



## Opinion

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# Hospice Reflections



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## Opinion

### Death awareness

*"While I thought that I was learning how to live, I have been learning how to die."* - Leonardo Da Vinci There are many wonderful signs of love and care that we can offer to the terminally ill and dying patients as they prepare for the fulfillment of their earthly lives. These include compassionate care and presence, efforts to understand them and their near death awareness, respect for their beliefs as well as respect for their own timing of death and their convictions. All these expressions of our love help a dying patient to experience anew the beauty of human life and ease the anxiety of a journey into the new existence.

These beautiful expressions of our love are so needed at the time when dying patients experience the most intimate moments of their lives. Beside all of these though, another element of our care needs to be recognized and offered. This important intervention is the awareness of our own death. Although at first, just thinking about it may cause us some anxiety, it often becomes a bridge between us and a patient for whom death appears imminent.

When caring for a dying person, often unconsciously, we may separate ourselves from them. We often care for a patient from our own perspective of someone who is well or someone who is not aware of own mortality. We become caregivers. We are well, we are not dying, and we are able to care. It is the other person who is dying and whose life ends, not mine. Such reasoning might at times create a gap between us and the person who is dying. Although we love them and care for them, we could cause an unintentional differentiation in existential status. What might help us to bridge the gap is our own awareness of death. To communicate, not necessary with explicit language, with the patient that we ourselves are mortal and are aware of our own life as a terminal condition, brings us closer to the person who is dying at this time.

Dying and terminally ill patients often struggle emotionally and spiritually thinking about their own death or that they are the only ones affected by a terminal disease. It seems to them like the rest of the world is just fine. It is only they who are not well and

who need to leave this beautiful life. Seeing others who are not affected by dying and dwelling on their own fate may cause anger, resentment, depression and a lack of cooperation in the provision of care.

In such situations, I try to connect with patients by communicating my own mortality. It is not only them who are dying I am mortal as well. I don't know my timeline. My life may end before theirs. Life is a terminal condition and we all are affected by it. I am walking this special journey with them as an equal in status. My timing just may be different. We are not only caregivers who have a professional role to fulfill. We are also companions on this journey. Mortals whose time has not yet arrived, but who will face the same experience, only at a different time.

### Hospice - giving up or a sign of courage?

Many family members are often distressed over their loved ones becoming part of the Hospice Program. It might appear to some that making that decision is to "give up" and to surrender to the inevitable. The first thing the families are asked to realize is that Hospice is just a different approach to care. Hospice care is a part of palliative medicine. When patients become part of the Hospice Program, medical care is applied to them with the same quality and concern, although in a different way than traditional curative methods. In other words, that care focuses on the needs that arise as one faces terminal disease and are often different than those needs that arise in the pursuit of a physical cure.

For the majority of patients, a decision to become a Hospice patient is not a sign of giving up but a brave acceptance of the normal process of life. A decision to become a Hospice patient is prompted by a patient's need to prepare for the final journey. When a patient is faced with a terminal diagnosis, the dying process becomes one of the most important events in their lives. The certain physical, spiritual and emotional needs that arise may have been of less importance when a patient was not faced with a terminal condition. A patient's decision to be a part of Hospice gives the patient time to respond to those needs and to deal with the issues that are very important to him or her. Patients feel that during that special time they need to face their own mortality, find

meaning in their existence and value this special experience. What for many may appear like “giving up” is actually a brave decision to ask for special “comfort time” to prepare for death that is part of every human existence.

When a patient is faced with a terminal disease, quality of life becomes more important than any other need a healthy patient might have. To prepare for death, to mend relationships, to spend those final days in quality and comfort, to satisfy spiritual or religious needs becomes more important for the patient than to undergo treatment that does not guarantee positive results. What is important for the terminal patient is to be comfortable, not to suffer, and to prepare spiritually and emotionally for the final transition.

When a patient decides to ask for Hospice support, it is a sign of their maturity, spiritual richness and emotional sensitivity. It is also a sign of strength, clear thinking, and expression of needs that, at the time of terminal illness, are more important than other needs we may have had during our regular life. Patients do not give up but ask for special time that would allow them to prepare for the transition into a new existence. Family members who understand such needs and respect them affirm the importance of such a decision and allow patients to accept their mortality in a peaceful way. The patient also feels supported, understood and comforted knowing that their loved ones share and respect those needs.

### A look into the eyes

*During the war, a commander of occupying troops said to the mayor of a small village in the mountains: “We are certain you are hiding a traitor in your village. If you don’t give him up we will torture you and all your people with all our possible means.” The village indeed was hiding a man who seemed to be so good, innocent and loved by all. However, what could the mayor do now being threatened not only himself but the entire village? After hours of debating with the village council, the mayor asked for help from the local priest. Both the priest and the mayor spent the entire night examining Scripture and in the end found a solution: “It is better that one man die so that the entire nation can be saved.”*

*Thus, the mayor gave the prisoner up asking him to forgive him. The man said there was nothing to forgive - he would not like for the village to suffer. He was tortured greatly and finally killed. Twenty years later a prophet passed through the village, went to the mayor and said: “What have you done? That man had been sent by God to save this village. You condemned him to be tortured and killed.” “What else could I have done?” said the mayor. “The priest and I looked in Scripture, and we followed it in consequence.” “And that was your mistake,” said the prophet. “You looked in the Scriptures, but you should have also looked into his eyes.”*

This simple story by Anthony de Mello puts into so much perspective our relationships that we have with our loved ones, patients or friends. Very often our relationships are based on external facts, motivated by religious requirements or simply taken

for granted. Don’t we catch ourselves doing something via routine, mechanically or offering someone what we want or are able to offer instead of what the needs of our loved ones are? Don’t we, like the priest and the mayor of the story above, council different “scriptures” instead of opening our hearts with compassion and understanding? To really understand the needs of people dear to our hearts, we need to look into their eyes! To look into the eyes of someone we care for with humility and genuine interest will enable us to see the feelings and movements of their hearts; to stop with patience and observe someone will allow us to better understand someone’s heart instead of an external behavior. It is so easy to miss “a savior” in our midst!

