

EIGHT MOTIFS OF DYING: AN INVESTIGATION INTO DYING AND THE INNER LIFE

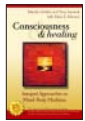
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The Project on Dying and the Inner Life (PDIL) was created with the aim of exploring what could be learned about the final stage of life from individuals who were in the very midst of that experience. This 3-year research project was designed to give voice to terminally ill patients' perspectives on death and dying during the last months, weeks, and days of life and to seek answers to such questions as the following:

- What can dying teach us about the human potential?
- What last opportunities remain as death approaches—opportunities for healing, for letting go of the pain and regrets, for using the remaining time fully, for finding a final freedom?
- What is it like to live with the awareness that one's life is coming to an end? What changes; what remains unchanged?
- What kinds of things do dying people say they learn or gain as they approach death? What stands out as important or meaningful at the end of life?
- What possibility is there for transformation and transcendence at the end of life?
- How might a greater knowledge of the spectrum of ways in which terminally ill people view their dying be of value in improving care at the end of life?

The PDIL took a phenomenological research approach to plumb the depths of the dying experience. The 35 subjects in the PDIL were individuals living with a life-threatening illness who had been told by their physicians that they were likely to die in 6 months or less. They participated in multiple in-depth semi-structured interviews continuing over days, weeks, or months up as close to the time of their death as possible. The interviews were audiotaped, transcribed, and subjected to inductive analysis using standard qualitative techniques. (For a more thorough description of the PDIL research methodology, see the published research report.¹) All the participants in the PDIL acknowledged that their lives were coming to an end ("I don't have much time"; "I know it's coming"; "I know I'm dying"). They were in fact living with an awareness of death. In the face of this knowledge, people responded in a wide variety of ways. For some, death was accepted, even actively 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 because they feared dying (some were terrified), because they wished to complete certain experiences (e.g., to see grandchildren mature), or because they wanted to continue the cherished experience of living, no matter how difficult or painful. Still others maintained a stance of neutrality, preparing themselves to "deal with whatever comes."

Some individuals wanted to meet their death in full consciousness; others did not want to know anything about it, often expressing the wish to die in their sleep. Some had a strong belief in a continuing existence after death; others did not have a particular belief, whereas some strongly believed death to be the end of existence. Some preferred to surround themselves with all that



was familiar and known to them from their lives; others expressed a desire for new experiences; still others reported opening up to new dimensions within themselves, at times describing transpersonal insights and non-ordinary ways of knowing. A few demonstrated a pronounced acceleration of learning and growth and significant movement toward resolution of long-standing issues, and one individual demonstrated a radical transformation and transcendent experience.

From the extensive descriptions given by the 35 subjects of their inner life experience as they moved through the dying process, eight "motifs of dying" 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), volatile (unresolved and unresigned), and transformation (self-acceptance, self-actualization, and grace). These motifs are not absolutely defined constructs but are a pragmatic means of painting a picture of the variety of paths that people follow as they traverse the final stage of life. They are not meant to give a comprehensive picture but are the motifs that emerged from this sample of individuals. Although the actual number of possible paths is undoubtedly infinite given that each human being is unique, nevertheless, a system of motifs, lightly held, may help us view the vast variety with some perspective.

MOTIFS OF DYING

The accounts of a number of individuals have been selected to illustrate the eight motifs of dying that emerged in the PDIL research. Passages from the interview transcripts that typify each motif will be presented to permit these individuals to speak for themselves. (Names have been changed to protect confidentiality.) A brief sketch of the background of each individual is included to give some sense of his or her life circumstances. Also included is a brief description of the way in which each person finally died.

STRUGGLE MOTIF: LIVING AND DYING IS A STRUGGLE

Some people described their experience of dying in terms of struggle. The central theme of their lives had been struggle, and the experience of facing death was a continuation of that theme:

José was a 41-year-old Hispanic man who had advanced AIDS and liver failure and was living in a group home for the destitute. Drug abuse had been a problem for him since the age of 12, and he had sought help intermittently at Narcotics Anonymous, Alcoholics Anonymous, and Methadone Maintenance Treatment Program. He had been employed on and off as a laboratory technician, had been married and separated three times, and 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 José, and he spoke of it in much the same language of pain and conflict that he used in describing other 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've done to myself, you know, from my drinking. That was my number one addiction, and heroin was my number two....

