



FOOD IS MORE THAN NUTRITION

Psychosocial consequences of a reduced
ability to eat in patients with cancer

NORA LIZE

Food is more than nutrition

Proefschrift

ter verkrijging van
de graad van doctor aan Tilburg University
op gezag van de rector magnificus, prof. dr. W.B.H.J. van de Donk,
in het openbaar te verdedigen ten overstaan van een door het
college voor promoties aangewezen commissie in de Aula van
de Universiteit op maandag 3 juli 2023 om 16.00 uur

door

Nora Lize,
geboren te Utrecht

PROMOTOR

prof. dr. L. van de Poll (Tilburg University)

COPROMOTORES

dr. S. Beijer (IKNL)

dr. N.J.H. Raijmakers (IKNL)

LEDEN PROMOTIECOMMISSIE

prof. dr. C. van Zuylen (Amsterdam UMC)

prof. dr. M.J. Schuurmans (UMCU Julius Center)

prof. dr. H. Schers (Radboud UMC)

prof. dr. E.J. Krahmer (Tilburg University)

dr. J.A.E. Langius (Haagse Hogeschool)

dr. M. Hoedjes (Tilburg University)

This PhD research was funded by a grant from Zorginstituut Nederland and Stichting Stoffels Hornstra. Printing this thesis was financially supported by Tilburg University and the Netherlands Comprehensive Cancer Organisation (IKNL). Cover artwork and design by © Franka de Groot for Franka.nu.

©2023 Nora Lize, The Netherlands. All rights reserved. No parts of this thesis may be reproduced, stored in a retrieval system or transmitted in any form or by any means without permission of the author. Alle rechten voorbehouden. Niets uit deze uitgave mag worden vermenigvuldigd, in enige vorm of op enige wijze, zonder voorafgaande schriftelijke toestemming van de auteur.



CONTENTS

Chapter 1	General introduction	9
PART 1	Mapping the problem of the psychosocial consequences of a reduced ability to eat	
Chapter 2	Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study	23
Chapter 3	Nutrition-related problems, nutritional support practices and barriers to adherence to nutritional guidelines during intensive treatment for acute myeloid leukemia: patients' and hematology nurses' perspectives and experiences	43
Chapter 4	Patients with cancer experience high impact of emotional consequences of reduced ability to eat: a cross sectional survey study	71

PART 2	To gain insights into the provided psychosocial support for a reduced ability to eat	
Chapter 5	Are gastrointestinal problems, nutritional care and nutritional care needs associated with quality of life in patients with advanced cancer: Results of the observational eQuiPe study	97
Chapter 6	Experiences of patients with cancer with information and support for psychosocial consequences of reduced ability to eat: a qualitative interview study	115
Chapter 7	Experiences of primary healthcare professionals with psychosocial support for reduced ability to eat in patients with advanced cancer: a qualitative interview study	135
Chapter 8	General discussion	155
Chapter 9	Summary of the thesis (in English and Dutch)	179
Appendices	Words of appreciation	189
	List of Publications	193
	About the author	195



CHAPTER 1

General introduction



GENERAL INTRODUCTION

In 2020 approximately 19 million people were diagnosed with cancer worldwide, and 10 million people died from the disease in the same year.¹ In the Netherlands, the number of people diagnosed with cancer increases every year. This is largely explained by the aging population. In 2020, almost 113.000 people were diagnosed with cancer in the Netherlands.² Fortunately, more and more people survive cancer in the Netherlands, due to earlier diagnostics and improved treatments. In 2020, the 20 year prevalence was a little over 816.000.² Despite the earlier diagnosis and better treatments, there is still a large proportion of patients who do not survive cancer. In 2020, almost 46.000 patients died of cancer in the Netherlands.^{2,3}

Cancer and nutrition-related problems

Nutrition-related problems due to cancer or its treatments are common. Overall, nutrition-related problems were reported by 45% of cancer survivors diagnosed and/or treated for cancer within the past five years.⁴ Patients can suffer from various nutrition-related problems depending on the tumour location, the course of the disease and the treatments. Nutrition-related problems include; anorexia, taste and smell changes, early satiety, dry mouth, swallowing problems, nausea and vomiting, constipation or diarrhoea.^{5,6} Some cancer types are known for their high impact nutrition-related problems; oesophageal, stomach, pancreatic, head and neck and lung cancer.⁷ For example, in patients with head and neck cancer the prevalence of nutrition-related problems is >90%, mainly as a result of swallowing problems induced by the location of the tumour and its treatment.⁸ Also cancer treatments, for example chemotherapy, can cause nutrition-related problems like nausea and vomiting⁹⁻¹¹ and taste and smell alterations¹². When the disease progresses, the severity of the nutrition-related problems are likely to increase. The most common nutrition-related problems are reported by patients with end-stage cancer. These problems are taste and smell alterations, constipation, and abdominal pain.⁶ Due to diminished nutritional intake in combination with metabolic alterations caused by the tumour, about 85% of the patients with advanced cancer will develop the anorexia-cachexia syndrome in the end stage of the disease.¹³ Cancer cachexia is defined as a multifactorial syndrome characterized by the loss of skeletal muscle mass. This loss of skeletal muscle mass cannot be fully reversed by nutritional support and leads to progressive functional impairment.¹⁴

Mapping the problem: the psychosocial consequences of a reduced ability to eat

Nutrition-related problems can lead to a reduced ability to eat in patients with cancer. The physical consequences of this reduced ability to eat were extensively described in the literature^{13,14}, while little research was done into the psychosocial consequences. This gap in the literature is strange because we all know that eating is more than meeting the intake of nutrient requirements. Sure, we eat to nourish ourselves, but eating holds so much more meaning in our lives beyond this bare fact. We eat because we like it, we enjoy it, we organise our day according to the daily meals. There are national and regional dishes and products that we see as part of our identity.¹⁵ For example, Dutch people may identify with a plate of mashed vegetables and potatoes ('stampot') or Brabant sausage rolls ('worstenbroodjes'). We use breakfast and dinner time as important moments to get the family together. We celebrate special occasions with festive meals. Cooking is a favourite hobby of many.¹⁶ Saturday shopping for food at the market is a popular outing, which we finish by enjoying a drink and a Dutch croquette ('bitterbal') on a terrace. In short, being able to eat well and enjoy eating is an important part of our (healthy) lives, including our emotional and social well-being.

Food as medicine

Somehow we get a much more functional view on eating when someone gets sick. Cancer? Good healthy food and extra protein. That is important to make it through the treatments and to live as long as possible.^{5,8,13} The words we use change from food and eating into nutrition and nutrients. Why does all the meaning of eating no longer apply to the life of someone who is sick? Both the disease itself and the treatments are known for their (multiplicity of) nutrition-related problems, but what does it mean to someone with cancer that he or she can no longer enjoy eating? What does it mean that our entire social life revolves around eating together when you struggle with every bite? And what does it mean when your loved ones who mean so well insist on eating every day, spending hours in the kitchen, keep on offering tasty snacks when you are insanely nauseous? Some informal caregivers are trying every day to get the patient to eat a few bites of healthy food, because it might help a little. When we get sick, caring for the patient's food is often one of the informal caregivers most salient way of expressing love, but the patient is not always able to eat it once it is in front of him or her. Eating is seen as medicine and the only way to perhaps have a tiny bit of positive influence on the disease process. Eating as the only anchor point in a powerless situation.

The psychosocial consequences of a reduced ability to eat in patients with cancer were explored in some qualitative studies conducted among patients

with advanced-stage cancer and/or patients with (refractory) cancer cachexia (e.g. patients with end-stage cancer). These studies showed that patients with end-stage cancer commonly experienced negative emotions related to bereavement¹⁷ or “depression, anxiety and frustration”^{18(p.6)} with regard to their reduced ability to eat. These studies also demonstrated that patients with end-stage cancer experienced a loss of control over their body due to weight loss and the loss of autonomy as a result of physical weakness. These patients expressed they lost the pleasure in eating, preparing and sharing meals and sharing food on special occasions.¹⁸

Informal caregivers

Informal caregivers of patients with end-stage cancer are also affected by the patients reduced ability to eat. Informal caregivers of patients with end-stage cancer expressed to feel angry when the patient refused their carefully prepared meals. They also expressed concerns about the physical condition of the poorly eating or non-eating patient. These concerns were sometimes accompanied by feelings of powerlessness. Furthermore, informal caregivers mentioned to feel sad and to mourn about the loss of preparing and eating the meals together.¹⁹ Furthermore, the reduced ability to eat of patients with end-stage cancer may influence the relationship of patients and informal caregivers. This relationship was positively influenced when patients and informal caregivers learned to consider the patient’s reduced ability to eat as a natural process related to dying, and when informal caregivers learned to seek other ways to care.^{20,21} However, the reduced ability to eat may also have a negative impact on this relationship, for example in studies were informal caregivers forced patients to eat²², or when patients ignored informal caregivers’ concerns about eating altogether²³.



The impact of the psychosocial consequences of a reduced ability to eat

Besides the range of psychosocial consequences, the level of burden of these problems and its impact on Quality of Life (QoL) of patients with cancer is largely unknown. Some research investigated the level of distress related to the patient’s reduced ability to eat. These studies indicated that patients with high impact nutrition-related problems also experienced high levels of eating-related distress. This is concluded from studies conducted among patients with advanced cancer^{24,25}, with cancer cachexia^{25,26}, with head and neck cancer^{27,28}, with haematological cancer²⁹ or among patients who received home parenteral nutrition³⁰. Also the family members of patients with end-stage cancer reported high levels of distress related to the patient’s reduced ability to eat.^{25,26,31} Amano et al.^{32(p.117)} coined the term “eating-related distress” to explain the multiple and intersecting emotional and social consequences of nutrition-related problems among patients with end-stage cancer.

In conclusion, most research that investigated the psychosocial consequences of a reduced ability to eat was conducted among patients with end-stage cancer. The psychosocial consequences of a reduced ability to eat during the whole cancer trajectory (including treatment, recovery and remission) were barely documented. *The impact* of the psychosocial consequences of a reduced ability to eat on the patient’s well-being was mainly investigated among patients with end-stage cancer or patients with very specific nutrition-related problems. There is little research conducted into the psychosocial consequences of a reduced ability to eat and its impact on the patient’s wellbeing among a broader population of patients with cancer.

Patients’ experiences: psychosocial support for a reduced ability to eat

The international ESPEN guidelines³³ on nutrition in cancer patients recommends standard screening of patients with cancer for (the risk of) malnutrition to identify, prevent and treat the reversible aspects of malnutrition. Assessing what experiences patients have regarding their reduced ability to eat and what psychosocial consequences they encounter due to these experiences is not included in these recommendations. Patients with end-stage cancer consistently reported a lack of recognition and information from HCPs (healthcare professionals)³⁴ or a lack of attention from HCPs³⁵ for the distress related to their reduced ability to eat. Other studies performed among patient populations with high impact nutrition-related problems demonstrated that patients want recognition from HCPs regarding the distress evoked by their reduced ability to eat, while their HCPs often tend to focus on the physical aspects of their nutrition-related problems.^{27-30,36} A study conducted among patients receiving hospice care showed that more than 75% of the patients experienced unmet nutritional support needs. More than half of these patients with unmet nutri-

tional support needs also indicated to need more attention for their eating-related distress and information about their nutrition-related problems from the hospice staff.²⁴

What patients need from their HCPs regarding the psychosocial support for a reduced ability to eat was mainly investigated in patients with end-stage cancer. There is little knowledge available about what the broader population of patients with cancer need regarding the psychosocial support for a reduced ability eat.

Healthcare professionals' experiences: psychosocial support for a reduced ability to eat

What we know about HCPs' experiences with providing psychosocial support for a reduced ability to eat for patients with cancer is focused on the often severe and progressive weight loss that may occur in late end-stage cancer stages. These studies consistently showed that primary HCPs seemed to be reluctant to discuss the patient's weight loss.³⁷⁻⁴⁰ This "weight loss taboo"^{40(p 304)} was explained by HCPs avoiding the topic due to the irreversible nature of the decline of the patient's condition and were therefore unsure how to help the patient^{37,38}. Furthermore, HCPs indicated to fear that patients might have unrealistic expectations regarding the available nutritional interventions and its effects.³⁹ There are no studies available that investigate HCPs' experiences with providing psychosocial support for patients' reduced ability to eat during curative treatments or in recovery and remission.

In the Netherlands, the care setting for patients with end-stage cancer is mostly in primary care. In 2021 about 40% of the Dutch patients with cancer died at home.⁴¹ Home is also often the preferred place of end-of-life care.^{42,43} Despite large and growing numbers of patients receiving palliative care at their homes and the increasing severity of nutrition-related problems during end-stage cancer, there is a paucity of literature regarding primary HCPs' experiences with providing psychosocial support for patients with a reduced ability to eat. The few available studies were mainly focused on HCPs' coping with the irreversible declining intake and weight loss of patients with end-stage cancer and a reduced ability to eat.

Aims and outline of thesis

The aims of this thesis are:

- 1) *mapping the problem of the psychosocial consequences of a reduced ability to eat in patients with cancer and their informal caregivers and,*
- 2) *to gain insights into the provided psychosocial support for a reduced ability to eat as experienced by patients with cancer and HCPs.*

Chapter two is dedicated to the first aim of the thesis by investigating patients and informal caregivers experiences with the psychosocial consequences of a reduced ability to eat during the whole cancer trajectory. *Chapter three* further investigates the topic among a patient population that recently received intensive treatments. This chapter describes how nutritional support practices can either alleviate or intensify patients' distress related to the patient's reduced ability to eat. *Chapter four* contributes to both aims of the thesis. First, the impact of emotional consequences of a reduced ability to eat is assessed. Second, it is evaluated how satisfied patients are with the support they receive for their reduced ability to eat from HCPs. *Chapter five* focuses on the association of gastrointestinal problems, received nutritional care and nutritional care needs with QoL in patients with advanced cancer. *Chapter six* describes patients' experiences with the information and support they received from their HCPs and their informal caregivers. *Chapter seven* aims to gain insights in a new topic of inquiry by investigating the experiences of primary HCPs with providing psychosocial support for patients with an end-stage cancer and a reduced ability to eat.



REFERENCES


1. International Agency for Research on Cancer (IARC). All cancers 2020. 2020 [January 3, 2023]. Available from: <https://gco.iarc.fr/today/data/factsheets/cancers/39-All-cancers-fact-sheet.pdf>
2. Nederlandse Kankerregistratie (NKR) IKNL. NKR Cijfers. 2022 [January 11, 2023]. Available from: iknl.nl/nkr-cijfers
3. Integraal Kanker Centrum Nederland (IKNL). Uitgezaaide kanker in beeld. 2020 [January 3, 2023]. Available from: <https://iknl.nl/getmedia/6ddb80c4-254f-4763-943f-1a50f5321b83/uitgezaaide-kanker-in-beeld-rapport.pdf>
4. Sullivan ES, Rice N, Kingston E, Kelly A, Reynolds JV, Feighan J, et al. A national survey of oncology survivors examining nutrition attitudes, problems and behaviours, and access to dietetic care throughout the cancer journey. *Clin Nutr ESPEN* 2021;41:331-9.
5. de Pinho NB, Martucci RB, Rodrigues VD, D'Almeida CA, Thuler LCS, Saunders C, et al. Malnutrition associated with nutrition impact symptoms and localization of the disease: Results of a multicentric research on oncological nutrition. *Clin Nutr* 2019;38(3):1274-9.
6. Omlin A, Blum D, Wierecky J, Haile SR, Ottery FD, Strasser F. Nutrition impact symptoms in advanced cancer patients: frequency and specific interventions, a case-control study. *Journal of cachexia, sarcopenia and muscle* 2013;4(1):55-61.
7. Muscaritoli M, Lucia S, Farcomeni A, Lorusso V, Saracino V, Barone C, et al. Prevalence of malnutrition in patients at first medical oncology visit: the PreMiO study. *Oncotarget* 2017;8(45):79884.
8. Crowder SL, Douglas KG, Yanina Pepino M, Sarma KP, Arthur AE. Nutrition impact symptoms and associated outcomes in post-chemoradiotherapy head and neck cancer survivors: a systematic review. *J Cancer Surviv* 2018;12(4):479-94.
9. Griffin A, Butow P, Coates A, Childs A, Ellis P, Dunn S, et al. On the receiving end V: patient perceptions of the side effects of cancer chemotherapy in 1993. *Annals of oncology* 1996;7(2):189-95.
10. Salihah N, Mazlan N, Lua PL. Chemotherapy-induced nausea and vomiting: exploring patients' subjective experience. *J Multidiscip Healthc* 2016;9:145-51.
11. Molassiotis A, Stricker CT, Eaby B, Velders L, Coventry PA. Understanding the concept of chemotherapy-related nausea: the patient experience. *Eur J Cancer Care (Engl)* 2008;17(5):444-53.
12. Bernhardson B-M, Tishelman C, Rutqvist LE. Taste and Smell Changes in Patients Receiving Cancer Chemotherapy: Distress, Impact on Daily Life, and Self-care Strategies. *Cancer Nursing* 2009;32(1):45-54.
13. Baracos V, Martin L, Korc M, Guttridge D, Fearon K. Cancer-associated cachexia. *Nat Rev Dis Primers* 2018;4:17105.
14. Fearon K, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, et al. Definition and classification of cancer cachexia: an international consensus. *The lancet oncology* 2011;12(5):489-95.
15. Mintz SW, Du Bois CM. The anthropology of food and eating. 2002.
16. Voedingscentrum. Helpt Nederlanders wil beter leren koken. n.d. [January 3, 2023]. Available from: <https://www.voedingscentrum.nl/nl/pers/persmappen/kookvaardigheden/helpt-nederlanders-wil-beter-leren-koken.aspx>
17. Holden C. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. *Hosp J* 1991;7(3):73-84.
18. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2014;6(3):307-14.
19. Wheelwright S, Darlington AS, Hopkinson JB, Fitzsimmons D, Johnson C. A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia. *Palliat Med* 2016;30(2):149-60.
20. 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.
21. McClement SE, Harlos M. When advanced cancer patients won't eat: family responses. *Int J Palliat Nurs* 2008;14(4):182-8.
22. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncol Nurs Forum* 1997;24(10):1751-7.
23. 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.
24. Amano K, Maeda I, Morita T, Tatara R, Katayama H, Uno T, et al. Need for nutritional support, eating-related distress and experience of terminally ill patients with cancer: a survey in an inpatient hospice. *BMJ supportive & palliative care* 2016;6(3):373-6.
25. Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Supportive Care in Cancer* 2018;27(8):2869-76.
26. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;36(4):439-45.
27. Larsson M, Hedelin B, Athlin E. Needing a hand to hold: lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs* 2007;30(4):324-34.
28. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 2013;22(7-8):1034-43.
29. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
30. Orreval Y, Tishelman C, Herrington M, 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. *Clinical Nutrition* 2004;23(6):1280-7.
31. Amano K, Maeda I, Morita T, Okajima Y, Hama T, Aoyama M, et al. Eating-related distress and need for nutritional support of families of advanced cancer patients: a nationwide survey of bereaved family members. *J Cachexia Sarcopenia Muscle* 2016;7(5):527-34.

32. Amano K, Baracos V, Hopkinson J. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Critical Reviews in Oncology/Hematology* 2019;143:117-23.
33. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2016;36(1):11-48.
34. Cooper C, Burden S, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. *Journal of Cachexia, Sarcopenia and Muscle* 2015;6(1):99-111.
35. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
36. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European journal of oncology nursing* 2011;15(2):145-51.
37. Dewey A, Dean T. Assessment and monitoring of nutritional status in patients with advanced cancer: part 1. *Int J Palliat Nurs* 2007;13(6):258-65.
38. Dewey A, Dean T. Nurses' management of patients with advanced cancer and weight loss: part 2. *Int J Palliat Nurs* 2008;14(3):132-8.
39. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage* 2006;31(4):293-305.
40. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs* 2006;54(3):304-12.
41. Palliaweb PZNP. Kerncijfers behoefte aan palliatieve zorg. 2023 [January 3, 2023]. Available from: <https://palliaweb.nl/publicaties/kerncijfers-behoefte-aan-palliatieve-zorg>
42. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013;12:7.
43. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Ann Oncol* 2012;23(8):2006-15.



PART 1

Mapping the problem of the psychosocial consequences of a reduced ability to eat

A close-up photograph of a silver fork holding a portion of spaghetti. The spaghetti is coated in a light-colored sauce and is garnished with black pepper. The background is dark. Overlaid on the image are several thick, wavy lines in bright pink and a single line in light green, creating a decorative, abstract pattern.

