

The Social Face of Death: Confronting Mortality in Paoli, Indiana

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Chapter 1: Introduction

Background

For the past twenty-five years, social reform movements bearing on medicine have stressed legal and ethical issues associated with death and dying, including questions of terminating treatment, euthanasia and assisted suicide. Every state has now enacted legislation on advance directives, and a growing body of judicial opinion focuses on associated issues. Unfortunately, the evidence does not reveal an improvement in the experience of dying in America.

The *Journal of the American Medical Association* recently reported the results of a major study conducted at five U.S. teaching hospitals. The researchers found that physicians discussed patients' preferences in only 41 percent of the cases in the study; that physicians misunderstood their patients' preferences in a staggering 80 percent of the cases; that physicians failed to implement patients' requests for do not resuscitate (DNR) orders in half the cases.¹

The SUPPORT study confirms the unsystematic observations of many observers. Americans continue to die badly, and current reform strategies are not working. Why have they failed?

Failure to improve the experience of dying may be related to the milieu in which legal and ethical reforms have occurred, a milieu characterized by the assumption that the core of the problem is political; that

professional bias, insensitivity and dominance have prevented Americans from dying as they would like. Given that assumption, it is natural to conclude that reform equates with increased power for patients. Hence the great stress on improved communication between patient and professional, on promoting advance directives and defending the right to refuse treatment. "Whose Life is it Anyway?" The question answers itself, and patient autonomy becomes the overriding concern.

If attempts to improve the lot of the dying based on this paradigm have failed, it is appropriate to question the accuracy of the original diagnosis. We may have been looking at the problem of death from the wrong angle; our social diagnosis may have been wrong. Perhaps we have focused too much attention on hospitals and other health care institutions, on doctors and nurses, on legislative reform.

We may need to take a fresh look at Americans' experiences with death and dying, how they feel about the end-of-life treatment their loved ones have received, and what average Americans think could be done to improve the lot of the dying and their families. To uncover the roots of the problems of dying in America, we believe we should try to listen again to what Americans say about their deaths and the deaths of those they know and love. Exactly what is it about death that they find most troubling?

This study offers a modest first step toward an answer to that question. We worked with limited staff and time; we studied a group of people easily to hand, and even at that we cannot claim a fully

¹The SUPPORT Principal Investigators, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)," *JAMA* 274: 1591-98.

representative sample of one small community. But we have listened to enough people to be confident that the concerns we identify are important to them. And they are important voices in the American chorus.

Why Paoli?

We chose Paoli as the site of our research for several reasons. First, Paoli is a good representative of an important segment of American life — the small, rural community. Further, Indiana University’s Center for Oral History Research, our collaborator in this project, conducted a community study of Paoli in the late 1980s, and we wished to capitalize on that entree to the community. Finally, the town is only 45 miles from Bloomington. Its proximity and small size eased the logistics of travel to the site and enabled us to find our way around easily. We envision this project as a pilot study; we hope to replicate this research in different settings.

In order to maintain some degree of confidentiality, we use our respondents’ real first names with surname initials.²

The excerpts from the interviews included in this monograph are faithful to the transcriptions, but they are not absolutely literal. We have silently deleted false starts (“She, she still seems to be aware, though?”), placeholders (“uh,” “okay?”), and brief interpolations by the interviewer (“I see”). Square brackets indicate that we have corrected a slip of the tongue by substituting the appropriate word (“We’re not [immortal]”) or to show that we have added

²Appendix A provides pertinent demographic information (sex, age, occupation), along with descriptions of Paoli and our methodology for this study.

words to clarify meaning. Ellipses (. . .) indicate the deletion of text. The pipe character (|) is used sparingly to indicate an abrupt change in the flow of thought (“She lived | She raised me”).

Talking about death

Americans’ reluctance to discuss death has been and continues to be well documented,³ and we observed that reticence repeatedly during our interviews. Some of our respondents recounted incidents that illustrate the difficulty of discussing these subjects even — or particularly — with family members. For example, when we asked Jim B how his parents had prepared for their deaths, he shared a poignant anecdote.

Jim B: Mom had a living will. Dad did not. Mom gave it to me several years ago, being the oldest in the family. She said, “I want you to have this.” And she broke down when she handed it to me. . . . I don’t know why she never explained it. All she did was hand it to me. And I read it. I looked at it and realized right off what it was, and tears came to my eyes, and she was crying a little bit, and that was the end of it.

JAG: She just gave it to you, and you didn’t talk about it at all?

Jim B: No. She said, “This is something I want you to have.”

Many of our respondents said outright that it is very difficult to talk about death. A notable exception was Hazel B, a 98-year-old-woman. She does not shrink from

³See, for example, Beverly A. Tyler, Michael J. Perry, Teresa C. Lofton and Frank Millard, *The Quest to Die with Dignity: An Analysis of Americans’ Values, Opinions and Attitudes Concerning End of Life Care* (Appleton, Wisc.: American Health Decisions, 1997); J. Hofmann, N. Wenger, R. Davis et al. for the SUPPORT Investigators, “Patient Preferences for Communication with Physicians about End-of-Life Decisions,” *Annals of Internal Medicine* 1997 (127): 1-12.

talking or thinking about death, but she is very aware that she is unusual in this respect.

Hazel B: Some people maybe think I'm nutty, I don't know, but I don't mind talking about it. I know that I can't live much longer. *I know*. And what's the use to worry about it? You'd live less if you did. You worry yourself to death about it, why, might go sooner than you think, you know.

Several respondents noted that Americans have a hard time accepting the reality of death, that shrinking from death is a part of our culture. Chris L, a 28-year-old school teacher and minister, believes that "most families are [not] willing to talk about death because they think that talking about it is going to bring it about." David C, a minister, believes that many consider discussion of death as a "taboo." Miriam G, a physician, illustrated the terror associated with the subject.

Miriam G: I have an elderly patient right now who | really, we ought to be thinking about [his death]. But every time we start to bring it up, everybody in the family starts to cry and turn around and like, "Oh, God. Let's not talk about that." He's sick, and 80. We have to discuss this. But we can't because it's frightening to even go in that direction. It's too terrifying.

Death is not an easy subject even for professionals who must confront the topic regularly. Chris L said, "I'm not very open about it myself, and I've dealt with people who are dying several times. And it's very difficult to broach the subject of death and what's going to happen."

Sadly, sometimes an elderly or ailing relative wants to plan for her or his death, but the family refuses to listen. As Dan F, a 39 year-old funeral director, put it, "I think some people are [reluctant to talk about death with their families], but I think it goes farther than that. I think that we're reluctant to listen to them." Lucille D, 79, regrets her refusal to talk with her mother about her

impending death and has learned a valuable, if painful, lesson from the experience.

Lucille D: A few years before my mother died, she had a stroke, and for three weeks she couldn't talk. But she wrote everything in little notebooks. And she knew that she was dying, and we did the wrong thing. My brother and sister don't feel as bad about it now as I do. She wanted to talk to us before she died, and every time she'd say anything about dying, we'd say, "Mother, you are going to be all right. You're going to get better." *We* couldn't handle it. It wasn't her. I have learned now: Let them talk. They want to talk to you about dying. Let them talk. I don't know if I can handle it that way if it happens again, but I do know that we did the wrong thing about Mother. She wanted to talk, and I knew *I* wanted to talk, but I was afraid to.

This quotation captures a major conclusion of our study: that despite their uncertainties and reservations, people want and need to talk about death. We will return to this issue in our conclusion.

Finding an idiom

To a significant degree, then, our interviews engaged our respondents in an unusual and uncomfortable activity. They spoke with grace, courage and generosity about painful experiences — painful merely to remember, let alone to articulate. In the midst of personal, concrete and specific comments, unique to every individual, we noticed a more social, abstract and shared idiom in which death is described as "a part of life," and the most important consideration in preparing for death is spiritual preparation.⁴ Insofar as this idiom is based in a strong religious faith in an afterlife, it may come naturally to our

⁴Although we did not use the phrase in any of our questions, eight of our respondents (31%) talked about death being a part of life. Sixteen out of the twenty (80%) respondents who were explicitly asked about relatives' or their own preparation for death responded initially in terms of spiritual preparation.

respondents. In Paoli, religion is a public and shared part of just about everyone's experience. In contrast, physical and emotional pain, the degrading aspects of debilitating illness, the mental anguish of the bereaved, are private and difficult to put into words.

For 98-year-old Hazel B, the conviction that death is a part of life and that she has been forgiven for her mistakes seems to be a source of considerable comfort.

Hazel B: Sometimes I feel like [my death] is going to be pretty soon, too. [laughs] Death is a part of life, and I don't let it worry me. I'm not afraid to die. . . . I know that with my heart like it is [pause], I could live three or four years, or I could die tonight, and there's no need to worry about it because it will pull on me if I do. That's the way I feel. I may be wrong in that, but I don't think I am.

Sometimes the observation that "death is a part of life" was offered in other contexts, as when Stanley H, a 41-year-old farmer, told us that he hoped his three young children would be able to accept the deaths of their loved ones as a part of life. Cynthia W, a 54-year old teacher whose family has experienced a number of painful deaths, expressed a similar sentiment: "[My children have] experienced a lot of sadness at a very young age. I think they're learning that death is a very natural part of life."

Jim P, a hospital administrator, noted that we must accept the painful aspects of life along with the pleasant ones.

Jim P: I soon will be 39, and I've had a very good life, very healthy life. And even when people around you have gone through that dying process — my grandfather and grandmother — that's just a part of living. And so you can't change it. And so I don't get angry.

John H, 44, a Catholic priest, uses the concept when he counsels families who are

trying to decide whether to continue life support.

John H: First of all, I tell them — whether they are Catholic or non-Catholic — I give them my religion's perspective, being that we don't have to use extraordinary [means]. . . . Help them to realize that death is part of living. That we're all going to die.

This stress on "death is a part of life" was supplemented by a strong and distinctive set of religious concerns. For David C, 49, a maintenance man and minister, the hereafter is real, and spiritual preparation is vital.

David C: We need to realize that death is a part of life. You know, all of us are going through that doorway. And much of the time when we're healthy and as we're younger, it never crosses our mind that we must go this way. And contrary to what a lot of people believe or some think, there is a hereafter. And preparation for that hereafter is important.

When asked how they thought their loved ones had prepared for death, or how they should prepare for their own deaths, a striking number of our respondents responded in terms of spiritual preparation. Here are just a few examples:

David C: I think [my mother] was prepared by her faith in God. And she said, "Whatever the Lord has in store, that's okay with me."

Bethel C: Let the good Lord take care of it, I think.

Mabel G: Well, I think you had better be ready to go at any time you are called. I think that you had better not do things that you don't want held against you.

Stanley H: Of course, I think you should be ready spiritually for that at any time.

Harvey M: Spiritually, I would want to be prepared. I don't want to have any question about where I'm going to be in the hereafter.

Religious language and belief are part and parcel of our respondents' thinking about death — or at least of the way they talk about death. Listening to or working with them entails speaking that language and taking those beliefs seriously.

“Death” and “dying”

It is clear from these excerpts that the majority of our respondents firmly believe in an afterlife. John T, 50, a school administrator, put it most explicitly: “I believe in a heaven and a hell.” This belief is relevant to some significant points about the words “death” and “dying” that became apparent as we analyzed the transcripts. In our interviews, it seemed that “death” often shifted in its significance depending on whose death was being discussed. Several of our respondents said, “I am not afraid of death,” meaning that they are not afraid they will face annihilation or damnation when their own lives end. But people who say they are not afraid of their own deaths may well find the thought or the experience of the death of a loved one intolerable. Jim P believes that for people who are prepared for their own death, dying is not hard; but it can be hard on their survivors.

Jim P: I am not ready for my parents to die. . . . And it’s going to happen. It’s going to happen. . . . But I also think about it and think death is not hard on the people that are dying. If they are ready to die. If they are ready to die. Death is hard on the people left behind.

Typically, when asked about their greatest concern about their own deaths, respondents emphasized their regret at having to leave their families behind. Harvey M is 44 years old, a funeral director and minister. He put it very simply.

JAG: What concerns you about dying?

Harvey M: My family. Just simply leaving my family. Other than that, I don’t have any fear of death at all.

Similarly, if Dan F, 39, were to die soon, he would be most concerned about family issues.

JAG: What worries you or concerns you when you think about your own death?

Dan F: Well, right now it’s that my wife would remarry and marry someone who would help take care of my kids. If I didn’t have the kids, I’d just want my wife to be happy.

In contrast to “death,” the term “dying” seems to refer to a *process* that can take minutes, days or months. Dying can begin and proceed without anyone being aware of it. Often, however, the dying process is measured from the time that the relevant parties (e.g., the dying person, friends and loved ones, health care providers) realize that this person will not survive this illness. In a way, this is a social, rather than medical, understanding of “dying.” This distinction is relevant because the physical or biological process of dying can begin long before anyone realizes it, and thus before it can be socially acknowledged. Sometimes it is only after death that survivors recognize that the deceased had been dying — before death, they had not realized he or she was mortally ill.

Our respondents know that the process of dying can be undignified, frightening, lonely and painful. Even though they have faith in a loving God and an afterlife, they still dread dying. Although Dan F’s greatest concern is about how his wife and children will get along after he dies, he is also worried about pain.

Dan F: I have a very low threshold for pain. . . . I don’t want to be in pain. I had kidney stones when I was in Indianapolis. I’d hate to live through something like that.

Similarly, Dan’s minister, Pat F, 41, does not want to die painfully.

Pat F: For most people, I think [the most difficult thing about dying is] the fear of the unknown. [In] my Bible school class, we were talking about death just last Sunday. And one man said, “Pat, how can you talk like that?” He said, “I am so afraid.” And I said, “Well, . . . I’m afraid of *how* I’m going to die. I mean, I don’t want

to die in a burning car wreck. I don't want to die of some really slow, painful disease."

Pat F, like many other respondents, does not perceive a contradiction between being unafraid of death and being afraid of dying. Spiritual preparation helps, but some concerns remain.

The plan of the monograph

Before we began interviewing for this study, we hypothesized that major concerns for people facing death would include *suffering*, both physical and emotional, including fear that pain and other symptoms would not be adequately treated; *control* of health care and the dying process; and concern over the *cost* of end-of-life care.

