

Models for Spiritual Care in Hospice and Palliative Care

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Spirituality is an essential part of human beings. Spiritual care, designed to meet the spiritual needs of terminally ill patients and their families, is one of the most important aspects of hospice and palliative care (HPC). This study reviewed and analyzed literature utilizing the most commonly used Korean and international healthcare databases to identify care models that adequately address the spiritual needs of terminally ill patients and their families in practice. The results of this study show that spirituality is an intrinsic part of humans, meaning that people are holistic beings. The literature has provided ten evidence-based theories that can be used as models in HPC. Three of the models focus on how the spiritual care outcomes of viewing spiritual health, quality of life, and coping, are important outcomes. The remaining seven models focus on implementation of spiritual care. The “whole-person care model” addresses the multidisciplinary collaboration within HPC. The “existential functioning model” emphasizes the existential needs of human beings. The “open pluralism view” considers the cultural diversity and other types of diversity of care recipients. The “spiritual-relational view” and “framework of systemic organization” models focus on the relationship between hospital palliative care teams and terminally ill patients. The “principal components model” and “actioning spirituality and spiritual care in education and training model” explain the overall dynamics of the spiritual care process. Based on these models, continuous clinical research efforts are needed to establish an optimal spiritual care model for HPC.

Key Words: Spirituality, Hospice care, Evidence-based practice

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INTRODUCTION

Life-threatening diseases are a great challenge to the lives of terminally ill patients and their families. When approaching death, patients tend to become more interested in the fundamental values of life. It is clear that HPCTs are the healthcare providers who must accompany terminally ill patients on this journey. HPCTs provide end-of-life care; they help patients adjust to pain, despair, and the inevitable changes that they and their families should experience, and provide professional and systematic spiritual care services that enable patients to

live a good-quality life during their final days (1). A systematic protocol for evidence-based practice grounded on evidence-based theories must be established for HPCTs to provide more effective spiritual care.

To provide a foundation for establishing a practical spiritual care model based on evidence-based theories, this paper provides a literature review about spiritual care models suitable for use in HPC. Studies were identified using both international databases (MEDLINE® via PubMed, Cochrane Library CENTRAL, EMBASE, and CINAHL®) and Korean electronic databases (KMBASE, KOREAMED, RISS, KISS, and

NANET). The authors have included published studies written in English and Korean from the earliest available publication date until May 2017.

This study examined the common characteristics of spiritual care models identified through the process described above, dividing the models into two groups that reflect two different perspectives. The first set of spiritual care models includes three models focusing on caring outcomes, whilst the second group consists of seven models highlighting the implementation of spiritual care.

THE COMMON CHARACTERISTICS OF SPIRITUAL CARE MODELS

Although various theoretical models for the spiritual care of terminally ill patients have been proposed, they all share common views about the concepts of spirituality and holistic humanity.

Spirituality is a key concept in the care of terminally ill patients, representing a vital sign for the need of spiritual care. When people experience pain, relating to disease, extreme life stress, or loss, they begin to ask existential questions regarding who they are and why they exist in the world. Spirituality reflects the fundamental nature of human beings; it is both the way individuals seek and express the meaning and purpose of life, and the way individuals experience the connection between themselves and other people, nature, or a divine being (2–4). Spirituality is related to patients' pain relief, which is the primary goal of HPC. It is also strongly associated with the cultural beliefs and religion of patients (3,5,6). The U.S. national palliative care guidelines suggest that "spirituality is a broader concept than religion and not limited to it," and that HPCTs must have the ability to recognize and understand the spirituality of the care recipient to improve the quality of spiritual care in HPC (7,8). Many studies have shown that expressing spirituality has a significant positive correlation with improved immune functions, positive coping, quality of life (QOL), and mental health in terminally ill patients (8,9). They have also argued for the need to develop spiritually-based interventions that respect individuals' meanings, as opposed to uniform interventions (10).

