RELATIONSHIPS WITH DEATH: THE TERMINALLY ILL TALK ABOUT DYING

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This article describes a qualitative study exploring the experiences of terminally ill patients and their families as they lived with the inevitability of death. Frustrated by the dominant discourse surrounding the culture of dying—namely that of Elisabeth Kübler-Ross's stage theory—I sought to revisit the experiences of the terminally ill by talking directly with them. Instead of focusing on how people reacted to the introduction of death into their lives, this research attended to how the dying began relating to life and death differently as a result of death's presence. Through an analysis of ethnographically collected data, the meanings participants constructed around their experiences were explored—culminating in the creation of seven "relationships" that participants shared with death.

Elisabeth Kübler-Ross (1970a) once suggested, "If you really want to . . . experience what it is like to have a very limited time to live, sit with . . . dying patients and listen" (p. 157). At the time I came across this statement, I was working as a family therapist in a hospice setting while completing my doctoral studies in marriage and family therapy. For months, these words echoed in my mind and eventually became the impetus for a qualitative study exploring the experiences of terminally ill patients and their family members as they faced impending death. In this article, I will provide an overview of the study, sharing with readers how I came to the research, what I learned, and the implications for therapists, health care professionals, and those who care for the terminally ill.

BACKGROUND OF THE STUDY

In 1969, psychiatrist Elisabeth Kübler-Ross offered an intimate glimpse into the world of dying patients with the publication of On Death and Dying. Using excerpts from conversations with more than 200 dying patients, Kübler-Ross focused society's attention on the plight of the terminally ill, teaching us that dying patients are in fact living and, therefore, deserving of attention and respect. Calling on helping professionals, family members of dying patients, and society to give up the "conspiracy of silence" (Kübler-Ross, 1970b, p. 111) surrounding death, Kübler-Ross's ideas offered a much-needed departure from the accepted wisdom of the time and helped to inspire a new approach to working with the terminally ill.

Since then, her work has dominated the field, and the stages of dying she theorized—denial, anger, bargaining, depression, and acceptance—have become household words and often the terms through which many dying patients, and those who assist them (caregivers and health care professionals), have come to define their experiences. Many believe Kübler-Ross's stages to be the final word—the official doctrine—in explaining the step-by-step process through which all patients (and their families) must progress in order to find "acceptance" and, therefore, die successfully.

Thirty years have passed since Kübler-Ross published her work and many have critiqued her ideas (e.g., Carter, 1989; Corr, 1993; Klass, 1981; Metzger, 1980; Schulz & Aderman, 1974), and, yet, her...
influence endures. As a family therapist and a qualitative researcher, I am continually surprised by the extent to which Kübler-Ross’s stage theory continues to shape our thinking. Repeatedly, I have witnessed patients pathologized when they failed to follow some prescribed, normative model of coping. Unfortunately, many assume there is a “right” way to die, and when the process does not follow a particular pattern, it is often assumed the dying are “unresolved,” “nonaccepting,” “in denial,” “unfinished,” or “having difficulty letting go.” Although it is unlikely that Kübler-Ross ever intended for her ideas to be used in such a manner, such simplistic interpretations of her work are not uncommon (e.g., Brower, 1991; Corr, 1993; Kastenbaum, 1981; Pattison, 1977).

METHOD

Frustrated by the damaging effects of such misguided interpretations, I set out to revisit the experiences of the dying by talking directly with them—much in the same way Kübler-Ross had 30 years earlier. Despite my frustration with the pervasiveness of her ideas and her conclusion that dying patients progress through a five-stage process of coping, Kübler-Ross’s work served as the inspiration for my research. She, more than anyone, recognized the dying as the experts in their own experiences.

Following in her footsteps, I set out to conduct in-depth, open-ended interviews with terminally ill patients and their family members; however, long before I conducted my first interview—even before I had conceptualized the research study—I began keeping notes of my experiences working with dying patients and their families. For several years, I immersed myself in hospice culture as a participant observer. Although these experiences offered an excellent opportunity in which I was allowed intimate access into the world of dying, in-depth interviews were the key to my gaining a better understanding of the thoughts, feelings, and perceptions that patients and families faced as they lived with dying.

Given my affiliations with several hospice organizations, I could have easily located participants there; however, this would have significantly limited the study. Hospice patients, by definition, have chosen not to pursue further treatment for their illnesses, instead opting for palliative care. Although I was interested in learning from participants who had come to this decision, I also wanted to interview participants who were aggressively battling their illnesses. Further, I was concerned that Kübler-Ross’s (1969) influence on the hospice culture would permeate the interviews. That is, I did not want to interview participants who were making sense of their experiences through Kübler-Ross’s descriptions. A total of 36 participants (12 dying patients and 24 family members), therefore, were located through an oncologist’s office, a hospital-based cancer center, and a not-for-profit agency serving cancer patients and their families. Two additional participants who I knew socially were also included when they asked to be able to share their experiences of living with a terminal illness. Although this limited the study in terms of the types of illnesses participants were facing (i.e., various types of cancer), by not focusing specifically on hospice patients, I was allowed greater variability in participants’ responses to their prognosis.

Given my belief that the interviews were a collaboration between myself and those who participated in the study, I chose the unstructured interviewing style characteristic of ethnographic investigation (Fetterman, 1989; Spradley, 1979). Multiple interviews (ranging from 1 interview to 10 interviews) were conducted in participants’ homes when they were willing and had the stamina. Without the pressure to “get it all at once,” conversations were allowed to unfold at a leisurely pace. By the second interview (if participants agreed), a more comfortable rapport had been established, and participants knew what to expect of the interviewing process. Also, participants were allowed time between interviews to reflect on the conversations, clarify anything that was unclear, and discuss any memories or thoughts they may have had since the earlier interview (Weiss, 1994).

