

(Geertz, 1973; Polkinghorne, 1988), who are dying to know from an emic (or insider's) perspective (Schwandt, 1994), can find much in qualitative research to inspire and intrigue them.¹

In this article, we describe how qualitative methods can help thanatologists investigate the lived experience (Ellis & Flaherty, 1992) of terminally ill persons and their families. We ground our ideas and suggestions with illustrations drawn from our own involvement in a naturalistic inquiry (Lincoln & Guba, 1985) into dying and death. Kristin Wright (KW) was the principal investigator of this project; Douglas Flemons (DF) was the chair of her doctoral dissertation committee.

Finding a Question, Finding a Method

The essence of qualitative inquiry is paying attention, being open to what the world has to show us, and thinking about what it means.

—Michael Quinn Patton (1990, p. 140)

Kristin Wright, a family therapist, began working in a hospice in 1992, assisting dying patients and their families as they grappled with impending death. She was struck by how many of her health care colleagues, as well as the patients and families they served, were influenced by the ideas of Elisabeth Kubler-Ross (1969). For example, many considered Kubler-Ross's five stages—shock and denial, anger, bargaining, depression, and, finally, acceptance—to be ontologically true, that is, the step-by-step process through which dying patients and their families must move. Unfortunately, some of the staff used the template as a normative strait-jacket, pathologizing patients who didn't respond to their fate in a "proper" Kubler-Rossian fashion.

Observing misguided attempts at helping, Kristin felt frustrated and angry. Why were patients' experiences being discounted in favor of a set of abstract categories? We started talking about how to turn her dismay into a research project. They fashioned many questions in an attempt to define and refine a research direction: How had Kubler-Ross arrived at her five stages? Did she already have them articulated when she conducted her patient interviews, or did she derive them during her analysis of her data? What would happen if Kristin interviewed dying patients about their experiences but didn't try to force their responses into

¹Agar (1996) argued that the line between *emic* and *etic* approaches to understanding is dissolving: "We have met the other and they are us" (p. 20).

Kubler-Ross's categories? Would the patients independently confirm Kubler-Ross's stages, or would they describe experiences that could better be understood in other ways? What could family members tell her? What would happen if patients and family members were interviewed together? Separately? What do patients and their families face day to day? What do they think about? What concerns them? How do they experience the medical community? How do they interact with their friends and families? What is their relationship with death? Does it change as death approaches? How?

Creating this tangle of design and topic-defining questions helped us make important methodological choices—or, more accurately, it helped us recognize the methodological choices we had already made by virtue of the questions we found ourselves posing. First, we were interested in what patients and families could teach us if we didn't let Kubler-Ross structure our listening. Questionnaires or structured interviews would thus be useless for us: We wanted to take a fresh look at dying and death. Second, we adopted a "naturalistic research approach" (Lincoln & Guba, 1985), recognizing that the design of such an inquiry "cannot be given in advance; it must emerge, develop, unfold" (p. 225). Our knot of questions helped us to orient the direction of our study and to take the first few steps toward articulating a design. As Kristin refined her research question—"How do patients and their family members understand their experiences of living while faced with the inevitability of death?"—we further defined our methodological choices; however, we continued to adapt the particularities of the study in response to contingencies, opportunities, and epiphanies.

Third, we wanted to make use of participant observation and in-depth interviews as a means of exploring the dying experience of patients and families. We don't consider ourselves ethnographers per se, at least not in the strict sense advocated by some anthropologists (Wolcott, 1995b); however, as naturalistic inquirers, we make use of ethnographic methods, bringing an ethnographic "sensibility" to our study of the subjective, emotional, experience (Ellis & Flaherty, 1992) of our research participants. Analysis of ethnographic data "involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations" (Atkinson & Hammersley, 1994, p. 248). We are interested in "thick ethnographic descriptions of emotions grounded in lived experience" (Ellis & Flaherty, p. 4), as well as "the interconnections among

emotional, cognitive, and physical experiences" (Ellis & Flaherty, p. 4) of dying persons and their family members.

Fourth, we did our utmost to appreciate and preserve the contextual integrity of the information gathered. According to Lincoln and Guba (1985), "Naturalistic inquiry is always carried out . . . in a natural setting, since context is so heavily implicated in meaning. Such a contextual inquiry *demand*s a human instrument, one fully adaptive to the indeterminate situation that will be encountered" (p. 189). The qualitative researcher, as participant observer and interviewer, "cannot stand above and outside what [he or she] stud[ies]" (Bochner & Ellis, 1996, p. 19).

