Palliative care and nutritional support for eating-related distress in patients with advanced cancer and their family members and questionnaires for evaluating eating-related distress among them

Koji Amano, M.D.
Department of Palliative Medicine,
Osaka City General Hospital
E-mail : kojiamano4813@gmail.com

Introduction

Management of cancer cachexia should address not only patients’ physical problems, but also psychosocial burdens of both patients and their families. Eating-related distress (ERD) is one of the most representative psychosocial burdens experienced by them during cancer. However, there is no validated tool for evaluating it.

Objectives

Summarizing the points of palliative care and nutritional support for ERD among patients and their families and presenting questionnaires for evaluating their ERD.

Methods

Narrative review and ad-hoc questionnaires.

Results

The points are described as below.

1. Management strategies for cancer cachexia should address not only patients’ physical problems, but also the psychosocial burdens, including ERD, experienced by patients and their family members.
2. If multimodal treatments reduce the negative impact of cachexia on advanced cancer patients, the psychosocial burdens, including ERD, placed on patients and their family members might be alleviated.
3. The main causes of ERD experienced by patients with cancer cachexia and their family members are a lack of knowledge about cachexia, unsuccessful attempts to increase body weight, expected occurrence of the patient’s death, and conflicts over food between them.
4. Supportive, communicative, and educational interventions would alleviate ERD of patients with cancer cachexia and their family members.
5. Palliative care for ERD experienced by advanced cancer patients and their family members needs to be tailored to the severity of the patient’s cachexia, especially in cases of refractory cachexia.

Questionnaires for both patients and their families have been preliminarily developed (Tables 1 and 2).

Conclusions

Since ERD can be a significant issue and change during cancer, palliative care and nutritional support need to be tailored to each patient and their family. Therefore, the development of further validated tools for evaluating their ERD is strongly needed in the near future.

References

1. Strasser F, et al. Fighting a losing battle: eating related distress of men with advanced cancer and their female partners: a mixed methods study. Palliat Med 2007.
2. Hopkinson JB, et al. What to eat when off treatment and living with involuntary weight loss and cancer: a systematic search and narrative review. Support Care Cancer 2011.
3. Oberholzer R, et al. Psychosocial effects of cancer cachexia: A systematic literature search and qualitative analysis. J Pain Symptom Manage 2013.
4. Reid J. Psychosocial, educational and communicative interventions for patients with cachexia and their family carers. Curr Opin Support Palliat Care 2014.
5. Hopkinson JB. Psychosocial impact of cancer cachexia. J Cachexia Sarcopenia Muscle 2014.
6. Cooper C, et al. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. J Cachexia Sarcopenia Muscle 2015.
7. Hopkinson, JB. Food connections: A qualitative exploratory study of weight- and eating-related distress in families affected by advanced cancer. Eur J Oncol Nurs 2016.
8. Wheelwright S, et al. A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia. Palliat Med 2016.
9. Amano K, et al. Needs for nutritional support, eating-related distress and experience of terminally ill cancer patients: A survey in an inpatient hospice. BMJ Support Palliat Care 2016.
10. Amano K, et al. Eating-related distress and need for nutritional support of families of advanced cancer patients: a nationwide survey of bereaved family members. J Cachexia Sarcopenia Muscle 2016.
11. Amano K, et al. Perception of need for nutritional support in advanced cancer patients with cachexia: a survey in palliative care settings. Support Care Cancer 2018.

Table 1 : Questionnaire about eating-related distress of patients with advanced cancer

Distress originating from the feelings of patients themselves	No	Seldom	Sometimes	Frequently	Always
Although I know that I have to eat enough, I cannot do that.	1	2	3	4	5
I want attention to be paid to my eating-related distress.	1	2	3	4	5
I do not know why I cannot eat enough.	1	2	3	4	5
I feel that a lack of nutrition makes my condition worse.	1	2	3	4	5
Distress originating from coping strategies	No	Seldom	Sometimes	Frequently	Always
What kinds of food can I eat?	1	2	3	4	5
Which nutrients should I preferentially consume?	1	2	3	4	5
How can I eat more?	1	2	3	4	5
I feel that more medical support about my daily diet is needed.	1	2	3	4	5
Distress originating from the relationship between patients and their families	No	Seldom	Sometimes	Frequently	Always
I am burdened by the meals that my family kindly serve me.	1	2	3	4	5
I have experienced conflict about my meals with my family.	1	2	3	4	5
I feel that I disregard the kindness that my family shows by making my meals.	1	2	3	4	5
I feel sad because I cannot enjoy dinner with my family.	1	2	3	4	5

Table 2 : Questionnaire about the eating-related distress of family members of patients with advanced cancer

Distress originating from the feelings of family members themselves	No	Seldom	Sometimes	Frequently	Always
Although I know that I have to help the patient eat enough, I cannot do that.	1	2	3	4	5
I want attention to be paid to my distress about the patient’s eating.	1	2	3	4	5
I do not know why the patient cannot eat enough.	1	2	3	4	5
I feel that a lack of nutrition makes the patient’s condition worse.	1	2	3	4	5
Distress originating from coping strategies	No	Seldom	Sometimes	Frequently	Always
What kinds of food can the patient eat?	1	2	3	4	5
Which nutrients should the patient preferentially consume?	1	2	3	4	5
How can the patient eat more?	1	2	3	4	5
I feel that more medical support about the patient’s daily diet is needed.	1	2	3	4	5
Distress originating from the relationship between patients and their family members	No	Seldom	Sometimes	Frequently	Always
I feel that the patient is burdened by the meals that I kindly serve him/her.	1	2	3	4	5
I have experienced conflict about the patient’s meals with him/her.	1	2	3	4	5
I feel that the patient disregards the kindness that I show by making his/her meals.	1	2	3	4	5
I feel sad because the patient cannot enjoy dinner with me.	1	2	3	4	5