It's scary to know that you're going to die, that you can't do anything, that you're hopeless. That's when you got to have that faith and say, one day at a time.... I handle whatever comes up,



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little by little. My mother always taught us, appreciate what you have-that slogan, "here today, gone tomorrow." All the things I've been 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.

Early in December José slipped into a coma associated with his liver failure but regained consciousness after a week. After speaking with a staff member at his group home about his brush with death and the approaching Christmas season, he lamented that he had not celebrated Christmas since he was a child. The staff members mulled this over and then took up a collection among themselves, presenting him with a small bedside television set wrapped in a large red ribbon. José was moved to tears. Having nothing to give in return but being endlessly resourceful, he then asked to have some of the hard candies always sitting in a bowl on the social worker's desk. With these and some holiday napkins from the dining room, he made little bundles that he wrapped with pieces of the red ribbon and presented them to every resident and staff member of the group home with his best wishes. Shortly after Christmas José developed acute septicemia, slipped back into a coma, and died, surrounded by his group home friends.

Esther was a 72-year-old woman who had a recurrence of breast cancer with bone metastases. She had had breast cancer several years before and had actively participated in successful treatment at that time. She had complained of depression virtually all of her adult life despite psychiatric care. She lived alone and was forcibly retired at age 65. She said that she had never had any real love in her life. Her father died when she was 9, and she had felt only resentment from her mother. She had no close friends, had never married, and found no meaning in her Jewish religion. From her perspective, life had brought her nothing but disappointment.

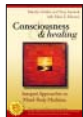
Well, I neglected it. I knew I had it. I knew it was breast cancer, and I knew if I had gone and had a simple mastectomy with a lumpectomy and radiation, I could probably fight it off for the rest of my life. I didn't want to. I deliberately wanted to allow it to grow so that I would die. I would say 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's happened.

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

She was propped up at a 45-degree angle, and she almost had a smile on her face. She was clutching her papers. She had a briefcase with her private 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.

For José and Esther and other PDIL participants who expressed a struggle motif, life had always been difficult and disappointing. There was some sense of overall direction for them, but it required great effort to keep going. The experience of being terminally ill and dying brought nothing new in this respect; it was just a further manifestation of the struggle. They got by in life by struggling through in the way they knew how.

These individuals tended to die with many unresolved issues. By and large, they seemed resigned to living and dying with their lifelong problems, as if they expected that was the way life was. They did not benefit greatly from efforts at psychosocial intervention; such well-intentioned outreach was often disregarded or refused. What they did appreciate, however, was being listened to and having their struggle acknowledged.



DISSONANCE MOTIF: DYING IS NOT LIVING

The theme that stood out in some descriptions of the dying experience was dissonance. These individuals no longer felt themselves to be the people they wanted to be, and they expressed the clear desire to be done with life.

Arthur was an 85-year-old Jewish man who had cancer of the bladder, prostate, and colon. He also had chronic renal failure and required regular dialysis. An affluent executive with a taciturn affect, he had moved in a fast-paced world of business before retiring. He declared that he had so many former business associates that he had no need for friends. His wife had died 7 years earlier from a degenerative neurological disorder, and he had observed her slow deterioration. After her death he preferred to live alone, although he had frequent contact with his two adult children, who continually urged him to persist with aggressive medical treatment. To Arthur the process of settling his affairs before dying meant putting his bank accounts in order; his main concern was to be able to leave his two children in a comfortable financial position.

I feel that I am fighting a losing fight now. So, I'm not anxious to go through all of this (medical treatment). I feel that maybe it is just a waste of time. Is it worth the effort of 6 months of going through all of this to live another 3 to 6 months? It makes my daughter and my son happy, but it doesn't make me too happy. 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....

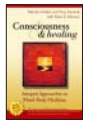
I figure I've lived my life, and it was a good life while it lasted. I was happily married for 60 years. Now it is time. I don't want to be a burden to my children. I don't want to be anything.... I'm 85 years old. I have nothing to look forward to. I'm not afraid to die; I'm afraid to live!... One thing 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 level of functioning and physical discomfort were not noticeably worse than that of other individuals in the study, for him his quality of life was unacceptable. He eventually persuaded his children to accept his decision to refuse further aggressive treatment. He enrolled in hospice care, which he found very much to his liking, and died with his children at his side.

Maria was a 92-year-old Italian-American woman who had rectal cancer. Her husband had died in 1982, and she lived with her son and daughter-in-law. A devout Catholic, she spent much of her time praying to Mother Mary and saying the rosary. She no longer felt well enough to go outside and could not tolerate solid food. She reported that the only thing she still enjoyed in life was the 2 hours in the afternoon when she could sit by the window in the sunshine and feel the sun's warmth on her body.