Fifth, as family therapists concerned with the relational ramifications of death, we considered the inclusion of family members to be crucial to our study. Many authors who have written about the terminally ill (e.g., Benoliel, 1979; Kalish, 1977; Kubler-Ross, 1969; Pattison, 1977; Saunders, 1974; Shneidman, 1978; Stedeford, 1979, 1984; Wahl, 1972; Walsh & McGoldrick, 1991) discuss the importance of involving family members as the unit of care, but few qualitative studies to date have included the dying patient's family members as part of the interviewing process (Barnard, Towers, Boston, & Lambrinidou, 2000; Davies, Reimer, Brown, & Martens, 1995; Young & Cullen, 1996).

Assessing Risks and Benefits

Internal Review Boards (IRBs) at universities and hospitals review research proposals to ensure that the safety, integrity, and rights of a study's human subjects will not be undermined. Until such boards become well-versed in non-quantitative designs, qualitative researchers can expect some challenges when they submit their proposals. The university IRB reviewing our submission criticized our sampling procedures (see below) and questioned the relevance of a project that did not set out to test hypotheses. Davies et al. (1995) had a similar experience with the hospital IRB examining *their* proposal. Board members initially denied approval of the research, arguing that the small sample size compromised reliability and validity. Fortunately in our case, Douglas Flemons was a member of the IRB reviewing the proposal, and he was able to provide his colleagues with a brief primer on the logic, rationale, and methods of qualitative research.

IRBs are concerned with protecting human subjects. Understandably, they will exercise caution when a researcher describes a plan to conduct

in-depth, open-ended interviews with terminally ill patients and their families. Of particular concern is the possibility that participants may suffer harm when asked to discuss potentially painful thoughts or feelings. Several articles have discussed the possible risks to those participating in qualitative studies (e.g., Cassell, 1978, 1982; Munhall, 1988; Rosenblatt, 1995), but although these risks cannot be denied, the potential benefits of participating should also be underscored. Most significantly, informants are given an opportunity to talk at length and in depth with a person who listens carefully and respectfully. Ideally, "the interview should not only not hurt the interviewees but, if possible, actually leave them somewhat better off for having talked with [the researcher]" (Rubin & Rubin, 1995, p. 40).

Kubler-Ross (1969) noted how participants in her study were unable to talk to physicians, family members, or friends about their fears; however, they found great relief in talking to the researchers. Such conversations allowed patients to talk to a caring, yet neutral, person about their illness and impending death. Hutchinson, Wilson, and Wilson (1994) likewise discussed the beneficial emotional effect many qualitative research participants report when they collaborate in in-depth interviews. Helping researchers understand their struggles and their triumphs can give informants a rewarding sense of purpose (Kubler-Ross, 1969; Hutchinson et al., 1994).

Sampling

There are no rules for sample size in qualitative inquiry. Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources.

—*Michael Quinn Patton* (1990, p. 184)

Unlike quantitative researchers, who use randomization to ensure their samples are representative of the populations to which they wish to generalize their results, qualitative researchers choose their samples with purposeful intent (Patton, 1990); they go in search of richly informative "stories that illuminate the question under study" (Kuzel, 1992, p. 39). In contrast to quantitative studies, qualitative studies favor smaller sample sizes, permitting researchers to intimately understand the various nuances that make the context under study unique (Lincoln & Guba, 1985).

Given KW's affiliations with a hospice, we could easily have located our informants there; however, this would have significantly limited our study. First, as Patton (1990) pointed out, "convenience sampling" is the least desirable strategy for choosing cases (p. 180). Second, hospice patients have, by definition, chosen not to pursue further treatment for their illness. Although we were certainly interested in learning from persons who had come to that decision, we also wanted to interview patients who were aggressively battling their terminal diagnosis. And third, we were concerned that Kubler-Ross's influence on the hospice culture would seep into our interviews. That is, we didn't want to interview persons who were construing their experience through a Kubler-Rossian lens. We managed, instead, to find our informants through an oncologist's office, a hospital-based cancer center, and a not-for-profit agency serving cancer patients and their families. Although this limited us in terms of the types of illnesses our research participants faced (i.e., various forms of cancer), it allowed for greater variability in participants' responses to their terminal diagnoses.

