

Spiritual suffering and spiritual needs in Palliative Care

Dr K K Lam

Nam Long Hospital

The focus of medical care is the sick person (rather than the disease) is a statement of a theory of medicine. The test of a system of medicine is its adequacy in the face of suffering. Modern medicine is too devoted to its science and technology and has lost touch with the personal side of sickness. There is increasing personal and social expectation that a more personal approach to the practice of medicine is required. We are dealing with a person who is afflicted by a disease and who may be suffering in his experience of the illness. The relief of suffering is increasingly considered one of the primary end of medicine by patients and the general public, especially in the care of dying .

Person or personhood is the result of a complex, essentially holistic, interplay between body, mind and spirit. The impact of the experience of illness will be multidimensional on the person—physical, psychological, social and spiritual – all are causes of suffering for the patient. Eric J. Cassell defines suffering as the state of severe distress associated with events that threaten the intactness of persons. Hauerwas says suffering occurs in an interpretive context and has its root sense the idea of being forced to submit to and endure some particular set of circumstances. The patient's meaning system impacts on the meaning given to suffering. The language that describes and defines the patients' suffering is different from the language of medicine. It is described by symbols, metaphors and stories. Our case history format is good at finding out what is wrong with the body in terms of disease and patho-physiology. It does not examine the persons. The persons can only be understood from the patient's own narratives. When you understand the patient more as a person, you understand more about his suffering. Sometimes, the only way to learn whether suffering is present is to ask the sufferer. Some injuries cause suffering universally but some suffering is very individual.

William Osler said, “ It is as important to know the person who has the disease as to know the disease the person has.” So, should we deepen our case history into a narrative tale? We should be beware of bias, preconceptions and judgments made about a patient that are not based on what you know about the patient when you try to find out the person.

Spirit is relational in its expression – it is expressed in relationship, in dialogue, in communion with others. The spiritual dimension of personhood has to be perceived if we are to respond to the needs of the whole person – holistic care. Spirituality is defined as the ‘life principle’ that pervades a person's entire being and that integrates and transcends one's biologic and psychosocial nature. A

broad, inclusive definition of spirituality is that which gives meaning to one's life and draws one to transcend oneself.

Spirituality is a broader concept than religion, though that's one expression of spirituality. Spirituality is a complex and multidimensional part of human experience. It has cognitive, experiential and behavioral aspects. The cognitive or philosophic aspects include the search for meaning, purpose and truth in life, and the beliefs and values by which an individual lives. The experiential and emotional aspects involve feelings of hope, love, connection, inner peace, comfort and support. The behavioral aspects of spirituality involve the way a person externally manifests individual spiritual beliefs and inner spiritual state. Distress can be defined as an unpleasant emotional experience of a psychological, social and or spiritual nature that interferes with coping. Spiritual distress occurs when individuals are unable to find sources of meaning, hope, love, peace, comfort, strength and connection in life or when conflicts occur between their beliefs and what is happening in their lives.

Signs of spiritual distress (suffering) will include:

- a) expressing a lack of support from others, feeling isolated, expressing guilt and expressing anger with self and others (love and relatedness);
- b) expressing no reason to live, questioning the meaning of suffering and expressing despair (meaning);
- c) suppressing of feelings, being withdrawn and failing to wonder or ask questions, hopelessness, helplessness (hope).

When distress is more severe it is described as suffering. Suffering occurs when one has distress from which there may be no escape and which threatens the self (Cassell, 1982). We should never assume. We should open our ears, listen to the patients. One can never predict what may cause another to suffer and how much suffering it may create. Suffering is a complex state of being- it involves our whole being. It is expressed in physical, psychological, spiritual symptoms. It is affected by our memory, insight, intellect. Suffering can be a positive as well as a negative experience. Charles Raven (*A wonderer's way*, 1928) wrote: most people at sometime or another have to stand alone, to suffer, and their final shape is determined by their responses – they emerge either as slave of circumstances or in some sense master of souls. In a biomedical paradigm , a need is defined by a loss of function and the presence of objective disease, and a need is addressed by the practical application of theoretical knowledge in the form of standardized interventions – dominant model in health care. Healthcare is provided because in order simply to live we have a basic need for health. In palliative care, the basic need for health is certainly much limited. Health in the usual sense may not matter as much as other values to a person close to death. The focus of palliative care is the individual patient and how that person can be enabled to live and die with a terminal disease in such a way that respects the individuals' interest. The interests of the individual are afforded greater consideration because of the preciousness associated with the remaining days of life such that the opportunities for satisfying the dying person's interests are likely to be decreasing. Spirituality provides meaning and values to a person. Nurturing and supporting a person's spirituality will contribute to their fundamental interests. This will definitely promote patient's best interest and critical interests which are basic and critical to who they are.

Palliative care will promote the well-being and quality of life of patients by caring for all dimensions of personhood including spiritual.

Addressing the issues of spiritual suffering and spiritual needs of patients is integral and essential to the practice of palliative care. Spiritual care should not be in the periphery of palliative care in actual practice. It's time to shift from the biomedical model of medicine to a more biopsychospiritual model in the practice of palliative medicine. The spiritual suffering in patients should be recognized and their spiritual needs should be addressed in our routine practice of palliative medicine.

References:

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