Finding Value and Dignity at the End-of-Life

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Jan’s Story
I was visiting a young female patient with end-stage breast cancer at her home. I’ll call her Jan. She was thin, emaciated, and weak - limited to her bed and the bedside commode, which was two steps away. Her previously long brunette hair was gone, as were the strong athletic legs and arms that had characterized her years as a college tennis player. “I’ve lost my dignity, Dr. Avery,” she sobbed, “I never thought it would happen to me . . . but I’ve lost my dignity.”

Questions
Every hospice purpose is to help every one of its patients face their death with dignity. Hospice websites are filled with expressions like “dying with dignity” and “living to the end with dignity”. But what does “dignity” mean? What was Jan telling me and how could I help her?

A Definition
According to the Oxford English Dictionary, dignity means “the quality of being honorable or worthy; true worth, excellence”. In other words, dignity consists of those qualities or characteristics that make us feel we are valuable or worthy. Perhaps Jan was simply saying, “Dr. Avery, I don’t feel I am valuable anymore”. And who could argue with her? Looking at things on the surface, Jan was no longer the supportive enthusiastic wife, the tennis player with a great serve, the hard-working loving mother, and the efficient businesswoman that she was only six months ago. Had Jan lost her dignity - her value? To answer this question, we must divide this concept called dignity into two categories – “attributed dignity” and “intrinsic dignity”.

Attributed Dignity
Attributed dignity is the value or worth that is given to us from others or from oneself. Because it is given to us by others or by oneself, attributed dignity can be taken away or lost. Examples are our appearance, prestige, income, abilities, productivity, possessions, or even our control over a situation. In Jan’s case, she used to feel valued because of her luxuriant hair, her abilities in tennis, her roles as a wife and mother and businesswoman, and simply in her ability to walk to the bathroom unaided. Her advancing breast cancer was taking a terrible toll upon her by robbing her of these things.

The stark reality for all of us to keep in mind is that Jan’s situation, though sad, is not a rare situation – all of us will die someday. Terminal diseases relentlessly tear down many of those characteristics and qualities that have constituted our attributed dignity. The dying person often loses her hair and her job. She becomes weaker and cannot enjoy simple activities – even walking to the mailbox may become impossible. She loses
weight and her clothes become ill fitting and awkward. Friends may avoid her. Families may become condescending. Her independence is lost. She suffers innumerable losses of modesty and control at medical facilities. Sometimes she will need help eating and drinking. She may even need help going to the bathroom and with bathing. Influence, power, and control slip away.

Despite heroic efforts to resist, terminal diseases wield a sharp ax and take out huge chunks of our extrinsic dignities. Of course, some people suffer more of these indignities during the dying process than others. But the truth is simple; all of us will die and most of us will face the sharp metal of the ax at the trunk of our dignity. Bob Dylan described his search to define and find dignity in a 1991 song appropriately called *Dignity*. Here are the last two stanzas of that song:

*Someone showed me a picture and I just laughed  
Dignity never been photographed  
I went into the red, went into the black  
Into the valley of dry bone dreams*

*So many roads, so much at stake,  
So many dead ends, I’m at the edge of the lake  
Sometimes I wonder what it’s gonna take  
To find dignity.*

Dylan seems to be saying that his search for dignity led him to the edge of the lake: the place of the unknown - the edges of life. Perhaps he is saying that dignity is to be found at the edge, at the border between life and death – which is where sickness and dying reside. Dylan showed a lot of insight for this was precisely the place where I learned to better understand dignity – sitting and listening at the bedside of my dying patients.

**Intrinsic Dignity**

When we fully embrace and acknowledge the harsh realities of the human journey, I can almost understand why the “Death with Dignity Act” is the name of the law in Oregon that legalized physician-assisted suicide. I assume that the well-meaning supporters of this law were saying that we should let a person out of “the life contract” when there are too many attributed dignity losses. It is the premise of this article that hospice is the dignified answer to this reality of lost dignities. And that leads us to the second type of dignity, which Daniel Sulmasy calls “intrinsic dignity”. **Intrinsic Dignity is the dignity or value or worth that we know every person is deserving of, equally, regardless of his or her station in life.** We all view a human being as more valuable than an ant. Why? It is ingrained in all human cultures, that every human being has worth and value that is incomparable with other living things. Look at some of the statements in these international documents:

Universal Declaration of Human Rights (1948): “. . . the inherent dignity and of the equal and inalienable rights of all members of the human family”
The preamble to the Charter of the United Nations (1945): "We the people of the United Nations . . . reaffirm faith in fundamental human rights, in the dignity and worth of the human person."

Basic Law of Germany (1949): “human dignity is inviolable. To respect and protect it is the duty of all state authority.”

