



ORIGINAL ARTICLE

# Home parenteral nutrition: A qualitative interview study of the experiences of advanced cancer patients and their families

Ylva Orrevall<sup>a,c,\*</sup>, Carol Tishelman<sup>b,c</sup>, Johan Permert<sup>a</sup>

<sup>a</sup>Department for Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

<sup>b</sup>Department of Nursing, Karolinska Institutet, Stockholm, Sweden

<sup>c</sup>Research and Development Unit, The Foundation Stockholms Sjukhem, Stockholm, Sweden

Received 8 May 2005; accepted 21 June 2005

## KEYWORDS

Home parenteral nutrition;  
Neoplasm;  
Home care;  
Family caregivers;  
Palliative care

## Summary

**Background & aim:** The benefit of home parenteral nutrition (HPN) to advanced cancer patients is often debated and an evidence-base for parenteral nutrition (PN) in palliative care is lacking. The aim of this study is to investigate the experiences of HPN from the perspective of advanced cancer patients and their family members.

**Methods:** Semi-structured interviews were conducted with 13 advanced cancer patients with experience of HPN and 11 family members. The qualitative data was analyzed inductively using constant comparison.

**Results:** The most salient positive feature of HPN 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, strength, and activity. Positive statements about HPN were often coupled to the benefits of being enrolled in advanced home care. The most salient negative effect of HPN described was related to restrictions in family life and social contacts for the whole family. However, benefits of the HPN treatment were generally said to outweigh negative aspects.

**Conclusion:** This study indicates that the interviewed cancer patients and their family members experienced physical, social and psychological benefits from HPN treatment.

© 2005 Elsevier Ltd and European Society for Clinical Nutrition and Metabolism. All rights reserved.

## Introduction

Despite high costs and lack of clarity about treatment benefits and risks, home parenteral nutrition (HPN) for cancer patients is increasing in many parts of Europe and the US.<sup>1–3</sup> In Sweden, no

---

\*Corresponding author. Tel: +46 86179353; fax: +46 86179333.  
E-mail address: [ylva.orrevall@cfss.ki.se](mailto:ylva.orrevall@cfss.ki.se) (Y. Orrevall).

empirical data is available but clinical experience suggests that HPN for cancer patients in palliative stages has increased. This may be due in part to shorter in-hospital stays and increased out-patient care,<sup>4</sup> as is the case in many high-income countries. Practical and technical advances also have simplified safe use of HPN. The situation in Stockholm is further facilitated by a well-developed system of physician-directed advanced home care teams (AHCTs) available 24/7 with intravenous treatments administered by registered nurses. For patients admitted to AHCT the cost of the care, including parenteral nutrition (PN) solutions and equipment, is covered by the Swedish National Health Care insurance.

Despite increased availability and use, an evidence-base for PN in palliative care is notably lacking, but often debated.<sup>5-9</sup> For example, McGeer et al.<sup>10</sup> and Klein et al.<sup>11</sup> concluded, after reviewing literature through the mid-80s, that PN should not be used routinely due to lack of significant benefits and potential for harm from infections. It should be noted that they qualified their conclusions noting poor study designs and emphasizing the lack of existing knowledge about "interactions between malignant disease, malnutrition and nutritional support".

In the mid-90s, guidelines for use of artificial nutrition to terminally ill cancer patients were developed by a group from the European Association for Palliative Care (EAPC).<sup>12</sup> This group also emphasized the lack of evidence, but suggested a process for systematic assessment to underlie decision-making. They pointed out difficulties in defining key concepts, i.e. when patients are "terminal"; as well as distinguishing patient needs, expectations, life expectancy, potential for medical intervention, and probable patient response in this very diverse patient group.

A number of recent studies give further knowledge relevant to PN use in palliative cancer patients.<sup>8,13</sup> Bozzetti et al.<sup>8</sup> concluded that patients with  $\geq 3$  months expected survival might maintain quality of life (QoL) if receiving HPN, based on data from Italian patients on nutritional status, survival time and QoL. Lundholm et al.<sup>13</sup> found through as-treated analysis of a Swedish randomized controlled trial, that active nutritional support, including HPN in a small group, combined with other treatments improved energy balance, prolonged survival and increased exercise capacity in a group of patients with solid tumours and progressive cachexia.

