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ORIGINAL ARTICLE

Acute impact of home parenteral nutrition in patients with late-stage cancer on family caregivers: preliminary data

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Abstract
Purpose Since there is no information regarding quality of life of caregivers assisting patients with advanced malignancy on home parenteral nutrition, herewith we report a preliminary series of 19 patients who received total parenteral nutrition at home under the strict supervision of their relatives.
Methods The relatives of 19 incurable patients with cancer-related cachexia, discharged from the hospital with a home parenteral nutrition program, were prospectively studied. They filled out a validated questionnaire, the Family Strain Questionnaire Short Form, prior to patient discharge and after 2 weeks of home care. The questionnaire included 30 items, which explored different domains regarding the superimposed burden on caregivers in relation to the assistance given to their relatives.
Results Our findings show that the basal level of strain was relatively high (about three quarters of positive answers) but did not increase after 2 weeks of home care. Similarly, there was no difference in the nutritional status and quality of life of the patients. Eight patients and their relatives could be also analyzed after 2 months and the results maintained unchanged.
Conclusion This preliminary investigation shows that home parenteral nutrition does not exacerbate the level of strain on caregivers involved in surveillance of such a supportive intervention. It is possible that the perception of an active contribution to the benefit of patients, who maintained unchanged their nutritional status and quality of life, could gratify caregivers despite the objective burden in the constant supervision of administering Parenteral Nutrition.

Keywords Family Strain Questionnaire · Patients with incurable cancer · Caregivers · Home parenteral nutrition

Introduction

The recent European Society of Nutrition and Metabolism (ESPEN) Guidelines on Nutrition in Oncology [1] strongly recommend (C6-2) that, apart from considering the expected benefit on patient survival and quality of life, take into account the indication for nutritional support of patients with advanced cancer also contemplating the potential burden of such treatment.

There is some evidence from prospective studies that parenteral nutrition can have some benefit in survival, especially in some incurable patients who would die prior from starvation than from tumor growth, and now a nomogram is available to estimate the life expectancy of patients on home parenteral nutrition (HPN), depending on some prognostic variables [2, 3]. Data on quality of life (QoL) [4] are definitely scanty and show stable QoL scores during HPN, with a decline in the last 2–3 months before death. On the contrary, the information on the potential psychologic and physical burden that HPN management causes on the family caregivers is totally lacking.

Indeed, this is a relevant issue not only in perspective of a modern comprehensive view of medical care, including the patient-family unit, [5] but also because a family caregiver, per se, appears to be extremely important for the QoL of patients on HPN [6].

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The aim of this paper is to report preliminary data on the acute impact, on the family caregivers, of the HPN program management in incurable cancer patients.

Patients and methods

We report data of a subset of 19 incurable patients with cancer cachexia, included in a prospective HPN database at the Internal Medicine and Clinical Nutrition Unit of the Federico II University Hospital, in Naples.

The daily nutritional regimen provided 30 non-protein kcal/kg/day and 1.34 g amino acid/kg/day, corresponding to 35 mL/kg/day of an all-in-one nutritional emulsion (*Nutriplus Lipid* or *Nutriplus Omega*, BBraun) that was administered through a central venous catheter (CVC), generally already implanted for chemotherapy. The time of daily infusion was set from14 to 18 h, preferably by the use of an infusion pump.

The nutrition team provided patients and/or their caregivers with oral and written instructions regarding home management for nutritional therapy and how to recognize the main potential CVC-related complications [7]. The practical training session lasted 30 min, after which each participant was given a brochure containing detailed written instructions with complete explanatory illustrations on the correct CVC management (sterile devices for the application of nutritional therapy, times and modalities for dressings, etc.…) including also first aid of potential complications.

The nutritional team was available by telephone from Monday to Friday, 8:30 a.m. to 5:00 p.m., followed by a 24 h availability of an Internal Medicine ward physician. Finally, a periodical (biweekly or according to the patient's needs) follow-up of the patient's clinical conditions as well as of routine haemato-biochemical values was performed.

