

NUTRITIONAL CARE FOR PATIENTS WITH HUNTINGTON'S DISEASE IN LONG TERM CARE

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Background

Weight loss is a well-known and common problem seen by patients with Huntington's disease (HD). Many patients lose weight unnoticed due to high energy needs and other food or diet problems such as dysphasia. This symptom can change during the various stage of the disease. In particular, weight loss is seen in the advanced stages of the disease.

Aim

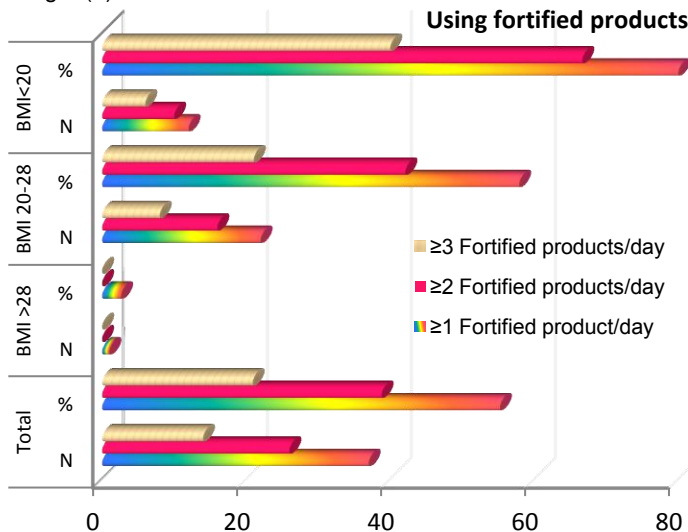
To describe the nutritional status and nutritional care for advanced HD patients living in Long term Care.

Methods

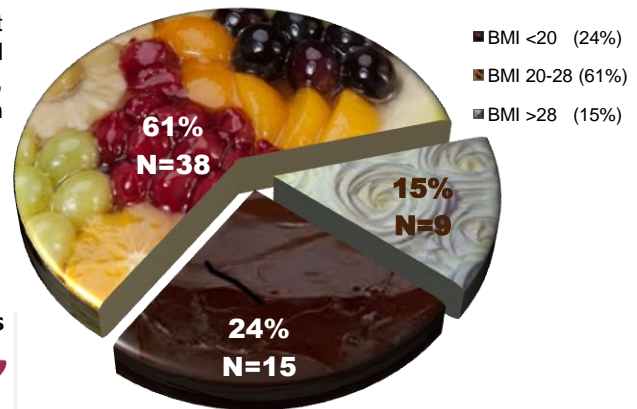
In a cross sectional study data were collected about the last available weight (febr-aug 2014), length and use of fortified products of patients with HD, living at the time in Topaz Overduin, a long term care facility, specialised in HD care. Topaz Overduin is home for 67 patients in the advanced stage of the disease.

Results

Data of 67 patients with HD (mean age: 55.9 years, range: 25-79, 25 males and 42 females) were collected. 5 patients were excluded because missing data about their weight (4) or length (1).



BMI of the HD patients Topaz Overduin



The mean HD BMI in Topaz Overduin is 23.1 (range: 14.8-37.3)

61% (N=38) of the HD patients have a BMI >20-28. 15 (24%) patients are underweight (<20) and 9 (15%) patients are overweight (>28). The EHDN Standards of Care classified¹ the target BMI at 23; 28 patients (45%) are ≥23; 34 patients (55%) <23.

1. Brotherton et al. Neurodegener Dis Man. 2012 2 nr. 1, pp. 33-43.

57.2% of the patients is using fortified products, like cake, desserts and/or drinks. 92.5 (N=62) patients have 1 or more diets. 38 (56.7%) patients have a fortified diet. Each day we give out 51 fortified drinks (300kcal), 7 fortified cakes (190kcal) and 38 fortified desserts (200kcal). There is one patient using tube feeding.

Conclusion

Patients with HD are known to have weight problems and are in need of Nutritional guidance's. With monthly weighing sessions the diet can be adjusted during the different stages of the disease. The mean BMI of the patients at Topaz Overduin is right on the target BMI set by the EHDN Standards of Care. Most of the patients are on a fortified diet (56.7%) receiving nearly 96 fortified products (average of 1,4 products/patient/day).

Future points of interest

- Monitoring the evolution of the weight over a prolonged period.
- Comparing the BMI and Nutritional care with other Long term Care facilities national and international and patients living at home.