We had neither the time nor the funding to mount a major longitudinal study, so Kristin asked contact persons at each referral source to identify patients they judged to have a life expectancy of approximately six months. They agreed; however, they also recommended that we include an additional person—in each case, a particularly sensitive and articulate patient—whose life expectancy was somewhat longer. We had 12 participants in our study; 3 are still living. We attempted to achieve "maximum variation" sampling (Patton, 1990) by including people in different geographical locations (South Florida, Illinois, and Colorado) and of different ethnicity (South African, South American, African-American, European-American), religion (Jewish, Catholic, Methodist, Born-again Christian), gender (5 males, 7 females), sexual orientation, age (from 9 to 71), and socio-economic status.

Gaining Entry/Access

Without access to informants, no study can be carried out. Fetterman (1989) suggested that the best way of entering a community is through an introduction by a member:

Walking into a community cold can have a chilling effect on ethnographic research An intermediary or go-between can open doors otherwise locked

to outsiders. The facilitator . . . should have some credibility with the group—either as a member or as an acknowledged friend or associate. (pp. 43–44)

To get access to patients, Kristin needed to first find people willing to help her locate them. Two oncologists whom she knew through her hospice work initially agreed to help provide referrals, but when she tried to set up appointments to discuss the study and explain what she needed from them, she found them inaccessible. After months of unreturned phone calls and canceled meetings, Kristin decided the doctors were simply too busy to keep pursuing. Feeling stymied, we reconsidered our decision not to include hospice patients, but when Kristin contacted the administrators of a hospice organization, they refused to allow her to interview their patients out of fear that she would interfere with the patients' dying process.

Davies et al. (1995) described similar difficulties in getting access to terminal patients. Wanting to protect vulnerable people at a sensitive time, health care professionals were reluctant to tell patients and families about the researcher's study (Davies et al., 1995). Clearly, investigators working in the thanatology field must work doubly hard to gain the trust of such "gatekeepers" (Lincoln & Guba, 1985, p. 253). We finally found an initial trusting and helpful gatekeeper through a personal connection. Douglas had undergone cancer surgery some years earlier, and he and his oncologist had enjoyed an excellent rapport since that time. During one of his regularly-scheduled follow-up appointments, he told the doctor about the study and asked if he could help Kristin contact terminally ill patients. The oncologist made a commitment to help and followed through on his word.

We composed an explanatory letter, to be signed by the oncologist, that introduced Kristin and the research study. The oncologist gave the letter to patients he considered appropriate, and she followed up with a phone call. She told patients and their family members about herself and her aspirations, and she assured them that if they chose to participate, she would meet them any time and place they considered convenient. In this, she was following Bogdewic's (1992) counsel: No matter how credible our research or how good our intentions, we impose upon others when we ask them to discuss private details of their lives. We thus must do everything we can to accommodate to our informants' schedules and preferences.

The importance of the oncologist's letter cannot be overemphasized. During her first meeting with each of her participants, Kristin asked

them why they had agreed to meet with her. "What," she asked, "had been the deciding factor?" All said the same thing: Without her association with their doctor and without the letter he had signed, they would not have opened their lives to her scrutiny.

Partway through the study, Kristin moved to Colorado, whereupon she once again began the search for referral sources. After 8 months-of writing letters, making phone calls, and visiting with various healthcare professionals, she found two gatekeepers who allowed her access to further patients.

Participant Observation

According to Wolcott (1995a), the essence of participant observation "is captured, although oversimplified, in the phrase 'being there'" (p. 95). By "being there," the researcher attempts to construe an empathic appreciation for—an emic understanding of—the culture he or she is studying. Such an effort must inevitably fail, for outsiders can never become insiders, and we are seriously limited in the degree to which we can "get others to act 'naturally' while we try to appear nonchalant about our own presence" (Wolcott, pp. 95–96). Nevertheless, participant observation is the best tool we have for grasping the significance of context, and it lays a good foundation for conducting in-depth interviews. Ethnographers recognize that the raw material of their research "lies out there in the daily activities of the people [the researcher is] . . . interested in, and the only way to access those activities is to establish relationships with people, participate with them in what they do, and observe what is going on" (Agar, 1996, p. 31).