Participants were interviewed both individually and with family members, depending on their preference. The decision of who-should-participate-when was left up to the interviewees. New and meaningful information came forth when family members were able to hear what each other thought and felt about important matters; however, some participants found it more comfortable or convenient to speak with me alone. In such instances, I included questions that invited the person to reflect on how others in the family might respond if they were present. For example, “If your daughter were here, what do you think she would say about...?” By using this style of interviewing, a more relational understanding of what families
experienced, how they coped, and how they made meaning when a family member was dying was gained.

All interviews were taped on a microrecorder, and all tapes were transcribed word-for-word with personally identifying information eliminated. Overwhelmed with literally hundreds of pages of transcripts, I began the process of making sense of what I had learned by following Glaser and Strauss’s (1967) constant comparison method to create categories of relationship between “data units,” or, as Dey (1993) terms them, “data bits” inductively. This began the very long process of working and reworking emerging and evolving categories: “It is this dynamic working back and forth that gives the analyst confidence that he or she is converging on some stable and meaningful category set” (Lincoln & Guba, 1985, p. 342).

Like Lincoln and Guba (1985), I did not adopt the positivist assumptions that guided Glaser and Strauss’s (1967) approach: I was not interested in developing a grounded theory of causal relationships; instead, I was more interested in creating a narrative understanding of participants’ lived experience. During this time, I was plagued by thoughts that my categories were failing to capture the richness of participant’s stories. The process of their experience was being seemingly ignored in favor of category names. As I had talked with participants about their experiences, I was guided by the overarching question, “How do patients and their family members understand their experiences of living while faced with the inevitability of death?” Although death and dying had become a very real part of participants’ lives, they were, in fact, “still living.” It was this relationship—between living and dying—that intrigued me as a researcher. Whereas Kübler-Ross’s focus was on how people reacted to the introduction of death into their lives, I was more interested in how participants began relating to life and death differently as a function of death’s presence. This interest in the relationship participants shared with death was fueled in two ways: First, as a systemic family therapist, I think relationally about people and their problems; therefore, when it came to analyzing data from the interviews, I began conceptualizing the analysis in terms of each participant’s relationship to death. Second, during an interview with one of the participants in the study, a metaphor was mentioned that invoked this notion of the dying person in relationship with death:

Dawn: You know the Grim Reaper is just kind of a funny character. I think kind of a humorous character that I’ve invented in a way, instead of the boogie man or . . . the devil or something . . . just kinda raggedy, and he’s kind of the picture of doom and gloom, and he comes to your door with a lantern and a sickle and knocks on the door, and he wants your soul [laughs].

Dawn’s vivid description anthropomorphized death—allowing me a way to conceptualize death as someone participants were relating to in a very real sort of way. Dawn’s metaphor was a way of acknowledging a relationship with death—in a way, befriending it. Guided by this thought, I too began to envision death as the “Grim Reaper” and for the benefit of the analysis, I began reflecting on the relationships participants shared with death. From that analysis, seven relationship styles evolved—six of which will be described below: Imprisoned by death, carpe diem (seize the day), carpe mortem (seize thy death), life and death transformed, silenced by death, and waiting for death.

RESULTS

Imprisoned by Death

I’m dying. That’s it. . . . There’s no more dot, dot, dot to it cause I’m dying. There’s no question mark. There’s no etc. Nothing. There’s this period—end of sentence. —Beth

When I first interviewed 42-year-old Beth and her partner, Alice, in May of 1999, Beth had recently been turned down for a bone marrow transplant—the last hope for potentially curing her metastatic breast cancer. Although Beth’s diagnosis introduced her to the world of cancer and potential death, the doctor’s time estimate became the undeniable reality of death’s presence in her life:

Beth: I mean until you know for sure you can try and escape the reality of the disease, but you know, once you’ve been told that you’ve six months—maybe on the outside 2 years—Whew.
For Beth, life suddenly became defined in terms of months until death, not months left of living:

_Beth:_ When I went into the Herseptin [the last chemotherapy regime], . . . I felt like the clock started ticking and like I was Captain Hook in [the story of] Peter Pan: 'Gee, okay, now I've got 5 months.' [Captain Hook was incessantly stalked by an alligator who had eaten not only Captain Hook's missing hand, but also a ticking clock that reminded Hook of his impending demise.]

For Beth the clock was ticking, and it permeated her every waking moment:

_Beth:_ I mean it's like the future has suddenly been taken. I mean, sure, okay, you get these talks, "miracles can happen," and "You can be on this [chemotherapy] 5 years." And you know, there's only like . . . a 10%-12% chance that I'll even last 2 years—something like that. So the future’s been taken from us. You can't dream about growing old together. We can't. I mean it's like the future has suddenly been taken from us.

_Kristin:_ Do you, I mean is that something you think about [interrupted].

_Beth:_ About every minute of every day!

Other participants also referred to the immutability of death’s presence—sensing it and seeing death daily; however, most were able to shift their focus periodically. Whereas they kept death in their peripheral vision—still present, but not obstructing their view of life—Beth constantly stared death in the face. Even something as benign as buying clothes was a reminder of death’s presence:

_Beth:_ We were in Target shopping, and I picked up a shirt that I wanted, and at the check out stand I said, “Well, I don’t need this.” She [her partner, Alice] probably thought I just didn’t want to spend the money, and it just . . . kinda hit me, “What the fuck difference does it make?” I mean, you know, it’s kind of betting on a three-legged horse to win the Kentucky Derby. I mean it’s just little reality things that jump out. I mean, why go out and buy new clothes?

Beth lives in the shadow of death. Thus, even though alive, all she can think about is the fact that she’s moving closer to death—every action, every part of her living is drowned out by the ticking of the clock. Beth’s coping was fueled by her “anger at the whole injustice” of death coming into her life. She frequently raged at death’s presence questioning, “Why me?” which kept her imprisoned by death. Whereas other participants focused on living despite the presence of death, Beth focuses on death despite the presence of life. Later in our conversation, I clarified something Alice (Beth’s partner) had said:

_Kristin:_ And it’s almost like, and please correct me if I’m wrong, it’s almost like Alice, you think Beth is dying more than she’s living right now even though she’s still alive right now. And you want her to be living more than she’s dying?

