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Conceptualization of psycho-existential suffering by the Japanese Task Force: The first step of a nationwide project

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ABSTRACT

Background and purpose: Although the relief of psycho-existential or spiritual suffering is one of the most important roles of palliative care clinicians, lack of an accepted conceptual framework leads to considerable confusion in research in this field. The primary aim of this article is to illustrate the process of developing a conceptual framework by the Japanese Task Force as the initial step of a nationwide project.

Methods: We used consensus-building methods with 26 panel members and 100 multidisciplinary peer reviewers. The panel consisted of six palliative care physicians, six psychiatrists, five nursing experts, four social workers or psychologists, two philosophers, a pastoral care worker, a sociologist, and an occupational therapist. Through 2 days of face-to-face discussion and follow-up discussion by e-mail, we reached a consensus.

Results: The group agreed to adopt a conceptual framework as the starting point of this study, by combining the empirical model from multicenter observations, a theoretical hypothesis, and good death studies in Japan. We defined "psycho-existential suffering" as "pain caused by extinction of the being and the meaning of the self." We assumed that psycho-existential suffering is caused by the loss of essential components that compose the being and the meaning of human beings: loss of relationships (with others), loss of autonomy (independence, control over future, continuity of self), and loss of temporality (the future). Sense of meaning and peace of mind can be interpreted as an outcome of the psycho-existential state and thus the general end points of our interventions. This model extracted seven categories to be intensively studied in the future: relationship, control, continuity of self, burden to others, generativity, death anxiety, and hope.

Conclusions: A Japanese nationwide multidisciplinary group agreed on a conceptual framework to facilitate research in psycho-existential suffering in terminally ill cancer patients. This model will be revised according to continuing qualitative studies, surveys, and intervention trials.

KEYWORDS: Existential suffering, Spirituality, Concept, Definition

INTRODUCTION

Relief of psycho-existential or spiritual suffering is one of the most important roles of palliative care clinicians. Recently, many empirical models, theoretical hypotheses, and clinical intervention studies have been reported in Western societies (Block, 2001; Kissane et al., 2001; Breitbart, 2002; Chochinov, 2002; Chochinov et al., 2002, 2005; Passik et al., 2004). In Japan, we have started a new nationwide program supported by the Ministry of Welfare, Health and Labor, named Third Term Comprehensive Control Research for Cancer, and orga-

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nized a multidisciplinary working group to explore effective intervention programs to relieve psycho-existential suffering in Japanese cancer patients. To date, however, Japanese researchers in this field have had no standard conceptual framework about psycho-existential suffering for research. This causes considerable confusion about the target population, the treatment goal, and the type of suffering that should be studied. This group has agreed that, before we plan each clinical research protocol, we should have an accepted definition and conceptual framework of psycho-existential suffering to be studied. Thus, at the beginning of this project, we intended to develop a conceptual framework. The primary aim of this article is to illustrate the development process of the conceptual framework by the Japanese task force.

METHODS

We used consensus-building methods based on face-to-face 2-day discussion, involving 26 panel members and about 100 multidisciplinary peer reviewers. The panel members were selected from those who had actively researched the psycho-existential suffering of cancer patients and who were expected to be principal investigators in this program. They consisted of six palliative care physicians, six psychiatrists, five nursing experts, four social workers or psychologists, two philosophers, a pastoral care worker, a sociologist, and an occupational therapist (see the Appendix). The peer reviewers voluntarily participated in this program after seeing Internet and journal announcements. On the first day, each panel member was required to present their previous or on-going research, and the peer reviewers provide oral or written comments. The next day, the panel members discussed an acceptable conceptual framework necessary to further develop clinical research protocols.

RESULTS

First, we clarified that the target population is terminally ill cancer patients, and that our primary aim was to establish a care strategy to minimize "psycho-existential suffering" at the end of life.