I feel it's 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're all dead. I don't know who to talk to. This new generation doesn't understand me, and I don't understand them. What am I doing here?... I can't do nothing! I'm losing my eyes, I'm losing my ears, I can't walk. What am I good for?

Maria's view was that life had left her behind. She retreated more and more into her own world, spending hours talking to God and Mother Mary. Eventually, she was diagnosed with senile dementia and admitted to a nursing home where she died a quiet death.



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The people who expressed the dissonance motif typically felt that they had had a good life, one that stood in stark contrast to their present state. They were dissatisfied, even distressed, by their current condition because it was not who they had been or wished to be. They had a certain frustration in common, expressed in the following ways: "What kind of life is this? No thanks, I don't want it!" Regardless of whether they believed in an afterlife (Maria did; Arthur did not), they would prefer death to life like this. They had no inclination to seek meaning in death; for them, it was not a new experience to be learned from or adapted to (as for people with other motifs) but rather was the end of their story. These people had no interest in life-prolonging treatments, and sometimes struggled to overcome resistance from family members and to make their wishes understood even to health-care providers. Assistance in bridging a communication gap and helping family members see matters from their perspective was generally welcomed by them.

ENDURANCE MOTIF: TRIUMPH OF INNER STRENGTH

The accounts these people gave of the experience of dying were grounded in the strength of their own inner character—the essence of who they were. In contrast to those who expressed the dissonance motif, these individuals felt they could rely on their inner character to carry them through to the end, regardless of how difficult it might be:

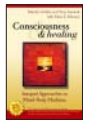
Evelyn was a tiny, white-haired, 82-year-old Jewish woman with colon cancer, liver metastases, and congestive heart failure. What she lacked in size and health, she made up for with her sharp wit and strong opinions. For many years she had worked as an administrative assistant in the mayor's office, a fact about which she often reminded others. She enjoyed continuing to wield a position of authority as president of her building co-op. Her husband had died of cancer 15 years earlier, and she lived alone. In spite of her poor health, she expressed a strong determination to maintain her equilibrium and continue 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 did [the treatment]. It had to be done, and I did it. 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 do. 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?

What is going to be will be. I can't stop it. There ain't nothing except that I shouldn't suffer. That's all I ask. When it's going to happen, let it go fast.... I told you, I don't think about it because I'm not going to make myself sick, and I'm not going to ask when, when? No, I don't live like that. Gone is gone. [This is just what she said about her husband: gone is gone. She said she couldn't let his dying stop her; she just kept on going.] 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 live!

Toward the end, Evelyn developed a fairly rapid onset of delirium and was admitted to the hospice inpatient unit where she spent the last 3 weeks of her life. Despite the complete loss of her cognitive abilities, she was in no distress. She spent most of the time napping and passed away very quietly, seemingly unaware of what was happening. It appeared that her wish about dying—not to know and not to suffer—was fulfilled.



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Angela was a 47-year-old African-American woman, a registered nurse, who had breast cancer and bone metastases. Her husband had died 2 years before, after a lifelong battle with 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. A strong, proud woman, Angela declined chemotherapy, given her poor prognosis. She did not want to experience the side effects, which she said she had seen too many times as a nurse. She sought help from herbal therapy, nutritional supplements, and palliative care practitioners and was supported by a strong church community. About her death, she made the following observations:

I don't want to know. I'm not that type. 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 go and do because I'm going to die today or tomorrow. You can't function like that. You have to just still continue like it's normal.

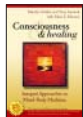
I'm not really discovering anything new. I look forward to sleeping at night and getting up. That has more importance, being able to eat and being able to go into the shower and come out and, you know, things like that.... I try not to worry. I try to take things as they come, because you can worry and it's not going to change anything. I used to be a very bad worrier. But after I got older and I started to read more, especially the Bible, I learned to relax and take things in stride....

I'm very upbeat and positive. I think in the years since I've been diagnosed, about 8 years, if I've been depressed five times, that's a lot!

I'm a person that has a lot of pride. If you sit and you think about it, and you feel, "Why do I have this?" or "Why did I have to get that?," it starts to mess with your 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—treat people nice, you know, and carry on my activities of daily living, raising my kids, cooking, reading, going to church. You have to help yourself. You can't just say to the doctors, "Fix it."

