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Spiritual pain and its care in patients with terminal cancer: Construction of a conceptual framework by philosophical approach

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ABSTRACT

Objective: In discussing spiritual care of patients with terminal cancer, it is important to clarify the structure of spiritual pain to be evaluated.

Methods: In this article, spiritual pain is defined as "pain caused by extinction of the being and the meaning of the self," and its structure was evaluated according to the three dimensions of the human being, that is, a being founded on temporality, a being in relationship, and a being with autonomy.

Results: As a result, spiritual pain of patients with terminal cancer could be described as meaninglessness of life, loss of identity, and worthlessness of living derived from loss of the future, loss of others, and loss of autonomy of a dying individual.

Significance of results: On the basis of these understandings, the author deduced principles of spiritual care of terminally ill cancer patients as recovery of the future beyond death, others beyond death, and autonomy toward death in each dimension of the human being.

KEYWORDS: Spiritual pain, Spiritual care, Definition, Coping strategy, Palliative medicine

INTRODUCTION

Patients with terminal cancer experience various physical, psychological, and social pains and distresses. However, pain called spiritual pain was also shown to be mixed among them by recent studies in Japan, and the importance for its care is emphasized (Morita et al., 1999; Tunetou, 1999).

Spiritual pain of patients with terminal cancer has been suggested to include a wide range of distresses such as loss of the meaning and purpose of life, reduced abilities for activities and increased dependence due to debilitation, loss of the sense of control over the self and living and increased uncertainty, burden of the family and people around the patient, sense of absurdity and unfairness toward fate, loss of the sense of satisfaction with the self or living, loss of peace of mind, sense of regret, shame, and sin about past events, loneliness, hopelessness, and anxiety over death (Kaye, 1989; Kearney & Mount, 2000; Morita et al., 2000; Kissane et al., 2001). In fact, this spiritual pain has been expressed verbally or in the forms of irritation, anger, and depression, and occasionally as a clear desire for death by patients with terminal cancer, and various approaches have been attempted for its care.

Spiritual Care and Religious Care

Spiritual care for patients with terminal cancer has been discussed as part of religious care in the United Kingdom and the United States. In the cultural background in which the term spirituality had been used interchangeably with religiosity (Hermann,

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2001), entire separation of religion and spirituality is probably unrealistic (Dyson et al., 1997).

However, many conceptual studies on spirituality have stressed the importance of distinction between spirituality and religion (Emblen, 1992; Reed, 1992; Dyson et al., 1997; McSherry & Draper, 1998). Emblen (1992, p. 45) examined terms used for defining "religion" and "spirituality" in the literature on nursing published in the United Kingdom and the United States between 1963 and 1989 by using concept analysis procedures, and attempted to redefine "religion" as a "[s]ystem [of] organized beliefs and worship [which the] person practices" and "spirituality" as a "[p]ersonal life principle [which] animates transcendent quality [of] relationship [with] God or god being." On the basis of these definitions, she concluded that spirituality is a term with wider meaning than religion, it embraces various phases of religion, and that the care related to personal life principles, relationships, and transcendent experiences (spiritual care) and care for personal beliefs and worship practices (religious care) may be confused if these concepts of spirituality and religion are not clearly defined.

Conceptual and Theoretical Studies of Spirituality

McSherry and Draper (1998) explored three debates surrounding the growing concept of spirituality as applied to nursing and presented them as (1) Spirituality: in pursuit of conceptual and theoretical unity, (2) The demise of spirituality and the rise of secularism within nursing, and (3) Spirituality: a unifying force at the foundation of holistic philosophy. They also observed that a practical definition of spirituality as a human science that is universal, practical, and adjustable to the uniqueness of individual patients is needed for clinical application.

The contention that spirituality can be empirically investigated and ultimately applied in practice, using methods of science and praxis accepted by the nursing community (Reed, 1992) is reflected in conceptual research to clarify the structure of spirituality from relationships. Dyson et al. (1997) considered that the self, others, and "God" provide the key elements within a definition of spirituality and that a conceptual framework for clarification of the themes "meaning," "hope," "relatedness/connectedness," "beliefs/belief systems," and "expressions of spirituality" can be derived from these three key elements and their interrelations. The "right" relationships between self, others, and "God" bring about spiritual well-being (Conrad, 1985; Fish & Shelly, 1988).

