

Editorial

Thinking Outside the Box: Depression, Hope, and Meaning at the End of Life

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Introduction

I met Jacques three years prior to his death (Jacques was not his real name, but I think the panache and elegance of this alias would have both pleased and suited him perfectly). His Head and Neck surgeon had referred him to me for a psychiatric consultation, six months following a base tongue resection and left neck dissection due to a squamous cell carcinoma. The consultation request contained descriptors such as depressive symptoms, sleep disturbance, and a general request for further follow-up and treatment; for all intents and purposes, a typical—even generic—consultation request for someone in my line of work.

The surgeon's note covertly suggested that there were several key issues needing to be addressed. Was Jacques clinically depressed? Did his symptoms imply the presence of a psychiatric syndrome? Would diagnosis lead to the recommendation of a specific treatment? Cause, effect, response, and outcome: all reasonable questions within the context of a contemporary medical, psychiatric model. In this case, cause being the assault of a life threatening, disfiguring cancer; effect being a likely diagnosis of a clinical depression; response, the possible prescription of a well-chosen psychopharmaceutical; and outcome, the hope or wish that Jacques would be able to carry on, or at the very least, face his future with some degree of equanimity or hope.

This model or paradigm has obvious merits, and has benefited multitudes of patients. In contemporary psychiatric practice, the Diagnostic and Statistical Manual of Mental Disorders, currently in its fourth edition (DSM-IV), has had a tremendous impact on patient care and our ability to describe human behavior.¹ It has also deeply affected, for better and worse, those practitioners who apply it. Models, like boxes, provide a neat and readily available place to put things. Eliciting symptom descriptions, accurate diagnostic labeling, and targeted therapeutic interventions, can each serve the cause of promoting quality patient care. There is, however, a comfort level in being able to categorize, label, pigeonhole—file and save—that can sometimes contaminate or even supercede the often more nebulous task of coming to a real appreciation of the patient's inner experience.

Looking Beyond Depression

Understanding Jacques' inner life, and a sense of the complexity of that inner life, extends far beyond the question of whether or not he was depressed. During the time I knew him, there were indeed periods when he seemed to benefit somewhat from the antidepressant trials I initiated; in

response to a pervasive depressed mood, occasional feelings of hopelessness, loss of interest or pleasure in most things, and feelings of guilt over perceived past indiscretions, it seemed a reasonable therapeutic maneuver. Palliative care researchers have tried to sensitize the field regarding the importance of understanding psychiatric morbidity that can arise among patients with life-limiting diseases.²⁻⁷ The past decade has seen studies that have examined how to apply standard diagnostic approaches for depression among dying patients, prevalence studies of psychiatric disorders in this vulnerable patient population, brief screening approaches to help clinicians identify depressive syndromes in palliative care settings, and relatively few interventional studies looking at psychopharmaceutical and psychotherapeutic applications for depressed patients nearing death.

The source of Jacques' angst, however, was far more difficult to influence, compared to the task of adjusting his doses of Paxil, or closer to dying, methylphenidate. Up until his cancer diagnosis at the age of 72, Jacques had been a professional classical violist. Music had been the center of his life, and the viola, his only chosen life partner. His career had seen him play with all the great orchestras of the world and befriend many of the world's finest musicians. One would describe him, as I envision the cover photograph from his last CD, as suave and dashing; a full head of dark hair combed straight back, clean-shaven, black tuxedo and white cravat, cradling his beloved viola, his gaze cast forward. His illness sequelae included some mild facial disfigurement, a long and hard struggle to learn to manage his own secretions, and total reliance on enteral tube feedings for the remainder of his days. These bodily assaults paled in comparison to the assault on his core sense of self or spirit. His cancer surgery involved the resection of the left base of his tongue, removal of the adjacent neck strap musculature and spinal accessory nerve, and a radical forearm free flap from his non-dominant hand to reconstruct the surgical deficient. Although right-handed, his left hand—the hand he used to finger the world's complete repertoire for the viola—soon developed loss of dexterity due to forearm strictures, finding him no longer able to play music. The session in which we discussed his decision to send his viola out of province for safekeeping had the quality of planning a funeral for one's only true love. I recall him saying, "My doctor tells me my prognosis is good for the future. What future?" Up until the end, he teetered between contemplating suicide (while never taking any measures to hasten his death) and trying to hold on to the remnants of those few things that still mattered.

