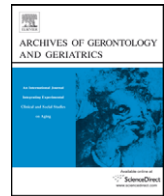




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## Cancer in home care: Unintended weight loss and ethical challenges. A cross-sectional study of older people at 11 sites in Europe

Liv Wergeland Sørbye\*

Diakonhjemmet University College, Box. 184, Vinderen, N-0319 Oslo, Norway

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### ABSTRACT

The aim of this study was to compare unintended weight loss in cancer patients to other elderly. Home care users, aged  $\geq 65$  from urban areas at 11 sites in Europe ( $N = 4010$ ) were assessed with the Resident Assessment Instrument for Home Care. Epidemiological and medical characteristics of clients and service utilization were recorded. A total of 321 (8%) patients had a cancer diagnosis; they were on average  $80.4 \pm 7.3$  years. Socio-demographic, functional and clinical parameters revealed small variations in the two groups. Compared to the non-cancer group, they more frequently suffered from: severe malnutrition (odds ratio = OR = 2.4) unintended weight loss (OR = 2.0), had been hospitalized during the last 6 months (OR = 1.8). Older patients with cancer suffer more frequently from problems associated with nutrition than non-cancer patients. A comprehensive assessment could lead to better management of food and fluid supply based on basic ethical principles.

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### 1. Introduction

The aim of the current study was to describe cancer patients aged  $\geq 65$  years with unintended weight loss in home care at 11 different sites in Europe. More specifically, to determine how a comprehensive assessment would help to identify early symptoms of undernutrition, leading to better management of food and fluid supply among home care clients.

Cancer is more common with increasing age; three-quarters of deaths from cancer occur in people aged over 65 (Davies and Higginson, 2004). A comprehensive literature review revealed few research articles concerning the older person's specific needs related to a cancer diagnosis (Extermann, 2005).

Older cancer patients are at increased risk of malnourishment. Several studies have documented the elderly as being especially vulnerable to undernutrition (Charles et al., 1999; Beck et al., 2001; Newman et al., 2001; De Groot and Van Staveren, 2002; Poulsen, 2005; Sørbye et al., 2008). On the other hand, unintended weight loss is often one of the first signs of cancer (Hamilton et al., 2006). The cancer itself, treatment and side effects of treatments are often associated with serious nutritional problems (Pasanisi et al., 2001; Bozzetti, 2003; Kruiženga et al., 2003; Hopkinson et al., 2006).

Several research articles concerning older people and cancer have been focusing on home parenteral nutrition (HPN) (Roberge et al.,

2000; Pasanisi et al., 2001; Jones, 2003; Orreval et al., 2004; Santarpia et al., 2006; Ugur et al., 2006; Violante et al., 2006; Wengler et al., 2006), and home enteral nutrition (HEN) (Schneider et al., 2001; Madigan et al., 2002; Loeser et al., 2003). General nutrition problems in cancer care are well documented (Bruera et al., 2001; Wilson et al., 2002; Kruiženga et al., 2003; Rustøen et al., 2003).

Clinical, legal and ethical issues concerning whether to start or withdraw medically provided nutrition and hydration raises emotional and medical concerns (Nolde, 2003; Slomka, 2003; Ferrell, 2006; Fine, 2006; Ganzini, 2006). Food has great symbolic value and affects common moral judgment with respect to treatment (Caspar, 1988). The principles of biomedical ethics described by Beauchamp and Childress (2009) have been recognized and may be useful tools in resolving actual dilemmas. Patient autonomy has been strengthened through enacted laws in a number of different countries, and the principles of nonmaleficence and beneficence have been integrated in professional ethical codes (ICN, 2002). National laws and health policy guidelines promote equal treatment and justice (Law nr. 63, 1999). However, in home care, health professionals do not always have easy access to a consulting team. Oftentimes, community-based, care providers must resolve ethical challenges as best as they can.

