

## TRADITION, HERITAGE AND SPIRITUALITY

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# Beyond Quality of Life: the Meaning of Death and Suffering in Palliative Care

Lodovico Balducci

### Abstract

The majority of patients treated for cancer will have pain at some point in their journey. Suffering and death are common events in cancer patients. Palliative care has been very successful in reducing the discomfort caused by physical pain, but does not have the means to address the questions related to the meaning of suffering and death. The soothing of physical pain has helped highlighting other forms of pain, such as spiritual and existential pain, that uniformly accompany the terminal phase of the disease. Health care providers should be able to identify existential and spiritual pain for several reasons. First, because misdiagnosing these conditions may lead to inappropriate use of opioids and sedatives and may deprive both the patient and the patient's family of the experience of death as an essential and irreplaceable experience of life. Second, because spiritual and existential pain may be addressed by properly trained professionals that should be involved in the management of the patients when needed. Chaplains and spiritual directors have no lesser role in the management of a patient than a cardiologist, a surgeon or a psychiatrist. Third because clinical scientists cannot close their eyes in front of one of the most common human experiences falling under their domain. Lack of training and of full understanding is a lame excuse for skirting the suffering of a person dying under our eyes. Health care providers unwilling or unable to abandon their areas of comfort and to embrace new and risky experiences are a liability for themselves, for their patients, and for the society they serve. Both spiritual and existential pain address the basic questions of human consciousness: while are we alive? Why do we die? Spiritual pain is most commonly experienced by a person who has a religious or otherwise sense of transcendence and may be helped by a hospital care trained chaplain. Existential pain is more typical of a person uninterested in a transcendent context and may be more challenging to address in the health care context. Though both may produce emotional pain, neither is by itself a form of emotional pain and cannot be fully cared for by a counselor. The clinical definition of spiritual and existential pain is evolving and so is its treatment. Classical clinical trials have little to offer for these conditions. Qualitative research in its various forms, including open ended questions, content analysis and mainly personal narrative are the most promising forms of research to comprehend spiritual and existential pain.

**Keywords:** Cancer suffering - palliative care - existential pain - spiritual pain

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### Introduction

The preservation of quality of life is seen as the main goal of patients receiving palliative care. The assessment of Health Related Quality of Life (HRQOL) has become usual in all forms of medical practices, including oncology. The acceptance of HRQOL assessment as a clinical tool should be credited with restituting to medicine the focus on the person (Granda-Cameron et al., 2008). One of the lasting consequences of this process has been the awareness that the whole personal experience cannot be circumscribed by questionnaires no matter how much detailed. Together with and beyond physical and emotional comfort, the person and especially the person affected by serious diseases needs to find the meaning of his/her suffering and his/her impending death. He or she needs to

reconcile him/herself with a past populated by regrets, mistakes, guilt and rancor. In other words, physical and emotional comfort are interwoven with the existential experience of the person, with a form of existential distress that no drugs or soothing words can alleviate (Puchalski et al., 2009).

In this article we contend that one way to address existential distress in a terminal patient is to lead this patient to recognize and accept the meaning of personal suffering and death, and in the process we explore novel instruments to recognize and address existential distress.

This contention is based on the assumption that death is unavoidable. If death is the ultimate enemy, we all are doomed to failure as all of us are going to die. Rather than avoiding death, accepting death as part of life is a basic human need and a strategy to conquer death. The

*Chief, Division of Geriatric Oncology, Senior Adult Oncology Program, Department of Interdisciplinary Oncology, University of South Florida College of Medicine, H. Lee Moffitt Cancer Center & Research Institute, Tampa, FL, USA \*For correspondence: Lodovico.Balducci@moffitt.org*

Biblical book of Qoeth had highlighted this simple truth 2500 years ago: "There is a time to be borne and a time to die...." This consideration is particularly relevant today, when one is able to manage his/her own death, and decide when the time has come to let death to take over. We suggest that the quest for personal meaning, rather than personal comfort is the compass guiding this decision. Human history is full of examples of individuals who have sacrificed their comfort, their wealth, and sometimes their very life to achieve a goal important to them. This may include becoming accomplished artists, athletes, professionals or missionaries. Thus, near death situations offer a unique opportunity to demonstrate how quality of life considerations should be complemented by considerations on the value and meaning of life, in medical decisions. We'll start the presentation with a clinical case.