While the above results offer some support for use of PN in palliative cancer care, the focus on objective endpoints<sup>14</sup> needs to be further comple-

mented with subjective data beyond QoL. The QoL instruments commonly in use do not provide specific information as to how nutritional problems and support are experienced, valued and related to the individual patient's and family's QoL. Several qualitative studies give indication of the problems and strategies used by patients and families in dealing with nutritional problems in the palliative phase,<sup>15-18</sup> with our prior work showing that the chaotic and desperate nutritional situation in the family was influential in patients' decisions to accept HPN.<sup>18</sup> No research-based data has been found on the experience of palliative cancer patients and their families with HPN. The aim of this explorative study is therefore to investigate the views and experiences of HPN in a group of patients with advanced cancer and their family members.

## Material and methods

### Interviews

Due to the dearth of data on this topic, a qualitative approach was used to obtain in-depth descriptive data. The relevant Research Ethics Committee approved this study prior to its initiation. Semi-structured interviews were conducted with 13 patients and 11 family members, recruited through seven AHCTs in demographically different areas in the Stockholm region in 2000-2001. AHCT nurses were asked to contact those patients with advanced cancer, who were able to communicate in Swedish and who had received HPN "all-in-one bags"  $\geq 2$  weeks and at least three times/week with  $\geq 900$  kcal/time. The names of relatives involved in daily care were provided by the patients. Both patients and family members received verbal and written information about the study, before consenting to participate.

All interviews were conducted by the first author, YO, a dietitian with extensive experience of cancer care, and were audio-taped and transcribed verbatim. The interviews explored views and experiences of HPN using an interview guide including areas such as: positive and negative experiences of HPN; how HPN affects the patient and family's norms, values and feelings about food and meals; how patients are affected (physically, socially, emotionally, etc.) by HPN; the influence of HPN on family relationships and other social contacts. As is standard in qualitative research,<sup>19</sup> the interview structure was modified as the interviewer became aware of new, potentially important issues. Thirty

to 90 min long conversation-like interviews were conducted separately with patients and family members, generally in their own homes. At the end of each patient interview, the respondent completed a Patient-Generated Subjective Global Assessment Form (PG-SGA).<sup>20–22</sup> Information about diagnosis, oncologic treatment, date of first HPN, weight at HPN initiation and date of death was obtained from medical records.

## Data analysis

Constant comparative analyses were used to compare meaningful data both between and within interviews.<sup>23</sup> The analysis process continued until distinct and stable patterns could be seen in the data, which remained unchanged by the addition of further interviews.

Initially, YO reread the interview transcripts while listening to the audiotapes to correct misunderstandings and avoid misinterpretations. The data was then coded into 30 units based on similar substantive content, e.g. “practical problems”, “effects on mealtimes”. Codes relevant to the research question explored were grouped into 14 larger categories: the meaning of PN; practical aspects of HPN; food and mealtimes during HPN treatment; the role of AHCT; the trajectory of care; HPN and autonomy; cancer experiences; knowledge of PN; issues related to the future; life and death issues; weaning off PN; re-initiating PN; psychological issues experienced by patients; and psychological issues experienced by family members. The research group, consisting of a dietitian, oncology nurse researcher and surgeon, discussed the coding based on their different perspectives. These categories were then examined for common themes that characterize them, presented below. Data related to the process leading to HPN was presented in a prior article.<sup>18</sup>

Quotes presented below typify the data and were translated by second author CT, fluent in both Swedish and English. All names used are fictitious, with both individuals in a patient/relative pair given names beginning with the same letter. Omitted phrases are indicated by (...) and words within the symbol // have been added by the authors for clarity.

## Results

The 13 participating patients, eight women and five men, were between 47–79 years old (median 65 years) and had a broad range of cancer diagnoses,

including gastrointestinal adenocarcinoma ( $n = 6$ ); breast ( $n = 2$ ); lung ( $n = 1$ ); gynecological cancers ( $n = 2$ ); lymphoma ( $n = 1$ ); and other ( $n = 1$ ) (see Orrevall et al.<sup>18</sup> for further description). There was a wide range in time span from diagnosis to receiving first HPN treatment, and from first HPN treatment to death, as shown in Table 1. Four of the six patients with “normal” BMI between 20–26, reported a 20–25% weight loss prior to the interview. Six patients were on palliative chemotherapy treatment at the time of the interview. Two patients had total HPN due to obstruction, while nine received partial HPN combined with oral intake, and two were recently weaned from HPN. HPN-solutions containing carbohydrates, amino acids and fats were administered through “all-in-one bags” via a subcutaneous venous access port 2–7 nights/week. An AHCT registered nurse connected and disconnected the infusion. Duration of HPN treatment varied from 10 days to >1 year.

