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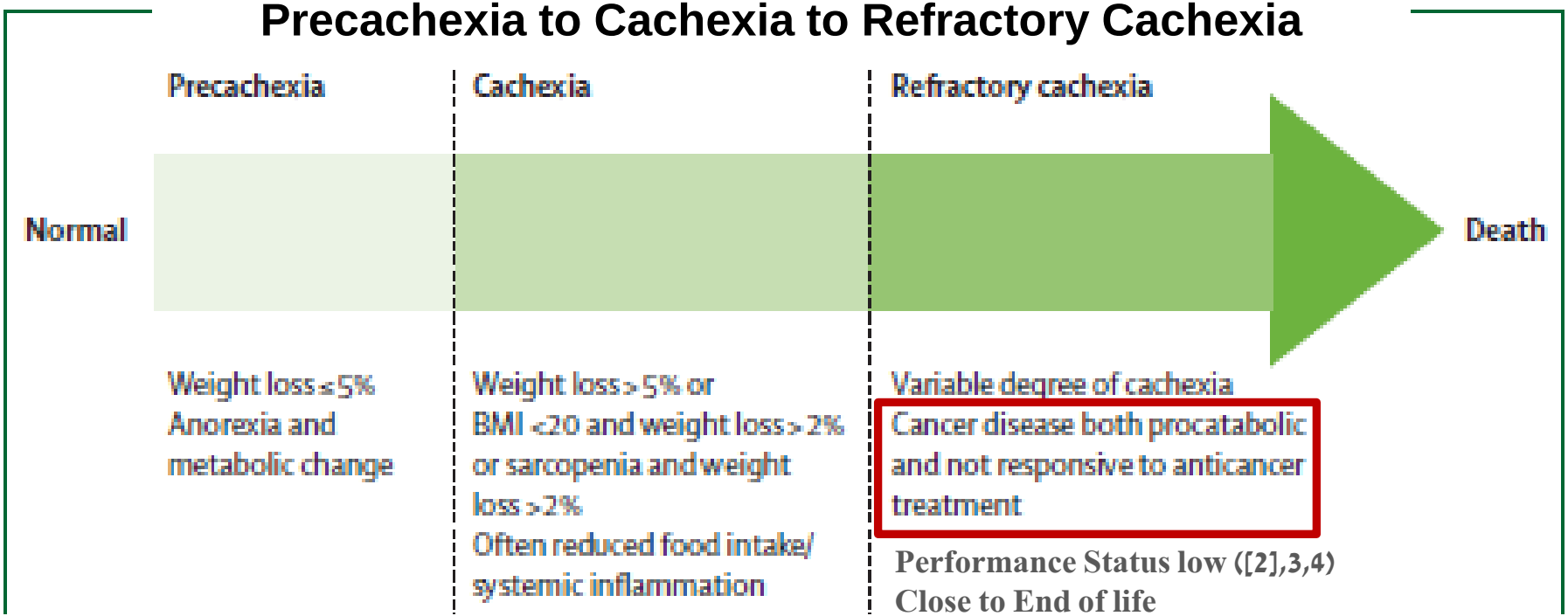
Cancer Anorexia Cachexia Syndrome can develop from Precachexia to Cachexia to Refractory Cachexia



Conceptual Framework: Fearon K & Strasser F, et al. Definition and classification of cancer cachexia, an international consensus. Lancet Oncol 2011;12(5):489-95

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 **threat 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**
  concious control of eating, engage physical exercise
  oncologist may promise 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

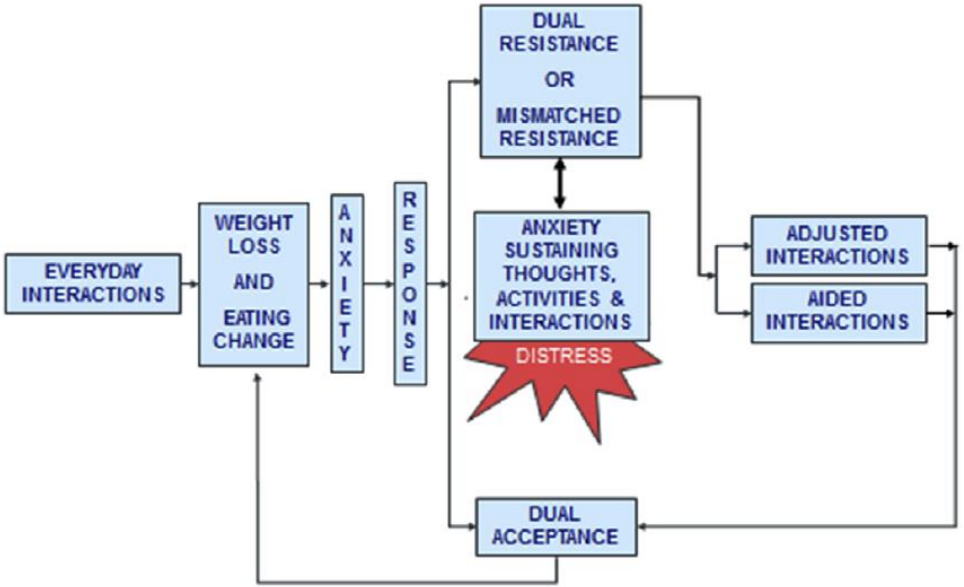
Reactions aggravating distress
caregiver: fighting back (causing pressure, force feeding), waffling, high expectations, monitoring, auditing, accusing
patient: trying hard to eat, difficult eating to please, lying, social withdrawal

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

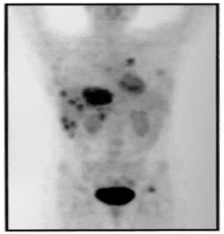
Syst Lit Review, RCTs, adult. 1066 screened, 117 eligible, 6 incl.

