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Home artificial nutrition in cancer

*Home Parenteral Nutrition:
The experiences of cancer patients and their family
members*

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Home Parenteral Nutrition: The experiences of cancer patients and their family members

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Background

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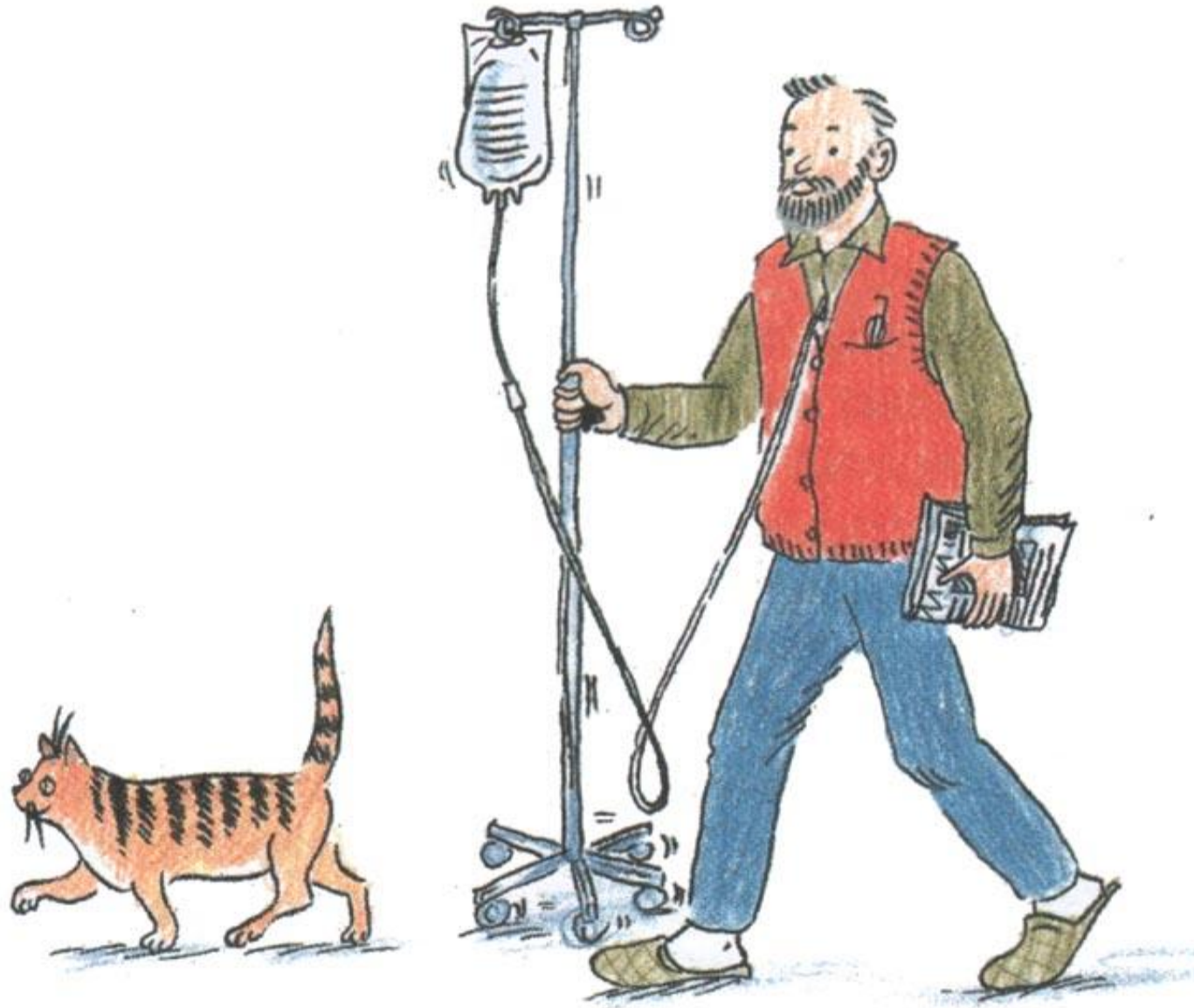
- Controversial to give PN to patients with advanced cancer
- Lack of knowledge about benefits and risks
- Increase in use of HPN for cancer patients in the US and parts of Europe
- Unclear definition of palliative care