“On Saturdays we used to go to the market, which is where we started buying nice fruit, fish and cheese. Now when I go to the market I’m actually just drooling so it’s not an outing anymore. When we went to the village, we would always go to the same pub in the morning, have a nice apple pie and coffee, and in the afternoon we would have a nice glass of wine and a ‘bitterbal’. That was a regular thing. And at the end of the afternoon, we would go to the fishmonger’s and eat a herring sandwich. If we went to the cinema, we ate at the Italian restaurant beforehand because it was opposite the cinema, one of the best Italians in town. And only when you can’t do it anymore do you notice it. My whole life was mixed with food and drink and sociability.”

CHAPTER 2

Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study

Lize N, Raijmakers N, van Lieshout R,
Youssef-El Soud M, van Limpt A,
van der Linden M, Beijer S

European Journal of Oncology
Nursing 2020: 49; 101838



ABSTRACT

PURPOSE Patients with cancer often experience a reduced ability to eat. This can have psychosocial consequences for both patients and informal caregivers. Current literature is mainly focused on patients with end stage advanced disease and cancer cachexia. This qualitative study provides new insights in the field of Psycho-Oncology by exploring psychosocial consequences of a reduced ability to eat in patients in different stages of the disease and in recovery and remission.

METHOD Semi-structured interviews (n = 26) were conducted in patients with head and neck, lung cancer or lymphoma. Patients' informal caregivers participated in 12 interviews. All interviews were recorded, transcribed and thematically analysed using Atlas.ti.

RESULTS Four themes emerged related to psychosocial consequences of a reduced ability to eat: struggle with eating, high sense of responsibility, misunderstanding by social environment and social consequences. Emotions mentioned by patients and informal caregivers were: anger, anxiety, disappointment, grief and sadness, guilt, powerlessness and shame. The theme social consequences was related to: less pleasure experienced and the social strategies: adjust, search for alternatives and avoid.

CONCLUSION Patients with cancer and their informal caregivers experience a wide range of psychosocial consequences of reduced ability to eat during all phases of the disease trajectory and in recovery and remission. It is important to recognise and acknowledge this struggle to optimise future care.



INTRODUCTION

Patients with cancer often experience nutritional problems, resulting in insufficient nutritional intake and unintended weight loss. Due to the tumour or related treatments, patients might experience several complaints such as lack of appetite (anorexia), food aversion, taste alterations, a painful mouth, chewing and swallowing problems, nausea and vomiting or other malaise symptoms such as fatigue and dyspnoea. Furthermore, a severe wasting syndrome may occur in the end phase of the disease, known as the anorexia-cachexia syndrome.^{1,2}

Besides severe physical consequences caused by these symptoms, a reduced ability to eat in patients with cancer can also have serious emotional consequences. Previous qualitative studies conducted among patients with advanced cancer and cancer cachexia consistently show that patients experienced negative emotions in relation to a reduced ability to eat. These studies were conducted among patients with advanced cancer³⁻¹², patients with cancer cachexia¹³⁻¹⁶, patients with terminal cancer¹⁷⁻¹⁹, and patients in palliative care²⁰⁻²². These nutrition-related emotions were summarised in two systematic literature reviews as “negative emotions such as depression, fear and frustration”^{23(p 6)}, and “negative emotions that accompany all loss”^{24 17 (cited in: 24 [p 92])}.

Informal caregivers of patients with end-stage disease and/or cancer cachexia also reported negative emotions surrounding patients' reduced ability to eat. While synthesising the literature on the impact of patients' nutritional problems on informal caregivers, Wheelwright et al.²⁵ identified the following emotions among informal caregivers: anger, fear, guilt helplessness, sadness and worry. These negative emotions were induced in informal caregivers by the patient rejecting prepared meals, the patients' physical condition, thoughts about the future and mourning about the loss of shared meals and togetherness. Furthermore, food-related conflicts were reported between patients and informal caregivers.^{23,25} Clearly, previous research has shown that a reduced ability to eat has psychosocial consequences for patients with advanced disease and cancer cachexia and their informal caregivers. The few studies conducted among non-advanced disease patients were focused on (physical) eating problems caused by treatment side effects²⁶⁻³⁰, patients' strategies towards food intake³¹⁻³³, and patients' nutritional status³⁴. Because these studies mainly focused on treatment side effects and (nutritional) intake strategies, psychosocial consequences and the impact of a reduced ability to eat for both patients and informal caregiver has hardly been described.

Although in the past thirty years the field of Psychosocial-Oncology has seen a rapid increase in knowledge, psychosocial consequences of a reduced ability to eat during the whole cancer trajectory and in recovery and remission have

barely been documented. Little research has been conducted at psychosocial consequences of a reduced ability to eat in patients with early advanced cancer and patients with lasting eating problems that persist in recovery and remission. Therefore, the aim of this study is to gain new insights in psychosocial consequences of a reduced ability to eat during all phases of the disease and in recovery and remission.

METHOD

Study design

A qualitative interview study was conducted to gain new insights in psychosocial consequences of a reduced ability to eat experienced by patients with cancer and their informal caregivers.

Participants

Patients were eligible for inclusion if they were diagnosed with head and neck cancer, lung cancer or lymphoma, and (had) experienced problems with eating due to their disease or the treatments. Head and neck cancer and lymphoma patients were selected because of the diversity in (onset and cause of) nutritional problems. Patients with lung cancer were included to supplement the research population with patients with early advanced disease. Patients with early advanced disease are patients with incurable disease, who are in the relatively long period of high functioning in their illness trajectory, before entering the shorter period of evident decline.³⁵ Thus, the reason for including patients with these three cancer types was to maximise insights into the diversity of the lived experiences of psychosocial consequences of a reduced ability to eat. Informal caregivers of all participating patients were also eligible to participate. Patients and their informal caregivers were recruited via patient organisations. It was considered that recruitment via patient organisations might lead to a selection bias favouring patients with a relatively good health status. Therefore, the research population was supplemented with patients with lung cancer in an early stage of advanced disease by recruitment via nurses of the department of pulmonology in the Máxima Medical Centre Veldhoven, The Netherlands. The involved patient organisations posted several calls on their websites and (social) media channels to invite people to participate in the interview study. Patients and informal caregivers subscribed for an interview by filling in an online form. The nurses in the Máxima Medical Centre selected eligible patients, informed them globally about the study, and asked permission for the researcher to contact the patient. Patient and informal caregivers who consented



were contacted by the researcher (NL), received detailed information about the study and were invited to participate in an interview. In total 29 patients responded to the calls of which 26 participated in an interview. Three patients did not participate in an interview. Reasons not to participate (or cancel) an interview were; the flu, treatment side effects and progression of the disease. When patients or informal caregivers agreed to participate, an appointment for an interview was made.

Interviews

One researcher (NL) conducted the interviews. Of these 26 interviews fourteen interviews were held with a patient alone. Eleven interviews were held with a patient and an informal caregiver simultaneously. One interview (n=1) was held with an informal caregiver alone, thus without the presence of the patient. Due to the sensitive nature of the questions, interviews were held at the participants' places of choice which were their homes (n=25) or at work (n=1). All patients and informal caregivers who subscribed and consented were interviewed. The interviews took place from February to May 2018.

The semi-structured topic list was developed in collaboration with an expert group consisting of dieticians specialised in oncology care, a psychologist and representatives of patient organisations and information platforms. This expert group guaranteed that the question in the developed topic list were appropriate for patients and informal caregivers who experienced problems with eating. The interviewer started by asking 'When did you get your diagnosis?' to encourage participants to talk about the disease trajectory. The second question on the topic list 'How are you doing now?' meant to establish trust and connection by showing interest in the participants current condition, i.e. building rapport.³⁶ Thereafter, follow-up questions and topics regarding a reduced ability to eat were addressed to further discuss what kind of psychosocial consequences patients and informal caregivers experienced during their disease trajectory. The semi-structured topic list is provided in Figure 1.

FIGURE 1 Semi-structured topic list

Questions: establish trust/building rapport	Topics and questions: encourage sharing of experiences
<ol style="list-style-type: none"> When did you get your diagnosis? Secondaries Treatment How are you doing now? 	<ol style="list-style-type: none"> How are you doing with eating and drinking? Evening meal Shopping Preparation Going out to eat
Topics and questions follow up 1: discuss psychosocial consequences (patient)	Topics and questions follow up 2: discuss psychosocial consequences (patient)
<ol style="list-style-type: none"> How did it go before you were ill? How did it go during your illness? Has it changed since you have become ill? Physical consequences Practical consequences Emotional consequences Social consequences Financial consequences Other consequences 	<ol style="list-style-type: none"> How do you feel about it? What does it mean to you? How did you experience this? Could you tell me some more about it? Physical consequences Practical consequences Emotional consequences Social consequences Financial consequences Other consequences
Topics and questions follow up 1: discuss psychosocial consequences (informal caregiver)	Topics and questions follow up 2: discuss psychosocial consequences (informal caregiver)
<ol style="list-style-type: none"> How did it go before your loved one became ill? How did it go for you? How do you feel about it? Physical consequences Practical consequences Emotional consequences Social consequences Financial consequences Other consequences 	<ol style="list-style-type: none"> How did it go for you? How do you feel about it? Physical consequences Practical consequences Emotional consequences Social consequences Financial consequences Other consequences

Data analysis

The interviews (n=26) were audiotaped and the records were transcribed verbatim (NL). One interview (n=1) was not transcribed nor analysed because it was inaudible due to the patients' laryngectomy. In total 25 interviews were transcribed. Transcripts of fourteen interviews were open coded³⁶ by three independently working researchers (NL, SB, NR). After coding the transcripts codes were compared and discussed (NL, SB, NR) to reach consensus and develop a code tree. This procedure was repeated until the first point of data saturation was reached, the point when no new themes emerged in the code tree³⁶ This was reached after coding fourteen transcripts and the remaining eleven transcripts were open coded by two independently coding researchers using the then established code tree (NL, ZN). After open coding, the codes and themes in the code tree were discussed by four researchers (NL, SB, NR, ZN) who then clustered codes into main categories to identify emotional and social consequences and its related themes. During the coding process a phenomenological approach was used to view the data. The goal of a phenomenological approach is to describe the lived experience of a phenomenon.³⁷ The open coding started in April 2018, the thematic analysis was conducted in November and December 2018. Inter-rater reliability³⁶ was ensured by discussing the interviews and the evolving code tree during thematic analysis.³⁶ Initial findings were discussed with the beforementioned expert group to ensure rigour in the data analysis.

Ethical considerations

The study was conducted according to the declaration of Helsinki. The study protocol was reviewed by the Máxima Medical Centre Veldhoven, the Netherlands (METC N18.032) and was exempted from ethical review, according to the Dutch Medical Research Involving Human Subjects Act (WMO). During data collection and analysis, the rules of the Dutch Personal Data Protection Act were followed. Informed consent was obtained prior to the interview. The transcripts were checked, and personal details were deleted to ensure participants' privacy (NL).

RESULTS

Of the 26 conducted interviews the transcripts of 25 interviews were operable for coding and analysis. In these 25 interviews, 24 patients and 12 informal caregivers participated. One interview was held without the presence of a patient, thus with an informal caregiver alone. Most patients were male (62,5%) and the median age was 63 years. Of the informal caregivers five were male (42%). Participants' sociodemographic characteristics are described in Table 1 and patients' clinical characteristics are described in Table 2. The participants gave a rich description of their experiences with psychosocial consequences of a reduced ability to eat. The findings of the thematic analysis are displayed in Table 3.

TABLE 1 Participants' sociodemographic characteristics

		Patients (N=24)	Informal caregivers (N=12)
Gender	Male	15 (62,5%)	5 (42%)
Age	Median (range)	63 year (31-79)	
Education ^a	Low	4 (17%)	
	Middle	4 (17%)	
	High	13 (54%)	
	Missing	3 (12%)	
Marital status	Married/partner	14 (58%)	12 (100%)
	Living alone (divorced/single/widowed)	8 (33%)	
	Missing	2 (9%)	
Relation with patient	Partner		11 (92%)
	Daughter (bereavement)		1 (8%)
Recruitment	Oncology ward	3 (12,5%)	
	Online	21 (87,5%)	

^a low educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = pre-university education, high vocational training, university

TABLE 2 Patients' clinical characteristics

Tumour type (N=24)			Time since diagnosis	
Tumour type (N=24)	Head and neck	9 (37,5%)		
	Lymphoma	9 (37,5%)		
	Lung cancer	6 (25%)		
Disease phase ^a (N=24)	Early advanced disease 7 (28%)	Current nutritional problems 3 (43%)	< 1 year	1 (33%)
			1-5 years	2 (67%)
			>5 years	0 (0%)
	Recovery or remission 17 (71%)	Current nutritional problems 14 (82%)	< 1 year	2 (50%)
			1-5 years	2 (50%)
			>5 years	0 (0%)
	Past nutritional problems 4 (57%)	< 1 year	2 (50%)	
		1-5 years	2 (50%)	
		>5 years	0 (0%)	
	Current nutritional problems 14 (82%)	<1 year	2 (14%)	
		1-5 years	6 (43%)	
		>5 years	6 (43%)	
	Past nutritional problems 3 (18%)	< 1 year	0 (0%)	
		1-5 years	1 (33%)	
		>5 years	2 (67%)	

^aDisease phases were interpreted from the interview context

TABLE 3 Emotional and social consequences of a reduced ability to eat

Themes	Consequences	Mentioned by
Struggle with eating	Anger Anxiety Disappointment Grief and sadness Guilt Powerlessness Shame	Patients
Misunderstanding by social environment		Patients Informal caregivers
High sense of responsibility		Informal caregivers
Social consequences	Less pleasure experienced Social strategies: adjust, search for alternatives, avoid	Patients Informal caregivers Patients Informal caregivers

Four themes emerged from the data: struggle with eating, high sense of responsibility, misunderstanding by social environment, and social consequences. Feelings of anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame were emotions mentioned by patients and informal caregivers. As a social consequence, less pleasure was experienced, and different social strategies were applied: adjust, search for alternatives and avoid.

Struggle with eating

Patients experienced a broad range of emotions because of their struggle with eating. In some patients these emotions occurred because they compared their current struggle with eating to how they used to eat before they got ill; spontaneous, with a broad range of choices and without considering any inabilities. Patients experienced feelings of disappointment and anger when confronted with their favourite foods of the past:

“I get angry really quickly when I can’t eat, it’s the disappointment of not being able to; I used to really love nuts” (patient 1, head and neck cancer, recovery or remission)

Patients with early advanced cancer experienced similar emotions with regard to their reduced ability to eat as patients in recovery or remission. However, patients with early advanced cancer also tried to focus on other enjoyments in life, emotions related to their reduced ability to eat might therefore be experienced differently:

“I have to think about it continuously [eating] my lack of appetite puts the disease in the spotlights. I just want to go to work and I want to focus on my daughters’ wedding. My daughters’ wedding should be in the spotlights, instead of me having this disease” (patient 8, lung cancer, early advanced disease)

Misunderstanding by social environment

The second theme related to emotions experienced by patients and informal caregivers is misunderstanding by social environment. When patients felt misunderstood by informal caregivers, family members or healthcare professionals in their struggle with eating this could provoke emotions:

“It wasn’t nice, especially during chemotherapy – the smell alone of all that food... and my husband said ‘go on, eat a bit more’; I ask you – eat a bit more...? That’s easier said than done. I fly off the handle when people tell me that I should eat more. What if you just can’t?! Because your mouth hurts? It’s alright for them to say...!” (patient 17, lymphoma, early advanced disease)

Misunderstanding could work both ways in the patient-informal caregiver relationship. Sometimes this led to informal caregivers feeling they were nagging which could arouse emotions:

“It is exactly because you lose weight so easily that we are continually trying to make you eat well, and that’s why I keep going on about it (...) and I really don’t want to nag, so I try and keep it to myself as much as I can” (informal caregiver 8, lung cancer, early advanced disease)

High sense of responsibility

Informal caregivers experienced emotions due to their high sense of responsibility for the patient’s well-being. Informal caregivers’ high sense of responsibility could stir up emotions such as powerlessness:

“Air, drinking and eating; eating is one of the necessities of life for a human being. And you just want to help, and when she herself wanted to eat as well (...) later on I wondered why I was still doing it. She wanted to eat but she simply couldn’t any more, it really makes you feel helpless” (informal caregiver 20, lung cancer, bereavement)

Social consequences

Social consequences of a reduced ability to eat were related to experiencing less pleasure from social contacts and social activities. Most patients and informal caregivers wished to maintain their friendships and social activities although they experienced less pleasure in doing so. Patients and informal caregivers developed different social strategies to cope with the decrease in pleasure: adjust, search for alternatives and avoid.

Patients felt understood by their informal caregivers and other family members. Informal caregivers often tried to mediate the problems surrounding eating within their broader social environment, or tried to educate others about the patients’ struggle with eating. Some remarks regarding conflicts between patients and informal caregivers were made. When conflicts occurred, these related to informal caregivers or other family members overtly pushing patients to eat.

Most patients described that their friendships and other close social relations were little affected by their reduced ability to eat. Patients felt that they were able to discuss their reduced ability to eat with their friends and felt they could eat together without shame. However, patients and informal caregivers felt that it was harder to maintain their social lives. Most patients told that since social life is often organised around eating, they would still go out to, although they experienced less pleasure in doing so:

“I have lunch with colleagues every so often, I force myself to go because it’s fun; if only the food wasn’t there ..., I have really mixed feelings about it” (patient 10, head and neck cancer, recovery or remission)

Because the confrontation with eating was often perceived as inevitable, some patients chose to adjust themselves to the situation and remained silent about their reduced ability to eat. Patients enjoyed social meetings less due to their reduced ability to eat:

“There is always something on the table that I think is really tasty. I used to just walk away, I don’t do that anymore, but I did at the beginning” (patient 1, head and neck cancer, recovery or remission)

Other patients mentioned to search for alternatives to their social activities. These patients tried to find creative alternatives for eating together:

“I really like it when we are all together, but after we had our special Easter breakfast I said I would much prefer to do something that wasn’t centred on food (...) so we got into the car and we went for a walk around the old neighbourhood where we used to live, and we consciously didn’t end the day by going somewhere to have something to eat and drink” (patient 9, head and neck cancer, recovery or remission)

Some patients mentioned that they avoid certain social activities due to their reduced ability to eat. These activities were avoided when they experienced less pleasure:

I don’t want to do it any more, it doesn’t taste good, I don’t want to cook for other people, and these days going to a restaurant is no fun for me at all” (patient 15, lung cancer, early advanced disease)

However, avoidance of social activities was a rare strategy as many patients were concerned that completely avoiding eating related social activities would isolate them from most of their social worlds. Nonetheless, the impact of a reduced ability to eat was substantial as many patients experienced less pleasure in participating in social life than they did before they got ill:

“Eating is not only enjoyable and delicious, it is also a social event – something you do with your friends and family, the enjoyment of cooking for each other together (...) the whole thing around it, not only the food but also the social aspect, I think it is a real shame that it no longer happens” (patient 25, lymphoma, early advanced disease)

DISCUSSION

The present study sheds light on psychosocial consequences of a reduced ability to eat for patients and their informal caregivers. This study identified four themes related to patients’ reduced ability to eat: struggle with eating, misunderstanding by social environment, high sense of responsibility and social consequences. Feelings of anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame were mentioned by patients and informal caregivers. When conflicts occurred between patients and informal caregivers, these conflicts were relatively mild and related to informal caregivers attempting to improve the patients’ intake. Patients reduced ability to eat had minor effect on patients’ relations, not on their relations with their informal caregivers and not on their relations with other family members or friends. As a social consequence, patients and informal caregivers experienced less pleasure in maintaining their friendships and going out for their social activities. Therefore, patients and informal caregivers developed three strategies; they adjusted themselves to the inevitability of the confrontation with food, they searched for alternative activities or avoided social activities.

In the present study, patients and informal caregivers reported a variety of emotions due to their reduced ability to eat. These emotions are similar to those negative emotions that resemble loss, mourning, fear and frustration as reported by patients with advanced disease and cancer cachexia and their informal caregivers.^{23,24} Similar emotions are reported in the limited studies conducted among patients under and shortly after treatment. Patients with head and neck cancer reported after emotional losses in relation to their reduced ability to eat.²⁸ Hospitalised patients and their informal caregivers reported to experience severe distress in relation to treatment side effects such as taste

alterations and lack of appetite.²⁷ The results of the present study provide evidence for the notion that a reduced ability to eat can cause emotions in all disease stages and in the phases of recovery and remission.^{26,31,32}

Emotions surrounding patients' reduced ability to eat need to be addressed because they might lead to conflicts in the patient-informal caregiver relationship. In extreme cases, these conflicts led to informal caregivers forcing terminally ill patients to eat^{24,38} (cited in: 24 [p 92]), or patients with advanced cancer going on hunger strikes⁴. These conflicts can also develop during curative treatment, as informal caregivers of hospitalised patients experienced anger and frustration when patients' consumption did not meet their expectations.²⁷ Conflicts-mentioned by participants in the present study were relatively minor compared to the findings in the above-mentioned studies. However, the mechanism underlying these verbal conflicts seems to correspond to those mechanisms underlying conflicts about food reported in previous research. The common denominator is that these conflicts about food happen when patients feel overtly pushed to eat. The themes misunderstanding and high sense of responsibility found in the present study, provides novel and explanatory insight in the underlying mechanisms that might lead up to conflicts about food and eating throughout the disease trajectory.