The holistic view of human beings is a common concept ad-

ressed in spiritual care models for terminally ill patients. From a holistic perspective, a human being is an integrated organism with physical, psychosocial, and spiritual aspects. He or she has an integrated holistic existence, which is not merely the sum of various parts, but something more (Figure 1) (11). Patients' psychological well-being is closely related to their physical symptoms, psychological states such as anxiety and depression, and social factors such as social roles or important relationships. Therefore, when the spiritual state of terminally ill patients is assessed, factors that affect other personality aspects should also be considered (12).

THE THEORIES OF SPIRITUAL CARE

HPC perceives human beings from a holistic viewpoint. The concept and practice of holistic care incorporate the physical, psychological, and spiritual aspects of the care recipient simultaneously, suggesting that spiritual aspects should be given more attention in end-of-life care. Such careful consideration of patients' spirituality is necessary because spiritual and existential suffering may occur in association with problems in many areas, including physical pain and symptoms, psychological anxiety, depression, or despair, religious faith and loss of faith, and social experiences, for example the breakdown or dissolution of a relationship.

Theoretical models for spiritual care rooted in various per-

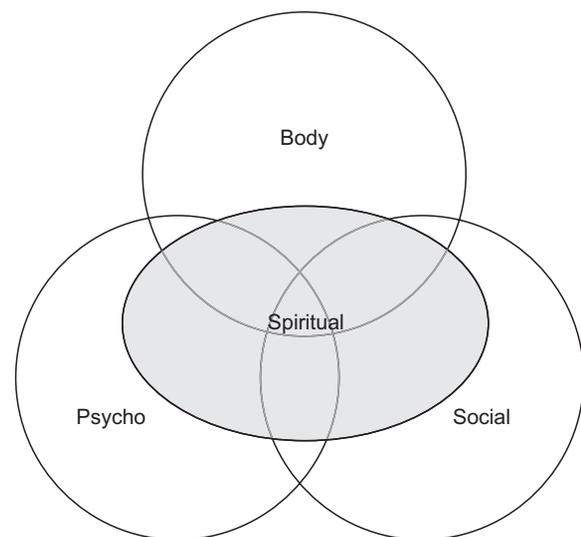


Figure 1. Holistic human concept.

Source: Korean Hospice and Palliative Nursing Association. *Hospice Palliative Nursing*. Seoul:Hyunmoon Press:2015.

spectives are presented in this paper to promote the spiritual well-being of the terminally ill patient as a whole person and produce more effective spiritual care outcomes. In this study, the theoretical models of spiritual care are grouped into two categories that prioritize outcome variables and the implementation of spiritual care.

MODELS BASED ON CARING OUTCOMES

1. The spiritual health model

For patients suffering from a terminal illness, spiritual prob-

lems are very significant in HPC practice. Spiritual health is a buffer that reduces depression, helplessness, and hopelessness among terminally ill patients. The attributes of spiritual well-being, transcendence, hope, meaning, and dignity in terminally ill patients are closely related to pain control, QOL, and adaptation to and acceptance of loss. Therefore, HPCTs need to understand that patients' physical and psychosocial issues have a strong relationship with their spiritual health. They should approach and respect patients' autonomy, values, and beliefs from different perspectives, including religion, culture, and personal beliefs, as well as adopting an open point of view (2,11,13). Figure 2A shows the spiritual health model based on the holistic view of human beings proposed by Taylor (2). This