We assessed the caregiver-related problems through the Family Strain Questionnaire-Short Form (FSQ-SF). The FSQ originally consisted of a brief semi-structured interview and 44 dichotomic items that explored the following five domains: emotional burden, problems in social involvement, the necessity of knowledge about the disease, family relationships satisfaction, and thoughts about death. Its validity and reliability were assessed in 818 caregivers (314 were involved with the care of oncologic patients) and were defined good [8]. However, we used the short form of this validated questionnaire, which includes thirty "yes-no" items selected from a previous list (Table 1). This version demonstrated to have very good fit statistics and to maintain the diagnostic qualities of the original form. The FSQ-SF [8] could be completed by caregivers in approximately 10 minutes and filled out at the first visit, after 2 weeks and after 1 and 2 months for surviving patients. The FSQ-SF items are reported in Table 1. The number of "yes" answers for questions 1–30 is counted; the higher the number of "yes", the more severe the caregivers' strain.

Table 1 Items for the Family Strain Questionnaire-Short Form

n.	Items	Yes	No
1	I am worried about the patient's illness		
2	I feel powerless in the face of the disease		
3	I feel the need for advice on how to look after the patient		
4	I sometimes think about the death of the patient		
5	I always think about how things will end		
6	I have too many things to think about		
7	I would like to know more precisely what treatment they are giving the patient		
8	I wish I could control my emotions better		
9	During this period I have felt very anxious about the future		
10	I often experience disturbances such as sleeplessness, indigestion, headache, fatigue		
11	I have felt very stressed during this period		
12	I would like to be able to speak to an expert about the things that are going badly (physician, psychologist, etc.)		
13	I would like to have more time for myself		
14	The patient's disease tires me		
15	During this period I have not wanted to go out much		
16	I have the impression that I can't face all of my problems		
17	I feel guilty when I leave the patient alone or with someone else		
18	I have little time to spare for the other member of my family		
19	I would like more information about the disease		
20	It is sometimes difficult for me to contain my anger		
21	I am pessimistic about the future		
22	I don't know whether I can overcome all of the difficulties of this period		
23	I have given up most of my personal interests		
24	I am very anxious in the presence of the patient		
25	I sometimes have the impression that I have lost the patient		
26	I sometimes feel irritated about the continuous demands of the patient		
27	I sometimes find my relationship with physician stressing		
28	Nobody understand the burden I am carrying		
29	I would like to talk about the possible loss of the patient		
30	If necessary, I can't rely on someone else in my family		

The statistical analysis was performed using the Statistical Package for Social Sciences (version 15.0 for Windows). Results are expressed as means ± SD, unless otherwise stated. Student's *T* test was used for mean comparison. Significance was set at $p \leq 0.05$.

The Ethical Local Committee approved the research (protocol number 124/12) and informed consent was achieved by all participants to the study.

Results

There were 19, 59 ± 9.0 years old (9 males, 10 women), patients with late-stage adenocarcinoma of the ovary (8 patients), stomach (4 patients), colon-rectum (3 patients), pancreas (2 patients), and gallbladder (1 patient). Patients were severely malnourished, their body weight being kg 50.5 ± 8.6, the weight loss (WL) being kg 11.8 ± 4.5 (23.5% ± 8.1 of the usual body weight) in the previous 6 months.

Patients can be defined cachectic according to the recent definitions of cachexia, which consider a WL ≥ 10% and systemic symptoms [9] or a WL > 5% or BMI < 20 + WL > 2% [10].

Their measured resting energy expenditure was 1217 ± 210 kcal/day, and respiratory quotient was 0.71 ± 0.23. Mean survival was 73.7 ± 45.5 days.

The biochemical markers did not change, significantly, as an indicator for the lack of toxicity of the HPN (data not shown).

The caregivers who completed the questionnaire were daughters (n.7), husbands (n.6), sons (n.3), wives (n.2), and one mother. Data show that FSQ-SF total “yes” answers were initially 22 (median; range 22–28) and at 2 weeks were 23 (median; range22–28) (Fig. 1). Similarly, there was no change in nutritional parameters (anthropometrics, biochemical, immunologic, functional, and those pertinent to QoL) of the patients. The time course of variables for eight survivors after 1 and 2 months of HPN was also evaluated; no significant differences emerged at the different time points both in patients and their caregivers (data not shown).

Discussion

There is a fair amount of literature [11–22] investigating the impact of disease on the lives of families of patients with cancer, but, so far, no study has considered the strain of family members involved in the management of HPN for their relatives, despite this procedure may be quite demanding and may result difficult for patients themselves and their families.

It is noteworthy that the vast majority of published studies focus on the affective burden that the disease per se imposes on family members-caregivers; whereas, in patients on HPN, caregivers have a double burden because they are also involved 24 h daily in the surveillance of a proper HPN administration.