In the present study, patients and informal caregivers experienced less pleasure in maintaining their social lives. Studies show the social significance of eating in the lives of patients, not only among patients with advanced disease and cancer cachexia; but also among patients receiving curative treatment.^{22,26,27,31,32} Previous research among patients with head and neck cancer, suffering from severe and long-lasting radiotherapy treatment side-effects; has drawn attention to the enormous impact of eating inabilities on patients' social lives.^{33,39,40} Sharing meals is an important aspect of social interactions and relations. Therefore, the consequences of this decreased pleasure should not be underestimated.³⁹ This study underscored these results of past research and provided novel insights in patients' strategies to maintain their social lives despite their reduced ability to eat. Patients either adjusted activities, searched for alternative activities or avoided activities.

Implications for practice and future research

To improve future care for patients with cancer it is important to acknowledge psychosocial consequences of a reduced ability to eat in all phases of the disease and during recovery and remission. Patients and informal caregivers need and want support of healthcare professionals. Previous research reports that these needs are often not addressed.^{4,10,14,41} Future nutritional care might start by acknowledging the struggle with eating and by addressing patients need for understanding emotions that might develop due to their struggle. The theme misunderstanding by social environment indicates that just providing informa-

tion about the possible psychosocial consequences of a reduced ability to eat would already partly address patients' needs.

Furthermore, previous research indicates that informal caregivers want and need help of healthcare professionals, as they strive for the best possible care.²⁵ Therefore, in future nutritional care, informal caregivers' high sense of responsibility should be acknowledged by healthcare professionals. Acknowledging the high sense of responsibility in informal caregivers should be done by facilitating a conversation about patients' reduced ability to eat between patients and informal caregivers.²⁵ This conversation could downplay patients' experienced misunderstanding. Furthermore, accepting patients' limited intake and maintaining a social life despite the difficulties with eating has shown to decrease negative emotions and can have a positive effect on quality of life in patients with advanced disease and cancer cachexia.²⁴

Strengths and limitations

As far as it is known to the authors, this was the first study investigating psychosocial consequences of a reduced ability to eat in all phases of the disease and in recovery and remission. Therefore, the explorative research design was the appropriate choice of conduct. This study also has some limitations. Recruitment via patient organisations by posting an (online) call might have led to a selection bias favouring patients with a relatively good health status. This might be further induced by the research methods of choice. Participation in an interview depends of the physical state of the patient. The reasons given by patients who cancelled their participation support this supposition. Furthermore, recruitment via patient organisations led to a selection bias in favour of a higher educated and relatively young research population compared to the general cancer population. Therefore, the results should be interpreted with caution and cannot be generalised to the whole cancer population. Furthermore, all interviews except one (n=1) were conducted with patients and informal caregivers simultaneously. It is possible that patients and informal caregivers were keeping up appearances, which might have led to socially acceptable answers and therefore underreporting of conflicts. Some patients and informal caregivers were interviewed one year to five years or more after diagnosis and did not experience current nutritional problems at the time of the interview. These participants might not have remembered psychosocial consequences of their reduced ability to eat accurately (recall bias). Despite these limitations this study provides new insights that can serve as a starting point for future research.

Conclusions

In conclusion, our study suggests that both patients and informal caregivers experience psychosocial consequences due to patients' reduced ability to eat. For healthcare professionals it is important to acknowledge patients' emotions and their struggle with eating. Findings in this study suggest that this might curtail negative emotions. Considering the high sense of responsibility underlying informal caregivers' emotions, they should actively be involved in patients' nutritional counselling. This can prevent patients feeling misunderstood by well-meaning informal caregivers targeting patients intake and the development of negative emotions in the family sphere.

CONFLICT OF INTEREST STATEMENT

DECLARATIONS OF INTEREST none

The Funding agency (Zorg Instituut Nederland) was not involved in: study design, in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.



REFERENCES

1. Vogel J, Beijer S, Delsink P, Doornink N, ten Have H, van Lieshout R. Handboek Voeding bij kanker. De Tijdstroom; 2016.
2. Baracos V, Martin L, Korc M, Guttridge D, Fearon K. Cancer-associated cachexia. *Nat Rev Dis Primers* 2018;4:17105.
3. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *Journal of Human Nutrition and Dietetics* 2000;13(2):113-7.
4. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage* 2006;31(4):293-305.
5. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs* 2006;54(3):304-12.
6. Hopkinson J. How people with advanced cancer manage changing eating habits. *J Adv Nurs* 2007;59(5):454-62.
7. Hopkinson JB. Carers' Influence On Diets Of People With Advanced Cancer. *Nursing Times* 2008;104(12):28-9.
8. Hopkinson JB, Fenlon DR, Okamoto I, Wright DN, Scott I, Addington-Hall JM, et al. The deliverability, acceptability, and perceived effect of the Macmillan approach to weight loss and eating difficulties: a phase II, cluster-randomized, exploratory trial of a psychosocial intervention for weight- and eating-related distress in people with advanced cancer. *J Pain Symptom Manage* 2010;40(5):684-95.
9. McClement SE, Harlos M. When advanced cancer patients won't eat: family responses. *Int J Palliat Nurs* 2008;14(4):182-8.
10. Orrevall Y, Tishelman C, Herrington M, 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. *Clinical Nutrition* 2004;23(6):1280-7.
11. Shragge J, Wismer W, Olson K, Baracos V. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med* 2007;21(3):227-33.
12. Strasser F, Binswanger J, Cerny T, Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat Med* 2007;21(2):129-37.
13. Hinsley R, Hughes R. 'The reflections you get': an exploration of body image and cachexia. *Int J Palliat Nurs* 2007;13(2):84-9.
14. Reid J, McKenna H, Fitzsimons D, McCance T. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer Care (Engl)* 2010;19(5):682-9.
15. Reid J, McKenna H, Fitzsimons D, McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud* 2009;46(5):606-16.
16. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;36(4):439-45.

17. Holden C. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. *Hosp J* 1991;7(3):73-84.
18. 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.
19. 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.
20. Hopkinson JB. The emotional aspects of cancer anorexia. *Curr Opin Support Palliat Care* 2010;4(4):254-8.
21. Muir CI, Linklater GT. A qualitative analysis of the nutritional requirements of palliative care patients. *J Hum Nutr Diet* 2011;24(5):470-8.
22. Souter J. Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences. *Int J Palliat Nurs* 2005;11(10):524-32.
23. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2014;6(3):307-14.
24. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
25. Wheelwright S, Darlington AS, Hopkinson JB, Fitzsimmons D, Johnson C. A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia. *Palliat Med* 2016;30(2):149-60.
26. Larsson M, Hedelin B, Athlin E. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *J Clin Nurs* 2003;12(4):562-70.
27. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
28. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European journal of oncology nursing* 2011;15(2):145-51.
29. Molassiotis A, Stricker CT, Eaby B, Velders L, Coventry PA. Understanding the concept of chemotherapy-related nausea: the patient experience. *Eur J Cancer Care (Engl)* 2008;17(5):444-53.
30. Wilson PR, Herman J, Chubon SJ. Eating strategies used by persons with head and neck cancer during and after radiotherapy. *Cancer nursing* 1991;14(2):98-104.
31. Locher JL, Robinson CO, Bailey FA, Carroll WR, Heimbürger DC, Saif MW, et al. Disruptions in the organization of meal preparation and consumption among older cancer patients and their family caregivers. *Psychooncology* 2010;19(9):967-74.
32. Locher JL, Robinson CO, Bailey FA, Carroll WR, Heimbürger DC, Magnuson JS, et al. The contribution of social factors to under-eating in older adults with cancer. *J Support Oncol* 2009;7(5):168-73.
33. Wainwright D, Donovan JL, Kavadas V, Cramer H, Blazeby JM. Remapping the body: learning to eat again after surgery for esophageal cancer. *Qual Health Res* 2007;17(6):759-71.
34. Larsson M, Hedelin B, Johansson I, Athlin E. Eating problems and weight loss for patients with head and neck cancer: a chart review from diagnosis until one year after treatment. *Cancer Nurs* 2005;28(6):425-35.
35. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330(7498):1007-11.
36. Boeije H. Analysis in qualitative research. Sage publications Ltd; 2009.
37. Starks H, Brown Trinidad S. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research* 2007;17(10):1372-80.
38. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncol Nurs Forum* 1997;24(10):1751-7.
39. Einarsson S, Laurell G, Tiblom Ehrsson Y. Experiences and coping strategies related to food and eating up to two years after the termination of treatment in patients with head and neck cancer. *Eur J Cancer Care (Engl)* 2019;28(2):e12964.
40. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 2013;22(7-8):1034-43.
41. Stamataki Z, Burden S, Molassiotis A. Weight changes in oncology patients during the first year after diagnosis: a qualitative investigation of the patients' experiences. *Cancer nursing* 2011;34(5):401-9.

CHAPTER 3

Nutrition-related problems, nutritional support practices and barriers to adherence to nutritional guidelines during intensive treatment for acute myeloid leukemia: patients' and hematology nurses' perspectives and experiences

van Lieshout R, Lize N, Tick L, Deursen J, Driessen E, Janssen T, Custers S, Kranenburg S, van der Lee B, Koene H, Beckers E, Schouten H, Beijer S

Clinical Nutrition ESPEN 2022; 48; 446-455



ABSTRACT

BACKGROUND & AIMS The updated guidelines of the European Society for Clinical Nutrition and Metabolism (ESPEN) and for Blood and Marrow Transplantation (EBMT) on nutrition in intensively treated acute myeloid leukemia (AML) patients recommend enteral nutrition instead of parenteral nutrition as the first-choice nutritional intervention. Despite this, PN remains the preferred route of nutrition administration in daily practice. The aim of this qualitative study was to gain insight into the patients' and hematology nurses' experiences and perceptions regarding nutritional problems and nutritional support and the reasons for the low adherence to the ESPEN/EBMT guidelines.

METHODS Semi-structured interviews were conducted in 23 patients from various Dutch hospitals who had completed intensive AML treatment. Interviews with 22 patients were audio-recorded and transcribed, one interview was summarized. The transcripts and summary were thematically analyzed using Atlas.ti. From each of the 22 Dutch hospitals providing intensive AML treatment, one hematology nurse participated in a telephone questionnaire survey. The results of this survey are presented in a descriptive way.

RESULTS Nutritional problems were a major source of distress in most participating patients. Nutritional support often led to mental peace and less concerns, provided that there were no conflicting nutritional support practices among treating hospitals. Patients perceived PN and EN as a life-line and necessary for the prevention of or recovery from physical decline, but they also experienced loss of independence, limited mobility, fear of unwanted body weight gain and problems related to the feeding equipment. Both patients and hematology nurses regarded PN as an easy method of nutrition administration, while EN was often seen as a necessary evil or was even refused by patients, owing to tube-related physical discomfort and EN intolerance. Both patients' and hematology nurses' reluctance to administer EN proved to be barriers to the ESPEN/EBMT nutritional guideline adherence. Among the surveyed hematology nurses, barriers to adherence included personal factors related to their knowledge (lack of awareness) and attitudes (negative outcome expectancy and lack of agreement), guideline-related factors (lack of evidence) and external factors (lack of collaboration).

CONCLUSION Individualized nutritional support, including EN and PN, may reduce nutrition-related distress in intensively treated AML patients, provided that conflicting nutritional support practices among hospitals are avoided or explained. The barriers to adherence to the ESPEN/EBMT guidelines on EN and PN in this patient group may be reduced by enhancing hematology nurses' awareness and knowledge of the guidelines, incorporating the guidelines into multidisciplinary clinical pathways, improving outcome of EN by proper triage of patients eligible for EN and increasing the level of evidence of the guidelines.



INTRODUCTION

Acute myeloid leukemia (AML) is the most common type of acute leukemia in adults.¹ Treatment of AML generally consists of intensive remission-induction chemotherapy, frequently followed by a conditioning regimen and hematopoietic stem cell transplantation (HSCT). These therapies often cause severe gastrointestinal side effects, resulting in poor nutritional intake and high risk of malnutrition.²⁻⁴ Evidence suggests that malnutrition before and after HSCT adversely influences complication rates, hospital stay, and survival.³⁻⁷ Since nutritional status is a potentially modifiable prognostic factor, nutritional interventions are considered important supportive measures during AML treatment.²⁻⁴

The guidelines on nutrition in intensively treated AML patients (European Society for Clinical Nutrition and Metabolism (ESPEN)/Blood and Marrow Transplantation (EBMT)) recommend enteral nutrition (EN) as the first choice nutritional intervention if nutritional intake becomes inadequate and to reserve parenteral nutrition (PN) for patients with severe gastrointestinal symptoms.^{2,8} However, there is low adherence to these guidelines resulting in high variation in the application of EN and PN during intensive AML treatment among hospitals.⁹⁻¹³ Although some centers apply EN as the primary nutritional intervention according to the ESPEN/EBMT guidelines, PN remains the preferred method of nutrition administration in many hospitals, while other centers limit EN/PN to exceptional and severe cases only.⁹⁻¹³ Consequently, many patients who receive AML treatment in different hospitals are confronted with varying or even opposite nutritional support practices between treating centers.¹³

The barriers to the ESPEN/EBMT nutritional guideline adherence are unknown.^{12,13} Some literature suggested that patients' and hematology nurses' negative attitude towards EN might play a role. Quantitative trials investigating HSCT-outcomes with EN versus PN attributed the frequent refusal of EN to its invasive nature.¹⁴⁻¹⁶ These authors assumed that hematology nurses' acceptance of EN may be important for its successful use.¹⁴⁻¹⁶

However, to the best of our knowledge, no studies explored in-depth patients' and hematology nurses' experiences and perceptions regarding nutritional problems and support, including EN and PN, during intensive AML treatment, nor did they address patients' experiences of being confronted with conflicting nutritional support practices. The few available qualitative studies incidentally identified nutritional problems among acute leukemia survivors as one of the most troublesome and distressing during treatment.¹⁷⁻¹⁹ Moreover, qualitative data about the patients' perspectives are becoming increasingly important for

improving quality of care and patient experiences, which are main goals of value-based health care.²⁰⁻²²

Therefore, the aim of the present qualitative study was to gain insight into patients' and hematology nurses' experiences and perceptions regarding nutritional problems and support during intensive chemotherapy and HSCT. Results might provide a better understanding of the barriers to adherence to the ESPEN/EBMT guidelines recommending EN over PN as the first-choice nutritional intervention, and starting points for improvement in nutritional information provision and support in AML patients receiving these treatments.

METHODS

Study design

This qualitative study with a descriptive phenomenological approach was performed between August 2017 and July 2020. Semi-structured interviews were conducted with AML patients, and a telephone questionnaire survey was conducted among clinical hematology nurses. The primary objective was to gain insight into patients' and hematology nurses' experiences and perceptions regarding nutrition-related problems and nutritional support practices during intensive AML treatment. Furthermore, we explored the barriers to adherence to the ESPEN/EBMT nutritional guidelines. The protocol of the study was reviewed by the accredited Medical Ethics Committee of the Maxima MC (N17.025) and was exempted from ethical review according to the Dutch Medical research Involving Human Subjects Act (WMO). The study procedures followed were in accordance with the Helsinki Declaration and with the rules of the European Personal Data Protection act.

Patient population and recruitment

In this study, purposive sampling was applied.²³ Adult patients (aged ≥ 18 years) were eligible for inclusion when they had completed an intensive treatment trajectory for AML, including intensive chemotherapy with or without HSCT. To obtain a wide range of experiences, patients who underwent an allogeneic, autologous or no HSCT after at least two cycles of intensive chemotherapy, patients who received only PN, only EN, both PN and EN, no PN nor EN, and patients who switched between hospitals with different nutritional support practices were sampled.

Patients who met the inclusion criteria and who had completed their treatment in the previous 2,5 years were recruited by a registered dietician (RL, SC, SK) or a

nurse specialized in hematology (JD) in three Dutch hospitals: Maastricht University Medical Center, Maastricht, Maxima MC, Veldhoven (teaching hospital), and Sint Antonius Hospital, Nieuwegein (teaching hospital). These centers were selected for their different nutritional support practices during intensive AML treatment. In two of these hospitals, nutritional support is an integral part of medical treatment. In these hospitals, all AML patients receive dietary counseling by a registered dietitian upon diagnosis and EN and/or PN immediately upon inadequate oral nutritional intake (EN/PN hospitals). In one hospital, consultation of a registered dietitian is not performed on a regular basis. This hospital has a wait-and-see approach towards both PN and EN, limiting their use to exceptional and severe cases only (no-EN/PN hospital).

Eligible patients received concise information about the study from the recruiting health care professionals. After patients' permission, they were contacted by a member of the research team (NL, RL) who provided more detailed study information. We continued with the interviews until data saturation was reached.²⁴ Initially, 21 patients were selected for inclusion, of whom 3 cancelled the interview due to illness or disease progression and 1 declined participation for unknown reasons. To ensure sufficient information, the study population was elaborated with 6 patients who were recruited via the central online cancer information platform for patients *kanker.nl*, and the website of the patient organization Hematon. Patients willing to participate subscribed by sending an email to the principal researcher (RL). All participants signed written informed consent prior to the interview. In total, 23 patients were interviewed.

For the telephone questionnaire surveys among hematology nurses, one clinical hematology nurse of each of the 22 hospitals that provide intensive AML treatment in The Netherlands was recruited. The registered dietitians working at the hematology wards of these centers selected participants upon first registration after an invitation call. The hematology nurses received in-depth verbal and written information about the survey by a member of the research team (RvL) and were included upon providing informed consent. The response rate was 100%.

Study Procedure

The semi-structured interviews with patients were performed by members of the research team (RvL, NL, ED, TJ) and were held on a location of the patients' preference, which was mostly at the participants' home or treating hospital.

The interviews were based on the interview guide shown in Appendix I, which was developed by investigators with experience in the field of nutrition in hematology patients and in performing qualitative studies (RvL, NL, JD, DvdL, SB). The interview guide included topics about the moment of AML diagno-

sis and treatment and about the patients' current well-being for the purpose of building confidence and encouraging patients to share their experiences.²⁴ The subsequent topics covered the patients' lived experiences regarding nutrition-related problems, nutrition-associated bodily changes, the received nutritional care and interventions during intensive AML treatment, including EN and PN, and differences in nutrition practices between hospitals. The duration of the interviews varied from 45–60 minutes.

The surveys with the clinical hematology nurses were conducted by telephone by two members of the research team (RvL, DdL) following the questionnaire shown in Appendix II. The topics that were addressed in the survey included the hematology nurses' experiences and perceptions regarding: patients' eating-related problems and associated distress, and the provided nutritional care and interventions, especially EN and PN. Furthermore, the hematology nurses were inquired about their awareness of the ESPEN/EBMT nutritional guideline recommendations on PN and EN in AML patients and on the possible barriers to ESPEN/EBMT guideline adherence and implementation.

The questionnaire was sent to the hematology nurses by email before the interview, to enable them to prepare for the telephone interview.

Data analysis

Twenty-two of the patients' interviews were audio-recorded and transcribed verbatim (RL, ED, TJ). One interview was not audio-recorded according to the patient's wishes. The executing researcher (NL) made extensive descriptive field notes of this interview that captured the essence of this patient's experiences and perceptions regarding the topics of investigation immediately upon completion of the interview (NL). To ensure patients' anonymity, personal details were deleted from the transcripts and summary.

The transcripts and one interview summary were analyzed thematically using a descriptive phenomenological approach.^{25–30} As a first step, nine transcripts were analyzed independently by four researchers (RL, SB, ED, TJ) using the open coding procedure.^{24,31} After coding, results were compared and discussed to ensure interrater reliability and to develop a code tree.²⁴ This procedure was repeated until no new information or themes relevant to the study aim emerged from the transcribed interviews (data saturation).²⁴ Subsequently, the established code tree was used for coding the other thirteen transcripts and the field notes of one interview. The codes were then clustered into overarching themes, which were formulated and discussed by two members of the research team (RL, SB). To illustrate the important themes that emerged from the thematic analysis, patients' quotes were selected from the transcripts, cleaned and translated.³² Atlas.ti version 9.0.15 (Berlin, Germany) was used to analyze the data.

