Spiritual Care Approaches in Death and Dying

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Introduction

Existential and spiritual issues are commonly encountered in end-of-life care. During a daily round in a palliative care ward, one may encounter snapshots like these: an old lady with advanced metastatic breast cancer requesting for cardiopulmonary resuscitation in order to continue her role as care-giver of her sister with psychiatric illness; a middle age man copying some scripts and drawing pictures from the Bible hoping to leave a legacy for his children; and a man finding no meaning in his suffering and asking for euthanasia. Should the palliative care team respond to these spiritual needs? Why and how?

Definition of Spirit and Spirituality

The Latin origin of the word spirit, “spiritus”, means breath. Like breath, spirit is essential to life though it is very difficult to define and describe. Spirituality, is a variably defined term with many different definitions. It has been defined as the search for existential or ultimate meaning within a life experience, such as illness. An encyclopedic definition of spirituality entails a sense of connection to something greater than oneself. The importance of the sense of connectedness is echoed by two qualitative studies about spirituality in end-of-life. A Canadian study identified four types of “healing connections”, the connections to Self, Others, the Phenomenal World, and Ultimate Meaning. These connections might enhance patients’ coping during a state of suffering and anguish to move toward a state of integrity and wholeness. A Taiwanese study revealed similar results: the “communion” with Self, Others, Nature and Higher Being identified as the four constitutive patterns of spirituality.

A theoretical model described by Kevin P Kaul puts the temporal perspective into the definition of human spirituality. The retrospective dimension (past memories and life experience) provides a historical context that may influence one’s present spiritual dimension. The ability to deal with spiritual issues in the present maybe affected by biological status, psychological processes, and socio-cultural factors; the occurrence of a life-threatening illness together with its treatment directly interact with these factors. Ultimately, a person’s spiritual beliefs influence future hopes, fears, and expectations (i.e. prospective dimension). An understanding of a person’s past experiences, belief system, and aspirations for future, as well as the impact of a terminal illness on the biopsychosocial aspects are essential in understanding the spiritual needs of a patient facing a terminal illness.

The Importance of Spiritual Care

Among the five domains of the Hong Kong Chinese version of McGill Quality-of-Life Questionnaire, namely the physical, psychological, social, existential, and sexual domains, the existential domain was found to be the most predictive of the overall quality of life in patients receiving palliative care. An analysis on the concept of good death by literature review identified twelve attributes of a good death; the majority of these attributes were directly or indirectly related to the spiritual realm, i.e. the sense of meaning, value and connectedness. These included: a sense of closure, appropriateness of dying, being in control, value of the dying person affirmed and recognized, beliefs and values honored, relationships optimized, burden minimized, family care, leaving a legacy, and trust in care providers. Hence, good spiritual care is desirable for terminally ill patients to live well (good quality of life) and to die well (good death).

Researches into Spirituality and Spiritual Care

Researchers around the world have been investigating into the various aspects of the spiritual realm of dying patients. Some looked into the nature, manifestations and causes of spiritual distress. Others attempted to develop theoretical models, design assessment tools and formulate treatment approaches based on these models. Their efforts greatly help our understanding of this abstract concept and provide insights into clinical care. However, like the Chinese metaphor of “The Blind and the Elephant”, each of these studies could clarify some aspects of the spiritual realm, but none of these studies could be said to have fully defined the whole picture. Table 1 outlines some of the researches around the world in the entities of spiritual distress, conceptual models in understanding the spiritual realm, and the corresponding assessment tools and treatment modalities.
Table 1: Researches on Spiritual Distress and Conceptual Models of Spiritual Needs in End-of-Life

