Original Article

Confronting the Prospect of Dying: Reports of Terminally Ill Patients

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Abstract

To identify dominant themes characterizing patients’ perspectives on death during their last months of life, an ethnographic technique of interviewing and an inductive qualitative approach to analysis were employed. Serial, in-depth, semi-structured interviews were conducted with 30 patients (mean = 4.2 interviews/patient) followed as close to the time of death as possible. The interviews were audiorecorded, transcribed, and subjected to independent analysis by both authors using standard qualitative techniques. Patients were referred to the study by Beth Israel Medical Center clinicians if they had a diagnosis of a life-threatening condition of which they were aware; were likely to die within one year according to their physician; had experienced symptoms of the illness; were sufficiently alert to discuss the topics addressed in the study; conversed easily in English; and consented to participate. Outlooks on dying were thoroughly grounded in patients’ frames of reference for giving meaning and consistency to other major events in their lives. Seven motifs characterizing these perspectives on death were distilled: struggle (living and dying are difficult), dissonance (dying is not living), endurance (triumph of inner strength), coping (finding a new balance), incorporation (belief system accommodates death), quest (seeking meaning in death), and volatile (unresolved and unresigned). Patients demonstrated a striking capacity for coherence, integrating their responses to dying with broader motifs in their life stories. Health care providers would be well advised to become aware of such motifs so as to better understand patient preferences for care and responses to treatment recommendations. J Pain Symptom Manage 2001;22:807–819 © U.S. Cancer Pain Relief Committee, 2001.

Key Words

Palliative care, terminal care, hospice care, attitude to death, personal narratives, medical sociology

Introduction

Dying is one of life’s unique experiences, ubiquitous yet largely unexamined; talk about it is difficult for some to initiate and hard for others to hear. This singular status poses emotional barriers as well as methodological challenges to research on dying, which may help to explain our limited knowledge of the perspectives of dying patients on the nature and meaning of their experiences. The research reported on here was undertaken to give voice to patients’ perspectives on death during their last months of life, through analyses of their firsthand accounts. A premise underlying this...
work is that a greater knowledge of the spectrum of ways in which severely ill patients relate to the prospect of dying will be valuable in providing a context for efforts to improve care at the end of life, useful to weighing the importance of some interventions and shaping the course of others.

The patient’s narrative account or story is the central focus of this research. It differs in structure and content from the medical history, the version of the patient’s story obtained in the clinical setting for the purpose of formulating a differential diagnosis. The format of the medical history, an abstracted and highly refined rendering of the patient’s version, is well suited to optimizing interpretation of its clinical significance. In contrast, in eliciting the patient’s story for purposes of this research, the emphasis is on permitting patients to choose their own ways of organizing their accounts and make decisions as to what to reveal. Narratives in this latter context have been studied to reveal the ways in which people create and give meaning to their social realities; in the health care realm, they yield insights into the forms in which patients shape and give voice to their suffering, and the dimensions of illness experience that lie outside of its biomedical formulation.

For the clinician, a fuller understanding of the narrative context of illness can provide a framework for approaching a patient’s problems more holistically while developing a treatment plan. For patients, the medical encounter constitutes one episode in a broader, ongoing narrative, and physicians’ treatment plans will be interpreted in that subjective context. Patients who cannot recognize their own stories in their clinicians’ formulation may not accept forthcoming recommendations. And physicians who do not have an adequate understanding of their patients’ narratives may find it difficult to appreciate their concerns and respect their therapeutic choices.

The opportunity to learn directly from those who are dying has not been fully realized. Those relatively few studies that emphasize the perspectives of dying patients have in common the aim of producing models or constructs that are generalizable to the population of severely ill patients. Reports on these studies are typically confined to addressing common denominators in patient experiences that are anticipated as being helpful to the clinical process. An early model was Kubler-Ross’s formulation of the stages of dying, characterized by six distinct coping mechanisms: denial, anger, bargaining, depression, acceptance, and hope. Posed as a series of sequential responses with universal applicability, the model suggests that clinicians can assist their dying patients in progressing toward an accepting and hopeful outlook. Other work has been organized around a conception of phases of illness—acute, chronic, and terminal; the research maps patients’ adjustments to each phase and identifies associated issues of interest and challenge to clinicians.

More recently, Byock and Doka have applied principles of human development to the end of life, identifying potential dimensions of growth within the psychological, social, and spiritual domains; the stated aim is to isolate commonalities of human experience, identifying universal needs and opportunities that people confront as they die, ultimately to help clinicians understand and positively intervene. Other efforts have attempted to incorporate more emphasis on patients’ experiences of dying in measures of quality of life, including a subscale addressing existential concerns about dying (e.g., search for meaning in death); consistent with the aim of producing a measure having relevance to all patients toward the end of life, the emphasis is on establishing general domains rather than on elaborating the particularities of human experience. While these areas of inquiry, informed by patients’ perspectives, have yielded important contributions, the design of the research was dictated by professional concerns and did not aim to investigate the scope and depth of the experiences of dying patients. Those few articles in the biomedical literature that present patients’ unfiltered perspectives on issues concerning their own deaths generally constitute brief testimonials, often written by dying physicians or other health care professionals.