Twelve patients completed the PG-SGA instrument. Four of the patients on HPN reported weight gain during the past 2 weeks, while two reported weight loss and three reported no change, with one person unable to assess this. One of the two patients who were weaned from HPN reported weight increase, whereas the other reported no change.

**Table 1** Patient characteristics.

Characteristic	Number of patients
<i>BMI at the start of HPN</i>	
14–19	7
20–25	5
26	1
<i>Time from cancer diagnosis to first HPN</i>	
<6 months	6
6 months–2 years	3
> 2 years	4
<i>Time from first HPN to death</i>	
1–3 months	2
4–6 months	3
7–12 months	4
13–19 months	3
20–33 months	1
<i>Time from interview to death</i>	
<1 month	1
1–2 months	1
3–6 months	8
7–12 months	2
13–23 months	1

In response to the PG-SGA question on food intake during the past month, one patient on total HPN reported eating "less than usual", while the other reported "really taking in very little of anything". Responses from those on partial HPN varied, with one person reporting "more than usual", two persons rating "no change", three reporting food intake "less than usual", one "taking only liquids" and one "really taking in very little of anything". Both patients weaned from HPN rated "no change" in food intake. The most common problems among patients receiving HPN at time of interview, said to keep them from eating enough were: taste changes (6 patients); nausea (5); no appetite (4); vomiting (4); dry mouth (4). Problems mentioned by one or two patients each included constipation; diarrhoea; being bothered by smells; and "unable to eat at all". Two patients reported having no problems inhibiting food intake. Nine of the 10 patients on HPN at the time of interview reported that they were out of bed at least half the day (5) or had fairly normal (3), or normal (1) activity levels. One person, who died shortly after the interview, reported being bed-ridden most of the day.

The eleven interviewed family members consisted of five wives, four husbands and two daughters. The daughters were the only family members interviewed who did not permanently reside with the patient. Two patients had no family members involved in their daily care. One husband was interviewed after his wife's death.

In the following sections, an overview of positive and negative features of HPN described in the interviews is first presented. This is followed by a more in-depth presentation of three particularly salient themes: the effects of HPN on food intake and mealtimes; autonomy and dependency in relation to HPN; and HPN as a nutritional support.

### Overview of positive and negative features of HPN

The most salient positive features of HPN described were in relation to a sense of relief and security that nutritional needs were met. Both patients and family members described this as having a direct and positive effect on QoL, as well as on the patients' weight and levels of energy, strength and activity. Gertrude, whose husband George recently began partial HPN, described this vividly:

"You can say that it gives quality of life to the rest of the family and to the patient if you can turn a negative spiral around like that (...) I can

only say that I'm happy about the drip, that he gets such energy and strength, and with that comes pleasure and yes, there's certainly a kind of harmony from it."

The strength that was said to be gained from HPN in turn affected social roles within the family. Edith, a retired woman in her late 60s, was similar to many women in that she had been unable to continue her responsibilities for preparing meals. She typified participants, in using her new strength to resume her normal activities: "*I felt right away that it helped. Maybe not the first day, but (...) the first week, and I got out of bed and cooked food.*"

Positive statements about HPN were often coupled to the benefits of being enrolled in the AHCT. Patients also said that it was difficult to distinguish if and when benefits and problems were related directly to HPN, and when they were due to other illness/treatment-related factors. As Harry said: "*I mean the question is how I would feel if I didn't get the drip. I don't know that. And I'd probably feel worse. I'm quite convinced of that.*"

Few negative side-effects were described as due to HPN, although occasional problems with nausea, vomiting, drowsiness and headache could be explained by the interviewed patients as due to HPN infusing too quickly or in excessive quantities. Patients preferred receiving HPN at night, although both patients and family members described sleep changes resulting from this. The most salient negative effect of HPN described related to restrictions in family life and social contacts for both patient and family.

One family member, daughter Jane, was exceptional in that she expressed doubt about HPN treatment for her mother Johanna. While Jane had initially been positive to the affects of HPN, she had become increasingly concerned that her mother might suffer unnecessarily: "*I want her to live and feel well and be healthy, but I don't want her to be plagued to death for an unnecessarily long time. That's sort of what you have to choose between*". This fear was not expressed in the interview with Jane's mother. Instead Johanna, who died 2 weeks after the interview, said she was content with HPN:

"If I don't get enough nourishment on my own, then I do want to have the drip. Despite everything, it's only a little disturbance in relation to what it gives. I feel stronger when I have some nourishment in my body than when I don't."