<table>
<thead>
<tr>
<th>Spiritual entity</th>
<th>Researcher</th>
<th>Key findings</th>
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<tbody>
<tr>
<td>Desire for hastened death</td>
<td>William Breitbart, USA 2000</td>
<td>Clinical depression and hopelessness are the most significant independent factors associated with wish to hastened death.</td>
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<tr>
<td>End of Life Despair</td>
<td>McClain, Rosenfield &amp; Breitbart, USA 2003</td>
<td>A low spiritual well-being score (FACIT-Spiritual Well-Being Scale), the meaning/peace subscale in particular, is the best predictor of the three components of end-of-life despair - hopelessness, suicide ideation and desire for hastened death.</td>
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<td>Will To Live</td>
<td>HM Chochinov, Canada 2005</td>
<td>Existential variables, including loss of dignity, burden to others and hopelessness, are most significantly associated with a low will to live.</td>
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<tr>
<td>Existential Distress</td>
<td>T Morit, Japan 2004</td>
<td>The factors contributing to existential distress are investigated: acceptance / preparation, relationship-related concerns, hopelessness, loss of control, loss of continuity, uncompleted life tasks and burden on others.</td>
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<tr>
<td>Self-Perceived Burden</td>
<td>McPherson, Wilson &amp; Murray, Canada 2007</td>
<td>Self-perceived burden is associated with loss of dignity, existential distress and suffering, and bad death. It is a factor for wish for hastened death and suicide.</td>
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<td>Request for Euthanasia</td>
<td>Y Mak, Hong Kong 2005</td>
<td>The desire for euthanasia incorporated hidden existential yearnings for connectedness, care and respect, understood within the context of the patient’s experience.</td>
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<td>Demoralisation</td>
<td>David Kissane, Australia 2000</td>
<td>The key elements of demoralization syndrome are hopelessness plus loss of meaning or purpose in life without clinical depression. A 24-item demoralization scale had been validated and a management framework of demoralization had been designed.</td>
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<td>Meaning</td>
<td>William Breitbart, USA 2001</td>
<td>Based on Victor Frankl’s model of the meaning in life and the will to meaning despite intense suffering, an eight-week meaning-centered group psychotherapy program was designed. Pilot study showed positive results while the result of a randomized controlled trial is awaited.</td>
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<td>Hope</td>
<td>K Herth, USA 1990</td>
<td>Factors fostering or hindering hope in the terminally ill were identified: interpersonal connectedness, attainable aims, spiritual base, personal attributes (determination, courage and serenity), light-heartedness, uplifting memories, and affirmation of worth can foster hope; whereas abandonment and isolation, uncontrollable pain and discomfort, and devaluation of personhood hinder hope. A 12-item Herth Hope Index is established for assessment of hope in clinical care and research.</td>
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<td></td>
<td>J Buckley, USA 2004</td>
<td>A controlled trial of a hope fostering treatment called the Living With Hope Program (comprising of a hope video plus performance of a hope-related activity) had been shown to increase the hope score and quality of life score in the treatment group.</td>
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<td></td>
<td>WD Duggleby, Canada 2007</td>
<td>Based on a qualitative study into the construct of dignity in the terminally ill, the Dignity Model had been formulated which comprised of illness-related concerns, dignity conserving repertoire, and social dignity inventory. This can act as a therapeutic map to locate the issue of importance for individual patient. A 7-point sense of dignity item score was used for research purpose. Based on the Dignity Model, Dignity Therapy was pilot trialed showing improvement in suffering measures and depressive symptoms. An international randomized controlled trial is underway.</td>
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Assessment Tools

Besides the demoralization scale, Herth Hope Index, and dignity model and score which look into more specific areas of meaning, hope and dignity respectively, several instruments can be used to assess general spiritual well-being and existential aspect in the terminally ill.

i. Quality-of-Life Concerns in the End-of-life (QOLC-E) – QOLC-E is a locally validated tool with 28 items comprising of eight subscales; three subscales are concerning existential and spiritual well-being, namely value of life, sense of alienation, and existential distress; 7

ii. McGill Quality of Life Questionnaire (Hong Kong Chinese Version): MQOL-HK is a locally validated tool with five domains and 18 items; there are 4 items in the existential domain; 5

iii. FACIT-Spiritual Well-Being Scale: It consists of two subscales- the Meaning / Peace subscale concerns about meaning and value while the Faith subscale looks into religious belief and faith system; 8

iv. FICA: the FICA assessment tool opens the door to further discussions about spiritual concerns if these are relevant to the patient. It has four components: 9

1. F: Faith, belief and meaning- What is one’s belief system? What gives one meaning?
2. I: Importance and Influence- How important is one’s belief system and faith to oneself?
3. C: Church and Community- What is one’s church or community of faith
4. A: Apply and Address- How one would like his/her spiritual needs to be addressed?

