

Original Article

Self-Perceived Burden in Terminally Ill Cancer Patients: A Categorization of Care Strategies Based on Bereaved Family Members' Perspectives

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Abstract

Context. Terminally ill cancer patients often experience a self-perceived burden that affects their quality of life; however, no standard care strategy for coping with this form of suffering has ever been established.

Objectives. The objectives of this present study were 1) to investigate the prevalence of self-perceived burden among terminally ill cancer patients based on a survey of family members, 2) to assess the level of family perceived usefulness of expert-recommended care strategies, and 3) to categorize the care strategies.

Methods. The subjects were bereaved family members of patients who had died in certified palliative care units throughout Japan. The Good Death Inventory was used to evaluate patients' self-perceived burden based on the proxy ratings of family members. The perceived usefulness of care was assessed using a 27-item questionnaire developed by a focus group of palliative experts and a systematic review.

Results. A total of 429 responses (64%) received from a member of each of 666 bereaved families was analyzed. In their responses, 25% of the bereaved family members reported that the patient had experienced a mild self-perceived burden, whereas 25% reported that the patient had experienced a moderate to severe self-perceived burden. The family members recommended the following as

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particularly effective care strategies: “Eliminate pain and other symptoms that restrict patient activity (53%);” “Quickly dispose of urine and stools so that they are out of sight (52%);” and “Support patients’ efforts to care for themselves (45%).” A factor analysis showed that the expert-recommended care strategies could be categorized into seven different components.

Conclusion. Many terminally ill cancer patients suffer from a self-perceived burden. Family members recommended a variety of care strategies to alleviate patient-perceived burden. Palliative care specialists should have adequate knowledge of promising care strategies for alleviating patient-perceived burden. *J Pain Symptom Manage* 2010;40:224–234. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Self-perceived burden, suffering, palliative care, terminally ill

Introduction

The end-of-life period is challenging for both patients and their families, and there is growing interest in the effects of caregiving as experienced by both patients and their family members. Although many studies have investigated the issue of burden among caregivers, very few studies have focused on the individuals who receive the care in a palliative care setting. Terminally ill cancer patients who are the recipients of such care can feel that they are “a burden to others.”¹ A previous study defined the sense of self-perceived burden as “a multidimensional construct arising from the care recipients’ feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt at being responsible for the caregiver’s hardship.”²

However, medical professionals often undervalue the self-perceived burden experienced by terminally ill cancer patients although the perceived sense of burden has been found to be an important factor in achieving a good death in terminally ill cancer patients in both Western and Eastern cultures.^{3,4} For example, Steinhauser et al.⁴ found that although 89% and 81% of patients with advanced illnesses considered “Not to be a burden on family” and “Not to be a burden on society,” respectively, to be important factors in terms of achieving a good death, only 58% and 44%, respectively, of physicians considered them relevant. Several recent studies have shown that a self-perceived burden is not uncommon among terminally ill cancer patients, and

34% to 77% of the terminally ill cancer patients receiving specialized palliative care in those studies experienced a self-perceived burden.^{5–8} Moreover, self-perceived burden is associated with negative psychological outcomes, including suicidal ideation, loss of dignity, hopelessness, anxiety, and depression,^{1,5,8} and it has been identified as a relevant factor in clinical decisions, such as the choice of place of death, advance directives, and acceptance of treatment.¹ A self-perceived burden can thus often cause profound suffering and acts as a barrier to the achievement of an optimal quality of life by terminally ill cancer patients.

McPherson et al.^{2,6} and Wilson et al.^{2,8} have stated that palliative care clinicians should recognize patients’ self-perceived burden to others as a common and distressing concern for terminally ill patients. Based on their clinical experience, palliative care specialists have recommended specific care strategies, such as physical interventions to reduce disability and routine care performed out of consideration for the patient’s dignity.^{9–11} However, all of these recommended strategies have been proposed by medical professionals and not based on findings obtained from data regarding the actual patients themselves. Chochinov et al.⁵ investigated the burden to others experienced by terminally ill cancer patients and suggested that reducing perceptions of burden to others may have as much to do with strategies that target improved psychosocial well-being as it does with optimizing physical autonomy because their study demonstrated that sense of burden

was more strongly associated with psychological and existential factors, such as depression and hopelessness, than with degree of physical dependency. Despite the potentially high prevalence and clinical importance of patients' self-perceived burden, very few empirical studies have assessed care strategies for alleviating it. Given the profound impact of self-perceived burden on the quality of life of terminally ill cancer patients, the development of effective care strategies based on relevant studies is essential to providing patients with good palliative care.

