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Dignity and Meaning in Supportive Care

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Editorial

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Successfully completing our 16th year of publication

With the publication of volume 16, issue 6, we are celebrating 16 years of continuous publication of *Palliative and Supportive Care*. We've succeeded in providing a high-quality international journal that publishes Original Research, Reviews, Case Reports, as well as Personal Essays and Poetry that address the existential, spiritual, psychiatric, and psychosocial aspects of palliative and supportive care. We have been privileged to publish high-quality manuscripts from a highly diverse and broad range of investigators and clinicians from all over the world. We have grown significantly in number of submissions, impact factor, visibility, and as a home for research and clinical contributions that expand the psychiatric, psychosocial, existential, and spiritual domains of supportive care.

An examination of the table of contents of volume 6, issue 6, demonstrates the breadth and of the subject matter featured in *Palliative and Supportive Care*: bereavement, caregivers, families, survivors, communication, symptom control, cancer and non-cancer medical conditions, cultural issues, end of life care decision making, measure development in supportive and palliative care, health care provider needs, and finally intervention research in palliative and supportive Care. Over the years, we've published research on interventions focusing on music therapy, art therapy, pharmacotherapies, and perhaps most frequently, interventions that have focused on dignity and meaning. Our two lead articles in the focus on two novel adaptations of meaning-centered psychotherapy (Breitbart 2010, 2012, 2015, 2017, 2018) and dignity therapy (Chochinov 2002, 2011; Chochinov et al., 2001a, 2001b).

Existential interventions in end-of-life care: if all you have is a hammer, everything looks like a nail

In the fall of 2004, I was a visiting lecturer at the Institut Curie in Paris. I gave a lecture on our newly developed psychotherapy intervention for advanced cancer patients, meaning-centered psychotherapy, which we had just begun to conduct clinical trials on. I spent time with the clinical psycho-oncology program clinicians and had a feedback session with the psycho-oncology research faculty and postdoctoral fellows. It was a busy day, made quite tolerable by the hospitality of my host (Professor Sylvie Dolbeaut) and the frequent coffee breaks that included pastries and macarons from Laudron. My final session was a 2-hour case conference with the clinical palliative care service. The chief of the service was a highly experienced leader of palliative care in France. The case presented was quite challenging and had a number of both psychiatric and existential care issues. At one point, I asked the chief of the palliative care service what he felt his role was in the care of terminally ill cancer patients. He responded without hesitation: "My role is to assure that no patient dies with uncontrolled pain or uncontrolled physical symptoms that can cause unnecessary suffering." I nodded in agreement. "Yes, of course. This is essential."

I agreed that it was difficult to address any existential issues in a patient who was in uncontrolled pain or physical distress. A discussion of any depth or sufficient duration would be impossible if pain was not controlled to some degree. Pain and physical symptom control was basic and necessary before one sought to deal with perhaps more ambitious issues of end-of-life task completion or acceptance of a life lived/acceptance of death. I asked, "So would you also see your role as a palliative care clinician to help a patient engage in end-of-life task completion, or acceptance of death, or achieving some sense of a meaning coherence to the trajectory of their life?" He looked at me with an expression that I interpreted, perhaps incorrectly, as one of a bit of hostility defensiveness. "No, of course not! This is the work of the clergy." A bit of a surprising answer since the French are typically strict about the separation of church and state and often do not allow clergy to interfere in medical care. "But, did you know that the vast majority of terminally ill patients want to discuss these issues with their physicians and healthcare providers?" I informed him. He had no response other than to repeat that this was not the role of the palliative care physician.