Management Tools

Based on research into the entities of meaning, demoralization, dignity and hope, specific treatment tools have been or are being developed. Individual logotherapy, meaning-based group psychotherapy 10, and demoralization management framework 11 deal primarily with the sense of meaning and meaninglessness. Dignity therapy helps to enhance patient’s dignity and value by recording and transcribing patients’ concern with the help of a Dignity Psychotherapy Question Protocol and creating a Generativity Document to leave behind to patients’ family. 12 Hope-based interventions like the Living With Hope Programs 13 had been tested to terminally ill patients and also to their family members with positive results.

Other specialized treatment tools that can address spiritual needs include:

- Narrative Therapy / Life review
- Creative means: art, music, nature, writing etc
- Body-Mind-Spirit interventions
- Religious approach
- Other individual or group psychotherapy

The Clinician as a Tool

With all these assessment and treatment tools, an essential element of successful spiritual care is the person who carries these tools. The ability of the clinician to actively listen and communicate with empathy, to detect spiritual suffering with a high index of suspicion and sensitivity to clues, and to know each patient as a unique individual are important attributes for a caregiver who is delivering spiritual care. The goal is to establish a therapeutic relationship that facilitates communication and understanding in order to recognize the person’s socio-cultural context, listen to his/her personal history, understand his/her efforts to search for meaning to life and death, and identify factors that create or reduce distress and impact on overall quality of life. This relationship is also a source of connectedness that may enhance patient’s meaning during life’s end. With the establishment of a good therapeutic relationship, sometimes simple questions like “are you suffering and why?”, “what are you worrying about?”, or “are you at peace?” can already facilitate the patient to express his/her spiritual suffering.

Concluding remarks

Delivering spiritual care in the modern health care system is not an easy task. Managed care with its emphasis on length of stay, risk reduction, cost control, and minimizing hospitalization puts spiritual care not at a high priority. The increased reliance on life-sustaining or -supporting technology, new costly chemotherapeutic agents with uncertain long term effects, and use of complementary therapies may shift the focus of patients, families and caregivers away from addressing the spiritual needs. Moreover, caregivers working with terminally ill patients may ‘shut down’ their spiritual awareness due to personal factors, cumulative losses, or suffering too intense to face.

Despite these difficulties, the ability to build healing connections in end-of-life care can be very gratifying to patients, families and caregivers. Caregivers’ self awareness and reflective ability as well as the formal and informal support system in palliative care settings are crucial in creating a sustainable environment conducive to good spiritual care.

A few questions that palliative care workers should ask themselves in spiritual care delivery are
listed as follows:

Do I see meeting spiritual needs as part of my responsibility?

Am I prepared to look for clues of spiritual suffering and to create openings to explore into the spiritual realm in my daily clinical care?

How do I handle the cumulative losses and grief after facing so many deaths?

Am I able to reflect on my own emotions and be aware of the influence of transference and counter-transference during my interaction with suffering patients and families?

How can my own personal suffering enhance my work in end of life care – the concept of wounded healer?

Am I still able to find meaning in patients’ dying and death?14

“Unless we are occupied in our own search for meaning, we may not create the climate in which patients can be helped to make their journeys of growth through loss.”

– Dame Cicely Saunders

Reference


9 Puchalski CM. Taking a Spiritual History: FICA. Spirituality and Medicine Connection 1999.

10 Breitbart W. Spirituality and meaning in supportive care: spirituality and meaning-centered group psychotherapy interventions in advanced cancer. Supportive Care in Cancer (on-line) 2001.