Walton (1996) attempted to explain spirituality from spiritual relationships themselves. Spiritual relationships are connections to self or soul, to others, to a higher power, or to nature with their interactions. Disruption of these connections leads to despair, perception of life as meaningless, and the self as powerless. Therefore, spirituality is "connections" of the inner self with others and the transcendental being accompanied by their interactions (Reed, 1992). When people encounter difficulties or crises such as illness and death, they rediscover their relationships with others and "God," through exploration of the inner self. Such spiritual relationships can be a great source of comfort, providing healing energy and strength to the human being (Granstrorm, 1985; Burkhardt, 1989; Walton, 1996).

The inclination to depart from the Christian theological tradition and to recapture spirituality as a universal phenomenon of human beings is a new trend of the 1990s. From the viewpoint of empirical research on spirituality, Narayanasamy (1999) contended that spirituality should be discussed on the basis of the biological principles that people seek for spirituality when they encounter illness, emotional stress, physical distress, or death regardless of whether they have a religion or not and that they have spiritual needs for meaning, purposes, and identity. Goddard (1995) also evaluated the current usages and definitions of spirituality by a philosophical analysis and proposed a philosophical definition of "spirituality as integrative energy."

Practical Approaches to Spiritual Care

Approaches in which spiritual care is separated from religious views and is studied as a phenomenon common to all human beings are observed also in psychiatry. In a standard textbook of psychiatry in palliative medicine, Kearney and Mount (2000) mentioned 13 specific aspects of the response to spiritual pain in dying patients, that is, to value the therapeutic relationship, to establish contact, to respect the patient's otherness, to control symptoms effectively, to obtain a "clinical biography," to determine the meaning of the illness for the patient and family, to explore sources of meaning in the person's life, to assist in redefining hope, to examine fears, particularly concerning the unknown, to explore the patient's need for reconciliation, to celebrate the transcendent, and to actively intervene if patient remains stuck. They described spiritual pain of terminal patients as distress of alienation from the deepest parts of the mind that give a person meaning, hope, and purposes, and the essence of spiritual care as for the caregiver to recog-

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nize this alienation, to respond to the distress, and to descend to the depth of "healing" of the Self.

Moreover, Fitchett and Handzo (1998) incorporated spiritual care in a systematic care process and suggested the necessity of spiritual assessment. They further presented six assessment theory models (Pruyser, 1976; McSherry et al., 1986; Kuhn, 1988; Kim et al., 1989; Stoddard & Burns-Haney, 1990; Berg, 1994) along with their original 7 × 7 spiritual assessment model.

Although the importance of spirituality has been emphasized by various theoretical studies (Scott et al., 1994), nurses often are not aware of the spiritual needs of terminal patients in actual clinical care (Highfield, 1992). Ascribing this to the fact that there has not been a study focusing on spiritual needs of dying patients, Hermann (2001) identified spiritual needs of dying patients in a qualitative study using semi-structured interviews, and extracted six themes of spiritual needs, that is, need for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature, and need for positive outlook. This study clarified specific points of intervention by the caregiver and provided guidelines for care such as support for religious practices, quiet time for prayer, reading materials, music, visits of chaplains or social workers, listening to life-reviewing, involvement in living, contribution to the family, sharing of information, and supporting their need to help others.

State in Japan

In Japan, there has been little scientific discussion about what is care for spiritual or existential pain in specific terms, that is, how should the caregiver actually meet the pain of terminal patients such as meaninglessness, reduced self-respect due to dependence, or loss of the sense of control (Morita et al., 2001). In these circumstances, Morita et al. (2001) attempted to systematically collect and organize specific methods for care considered in Western countries to be effective for palliating spiritual or existential pain in order to propose integrated care expected to be effective in Japan.