## Clinical case

The young violinist. At 17 John was diagnosed with rhabdomyosarcoma of the leg. Despite surgery, radiotherapy and aggressive chemotherapy, by age 18 his cancer had recurred and had invaded both his lungs. After the failure of experimental treatment, we let him know that he would have died in the next few months. Both he and his mother who was a widow and had no other children appeared lost even more than depressed or desperate. I believe the holocaust victims must have felt that way when they were separated from their family and herded toward their ultimate fate over cattle trains. All of a sudden they were taken away from all familial surroundings and led toward the unknown in an uncomfortable and perilous journey, having lost all attributes that they had learned to identify as humans.

The hospital chaplain started paying daily visits to John. As John and his family were agnostic and had no church affiliation, he did not even try to mention the name of God. Instead, he asked the patient to think back to his brief personal history and to extract out of it the moments he considered more meaningful, the times he had felt best and worst about himself. John was a promising young violinist. For his fifteenth birthday his mother had bought him a very expensive instrument, that had allowed him to take part in regional performances, with remarkable success. Before his cancer recurred he had been scheduled to participate in a National competition for young musicians in Chicago. During his performances he had felt both distressed and fulfilled: distressed because he had not reached yet the flawlessness he aspired to, fulfilled because he had realized that perfection was within his reach. He was aware to have a unique gift that would have enriched the world, he had identified what he was good for. This sense of fulfillment was reinforced by his girl friend, a 19 year old freshman in college who had attended one of his performances and let him know she considered it a privilege to accompany and assist him in his journey to excellence. The awareness of a unique vocation and mission also gave meaning to the humiliation he had suffered during childhood and adolescence. In primary school his schoolmates had conjured against him: they considered him a nerd with weird tastes and joined him

only to make fun of him. He had been regularly excluded from other children's game and from party invitations. Indeed, trying to overcome his isolation, his parents had invited fifteen kids to his tenth birthday party and only his two cousins showed up. The girl with whom he had his first sexual encounter at age 14 mocked him when he could not contain his orgasm and made fun with the coeds of his "lean dick." Close to death he had no problem to call back these painful memories he had suppressed for a long time. In the light of his accomplishment as a violinist, the rejection of his coeds appeared as a necessary consequence of being uniquely gifted. He realized that his deeper fulfillment derived from what he was able to give to the world rather than from what he was able to take from others.

The exploration of his life, led by the chaplain, operated a progressive change in the attitude of John and that of his mother. The daily visits to his room had become more prolonged and relaxed. Immediately after his cancer recurrence his eyes had avoided mine and his answers had consisted of barely hearable monosyllables. In the following days his countenance had changed to that of a proud host showcasing his home for his guest. He started questioning me about my family and my work and once commented that I looked tired and I should have taken some time off. Before he died surrounded by his mother, his girl friend and few like minded friends who had enjoyed his music, he made the following comment: "The last year of my life has been the most fulfilling and meaningful. Through dying I could appreciate my unique mission in this life and feel to a full extent the depth of love by which I have been surrounded; these discoveries have redeemed all the pain I had encountered in my life."

John's history underlines how meaningfulness and creativity supersede comfort and possessions when it comes to personal fulfillment. The case illustrates how personal riches consist of what one is able to give to the world rather than of what one is able to take from it. When he could revisit them at the light of his later accomplishments, the defeats of his earlier life appeared to John as a welcome price to pay to discover and develop his unique vocation; he did not begrudge them anymore. Pain becomes fully acceptable and welcome when one can understand its sense.

In addition, the proximity of death allowed John to enjoy his life fully, in his own words. Thanks to death he had been able to distillate out of life what really had mattered to him, like the few drops of rose essence extracted from thousand of Bulgarian roses that keeps alive the perfume of the flowers for years after they have gone. I like to compare John's journey toward death to that of a traveler who is allowed only 12 hours to visit Rome and decides to go to the top of the Gianicolo hill, from where he can get a global vision of the city and can select the monuments he really cares to see. In that way his visit can be unhurried and his impressions of the city lasting.

