



ORIGINAL ARTICLE

# The path from oral nutrition to home parenteral nutrition: a qualitative interview study of the experiences of advanced cancer patients and their families

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## KEYWORDS

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**Summary Background & aim:** Little is known about the perspectives that patients with advanced cancer and their family members have concerning nutritional problems and nutritional support. The aim of this study was to investigate their experiences of the nutritional situation prior to introduction of home parenteral nutrition (HPN) in order to understand factors contributing to the decision to accept HPN.

**Methods:** Semi-structured interviews were conducted with 13 patients with advanced cancer who had received HPN and 11 family members. The constant comparative method was used for data analysis.

**Results:** Patients and family members described the nutritional situation prior to HPN as a source of worry and often desperation. Patients reported wanting and trying to eat, but being unable to do so. Family members experienced powerlessness and frustration, as they could not enable the patient to eat. A lack of attention to nutritional problems by the hospital staff was described. The offer of HPN came when patients and family no longer felt able to solve the nutritional problems within the family.

**Conclusion:** The desperate and chaotic nutritional situation in the family led to willingness to accept HPN. Because of the severity of the problems, HPN was viewed as a positive alternative.

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## Introduction

Many patients with advanced cancer live for an extended time with the support of palliative oncological and medical treatment. Because there is a high frequency of malnutrition in this group of patients,<sup>1-4</sup> it is likely that these individuals and their families would experience nutrition-related problems. Mealtimes are an important part of daily life since food is more than just a source of nutrition. It is an integral part of social, religious, and economic aspects of life and is one way of creating and expressing relationships between people.<sup>5,6</sup> Changes in nutrition-related areas, such as the ability to eat and enjoy food, the times and settings of meals, and interactions with other people during mealtimes, may have important effects on patients' lives. Despite these subjective aspects, evaluations of the interventions used to optimize nutritional intake in cancer patients have generally used objective end points (weight, survival, treatment outcome, etc.) and have not investigated the patients' and families' perspectives on nutritional problems and nutritional support.

According to the World Health Organization,<sup>7</sup> the goals of palliative care include improving the quality of life of patients and their family members, providing relief from distressing symptoms, helping patients to live as actively as possible and integrating the psychological and spiritual aspects of patient care. If hospital staff members, palliative care teams, and other health professionals are to provide nutritional support (oral, enteral or parenteral) in a way that will help reach these goals, it is necessary to know how nutritional issues affect patients with advanced cancer and their families. A few studies have investigated cancer-related nutritional problems from the perspective of patients in the final stage of the disease and their family members.<sup>6,8,9</sup> However, the nutritionally related experiences of cancer patients and their relatives during earlier stages of palliative care have not been investigated in depth either in institutions or at home. The importance of the home-care setting is increasing in Sweden and many other highly developed countries as hospital stays become shorter.<sup>10,11</sup>

The majority of patients with advanced cancer rely on oral nutrition alone, but the use of home parenteral nutrition (HPN) in these patients is increasing in many parts of Europe and the United States.<sup>12-14</sup> No studies have been conducted concerning the circumstances leading to the acceptance of HPN, which is a time-consuming,

expensive treatment that can involve severe complications and requires regular contact with nursing staff. The aim of the present study was, therefore, to investigate the nutritional situation prior to the introduction of HPN from the perspective of patients with advanced cancer and their family members in order to understand the factors contributing to their decision to accept HPN.

## Materials and methods

### Interviews

Because of the lack of prior studies about the experience of nutritional problems during palliative care, qualitative methods were used to obtain in-depth descriptive data about this subject. Approval was obtained from the Research Ethics Committee at Huddinge University Hospital, Stockholm, Sweden, prior to the initiation of the study. Data were collected through qualitative semi-structured interviews<sup>15</sup> that were audio-recorded and transcribed verbatim. Thirteen patients and 11 of their family members were recruited during the winter of 2000–2001 through facilities for advanced home care in the Stockholm region. All interviews were conducted by the first author, a dietitian with extensive experience in cancer care.