These issues were of concern, although we were discovered that financial issues featured less prominently in respondents' comments than we had anticipated. The structure of this report is adapted from our original hypotheses in accord with our findings from the interviews. In Chapter 2, we describe some of the dramatic impact of improved medical technology in this century. Many respondents remember a time when dying was a relatively quick and seemingly inevitable process, when people often died at home with little medical intervention. Unlike their parents and grandparents, our

respondents all too often face decisions about terminating treatment for their dying loved ones. Virtually all of them have thought about enacting an advance directive, but hardly any of them have followed through.

In Chapter 3, we describe many of the challenges that respondents have confronted when their loved ones were dying, including the challenge of communicating with health care professionals and the differences they encountered in end-of-life care in hospitals, hospice and at home. We also recount respondents' attitudes toward the termination of treatment, their fears about pain, and their financial concerns.

In Chapter 4, we describe sources of comfort for survivors, including the power of religious belief and the importance of emotional support from friends, church members, and professionals. We found that funerals are important rituals in Paoli, and that disposing of the deceased's property is painfully divisive for some families.

In the conclusion, we summarize our findings and offer some suggestions for change — either building on initiatives already in place or branching out in new directions.

Chapter 2: Changing Experiences

Dramatic changes in medicine over the last hundred years have had a profound impact on the experience of death and dying. Death rates have plummeted, especially among children, and life expectancy has increased so that most people can now expect to live past middle age. The dying are cared for in institutions, rather than at home, and Americans have lost their familiarity with the dying process. Medical technology has enhanced our ability to sustain life to the point that death now occurs as the result of decisions made by families and health care professionals.

When we asked our respondents how they thought the experience of dying in America had changed since their parents' generation, the question was interpreted in a variety of ways. For example, Stanley H, a 39-year-old farmer, said that he did not think changes in technology make much of a difference in the experience of death because "you're dealing with a human emotion there, and I don't think technology is going to do a whole lot to change the human emotion."

Others mentioned ways in which the experience of dying has been transformed, including changed attitudes toward treatment and customs surrounding illness and death. Many of our respondents observed that death was more familiar in previous generations, more a part of the domestic sphere, less removed from everyday experience. They reported that their parents and grandparents were more resigned to death, in part because medicine was less effective in the past. Before the widespread use of antibiotics, for example, many young people died quite suddenly of infection.

With advances in medical technology, more and more conditions have become treatable and curable. One ill effect has accompanied advances in medicine, however: In contrast to the time when once death was typically sudden and inevitable, many respondents have had to face decisions about continuing treatment — or, as some of them suggest, prolonging dying — for their loved ones. One societal response to this change has been the enactment of legislation on advance directives allowing people to specify what kind of treatment they want (or do not want) at the end of life through living wills and to name a proxy who can make decisions for them if they are unable to make their own decisions.

When death was domestic and inevitable

Many of our middle-aged and older respondents recounted childhood memories of illness and death in which extra-family institutions, such as hospitals and funeral homes, played a much smaller role than they do today. Hazel B, who was born in 1899, described the death of her 14-year-old brother.

Hazel B: He had a congestive chill. He had scarlet fever, you know, and he had a vaccination, and I guess that was infected. . . . My mother had a wood stove. It sat out a little ways from the wall. And he had on a leather jacket and all that, but he just got in behind that stove and just squatted down and said, "Oh, I'm so cold." And he just kept getting worse and worse, and they called the doctor. . . . And the doctor came, and he said, "Well, I—" He couldn't find very much of anything, only just chills, and this thing. And he said, "I'll give him a shot, and I believe he'll be all right in the morning." But you know, he died before morning.

Pat F, a 41-year-old minister, told a story that vividly captured earlier generations' familiarity with death.

Pat F: I can remember my grandfather telling me a story about how his brother had an emergency appendectomy right there on the kitchen table. They operated, and he died right there on the kitchen table. . . . And I said, "Threw away the kitchen table, didn't you?" And he said, "Well, no. It was the family table." And I thought, "How can you eat off the table on which your son or your daughter died . . . with emergency surgery?" But I guess because they were so exposed to death. People died at home. . . . A lot of times [nowadays] people don't know how to deal with death because they have never seen death.

Blanche and Exum H, a married couple now in their seventies who are farmers, described the customs of their youth. They reported that people who were seriously ill were kept at home, and others gathered around to offer comfort and support. In contrast to the present, when illness and death are cordoned off in hospitals or nursing homes, illness was a social occasion in those days.

Blanche H: I can remember when I was a kid that when people were real bad sick, they kept them at home. And like on Sunday afternoons, all the neighbors that would be going to church would gather in, and they'd sing songs, and they would sit around and tell stories and laugh and, you know, try to be cheerful. And here's this person that's really sick and about ready to die in the next room or maybe in the same room. Well, people don't do that any more.

They do not regret the passing of this custom.

Exum H: How would you like to be hurt and suffering and then the neighbors gather right in and sit right around your bed?

Blanche H: Yeah, even if you're just sick like with the flu or something, you don't really want a lot of people around you. You just want to get out by yourself and lie there in the bed.

In those days, the custom was to bring home the body of the deceased for another social event. The H's are glad that this custom has disappeared, in part because of the imposition it made on the family of the deceased.

Blanche H: A lot of times they would take the body back to the house.

Exum H: They did Grandma, and then they came and sat up. That was standard practice, to sit up with them all night long.

KDP: So you don't miss the fact of people coming over when you're sick. But how do you feel about the fact that we don't sit up with bodies anymore?

Blanche H: I think it's okay to take them to the funeral home. . . . I don't miss that either, having people come here and sit here all night and have to stay awake. Maybe try to feel like you have to entertain them.

Brenda C is a 45-year-old newspaper reporter. Her grandmother died when she was six years old, and the body was brought to her home. Her memories of that experience are not warm.

Brenda C: The practice of bringing the body home and the wake at the house was still going on. And I remember that the bedroom where the casket was, was a room that we just passed through as fast as we could go through after that, some kind of scary aura about that room at Granny's house. We didn't ever go in there again. . . .

KDP: Well, it doesn't sound like a custom you miss. [laughter]

Brenda C: No, not at all.

Some of these customs may have been peculiar to rural Indiana. But death may have been more of a domestic experience in the early years of this century because society was less mobile. Especially in small towns like Paoli, grandparents, parents and children were more likely to live in the same town, the same neighborhood or even the same house.

David C: It had been typical in days gone by that death was kind of a community thing. Family was close by. And you stayed close together. . . . My grandmother and grandfather just lived right next door [to my parents].

To Harvey M, the previous generation's more domestic experience of death is linked

to their ability to accept death better than many of today's young people.

Harvey M: Most of those people died at home, and a lot of times the family was always around . . . more than they are today, where in my experience, most people are dying in the hospitals, and sometimes the family is there, and sometimes they're not. I think the feeling of accepting death is different. You know, I think with the older generation, I think they accepted death more as a part of living, where the younger generation feels like that they're almost indispensable. "We're going to live forever." And they don't accept death as well.

We encountered differences of opinion on how well the previous generation accepted death, however. Brenda C described her father's prolonged mourning for his own father

Brenda C: I remember as a child when my dad's father died, I was only six, and I have this vivid memory of every time that we went by the cemetery where he was buried, we pulled into that cemetery. He was buried in the very front, and so his headstone was the first one there in the front row, and we parked the car, and we sat there while Daddy cried. And it happened every time we went by that cemetery, and so | and maybe it's just because we're different people, but I remember that that was always such a sad time to go down that highway because I knew what was going to happen sooner or later.

Brenda C also described a vivid childhood memory of funerals characterized by "a church of wailing people."

Between the domesticity of death and the relative ineffectiveness of medicine, death was more a part of everyday life and people did not tend to — did not have the chance to — avoid it or fight it to the extent that we do today. Pat F commented on this change in attitude.

Pat F: I think in some ways when people died then, they died. Here you can keep people alive. And I don't think I would have a problem with a DNR, but . . . I really think . . . maybe my parents might. But back then, you didn't have that choice.

Higher expectations

Many respondents commented on the ways in which the experience of death and expectations about treatments have changed since their parents' and grandparents' days. A few expressed a similar sentiment without explicitly comparing the modern-day setting with their elders' experiences. The expectations associated with more effective health care — the fact that serious illness is no longer generally seen as leading inevitably to death, and the fact that sudden death is less common — may make it harder to accept death. For example, Gerald J, a 51-year-old school administrator, reported that his father was in poor health for the last 22 years of his life, and spent the last 18 months in a hospital. For Gerald J, the long illness made it easier to accept his father's death, but that was not the case for his mother and sister.

Gerald J: My mother and my sister never did realize [that my father was going to die]. The [doctors] had fixed him so many times. And they had literally fixed him a dozen times anyway. . . . And he'd come home and be good for two or three years, you know. But they literally didn't believe he'd ever die. They thought that they could fix him again.

Harvey M, a funeral director, agrees that we may have unrealistic expectations of our health care system. "I think so many times we put a lot of faith in our health care providers, and we think the ultimate miracle is always going to come through." He repeated this sentiment when he was asked about the most surprising aspect of death.

Harvey M: I think that. . . we put so much faith in our health care providers in this country that I think the realization that we are human, and we're not [immortal], and we're going to die. That age has nothing to do with it. You know, I think that's one of the things that probably is the most shocking. . . . [A]s young as [my friend] was, we just never thought he would pass away. I mean, we thought. . . "[H]e's strong,

he's healthy and... he'll come out of this and have to have some treatments." You know, the regular routine with cancer. And it just didn't happen. . . . [W]hat happened just was not what we thought.

The loneliness of dying

Jim B remarked on what many consider to be the most dreadful aspect of facing death.

Jim B: In death we do it basically alone. And a lot of things in this life we don't do alone necessarily. . . . But that in itself is going to be a lonesome trip.

Jim B is describing an essential part of the human condition. However, it seems likely that more people are experiencing death in isolation from their loved ones as death has moved into institutions and traditional networks of support have shrunk or vanished with the increased mobility of the population.

When asked what people feared most about dying, Ann W, a nursing home social worker, mentioned dying alone, even though the interviewer named a host of other, perhaps more obvious concerns.

Ann W: The biggest thing I see in the nursing home is that they don't want to die alone. As long as there is somebody there with them, even | I had a lady die about a week and a half ago, and her roommate asked two days ago, "Can you please put somebody in this room? I can't stand being alone." And she's a person that comes to activities, she has visitors that come in, her family comes in, but she can't stand being by herself. . . . [For one patient in particular] that was the only thing that ever worried her, was dying alone. That she was going to be alone. Because her family never came to see her. . . . I went and sat with her the night she died for hours, just because she didn't want to be by herself.

Chris L, a 28-year old minister and teacher, described his efforts to console a dying woman and his feelings of inadequacy in the face of death. He concluded that his mere presence made a difference.

Chris L: [T]he main thing was just hand holding. . . . That's what she wanted more than anything. If she wanted me to come over that day, she wanted me to

hold her hand, she wanted me to talk and just to be with her. And that's what most people want. You see, I think a good death, to go back to that question, includes not dying alone in some cold, sterile hospital room far, far away from home. That it should be in a place where those that you love are able to be with you to the very, very end.

Difficult decisions

The dark side of improved medical care is that it may force wrenching decisions on people whose loved ones are critically ill. Funeral director Dan F told us about a woman whose insistence on continuing treatment for her mother exacted a tremendous cost from the woman, her mother and her family.

Dan F: [Her mother] was covered in bed sores from four years being in a fetal position. And she would go there every day and visit. And it wrecked her marriage. Her kids didn't care for her. But she had forsaken everyone because, I guess, of the guilt feelings she had with all the stuff that she maybe didn't do for her mom. And she finally died. It was like her body had died years ago, but her brain just forgot to tell her heart to quit beating. And that was sad. Not for what it did to that poor lady, and she finally got out of her misery, but what it did to the rest of the family.

Sometimes the decision to continue treatment is made by the patient, as was the case with Cynthia W's father. While he was capable of making decisions, he demanded aggressive treatment — "Give me anything that will help me." But when he lapsed into a coma, Cynthia W and her sister were forced to make decisions for him, which has been agonizing.

Cynthia W: Since my dad had cancer of the pancreas, he wasn't able to eat, and he was just wasting away. And so the oncologist suggested we put him on IV feedings | It's called TPN, total [parenteral] nutrition. | to build him up a little bit so he could endure the chemotherapy. Well, we did, because my dad wanted the chemo. He knew about the TPN. He agreed to that. And the oncologist said, "We will dispense with the TPN once he's over the first few treatments and he gains his strength." But my dad never did gain his

strength to the extent the oncologist wanted. So he is still on TPN today [about six months later], and it is keeping him alive, basically to suffer. . . . And the nurses that saw him said they had never known anyone who stayed on TPN this long and that when they're as bad as my dad they have long discontinued this, because it's just prolonging the inevitable.

When it became clear that the treatment was not having the desired effect and her father would never be strong enough to undergo chemotherapy. Cynthia W and her sister asked him if he wanted the treatment discontinued.

Cynthia W: We spoke with my father about it two weeks ago and asked him if he wanted to be removed from it. And he said, "Yes." So they came to remove it, and when he realized what he had said yes to — which we thought he *did* understand — when he saw them taking it out, then he screamed, "Oh, I want it back, because I'll be committing suicide if I don't use it." So we hooked him back up to it. Now he's at the point where he can't make *any* decisions.

This story is a wrenching example of how the hope offered by advanced therapy can dashed, transformed into a nightmare of prolonged suffering and has imposed the need for agonized decision making that could not have been imagined a century ago.

Even when patients have clearly expressed their wishes, family members may experience anguishing situations. Dan F found himself in the painful position of defending his father's refusal of treatment against the urging of the medical staff, in effect supporting his father's decision to die.

Dan F: [My father] had a living will. He did not want to be resuscitated. No heroic means of any type. And they called us from the hospital [and told us] that his kidneys had shut down, and they could take him to the hospital and pump all the fluid off of him and put a feeding tube in him and then put him on dialysis. That's the first time I ever saw my father cry. He looked up at me from his hospital bed, and he said, "Danny, please don't let them do it." They had a feeding tube in his nose, and he had pulled it out three times. And they just threatened him and said, "We're going to surgically implant it."

And he looked at me and said, "Danny, please don't let them do it." And you know, the Sunday night when they called and said he was real bad and they could take him to the hospital and do all this stuff, I called my sister, who is in the health care field, and she said, "Well, if you want to, I'll back you." But she said, "Are you doing this for yourself or for Dad?" And it was hard.

Dan F honored his father's wishes, and treatment was discontinued.

Jim P's account of his uncle's death also reveals some tension between the wishes of the patient and the health care providers, who favored chemotherapy. Jim P's uncle, however, preferred to accept the fact that he was dying. He remembers his uncle's experience as an example of death with dignity.