Kristin began working with terminally ill patients and their families early in her doctoral studies. She made hospice home-visits, following patients through their last days. Later, she worked as a therapist on a hospice unit, helping patients and their families cope with impending death. Keeping field notes and a journal of her experiences, she spent a year observing hospice culture. She quietly and unobtrusively became a "tag-along," watching nurses start PICC lines, access ports, and start catheters. She watched assistants bathe and turn patients, watched as people lay dying, watched funeral workers come and pick up the dead bodies. She saw loving interactions and insensitive brush-offs. She noted how doctors responded to tough questions, such as, "When am I going to

die?" and witnessed the fear and panic in family members' faces when they heard dreaded news. She heard agonized disagreements about feeding tubes and life support, and she saw families rallying around their loved ones, helping them pass away. Through it all, she listened to mesmerizing stories of amazing lives—stories of meeting spouses, of coming to America, of dreams and visions, of cherished treasures and painful losses.

Such experiences helped Kristin formulate her research question and allowed her to understand the culture of dying patients in a way not possible through interviews alone.

Because a participant observer

sees and hears the people he studies in many situations of the kind that normally occur for them, rather than just in an isolated and formal interview, he builds an ever growing fund of impressions, many of them at the subliminal level, which give him an extensive base for the interpretation and analytic use of any particular datum. The wealth of information and impression sensitizes him to subtleties which might pass unnoticed in an interview and forces him to raise continually new and different questions, which he brings to and tries to answer in succeeding observations. (Becker & Geer, 1970, p. 141)

Interviewing

Participant observation is essential, but "there are, of course, no observers of the internal events of thought and feeling except those to whom they occur. Most of the significant events of people's lives can become known to others only through interview[s]" (Weiss, 1994, p. 2). According to Kvale (1996), "the qualitative research interview attempts to [help the researcher] understand the world from the subjects' points of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations" (p. 1).

Getting inside the lived experience of others requires sensitivity, empathy, and the trust of the informant. Such trust often builds slowly. As interviewees relax into the interviewing process and get to know and respect the researcher, they can more easily let down their guard. We planned for KW to conduct multiple interviews with each person (depending on their willingness and stamina), and, indeed, her best conversations were with persons whom she interviewed several (four, five, even seven) times. Without the pressure to "get it all at once," she was able to allow the dialogue to unfold at a more leisurely pace. Approaching

conversations in this manner holds risks, though, particularly when the persons being interviewed are close to death: One participant died soon after a first interview and another died after a second. Nevertheless, communicating that she was "in no hurry" helped create a relaxed atmosphere that welcomed thoughtful reflection and quiet musing. She never pushed for details, never questioned persistently, never risked losing rapport or respect for the sake of a nugget of information.

Researchers can do too good a job at encouraging the comfort that comes with a sense of informal friendliness. For example, by interviewing informants in their homes, "the researcher is selecting an informal atmosphere and thus wittingly or unwittingly encouraging friendliness, trust, and self-disclosure. This predisposes the family to perceiving the interviewer, not as a researcher, but as a clinician, or even as a friend" (Davies et al., 1995, p. 106). Kristin developed close relationships with her interviewees, but she didn't let them forget that she was visiting them as a friendly researcher, not as a curious friend. We didn't want people to feel badgered into divulging, but we also didn't want them to feel lulled.

Sometimes a relaxed atmosphere can be created but can't be maintained. In addition to experiencing emotional turmoil, informants are often suffering from physical pain. The researcher must stay closely attuned to the patient's non-verbal behaviors and paralinguistic cues and be prepared to end an interview at the first signs of fatigue or distress. Although our informed consent forms noted that research participants could stop an interview at any time, Kristin Wright always reiterated this point verbally and repeated it to patients and their families if she thought they were struggling too much. The well-being of participants was far more important than the goals of the research.

Sometimes when she contacted patients for interviews, they were feeling so poorly that they didn't want her to come to see them. Unfortunately, she wanted to talk with them on such days, so she could learn more about their experience. Talking about bad days on good days was better than nothing, but it lacked the immediacy and depth of talking about bad days in the midst of pain and despair. Again, however, the needs of the study had to be balanced against and considered secondary to the needs of the patient and family. We settled for a policy of "asking but not insisting."