The current study focused upon three specific topics: the clinical characteristics of cancer home clients and in comparing the nutritional status of cancer patients to other elderly in home care with a larger sample of non-cancer patients and how do the HC professions at different sites manage nutrition-related problems in patients with cancer.

\* Tel.: +47 22 451 978; fax: +47 22 451 914.  
E-mail address: [sorbye@diakonhjemmet.no](mailto:sorbye@diakonhjemmet.no).

## 2. Subjects and methods

### 2.1. Study population

The data for this analysis were derived from the Aged in Home Care Project (AdHOC). The AdHOC is a cross-sectional study, performed at 11 sites in Europe. Each site selected a random sample of approximately 400 persons aged 65 years or more from agencies providing home care services in an urban area. Potential participants were identified from either the health or social care records and selected randomly. Ethical approval for the study was obtained at all the sites according to national regulations. Participants were assured of the confidentiality of the study information and asked to provide informed consent. The final study sample included 4010 older individuals, the respond-rate was 80.4%. Further characteristics of the AdHOC sample and other details of the larger study are published elsewhere (Carpenter et al., 2004).

### 2.2. Measurements

The clients were assessed with the international Resident Assessment Instrument for Home Care (RAI-HC), version 2.0. The RAI-HC contains more than 300 items, including the socio-demographic, physical, and cognitive characteristics of clients as well as medical diagnoses; medications received, and service utilization. The assessors were specially trained to use the manual that accompanies the RAI-HC (Morris et al., 2000). Information with which to complete the RAI-HC assessment was obtained from the clients and/or their next of kin, clinical observations, health care workers and/or medical records. The instrument has been tested for validity and reliability in several countries with satisfactory results (Morris et al., 1997).

### 2.3. Variables and definitions

#### 2.3.1. Epidemiologic variables

Site, gender, living alone, ages: <80 versus >80 years.

#### 2.3.2. Formal and informal services

Hospitalization in last 90 days, use of home care services and informal help, special diets, use of intravenous and parenteral gastric tube.

#### 2.3.3. Unintended weight loss, nutritional, oral, and gastrointestinal status (GI)

Weight loss was assessed according to information about unintended weight loss of 5% or more in the last 30 days (or 10% or more in the last 180 days). Severe malnutrition (cachexia) was defined as a disorder of nutrition; it may be due to a deficient diet or deficient breakdown, assimilation, or utilization of food.

Problems with food and fluid consumption and other indicators of impaired GI-status included reduced appetite, vomiting, constipation, or diarrhea (during the 3 days prior to the assessment). The use of gastric tube and intravenous nutrition is illustrated by minor cases, built on individual RAI-data.

#### 2.3.4. Pain

We included: (a) frequency with which client complains or shows evidence of pain: daily, one period or more, (b) intensity of pain: moderate/severe or stronger; (c) from client's point of view, pain intensity disrupts usual activities; (d) character of pain: localized – single or multiple sites; and (e) from the client's point of view, medications adequately control pain.

#### 2.3.5. Falls

Any falls during the last 90 days; pressure ulcer: (i.e., any lesion caused by pressure or shear forces resulting in damage to underlying tissues). Social functioning indicators included (a) reduced social activity, (b) client feels lonely, and (c) client has not been out of the house in the last week.

#### 2.3.6. Other health indicators

We included: "Has conditions or diseases that make cognition, ADL, mood, or behavior patterns unstable (fluctuations, precarious, or deteriorating)," "Experiencing a flare-up of a recurrent or chronic problem," self-reported poor health and terminal diagnoses (less than 6 months to live). The Cognitive Performance Scale: CPS is used to determine an individual's ability to make everyday decisions. It is based on the following items: memory, cognitive skills of daily decision making, expressive communication, and ability to eat. The scale is hierarchical, starting from "0", indicating the absence of cognitive impairment, to "6," meaning "totally cognitively impaired." Individuals with a score of 3 (cut-point) or more are classified as cognitively impaired. Scores of 4–6 indicate severe to complete cognitive impairment and are equivalent to a