Nurses in advanced home care teams (AHCTs) were asked to contact patients with advanced cancer who were receiving palliative care and were able to communicate verbally. Only individuals who had received HPN at least ten times on a schedule of at least three times per week, with a minimum of 900 kcal/time were considered for selection. To ensure variation in the patient population, patients were recruited through seven AHCTs in demographically different parts of the Stockholm region. The names of relatives involved in the patients' nutritional care were provided by the patients. Patients and family members were given verbal and written information about the study, prior to obtaining their consent to participate in the study. The interviews explored nutritionally related issues and experiences prior to the introduction of HPN. As is standard in qualitative research,<sup>16</sup> the interview structure was modified as the interviewer became aware of new, potentially important issues. Patients and family members were interviewed separately in interviews lasting from 30 to 90 min, usually in their own homes. Patients and family members were interviewed on the same day, with the exception of one husband, who was interviewed after the death of his wife. Information

about each patient's diagnosis, oncological treatment, starting date for the first HPN, weight at the start of HPN, and date of death was obtained from the medical records.

### Data analysis

Analysis was conducted using a constant comparative method that compared meaningful data both within and between interviews.<sup>17</sup> The interview-analysis process was continued until clear and stable patterns could be seen in the data, which were unchanged by the addition of further interviews.

The investigators reread the transcribed interviews while listening to the original tapes in order to correct misunderstandings and avoid misinterpretations. The interviews were then coded into smaller units with similar content such as "nutritional advice prior to HPN" and "appetite". The dietitian, oncology nurse researcher, and surgeon from the research group read and discussed the coding based on their different perspectives. After the coded data had been sorted into broader categories, themes that characterized and described the period before HPN and the motivation for beginning HPN were formulated.

Quotations typifying the data and the effects of nutritional problems on the lives of individual patients and their families were selected from the transcripts and translated by a person fluent in both Swedish and English. Fictitious names were chosen for the people interviewed, and the two individuals in a patient/relative pair were given names beginning with the same letter. In the results section, an ellipsis (...) is used to indicate omitted phrases. Words within the symbol // have been added by the authors for clarity.

### Results

Eight women and five men between 47 and 79 years old (median 65 years) with a wide range of cancer diagnoses participated in the study. Table 1 shows the patient characteristics. Four of the patients who had a BMI between 20 and 26, which is considered to be normal, reported having experienced a 20–25% weight loss from their previous body weight. At the time of the interviews, six patients were receiving chemotherapy.

Eleven family members (five wives, four husbands and two daughters) were interviewed. All spouses lived with the patients, while two daughters resided intermittently with the patient. Two

patients did not have family members involved in their daily life.

### Nutritional situation prior to the introduction of HPN

*Physical changes experienced:* All patients interviewed described periods of weight loss prior to the introduction of HPN. One patient said that it was her weight loss that forced her to accept the fact that she had cancer. For some patients, weight loss had been gradual and had been seen as something positive prior to the diagnosis of cancer. Some family members said they were not aware of the extent of gradual weight loss until the patient was quite undernourished. However, as the illness progressed, both patients and families came to regard weight loss as something threatening and said that weight loss made them fear the patient would die from starvation.

I saw that she lost one kilo after another, before the last operation. I've judged the situation and believe that she was starving to death. She got no food at all —she just threw everything up.

*Patients' inability to eat:* The patients indicated that they were fully aware of the importance of adequate food intake and described themselves as wanting to eat. However, they said they were unable to eat because of a variety of factors including nausea, loss of appetite, weakness, swallowing difficulties, gastrointestinal dysfunction, and the changes in the smell and taste of food that they experienced. Some of these problems were said to be due to side effects of oncological treatment. Many of the patients described having more than one problem that affected their food intake. Some patients described disorders that severely affected their food intake that might have been treated if recognized.

Early in the spring, I had this infection that no one knew about for some reason. I must have had it when I was discharged from the hospital. And then she /the AHCT nurse/ said 'It's not strange you couldn't eat'. I had to really struggle to get any food down, since I had no appetite.

*Changes at mealtimes:* The weakness associated with malnutrition, along with nausea induced by the sight and smell of food, led to role changes within the families of most of the women patients. The patients described various degrees of dependence on their husbands for shopping and cooking meals because they could no longer plan and prepare meals as they had done previously.

**Table 1** Patient characteristics.

Characteristic	Number of patients
Total patients	13
Male	5
Female	8
Age	
47–59	6
60–69	3
70–79	4
Primary malignancy	
Gastrointestinal adenocarcinoma (pancreas, esophagus, gastric, rectal)	6
Extra-gastrointestinal adenocarcinoma (breast, lung, ovarian)	4
Other malignancy	3
Time from cancer diagnosis to first HPN	
< 6 months	6
6 months–2 years	3
> 2 years	4
Time from admission to AHCT to first HPN	
0–1 week	7
2–4 weeks	4
4–8 weeks	2
BMI at the start of HPN	
14–19	7
20–25	5
26	1

Meals prior to the introduction of HPN were described as a source of worry and often despair that affected the families' interpersonal relationships and interactions. One patient's wife said:

Usually, well, I make the food and it's no fun to cook and never get to hear that it's tasty or that it tastes good like I've been told before...No, these /meal-times/ are torture.

