JOURNAL OF PALLIATIVE MEDICINE
Volume 19, Number 8, 2016

DOI: 10.1089/jpm.2016.0251

What Makes Us Whole?

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> We began to realize that for our existence to hold any value, it must end. To live meaningful lives, we must die and not return. The one human flaw that you spend your lifetimes distressing over … Mortality is the one thing … Well, it's the one thing that makes you whole.
> —Number Six, *Battlestar Galactica*

When I met MC he was 28 years old, and despite his great height, he could not have weighed more than 115 lbs. He had a venting gastric tube to resolve the acute symptoms of his complicated upper gastrointestinal obstruction. I came with the support of my full interdisciplinary palliative care team—a palliative care certified social worker, a chaplain, a nurse practitioner, and myself as the physician on the team. His distress was palpable when we entered the room. He was sitting in bed silently crying while his mother stood silently by the bedside looking out the window at the snow-covered mountains to the west of us. He started explaining that he had done everything asked of him, extensive complex surgeries, chemotherapy, and surveillance after treatment. He could not wrap his head around how or why he now sat here in this hospital bed, metastatic disease consuming his frail body, unable to tolerate even a sip of water.

We talked together for more than an hour. We listened, we empathized, we validated, and we grieved. We came back. Every time I saw him, I had the benefit of at least one other team member. To sit in the presence of his profound existential and spiritual distress was humbling, challenging, and exhausting. He often asked about physician-assisted suicide (not legal in Colorado). At one point, he made a comment about the other services involved in his care—oncology, hospital medicine, and gastrointestinal medicine. He noticed that they could not get out of his room quickly enough. It is easy to understand why. All too often, we as healthcare providers are poorly equipped and inadequately trained to assess and support the spiritual suffering of our patients.

The literature suggests that the medical team provides significant spiritual support only 25% of the time for cancer patients.[1] Yet, evidence suggests that spiritual support from the medical team can have an important impact at the end of life. When cancer patients perceived adequate spiritual support by the medical team, patients reported higher quality-of-life scores near the end of life. Patients who reported high religious coping and had their spiritual needs met by the medical team also had higher rates of hospice use and less aggressive care at the end of life than patients whose needs were not met.

Key recommendations from a 2009 consensus conference on spirituality in palliative care prioritized that all medical providers should be trained to conduct a basic spiritual screening and to recognize spiritual distress in patients who would require specialty chaplaincy care.[2] Robinson, et al. in this month's issue of *JPM* present their findings from a one day elective spiritual generalist training program for interdisciplinary health professionals.[3] Attendees included medical, nursing, social work, psychologist, and child life specialists. The training focuses on the use of experiential simulation opportunities for observation and practice for challenging conversations. In addition to the evidence-based curriculum and focus on an interdisciplinary approach, this research has some additional key strengths. The self-reported skill ability after the training demonstrated improvement over baseline immediately after the training and remained significant three months later. The largest gains were seen in the areas of spiritual screening and developing a basic spiritual care plan, aligning with the core consensus panel recommendations. Despite the limitations of this research, self-reported assessment, and self-selection for the training, authors have developed and tested a training that has a potential for scale similar to the model of Oncotalk®.

The field of palliative care research in spirituality and existential distress remains in its infancy. This is at least, in part, due to the challenges of obtaining funding to pursue this research. Focused funding opportunities in the form of Request for Applications or Program Announcements (RFAs) from the Veterans Administration or National Institute of Nursing Research could drive the field forward. Although the American Psychosocial Oncology Association incorporates the distress associated with spiritual or existential suffering within their core mission, other specialty associations such as the American Heart Association and American Thoracic Society should also advocate for the importance of addressing spiritual distress. Developing and testing interventions that address spiritual and existential distress should be at the forefront of this research agenda, for the current tested interventions are limited in their efficacy and scalability.[4] Promising, theory-based interventions such as Dignity Therapy demonstrated subjective value and improvement, but did not have a significant impact on validated measures of dignity, meaning, and distress.[5] This may have been due to a ceiling effect for participants had very low baseline distress. Later smaller trials showed some improvement but effects extinguish. Meaning-centered psychotherapy demonstrated significant improvements in measures of distress, some of which are sustained.[6] However, results are not easily generalizable as enrollment rates were very low and drop-out rates very high, suggesting that the time-intensive intervention may not

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be easily scalable or accessible to most patients. A potentially promising avenue of research combines some of the meaning-centered work of Breitbart and a single dose administration of psilocybin (a purified extract of the psychedelic mushroom) in cancer patients.[7] This intervention is both brief and scalable, and with publication of results from the two Phase 2 trials, we will learn whether there is preliminary objective evidence of the effectiveness and whether those effects are sustained.

What I had to offer to MC was empathy, compassionate listening, and, in lieu of physician-assisted suicide, the assurance that palliative sedation was an option if his suffering became unbearable. MC eventually was discharged from the hospital to home hospice. He remained obstructed and despite his hope to enjoy a single bite of a Big Mac©, he remained intolerant of any intake by mouth. I took comfort knowing that he would have the ongoing spiritual support through hospice care. I hope he found a sense of peace in his last days of life.

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