To address this deficiency, the study reported here relied upon an ethnographic technique of interviewing and an inductive, qualitative approach to analysis as the dominant methodological approaches. To learn from the insights of those who are dying, it was essential that the research employ a strategy that does not by its very nature adopt the preconceptions and priorities of the investigators. Two further
distinctions differentiate this research from prior work. It is similar in approach to the study of illness narratives, analyses of first-person memoirs yielding an assessment of the patient’s experience of illness as distinguished from the doctor’s attention to disease; however, most of the prior work in this tradition has been written by or about survivors and does not address the prospect of dying in a sustained and direct manner. Further, the published work in this genre that does focus on dying tends to rely on self-reports of highly educated individuals, often clinicians themselves who are eager to convey the lessons of their experiences to their colleagues in the health professions. In contrast, the research reported here was designed to capture the insights of patients from diverse social backgrounds and to have relevance to a broad spectrum of circumstances. The methodological procedures, as described below, conform to prescribed standards for assuring the soundness of qualitative research, including systematic sampling, an inductive data collection and analysis strategy, and concern for reliability and validity in analyzing the data and reporting results.

**Methods**

The analysis relies upon serial interviews with thirty patients who were referred to the study by Beth Israel Medical Center clinicians if they met the following criteria: had a diagnosis of a life-threatening condition of which they were aware; were likely to die within one year according to their physician; had experienced symptoms of the illness; were sufficiently alert to discuss the topics addressed in the study; conversed easily in English; and consented to participate. Involvement of human subjects was approved by the institutional review boards at Beth Israel Medical Center and New York University. An additional three patients enrolled in the study but dropped out after several interviews, citing fatigue or anxiety about the topic of dying. The sample, described in Table 1, included adult men and women ranging in age from 40 to 94, from varied socio-economic and ethnic backgrounds, and with a variety of conditions (cancer being the most prevalent). Almost half of the subjects were enrolled in hospice and receiving palliative care from the onset of their participation in the study, a quarter enrolled in hospice during the study, and a quarter received aggressive treatment until death. Upon entry into the study, all patients but one had a Karnofsky performance status of less than or equal to 50%; the average score was 39.7%. Participants were followed to within a few days of their deaths unless interviewing was prohibited by their medical conditions (e.g., dyspnea, delirium) or death was sudden. The median number of months between entry into the study and death was 2.6. The average number of interviews per participant was 4.2.

Interviews took place either at the medical center or at patients’ homes, depending upon patients’ preferences. Questions were framed to encourage patients to tell their stories. Respondents were asked to recount what it feels like to be seriously ill, what provides strength, etc.

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<tr>
<th>Table 1</th>
<th>Characteristics of the Sample</th>
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<td><strong>Age</strong></td>
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<tr>
<td>40–49</td>
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<td>50–59</td>
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<tr>
<td>Male</td>
<td>26.7</td>
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<tr>
<td>Female</td>
<td>73.3</td>
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<tr>
<td><strong>Diagnosis</strong></td>
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<tr>
<td>Cancer</td>
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<td>HIV/AIDS</td>
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<td>COPD</td>
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<td>ASHD</td>
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<td>Cirrhosis</td>
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<tr>
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<td>Hispanic</td>
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<td><strong>Religion</strong></td>
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<td>Protestant</td>
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<tr>
<td>Jewish</td>
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<td>Homemaker</td>
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<td>Unemployed/public assistance</td>
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<td><strong>Primary Source of Care</strong></td>
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<tr>
<td>Hospice home care</td>
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<td>Visiting nurse, health aide</td>
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<tr>
<td>Chronic care hospital</td>
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<td>Other</td>
<td>6.7</td>
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what is meaningful, what is difficult, how they view the future, and how they perceive death (see Table 2 for topics and sample questions). Data collection was structured to suit the inductive analytic strategy described below. Initial questions were broad, followed by probes addressing central features of the patient’s account. For example, to elicit their outlook on the prospect of dying, patients were asked, “What does it feel like to think you might die?” One of several probes was: “Does that change the way you look at life, to know that you really could be leaving sometime soon?” The interview was organized with the aim of maximizing the prospect of capturing insights that were not anticipated by the researchers; the goal was to learn from dying patients. Drafts of the questions were reviewed by experts in palliative care education and practice, and their input was incorporated as appropriate.