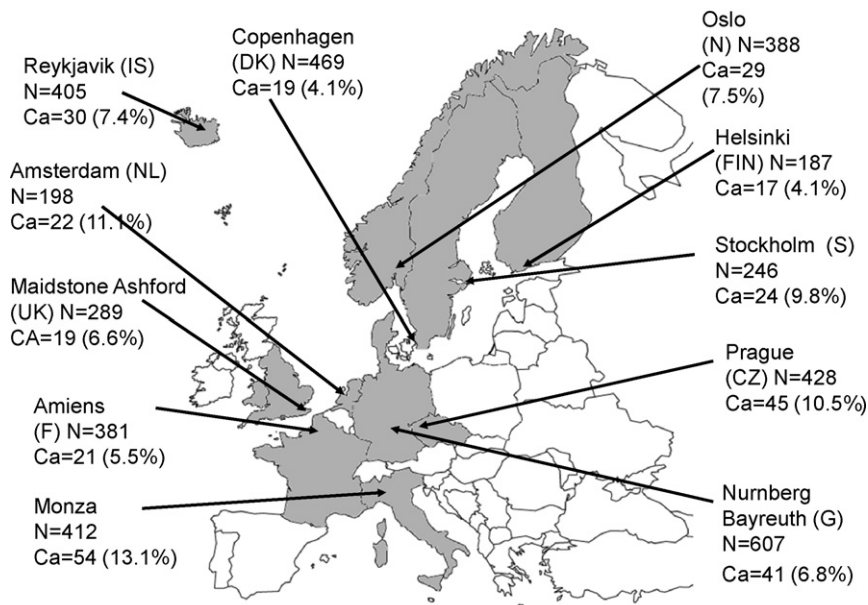


Fig. 1. Participating sites according to country, informants and prevalence of cancer.  $N = 4010$  and  $n = 321$ .

score of 15 or less on the mini mental state examination (MMSE) (Morris et al., 1994).

For physical functioning, we used two hierarchical scales for activity of daily living (ADL) (0–8) and instrumental activity of daily living (IADL) (0–7) measuring dependency in different functions. A higher score means dependency in more functions. ADL assessed: mobility in bed, transfer, eating, toilet use, personal hygiene, dressing upper and lower body, locomotion inside and outside home, and bathing. IADL assessed: meal preparation, housework, managing medication, managing finance, phone use, shopping and transport; primary modes of locomotion indoors and outdoors. For both scales dependency in four or more functions were used to designate clients having moderate or severe physical impairment.

For indicators of depression, anxiety and sad mood, we used nine different characteristics; one or more had to be assessed during the three last days. Further potential nutritional risk factors included were medications (antipsychotics, antidepressants, and antianxiety/hypnotics) (Huffman, 2002).

#### 2.4. Statistical analysis

Statistical analyses were performed on baseline data. Dividing the sample in two groups resulted in a design with its own control according to nutritional problems: (1) those with a cancer diagnosis and (2) non-cancer patients. All analyses were performed using SPSS software version 15 ([www.spss.com](http://www.spss.com)). Variables associated with cancer and nutritional problems were identified (analysis for dichotomous variables). We used Pearson's  $\chi^2$  and odds ratios (OR) with 95% confidence intervals (CI) for risk estimates. A  $p < 0.05$  was considered to be statistically significant.

### 3. Results

#### 3.1. Characteristics of study sample

The sample consisted of 4010 persons; 321 (8%) had a cancer diagnosis. The prevalence of clients with a cancer diagnosis varied from 4.1% in Copenhagen and Helsinki to 13.1% in Monza (Fig. 1).

Descriptive analyses of baseline socio-demographic, functional and clinical parameters according to non-cancer and cancer older patients revealed small variations in the two groups. The mean age was  $82.5 \pm 7.3$  years for non-cancer patients versus  $80.4 \pm 7.3$  years for cancer patients (Table 1).