Jim P: They wanted to go through chemotherapy, and his question was, "Is it going to make a difference? And if it is not going to make a difference, I don't want to be drugged up. I don't want to be sick the last three or four or five weeks or months or however much time I have left. I want to be as with it as I can be. I want to spend time with my family." You know, they wanted to keep him in the hospital, and he said, "No. It's not going to make a difference. They can come in, and they can help me with the medication pumps or whatever I need."

When David C's mother was dying of cancer, she received home care. He and his family were confident in their decision not to revive her if she were to experience cardiac arrest.

David C: [The health care providers wanted to know] if she would go into cardiac arrest, if they would want us to revive her. I was the only one there when the doctor asked that question, and I said, "Absolutely not. We're in a no-win situation. Why prolong | You know, if the Lord decides to take her with heart failure, then let's allow that to be."

Advance directives

In earlier times, no one would have had to face the difficult decisions described above, but today they are a constant threat. Ever since the name Karen Ann Quinlan

became part of our national vocabulary, we have been haunted by the specter of uncontrolled medical technology keeping a patient alive via artificial means long after her family had concluded that it was time to allow her to die. The Quinlan case and others like it led to legislative reforms, most notably the enactment of legislation allowing for advance directives or living wills, which allow people to specify in advance the degree of medical intervention they want. It is not clear how faithfully health care providers respect living wills, but it is clear that not many people implement them. We explicitly asked sixteen respondents whether they had a living will; only two (12.5%) had executed such a document, although others reported that they were considering it or definitely planned to do so.

Mere awareness of the availability and importance of living wills is not an adequate motivator to get people to prepare them. That fact was brought home by the comments of Jim P, a 39-year-old hospital administrator. He reported that his parents have living wills, but although he has spoken on the importance of advance directives on many occasions (“how to do it, why you should do it”), he and his wife have not yet completed living wills.

Arthur D, a 59-year-old attorney, has not executed a living will himself, although he has often helped other people prepare them.

Arthur D: I don't think people have really taken advantage of living wills, maybe like they should. They think they'll live forever. . . . Usually the one that requests a living will has had a relative to die and kept alive artificially, . . . and they always remark, “I don't want that to happen to me. . . . I don't want to be kept a vegetable for the rest of my life.”

Some respondents described their gratitude that a dying relative had prepared a living will, although they had not yet

executed living wills of their own. Cynthia W is one example.

Cynthia W: I don't [have a living will] now, but I'm going to get one. My father-in-law had one. It made things so much easier. He was just very up front about what he wanted and what he didn't want. My father didn't have one, and my father's been, “Give me anything that will help me.” And his death has just been a very dragged out affair. Now he's not capable of making those decisions, and my sister and I are having to make those decisions, and it's very, very hard.

One reason Cynthia W's father did not have a living will was a misunderstanding. He feared that preparing an advance directive might be final, precluding the possibility that he might change his mind.

Cynthia W: My dad has said, “Why do I want to write out a living will? Tomorrow they may have a cure.” And he says, “What if I signed that living will? Then I can't get out of it.” And we told him, “Well, Daddy, yes you can. If you're still able to talk and there's a cure and you want the cure, we're going to give it to you.” But he says, “No, somebody might mess it up some way, and then I wouldn't get it.” In Daddy's case, he was afraid to sign it because he felt legally he'd walked into something that he couldn't ever change.

In a similar vein, Dan F expressed a belief that may be shared by many people in our society: that once heroic measures are initiated, they cannot be terminated short of brain death.

Dan F: That is what you always hear, though. You know, “Once we put them on it.” Once we put that feeding tube in my father | And then if you do do it, and then you are going to be held responsible for it.

Several respondents have been involved in the death of a loved one who has had a living will; all have found them helpful. One example is Blanche H's mother, who is in a nursing home on tube feedings. Although her living will is silent on the topic of artificial nutrition and hydration, it specifies that she does not want to be maintained on a respirator. Blanche H described her feelings of gratitude that her mother has made known

at least some of her wishes about end-of-life care.

Unfortunately, health care providers do not always have living wills on hand at the crucial moment, as Dan F learned to his great frustration.

Dan F: I just went through this with a dear friend of mine. They had the do-not-resuscitate order at the nursing home, but it didn't come over to the hospital. So they had to fax it over. . . . They send charts back and forth. Why can't that go with them? . . . That was kind of frustrating. . . . I was the one that told them. It was February 1 when he died, and I was the one that told them. You know, I said, "He has a living will." And they said, "No." And that was just kind of frustrating.⁵

It is clear that advance directives can be useful, but only if health care providers are aware of them and respect them. We fear that the legislative reform that authorized advance directives was easy compared to the social and cultural changes that will be necessary to increase significantly the number of people who execute living wills or health care proxies and to ensure the health care system's compliance with living patients' wishes.

Physician-assisted suicide vs. withholding treatment

One recent response to fears about prolonged dying is the movement toward legalizing physician-assisted suicide. We did not ask explicitly about physician-assisted suicide or euthanasia, but a few respondents raised the subject on their own. They clearly distinguished between actively taking a life,

which they disapproved, and withholding treatment, which they thought in some cases was not only acceptable but morally necessary. For example, Blanche H believes that her elderly mother is suffering, although she is not experiencing physical pain, and death will be welcome. In keeping with the provisions of her mother's living will, she would not authorize the use of a respirator.

Blanche H: I don't think it's up to [family members] to make the decision, because she has the living will that she said she didn't want to be put on those things, and so we would honor her wishes. . . . [My mother] is in mental anguish because she can't communicate with us. But as far as physical pain, I don't really believe that she is. . . . You'd hate to see people just waste away like that and suffer so long. But still I don't believe in this doctor-assisted suicide, either, or killing them to get them out of their misery. I don't think that's right. . . . Let them die a natural death, but don't hurry it up. Don't give them something to kill them.

Several respondents who had had to make decisions about withholding or withdrawing treatment agreed with that assessment.

Hospital administrator Jim P attributed public approval of the practice to Americans' wish to assert control over the manner and timing of their deaths.

Jim P: I think [people turn to assisted suicide because of] a fear of having to watch someone go through a very morbid dying process. . . . I just think that we are a fast food world. And we don't want to have to wait. And we don't want to be inconvenienced. And in a lot of ways, we don't want to inconvenience the family that's left behind. We don't want to bankrupt them. So let's get it over with. Let's make it happen.

He thinks that people who seek assisted suicide are often "weaker," not "strong-minded."

Jim P: And they are, in some ways, being led by what's easy. You know, let's take the easy road out.

The few other respondents who mentioned physician-assisted suicide also disapproved of it.

⁵Dan F's experience was not unique; see R. Sean Morrison, Ellen Olson, Kristan R. Mertz, and Diane E. Meier, "The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings," *Journal of the American Medical Association* 274:478-482.

On the other hand, no one seemed to think that every life should be extended at all costs. The most eloquent and impassioned statement on that issue came from Ann W, a social worker in a nursing home.

Ann W: When you're 88 years old or 90 years old and you've had a great, wonderful, full life, and you are literally *suffering*, why not just let that person go? . . . I start early with families, saying, "Trust me. Honestly. If this person were 50 years old or 60 years old, and he was going to get up and walk around next week and be fine, you know, and suffer from a heart attack and you could do CPR and bring him back, there would be *nothing* that would keep me from doing it. But this person is 98 years old. And the first time they lean on his chest to do CPR, they're going to break every rib. They are going to puncture his lungs. He's going to go through more pain than you can imagine to be brought back for fifteen or twenty minutes? Or two weeks, even. Do you want to do that to somebody?" I mean, that's the last thing that they can possibly know is this *crunch* from a 200-pound doctor? You know, and unless you get really specific and very vivid, no. They want Grandma and Grandpa to be kept alive at all costs.

Summary

Many respondents have observed at first hand the change from a time when death was a familiar aspect of the domestic sphere to a time when death is hidden away in hospitals; from a time when most forms of serious illness amounted to a death sentence to a time when medical technology is able to combat, if not defeat, virtually all kinds of ailments. Modern medicine has not conquered death, however. As Stanley H observed, the essential experience of loss and grief has not changed.

Modern medicine has virtually eliminated many causes of death. It has made it possible to prolong life and to maintain a high quality

of life in the face of death. At times, however, modern medicine prolongs *dying* rather than living. One of the few tools available for dealing with such circumstances is the advance directive. Almost all of our respondents knew about the availability of advance directives; many whose deceased relatives or friends had advance directives found them very helpful and expressed their gratitude for the security of knowing the individuals' wishes. Very few of our respondents have executed advance directives of their own, however — including the attorney, who has drafted living wills for clients, or the hospital administrator, who frequently tells audiences about the importance of preparing an advance directive. Only a few respondents mentioned physician-assisted suicide, and none of them favored or endorsed the practice.

With or without a living will, death always prevails in the end, and in some ways the delaying tactics of modern medicine make that final curtain all the more agonizing for survivors. Perhaps the most difficult aspect is making the decision that *the time has come*, a decision that people seldom, if ever, had to face before the advent of modern medicine. Cynthia W, who has witnessed many painful deaths, described the twin agonies of watching a loved one suffer and witnessing the end of that suffering.

Cynthia W: [One day I was really crying and upset, and my grandmother] told me, she said, "You shouldn't feel that way." She said, "There are things much worse than death." And I know now what she meant. It was the suffering that one goes through before you die. Death is almost merciful after that.

Chapter 3: Coping

Although some respondents had first-hand experience of serious or even life-threatening illness, they were not terminally ill patients. Rather, they were survivors who, for the most part, were reporting their impressions and observations about *others'* illnesses and deaths. Several major themes emerged from the interview questions that addressed issues of coping.

First, we asked specific questions about the deaths respondents had encountered, whether their loved ones had had the deaths they wanted, and what kind of death they would prefer for themselves. Another constellation of questions about coping had to do with patients' and families' interactions with professional health care givers. We wanted to know whether our respondents had experienced the communication problems that have been widely reported. We heard some accounts of physicians who failed to offer accurate, comprehensible information or who tried to treat patients more aggressively than they or their families wanted. On the other hand, many respondents praised physicians and other health care givers' compassion and support.

Third, we tried to explore some options for care at the end of life. We found that our respondents had little experience with hospice, which is relatively new to the area. They had divided opinions about the impact of high technology in medicine, acknowledging its positive potential but also its ability to prolong the dying process and to maintain the lives of persons whose quality of life appears to be poor. In addition, their comments appeared to reflect the

community's deep reservations about placing family members in nursing homes.

Finally, we asked about the costs of medical care for the terminally ill and funeral expenses. To our surprise, respondents' comments did not reveal a major role for these concerns in their thinking about death and dying.

How we die

Many respondents firmly stated that the manner of their death is in God's hands, not theirs, so that discussion of what constitutes a good death struck them as abstract or hypothetical. When they were pressed, the most common answers to "What kind of death would you want?" were "quick" or "in my sleep." As John T put it, "I'd like to just go to sleep and not wake up." Similarly, Hazel B said, "I hope that God sees fit for me to just be found here."

As we mentioned in Chapter 2, we did not speak with anyone who endorsed euthanasia or suicide, whether physician-assisted or not, and several respondents explicitly condemned it.

Although "quick and painless" was clearly the most popular choice of death, a few respondents preferred to have some warning before they died, so that they could make preparations and say goodbye. Exum and Blanche H agreed on this point.

Exum H: I'd say that a pretty way to go [would be like] L.L. up there. 87 years old, relatively good health . . . right up until the last, and then he finally realized his time was getting short. And I'm not so certain that that's not a pretty good way to go. . . . You live a fairly healthy life to a fairly old age and . . . then realize that your time is short.

Blanche H: So you have time to tell people goodbye, I guess.

However, David S, a 43-year-old minister, was ambivalent about forewarning of his death.

David S: Ten or fifteen years ago, I thought that the kind of death that I would want would be a death that I knew was coming. Now I don't know that I still hold to that. . . . But I think it affords a person the opportunity to do some important things that you wouldn't have the opportunity to do if death were unexpected. Even though it may mean a prolonged illness, even though it may mean the treatment and the suffering and all the sickness that goes along with that. And it would still, I think, give me an opportunity to talk to my family about it and prepare them and to think about it myself. And so you know, maybe that would still be the kind of death I would choose. I don't know.

Pain

No one wants to die a painful death, although David S's comments clearly reveal his understanding that an opportunity to prepare for death might entail suffering. Similarly, David C, 49, a maintenance man and minister, noted that it might be God's will that he die in pain.

David C: [W]e do not get the privilege to choose what we must endure. Hopefully, it would be quick. But then it may serve the purpose of God more for me to endure something for a long period of time to show strength and stamina to those around me.

Surprisingly few respondents reported that relatives or friends had suffered significant physical pain at their deaths; when asked specifically, many said that they did not think that pain was a major concern. However, those few who did have direct experience with painful deaths were seared by the experience. Brenda C had a co-worker who had been in pain for years before her death.

Brenda C: Her spine was so curved that she eventually had trouble breathing because of it and was on oxygen. . . . I think in the last year of her life, she was basically

bedridden. And her bones were so fragile that just moving, she'd end up with a hairline fracture, and so she had to be in terrific pain all the time. . . . I thought, "I don't understand why she's being punished so."

Likewise, Cynthia W witnessed the suffering and death of many relatives — her grandmother, her mother, her father-in-law, her cousin — all of cancer.

Symptom control

With these exceptions, most respondents expressed confidence that pain and other symptoms can be and are adequately controlled. Pat F, a minister, clearly thinks that pain control has improved dramatically.

Pat F: Ten years ago, when I'd see people dying in pain, they died in agony. I don't see people doing that any more.

Some respondents whose professions expose them to contact with death disagreed on this point. Dan F, a funeral director, described one case.

Dan F: They had her on so much morphine that she did not know she was in pain. But when I went to embalm her . . . I opened up her hand, and she had been digging . . . just dug the fingernails and just tore the skin out. You know, she was in pain. Now that was not a nervous habit. . . . She had to be in pain. And I don't think anything can stop the pain.

Similarly, Miriam G, a physician, told us that in her experience, efforts at pain control are not always absolutely successful, in spite of claims commonly made to the contrary.

Miriam G: I know that we're told over and over again that you should be able to do it, but I'm not absolutely convinced that we have all the tools to do it. And I don't tell patients that, because I don't want to terrify them.