Stepping Outside of the Box

The euthanasia and assisted suicide debate has unwittingly moved forward the genre of psychiatric palliative care research. Trying to understand why some patients might lose the wish to go on living has seen researchers extend beyond the conventional DSM-IV paradigm, and look at sources of distress that have informed the field of palliative care.⁸⁻¹¹ Several independent groups, for example, have confirmed the dominance of depression as a predictor of desire for death, or interest in physician-assisted suicide.^{8,12,13} Those same investigators have also looked at the construct of hopelessness, and found it to be an ardent predictor of a wish to die, even among patients close to death.^{8,14,15} In this issue, Dr. Ben Zyllicz of the Netherlands argues that in a country where euthanasia and assisted suicide are legal, exemplary palliative care is particularly important in staving off hopelessness and the wish to end one's life.

Within jurisdictions where death-hastening measures are legal, researchers have helped us understand the various factors that can move patients toward life-terminating measures.¹⁶⁻²² As one might expect, depression and pain figure prominently, but constructs such as being a burden to others, loss of sense of purpose, meaning, and hope, and notably loss of dignity all emerge as significant forces that can move patients toward a hastened death. Clearly, an honest engagement of these issues requires that palliative care clinicians and researchers conceive of ways to expand, if not

step well outside of a too-narrowly defined model of end-of-life care.

The need for a broad and inclusive model of palliative care is further supported by the observation that symptoms relating to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms among those with life-limiting conditions.²³ The Institute of Medicine recently released a report entitled, *Approaching Death: Improving Care at the End of Life*.²⁴ The domains of quality supportive care they identified from a professional perspective include: 1) overall quality of life; 2) physical well-being and functioning; 3) psycho-social well-being and functioning; 4) spiritual well-being; 5) patient perception of care; and 6) family well-being and functioning.¹⁷ Singer and colleagues reported the domains of supportive care which were found to be most important from the perspective of cancer patients include: 1) receiving adequate pain and symptom control; 2) avoiding inappropriate prolongation of dying; 3) achieving a sense of spiritual peace; 4) relieving burden; and 5) strengthening relationships with loved ones.²⁵ Moadel and colleagues surveyed 248 cancer patients and asked them what their most important needs were. Nearly half indicated they needed help overcoming fears, finding hope, meaning in life; finding peace of mind and finding spiritual resources.²⁶ A national survey by Meier and colleagues found that "loss of meaning in life" was a reason highly cited by physicians as to why patients request assisted suicide.²¹ Clearly, from the vantage point of professionals and patients alike, acknowledging and addressing issues such as meaning, purpose, and hope needs to be included within the realm of quality end-of-life care.

New Boxes

Broadening the paradigm, expanding the model, finding new boxes, call it what you will, but within palliative medicine, there is evidence that this has started to happen. For example, Kissane and colleagues have proposed "demoralization syndrome" as a diagnostic entity within palliative care, with hopelessness, loss of meaning, and existential distress identified as its core features.²⁷ They suggest that this syndrome can be differentiated from depression, and is associated with chronic medical illness, disability, bodily disfigurement, fear of loss of dignity, social isolation, and—where there is a subjective sense of incompetence—feelings of greater dependency on others or the perception of being a burden. Because of the sense of impotence or helplessness, those with the syndrome are thought to have a propensity to progress toward a desire to die or commit suicide.

Over the last five years, our group has been studying the notion of dying with dignity, in an attempt to understand what supports, or conversely, what undermines the dignity of a patient nearing death.²⁸⁻³⁰ These studies led to the development of a model of dignity in the terminally ill, which incorporates physical, psychological and spiritual, and social aspects of the illness experience (Illness Related Concerns, Dignity Conserving Repertoire, and Social Dignity Inventory, respectively). Each of these broad categories contains sub-themes that further elucidate components of a broadly based, empirically validated dignity-conserving model of end-of-life care. Besides including issues pertaining to hope, meaning and purpose, the model suggests that dignity concerns can be multi-factorial. For example, for some patients, a sense that nothing of one's life will be transcendent of death—a concept we labeled generativity and legacy—was experienced as an assault on dignity. For many patients, maintained dignity was highly dependent on how they perceived themselves to be seen. Therefore, supporting the perception that patients maintain their sense of worth, as affirmed by those who care for them, is a powerful dignity-conserving strategy.