The HPN program indications mainly relied on the assumption that aphagic cancer patients (usually for malignant sub/obstruction) would earlier succumb due to starvation than tumor growth. Previous experiences [23, 24] have shown that a similar group of patients discharged without any nutritional support can survive only very few weeks at home; hence, it was considered a reasonable option to plan a HPN program in such patients, provided they were not judged to be in a phase of rapidly progressing disease.

We were solicited to present preliminary data on QoL of caregivers’ assisting incurable cancer patients on HPN for two reasons. Firstly, because the current ESPEN recommendations on HPN in advanced cancer patients have a “low level of evidence” [1] and secondly, because there was a specific suggestion of further investigation in this area on behalf of the ESPEN guideline committee experts [1].

Results showed that the basal strain level of caregivers was already considerably high (“yes” answers equivalent to three quarters) probably due to the fact that family members were already long-dealing with a dramatic progressive trajectory towards the death of their relatives; of note, the strain level did not increase when involved in managing HPN. The low number of patients and caregivers recruited in our study is certainly a limitation; nevertheless, the results are quite homogeneous, and hence, it is unlikely that results might change by increasing the number of the caregivers investigated. Considering the fact that the overall experience demonstrated that individuals over time tend to

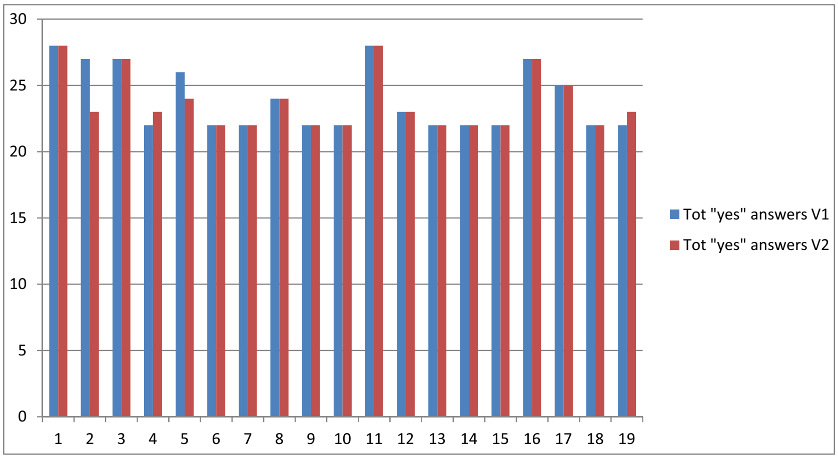

Fig. 1 Total “yes” answers at V1 (basal) and V2 (after 15 days HPN) visit in the caregivers of the 19 terminal cancer patients. Total items = 30

progressively cope with adverse events, it is also unlikely that caregivers positively facing the initial acute burden of HPN administration would later become more stressed once the procedure is familiar and easy.

Indeed, we could hypothesize that caregivers might even be somewhat gratified by their involvement in what they deem essential for the survival of their relatives, consequently possibly mitigating the effort needed to manage HPN.

This is in keeping with the observations of Orrevall et al. [25] who described in 13 cancer patients that the most salient positive features of HPN were in relation to a sense of relief and security, furthermore, that nutritional needs were met and both patients and family members reported the experience as having a direct and positive effect on QoL. In fact, nourishment, also the intravenous one, has a cultural and symbolic value and is experienced by the family caregiver as an expression of love and care for the severely ill relative. While physicians tend to see nourishment as a "medical treatment" aimed at achieving physiological objectives (and this is the official position of many Scientific Societies), families see feeding as an "act of community" [26]. Likewise, it is noteworthy that caregivers possibly realized that HPN was somewhat effective in maintaining their relatives in a steady state. De facto, these patients had a measured resting energy expenditure of about 24 kcal/kg; hence, their total energy expenditure was expected to be about 31.3 kcal/kg [22] and was well covered by a daily HPN regimen providing them 35 kcal/kg. This is in accordance with our previous experience [3, 27] and reflects the adequacy of the HPN nutritional regimen.

Lastly, it should be also considered that QoL of patients on HPN declines in the last weeks of life [3], and hence, the QoL score maintenance at stable levels must be viewed as a positive result.

In conclusion, these preliminary data, which warrant a further confirmation on larger prospective studies, show that the level of strain was high in familial caregivers of patients with incurable cancer, but no worsening was seen when involved in the HPN management. This may also indirectly translate into a benefit of QoL of the patients themselves [6].

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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