But let’s make it more personal. Hopefully, all of us would agree that a man who is rich does not have more value or dignity than a man who is poor. I don’t think anyone would say that a man who has a lighter color skin has more dignity than a man whose skin is darker in color. Or that a man who is 6’10” tall has more dignity than a man who is 5’10” tall. We say this instinctively, intuitively, because dignity is something we understand as being enjoyed by all persons. This is what we call Intrinsic Dignity - the value one has simply because one is human, a member of the human family. Once you understand and consciously embrace this principle, then it becomes clear that it is not up to any individual to decide what constitutes the intrinsic value of any human being – including the individual himself or herself.

Although terminal disease mounts a relentless attack on extrinsic dignity, it can’t touch the intrinsic dignities. Suddenly the sharp ax is dull – its’ blows are weak and ineffectual. Dr. Sulmasy tells, in one of his books, the lesson that Martin Luther King, Jr. learned from his grandmother. She told him, “Martin, don’t let anyone ever tell you that you’re not a somebody”. Her point was that everyone is somebody. Everyone has equal worth – whether they are black or white, rich or poor, healthy or sick, confused or clear thinking, powerful or powerless, newborn or near the end of life. As Daniel Sulmasy wrote, “You pick up the homeless schizophrenic from the street for the same reason you pick up the Wall Street executive from the bathroom floor – intrinsic dignity”.

Intrinsic dignity by definition involves those qualities or characteristics that cannot be taken away. Dr. Viktor Frankl, who had virtually everything taken away from him as he languished in a Nazi concentration camp, addressed these dignities in his book, “Man’s Search for Meaning”. Some of the values that Frankl felt could not be taken away included religious faith, one’s chosen attitude, one’s integrity, one’s love of others, the love of God, and one’s hopes in the afterlife. The key fact is that these cannot be taken from us – regardless of the circumstances of our life – not even in a Nazi concentration camp.

The Role of Hospice
Having been a hospice physician and taken the final journey with countless patients and families, I know that dying inevitably raises questions about one’s worth and value. The goal of hospice is to help people deal with these very real issues. Patients receive visits from a nurse, a counselor/social worker, and in some programs a chaplain. The hospice team works hard to help mitigate the extrinsic dignity losses of a dying patient and their family. We do this by helping to control pain and other symptoms, by honoring patient choices, by assisting patients and families with their social and emotional losses. At the same time hospice tries to bolster the patient’s sense of their own intrinsic dignity by
validating, reinforcing, and demonstrating that they have value and worth and are
deserving of honor.

I have found that the process usually goes something like this. As the extrinsic dignities fade (as they inevitable will for everyone), certain questions naturally arise. As one loses one’s hair from chemotherapy - am I more than a pretty face? As one loses the ability to work – am I more than a lawyer? As one loses the ability to generate an income – what is my worth and value to my family now? As one loses the ability to walk and toilet – am I a burden to my family? And these questions will often lead to further questions: Is this all that there is? What is life about? Did my life have value? Will anyone remember me? Will my death have value? If there is an intrinsic value to my life, what is the source of this value? Can such a belief be validated? All of these final questions, even if not asked or addressed in a religious framework, are spiritual. That is why it is imperative that the hospice program you chose provides an opportunity for the patient to receive a visit from a chaplain and that all members of the hospice team are knowledgeable about and can address spiritual pains.

Cicely Saunders, the founder of the modern hospice movement, said, “Soul pain is reached and healed by the way care is carried out.” As we tenderly dress the bedsore of a patient with Alzheimer’s or gently help change the bed sheets in a patient with cancer or patiently listen to a sad and lonely widow tell the story of her life – we are affirming and validating the value and dignity of that person. When a health care professional, like a nurse or a physician or social worker, pray with a patient, he or she is confirming that the patient is more than a disease – more than a simple collection of cells and atoms.

**Autonomy**

It is important to note in the context of dignity, that one aspect of granting dignity is allowing an individual to make his or her own choices and determine his or her own life journey. Some patients may elect to not grapple with the questions listed above. For example, many hospice patients refuse a visit from a hospice chaplain. Some patients may believe that there is no intrinsic value to human life. Your hospice provider should respect patient autonomy and go with them on the journey to the end showing consideration for and honoring their choices.

**Back to Jan**

*When Jan, our breast cancer patient from the beginning of this article, cried saying that she had lost her dignity, I told her, “Jan, you can never lose the dignity that is within you – it is something that can never be extinguished”. Then, the hospice team and I reinforced this truth to her by carefully treating her pain and nausea, by helping her husband and children cope, by listening to the hopes and dreams she had for her children, by giving her tender loving care, by praying with her at her bedside – by simply valuing and honoring her as a member of the human family.***

If you are interested in reading more about these concepts of dignity, please consider reading any number of books or journals by Dr. Daniel Sulmasy. I would particularly recommend two: *The Healer’s Calling*
and *The Rebirth of the Clinic*. There are plenty of articles by Dr. Sulmasy available for free on the Internet also. I am indebted to him for much of the content of this.