We, therefore, concluded that it is very important to gain insight into the perceived usefulness of care strategies for alleviating patients' self-perceived burden, and that categorization of care strategies might be useful in developing a comprehensive care model for alleviating patients' self-perceived burden. Finally, to the best of our knowledge, no surveys designed to estimate the prevalence of such feelings has ever been performed in Asian countries.

This study had three primary objectives: 1) to investigate the prevalence of self-perceived burden among terminally ill cancer patients based on the impressions of bereaved families (see the *Methods* section in regard to the advantages and disadvantages of using proxy measures), 2) to assess the level of family perceived usefulness of expert-recommended care strategies, and 3) to categorize the care strategies for self-perceived burden of terminally ill cancer patients.

Methods and Subjects

This study was part of a large, cross-sectional, anonymous survey of the bereaved families of cancer patients that was conducted in Japan (the Japan Hospice and Palliative Care Evaluation [J-HOPE] study). A previous article described the survey methodology in detail.¹² Briefly, the primary aims of the J-HOPE study were to investigate the dying experience of cancer patients and evaluate the quality of care provided by certified palliative care units in Japan from the perspective of bereaved family members. The survey questionnaires of the J-HOPE study were composed of two sections: 1) common questionnaires targeting all the subjects for evaluating the care process (Care

Evaluation Scale) and death experience (Good Death Inventory) and 2) 12 additional questionnaires targeting a portion of the subjects for assessing further factors. The questionnaire to evaluate care strategies to alleviate the sense of burden (the aim of the present study) was included as one of these additional questionnaires.

Study Procedure

The two universal questionnaires were mailed to every bereaved family, but to avoid imposing an excessive burden on the eligible families, they were randomly divided into 12 groups, and only one of the additional 12 questionnaires was mailed to each group. This survey was conducted in June 2007, and questionnaires were mailed to nonresponding families again in August 2007. If the recipients did not wish to participate in the survey, they were asked to mail the questionnaires back with the words "no participation" written on them. Return of completed questionnaires was assumed to mean consent to participation in this study. The institutional review board at each hospital confirmed the ethical and scientific validity of this study.

Subjects

We recruited all 153 certified palliative care units of the Japanese Association of Hospice and Palliative Care Units that had been approved before September 2005. One hundred of them ultimately participated in the study.

We asked each institution to identify bereaved family members of consecutive patients who had died between November 2004 and October 2006 (one family member per patient, up to 80 subjects at each institution). The mean interval between the date of death and the date of the survey was 13 (standard deviation [SD] = 4) months, and that interval was consistent with the intervals in previous studies whose mean interval between patient death and time of the survey was 13 months (SD = 13) and 12 (SD = 1) months, respectively.^{13,14} The primary physicians identified potential participants on the basis of the following inclusion criteria: 1) bereaved family member of a cancer patient who had died in the palliative care unit, 2) patient at least 20 years of age at the time of death, 3) bereaved family member at least 20 years of age,

4) capable of filling out and returning a self-report questionnaire, and 5) absence of serious psychological distress in the view of the primary physician.

Based on our previous experience, the last criterion was adopted on the assumption that the primary physicians would be able to identify family members who would experience a serious psychological impact as a result of taking the survey.