## Effects of HPN on food intake and mealtimes

As mentioned above, the most striking feature described by patients and family members was the experienced sense of relief after initiating HPN treatment. As nourishment was seen as a necessary prerequisite for life, patients feared “*wasting away*” when relying on their own oral intake alone. Both patients and family members described HPN as alleviating the feeling of pressure to eat. Anna typified this, when she said:

“There’s just this sense of security that I have this drip, because—if it’s hard to eat during the evening and I feel that I don’t want to, I’m not able to—I don’t have the energy. To stuff something in when you have no appetite at all is no fun, but now I can eat a little less, more calmly, and think—yes, in any case I’m getting nourishment (...) that I know I need from the drip.”

Most interviewed patients regarded HPN as a complement to their oral intake. Patients and family members clarified that patients desired and preferred to eat, and had a continued ambition to receive as much of their nourishment as possible through oral intake. HPN was not said to lead to exclusion of meals, and family members said they continued to prepare and serve food they believed to be energy-rich and nourishing. They said that they were able to better accept that the patient ate as much as s/he felt comfortable with, with mealtimes thus becoming more pleasant, with less tension and less need for control.

It became clear from both patients receiving total HPN, that food played an important role to them beyond that of nourishment. One of these patients continued to prepare food for others, while Karin spoke of longing for food she knew she could not retain:

“Sometimes I can feel hungry (...) and long for food. Then I eat and throw up and I don’t care, because I know that what my stomach doesn’t want will just come up again. Sometimes I feel like this—no, today I want boiled potatoes and herring and sour cream, and then I eat it.”

There was little consistency between patients in how HPN was said to affect their appetite. Some participants felt that HPN helped increase the patient’s appetite, whereas others reported little change. Iris described a common situation, in that her appetite had improved after receiving HPN but other aspects of her sickness still hindered her from eating:

“I’ve begun to eat more than before. So I eat rice, potatoes, and pasta. Larger portions and I often enjoy the food. You see, my appetite’s returned. But there are still things I can die of longing for, and then we prepare it and when I’m going to sit down and eat, I just can’t eat it. But that’s been the case since I started treatments, chemo and all that.”

In contrast to Iris, Edith felt that her appetite decreased after receiving HPN, although her husband Eric did not feel that HPN affected her appetite. Edith explained: “I think I’m hungrier when I don’t get the drip. But that’s also the point, that I get calories from the drip because I wasn’t able to eat and just lost a lot of weight.”

Patients describing increased appetite in conjunction with HPN often said they now drank nutritional supplements that they had previously found unpalatable.

## Autonomy and dependency in relation to HPN

As previously mentioned, HPN was said to increase strength and energy, although this effect differed radically in degree. Bob related this new strength to increased independence in relation to his family:

“The drip means that I’m not worse, you know. Because it’s very difficult not to be able to do things oneself, to have to call for help every time you have to go to the toilet and get out of bed (...). Since I’ve gotten the drip, I can manage by myself in a whole different way.”

In this study all the patients received palliative supportive care from an AHCT. The AHCT nurses thus regularly visited the patient’s home to connect and disconnect the drip, in addition to other care provision. While family members could describe this as interfering with family life, contact with the AHCT was described on the whole as positive. The positive effects of HPN were very interrelated with the positive effects of contact with AHCT. Edith described this:

“It’s /HPN/ meant a lot to me. I have—I’m more fit, food tastes better, and then they /AHCT staff/ come too. They’re so very nice, very nice, the whole group. We have the doctor, who we can call anytime at all if something happens, and I can see that Eric also became much happier because he thought he had the responsibility /prior to AHCT enrollment/. Even if he didn’t, he felt that way, and now I can see that he feels better now that he knows we can call anytime

and all that, and they are so nice when they come in the evening and in the morning also, it doesn't disturb us, not me anyway."

Edith's husband Eric confirmed this:

"I felt an enormous relief /when HPN was initiated/. I felt relieved in general when AHCT began to take care of her (...) It wasn't until the girls /AHCT staff/ began to come home to us that they checked to see if she had a fungal infection in her mouth. She did, and that's why she always thought food tasted so strange. And then I started to realize, but couldn't know that you can get fungus in your mouth."

Eric and Edith thus illustrate how important it was felt to be that family responsibility for patient care, including nutritional care, was now shared with the AHCT. It became clear to patients and family members that new forms of symptom relief offered by professionals who were knowledgeable and attentive to palliative care needs could also alleviate nutritional difficulties.