Angela went on with her life, shouldering her health problems as well as her family problems with firm determination. As her health began to fail, she enrolled in hospice in order, as she put it, to give her the best quality of life in the time that remained to her. She took care to make arrangements for the future well-being of her children, recruiting other family and friends to take on her responsibilities, and finally died at home, surrounded by those she had cared for in her life.

Evelyn, Angela, and others who died with the motif of endurance, approached terminal illness in the way they approached other difficult events they had experienced in life. They were not about to let the prospect of dying interfere with what was important to them in their lives. They were determined to continue as they always had, standing firm in the strategies that had served them well. By refusing to worry or to think overmuch, by refusing to be overcome by emotion, and by sustaining an upbeat outlook, they were prepared to endure whatever adversities might come. It simply did not occur to them to do otherwise. They had little interest in introspection. Their inner strength was not the product of rational analysis or of a belief system. Rather, it was an intrinsic character trait, a reliable anchor in their daily lives. Some of these people might have erroneously been labeled as being in denial, although a close listen revealed the unmistakable coherence of their inner stance. An important goal in caring for people such as these at the end of life would be to uphold the consistency of their lives.



INCORPORATION MOTIF: BELIEF SYSTEM ACCOMMODATES DEATH

For some people, their views of approaching death were powerfully shaped by their core belief systems, and it was these beliefs that sustained them in the face of the challenging circumstances of dying.

Alice was a 54-year-old woman who had end-stage ovarian cancer with extensive metastatic disease. She was bed-ridden, with intestinal obstruction and poorly controlled pain despite aggressive treatment. Married for 35 years, she had eight children, ages 15 to 33, with strong family ties. She had worked at the Board of Education for nearly 30 years. She had a proud sense of identity as a devout Jehovah's Witness and a member of a close-knit African-American community. Her beliefs were paramount in shaping her experience of dying just as they had been in her experience of life.

God gives us life. He gives it to us to live it. I plan to live it as long as He gives it to me. It might be painful to stay here, but I plan to stay, for however long he gives me to stay-I know that God may make a place for me to come to him. I'm not afraid. I get tired sometimes but I'm not afraid... Whatever's going to happen, as far as death or whatever, is going to happen. I can't run from it, and I'm really not trying to. I just want to be peaceful. I just don't want to be in a lot of pain, that's all...Life is a miracle, and I want to appreciate every second of it!

Alice was determined to remain at home, where she felt happiest and closest to the people she loved. Eventually, however, her family begged her to enter the hospice inpatient unit, where they felt her pain could be better controlled and her suffering lessened. She died there, holding her youngest son's hand.

Ella was a stately 50-year-old African-American woman who had end-stage breast cancer with metastases to the bone and liver and malignant pleural effusions. She was a nurse and had run cancer support groups before her illness. She lived alone with her two Siamese cats, and she had two grown children. She described herself as New Age in her spiritual beliefs, having studied a number of spiritual teachings.

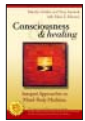
We take up space, we're matter, we're material now. When we die, that stays here. But we have a spiritual life, a spiritual being, and we move on, too. That's how I see dying. Spiritually, I'm going to be with Jesus Christ, with God, and my mother and father. I'm going to see them in a new life, a new beginning. This is just matter. It takes up space. That's all this is really, so that's 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're 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's already ceased to do? It just seems to me so torturous. I don't want that; just let me go in peace.

Ella eventually refused further aggressive treatment. She said the invasive procedures were no longer helping her. She knew her time had come, as she put it, and felt ready to meet it. She died of multiple organ failure while hospitalized on the oncology floor.

Alice, Ella, and others expressing the incorporation motif valued life but were not fearful of dying. For them, death was part of a larger plan, even if it was happening earlier than they would have chosen. Their thoughts about death were not newly adopted as a defense in



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reaction to their life-threatening situation. Rather, they were part of the belief system that had sustained them over the course of their lives and that was the reference point for all that happened to them. For these people, dying was understandable within their overarching belief system. Death was organically tied to this system, and their experience of dying was incorporated seemingly without the need for alteration. They may have had questions and personal preferences, but ultimately they had faith that their life, as well as their death, was in accordance with a larger purpose or in the hands of a higher being.

COPING MOTIF: WORKING TO FIND A NEW BALANCE

For some individuals, the experience of dying was one of trying to maintain equilibrium while their lives went through the overwhelming changes brought on by severe incurable illness and the prospect of death. Their work was to adjust.

