Death and dying: what the patient wants†

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A good death and a death with dignity may be achieved when death is congruent with the personal values of the patient. It behooves the practitioner to recognize these values and to cater to them. This paper describes effective communication with the dying person, and the partnership of the treatment team, patient and family in face of the patient death. To identify and define the patient wishes it is necessary to learn how to interpret the patient’s non verbal as often patients are unable to formulate the questions they wish to ask concerning their passing. These difficulties stem from several cultural factors including concern about disturbing the practitioner. It is the treatment team’s responsibility to facilitate this discussion. A good death is achieved when symptoms are controlled and when patients and family recognize death as a unique living experience to be treasured as any other living experience. A death with dignity brings healing, that is always possible even when cure is out of reach. Patient’s and practitioner’s values may be at odd in face of controversial issues including euthanasia, assisted suicide and terminal sedation. Though he/she should not be compelled to execute these requests, the practitioner should be able to entertain an open discussion with the patient concerning these issues. Open communication and reflective listening even in presence of disagreements are the venue of healing. The study of death and dying requires novel approaches including personal narrative and qualitative research to complement traditional research instrument, such as questionnaire that cannot embrace the whole human dimension.

**Key words:** end of life, wishes, value history, healing, reflective listening

**a tale of two patients**

‘Nobody tells me anything!’ complained Mr Jones once more. I dreaded his room during the morning round. Food was always rotting on his night table, close to a half-full urinal; his pyjamas had not been changed since he entered the hospital 1 month previously; he might not have shaved for a week; and his hair was oily, long, and unkempt. More than by the filth and the smell, I was mortified by the conversation that sounded as disagreeable as a broken record. Every morning I repeated to him the same message: his stomach cancer had gotten worse, no chemotherapy could help him, and we were waiting for his brother to make arrangements to care for him at home. After my five-minute talk he would invariably comment: ‘Nobody tells me anything,’ looking at the empty space.

That morning I decided I had enough. I sat on the side of the bed, overcoming my repulsion for the soiled sheet, grabbed his hands, compelled him to look me in the eye and I told him: ‘What I try to say to you Mr Jones, is that you are going to die very soon, maybe in the next couple of weeks, and nothing or nobody can prevent your death.’

The following morning I found a completely changed landscape. Mr Jones had shaved, and cut and washed his hair, he had changed his pyjamas, the room had been cleaned, the bed sheets were fresh from the laundry, and the whole room smelled like fresh air. A young woman, half of his age, was sitting on the bed, holding him and kissing his cheeks. We never figured out who she was. Officially Mr Jones had been divorced and childless.

‘Hi doc!’ he greeted me with his best smile, ‘How are you doing this morning?’

He was discharged to his own home where he died 2 weeks later under care of his unidentified girlfriend.

Reverend Smith came to see me with his spouse. The pastor of a major Universalist church, he held two doctorates. He was elegant and well groomed as befits a community leader. During a regular check-up his blood count turned out to be low, a finding that prompted a bone marrow examination and led to the diagnosis of poor prognosis myelodysplasia. He insisted that I told him how long he had to live, though I had explained that I would have preferred to have an independent confirmation of the diagnosis prior to committing myself. When I told him ‘I don’t believe you will be around more than a year’ his wife started crying, ‘I don’t want you to die’ she kept saying between hiccups. The good reverend himself had had hard time to keep his peace; his hands were shaking and his color had turned grey. ‘Are you sure, doctor?’ he asked after he had regained some type of composure and his spouse paused her crying to get some breath. ‘Reverend, as I promised, I am not sure of anything, medicine is far from a perfect science and every patient is different. We learn something new every day! What I was saying is that if the diagnosis is correct, more than
80% of the people with your disease are dead in 1 year. I have no way to know now whether you will be among the 20% that survive longer.’

They left the room looking at the floor with a barely audible ‘goodbye’. Unhappy with my comments they looked for a second opinion with another oncologist that convinced them that he might have had a more prolonged survival. One week later he called me with a paternal reproach as it fits a minister of a God we call father: ‘Doctor, you dropped a bomb in our household the other day. My wife did not sleep and barely ate anything for three days. If you don’t mind the recommendation of an old and experienced man, for the sake of your patients, you need to learn how to talk to them.’