Cancer patients had several characteristics significantly associated with nutritional problems ( $p < 0.001$ ). Compared to the non-cancer group, they more frequently suffered from: unintended weight loss, insufficient food and fluid intake, reduced appetite and diarrhea. In addition, cancer patients were

more likely to identify with poor self-reported health and more were more likely to have been hospitalized during the last 6 months prior to their RAI-HC assessment. Nutrition supplements like special diet (excluded for diabetics), intravenous nutrition, or gastric tube were not used significantly more frequently in cancer patients versus non-cancer patients. Malnutrition was seen in 17 (5.3%) of the cancer patients and in 84 (2.3%) of the non-cancer group. The data were analyzed using malnutrition as the independent variable; with the exception of one variable, there were no significant differences between cancer and non-cancer patients in the variables displayed in Table 2. The cancer patients were more often at risk of hospitalization during the last 6 months (OR = 5.87; 95%CI = 1.92–17.88)  $p < 0.001$  (data not shown).

#### 3.2. Gastric tube and intravenous nutrition

Of the total sample, five cancer patients used gastric tubes, two from Germany and three from Italy.

##### 3.2.1. Nurnberg/Bayreuth, Germany

A male, 69 years old, had never married, lived alone, hospitalized last 90 days. He had diarrhea, skin problems and was dependent on assistance for "eating." He needed help with one of his ADL functions. He was cognitively intact, and was assessed to have more than 6 months to live.

A widow, 73 years old, lived alone; she had been hospitalized last 90 day. She had reduced appetite and weight loss. She was dependent in three of seven ADL- and five of eight IADL functions. She was assessed to have less than 6 months to live and received palliative care.

##### 3.2.2. Monza, Italy

A male, 71 years old, was married. He had urinary catheter and was dependent in seven IADL and seven ADL functions. He was assessed to have more than 6 months to live.

A widow, 76 years old, lived with her family. She had been hospitalized during the last 90 days. She had ostomy, urinary catheter and used pads. She was dependent in all of the IADL and the ADL functions, and her CPS was assessed to be "4" (moderate demented). She was assessed to have less than 6 months to live and received palliative care.

A widow, 88 years old, lived with her family. She had been hospitalized the last 90 days. She had diarrhea, urinary catheter and was dependent in all of the IADL- and seven of the ADL functions and her CPS was "2". She was assessed to have more than 6 months to live.

Six of those ten patients receiving IV treatment at the time of assessment were from Germany, three from Italy and one from the Czech Republic. They had a mean age of 79.34 (72.9–87.46); four lived by themselves and eight were female. Two were assessed to have less than 6 months to live; one of them received palliative care. Two had been hospitalized within the last week, two between 14 and 40 days, and two more than 30 days ago.

### 4. Discussion

The present study has described a group of home care patients who are at twice the risk for nutritional problems; they are elderly and have a cancer diagnosis. In this article, we have compared unintended weight loss and its associations in cancer patients to other older, home-dwelling clients at 11 sites in Europe. As far as we know, such a comparison has not been previously published. We will describe the ethical implications associated with unintended weight loss and different culture for using parenteral nutrition supply.

**Table 1**

Selected characteristics of the study populations: non-cancer and cancer older patients, mean  $\pm$  S.D., or  $n$ (%).

Clinical characteristics	Non-cancer	Cancer
Number	3689	321
Age	82.5 $\pm$ 7.3	80.4 $\pm$ 7.3
Gender: Female	2754(75)	220(69)
Married	871(24)	82(26)
Living alone	2234(61)	191(60)
Intravenous feeding	65(1.8)	10(3.1)
Tube feeding	41(1.1)	5(1.6)
Help for meal preparation	2237(60.6)	194(60.4)
Help for shopping	2888(78.3)	241(75.1)
Help for eating	759(20.6)	66(20.6)
CPS score	1.2 $\pm$ 1.7	0.9 $\pm$ 1.3
No. of medications	5.4 $\pm$ 2.9	5.7 $\pm$ 3.0