_Alice:_ Yes, that’s it. You summed it up nicely.

_Beth:_ In a way, I feel like I’m already dead.

Beth’s words—"I feel like I’m already dead"—illustrate all too painfully how, for her, not only has life been ticking away, but in some aspects life is already over. Since death made its presence known, Beth has been unable to escape its grip. The fact that death has Beth in its clutches infuriates her, which in turn keeps her more connected to it.

Beth’s perception of feeling “already dead” conveyed a sense of hopelessness that other participants did not express. Whereas other participants did refer to times of incredible sadness and despair, they simultaneously talked about maintaining the hope that they would survive. In contrast, Beth has no hope—death is a constant:

_Beth:_ I am past help. There is no more help for me. . . . I have no more options.

Whereas others were comforted or “nourished by [hope] in especially difficult times” (Kübler-Ross, 1969, p. 139), Beth was only embittered by such thoughts:
Beth: In the early months, I actually had a little bit of hope . . . but as far as I'm concerned, I'm not really holding out for God having some little miracle tucked away in his fuckin' back pocket for me.

It seems that death's constant presence leaves Beth feeling hopeless and angry which in turn keeps her imprisoned by death.

Carpe Diem [Seize the Day]

I have a saying . . . "You're not ready to live until you're ready to die, and that's what I've learned. It's never meant much to me until now, and now it seems profound . . . It never meant much to me until I . . . looked death in the eye, and now I'm living . . . This life is a lot better than the one before. —Faith

When I first met with Faith in September of 1998, she had recently made the decision to stop the chemotherapy she had been receiving for her lung cancer since the treatments robbed her of quality time:

Faith: You know, if I don't have 6 months, I don't want to live this way and then die. I want to come back to sharing with my children and caring about what they do and then die.

Although Faith's children and her primary care physician agreed with her decision, her oncologist did not:

Faith: He just did not really understand why I would [quit]. He is a fighter, and he doesn't understand a person who is not a fighter . . . not really thinking that I was fighting in my own way.

Given what I would come to learn about Faith, I understood her desire to not fight death—a battle she knew she would eventually lose. Instead, she wanted to fight to regain her life until she died—she wanted to "seize the day." The likelihood that she would only gain a few extra months despite all her suffering made Faith's decision to stop treatment the only logical choice for her.

Similarly, Helen, a 71-year-old woman diagnosed with colon cancer experienced horrendous side-effects from the chemotherapy she was receiving and decided to discontinue her treatments. Both Faith and Helen were living under the same time prognosis as Beth, and yet, death was abstract: "It wasn't happening yet." Whereas Beth was unable to focus on anything but the ticking of the clock and what it represented, Helen and Faith instead focused more intently on life and living: Death was present, it simply had not overtaken their lives. Where Beth's life had become defined and greatly hampered by the ticking of the clock, Faith and Helen perceived the ticking as bringing a new awareness to their lives—giving their lives new meaning. While some things seemed "already dead" to Beth, for Helen and Faith, living became more vivid:

Helen: I might not be here next month or in 2 months time or on my next birthday. You then become much more aware of people, your beloved people around you. You know, my little, my little granddaughter . . . I keep on hugging and kissing because I don't know how long I will be able to do that. And your senses are sharpened. Suddenly pink roses are much pinker than they used to be, and the blue sky is bluer than it used to be. And you just observe things in a different way. Most of us take things for granted—that's human nature, you know?

Similarly, Faith spoke about her increased awareness of the world around her and a greater appreciation for the moment:

Faith: Everything is in focus. Uh, I call it crystal. What this crystal means, it's like after a snow, on a real cold night when there's fog in the air and every tree branch is covered with ice the next morning, and the sun shines, and it's just a different world—beautiful. That is as close as I could come to describing crystal. My world is in focus. It's . . . crystallized. It is that this moment with Kristin is of an extreme value to me, and it is a high point in my life, and it is just enjoy the moment. Don't worry about the next one . . . It is an enjoyment. Every moment has meaning to me.
Clearly, for both Faith and Helen, death’s presence had heightened the meaning of life. Instead of allowing death to negate living, death was a constant reminder to them of life’s preciousness. Death’s presence brought new poignancy to their lives and informed how each woman lived her remaining days; however, neither woman fixated on it:

**Faith:** I don’t think a day goes by that death doesn’t come into my thoughts. . . . It comes in, in conversation with people. I can’t go downstairs without somebody saying, “How are you.” Well, right there’s a reminder. . . . Uh, every time I go out of the apartment, and I have to use my walker, it’s a reminder. . . . I mean, death comes into the picture daily. . . . I just don’t dwell on it. It, it’s a fact of my life, and I don’t deny it anymore than I deny my blue eyes, you know. It’s just, it’s just there.

Likewise, for Helen, death was not the focal point:

**Helen:** You can’t focus . . . you can’t focus on death. Uh, you’ll drive yourself crazy if you do.

Instead Helen concentrated on the present:

**Helen:** At this point, I’m feeling good. . . . I focus on that.

Both women, like Beth, were reminded of death’s presence daily; however, death did not bully them in quite the same way. Instead of being imprisoned by death, death had become a talisman they wore—constantly reminding them of life’s preciousness. Quite simply, death did not interfere with their ability to enjoy life—possibly because they, in contrast to Beth, were able to focus on the fact that they were still living: Death was coming, but they were not dying yet.