Ellen was a 47-year-old Irish Catholic woman with terminal ovarian cancer and a raucous sense of humor. She had one son, was divorced, and lived in an apartment next to her sister. An eclectic person, she had worked as an administrative assistant and office manager but was also a poet, musician, and artist. She had considerable support from her family and friends. In fact, when she enrolled in hospice, she called up her brother and best friend and told them, "The treatment's not working; come and party with me!" They immediately packed their bags and traveled across the country to stay with her during her final months. Ellen's path through dying was a grueling one; she experienced overwhelming bouts of fear that she struggled to cope with by turning to her friends and family and allowing them to care for her.

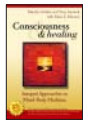
I was diagnosed with cancer, and it was absolutely devastating, very frightening. Fear is the utmost word I can use. It's overwhelming. The fear that I feel every day is that I'm going to go nuts from this. There are moments when I look at this and go, "I can't do this. I can't do this and stay sane..."

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 lifesaving. So I'm learning to just let people give it to me, their support and love. 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 is 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 course fluctuated between the extremes of fear-filled turmoil and hard-earned release. Together with her family and friends, she filled the good times with music and poetry. She stayed at home until her disease became very advanced, at which time she agreed to enter the hospice inpatient unit for respite care. Finally relinquishing the effort to stay in control and at last allowing others to fully support her, Ellen became entirely free of fear—to her amazement and to the great relief of those caring for her. One week later, after having one last party to say goodbye to all of her loved ones, she died, finally able to say that she was at peace.

Bob was a 92-year-old man with prostate cancer and bone metastases. He was a world-renowned musician, a professor at a prestigious music school, and a successful author. A



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flamboyant socialite and prominent member of the gay community, he had led a life filled with cultural events and parties. He responded to the shock of his illness and the loss of his old life by attempting suicide. However, the doorman of his building discovered him as he was close to death. Having survived, Bob discovered that he wanted to live, and he sought to find a way to accept the radical changes taking place in his life.

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 that. 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? At 92, it's not bad. A lot of people at 92 are sitting in a wheelchair waiting to die. So at least I read and see my friends, and those are my two activities.

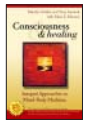
Bob's niece and primary caregiver urged him to engage in a vigorous rehabilitation program "to keep his strength up," but he had no interest. She still saw him as the old Bob and wanted him to maintain that identity, whereas his goal was to accept his changed condition. He seemed very pleased that he was able to do this, and he died in his sleep at home in the care of hospice.

When confronted with immense forces of change, Ellen, Bob, and others with the coping motif worked hard to adapt. Their approach was ultimately a practical one: 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 their lives, and now they sought to cope with their losses and fears so as to experience life as positively as possible in the midst of illness and dying. Finding a new balance was not an effortless experience for them. They did not rely on a core of inner strength as did those embracing the endurance motif; nor did they rely on a defining belief system as did those who expressed the incorporation motif. Rather, they worked diligently to change their expectations of life and to let go of the past as they had known it. As a result, they were able to find good in their vastly altered life circumstances. Acceptance was the fruit of their effort.

QUEST MOTIF: SEEKING MEANING IN DYING

In contrast to the coping motif, the quest motif characterized individuals for whom reflection on life was of central importance. They subjected their experience of illness and dying to intensive examination with a great interest, even need, to find meaning therein.

Robert was an 82-year-old man with advanced prostate cancer and bone metastases. He had sweeping white hair and a debonair manner. A former university chancellor and dean of international studies, twice divorced, he lived in a large townhouse with a housekeeping staff and prided himself on his intellect and his golf game. When told that his prognosis was less than 6 months, he began to read avidly about death and dying. During the following months he described numerous transpersonal and transcendent experiences, something he had previously dismissed as "nonsense."



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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....

I'm sitting here [unable to walk] and observing. I thought I was always an observer, but I'm much more observant now, as if I want to take in as much as I can see. In a sense, I have a greater feeling for the things that life does offer, and that's part of the road that I'm on. The road in that way, instead of getting narrower and more desolate, becomes wider and has more things in it!...

I now feel more room for things. I must confess that I'm fascinated by it! It would almost seem, what is the point in gaining these insights or sensitivities at this late part of the game, but I don't want to feel that way. I mean, I'm 82, but I no longer know what 82 means!...

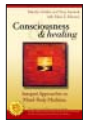
I have a feeling that I'm beginning to understand at a deeper level than I might have intellectually what this is all about. I can almost physically feel the return. It's almost as if one begins again somewhere. Somehow there is a kind of continuum. I never thought I would be saying this in the face of some of the doubts I've had. Somehow, they're gone!...