**Table 2**  
Characteristics of patient with non-cancer and cancer in 11 sites in Europe, n(%).

Characteristic	No-cancer	Cancer	OR (95%CI)	p < ( $\chi^2$ -test)
Gender: males vs. females n = 1036	935(25.3)	101(31.5)	1.35(1.06–1.73)	0.016
Age: <80 years n = 1476	1321(35.8)	155(48.3)	1.67(1.32–2.11)	0.001
CPS > 3, n = 401	401(10.9)	18(5.6)	0.49(0.30–0.81)	0.003
<b>Nutrition data</b>				
Unintended weight loss, n = 522	451(12.2)	71(22.1)	2.04(1.54–2.70)	0.001
Severe malnutrition n = 101	84(2.3)	17(5.3)	2.40(1.41–4.10)	0.01
Less than 1 meal/day n = 181	155(4.2)	26(8.1)	2.14(1.32–2.11)	0.001
Insufficient food and fluid intake n = 165	140(3.8)	25(7.8)	2.14(1.38–3.33)	0.001
Dry mouth n = 347	308(8.3)	39(12.2)	1.52(1.07–2.16)	0.020
<b>Gastrointestinal data</b>				
Problem swallowing n = 603	542(14.7)	61(19.0)	1.36(1.02–1.83)	0.038
Reduced appetite n = 394	340(9.2)	54(16.8)	2.00(1.46–2.72)	0.001
Diarrhea n = 199	170(4.6)	29(9.0)	2.06(1.36–3.10)	0.001
<b>Other symptoms</b>				
Moderate/severe pain n = 659	587(15.9)	72(22.4)	1.53(1.16–2.02)	0.003
Skin problems n = 1090	986(26.7)	104(32.4)	1.31(1.03–1.68)	0.029
Sad, pained, worried expression n = 739	654(17.7)	85(26.5)	1.67(1.29–2.17)	0.001
Reduces social activity n = 1394	1261(34.2)	133(41.4)	1.38(1.09–1.74)	0.007
<b>Personal reflections health status</b>				
Multiple health complain n = 377	331(9)	46(14.3)	1.7(1.22–2.37)	0.002
Self-reported poor health n = 1193	1069(29)	124(38.6)	1.54(1.22–1.95)	0.001
Terminal prognosis < 6 month n = 32	17(0.5)	15(4.7)	10.59(5.24–21.5)	0.001
<b>Use of formal services</b>				
Hospitalization in last 6 months n = 698	614(16.6)	84(26.2)	1.78(1.37–2.32)	0.003
Palliative care n = 387	341(9.2)	46(14.3)	1.64(1.18–2.29)	0.003
Special diet n = 217	193(5.2)	24(7.5)	1.47(0.94–2.27)	0.09
Intra venous n = 75	65(1.8)	10(3.1)	1.80(0.90–3.59)	0.09
Gastric tube feeding n = 46	41(1.1)	5(1.6)	1.41(0.55–3.59)	0.471
Ostomy n = 134	102(2.8)	32(10.0)	3.89(2.57–5.90)	0.001

The prevalence of individuals over the age of 65 years is increasing (Yancik, 1997). Three-quarters of deaths from cancer occur in this age group (Davies and Higginson, 2004) and 61% of cancer survivors are at least 65 years old (Rao and Demark-Wahnefried, 2006). The current study revealed that 8% of home care clients aged 65+ had a cancer diagnosis; the frequency varied between the different sites. We thought this was a low rate compare to the prevalence among cancer patients in the European population. However the corresponding value for the home care population in USA was 5.9% (Dey, 1996). The cancer patient may be cared for by their next of kin, until the final hospitalization or a permanent institution bed. Many older cancer patients are under-diagnosed (Litvak and Arora, 2006). However, those older individuals with a cancer diagnosis differed significantly from those older individuals who did not have cancer. In the current study, cancer patients were on average 2 years younger than their counterparts. This may be the main reason that the frequency of dementia was lower among the cancer patients and the frequency of men slightly higher, 31% versus 25% in the non-cancer group. Both groups had the same marital status, similar frequency of living alone, 60%, and similar activity of daily living scores. However, cancer patients reported poor health far more frequently than the non-cancer group. Self-rated health has been found to be a valid measure of a person's health condition (Heistaro et al., 2001). Self-rated health is comparable across cultures and genders (Okamoto and Tanaka, 2004).