**Carpe Mortem [Seize Thy Death]**

It’s . . . okay because I lived fourteen years past my diagnosis, and uh, I had such an astounding 14 years. Who could gripe about that? And it’s okay. I’m not, I’m not afraid of it. I, I’d be crazy . . . really crazy if I said there weren’t thoughts and feelings I have of being a little anxious. I mean, I feel like I’m getting ready to take a journey that you take once in a life time. . . . And I don’t know what that’s like. I don’t know where it’ll end. I don’t know where it begins, and uh, it’s rather exciting. I find it extremely exciting. —Dawn

This relationship with death was characterized by participants’ connection to both life and death. Life and death were inexorably bound, and participants did not view themselves as living or dying. Instead, they were intensely involved in both and seemed to view death as part of their life-experience. For them, dying meant still living, and living meant gradually moving toward death. Death was viewed as part of their personal journey and an opportunity to learn more about themselves.

In December of 1999, I went to meet with Dawn, who had recently admitted herself to a hospice unit, where she lived until her death in January of 2000. She was a 57-year-old woman who had been diagnosed with colon cancer 14 years earlier and had been in remission for 9 years before her cancer reoccurred.

Although some participants wanted to know very little about their illnesses, and others recalled simply wanting to turn their care over to physicians, these participants turned to research as a way to learn about their illnesses—and, in turn, learn about themselves:

**Dawn:** I learned all about my disease. . . . I felt very comfortable going to the Health Sciences Center Library . . . and I’d check out those big texts and take home 13–15 at a time. . . . I’d go in, and I would read and read. . . . I want to know as much as I can about it, and I don’t think hiding . . . behind the door, or jumping under the covers could help me at all. And, I realized for the first time in my life—really, really, realized that I was strong, and I could handle anything. If I could sit down and read about myself, it’s like, “My God, that’s me,” you know? Whoa.
Like Dawn, Cissy, a 50-year-old woman diagnosed with non-Hodgkins lymphoma, turned to research as well—a coping strategy she had relied on throughout her life: “I think I’ve handled it [cancer] like I’ve coped with everything else”—by researching and getting as much information as possible:

Cissy: Any time during my life that I had a problem, no matter what, step-children or anything, the first thing I do is read everything I can find out about it—go on the internet, find out about it, and that’s how I deal with things.

Cissy and Dawn’s reaction of turning to research was not uncommon. In the early days of a diagnosis, educating oneself and becoming proactive was a strategy other participants followed as well; however, for those participants research was a way to better prepare for the fight ahead—a way of sizing up the enemy. For Dawn, it was a way of better understanding herself and her experience:

Dawn: If you don’t know what you’re dealing with, I wonder how you deal with it? What do you do with it? I found it to be extremely empowering, ‘cause it’s like... it’s like, **this is mine. I don’t want this, but it’s mine. I’ve got it...** I found that extremely empowering because it did belong to me and nobody could take it away. I wish they could have at times... **This is what I am, and this is my experience.** You can’t change that.

For Cissy, exploring what her death might look like was comforting:

Cissy: I could... die suddenly. Or, like if my liver shuts down, I could put all these toxins in my body, and then it’ll cause other organs to shut down, and that would take about 2 weeks to die. Or, I could cough wrong and burst a blood vessel in my brain, or I could have internal bleeding from [a] lack of platelets and stuff. Or, I could have a heart attack just because my heart has to work a lot harder or something like that, and die suddenly. But I somehow don’t think that’s going to happen. I think more the organ shut down might happen, or I’ll just gradually get to the point where I don’t have any reserves at all.

Kristin: Is it helpful for you knowing?

Cissy: Yeah... that’s the thing that really pissed me off because I couldn’t find anything on the internet or in books about how you die from non-Hodgkin’s lymphoma... Like what’s involved? How does it happen? What’s [the] process? Is it like you get shortness of breath, and you know, like usually in the last week there’s all these indicators which I found on... on the internet... [things] that let you know that there’s about a week left or 2 weeks left. And so, that’s been very helpful because I’m one of these people, I want to know everything. And so that’s been real reassuring.

Although knowing the specifics of the dying process would be too overwhelming for many patients, Cissy was comforted by such information. She added:

Cissy: I’m kind of able to remove myself from the situation in some ways... and look at it very objectively.

To some, this comment may imply that in researching her illness, Cissy had found a way to avoid or, in Kübler-Rossian vernacular, “deny” the reality of impending death. Instead, like Dawn, Cissy was more able to connect to her experience by better understanding the medical aspects.

By improving their knowledge about their illnesses, both Dawn and Cissy were able to integrate cancer and death into their lives. These women were not unwitting victims, but women who continued to live despite cancer and death being part of their experience. Both learned about cancer, kept in tune with their experience, and embraced death as part of themselves.

Although impending death was not easy for anyone, least of all the dying and their families, for Dawn and Cissy dying was part of who they were. In a sense, both women “seized” death—appreciating it as part of their life journey. Time and time again, this attitude was reflected by both women—in their insistence on being up-front with themselves about what was happening, in their interactions with friends and family, and in their willingness to talk with me about their experiences. Whereas Beth viewed herself as “already dead,”
and Helen and Faith viewed themselves as “living more vividly,” Cissy and Dawn acknowledged death’s presence without allowing it to become the guiding template for their lives. Death’s presence did not hinder their ability to live as it did with Beth, nor did it become the lens through which they looked at life, as it did for Helen and Faith. Instead, these two women maintained a relationship with both living and dying that allowed them to live toward death without turning their back on either. Death was simply one of their many life experiences. Despite this, Cissy was emphatic that she did not want to die:

Cissy: I don’t want to die. Do you want to die? . . . It has nothing to do with being fearful of what’s coming, being frightened or unresolved. It has to do with not wanting to leave life.

Cissy’s comment illustrates that perhaps no matter how well a person comes to terms with impending death there may always be feelings of sadness and loss. Less than a month before her death, Cissy struggled with “leaving life”:

Bread (Cissy’s husband): We’re not talking about you dying of a heart attack here; we’re talking about somebody releasing. You’ve been at death’s door two or three times. . . . You haven’t gone. You told ’em to come back later. . . . The question is, are you ready to die?
Cissy: There’s a couple of things I gotta do.