The telephone questionnaire surveys with the clinical hematology nurses were audio-recorded (RvL, DdL), data were clustered into overarching themes similar to those that had emerged from the patients' interviews, and results are presented in a descriptive way (RvL). The barriers to the adherence of the ESPEN/EBMT nutritional guideline recommendations regarding EN and PN were divided into personal factors, guideline-related factors and external factors (RvL).³³

RESULTS

Of the total study population of 23 AML patients who had completed an intensive treatment trajectory, 57% was female and the mean age was 53 years (Table 1). Information on medical treatment, nutritional interventions during the AML treatment trajectory, the different nutritional support practices in the treating hospitals and the time since diagnosis is displayed in Table 1.

TABLE 1 Patient and (medical and nutritional) treatment characteristics

	Patients (n = 23)
Age in years, mean (range)*	53 (42–67)
Sex, n (%)	
Female	13 (57)
Male	10 (43)
Treatment following RI chemotherapy, n (%)	
Autologous HSCT	12 (52)
Allogeneic HSCT	9 (39)
Post-induction chemotherapy	2 (9)
Nutritional support practices in treating hospitals, n (%)	
Treatment in both EN/PN hospital and no-EN/PN hospital**	10 (44)
Total treatment in no-EN/PN hospital	7 (30)
Total treatment in EN/PN hospital	6 (26)
Received artificial nutritional support during treatment, n (%)	
No PN and no EN***	10 (43)
Only PN	7 (30)
PN and EN	4 (17)
Only EN	2 (9)
Time since treatment, n (%)	
< 1 year	8 (35)
1–5 years	13 (56)
> 5 years	2 (9)

EN = enteral nutrition, HSCT = hematopoietic stem cell transplantation, PN = parenteral nutrition, RI = intensive remission induction.

* Data available for age: n = 22

** EN/PN hospital: hospital where nutritional support (dietary counseling by a registered dietician and the use of PN and/or EN in patients who are unable to achieve an adequate oral nutritional intake) is provided as an integral part of medical treatment. No-EN/PN hospital: hospital where nutritional support is provided in exceptional and severe cases only.

***Patients who had not received EN/PN were able to eat sufficiently (n=2), were unable to receive EN/PN (n=1) or had received (part of their) treatment in the hospital where nutritional support is provided in exceptional and severe cases only (n=7)

A total of 22 clinical hematology nurses participated in the current study; one from each of the hospitals providing intensive AML treatment in The Netherlands. Whereas all hospitals provided remission-induction treatment, only 8 university centers performed both autologous and allogeneic HSCTs, 4 centers performed autologous but not allogeneic HSCTs, and 7 hospitals provided only care after autologous HSCT.¹³



Results of the thematic analysis of the semi-structured interviews conducted with AML patients are summarized in Table 2.

TABLE 2 Themes that emerged from the patients' interviews

	Themes
Nutritional problems and related physical decline	Distress Acceptance
Nutritional support	Mental peace Problems related to artificial nutrition Conflicting nutritional support practices

Two themes emerged from the data covering the patients' lived experiences and perceptions regarding nutritional problems and related physical decline: 1) distress and 2) acceptance. Patients' experiences and perceptions regarding nutritional support during intensive AML treatment were categorized into three themes: 1) mental rest, 2) artificial nutrition-associated problems, and 3) conflicting nutritional support practices.

Nutritional problems and related physical decline

The vast majority of patients reported that they suffered from multiple and often severe nutritional problems during intensive AML treatment, including anorexia, taste disturbances, nausea, vomiting, both oral and gastrointestinal mucositis, diarrhea and/or ileus. These patients experienced prolonged time periods of diminished oral nutrient intake, resulting in body weight loss and other physical decline, including loss of muscle strength. Patients coped with these issues differently.

Distress

In most of the patients, nutritional problems, body weight loss and other physical losses caused substantial emotional distress. The emotional distress resulting from the reduced ability to eat included feelings of disappointment, anxiety, concern, powerlessness, fear and panic. Furthermore, the fact that nutrition is a necessity to sustain life contributed to these feelings of distress.

Body weight loss and other physical decline negatively affected both patients' body image and social and/or family roles. Many patients who suffered from profound body weight loss experienced impaired body image and loss of self. Patients reported sagging body parts and loosening skin and felt their body had

aged rapidly. Moreover, they felt alienated from their own reflection and did not recognize themselves anymore. Several patients who experienced severe loss of muscle strength mentioned that they were unable to perform simple daily life activities, including climbing stairs, doing groceries, preparing meals, opening a tin can, brushing their teeth, putting on and taking off their clothes, raising themselves to a standing position from the toilet or lifting their children. This physical decline was accompanied with feelings of grief, frustration, concern and powerlessness and thus enhanced emotional distress.

“And then you’ve had your stem cells, and then, then your blood test results are good, only then you can’t eat any more. So those are the side effects then, um, and after effects that probably aren’t so important, but they have a big [stutters] im, im, impact, on how you, how you, how you, how you feel about yourself as a person. Because, um, because eating is such a basic um, basic part of, of, of your life and you’re afraid, you know what I mean, because you were also regularly weighed, that, uh, ... but where does it stop? [.....] Yes, you know, and then you look at yourself and you think, gee, there’s not much left.....So that really has a big impact.” (patient 18: EN in EN/PN hospital)

Acceptance

Some of the participating patients accepted the nutritional problems, including the related physical decline, as an inevitable consequence of the disease and the necessary treatment. Several of these patients adjusted their diet to their eating abilities and just kept on eating. Others simply regarded the nutritional issues and subsequent physical losses as the price they had to pay for survival, and/or put them into perspective believing that higher burden might reflect treatment success and a lower relapse risk. In some cases, losing and achieving a healthier body weight were even considered favorable treatment side effects and contributed to a more positive body image.

“Yes, and I lost an awful lot of weight in the no-EN/PN hospital. But that’s all part of it, isn’t it? And er, well, I’m someone who thinks if it’s going to happen, it’ll happen anyway, so let’s spend no more time on it.” (patient 5: PN in EN/PN hospital and no EN/PN in no-EN/PN hospital)

Nutritional support

Mental peace

Nutritional support during intensive AML treatment offered peace of mind in most patients. In general, hospital meal services and catering facilities with a variety of food options and snacks available at multiple time points were evaluated positively. However, the health care professionals' (HCPs') attitude and approach to the patients' nutritional problems and their psychosocial and physical consequences were perceived as more important than the quality and number of available foods.

Recognition of and attention to their eating problems from the multidisciplinary team of HCPs were regarded as valuable. It made patients feel they were being watched over, taken care of, and able to share the burden of their struggle with eating, especially when HCPs showed empathy and understanding regarding their nutritional problems. Furthermore, it was highly appreciated when HCPs showed efforts to provide nutrition tailored to the patients' dietary preferences and individual nutritional needs and subtly encouraged them to eat.

Many of the patients who were unable to maintain adequate oral nutrient intake during treatment, received EN and/or PN. Overall, patients believed that these artificial nutritional interventions helped to prevent or minimize and recover body weight and other physical losses. Moreover, patients perceived these artificial nutritional interventions as their lifeline. Besides physical advantages, artificial feeding attributed to patients' mental well-being through releasing the pressure to eat and reducing feelings of concerns regarding diminished nutrient intake and its consequences.

“Then you know it’s OK, it’s like now I don’t need worry any more that I am not getting enough nutrition. So, I don’t need to torture myself by stuffing myself with food ... But I thought, yes, the mental peace it gives, I’m getting enough nutrition into my body through, the er, IV, and then I don’t have to worry that I’m losing too much weight, or er...”
(patient 1: PN in EN/PN hospital and no EN/PN in no-EN/PN hospital)

Problems related to artificial nutrition

In general, patients' negative experiences regarding artificial nutritional support (EN/PN) included a loss of independence, limited mobility, problems related to the feeding equipment, and fear of unwanted body weight gain. Due to these factors, cessation of artificial nutrition felt as a relief for some participants.

Patients perceived PN as an easy and comfortable method of nutrition administration. In some participants, PN-related complications, including hyperglycemia,

serum liver test abnormalities, and catheter-associated infections or thrombosis were a source of concern. When compared to PN, patients' experiences with EN were far more negative. Whereas most patients who required artificial nutrition accepted PN without objection, many refused EN, among others due to fear of the feeding tube insertion and/or because its necessity was associated with dying or a sign of personal failure. Patients who had received EN mostly perceived it as a necessary evil. EN was often poorly tolerated and associated with increased gastrointestinal symptoms, including nausea, vomiting and abdominal pain. In addition, patients frequently experienced specific tube-related distress, involving soreness of the nose and throat, cosmetic unacceptability, and tube blockage and/or dislodgment.

For patients who reported fear of unwanted body weight gain, the dietary approaches of HCPs to enhance nutritional intake by applying EN/PN were perceived as too invasive by some patients and even caused feelings of irritation. In these cases, the HCPs' goal, i.e. prevention of body weight loss by compensating the nutritional deficits with PN or EN, was inconsistent with the patient's sense of satisfaction with losing or the desire to lose some body weight.

“But then it [feeding tube] began to irritate me so much that I said to the nurse, I said “that thing must be taken out now!”. I said because it is only causing me... it’s only distressing me and I’m getting no benefit from it any more... It was so irritating, and then she said “I’ll go and ask about it”. But after a while it started to hurt so much that I said “listen, you can go and ask about it, but then I’ll take it out myself.” (patient 23: EN and PN in EN/PN hospital and no EN/PN in no-EN/PN hospital)

“I lost hardly any weight there. I have to say, they, um, really looked after me there, because if I lost even a few hundred grams a dietician would immediately appear next to my bed... and I had quite a fight on my hands convincing them that as my weight was 111 kg, I was about 30 kg too heavy. And that I didn’t mind shedding those kilos at all.”
(patient 8: no EN/PN in EN/PN hospital nor in no-EN/PN hospital).

Conflicting nutritional support practices

The differences in nutritional support practices between treating hospitals led to confusion and a reduced confidence in health care. The patients who changed from a hospital where they received dietary counseling by a registered dietician and EN or PN immediately upon inadequate food intake to a hospital where nutritional support was provided in exceptional and severe cases only, had come to appreciate nutritional care even more and became aware of its

importance. Even the patients who initially perceived the assertive dietary approach to nutritional problems in the EN/PN hospital as negative, afterwards felt grateful for it as it had prevented deterioration of nutritional status during the initial treating phase.

Many of the patients who received intensive nutrition support during the first treatment phase (in a EN/PN hospital), experienced body weight loss and other physical losses during the second part of AML treatment when this was carried out in another hospital where a minimum of nutrition support was provided (no-EN/PN hospital). These patients believed the nutritional and physical decline were unnecessary, could have been prevented, caused feelings of regret, and adversely affected recovery and the performance of daily life activities or hobbies, and sometimes even resulted in hospital re-admission. The minimum of nutritional support they perceived in the no-EN/PN hospital during the second treatment phase were difficult to accept, and provoked feelings of neglect, dependence, being treated as a number instead of a human being, concern and panic.

“But anyway, in that no-EN/PN hospital, at least for me, it was a ‘yes, OK, it doesn’t matter if you don’t eat for a few days’ sort of thing. The doctor said that it wasn’t such a big problem. And, um, in itself I trust that, that judgement, because these people have an awful lot of experience. But from my point of view, I didn’t like it at all. Because, I was thinking to myself, you know, you’ve got to keep eating to stay, um, to stay as strong as possible. To get through the treatment. So, I really wanted make sure that I got enough, um, nutrition. So then they said ‘no, no it doesn’t matter, so what if you don’t eat for a few days’, and then I got, er, got a bit panicky.” (patient 1: PN in EN/PN hospital and no EN/PN in no-EN/PN hospital)

The majority of the participating patients who had received their complete AML treatment in a hospital providing minimal nutritional support experienced body weight losses exceeding 20–30 kg but often did not realize the severity and impact of it until after hospital discharge. In many of these patients, the severe body weight loss and the adverse effects of muscle weakness on performing everyday life activities post-treatment were a major source of concern. Moreover, some of these patients strongly believed that their high body weight prior to treatment was one of the reasons they survived. However, the negative emotions regarding the little nutritional support they received during treatment in the no-EN/PN hospital were less pronounced when compared to the patients who received part of their treatment in a EN/PN hospital.



“And eating was just no longer possible. They tried and tried, with oral nutritional supplements and, oh I don’t know, with all sorts of things. Yes, and then I even had a dietician who asked me what I liked and so on, but I was so sick, too weak. I didn’t want anything. And, what saved me, and I’m quite convinced of this, I have never been really big but just before I was admitted I weighed 86 kilos. [...] if I hadn’t weighed that, I wouldn’t have made it. I really wouldn’t have made it, because I lost 31 kilos there.” (patient 12: no EN/PN in no-EN/PN hospital).

Hematology nurses’ perceptions regarding patients’ nutritional problems and support, and barriers to nutritional guideline adherence

The hematology nurses’ surveys provided information on three main themes, including 1) perceived patients’ nutritional problems, 2) experiences and perceptions regarding the provided nutritional support, especially EN and PN, and 3) barriers to adherence to and implementation of the ESPEN/EBMT recommendations on EN and PN in AML patients receiving intensive treatment.

Patients’ nutrition-related distress

In clinical practice, hematology nurses observe a broad range of emotions in response to nutritional problems and their physical consequences among AML patients who receive intensive treatment. In many cases they perceive that nutrition-related problems cause emotional distress, including feelings of anxiety, fear, concern, powerlessness, sadness and embarrassment. Hematology nurses often bear witness to the patients’ feelings of frustration and disappointment resulting from their unsuccessful attempts to increase oral nutritional intake. According to the hematology nurses’ experiences, some patients are able to relativize and/or accept the nutritional problems and related physical decline, regard them as inevitable treatment side effects and apply self-management strategies

(i.e. adjusting dietary habits or just keep on eating). Hematology nurses feel they play a pivotal role in managing and reducing patients' nutrition-related distress through providing information prior to treatment and reassuring patients during treatment that the nutritional problems are common and transient side effects.

Nutritional support

In general, hematology nurses perceive that patients show appreciation when their nutritional problems are recognized by HCPs and when nutritional support is provided. However, according to the hematology nurses' experiences, it is challenging but important not to cross the fine line between support and pressure to eat. Hematology nurses expressed they felt that patients are aware of the need to eat. Therefore, repeated well-intended encouragements to eat might enhance rather than alleviate nutrition-related distress, especially in those patients who are unable to maintain adequate oral intake.

Parenteral and enteral nutrition

Artificial nutritional interventions (EN/PN) are frequently applied during intensive AML treatments in all but one of the participating hospitals. Hematology nurses consider themselves as part of the multidisciplinary team that indicates artificial nutrition. According to the hematology nurses, artificial nutrition often contributes to patients' well-being through reducing the pressure to eat and reducing concerns about insufficient nutrient intake. The vast majority of hematology nurses prefer PN over EN during intensive AML treatment for several reasons, including the easy and little time-consuming method of administration through an already available central venous catheter, the poor patients' tolerance of EN and tube tolerability, and the risk of bleeding during tube placement. Although PN is often accompanied by several complications, including hyperglycemia, serum liver test abnormalities and catheter-related infections, hematology nurses do not recognize these as a major source of patients' distress.

Barriers to nutritional guideline adherence

In contrast to the preference of most hematology nurses and current clinical practices, ESPEN and EBMT recommend EN as the first choice nutritional intervention, while PN should be reserved for patients with severe gastro-intestinal symptoms. The hematology nurses' barriers to the adherence to these ESPEN/EBMT recommendations could be classified into three categories: 1. personal barriers related to the hematology nurses' knowledge (lack of awareness/familiarity) and attitudes (lack of agreement and negative outcome expectancy), 2. guideline-related barriers (lack of scientific evidence), and 3. external barriers (lack of collaboration among HCPs) (Table 3).

TABLE 3 Hematology nurses' barriers to adherence to the ESPEN/EBMT nutritional guidelines recommending enteral nutrition over parenteral nutrition as the first-choice nutritional intervention in intensively treated AML patients (n=22).

Personal factors	
Lack of awareness/familiarity	Unaware of the nutritional guidelines (n=9). Aware of or heard by chance about the nutritional guidelines (n=13); some believed their colleagues were unaware of the guidelines (n=5).
Lack of agreement	Supportive of nutritional guidelines (n=5). Acknowledge the theoretical background of the nutritional recommendations (EN for preservation of bowel integrity), but question the feasibility (n=8). Regard the nutritional guidelines as not feasible (n=9); regard PN as the preferred route of nutrition administration (n=8) or reluctant to both EN and PN (n=1).
Lack of outcome expectancy	Anticipated/perceived adverse effects of EN (n=17): EN intolerance (gastrointestinal symptoms; nausea, vomiting, diarrhea, malabsorption, mucositis, abdominal pain) (n=15). Tube intolerability (inconvenience, pain/wounds in the nose and throat, especially in the presence of (oral) mucositis) (n=9). Risk of bleeding during tube placement (n=6). EN is a burden for patients and causes emotional distress and anxiety (n=4). Patients' refusal of EN (n=3). Make patients look more ill (n=1). Anticipated/reported adverse effects of PN: Serum liver tests abnormalities (n=1).
Guideline-related factors	
Lack of evidence	Low level of scientific evidence for the nutritional guidelines (n=3). Lack of evidence for adverse effects of PN on treatment outcome (n=1).
External factors	
Lack of collaboration	Nutritional support practices vary among hematologists and/or dietitians, opinion of treating hematologist unknown (n=4).
Organizational constraints	Lack of internal protocols on the use of EN and PN (n=1).

AML = acute myeloid leukemia, EN = enteral nutrition; EBMT = European Society of Blood and Marrow Transplantation, ESPEN = European Society of Clinical Nutrition and Metabolism, PN = parenteral nutrition

Results show that only a small majority of the 22 hematology nurses (n=13, 59%) were aware of or had heard by chance about the ESPEN/EBMT guidelines on nutrition during intensive AML treatment, whereas 9 of the participating nurses (41%) was unaware of these nutritional guideline recommendations (lack of awareness/familiarity). Nine of all participating hematology nurses (41%) disagreed with the ESPEN/EBMT recommendations on EN and PN in intensively treated AML patients because in their opinion, the difficulties related to EN in this patient group overruled the possible advantages of this feeding method (lack of agreement). Of the participants who did agree with the ESPEN/EBMT recommendations (n=13), most (n=8) questioned their feasibility. Moreover, 17 of the hematology nurses (77%) expected or reported negative effects of EN, including limited tolerance of EN and intolerability of the enteral feeding tube (lack of outcome expectancy). The low level of scientific evidence to support the use of EN versus PN as the preferred method of nutrition administration during intensive AML treatment was a barrier to the ESPEN/EBMT guideline adherence in 4 of the nurses (18%) (lack of evidence). The same number of hematology nurses reported heterogeneity in nutrition support strategies among hematologists and dieticians and/or were unaware of the opinion of the treating hematologist regarding the use of EN and PN (lack of collaboration). One of the nurses reported the lack of internal protocols on the use of EN and PN (organizational constraints).

DISCUSSION

This qualitative study showed that intensively treated AML patients differently experienced nutritional problems, varying from substantial emotional distress in most patients to acceptance. These variations in nutrition-related distress were well recognized by the hematology nurses. Furthermore, nutritional support provided mental peace in most patients although some patients experienced loss of independency, limited mobility, feeding-equipment-related problems and/or fear of unwanted body weight gain with EN/PN. Both patients and hematology nurses preferred PN over EN. Conflicting nutritional support practices between treating hospitals led to emotional distress, confusion and reduced confidence in health care among patients.

Hematology nurses' barriers to apply the ESPEN/EBMT guidelines recommending EN over PN as the primary nutritional intervention during intensive AML treatment included personal factors (lack of awareness/familiarity, agreement

and expected outcome), guideline-related factors (lack of evidence) and external factors (lack of collaboration).