This difference in the experience of pain control raises interesting questions. Perhaps the physician and the funeral director think that pain control is not always adequate because they have more occasions than other

respondents to observe dying and death and thus are more likely to see difficult cases. It is possible that pain control is generally inadequate and respondents were simply lucky in their experiences of death. It is also possible that respondents tended to block out memories of painful deaths, or simply did not know that some of their loved ones or friends had painful deaths, or avoided thinking and talking about painful deaths.

Prolonged dying

Respondents seemed to have reached a consensus that a long, lingering death, particularly a death preceded by dementia, is more to be dreaded than pain. Many respondents expressed a widely shared horror of prolonged decline and debility. They described their dread of the loss of independence and finally of capacity and asserted that some fates are "worse than death." These comments reflect familiar and widespread American attitudes, which are often reflected in the debates about physician-assisted suicide or euthanasia. Fear and rejection of helplessness and dependence, even in dying, are not confined to Paoli.

When Blanche H spoke of her 87-year-old mother's condition, the pain was evident in her voice.

Blanche H: She had a stroke a year ago in August. It left her paralyzed on the right side, and she can't speak, and she can't eat. She has to be fed through a feeding tube . . . [S]he was just on the go all the time, and she loved to talk, and it's really been hard on the whole family, because she can't communicate with us . . . It just seems like she keeps kind of going down. . . . We just have to understand that she's not like she used to be at all. But it seemed like right after the stroke, she was aware. And she'd smile, and she'd listen to our stories we'd tell about things that were happening. And she was interested. It was strange, because it seemed like after she had been there for a year, she just sort of changed. It looked like she just looked at the calendar

and just kind of gave up. Like she's thinking, "Well, I've been here a year, and I'm not any better." And that may be just my imagination, but it seemed that way to me, and I think some of the others noticed it, too.

Similarly, Gerald J, 51, was virtually raised by his paternal grandmother and had a very close lifelong relationship with her. As he spoke of his grandmother, his respect and admiration for her clearly showed. "She knew how to live a good life," he said; "she was my answer person." He described her deterioration in her last years as "probably as hard on me" as her death.

Gerald J: She was 96 when she died. She had Alzheimer's the last few years she lived, which was a very sad thing. And I really and truly believe. . . that I would have rather seen her die than have to go through that. Because she was such a fine person and such a thoughtful person and such a caring person. . . . Her body outlived her mind. . . . She lived too long. She literally lived too long.

Communicating with professionals

As noted in Chapter 2, dying is no longer a domestic experience. Coping with death today almost always means coping with a massive, complex and potentially intimidating health care system. Medical professionals oversee the dying process and, to a degree, control it, and communication with them can be a source of great frustration and anxiety for the dying and their families. It can also be a source of considerable comfort, however.

Learning to communicate

Many respondents praised physicians and other professionals they had encountered during the illness and death of loved ones, citing moving examples of empathy and support. David C described his mother's final illness.

David C: She was in the hospital several weeks. And the nurses became so attached to her that they came by and kissed her goodbye.

Jim P described a care giver who extended herself for a bereaved family.

Jim P: [R]ecently, when an individual died, the home health nurse actually went with the family members — the wife — to pick out the casket. And she didn't have to do any of that. . . . You know, it's like, . . . "I know you've got other work to do. . . ." And she said, "Well, my boss would expect that this would be a part of what we're about. . . . You don't have that support mechanism. You don't need to go do that alone."

However, several individuals reported problems in communicating with health care givers. This finding is hardly groundbreaking: Physician-patient communication has been exhaustively studied, problems have been thoroughly documented, and numerous improvement strategies have been proposed. Breakdowns have been variously attributed to paternalism on the part of professionals; patients' and families' intimidation or insecurity; barriers imposed by complex technical language; and the inability of individuals under stress to absorb the information that professionals are attempting to convey.

It may be useful to identify the specific contexts of some of the communication problems reported by our respondents. One of the most anguishing experiences they described was the effort to determine the condition or prognosis of a sick or dying person. Physicians may lack the data to assess a patient's condition; they may hesitate to make predictions in a situation of uncertainty; or they may shrink from giving bad news to the patient's family. On the other hand, families may have difficulty identifying the best — or any — source of information. The most striking story we encountered was Pat F's nightmare experience when his four-week-old son was diagnosed with bacterial meningitis. The child was hospitalized in a teaching hospital.

Unfamiliar physicians delivered the terrifying prognosis that the child would be "mentally handicapped, blind, deaf" and "because of his age and inability to fight the infection, that he would probably die."

Pat F: I don't think we ever met the primary care physician. We dealt mostly all with nurses, students, but to ask a specific question? Nobody could answer it. They'd say, "Well, you would have to talk to your doctor." We didn't know who our doctor was, because our family physician did not have privileges at that hospital. . . . But here he was, all plugged in with all those wires . . . all these monitors and tubes. . . . And to see a little four-week-old, you know, just taped down to boards. . . where he couldn't move.

Compounding this professional indifference, Pat F's family ultimately learned that their child would be discharged from the hospital not through a doctor but through a friend who had called the hospital to check on his condition. (The baby made a complete recovery.)

Inadequate or unsatisfactory communication with health care providers need not be attributed to paternalism or professional indifference; many explanations are possible. Cynthia W's comments led us to think that one significant factor is simply experience. Few people outside the health care profession have much experience communicating with physicians. Perhaps, like most of the complex and difficult tasks we face in life, communicating with health care providers during a serious illness is a learned skill. (It may be that discussing these matters with anyone is a learned skill; that would be one explanation for the difficulties we recount in Chapter 1.) Cynthia W's daughter has had frequent hospitalizations, and many of her relatives have died. Over time, this 54-year-old teacher has learned how to talk to physicians.

Cynthia W: I used to think of doctors as gods, almost, and that whatever they told you it was gospel truth and

you had to do exactly what they told you and there was no other way to think of it. And with [my daughter], I found that some doctors are better than others and that you as a parent have a right to question the treatment of your child. And I spend more time with my child than anyone else, and if I know and have observed something about her that they haven't, then it is my right to speak up and say something, even if it contradictory to what the doctor says. . . . So by the time Mother became ill, it didn't bother me to ask the doctor a question. What had changed was that we were dealing with a disease that I knew very little about, so I wasn't sure what questions to ask. And now in the case of my father, I know more about the disease and what kind of questions I need to ask, so therefore I'm getting better answers.

Chris L, a teacher and minister, learned that deference to the doctor's expertise is not always in order and that it is sometimes necessary to be assertive with health care providers to obtain the information needed.

Chris L: They are not going to go out of their way a lot of times to be a help to you. You have to buttonhole them and say, "This is what I want to know," and really follow up on it and be serious about it. Otherwise they are not going to do that for you.

We have a sense that for many of our respondents, as is probably the case for many Americans, this kind of assertiveness with health care professionals does not come naturally. Strategies to increase patients' and families' sense of empowerment and comfort in communicating with professionals will be helpful.

Having a translator

Several respondents described the advantages of having a relative in the health care profession. These interpreters can translate technical language for the family and provide an informed liaison with the professionals involved; in addition, their familiarity with the family may give them a better sense of how much bad news people can take, and when.

For example, when his father-in-law died of cancer, Arthur D and his wife were frustrated by their attempts to communicate with health care providers.

Arthur D: Some of the local physicians tried to ease the pain, and they don't really | They talked in circles as to what the nature of the cause was, and I have a nephew that is a medical intern in Philadelphia, and my wife called him, and we got more straight information from him than we did local or state doctors. . . . She asked direct questions, and he gave her direct answers as to cancer treatment available, why a doctor does this, why he does not do this, what is the likelihood of survival, chemotherapy, radiation, what have you, but we got more information from my nephew than we did perhaps from the doctors at the [hospital].

Similarly, when Harold M's mother died, communication with health care providers was facilitated by a nephew.

Harold M: My nephew at the time was living in Sellersburg and was going to nurses school. . . . And he had a way of kind of getting information that many of the rest of us couldn't get. . . . He knew how to approach it.

Likewise, when their father was dying, Dan F's sister, who runs a rehabilitation hospital, did most of the communicating with health care providers.

Softening the blow

Health care providers are more successful at getting information from their doctors than other people for a variety of reasons (although even Miriam G, a physician herself, reported problems in communicating with health care providers during her husband's illness). The general tenor of the discussion of medical ethics would lead one to speculate that paternalism is the chief cause of communication breakdowns. Harvey M believes that sometimes even treatment may be an attempt to soften the blow, undertaken more for the sake of the survivors than the patient.

Harvey M: Most of the time [doctors will] come in, and they'll say, you know, "They're not doing very well. You know, we need to put them on a ventilator or respirator. And this will help them breathe." And you know, I think a lot of times they know that probably pneumonia is going to set in and, you know, they are not going to come off that respirator. But I think that they think that we need to go through this. And . . . it's . . . not necessarily for the patient as much as it is for their survivors, to give them time to realize Grandmother is not going to make it, or Mom's not going to make it, or Dad's not going to make it. I just wonder sometimes if they realize that this is not really going to sustain their life. And when it comes time for them to die, they're going to die. But I think that they think we have to do this to prepare folks.

It is not clear whether Harvey M approves of this kind of treatment. Intended to provide an opportunity for families to prepare for a death, it may raise false hopes.

As a physician, Miriam G has often faced the challenge of deciding when to tell patients they are dying. She thinks it is important to share this information when the patient or the patient's family is ready to hear it.

Miriam G: Except where there's a need for them to know immediately so that they can make arrangements, I tend to wait for them to come to a point where they say to me, "This is not going to get better, is it, doc?" And then I can generally say it, because I feel very strongly that people mostly know what's happening to them and that if I push that on them, then that's dealing with it at my pace as opposed to theirs. I will never, ever, ever not tell someone the absolute truth when they ask me.

Disagreements with health care providers

Sometimes difficulties in communication arise when patients and their families differ with health care providers. We heard of a few situations in which health care providers seemed to try to appropriate decision-making authority or to make it more difficult for the family to make or stick to a decision. Lucille D's mother was diabetic, had cancer

and suffered a paralyzing stroke a few weeks before her death. The health care providers barred the family from her mother's hospital room when she was dying.

Lucille D: I didn't see my mother just before she died. She was in the hospital. We were there, but we were on the outside of the door, and they wouldn't let us in. And they kept coming to the door, and the nurses would say, "We'll let you in in a minute." But when they came they said, "We can't get her back." So apparently they were trying to revive her. Why would they, when she was paralyzed on one side, she couldn't talk, she couldn't swallow, she couldn't eat. Why would they? I don't know.

Lucille D's comments raise the question of whether she would have authorized a resuscitation attempt, given her mother's multiple problems. Another example of conflict between care providers and a patient's family was related by David S, a minister, about a woman in his church.

David S: Her mother wouldn't eat, wouldn't take any medication by mouth, really wouldn't do anything. And they were wanting to put the feeding tube in. [The daughter] didn't want the feeding tube. Her brother didn't want the feeding tube. The lady herself didn't want it. But the doctors and the nursing home felt like that would be the thing to do.

Harvey M is a funeral director and minister. He encountered a similar conflict with a physician over the treatment of A, a friend he cared for at the end of her life.

Harvey M: Her blood count got very low, and [her doctor] came in, and he said, "Well, if A was looking down upon us today, do you think that she would want a blood transfusion?" And I said, "No. She . . . has expressed to me she does not want that." And then of course he began to . . . question me, you know. "Well, who gave you this authority to make this decision?" You know, and of course *she* did.

Physicians have a profound responsibility to ensure that their patients receive appropriate treatment, but wrangling over treatment aggravates an already painful experience for the dying person's family.

Jim P is a hospital administrator who worked for six years as a paramedic in an emergency room. He provided a partial explanation for this kind of conflict when he observed that physicians often have a hard time admitting that a patient is dying.

Jim P: It is hard for them to [face] the fact that when it's time for someone to go, it's time for them to go. And by equipment or medications or whatever, they may be extending the dying process. They're certainly not extending the living process.

Jim P has observed this problem firsthand, as when an oncologist was inadequately forthright in informing a friend of his true prognosis.

Jim P: I had trouble with the oncologist that took care of our friend. . . . I thought he waited too long in telling him the prognosis. And as such, then, they weren't prepared initially to deal with that. And I think he could have let them know more about the negative side of the prognosis.

Jim P believes that health care providers are reluctant to tell their patients that death is imminent because "they don't like to deal with death and dying any more than anybody else."

Jim P: I think it's easier if they give somebody a little bit of hope than there is to say, "There is no hope. We can make it palliative. We can take care of you. We can try to control your pain. But let's think about that. Let's think more about how to control the pain. How do we control the dying process? How do we bring your family and friends into this? How do you want to deal with that?" And that's where I think the hospice programs are much more adept at handling that than other physicians. Physicians go back to a chance to cut or a chance to take care, a chance to cure. And some things aren't meant to be cured.

He told us that some physicians consider the death of a patient to be a failure, and that they are no better at dealing with illness and death in their personal lives than anyone else.

Jim P: I think if you look at how [health care providers] deal with death in their own families, you can see that

as they go through that process that they don't deal well with that death at all.

These issues are so important to Jim P that he describes the best physicians as those who understand when it is time to let someone die.

Jim P: [The best doctors are] the ones that can sit back and listen and see what that person's needs are. What it's going to take for them to go through it. . . . That is the kind of physician that I want taking care of me, is one that isn't going to keep tubes in me when everybody knows you're going to die. Let it go. Let it go.

Good communication

It is easy to overemphasize difficulties communicating with health care professionals, and we must note that many of our respondents had nothing but praise for the people who treated their loved ones. When his father was dying, John T found the health care providers forthcoming, frank and compassionate. Pat F, a minister, recently observed excellent communication between the family of a dying person and a local physician.

Pat F: Just [recently], someone in our congregation passed away. And it was so neat to see the way Dr. M in town came in and talked to the family. Told them their options. I mean, the options were not good. Basically he said, "We can do this procedure here, and we can keep him alive." . . . He said, "We can keep him alive, but he is not going to survive. You know, so it's a matter of do we want to just prolong this existence in this bed, which is no quality of life, or do you want us to pull the plug?" . . . He knew the family for a long time. And that may make the difference, too.

Miriam G shared an example of close communication from a physician's point of view.

Miriam G: I think the most intimate experience that I've had was when I lost one of my patients at 38 to breast cancer. And I became extremely close to her over a period of time. In fact, I was there at the moment of her death at home. And I can remember the exact moment. She was an incredibly humorous and tough

and a marvelous person. I don't remember whether she said to me, "This is not going to go away." Or I said, "Look, I'm not sure we can do anything else about it." But I know that there was a moment when both of us realized that there was going to be an end to this process that I could not in any way stop. So we knew each other quite well at that point.

