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SHORT COMMUNICATION

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Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan

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Abstract *Background:* Although alleviation of existential distress is important for terminally ill cancer patients, the concept of existential distress has not been fully understood. The aim of this study was to categorize existential concerns of Japanese terminally ill cancer patients and explore care strategies based on the categorizations. *Methods:* A multicenter cross-sectional study in 88 terminally ill cancer patients receiving specialized inpatient palliative care was performed. The nurses explored patient existential concerns by asking several key questions, and recorded the answers that they considered typically described the patients' concerns. All statements recorded by the nurses were analyzed using content analysis methods. *Results:* A total of 89 statements were subjected to analysis. The categories and their prevalence were: relationship-related concerns (22%; isolation, concerns about family preparation, conflicts in relationship), loss of control (16%; physical control, cognitive control, control over future), burden on others (4.5%), loss of continuity (10%; loss of role, loss of enjoyable activity, loss of being oneself), uncompleted life task (6.8%), hope/hopelessness (17%), and acceptance/preparation (25%). *Conclusions:* Existential concerns of Japanese terminally ill cancer patients were categorized as relationship-related concerns, loss of control, burden on others, loss of continuity, uncompleted life task, hope/hopelessness, and acceptance/preparation. These themes seemed to encompass universal human suffering beyond cultural differences, and this conceptualization may contribute to the development of effective therapeutic interventions to alleviate existential distress.

Keywords Existential distress · Spiritual care · Palliative care · Neoplasms

Introduction

Comprehensive care to alleviate the existential distress of terminally ill cancer patients is one of the main focuses of recent medical literature [1, 12]. Empirical studies have suggested that terminally ill cancer patients have a variety of existential concerns, associated with serious psychological morbidity such as desire for death and suicide [3, 5, 8, 9, 18, 23]. Existential distress described in the literature includes hopelessness, dependency, loss of control, loss of self-continuity, relatedness/isolation, meaninglessness, and loss of dignity [2, 3, 5, 6, 7, 8, 9, 14, 15, 18, 21, 23]. However, these concepts have not been fully supported by empirical data, and few studies have been performed in Japan [11, 16, 22]. Therefore, the primary aim of this study was to categorize existential concerns of Japanese terminally ill cancer patients and explore effective care strategies based on the categorizations.

Subjects and methods

This was a database survey on consecutive terminally ill cancer patients admitted to one of the four palliative care units of the Japanese Association of Hospice and Palliative Care Units.

The nurses were requested to explore patient existential concerns by asking several key questions: “What is your greatest concern?”, “Are there any concerns about your family?”, “What is the most important thing for you now?”, “What is your goal or expectation?”, and “Do you have any concerns about the future?” Then the nurses recorded the answers that they considered typically described the patients’ concerns. This assessment was completed within a week after admission as part of daily practice, and no structured interview format or tape-recording methods were used. Religious concerns were not specifically addressed, because our primary interests were existential distress rather than religious distress, and many Japanese have no specific religion.

All statements recorded by the nurses were analyzed using content analysis [13]. Concerns were defined as needs or distress expressed by the patients. First, two groups each of two raters independently categorized these statements with regard to similarities and differences in their meanings in the context, and discordance was then resolved through discussion. The raters were a palliative care physician (principle investigator), a hospice nurse, and two nurses from the academic institution who participated in another qualitative study to investigate the spirituality of Japanese terminal patients [11]. The validity of the categorization was confirmed by consensus of the authors. The percentages of the total number of patients who expressed concerns in each category were calculated.

Ethical and scientific validity was confirmed by the institutional review boards of each hospital.

Results

Of 211 patients enrolled in the original database survey, 123 were excluded from analysis due to cognitive impairment, inability to communicate verbally, and/or no data recorded. We therefore obtained a total of 89 statements from 88 patients. The median age of the patients was 66 years (range 25–94 years), and 58 (66%) were male. Primary tumor sites were: colon/rectum (17), lung (15), liver/bile duct/pancreas (15), stomach (13), genitourinary (10), head and neck (7), breast (3), and others (8). The ECOG performance statuses were: 1 or 2 (15), 3 (38) and 4 (35). The diagnosis of malignancy was explicitly disclosed in 80 patients (91%).