The interviews were audiotaped, transcribed, and subjected to inductive analysis using standard qualitative techniques: 1) multiple readings of the transcripts to identify recurrent themes, 2) coding the transcripts by themes and creating files of relevant verbatim passages, 3) sub-dividing these categories of passages so as to refine the concepts, 4) seeking explanations for discrepant cases (i.e., those that contradict the dominant patterns), and 5) examining how the themes relate to each other and to the central topic of the study. The transcripts were reviewed and coded independently by both authors, drawing upon their complementary expertise in medical sociology (MJY) and clinical medicine (BM). Discrepant codes were discussed in depth, and a consensus was reached as to dominant themes and their conceptual significance. To further assure their validity, selected themes and individual transcripts were also discussed with a clinical psychologist and a theologian, consultants to the study, who assisted with their interpretation. In addition, interviews were conducted with a subset of relatives to confirm the relevance of the motifs.

The findings are presented here as a series of motifs exemplifying the narratives through which patients respond to and ascribe meaning to the fact of their dying. Passages from the interview transcripts that typify these motifs are presented in order to permit patients to speak for themselves (names have been changed to protect confidentiality). Those motifs captured here were observed to characterize patients’ outlooks for at least a significant segment of their experience. Analysis of multiple interviews with the consecutively referred patients

<table>
<thead>
<tr>
<th>Topic</th>
<th>Sample Questions</th>
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<tr>
<td>Illness Experience</td>
<td>I know a little bit about your medical condition and your medical history, but perhaps we could start by you telling me briefly what it has been like for you in the most recent days or few weeks.</td>
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<tr>
<td>Initial Question</td>
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<tr>
<td>Probe</td>
<td>You are going through a lot of changes. How are you holding up?</td>
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<td></td>
<td>I want to know how you are feeling in your body and in your mind. Tell me, what do you mean you are half in the other world?</td>
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<td></td>
<td>Do you have any sense about that—why cancer came into your life?</td>
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<tr>
<td>Awareness of Dying</td>
<td>Tell me about what you think is going to happen to you in the future. Do you think you’ll get better, get worse, or stay the same?</td>
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<tr>
<td>Initial Question</td>
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<tr>
<td>Probe</td>
<td>You said that things have gotten more serious for you. Can you tell me what you mean by that, by serious?</td>
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<td>What are you thinking will be the eventual outcome for you of your present illness?</td>
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<td>How do you see your illness now, and where do you see it going?</td>
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<tr>
<td>Prospect of Dying</td>
<td>What does it feel like to think you might die?</td>
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<tr>
<td>Initial Question</td>
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<tr>
<td>Probe</td>
<td>Does that change the way you look at life, to know that you could be leaving any time?</td>
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<tr>
<td></td>
<td>How do you feel about staying here? Do you want to stay here as long as possible? Or, do you feel like you might be ready to go at some point?</td>
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<td>Tell me a little bit about how it was for you to be diagnosed with cancer and then come to realize that the treatments were not working. How did that all happen?</td>
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<tr>
<td>Process of Dying</td>
<td>Do you have any sense of what dying might be like?</td>
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<tr>
<td>Initial Question</td>
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<tr>
<td>Probe</td>
<td>What does being close to death feel like? Can you say?</td>
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yielded theoretical saturation, namely, analysis of transcripts of newly added patients did not generate additional motifs. The qualitative methodology, by virtue of the density of data collection and the inductive style of analysis, was designed to maximize the validity of the motifs for the individual patients studied here.

**Results**

All study participants had advanced illness and were aware of their limited prognoses. All of them acknowledged that their life was coming to an end (“I don’t have much time”; “I know it’s coming”; “I know I’m dying”). In the face of this knowledge, participants’ responses differed widely. For some, death was desired; it was anticipated as a welcome release from a difficult life, from progressive disabling illness, or from advanced age, or it was viewed as the timely ending of a good life. Others were resistant, whether out of fear of dying, or due to the desire to complete certain experiences (e.g., see grandchildren mature), or from a general unwillingness to relinquish the cherished experience of living. Still others maintained a stance of neutrality, preparing themselves to deal with “whatever comes.” Inductive analysis of the interview transcripts led to identification of seven motifs, that is, cohesive patterns characterizing the ways in which participants viewed the prospect of their own death. Over the course of their enrollment in the study, individual responses to dying remained consistent over time. Retrospective review of the series of interviews by both researchers did not reveal shifts from one motif to another. Aspects of the backgrounds of those patients whose accounts were selected to illustrate these motifs are provided, within the constraints of space, to yield a broader biographical context for this last chapter of their lives.

**Struggle Motif: Living and Dying Is a Struggle**

José was a 41-year-old Hispanic man who had AIDS and liver failure and was living in a group home. He had been abusing drugs since he was 12 and had been going to Narcotics Anonymous in his later years. During his adulthood, he had attempted suicide three times. He had three children and several grandchildren but had been barred from seeing them because of episodes of violence, a source of ongoing pain for him. Death was not an unfamiliar topic for him, and he spoke of it in much the same language of pain and conflict that he used in relating other major aspects of his life.

It’s not easy living with AIDS. I cry about it. I want help, but there isn’t anything that can help me. All my life, it’s been hard.—It was not like I had AIDS and it was stable, and I’ll be around for while. I have AIDS, but I also have a couple of liver disorders and whatever else I have done to myself, you know, from my drinking. That was my number one addiction, and heroin was my number two.