Earlier analyses have revealed unintended weight loss and other nutrition-related problems in older home care patients (Sørbye et al., 2008). When we compare nutritional status in the cancer patients versus other elderly, we find that cancer patients' health is worse in many areas. This is a medical and ethical challenge. Several studies have documented hospitalization as an important risk factor for unintended weight loss (Liu et al., 2002; Gazzotti et al., 2003; Sullivan et al., 2004; Fugate, 2005; Thorsdottir

et al., 2005). Cancer patients were more frequently hospitalized during the last 3 months than their counterparts. This difference was still significant ( $p < 0.001$ ) using malnutrition as an independent variable. Hopkinson et al. (2006) found that older patients were less concerned about eating than younger patients; their next of kin were more concerned. For the 60% of patients who lived alone, the motivation to eat was less. The combination of old age and cancer puts patients at high risk (Kruizenga et al., 2003) and may reflect a general attitude: When an older cancer patient loses weight, then there is no need for active treatment. Jordhøy et al. (2003) emphasized that older cancer patients in her sample received less palliative care than younger patients with the same diagnosis.

In spite of several different nutritional and gastrointestinal-related problems, few of the cancer patients received intravenous (IV) or HEN. Among the cancer patients, 24 (7.5%) were assessed to require a special diet, although 12 were diabetic (data not shown). One may assume that the older cancer patients were at the end-of-life, but only a few (15 persons) were assessed to have a life expectancy of less than 6 months. For individuals with a high frequency of self-rated poor health and without a terminal diagnosis, more active treatment seemed to be provided.

Pain is often associated with cancer and care for the elderly (Bernabei et al., 1998; Davies and Higginson, 2004). In this sample, cancer patients did not suffer more from pain, and they did not use more medication than other frail older people. However, they did report poor health more often. Suffering related to nutritional problems distinguished cancer patients from their counterparts. Our data revealed that home care patients received few active treatments to address their multiple health complaints.

The only sites that used IV and HEN for cancer patients were Germany and Italy. We do not have background data available to discuss the reason why some patients received artificial nutrition in our sample. Two of those ten patients receiving IV treatment at

the time of assessment had been determined to have less than 6 months to live. Only four of them had been hospitalized during the previous 4 weeks. We suggest that IV treatment was not an emergency treatment, but it was started as nutritional supplement over time. Orrevall et al. (2004, 2005) concluded in their study that HPN was viewed as a positive alternative due to the severity of the problems without this treatment. Roberge et al. (2000) did a prospective study on neck or oesophageal cancer and concluded that HPN was physically well accepted, but some patients experience psychosocial distress. Wengler et al. (2006) found that, in Europe, 66% of the centers with specialized team monitoring of HPN patients, had some kind of written guidelines regarding appropriate use. Ugur et al. (2006) stated that HPN has evolved from an experimental approach to standardized therapy for patients with intestinal failure.

Five cancer patients in our sample were tube fed. Two of them were assessed to have less than 6 months to live, but none of them were assessed to be at an end-of-life stage. In a retrospective case-note analysis, Madigan et al. (2002) found that cancer patients need more intervention compared to those patients with other medical conditions. They concluded that more intensive dietetic monitoring of HEN is necessary.