The Dignity Model in the Terminally Ill also provides the theoretical foundation for a novel, brief, individual intervention we have coined dignity psychotherapy.²⁹ Dignity psychotherapy is currently the focus of an international feasibility study, being piloted with palliative care patients in Winnipeg and Ottawa, Canada, and Perth, Australia. This intervention incorporates those facets from the

model that are most likely to bolster the dying patients' sense of worth, purpose, or meaning. Patients are offered the opportunity to speak to issues they hold to be most important, such as recounting aspects of their life they feel proudest of, things they feel are or were most meaningful, the personal history they would most want remembered; or words they might provide in the service of helping to look after their family and friends, such as hopes, wishes, or directives for those they will soon leave behind. Because of the importance of generativity as a significant dignity theme, dignity psychotherapy sessions are taped, transcribed, edited for clarity, and quickly returned to the patient. The creation of a tangible product that will live beyond the patient acknowledges the importance of generativity as a salient dignity issue. The immediacy of the returned transcript is intended to bolster the patient's sense of purpose, meaning, and worth, while tangibly experiencing their thoughts and words as continuing to be valued. If shown to be effective, this will be one of the few new nonpharmacological interventions for suffering or psychosocial distress that so often arises among dying patients.

Meaning-Centered Group Psychotherapy

The work of Dr. William Breitbart has been seminal in the field of psycho-oncology and palliative care.^{3,4,13,15,31,32} The studies published by his team have provided crucial descriptive data regarding the nature of depression, delirium, pain, and other various sources of symptom distress commonly seen in patients with life-limiting conditions. What is perhaps most notable about his recent work featured in this issue of *Innovations*, is the evolution toward interventional studies targeted at enhancing spiritual well-being among patients with advanced cancer.^{33,34} The novel intervention they have coined meaning-centered group psychotherapy is based on the concepts and principles of Viktor Frankl's logotherapy.³⁵ Frankl's work raised awareness regarding spiritual issues and the importance of meaning or the *will to meaning* as a driving force or instinct in human experience.

Frankl's logotherapy was not designed for the treatment of those with a life-threatening illness. Nevertheless, Breitbart and colleagues have incorporated these concepts of meaning and spirituality into their psychotherapeutic work with advanced cancer patients, many of whom seek guidance and help in dealing with issues of sustaining meaning, hope, and understanding impending death in the context of their lives. Clearly, meaning-centered therapies are not a panacea for all sources of suffering, nor are they likely to be applied effectively to everyone. Patients will vary in the degree to which they experience their angst in terms of lost meaning and hope, and enthusiasm for new approaches should not distract us from paying close attention to depressive disorders and cognitive limitations (including pseudodementia). In some instances, these conditions may render meaning-centered approaches ineffective, while in others they may be applied as an adjunct to more conventional psychiatry interventions. That having been said, the incorporation of interventions such as these will not only address a vital therapeutic need, but will broaden the model of palliative medicine that will enable it to provide dignity-conserving care for patients—and their families—facing death.

Conclusions

I last saw Jacques a few days before he died. He was in the hospital at the time, vaguely confused but nevertheless aware of who I was and that I sensed his recent, grave deterioration in health. During our last visit, I was thinking about the notion of Jacques' dignity, and the extent to which preconceived models or boxes had failed to encapsulate the full extent of his suffering. I recall the presence of a nurse at the foot of his bed, attending to charting or some such mechanical task. Turning to her, I said, "Did you know that Jacques was a professional musician? He played viola with all the world's finest orchestras and musicians, including the likes of Leonard Bernstein,

Herbert Von Karajan, Jean-Pierre Rampal, Vladimir Ashkenazy, and Glen Gould." (I must admit, those that I could not remember I simply made up.) The effect was immediate and, I thought, profound. Jacques broke out in a full body blush, and a smile his face could barely contain. Later that morning, I overheard his nurse sharing the impressive details of Jacques' glorious past with one of her colleagues. He was no longer simply an elderly male with an oral malignancy and secondary complications, admitted for palliative care, but someone deserved of honor, respect, and esteem—words corresponding to the definition of dignity itself.

Not every patient necessarily has an account of former glory. Yet every patient, without exception, has a past, a story— something that ultimately and uniquely defines who and what they were or continue to be. Dignity-conserving care, in part, is comprised of being able to identify and acknowledge those fundamental and defining aspects of personhood. Seeing patients for who and what they are or were, profoundly enhances their quality of end-of-life care. This will require care staff to be trained and sensitized to appreciate the importance of their own perceptions toward patients for whom they care. Helping patients to find a sense of purpose, meaning, and dignity requires us to step outside of the box and develop a model of palliation that incorporates the patients' experience in its entirety. By so doing, palliative medicine stands to accomplish so much more, and patients nearing the end of life deserve nothing less.

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