

Original Article

The Care Strategy for Families of Terminally Ill Cancer Patients Who Become Unable to Take Nourishment Orally: Recommendations from a Nationwide Survey of Bereaved Family Members' Experiences

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Abstract

Context. Anorexia is one of the most common symptoms in terminally ill cancer patients and causes considerable distress for both patients and their families.

Objectives. The primary aims of the present study were to clarify the level of the family-perceived emotional distress and necessity for improvement in professional practice when a relative becomes unable to take nourishment orally and explore the determinants of these outcomes. The ultimate aim was to develop an effective care strategy for family members of terminally ill cancer patients who become unable to take nourishment orally.

Methods. A cross-sectional anonymous nationwide survey was conducted involving 662 bereaved family members of cancer patients who had been admitted to 95 palliative care units throughout Japan.

Results. A total of 452 bereaved family members returned the questionnaires (effective response rate, 68%). Overall, 80% of family members experienced the situation where a terminally ill relative became unable to take nourishment orally. The reported level of family-perceived emotional distress was very distressing (38%) and distressing (33%). Responses to the family-perceived necessity for improvement in professional practice they received were much improvement needed (4%), considerable improvement needed (10%), and some improvement needed (46%). The independent determinants of a high level of family perceived

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emotional distress were a sense of helplessness and guilt, and belief that dehydration causes profound distress for dying patients. Independent determinants of a high level of family-perceived necessity for improvement in professional practice were a sense of helplessness and guilt, experience that health care providers did not pay enough attention to family members' concerns, and insufficient relief of the patient's symptoms.

Conclusion. A considerable number of family members experienced high levels of emotional distress when a terminally ill cancer patient became unable to take nourishment orally, and many perceived a necessity for improvement in professional practice they received. A recommended care strategy includes the following four major domains: 1) relieving the family members' sense of helplessness and guilt, 2) providing up-to-date information about hydration and nutrition at the end of life, 3) understanding family members' concerns and providing emotional support, and 4) relieving the patient's symptoms. Further research is needed to evaluate the effects of this care strategy on family members' outcomes, including clinical studies to obtain more accurate understanding of the symptomatic effects of hydration and nutrition in terminally ill cancer patients. *J Pain Symptom Manage* 2010;40:671–683. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Cancer, artificial hydration, family, end of life, anorexia

Introduction

Anorexia occurs in 39%–82% of terminally ill cancer patients,^{1–4} and 70%–87% of their family members experience considerable distress.^{5,6} In fact, family members are sometimes more distressed than the patients themselves.^{1,7} Palliative care is intended for not only the patients but also their family members, and one of the primary goals of palliative care is to relieve family members' distress.⁸ It is, therefore, important to develop care strategies to relieve the distress of family members who deal with a loved one's terminal anorexia. Learning about the experiences of family members of terminally ill cancer patients who are unable to take nourishment orally can contribute to establishing effective care strategies.

Several professional societies have published clinical guidelines for artificial hydration at the end of life,^{9–15} and a few guidelines make specific reference to care for family members. Multiple qualitative studies have explored the actual experiences of family members^{16–23} and provided meaningful important clinical implications. On the other hand, only a few quantitative empirical studies have investigated family members' experiences when a terminally ill relative becomes unable to take nourishment

orally, with a considerable limitation in generalizability because of small sample sizes.^{1–7}

The primary aims of the present study were thus to 1) clarify the levels of family-perceived emotional distress and the necessity for improvement in professional practice when a terminally ill cancer patient becomes unable to take nourishment orally and 2) explore the determinants of these factors. The ultimate aim was to develop a care strategy for family members of terminally ill cancer patients who become unable to take nourishment orally.

Methods

The present study was carried out as part of the Japan Hospice and Palliative Care Evaluation study, a cross-sectional anonymous nationwide survey of bereaved family members of cancer patients.²⁴ Of 126 certified palliative care units in Japan, 95 agreed to participate in the survey, and 662 bereaved family members were included. There were no data about the backgrounds between participating and nonparticipating institutions.

