

Palliative care patients experiences of diminished appetite or food intake, and/or cachexia – a narrative literature review (NSCPM 2017-2019, Camilla Öberg)

Background: Weight loss and diminished appetite are common symptoms in palliative care, independent of medical diagnosis. In newly diagnosed patients with cancer approximately 50 % suffer from anorexia, and in patients with advanced disease up to 70 % or more. The prevalence of concern about weight loss, or decline in food intake, was 36-43 % in a study of palliative care patients.

Aim: To perform a narrative review on what is known about the experiences of lack of appetite, and/or cachexia, among patients in palliative care.

Method: Literature searches were made in late 2017, and in December 2018. From approx. 200 abstracts, valid papers were chosen. 24 papers were finally used for the review.

Inclusion criteria: MeSH terms were used for search in PubMed (Meals, Portion Size, Taste Disorders, Feeding behavior, Anorexia, Appetite in a combination with either of Hospice Care, Palliative Medicine, Terminal Care, Palliative Care). Only papers written in English were included. Reviews or papers reporting primary research of patients' experiences were chosen.

Results: We need food for our physical well-being, but food and eating also have social and emotional meanings, and functions. Feeding problems and weight loss among people with progressive life-limiting disease are existentially loaded markers of impending death. Decreased food intake at the end of life, has different symbolic meanings in different countries and cultures.

An association between starvation and cachexia is often made among patients. Eating more or better is thought to change the situation. Weight loss might lead to loss of the familiar physical body. Patients may fear looking at themselves in the mirror, or want to protect others from the sight. The change in appearance is a reminder of what will come. Many patients find the flickering nature of appetite and desire/disgust for food depressing and distressing. Cachexia, or the disease itself, leads to weakness, which makes shopping, preparing, and/or eating food more difficult. Some people can, at least at first, appreciate weight loss.

Diminished food intake or cachexia might lead to social consequences. Not being able to share meals with others due to e.g. embarrassment over coughing, needing liquidized foods, not being able to eat as much as before, or smells causing nausea, can lead to avoidance of social events. Conflict over food within family is common. Carers put pressure on the ill person to eat, or show disappointment if the patient cannot. Patients report forcing themselves to eat to please. The eating difficulties can increase the feeling of being a burden to family, and fear of rejection. The lowered appetite might be more of a distress for the family than for the patient.

Choices of food, in some ways, define us as persons – “you are what you eat”. Prior preferences might change with the life-threatening disease or treatments, causing a feeling of loss. Patients with a great interest in food prior to the illness, loses a part of their identity, not being able to enjoy meals.

Eating difficulties and cachexia are signs of lost control. Patients handle the situation in two major ways, i.e. acceptance, or resistance. Control can be taken through planning and having something nutritious at hand, if an opening is shown. Persons can promote self-worth by choosing “good” food or focus on the value of what is eaten. They distract themselves and others through humor, and stories about prior life accomplishments. Patients want others to acknowledge their problems, and to listen to their thoughts about it, and how they manage.

Knowledge about eating problems, anorexia, and cachexia among patients has been demonstrated to be low. Lack of knowledge probably leads to further distress.

Conclusion: This narrative literature review reveals that eating problems, anorexia, and cachexia are common and distressing signs and symptoms among patients in palliative care, independent of underlying diagnosis. The experiences can be divided into themes of physical, social, and emotional loss. Persons handle these problems in different ways. Patients wish that health care workers acknowledge the problems, offer explanations, and listen to the patients' worries, thoughts and ways of managing the challenges.

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