At the same time, clarification of the structure of spiritual pain to be cared for is important for discussing spiritual care. Hermann's (2001) study that focused on spiritual needs of dying patients suggests many key points in practical care. However, the care suggested there is no more than symptomatic care to meet the needs. Why do spiritual needs occur in patients with terminal cancer? What is spiritual pain that produces spiritual needs? When a person is debilitated in the face of death, why and how do they feel spiritual pain? Unless the structure of spiritual pain that is experienced by patients with terminal cancer is clarified, methods for care to alleviate pain will also end up in symptomatic treatments, and guidelines of spiritual care with theoretical grounds will be difficult to obtain.

This paper, in which spiritual pain is defined as "pain caused by extinction of the being and meaning of the self," intends to clarify the structure of spiritual pain characteristic of patients with terminal cancer expressed as meaninglessness of life, lack of purpose, loss of identity, and sense of worthlessness through philosophical investigation and to obtain guidelines for its care.

SPIRITUAL PAIN OF PATIENTS WITH TERMINAL CANCER AND GUIDELINES FOR ITS CARE

Spiritual Pain of the Person as a Being Founded on Temporality

Death does not only terminate the patients' lives but also deprives them of the future. For many people who live their daily lives without being conscious of death, death is something that should be concealed and not talked about. For this reason, death strikes patients as an unexpected event and sudden interruption of life with emotions of anger, sorrow, and absurdity and forces them to become acutely aware of loss of the future.

At this time, the consciousness of patients with terminal cancer directed to the limitation of life and loss of the future produces spiritual pain of meaningless, purposeless, and absurd life. Why so? Why do the limit of life and loss of the future appear as painful meaninglessness of life to terminal patients? To understand this, thoughts about how we live our daily lives without being conscious of death, that is, analyses of the temporal structure of our daily life, are needed.

Temporal Structure of Daily Life and Spiritual Pain

One's daily life is lived by the person as a being founded on temporality (Dostal, 1993). A being founded on temporality means that one's being and its meaning are formed in the framework of temporality. According to Heidegger, human life has a temporal structure in which "the present bears within it the past and the future. Past and future make it up" (Dostal, 1993, p. 156). People give birth to the future by accepting the existing (past), which is already given, and opening the possibility forward (future) in the reality which they have been

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cast into, and find meaning in the present life by trying to realize the envisioned future. All people establish the meaning and being of the present by supports of the future and the past as a being founded on temporality.

However, the person as a being founded on temporality loses the future with the approach of death. A person who has lost the future cannot establish the meaning and being of the present. A patient with terminal cancer who is aware of impending death, deprived of the future, feels spiritual pain of meaninglessness, purposelessness, and absurdity of his/her life.

Spiritual Pain of the Person as a Being in Relationship

Death is not only extinction of the self but also termination of relationships with others. The loss of relationships with others makes patients with terminal cancer feel spiritual pain of loss of identity and meaninglessness of their lives.

Why does loss of relationships with others make terminal patients feel loss of identity and meaninglessness? Because one's daily life is lived by the person as a being in relationship. A being in relationship means that the being and meaning of the self are established in relationships with others. Laing (1969, p. 82) observes, "All 'identities' require an other: some other in and through a relationship with whom self-identity is actualized." Others give the identity of the self (its being and meaning) in relations with them.

However, people as beings in relationships lose their relationships with others in the face of death, and terminal patients, who lose support for the being and meaning of their selves, are forced to experience spiritual pain of loss of identity and meaninglessness of life.

Spiritual Pain of the Person as a Being with Autonomy

A being with autonomy means that individuals are able to make decisions regarding choice of activity, method, and manner of engagement, timing, pace, and the like (Rowe & Kahn, 1987). The concept of autonomy contains not only the idea of self-determination but also independence and productivity, which are key elements to be a person as a being with autonomy, that is, to be a respectable man in American society (Akiyama, 2000).

However, the person as a being with autonomy suffers weakening of the body as death approaches and experiences various disabilities and dependence. He/she feels spiritual pain of uselessness, worthlessness, and meaninglessness of life by losing autonomy (Kissane et al., 2001).