Again, Cissy’s comment was not an indication of denial or avoidance—of nonacceptance—but simply a testament to Cissy’s continued connection to life and living. Cissy lived toward impending death with the same zest she had shown throughout her life:

Cissy: One thing I did that was my favorite thing is . . . like after you die, your clothes and everything get distributed to people. I decided I wanted to do it while I was still here. So, my mother-in-law . . . my sisters . . . my stepdaughters and some friends . . . we went through all my clothes . . . and went through everything, and [I] gave it away. Then we went through my jewelry. We were all bawling over that . . . I had a lot of jewelry that’s been in my family for a long time, and . . . I think everybody got what they really loved. . . . It was just so cool to do that, you know. I got pleasure from seeing their pleasure. The parting is . . . well . . . that made it so much easier. It was so much fun because I got to see the joy and happiness in their faces. I don’t know why everybody doesn’t do it that way. . . . And you know, I’ve already planned my complete memorial service with the priest.

Life and Death Transformed

Some participants shared a relationship with death that allowed for a transformation to occur—either death was transformed into something different, or life was transformed making living more bearable. For example, Charles, a 63-year-old man dying of lung cancer, described a sense of desperation when he realized that he had no control over the cancer raging in his body. Death was exerting itself, and he could do nothing to stop it—a realization other participants described as well. For Charles, someone who had shared a life-long relationship with God, peace came when he surrendered to what he considered to be a power greater than death. Understandably, for Charles, hope had always been tied to living and therefore, was contingent on being cured. Since he “couldn’t find anything in reality that would provide hope,” he turned to God. As a result, death was transformed:

Kristin: Have similar changes occurred in your views of death?
Charles: I think it happened at the time of abandonment . . . uhm, I think of the eternal reality not in the context of impending death.
Kristin: I want to make sure I’m grasping what you’re saying. So, in essence, for you, death is eternal reality?
Charles: Yes. It’s not really death, but eternal reality. A doorway. . . . It’s looking beyond this life with the expectation of being with Him [Jesus] in His presence. . . . A rejection of death.

Earlier in his illness, Charles had experienced a period of despair—perceiving death as a separation: Death would take him away from life and away from his loved ones. However, as he surrendered to God, death became something different: Charles was no longer dying away from life, but instead was now going
to meet Jesus—a much less scary and depressing proposition. The fact that he was dying did not change, simply the meaning attributed to dying, thus making it more tolerable. During our last interview, as I prepared to leave, Charles clarified:

*Charles:* The most significant thing I want you to take away from this meeting is that... death is back again, and the fear and sadness is not... Life is like a door closing, and death is the alternative. I'm going to be with Him.

In the end, death was transformed: Charles was not separating from loved ones, but was going to be with Jesus:

*Charles:* I was very close with my father and when he passed away, you know, we went to the funeral home. I felt no separation. I felt... I wasn't troubled. I wasn't challenged. There [was] no sadness because he wasn't there. I knew where he was. I want her [one of his daughters] to know that. I said to her, “Don’t think of missing me or that I’m not here, but think of with whom I am.”

Where Charles transformed death, other participants periodically transformed themselves in relation to death as a way of making their experience with cancer and death more bearable. For example, Sam, a 9-year old boy, battling a brain tumor, talked about how dreams and fantasies helped him to cope:

*Sam:* Sometimes I just like to dream... nothing has happened to me. I just like to dream about that when I’m mostly alone. I either dream about that, or just imagine myself as a sports player, cause I like sports, and I dream that nothing has happened to me.

Similarly, as 66-year-old Patty struggled to cope with impending death, she found herself following an approach that she had heard about while watching The Tonight Show years earlier following her first diagnosis of breast cancer:

*Patty:* I had heard on Johnny Carson’s program once. He had a guest, a fellow who had been a prisoner-of-war in Vietnam, and they learned how to keep themselves, their wits about them as prisoners by uh, each playing a different character in a Star Trek program. And they’d say, “Well, I want to be Sulu tonight. I want to be the captain,” and so forth... And I thought, “What'll I do, what'll I do when they told me I had cancer, and again years later when I found out it was terminal, so I thought, “Well, I can do that.” I am an avid, rabid fan of Star Trek, a trekkie like there never has been... And I have watched it, and I tape all the episodes, and I watch it to the point that I've memorized it, and I used to go over that in my mind while I cleaned the floor and as I did other things. In fact, Star Trek got me through a root canal. I was thinking about... the pilot of the newest series... and the dentist kept talking to me, and I thought, “I wish he'd quit so I could think about Star Trek.”... In doing that, I'm not thinking about cancer or dying.... I think that's how I get through it—in a make-believe world.

Many may characterize the manner in which Patty, Sam, and Charles interacted with death as problematic—another example of “denial.” However, I saw their actions remarkably similar to strategies frequently utilized by family therapists as a way of encouraging change. In essence, Charles had “reframed” his problem. That is, he:

Chang[ed] the conceptual and/or emotional setting or viewpoint in relation to which a situation is experienced and... place[d] it in another frame which fit the “facts” of the same concrete situation equally well or even better, and thereby change[d] its entire meaning. (Watzlawick, Weakland, & Fisch, 1974, p. 95)

By changing the meaning of death—from that of separation, to that of being united with Jesus—death became less frightening and more bearable. In a similar manner, Sam and Patty transformed themselves: Occasionally, they became people who did not have cancer. In reality, they knew that they were sick, and
Patty knew she was dying, but by pretending to be other people they were periodically relieved of death’s constant presence.

