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Joyce A. DeShano

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Quality of Life: What Does it Mean?

Joyce A. DeShano, SSJ

I was a chaplain on the oncology units in the Detroit area for about 15 years, working primarily with people whose lives were ending and with their families and with staffs. They taught me most of what I know about quality of life.

The following excerpt from The Shoes of the Fisherman by Morris West (1) says much about quality of life:

"Yesterday I met a whole person. It’s a rare experience but always an illuminating and ennobling one. You see, it costs so much to be a whole human being and there are often very few who have the wisdom or the courage to pay the price. To be a whole person one has to abandon altogether the search for security and reach out to the risk of living with both arms. One has to embrace the world like a lover and yet demand no easy return on that love. A whole person accepts pain as a condition of existence and is able to court doubt and darkness as the cost of growth. A whole person needs a will stubborn in conflict but always accepting that life and death are part of one another."

Quality of life is about wholeness, about being the fully human being we were brought into this world to be.

Principles of Dying

There is a difference between dying persons and persons who are dying. Society often alienates or separates people classified as “dying persons,” but in reality there is no such group of people. Dying persons are living people who happen to know that their death is imminent. That fact has much to do with the quality of life.

A friend of mine, who has multiple sclerosis and is quite handicapped, was in the hospital a few years ago in Detroit. One night a nurse walked in her room and said, “Oh, my! All MS patients must have the rails up on their bed,” and she proceeded to pull the rails up. Then my friend said something that I have always remembered about persons labeling others: “I do have multiple sclerosis, but I am not an MS patient. I just have that disease. So I won’t think of you as ‘nurse’ if you won’t think of me as ‘MS patient.’” Quality of life is enhanced when we see all people as “living people” with brains, hearts, dreams, hopes, failures, relationships, abilities, talents, and limitations. If we think of them as “dying people” or “cases of disease,” the quality of their life is diminished.

Something about quality of life is lost when we forget that the disease exists in a whole (or at least attempting to be whole) person. If we cannot be whole and have a disease, there isn’t much hope for any of us. Patients respond differently when I relate to them as a person, not as a disease. After all, it is not that they are diseased people but people who have a disease.

Another important principle is that people die as they have lived. There are people in this world who will die without ever talking about their deepest feelings, their spiritual realities, their fears, their loves, their regrets. Many caregivers believe it is better if dying people talk about such matters. It is more satisfying to those of us who are the caregivers, feeling that we have helped somebody talk about their needs, but I suspect we often help people even when we have no dialogue.

I remember sitting for a couple of hours in almost total silence with a man whose son had died. I sat in total silence because I didn’t have the least idea what to say, but when we parted he said, “Thank you for not saying anything; that helped more than anything you could have said.”

It is important that we give people the right, the privilege, of dying as they have lived. It is important to know what people’s losses mean to them. They will die as they have lived, according to their choices and preferences. The gift of hospice allows people to die closer to the pattern of their lives.

The Mystery of Dying

When we die, whenever that is, it will be for the last time, not the first. The letting go at the end of life is unique and unlike every other “letting go.” What makes dying most frightening to many people is the unknown. Perhaps if we could make a dry run and come back, it wouldn’t be as frightening. Yet we must face the unknown because this is the way it will always be.

As we get older and wiser we realize how little we know about the mystery of dying, facing a great unknown. Will we not survive the last unknown? We have survived so many. Someone once told me that resurrection is looking back over your shoul-
der and saying, "My God, did I survive all that?" We die for the last time. People in hospice programs "know" how to die. Their hope is that they won't have to die alone. That is the gift of hospice.

As a chaplain of many years, the tragedy is not that people die. We know that death and life are one, that dying is a stage of life. The tragedy is that so many people die alone, even when people are all around.

We do not really help people to die. I used to stay with patients for long hours, overnight sometimes, because I could not imagine someone dying without my being there. The incredible fact was that they did. Even more incredibly, they did it quite well when I was away. We really do not help people die, but we can companion them. Many people are terribly afraid of the human experience of dying. Family, relatives, and friends stay away or come less often. When they do come, people stand far from the bed and almost have to shout to talk to the patient. Some patients with cancer feel like lepers because people do not come close anymore. They do not touch them and are less affectionate. The hospice principle of companioning people through the death experience is a tremendous gift; it does make a difference. We are people who are not afraid of dying, not afraid of standing with our brothers and sisters who are making the transition.

There are some caregiver attitudes that contribute to the quality of life of those in hospice. Learn to touch people despite all your limitations. I do not have people introduce me with my full academic or clinical background. Such background does not help us to be effective with people; it is the attitudes with which we bring ourselves into their lives that count. Be vulnerable with people. Let them see our limitations, the unanswered questions, and doubts. Of course we must not put ourselves down. We are good at what we do, but we are limited and vulnerable. Patients need us to be one with them.