Then, after a 2-day discussion to evaluate empirical studies and major conceptual frameworks proposed in Japan (Morita et al., 2000, 2004*a*, 2004*b*; Kawa et al., 2003; Murata, 2003; Morita, 2004; Noguchi et al., 2004*a*, 2004*b*; Hirai et al., 2006; Miyashita et al., 2006), we agreed to adopt a conceptual framework as the starting point of this project, on the basis of the empirical model from multicenter observations (Morita et al., 2004*a*), a theoretical hypothesis (Murata, 2003), and good death studies (Hirai et al., 2006; Miyashita et al., 2006).

Brief Review

We initially identified three major empirical or theoretical research studies in Japan (Murata, 2003; Morita et al., 2004*a*; Hirai et al., 2006; Miyashita et al., 2006).

One multicenter observation study focusing on patient psycho-existential suffering conceptualized seven categories: relationship-related concerns (including isolation, concerns about family preparation, and relationship conflicts), loss of control (including physical control, cognitive control, and control over the future), burden to others, loss of continuity (including loss of role, loss of enjoyable activity, and loss of being oneself), uncompleted life tasks, hopelessness, and preparation for death (Morita et al., 2004*a*).

Murata proposed a theoretical model from a philosophical point of view (Murata, 2003). He defined "psycho-existential suffering" as "pain caused by extinction of the being and the meaning of the self" (p. 17). He assumed that psycho-existential suffering is caused by loss of essential components composing the being and the meaning for human beings, either of relationship with others, autonomy (independence, productability, and self-determination), or temporality (i.e., the future). This "three-dimensional ontological theory" is, although untested in empirical data, widespread in recent years in Japan. This conceptual framework further proposes the direction of care in psycho-existential suffering: as the recovery of relationships with others continuing beyond death, recovery of autonomy continuing beyond death (self-determination), and recovery of the future continuing beyond death. In this model, clinicians enable "spiritual care" by minimizing factors that weaken the being and meaning for patients and strengthening factors that support the being and meaning for patients in each dimension of relationships, autonomy, and temporality.

In addition, recent nationwide qualitative and quantitative studies identified the core concept of good death for Japanese (Hirai et al., 2006; Miyashita et al., 2006). Good death in Japan consists of physical and psychological comfort, good environment, good relationship with medical professionals, fighting against cancer, natural death, good relationship with family, preparation for death, physical and cognitive control, control over the future, role accomplishment and contributing to others, respect as an individual person, pride and beauty, not being a bur-

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den, life completion, unawareness of death, maintaining hope and pleasure, and religious/spiritual comfort.

Integration of the Empirical Findings about Suffering, the Theoretical Model, and Good Death Study

We tried to integrate these three models into one conceptual framework for this study project (Murata, 2003; Morita et al., 2004*a*; Hirai et al., 2006; Miyashita et al., 2006).

We first agreed that the seven categories in the empirical study could be incorporated into Murata's theoretical hypothesis (Murata, 2003; Morita et al., 2004*a*). *Loneliness, family preparation, and conflicts in human relations* (Morita et al., 2004*a*) are interpreted as *pain derived from relationships with others* (Murata, 2003; Table 1, central bar). *Loss of control (physical control, cognitive control, control over the future)* and *loss of continuity* (*roles, enjoyment, and being one self*; Morita et al., 2004*a*) are interpreted as *pain derived from loss of autonomy* (Murata, 2003). *Uncompleted life tasks, hopelessness, and acceptance/anxiety over death* (Morita et al., 2004*a*) are classified as *pain derived from the future* (Murata, 2003). Burden to others seems related to both relationships and autonomy, and we agreed that burden to others is pain derived from loss of autonomy and relationships. Thus, we agreed that all seven categories in the empirical observation (Morita et al., 2004*a*) can be incorporated into the three dimensions of relationships, autonomy, and temporality (Murata, 2003).