As a personal note, John's death was very consequential to me in two ways. First, he rekindled my own religious faith. I don't know whether John ever encountered God, but I gained a feeling of God and

eternity in the progressive acceptance of his own death. The essence of his life involved two steps: the simultaneous acceptance of his sacredness and of its emotional toll. This twofold acceptance allowed him to die in peace, despite extreme discomfort from progressive air hunger. I could not help seeing the essence of John's life as lasting and imperishable, I could not help seeing in his death an encounter with eternity, that is with God.

Second, he and his girl friend overturned my perception of sexuality. Despite their inability to have intercourse during the last year of his life, by their own testimony they enjoyed intimacy more than ever, as they lay together in his hospital bed. I too had been the butt of my coeds' jokes, because of my sexual inexperience, and throughout my whole life I had felt haunted by the pressure to mount a satisfactory performance for my partner. Through John I finally understood what my loving spouse has tried to tell me since the beginning of our marriage: relax! This is not a context or a school test: let's enjoy each other as we are.

John's history shows how death and suffering may become an opportunity to find oneself. With the help of the chaplain he could isolate and enshrine the most consequential aspects of his life, those that made life worthy of living for him. His decaying quality of life that would have been scored very poorly by any of the instrument of common use, had not been an impediment to find lasting peace in contemplating the ultimate sense of his life.

### **Analysis of the Case of John**

The year has been 1976. The hospice movement in the USA was in its infancy; most of the patients received terminal care in the hospital and we, the physicians knew very little about the management of pain and discomfort. John experienced both severe pain and dyspnea in the last couple of weeks of life. By any HRQOL instruments, his HRQOL must have been terrible. Yet he died in peace with himself and with the world, confident to have left a small but inerasable print of himself

What did the proximity of death do for John? First of all, death allowed him to appreciate his own life. The balance between his unique talents and the suffering and ostracism he endured because of them was highly positive. Not unlike a mountain climber enduring all types of deprivation to reach a summit, he recognized that the persecution he has suffered by his peers was the unavoidable price to assert himself, to leave a unique print on this world.

Second, death and suffering allowed him to taste the sweetness and to experience the power of human bondage. Those of us who have experienced the relief of a sip of iced water after running a marathon in the sun know what I am talking about. The devotion of his girl friend that lied by him and hold his hands when he started Chaine Stoking represented a more lasting and meaningful relief that that afforded by an aerosol of morphine administered by a foreign respiratory technician, fearful of looking into his eyes.

Third, John experienced the privilege of being cared

for. The friendly competition of his mother and his girl friend at his bedside told him that his suffering was not in vain. Rather than a burden he was perceived as a unique opportunity to provide care by the women of his life. They discovered the gift of being caregivers, they let him know that they had discovered in themselves unexpected and untapped riches of caring, thanks to his suffering and his death.

Another way to express the same concept is that John, and through him his girlfriend and his mother discovered their own sacredness. Derived from the Latin sacer that means "reserved" for a special function that only that particular person can accomplish, sacredness implies that each and every life is consequential, because each life has been endowed with a unique mission and a unique vocation. The concept of sacredness is strictly linked to the concept of "sacrifice" from the Latin "sacrum facere" that means "to render sacred, reserved, unique." As an example, in a marriage a couple makes a "sacrifice" of their sex, that is "reserve" their sex to each other, and in that way they find a final, unique meaning to their sexual expression. The opportunity to make a sacrifice of one's own life is the opportunity to discover one's own sacredness. John found his own sacredness at the time he had to abandon his life: by dying he realized and accepted his life as a sacrifice of his talent to the world surrounding him. The last sacrifice of John was that of the pain and humiliation he had suffered for being "different" from the other kids. At the meantime, the people caring for him recognized their own sacredness as "caregivers" for John. Together they discovered the meaning of the world redemption. In ancient Judaism, the redeemer was the person who paid the debts of a family member to prevent him and his family from being sold into slavery. The humiliation of his early life had been redeemed by the emergence of his art; the suffering of his agony have been redeemed by the care of his girl friend and his mother. At his death, John has been able to say with the country priest of Bernanos, drowned from the blood hemorrhaging from his stomach cancer "qu'est ce que cela fait? Tout a grace!" "no matter what everything is grace (Bernanos)".