The few studies that incidentally reported on AML patients' experiences regarding nutritional problems during intensive treatment were in line with our findings, demonstrating that nutrition impact symptoms and a reduced ability to eat were a major source of distress in most patients.¹⁷⁻¹⁹ The nutrition-related distress described in the literature among other cancer populations resembled the experiences of our study population, including diminished body image, feelings of disappointment, concern, powerlessness and fear versus acceptance among patients who successfully applied self-management strategies and reasoned that nutritional problems were inevitable consequences of disease and treatment.^{22,34-43}

In line with preliminary findings in intensively treated hematological patients and literature among other cancer patients, the current study showed that HCPs' acknowledgement of and multidisciplinary individualized support for nutritional problems are important for reducing patients' nutrition-related distress.^{19,34-36,39,44-46} The present study also confirmed research among other cancer patients showing that conflicting nutritional support practices negatively impacted patient understanding and led to feelings of confusion and uncertainty, especially when this confusion/uncertainty was left unaddressed by HCPs.^{37,46} The perceptions and lived experiences regarding EN/PN among patients and hematology nurses of our study mirrored those of other cancer populations and incidental findings or assumptions of quantitative research in HSCT recipients.^{14-16,37,45-47}

A systematic review on experiences of having EN among nutritionally vulnerable cancer patients also found initial reluctance and fear, different understandings and expectations, and physical discomfort, but thereafter acceptance and overall, a worthwhile decision.⁴⁶ In quantitative trials among post-allogeneic HSCT patients, 22-50% of the potentially eligible patients refused EN, and intolerability of EN/the feeding tube occurred in about half of the EN users.^{14-16,47} Our study confirmed previous literature assuming that the high acceptance of PN as opposed to EN in both patients and HCPs may be explained by its less invasive nature.^{14-16,45}

Our findings support the hypothesis proposed in some literature that the common non-adherence to the ESPEN/EBMT nutritional guidelines in intensively treated AML patients may be explained by the patients' and HCPs' reluctance to EN, owing to the anticipated physical discomfort.⁹⁻¹⁶ Furthermore, evidence from the current study is in accordance with previous literature assuming that the lack of scientific evidence for the physical benefits of EN versus PN in these patients withholds HCPs to implement EN in clinical practice.^{4,12,13}

Importantly, many hematology nurses in our study were neither aware nor supportive of the ESPEN/EBMT recommendations and questioned the feasibility of EN due to the high prevalence of severe gastrointestinal symptoms. The nurses' negative attitude towards EN may reinforce the patients' reluctance, as some literature assumed that HCPs' acceptance of EN may be crucial for its successful use.^{14-16,48} The lack of awareness, collaboration and internal protocols on the use of EN/PN observed in the current study indicates inadequate incorporation of the ESPEN/EBMT guidelines into multidisciplinary clinical pathways, which may additionally contribute to low adherence.^{13,33}

To the best of our knowledge, this is the first study that explored in-depth both patients' and hematology nurses' perspectives and lived experiences regarding nutritional problems and support, and barriers to the ESPEN/EBMT guideline adherence during intensive AML treatment. Furthermore, variation within our study populations was large, since we included hematology nurses of each Dutch hospital providing intensive AML treatment, and AML patients who received varying medical treatments and nutritional interventions and switched between hospitals with different nutritional support practices.

A limitation of our study is that we included only one hematology nurse of each hospital, while perceptions regarding nutritional problems, support and guidelines may vary among nurses of the same hospital.^{14-16,46} Furthermore, selection bias may be present because dietitians might have approached hematology nurses with a special interest in nutrition. Due to this selection bias, the hematology nurses' awareness of patients' nutrition-related distress and the ESPEN/EBMT nutritional guidelines may have been overestimated, whereas the barriers to guideline adherence may have been underestimated.

To reduce nutrition-related distress in intensively treated AML patients, psychosocial consequences of nutritional problems and patients' needs for support should be identified and acknowledged through continuous screening (e.g. Distress thermometer and problem list).^{19,34,35,39,40,44,49,50} Furthermore, personalized multidisciplinary nutritional support is most appreciated and conflicting practices should be resolved or explained.^{12,13,37,44-46,50}

To increase ESPEN/EBMT nutritional guideline adherence during intensive AML treatment, hematology nurses' barriers, especially their reluctance to EN, should be addressed.^{12,13,33} The first step may be improving hematology nurses' awareness and knowledge of these standards.³³ Besides education, involvement in nutritional guideline development may improve hematology nurses' attitudes, and incorporating the ESPEN/EBMT guidelines into clinical pathways may enhance adherence.^{13,33} Outcome expectancy with EN may be improved by properly triaging patients eligible for EN (patients without severe gastrointestinal symptoms), multidisciplinary counselling of EN-related problems and

enhancing practice experiences.^{14,15,33,44} Importantly, further research providing solid scientific evidence that advantages of EN in AML patients outweigh those of PN may enhance guideline adherence.^{2,4,12,13,33}

Patients' reluctance towards EN may be reduced by enhancing patients' knowledge of EN through uniform information from a multidisciplinary HCPs' team or by hearing other patient experiences.^{14,15,44-46} Patients' involvement in choices surrounding EN may either promote a positive EN experience, or overwhelm patients with that responsibility.⁴⁶ Therefore, shared-decision making should be applied respecting patients' autonomy and considering psychosocial, cultural and existential aspects and needs.^{43,46,51}

In conclusion, the present study shows that nutrition-related problems and conflicting nutritional support practices were a major source of distress in most intensively treated AML patients and that nutritional support often provided mental peace. Opposed to the ESPEN/EBMT guidelines, PN was preferred over EN by both patients and hematology nurses due to the easy administration of PN versus the physical discomfort, intolerance, feeding-equipment-related problems and/or misperceptions related to EN. Other barriers to ESPEN/EBMT nutritional guideline adherence related to hematology nurses' knowledge and attitude, guideline-related factors and external factors.

To reduce patients' nutrition-related distress, HCPs should recognize and acknowledge psychosocial consequences of nutritional problems and assess patients' need for support. Nutritional support should be uniform across treating hospitals, individualized and multidisciplinary, and shared-decision making should be applied. ESPEN/EBMT guideline adherence may be improved through enhancing hematology nurses' awareness and knowledge of the guidelines, involving them in nutritional guideline development, incorporating recommendations into clinical pathways, applying proper triage of patients eligible for EN, multidisciplinary treatment of EN-related complications, and increasing the level of scientific evidence of the guidelines by further research.

ACKNOWLEDGEMENTS

We thank Jeanne Dieleman, PhD, Department of Research, Maxima MC, for her comments that greatly improved our work, Daphne de Laat, Department of Dietetics and Nutrition, Maxima MC, for her contribution to the hematology nurses' survey, Daphne Visser-Lees, Specialist Dutch-English medical editor/translator for translating patients' quotes from Dutch to English, and the hematology nurses' teams of the following hospitals for their participation in

the telephone survey: Albert Schweitzer Hospital, Dordrecht; Amphia Hospital, Breda; Amsterdam University Medical Centers, locations VU University Medical Center and Academic Medical Center, Amsterdam; Canisius Wilhelmina Hospital, Nijmegen; Erasmus University Medical Center, Rotterdam; Gelderse Vallei Hospital, Ede; Haga Hospital, The Hague; Isala Hospital, Zwolle; Jeroen Bosch Hospital, Den Bosch; Leids University Medical Center, Leiden; Maastricht University Medical Center, Maastricht; Maxima MC, Veldhoven; Meander Medical Center, Amersfoort; Medical Center Leeuwarden, Leeuwarden; Medical Spectrum Twente, Enschede; Onze Lieve Vrouwe Gasthuis, Amsterdam; Radboud University Medical Center, Nijmegen; Reinier de Graaf Gasthuis, Delft; Rijnstate Hospital, Arnhem; Sint Antonius Hospital, Nieuwegein; University Medical Center Groningen, Groningen; University Medical Center Utrecht, Utrecht.

Statement of Authorship

Rianne van Lieshout contributed to the conception of the study. Rianne van Lieshout, Judith van Deursen, Debbie van der Lee and Sandra Beijer contributed to the design of the study. Rianne van Lieshout, Nora Lize, Judith van Deursen, Eline Driessen, Tina Janssen, Stephanie Custers and Suzanne Kranenburg contributed to the acquisition of the data. Analysis of the data was performed by Rianne van Lieshout, Eline Driessen, Tina Janssen and Sandra Beijer. Rianne van Lieshout, Nora Lize, Lidwine W. Tick, Harry R. Koene, Erik A.M. Beckers, Harry C. Schouten and Sandra Beijer contributed to the interpretation of the data. Rianne van Lieshout drafted the manuscript. All authors critically revised the manuscript for important intellectual content and approved of the final version to be submitted.

Conflict of Interest Statement

R. van Lieshout has received unrestricted research grants from Baxter B.V. Utrecht, The Netherlands, and Fresenius Kabi Nederland B.V., Huis ter Heide, The Netherlands. The other authors have nothing to disclose.

Funding sources

This work was partially supported by the Vrienden Integrale Oncologische Zorg Foundation, Utrecht, The Netherlands (2017); Baxter B.V., Utrecht, The Netherlands (GHOL6759, 2018); Fresenius Kabi Nederland B.V., Huis ter Heide, The Netherlands (2019). These funding sources did not play any role in the design of the study, the collection, analysis and interpretation of data, in writing of the report nor in the decision to submit the article for publication.

REFERENCES

1. Comprehensive Cancer Center the Netherlands. Netherlands Cancer Registry. Available from: <https://www.iknl.nl/nkr-cijfers>
2. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2017;36(1):11-48.
3. Baumgartner A, Bargetzi A, Zueger N, Bargetzi M, Medinger M, Bounoure L, et al. Revisiting nutritional support for allogeneic hematologic stem cell transplantation—a systematic review. *Bone Marrow Transplant* 2017;52(4):506-13.
4. Baumgartner A, Hoskin K, Schuetz P. Optimization of nutrition during allogeneic hematologic stem cell transplantation. *Curr Opin Clin Nutr Metab Care* 2018;21(3):152-8.
5. Baumgartner A, Zueger N, Bargetzi A, Medinger M, Passweg JR, Stanga Z, et al. Association of Nutritional Parameters with Clinical Outcomes in Patients with Acute Myeloid Leukemia Undergoing Haematopoietic Stem Cell Transplantation. *Ann Nutr Metab* 2016;69(2):89-98.
6. Deluche E, Girault S, Jesus P, Monzat S, Turlure P, Leobon S, et al. Assessment of the nutritional status of adult patients with acute myeloid leukemia during induction chemotherapy. *Nutrition* 2017;41:120-5.
7. van Lieshout R, Tick LW, Dieleman JP, Custers S, van Dongen MS, van der Lee D, et al. Changes in body weight and serum liver tests associated with parenteral nutrition compared with no parenteral nutrition in patients with acute myeloid leukemia during remission induction treatment. *Support Care Cancer* 2020.
8. Baumgartner A, Schuetz P. Nutritional Support. In: th, Carreras E, Dufour C, Mohty M, Kroger N, editors. *The EBMT Handbook: Hematopoietic Stem Cell Transplantation and Cellular Therapies*. Cham (CH); 2019. p. 171-6.
9. Fuji S, Mori T, Vincent L. A multi-center international survey related to the nutritional support after haematopoietic stem cell transplantation endorsed by the ASIA Pacific Blood and Marrow Transplantation (APBMT). *Food Nutr Sci* 2012;3:417-21.
10. Botti S, Liptrott SJ, Gargiulo G, Orlando L. Nutritional support in patients undergoing haematopoietic stem cell transplantation: a multicentre survey of the Gruppo Italiano Trapianto Midollo Osseo (GITMO) transplant programmes. *Ecancermedalscience* 2015;9:545.
11. Peric Z, Botti S, Stringer J, Krawczyk J, van der Werf S, van Biezen A, et al. Variability of nutritional practices in peritransplant period after allogeneic hematopoietic stem cell transplantation: a survey by the Complications and Quality of Life Working Party of the EBMT. *Bone Marrow Transplant* 2018;53(8):1030-7.
12. Baumgartner A, Bargetzi M, Bargetzi A, Zueger N, Medinger M, Passweg J, et al. Nutritional support practices in hematopoietic stem cell transplantation centers: A nationwide comparison. *Nutrition* 2017;35:43-50.

13. Van Lieshout R, Tick, L.W., De Laat, D., Custers, S., Dekker, I.M., Douma M.D., Kalter D., Kranenburg S., Van der Lee, D., Roohn-Bruijnzeel, P., Schlösser, Somer, M., Van Tilborg, C. J., Visser, W.K., Schouten, H.C., Beijer S. Adherence to guidelines on nutrition support during intensive treatment of acute myeloid leukemia patients: a nationwide comparison. *Journal of Clinical Nutrition ESPEN* 2020 ahead of publication.
14. Seguy D, Duhamel A, Rejeb MB, Gomez E, Buhl ND, Bruno B, et al. Better outcome of patients undergoing enteral tube feeding after myeloablative conditioning for allogeneic stem cell transplantation. *Transplantation* 2012;94(3):287-94.
15. Andersen S, Weber N, Kennedy G, Brown T, Banks M, Bauer J. Tolerability of proactive enteral nutrition post allogeneic haematopoietic progenitor cell transplant: A randomised comparison to standard care. *Clin Nutr* 2019.
16. Guieze R, Lemal R, Cabrespine A, Hermet E, Tournilhac O, Combal C, et al. Enteral versus parenteral nutritional support in allogeneic haematopoietic stem-cell transplantation. *Clin Nutr* 2014;33(3):533-8.
17. Stalfelt AM. Quality of life of patients with acute myeloid leukaemia. *Leuk Res* 1994;18(4):257-67.
18. Persson L, Hallberg IR, Ohlsson O. Survivors of acute leukaemia and highly malignant lymphoma--retrospective views of daily life problems during treatment and when in remission. *J Adv Nurs* 1997;25(1):68-78.
19. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
20. Teisberg E, Wallace S, O'Hara S. Defining and Implementing Value-Based Health Care: A Strategic Framework. *Acad Med* 2020;95(5):682-5.
21. Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167.
22. Bressan V, Bagnasco A, Aleo G, Catania G, Zanini MP, Timmins F, et al. The life experience of nutrition impact symptoms during treatment for head and neck cancer patients: a systematic review and meta-synthesis. *Support Care Cancer* 2017;25(5):1699-712.
23. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy Ment Health* 2015;42(5):533-44.
24. Boeije H. Analysis in qualitative research. Sage Publications; 2009.
25. Bernard HR WA, Ryan GW. Analyzing qualitative data: systematic approaches. Second Edition ed: Sage Publications, Inc; 2016.
26. Braun V. CV. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101.
27. Rennie DL. Qualitative research as methodical hermeneutics. *Psychol Methods* 2012;17(3):385-98.
28. Creswell J. Qualitative inquiry & Research Design. Chossing Among Five Approaches. Third Edition ed: Sage Publications, Inc.; 2013.
29. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res* 2007;17(10):1372-80.
30. Sundler AJ, Lindberg E, Nilsson C, Palmer L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* 2019;6(3):733-9.
31. Strauss A. Basics of qualitative research: techniques and procedures for developing grounded theory. Sage, Thousand Oaks; 1998.
32. Wellard S, McKenna L. Turning tapes into text: issues surrounding the transcription of interviews. *Contemp Nurse* 2001;11(2-3):180-6.
33. Fischer F, Lange K, Klose K, Greiner W, Kraemer A. Barriers and Strategies in Guideline Implementation--A Scoping Review. *Healthcare (Basel)* 2016;4(3).
34. Lize N RN, Van den Berg M, Emmaneel L, Kok A, Lagendijk M, Van Leeuwen-Bouhuis K, Van Lieshout R, Nagel Z, Beijer S. Which patients need psychosocial support for their cancer-related reduced ability to eat? A cross-sectional survey study. Submitted 2021.
35. Lize N, Raijmakers N, van Lieshout R, Youssef-El Soud M, van Limpt A, van der Linden M, et al. Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: A qualitative study. *Eur J Oncol Nurs* 2020;49:101838.
36. Ganzer H, Touger-Decker R, Byham-Gray L, Murphy BA, Epstein JB. The eating experience after treatment for head and neck cancer: A review of the literature. *Oral Oncol* 2015;51(7):634-42.
37. 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.
38. Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Support Care Cancer* 2019;27(8):2869-76.
39. Oberholzer R, Hopkinson JB, Baumann K, Omlin A, Kaasa S, Fearon KC, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
40. Wheelwright SJ, Darlington AS, Hopkinson JB, Fitzsimmons D, White A, Johnson CD. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2016;6(3):307-14.
41. Cooper C, Burden ST, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. *J Cachexia Sarcopenia Muscle* 2015;6(1):99-111.
42. Hopkinson JB, Okamoto I, Addington-Hall JM. What to eat when off treatment and living with involuntary weight loss and cancer: a systematic search and narrative review. *Support Care Cancer* 2011;19(1):1-17.
43. Amano K, Baracos VE, Hopkinson JB. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Crit Rev Oncol Hematol* 2019;143:117-23.
44. Lize N, V IJ-H, van Lieshout R, Wijnholds-Roeters Y, van den Berg M, Soud MY, et al. Experiences of patients with cancer with information and support for psychosocial consequences of reduced ability to eat: a qualitative interview study. *Support Care Cancer* 2021.

45. Amano K, Morita T, Miyamoto J, Uno T, Katayama H, Tatara R. Perception of need for nutritional support in advanced cancer patients with cachexia: a survey in palliative care settings. *Support Care Cancer* 2018;26(8):2793-9.
46. Hazzard E, Gulliver S, Walton K, McMahon AT, Milosavljevic M, Tapsell L. The patient experience of having a feeding tube during treatment for head and neck cancer: A systematic literature review. *Clin Nutr ESPEN* 2019;33:66-85.
47. Beckerson J, Szydlo RM, Hickson M, Mactier CE, Innes AJ, Gabriel IH, et al. Impact of route and adequacy of nutritional intake on outcomes of allogeneic haematopoietic cell transplantation for haematologic malignancies. *Clin Nutr* 2019;38(2):738-44.
48. Herrmann VM, Petruska PJ. Nutrition support in bone marrow transplant recipients. *Nutr Clin Pract* 1993;8(1):19-27.
49. Tuinman MA, Gazendam-Donofrio SM, Hoekstra-Weebers JE. Screening and referral for psychosocial distress in oncologic practice: use of the Distress Thermometer. *Cancer* 2008;113(4):870-8.
50. Koshimoto S, Arimoto M, Saitou K, Uchibori M, Hashizume A, Honda A, et al. Need and demand for nutritional counselling and their association with quality of life, nutritional status and eating-related distress among patients with cancer receiving outpatient chemotherapy: a cross-sectional study. *Support Care Cancer* 2019;27(9):3385-94.
51. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clin Nutr* 2016;35(3):545-56.





CHAPTER 4

Patients with cancer experience high impact of emotional consequences of reduced ability to eat: a cross sectional survey study

Lize N, Raijmakers N, van den Berg M, Emmaneel L, Kok A, Lagendijk M, van Leeuwen-Bouwuis K, Lieshout R, Nagel Z, Beijer S

European Journal of Cancer Care:
2022; 31: 13595

ABSTRACT

OBJECTIVE Patients with cancer can experience emotional consequences of reduced ability to eat, their impact is unknown. This study assesses the impact of these emotional consequences, and patients' satisfaction with healthcare professionals' (HCPs) support.

METHODS A cross-sectional survey was conducted among patients with head/neck, lung cancer and lymphoma, who experienced reduced ability to eat in the past year. Patients were recruited through patient organisations and hospitals. The questionnaire encompassed the impact of emotional consequences of reduced ability to eat (scale 1-10) and satisfaction with HCPs' support for reduced ability to eat (scale 1-10). The differences in patient characteristics between unsatisfied (score<6) and satisfied patients (score≥6) were tested using independent t-tests and the Chi-square-or Fishers' exact tests

RESULTS Overall, 116 patients (48%) responded and 98 were included in the analyses. The most impactful emotional consequences were: disappointment (mean ± SD: 8.31±1.49), grief/sadness (7.90±1.91), and anger (7.87±1.41). Patients were less satisfied when more time had passed since their diagnosis ($p<.002$) and when they expected no improvements regarding their eating problems ($p<.001$).

CONCLUSION The impact of emotional consequences of reduced ability to eat is high. Support for emotional consequences is needed, especially for patients with reduced ability to eat, which persists in recovery and remission.



INTRODUCTION

Patients with cancer often experience nutritional problems, such as anorexia, taste and smell changes, dry mouth, swallowing problems and nausea¹, which can result in insufficient nutritional intake and unintended weight loss². Some types of cancer have a high prevalence of nutritional impact symptoms, such as; head and neck cancer >90%³, and lung cancer 67-88%⁴. In addition to these physical consequences, patients also experience psychosocial consequences of reduced ability to eat. Lize et al.⁵ demonstrate that patients in different stages of the disease trajectory, including recovery and remission, experience a broad range of emotions. Patients mentioned experiencing feelings of anger, anxiety, disappointment, guilt, grief/sadness, powerlessness and shame. These emotions were evoked by patients' struggle with eating, and by misunderstanding for this struggle from the people around them. Furthermore, patients experienced less pleasure in social activities because many are related to food and eating.