The rationale used to select the bereaved family members as subjects, despite the fact that patient-reported perceived burden has been found to not be completely consistent with the actual burden reported by the family,¹⁵ was based on the following: 1) family members served as proxies; the study did not evaluate the burden actually experienced by the family members; 2) the family members were expected to be capable of recommending potentially useful strategies for alleviating patient-perceived burden because they experienced the entire course of the patients' disease, including the period when the patient was too ill to participate in a study that required an interview or completion of a questionnaire; and 3) the results of a previous study showed only a weak association between patients' symptoms and proxy reports;¹⁶ however, we think that using proxies is a valid alternative when the target population consists of very frail or weak subjects, such as terminally ill patients.¹⁷

A total of 7955 bereaved family members were included in the original J-HOPE study, and our survey targeted a total of 666 family members (about 1/12 of the J-HOPE study population).

Questionnaires

Patient's Self-Perceived Burden From the Bereaved Family Member's Perspective. Self-perceived burden was evaluated by using a 1-item subscale of the Good Death Inventory short version.¹⁸ The Good Death Inventory consists of 18 subscales designed to quantify the levels required for a terminally ill cancer patient to achieve a good death from a bereaved family member's perspective, and its reliability and validity have been established.¹⁶ The item regarding sense of burden is "Patient was distressed for feeling a burden to others," and the subject is asked to rate it on the following 7-point scale:

1, absolutely disagree; 2, disagree; 3, somewhat disagree; 4, unsure; 5, somewhat agree (defined as a "mild" level in this study); 6, agree (defined as a "moderate" level in this study); and 7, absolutely agree (defined as a "severe" level in this study).

Effective Care Strategies From the Bereaved Family Member's Perspective. We developed a questionnaire to assess the means of effective care strategies for alleviating self-perceived burden to others based on a systematic review of the literature retrieved by a Medline search and hand searches^{9,11,19-25} and based on a focus group discussion conducted by an interdisciplinary panel of palliative care experts (three palliative care physicians, one certified oncology nurse specialist, and two certified palliative care nurses). The Medline search terms used were "spiritual or existential" and "terminal or palliative or hospice or neoplasm or cancer," and "care or treatment or therapy or intervention." The systematic review included original articles, review articles, and textbooks, and as many potentially useful strategies for alleviating perceived burden as possible were compiled, with no intent to conceptualize a variety of care strategies. The literature retrieved was first reviewed by one author (T. M.), and the final selections were made by four of the authors in conference. Based on the results of the review and discussion, an item pool consisting of 35 care strategies was created. We then narrowed the pool down to 27 items by weighing similarities and differences among the potential items and by arriving at a panel consensus among the researchers. The face validity was confirmed by a pilot test with five members of the general public as subjects (the general public was selected because we think that most members of the general public have and are able to rate the questionnaire items from a point of view similar to that of the bereaved family members who were the subjects of our study) and by an external review by 17 palliative care professionals. All 27 items were judged as appropriate for the means of effective care strategies for alleviating self-perceived burden to others (Table 1). The family members were asked to rate perceived usefulness of each of the 27 care strategies on a 3-point scale: "not useful," "useful," or "very useful."

Table 1
Usefulness of Expert-Recommended Care Strategies for Reducing the Self-Perceived Burden of Terminally Ill Cancer Patients