In the European countries, 75–80% of elderly die in an institution (Jordhøy et al., 2000; Van Rensbergen et al., 2006). In Norway 14% of patient with a cancer diagnosis died at home (Norwegian Public Reports, 1997). The health professional's duty is to give life prolonging care. This intention represents the principle of beneficence, doing good. Food has a great symbolic value. Both the family and the patient know that, without food and fluid, life expectancy is limited. This knowledge activates feelings more often than rational judgments. The New York State Health Care Proxy Law allows a surrogate to make all kinds of medical decisions on the behalf of the cognitively impaired. However, this law dictates that if the agent is not aware of the patient's wishes regarding hydration and nutrition, the agent cannot make decisions about these types of treatments (Nolde, 2003). Hebuterne et al. (2003) described variations in use of home enteral nutrition (HEN) in a cross-national study. They expected that the incidence of HEN in the European population would grow in the future, but they predicted that different social, economical, and ethical attitudes toward HEN use would persist. Pope Pius the XII (1958) defined the difference between ordinary and extraordinary treatment at the end-of-life. Nutrition and fluid were categorized as ordinary means; these are still relevant guidelines today, especially in countries where the Catholic Church is more common.

We understand that artificial nutrition could be an effective solution for a complicated nutritional situation. We agree, however, with Schneider et al. (2001) that one needs more accurate selection criteria for older patients with a serious underlying disease before starting artificial nutritional support. The money spent on the administering of artificial nutrition could be used as ordinary means to reduce older patients' symptoms. In Norway, nurses working in cancer care ranked problems related to nutrition as number two, next to patients' anxiety as their primary challenge (Rustøen et al., 2003). Wilson et al. (2002) described an unmet need for psychological support related to nutrition among patients and caregivers in the district nursing service.

Demark-Wahnefried et al. (2006) emphasized that oncologists should promote lifestyle changes that may improve their patients' life expectancy and quality of life. Younger people with a cancer diagnosis are often eager to change their lifestyles; similar lifestyle changes may be more difficult for older people. Food is connected to culture, habits and emotions. Bruera et al. (2001) and colleagues described how a multidisciplinary symptom control clinic in a cancer center met the limitation of competence in community care. The center carried out a 4-week follow up study of counseling

cancer patients. Overall, symptom distress (including nausea and loss of appetite) improved significantly during the intervention. Challis and Hughes (2002) concluded that extension of intensive home support service is likely to be required to provide real home-based alternatives to residential and nursing-home care. Slomka (2003) suggests focusing on the disease process rather than on starvation and dehydration as the cause of death, as this may help the family and the physician provide optimal end-of-life care. Our concern is that older people with a cancer diagnosis may be treated as if they were at the end-of-life, before their time is due. We do not have background data available to discuss the five examples in our sample where tube feeding was used or for those patients that were receiving IV treatment at the time of assessment. We know, however, that the other cancer patients in the current study with similar problems did not receive artificial nutrition.

Before any decision is made concerning nutrition treatment, clinical issues have to be addressed. The first step is to assess and document the patient's nutrition status; the second step is to eliminate symptoms associated with limited food intake; the third step is to plan a proper diet with the patient; the fourth step, if the patient continues to lose weight, is to make an ethical decision whether to provide artificial nutrition.

The AdHOC study had some limitations. The sites had on average only 8% of patients with a cancer diagnosis in their home care population. We do not know what type of selection this was, it could have been that those patients with greatest need of help were enrolled in home care. An important limitation was the use of unspecified cancer diagnoses. All cancers except skin cancer were included. In addition, the RAI-assessment form had embedded a reduced set of variables measuring nutrition. On the other hand, the design of this study created a unique control group, enabling the comparison of older cancer patients to non-cancer patients in a home care setting. The results confirm that cancer patients are more frequently in need of nutritional care than other frail older patients.

## 5. Conclusions

Older cancer patients suffer more frequently from problems associated with nutrition than non-cancer patients, but special diets are seldom used. A comprehensive assessment would help identify early symptoms. This could lead to better management of food and fluid supply. Health professionals have to know their country's laws and guidelines. Laws express what one has to do, while guidelines tell what one can or ought to do. Health professionals are responsible for adequate treatment for each patient. They decide when it is medically reasonable or unreasonable to intervene or not to intervene. Competent patients have the right to make their own choices, and it is important to listen to the opinion of the proxy.

## Conflict of interest statement

None.

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