Author, year	Intervention group format (*n*)	Time of study	Outcome variables	QoL measure used	*d*
Campbell *et al.*, 2007 [29]	Telephone-based, dyad CBT coping and problem-solving skills (12)	6 sessions	QoL, self-efficacy	POMS-SF and CSI	
Carter, 2006 [30]	In-person, individual sleep CBT (17)	2 sessions	QoL, depression	CQOL-C	0.048
McMillan *et al.*, 2006 [31]	In person, 1. Supportive visit (108), 2. Problem solving and support (111)	1 session	QoL, problem coping, emotion coping	CQOL-C	
Northouse *et al.*, 2005 [32]	In-person, family based, informative and supportive (94)	3–90 min home visits and 2–30 min phone sessions	QoL – mental, QoL – physical, active coping, appraisal	FACT-G and SF-36	0.099
Northouse *et al.*, 2007 [33]	In person, family based, informative and supportive (129) * adaptation of Northouse *et al.*, 2005	3–90 min home visits and 2–30 min phone sessions	QoL, coping, self-efficacy, appraisal	FACT and SF-36	0.264
Walsh *et al.*, 2007 [34]	In person, supportive (137)	6 sessions	QoL, strain	CQOL-C	0.271

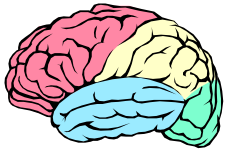
Supportive - educational communication interventions (family involvement, optimistic attitude, coping skills, uncertainty reduction, symptom management) can improve caregiver QoL

Waldron EA et al. Psycho-Oncology 2013;22:1200-7

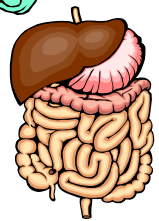
Patient Education Cancer cachexia



Tumor is metabolic active and causes Inflammation and loss of muscle



Hungersignals are in Stress-situations down-regulated



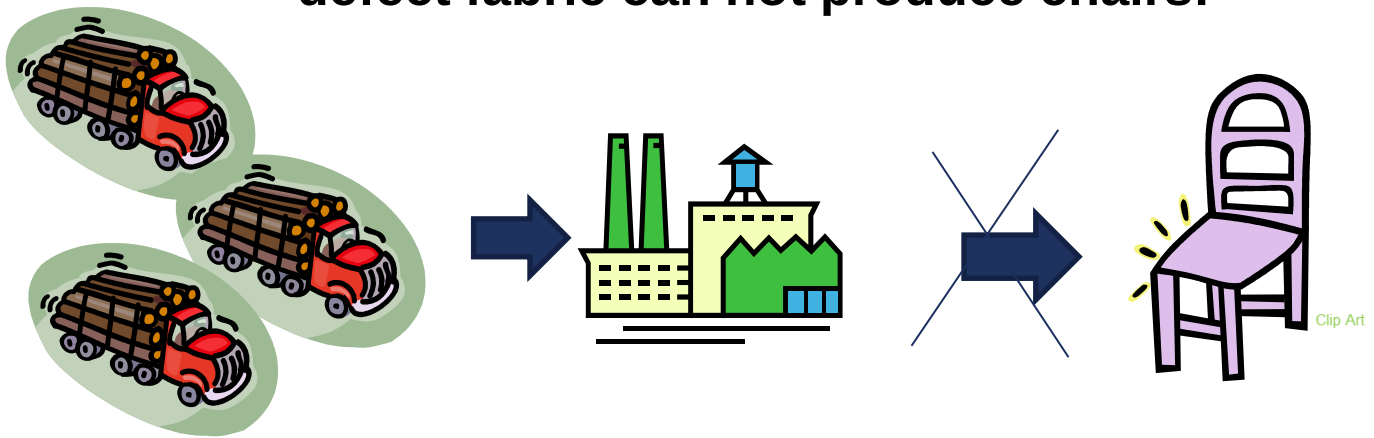
Different Satiety-Signals are activ but without full stomach and despite energy deficit

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

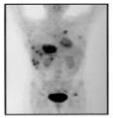
Understanding Refractory Cancer Cachexia [1]

(Cancer disease procatabolic and not responsive to anticancer treatment, patient low function)

– defect fabric can not produce chairs!

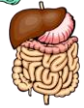


Tumortissue is metabolic active and causes Inflammation and Muscle loss



Hungersignals are down-regulated in Stress-Situations

The different Satiety-Signals are activ but without full stomach and despite energy deficit



1: Fearon K & Strasser F, et al. Definition and classification of cancer cachexia. Lancet Oncol 2011;12:489-95

Clinical practice: Takes 7-15 minutes

I. Depletion of Reserves | II. Limitation of food intake | III. Catabolic Drivers

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 syndrom 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, testosteron 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