A maneuver that can help us relate to hospice patients is to explore our own losses. What loss is still hurting in my life? What loss am I still working through? We spend much time helping others and often very little time ministering to ourselves. It is just as frightening for you to grieve as it is for our patients and their families. To the extent that we can explore our own losses, we achieve a better concept of what we are encouraging our patients to do.

It is important to honor the dying process as a creative venture. People find some astounding ways to die. Hawaii has some unique cultural rituals for dying. A patient in one Hawaiian hospital asked to die on the beach, not in the intensive care unit. She wanted to see the sunrise before she died. They took her to the beach; a companion stayed with her, and, as the sun rose the next morning, she died. Her's was a wonderful creative venture. In hospice we have the opportunity to help dying people be creative, to choose how, where, and with whom they will die.

How comfortable are we with mystery? Reading mystery stories could help the quality of your work. You can't read the last page first to find out how it ends because the hospice people we are working with know little about the end, other than its certainty. We need to learn to work with ambiguity and the unknown, the inability to predict. Eli Weisel (2) commented in Night: "Pray not that you will find the right answers, but pray always that you will learn to ask the right questions." Some of us don't like to live with questions. Caregivers in hospice are inundated with questions. How will I die? What will it be like? Does my family know that I'm dying? One who must have everything this way or that way, black or white, will have difficulty providing quality of life in a mysterious and spiritual reality. One attitude that helps bring quality of life is being able to live comfortably with mystery.

**Concerns of Hospice Care**

Many people do not grieve because they are ashamed to do so. Some believe that expressing grief is an unacceptable response to pain and loss. On the contrary, I believe that all grief is love. People who are grieving are people who have truly loved. We do not miss what we did not value. The selfish do not grieve because no one has meant much to them. Grief is the price paid for having loved. So as we companion with people who are grieving, a helpful attitude is to see grief not as pathological, though it can be, but as a form of love.

In hospice work we see more of life than we do death. We see people at their best. My years with persons who are dying have made me want to center my life around things that are really important. The saddest emotion to experience is regret. Family members say, "Why didn't I say this, why didn't I do that, why didn't we take that vacation, why did I work those last three years, why didn't I go to the doctor sooner." We must learn to communicate love to escape regret when we lose dear ones. We must tell those who are important to us that we love them and how lucky we are to have them. Someday they or you will die and the most sustaining attitude one can have, even though all grief, is the lack of regret. Conversely, regret is an almost unredeemable aspect of dying. We must try to help our patients finish their unfinished business to minimize their regrets.

Hospice is concerned with spirituality rather than religion. Not everybody has religious needs because not everybody has a religion. That is a personal choice. There is a part of every human being that is intangible, and every one of us has spiritual needs. Hospice is that part of health care where spirituality is validated. We must not be afraid to be involved in a religious discussion nor, out of that fear, deprive people of their spiritual needs. Death is a mystic experience, and the dying deserve companions. One night a patient asked me, "How can I believe there is a God waiting for me on the other side when there's nobody..."
waiting with me here?” You and I may be the only “God” some people will meet. We must be there.

Hospice people are those who are willing to walk some of the most meaningful miles with their brothers and sisters; those who

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are willing to walk the loneliest mile of another person’s life; those who will recognize it, respond to it, and give it dignity up to the very last moment in all of its weakness and limitations. Do you know how rare that is? Do you know how necessary that is?

Hospice people have integrated saying good-bye into a whole life’s work. I believe that God is smiling at and about them because of what they are trying to do. And She smiles, very broadly.

Certain attitudes and activities will help to bring this quality of life to ourselves. We hospice caregivers must continue to be professionals in every way. A professional is one who becomes so competent and effective that one can relax and be human. In no way does this detract from the importance of medical competence, nursing expertise, or social work skills. Yet only through true professionalism can the hospice worker relate to people effectively.

We place our humanness at the disposal of everyone, to the extent we can. That is what we’re best at. Being human means communicating warmth and sincerity, bringing gentleness, love, caring, fidelity, responsibility, and even silence into the lives of otherwise isolated people. To do so, we must minister to our own losses and grief. We all have to have support.

We won’t always get support from our families. They often do not want to hear about dying people. They will sometimes say, “If it is too hard, do something else.” Hospice workers do not want to do something else; we just need to be able to unload sometimes. One way to maintain quality of life is to find support by talking to another professional caregiver, a psychologist, counselor, or minister. We need to have someone. If we become burned-out, it will not be because of overwork but because of lack of balance. We lack balance when we give out more than we take in.

Learn to go home. Many of us in hospice care don’t know when to quit; we don’t know when to go home to our families, those people who need us even more than our patients. Our families may pay a high price for our work in hospice. Never forget that we, like the people we are companioning, have relationships, families, and loved ones.

Quality of life is what hospice is about. Quality of life is what our people seek. Quality of life is what will keep us walking with them. We must continue to help one another, to be encouraged, and to be grateful to those who help us do it better.

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