These two cases are the proper introduction to the article I am asked to write, as they are emblematic of the difficulty of finding out what a patient really wants when faced with his/her mortality.

Mr Jones craved clarity. Confused by my talk of ‘cancer progression’ he wanted to know how long he had to live and why he was wasting his scarce and precious time in the hospital if no more treatment was planned. He did not know how to ask the proper question and he was obviously scared to antagonize the doctor and the health care team. This confusion affected his demeanor and his countenance. He felt like a man carried adrift by a current without goal or destination. When I leveled with him and communicated to him his prognosis in terms he could understand, he got hold of his life again: he knew what to expect and what to plan for. In other words, I re-instituted to him his dignity, i.e. his ability to run his own life to his liking even in the context of the limited choices left to him. Dignity derives from the Latin ‘dignus’ that means ‘worthy’. As long as my talk skirted the subject of his death he felt as a human being deprived of the right to make his own choices, i.e. deprived of dignity. By making him free to control his life again the brutal truth had restored his dignity.

Another important aspect of his story is the fact that he was ready to receive the news of his imminent death, once that it was conveyed in plain terms. For him a ‘good death’ meant a death he could manage even in the context of pain and discomfort.

The case of Mr Jones occurred more than 30 years ago, when the hospice movement was just starting, and the home health care resources were more limited. Then, a terminal disease justified hospital admission for terminal care. At that time it was very controversial whether patients should be told about their impending death, and my indirect reference to death when I talked about cancer progression and ineffective medications was more than most of my colleagues would muster. I remember another oncologist that routinely said to the incurable patients ‘You must be patient and give time to the medicine to work’ until the patient became comatous or ‘Now we are going to give you a break from chemo so that you can regain your strengths before we hit you with chemo again.’

I learned a number of durable lessons from Mr Jones that include:

- To look at the patient’s demeanor and non-verbal communications. Mr Jones’ unkempt appearance, his monotonic complains about lack of information, his inability to establish eye contact should have told me that he was so confused that he had lost all self-respect and any confidence in his interlocutors.

- The meaning of dignity. ‘To die with dignity’ was already a common slogan, but dignity was referred mainly to some objective findings that included unnecessary intrusion into a person’s body (respirators, catheters, intravenous lines), as well as cleanliness and freedom from discomfort. Mr Jones taught me that the medical system may deprive a person of his/her dignity when it deprives a person of the ownership over his/her disease. The source of the patient’s dignity is the restoration of this ownership to its fullness. The external aspects of death are important because they reflect this interior condition of ownership that we may want to call ‘spiritual’.

- There is a time when a person becomes ready to receive the news of an imminent death. As the case of Reverend Smith demonstrates this time is difficult to gauge. More than on the patient’s own words, the experienced practitioner should rely on the patient’s behavior. The only way to gain and maintain a patient’s trust is to deliver the message as soon as the patient is ready and in a way that is congruent with the patient’s emotional and spiritual condition.

- To my surprise I learned that there may be such a thing as a ‘good death’ [1, 2]. Prior to meeting Mr Jones I had avoided the thought of death. I shared the impression that Elizabeth Kubler Ross expressed at the beginning of her career that no person can think of ‘his/her own death’ [3]. Now I came to recognize at least one condition of a good death, i.e. a death on which the patient is allowed some sort of control.