Table 1 Existential concerns of Japanese terminally ill cancer patients

	Prevalence (%)
Relationship-related concerns	22 (*n*=19)
Isolation	
Concerns about family preparation	
Conflicts in relationship	
Loss of control	16 (*n*=14)
Physical control (dependency)	
Cognitive control	
Control over future (uncertainty)	
Burden on others	4.5 (*n*=4)
Loss of continuity	10 (*n*=9)
Loss of role	
Loss of enjoyable activity	
Loss of being oneself	
Uncompleted life task	6.8 (*n*=6)
Hope/hopelessness	17 (*n*=15)
Acceptance/preparation	25 (*n*=22)

Table 1 summarizes the categories identified and the prevalence rates. A total of 7 categories and 13 subcategories were identified. Existential concerns related to relationship were: (1) isolation, (2) concerns about family preparation, and (3) conflicts in relationship. Isolation was expressed as the patients’ need for being with or receiving support from their loved ones, generally family members, such as “I feel lonely and want my wife to be close to me” and “my wife is a big support for me. I want her to be always with me”. Concerns about their family preparation included patients’ concerns about the family’s preparation for the patient’s death and the family’s life after the patient’s death, such as “I worry how my wife will get along after I die” and “I worry about the future of my son”. Conflicts in relationship means a practical problem in the patient-family relationship, such as “I have concerns about the relationship with my (common-law) husband and children”.

The category loss of control was classified into three subcategories: physical control, cognitive control, and control over one’s future. Loss of physical control was related to inability of self-care and daily activity, typically expressed as “I feel shameful when I become unable to do things that I have always done myself”. Loss of cognitive control was related to lowered mental activity, expressed for example as “I would rather die if I have to use morphine and remain half unconscious, not knowing whether I am alive or dead”. Loss of control over one’s future was related to distress from the uncertainty of when death would come, what would happen, and uncertainty about the dying process, such as “I am seized with thoughts of when and how death will come to me” and “I am confused, because I just don’t see how things will turn out in the future”.

Burden on others was typically expressed as “I just want to drop dead one day without bothering my family”, which was associated with both relationship and loss of physical control. Loss of continuity was expressed as the patients’ need to maintain their role and enjoyable activity, and to be themselves as they had been, such as “I want to go back to missionary work again to help others”, “I want to enjoy living here, since I can feel alive most when I am talking like this”, and “I want to live in my own way”.

Uncompleted life task was recognized by patient expressions indicating that they had work, hobbies, legal affairs to arrange and funerals to be completed before death, such as “I have things to tell my family about, like the house and the work.” Hope/hopelessness included broad areas of patient life, such as completion of a new house, birth of a child, the ballet show of a grandchild, returning home, and cure of the disease. Existential concerns related to acceptance/preparation were seen in patients who did not accept the imminence of death, did not sufficiently prepare for death, or felt significant death anxiety, typically stated as “I don’t want to die” and “I fear that I am going to die”.

Discussion

This study is the first to categorize existential concerns expressed by non-selected Japanese terminally ill cancer patients. A total of seven categories of existential concerns were identified: relationship-related concerns, loss of control, burden on others, loss of continuity, uncompleted life task, hope/hopelessness, and acceptance/preparation. These are generally consistent with a previous qualitative study about spirituality in Japanese, a preliminary observational study from a single Japanese inpatient hospice, and many empirical studies from Western culture [2, 4, 11, 14, 15, 16, 19, 20, 21]. This suggests that the themes identified in this study are universal aspects of human suffering beyond cultural differences.