We mailed questionnaires to the patients' primary family member listed in the hospital medical chart. We asked them to have a primary caregiver respond in February 2007,

and mailed again in March 2007 to nonresponding subjects. If the family members did not want to participate in the survey, we requested that they return the questionnaire with “no participation” indicated. The completion and return of the questionnaire was regarded as consent to participate in this study. Ethical and scientific validity was confirmed by the institutional review board of each hospital.

Subjects

Primary physicians identified potential participants with the following inclusion criteria: 1) bereaved adult family members of an adult cancer patient who had died in a palliative care unit (one family member was selected for each patient), 2) capable of replying to a self-report questionnaire, 3) aware of the diagnosis of malignancy, and 4) no serious psychological distress recognized by the primary palliative care physician. The last criterion was the same as in our previous surveys^{5,25–28} and was adopted on the assumption that primary palliative care physicians were able to identify family members suffering from serious psychological distress because they were closely involved in caring for their relative in an inpatient care setting with a mean hospitalization period of 43 days.

Questionnaire

The questionnaire for the present study was developed by the authors on the basis of a systematic literature review and discussion among the authors.^{1–7,9–33} Face validity of the questionnaire was confirmed by a pilot test on 10 bereaved family members.

The primary endpoints of this study were the 1) level of family-perceived emotional distress when a terminally ill cancer patient became unable to take nourishment orally and 2) family-perceived necessity for improvement in professional practice they received when a terminally ill cancer patient became unable to take nourishment orally. These measurement methodologies were consistent with our previous studies.^{5,25–28}

We first asked whether the family member had experienced a situation in which a terminally ill cancer patient had become unable to eat or drink. We then asked family members who had this experience to answer two

questions regarding the primary endpoints: 1) “How much emotional distress did you feel when your relative became unable to eat or drink?” (rated on a 5-point scale as 1: no distress at all to 5: very distressed) and 2) “How much improvement in professional practice did you think was necessary when your relative became unable to eat or drink?” (rated on a 4-point scale as 1: no need for improvement to 4: need for much improvement).

The family members also were asked questions about 27 factors that were potential contributors to the primary endpoints, as conceptually classified into four categories before this survey.

Category 1 included five demographic variables: the patient’s age and sex and the responding family members’ age, sex, and relationship to the patient.

Category 2 included seven variables related to the condition of the patient and family members when the patient became unable to take nourishment orally at the end of life. These variables were examined by the degree of agreement with the following statements on a 5-point Likert-type scale of 1: strongly disagree to 5: strongly agree (1–3) or yes-no format (4–7): 1) family member wished that the anticancer treatments be continued, 2) family member was insufficiently prepared for the changes in the patient’s condition, 3) family member had sense of helplessness and guilt, 4) patient’s symptoms were not sufficiently relieved, 5) patient had fluid retention, 6) patient expressed clear wishes about artificial hydration, and 7) family member had the opportunity to communicate with physicians about the decision to use artificial hydration.

Category 3 included seven variables related to beliefs about artificial hydration at the end of life.^{15,30–33} These variables were evaluated by the degree of agreement with the following statements on a 4-point Likert-type scale of 1: strongly disagree to 4: strongly agree: 1) artificial hydration contributes to relief of the patient’s fatigue, 2) artificial hydration can exacerbate distress caused by edema and ascites, 3) withholding and/or withdrawing of artificial hydration can relieve distress caused by edema and ascites, 4) mouth care is more effective in alleviating dry mouth than artificial hydration, 5) withholding and/or withdrawing of artificial hydration shortens the patient’s

life, 6) dehydration causes profound distress for dying patients, and 7) artificial hydration is the minimum standard of care.

Category 4 included eight variables related to professional practices by health care providers when the terminally ill cancer patient became unable to take nourishment orally.^{9–23} These variables were evaluated by the degree of agreement with the statements on a 5-point Likert-type scale of 1: strongly disagree to 5: strongly agree: 1) explored what the family could do for the patient other than provide hydration and nutrition, 2) paid enough attention to the family members' concerns and provided emotional support, not only to the decision about artificial hydration, 3) made maximum efforts to enable the patient to take nourishment orally, 4) portrayed eating and drinking as satisfying or comforting rather than merely nourishing, 5) proposed a time-limited trial of artificial hydration when the family member could not make a decision, 6) reassured the family that a decline in oral intake is a part of the natural dying process, 7) instructed the family to withhold and/or withdraw artificial hydration without providing adequate information and emotional support, and 8) focused only on nutritional requirements or diet supplements rather than the wishes of the patient and family member.