All of the things I have gone through, I try to accept the good and the bad. It’s hard to accept, but I have to keep my faith. It’s easy to pass away. It’s a long struggle to hang in there.

José received aggressive medical treatment until his death from an acute episode of sepsis.

Esther was a 72-year-old Jewish woman who had breast cancer with bone metastases. She had had breast cancer several years before and had actively participated in successful treatment. She had been depressed virtually all of her adult life and lived with a persistent wish to die despite psychiatric care. She was living alone and was forcibly retired at age 65. She reported never having had love in her life; her father died when she was 9, she always felt resentment from her mother, and she had never married.

Well, I neglected it. I knew I had it. I knew it was breast cancer and I knew if I had gone and had a simple mastectomy with a lumpectomy and radiation, I could probably fight it off for the rest of my life. I didn’t want to. I deliberately wanted to allow it to grow so that I would die. I would say that shows the tremendous hate of the person for themselves. That revelation really closed off all my feelings. If I have no feelings about myself, I’ll never change. I might as well get it over with. And that’s what happened.

Her brother described her entering the hospice inpatient unit a few days before her death:

She was propped up at a forty-five degree angle and she almost had a surreal—she almost had a smile on her face. She was clutching her papers. She had a brief case with her pri-
vate papers and she almost had a smile on her face and my wife looked at me and I looked at her and I said, “You know, she planned it this way. She really honestly planned it this way.” And in days, she was gone. I know my sister. I think she almost enjoyed it. She was a very, very controlling person.

According to Esther, death was always a considered option in confronting a life that she increasingly regarded with disdain and disappointment. Ultimately, she put her dying into service of a reenactment of a defining drama, an essential theme of her life.

For respondents demonstrating the struggle motif, life had always been difficult and required tremendous effort. Dying was not new in this respect; it was a further manifestation of the struggle.

Dissonance Motif: Dying Is Not Living

Arthur was an 85-year-old Jewish man who had cancer of the bladder, prostate, and colon, and was in chronic renal failure. He was an affluent, retired business executive who lived alone. His wife had died seven years before from a progressive neurological condition, and he had observed her slow deterioration ending in death.

I feel that I am fighting a losing fight now. So, I’m not anxious to go through all of this. I feel that maybe it is just a waste of time. Is it worth the effort of six months of going through all of this, to live another three to six months? There are too many things wrong with me and the odds are against me. If I had my way, I would like to go to sleep.

I figure I have lived my life and it was a good life while it lasted. I was happily married for 60 years. Now, it is time. I don’t want to be a burden to my children. I don’t want to be anything.

I am not afraid to die. I’m afraid to live. One thing leads to another. You see people in wheelchairs and bent over. They keep you alive, but for what purpose? I’ve already been; I’m not becoming anything else. My wife was my joie de vivre. You have to be old to understand it. I don’t want to be married to a machine. Now I’m married to the visiting nurse service.

Although Arthur’s functioning and physical pain were not markedly worse than for other patients in the study, for him, his quality of life was unacceptable. He eventually refused further aggressive treatment, entered hospice care, and reportedly died peacefully, in renal failure.

Maria was a 92-year-old Italian-American woman, a devout Catholic, who had rectal cancer. Her husband had died in 1982, and she lived with her son and daughter-in-law. She reported that the only thing she still enjoyed in life was the two hours of sunshine in the afternoon when she could feel the warmth on her body.

I feel it is time to go. In fact, I lost seven sisters-in-law in one year, younger than me—74-years-old, 72—all younger than me. I’m the only one left, so I say to God, “Why don’t you take me? I want to die. I want to die. Please come and get me.” They are all dead. I don’t know who to talk to. This new generation does not understand me and I don’t understand them. What am I doing here?

Maria was not longing for something lacking in her past, nor did she view the present as a time for growth. In her words, “Life has left me behind.” She developed progressive senile dementia and eventually was admitted to a nursing home where she died.

Respondents exhibiting the dissonance motif typically felt positive about their past lives which they contrasted negatively to their present state of illness. They were dissatisfied, even distressed, by their present condition, because it was foreign to their views of who they had been or wished to be. They expressed no inclination to seek meaning in death; for them, it was not a new experience to be learned from or adapted to, but rather was the end of their story.

Endurance Motif: Triumph of Inner Strength

Evelyn was an 82-year-old Jewish woman with colon cancer and liver metastases; she also had heart disease. She was very direct, sharp-tongued, and opinionated. Her husband died of cancer in 1986, and she lived alone. She exhibited a marked determination to maintain her equilibrium and continue on with her life as she always had.
(The doctor) couldn’t come out to face me. He called me on the phone and said to me, “Evelyn, I hate to tell you but you have cancer of the rectum.” I said, “Oh.” I didn’t shed a tear. . . I just (went on). That’s how I get along. Otherwise I would be a raving maniac. I can’t afford that. I’ll tell you what I did. I became very active. I’m a member of the board, in fact, I’m president of this whole co-op. . . I did what I had to. I kept my sanity, you know, helping neighbors and listening to a lot of junk, like I was the mother confessor, you know what I mean?