	Very Useful	Useful	Not So Useful
	%		
Eliminate pain and other symptoms that restrict patient activity	53	40	1
Quickly dispose of urine and stools so that they are out of sight	52	37	1
Support patients' efforts to care for themselves	45	45	1
Present a variety of alternatives for daily life assistance from which the patient may choose (not just a single option)	45	43	3
Ask, "Is there anything I can do for you?" (not, "What do you need me to do?")	42	39	8
Make rounds at individually adjusted shorter intervals, so that patients do not have to call for a nurse as frequently	39	52	5
Place daily necessities within the patient's reach	39	52	4
Express appreciation for the patient's cooperation by saying, "Thanks for your patience"	39	39	14
Arrange an environment that maximizes the patient's physical functioning	38	51	4
Tell patients clearly that their families do not see them as a burden	38	48	8
Tell patients that they are the same person as they were before their illness (e.g., an important person to their children)	36	46	7
Do not let patients see that you are busy (e.g., recover your breath before entering the room)	35	53	6
Do not say, "I will do this for you"	35	45	9
Express some words of gratitude to the patient (e.g., "Thank you for letting me help you")	35	46	10
Relieve the caregiving burden on the family to help maintain their health (respite)	34	51	9
Ensure that patients can continue what they regard as important (e.g., interacting with their families, work)	33	52	4
Arrange an opportunity for patients to be able to talk frankly with their families about their sense of being a burden	32	49	13
Provide patients with the view that everyone inevitably needs help from others at some time in their life	32	44	14
Ensure that patients can continue using cosmetics to maintain their appearance	31	53	5
Set your pager volume on "low" so that it will not be noticed by patients	29	53	9
Do not intervene when patients want to care for themselves, even if it takes longer	29	56	5
Tell patients that their feelings of being a burden to others is an expression of their love for their caregivers	29	50	9
Offer patients the perspective that this period when they need help is relatively short	28	46	14
Provide patients with an opportunity to reflect on their unique contribution to their family and society before the onset of their illness	27	55	6
Recommend rehabilitation and aids to improve their physical function	26	56	9
Assist the patient to convey what they value to the family so that something of the patient's essence will survive beyond their death (e.g., a legacy letter)	24	54	9
Minimize psychotropic use, which might influence the patient's cognitive capacity	15	54	22

The values do not total 100% because of missing data.
 Decreasing order of usefulness (very useful).

The family members also were asked the patient's age and sex; their own age, sex, and relationship to the patient; time spent with the patient during the final week of life; and the interval between the patient's death and completion of the questionnaire.

Analyses

Descriptive statistics were used to assess the degree of burden and the perceived usefulness of each care strategy. To explore the underlying structure and categorize the 27 care strategies, an exploratory factor analysis was performed using the maximum likelihood method and promax rotation. The number of factors was

determined using a scree plot, and items with factor loadings of greater than 0.3 were retained. All analyses were performed using the Statistical Package for the Social Sciences, ver. 11.5 (SPSS, Inc., Chicago, IL).

Results

Questionnaires were mailed to 666 bereaved families, and a member of 469 families responded (response rate: 70%). Forty of those who replied refused to participate, and ultimately 429 responses were analyzed (effective response rate: 64%). Table 2 summarizes the background of the bereaved families and the

patients. The mean age of the patients was 71 years, and 43% of the patients were female. The most common relationship of the family member to the patient was spouse (45%), and the second most common was child (38%).

Prevalence of Self-Perceived Burden

Of the 429 bereaved families, 109 families (25%), 68 families (16%), and 38 families (9%) reported that the patients had experienced a mild, moderate, and severe self-perceived burden, respectively (Table 3).

Usefulness of Expert-Recommended Care Strategies for Reducing Self-Perceived Burden Among Terminally Ill Cancer Patients

Among the 27 care strategies, "Eliminate pain and other symptoms that restrict patient activity" (53%), "Quickly dispose of urine and stools so that they are out of sight" (52%), "Support patients' efforts to care for themselves" (45%), "Present a variety of alternatives for daily life assistance from which the patient may choose (not just a single option)" (45%), and "Ask, 'Is there anything I can do for you?' (not, 'What do you need me to do?')," (42%) were rated by 40% or more of

Table 2
Backgrounds of Bereaved Families and Patients
(n = 429)

Characteristics	No. of Participants (%)
Patient	
Age, years (mean ± SD)	71 ± 11
Sex	
Male	241 (57)
Female	184 (43)
Bereaved families	
Age, years (mean ± SD)	58 ± 13
Sex	
Male	125 (30)
Female	298 (70)
Relationship with patient	
Spouse	191 (45)
Son/daughter	162 (38)
Son-in-law/daughter-in-law	29 (7)
Brother/sister	23 (5)
Parent	7 (2)
Other	13 (3)
Interval from patient's death, months (mean ± SD)	13 ± 4
Time with patient in the final week	
Every day	280 (65)
Four to six days	56 (13)
One to three days	74 (17)
None	14 (3)

The values do not total 100% because of missing data.