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! I'm looking for little signs; I do notice changes. Happily, I think I'm less critical.... I used to live entirely in my mind; now, for the first time, I'm feeling my heart. It's almost as if there's some form of new wisdom.... 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 long-term care facility, where he experienced a slow decline in his health. He remained conscious until the day he died-writing, reading, and talking about dying. Toward the end, he often described having the sensation of standing in two worlds simultaneously, one that he could see and one that was just beyond his seeing. He said his greatest source of enjoyment was having someone to discuss his insights with, even when he had only enough strength to speak in a whisper.

Stacy was a 40-year-old Jewish-Christian woman who had lung cancer that had metastasized to multiple sites. She was an accomplished poet, author, and teacher and was in the process of completing a master's degree in counseling. She came from a very dysfunctional, alienated family in which there was alcoholism, abuse, and mental illness. Married briefly, she had a 17-year-old daughter and had been living in a domestic lesbian relationship for the past 7 years, something that had further alienated her schizophrenic mother. Despite their difficult history, which entailed years of not speaking, when Stacy told her mother, brother, and sister that she was going to die, they gathered around her and became actively involved in her care.

I find that the things you thought were important before really have no importance. Things like money. Even though it's good to be able to pay your rent and pay your bills, you can see how really unimportant something like money is, because as rich as I would be, there would be no way I could cure this just with money, you know. So, yes, dying does change your idea of what is important in life in a lot of ways. Things like nature, or just sitting outside, are incredible to me, seeing the sun and the trees and the beauty of the world. I think I was too busy to appreciate it before....



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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 think there's a beauty to having a life, you know. I think that the meaning of having a life is to have choices, and to make the right choices for the most part, and actually to help each other and to connect with each other as human beings.... I had quite a few purposes in life before I got sick. One was the writing, which was really a big purpose in my life. The other purpose was loving, and that I deepened. I think that those are the two main purposes in life: something to do that you enjoy doing, and the other is love. I think that's the purpose of why we're here....

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 and reflection and to marvel at what she saw. She was forthright in examining her feelings, whether addressing concerns about her daughter's future or reflecting on major lifestyle decisions in her past. The intense process she was in had a remarkable effect on those around her. Watching Stacy suffer and yet continue to express love and forgiveness allowed her family members to let go of their long-standing grievances and find common ground. Seeing Stacy's ability to face death without fear had a profound strengthening effect on Stacy's daughter, Renate, who was initially depressed and desperate. Renate was ultimately able to meet her mother's dying and her own future without fear. Stacy died peacefully at home, surrounded by her family as she had wished.

For individuals like Robert and Stacy who demonstrated the quest motif, the opportunity to grow and learn was paramount in dying as it was throughout their lives. Reflection was essential to them as they sought meaning in their experiences at the end of life. These were people who did not feel diminished by the experience of being old or disabled or dying because their sense of who they were and what was important to them was not defined by these conditions. 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 for learning and growth.

VOLATILE MOTIF: UNRESOLVED AND UNRESIGNED

The theme that characterized some accounts of the dying experience was that of volatility and lack of direction or resolution. These people seemed almost to have lost their way, in living as well as in dying.

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 in various housing projects for most of her life, cleaning people's houses for additional income. Violence played a major role in her life, having been in abusive relationships with a series of male partners. She had had a son and daughter with different fathers, and her son was shot to death by her daughter's boyfriend. Although she knew many people, she said she didn't trust any of them. She often expressed anxiety or anger or broke into tears as she related her thoughts.



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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....

We had real bad times together [Mary and her daughter]. I threw her out with the police. Georgie [Mary's 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.

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. I just wish I didn't have to die. It's horrible! You feel like you have nothing left, nothing to hold on to....

Major unresolved issues were at the heart of Mary's turmoil, and she had few social supports or skills of her own to assist her. Her fears grew, and she became increasingly confused until eventually she was diagnosed with progressive dementia with paranoid features. She was then admitted to a long-term care facility, where she remained until her death.

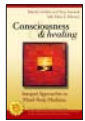
Susan was a 52-year-old woman who had end-stage breast cancer with metastases to the brain and bone. She had completed 2 years of college before dropping out and thereafter lived in a basement apartment and obtained work in temporary positions. Her real aspiration was to be a writer, but she never pursued it. She regarded herself as a lesbian but was apprehensive about sharing this fact with anyone. The few friends she had drifted away when she became ill.