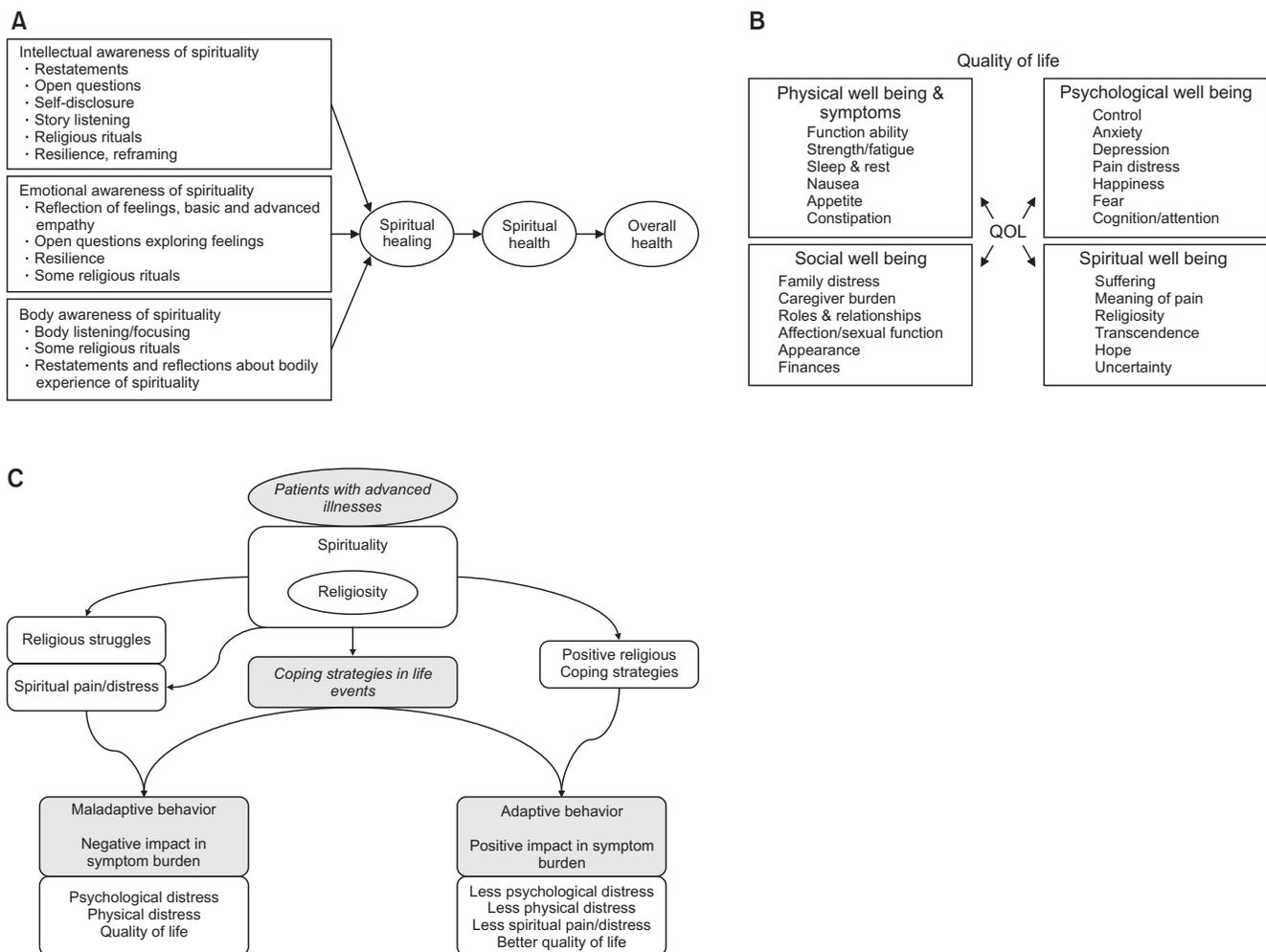


Figure 2. Models based on caring outcomes. (A) Model for supporting patient spiritual health. (B) The City of Hope Quality of life model. (C) Spirituality and religiosity model.

Source 1: Taylor EJ. What do I say? Talking with patients about spirituality. Philadelphia:Templeton Foundation Press:2007. p. 8.

Source 2: prc.coh.org [Internet]. Duarte, CA: Pain and Palliative Care Center; 2017 [cited 2016 Oct 28]. Available from: <http://prc.coh.org>.