Table 3
Prevalence of Self-Perceived Burden (n = 429)

	Rating	No. (%)
Patient was distressed for feeling of being a burden to others	1. Absolutely disagree	21 (5)
	2. Disagree	46 (11)
	3. Somewhat disagree	42 (10)
	4. Unsure	81 (19)
	5. Somewhat agree (mild)	109 (25)
	6. Agree (moderate)	68 (16)
	7. Absolutely agree (severe)	38 (9)

Response options quoted from the Good Death Inventory.

the respondents as "very useful" for relieving patients' self-perceived burden (Table 1).

By contrast, "Minimize psychotropic use, which might influence the patient's cognitive capacity" (15%) and "Assist the patient to convey what they value to the family so that something of the patient's essence will survive beyond their death (e.g., a legacy letter)" (24%) were rated "very useful" by 25% or fewer of the respondents.

Categories of Care Strategies for Reducing Self-Perceived Burden: Factor Analysis

A factor analysis resulted in the emergence of seven interpretable categories from the 27 care strategies: 1) offer different perspectives, 2) assist patients with their daily life activities in a natural manner, 3) strengthen the sense that the patient's value is intact, 4) avoid a condescending attitude, 5) facilitate communication between patient and family, 6) support patients' efforts to care for themselves, and 7) minimize patient disability (Table 4). One of these seven categories, "assist patients with their daily life activities in a natural manner," included three of the five care strategies rated as "very useful" by 40% or more of the respondents. The other two care strategies that were rated as "very useful" by 40% or more of the respondents were included in the category "avoid a condescending attitude" and the category "support patients' efforts to care for themselves," respectively.

Discussion

To our knowledge, this is the first study to assess the family-perceived usefulness of expert-recommended care strategies and categorize the care strategies, in addition to investigating

Table 4
Categories of Care Strategies for Reducing Self-Perceived Burden: Factor Analysis

Domain	Factor Loadings
Offer different perspectives	
Offer patients the perspective that this period when they need help is relatively short	0.77
Provide patients with an opportunity to reflect on their unique contribution to their family and society before the onset of their illness	0.74
Tell patients that they are the same person as they were before their illness (e.g., an important person to their children)	0.63
Tell patients that their feelings of being a burden to others is an expression of their love for their caregivers	0.57
Express some words of gratitude to the patient (e.g., "Thank you for letting me help you")	0.47
Express appreciation for the patient's cooperation by saying, "Thanks for your patience"	0.37
Assist patients with their daily life activities in a natural manner	
Place daily necessities within the patient's reach	0.69
Make rounds at individually adjusted shorter intervals, so that patients do not have to call for a nurse as frequently	0.62
Do not let patients see that you are busy (e.g., recover your breath before entering the room)	0.56
Set your pager volume on "low" so that it will not be noticed by the patients	0.52
Eliminate pain and other symptoms that restrict patient activity	0.49
Quickly dispose of urine and stools so that they are out of sight	0.39
Present a variety of alternatives for daily life assistance from which the patient may choose (not just a single option)	0.33
Strengthen the sense that the patient's value is intact	
Provide patients with an opportunity to reflect on their unique contribution to their family and society before the onset of their illness	0.65
Assist the patient to convey what they value to the family so that something of the patient's essence will survive beyond their death (e.g., a legacy letter)	0.63
Ensure that patients can continue using cosmetics to maintain their appearance	0.61
Ensure that patients can continue what they regard as important (e.g., interacting with their families, work)	0.59
Avoid a condescending attitude	
Ask, "Is there anything I can do for you?" (Not, "What do you need me to do?")	0.76
Do not say, "I will do this for you"	0.62
Facilitate communication between patient and family	
Arrange an opportunity for patients to be able to talk frankly with their families about their sense of being a burden	0.91
Tell patients clearly that their families do not see them as a burden	0.39
Relieve the care-giving burden on the family to help maintain their health (respite)	0.34
Support patients' efforts to care for themselves	
Do not intervene when patients want to care for themselves, even if it takes longer	0.91
Support patients' efforts to care for themselves	0.43
Minimize patient disability	
Recommend rehabilitation and aids to improve their physical function	0.69
Arrange an environment that maximizes the patient's physical functioning	0.55

Only items with factor loadings greater than 0.3 have been included.

the prevalence of terminally ill cancer patients with a self-perceived burden from family members' perspectives.

