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## **Nutritional support among cancer patients enrolled in palliative home care services**

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# ABSTRACT

Nutritional problems are common in palliative cancer care. Little is known about nutritional problems and nutritional support in home care. **AIMS:** The primary aim of this thesis was to investigate experiences of nutritional problems and home nutritional support, with a special focus on home parenteral nutrition (HPN), from the perspectives of cancer patients and their family members. Further aims were to investigate the prevalence of nutritional risk and use of nutritional support among cancer patients enrolled in palliative home care services.

**METHODS:** Two explorative studies were conducted. The first was a qualitative interview study with 13 cancer patients with experience of HPN and 11 of their family members. In a second study 621 patients with various malignant diseases participated in structured telephone interviews. These patients were recruited from all 21 palliative home care services in the Stockholm region. **RESULTS: Paper I:** Patients and family members described the nutritional situation prior to HPN as a source of worry and often desperation. Patients reported that they wanted and tried to eat, but were unable to do so. Family members experienced powerlessness and frustration when they could not enable the patient to eat. A lack of attention to nutritional problems by hospital staff was described. HPN was offered at a point when patients and family no longer felt able to solve the nutritional problems themselves. **Paper II:** The most salient experience of HPN described by patients and family members was a sense of relief and security that nutritional needs were met. This was said to have a direct and positive effect on quality of life, and on body weight, level of energy and strength, and activity. Positive statements about HPN were often coupled to the benefits of being enrolled in palliative home care. The most salient negative effect of HPN was described as related to restrictions in family life and social contacts. However, benefits of the HPN treatment were generally said to outweigh negative aspects. **Paper III:** Sixty-eight percent of the 621 interviewed patients were scored as at nutritional risk according to the modified version of NRS-2002. Nutritional support, mainly oral nutritional supplements, was used by 55% of the patients. Fourteen percent of all patients used artificial nutrition, i.e. HPN or home enteral tube feeding (HETF). Use of nutritional support was related to low BMI and severe weight loss, and was more common in patients with shorter survival times. **Paper IV:** HPN was more common (11%) than HETF (3%). Artificial nutrition was usually introduced more than four months before death. Three of four HPN recipients also had solid food intake. HPN use was associated with eating difficulties, nausea/vomiting, and fatigue rather than gastrointestinal problems per se. HETF was generally used for patients with problems chewing and/or swallowing.

**CONCLUSIONS:** A desperate and chaotic nutritional situation in the family led to a willingness to accept HPN. The patients and their family members experienced physical, social and psychological benefits of HPN. Nutritional support was used to treat already malnourished patients with short survival times, rather than to prevent malnutrition. Contrary to existing guidelines, HPN was used to supplement oral intake, and not only for patients with a non-functioning gastrointestinal tract. A more structured approach to nutritional issues taking life expectancy and psychosocial aspects into consideration could help identify potential candidates for nutritional support. There remains a need to investigate how to best individualise use of nutritional support for patients in palliative phases.

**Key words:** Enteral tube feeding, Food intake, Home care services, Neoplasm, Nutrition assessments, Nutritional support, Palliative care, Parenteral nutrition