Close, long-standing relationships between care providers and patients must make this kind of communication easier and more common. But a high level of professionalism can have a similar beneficial effect. Jim B's father died at a hospital outside Orange County.

Jim B: I can't say enough good things about the hospital, from the doctors, to the nurses, to everybody we've met there, and I've said this to so many different people. I felt the doctors were very empathetic but also very informative, did not hesitate to call a spade a spade, but by the same token, they tried to be optimistic and encouraging as much as they could.

Respondents often stated that established, personal relationships with health care providers helped immeasurably as they confronted death and dying. Those whose loved ones died under the care of a physician with whom they had had a long-term relationship thought that communication was better and care more compassionate. For example, when Dan F was facing the possibility of extending or curtailing treatment for his dying father, a local physician told him how he had responded in a similar situation.

Dan F: He said, "You know, we went to all the heroic measures on my mother. She lived for a whole 'nother year," he said, "drawn up in a fetal position laying in a bed." And he said, "You know, we done my mother wrong." And I thought about that a lot since he told me that.

Likewise, Harvey M said, "I think a lot of times in the rural area, [doctors will] be more honest with you because they're closer to their patients."

Hospital administrator Jim P told us that he believes his hospital is able to provide more personal service than hospitals in larger communities. Earlier, we reported his story about a home health care nurse who accompanied a widow to pick out a casket.

Jim P: And I think you get that in a smaller community, where in a bigger hospital or a bigger community, you can't. Because they're moving from patient to patient to patient. Here, we have fewer patients per each nurse because of the geographic distance that we have to cover. And in a Louisville, you know, they're going to give you, "Here's your ten patients. Go take care of them." . . . But so I think here, as health care providers, we have more of the opportunity to give a more personalized care than what you are going to get in a bigger community.

In general, respondents seemed to prize candor and realism from their care givers. They wanted honest assessments of the patients' condition and prognosis, and they particularly appreciated physicians and others who could deliver these assessments with kindness and compassion.

Where we die

Respondents talked about deaths that occurred in hospitals, nursing homes, hospices and at home. Many factors determine the preferred option, including the patient's personal preferences and the availability of appropriate care. Several respondents noted that having many options for end-of-life care is important. Dan F drew on his own profession as a funeral director for an analogy with health care.

Dan F: The thing is, when people came in here to buy, we have [never] said, "You have this copper casket. That's what you're going to go in." No, we have 19 in this small little funeral home. Why not give people a choice on their dying? Give them three or four different options.

Opinions were divided on the abstract question of whether it is better to die at

home or in an institution. Hazel B, 98, thinks it is better for survivors if their loved ones die in the hospital.

Hazel B: Now if they die at home that memory is with you all the time, you know, and if they die in the hospital, why, you do get away from that part of it, you know. . . . It just seems like a make-believe thing.

Harvey M shares this belief, based on the experience he had as a child, recounted in Chapter 2, of staying in a bedroom in his grandmother's house where a man had hanged himself.

Harvey M: I don't necessarily want to die at home. I think it would be better for my family if I died in a facility like a hospital or a nursing home. Because I think there's a lot of feelings where they come in and they say . . . "I don't believe I can live here in this house any more." . . . Or I don't want people saying, "Well, he died here in this bedroom, and I hear him walking around all the time."

In contrast, several respondents talked about the institutional restrictions that can be avoided if one dies at home.

Jim P: I don't want to die in a hospital. You know, I'd rather die at home or some place where | Because we're so restrictive on how many people can be in a room. And you know, you can't have twenty people around.

As Dan F put it, "I think hospitals are good for illness, surgeries and getting better, but they're cold. You know, institutionalized."

Of the options for care at the end of life, nursing homes were clearly the least favored. Respondents do not want their relatives to go into a nursing home or to have to go into a nursing home themselves. Pat F expressed this sentiment concisely.

Pat F: I was really comforted when I read one time that only like 1 percent of Americans go into nursing homes. And I don't know how ancient that statistic is, but that gives me a lot of comfort, because I don't want to go to a nursing home.

Several persons indicated that they regarded nursing homes as a last resort, adopted only in cases where the family was unable or was no longer able to care for a loved one. While they acknowledged the need for professional care at a time when traditional care givers are now employed outside the home, many nonetheless associate nursing home placement with feelings of shame and guilt over the "failure" to provide care at home.

For about the last eight years of her life, Gerald J's grandmother lived with her son, L. Eventually, her health deteriorated to the point that L could no longer adequately care for her. Gerald J spoke at length about how difficult it was to make the decision to admit her to a nursing home.

Gerald J: That was a tough one. My uncle couldn't do it. I finally went and took her and put her in the nursing home personally. Because he was down. Emotionally it was getting him down. . . because he had to watch her all the time. She got to where she would run off. . . [and] he just couldn't deal with that. . . . He just had to watch her all the time, and he really couldn't make a decision to put her [into a nursing home]. . . . He just couldn't do that. That was the thing that she always told us she didn't want, and we all respected that. And we really tried hard to avoid that, but it just got to be where | My sister, my mother and myself were all working steady jobs, and he was at the point where he couldn't do it any more. . . . So I just went one day, and I said, "L, we're taking her to a nursing home." He said, "We can't do that," and I said, "We've got to do that if you're going to live." And that's all there was to it.

On the whole, he felt that his grandmother received good care, and he was certain that nursing home placement was the best option available to the family. But he also clearly felt that it would have been much better for his grandmother to have been cared for at home, had it been possible. His comments accurately reflect attitudes expressed by many respondents.

Gerald J: [A nursing home is] no place to be if there is any way to avoid it. I don't care how good they are. . . . I suppose there's just nobody that can replace your family. . . . Anybody that I've ever seen go there has a tendency to feel that their family has abandoned them. And there's no way around that.

Other respondents echoed this view. Even when a good nursing home is available, sending a relative there represents, to them, the family's failure. When someone is sick enough to be hospitalized, the decision has a certain clarity that makes it a bit easier. But families often have the sense that if they would or could just work a bit harder, they would be able to keep their relative at home. Thus sending a relative to a nursing home, away from the family, often brings on a sense of failure.

This aversion to nursing homes is not primarily due to a perception that the level of care is inadequate (although a few respondents mentioned understaffing and other problems), but rather because nursing homes represent the family's inability to care for the dying person and they are associated with a long, lingering death. Everyone seemed to agree, though, that there are cases where a nursing home is the best option. Dan F seemed more favorable toward nursing homes than average, but most respondents probably would have agreed with the sentiment he expressed.

Dan F: I think the nursing homes are a very good thing, because I think there comes a time when people cannot take care of them on their own. Why burden them by making them do so?

Much the same can be said of hospitals: People generally do not want to die in a hospital, but they know that only hospitals can provide appropriate care in some situations. Respondents generally seem to share two perceptions about the differences between hospitals and nursing homes. First,

hospitals more often represent continued hope of a cure, whereas nursing homes tend to be seen as places where people slowly decline and eventually die. Second, hospitals are believed to be designed for relatively short-term care, whereas a nursing home stay can go on for years. The lack of hope associated with nursing home care, combined with the dread of a long, drawn-out death, make the prospect of being committed to a nursing home dismal.

Care in bigger hospitals vs. care closer to home

Although local, familiar health care providers may offer a more personal touch, several respondents expressed the belief that Orange County's small hospital lacks the capacity to treat some serious conditions. They feel that patients would get better care for some grave diseases at a larger, more distant hospital.⁶ Distance makes it more difficult for friends and family members to visit the patient, but respondents generally asserted that the benefit of better care outweighed this inconvenience. This sentiment was expressed both by respondents who had had the experience of their own or others' hospitalization in a more distant city and by respondents who were speculating on what they would choose if faced with such a decision. Arthur D, a 59-year-old attorney, provided one example of the latter group.

Arthur D: I told my wife that the best medical care available is in Indianapolis or Louisville. . . . Better physicians tend to gravitate toward larger metropolitan centers. . . . I'm not saying all physicians are better, but I think the quality of medical care is far superior in a large metropolitan area. So if I were seriously ill I

⁶ From Paoli, it is about a one-hour drive to Bloomington, two hours to Indianapolis or Louisville.

would not want to be treated locally. I would want to go to a larger metropolitan area.

Hospice

Several respondents had friends or relatives who received hospice care at the end of their lives, and they had nothing but praise for hospice. David S, a minister, spoke of a man he knew whose death was significantly eased by hospice care — as was the life of the man's wife, his primary caregiver.

David S: This man had prostate cancer, and he was having all kinds of complications from that. And [his wife] really benefitted a lot, both of them did, from hospice. . . . They were able to keep him at home and control the pain and all those aspects of the illness and keep him fairly comfortable almost to the end.

Dan F has also observed the benefits hospice care brings to the family of a dying person as well as the patient himself. M was caring for her husband, C, when she became ill.

Dan F: M's a saint. But she came down with that virus that went around this winter. And she was giving C round the clock care. And she was so weak and throwing up. And her son came over, and I talked to him and told him who was head of the hospice. And in the three days of hospice care, M's life changed. I think hospice care is a great thing.

Cynthia W also noted the value of hospice for family members.

Cynthia W: Hospice I think is a very great organization. And they have made it much easier with my father, because my sister and I have had someone who could talk to us and has helped us deal with our feelings. . . . If everyone had a group like hospice, that would make it much easier.

As noted in Chapter 2 with regard to advance directives, people do not always take advantage of the available choices. David S, a minister, has observed that patients sometimes reject or resist the hospice option.

David S: In suggesting hospice to some people who I thought surely could benefit from it, there was resistance there, because . . . I think [they] saw it at that time as being an admission of giving in to death and giving up. . . . In the city, I think you have maybe more openness to the services that are available, especially hospice. Hospice, I think, is something that's fairly new. I think it's only been about a year and a half that it's been underway here.

Home-based care

Several respondents acknowledged the contributions of professional home-based health care in enabling them to care for their loved ones at home. One was John T, a 50-year-old school administrator.

John T: Two years ago last February my dad died. About ten years before that he had Alzheimer's progressively. For the last three years, he was confined to a wheelchair and bed. We did not institutionalize him because of home health care. If it hadn't been for the visiting nurses coming in | They began to come in once a week and then twice a week and then finally every day. And if it hadn't of been for that, we couldn't have kept him at home. . . . [H]e had told me a long time ago — I mean, before this ten years — "John, don't take me to the hospital. They don't bring people home my age. I want to die here." Well, my mother had always said, "We won't take you anywhere if we don't have to." And we didn't have to. But had it not been for the home health care, we would have.

Cynthia W, however, complained about the federal government's inflexibility in providing a choice of options at the end of life.

Cynthia W: What would make [dying in America] a better experience from my perspective is if the federal government made it easier to take care of your parents. Because parents are Medicare patients. And even though they have insurance supplements, Medicare pretty much dictates — if you're going to use their services — where you have to be for your medical [care]. My father could have been cared for at home, and that was his choice. He wanted to be at home. Medicare won't pay for a lot of the care in his home. So we had to place him in a nursing home in order to receive this care. And it has cost the federal government much more money than what they would have had to pay if my father could have been at home.

She cited other institutional changes that would improve the lot of the dying and their families.

Cynthia W: If we could honor the wishes of family members and try to do for them what they would like us to do. It would make it easier if employers allow you an absence or leave for extended care. I know you can take off some time to care for a child, but it would be nice if I could have taken off like three months to help take care of my mother. I could have, but my employer wouldn't have been very happy about that. And it would be nice to know that people could do that on occasion.

Financial concerns

We initially hypothesized that the high cost of medical care would seriously concern the dying and their families. We believed that financial stress would be particularly prevalent in an economically depressed area such as Paoli and neighboring communities, where incomes are limited and unemployment is relatively high. We received some confirmation of this hypothesis from Miriam G, a physician, who said, "In this community, it's very sad, because the cost of dying is an issue to people. You know, the cost of funerals. Whether they have enough money to be buried."

Although most respondents were well aware of medical costs — and financial concerns weighed on them, as our last quotation from Cynthia W shows — this issue surfaced only rarely in the interviews, and then primarily in response to a direct question. It tended to be raised by respondents who are professionally involved with clients' financial matters — an attorney or a bank trust officer — or by funeral directors, who witness first-hand the impact of finances on families' decision making related to funerals.

Most respondents denied that the financial burden associated with serious illness and death is a major concern for themselves or their loved ones. Hospital administrator Jim P put it simply and eloquently: "Money shouldn't drive your dying process." The only explanation we received for this attitude came from Jim B, a 60-year-old school administrator.

Jim B: I don't think that [money] was an issue. With any of us, whatever it took, we would do.

DHS: But what if you didn't have it?

Jim B: There's a lady told me the other day, she had her son. She took him to the orthodontist and paid \$4,000 to have his teeth straightened. And she said, "I have faith that I'm going to come up with the money." And I think that's an attitude that we have, that some way or another, you know, family will chip in. And you know, churches in this community are really good about helping, okay? And people in the community are good about helping each other. . . . People are there to help and to do anything they can. And I think we all just realize, "Hey, we may have to dig down a little deeper, but this is going to be taken care of." That's our responsibility as a child or a parent. I'm looking after my aunt right now, because she really doesn't have too many people to look after her. And I think we just pick that up. That's just part of our nature. You know, we want to do for people.

Medical care

There were a few exceptions to our respondents' lack of concern about the cost of medical care. Harold M, a 68-year-old retired bank executive, joked about the issue.

DHS: When you think about hospitalization for yourself at the end of your life, what worries you the most? . . .

Harold M: Being able to pay for it. . . .

DHS: But you worry about whether your health insurance or Medicare or whatever would be enough?

Harold M: I think most people my age do.

It is worth noting that as a bank trustee, Harold M occasionally acted as guardian for people who had no relatives or whose

relatives were distant or uninvolved, even making decisions about their medical treatment and nursing home placement. Most of his charges were medically indigent, and their medical expenses were covered by Medicaid.

Arthur D, an attorney, was most explicit about the cost of dying.

Arthur D: Well, the biggest concern I have nowadays would be the cost of medical care and nursing home care. It is absolutely staggering. . . . You can go through a person's life savings in this county in a matter of one or two years. . . . I mean, it's just unbelievable, and I don't think the population is fully aware until you get a relative in and you have to pay for that, and you realize how staggering the medical expenses are.