Despite restrictions involved in HPN treatment, it was explicitly expressed by patients and family members that they did not want to care for the drip themselves. This was explained in relation to the need for the security provided by regular visits from the AHCT professionals; having the drip was one reason for those visits. Anna expressed an ambivalence shared by many:

"I don't think that there are any problems /with HPN/ but the problem is that I can't connect it myself. But then I would miss the contact and the security, so it wouldn't be good anyway. No, I think about if you would go travelling or so—think about if I could with this /HPN drip/. But it wouldn't work. Some injections and such I've learned to take, but I need help with this."

### HPN as a form of nutritional support

It should be recognized that the study participants generally had long experience with cancer and with a variety of treatments. HPN involved use of technology in the home environment. The benefits were generally said to outweigh the negative aspects. Gertrud was married to George, one of the patients most recently diagnosed with cancer. She said: *"I mean it doesn't matter if there are tubes in four places in his body, because it means so much to get the energy and the positive things /from HPN/."*

Michael, on the other hand, had cancer for a longer period of time, and had previously received

enteral nutrition, through a percutaneous gastrostomy (PEG), which he was able to manage alone. This was said to allow him great flexibility, such as staying at his country home alone. Neither Michael nor Maria spontaneously compared the nutritional treatments, but in response to the interviewer's probing indicated that they recognized that the disease progression meant that both Michael's nutritional situation and their needs for support had changed. Despite their positive experiences in caring for the PEG, neither wished to learn to care for the HPN drip. Maria explained: *"Because it gives him security that they /AHCT/ come here. Or gives us both security. If you have to have a drip now, I think it should be professionals who care for it. You shouldn't do it yourself."*

HPN was always connected during the evening and disconnected in the morning for the patients in this study. While this was said to be preferable, as it allowed the patient increased freedom during the day, HPN was said to affect night sleep. One cause for sleep changes was that either patients or family members regularly checked the speed and amount of the infusion. They described how they learned through experience to regulate the infusion. Another affect on sleep was that the increase of fluid intake led to increased frequency of toilet visits at night. The IV stand often did not fit into the bathroom, which meant that the toilet door could not be shut, prohibiting privacy. However, these effects were described matter-of-factly, rather than as problematic by the interviewees.

The restrictions involved in connection to an IV on a stand affected not only patients but also family members, as they expressed reluctance to leave the patient alone while connected to HPN. Social contacts and family life had to be planned around the time for the evening AHCT visit. While some patients preferred to go to bed before starting the infusion, other patients said they continued with other activities. While some preferences and possibilities appear to be related to personal choice and to the logistics of the home environment, others seemed directly related to the HPN treatment. For example, some patients had been given more than one IV stand from the AHCT, to ease movement between different levels in the house. The two patients with infusion pumps attached to the IV stand both lacked the flexibility of changing stands and described greater difficulties in moving about when receiving HPN as the equipment was heavier.

Many patients and family members described the importance of minimizing the number of nights/week on HPN. "Free" evenings were said to provide an opportunity to be away from home or

allow for more relaxed family life without an AHCT visit, as well as sleep without being attached to the IV. The participants said they appreciated the possibility to change routines concerning time and day for the HPN treatment if and when it interfered with prioritized activities, i.e. doctor visits, holidays, etc.

In general, the possibility of setting and meeting individual goals related to HPN was emphasized. These individual goals could vary from a desire to adapt HPN to allow travel, to influencing decision-making about HPN. Although HPN prescription was the responsibility of the AHCT staff, patients commonly stated that they could influence the amount and frequency of HPN. For some patients this meant being weaned from HPN when doing well, while for others the treatment could continue but be less intense:

“And then when I stopped /loosing weight/, when I even gained a few hundred grams, then I thought anyway that I maybe could go down a bit /re:HPN treatment/and even the doctor thought it was a good idea, so we tried with three times a week. And I don’t know for how long, a couple of weeks or maybe just one, and then we cut down to twice a week. And that’s where I am now, so I have it twice a week.”

However, a sense of security was also described in the possibility to receive more HPN if the nutritional situation worsened. HPN was explained as helping the patient fight the cancer disease, receive other medical treatments and improve QoL. Doris had stopped HPN treatment at the time of the interview, but matter-of-factly declared:

“If I don’t eat during these periods /referring to periods of depression/, I don’t hesitate a second to ask for nutritional support, because it means everything that I have nutrients in my body so you can fight this (...) so really, it /HPN/ could be as awkward and difficult as anything, but if it helps me, then—then it’s good.”