Statistical Analyses

For the comparisons, the respondents were classified into two groups for each primary endpoint: 1) family members who rated their emotional distress level as "very distressed" or "distressed" (defined as a high level of distress) and others (low level of distress), and 2) family members who rated the necessity for improvement in professional practice as "much," "considerable," or "some" (high level of perceived necessity for improvement) and others (low level). These cut-off points were determined on the basis of the actual data distribution to divide the whole sample into appropriately sized comparison groups. Univariate analyses were performed using the Mann-Whitney test, *t*-test, or Chi-square test, where appropriate. Multiple logistic regression analyses were then performed in a forward-elimination fashion. All potential predictors with statistical significance were entered into the equation as independent

variables. We reported the factors that achieved $P < 0.1$ by multiple logistic regression analyses as the determinants because they had a clinically meaningful interpretation despite marginal statistical significance and the lower limit of the 95% confidence interval was 0.9 or more. All analyses were performed using the Statistical Package for the Social Sciences (ver. 11.0) (SPSS, Inc., Chicago, IL).

Results

Of the 662 questionnaires sent out, 495 family members responded (response rate, 75%). Forty-three family members who responded refused to participate, and thus we obtained 452 effective responses (effective response rate, 68%). We analyzed the data from the 354 family members who reported that their relative had become unable to take nourishment orally at end of life (Table 1).

Overall Level of the Family-Perceived Emotional Distress and Necessity for Improvement in Professional Practice

The degree of family-perceived emotional distress when a relative became unable to take nourishment orally was very distressing (38%, $n = 94$), distressing (33%, $n = 83$), slightly distressing (22%, $n = 55$), not so distressing (5.0%, $n = 12$), and not distressing at all (2.0%, $n = 4$). The family perceived necessity for improvement in professional practice was much improvement needed (4.0%, $n = 8$), considerable improvement needed (10%, $n = 22$),

Table 1
Patient and Family Member Characteristics

Patients	
Age \pm SD, years	71 \pm 12
Sex, n (%)	
Male	251 (56)
Female	196 (43)
Bereaved family members	
Age \pm SD, years	59 \pm 12
Sex, n (%)	
Male	147 (33)
Female	300 (67)
Relationship, n (%)	
Spouse	231 (47)
Child	161 (36)
Son/daughter-in-law	35 (7.7)
Sibling	16 (3.5)
Parent	11 (2.4)
Other	14 (3.1)

Some data do not add up to 100% because of missing values.
SD = standard deviation.

some improvement needed (46%, $n = 101$), and no improvement needed (40%, $n = 88$).

Family-Reported Emotions and Condition of Patients and Family Members

Sixty-nine percent of family members ($n = 287$) reported that they had a sense of helplessness and guilt when their relative became unable to eat or drink at the end of life. The proportions of family members who were unable to prepare sufficiently for the changes in the patient's condition and wished for anticancer treatments to be continued were 52% ($n = 211$) and 47% ($n = 193$), respectively. Moreover, 58% ($n = 240$) of family members reported that the patient had fluid retention symptoms, and 44% ($n = 189$) reported that the patient's symptoms were insufficiently relieved when they became unable to take nourishment orally. Fifty-seven percent of the family members reported that they had an opportunity to communicate with the physician about their wishes for artificial hydration, and they reported that 29% of patients expressed clear wishes about artificial hydration.

Family-Reported Beliefs About Artificial Hydration at the End of Life

Approximately 60% of family members agreed that artificial hydration contributes to relief of the patient's fatigue, dehydration causes profound distress for dying patients, and artificial hydration is the minimum standard of care (Table 2).