Aim:

- To investigate the experiences of HPN from the perspective of advanced cancer patients and their family members

Palliative home care services

- Physician directed
- Multi-professional
- Medical care in the patient's home
- Available 24h/7days per week



Methods and analyses

- Audio-taped semi-structured interviews
 - transcribed
 - coded
- Analysed using constant comparison

Participants

- 13 patients
 - 47-79 years old
 - 5 male/8 female
 - 6 patients on chemotherapy treatment
- 11 family members (spouse/daughter)

HPN treatment

- HPN was delivered in “all-in-one-bags” via subcutaneous venous access port, 2 to 7 nights per week, and administered by a nurse in the palliative home care team

HPN treatment

- 2 patients on total HPN
- 9 patients on partial HPN and oral intake
- 2 patients had recently stopped HPN

Results

- Nutritional situation prior to HPN
- Decision to start HPN
- Experience of receiving HPN

Nutritional situation prior to HPN

- Patients described periods of weight loss
- Weight loss was at first seen as something positive
- Later a sign of disease and death

Nutritional situation prior to HPN

- Meals were a source of worry and often despair
- Meals were no longer pleasurable social events
- Food served only a survival function

Family member

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 not the way things should be

Nutritional situation prior to HPN

- Family members tried to help the patients eat more
- Family members felt totally responsible for patients' nutritional care

Nutritional situation prior to HPN

- During hospital visits attention was not focused on nutritional issues

Nutritional situation prior to HPN

- All patients had tried oral nutritional supplements with limited success
- Dietitians were used as consultants and did not follow the patient during the illness trajectory

The decision to begin HPN

- Patient and family had come to realise they were unable to solve nutritional problems by themselves

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- Patient and family had come to realise they were unable to solve nutritional problems by themselves
- HPN was seen as necessary for the survival of the patient
- The desperate and chaotic situation in the family led to willingness to accept HPN

Patient

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

The experience of receiving HPN

- Sense of relief and security
- Effect on quality of life
- Effect on weight and energy, strength and activity
- Effect on food intake and mealtimes

Patient

There's just this sense of security that I have the drip, because – if it's hard to eat during the evening and I feel that I don't want 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 the nourishment that I know I need from the drip.

The experience of receiving HPN

- Autonomy and dependency in relation to HPN

Patient

This drip means that I'm not getting 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 had the drip, I can manage by myself in a whole different way.

Patient

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.

The experience of receiving HPN

- HPN treatment means regular visits from the home care nurses.

Patient

I'm more fit, food tastes better, and then they come also. They're so 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 my husband also became much happier because he thought he had the responsibility.

The experience of receiving HPN

- Restrictions in family life



The experience of receiving HPN

- Restrictions in the family life
- Sleep disturbance

The experience of receiving HPN

- HPN-free evenings and nights
 - Possibility of changing routines
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The experience of receiving HPN

- Patients and family members expressed physical, social and psychological benefits from HPN treatment.
 - Benefits of HPN treatment were generally said to outweigh negative aspects.
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Time from first HPN to death

No of patients	Months
2	1-3
3	4-6
4	7-12
3	13-19
1	20-33

Aim:

- To investigate the prevalence and use of oral, enteral and parenteral nutritional support in palliative home care services

Methods

Patients recruited from:

- 21 palliative home care services
- telephone interviews with 621 patients

Participants (n=621)

- Mean age 67 years
 - Mean BMI 22
 - 68% nutritionally at risk
 - 40% died within 4 months post-interview
 - >25% lived >1 year post-interview
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Nutritional support (n=621)

- 55% reported use of nutritional support
- 41% oral nutritional support alone
- 14% artificial nutrition

Artificial nutrition

- 14% Artificial nutrition
 - 3% HETF
 - 11% HPN

Characteristics of HPN-users

- Gastrointestinal malignancies most common
 - $>1/3$ had lost $>20\%$ of pre-cancer weight
 - Mean BMI was in lower normal range
 - The majority survived more than 4 months after first HPN-treatment at home
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Use of HPN