I realized that the lack of his willingness to see these existential issues as a domain of care for which palliative care clinicians were responsible was not really his fault. It was my fault. It was the fault of my entire field of psycho-oncology, of psychiatric and psychosocial palliative care clinical researchers. We had not yet developed, tested, and disseminated the existential

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interventions that could be used by palliative care clinicians to intervene in this area of suffering in the palliative care setting. My palliative care colleagues had opioids and other drugs to effectively treat and control pain and other physical symptoms, so naturally they focused on what they had the tools to treat. We had not given them tools to treat loss of meaning, loss of dignity, or a way to help patients approach death with a sense of peace and equanimity. All they had was a hammer (e.g., opioids) and so all they focused on to treat were nails (e.g., pain). I promised him that help was on the way. That there was a group of us, around the world, who were hard at work developing interventions that addressed these existential issues, and that someday these would be tools that could be used by palliative care teams to expand the focus of adequate palliative care beyond a focus on pain and physical symptom control to include the psychiatric, psychosocial, spiritual and existential domains of palliative care. It took us a few more years to complete the randomized, controlled trials to demonstrate efficacy, and to train clinicians around the world and disseminate interventions such as dignity therapy and meaning-centered psychotherapy around the world. And clearly the work is not completed. We have much more to do. And so many have joined the effort to expand and innovate upon this initial work, and create new novel interventions, as well as cultural adaptations. We've been proud to publish much of this work in the pages of *Palliative and Supportive Care* over these past 16 years.

Meaning and dignity: are they two different constructs?

Harvey Chochinov and I have been friends for 32 years. Our friendship started in 1986 when I completed my fellowship in psycho-oncology with Dr. Holland at Memorial Sloan Kettering Cancer Center and joined the faculty as a new attending psychiatrist. Dr. Chochinov and I had a date with destiny. He was assigned to be supervised by me: my very first fellow at Kettering Cancer Center. This began a great friendship as well as an intellectual collaboration that has lasted through today.

We had similar backgrounds despite being born and raised in two different countries and cities thousands of miles apart. We shared the need to understand human suffering and the human experience. Our research interests paralleled each other's through our entire careers. And in the early 2000s, we both found ourselves immersed in trying to develop interventions that addressed existential despair. Dr. Chochinov focused on the concept of dignity and methods to conserve dignity. I was inspired by the work of Viktor Frankl and began to focus of meaning and an intervention aimed at re-creating, sustaining, or enhancing a sense of meaning in patients with advanced cancer. We had thousands of conversations about our work and sometimes collaborated in an effort to help our individual ideas and interventions move forward. It was an exciting time for both of us and our research laboratory colleagues. The result is the availability now of two evidence-based, efficacious interventions for existential distress and despair in patients with advanced cancer. Dignity therapy and meaning-centered psychotherapy have both now been replicated, adapted, translated into multiple languages, disseminated, and used in palliative care settings around the world.

Dignity and meaning. Are they two different constructs or do they represent elements of the same construct? I've given some thought to the differences, partly because I get asked that question almost every time I lecture about meaning-centered psychotherapy. My sense is that they are in fact two distinct constructs or concepts, but are both essential to the experience of suffering and the nature of human existence. I see meaning as both a cognitive and experiential construct, Human beings need to believe that "My life has meaning." Human beings also need to "experience meaning in their lives through connecting to the world through love and engaging in the world through who we are and the impact we have in the world." I sometimes describe "joy" as the emotion of meaning, and "beauty" as the adjective of meaning. So meaning is a belief and a feeling. I see dignity as a somewhat different construct, perhaps a social construct in which the "value" of a person is perceived by the world or by the person themselves. It is a matter of being treated with respect, as a human being worthy of respect, worthy of being valued; valued by one's self and by the world one interacts with. It's a matter of the sense that one's human essence is intact, even in the face of physical degradation by illness or socioeconomic, political, and cultural circumstances. Dignity and meaning converge around the concept of "attitude." In an advanced cancer patient who has lost multiple physical functions and independence, there is a state of loss of independence that can lead to shame. Our imperfections, losses, and mortality itself can lead to shame or loss of dignity or loss of meaning depending on the attitude one takes toward their self-worth, toward their sense of being worthy of unconditional love (and forgiveness).

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