When you get to feeling really miserable, I thought, well, maybe that's 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, or even if there is a proper way. That's 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's a part of what's going on, you know, what I'm 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's sort of like someone went and clipped my wings, and the person who did that was me.

Susan became more and more absorbed in her guilt despite all efforts of the hospice team to help her. Her mental status gradually deteriorated, and when her confusion began to interfere with her ability to care for herself, she was admitted to a chronic care hospital with a diagnosis of progressive dementia. She died there some weeks later.

Mary, Susan, and others with the volatile motif exhibited no clear idea of direction or meaning in their lives, nor in their dying. For them, life was chaotic and unpredictable. They had many unresolved issues and were buffeted by forces they could not understand or control. They did not seem to have the sense that, if they tried, they might be able to reach a goal. They demonstrated a passivity or helplessness, as if to say, "What's the use?" Despite psychosocial interventions, their disease engulfed them, much like other events in their lives, and they were swept along through their dying to an unfulfilled and chaotic end.



TRANSFORMATION MOTIF: SELF-ACCEPTANCE, SELF-REALIZATION, AND GRACE

The dominant theme in one individual's account of facing death was transformation. In contrast to all the previously described motifs, wherein the dying experience was essentially shaped by who the person had been in life up to that point—the qualities, values, beliefs, and experiences—this motif was shaped by who the person had not yet been but had the possibility of becoming. At the point of facing death, this individual became able to do what she was unable -or unwilling-to do throughout her entire life. To her, this was the gift that dying brought: She called it grace.

Pamela was a 50-year-old woman of Italian descent with advanced AIDS, chronic hepatitis, and liver failure. She had abused a wide range of drugs since the age of 12. From the age of 21, when her mother died of causes related to alcoholism, Pamela lived on the streets. Her goal was to get high every day. To support her habit, she became skilled at shoplifting, petty robbery, and forgery. She spent a total of 11 years in prison and considerable time in various hospitals for acute illness related to drug use or AIDS. She had one son whom she kept with her until the age of 8 because he was useful in her efforts to obtain drugs or get admitted to shelters; she relinquished him to foster care when he began to get too big. She refused all psychosocial intervention, preferring her chosen lifestyle to all others.

At age 49, Pamela suffered an acute episode of liver failure and was in hepatic coma for a week. When she recovered, her doctors informed her that she had nearly died and that, given the condition of her liver, she did not have long to live. It was at that point that something shifted for Pamela, and she chose to give up all drug use and enter a residence for homeless people with AIDS.

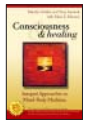
All my life I used drugs. That's what I lived for—to get high every day. I didn't want to face life without being high. I was running...from what, I don't know...from life, from myself, from everything! I always thought I wanted to die with a needle in my arm, high. But when my doctor told me I was dying, something happened—I felt something in me turn around. It was like, if my time's almost up, what do I really want? And, well, I wanted to know what I'd been running from! Before it was too late, I wanted to know, who is that person, Pamela, that I didn't want to look at? I was too busy getting high, but she was waiting there all the time. The funny thing was, I thought she was worthless, because they all told me she was, but they were wrong!

Damn, what a surprise! Once I started to look, I didn't want to stop. It was like, there was this person back there, waiting so patient-like, waiting to love me, and I didn't even know. The crazy thing is, that person was ME!... It was like, I was coming home. And I was being welcomed, instead of put down. I could accept myself. Imagine that!...I could love myself!...

It keeps opening up more and more—I might die soon, but right now I'm more alive than ever. But that's just it—there IS no death! We go on from this place, on and on—I can feel it. And we're not alone. I can feel them waiting for me, like arms waiting to hold me when I go over. I don't know who they are, angels maybe. It's like, the more you offer yourself, the more they're preparing to receive you....

Now I see that my whole life was just about leading me to this point. I had to go through all that pain to finally know what love is. Anyone can do it—it's there for everyone! All you've got to do is stop running.

Other residents at the group home sought Pamela out. There was something that drew them to her. The staff spoke about her being "enlightened." Pamela's exit from life was done with flair. One day the social worker followed up a lead and discovered that Pamela had relatives living



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in a nearby state. Pamela contacted them by phone; they were shocked. They had not seen her since she was a teenager and had presumed she was dead long ago. Delighted to learn that wasn't true, they invited her to come for a visit. The staff authorized the purchase of airline tickets, made the necessary arrangements, and accompanied her to the airport. Then Pamela, who had never been on a plane in her life, flew off to visit her rediscovered family. She spent a day celebrating with them, then developed a fever, was rushed to their local hospital, went into septic shock, and died 2 days later. At the memorial that was later held in the group home, the residents and staff gave her a standing ovation. They said she went out in style.