The results of this study revealed that approximately half of the terminally ill cancer patients in the certified palliative care units in Japan experienced some degree of self-perceived burden. According to the replies, 25% of the patients felt a moderate to severe self-perceived burden. This figure is generally close to those reported by patient and family studies conducted in Western countries, where the results of studies of terminally ill cancer patients indicated that 34%–77% of them felt some degree of burden and 19%–38% experienced moderate to severe levels of perceived burden.^{5–8} In addition, previous studies in

both Western and Asian countries have demonstrated that perceived burden to others, in addition to actual dependency, can cause profound distress among terminally ill cancer patients receiving palliative care.^{17,23,26–28} These findings confirm that many terminally ill cancer patients, even those receiving specialized palliative care services, actually suffer from a self-perceived burden, and a sense of burden seems to be a universal form of suffering that extends beyond cultural differences.

This study identified seven categories of potentially useful care strategies for alleviating patients' self-perceived burden: offer different perspectives, assist patients with their daily life activities in a natural manner, strengthen the sense that the patient's value is intact, avoid

a condescending attitude, facilitate communication between patient and family, support patients' efforts to care for themselves, and minimize patient disability.

"Offer different perspectives" refers to cognitive restructuring to alleviate patients' subjective feelings of burden. However, a considerable number of family members in the present study rated more than one item in this category as "not useful" (e.g., offer patients the perspective that the period during which they need help is relatively short). These findings suggest that a cognitive-restructuring approach that focuses on patient cognitions that give rise to the perception of burden may be challenging and should be applied only to selected patients. Further study is needed to clarify the actual efficacy of these approaches and to determine when, for whom, and how a cognitive-restructuring intervention should be provided.

"Assist patients with their daily life activities in a natural manner" includes many "routine" nursing practices, and a large proportion of family members rated items in this category as "very useful." McPherson et al.² found that some terminally ill cancer patients deal with their sense of burden by "hiding their needs" for care from their caregivers (families). In the home care setting, family members' remarks and/or attitudes, such as expressing their caregiving experience as a reward and not a burden, can be regarded as promising interventions for alleviating patients' distress. For inpatients, nurses are the main caregivers, and the findings in this study strongly suggest that medical professionals can have a positive influence on the self-perceived burden experienced by terminally ill cancer patients by adopting "routine" nursing practices. Potentially useful care strategies include: "Placing daily necessities within the patient's reach," "Make rounds at individually adjusted shorter intervals, so that patients do not have to call for a nurse as frequently," "Do not let patients see that you are busy (e.g., recover your breath before entering the room)," "Set your pager volume on 'low' so that it will not be noticed by patients," "Quickly dispose of urine and stools so that they are out of sight," and "Present a variety of alternatives for daily life assistance from which the patient may choose (not just a single option)." Although no studies have

investigated how everyday health care practices actually affect the sense of burden experienced by patients,²⁹ and it is very difficult to design empirical studies to estimate the definite efficacy of such routine practice interventions, qualitative studies on patients and their families, as well as nurse education programs, may enable further insight into how medical professionals can relieve patients' self-perceived burden through routine care practices.

The role of "strengthen the sense that the patient's value is intact" is largely consistent with the core concept of Chochinov's framework.²² Continuity of self, role preservation, and generativity are components of dignity-conserving repertoires to maintain dignity and focus on "continuing the essence of one's self" in the past, present, and future in his Dignity model. Furthermore, McPherson et al.² proposed that self-perceived burden can be understood on the basis of "equity theory," which posits that individuals strive to maintain a balance between benefits (receiving help and support) and contributions (giving help and support) based on the norm of equity in social relations. These conceptual frameworks indicate that strengthening the sense that the patient's present value is and will remain intact might alleviate the patient's sense of burden by increasing the patient's perception of the patient's contribution. Promising practical methods include a life review interview, maintaining the patient's current role, and enhancing generativity (e.g., dignity therapy).³⁰ These results indicate that clinical intervention, such as a life review interview, might help patients to recognize the value that they have had and might be a useful strategy for alleviating sense of burden.