As implied by Cecilia and Doris above, food intake and weight change was often used implicitly as criteria for HPN evaluation and decision-making by patients and family members. The interviewees could talk about wanting to gain weight. The patients sometimes expressed a desire to return to pre-disease body weight but appeared to recognize that this was unrealistic through contact with AHCT. Professional goals influenced the patients in reformulating their own, as Cecilia described later in the interview:

“I have the ambition to regain my weight. But the nurses here say that their ambition is that I can keep what I have. It’s maybe more realistic. They’ve seen it so many times. It isn’t possible to go back. But it’s thanks to the drip that I haven’t gone down even more.”

Despite the strong descriptions by patients and family members of satisfaction and relief with receiving HPN, it should be noted that the patients are not fully content with their situation. Nutritional problems seemed to be considered as only partially solved while on HPN; the treatment is viewed as a means to an end, rather than as an end in itself. While patients receive nourishment, eating and mealtimes were described as having other important functions, such as enjoyment, that are not fulfilled by technology.

## Discussion

The findings from this qualitative study indicate that the interviewed patients with advanced cancer and their family members experienced physical, social and psychological benefits from HPN treatment. The treatment involved restrictions which affected both patients and their families but which were accepted due to the perceived benefits of HPN. The frequent home visits from the AHCT registered nurses to administer HPN appear to be a particularly positive part of the HPN experience, in the sense of security afforded to both patient and family. As self-administration of HPN is more common in other countries, it would be of interest to investigate if patients and family members, who have experience of self-administration of HPN, report similar benefits of HPN. There was some ambivalence toward HPN; however; while the treatment was seen as valuable, being HPN-free was also highly valued. Positive changes in appetite and weight functioned as informal criteria for diminishing HPN treatment intensity, from the perspective of patients and families.

Studies have shown that non-cancer patients on long-term HPN rate their QoL as low.<sup>24,25</sup> This study indicates that advanced cancer patients, who are in a very vulnerable position, might experience HPN differently. This is in line with Van Gossom and Messing<sup>25</sup> who point out that the shift from HPN use for predominately long-term non-cancer patients to short-term use in cancer patients demands an exploration of differences in management of these very different patient groups.

When planning the study we expected a wider range of opinions about HPN from the participants.

Special efforts were therefore made to include patients with negative experiences, without success. This may be a feature of the inclusion criteria of receiving PN for at least 2 weeks prior to the interview, as patients with negative experiences might quickly discontinue treatment. It is also possible that AHCT staff acted as gatekeepers during study recruitment, and did not recruit patients who were discontent with HPN treatment or AHCT care in general. It should be emphasized that the study aim was to investigate experiences of HPN, which demands a certain degree of familiarity with HPN on the part of patients and families. It should be noted that we did not aim to evaluate HPN treatment in regard to nutritional parameters and/or the patients' calculated nutritional needs. The research group had no influence on prescription of HPN, which is solely the responsibility of AHCT physicians.

Complementing interview data with the PG-SGA questionnaire<sup>20-22</sup> provided new insight into limitations of the PG-SGA. In particular, responses to PG-SGA questions about appetite and activity level seemed to contrast with interview data. Whereas some patients rated their food intake and activity as quite close to "normal", this was contradicted by descriptions during the interviews. This puts into question the appropriateness of asking patients, who have been ill for a long period of time, to make comparisons with the "normal". These patients appear to adjust responses to their "normal" situation as chronically ill, with limited food intake and limited physical activity, rather than using their pre-sickness state as the norm.<sup>26</sup> This section of the PG-SGA instrument might be more appropriate for patients in earlier disease stages.

PN is often discussed in relation to its use and value in palliative care, often in reference to end-of-life care.<sup>5,7-9,27</sup> It should be noted that, although receiving palliative care for advanced cancer, the majority of the patients in this study were not in the final three months of life. Our clinical experience leads us to question whether reluctance among clinicians and medical staff to prescribe PN at the end of life might even lead to reluctance to prescribe in earlier disease stages. It should be emphasized that the palliative phase can often be of considerable duration, and include wide variation in treatments. Severe eating problems due to side effects of oncologic treatment, tumour location or postoperative problems may all be experienced. Compromised nutritional status might be related to issues other than metabolic changes due to the tumour or disease progress.<sup>28</sup> In this study it was noted that some patients' nutritional problems seemed largely due to simple starvation rather than

metabolic changes, as in the case of the two patients who had regained their appetite and therefore discontinued the HPN at the time of interview. Knowledge in this area would be furthered by study of the relationship between causes of nutritional problems and outcome of PN treatments.