The effect of these emotions on patients well-being is not yet clear. Although some research has been conducted, these studies were mainly conducted among cancer patient populations known to have a high prevalence of nutritional impact symptoms, such as patients in late advanced disease stages and patients with cancer cachexia. These studies show that the emotional consequences of reduced ability to eat can result in high levels of distress.⁶⁻²² Recently, Amano et al.¹⁹ coined the term "eating-related distress" to explain the multiple and intersecting emotional and social consequences of nutritional problems among patients with cancer cachexia. Eating-related distress relates to the physical consequences of eating problems, patients' feelings about food and eating, their concerns regarding their diets, and the effect of eating problems on their relationships.²² Studies conducted among other patient populations with a high prevalence of nutritional impact symptoms such as; patients with head and neck cancer, patients with hematologic cancer and patients receiving parenteral home feeding, also showed that the emotional consequences of reduced ability to eat can result in high levels of distress.²³⁻²⁷

Patients with cancer cachexia generally receive intensive nutritional support for the treatment of their physical consequences.¹ However, little attention has been paid to the emotional consequences of cancer cachexia.^{22,28,29} Healthcare professionals (HCPs) seem to avoid this topic, owing to feelings of uncertainty and the lack of a solution for the often-irreversible nutritional symptoms.^{30,31} In contrast, patients with cancer cachexia want their emotional consequences of reduced ability to eat acknowledged, and subsequently need information and support on how to manage this.^{28,29} Other studies conducted among patient

populations with high prevalence of nutritional impact symptoms showed the same tendency; patients wanted HCPs to acknowledge their distress which is evoked by their nutritional symptoms. However, their HCPs tended to focus on the physical aspects of inadequate nutritional intake.^{24,27}

The emotional impact of reduced ability to eat is mainly investigated among cancer patient populations with late advanced disease and cancer cachexia. Studies conducted among other patient populations with a high prevalence of nutrition impact symptoms only touched the subject but explored the topic among small patient populations with very specific complaints. Therefore, this study aim is to assess the impact of cancer-related emotional consequences of reduced ability to eat among a broader and larger patient population. This study further assesses patients' satisfaction with HCPs support for their reduced ability to eat. Based on these insights, this study aims to formulate recommendations to improve HCPs support for the emotional consequences of reduced ability to eat.

METHODS

Design, setting and participants

This study conducts a cross-sectional survey to assess the impact of the emotional consequences of reduced ability to eat among patients with cancer, and patient satisfaction with the support of HCPs for reduced ability to eat. The data were collected in the Netherlands between September 2018 and July 2019. Patients were eligible for inclusion if they (had) experienced reduced ability to eat due to cancer or its treatment in the past year, were ≥ 18 years, were diagnosed with head and neck cancer, Hodgkin or non-Hodgkin lymphoma or lung cancer, and had signed an informed consent. We chose for head and neck cancer and lung cancer owing to their high prevalence of nutritional impact symptoms. We chose for patients with lymphoma owing to the relatively younger population and better prognosis. The rationale for including patients with one of these three types of cancer is that they differ in age, prognosis, onset and the cause of the nutritional impact symptoms and perspectives for recovery. These differences may influence the need for the support of HCPs for reduced ability to eat.

Patients were recruited through an online call posted via the channels of patient organisations for head and neck cancer (Patientenvereniging Hoofd/hals), lymphoma (Hematon) and lung cancer (Stichting Longkanker Nederland). This patient population was supplemented by recruitment by dietitians from four participating hospitals in the Netherlands: Leiden University Medical Center, Máxima Medical Centre, Radboud University Medical Center and University

Medical Center Utrecht. Patients were recruited through these two methods, because online recruitment can result in a self-selection bias of patients interested in health topics and with active information seeking behaviour.³²

Procedure

The participating patient organisations disseminated information about the study via online platforms. Regarding this information, patients were invited to contact the research team via an online contact form, phone or email. Furthermore, dietitians in the participating hospitals assessed eligible patients, informed them about the study, and asked them for permission to be contacted by the research team. Thereafter the research team called the patients, informed them about the study comprehensively, and answered their questions. All the patients that decided to participate could choose between a web-based survey or a paper survey sent to their home address. A web-based survey was hosted by a secure website. Patients were sent one reminder to complete the survey three weeks after subscription. After six weeks the time frame for completion of the questionnaire was closed.

Questionnaire

The questionnaire was developed in collaboration with a broad expert group that comprised; two dietitians specialising in oncology care, one psychologist, and four representatives of patient organisations or patient information platforms. The questionnaire contained self-designed questions and statements regarding the impact of emotional consequences of reduced ability to eat and HCPs support. The questionnaire was pilot tested among three patients to ensure that the questions were readable and understandable and participation would take patients a maximum of 30 minutes of their time. Based on their feedback, linguistic refinements were made. In particular, they found items that were worded negatively and were considered as too confrontational. These items were rephrased. Patients who did not experience reduced ability to eat currently or in the past year were excluded based on two selection questions at the start of the questionnaire: 1) Do you currently experience reduced ability to eat? 2) Did you experience reduced ability to eat in the past year? The reason to exclude those patients was that patients who do not experience reduced ability to eat cannot have emotional consequences of reduced ability to eat.

Measurements

Sociodemographic and clinical characteristics

Sociodemographic characteristics were self-reported in the questionnaire including: gender, age, level of education (no education/primary school, lower

general secondary education, vocational training, pre-university education, university) and living situation (living together [with partner/children], living alone). Clinical characteristics were also self-reported in the questionnaire including: primary cancer type (head and neck cancer, Hodgkin or non-Hodgkin lymphoma, lung cancer), time since diagnosis (<1 year, 1-5 years, ≥5 years), treatment phase (currently receiving treatment, not under treatment), intention of treatment (curative intent/palliative), treatment type (chemotherapy, immunotherapy or targeted therapy, radiotherapy, surgery), treatment frequency (no treatment, 1 treatment, ≥2 treatments).

Nutrition and nutritional symptoms

The following questions were part of the questionnaire: 'Do you expect to eat well or better in the future' (yes/no) and 'Compared with what I ate before I got ill, I currently rate my food intake as' (more than usual, less than usual, unchanged). Most patients had experienced weight loss (60%), medical nutrition (oral nutritional supplements, parenteral and tube feeding, no medical nutrition), and nutritional symptoms (anorexia or food aversion, diarrhoea, dry mouth, early satiety, emotional problems, fatigue, mucus formation in mouth, nausea and/or vomiting, obstipation, obstruction, pain while eating, taste and smell changes and an open field for other non-predefined symptoms).

Impact of emotional consequences

Patients listed a top three of most impactful emotional consequences: 'Please indicate below which emotions, related to reduced ability to eat, you currently experience or experienced in the past year. You can list a maximum of three emotions'. The predefined list of emotions was based on previous qualitative research.⁵ The list included anger, annoyance, anxiety, concern, confrontation [with the disease], disappointment, grief/sadness, guilt, jealousy, less enjoyment, loneliness/social isolation, longing [for certain foods], misunderstanding [from others], powerlessness, rejection, reluctance [to eat] and shame, and an open field for other emotions. Patients rated the impact of their top three of most impactful emotions on a scale ranging from 1 'no impact at all' to 10 'extreme high impact'.

HCPs support for reduced ability to eat

Patients were asked about their experiences with the support of HCPs for emotional consequences of reduced ability to eat: 'Did you receive support for the emotional consequences of your reduced ability to eat from HCPs, or have you received this support in the past year?'. If yes, the patients were asked to list from whom they received this support (general practitioner, physician, psychologist/therapist, dietitian, nurse, dental hygienist/dentist and others). Thus,



more than one option was possible. If not, patients were asked if they felt the need for support at the time or in the past year. Furthermore, patients gave their opinions about a self-developed statement regarding their experiences with the support of HCPs for reduced ability to eat: 'Healthcare professionals support me well regarding my reduced ability to eat'. This statement was scored on a scale ranging from (1 'very strongly disagreed') to 10 ('very strongly agreed').

Statistical analysis

Descriptive analyses were used to assess the sociodemographic and clinical characteristics of the patients, their experiences regarding nutrition and nutritional symptoms and the impact score of their top three emotional consequences with the highest impact. Patients were categorised into three subgroups, based on their primary cancer type (head and neck cancer, Hodgkin or non-Hodgkin lymphoma and lung cancer). Furthermore, we also compared patients based on their satisfaction with the support of HCPs, defining two groups by using the statement: 'Healthcare professionals support me well regarding my reduced ability to eat' (unsatisfied: score <6 (scale 1-10) vs. satisfied ≥6). In the development of measures to assess patient satisfaction of Dutch patients, this 1-10 scale showed to be understandable and reliable.³³ This rating system is similar to the Dutch grading system of primary and secondary schools. In this grading system scores <6 were considered insufficient and scores ≥6 were considered as sufficient. Differences in the sociodemographic and clinical characteristics and emotional consequences of patients between the satisfied and unsatisfied group were tested using independent sample t-tests (for age) and for all other variables Pearson's Chi-square test or Fisher's exact test for categorical variables with respectively >5 and <5 expected numbers in cells). The missing observations were reported in the footnotes below the tables. Data were analysed using SAS (version 9.4) and a p-value <.05 was considered statistically significant.

Ethical considerations

The study protocol was reviewed by the Máxima Medical Centre in Veldhoven, the Netherlands (METC N18.032), and was exempted from ethical review according to the Dutch Medical Research Involving Human Subjects Act (WMO).

All the patients gave written informed consent and were informed that the survey would be analysed anonymously. To ensure that completing the questionnaire was not too confronting for patients the questions were not made mandatory and patients were assured that they could always withdraw without providing a reason.

RESULTS

The overall response rate was 48%. More than two thirds of the patients recruited from the participating hospitals responded (n=88; 69%). A lower response rate was observed among patients recruited by the patient organisations (n=155; 35.5%). The reasons for non-response were unknown (n=114). The known reasons were burden (n=4), survey not applicable (n=4), no interest in participation (n=3), and patient died (n=2). The reasons for excluding surveys after enrolment were: other or an unknown primary cancer type (n=13), no eating problems (n=4) and incomplete questionnaires (n=1). In conclusion, the surveys of 98 patients were included in the analysis (Figure 1).

Patients' characteristics

The mean age of the participants was 61.7, ranging from 24 to 91. Most patients were diagnosed with head and neck cancer (50%), followed by lung cancer (32%) and Hodgkin or non-Hodgkin lymphoma (18%). Most respondents received their diagnosis <5 years before participating in the study (85%), and most patients (had) received treatment with curative intent (63%). Almost three quarters of the population (71%) expected improvement in their reduced ability to eat in the future. Less than half of the patients with head and neck cancer had finished their treatments (45%), while most patients with Hodgkin or non-Hodgkin lymphoma and lung cancer were under treatment at the time of the questionnaire (62.5% and 80%). Patients with lung cancer received more often treatments with palliative intent (68%) compared with patients with head and neck cancer (12%) and Hodgkin and non-Hodgkin lymphoma (11%). More patients with head and neck cancer received two or more treatments (82%) compared with patients with Hodgkin or non-Hodgkin lymphoma (41%) and lung cancer (47%). Little over half of the patients with head and neck cancer expected to eat well or better in the future (59%), while most patients with Hodgkin and non-Hodgkin lymphoma and lung cancer expected to eat well or better in the future (89% and 80%) (Table 1.)

FIGURE 1 Flowchart patients

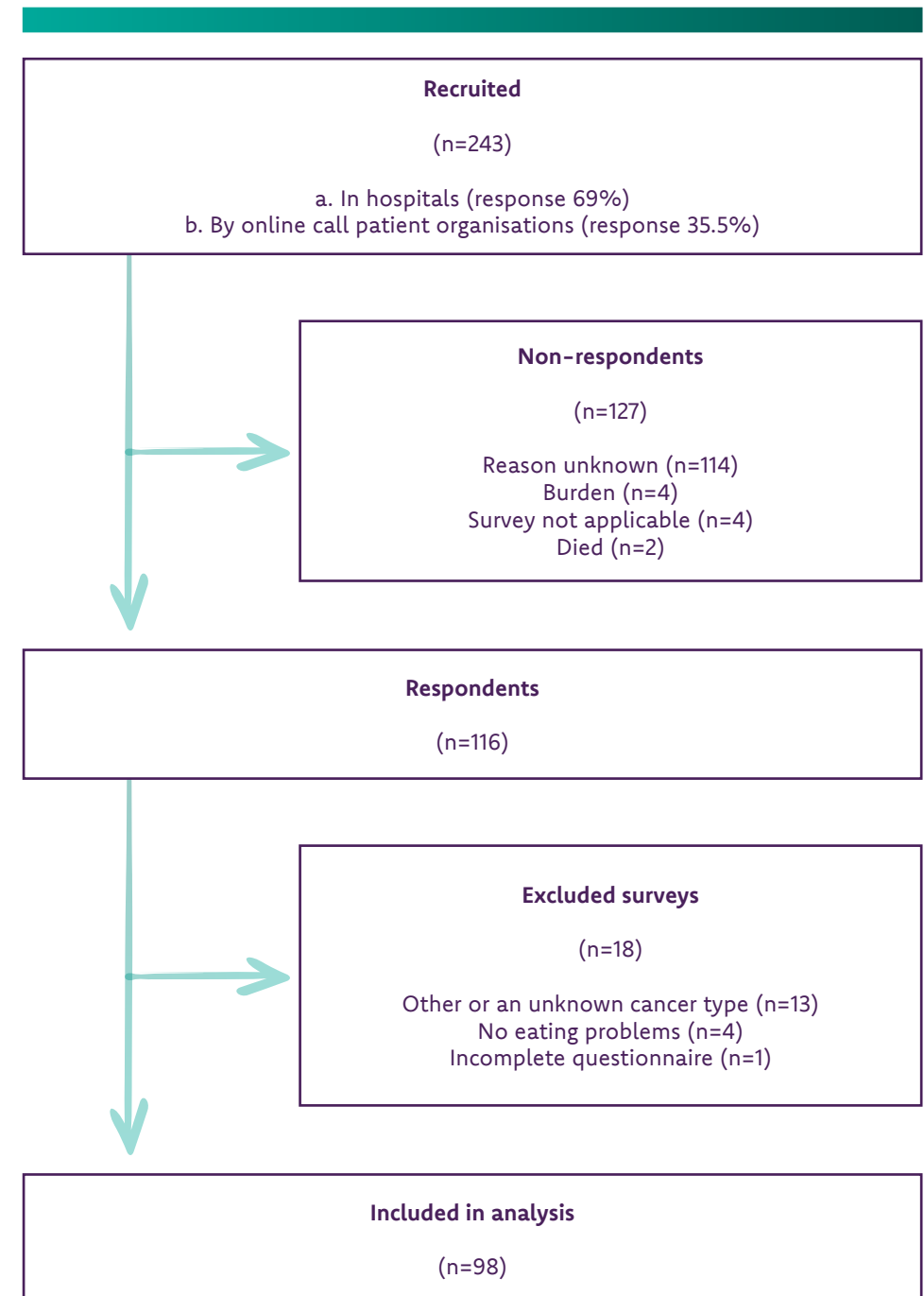


TABLE 1 Patients' sociodemographic and clinical characteristics (n=98)^{†‡}

Characteristics	Number (%)			
	Total Group (n=98)	Head and neck cancer (n=49)	Hodgkin or non-Hodgkin lymphoma (n=18)	Lung cancer (n=31)
Gender				
Male	46 (48%)	28 (57%)	4 (25%)	14 (47%)
Female	49 (52%)	21 (43%)	12 (75%)	16 (53%)
Age (mean, range)	61.7 (24-91)	61.4 (24-91)	60.7 (26-80)	62.2 (43-78)
Level of education [§]				
Low	23 (24%)	10 (20%)	6 (35%)	7 (24%)
Middle	41 (43%)	22 (45%)	6 (35%)	13 (45%)
High	31 (33%)	17 (35%)	5 (29%)	9 (31%)
Living situation				
Living together (with partner/children)	78 (82%)	36 (73.5%)	17 (100%)	25 (86%)
Living alone	17 (18%)	13 (26.5%)	0 (0%)	4 (14%)
Time since diagnosis				
<1 year	48 (51%)	21 (45%)	9 (53%)	18 (60%)
1-5 years	31 (33%)	17 (36%)	3 (18%)	11 (37%)
≥5 years	15 (16%)	9 (19%)	5 (29%)	1 (3%)
Treatment phase				
Currently receiving treatment	57 (60%)	22 (45%)	10 (62.5%)	25 (83%)
Not under treatment	38 (40%)	27 (55%)	6 (37.5%)	5 (17%)
Intention of treatment				
Curative intent	62 (63%)	42 (86%)	12 (67%)	8 (26%)
Palliative	29 (30%)	6 (12%)	2 (11%)	21 (68%)
Unknown	7 (7%)	1 (2%)	4 (22%)	2 (6%)
Treatment type				
Chemotherapy	56 (58%)	20 (41%)	14 (82%)	22 (73%)
Immunotherapy or targeted therapy	18 (18%)	4 (8%)	2 (12%)	12 (40%)
Radiotherapy	60 (62.5%)	47 (96%)	2 (12%)	11 (37%)
Surgery	33 (34%)	29 (59%)	2 (12%)	2 (7%)
Treatment frequency				
No treatment	3 (3%)	2 (4%)	0 (0%)	1 (3%)
1 treatment	32 (33%)	7 (14%)	10 (59%)	15 (50%)
≥ 2 treatments	61 (64%)	40 (82%)	7 (41%)	14 (47%)

Characteristics	Number (%)			
	Total Group (n=98)	Head and neck cancer (n=49)	Hodgkin or non-Hodgkin lymphoma (n=18)	Lung cancer (n=31)
Do you currently experience reduced ability to eat?				
Yes	80	47 (96%)	13 (72%)	20 (64.5%)
No	18	2 (4%)	5 (28%)	11 (35.5%)
Do you expect to eat well or better in the future?				
Yes	69 (71%)	29 (59%)	16 (89%)	24 (80%)
No	28 (29%)	20 (41%)	2 (11%)	6 (20%)
HCPs providing support for emotional consequences of reduced ability to eat (n=44)				
1	11 (25%)	5 (19%)	3 (37.5%)	3 (33%)
>1	33 (75%)	21 (81%)	5 (62.5%)	7 (77%)

[†] Missing: gender 3, age 4, level of education 3, living situation 3, time since diagnosis 4, treatment phase 3, intention of treatment 7, treatment type 4, treatment frequency 2, Do you currently experience reduced ability to eat 0, Do you expect to eat well or better in the future 1

[‡] Percentages do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding

[§] Low educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = pre-university education, high vocational training, university

Most patients had experienced weight loss (60%), 18% of the patients had gained weight and 22% of the patients had stable weight. In total 30% of the patients did not use medical nutrition in the past year. The majority of the patients used oral nutritional supplements, and 34% of the patients used parenteral or tube feeding. Taste and smell changes were the most common nutritional symptoms reported by patients (63%), followed by anorexia and food aversion (51%) and dry mouth (47%). Patients with head and neck cancer more often experienced mucus formation in the mouth (61%) compared with patients with other primary cancer types. Patients with Hodgkin or non-Hodgkin

lymphoma and lung cancer experienced more nausea and/or vomiting (50% and 52%) compared with patients with head and neck cancer (12%) (Table 2.).

TABLE 2 Patients' characteristics concerning nutrition (n=98) †‡

Characteristics	Number (%)			
	Total group (n=98)	Head and neck cancer (n=49)	Hodgkin or non-Hodgkin lymphoma (n=18)	Lung cancer (n=31)
Current nutritional intake				
More than usual	12 (12%)	6 (12%)	2 (12%)	4 (13%)
Less than usual	70 (72%)	39 (80%)	11 (65%)	20 (67%)
Unchanged	14 (14%)	4 (8%)	4 (24%)	6 (20%)
Weight change				
Weigh gain	17 (18%)	8 (17%)	4 (22%)	5 (17%)
Weigh loss	57 (60%)	27 (57%)	10 (56%)	20 (67%)
Unchanged	21 (22%)	12 (26%)	4 (22%)	5 (17%)
Medical nutrition				
Oral nutritional supplements	58 (60%)	36 (73%)	9 (50%)	13 (43%)
Parenteral and tube feeding	33 (34%)	23 (47%)	7 (39%)	3 (10%)
No medical nutrition	29 (30%)	8 (16%)	6 (33%)	15 (50%)
Nutritional impact symptoms				
Taste and smell changes	62 (63%)	32 (65%)	12 (67%)	18 (58%)
Anorexia or food aversion	50 (51%)	20 (41%)	12 (67%)	18 (58%)
Dry mouth	46 (47%)	32 (65%)	7 (39%)	7 (39%)
Mucus formation in mouth	43 (44%)	30 (61%)	5 (28%)	8 (26%)
Obstruction	41 (42%)	22 (45%)	9 (50%)	10 (32%)
Fatigue	38 (39%)	21 (43%)	5 (28%)	12 (39%)
Pain while eating	35 (36%)	22 (45%)	5 (28%)	8 (26%)
Nausea and/or vomiting	31 (32%)	6 (12%)	9 (50%)	16 (52%)
Early satiety	30 (31%)	11 (22%)	9 (50%)	10 (32%)
Emotional problems (i.e. fear)	12 (12%)	9 (18%)	1 (6%)	2 (6%)
Obstipation	11 (11%)	5 (10%)	3 (17%)	3 (10%)
Diarrhoea	10 (10%)	3 (6%)	3 (17%)	4 (13%)
Other symptoms [§]	3 (3%)	1 (2%)	2 (11%)	0 (0%)

† Missing: current nutritional intake 2, weight change 3, medical nutrition 1, nutritional impact symptoms 0

‡ Percentages do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding

§ Social problems (n=1), bloating and flatulence after eating (n=1) pain in stomach (n=1)

Impact of emotional consequences of reduced ability to eat

Most patients (96%) reported one or more emotional consequences of reduced ability to eat, and 4% of the patient population experienced no emotional consequences. The impact of these emotional consequences was high, and emotional consequences with the highest impact scores were disappointment, with a mean impact of 8.31 (standard deviation (SD) 1.49) followed by grief/sadness (7.90; SD 1.91), anger (7.87; SD 1.41), confrontation with the disease (7.53; SD 1.91) and longing for certain foods (7.32; SD 2.12). The most often listed as one of the top three most impactful emotional consequences were: less enjoyment (n=44), longing for certain foods (n=40) and powerlessness (n=27). (Figure 2 and Figure 3).