Patients and family members said that meals during this period were no longer pleasurable social events.

George /a patient/ has always liked food. It's been the main event in the family and we've always liked going out to eat and enjoying our food. But this last year there have been very few occasions when he has enjoyed his food and since he hasn't enjoyed eating it isn't any fun to invite people for dinner either, if they are going to sit and eat for several hours and he just thinks it's a hard time and it starts to taste bad.

The loss of the social aspects of food was described as distressing to both patients and family members. Some patients told they came to see food as serving only a survival function.

The waste of food caused by the patients' difficulties with eating was said to be expensive for some families and was described as being distressing to all involved. Problems with nausea disrupted normal eating habits and added to mealtime stress. Eric, the husband of a patient, described the situation this way:

When there's a person sitting at the kitchen table with a vomit bag in one hand and a fork in the other, it's—it's not the way things should be.

*Families' efforts to help patients eat more:* Family members and patients described numerous strategies to improve food intake, but the difficulties persisted regardless of their attempts to cook special dishes, serve food differently, or fortify it with additional nutrients.

I tried with every possible kind of food, everything that you can imagine. I gave her whatever worked at that moment but if I later suggested that she try that food again, she said she didn't want to see it again.

Family members described feeling totally responsible for the sick person's nutritional care.

They expressed the fear that if they were not always present to prepare food and to encourage eating, nothing would be consumed. Some family members reported that they observed and controlled the patient's food intake to the point of calculating calories, which they said led to a tense atmosphere at meals. Most patients were grateful for their family members' efforts to support them with food they could eat, even when these approaches were not successful.

He didn't go on nagging, I knew I had to eat and get my strength back, but it didn't work; I just couldn't do it. I think he understood that. If I mentioned anything at all that I wanted to eat, well, he would already be halfway to the shop to get it. But then when he got home, it might not taste at all. It wasn't pleasant for him, either, to keep trying and trying and then it didn't work.

Many family members expressed concern that their encouragement to eat might become nagging and worsen the situation. In some cases, urging patients to eat seemed to decrease rather than increase food intake. David said:

I give her food and then she doesn't eat it, then I feel guilty that she isn't getting anything inside her ... I was worried and sad that she wouldn't eat and she got angry with me for nagging about food and it almost went the opposite way you see, that she would simply refuse to eat any food.

*Involvement of physicians and hospital staff:* Both patients and family members said that attention was not focused on nutritional issues during physicians' appointments at the hospital. The reasons given included an apparent lack of time coupled with a feeling that physicians are mainly interested in the oncological disease and treatment. Helene, who accompanied her husband Harry on his visit to the physician, said:

I mean everyone is stressed and then there are these measly 15 min /with the physician/ or whatever it is and bang, bang, bang. It's all about the sickness and what's going to be done and not be done and then that's it.

The patients and relatives said that most physicians did not ask about weight changes and that some physicians did not react to weight loss even when they were told about it. Patients and families reported that the physicians who did inquire about food intake usually did not give advice on how to deal with eating problems, beyond general encouragement to eat.

Doris's husband expressed appreciation about the direct approach a hospital staff member had taken to encourage her eating.

Then she /the radiotherapy nurse/ said to Doris, 'You've got to eat and drink or you won't get through this' she said straight to her face, Doris's that is. And I think that pretty much did the trick, because if I had said it, she would have smacked me, you know.

Some of the interviewed patients had been in hospital immediately prior to the introduction of HPN and reported that their food and drink intake was recorded although they noted no action related to low intake. A number of patients and family members expressed the opinion that the routines, meal preparation, and meal delivery system at the hospital contributed to the patients' malnourishment. Frequent fasting prior to examinations was given as one reason for weight loss. Unpredictable waiting time in connection to oncological treatments without available food was discussed as another contributing factor. A few patients described the hospital food as well-prepared, even though they were not always able to eat it.