Silenced by Death
In March of 1997, I went to meet with Noah, his wife Colleen, and their two young children (ages 7 and 4). Noah had been diagnosed with pancreatic cancer in January of the same year. Despite his continued physical deterioration—as evidenced by medical tests showing his cancer’s progression and his need for ever-increasing dosages of pain medication—during our interview, Noah and his wife spoke little about death or the very real possibility that he was dying from his illness. Guided by her strong spiritual beliefs, Colleen believed that God would save Noah:

Kristin: Both of you have a very strong faith... but do you ever talk about or do you ever think about him dying?
Colleen: No, he’s not going to die. No.
Kristin: Do you Noah?
Noah: No... 

When I asked the couple about their children, Colleen was again steadfast in her belief that Noah would survive. He, though, was not as certain:

Kristin: So tell me, the kids don’t understand the seriousness of your illness?
Noah: No, I don’t think so. No, they just think that I’m gonna get better.
Colleen: You are gonna get better!

Later in the conversation, Noah acknowledged thinking about death:

Kristin: You stay focused on that he is going to get well [to Colleen]?
Noah: Oh yeah!
Colleen: Uh huh [nodding her head in agreement]
Kristin: And you don’t waver in that?
Colleen: No way!
Kristin: Noah, do you waver?
Noah: Sometimes. [whispers and smiles]

Noah’s comment, “sometimes,” accompanied by his sheepish grin, conveyed a sense of guilty admission—as if he had been caught thinking about something he should not. Following this, Colleen promptly left the room.

Whereas privately Noah was aware of his deterioration, together he and Colleen were silenced by death’s presence. Death had become “the horse on the dining room table” (Kalish, 1985, p. 2)—they both noticed its presence, but neither one could bring themselves to broach the topic. In fact, even Noah’s failing health was a sign to Colleen that help was on its way:

Colleen: God’s not gonna put no more on you than you can bear, and sometimes when you think it’s at the craziest and the worst, then it’s just blessings come. So... blessings are on their way.

According to Colleen’s faith, they were simply being tested—Noah’s cancer was an opportunity to show God the purity of their faith. In order to save Noah, they had to maintain their prayers and the belief that he was going to live. Talking about death would allow death to gain a foothold:

Colleen: When you’re around a lot of people that’s talking negative and talking about death and dying, and... once you begin to hear all this it just, it like makes your head go [makes swirling gesture]. So, you got to get away—get your bible reading done, listen to tapes, regroup, and get back. Because that’s only the enemy trying to come and get into your thoughts—your words. And if he can get... into what’s in your heart, [pause] you’re in trouble. First, you need to start saying it [that Noah will be healed] over and over and over until it gets into your heart, into your spirit—until it’s part of you.
Colleen was fervent in her beliefs—beliefs that comforted Noah as well: As long as Colleen remained steadfast and believed that he would be cured, there was hope that Noah would survive. Although the couple did not talk about death with one another, Noah recognized our conversation as an opportunity to do so. Repeatedly, however, as he mentioned dying, Colleen disregarded his concerns:

Noah: Dying, you know, it doesn’t enter my mind, but once in a while . . . I start thinking about my kids. . . . You know, I have a videotape. I can videotape something for the kids, for the kids to always remember.

Colleen: That doesn’t—that does nothing.

Undoubtedly, Colleen could be described as someone who was denying her husband’s impending death or possibly as someone who was fighting death. However, I saw her as a woman rebuking death—unwilling to give voice to death’s name. She was convinced that her husband could be healed if they simply believed and remained steadfast in their prayers. Colleen had to turn away from death, because to acknowledge it risked Noah’s life. Unfortunately, this left Noah isolated—how could he talk to Colleen about death when she could not even allow herself to think about it? Surrounded by so much faith, Noah had little choice but to follow Colleen’s lead:

Noah: Her faith is amazing isn’t it? See, I can’t not believe.

It seemed that Colleen’s faith was informing how Noah coped:

Noah: Do I ever have. . . . doubt? Of course I have. . . . See, she’s the believer. Like I said, I’m the newcomer to this God thing.

Although Noah admitted having doubts, he also felt a huge responsibility not to speak of death’s presence:

Noah: She has never shed a tear in front of me, and I tell people, “My wife, I never knew how strong she was until I got sick because she never shed a tear in front of me. Not one time.” So . . . if she can stay strong considering that she has so much to do now. . . . Well, I try to stay up too.

Despite their prayers, Noah continued to deteriorate. He was admitted to an area hospital, where I went to meet with the couple again. Noah lay unresponsive in a hospital bed, while Colleen’s faith remained unwavering. Contrary to Colleen’s prayers, Noah died the following day. In an interview with her following Noah’s death, Colleen noted how her coping had influenced her husband’s:

Colleen: He might [have] been saying one thing so I wouldn’t pressure him, you know what I’m saying? ‘Cause sometimes you ask a person, and they might tell you what you want to hear at that moment, but they don’t want you, you to worry. So Noah might’ve wanted to let go, but didn’t want to tell me that.

Colleen was left with a sense of deep regret—sorry that she and Noah had not talked more openly:

Colleen: Even though I was praying for him to live . . . you can’t override his [Noah’s] will. I don’t know what his will was, you know? . . . Maybe the pain got too big. He never did tell me about the pain. He would just say, “You don’t understand sometimes.” . . . And in the last couple of weeks he really didn’t talk as much [her voice gets very quiet]. He could talk, but he never wanted to talk. . . . But he might have been trying to tell me he was ready to go to heaven. . . . Maybe he was trying to tell me [crying]. He didn’t tell me all the things that was going on or what he truly felt. . . . He shoulda told me or shared with me a little bit more or . . . maybe he didn’t know how to. . . . He probably didn’t know how to. . . . We never talked about dying. . . . We never talked about how he wanted me to raise [the kids]. We never talked about a lot of things. [crying]

Repeatedly, through these interviews, I was reminded just how difficult talking about death can be for terminally ill patients and their family members. With couples such as Noah and Colleen, I noticed how non-ill spouses suddenly became uncomfortable when I asked questions about dying or death. It was as if they
perceived my questions as encouragement for their loved ones to give in to death. Possibly, they felt as Beth did, “I guess the more you talk about it [dying], the more real it becomes.”