Source 3: Delgado-Guay MO. Spiritual care. In: Bruera E, Higginson I, von Gunten CF, Morita T, eds. Textbook of palliative medicine and supportive care. 2nd ed. Boca Raton:CRC Press:2016.

model postulates that HPCTs' understanding and perception regarding intellectual (mental), emotional, and bodily (physical) aspects of terminally ill patients' affect the spiritual healing and spiritual health of care recipients, and that spiritual health has a positive effect on human beings' overall health.

2. The quality of life model

The QOL model has been adopted for the provision of high quality HPC in the End-of-Life Nursing Education Consortium (ELNEC) Project implemented by the City of Hope and the American Association of Colleges of Nursing (Figure 2B) (14). The ELNEC Module I Palliative Care Faculty Guide provides the following advice to HPC professionals:

QOL dimensions encompass the physical, psychological, social and spiritual dimensions of a person. The dying experience impacts all dimensions. The meaning of QOL: Differs from person to person, Can only be defined by the patient based on their own life experience, Important to examine aspects of each dimension from the patient's and family's perspective, Do not assume what "quality" means to them. Focus on both negative and positive attributes. Only assessing and focusing on fears, for example, misses the opportunity to help patients and families realize their hopes. QOL is considered throughout the illness/dying trajectory (including the time of death and the bereavement period) (15).

In addition, recent studies have emphasized the importance of assessing physical symptoms, spiritual needs, the control of physical symptoms, and spiritual care, and present QOL as an indicator for assessing care outcomes. In a study of 403 elderly patients with terminal cancer which used QOL as an outcome variable, the results showed that physical (frequency and intensity of symptoms), psychological (depression and despair), and spiritual (spiritual needs) variables accounted for 67 percent of the subjects' QOL. The worse a patient's physical and psychological state became, the lower his or her QOL became. By contrast, the higher the degree of spiritual experience, the higher the QOL (16).

3. The coping model

The present study introduces two models that view coping as an outcome of terminally ill patients' care. The first model

is the spirituality and religiosity model (17). This model focuses on patients' spirituality, religiosity (antecedents), coping strategies (intervening factor), and coping (outcome variable). It argues that spirituality consists of lived experiences that occur among terminally ill patients and their families near the end of life. Spirituality influences the religious coping strategies of patients and their families, resulting in either adaptive or maladaptive behavior. This theory defines spirituality as an imperative factor in the adaptive strategies of terminally ill patients. However, although it is a practical theory that presents indicators for measuring adaptation as an outcome variable (physical, psychological, and spiritual pain, and QOL) and thus enables the assessment of specific effects of spiritual care, it does not propose specific methods regarding adaptation strategies (Figure 2C).

The second model also applies the coping concept proposed by Folkman et al. (18,19) to terminally ill patients' treatment (20). It argues that HPC can supplement the lack of specific adaptation strategies in the spirituality and religiosity model. Additionally, Daaleman (21) has found that, among spiritual care recipients, spiritual care helped in coping with illness. This coping model considers internal mechanisms (hope, dignity, meaning, reminiscence, courage, fighting spirit, and resilience) and external resources such as supportive and complementary therapies, magic and alternative therapies, psychopharmacology, psychotherapy, caregivers, volunteers, palliative care, and religion. The therapies that have been used at HPC include meaning-based therapies, dignity therapy, cognitive behavioral therapy, psychopharmacology, and supportive and complementary therapies (art, relaxation, and music) (22).

MODELS FOCUSING ON CARING IMPLEMENTATION

1. The spiritual care implementation model

This model requires varying degrees of expertise, and the chaplain, as the spiritual care specialist, must be fully involved in patients' medical care. The role of HPCTs in providing generalized spiritual care is to: 1) provide compassionate care by careful listening; 2) make a formal spiritual screening or history; 3) assess for spiritual distress or spiritual resources; 4)

integrate spirituality into the biopsychosocial assessment and treatment plan; 5) integrate patients' resources for strength, including their spiritual resources, into the care of patients; 6) work with specialists such as the Board Certified Chaplains; 7) recognize that the clinician-patient relationship is key to patients' healing; and 8) reflect on HPCTs' personal values and beliefs as essential to their calling of service to the patient as a whole person (Figure 3A) (23-25).