*Involvement of dietitians:* Almost all interviewed patients said they had contact with a hospital dietitian prior to HPN, and a few patients had seen a dietitian from the community/home care team. Family members were not always involved in the meetings between the patient and the dietitian. The patients commonly described the dietitian as acting as a consultant with a marginal role who did not follow the patient during the sickness trajectory. Some of the interviewed family members said that little of the dietitian's advice was new or offered anything beyond common sense. Most of the advice given was said not to deal with the situations the patients and families were actually facing.

When he was taken in at the Oncology ward the last time, there was a dietitian there. We got one of those papers about different dishes, what they contained and how much protein and calories and that kind of thing, so we have got that at home. But what's the use when he won't eat?

Some patients had been referred to one dietitian concerning their eating problems and to a different dietitian for advice about an additional condition such as diabetes, short bowel syndrome, or an ileostomy. These patients said they felt confused and uncertain about what they could eat when the advice they received was contradictory.

*Oral nutritional supplements:* All the interviewed patients had tried oral nutritional supplements at home or in hospital with limited success. Both family members and patients described having been eager to try the supplements. Family members put a great deal of effort into urging the patients to consume the supplements and/or trying

to make the drinks more palatable by mixing them with fruit, ice cream, etc. However, patients reported that they still felt unable to drink the supplements because of their smell and taste. Other patients said they experienced stomach pains or nausea and sometimes vomited after drinking supplements.

The first thing */the hospital staff/* did to increase her weight was these small liquid supplements, with names like forest berry and everything possible, but at that point she was so ill in every way that she just threw it all up. I tried to mix them with ice cream and milk and make some type of milkshake or something like that, but that didn't work either and we had to throw them all away. It didn't work well, definitely not, and not only that—when she threw them up, the pills she took also came up. Just disappeared to no help and that was the worst you know.

Families and patients generally attempted to use nutritional supplements for only a short time, saying they quickly realized that the supplements would not solve their nutritional problems. This was described as being a great disappointment to everyone involved, especially in light of the extra effort that had been put into trying the supplements and the increased tension associated with these efforts. No patients reported having received enteral nutrition during the palliative phase of their illness.

### The decision to begin HPN

HPN was generally suggested to the patients by the AHCT, rather than by hospital staff. In most cases, the patients and families had gradually come to realize that they were unable to solve their nutritional situations by themselves but generally knew of no other alternatives before the AHCT became involved in their care. Many of the interviewed patients said they were severely malnourished when the suggestion to start HPN was first made. Iris said:

I was in such bad shape that I was happy with whatever they did to me.

Patients and family members reported that the decision to start with HPN was made jointly by the AHCT staff, patients and family members. The patients and families seemed to trust the assessment of the AHCT staff:

I just kept losing weight, and I was so tired that I didn't have enough energy to do anything. And then she */the AHCT nurse/* visited me, and she said, 'You'll have this drip thing because it's going to do you good'. And so it did, because I stopped losing weight.

No patients or family members described feeling pressured to accept HPN.

HPN was described by both patients and family as necessary for the survival of the patients. It was said to be both logical and a relief to accept the offer of HPN, since a person who does not eat will die. The AHCTs were often said to offer HPN as a means of enabling patients to achieve their own goals, for example, to be stronger and/or more active, to accomplish specific tasks prior to dying, or, as in the case of one man, to enable him to travel to his home abroad as usual with his wife.

Both patients on total HPN were introduced to parenteral nutrition at the hospital because they were unable to eat at all. The regime was continued upon discharge. Karin described her realization that she would not be able to rely on oral nutrition, saying:

Well, in the end there was no point in it. It was meaningless to eat...Cooking every day and eating just to go and put it down the toilet is a waste of effort, I think, a waste of money.

The few doubts expressed by patients about HPN were related to the technology involved rather than to nutritional issues. One patient described her previous negative experience of receiving PN in the hospital through a peripheral vein. Before beginning HPN, she received an implanted subcutaneous venous access port, which contributed to her positive view of HPN. Another patient, Harry, initially thought of his previous experiences of a central venous catheter:

Then I thought about those tubes and how inconvenient it was. You know, there were tubes protruding here and in connection with taking a shower and all that kind of thing. But then they explained the port-a-cath */implanted port/*. I mean it's just a box inside there and then when you use it; you stick it */the needle/* in. First I thought, I don't know—but then I realized that all that none of that really matters, of course.

Although a few patients and family members had previous knowledge of HPN, relatively few described initial concerns about the technology. Most of the interviewed patients had been ill for extended periods, which had entailed a variety of treatments. They described becoming gradually accustomed to technical equipment.