The case of John represents also an opportunity for health care providers to define their role in ministering to sick and terminal patients. A recent convention on medicine and spirituality, summarized in reference 2, recommended that all people involved in the medicine, from the physicians to the housekeeper be instructed on recognizing spiritual and existential distress, so that the patient may obtain a proper referral to a chaplain or a spiritual director experienced in the management of this condition. In the last part of this paper I will try to highlight what we know and what we need to know about spiritual and existential distress.

### **Health Care Provider Roles in the Management of Spiritual and Existential Distress**

The case of John had a happy ending because the chief of oncology at the Center where I trained had invited the chaplain to make round with us, and because that particular chaplain had been trained in clinical and pastoral care.

Without the presence of the chaplain during the daily round none of us would have even thought of referring John to a chaplain, given his professed agnosticism. If he had not been trained in clinical pastoral care, that chaplain probably would have not been able to minister to John's need. He would have probably recused himself or made an unfruitful attempt to bring John back to his denomination of Christianity.

The case of John had a clear message for health care providers. The diseases, especially those that threaten one's life, elicit concerns that are beyond the physical and emotional domain. These concerns, if unresolved, represent a stumbling block to the achievement of healing, the condition of peace with oneself that is always possible, even when cure is out of reach (Byock, 2009). Contribution to a person's healing is a well established and cherished duty of every health care provider.

Clearly healing implies awareness of a spiritual/existential dimension (Puchalski et al., 2009). It is not clear at this point whether existential and spiritual discomfort are separate entities or two faces of the same. Spiritual distress may have close correlation with ethics and religion, while existential distress may originate by one's inability to define the meaning of life in rational and emotional terms. An example of spiritual distress is that of a woman who had an abortion when she was younger and feels that the disease is God's punishment, while an example of existential distress is that of a man or a woman that witness the faltering of their enterprises as a result of the disease and ask themselves whether all of their work was in vain. Irrespective of these nuances, it is clear that spiritual/existential distress may cause an emotional pain that cannot be soothed by medication or psychiatric intervention.

After diagnosing spiritual/existential distress, the next step involves the referral to the proper specialist, that ideally is a clinical-pastoral trained chaplain. If he or she feels comfortable in doing so, the practitioner may engage the patient in a discussion of his/her problems, aware of one's own limitations. Unlike a chaplain, a physician or a nurse have no authority in matter of religion and spirituality and may be wiser in providing understanding rather than recommendations. In my opinion understanding and compassion may extend to the point of participating in prayers or other religious activities upon the patient's request. In any case judgment should be avoided at all cost. I still remember with disgust a cigar smoking psychiatrist that walked in anger out of the room of an American Indian woman calling her a "religious fanatic" because she was distressed by her husband's vasectomy that was not congruent with her Roman Catholic faith. In the absence of a properly trained chaplain or spiritual director, the provider should acknowledge the problem and try to allow the patient to find his/her own answers.

The practitioner may be involved in the management of existential or spiritual distress in the case of a dying patient, if the patient or the family ask for the administration of the so called "terminal sedation (Quill et al., 2009a)." This practice involves either the relief of terminal suffering from physical symptoms, such as pain

and air hunger, which is not controversial, or the induction of a condition of sleepiness with sedatives in a patient unable to face the incoming death. This second aspect of terminal sedation is highly controversial and in my opinion is rarely justified, and never justified without a previous attempt to address the patient's concern that are causing this terminal distress.

Clearly, the practitioner needs to be in touch with his/her own spirituality (Puchalski et al., 2009) to be able to deal with spiritual and existential distress. While religious faith cannot be mandated, familiarity with different beliefs in a multi-ethnic society is essential for any medical person, the same way that it is important to learn how to communicate bad news with simultaneous truthfulness and compassion (Quill et al., 2009b). One cannot expect the patient and their families to treasure one's death if they are not properly prepared to it (Rio-Valle et al., 2009).

Finally it is important to ask what kind of instrument one can utilize to study existential and spiritual distress. Clearly questionnaires are inadequate for this purpose. Qualitative research and especially the patient's own narrative may represent the clue to appreciate this important and elusive aspect of medical care (Morton et al., 2010). With the description of John's case I tried to provide an example of how narrative may highlight the most compelling aspects of a medical history when it comes to existential/spiritual distress.

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