The case of Reverend Smith reveals the uncertainty that hovers concerning the time of communicating a message of imminent death. Despite his statement to the contrary the reverend was not ready to receive the bare truth, which is understandable in more than one way. Unlike Mr Jones, who had been practically bedridden for months and had been slowly fading away, the Reverend had no symptoms. He had no opportunity to become adjusted to his disease. Unlike Mr Jones, Revered Smith was a worldly person with a number of social commitments that extended well beyond the year of life I had given to him. Like a CEO with pancreatic cancer of whom I took care and who told me until 2 months prior to his death ‘Doctor, I am going to beat this’ at each visit, Reverend Smith was not ready to surrender his life and his life achievements without a fight. Should I see him again I would probably be more careful in my choice of words, though in no circumstances would I lie. I would say something like ‘It is virtually impossible to predict a person’s time of death, especially for a person in excellent clinical condition as you are. With proper treatment which includes both blood transfusions and medications you may be able to live few more years. I would, however, get my things in order, because some patients with your disease may develop acute leukemia that is generally fatal.’

The main lessons to learn from Reverend Smith case are

- Countenance and non-verbal responses are always more meaningful than the patient’s own words. I should have
understood from his appearance and his attitude that the Reverend was not ready to die without a fight.

- Each message must be personalized, i.e. adapted to a person’s circumstances. I restored Mr Jones’ dignity in announcing to him his death. In some way I dismissed Reverend Smith’s dignity when I failed to consider in my message his position in the world and his own mission. Somehow I disowned him once I announced to him his death, without considering the repercussion that his death would have had on the wealth of activities that represented the current source of his own dignity.

Both cases show the difficulty in conducting clinical research on the issues of death and dying. The patients’ own statements concerning their desire may be unreliable, and some patients would refuse to participate, to sign the informed consent to the study simply because they are not ready to accept that they are dying. One should also add the difficulty to predict the time of death in the terminally ill patient [4–6], and the existential/spiritual variables that may influence the quality of death [7]. Not surprisingly, most of the studies on death and dying are based on personal experience as well as qualitative research [8, 9], as the externally validated research instruments are relatively few [7, 10, 11].

The analysis of our two cases revealed three constructs that are paramount to honor the patients’ wishes. These include: a communication congruent with the patient’s expectation that is based on a ‘value history’ [12, 13]; the meaning of a ‘good death’; and of a ‘death with dignity’.

value history

The enunciation of a person’s existential values has two essential and distinct roles in palliative care.

The first role is to establish how a patient wishes that his/her death be managed. That defines the conditions in which each patient wishes that any form of intrusive life-supporting treatment be instituted, continued or withdrawn. Ideally this discussion should occur before the death is imminent and with a practitioner that has a long familiarity with the patient [14, 15]. This approach would avoid the emotional overtones and conflicts likely to emerge when the end of life is imminent. In any case the focus of the discussion should be to support the patient’s autonomy in a multicultural society to take the decision that best fits his/her values and desires.

The second role is to provide all possible emotional and spiritual support to a patient close to death. I found it particularly important to find out whether the patient has some unfinished endeavor that he/she feels it has to be completed prior to death. Once I took care of the chief of a disbanded tribe of American Indians with metastatic prostate cancer who confided in me that the main goal of his life was to finish writing the history of his tribe that would have been completely lost with his death [16]. Together we decided to forgo chemotherapy that might have prolonged his life of a few months but would have prevented him to complete his book by causing fatigue, nausea and other distracting symptoms. Likewise, the exploration of one’s personal value may help restore a sense of positive narcissism [17], i.e. of personal self-esteem that may be lost in face of disability and discomfort. Once I ministered to a young man, a talented violinist desperate because he was dying at 18 from metastatic sarcoma [16]. The exploration of his past life with the hospital chaplain made him realize he had been endowed with unique talents that had left a perennial imprint on this earth and had gained him love from a dedicated girlfriend who accompanied him throughout to his death.

Another important resource is represented by a patient’s religious and spiritual beliefs [17, 18]. The discussion of these beliefs may lead to the acceptance of death and even suffering as a unique living experience that should be treasured as any other living experience [18, 19]. Many patients come to realize that the way they die is the way they will survive in their loved ones. In addition, the presence of a religious community, such as a church, may provide important material resources for the assistance of the patient and his/her family.