What were her thoughts about dying?

I told you, I do not think of it (dying) because I am not going to make myself sick. No, I don’t live like that. Gone is gone. What is going to be will be. I’m not looking into the future. You get it off your chest and you go on your merry way. That’s the way I feel and that’s the way I lived.

Toward the end, Evelyn developed rapid-onset of delirium and was admitted to the hospice inpatient unit where she spent the last three weeks of her life. Her physical status was fairly good, but she spent most of the time napping and passed away very quietly, seemingly unaware of her dying.

Angela was a 37-year-old African American woman, a registered nurse, who had breast cancer and bone metastases. Her husband had died two years before from complications of sickle cell disease. They had three children, a 25-year-old son who was in jail, an 18-year-old daughter who had recently won a scholarship to college, and an 11-year-old daughter in grade school. Angela refused chemotherapy, because she did not want to experience the side effects, given her poor prognosis; she sought herbal therapy and palliative care.

About her death, she said:

I don’t want to know. If it’s not an excellent statement, then I don’t want to hear it. That’s how I am—just continue what I’m doing, you know, for my kids and myself and being around people and doing whatever I can (to) help people. Just the regular things, nothing extra that I have to do because I’m going to die today or tomorrow.

I’m not really discovering anything new. I look forward to sleeping at night and getting up. That has more importance, being able to eat and being able to go into the shower and come out and, you know, things like that.

I am very upbeat and positive. I think in the years since I have been diagnosed and it has been what, since 1990, so that is about eight years, I think, if I have been depressed five times that’s a lot.

I’m a person that has a lot of pride, and if (I) sit and think about it, and (ask), “Why do I have this?” or, “Why did I have to get that?” it starts to mess with my dignity, but I don’t let it get to that point. I still try to think about myself as how I want to think about myself, with a lot of pride. I carry myself in a certain way. I still continue to do what I have to do—you have to help yourself. You can’t just say to the doctors, “fix it.”

Evelyn and Angela, and other patients exhibiting the endurance motif, dealt with difficult events in their lives by taking control over their emotions and sustaining an upbeat outlook; they had little interest in introspection. They demonstrated an inner strength that appeared to take primacy in their daily lives. To them, it was of paramount importance to be strong in the face of adversity, as they had always done. Their strength was a product of an intrinsic character trait rather than a belief system.

Incorporation Motif: Belief System Accommodates Death

Alice was a 54-year-old African American woman who had end-stage breast cancer and was bed-bound. She was married and had 8 children and was a devout Jehova’s Witness. She had advanced illness with malignant effusions and intestinal obstruction.

God gives us life, he gives it to us to live it. I plan to live it as long as he gave it to us. It might be painful to stay here, but I plan to stay, for however long he gives us to stay—I know that God may make a place for me to come with him. I’m not afraid. I get tired sometimes but I’m not afraid.

Ella was a 50-year-old African American woman who had end-stage breast cancer with metastases to the bone and liver. She was a nurse and, before her illness, was active in a cancer support group. She was living alone and had two grown children.
We take up space. We are matter. We are material now. When we die that stays here, but we have a spiritual life, a spiritual being and we move on too. That is how I see dying. Spiritually, I am going to be with Jesus Christ, with God, my mother, and my father. I am going to see them in a new life, a new beginning. This is just material. It is matter. It takes up space. That is all this is really, so that is how I see us dying.

At the same time, you don’t want to die. I want to see my grandchildren grow up, so you are in between mixed feelings, but not in a panic about dying because certain things are already set and you know, sooner or later, you have to die. You have to go from this space to that space.

Life support—Why force the body to do something it has already ceased to do? It just seems to me so tortuous. I don’t want that, just let me go in peace.

Alice and Ella, and others embracing the incorporation motif, valued life but were not fearful; for them, death was a part of a broader plan, even if it was happening earlier than they would have chosen. Their thoughts about death were not newly adopted in service of their current status. Rather, they were part of the belief system that provided cohesion over the course of their lives. Both Alice and Ella declined further aggressive treatment and died in the hospital.

For these patients, dying is understandable within their overarching belief systems, whether spiritual or secular. Death was organically tied to this system, and their experience of dying was incorporated seemingly without assessment or adjustment. They may have had questions as well as preferences, but ultimately they experienced their life and death as being in accordance with a larger purpose or in the hands of a higher being.

Coping Motif: Working to Find a New Balance

Ellen was a 47-year-old Irish Catholic woman with terminal ovarian cancer. She had one son, was divorced, and lived alone. She had considerable support from her brother, sister, and a friend who came across country to stay with her during her final days.