2. The existential functioning model

In the United States, national palliative care guidelines include spiritual care, particularly as they relate to existential concerns, life review, and the meaning of life. In the existential functioning perspective, HPCTs' role is to: 1) recognize the dynamic relationship among emotionally-related, existentially-related, and spiritually-related distress; 2) address processes causing distress and functional impairment; and 3) treat patients as integrated wholes, appreciating how they may need to draw on existential, spiritual, and emotional resources in to acknowledge, bear, and put into perspective the issues that matter most to them (13).

Puchalski et al. (25) and Koenig et al. (26) stress the relationship between spirituality and experiencing transcendent meaning in life. Spirituality consists of the concepts of religious issues (faith) and existential problem (meaning). The faith part of spirituality is frequently associated with religion and religious beliefs, whereas the meaning aspect of spirituality seems to be a more universal concept that can be found in religious or nonreligious individuals. Breitbart et al. (27), Chochinov et al. (28,29), and others have tested what has become known as meaning-centered psychotherapy and an intervention that supports patients' dignity. This literature documents that all the team members can participate in these therapies.

1) Meaning-centered psychotherapy (MCP)

According to Frankl (30), meaning of life involves a belief that one is accomplishing a unique role and purpose in one's life; a life associated with a responsibility to live according to one's full potential as a human being, thereby achieving a sense of peace, contentment, or even transcendence through connectedness with something greater than oneself. The goal of MCP is to enhance psychological and spiritual well-being and QOL

(1). An important part of spirituality can be guiding patients to reflect on meaning and purpose in their lives, along with their contributions and experiences. Two types of MCPs are presented in Table 1 (31,32).

2) Dignity psychotherapy (DP)

Dignity refers to the sense of self-esteem and self-worth (33). Patients whose personal psychological, spiritual, and physical needs are successfully met by the end of life may be perceived as having achieved a sense of dignity (34,35). Patients enrolled in DP are asked to record their life from the numerous angles they would want to remember most. They respond to a series of questions (Table 2) which focus on things they feel are most important and would want their loved one(s) to remember most. The recorded tape is transcribed, edited, and given back to the patients. This intervention can bring about a sense of legacy, coherence, enhanced identity, and emotional reconciliation (35).

3. The open pluralism view

The open pluralism view stresses the importance of differing spiritual and cultural traditions in forming relationships (22). Open pluralism refers to a "commitment to explore, understand, and hear the voices of the particular moral communities that constitute our culture" (36). Its goal is to have greater ownership of the role that the visions and commitments of communities including religious, cultural as well as secular humanist perspectives, have for institutional structures and social processes. People's own spiritual beliefs and practices are a source of comfort, coping, and support and are the most effective way to influence healing (37). Given the developing ethnic diversity within HPC settings, it has become essential that healthcare providers have some understanding of the complexities of culture and spirituality (24).

4. The spiritual-relational view

This conceptual nursing model explains spiritual care by nurse practitioners (NPs) and reflects the importance of the initial NP-patient relationship and spiritual assessment rather than NPs immediately implementing specific religious practices (Figure 3B) (38). This model consists of three interconnected circles (Figure 3B). Each circle represents an NP, patient, and