Family members seemed to believe that they could keep death at bay for themselves and their loved ones as long as no one mentioned it. Frequently, spouses would change the subject, interject humor into the conversation, or simply leave the room when our talks turned to topics of death or dying. Again, the argument could be made that these participants were in “denial”; however, in my view, “silenced by death” captured the essence of their relationships with death. With such couples, non-ill spouses knew that their partners were going to die from their illnesses, but chose not to speak about the “unspeakable.” In each family, the ill member maintained the status quo—similarly choosing not to talk about death’s presence with their families.

Waiting for Death

It was certainly intense, to a place that I hadn’t ever been before—just attending death. Waiting. Death is the next portal, and you don’t know where or when it’s gonna be. —Brad

Some people may argue that the dying begin waiting for death at the very time they are diagnosed as terminal, and certainly, in some manner of speaking, this may be true. However, the waiting that I am referring to in this “relationship” is of a particular type: one that comes with knowing that death is near—sensing it intuitively, seeing it visually, expecting it at any time.

Faith: I’m expecting death now. . . . There was a time when I was looking for it, in the sense that . . . remember way back, a year-and-a-half, maybe even as much as 2 years ago, when I was still sick [from] the chemo, I was looking for death in the sense of uh, wanting it to happen. I wanted death. . . . As I think about it, the difference [between then and now] is, uhmm . . . then, I was looking for death as a sort of relief, something that I wanted . . . to do instead of . . . the chemo. Where now, I’m looking for it in the sense of . . . it’s happening. “Is, is it going to be around this next corner?” I’m looking for it in the sense of expecting it . . . waiting for it.

In December of 1999, Faith experienced a number of setbacks: Her cancer progressed rapidly, she was informed that she had 3–6 months to live, and she suffered a severe fracture of her femur leaving her bedridden. Together, these disappointments reaffirmed the inevitable:

Faith: Every time something like this happens [she had just had a reaction to a medication] . . . and [I] have more things happen and so forth, I feel more certain that I truly am dying. . . . Uh, I’ve never been in denial, but at the same time, I’ve never been uh, looking for it. And so, as far as when things happen, I think, “Oh yes, I’m dying,” kind of a renewal of the recognition.

Intuitively, Faith sensed death’s foothold, and when she looked at herself in the mirror, she saw death:

Faith: Not being able to eat. . . . Uh, looking at my arms and realizing they’re at half the size they use to be. [I’m] wrinkled and uh, pale, and uh, [have] black around my eyes, dark around my eyes. . . . This thing is really happening. Uh, my arm is swollen . . . and it doesn’t go away. It gets bigger instead of going away. Well, that’s the reversal of health. Health, it goes away. Healthy—you get better, and lack of health, it stays or gets bigger, which I believe . . . is the way we’re going.

Faith saw death in her own face, whereas Max saw it in the eyes of his loved ones:

Max: They look at me with a [long pause], a sense of hopelessness that . . . they see what I’m going through and there’s nothing they can do to help. It’s like they’re seeing a dog get hit and suffering in the street, and they can’t do a thing about it. . . . At this point, I wait. That’s all. I don’t have any . . . any alternative.

Max had resigned himself to death—a feeling also conveyed by Patty during the final week of her life:

Patty: I wish it would come and get it over cause I can’t do anything the way it is now. When I think
about dying, really honestly dying, I don’t like it. But, if it’s going to be, what are we waiting for? What can I possibly do? What am I possibly doing in my own little niche, let alone for the world, in the, in the situation where I am now. There isn’t anything that I am doing that can be construed as helpful. It’s as though I’m living my own little purgatory or portion of hell just waiting. I hate to wait for people who are late, you know . . . I’m always on time, therefore they should be. And death, if it’s coming, for goodness sake, get here . . . It’s past time. And, I, I really am very impatient.

DISCUSSION

“It is appealing to have simple recipe theories because they offer neat and tidy explanations. The problem is that social reality is a very messy thing and can rarely be understood with such easy prescriptions.” (Karp, 1996, p. 20)

Through the years of this research, I have often been asked to describe the essence of my study, that is, “What has this research brought to light about the experiences of the dying and their families?” This is undeniably a valid question, and yet the asking of it, as well as my attempts to answer it, have proven excruciatingly frustrating. For months, I struggled to understand why the question itself was so troubling as opposed to exciting—why was I feeling irritated rather than inspired? After all, I looked forward to sharing all I had learned—patiently anticipating, choreographing in my mind, the day when I could finally contribute my own ideas. Why then was I stumbling?

Gradually it dawned on me. Although I had not embarked on this research with the hope of developing a universal theory, I was also painfully aware that much of social science research concludes with researchers offering “truths” and making far-reaching generalizations. Quite simply, it’s expected. Our fast paced culture values condensing knowledge into “bite-sized” nuggets, and people assume that any experience—even that of dying—can be explained or “captured” by a number of catchy phrases. It seems that we live in a world where people want simplistic explanations for overwhelmingly complex issues (Karp, 1996)—even something as complex as dying.

My frustration, therefore, made sense: I was worried that readers would feel disappointed—possibly even “cheated”—since I hadn’t created any chic “phases,” “stages,” or “tasks” to describe the experiences of the terminally ill. I didn’t have the answer—no suggestion advising how all people should cope. And certainly, my work did not offer any universal theory of dying. Although initially I felt apologetic, I soon realized that herein lies the strength of this study: My conclusions are the antithesis of such tidy summations—“an antidote to overly pat . . . explanations” (Karp, 1996, p. 20). As this became clear to me, one underlying message began to echo: We must be careful not to jump to quick conclusions, simplistic understandings, or easy answers. Instead, we must appreciate that dying is as complex and diverse as living.

Given that I am not providing universal explanations about the dying experience, what then does this study have to offer? What are the implications of this research for theorists and practitioners? What does it contribute?