Structures and Assessment of Spiritual Pain

Thus, spiritual pain of patients with terminal cancer, which is expressed as meaninglessness of life, loss of identity, and worthlessness of life, is caused in the patient as a being founded on temporality, a being in relationship, and a being with autonomy by loss of future, others, and autonomy due to approaching death.

A theoretical framework necessary for spiritual assessment and caring can be obtained by clarifying these existential mechanisms that cause spiritual pain in patients with terminal cancer. That is, we can derive guidelines for spiritual care of complex spiritual pain of patients with terminal cancer through analyzing these structures of spiritual pain according to the three dimensions of the human being, and clarifying their mutual relations.

Guidelines for Spiritual Care

Spiritual pain of the person as a being founded on temporality develops when the patient is deprived of the future by death. Thus, if the patient can find "the future beyond death" through his/her talks with spiritual care workers, he/she is sure to recover new meaning to live the present for the future. Here is a guideline for spiritual care of the person as a being founded on temporality.

Spiritual pain of the person as a being in relationship is caused by deprivation of its relationships with others by death. Thus, if the patient can find "others beyond death" through his/her talks with spiritual care workers, new identity and meaning of life are given by his/her relationships with these others. Here is a guideline of spiritual care for the person as a being in relationship.

Spiritual pain of the person as a being with autonomy develops from the experience of heteronomy and dependence on others, that is, "becoming unable to do anything" with the approach of death. Then, if the patient becomes aware that he/she still has enough freedom of self-determination in each dimensions of perceiving, thinking, speaking, and doing, that is, the perception, thoughts, expression, and activities through his/her talks with spiritual care workers, he/she is certain to recover the sense of value as a being with autonomy. Here is a guideline of spiritual care for the person as a being with autonomy.

As observed above, guidelines of care for spiritual pain of dying patients can be derived as "re-

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covery of the future beyond death, recovery of others beyond death, and recovery of autonomy toward death" when their spiritual pain is understood in the three dimensions of the human being, that is, the dimensions of temporality, relationship, and autonomy.

SIGNIFICANCE AND METHODS OF SPIRITUAL CARE

Exploration for Methods of Spiritual Care as Coping Strategies

Baldacchino and Draper (2001) reported that spiritual coping strategies may help patients find meaning, purpose, and hope in illness to enhance self-empowerment, suggesting that various coping strategies can be applied to safeguard the wholeness and integrity of the patients. They outlined spiritual coping strategies of patients in illness based on the stress-coping theories of Lazarus and Folkman (1984). Patients realize their personal nothingness and lack of control over their lives in the face of life-threatening illness and find coping measures available to them to be ineffective. However, this realization of incompetence urges them to explore their inner selves and to go beyond themselves to reach a higher power to gain control over their life process. They reflect on their lifestyles and values that they have had and search for the self that is not disturbed by illness or death. This restructuring of values in its new relationships with others, transcendental being, and nature is spiritual growth. The use of such spiritual coping strategies may help the patients achieve new integration, find meaning and purpose in illness, and acquire new strength, sense of security, love, and hope.

Spiritual care of patients with terminal cancer is given a clearer framework of supportive methods from this viewpoint of spiritual coping strategies. Supporting spiritual growth of patients with terminal cancer in the framework of [Experience of meaninglessness of life, loss of identity, and worthlessness in confrontation with illness and death (spiritual pain) $\rightarrow$ exploration of the inner self and restructuring of values (awakening of spirituality) $\rightarrow$ recovery of the future, others, and autonomy beyond death $\rightarrow$ recovery of new being and meaning] is considered to be the support process of spiritual care.

Spiritual Care of the Person as a Being Founded on Temporality

Patients with terminal cancer who have lost the future and cannot find meaning in the present inevitably reflect on "me" in the past. The awareness of death urges life-review, and reevaluation of their "entire lives" in the past. Furthermore, patients who have been lost with the meaning of the present search for what is truly meaningful and valuable beyond their everyday lives. These are spiritual actions to quest for meaning and purpose in life, trying to transcend to inner, true self.