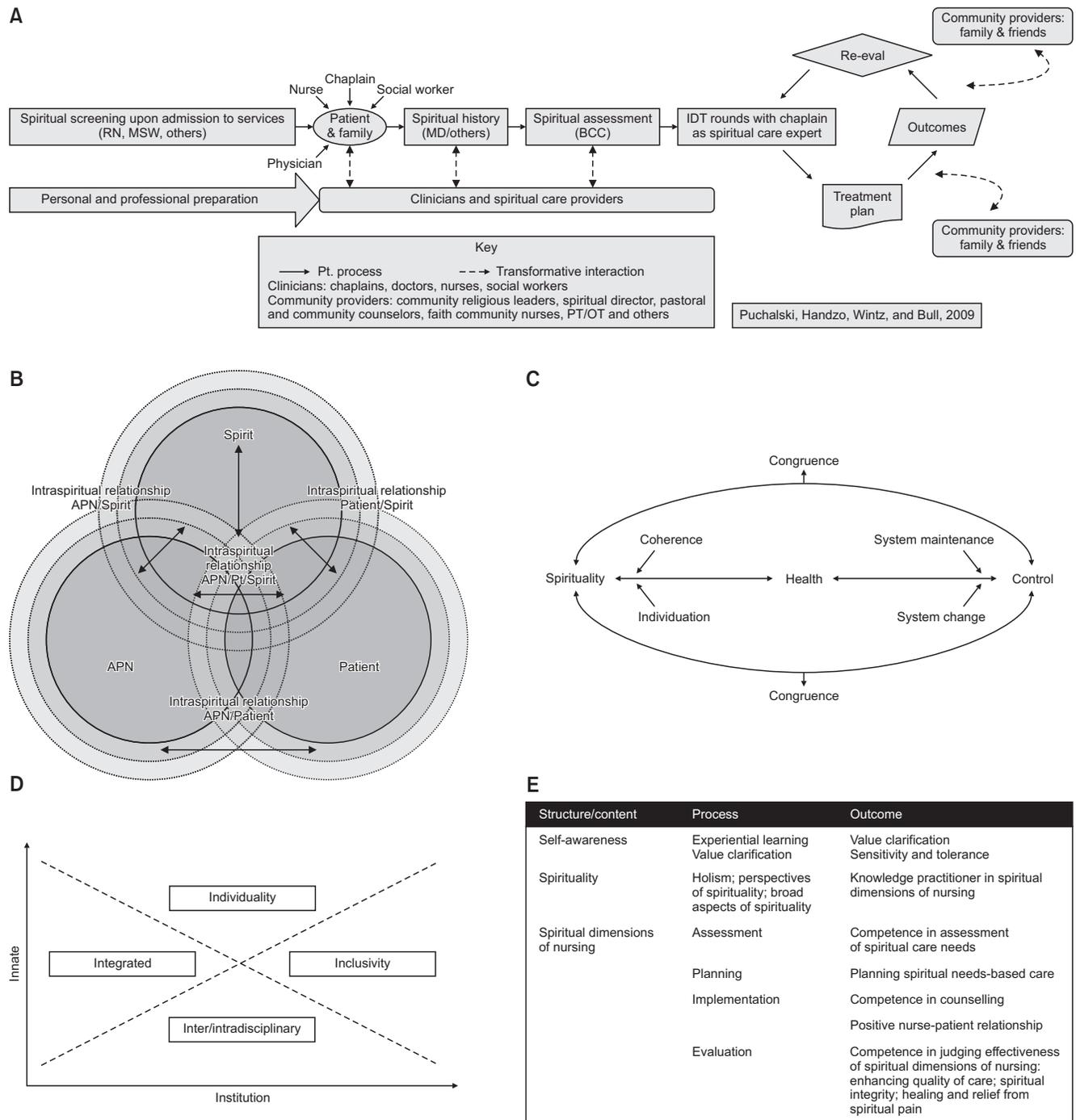


Figure 3. Models focusing on caring implementation. (A) Spiritual care implementation model. (B) Nursing model for the implementation of spiritual care by nurse practitioners. (C) The framework of systemic organization. (D) Principal components model. (E) The ASSET model.

Source 1: Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885-904.

Source 2: Carron R, Cumbie SA. Development of a conceptual nursing model for the implementation of spiritual care in adult primary healthcare settings by nurse practitioners. *J Am Acad Nurse Pract* 2011;23:552-60.

Source 3: Friedemann ML, Mouch J, Racey T. Nursing the spirit: the framework of systemic organization. *J Adv Nurs* 2002;39:325-32.