IMPLICATIONS FOR THEORY AND PRACTICE

“I want to arouse clinicians’ . . . assumptions that the ill person . . . ought to be in some other . . . space than where he or she is.” (Frank, 1998, p. 206)

“Stories are not material to be analyzed; they are relationships to be entered.” (Frank, 1998, p. 200)

I have come to view dying as more than simply a progression toward death. In conversations with dying patients, I was continually struck by how they related with death, as opposed to simply reacted to it. The reader might ask, “What changes by this simple shift in thinking?” What do “relationships” offer us that other normative models of coping do not? In my mind, if we are thinking relationally, many things will change in our interactions with the dying and their families.

First and foremost, therapists become freer to hear the uniqueness of each individual story, appreciating
the complexity of living while dying. Where most models of coping are generic—characteristic of how we all react to the knowledge of impending death, relationships with death are characterized by the particularities of people’s lives. Living and dying are recursively connected—each influencing the other. Therefore, a person’s dying cannot be understood without intimately understanding his or her life, that is, by attending to such factors as the age of the dying person, the type of illness, the dying person’s relationships with loved ones and with the medical community, previous experiences with loss, religious and spiritual beliefs, ethnicity, and general beliefs about the world. These factors, then, give meaning to a person’s life and are inexorably woven together shaping both how a person lives and dies.

Second, most models of coping presuppose a normative process, implying that there is an accepted, or even prescribed, manner in which people are expected to progress towards death. In contrast, when we focus on a person’s relationship with death, notions of right and wrong are abandoned. Dying patients and their families are not, therefore, pathologized when they fail to follow some prescribed model, because there is no expected way of coping. Instead, we acknowledge themes, patterns, and similarities in how they cope, while simultaneously valuing the differences among their experiences. Thus, relationships imply a multitude of ways in coping.

Third, when we think of relationships with death, death and the dying person are viewed as completely intertwined—death continually shapes the dying person and the dying person continually shapes his or her relationship to death. There is a mutual coevolution that is part and parcel of relationships. It then follows that the person’s coping is constantly shifting and evolving—therefore, flexible and open to change.

In summary, then, the greatest shift in thinking lies in the change from an intrapsychic, linear view of death and dying, to a relational view—from a stance of searching for pathology, to a stance of recognizing strengths. Given these differences, what would change in the interactions between the dying and those who work with them if this notion of relationships were embraced? First, rather than assuming we know what families are experiencing, we would instead allow families to educate us about their experiences. This would demand that we, as helping professionals, abandon the role of expert—not as a strategic maneuver—but informed by the belief that dying patients are truly the experts of their own lives—and deaths.

As we abandon the role of expert, we would similarly give up any normative ideas we held about how people should or should not cope with impending death. In doing so, we would recognize differences as a testament to our diversity and uniqueness, not as indicators of pathology. Therefore, as we listened to the dying, we would maintain our curiosity—always working to refine our understanding, while simultaneously recognizing that our understanding is always limited. Of course, this would demand that we stay in relationship with the dying, as opposed to acting as distant observers.

Relationships require listeners—not evaluators or judges. Therefore, if we were to find ourselves making value judgments about a person’s coping, we would have failed to acknowledge or hear the legitimacy of his or her story. For example, when we label a person’s hope for a miracle as “denial,” we fail to see how their hope keeps them afloat during times of overwhelming despair. When we label a person as “stuck in anger,” we fail to see the warrior who is staring death in the face, or the competitor who is fighting for that “5% chance.” When we label someone’s bargaining as immature, we fail to see his or her struggle to make sense of what is happening. When we label someone as “depressed,” we rob them of their experience by making their feelings an illness. In each scenario, instead of seeing people, we see dysfunction, and this keeps us from truly being with the dying—the very thing that is most helpful to them. In each scenario, we dismiss ourselves of the obligation to enter into the world of the dying patient.

For many years, normative ideas of coping have served as an illusory cure all: If we can simply help people progress to “acceptance” or “resolution,” somehow death will be more palatable—for both the dying and for us. Unfortunately, many people have embraced these notions such that any other response by the dying becomes problematic: We (as helping professionals and/or loved ones of the dying) can become condescending to those who focus on hope in spite of overwhelming signs that they are dying. We sometimes grow tired of those who cry and frequently talk about the sadness of leaving loved ones. And, many times, we become angry with those who express rage about all being lost. Without question, it is difficult to sit with people who are suffering, who are in pain both physically and emotionally, who are angry that they are dying, and who are sad about leaving this world. As helping professionals we want to alleviate their suffering, and as compassionate beings, we are uncomfortable with their pain.
Because such feelings are both uncomfortable and painful, we sometimes encourage the dying to move away from their experience for our benefit. As sociologist Arthur Frank (1998) suggests in his work with the chronically ill, "The first thing a person . . . needs is someone who will just listen, without attempting any change. Too quick offers of help may show the listener's own dis-ease with what is being told" (p. 203). No relationship is qualitatively better or worse than another. Therefore, if we experience discomfort on hearing a particular story, it tells us more about our own expectations and assumptions than it does about the dying themselves (Frank, 1998). When I interviewed Beth and Alice, I found Beth's story both painful and frustrating. Everything she said was tinged with rage, and I found myself desperately struggling to look beyond her story and find something meaningful. I wanted her to have hope, to find something good in the midst of her hell, to tell me it was not all that bad. Interviewing Beth demanded that I give up my assumptions and honor her story. Beth was telling the story she needed to tell (Frank, 1998), and I had to respect her need to tell it as she experienced it. What this research poignantly illustrated for me—although seemingly simplistic—was that the very least I could do for the dying was to encourage them to tell their stories in their own ways.

REFERENCES


NOTES

1 For a more detailed description of the research methodology, see Wright and Flemons (2002).
2 Pseudonyms have been used throughout the document to protect anonymity. In addition, emphasis on the part of participants is represented by bold print.