I was diagnosed with cancer, and it was absolutely devastating, very frightening. Fear is the word. It’s overwhelming. There are moments when I look at this and go, “I can’t do this. I can’t do this and stay sane.”

How I deal with the fear is by having people around me. That makes a big difference. Sometimes I don’t allow the support to come that I need. When I do stop and allow it to come, it’s very different—literally life-saving. The fear, that panicky feeling, that’s not how I want to die. I know I can’t control it at all, but it would be nice to have it be somewhat peaceful, as opposed to frothing and screaming and carrying on.

I just can’t imagine how anyone does this without the support system that I have. There are so many people who’ve helped me in huge ways. That’s how I’ve gotten through this with my family and friends. What I’m looking for is to be able to take this with a little more grace. I am not a brave little soldier, never pretended to be. I would just like for all of us to be sure that we all know how much we love each other, and how important that love is in a person’s life. All you need to get you through this life is love. To me, that’s the bottom line.

Ellen’s feelings routinely fluctuated between turmoil and hard-earned release. She stayed at home until her disease became very advanced, at which time she entered the hospice inpatient unit. Finally relinquishing the effort to stay in control and at last allowing others to fully support her, Ellen died one week later, reportedly free of fear and distress, with her family and friends around her.

Bob was a 92-year-old man with prostate cancer and bone metastases. He was a musician, a professor at a prestigious music school, and a successful author. He responded to the onset of his illness and the loss of his old life by attempting suicide. Having survived, he discovered that he wanted to live, and he sought to find a way to accept his new status.

You know, all my life I was well enough that I went out a great deal in the world, and I like the world, but now it’s too difficult. I’m not saying life ends, it’s just that it becomes less interesting and it becomes less playful and less of an adventure. It becomes-like tonight. A friend of mine will come and we’ll sit here and chat. Now, that’s not the worst
thing in the world. It’s very pleasant to be with a friend whom you love and who loves you, so it’s bearable. In other words, you have to make an adjustment, because you’re no longer part of the world as you were.

I’m toward the end. There’s nothing upsetting about it, and it’s pleasant. Life can go on. It’s livable. It is merely that. You have to come to peace with what you can no longer do. I can no longer go out like I did. Every night another concert or performance or art. I can no longer do. It is a different life because I am no longer in the center of things. I am peripheral. On the other hand, I will be 92 in August, so what is wrong with being peripheral?

Bob’s niece urged him to engage in a vigorous rehabilitation program, but he had no interest. She saw him as the old Bob and wanted him to maintain that identity, while his goal was to accept. He died at home in the care of hospice.

When confronted with major change, Ellen and Bob worked hard to adjust. Their outlook was instrumental: Coping was the goal. They did not seek meaning or understanding in their newfound situations nor did they have a significant need to address unresolved issues. They had always endeavored to maintain an optimistic outlook on experiences in their lives, and now they sought to cope with their fears and disappointments so as to experience illness and dying as positively as possible. Finding a new balance was not an effortless experience for them. They did not utilize a core of inner strength that those embracing the endurance motif drew upon in facing the end of life; nor did they rely upon a defining belief system serving those with the incorporation motif. Rather, they worked diligently to find new sources of strength or renew old ones to re-establish equilibrium in their lives.

**Quest Motif: Seeking Meaning in Dying**

Robert was an 82-year-old man with advanced prostate cancer and bone metastases. He was married and was a former dean and chair of a university department of English.

I’m learning, and it’s just nourishing. For me, to learn is almost an appetite, and that appetite is being met. It’s wonderful. I’m learning to die. It seems that, under certain circumstances, there’s room for growth, which I never expected. You know, I used to think dying was like going downhill and into the bottom of a cone. It’s not that at all. I feel a new dimension in me, which I will tell you, serves me. I’m very curious to know for myself how I’ll respond to a worsening condition. If tomorrow the metastases do something, I really think I would take it with equanimity.

This voyage is just expanding onto horizons that I’ve not quite made out. It’s all very affirmative, very freeing. I’m almost enjoying studying it. Who would think that a dying person is capable of making it worthwhile for others to nurture him? What is a dying person capable of? There is something worthwhile in this. It means that not so much will have been lost. It will have made life a success. Not only my life, but it confirms that human life can be very good, even in very dire circumstances.

Robert entered a hospice unit where he experienced a slow decline in his health, but he remained conscious until the end—writing, reading, and talking about dying.

Stacy was a 40-year-old Jewish woman who had lung cancer that had metastasized to multiple sites. She was an accomplished poet and a teacher and was in the process of completing a master’s degree in counseling. She had a 17-year-old daughter and had been living in a domestic relationship for the past 7 years.

What is the meaning of suffering? That’s the kind of question you ask yourself now. A big question. I came up with an answer. The meaning of my suffering is that it has deepened the faith of everyone around me, their spirituality. And it’s brought them closer to each other. I think it’s important to say that I’m not going through this suffering for no reason. There’s a reason for this suffering.

