Refractory cachexia: eating and weight loss related distress and end-of-life

Definition of refractory cachexia

Eating- and weight loss related distress

Communication / counselling interventions

Pseudo-refractory symptoms

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Cancer Anorexia Cachexia Syndrome can develop from Precachexia to Cachexia to Refractory Cachexia

Refractory (late) cancer cachexia

Advanced muscle wasting (with or without loss of fat) due to progressive cancer, not anymore responding to anticancer treatment. Patients have a low performance status and short life expectancy (<3months). It is evident that the burden of artificial nutritional support would outweigh any potential benefit.

Therapeutic interventions focus typically on alleviating the consequences/complications of cachexia, e.g. symptom control (appetite stimulation, nausea), eating-related distress of patients and families.
Need for cachexia-related communication for patients and family members

- Cancer cachexia is frequent in advanced cancer patients. Loss of appetite, early satiety, physical fatigue, etc.

- Eating is a central element of being human & interact socially. Eating-related, weight-loss related distress of patient & family.

- Weight loss and decreased function threaten human existence. Low BMI, weight loss, sarcopenia, cachexia: decreased OAS coping with limited life prognosis and end-of-life.

- Cancer cachexia management requires patient participation. Conscious control of eating, engage physical exercise. Oncologist may promote anticancer treatment if patient better.
The communication challenges and interventions both for patient and family

Understand what happens to patient- illness
Having lung cancer and experiencing cancer cachexia

Understand limited time in incurable cancer – prognosis
Reconsidering live values, preparation for end-of-life

Distress in families caused by cachexia and prognosis
Family members as carers, suffering and interacting humans

Patient empowerment: palliative cancer rehabilitation
Calman gap on both sides: too optimistic – too pessimistic
In patients having refractory cachexia:

alleviate eating-, weight loss related distress

systematic literature review

Reactions aggravating distress

**caregiver**: fighting back (causing pressure, force feeding), waffling, high expectations, monitoring, auditing, accusing

**patient**: trying hard to eat, difficult eating to please, lying, social withdrawal

Reactions alleviating distress

**patient & caregivers**: knowledge of irreversible nature, acceptance, letting nature take its course, finding other ways to care, lower expectations of eating, patient driven feeding, constructive dialogue, facilitating self-action

Oberholzer R, Hopkinson J, et al., JPSM 2013; 46:77-95
Weight- and eating-related distress in families affected by advanced cancer: food connections

Exploratory qualitative study, 31 dyads (27 pts men)
Eating- & weight loss related distress pat vs carer 32/22 vs 48/47

Couples disrupted food connection:
Interaction of patient and carer are important independent of individuals

Fig. 1. Conceptual model of patient and family carer experience of weight loss and changing eating habits.

Hopkinson J. Eur J Oncol Nursing 2015
Psychosocial interventions to improve cancer caregiver QoL

Syst Lit Review, RCTs, adult. 1066 screened, 117 eligible, 6 incl.

Supportive - educational communication interventions (family involvement, optimistic attitude, coping skills, uncertainty reduction, symptom management) can improve caregiver QoL

Tumor is metabolic active and causes **Inflammation** and **loss of muscle**

**Hunger** signals are in Stress-situations down-regulated

Different **Satiety**-Signals are activ but without full stomach and despite energy deficit

Blum D et al. Supp Care Cancer, 2009
Strasser F Oxford Textbook
Understanding Refractory Cancer Cachexia

(Cancer disease procatabolic and not responsive to anticancer treatment, patient low function)
– defect fabric can not produce chairs!


Clinical practice: Takes 7-15 minutes
62y man, SCC-Head & Neck
Weight loss 18% / 6 mts
Referral inpatient PC unit for terminal care („dying patient“)
Prepared for death, prayers for good death, family „ready“

Incident pain syndrome in lumbal vertebra, opioid treatment
Epipharynx-SCC 5 years ago radio-chemotherapy
Patient refused controls since years, at unit refused labs
Respected his will, prayers for gifts & meaning, SSRI
NSAR & pamidronate, testosterone pills, protein-rich food
prokinetics, laxatives → after 1 mts patient walked home

Starvation, Sarcopenia, NO cachexia

This is an example of a pseudo-refractory syndrome (cachexia)

Other example:
pseudo-refractory pain
lack of checking
. Location
. Compliance drugs
. Risk factors
  incident neuropathic
  emotional amplific.
cognitive impairm.
  addiction history
  chronic pain
  opioid barriers