"Avoid a condescending attitude," "Support patients' efforts to care for themselves," and "Minimize patient disability" refer to care strategies for increasing patient independence and autonomy. The findings in this study suggest that to alleviate patients' self-perceived burden, medical professionals should support patients' efforts to care for themselves and perform practical interventions to minimize patient disability, such as rehabilitation and the use of orthotics. Several studies have shown that rehabilitation programs that involve sufficient communication to set achievable goals are useful for maintaining patient

independence.^{31–34} On the other hand, several empirical studies have reported only a moderate association between the level of a patient's physical dysfunction and patient's self-perceived burden.^{34,35} These findings point to the importance of educating medical staff members that patient's self-perceived burden to others is not only a physical phenomenon but a component of total suffering, and that caring attitudes should be based on a thorough consideration of the relevance of patient autonomy and independence and not only of their level of physical activity. The intervention studies with the aim of evaluating physical therapy should include education about the basic attitudes of medical professionals; and the outcome measures should include patient's self-perceived burden, in addition to physical activity levels.²⁹

“Facilitate communication between patient and family” refers to the importance of close communication between patients and family members. McPherson et al.⁶ reported finding a relatively weak to moderate correlation between cancer patient's perceived burden and actual burden perceived by their families, and their findings were consistent with those obtained in regard to patients with neurological disease.^{16,35} It is noteworthy that 13% of the Japanese family members in the present study reported that facilitating direct communication between patient and family was “not useful” and that instead they preferred to have a medical professional act as an intermediary in discussions of the family's opinions. These findings suggest that in some cases in which the patient feels a self-perceived burden but the family members do not actually experience a burden, medical professionals can sometimes act as an intermediary to convey the family's feelings to the patient, rather than encouraging direct conversation. This may be especially true in Japanese culture, where a “direct” conversation might not be welcomed in certain complex situations.

In conclusion, many terminally ill cancer patients, even those receiving specialized palliative care services, experience a self-perceived burden to others. Family members generally perceive expert-recommended care strategies as being useful. These care strategies were categorized into seven different categories: offer different perspectives, assist patients with their

daily life activities in a natural manner, strengthen the sense that the patient's value is intact, avoid a condescending attitude, facilitate communication between patient and family, support patients' efforts to care for themselves, and minimize patient disability. Palliative care specialists should have adequate knowledge of these care strategies for alleviating the self-perceived burden experienced by terminally ill cancer patients. Future qualitative and quantitative studies should investigate the patient-perceived and family perceived usefulness of these interventions, and novel comprehensive interventions should be explored to alleviate patients' self-perceived burden.

The present study had several limitations. First, because the data were obtained from bereaved family members, not from the patients themselves, and the intervals between death and completion of the questionnaires were relatively long (more than one year), the estimated prevalence may have been distorted by observer bias (modest associations between patients' and proxies' ratings of self-perceived burden have been reported) and recall bias.^{16,36} Second, because the validity and reliability of the questionnaires used to assess the means of effective care strategies for alleviating self-perceived burden to others have not been rigorously confirmed, this may also have influenced the findings. Third, because this study focused on terminally ill cancer patients receiving specialized palliative care, the results may not be applicable to patients in other types of medical settings, especially in a community home setting, where the burden might be more problematic than in an inpatient setting. Finally, because distress in terminally ill cancer patients can be influenced by the patient's cultural background and the country's medical system,^{3,37} the findings in this study may not be applicable to patients in Western countries. Be that as it may, the usefulness of the findings in this study and the actual effectiveness of the suggested care model should be investigated in future empirical studies because the findings merely provide promising information for the development of novel intervention strategies to alleviate patients' self-perceived burden.

The present study also had several strengths. Two of them, the fact that the survey was relatively large scale and conducted nationwide and that the response rate was relatively high,

suggest a minimal selection bias in regard to the findings in palliative care settings in Japan.¹⁵

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