Second, we reclassified each component of the good death concept into the above model (Hirai et al., 2006; Miyashita et al., 2006). Besides religious/spiritual, environmental, physical, and medical components, all components of good death seemed successfully included in the model (Table 1, right bar). We thus agreed that the good death concept represents a state that patients evaluate as desirable, whereas suffering represents a state in which patients feel the substantial gap between the current status and desirable status (Kawa et al., 2003). Therefore, we conclude that the categories

Table 1. *Integration of an empirical study about suffering, a theoretical model, and good death studies*

	Theoretical model[a]	Empirical study about suffering[b]	Good death studies[c]
	Suffering is due to the loss of . . .	Relationship-related distress	Good relationship with family
		—Isolation/lack of support	—Being with family
		—Concerns about family preparation	—Family is prepared
	Relationship with others	—Conflicts in relationships	—Resolve conflicts
		Burden to others	No burden to others
Psycho-existential suffering	Autonomy (independence, productivity, and self-determination)	Loss of control	Physical and cognitive control
		—Physical control (dependency)	Control over the future
		—Cognitive control	Role accomplishment and contributing to others
		—Control over future	Respect as an individual person
		Loss of continuity	Pride and beauty
		—Role	
		—Enjoyable activity	
		—Being oneself	
	Temporality (the future)	Uncompleted life tasks	Life completion
		Acceptance/preparation	Preparation for death
		Hopelessness	Unawareness of death
			Maintaining hope and pleasure
			Religious/spiritual comfort
			Physical and psychological comfort
			Environmental comfort
			Medical components
			—Good relationship with medical professionals
			—Fighting against cancer
			—Natural death

[a]Murata (2003).
[b]Morita et al. (2004*a*).
[c]Hirai et al. (2006); Miyashita et al. (in press).

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revealed from the suffering study and the good death studies are basically identical.

Meaning and Peace of Mind as General Outcomes

We found, through discussion, that although meaning and peace of mind are often used as expressions of psycho-existential suffering in the literature (Block, 2001; Kissane et al., 2001; Breitbart, 2002; Chochinov, 2002; Chochinov et al., 2002, 2005; Passik et al., 2004), our model had no specific description of them. As stated by Heidegger (1962), meaning is an *existentiale* of Dasein, not a property attached to entities, lying "behind" them, or floating somewhere as an "intermediate domain." Hence only Dasein can be meaningful [sinnvoll] or meaningless [sinnlos]. Meaning is thus a basic concept that makes the being of oneself possible, and people ultimately feel meaninglessness when they lose the basic elements supporting them, namely, relationships, autonomy, or temporality. We therefore assume that meaninglessness is contained in the basis of all psycho-existential suffering, and cannot be separated as a single category, as is peace of mind. This interpretation is consistent with some psychometric instruments measuring sense of meaning and peace of mind as core concepts of the state of spiritual well-being (Noguchi et al., 2004*a*, 2004*b*). We concluded that, therefore, sense of meaning and peace of mind should be interpreted as an outcome of the psycho-existential state and thus regarded as the general end points of our intervention.

Summary of the Conceptual Model

On the basis of the above discussion, we developed an initial conceptual framework for this group (Table 2). In this framework, "psycho-existential suffering" is defined as "pain caused by extinction of the being and the meaning of the self," according to Murata's hypothesis (Murata, 2003). The suffering is caused by loss of either relationships, autonomy, or temporality. Therefore, to alleviate psycho-existential suffering, the care strategies should be to help patients recover their being and meaning of the self by (1) minimizing the perceived loss of relationships, autonomy, or temporality, and (2) exploring the novel source of relationships, autonomy, or the future continuing beyond death.

Relationships

Relationships refer to the first element that supports the being and meaning for human beings. People achieve a sense of meaning from relationships, and it is viewed as psycho-existential suffering for a patient to lose relationships that have provided being and meaning. Thus, if we minimize the perceived loss of relationships and support the patient to find relationships continuing beyond death, the patient's suffering can be alleviated.

Autonomy

Autonomy refers to the second element that supports being and meaning for human beings. People achieve a sense of meaning from independence, control over the future, a role, or self-continuity. It is viewed as psycho-existential suffering when a patient loses autonomy. Thus, if we minimize the perceived loss of autonomy and support the patient to find self-determination beyond death, the patient's suffering can be alleviated.

Core concepts include: *control* (physical control, cognitive control, and control over the future), *continuity of the self*, and *burden to the others*.

