

Facing death: embracing life

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Editor's Note: In 1996, as a palliative care physician at St Paul's Hospital, Dr Kuhl became a Soros Faculty Scholar on the Project on Death in America. This allowed him to conduct a qualitative study, Exploring Spiritual and Psychological Issues at the End of Life.¹ These observations are based on the findings of his research.

"Despite having a terminal illness, one is alive. After confronting death, every day is a miracle."

Only people with terminal illness know what it means to live with those illnesses. That makes their stories very important.^{1,2}

What is the lived experience of knowing that you have a terminal illness? What is it like to get up in the morning with the knowledge that the disease process going on within you will likely be the cause of your death? In asking those questions of people who knew they had terminal illnesses, the following themes emerged.

Time

We share time: 60 seconds in a minute, 60 minutes in an hour, 24 hours a day, 7 days in a week. Psychologist Ken Wilber speaks of narrative time as "the time that marks the history of one's own life story or self; the time that carries and recreates hopes and ideals, plans and ambitions, goals and visions."³ It is narrative time that is altered by knowledge of a terminal illness, for such knowledge affects one's life story, one's hopes, plans, ambitions, goals, and visions.

I have no idea whether I'm going to live a year or I'm going to live a month. That's very hard to take, especially when I'm just living to live. That's what I'm doing. I live to take the puffers six times a day, to take the pills so many times a day, to fill the pills up every four days; ... all I'm doing is working with pills and puffers. ... It absolutely controls my life.

Ambivalence sets in after hearing words like cancer or AIDS. Time stops. One is left with thoughts of "if only." If only I had not ignored that lump, if only I had stopped smoking long ago, if only. ... Thoughts go to those who are important—spouses, partners, children, friends. In the midst of ambivalence a question emerges: "Do I embrace life or do I prepare to die?"

Communication and iatrogenic suffering

Peggy, a woman with lung cancer in her early 60s, observed:

I guess the first thing is I trust all my physicians. They've been totally up front and answered questions in detail. I couldn't have asked for it to be handled better. They have told me what it might be, what it might not be; they couldn't have been more honest. It didn't come as a shock, not as a bolt out of the blue. It was just one of those case scenarios they described that they hoped it wouldn't be.

There are always two experts in the room, the one with the knowledge about the disease and the disease process, and the one who knows how that disease will affect his or her life.

Marjorie, a woman in her late 70s had a different experience. After months of being reassured that the mass in her groin was benign, her doctor gave her another message from the doorway of her room, as she was waking from the general anesthetic. "Oh, by the way, we were wrong; it is cancer.

This editorial is based on a paper presented by Dr Kuhl, who was awarded the 2003 Carl Moore Lectureship in Primary Care. The Lectureship is awarded annually by the Department of Family Medicine at McMaster University in Hamilton, Ont, to those who have made an important contribution to the understanding or development of primary care and are able to present a lecture that will engage, challenge, and be accessible to a general audience.

I have made an appointment for you to see the oncologist in a few days.” No interaction, no touch, no discussion, no hope. For Marjorie, “The way the doctor talked to me caused me more pain than the disease itself.”

The moment when patients experience the greatest psychological and spiritual need might be the moment for which physicians have the least training. The patient can experience iatrogenic suffering (ie, suffering that originates from the care provider). Perhaps the care provider suffers as well.

Pain

Pain is part of the experience of living with a terminal illness. For some it is a constant reality, for others it is intermittent, and for some it is fear or anxiety that pain is yet to come.

I’m not sleeping at all, so it’s getting to the point where in the middle of the night, at 4 or 5 o’clock in the morning, I’m tossing and turning from the pain and from the discomfort. And I’m just so exhausted, you know. This has gone on for weeks on end. I fall asleep from sheer exhaustion. ... I was just thankful if I got 40 minutes, 50 minutes, whatever the case might be.

When pain is present, it becomes the focus of existence.

Touch

Touch is healing, emotionally and psychologically. It is essential to one’s sense of well-being. Marjorie explained, “For me, touch is almost a necessity of life. Yes, it is a necessity of life. We need to be touched ... touching; I think it’s magical. I really do feel that if it isn’t physically healing, it is certainly emotionally and psychologically a way of healing.”

Touch counteracts the sense of aloneness, the sense of being out of touch, of being untouchable.

Life review

A process of life review seems to erupt from within—into thoughts, conversations, and dreams. It is a process of looking back to make sense of one’s past or simply to understand a lifetime of

memories and relationships. Part of what one sees and understands from the past can provide direction for the future. “You really do wake up. All of a sudden all these things that were hidden are front and centre; there is no hiding any more.”

It has to do with taking the parts of one’s life that have been forgotten and integrating them into a new wholeness.

Truth

“By telling yourself the truth, you allow yourself to heal.”

A person that’s terminally ill, they don’t have time, all they want is the truth, they want it from their doctor, they want it from their friends, they want it from their family ... if you don’t tell the truth, you play games and you’re just wasting everybody’s time ... you don’t have time to waste.

Truth and hope are not mutually exclusive. In fact, without the truth, some people cling to a false hope, which will likely affect their grieving process.

Longing to belong

I’ll never forget an incident when I was about 5 years old. My mother, my brothers, my sisters, and I were at the breakfast table. My sisters and I were fighting over something and I said, “You’re not my sisters anyway!” My mother said, “Go to your room and pack up all your stuff.” I packed up one of those wicker baskets with handles. I put in all my toys, my teddies, my pillow, and my blanket. She came into my room and dumped the stuff out on the bed, and then she took the empty basket and me to St Clair’s Hospital, which I thought was the Children’s Aid Society, and left me there all day. She was telling me two things; that they could take me back at any time, and that nothing belonged to me.

The longing to belong is a deep desire; it is the yearning of one person to be connected to another. “I say I’m glad I got cancer because it turned my life around. Now I can see what’s worthwhile and what’s not—what’s not worth spending any time on. The things that really matter are relationships with other people. Love matters.”

Who am I?

“Not all, but most people wear a mask of what they think people want them to be.”

That’s what I think makes us lucky, people who do come close to death. All of the negative stuff that you were taught is now replaced with positive things, loving things, caring things, things that make you a better, happier person. Funny how it affected me that way.

“I have faith and believe in myself now that I never had before ... and in being who I am, I’m not afraid of being who I am.” The process of individuation seems to begin when someone asks the question, Who am I? James Hollis, a Jungian psychologist, defines that process as “the developmental imperative of each of us to become ourselves as fully as we are able, within the limits imposed on us by fate. Unless we consciously confront our fate, we are tied to it.”⁴

Transcendence

The spiritual experience of the people who participated in this study¹ was described as being a gift: a gift of time, of relationship, of connection to a Greatness beyond themselves, of forgiveness and love, such that fear of death was diminished or eliminated. “I was where I wanted to be. I was surrounded by nature and the trees. When I woke in the morning, here was my tree and in it was a little

nest of birds. ... I think it helped me to live. I was surrounded by healing.”

To experience healing within ourselves is to face that which we carry within us. It is no different for those who know they have a terminal illness and those who do not have that knowledge; it is no different for the patient or the care provider. In order to respond to the patient, the health care provider might begin by asking the same questions. Who am I? Do I embrace living? Do I prepare to die?

In understanding the experience of dying, we might better comprehend the purpose of living. ❁

The opinions expressed in editorials are those of the authors and do not imply endorsement by the College of Family Physicians of Canada.

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