I am not uncomfortable with mystery. Actually, I’m really enjoying this time I’m having. It’s like, if you have a giant cake, you don’t enjoy that giant cake after a while. You know, it’s a lot of cake! If you just have this little tiny piece of cake, it’s easier to enjoy, and you can savor it. I try to explain to my family that this is not about living longer, it’s about living my life to the fullest. Each day is a gift. It really is.
Consistent with her past experience in meeting challenges in her life, Stacy welcomed the opportunity to subject her experience of dying to intensive examination, to reflect and marvel at it. She was forthright in examining her feelings, whether addressing current concerns about her daughter’s future or reflecting on major lifestyle decisions in her past. Her disease progressed rapidly, and she died at home, surrounded by her family and a hospice worker.

For patients demonstrating the quest motif, the opportunity to grow and to learn was paramount in dying as it was throughout their lives. Reflection was critical to them, and they had a dominant interest in finding meaning in their experiences at the end of life. They were not likely to experience feelings of diminishment resulting from being old or disabled or dying, because these latter characteristics were not determining features of their identities. To them, life did not stop when they became ill or were moving toward death. If anything, life became more meaningful than before, presenting new opportunities to be pursued, new perspectives to be examined.

Volatile Motif: Unresolved and Unresigned

Mary was a 52-year-old Irish woman who came to the United States as a child. She had breast cancer with metastases to the bone and lung. She had lived on public assistance most of her life, cleaning people’s houses for additional income. Violence played a major role in her life, having been beaten by several of her male partners; she had a son and daughter with different fathers, and her son was shot to death by her daughter’s boyfriend.

I get very scared, and I’ll cry. Then, after I cry, I get a little better, and I get over it. I’ll be happy and laughing and joking again. But it’s very depressing because you want to die sometimes. You actually want to die. I’ve felt it many times. It’s just a feeling that comes over me, and then I’m scared to die at the same time.

I’m just going to go over the edge, and there’s not too much I can do about it. She (the cancer) is not going to leave me. You feel like you have nothing left, nothing to hold on to.

We had real bad times together (she and her daughter). I threw her out with the police [enforcing it]. Georgie (her son) got killed. When he died, it was like, you know, you get weak in the face. I tried to kill myself in 1992. It just piled up, and I couldn’t take it anymore. But maybe, if you can see beyond that, that will help.

Major unresolved issues were at the heart of Mary’s turmoil, and she had few social supports available to her. She became increasingly disoriented and paranoid, and died in a long-term care facility.

Susan was a 52-year-old woman who had end-stage breast cancer with metastases to the brain and bone. She had completed two years of college before dropping out, aspired to be a writer but never pursued it, and regarded herself as a lesbian but repressed her sexuality.

When you get to feeling really miserable, I thought well, maybe that is the nature of this disease, that you just get to feeling so bad at some point that you don’t care and that dying will be a relief. I don’t know where I stand on it. I don’t know if I’m handling it properly, if there is a proper way. That is not a pleasant place to be in. I don’t know. I just seem to be bobbing along on the waves.

I have to find a way of forgiving myself and maybe that is a part of what is going on, you know, what I am supposed to be doing, forgiving myself for not giving myself a chance, not helping myself to a better education when I could have, maybe, and done some of the things that I wanted to do. You know, wanting to do that, having that in me and yet, never leaving the ground. It is sort of like someone went and clipped my wings and the person who did that was me.

Susan also became disoriented and increasingly confused; she died alone, in a chronic care hospital.

Mary and Susan had many unresolved issues in their lives and were buffeted by forces that they could not understand or control. They lacked clarity of direction in their lives as well as in dying. Despite psychosocial interventions, their disease engulfed them, much like other events in their lives, as
though they were swept to an inevitable, but chaotic end.

Discussion

Outlooks on dying among patients interviewed for this study were thoroughly grounded in the frames of reference that gave meaning and consistency to other major events in their lives. The motifs presented here reveal rich trajectories or life stories within which their accounts of dying were woven. The relevance of these motifs is twofold: First, as distilled from the firsthand accounts of terminally ill patients, they provide an uncommon perspective on the human experience of dying. Second, recognition of these motifs in individuals’ experiences of dying can assist health care providers in understanding patients’ preferences for treatment and their responses to providers’ recommendations—ultimately contributing to shared medical decision-making.

As evidenced in the motifs, patients’ responses to dying are seamlessly integrated with broader themes in their lives, and appreciation of their distinctive outlooks requires awareness of their life stories as well as other salient characteristics that distinguish them as people. The internal logic of their accounts, and the extent to which most patients appeared reconciled to the fact of their dying, however, does not warrant a positive judgment as to the quality of their lives or their deaths. Coming to terms with death may harmonize as elegantly with a hopeless or chaotic disposition (e.g., the struggle or volatile motif) as with one characterized by inner strength or a quest for meaning. Overall, these outlooks were consistent with how respondents viewed themselves and the meanings that they attributed to key facets of their lives.