Temporality

Temporality refers to the third element that supports being and meaning for human beings. People create the future by accepting the existence of a past that has already occurred, and opening possibilities in the future in the reality into which they have been cast, and find meaning in the present by trying to realize the envisioned future (Kawa et al., 2003). Therefore, it is viewed as psycho-existential suffering when a patient loses the future. Thus, if we minimize the perceived loss of future and support the patient to find the source of a future continuing beyond death, the patient's suffering can be alleviated.

Core concepts include: *generativity*, *death anxiety*, and *hope*.

Care Model

Finally, we developed a care model on the basis of the above conceptualization (Table 3).

In this model, we added patient-centered care, psychology, and psychiatry as conceptual backgrounds to the suffering concept, because we believe that clinicians should consider the patient's need for care (i.e., clinicians should select care options the patient actually wants), psychological vulnerability (i.e., clinicians should select care options the patient can tolerate), and psychiatric morbidity (i.e., clinicians should address treatable psychiatric disorders such as depression) in daily care provision.

In the suffering assessment, the origin of suffering should be explored throughout the three dimen-

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Table 2. *Conceptualization of psycho-existential suffering for the Japanese task force*

	The origin of suffering is the loss of . . .	Care principle: To help patients recover their being and meaning of self by . . .	Core concepts	Definitions
Psycho-existential suffering	Relationships	minimizing the perceived loss of relationships, and exploring the novel source of relationships continuing beyond death	Relationships	Comfort or discomfort related to relationships with others, such as wishing to be with family, knowing family is prepared, resolving interpersonal conflicts, and interpersonal guilts.
			Burden to others	Sense that one is a burden to family, medical professionals, and society.
	Autonomy	minimizing the perceived loss of autonomy, and exploring the novel source of autonomy continuing beyond death	Control	Sense/wishes of control over physical functioning (independence), cognitive functioning (metal alertness), and the future (control what happens in the future; medical conditions or personal affairs).
			Continuity of the self	Sense/wishes that the core of the self (role, enjoyable activity, beauty, pride, individualized value system) continues to be constant.
	Temporality	minimizing the perceived loss of the future and exploring the novel source of a future continuing beyond death	Generativity	Sense/wishes that what is important for oneself will be taken over, remembered, or last even after death.
			Death anxiety	Struggle with death-evoked anxiety in one's way, such as accepting, denying, fighting, or letting go.
			Hope	Sense/wishes of maintaining hope on a variety of levels, such as recovery, better quality of life, fulfillment of specific goals, meaning, or unspecific general expectations that something good may happen in the future.

sions of relationship, autonomy, and temporality. Care options include minimizing the perceived loss of relationships, autonomy, and temporality and helping patients to find the novel source of relationships, autonomy, and temporality continuing beyond death.

LIMITATIONS AND COMMENTS

This is merely the first step in exploring effective clinical approaches for suffering in terminally ill cancer patients. The primary aim of this process is not to develop an entirely acceptable or evidenced conceptual framework for all patients, but to develop an ad hoc model on the basis of which researchers can construct their research plans. Future qualitative studies, surveys, and intervention trials will be performed with reference to this initial model, and the model will be revised. Especially, we should focus on several areas for which we have not had adequate discussion, such as the potential role of religious/spiritual comfort and environmental factors (e.g., role of nature in perceived suffering) for Japanese patients.

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Table 3. *Care model of psycho-existential suffering*

Background	Assessments	Plan
• Patient-centered care	• Patient needs: what degree of involvement of medical professionals does the patient want?	• Select care options that the patient wants
• Psychology, Psychiatry	• Personality (vulnerability): what degree of invasive approach can the patient tolerate? • Psychiatric diagnoses: Does the patient have treatable psychiatric disorders?	• Psychological/psychiatric treatments
• Suffering	• Suffering assessment • Identify origin of suffering: relationships, autonomy, or temporality	• Suffering care options 1. Minimizing the perceived loss of relationships, autonomy, or temporality 2. Help the patient to find the novel source of relationships, autonomy, or temporality continuing beyond death

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APPENDIX: PANEL MEMBERS

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