On the other hand, family members reported that they were significantly more likely to think that "artificial hydration can exacerbate distress caused by edema and ascites," "withholding

and/or withdrawing artificial hydration can relieve distress from edema and ascites," and "mouth care is more effective than artificial hydration in alleviating dry mouth" after actual experience in the palliative care units than before. Family members also reported that they were significantly less likely to think that "artificial hydration contributes to relieving the patient's fatigue," "withholding and/or withdrawing of artificial hydration shortens the patient's life," "dehydration causes profound distress for dying patients," and "artificial hydration is the minimum standard of care."

Family-Reported Professional Practice When a Patient Became Unable to Take Nourishment Orally

More than 60% of the family members reported that health care providers explored what family can do for the patient other than providing hydration and nutrition, paid enough attention to the family members' concerns and provided emotional support, not only the decision about artificial hydration, and made maximum efforts to enable the patient to take nourishment orally (Table 3). On the other hand, 5.6% of the family members reported that health care providers instructed the family to withhold or withdraw artificial hydration without providing adequate information and emotional support.

Determinants of Family-Perceived Emotional Distress and Necessity for Improvement in Professional Practice: Univariate Analysis

Neither patient nor family member characteristics were significantly associated with

Table 2
Family-Reported Beliefs About Artificial Hydration at the End of Life

	Before	After	P
Artificial hydration contributes to relieving patient's fatigue	2.8 ± 0.8 (62%)	2.4 ± 0.9 (38%)	<0.001
Artificial hydration can exacerbate distress caused by edema and ascites	2.1 ± 0.8 (23%)	2.5 ± 1.0 (39%)	<0.001
Withholding and/or withdrawing artificial hydration can relieve distress from edema and ascites	2.0 ± 0.8 (15%)	2.2 ± 0.9 (23%)	0.001
Mouth care is more effective in alleviating dry mouth than artificial hydration	2.8 ± 0.8 (50%)	3.0 ± 0.7 (68%)	<0.001
Withholding and/or withdrawing artificial hydration shortens the patient's life	2.7 ± 1.0 (43%)	2.4 ± 0.9 (38%)	<0.001
Dehydration causes profound distress for dying patients	3.2 ± 0.8 (60%)	3.0 ± 0.9 (51%)	0.001
Artificial hydration is the minimum standard of care	3.0 ± 0.8 (56%)	2.5 ± 1.0 (34%)	<0.001

The values express the mean ± standard deviation for the degree of agreement for each statement from 1: strongly disagree to 4: strongly agree. The proportion of respondents who answered "agree" and "strongly agree" is expressed in parentheses.

Table 3
Family-Reported Professional Practice When a Relative Became Unable to Take Nourishment Orally

	Agree or Strongly Agree, n (%)
Explored what family can do for the patient other than provide hydration and nutrition (e.g., massage, moistening the mouth)	278 (68)
Paid enough attention to the family members' concerns and provided emotional support, not only to the decision about artificial hydration	278 (68)
Made maximum efforts to enable the patient to take nourishment orally	259 (64)
Portrayed eating and drinking as satisfying or comforting rather than merely nourishing	188 (48)
Proposed a time-limited trial of artificial hydration when the family member could not make a decision	133 (35)
Reassured the family that a decline in oral intake is a part of the natural dying process	81 (21)
Instructed the family to withhold or withdraw artificial hydration without providing adequate information or emotional support	21 (5.6)
Focused only on nutritional requirements or dietary supplements rather than the wishes of the patient and family	16 (4.1)

family-perceived emotional distress or necessity for improvement in professional practice (Table 4). As shown in Table 5, the factors significantly associated with high levels of emotional distress were family members' wishes for anticancer treatments to be continued, insufficient preparation by family members for changes in the patient's condition, family members' sense of helplessness and guilt, and four family members' beliefs that artificial hydration can exacerbate distress caused by edema and ascites, that withholding and/or withdrawing artificial hydration shortens the patient's life, that dehydration causes profound distress for dying patients, and that

artificial hydration is the minimum standard of care. The factor significantly associated with low levels of emotional distress was family experience that health care providers proposed a time-limited trial of the artificial hydration.