Previous studies illustrate relationship-related concerns as a single term such as “maintaining relationships”, “social support”, “relations”, “relational pain/abandonment”, and “someone to talk to” [2, 4, 11, 14, 15, 19, 21]. This study suggests, however, that a further subcategorization of isolation, concerns about family preparation, and conflicts in relationship could be useful to describe patient conditions more precisely. Similarly, loss of control has been described as “independence/dependency”, “clear decision-making/autonomy”, “uncertainty”, or overall “control” in previous studies [2, 4, 11, 16, 19, 20]. This study identified three specific areas influenced by sense of control, namely, physical control (independence), cognitive control (autonomy), and control over the future (uncertainty). We believe that this classification could be useful in understanding which area is the chief component of a specific patient’s distress related to loss of control.

The category of “loss of continuity” includes three areas: role, enjoyable activity, and being oneself. Although this corresponds to “continuity”, “role”, “contribution”, “loss of previous identity”, “loss of self”, and “cosmetic loneliness” described in previous studies [4, 11, 14, 16, 20], we think that this category might include heterogeneous concepts, compared with other categories. Further studies should clarify whether this category is the best description for this type of existential suffering. On the other hand, the remaining categories coincide well with those described in previous studies: burden on others refers to “burden on others” and “troubling others” [4, 11, 16, 19]; uncompleted life task corresponds to “completion”, “legacy”, “generatavity”, and “unfinished business” [4, 16, 20]; hope/hopelessness corresponds to “hope” [4, 15, 16]; and acceptance/preparation corresponds to “acceptance”, “wishes for health”, “preparation”, “death anxiety”, “life after death”, “imagery of death”, “parting from life”, “fears”, and “death and dying” [4, 11, 15, 16, 20, 21].

The conceptualization of existential concerns suggests effective therapeutic strategies for each specific situation, in addition to general psychoexistential care including a support-expressive approach, person-centered care, and intensive symptom control. Table 2 shows the specific interventions we believe would be effective in alleviating each existential distress. The bases of these proposed care strategies are a systematic review of the Japanese and English literature, an opinion survey of Japanese experts, and discussion among the authors [10, 17]. These care strategies are similar to the practical model of Block [1] and Chochinov [4]. Clinical studies of the usefulness of these recommended care strategies are promising.

Despite its strengths in obtaining a non-selected sample from multiple centers, this study had several limitations. First, as the nurses recorded all data as a part of daily practice, some expressions about existential concerns that nurses could not identify might not have been recorded. Especially, we found no categories related to meaning, calm and peaceful state of mind, or guilt, which have frequently been identified as expressions of existential distress in terminally ill patients [2, 11, 16, 21], and the prevalence of each concern was generally low. This suggests a significant observer bias in identifying existential concerns that might not be always voluntarily reported by patients. Second, as all study populations were patients admitted to palliative care units, the findings could not be straightforwardly applied to other populations. Finally, the small sample size makes generalization of the findings difficult.

In conclusion, existential concerns of Japanese terminally ill cancer patients were categorized as relationship-related concerns, loss of control, burden on others, loss of continuity, uncompleted life task, hope/hopelessness, and acceptance/preparation. This classification can contribute to the development of effective therapeutic interventions to alleviate existential distress.

Table 2 Proposed care strategies for specific existential distress

	Specific care strategies
Relationship-related distress	
Isolation/lack of support	Help patients and family to share feelings and time
Concerns about family preparation	Facilitate family grief, support patients to complete life tasks for family
Conflicts in relationship	Identify practical problems and facilitate the resolution
Loss of control	
Physical control (dependency)	Maintain function by rehabilitation and orthotics; facilitate self-care and enhance cognitive control
Cognitive control	Minimize sedative medications; treat cognitive impairment; facilitate "letting-go"
Control over future (uncertainty)	Educate on predicted course; focus on emotional control, not what happens in future; facilitate "letting-go"
Burden on others	Help patients and family share feelings and discuss reality; support patient value
Loss of continuity (role, enjoyable activity, or being oneself)	Preserve achievable role/activity; explore a new role/activity; facilitate review of past accomplishments
Uncompleted life task	Help patients to complete life tasks
Hopelessness	Establish achievable goal; explore expectations after death
Acceptance/preparation	Support patients to receive available treatments and second opinion; support patient coping style; religious counseling

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