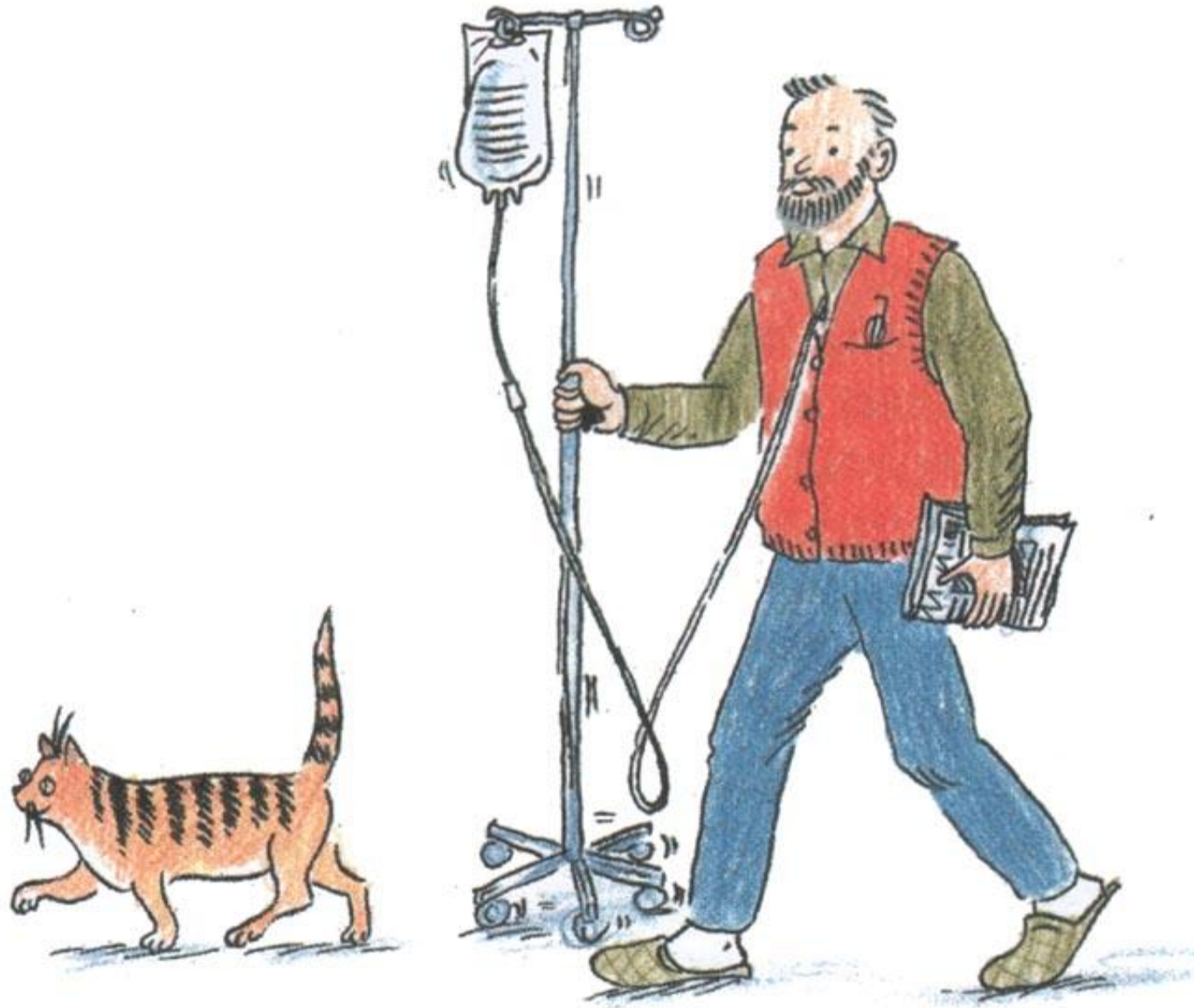
- Almost 3/4 were able to eat solid food
 - More than half used oral nutritional support products
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Most common reason for use of HPN as reported by patients

- Concerns about body weight
 - Concerns about nourishment
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Use of artificial nutrition

- Use of HETF was limited
 - HPN was used to supplement oral intake rather than only for patients with a non functioning GI tract
 - HPN was generally not introduced at the end of life
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References

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