Source 4: McSherry W. The principal components model: a model for advancing spirituality and spiritual care within nursing and health care practice. *J Clin Nurs* 2006;15:905-17.

Source 5: Narayanasamy A. The puzzle of spirituality for nursing: a guide to practical assessment. *Br J Nurs* 2004;13:1140-4.

Table 1. Meaning-Centered Psychotherapy Intervention.

Session	Topic	
	MCP, as defined by Breitbart (2002)	MCP, as defined by Kang et al. (2009)
1	Concepts and sources of meaning: experimental exercises	Three natures of the human mind: Meaning of life, Freedom of will, and Will to meaning
2	Cancer and meaning: experiential exercises	Creative value is revealed by creative and productive activities such as hobbies or occupations including reasons to live
3	Meaning and historical context of life: exercises	Experiential value is obtained through life experiences by learning life values, communicating with useful persons, and enjoying the nature or arts with affection
4	Meaning and historical context of life: exercises	Attitudinal value refers to acquiring a certain attitude toward suffering. Based on the way suffering is acknowledged, the reason for life will not disappear until the end of one's life
5	Meaning and attitudinal values: limitations and finiteness of life	Importance of selection and responsibility in life-management
6	Meaning derived from creative values and responsibility	-
7	Meaning and experiential values: nature, art, beauty, and humor	-
8	Review and termination	-

MCP: Meaning-centered Psychotherapy.

Source 1: Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer* 2002;10:272-80.

Source 2: Kang KA, Shim JS, Jeon DG, Koh MS. The effects of logotherapy on meaning in life and quality of life of late adolescents with terminal cancer. *J Korean Acad Nurs* 2009;39:759-68.

Table 2. Dignity Psychotherapy Questions.

- Can you tell me a little about your life history, particularly those parts that you either remember most or think are the most important?
- When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles (e.g., family, vocational, community service) you have played in life?
- Why are they so important to you, and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others?
- What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parent, other [s])?
- Are there words or perhaps even instructions you would like to offer your family, to provide them with comfort or solace?
- In creating this permanent record, are there other things that you would like included?

Source: Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA* 2002;287:2253-60.

spirit. The first stage of spiritual care is to develop an interpersonal relationship between the NP and patient. During this phase of development, the NP can conduct either a written or an oral spiritual assessment to decide the patients. For an adept assessment, the NP must recognize and acknowledge the role of his or her own spirituality. The dotted circles represent the growth and evolving dynamic that can occur between the NP and patient. Simultaneously, the NP and the patient each have their own unique spirituality that is developed as an intra-spiritual relationship. As the NP and patient each de-

velop within their interpersonal spiritual relationship, the NP-patient relationship can enter the spirit dynamic. The NP can use the spirit dynamic as a support system for both the patient and themselves. In this way, the model becomes an evolving dynamic relationship between the NP, patient, and spirit (38).

5. The Framework of Systemic Organization

The Framework of Systemic Organization (FSO) (39) is introduced as an organizing structure by which nurses can engage in nurse-patient relationships to find out their patients'

spiritual needs (Figure 3C).

The right side of Figure 3C shows the two processes involved in gaining control; system maintenance and system change. The goal is to maintain individuals' physical function through measured planning and acting (system maintenance) while channeling energy, integrating knowledge, and changing behavior patterns to minimize unwanted changes (system change). The struggle to gain control takes place at the level of individuals, families, social groups, and the society at large. The left side of Figure 3C shows system processes of coherence and individuation used when individuals strive for spirituality. Coherence allows for a sense of unity within and is achieved through activities that nurture mind and spirit; religious practices, meaningful relationships with others, music and the arts, or experiencing the beauty of nature. Individuation, the second process inherent in spirituality, includes human effort to connect with and become a part of something outside of oneself through integration of knowledge, adjustment of values and opinions, and subsequent alteration of behavior patterns (39).