FIGURE 2 Top three emotional consequences impact score

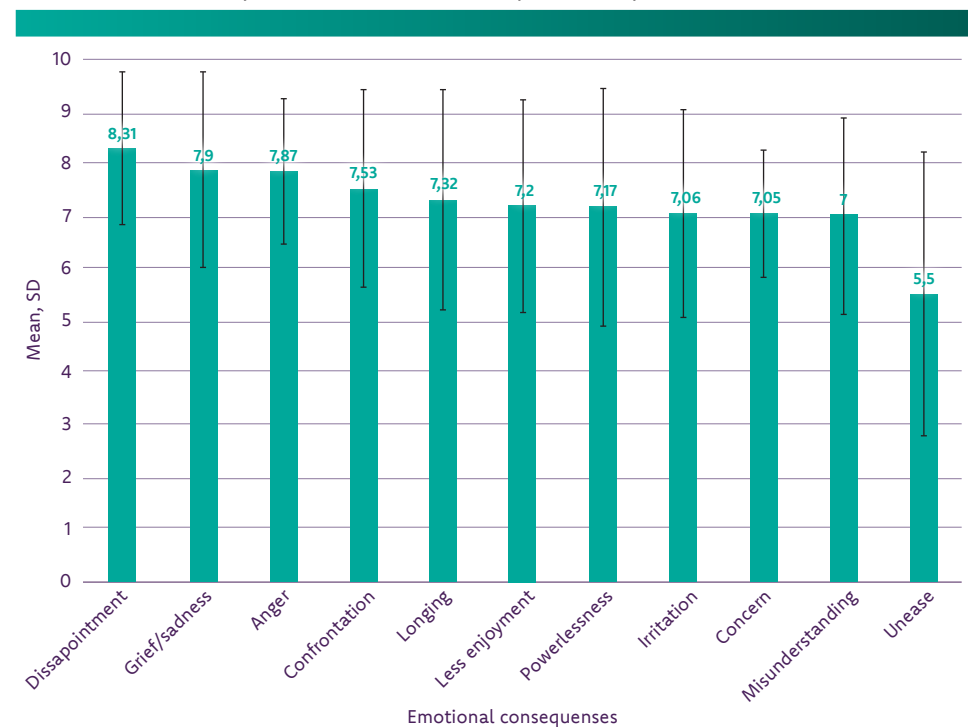
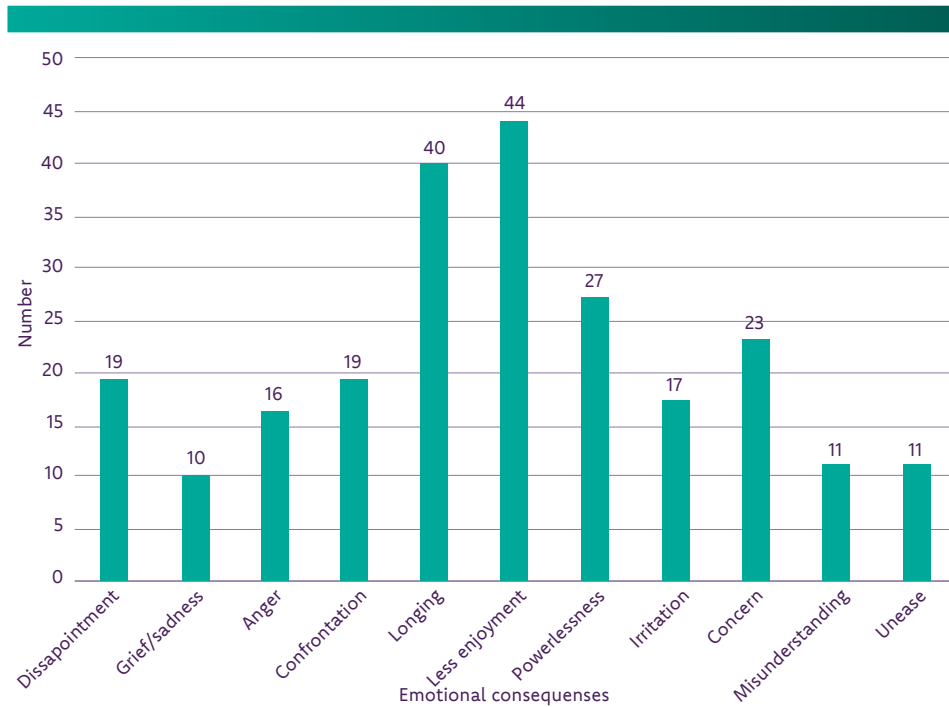


FIGURE 3 Most impactful emotional consequences



Support of HCPs for emotional consequences of reduced ability to eat

Almost half of the patients received support from one or more HCPs for emotional consequences of their reduced ability to eat (45%). The patients who received this support (n=44), received support from a dietitian (89%), physician (36%), nurse (27%), dentist/dental hygienist (25%), psychologist/therapist (23%), general practitioner (20%), and speech therapist (4%). Of the patients who did not receive HCPs support for emotional consequences (45%), 20% (n=9) felt that they needed this support.

Satisfaction of patients with the support of HCPs for reduced ability to eat

Overall, 66% of the patient population was satisfied with the support of HCPs for their reduced ability to eat. Patients who were satisfied did not differ in gender, age, level of education, living situation, primary cancer type, treatment phase, intention of treatment, treatment type, treatment frequency, weight change or medical nutrition when compared with patients who were not satisfied. Patients who received support for the emotional consequences of reduced ability to eat from one HCP (1) and patients who received this support from

more than one HCPs (>1), were equally satisfied. Patients who were diagnosed less than one year ago (<1) experienced higher satisfaction with HCPs support for reduced ability to eat when compared with patients who were diagnosed 1-5 years or ≥5 years ago. Therefore, the more time passed since the patients' diagnosis, the less satisfied they were (<.002). Furthermore, patients who expected to eat well or better in the future were more satisfied with HCPs support for reduced ability to eat than patients who did not expected to eat well or better in the future (p<.001) (Table 3.).

TABLE 3 Patients' characteristics and satisfaction with HCPs support for reduced ability to eat (n=96)* †

Characteristics	'Healthcare professionals support me well regarding my reduced ability to eat'		p-value
	Not satisfied <6 33 (34%)	Satisfied ≥6 63 (66%)	
Gender			
Male	15 (33%)	31 (67%)	.77
Female	17 (35%)	31 (65%)	
Age (mean, range)	61.6 (37-75)	61.16 (24-91)	.86
Level of education [§]			
Low	8 (36%)	14 (64%)	.67
Middle	16 (39%)	25 (61%)	
High	9 (29%)	22 (71%)	
Living situation			
Living together (with partner/children)	26 (33%)	52 (67%)	.43
Living alone	7 (44%)	9 (56%)	
Primary cancer type			
Head and neck	18 (37.5)	30 (62.5%)	.79
Hodgkin or non-Hodgkin lymphoma	6 (33%)	12 (67%)	
Lung	9 (30%)	21 (70%)	
Time since diagnosis			
<1 year	8 (17%)	39 (83%)	<.002
1-5 years	15 (48%)	16 (52%)	
≥5 years	9 (60%)	6 (40%)	
Treatment phase			
Currently receiving treatment	22 (39%)	35 (61%)	.25
Not under treatment	10 (27%)	27 (73%)	

Intention of treatment			
Curative intent	19 (31%)	43 (69%)	
Palliative	13 (46%)	15 (54%)	.15
Treatment type [§]			
Chemotherapy	19 (34%)	37 (66%)	.83
Immunotherapy or targeted therapy	6 (33%)	12 (67%)	.89
Radiotherapy	21 (36%)	38 (64%)	.83
Surgery	13 (41%)	19 (59%)	.39
Treatment frequency			
No treatment	1 (33%)	2 (67%)	
1 treatment	9 (28%)	23 (72%)	
≥ 2 treatments	23 (38%)	37 (62%)	.62
Weight change			
Weight gain	7 (47%)	8 (53%)	
Weight loss	18 (32%)	38 (68%)	
Unchanged	7 (33%)	14 (67%)	.57
Medical nutrition			
Oral nutritional supplements	16 (28%)	41 (72%)	.09
Parenteral and tube feeding	10 (31%)	22 (69%)	.06
No medical nutrition	13 (46%)	5 (54%)	.12
Do you currently experience reduced ability to eat?			
Yes	30 (38%)	48 (62%)	
No	3 (17%)	15 (83%)	0.08
Do you expect to eat well or better in the future?			
Yes	14 (21%)	54 (79%)	
No	19 (70%)	8 (30%)	<.0001
HCPs providing support for emotional consequences of reduced ability to eat (n=44)			
1	1 (9%)	10 (91%)	
>1	9 (27%)	24 (73%)	.21

[†]Missing: gender 2, age 3, level of education 2, living situation 2, primary cancer type 0, time since diagnosis 5, treatment phase 2, intention of treatment 6, treatment type 4, treatment frequency 1, weight change 3, medical nutrition 1, Do you currently experience reduced ability to eat 2, Do you expect to eat well or better in the future 1

[‡]Percentage do not add up to 100% due to the fact that patients could provide more than one answer or due to rounding

[§] Low educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = pre-university education, high vocational training, university

Only the mean impact score of misunderstanding did differ between patients who were satisfied and those who were not satisfied; respectively mean 8.20 and 5.80 ($p=.03$). The mean impact scores of the other emotional consequences did not differ.

DISCUSSION

Our study shows that patients with cancer-related reduced ability to eat experienced high impact of emotional consequences. The most impactful emotional consequences of their reduced ability to eat were disappointment, grief/sadness and anger. The most frequently mentioned emotional consequences were less enjoyment, longing for certain foods and powerlessness. The majority of the patients who received HCPs support for the emotional consequences of reduced ability to eat, received this support from a dietitian (89%). Of the patients who did not receive such support, 20% felt they still needed this support. Most patients (66%) who received support from HCPs for their reduced ability to eat were satisfied with this support. Patients 1–5 years and ≥5 years after diagnosis experienced lower satisfaction with the support of HCPs for reduced ability to eat compared to patients diagnosed <1 year. Therefore, the more time passed since the patients' diagnosis, the less satisfied they were with the support of HCPs (<.002). Furthermore, patients who expected no improvements in their reduced ability to eat in the future were less satisfied with the support of HCPs than patients who expected to recover (<.001).

Previous research shows that patients with advanced cancer and cancer cachexia experienced high levels of distress owing to disease-related eating problems. Amano et al.¹⁹ demonstrate that many advanced cancer patients had eating-related distress, and that patients with cancer cachexia had significantly greater eating-related distress than those without cachexia. Overall, Amano et al. indicate that food and eating is not only related to nutrition and the nutritional intake of patients, but also concerns the emotional and social well-being of patients. Our study underscores this idea and adds to the findings of Amano et al. stating that reduced ability to eat can have high emotional impact, not only among patients receiving palliative treatments, but also among those receiving curative treatment and those whose reduced ability to eat persists in recovery and remission.

This study emphasises the findings of previous research that patient populations in less advanced disease stages might need support regarding reduced ability to eat, which is often left unaddressed by HCPs. Patients with head and neck cancer undergoing radiotherapy expressed that they needed to remain in continuous contact with an HCP who was familiar with the eating challenges

that head and neck cancer and its treatment entail. Patients felt “Left to One’s Own Devices” when the HCPs did not respond to their needs.²⁷ Head and neck cancer patients in the Netherlands, mentioned that emotional support from the general practitioner during aftercare is crucial, because the support from HCPs from the hospital decreased after treatment.³⁴ In this study, 20% of the patients who did not receive support from HCPs for the emotional consequences of reduced ability to eat felt they needed support. Considering the high impact of emotional consequences of reduced ability to eat, also found in this study, it is important to gain more insight into the patients that might need more support from their HCPs regarding these problems. The more time passed since patients diagnosis the less satisfied patients were, and patients who expected no improvement regarding their reduced ability to eat were less satisfied with support of HCPs. These findings can serve as a starting point to improve future support of HCPs and as a starting point for future research.

Strengths and limitations

To the best of our knowledge, this is the first study to assess the impact of emotional consequences of reduced ability to eat and satisfaction with the support of HCPs among patients with cancer throughout the disease trajectory and in recovery and remission. Other studies only touched upon this topic. However, it has not yet been studied comprehensively as a primary research aim.

This study has some limitations that need to be addressed. First, we used a self-developed questionnaire because no validated measures were available. The recruitment of patients through patient organisations and participating

hospitals limits the generalisability of the study results. Recruiting patients through patient organisations might have resulted in a selection bias favouring patients with a relatively good health status.³² The study results show that patients’ satisfaction with HCPs declined after diagnosis, therefore recruitment through patient organisations might have resulted in a selection bias of patients who were less satisfied. Recruiting patients in hospitals can result in more patients who probably received (nutritional) counselling at the time of the survey, and patients who expect their reduced ability to eat to improve. This might have skewed the patient population to a population more satisfied with the support of HCPs. In conclusion, information (recall) bias needs to be considered, as we also asked patients to think back about the support they received in the last year.

Implications for practice and future research

As suggested in the international guidelines¹ nutritional and psychosocial screening are integrated into oncological care in Dutch hospitals. However, screening for the emotional consequences of reduced ability to eat requires more attention. Dietary treatment often ends when nutritional requirements are met and a steady nutritional state is reached. Medical follow-up visits after treatment are mainly focused on the (recovery from) physical side-effects of treatments and screening for residual tumour and cancer recurrence. Further research is needed to determine what patients need from their HCPs regarding follow-up care for their reduced ability to eat. For future care, it is important that HCPs recognise and assess the needs of patients for the emotional support for reduced ability to eat in all stages of the disease and in recovery and remission. The use of screening instruments such as the Distress thermometer and problem list³⁵, can serve as a starting point for early recognition and assessment of emotional consequences of reduced ability to eat throughout the care process.

In conclusion, most patients with cancer reduced ability to eat due to their cancer and its treatment experience a broad range of emotional consequences, including disappointment, grief/sadness and anger. Moreover, the impact of these emotional consequences was high. The more time passed since the patients’ diagnosis, the less satisfied they were with the support of HCPs for reduced ability to eat. Additionally, patients who expect no improvements in their reduced ability to eat in the future are less satisfied with the support of HCPs. Clearly, more attention and support from HCPs for the emotional consequences of reduced ability to eat, its emotional impact and need for supportive care for these problems are needed. To improve future care, early recognition and assessment of the emotional consequences of reduced ability to eat by HCPs are important, both during and (long) after treatment.



REFERENCES

1. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2016;36(1):11-48.
2. Baracos V, Martin L, Korc M, Guttridge D, Fearon K. Cancer-associated cachexia. *Nat Rev Dis Primers* 2018;4:17105.
3. Crowder S, Douglas K, Yanina Pepino M, Sarma K, Arthur A. Nutrition impact symptoms and associated outcomes in post-chemoradiotherapy head and neck cancer survivors: a systematic review. *Journal of Cancer Survivorship* 2018;12(4):479-94.
4. Lin T, Yang J, Hong X, Yang Z, Ge T, Wang M. Nutritional status in patients with advanced lung cancer undergoing chemotherapy: a prospective observational study. *Nutr Cancer* 2020;72(7):1225-30.
5. Lize N, Raijmakers N, van Lieshout R, Youssef-El Soud M, van Limpt A, van der Linden M, et al. Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study. *European Journal of Oncology Nursing* 2020.
6. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *Journal of Human Nutrition and Dietetics* 2000;13(2):113-7.
7. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage* 2006;31(4):293-305.
8. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs* 2006;54(3):304-12.
9. Hopkinson J. How people with advanced cancer manage changing eating habits. *J Adv Nurs* 2007;59(5):454-62.
10. Shragge J, Wismer W, Olson K, Baracos V. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med* 2007;21(3):227-33.
11. Strasser F, Binswanger J, Cerny T, Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat Med* 2007;21(2):129-37.
12. Hinsley R, Hughes R. 'The reflections you get': an exploration of body image and cachexia. *Int J Palliat Nurs* 2007;13(2):84-9.
13. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;36(4):439-45.
14. Reid J, McKenna H, Fitzsimons D, McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud* 2009;46(5):606-16.
15. Holden C. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. *Hosp J* 1991;7(3):73-84.
16. Reid J, McKenna H, Fitzsimons D, McCance T. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer Care (Engl)* 2010;19(5):682-9.
17. Souter J. Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences. *Int J Palliat Nurs* 2005;11(10):524-32.
18. Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Supportive Care in Cancer* 2018;27(8):2869-76.
19. Amano K, Baracos V, Hopkinson J. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Critical Reviews in Oncology/Hematology* 2019;143:117-23.
20. Amano K, Maeda I, Morita T, Okajima Y, Hama T, Aoyama M, et al. Eating-related distress and need for nutritional support of families of advanced cancer patients: a nationwide survey of bereaved family members. *J Cachexia Sarcopenia Muscle* 2016;7(5):527-34.
21. Amano K, Maeda I, Morita T, Tatara R, Katayama H, Uno T, et al. Need for nutritional support, eating-related distress and experience of terminally ill patients with cancer: a survey in an inpatient hospice. *BMJ supportive & palliative care* 2016;6(3):373-6.
22. Amano K, Morita T. Palliative Care and Nutritional Support for Eating-related Distress in Patients with Advanced Cancer and Their Family Members. *Palliative Care Research* 2018;13(2):169-74.
23. Larsson M, Hedelin B, Athlin E. A supportive nursing care clinic: conceptions of patients with head and neck cancer. *Eur J Oncol Nurs* 2007;11(1):49-59.
24. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
25. Orrevall Y, Tishelman C, Herrington M, 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. *Clinical Nutrition* 2004;23(6):1280-7.
26. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 2013;22(7-8):1034-43.



27. Larsson M, Hedelin B, Athlin E. Needing a hand to hold: lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs* 2007;30(4):324-34.
28. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
29. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2014;6(3):307-14.
30. Millar C, Reid J, Porter S. Refractory cachexia and truth-telling about terminal prognosis: a qualitative study. *Eur J Cancer Care (Engl)* 2013;22(3):326-33.
31. Millar C, Reid J, Porter S. Healthcare professionals' response to cachexia in advanced cancer: a qualitative study. *Oncol Nurs Forum* 2013;40(6):E393-402.
32. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. *Journal of medical Internet research* 2002;4(2):e13.
33. Moll van Charante E, Giesen P, Mookink H, Oort F, Grol R, Klazinga N, et al. Patient satisfaction with large-scale out-of-hours primary health care in The Netherlands: development of a postal questionnaire. *Fam Pract* 2006;23(4):437-43.
34. van Overveld L, Takes R, Turan A, Braspenning J, Smeele L, Merckx M, et al. Needs and preferences of patients with head and neck cancer in integrated care. 2018:553-61.
35. Tuinman M, Gazendam-Donofrio S, Hoekstra-Weebers J. Screening and referral for psychosocial distress in oncologic practice: use of the Distress Thermometer. *Cancer* 2008;113(4):870-8.





PART 2

To gain insights into the provided psychosocial support for a reduced ability to eat

“When everyone offers food, no matter how well they mean it, I just didn’t have the energy to turn that food down. Sometimes people get so insistent and they keep on offering food. I would say, it’s better to just be there, just sit at the bedside. Yes, at some point you are so sick then everything is nagging, I don’t know how to explain how I felt at those moments”

“Yes it was very difficult, eating was really a struggle for the both of us. I still wanted to help her but I didn’t know how. I asked friends if they had any ideas about eating. Or I looked on the Internet, spending whole evenings scrolling in bed to see if I could find any ideas to get my mother to eat something, anything. What liquid food is there that is also tasty? Often she would not eat it. That really bothered me because I tried so hard to help her.”