Last, but not least, a value history is also important for the support of overstrained home caregivers [20, 21]. A review of the literature revealed that spiritual and religious resources were beneficial to the self-esteem of the caregiver, and reduced the burden of caring for terminally ill family members. In the Christian tradition caring for a dying person is interpreted as caring for the dying Christ himself. In the Moslem and Jewish tradition caregiving is a specific commandment to honor one’s elders.

a good death

The idea of a good death is not new. For example in Italy the ‘Confraternita per la buona morte’ [Confraternity for a good death] has been operating since the 1600 and has promoted a religious-assisted death and prayers for the dying and the dead. However, this association and other similar initiatives emphasized the Christian construct of death which is not applicable to a secular and multicultural society.

One of the first models of ‘a good death’ was proposed by Emanuel and Emanuel [1] and included in addition to freedom from pain and suffering patient’s awareness of the incoming death and patient’s ability to make decisions related to the imminent death, including the ability to direct one’s treatment and ability to restore broken relationships, by granting and receiving forgiveness. All existing models of a good death involve the patient’s ability to decide what actions are important for him/her at the end of life, in addition to being free of symptoms, receiving appropriate information concerning his/her condition, and respect of his/her privacy [8–11].
The Quality of Dying and Death questionnaire (QODD) [10, 22] is probably the most utilized instrument to assess the quality of death and may thus be considered emblematic of the construct of a ‘good death’. It explores six domains with 31 items (Table 1). At least three of the domains – time with the family, whole person concern, and treatment preferences – emphasize that autonomy, personal relationships, and personal concerns are critical to a good death. This statement could be also phrased by saying that spiritual elements are critical to a good death.

At this point it is important to emphasize the difference between pain and suffering, and the spiritual nature of suffering [19]. The International Association for the Study of Pain defines pain as: ‘Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ [23]. Suffering is a personal experience that includes but is not limited to the awareness of one’s pain [19]. Suffering may be caused by symptoms different from pain, such as dyspnoea, nausea or fatigue. Most important, suffering may be independent from physical symptoms and may be caused by the inability to appreciate the reason of one’s pain, as well as the meaning of one’s living experience. This type of suffering, that we may call existential or spiritual suffering, is particularly common when a person has to face his/her own mortality and may lead to desperation and suicide if it is not properly addressed. In the USA, hospital chaplains receive a very special training called Clinical Pastoral Training [24] that enables them to minister to patients of any religions as well as to those without religious beliefs. Any health care personnel should be able to identify spiritual and existential suffering and refer the patient to the proper specialist, i.e. the hospital chaplain.

### death with dignity

It may sound self-evident that a good death is a death with dignity, as all models of a good death emphasized patient’s autonomy as central to a good death. It is worthwhile to mention that some investigators have tried to define dignity in operational terms [11] and to propose ‘dignity therapy’ as a psychotherapeutic intervention at the end of life [24]. Based on a validated model of dignity (Table 2), Canadian and Australian investigators asked terminally ill patients to discuss the issues that most were concerning them. Sessions were recorded, transcribed and edited and the final version was returned to the patients who could bequeath them to friends and family member. Some 91% of patients were satisfied with this intervention, 76% reported increased sense of dignity, 68% increased sense of meaning and 81% felt that their experience would be helpful to their family.

In my view, dignity therapy allows the patient to see their death as a unique living experience to be treasured and bequeathed. While the emphasis of a good death was symptom control and personal peace, the emphasis of ‘death with dignity’ is on the unique value of the dying experience, and is this value, that can be shared with one’s loved ones, that confer to the dying patient a unique dignity.

### areas of controversy: euthanasia, physician-assisted suicide, and terminal sedation

If the patient autonomy is central to end-of-life care, should a practitioner honor a request for euthanasia or assisted suicide? The arguments in favor of these practices vary in their scope [26]. Some physicians believe that to deny this option to a dying patient is tantamount to desertion in times of need. Others prefer to skirt the ethical issue and take a more practical approach: since some forms of euthanasia and assisted suicide are practiced daily, in the shadow, it would be safer for both patients and practitioners to establish clear rules related to when and how these interventions should be implemented, I believe that the first argument is flawed as it fails to take into consideration the autonomy of the practitioner. Nobody will ever deny that the patient is entitled to refuse whatever intervention is proposed, but it is much less clear whether the patient is entitled to ask for interventions with which the practitioner disagrees. You are entitled to refuse the course of action proposed by a lawyer, but the lawyer is