The factors significantly associated with high levels of family-perceived necessity for improvement in professional practice were family members' wishes for anticancer treatments to be continued, insufficient preparation by family members for changes in the patient's condition, family members' sense of helplessness and guilt, insufficient relief of the patient's symptoms, health care providers' instructions

Table 4
Association Between Patient and Family Member Characteristics and Family-Perceived Emotional Distress and Necessity for Improvement in Professional Practice

	Emotional Distress		<i>P</i>	Necessity for Improvement		<i>P</i>
	Low, No. (%) <i>n</i> = 71 (29%)	High, No. (%) <i>n</i> = 177 (71%)		Low, No. (%) <i>n</i> = 88 (40%)	High, No. (%) <i>n</i> = 131 (60%)	
Patient						
Mean age ± SD, years	72 ± 14	70 ± 12	0.41	73 ± 12	70 ± 12	0.13
Sex (male)	29 (41)	78 (44)	0.67	46 (52)	48 (37)	0.051
Family member						
Mean age ± SD, years	60 ± 11	59 ± 13	0.76	59 ± 14	59 ± 12	0.69
Sex (female)	45 (63)	118 (67)	0.77	58 (66)	87 (66)	1.0
Relationship			0.29			0.98
Spouse	33 (46)	91 (53)		40 (45)	65 (50)	
Child	25 (35)	58 (33)		29 (33)	47 (36)	
Son/daughter in-law	7 (10)	13 (7.3)		11 (13)	8 (6.1)	
Sibling	2 (2.8)	5 (2.8)		5 (5.7)	1 (0.8)	
Parent	2 (2.8)	4 (2.3)		3 (3.4)	3 (2.3)	

SD = standard deviation.

Table 5
Determinants of Family-Perceived Emotional Distress and Necessity for Improvement in Professional Practice

	Emotional Distress Level					Need for Improved Care				
	Univariate Analyses			Multivariate Analysis ^a		Univariate Analyses			Multivariate Analysis ^b	
	Low (n = 71)	High (n = 171)	P	Odds Ratio (95% CI)	P	Low (n = 88)	High (n = 131)	P	Odds Ratio (95% CI)	P
Condition of patients and family members										
Family wishes for anticancer treatments to be continued ^c	2.7 ± 1.4	3.6 ± 1.2	<0.001			3.1 ± 1.5	3.5 ± 1.1	0.049		
Insufficient family preparation for changes in the patient's condition ^c	2.9 ± 1.2	3.7 ± 1.1	<0.001			3.2 ± 1.4	3.7 ± 1.0	0.008		
Sense of helplessness and guilt ^c insufficiently relieved	3.1 ± 1.3 26 (38)	4.2 ± 1.0 85 (52)	<0.001 0.061	2.5 (1.6–3.8)	<0.001	3.6 ± 1.4 32 (37)	4.1 ± 0.9 69 (56)	0.026 0.011	1.3 (0.9–1.6) 1.8 (0.9–3.4)	0.098 0.084
Fluid retention symptoms, n (%)	41 (60)	99 (58)	0.77			46 (54)	77 (61)	0.33		
Patient expressed clear wishes about artificial hydration, n (%)	14 (21)	53 (31)	0.15			24 (29)	38 (36)	0.44		
Opportunity to communicate with physicians about family wishes for artificial hydration, n (%)	35 (55)	100 (62)	0.37			52 (62)	74 (61)	0.89		
Beliefs about artificial hydration ^d										
Artificial hydration contributes to relieving patient's fatigue	2.7 ± 0.7	2.8 ± 0.8	0.20			2.6 ± 0.9	2.8 ± 0.8	0.18		
Artificial hydration can exacerbate distress caused by edema and ascites	2.3 ± 0.9	2.0 ± 0.8	0.032			2.0 ± 0.9	2.1 ± 0.8	0.30		
Withholding and/or withdrawing artificial hydration can relieve distress from edema and ascites	2.1 ± 0.8	1.9 ± 0.8	0.45			2.0 ± 0.9	2.0 ± 0.8	0.83		
Mouth care is more effective in alleviating dry mouth than artificial hydration	2.5 ± 0.9	2.8 ± 0.8	0.11			2.7 ± 0.9	2.6 ± 0.8	0.44		
Withholding and/or withdrawing artificial hydration shortens patient's life	2.4 ± 1.0	2.8 ± 1.0	0.018			2.7 ± 1.0	2.6 ± 1.0	0.85		
Dehydration causes profound distress for dying patients	2.7 ± 0.9	3.3 ± 0.8	<0.001	1.9 (1.1–3.5)	0.018	3.1 ± 0.9	3.1 ± 0.7	0.79		
Artificial hydration is the minimum standard of care	2.7 ± 0.8	3.0 ± 0.8	0.021			2.8 ± 0.9	2.9 ± 0.8	0.42		