Pamela's account of the experience of facing death testifies to the possibility of radical transformation at the end of life. Her story suggests that the awareness of the approach of death can accelerate the inherent tendency toward self-actualization by strengthening the ability to choose, as if the question, "Is this how I want my life to be?" gains power when accompanied by the realization that very little time remains.

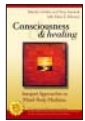
LEARNING FROM DYING PEOPLE

The accounts of dying presented here and the motifs of dying distilled from these accounts reveal the richness of the tapestry of human life and offer an uncommon insight into the experience of dying. These accounts and their corresponding motifs have much to teach us about human nature and its potentials and possibilities, and they can provide valuable guidance in making care for people who at the end of life more sensitive and relevant.

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 encouraging a shared process of medical decision making. As revealed in the motifs, individuals' responses to dying were generally integrated with broader themes in their lives. Appreciation of their distinctive outlooks on the final stage of life requires awareness of their life stories as well as of other salient characteristics that distinguish them as people. These motifs point to a broader context, born of a lifetime of experience, that shapes patients' perspectives on dying and gives them authenticity and coherence.

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 could fail to distinguish between Mary's openness to addressing unresolved issues (volatile motif) and Esther's resignation (struggle motif); Angela's inner strength could be confused with denial; Bob's acceptance of his changing status (coping motif) could be misinterpreted as depression; and Arthur's contempt for his quality of life (dissonance) could mistakenly 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 individuals in the study with the volatile motif, psychosocial intervention addressing unresolved issues was generally welcomed, even though a chaotic overlay to their lives was likely to persist. Those individuals who exhibited the struggle motif, in



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contrast, were not likely to embrace a new psychotherapeutic effort to reassess their lifelong conflicts, no matter how justified a psychiatric referral might have seemed to be.

For individuals manifesting the dissonance motif, pain and other debilitating symptoms had a particularly adverse significance. They underscored the sense of decline and compounded the feelings of revulsion associated with existence as a dying person. Life-prolonging care was viewed as irrelevant, even onerous, by such individuals; aggressive pain management and palliative care, however, played a critical role in alleviating both psychological as well as physical distress.

Individuals exhibiting the endurance motif, who summoned an inner core of strength despite the inevitable course of illness, benefited from treatment plans that supported those inner resources. Taken out of context, with little awareness of their patients' past, health-care providers could mistake their outlooks on death for denial and could thus pursue an ill-conceived plan of care. On the contrary, those individuals were very aware of the seriousness of their conditions and had a realistic appraisal of the likely course of their illness. Their confidence was not associated with hopes for survival but rather was an affirmation of the strength of their own identity.

For those individuals demonstrating the incorporation motif, it was important that their faith be acknowledged and respected and that their plan of care harmonize with their belief system. Individuals with the coping motif, who met adversity and change with significant efforts to re-establish equilibrium, were appreciative of caregivers who helped them to marshal their own resources to find a new balance in confronting death. For people who embraced the quest motif, seeking meaning and opportunity for reflection and growth was vital; feeling disregarded or condescended to merely because they are old or frail or dying was particularly distasteful to them because such reactions were not consonant with the way they experienced themselves. For them, the opportunity to speak about their experiences was greatly valued.

The PDIL study was confined to in-depth analysis of the perspectives of 35 patients, a limitation as well as strength of the research. The method does not permit testing of hypotheses or estimating the overall distribution of specific motifs in the larger population. The richness of the data, however, affords a degree of validity unattainable by other research approaches. The motifs do not denote an exhaustive set of models, to be applied to the 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 shed light on the rich and varied possibilities for relating to the prospect of dying and to provoke a search for mindful responses in the work of caring for people at the end of life.

Dying people might be viewed as explorers traveling through a largely unmapped territory—the final stage of life. It is a territory we would be well-served to know more about. We can benefit from seeking out these explorers to learn what they have to report and asking their help in mapping out this territory more fully. And we are right to stand with them in respectful witness to their journey, the journey that all of us will ultimately take.

1. Yedidia M, MacGregor B. Confronting the prospect of dying: reports of terminally ill patients. *J Pain Symptom Manage* 2001;22: 807-819