Eleven of the 13 patients in this study lived >3 months after initiation of HPN. This data indicates that there might be a period in the palliative phase in which HPN is experienced as beneficial. These findings correspond with those from Bozzetti et al.<sup>8</sup> indicating that patients surviving longer than 3 months might have enough time for QoL benefit from HPN. We have found no nutrition-related QoL instruments appropriate for evaluation of the impact of the HPN treatment in relation to patients' QoL. Development of QoL instruments sensitive to nutritional aspects would be an important complement to the traditionally used objective end points in nutritional research,<sup>12,29</sup> which may not be those most important from the patient's perspective.

Health care professionals sometimes express concern that patients would stop eating orally while receiving PN. This concern was not confirmed in these interviews, in which patients graphically described their efforts to eat as much as they could manage and rarely related eating problems due to HPN. On the contrary, a desire to regain their appetite and taste for food dominated. The HPN treatment relieves the patient from worries about not receiving enough nutrients but does not satisfy other needs. As Hopkins<sup>30</sup> points out, the central role played by food and meal times is not diminished for patients in palliative care. The inability to take part in meal times might thus make the patient feel alienated from the family and the social interaction that takes place at meal times. HPN is thus described by patients and family members as only a partial solution to existing food-related problems, as the patient feels the continued loss of other functions played by food and mealtimes.

In this study most of the patients could eat orally and could digest food. HPN was often described as a complement to the patients' oral intake. This contradicts the most common indication for PN,<sup>31</sup> that is that PN should only be used when it is not possible to feed the patient via the gastrointestinal tract. According to these criteria many of the interviewed patients should instead have been candidates for home enteral nutrition (HEN). To our knowledge, none of the patients had been offered HEN at this stage of the disease. Our clinical impression is that staff often argues that PN is preferable for this patient group due to fewer



gastrointestinal complications and well-established routines for HPN administration. No general guidelines for HPN and HEN are available in the Stockholm area.

Several factors were described as fostering patient and family friendly HPN treatment, including flexibility in scheduling home visits, HPN-free days, and availability and assistance from knowledgeable AHCT professionals. It also became clear that much could be done to allow patients and their families to live with fewer restrictions, by optimizing use of existing technology. Small portable infusion pumps, rucksacks for PN and additional IV stands, all increase flexibility for patients. In this study such products had not been offered to all patients. For example, rucksacks were not used for PN solutions, despite the availability of several brands designed for infusion pump and PN solutions. Even if a rucksack is not feasible for long-distance use for weakened patients, it might still be beneficial as it is not as "hospital like," clumsy, and obvious as an IV stand, and is far more portable. The growing use of HPN makes it valuable to find new technical and practical solutions to facilitate patients' possibility of living an active life, including the possibility of leaving the home.

In this study many interviewed patients received HPN 3–4 times a week or had HPN-free weekends. While HPN-free days were appreciated by the patient and families, and saved time and resources for the AHCT, it remains unclear if this is an optimal form for providing nutritional support. Further study of regimes designed to meet patient/family needs, conserve economic resources in health care, and provide optimal nutritional support is needed.

Further studies are needed to systematically address questions such as whether or not PN should be given to patients with limited time to live; which patients would benefit from PN; what criteria should be used for initiating and ending PN; and how the effects of treatment should be evaluated. Every patient, with his/her family, is unique and palliative support therefore needs to be flexible, and take a variety of circumstances into consideration. There is also a need to develop guidelines for giving HPN that consider not only nutritional aspects but also the best way to give home care nutritional support in order to optimize QoL for both the patient and family members.

## Acknowledgements

This study was supported by grants from the Swedish Cancer Society (#311803) and Fresenius Kabi AB Sweden.