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**Table 2.** Factors involved in maintenance and restoration of dignity

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<th>b) Dignity-conserving repertoire</th>
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<td>1. Dignity-conserving perspectives</td>
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<td>- Psychological</td>
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<td>- Medical uncertainty</td>
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<td>b) Dignity-conserving repertoire</td>
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<td>- Living in the moment</td>
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<td>c) Social dignity inventory</td>
<td>2. Dignity-conserving practices</td>
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**Annals of Oncology symposium article**


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entitled to refuse to take the course of action you propose if he/she feels that it would be ineffective, detrimental to his/her professional name, or contrary to his/her integrity. This is true for every profession. Why should it not be so for medicine?

The second argument has merits as it is inspired to the principle of lesser evil. A lady, who is also a well-known physician, reported how her father shot himself after discovering that he had terminal prostate cancer. The family members who loved him had to carry two burdens for the rest of their lives: the gory scene of the suicide and the pain of having been excluded from this terminal determination. If physician-assisted suicide had been available the patient might have been able to communicate with his family without concern of being restrained and his death might have occurred in a much less dramatic context. He might have peacefully died in his own bed, surrounded by his loved ones and maybe he could have even received religious or spiritual comfort.

As I said, I respect this argument and I believe that in borderline situations, where the management of pain, discomfort or anxiety may hasten one person’s death the practitioner should always err on the side of compassion and implement an intervention that may ultimately end a patient’s life. This position is based on the ‘two effects’ principle. The goal of the intervention is to restore a patient’s comfort and this is legitimate. Death is an acceptable and accepted side effect as it would be for virtually any medical intervention. Personally, however, I like to offer to the reader two reasons to oppose the legalization of euthanasia and physician-assisted suicide.

The first reason is that as physicians we are duty-bound to preserve life. The American Medical Association code of ethics prevents a physician from participating in an execution, even when physician participation might relieve the suffering of the person condemned to death, because termination of one’s person’s life is seen as antithetic to a physician’s duty. For the same reason, to hasten a patient’s death appears incompatible with a physician’s duty. And really, if these practices become legal, why should they be carried out by physicians instead of properly trained ‘death technicians’ who chose freely this profession?

The second reason is that euthanasia or suicide are tantamount to a declaration that a life is not worth living, i.e. a denial of the personal dignity we are determined to uphold. There is an intimate contradiction in the ideas to use ‘dignity therapy’ from one side to highlight the unique value of the dying experience and to hasten a person’s death because that person’s life seems to have lost any value once that death becomes unavoidable.

I offer these arguments as the beginning of a dialogue on the issue, of course, not as conclusions. Terminal sedation involves the use of medications to blunt a patient’s consciousness and relieve terminal pain [27]. There are two forms of terminal sedation. One is not controversial and is applied to a conscious person after withdrawal of life support, to blunt the related symptoms that include air hunger or chest pain. Controversial is instead the use of terminal sedation in the presence of existential suffering, i.e. when a patient is emotionally unable to face his/her imminent death.

collection

This review demonstrates that the practitioner of oncology should be involved in the treatment of the dying patients. The primary role of the practitioner is clear and compassionate communication of the patient’s prognosis, congruent with the patient’s own values and with the degree of acceptance the patient has gained of his/her death.

The physician as part of a multidisciplinary team should also facilitate a good death by relieving the common symptoms of a terminal disease and by honoring the patient’s autonomy in the pursuance of the treatment that best fits his/her desire. The physician should also be familiar with the issue of existential and spiritual suffering and involve the chaplain in the management of that type of suffering.

Finally the physician should face controversial issues including euthanasia, assisted suicide and terminal sedation, and develop a personal position on these issues based on one’s ethical principles and personal values.

disclosure

The author declares no conflict of interest.

references


