges us to act in ways that would be inappropriate in personal contexts; and thus traditional ethics would often be dangerous and destructive in those contexts.

We do not search for what we already have. I do not have an ethics of personal relationships, though I offer some suggestions about what such an ethics would and would *not* look like. Since my views about the ethics of personal relationships depend, naturally enough, on what I take a personal relationship to be, I begin with a brief discussion of the nature and structure of personal relationships.

But I'm going to cheat some: Throughout, I speak of personal relationships as if they were static. Although this is obviously a gross oversimplification, limitations of space and understanding preclude a discussion of the beginnings and endings and dynamics of personal relationships.

I

So what's a personal relationship? Personal relationships, as opposed to impersonal relationships, are of course relationships such as love, being lovers, friends, spouses, parents, and so on. But these sorts of relationships aren't always very *personal*, since there are all sorts of marriages of convenience, Aristotle's "friendships of utility,"

Hobbesian power alliances, and many varieties of quite impersonal sexual relationships. Consequently, we need to distinguish what are commonly *called* personal relationships (love, friendship, marriage) from personal relationships in a deeper sense. Even when they are not *personal* in the deeper sense, relationships like love, friendship, and marriage are not exactly impersonal relationships either. So I use the phrase “quasi-personal relationships” to cover such cases, reserving the term “personal relationships” for those relationships which are personal in the deeper sense I hope to explicate. I thus work with a threefold distinction between personal, quasi-personal, and impersonal relationships.

Let us begin with the distinction between personal and impersonal relationships. I want to say two things by way of characterizing personal relationships: (1) If I have a personal relationship with you, I want you. You (and your well-being) are then one of my *ends*. This would seem to be part of what it means to care for or care about another person. (2) If my relationship to you is to be personal, this end must be *you*—precisely you and not any other person. The persons in personal relationships are not substitutable, *salva affectione*.

Now, I need to explain these two points. But a full explanation of either would take at least a paper. And the first point raises all sorts of issues in action theory; the second, all sorts of metaphysical problems about what persons are and how they are individuated. Thus my strategy in this section is to say no more than necessary and to try to make that as susceptible to latitudinarian interpretation as possible. Hopefully, what I have to say will be acceptable to a broad spectrum of action theorists and metaphysicians. Ideally, all would be able to agree that there’s something right and important about what I’ve said, and the familiar disputes could then be rejoined, including discussion of the presuppositions and implications of my statements.

First, then, the idea of having you as one of my ends is to be contrasted with both sides of the Kantian dichotomy between respecting you as an end in yourself and treating you as a means to my ends. Kant would have me respect you as a person, just as I would respect any person, simply because you (all) are persons. To respect you as an end in yourself is to recognize that you have value apart from whatever use I might be able to make of you. It is, moreover, to recognize that your goals and purposes have validity independent of whatever goals and purposes I may have and to acknowledge in my action that your goals and purposes have an equal claim to realization. Although

respect for you and your goals is a part of a personal relationship, it is not what makes a personal relationship *personal*, valuable, or even a relationship. Instead, having you as one of my ends is valuing you in *relation* to me; it is seeing you and the realization of your goals as part of me and the realization of my goals. This is not, of course, to reduce you to a means to my ends. On the contrary, I want you. You are one of my *ends*.

The second characteristic of a personal relationship—that I want precisely *you*—serves to highlight the difference between this kind of relationship and impersonal relationships and also to further elucidate the difference between seeing you as one of my ends and seeing you either as an end in yourself or as a means to my ends. The characteristic intentions in personal relationships are different from those in impersonal relationships. It is the difference between:

wanting *to get* something (*T*) and wanting to get *T from you*.

wanting *to give* *T* and wanting to give *T to you*.

wanting *to do* *T* and wanting to do *T with you*.

The first set of intentions or desires structures impersonal relationships; the second, personal relationships. There is a big difference between wanting to be loved, for example, and wanting to be loved *by you*; a crucial difference between wanting to go to bed (with someone) and wanting to go to bed *with you*. This difference seems to retain its significance whether “*T*” ranges over relatively insignificant things like taking a walk, having your breakfast made, sharing a ride to a party, and going to a movie, or over crucially important things like baring your soul, receiving love and emotional support, sharing your living space, and having children.

If I want *something* (as opposed to wanting something *from you*), I depersonalize you, reducing you (in my eyes) to an *X* who is a possessor or producer of certain goods. For it's these good things I want, not you; anyone who could and would deliver these goods would do as well. The language captures the depersonalization nicely: I want “someone who. . . .” It is when I want *something* and you become for me a “someone who” is the possessor or producer of this good that I reduce you to a means to my ends. This kind of desire and the intentions it gives rise to structure an impersonal relationship, though many of what are usually called “personal relationships” are structured by precisely this sort of impersonal desire.

By contrast, in personal relationships of the deeper sort, “some-