But it was like it */HPN/* was a continuation of this thing with the PEG */percutaneous endoscopic gastrostomy/* and the whole treatment and everything, the way the illness was. So what started was nothing new.

## Discussion

This qualitative study investigated factors leading to the introduction of HPN from the perspective of patients with advanced cancer and their family members. In summary, analysis of the conducted interviews indicated that patients and family members described the nutritional situation prior to HPN as a source of great worry and often desperation. Patients reported wanting and trying to eat, but being unable to do so. Family members experienced powerlessness and frustration, as they could not enable the patient to eat. In addition, they described limitations in the care received regarding nutritionally related issues.

A number of previous studies have investigated the management of nutritional problems and cancer cachexia.<sup>4,18–23</sup> However, the current study focused on how nutritionally related issues affected different aspects of the lives of the patients and their relatives. The patient population in the present study was restricted to individuals who had received HPN at least ten times. Future studies of patients who turned down or discontinued HPN could provide additional information about nutritionally related issues in the lives of patients with advanced cancer.

The current study found that the desperate and chaotic nutritional situation in the family influenced the patient's willingness to accept HPN. Some studies of dying cancer patients reported that anorexia was of less concern to patients than to their family members.<sup>8,24</sup> However, in the present study of patients who were not yet in the final stage of the disease, both the patients and families members expressed the fear that inadequate food intake would lead to death by starvation. The patients and family members who were interviewed therefore saw the possibility of receiving HPN as a relief and a positive alternative. It is therefore unclear from this study if patients offered HPN at an earlier stage of the disease might not be as interested in HPN, if they still hoped to be able to solve their nutritional problems orally. In this study, AHCT staff members were always available and responsible for starting and stopping the infusions, which may have been a consideration in accepting HPN.

The patients and family members interviewed in the present study reported that hospital routines, meal preparation, meal delivery systems contributed to the patients' malnourishment. This finding is in agreement with previous studies by the Council of Europe identifying a number of problems in the current practice of nutritional support in European

hospitals.<sup>28,29</sup> The individuals interviewed in the current study also described a lack of attention to nutritional problems on the part of physicians. The patients who said they received nutritional suggestions from doctors and dietitians also reported being unable to implement the advice due to nausea, dysphagia, and other physical problems. The AHCT members, rather than the hospital staff, were generally the people who suggested starting HPN, which may indicate that the AHCTs were more observant of the severity of the patients' nutritional problems.

If all the members of the health care team were to work toward optimizing the patient's nutritional situation from the time of cancer diagnosis, it might be possible to achieve a decrease in the number of patients experiencing nutritionally related problems as extreme as those faced by the patients in the present study. If dietitians were integrated as members of the health care team, they could better offer dietetic advice and assist in developing coping strategies throughout the illness process. The development of problems leading to inadequate oral intake might thus be avoided or postponed. Improved dialogue between family members and the physician and/or dietitian might increase the likelihood that nutritionally related suggestions could be successfully implemented. The increased contact might decrease the stress that family members can experience when they feel they are solely responsible for meeting the patient's nutritional needs. More interaction between the patient, the family, and the medical team on nutritionally related issues might also increase the chances of finding approaches to nutritional problems that would improve the patient's situation without adding to the tension and distress already present in the family. Such discussions could make it more likely that problems such as nausea, pain, and mucositis that contribute to poor food intake would be identified and treated. Bozzetti et al.<sup>30</sup> argue the usefulness of specific criteria to determine the appropriateness of HPN for cancer patients in the palliative stage. They suggest that in order to initiate HPN, the patients should have a "valid medical indication" and be expected to survive at least three months after the start of HPN. In Stockholm, there are no general guidelines for indications for starting HPN in patients with advanced cancer.

The patients and family members who were interviewed in the present study described nutritionally related difficulties that not only resulted in physical problems, such as weight loss and weakness, but also altered their social lives and their family interactions. The nutritional issues raised by



these patients and their family members could serve as a basis for designing questions for inclusion in quality-of-life instruments to be used in evaluations of treatments that might affect patients' food intake and nutritional status. They could also serve as a basis for restructuring health care in a way that would provide a more coordinated response to the cachexia and anorexia associated with cancer and might help reduce the need for as highly technically sophisticated approaches as HPN.

Both patients with advanced cancer and their families have to deal with many difficult circumstances and decisions as a result of the disease. The effectiveness of health-care staff members in helping patients and their relatives cope with the situation might be significantly increased if the nutritionally related issues raised in this study were consistently addressed.

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