Kristin interviewed dying patients alone, family members alone and in pairs, and patients and families together. The decision of who-should-participate-when was left to the interviewees to decide. We went with

whatever choice was most comfortable for them at the time. If family members were missing, though, KW would, at times, invite a person to reflect on how others in the family might respond had they been present—for example, “If your daughter were here, what do you think she would say about X?” This style of “circular” questioning, originally developed by the Milan Family Therapy Team as a way of eliciting relational information in clinical interviews (Selvini Palazzoli, Boscolo, Cecchin, & Prata, 1980), helped us inquire about intra-family fears, beliefs, meanings, and expectations.

All interviewer–interviewee relationships come to an end as a study concludes, but when the research is about dying, the end of the relationship is interrupted and complicated by death. When a terminally ill person died, KW offered a sense of closure for the family and herself by sending a sympathy card and, after an appropriate interval, by scheduling a follow-up interview with the bereaved.

Happily, but also complicatedly, informants don’t always die as predicted. Two of KW’s informants rallied and are, at the time of this writing, doing so well that death is no longer deemed imminent. Not wanting to tell them that they were too healthy to be interesting, and not wanting them to feel betrayed or used, Kristin has continued to stay in touch with them by phone.

Data Analysis

Our sense of the social world is shaped by the sense of what can be written about it.

—Paul Atkinson (1992, p. 6)

Qualitative studies ultimately aim to describe and explain (at some level) a pattern of relationships, which can be done only with a set of conceptually specified analytic categories. . . . Starting with them (deductively) or getting gradually to them (inductively) are both legitimate and useful paths.

—Michael Huberman and Matthew Miles (1994, p. 429)

Data gathering and data analysis are not discrete activities. Qualitative researchers delimit and influence the form (i.e., the analysis) of the data they gather by who, what, and when they observe; by what captures their attention, what they remember, and what they write down; and by whom they interview, what they ask, and how they ask it. This means that researchers never analyze “raw” data. The ingredients they cook into a final, presentable form are “parboiled” from the start.

Researchers don't usually wait until all the data have been collected before beginning the activities more traditionally recognized as "data analysis"—that is, creating categories, defining patterns, shaping narratives, and so on. Rather, they begin analyzing during their first foray into the field, with their first interview: "There is typically not a precise point at which data collection ends and analysis begins. In the course of gathering data, ideas about possible analysis will occur. Those ideas constitute the beginning of analysis; they are part of the record of field notes" (Patton, 1990, p. 377).

Until researchers have textualized their data (by transcribing their field notes, journals, and interviews) and have fully immersed themselves in the narratives of these texts, they are limited in the degree to which they can bring coherence and rigor to their understanding and interpretation of the data. Huberman and Miles (1994) estimated that data management takes 5–10 times longer than data generation (p. 430).

For the analysis, we followed Lincoln and Guba (1985) and used Glaser and Strauss's (1967) constant-comparison method to inductively create categories of relationship between "data units," or, as Dey (1993) termed them, "data bits." However, like Lincoln and Guba, we didn't adopt the positivist assumptions of Glaser and Strauss's approach; we were more interested in creating a narrative understanding of lived experience than a grounded theory of causal relationships.

From this study's inception, we were intrigued by the relationship between living and dying. While Kubler-Ross's focus was upon how people reacted to the introduction of death into their lives, we were more interested in how participants began relating to life and death differently as a result of death's presence. Our analysis, guided by our relational curiosity, yielded seven categories, seven "styles" of dying-and-living: (1) Imprisoned by Death; (2) *Carpe Diem* [Seize the Day]; (3) *Carpe Mortem* [Seize the Death]; (4) Knowing the Enemy; (5) Life and Death Transformed; (6) Silenced by Death; and (7) Waiting for Death.

Perhaps the most striking experience our informants described was the doubleness of dying. Family members had to contend with the mundane necessities of their own lives and the universal questions occasioned by their loved one's approaching death. And the patients found themselves simultaneously hanging on to life and reaching out to death.

Establishing Relational Integrity

[Cultural analysis] is strange science whose most telling assertions are its most tremulously based, in which to get somewhere with the matter at hand is to intensify the suspicion, both your own and that of others, that you are not quite getting it right.