Funerals

In addition to the medical costs associated with terminal illness, the dying and their families must confront the expenses associated with funerals. Beginning with Jessica Mitford's scathing 1963 critique, *The American Way of Death*, the American funeral industry has received its share of criticism, focused on unreasonable charges, deceptive billing practices and some funeral directors' willingness to take advantage of the grief-stricken. David C, a maintenance man and minister, described one such individual.

David C: My wife's uncle . . . helped a neighbor. . . [whose] wife was gravely ill. And when she passed away, he went with him. And he said that the mortician was . . . unscrupulous in his dealings with him. And when it came to discussing payment for everything, he hadn't even thought of it. . . . So the funeral director offered to take his farm as collateral. . . . [T]his unscrupulous funeral director was the same one who took care of my dad. And he took us into the viewing area, and he showed us his most expensive coffin that he had. And he says, "My, wouldn't Everett look fine in that?" . . . After that, I just didn't have much use for the gentleman.

With that single exception, however, our respondents described funeral directors who had approached these difficult transactions with high ethical standards. Furthermore, many of them cited funeral directors as a significant source of support at a time of loss (see page 32).

Our respondents included three present or former funeral directors, who described their own practices very differently from David C's example. They stressed the importance of preplanning, noting that it helps the survivors when the deceased have discussed their preferences with family members or have actually consulted funeral directors. Forethought reassures the survivors that final arrangements are handled in accord with the wishes of the deceased. Harvey M discussed these points at some length.

Harvey M: I think that's an issue that's very important where people need to discuss where they want to go, who they want to take care of their arrangements. I think they need to plan it. I think they need to go and investigate it. A lot of money is involved. . . . I think they should do it together. I think that's very important. . . . I think if they have to make that decision on the spur of the moment, they don't make necessarily good decisions. . . . And I think sometimes they overspend. And that's a real concern for me. And I share it with my families, you know. I think that you should be buried like you lived. Not necessarily overdo it. Don't try to put Mom or Dad in something real expensive to cover up a guilt complex. You know. Bury them like they lived.

Several respondents discussed their views about funeral costs at a purely practical level. These comments were frequently — but not always — prompted by specific questions about preparation for death. For example, Harold M reported that he is determined to limit the cost of his funeral. He contrasted his own attitude with that of his parents, describing the earlier generation's ideas of appropriateness in

“being put away” and citing their desire to have a funeral that was “about what everybody else was doing and about that price.” In his own case, however, he had different plans.

Harold M: My wife and I have an agreement. . . . The cheapest thing possible. We don't believe in putting all that money in the ground where it's not going to do anybody any good. They can put me in a pine box. That would be fine.

Attorney Arthur D may be correct in saying that most people do not realize how expensive end-of-life care is, but many respondents who have been responsible for caring for dying relatives did not cite finances as a major concern. Perhaps Jim B is right, that people in Paoli somehow find a way to pay these expenses. Or perhaps the people we talked to were reluctant to discuss financial hardships in the context of an interview about their loved ones' deaths. Our sense, however, is that our initial supposition that finances would be a major concern was simply mistaken, at least for this cohort.

Summary

If they were given a choice, most respondents would choose a quick death; a few hoped for some forewarning that would allow them to prepare. No one wants to die in pain, but a more dreaded prospect is a long, drawn-out death preceded by dementia.

One key factor affecting the quality of end-of-life care for patients and families is effective and compassionate communication with health care professionals. Many respondents praised the physicians and nurses who cared for their loved ones in their last days. We also heard stories of inadequate communication. In some cases,

simply having experience in dealing with health care providers leads to better communication; in others, having a family member who is in the field and can act as a translator helps.

Some respondents think it is better to die at home than in an institution; others prefer the opposite. Generally, they feel that nursing home placement is a bad option, even when it is the best choice available. Several respondents said that the more sophisticated care available in a larger hospital would outweigh the inconvenience of being treated outside the community. All respondents who were familiar with hospice praised it; all who had experience with home-based end-of-life care were very positive about that form of assistance to families. Several asserted that it is important to have a range of health care options at the end of life.

No respondent thought that every dying person should receive aggressive treatment to the very end; all felt that sometimes terminating treatment is appropriate. Discerning *when* it is appropriate can be terribly difficult, however. No respondents spoke favorably about euthanasia or physician-assisted suicide. Few respondents had experience with painful deaths, and most felt that pain can be, and is, adequately controlled.

Respondents did not express significant concerns about the cost of medical care at the end of life or the cost of funerals. Whatever the reasons for this reticence, financial issues did not loom large in interviews with this cohort of respondents.

Chapter 4: After Death

After a death, the bereaved must come to terms with loss and grief. The experience of bereavement is profoundly affected by many complex variables, including the circumstances of the death, the quality of the relationship with the deceased, spirituality or religious beliefs, and cultural factors such as funeral rituals.

Virtually all respondents mentioned the need for emotional support and comfort during the final illnesses of their loved ones and after their deaths. Most of them stressed the importance of religious or spiritual beliefs as a source of strength at a time of loss; many attested to their belief in an afterlife, and a few reported witnessing mystical experiences or moments of transcendence, confirming this belief.

Many respondents stressed the crucial help they had received from family, friends and acquaintances. They gratefully described the support of the community (including neighbors, coworkers and distant acquaintances), from their churches and ministers, and from professionals they knew personally (such as physicians and funeral directors). They were comforted not only by condolences or expressions of concern from others, but also by practical offers of help. Several respondents reported their belief that this kind of assistance may be taken as a matter of course in a small town like Paoli, contrasting that response with the experience of city residents.

In addition to confronting the prospect of life without the loved one, the survivors must address many practical tasks, such as arranging the funeral, paying final expenses and disposing of the deceased's property.

Many respondents regard funerals as an important step, noting that they help the bereaved to confront their loss and serve as a way of bidding the deceased farewell. Families may handle the division of property gracefully or rancorously, as we learned particularly from funeral directors.

Religious belief

Most of the people we talked to mentioned religious belief as a great source of strength and comfort at the time of death. Blanche H, a farmer, reflected on the importance of belief in God.

Blanche H: When I was a kid, my daddy had an uncle who lived across the woods from us. And he claimed that he was a atheist, and he didn't believe in God, he didn't believe in life after death or anything. And, you know, and so they kind of discussed things, you know. And my dad, of course, believed in God. And he told his uncle, he said, "Well, there's one thing about it. If I'm wrong, I won't have lost anything. But if you're wrong, you've lost everything." And so I just kind of always remembered that, you know, and I'm thankful that we did grow up in a Christian home, and we were taught that there is a hereafter and life after death. So I think that makes it easier to accept death. And I've often wondered how people can go through something like that if they know that this person has never believed in God or Jesus. And it would be very much harder to take.

In another interview, Jim B, a 60-year-old school administrator, eloquently affirmed his belief in a benevolent creator.

Jim B: Death doesn't scare me. Death is a process that I understand God initiated very early in existence when He breathed into man | into his nostrils the breath of life. He took him from the dust of the earth, and He said that he would return to that. So, you know, I think I see the whole picture, how that unfolds. And I guess I take exception to the questioning of Genesis by some of the modern theologians today, that maybe some of those things didn't really happen. I guess I am a literalist in those respects that I do literally believe the Bible, from

the account there of when God created the earth and when He created man and all living things. Then I think God had a plan, and by the same token, He put this plan into effect. And His son came to earth many hundreds of years later and lived here for a period of time, was crucified and taken back to Heaven, and some day there will be a judgment. And I believe all those things.

Many respondents agreed with these views. For several respondents, observing the serenity and resignation of the dying powerfully confirmed the solace provided by reliance on God's providence and belief in an afterlife. Elizabeth M, 66, described her mother's death.

Elizabeth M: She shut her eyes and was very placid, and she was gone.

JAG: Peaceful. . . . It was just ideal, almost, that she had told you that she was ready to go and then she passed away peacefully.

Elizabeth M: Yes, she had us | The night before, there were several of us in the room. And she said, "Well, let's sing." [laughs] And I said, "Well, Mom." . . . And I said, "What do you want to sing?" "Well, let's sing 'Joy in My Heart.'" And so I proceeded to sing "Joy in My Heart," but it was sure hard to muster up some joy in my heart to sing that song. But it means a lot to me.

A few respondents reported witnessing moments of transcendence at or near the point of death. These experiences provided solace not only for the dying person but for the survivors as well.

Jim B spoke of his father's efforts to prepare the family for his death after his diagnosis of terminal cancer.

Jim B: He had premonitions of seeing angels, Jesus and so forth. But I think from the standpoint of just trying to condition all of us that he had lived a full life and that he was prepared. He felt he was prepared spiritually, and he was trying to prepare us to face the fact that he should be allowed to go on from this life.

Bethel C, 82, reported that her husband apparently had a vision shortly before his death.

Bethel C: I was in the room with my husband, and we knew he couldn't live but a few hours or less. And just before he went, he raised his hands in the air with a beautiful smile. And he had previously just said to me, he said | One of the doctor's names was M. He said, "Did you see Dr. M go down that golden road?" And I'll never forget that.

David C reported that experience of his mother's death was eased not only by his conviction that she was ready to die, but also by a mystical experience near the end of her life.

David C: [One night, she was] gazing up at the ceiling and her hands up, and she said, "Oh, it's so beautiful. Oh, it's so beautiful. Everybody needs to know how beautiful it is." . . . So you know, I felt like she was looking into Heaven that night.

In contrast, Cynthia W's mother met her death not with resignation but with anger. She knew that she was dying.

Cynthia W: And the last day she was able to walk, she stood in front of the mirror in her bedroom and looked at herself very carefully. And her disease was so advanced that . . . her neck and part of her forehead and her head, her scalp were covered in cancerous tumors. And she examined them very carefully. And she said, "I *used* to be pretty." And walked over and got in bed and that's the last time she spoke.

Cynthia W's mother died about five days later.

Support from friends

The importance of expressions of support from other people at a time of bereavement can hardly be exaggerated. Almost without exception, respondents attested to the help — both emotional and practical — provided by members of their communities,

Ann W shared a striking example. Even though the family had not been part of the community for very long, she encountered a heartening show of support when her husband died in an accident.

Ann W: And I had only lived here for a year, but it was amazing. I mean, everybody came. All the teachers from school, all the boys' teachers. And some of those teachers have remained really close friends of mine for years since then because they took the time to come out and take that individual child they had in class and take him for a walk or just do something special.

John T pointed to the importance of people simply showing up at funerals or visitations.

John T: There needs to be some way of support. I like the idea of people coming and giving support. They don't have to say anything. They just come and say, "Hey, I understand. I'm sorry." And that's enough. Really. You don't have to be eloquent to provide support.

Several respondents cited the sheer numbers of people who attended visitations or funerals as a meaningful index of concern for the bereaved. Stanley H, a 41-year-old farmer, reported that about 200 people came to his aunt's funeral at a small country church. Jim B also described the numbers who came to offer condolences.

Jim B: [W]hen Mom died, we had over a thousand people at the funeral home. I stood in one spot for about six hours and didn't even move. . . . People were coming in from everywhere. But they were fixtures for a long time in Paoli. Mom was a township trustee, and Dad helped her, and so they got to know a lot of people, but they grew up here. Their roots were here, and we all grew up here, and except for the one brother, we have all chosen to stay here.

Singled out as especially meaningful by many respondents were the help and support offered by their church communities. They cited the efforts of the laity as well as the clergy.

John T: I don't know how people survive without some support system around them. . . . Without the church, it would have been much, much harder. Without the people who | I mean, they care. And they share. And you don't have to do anything other than allow somebody to know, "Hey, if I could carry the load, I would carry it." . . . Certainly the church was a big support.

Jim B: We attend a small congregation of 70 or 80 people max. . . . We meet Sunday morning, Sunday night and Wednesday night. . . . And I make a comment to the people there how much it encourages me to be there around those people. Those are the people that will help to strengthen me, and many of those people came to both Mom and Dad's visitation. You know, they saw that they were there. And they brought food. Many of them brought much food to our house, or to Mom and Dad's house. . . . I think that's when we strengthen and encourage and bolster up each other's faith by being available at those times.

Pat F, a minister, mentioned how much the members of his congregation did for his family when his four-week-old son was hospitalized. Dan F also specifically mentioned support from members of his church. After his father died, many members of his church told him to call on them if he needed anything. One day he was unable to find his mother, so he called one of those friends.

Dan F: I said, "I haven't been able to get ahold of her, and I'm worried sick." [My friend] said, "I'll find out." And an hour and a half later [my friend] called back, said, "Well, she's over at the cemetery walking. She needed exercise." Said, "You know, that was the last place I looked."

In addition to the gifts of time and concern, many respondents described practical help provided by friends and colleagues. Bringing food — often in staggering amounts — is one customary way of helping the bereaved cited by almost every respondent, but some found they were helped in other imaginative ways.

Dan F described some of the kind deeds friends and neighbors performed for his mother when his father died.

Dan F: You know, when my father passed away, we got down here Monday evening. And when we got to my mother and father's house, I bet there was twenty, twenty-five, thirty plates of food that people had brought in. . . . A lady came over, cleaned the house. Somebody came over and mowed the yard. And some

lady, bless her heart — I don't know why, [but] she came and washed the windows.

Several respondents asserted their belief that the availability of this kind of personal support is one of the benefits of living in a small town. More people are more likely to know about a family's trouble, and they are more likely to offer help. John T agreed that help may be more forthcoming in a smaller place than in a city, for a variety of reasons.

John T: Rural communities are much more positive in the sense that we know people, and there's a better support system in a lot of cases, I think. . . . We know people well enough to talk about them. So I mean, there's pros and cons. . . . I think the support system in rural communities where you can know each other . . . is much better. And besides we're a lot slower. . . . We do less. We don't get in as big a hurry. The anxiety level is lower.

Support from funeral directors

Many respondents reported significant levels of support from professionals, particularly professionals they knew personally. We discussed the helpfulness of health care providers in Chapter 3.

Interestingly, having a personal relationship with a funeral director may offer significant benefits to the bereaved. In a small, relatively stable community like Paoli, people may find themselves dealing with a funeral director whose parents knew their parents. At a time of loss and grieving, such relationships can offer real support. With an evident sense of comfort, Hazel B reported that she has made her arrangements with a funeral director she knows well.

Hazel B: The man that I'm having for my undertaker, he's a minister. . . . He preaches down in a little church called Rock Springs out of Paoli, but his mortuary is here in Paoli. His name is Harvey M, and his whole family is just so wonderful. . . . [Our church] just now got a new minister. I've never met him. He's never been out here. He will be out here one of these days, but I've never met him and I'd feel so much better to

have Harvey . . . just take care of the whole thing, you know. . . . He'll take care of the funeral and do the service. . . . I think so much of Harvey and his whole family, you know, and that's my choice. And he knows it.