(Continued)

Table 5
Continued

	Emotional Distress Level					Need for Improved Care				
	Univariate Analyses			Multivariate Analysis ^a		Univariate Analyses			Multivariate Analysis ^b	
	Low (n = 71)	High (n = 171)	P	Odds Ratio (95% CI)	P	Low (n = 88)	High (n = 131)	P	Odds Ratio (95% CI)	P
Professional practices ^c										
Explored what family can do for the patient other than providing hydration and nutrition	3.7 ± 1.0	3.5 ± 1.2	0.55			4.1 ± 0.9	3.5 ± 1.0	0.025		
Paid enough attention to the family members' concerns and provided emotional support, not only the decision about artificial hydration	3.7 ± 1.3	3.7 ± 1.1	0.64			3.8 ± 1.2	3.4 ± 1.2	<0.001	0.61 (0.4–0.8)	
Made maximum efforts to enable the patient to take nourishment orally	3.5 ± 1.3	3.6 ± 1.1	0.10			2.7 ± 1.4	2.7 ± 1.3	0.81		
Portrayed eating and drinking as satisfying or comforting rather than nourishing	3.1 ± 1.3	3.5 ± 1.2	0.049			3.8 ± 1.2	3.6 ± 1.1	0.29		
Proposed a time-limited trial of artificial hydration	2.7 ± 1.4	2.7 ± 1.3	0.94			3.4 ± 1.3	3.2 ± 1.2	0.81		
Reassured families that a decline in oral intake is a part of the natural dying process	2.5 ± 1.3	2.7 ± 1.1	0.37			2.6 ± 1.3	2.6 ± 1.2	0.66		
Instructed families to withhold or withdraw artificial hydration without providing adequate information or emotional support	1.5 ± 0.9	1.7 ± 1.1	0.53			1.3 ± 0.9	1.7 ± 1.0	<0.001		
Focused only on nutritional requirements or dietary supplements	1.5 ± 0.9	1.5 ± 0.8	0.65			1.3 ± 0.7	1.6 ± 1.0	0.021		

CI = confidence interval.

^aR² = 0.37.

^bR² = 0.69.

^cRated on a 5-point Likert-type scale of 1: strongly disagree to 5: strongly agree.

^dRated on a 4-point Likert-type scale of 1: strongly disagree to 4: strongly agree.

to withhold and/or withdraw artificial hydration without providing adequate information and emotional support, and care focusing only on nutritional requirements or dietary supplements rather than the wishes of the patient and family. In contrast, the factors significantly associated with low levels of family-perceived necessity for improvement in professional practice were the experience that health care providers explored what the family member could do for the patient other than providing hydration and nutrition, paid enough attention to the family members' concerns and provided emotional support (not only to the decision about artificial hydration), and portrayed eating and drinking as satisfying or comforting rather than merely nourishing.

Independent Determinants of the Family-Perceived Emotional Distress and Necessity for Improvement in Professional Practice

Multiple logistic regression analyses revealed that the independent determinants of high levels of family-perceived emotional distress were family members' sense of helplessness and guilt, and family members' belief that dehydration causes profound distress for dying patients (Table 5). Independent determinants of family-perceived necessity for improvement in professional practice were family members' sense of helplessness and guilt, insufficient relief of the patient's symptoms, and the experience that health care providers did not pay enough attention to family members' concerns.