This continuity with their broader outlook is not surprising, given what is known of the human need for cognitive consistency and capacity for contributing to a socially constructed reality. However, existing accounts of dying do not capture this element: Many of them suggest a life in a state of homeostasis, beset by terminal illness—precipitating a crisis of meaning and demanding a reassessment of the past, unique solutions to emerging problems, or a new vision of the future. Other accounts are subjugated to the aim of describing the dying experience in terms of stages, phases, or measures that have universal application. These approaches tend to ignore the context, born of a lifetime of experience, which shapes patients’ perceptions of dying and gives them authenticity.

For physicians and other health care providers, neglect of this context—the patient’s broader biography or narrative—may undermine efforts to implement an effective care plan. Well-intentioned but uninformed providers may fail to distinguish between Mary’s openness to addressing unresolved issues (volatile motif) and Esther’s resignation (struggle motif); Angela’s inner strength may be confused with denial; Bob’s acceptance of his changing status (coping motif) may be interpreted as depression; and Arthur’s contempt for his quality of life (dissonance) may suggest a need for aggressive rehabilitation. Some of these responses would culminate in missed opportunities and others in unwanted interventions.

Awareness of the motifs underlying patients’ perspectives may reveal opportunities for effective intervention and may minimize misunderstandings or discrepant expectations; such familiarity may be helpful in identifying existing coping mechanisms that merit support or enhancement, or in addressing patient resistance to recommendations that are incompatible with their organizing models. For patients embracing the volatile motif, psychosocial intervention addressing unresolved issues may be welcomed, even though a chaotic overlay to their lives is likely to persist. Those patients who exhibit the struggle motif, in contrast, are not likely to embrace a new psychotherapeutic effort to reassess their life-long conflicts, no matter how well-justified a psychiatric referral might be. With regard to this motif as well as others, involuntary defense mechanisms, deeply rooted in patients’ personalities, may contribute to their outlook. In psychological terms, some of these patterns may be judged to be unhealthy, as ego mechanisms of defense suitable for intervention. Indeed, Esther had undergone psychiatric treatment for depression over the course of most of her adult life. Nevertheless, she was resigned to living—and dying—with unresolved issues. The negative prospects for success of further psycho-social intervention are not a reflection of deficiencies in therapy but rather are evidence of the robust character of the motifs organizing these individuals’ life stories.
For patients manifesting the dissonance motif, pain and other debilitating symptoms have a particularly adverse significance. They underscore the sense of decline and compound the feelings of revulsion associated with existence as a dying person. Life-prolonging care is viewed as irrelevant, even onerous, by such patients; aggressive pain management and palliative care, however, can play a critical role in alleviating both psychological as well as physical distress.

Patients exhibiting the endurance motif, who summon an inner core of strength despite the inevitable course of illness, would benefit from treatment plans that support these inner resources. Taken out of context, unaware of their past, health care providers may mistake their outlooks on death for denial and may pursue an ill-conceived plan of care. They were very aware of the seriousness of their conditions and had a realistic appraisal of the likely course of their illness. Their confidence is not associated with hopes for survival but rather is an affirmation of the strength of their own identity.

For patients demonstrating the incorporation motif, it is important that their faith is acknowledged and respected and that they are able to harmonize their plan of care with their belief system. The coping motif is characteristic of people who meet adversity and change with significant efforts to establish equilibrium; an appropriate goal for caregivers would be to help them to marshal their own resources to find a new balance in confronting death. For people who embrace the quest motif, seeking meaning and opportunity for reflection and growth is vital; feeling disregarded or condescended to merely because they are old or frail or dying is particularly distasteful to them, because it is not consonant with how they experience themselves. For them, the opportunity to speak about their experiences is greatly valued.

This study was confined to in-depth analysis of the perspectives of thirty patients, a limitation as well as strength of the research. The method does not permit testing of hypotheses or estimating the overall distribution of a specific belief or trait in the population. The richness of the data, however, affords a degree of validity unattainable by other approaches. The motifs do not denote an exhaustive set of models, to be applied to experiences of all dying patients. They are not presented with the aim of forcing particular experiences into stages, phases, or other generalized constructs; nor to reduce differences to common denominators. Their purpose is to provoke a search for constructive responses to the rich and varied possibilities for relating to the prospect of dying given voice to by these patients.

Shared decision-making in the doctor-patient relationship, which is premised on an understanding of the perspectives that patients bring to the health care encounter, is increasingly acknowledged as essential to patient adherence to treatment plans. Considerable research has established a link between a mutual, deliberative strategy and positive patient outcomes and, in some cases, more efficient use of physician time through more appropriate referrals. In caring for dying patients, awareness of relevant features of the patient’s biography can be facilitated by a few, carefully phrased questions, similar to those presented in Table 2. Once engaged, patients can be relied upon to participate in shaping a care plan that is compatible with their overall outlook, preserving their integrity and promoting mutual cooperation.

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References