## References

1. Van Gossum A. The ESPEN artificial nutrition workinggroup: multicentre research in home artificial nutrition. *Clin Nutr* 2001;**20**(Suppl. 2):77–80.
2. Howard L. Home parenteral and enteral nutrition in cancer patients. *Cancer* 1993;**72**(Suppl. 11):3531–41.
3. Howard L. A global perspective of home parenteral and enteral nutrition. *Nutrition* 2000;**16**(7-8):625–8.
4. SBU (Statens beredning för medicinsk utvärdering (SBU), *Avancerad hemsjukvård och hemrehabilitering, effekter och kostnader*. Report no. 146, 1999.
5. Torelli GF, Campos AC, Meguid MM. Use of TPN in terminally ill cancer patients. *Nutrition* 1999;**15**(9):665–7.
6. Jonkers-Schuitema CF. HPN = home palliative care? *Clin Nutr* 2004;**23**(6):1253–5.
7. Bozzetti F. Home total parenteral nutrition in incurable cancer patients: a therapy, a basic humane care or something in between? *Clin Nutr* 2003;**22**(2):109–11.
8. Bozzetti F, Cozzaglio L, Biganzoli E, et al. Quality of life and length of survival in advanced cancer patients on home parenteral nutrition. *Clin Nutr* 2002;**21**(4):281–8.
9. Buchman AL. Must every cancer patient die with a central venous catheter? *Clin Nutr* 2002;**21**(4):269–71.
10. McGeer AJ, Detsky AS, O'Rourke K. Parenteral nutrition in cancer patients undergoing chemotherapy: a meta-analysis. *Nutrition* 1990;**6**(3):233–40.
11. Klein S, Simes J, Blackburn GL. Total parenteral nutrition and cancer clinical trials. *Cancer* 1986;**58**(6):1378–86.
12. Bozzetti F. Guidelines on artificial nutrition versus hydration in terminal cancer patients. *Nutrition* 1996;**12**(3):163–7.
13. Lundholm K, Daneryd P, Bosaeus I, Korner U, Lindholm E. Palliative nutritional intervention in addition to cyclooxygenase and erythropoietin treatment for patients with malignant disease: effects on survival, metabolism, and function. *Cancer* 2004;**100**(9):1967–77.
14. Barber MD, Fearon KC, Delmore G, Loprinzi CL. Should cancer patients with incurable disease receive parenteral or enteral nutritional support? *Eur J Cancer* 1998;**34**(3):279–85.
15. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncol Nurs Forum* 1997;**24**(10):1751–7.
16. McClement SE, Degner LF, Harlos M. Family responses to declining intake and weight loss in a terminally ill relative. Part 1: fighting back. *J Palliat Care* 2004;**20**(2):93–100.
17. McClement SE, Degner LF, Harlos MS. Family beliefs regarding the nutritional care of a terminally ill relative: a qualitative study. *J Palliat Med* 2003;**6**(5):737–48.
18. Orrevall Y, Tishelman C, Herrington MK, Permert J. The path from oral nutrition to home parenteral nutrition: a qualitative interview study of the experiences of advanced cancer patients and their families. *Clin Nutr* 2004;**23**(6):1280–7.
19. Patton M. *Qualitative Research and Evaluation Methods*, 3rd ed. Beverley Hills, CA: Sage Publications, Inc.; 2002.
20. Persson C, Sjoden PO, Glimelius B. The Swedish version of the patient-generated subjective global assessment of nutritional status: gastrointestinal vs. urological cancers. *Clin Nutr* 1999;**18**(2):71–7.
21. Ottery FD. Definition of standardized nutritional assessment and interventional pathways in oncology. *Nutrition* 1996;**12**(Suppl 1):S15–9.

22. Ottery FD. Rethinking nutritional support of the cancer patient: the new field of nutritional oncology. *Semin Oncol* 1994;21(6):770–8.
23. Strauss A, Corbin J. *Basics of qualitative research, techniques and procedures for developing grounded theory*, 2nd ed. Beverley Hills, CA: Sage Publications; 1998.
24. Carlsson E, Bosaeus I, Nordgren S. Quality of life and concerns in patients with short bowel syndrome. *Clin Nutr* 2003;22(5):445–52.
25. Van Gossum A, Messing B. Home parenteral nutrition in adults: new trends raise new questions. *Nutrition* 1997;13(5):479–80.
26. Tishelman C, Sachs L. The diagnostic process and the boundaries of normality. *Qual Health Res* 1998;8(1): 48–60.
27. Jonkers CF, Prins F, Van Kempen A, Tepaske R, Sauerwein HP. Towards implementation of optimum nutrition and better clinical nutrition support. *Clin Nutr* 2001;20(4):361–6.
28. Ravasco P, Monteiro-Grillo I, Vidal PM, Camilo ME. Cancer: disease and nutrition are key determinants of patients' quality of life. *Support Care Cancer* 2004;12(4):246–52.
29. Barr JT, Schumacher GE. The need for a nutrition-related quality-of-life measure. *J Am Diet Assoc* 2003;103(2): 177–80.
30. Hopkins K. Food for life, love and hope: an exemplar of the philosophy of palliative care in action. *Proc Nutr Soc* 2004; 63(3):427–9.
31. Stratton RJ, Green CJ, Elia M. *Disease-related malnutrition, an evidence-based approach to treatment*. Oxon: Cabi Publishing; 2003.

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