In our professional ways of dealing with others, we are often tempted to lose our human side. We act as a parent, a spouse, an older brother, a priest or a mayor. What is often needed is to be another human being with the same problems, similar situations, similar weaknesses and with the same inability to make things work. Such an approach is especially needed in our relationships with terminally ill patients. When we go through the process of death, we do not need as much expertise in Scripture or medical knowledge. We need to be able to look into their eyes and see in them a “savior,” a friend, a human, a loved one.

### Let me be free

Several times I have witnessed, in my hospice ministry, dying patients who take off their clothing. It causes embarrassment to the family, especially when such actions were never before experienced with the patient. To see our own parent uncovering in a time when ways of communication are closed by terminal restlessness, dementia or anxiety causes distress and emotional pain.

There may be several reasons for such actions, e.g., a skin disease or rash that irritates the patient physically. It could also be caused by terminal restlessness. Another reason, that often is missed, could be a spiritual one. There are several references in different holy texts that refer to being born with nothing and leaving this earth with nothing. Often, those texts use the word “naked” to describe the meaning of being not contaminated by the materialism of an earthly existence. When we are born, we come into this life in the most natural way. We are not covered with anything. Although it is necessary for survival, a newborn’s skin is actually irritated by blankets or clothing in his or her first few minutes of life.

When a patient is dying, he or she might see a cover or clothing as a barrier that separates him or her from the non-material world that person is about to enter. Transferring into a new, perfect reality prompts feelings of being “emptied, stripped.” The patient might feel the need for purification. Everything that is part of this material world might be seen as a “contamination” of that perfect state. Clothing and sheets become part of a patient’s existence. They are the patient’s “property.” Taking them off constitutes a readiness to meet with the Creator in a most perfect

physical state, without anything that could separate us from Him. It is a desire to return to the original perfect state; to return to God the same way in which we were born.

Taking the clothing off during the dying process is not about being naked. It is about being completely free of any material thing. When a patient is dying there might be so many things happening in their heart and mind that are invisible to us. When we die, we enter into a new reality, a new dimension that cannot be grasped by those who are not a part of it. We might force people to do things that we think are appropriate. As the patient leaves this earthly existence, their understanding and vision of things might be completely different than ours. That vision might prompt certain behaviors that cannot easily be understood by us. We need to be sensitive, trusting and able to stretch our minds to at least allow ourselves the knowledge that there are occurrences that transcend our understanding.

### How much longer?

A hospice experience very often proves how amazingly strong our bodies are and how they can survive without sources of nutrition or hydration. In many instances, hospice patients continue to live for days or weeks without food and water. When a patient is admitted to hospice, a physician or hospice staff member might predict an approximate time of death by observing natural disease progression as well as signs associated with the dying process. Physical signs like cold and bluish extremities, increased fever, changes in skin color, shallow breathing, etc., are indicators of approaching death, according to science.

There are times, however, that despite the presence of these indicators, patients continue to live for a long period of time. It is quite challenging to offer any scientific answers as to why that happens. The prolonged dying process very often puzzles families and makes them wonder if there is something to which a patient clings. There might be several spiritual factors as to why this happens.

We all are created in a beautiful way where body and spirit harmoniously make us a human being. During the dying process, spiritual needs intensify while the functions of our body diminish. Although the body might not have many needs during the dying process, some patients need time to spiritually prepare for their journey toward fulfillment and perfection.

A common reason for prolonged dying might be a need to complete unfinished business. A patient might be waiting for a visit from a relative that is dear to his or her heart. The death will not occur until that person visits and has had a chance to spend time with the dying patient. Some patients wait for verbal permission to die. They might be concerned about the future of their relatives and will wait until they are assured of their well being. Some other patients need to prepare for their encounter with their Creator. That time might serve the patient as a certain purification or “fusion” with their God. Other patients will wait until they receive their religious, near death rituals, e.g., the sacrament of anointing celebrated by a priest.

I also believe in a theological reason for a prolonged process of dying that is based in Christian tradition. Patients may be invited to participate in God’s redemptive mission. They may be called to “go an extra mile” in order to offer their pain, suffering, and prolonged dying to aid others in need. In that way, God uses everything they go through and applies it to different people and situations around the world. In a mystic way, a patient’s prolonged dying becomes a means of help, redemption and alleviation of pain and suffering for others. Although the results of a patient’s mission will not be known to us in this life, its effects will be revealed in the life to come. I personally believe that even a patient who spends his or her day in bed, who is not able to communicate or do anything, makes this world more beautiful with their presence. Their silent suffering, inability to communicate or understand, or prolonged dying may do much more in God’s economy than the many supposed accomplishments of our own busy days.

Although, in many instances, the family members don’t want patients to suffer and would like them to die in a naturally short time, we need to remember to respect a patient’s own dying process. It is important for a family to give the family member patient permission to die, yet families need to let that family member know that they respect their timing. To allow a patient to “take time” is as important as to give them permission to die.

Finally, we need to remember that many things that are real to a dying patient are invisible to the rest of us. We need to respect their visions, statements, and behaviors allowing them to be our guides through their dying process.



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