Discussion

This was the first large quantitative study, to the best of our knowledge, to investigate family members' experiences when a terminally ill cancer patient becomes unable to take nourishment orally. The first important finding was the prevalence of family members who experienced considerable distress; 70% of family members were distressed or very distressed when faced with a situation in which a terminally ill loved one was unable to eat or drink. This figure was generally consistent with previous smaller studies.⁴⁻⁶ Furthermore, 60% of family members reported that some, considerable, or much improvement was necessary in the health care provider's care that they

received. This finding suggests that more effort is needed to improve the professional practice for family members of terminally ill cancer patients who are unable to take nourishment orally.

The second and most important finding of this study was the identification of factors related to family-perceived emotional distress and the necessity for improvement in professional practice when a terminally ill cancer patient becomes unable to take nourishment orally. The relevant factors include family members' sense of helplessness and guilt, family members' belief that dehydration causes profound distress, the experience that health care providers did not pay enough attention to family members' concerns, and insufficient relief of the patient's symptoms. Based on these findings, we recommend a four-domain care strategy for family members of terminally ill cancer patients who become unable to take nourishment orally: 1) relieving the family members' sense of helplessness and guilt, 2) providing up-to-date information about hydration and nutrition at the end of life, 3) understanding family members' concerns and providing emotional support, and 4) relieving the patient's symptoms.

Relieving Family Members' Sense of Helplessness and Guilt

In this study, about 70% of family members had a sense of helplessness and guilt. This was one of the independent and strong determinants of both family-perceived emotional distress and the necessity for improvement in professional practice. This result indicates that the relief of family members' sense of helplessness and guilt is very important in the care of family members of a terminally ill cancer patient who becomes unable to take nourishment orally. Providing nutrition and hydration have been viewed as a symbol of support, nurture, and care,²⁰ and family members who nourished a patient felt that they were providing essential care to lengthen patient survival.¹⁷ Conversely, when family members were not successful in nourishing the patients, they reported feeling helplessness and guilty in addition to frustrated, incompetent, and rejected.¹⁶ A "fighting back" strategy, in which family members sometimes crave the patient to eat or drink to lessen their sense of

helplessness and guilt, could lead to distress for some patients or strain the relationship between the patient and family members.^{16,18} The present study revealed that the health care professionals' behavior to explore what the family member can do other than providing nourishment was significantly associated with a reduction in family-perceived necessity for improvement in professional practice. These findings suggest that redirecting family members' care efforts into a more achievable direction, such as offering ice chips or moistened swabs and giving a massage, can help them cope with the sense of helplessness and guilt when a terminally ill relative is unable to take nourishment orally. Health care providers should see the relief of family members' sense of helplessness and guilt as one of the core goals for palliative care and explore in what ways family members themselves can feel they contribute to patients other than by offering nourishment. Psychology-based discussion about helplessness and guilt is beyond the scope of this study and should be addressed in future studies.

Providing Appropriate Information About Hydration and Nutrition at the End of Life

The present study revealed that belief that dehydration causes profound distress for the patient, withholding and/or withdrawing artificial hydration shortens the patient's life, artificial hydration can exacerbate distress caused by edema and ascites, and artificial hydration is the minimum standard of care were independent determinants of family-perceived emotional distress. Family members, however, reported that they were significantly more likely to think that dehydration does not cause profound distress for the patient, withholding and/or withdrawing artificial hydration does not shorten the patient's life, artificial hydration can exacerbate distress caused by edema and ascites, and artificial hydration is not the minimum standard of care, after actual experience in the palliative care unit than before. In some qualitative studies, family members said that, before being informed by health care providers, they were not aware that decreased oral intake is normal for terminally ill patients and that it caused minimal discomfort.^{18,23} The present study indicates that health care providers should offer the best up-to-date

information available to family members about hydration and nutrition at the end of life, especially that dehydration itself does not always cause profound distress for dying patients, that the withholding and/or withdrawing of artificial hydration does not always shorten the patient's life, and that artificial hydration can exacerbate distress caused by edema and ascites. Health care providers should recognize, however, that the education of patients and family members is not based on robust clinical evidence but rather on anecdotal evidence, in addition to expert opinion.³⁰⁻³³ A well-designed clinical study to obtain a more accurate understanding of the effects of hydration and nutrition in terminally ill cancer patients is clearly necessary, and in the meanwhile a case-by-case evaluation regarding hydration is vital.