—Clifford Geertz (1973, p. 29)

Lincoln and Guba (1985) laid out a comprehensive set of “operational techniques” through which qualitative researchers can establish the trustworthiness of their work. By reporting on their use of such techniques—prolonged engagement and persistent observation, triangulation, peer debriefing and member checking, negative case analysis, thick description, and auditing (Lincoln & Guba, p. 219)—investigators seek to reassure their readers (and themselves!) that they have successfully avoided blindered vision, self-deception, questionable data, and unsubstantiated claims.

Wolcott (1994) went to “considerable pains not to get it all wrong” (p. 347). Noting that “in its broad sense of scientific accuracy or correctness, validity haunts qualitative researchers as a specter” (p. 347), Wolcott described nine ways he attempted “to satisfy the implicit challenge of validity” (p. 347) in his work: He talks little and listens a lot, records accurately, begins writing early, lets readers “see for themselves,” reports fully, is candid about his biases, seeks feedback from others, tries to achieve balance, and writes accurately (pp. 348–356). Yet, he added, “Validity neither guides nor informs my work. What I seek is not unrelated to validity, but ‘validity’ does not capture its essence and is not the right term. I am hard pressed to identify the expression that is” (p. 356).

The expression that fits for us is *relational integrity*. Aware of and humbled by the degree to which our *dying to know* shapes our *knowing about dying*, we seek integrity in all of our research relationships. In our interactions with each other and our colleagues, with our research participants, and with our data—gathering it, textualizing it, going into it (analyzing), and going beyond it (extrapolating)—we hold relationships to be inviolable. That is, we make sure we don’t impose ourselves on the person or thing with whom or which we are in relationship (a colleague, an informant, the data, an idea), and, recognizing that what we report in our research is the story of *our participation* in the project, we also make sure we don’t disappear or withdraw from these others. We want our informants, our experience, our data, and our analyses to

speak for themselves, and we appreciate the degree to which our participation is responsible for giving them a voice.

For us, researching with relational integrity involves our making the following choices:

1. We put the needs of research participants ahead of our own.
2. We approach participant observation as the impossible necessity of crossing the boundary between self and other.
3. We treat interviews as conversations, where participants are invited (never pulled or pushed) into an exploration of subjective (cognitive, emotional, and physical) experiences and understandings that they (and we) deem important.
4. We think of data analysis as a process of composing stories about participants' stories—that is, as the creation of meta-stories that retain the uniqueness of individual participants' voices and that weave these voices contrapuntally.

Personal Challenges: Final Comments by Kristin Wright

If I'm no different as a human being or as an ethnographer after returning from the field, then what can I say I learned?

—*Arthur Bochner* (Bochner & Ellis, 1996, p. 40)

Don't be afraid to make ethnography dangerous, political, personal. Take risks. Write from the heart as well as the head.

—*Carolyn Ellis* (Bochner & Ellis, 1996, p. 42)

Qualitative research places considerable demands upon investigators. It requires considerable time and effort, flexibility and comfort with ongoing uncertainty, clear thinking and writing, and a personal commitment to the process, to colleagues, and to the research participants. This is particularly the case in the field of thanatology, given the complexity of getting connected to people who are preparing to die.

I sometimes teared up when interviewing participants. I didn't try to hide this; I just allowed it to happen. If they noticed and asked about it, we would talk about what it was like for the people surrounding them to experience their movement toward death. I remember early on being concerned that I was crying so little, given the stories I was being told and the pain and loss I was witnessing. Then one night I began crying in my sleep. As I awoke, I felt an overwhelming sadness, and my tears and grief broke loose.

Later, looking back at this night, I was able to better acknowledge how emotionally involving I find this area of research. Sometimes it gnaws at me, and I wonder why I chose this field. But I find ways to keep going, and I recognize how meaningful this work is for me, both personally and professionally. I live with the understanding that I too will die, as will my loved ones, and my research keeps me grounded in that knowledge. It keeps me from becoming too self-absorbed, and it helps me focus on living. While I'm no more comfortable with death, I can stay balanced in my personal life, and I can use my thoughts and feelings to help me more fully appreciate the doubleness of dying—the intensity of the loss and the heightened sense of connection and meaning that accompanies it. Thus, amidst the sadness and grief, there is also pleasure and joy, not only for me, but also for the patients and families. Sometimes I see how my research makes a difference for them, and sometimes they appreciate how their experience carries a significance beyond the limits of their personal pain.

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