6. The principal components model

The principal components model (PCM) advances spirituality and spiritual care within HPC and contains six components; individuality, inclusivity, integration, inter/intra-disciplinary collaboration, innate, and institution (40). Individuality means individual perceptions of spirituality. Inclusivity refers to the need to capture and reflect the perceptions and concerns of all stakeholders involved in HPC delivery. Integrated spiritual care refers the idea of integrated care. The terms "inter" and "intra" in the context of inter/intra-disciplinary collaboration are defined as "inter" working with other HPCTs and "intra" working within the same HPCT. Thus, spiritual care comprises "team working." The reference to innate and institution includes the view that spirituality is innate within all individuals. It is critical in the advancement of spiritual care, namely the innate nature of spirituality and the institution. The PCM may assist HPCTs to participate in and overcome some of the structural, organizational, political, and social variables that impact spiritual care (Figure 3D).

7. The actioning spirituality and spiritual care in education and training (ASSET) model

The ASSET (5) offers a foundational structure promoting to have spirituality and spiritual care education and training in action within HPC (Figure 3E). This model offers workable definitions and theoretical perspectives rooted in theology, sociobiology, and philosophy. ASSET can be used as a foundational structure for the assessment of spiritual needs, and planning, implementing and evaluating spiritual care.

CONCLUSION

Spiritual care is one of the core components of HPC. The aim of this study was to identify care models that meet the actual spiritual needs of terminally ill patients and their families, by conducting a literature review using the Korean and international databases most commonly used in healthcare. After having analyzed the content of many spiritual care models, this study suggests that the holistic view of human beings is a common characteristic of HPC models. In addition, the models tend to agree that spirituality is an intrinsic aspect of human beings and an ontological characteristic that needs to be fulfilled, especially during life-crisis situations. HPCTs should all be equipped with the ability to assess terminally ill patients' spirituality. Moreover, this study has also analyzed and classified ten models of spiritual care through a literature review. Three of these models focused on spiritual care outcomes, and seven focused on the implementation of spiritual care. Based on these models, this study concludes that continuous clinical research is needed to build an optimal spiritual care model for HPC.

요약

영성은 인간의 본질적인 부분으로 말기 환자와 가족의 실제적인 영적요구 충족을 위한 영적돌봄은 HPC에서 가장 중요한 영역이다. 말기환자와 가족의 실제적인 영적요구에 부응하는 돌봄모형을 확인하기 위해 최근 보건의료계에서 가장 많이 사용하는 국·내외 database를 검색하여 분석한 결과, 영성은 전인적 존재인 인간의 본질적인 부분으로, 삶의 위기상황에 더욱 충족되어야 할 존재론적 특성으로서, 말기 환자의 영성평가는 HPCT이 기본적으로 갖추어야 할 역량임

이 확인되었다. HPC에 evidence based theory로 활용 가능한 총 10개의 모델이 제시되었다. 세 개의 모델들은 영적돌봄 결과에 초점을 둔 모델로서, spiritual health, QOL, and coping을 중요한 outcome으로 보는 모델들이었다. 영적돌봄수행에 초점을 둔 모델은 7개였으며, HPCT의 다학제간 협력을 통한 돌봄과정을 나타낸 ‘Whole-person Care Model’, 인간의 보편적인 실존적 요구충족이 보완된 ‘An Existential Functioning Model’, 대상자의 문화적, 그 외 다양성을 고려하는 ‘An Open Pluralism View’, HPCT와 말기환자와의 관

계중심모델인 ‘A spiritual-relational view’ and ‘The Framework of Systemic Organization’, 영적돌봄과정의 전체적 역동을 설명하는 ‘The principal components model’ and ‘The Actioning Spirituality and Spiritual care in Education and Training model’이 있다. 이러한 모델을 토대로 HPC에서 가장 최선의 영적돌봄 모델 구축을 위한 지속적인 임상연구 노력이 계속될 필요가 있겠다.

중심단어: 영성, 호스피스돌봄, 근거중심실무

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