Spiritual Care as a Fundamental Component of Quality Palliative Care Gets a Major Boost

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As we celebrate the birthday of Dame Cicely Saunders who would have been 92 years old this week (July 22, 1918 - July 14, 2005) it is fitting to focus on a core concept of palliative care, that of ***Total Pain***, particularly spiritual pain. Although the bio-psycho-social approach in medicine traces back to the 1950's, when George Engel, MD who was later on the faculty of the University of Rochester School of Medicine, began to develop and refine that concept, it was Dame Cicely Saunders who, in 1948, had added the spiritual domain of suffering to this mix which she referred to as ***Total Pain***. As Dame Cicely recounted, "My story in this field goes right back to 1948 when I was a social worker… meeting a young Polish Jew who had an inoperable cancer. ... I became very fond of him. [David Tasma had escaped the Warsaw ghetto and was dying in a London hospital. .... Tasma's pain, loneliness and anguish had a profound affect on Saunders. She visited Tasma frequently in the last two months of his life. As Saunders and Tasma spoke of his looming death, Saunders had a revelation,] I realized that we needed not only better pain control but better overall care. People needed the space to be themselves. I coined the term '***total pain***,' from my understanding that dying people have physical, spiritual, psychological, and social pain that must be treated. I have been working on that ever since."

In my view, there are three major documents that have been critical in the development of Palliative Care in the United States. **First**, the ***SUPPORT Study*** funded by the Robert Wood Johnson Foundation was printed in the *Journal of the American Medical Association* in November 1995. That document was the first to give public view to palliative and end-of-life care and raised the issues about dying in America. Among other things it led to the *EPEC* and *ELNEC* training projects to train physicians and nurses in palliative and end-of-life care and other programs as part of the *Project on Death in America*, and gave early impetus to palliative medicine as a subspecialty.

Second, twelve years later, in October 2007, when the Institute of Medicine report about the need for psychosocial services to cancer patients and their families, ***Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs***, which led to increased attention to the psychosocial needs of patients who have life limiting illnesses and their families, using the context of cancer. Still, there was a limited was focus on spirituality in palliative and end-of-life care.

Third, finally, in February 2009 a consensus conference on spirituality in palliative care was convened. The result of that conference was a report titled, ***Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference***, which was published in the Journal of Palliative Medicine as a special report in its October, 2009 issue. That report made it

clear that spiritual care is a fundamental component of quality palliative care. It also made it clear that health care providers other than board certified chaplains can provide spiritual assessments and interventions and should be trained to do so as part of transdisciplinary teams, leaving the board certified chaplains to be brought in as spiritual experts. The report of the Spiritual Consensus Conference marks the time where we now have clear cut documents that support Dame Cicely's concept of ***Total Pain*** and the need for attention to the biological, psychological, social **and spiritual domains as critical and interdependent** to the provision of quality palliative care services.

I am a participant in the ACE Project (Advocating for Clinical Excellence - Transdisciplinary Palliative Care Education) which is a palliative care educational experience funded by a major 5-year National Cancer Institute R-25 Grant Award to the City of Hope Medical Center in Duarte, California, for development and implementation of this program to enhance the advocacy, leadership and support skills of competitively selected psycho-oncology professionals throughout the United States. As part of the ACE program, each participant has to do a project which will help further palliative care in their institution or community.

The project I chose is to further the ability of palliative care patients and their families to receive quality spiritual care. **The major part of that project is to train members of the clergy in palliative care**. Although there are chaplains in institutions (most of whom have training in chaplaincy) the chaplains are limited to working with patients and families when the patient is in their institution (except in hospice where they may provide bereavement services after the death of the patient).

The largest need for palliative care trained clergy is in the communities. The community clergy who are working in congregations and parishes are the first line in providing spiritual care, as congregants/parishioners often seek assistance from their clergy in relation to spiritual concerns that arise in the context of end-of-life and/or serious illnesses or injuries which are life altering. These parishioners/congregants have indicated they want to have their clergy come to the hospitals rather than have a chaplain they do not know and who may not be from their faith group to attend to them in the hospital. In this regard, as the elderly population increases dramatically, as more terminally ill patients are being cared for at home, and as the number of people who suffer from chronic (and at time debilitating) illnesses who remain in the community rather than in hospitals, there will be an increasing demand for community clergy to provide spiritual care to these people and their families. If you wish to have me train a group of clergy, please feel free to contact me at:
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The second portion of this project is to facilitate, using a transdisciplinary model, the ability of physicians, nurses, social workers, psychologists and clergy who work in palliative care, to perform spiritual assessments and provide interventions to address spiritual issues/concerns/crises in the absence of chaplains trained in palliative care. To this end I have I have updated an educational module, ***Spirituality in Palliative and End-of-Life Care***, which I developed in 2003

when I first trained chaplains (some of who were also community clergy) in palliative care. When I created this module in 2003, it appeared that spiritual care was not talked about very much in working with the chronically or terminally ill, or with people who have suffered from traumatic injuries and disabilities, which was a surprise to me, because it was such a clear domain to be addressed in the treatment of such patients. **Those educational materials are now accessible for downloading from the Growth House website using the following url; www.Growthhouse.org/spirit, without charge.** If you wish to have training for a group of health care providers using the spirituality curriculum described above, you may contact me at: PalliativeCare.Pain_ClinicalSW@Verizon.Net.

The third portion of this project is advocacy. It is an imperative to seize the moment of the issuance of the consensus report on spiritual care as a critical domain of palliative care, along with the physical, psychological and social domains. If the palliative care and faith/religious communities as a group do not seize upon this important moment in the history of palliative care to energize a nationwide movement to bring spiritual care services into the fabric of palliative care as a co-equal services along with those services which address physical and psychosocial suffering, we may well miss out on the potential momentum that can be generated from this consensus report, thereby squandering the opportunity the report presents to bring spiritual care to its rightful, critically important place in palliative care's core mission to treat total pain. If you wish to help in this endeavor, please feel free to contact me at: PallitiveCare.Pain_ClinicalSW@Verizon.Net.