Understanding Family Members' Concerns and Providing Emotional Support

The family experience that health care providers paid enough attention to family members' concerns and provided emotional support, not only medical decisions, was one of the independent determinants of the family-perceived necessity for improvement in professional practice. Their experience that family members were instructed to withhold and/or withdraw artificial hydration without adequate information and emotional support from health care providers was also significantly associated with the family-perceived need for improvement in professional practice.

Some family members of cancer patients expressed concern about lack of support for terminal anorexia and described that health care providers often avoided discussing terminal anorexia because they are not confident about how to support family members.^{7,16} Previous studies clarified that health care providers' empathy for the distress of family members was of great help in this setting.^{6,16} The findings of the present study reinforce that health care providers need to understand the concerns of the patient and family members and provide emotional support. In addition to the general importance of empathic communication, this study highlights the special meaning of food and artificial hydration for family members; they are more than nourishments to maintain physical function. Health

care providers should pay enough attention to family members' concerns, not only medical decisions, especially the meaning of food and artificial hydration, and provide sufficient emotional support. More research is needed to better understand how patients and family members cope with this difficult task, find the meaning in food and artificial hydration, and what is the most effective communication in this specific situation.

Relieving the Patient's Symptoms

In addition, this study revealed that insufficient relief of patient's symptoms was one of the main determinants of the family-perceived necessity for improvement in professional practice. Alleviation of the patient's symptoms has been identified as an essential component of palliative care^{8,30} and is indispensable for family members and patients. The results of the present study confirmed that health care providers should make maximum efforts to relieve the patient's symptoms.

Of note was that a health care provider's portrayal of eating or drinking as satisfying or comforting rather than merely nourishing was significantly associated with a low level of family-perceived emotional distress. Qualitative study has demonstrated that patients and family members sometimes welcomed interventions facilitating the enjoyment of food.¹⁶ These findings suggest that specifying the care goal (i.e., joy rather than nutrition) might be helpful for some family members in this difficult situation.

Despite the strengths of a large multicenter study, the present study had several limitations. First, the survey subjects are family members, and care strategies suggested from the present study are for family members not for patients. We do not, however, believe that this is a fault of the present study because family members are a main subject for palliative care. As the issues that are of concern to families might not be always shared by patients, whether care strategies proposed in the present study are useful for patients should be explored in other studies. Second, the study subjects were limited to the family members of patients who received specialized palliative care, so the findings cannot be generalized to other settings. Third, there may have been recall bias because of the retrospective design of the

study. Fourth, the cross-sectional design of this study cannot conclude the true causal relationships, especially in the interpretation of the family members' sense of helplessness and guilt. Fifth, the changes in the family members' beliefs before and after the use of palliative care units might reflect a response shift.

In conclusion, a considerable number of family members experienced high levels of emotional distress when a terminally ill cancer patient became unable to take nourishment orally. Many family members confronted with this situation perceived the necessity for improvement in professional care they received. The relevant factors include family members' sense of helplessness and guilt, the belief that dehydration causes profound distress for dying patients, the experience that health care providers did not pay enough attention to family members' concerns, and insufficient relief of the patient's symptoms. On the basis of these findings, we propose a four-domain care strategy for family members of a terminally ill cancer patient who becomes unable to take nourishment orally: 1) relieving the family members' sense of helplessness and guilt, 2) providing up-to-date information about hydration and nutrition at the end of life, 3) understanding family members' concerns and providing emotional support, and 4) relieving the patient's symptoms. Further research is needed to evaluate the effects of this care strategy on family members' outcomes, including clinical studies to obtain more accurate understanding of the symptomatic effects of hydration and nutrition in terminally ill cancer patients.

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