It is worth noting that the comfort of dealing with funeral directors who are long-time friends is not all one-sided. Dan F told a moving story that illustrates this point.

Dan F: We put her on the cot and took her out to the coach. I walked back in and talked to them, and they were just so glad it was Danny. . . . I knelt down with them and sat and talked to them for a half hour. . . . That's something that nobody can take away from you. Those tears that you shed with people that are friends like that. . . . You know, that's a bond that | That's a special thing. The most wonderful thank you card that I've ever received, I received from that family. And it's been that way with a lot of families . . . just very special things.

In another interview, Harvey M described his struggle to control his own emotional reactions during the funerals of close friends and relatives.

Harvey M: It was very difficult to conduct those funerals. . . . And you have to push your personal feelings a little bit to the side to meet the needs of those that are there. And you have to restrain your feelings, because you want to be strong and supportive to the family. And there's nothing wrong with the funeral director crying, even though people think they never cry, and they never have those moments when they feel just like the family does. We do have those moments.

The majority of respondents said that support — from the general community, from the church, from professional health care providers — is easy to find in Paoli, where, unlike city dwellers, people are not surrounded by strangers. Perhaps Jim P expressed it most effectively. He noted that people do not get to know each other as well living in the city: "We could be neighbors in a big city, and our kids go to different schools, and we would never see each other. Here, if something were to happen to my

neighbor, I would know it.” Furthermore, as he puts it, he has many acquaintances but only a few friends. Friends, he observes, will help you when you are in need no matter where you live, but acquaintances only help out in small towns. “[People living in a big city have] a hundred thousand other acquaintances.”

Funerals

In Paoli, most funerals are preceded by several hours of “visitation” at the funeral home. The family gathers to receive condolences, and visitors have an opportunity to bid farewell to the deceased and offer words of comfort to the bereaved. The usual practice is to have an open casket funeral; a religious ceremony may occur either in the funeral home or in a church. Cremation appears to be chosen only rarely.

Our respondents agreed that funerals provide a way to say good-bye, a way to help the bereaved reach closure after a death. Again and again, they affirmed the importance of funerals. One experience convinced Harold M and his wife of the need for some form of ritual.

Harold M: Well, my wife’s sister died quite a few years ago. She was cremated and no final services and no nothing. And that’s when my wife decided maybe there should be something. . . . A final goodbye or whatever you want to call it

One exception to the wholesale endorsement of open casket funerals was Ann W.

Ann W: My mother has the same aversion that I’ve always had to funerals and anything related to death. And so I wasn’t ever taken to my grandparents’ funerals or anything like that. . . . [Our children were] eight, seven, five and three when [my husband] died. And I didn’t want their last memories to be seeing somebody in a coffin because I had never even seen anybody in a coffin. And just the whole idea just appalled me of people standing around staring at a dead

body. And so I at first insisted on a closed casket. I mean, there wasn’t any reason to have one, but I just insisted on a closed casket. And I would not have a viewing. And so I had anybody that wanted to come see me or the kids come here. . . . And we had visitation out here.

Ann W admits that she is nearly phobic about funerals. In spite of her aversion, however, she understands on an intellectual level why people find funerals important.

In contrast to Ann W, most of our respondents said explicitly that having a chance to see the deceased is very helpful to them. As attorney Arthur D put it, an open casket viewing helps make the death real and provides an opportunity to say good-bye.

Arthur D: [When my father died of cancer, we had] open casket viewing. A lot of people, when they die of cancer, they want a closed casket, even though the body is perfectly normal and can be viewed. And I think that in a sense helps the reality that knowing someone has passed away. And we’ve had other friends that absolutely sealed the casket and no viewing or anything like that. It’s just the emotional, psychological effect of having a sealed casket compared to an open one. . . . I think it’s more | You’re in a position to accept death more if you see someone there. Where if it’s sealed, you don’t know. You wonder what he looked like. Is he there? All these wild ideas run through your mind.

Lack of support

A few notable exceptions to the accounts of community support were mentioned, primarily by respondents whose professions have brought them into contact with the dying or their survivors. Harold M found that as a trust officer of the bank, “one of the things you inherit is people who have no close relatives.”

Harold M: Some of them had relatives, but they weren’t around where they could take care of them or see that they got the care they needed. And you just hope that you made that right decision.

DHS: Do you mean decision about whether treatment should be continued?

Harold M: Right. Treatment continued or whether they should have this operation or whatever came up, as far as health concerns. . . . As well as [being] guardian of the estate, [the bank] was also guardian of the person. . . . So we acted as a child or a husband or a wife or whatever in making those decisions. . . [for] months or years. There's one particular lady who | We probably had her fifteen years.

Harvey M, a funeral director, said that he tries to prepare survivors for the fact that while there is a great outpouring of support at funerals, help is not always so forthcoming afterward.

Harvey M: I tell all of my families they have a very long year ahead of them. And I think that's important. You know, the day of the funeral, the day of the visitation, or the day of death, family is all around. About a week later, they're there, but about six weeks later, you're standing there or sitting there staring at the walls. Maybe someone calls, and maybe they don't.

Two ministers also noted that community support is not as strong as they might have hoped. David S observed that people are more likely to offer support after a death occurs than to visit a terminally ill person.

David S: [A] lot of times, . . . whether it's out of fear or whether it's out of not knowing how to respond to the person, . . . church people are not as supportive as you might hope they would be. And I think a lot of it is just not being comfortable with being around a person that you know is probably not going to get any better. . . . Now I have seen church people be very supportive. But in general, I think they tend to to *ask* about the person rather than go and *see* about them. . . . I think there is just a discomfort with being exposed to something that, I suppose, makes us consider our own mortality.

And Pat F noted that not everyone in Paoli is still surrounded by family.

Pat F: I've had funeral services where the kids all moved out of the area, but the parents still were here and passed away here. And if they . . . were elderly, where they had very few friends still, I've had funeral services | I had one funeral service where I had, I think, eight people show up for it.

It was clear from the interviews that most respondents felt that support systems

were strong in Paoli; far fewer expressed the view that support is sometimes inadequate. It is telling that people who encounter death as part of their profession, who must deal with the deaths of strangers and with more deaths than most of us, observe and comment on these deficiencies. All of our respondents have families and friends in Paoli; none of them reported direct experience of the kind of isolation mentioned by Harold M, Harvey M, David S and Pat F. If we had sought out isolated patients in hospitals or nursing homes, we may have found significant fear and loneliness. We can say with some confidence that people who still have family in Paoli generally get very good community support; we cannot say what portion of the population they represent.

Dividing the property

In our early interviews, a few respondents spontaneously mentioned the disposition of the effects of the deceased; we soon added the topic to our schedule of questions. Families handle this issue with various degrees of affection and composure; for some it can be a rending experience.

Members of the clergy and funeral directors were particularly aware of the painful outcomes experienced by some families. Pat F, a minister, told one poignant story.

Pat F: That's probably been the most disappointing thing I've ever seen in my life. I mean, sometimes people become vultures. And some of it is greed. . . . But I think another element is just pure selfishness. . . . [T]here's a family . . . whose parents died and left their possessions to the three children. And one of the kids would not agree to the terms and would not deal with it. And that's been twenty-five years ago. And the house has remained unsold. . . and it's literally falling apart. It's not been lived in for all this time, because he would not allow it. And so the house is now nothing but junk. For twenty-five years, it's been left unlive in, and the furnishings are still in there. And no one has been able

to go in there to clean it out, and no one's taken any clothing. They've never touched it in over twenty-five years. And just because one person didn't think he got enough.

Funeral directors are acutely aware of the problems that can be created by disagreements over property. They point out that the objects at issue are often trivial, and they may even remonstrate with families in an effort to get them to resolve their differences. Harvey M and Dan F, both funeral directors, shared these observations.

Harvey M: I personally think that's why people should have a will. I think they should. If they see they're in a situation where they are going to go into a nursing home or they're terminally ill, I think they should give whatever they want to their loved ones specified. Give it to them then. Because a lot of times there is a lot of conflict with families. There is a lot of trouble. There's a lot of families that the children never speak to one another again over something so simple as a plate or a quilt or a piece of furniture. You know, something that in five minutes could be all lost in a fire.

Dan F: That's probably some of my worst memories about the funeral industry, and that's how petty some people can be. . . . We had one not too long ago where it started to be a problem, but I told her, I said, "Now this is the last memory you are going to have of your mother. And you're going to trash that memory by this juvenile behavior." And you know, when you chastise someone, especially at this time, you know, you are treading on thin ice, and she thanked me for it afterwards. . . . It's amazing how people will fight at this time over the silliest things.

Summary

The dying may suffer both physical and emotional pain, and their loved ones suffer emotionally both during the dying process and after death. When a person dies suddenly, his or her suffering may be quite abbreviated, but the suffering of survivors can be acute and prolonged. Emotional support during the dying process is important both for the dying person and the bereaved, who also need support after the death. Respondents reported finding comfort in their religious beliefs; they said that support is very important and is generally forthcoming in Paoli, whether from neighbors and acquaintances, from their church community, or from professionals. A few respondents who had professional contact with the dying or survivors had observed instances in which support seemed inadequate, notably for older persons whose families had left the community.

Most respondents declared that funerals provide a welcome and important opportunity to say good-bye to the deceased and attain a level of closure. They generally expressed a preference for open-casket services, feeling that this tradition makes the death real to them.

Chapter 5: Conclusion

Without retracing all of our previous steps, suffice it to say that our respondents, like many Americans, are aware of changes in the circumstances of dying. They realize that dying has been taken out of the home, that the causes of death have changed. They worry about pain, but even more they worry about a lingering death. For the most part, they do not report major financial concerns.

Our respondents resist use of nursing homes and find them embarrassing, not because they are associated with the end of life, or because the quality of care is not good — although they say that sometimes it isn't — but because nursing home placement represents a failure of family community. They also associate death in a nursing home with a lingering death, which they dread, and a loss of hope. Guilt, fear and shame are the emotional fuel for their resistance.

One of the main resources in facing death in Paoli is the community of Paoli itself. It is a community in which our respondents feel known and valued. Rightly or wrongly, they think they receive better communal support than people in bigger cities. They depend on family, but they find support from other sources as well, notably from church communities and funeral directors.

Their attitude toward health care professionals, and physicians in particular, is ambivalent. They are grateful for competent and loving medical care; they celebrate medical advances. They do not regard physicians as persons who impose their values on others. On the other hand, they find health care institutions overwhelming and bewildering. They are not accustomed to asserting themselves in the face of medical

authority. They clearly have problems in talking about death and dying with physicians, and they welcome the presence of a family member or friend who can serve as an advocate and translator.

Indeed, our respondents find it difficult to talk about death and dying with anyone. Few of them have advance directives in place. The two philosophical points repeated in many of our conversations were the widely used observation “Death is a part of life” and a concern for “spiritual preparation,” reflecting their belief in a last judgment and life in a hereafter. These convictions, however, did not mean that death was domesticated or easy to talk about. Nor did they clearly connect with judgments about how care for the dying might be improved, except to the extent that they provided reasons for acceptance of the suffering associated with dying and bereavement, and the hope that such suffering is not pointless.

These observations suggest both strengths and limits of the reform strategies that have received the greatest national attention to date. Those strategies, as we understand them, have focused on empowering patients — through stress on patients' rights and autonomy — and on changing health care institutions. It is what one of our advisers describes as a consumer choice model: Give the consumer more power, and make the delivery institutions more user friendly. Some of those things have happened in Paoli, and more changes in that direction would respond to some of the concerns expressed by our respondents.

An obvious example is our respondents' wish that they had a better sense of what is going on and more control. As Dan F, a funeral director, put it: "The thing is, when people came in here to buy, we haven't said, 'You have this copper casket. That's what you're going to go in.' No, we have 19 in this small little funeral home. Why not give people a choice on their dying? Give them three or four different options." However, like many Americans, most of our respondents have not implemented advance directives such as living wills or durable powers of attorney for health care; for those who have, they may be a dead letter, not a regular subject of conversation between patients, physicians and families. We were struck by the extent to which families felt helped by a relative or friend who, as a nurse, technician or physician, was able to provide reliable information and serve as a translator and liaison between family and care givers. **Our respondents would be helped if they felt more empowered and if the health care system were more effective in communication and more responsive to perceived problems.** How might that happen?

- Local and regional hospitals might offer structured educational visits to facilities such as critical care units in advance of need.
- Special training programs could be established for those who are likely patient advocates, such as clergy or spouses of seriously ill persons. Hospice might run those programs.
- Private space for serious conversations about care options might be provided on all wards and services.

- Physicians might make serious discussion of advance directives an important part of medical history taking, before the need becomes immediate.
- Serious conversations between health professionals and patients or families might be audiotaped — with patient or family consent — to provide patients and families with a better record of the information conveyed and to afford health professionals an opportunity for professional growth.
- Medical education programs could improve physicians' training for their crucial role in communication.
- Continuing education for physicians could stress listening and communication skills with patients and families at the end of life.

In particular, **we believe that our respondents will appreciate more alternatives to hospital and nursing home care, such as hospice and home-based terminal care, and better information about those services that already exist.** Hospice has begun to be a presence in the area, and the services it can deliver are widely appreciated. Hospice care and home-based terminal care clearly build on our respondents' view that "Death is a part of life." Our respondents seem to be ready for alternative services, and anything that can be done to make them widely known and easily available will meet a major perceived need.

We did hear two hints of reluctance about using hospice services. First, hospice is new to the area; it will take time for it to become part of the landscape. Public education may speed up the process of familiarization. Second, and more difficult, is the feeling that turning to hospice means

giving up. In American society in general, there is a vast emotional chasm between *giving up* and *accepting*, a chasm that cannot be bridged by hospice alone.

Reforms designed to give patients more choice and new institutional options, such as hospice, are definitely moving in the right direction. They do not, however, get at the most fundamental obstacles standing between our respondents and a better experience of death and dying. Those obstacles are cultural, and we hypothesize that they are associated with reserve and reticence in talking about death.

Indeed, we had a strong sense that our respondents want and need to **talk more about their experiences with and worries about death than they now do**, especially with their own loved ones. For example, their observations about changing experiences, their concerns with loneliness, the fact that they find themselves having to make novel and painful decisions — all provide openings for informative and mutually supportive conversations. People who cannot talk about death with family and friends also may find it difficult to discuss those subjects with professionals in an institutional setting. They must be encouraged and supported in efforts to have both kinds of conversation. Our respondents do not need to be preached to about death, nor even informed about medical options; rather, they need to find themselves in contexts where they can talk to and listen to each other. Identifying and creating those contexts, however, is not easy.