Heidegger (1962, pp. 303–311) analyzed "Being-towards-death" of human beings and pointed out "awakening to Being-a-whole (entirety) and Authentic Being-towards-death(essentiality)" in people who have become conscious of death. In the light of spiritual needs of actual patients with terminal cancer, this "awakening to the entirety and essentiality of life" is considered to be equivalent to "life-reviewing" and "exploration of the true Self" (Murata, 1999, p. 452). Using this "life-reviewing" and "exploration of the true Self" as clues, we can listen to spiritual needs of patients with terminal cancer among various distresses, read spiritual coping strategies to help patients rediscover the past endowed with new meaning, the future that transcends even death, and the irreplaceable present. Here is an actual framework of a supportive method for spiritual care of the person as a being founded on temporality.

Spiritual Care of the Person as a Being in Relationship

To alleviate spiritual pain of the person as a being in relationship, patients must find "others beyond death." Patients are given new being and meaning of the self by their relationships with these "others beyond death." However, who are "others beyond death" for patients with terminal cancer? Clues to the answer are often found in the "life-review" of the patients, too.

In listening to "life-review" of patients with terminal cancer, we must pay attention to those who connect the patients to others beyond death among various persons and events that are mentioned. They may be, for example, persons who were important to the patients but have died. Listen to the patients' memories and thoughts about these persons and ask the patients where they are now. In many cases, patients reflect deep into themselves and begin to prepare for a journey to the next world being guided by these persons who have gone before them. For example, their fathers who loved them or their mothers who were kind to them serve as "others beyond death" and guide them. The patients are given the new being and meaning from their relationships with specific "others beyond death" and restore strength to live the remaining days.

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Alternatively, they may be their children or grandchildren whom they are going to leave behind in this world. To think about the state after their deaths and express their thoughts in concrete forms amount to their messages to this world from the next world. Through talking or writing their thoughts about people whom they are going to leave behind the patients undergo the process of giving meaning to their present beings in concrete forms.

Spiritual Care of the Person as a Being with Autonomy

The person as a being with autonomy experiences many disabilities and dependence as they are debilitated with the approach of death, and they complain of spiritual pain of uselessness, worthlessness, and meaninglessness of life.

In such situations, many terminal patients think "everything is . . ." as observed in expressions such as "I can do nothing anymore," "I am good for nothing," and "I am simply a burden." What we can do about these thoughts of terminal patients is to talk to them so that they can realize their still having freedom of self-determination and self-control in each of the dimensions of perceiving/thinking/speaking/doing (perception/thoughts/expression/actions) (Beck et al., 1979; Morita, et al., 2001).

Even if patients can no longer move their legs, they can still perceive (perception). They are free to choose how they interpret what they have perceived (thoughts). They can further express their thoughts or choose not to express them (expression). Also, they have enough alternatives about how to put their expressions into actions (actions). That is to say, perception, thoughts, expression, and actions belong to different dimensions, and there are areas of infinite possibility of the patients' self-determination and autonomy in each dimension.

Moreover, dependence is not necessarily "passivity" or "heteronomy." Terminal patients, who have debilitated dying bodies and cannot actually live without full dependence on others, can still keep their autonomy by actively "submitting" their bodies to others or the natural process (Frankl, 1969). This active "submission" of the body to others or the natural process is a preparation for "me existing as a body" to perceive myself as an being not belonging to the body, and it is an important process of spiritual growth of patients who, facing death, still live as a being with autonomy.

CONCLUSIONS

Spiritual pain of patients with terminal cancer is caused by extinction of the being and meaning of the self due to the approach of death. It can be explained as meaninglessness of life, loss of identity, and worthlessness of living that are derived from deprivation of the future, others, and autonomy of people as beings founded on temporality, beings in relationship, and beings with autonomy. Therefore, according to this structure of spiritual pain, principles of spiritual care can be deduced as recovery of the future beyond death, others beyond death, and autonomy toward death in each of the dimensions of the human being.

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