One possible locus is the churches. Even a religiously observant outsider will be struck by the extent to which the culture of Paoli is permeated by piety nurtured in the community's churches. Our respondents

look to their churches for support at time of crisis, and in a very large percentage of cases they report that support is forthcoming. They benefit from the presence and efforts of friends and others especially during bereavement. Help in preparation for dying, however, may be more problematic. It is less clear that the churches in Paoli are places in which the earthly problems of the dying are discussed and options for action are considered. Where will that discussion go on for adults, if not in the churches? We can imagine several ways in which the conversation might be encouraged:

- Regular meetings of Paoli clergy that will afford them an opportunity to support each other.
- Meetings of the clergy with local experts such as physicians, hospice representatives, funeral directors, nursing home administrators, attorneys or other civic officials with relevant expertise.
- Use of adult Sunday School classes for presentation of relevant material, perhaps using this report as a starting point.
- Use of local expertise in adult Sunday School classes.
- Identification and use of age-appropriate programming for church youth.
- Meetings of the clergy and other religious leaders with outside consultants who might be able to provide help with these or other programmatic ideas.

Church-sponsored programs, however, will not reach everyone. Social, economic and political relationships in Paoli — as elsewhere — cut across denominational lines. As our report suggests, we found distinctive perspectives in many sectors of the community ranging from funeral

directors to bank officers. How can informative and serious discussion outside the churches be promoted?

- Appropriate informative material might be found for use in school curricula. Students at almost all grade levels are interested in the subject of death. Religious divisiveness can be avoided; school discussion may lead to family discussion.
- Paoli's newspapers, *The Republican* and *The News*, run a regular column written by representatives of Hoosier Uplands Economic Development Agency. The column often discusses health care issues. This feature could be supplemented and expanded, and other voices could be added to the conversation in the papers.
- Appropriate programs could be part of the agenda at service clubs.

In raising these possibilities, we do not suggest that residents of Paoli should talk about nothing but death and dying! These serious subjects come to our attention at some times and recede into the background at other times. Reticence about them is natural and appropriate. But our interviews suggest that our respondents would welcome opportunities for discussion and planning. The increased thoughtfulness of perspective that comes from these conversations would be valuable in itself; it would empower work for changes that our respondents and other residents of Paoli may desire.

This discussion raises a final dimension of care for the dying that has not been addressed by traditional reform: the nature of the communities in which death and dying takes place. One of the great advantages of dying in Paoli, as our respondents perceive

it, has been continuity and rootedness. People there often die under the care of a physician who has known them for years; church membership provides them with a strong sense of supportive community. This support may be offered most consistently to the bereaved rather than to the dying. As David S, a minister, said, "I have seen church people be very supportive. But in general, I think they tend to to *ask* about the [dying] person rather than go and *see* about them." The community is more likely to rally to support the bereaved than the dying or their families before the death. Still, support in bereavement is wonderful, and communal support at the end of life is significant.

However, changes in the organization and distribution of health care signaled by the term "managed care" may change this situation. The move to managed care was not the main subject of our project, nor did our respondents frequently mention it. But managed care may lead to disruption of continuities for the sake of economic efficiency and, perhaps, in order to provide more people with access to some higher quality services. We think that residents of Paoli should be alert to this possibility so that the best of what they now have and value can be preserved in changed circumstances.

In brief, the legal and medical dimensions of care for the dying seem to have been adequately addressed by reform initiatives that are already in place, such as provision of hospice services, legal support for a right to refuse treatment and advance directives.⁷

⁷The one regulatory change we would urge is to make advance directives part of the medical chart so that it is harder to ignore and cannot be lost when a patient is moved from one facility to another.

These initiatives, justified by our society's commitment to personal autonomy, are not wrong or mistaken — to the contrary — but the next steps may not be suited to legislation. Our respondents voiced distinctive and pressing needs that concern social and personal issues and may be best addressed through religious, educational and other cultural centers of initiative. That does not make these needs less pressing; arguably they are the most important. It does mean that different and perhaps less efficient and visible strategies are needed to improve the lot of the dying. We have ventured a few first suggestions about what the components of those strategies might be.

Paoli, Indiana, has managed to retain some of the traditional strengths of small town life. People know and care for each other; emotional and material support from neighbors, friends and church are available in times of crisis. Many formal and informal supports for the dying and bereaved are already in place; others, notably hospice, are becoming established. A modest amount of intentional work to link and reinforce support systems, and to empower people to cope with changing medical possibilities and systems, might improve the experience of dying for many of Paoli's residents.

Appendix A: Paoli, Methodology, Demographics

Paoli, Indiana

The wooded hills of south central Indiana around the future site of Paoli were settled by Quakers who emigrated there from the slave-owning society of North Carolina in the early 1800s. They named the town after the 12-year-old son of Samuel Ashe, the governor of North Carolina; the boy had died shortly before the group moved to Indiana.

Paoli was named the county seat of Orange County in 1816 and incorporated in 1869. A series of disastrous fires between 1879 and 1917 destroyed several important early buildings in the heart of the town, but the Paoli Historic District now includes structures that date from the late nineteenth and early twentieth centuries. The town's central square is dominated by the Orange County Courthouse, built in 1850 in the Greek Revival style and listed on the National Register of Historic Places. Mineral Springs Hotel, on the south side of the courthouse square, was built in 1896 by Lithia Springs Hotel Company, an enterprise that also drilled a mineral well on Lick Creek and operated the Lithia Bottling Plant. The hotel, constructed of bricks from J. P. Throop's brickyard, had horse-powered elevators and a 70 hp dynamo driven by a boiler, which enabled Paoli to install its first electric streetlights.

With the completion of the Monon Railroad in 1887, business interests sought to generate tourism by developing mineral wells, but the nearby resort towns of French Lick and West Baden Springs soon eclipsed Paoli's attractions. The closing of several industries after the 1920s led to a faltering

economy and a declining population. According to the 1990 census, Paoli's population was 3,542, fewer people than reported in 1980.

The town is located at the intersection of state highways 37 and 56 and U. S. Highway 150, 95 miles south of Indianapolis and 46 miles northwest of Louisville. State Road 37, running north and south, becomes Gospel Street within the town limits. Paoli's one stoplight is east of the square on Main Street, which forks into U. S. 150 and State Road 56.

Forest and lumber products dominate local manufacturing. The town's industries include four furniture or wood products factories, employing more than 750, as well as manufacturers of shoes, computer discs and small electric motors. Farming continues to be an important element in the local economy. A large JayC grocery store and a Wal-Mart Superstore have opened within the last year. Paoli is near Spring Mill State Park and Patoka Lake Reservoir-State Recreational Area, and Paoli Peaks resort offers downhill skiing in the winter. The town boasts two weekly newspapers and two radio stations.

Health care is provided at 26-bed Orange County Hospital, with support from larger hospitals in Bedford, Bloomington, Louisville and Indianapolis. Paoli also has two nursing homes.

Like most of south central Indiana, Orange County is economically depressed. June 1997 figures from Indiana's Department of Workforce Development reported an unemployment rate of 8.2

percent in April, the third highest in the state. The county's per capita income was \$15,607 in 1994, ranking 85th among Indiana's 92 counties.

Paoli's residents are overwhelmingly white and Protestant. The 1990 Census recorded fewer than 20 members of minorities in the population; the telephone book for Paoli and surrounding towns lists 52 Protestant and two Catholic churches.

Methodology

Indiana University's Oral History Research Center completed 40 interviews for its community study of Paoli, some including more than one individual. We began by inviting those respondents to participate in our study.

We used several strategies to recruit the remaining respondents. First, we asked the original fourteen respondents in our study to identify persons we might invite to participate, which produced seven additional interviews. On April 16, we sponsored a site for the Hospice Foundation of America's National Bereavement Teleconference, "Living with Grief: When Illness is Prolonged." We asked attendees to register, and we invited them to participate, netting three additional interviews. Finally, one of the advisers to the project suggested two persons who agreed to be interviewed.

We began by sending a letter to potential respondents that described the project and invited them to participate in an interview. We scheduled interviews in follow-up

telephone calls, which also offered an opportunity to request directions to respondents' homes or places of business. We interviewed respondents in Paoli and surrounding communities, including Mitchell, Orleans, French Lick and Pumpkin Center. We read the transcripts of the Oral History Research Center's interviews, if available, in advance. These transcripts provided background details about respondents' families, occupations, etc.; they often suggested introductory questions or ice breakers and raised themes to be pursued during the interview. Each respondent signed an informed consent form (Appendix B) before the interview began. All interviews were tape recorded; all were transcribed by Beverly Davis; all transcriptions were edited by JAG. Respondents reviewed transcripts

of the tapes and signed a deed of gift (Appendix C) either at the time of the interview or when they returned their corrected transcripts. We photographed respondents unless they demurred. We tried to schedule more than one interview on each trip to Paoli to minimize driving

time and expense, but that often proved to be impossible. We began interviewing on November 1, 1996, and conducted our final interview on June 12, 1997. All co-investigators conducted at least two interviews; the majority of the interviews were conducted by JAG.

Demographics

Reflecting the composition of the community, our sample is exclusively Caucasian. Based on data for 26

Table 1: Oral History Study Respondents (n=43)

Interviewed	13
Deceased	6
Lost to follow up	12
Declined to participate	10
Could not schedule	2

respondents, the mean age is 56.27 years; the median is 51.5; and the range is 27-98 years.

Remaining demographic information is summarized in the following tables.

Table 2: Occupation (n=26)

Clergy or ordained	6
Retired	6
Farmer	5
Teacher	4
Retail store owner	4
School administrator	3
Funeral director	3
Professional	3
Housewife	2

Note: Several respondents reported more than one occupation.

Table 3: Educational Attainment (n=26)

Grade school	1
Some high school	5
High school graduate	2
Undergraduate degree	4
Graduate degree	8
Unknown	6

Table 4: Religious Affiliation (n=26)

Quaker	6
Baptist	3
Methodist	3
Church of Christ	2
Roman Catholic	2
Wesleyan	1
Christian	1
Disciples of Christ	1
Jewish	1
Nondenominational	1
Unknown	5

Table 5: Marital Status (n=26)

Married	20
Widowed	3
Divorced	1
Never married	2

Table 6: Respondents

Name	Sex	Age	Occupation
Ann W	F	52	Social worker
Arthur D	M	59	Attorney
Bethel C	F	82	Teacher, farmer (retired)
Blanche H	F	66	Farmer
Brenda C	F	45	Store owner, reporter (retired)
Chris L	M	27	Teacher, minister
Cynthia W	F	54	Teacher
Dan F	M	39	Funeral director
David C	M	49	Maintenance man, minister
David S	M	43	Minister
DHS	David H. Smith, interviewer		
Elizabeth M	F	66	Store owner (retired)
Exum H	M	69	Farmer
Gerald J	M	51	School administrator, farmer
Harold M	M	68	Bank executive (retired)
Harvey M	M	44	Funeral director, minister
Hazel B	F	98	Teacher, farmer (retired)
JAG	Judith A. Granbois, interviewer		
Jim B	M	60	School administrator
Jim T	M	50	School administrator
John P	M	39	Hospital CEO
John H	M	44	Priest (Roman Catholic)
KDP	Kenneth D. Pimple, interviewer		
Lucille D	F	79	Writer
Mabel G	F	85	Store owner (retired)
Melvin D	M	69	Store owner, funeral director, tool and die
Miriam G	F	43	Physician
Pat F	M	41	Minister
Stanley H	M	41	Farmer

Appendix B: Informed Consent Form

(City) _____

(County) _____

(Date) _____

Indiana University Oral History Research Center

Informed Consent

1. I hereby agree to participate in an interview in connection with the oral history project known as “The Social Face of Death.” I understand that the project’s goal is to learn about the meaning that people attach to death and that approximately twenty-five people will be interviewed in connection with the study. I understand that the interview questions will cover my personal background, my experiences with death and my opinions about medical care received by dying persons.
2. The interview will be audiotaped. In the interview, I will be identified by name. I will also be identified by name in any transcript (whether verbatim or edited) of the interview.
3. I understand that the interview will take approximately two hours. I understand that I can stop the interview at any time. I understand that I can withdraw from the project at any time prior to the execution and delivery of a deed of gift, a form of which is attached. In the event that I withdraw from the interview, any tape made of the interview will either be given to me or destroyed, and no transcript will be made of the interview.
4. Subject to the provisions of paragraph 7, below, I understand that, upon completion of the interview, the tape and content of the interview belong to Indiana University, and that the information in the interview can be used by Indiana University in any manner it shall determine, including, but not limited to, use by researchers in presentations and publications.
5. I understand that photographs will be taken of me. These photographs may be used by Indiana University with restrictions I may specify.
6. I understand that my photograph, excerpts from the transcript and portions of the audiotaped interview may be posted on the World Wide Web. Before that is done, I understand that I will be asked to consent specifically to the use of those materials at a later time. I understand that I may refuse to permit posting of these materials, and that I may specify restrictions on their uses at the time I am asked for this second consent.
7. Indiana University agrees that 1) it will not use or exercise any of its rights to the information in the interview *prior* to the signing of the deed of gift; 2) the deed of gift will be submitted to me for my signature at the completion of the interview, but I may wait until I review a transcript of the interview before signing and delivering the deed of gift; and 3) restrictions on the use of the interview can be placed in the deed of gift and will be accepted as amending Indiana University’s rights to the content of the interview.

8. I understand that I may restrict use of portions of the tape. These restricted portions will be edited out of the final copy of the transcript.

9. I understand that at the conclusion of this study and upon signing the deed of gift, one copy of the tape and one copy of the transcript will be kept in the Oral History Research Center and at the Lilly Library, and one copy of the transcript will be kept at the Poynter Center, all at Indiana University/ Bloomington, for academic use.

10. If I have any questions about the project, I may contact

Judith Granbois
Poynter Center
Indiana University
410 N. Park Ave.
Bloomington, IN 47405
812/855-0261

11. If I have any questions about my rights as a participant in this project, I may contact

Human Subjects Committee
Bryan Hall 10
Indiana University
Bloomington, IN 47405
812/855-3067.

12. I have read and understand this consent form, and I voluntarily agree to participate in the study.

Interviewer _____

Interviewee Signature _____

Address _____