CHAPTER 5

Are gastrointestinal problems, nutritional care and nutritional care needs associated with quality of life in patients with advanced cancer? Results of the observational eQuiPe study

Paschos S, Lize N, Eussen S, van der Padt-Pruijsten A, van den Beuken-van Everdingen M, van Laarhoven H, den Boer M, de Graeff A, van den Borne B, ten Have H, Kennis M, Beijer S, Raijmakers N, van de Poll-Franse L

ABSTRACT

PURPOSE To assess the association of gastrointestinal problems, received nutritional care and nutritional care needs with quality of life (QoL) in patients with advanced cancer.

METHODS A cross-sectional analysis within the observational prospective eQuiPe cohort study on experienced quality of care and QoL in patients with advanced cancer was performed. QoL and gastrointestinal problems were measured using the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-C30. Received nutritional care (yes/no) and nutritional care needs (yes/a little bit/no) were measured by two questions. Gastrointestinal problems were categorized as clinically important based on the Giesinger thresholds. Univariable and multivariable linear regression analyses adjusted for age, gender and treatment were used to analyze the association of gastrointestinal problems, received nutritional care and nutritional care needs with QoL.

RESULTS Half of the 1080 patients with advanced cancer had clinically important gastrointestinal problems, 17% experienced nutritional care needs and 14% received nutritional care. Multivariable analyses revealed that the presence of clinically important gastrointestinal problems ($\beta(95\%CI):-13.0 (-15.6;-10.4)$), received nutritional care ($\beta(95\%CI):-5.1(-8.5;-1.7)$) and nutritional care needs ($\beta(95\%CI):-8.7 (-11.9;-5.5)$) were associated with a low QoL.

CONCLUSION Many patients with advanced cancer experience gastrointestinal problems, while only few patients receive nutritional care. These gastrointestinal problems, nutritional care needs and nutritional care are associated with lower QoL, probably due to reversed causality or the irreversible nature of these problems in the palliative phase. More research on the relation of nutritional care, gastrointestinal problems and QoL is needed to optimize nutritional support in end-of-life care.



INTRODUCTION

In 2020, over 19 million new cases of cancer were diagnosed worldwide.¹ Cancer is still a leading cause of death, accounting for approximately 10 million deaths per year.¹ In the Netherlands, the estimated number of new cancer diagnoses is 115,000 per year² and 21,000 persons with a solid cancer diagnosis already have distant metastases at diagnosis. In addition, there are over 38,000 patients annually who develop distant metastases, and require palliative care.³ Studies have shown that early palliative care improves quality of life (QoL) in patients with advanced cancer.⁴ In the course of progression of disease, this care gradually moves from a disease-oriented perspective to a more symptom-oriented treatment only.⁵

Patients with advanced cancer often suffer from disease- and treatment-related gastrointestinal problems. The most common gastrointestinal symptoms are appetite loss (53%), dry mouth (40%), constipation (34%) and nausea (31%).⁶ Literature shows that these gastrointestinal problems are all associated with lower QoL.^{7,8} From the gastrointestinal problems, appetite loss was most predictive of overall QoL.⁷ Due to the high prevalence of gastrointestinal symptoms and weight loss in patients with advanced cancer, nutritional care needs might be high. In line with this, Amano et al.⁹ showed that 76% of terminally ill patients had general unmet needs for nutrition therapy for cancer cachexia, and 61% indicated that they needed specific support by health care professionals such as attention and explanation concerning their distress about eating. The role of dietitians in palliative oncology care is important. Dietitians can have a positive impact through nutritional evaluation, counseling, psychosocial support, follow-up and nutritional interventions.¹⁰ When the focus of palliative care is still on disease-modifying treatment, dietitians contribute to the identification of malnutrition, the treatment of weight loss and diminishing gastrointestinal problems, which may improve QoL.¹¹ However, when palliative care shifts from disease-modifying treatment towards the alleviation of symptom burden only, also the role of nutritional care will change in enhancing patient comfort and quality of life.

Few studies have investigated the association between nutritional care needs and nutritional care with QoL in patients with advanced cancer. A review showed that gaps in the availability or access to nutrition care is a major source of distress for patients and family members.¹¹ However, only preliminary studies have shown that nutritional support may be associated with beneficial effects, i.e., prevented bedsores, improved performance status in the very advanced cancer patients^{12,13} but have not specifically looked at QoL. Therefore, the aim of this study was to investigate the association of gastrointestinal problems, received nutritional care and nutritional care needs with QoL in patients with advanced cancer.

METHODS

Study design

A secondary analysis was conducted, using the baseline data of the observational prospective eQuiPe cohort study on the experienced quality of care and QoL in patients with advanced cancer and their relatives.¹⁴ Patients were identified and recruited in the departments of medical oncology, pulmonology or urology of more than 40 hospitals in the Netherlands. Participants in this analysis were recruited between November 2017 and January 2020, and completed questionnaires using the Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry. PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of people confronted with cancer.¹⁵ The eQuiPe study was exempted from full medical ethical review according to the Dutch Medical Research Involving Human Subjects Act (WMO), declared by the Medical Research Ethics Committee of the Antoni van Leeuwenhoek hospital (METC17.1491). Informed consent was obtained from all participants.

Participants

All adult patients with advanced cancer were eligible. Advanced cancer was defined as the presence of a solid metastasized tumor, including both synchronous (at diagnose) and metachronous distant metastases without possibilities for cure.¹⁴ Additional criteria for patients with breast cancer were the presence of metastases in multiple organ systems. For patients with metastasized prostate cancer, the tumor had to be castrate-resistant. Patients also had to be able to complete Dutch questionnaires.

Measures

Quality of Life

Quality of life (QoL) was assessed using the validated European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 items (EORTC-QLQ-C30) questionnaire.¹⁶ The subscale global QoL was used, consisting of the two following items: “How would you rate your overall health during the past week?” and “How would you rate your overall quality of life during the past week?” with answer options ranging from 1 (very poor) to 7 (excellent). The presence of gastrointestinal problems was derived from the following items and scales of the EORTC-QLQ-C30: appetite loss, constipation, diarrhea and nausea/vomiting. The mean scores of the subscales of nausea and

vomiting and global QoL and the item-scores were linearly transformed to a 0-100 scale, with a higher score implying a higher level of symptoms or a higher global quality of life, respectively.

Based on the thresholds for clinical importance of Giesinger et al.¹⁷ for each symptom (score above 8 for nausea/vomiting, above 17 for diarrhea and above 50 for appetite loss and constipation), patients were categorized into three categories: “No gastrointestinal problems present” (all scores were 0), “Non-clinically important gastrointestinal problems present” (no score higher than the thresholds, but at least one symptom was present) and “Clinically important gastrointestinal problems present” (at least one score higher than the thresholds). Clinical importance of each symptom was rated by cancer patients with mixed tumor types and treatments based on concerned limitations in daily life, need for help/care, and worries of the patient and his/her partner/family.

Nutritional care and care needs

Nutritional care by a dietician was assessed as a binary variable (yes/no). Nutritional care was present when patients answered positively to the question “Have you consulted a dietician in the last month?”. Information regarding nutritional care needs was added to the Problems and Needs in Palliative Care short version questionnaire (PNPC-sv).¹⁸ It was defined as “insufficient information regarding nutrition”. Patients were asked whether this was a problem for them, with the response options “yes”, “a little bit” and “no”. The responses “yes” and “a little bit” were combined, resulting in a binary variable. The total questionnaire, including the questions regarding nutritional care and care needs, was tested using the “think-aloud” method and yielded good results in terms of comprehensiveness and appropriateness (face validity).¹⁴

Sociodemographic and clinical characteristics

Sociodemographic and clinical characteristics were available from the Netherlands Cancer Registry (NCR) and from self-administrated questionnaires. Particularly, level of education (categorical) was reported as low (no education or primary school), intermediate (lower general secondary education, vocational training or equivalent) or high (pre-university education, high vocational training, university) and relationship status (binary) as having a partner or not. Socio-demographic variables included age and sex. Patients were also asked to report whether they had received any treatment in the last month. If they answered yes, they could tick radiotherapy, chemotherapy, surgery, targeted therapy, immunotherapy or a combination of these treatments.

Statistical methods

Descriptive statistics and univariable linear regression analyses were conducted with gastrointestinal problems, received nutritional care and nutritional care needs as separate independent variables, and QoL as dependent variable. Dummy variables were used for the categorical variable regarding gastrointestinal problems with the category “No gastrointestinal problems” being the reference category. Next, a multivariable linear regression model was fitted combining the previously mentioned variables and adjusting for age, sex and treatment, which were selected a priori as confounders. All statistical analyses were performed using STATA version 16 (StataCorp, College Station, Texas 77845 USA). P-values <0.05 were considered statistically significant.

RESULTS

In total, 1695 eligible patients with advanced cancer were invited to participate by phone, 1440 (85%) were enrolled in the study, and 1103 (65%) patients completed the baseline questionnaire. Due to missing data on the global QoL scale, 23 patients had to be excluded, leaving 1080 patients for further analysis. The mean age of participants was 65 years (SD 9,8), 51% was male and 74% had received anti-tumor treatment during the past month (Table 1).



FIGURE 1 Flow Diagram Respondents

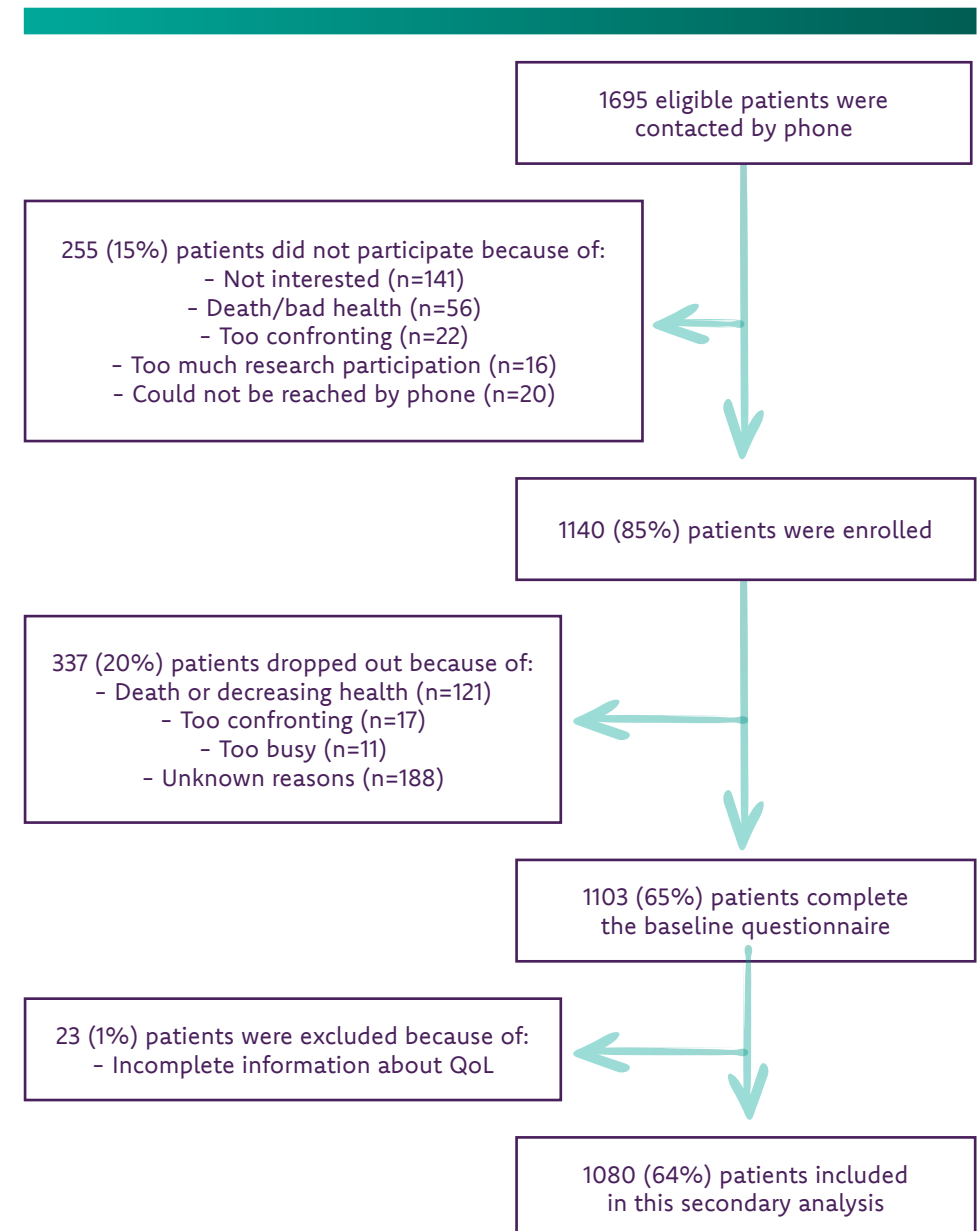


TABLE 1 Socio-demographic and clinical characteristics of patients with advanced cancer, by having gastrointestinal problems (n=1,080)

	Total study population N=1080	Clinically important gastrointestinal problems N=536	Non clinically important gastrointestinal problems N=167	No gastrointestinal problems N=366
	Mean ± SD or number (%)	Mean ± SD or number (%)	Mean ± SD or number (%)	Mean ± SD or number (%)
Age ^a , (years)	65.2 ± 9.8	65.0 ± 9.7	64.5 ± 10.3	65.6 ± 9.8
Sex				
Male	552 (51%)	272 (51%)	78 (47%)	194 (53%)
Relationship status ^b				
Having a partner	895 (83%)	436 (81%)	134 (81%)	315 (86%)
Single	184 (17%)	100 (19%)	32 (19%)	51 (14%)
Education level ^c				
Low	320 (30%)	184 (35%)	48 (29%)	84 (23%)
Medium	441 (41%)	209 (40%)	63 (38%)	164 (45%)
High	309 (29%)	136 (26%)	55 (33%)	116 (32%)
Tumor type ^d				
Lung	314 (29%)	150 (28%)	47 (29%)	114 (32%)
Breast	150 (14%)	72 (14%)	35 (21%)	57 (16%)
Colorectal	197 (18%)	108 (20%)	35 (21%)	50 (14%)
Prostate	127 (12%)	54 (10%)	18 (11%)	52 (14%)
Other	278 (26%)	149 (28%)	28 (18%)	86 (24%)
Treatment in the last month ^e				
No	60 (6%)	25 (7%)	10 (6%)	23(4%)
Yes	1016 (94%)	339 (93%)	157 (94%)	511 (96%)
Radiotherapy	141 (13%)	72 (13%)	25 (15%)	44 (12%)
Chemotherapy	650 (61%)	173 (47%)	107 (64%)	370 (69%)
Surgery	36 (3%)	26 (5%)	2 (1%)	8 (2%)
Immunotherapy	297 (26%)	137 (10%)	47 (28%)	113 (31%)
Other	205 (19%)	92 (17%)	28 (17%)	85 (23%)
Gastrointestinal symptoms and quality of life				
Nausea/vomiting	9.4 ± 18	19 ± 21	0	0
Appetite loss	19 ± 27	32 ± 31	17 ± 17	0
Constipation	13 ± 23	20 ± 28	21 ± 16	0
Diarrhea	12 ± 23	25 ± 28	0	0

	Total study population N=1080	Clinically important gastrointestinal problems N=536	Non clinically important gastrointestinal problems N=167	No gastrointestinal problems N=366
	Mean ± SD or number (%)	Mean ± SD or number (%)	Mean ± SD or number (%)	Mean ± SD or number (%)
Global quality of life	68 ± 20	62 ± 20	69 ± 19	76 ± 17
Received nutritional care ^{f*}				
Yes	142 (14%)	92 (19%)	21 (14%)	25 (8%)
Nutritional care needs ^{g*}				
Yes	67 (6%)	48 (9%)	10 (6%)	8 (2%)
A little bit	109 (10%)	60 (12%)	15 (9%)	32 (10%)
No	869 (83%)	413 (79%)	137 (85%)	314 (89%)

SD: Standard Deviation, Missing values: a:3, b:1, c:10, d:14, e:4, f:79, g:35.

Variables may deviate from 100% due to rounding off. Received nutritional care and nutritional care needs were tested using Chi2, * p<0,05

Gastrointestinal problems, nutritional care and nutritional care needs

Half of all patients had at least one clinically important gastrointestinal problem (nausea/vomiting, loss of appetite, constipation or diarrhea) whereas 16% reported ≥1 non-clinically important gastrointestinal problems, and 34% reported no gastrointestinal problems. The mean scores were 9,4 (SD 18) for nausea/vomiting, 19 (SD 27) for appetite loss, 13 (SD 23) for constipation and 12 (SD 23) for diarrhea.

Fourteen percent of all patients had received nutritional care by a dietician during the past month. Patients with clinically important gastrointestinal problems more often received nutritional care compared to patients with no clinically important problems or with no gastrointestinal problems at all, respectively 19%, 14% and 8% (p<0,05) (Table 1). Of all patients, 176 patients (17%) had nutritional care needs. The nutritional care needs were similar in patients receiving nutritional care compared to patients receiving no nutritional care. Patients with clinically important gastrointestinal problems more often had (some) nutritional care needs compared to patients with no clinically important problems or with no gastrointestinal problems at all, respectively 21%, 16% and 12% (p<0,05).

Association between gastrointestinal problems, nutritional care and nutritional care needs with QoL

Quality of life was lower in patients with clinically important gastrointestinal problems compared to non-clinically relevant or no gastrointestinal problems, respectively 61.9(SD 20), 69.4 (SD 19.1) and 76 (SD 17.2). Of the four questions on gastrointestinal problems of the EORTC-QLQ-C30, appetite loss had the highest association with lower QoL (Table 2).

TABLE 2 Associations of gastrointestinal problems, nutritional care and nutritional care needs with QoL

Global QoL	Univariable Model			Unadjusted multivariable model ^b			Adjusted multivariable model ^c		
	β	Lower bound 95% CI	Upper bound 95% CI	β	Lower bound 95% CI	Upper bound 95% CI	β	Lower bound 95% CI	Upper bound 95% CI
Nausea/vomiting									
Clinically important	12.1	-14.6	-9.7						
Non-clinically important	-	-	-						
Appetite loss									
Clinically important	-22.8	-26.1	-19.6						
Non-clinically important	-10.9	-13.5	-8.3						
Constipation									
Clinically important	-10.2	-14.8	-5.6						
Non-clinically important	-5.9	-8.7	-3.04						
Diarrhea									
Clinically important	-8.6	-11.2	-5.9						
Non-clinically important	-	-	-						
Gastrointestinal problems ^a									
Clinically important	-14.1	-16.6	-11.5	-12.9	-15.5	-10.3	-12.9	-15.5	-10.3
Non-clinically important	-6.6	-10.1	-3.1	-6.4	-10.0	-2.8	-6.5	-10.1	-2.9
Received nutritional care	-7.3	-10.9	-3.8	-5.1	-8.5	-1.7	-5.1	-8.5	-1.7
Nutritional care needs	-10.1	-13.3	-6.9	-8.6	-11.7	-5.4	-8.7	-11.9	-5.5

^a No gastrointestinal problems was set as the reference category,

^b Multivariable regression model including gastrointestinal problems, received nutritional care and nutritional care needs (no collinearity was present),

^c Multivariable regression model including gastrointestinal problems, received nutritional care and nutritional care needs, adjusted for age, sex and treatment yes/no (no collinearity was present). CI: Confidence Interval

Nutritional care needs and receiving nutritional care were also associated with lower QoL. Age, sex and treatment adjusted multivariable linear regression analysis showed that having clinically important gastrointestinal problems ($\beta = -12.9$ (95%CI (-15.5 to -10.3)), receiving nutritional care ($\beta = -5.1$ (95%CI (-8.5 to -1.7)) and having nutritional care needs ($\beta = -8.7$ (95%CI (-11.9 to -5.5)) were independently associated with a lower QoL. This also holds for non-clinically important gastrointestinal problems, although the association was less strong (Table 2). No collinearity was present in the model (VIF for all variables was <10).

Discussion

This study showed that almost 50% of patients with advanced cancer had clinically important gastrointestinal problems, while only 14% received nutritional care. Having clinically important or non-clinically important gastrointestinal problems, nutritional care needs and received nutritional care were independently associated with a lower QoL.

To the best of our knowledge, there are no studies investigating the combined associations of gastrointestinal problems, received nutritional care and nutritional care needs with QoL in patients with advanced cancer. Only studies investigating the univariable association between gastrointestinal problems or nutritional care needs and QoL were found.^{7,8,19} Studies investigating the association between gastrointestinal problems and QoL in advanced cancer showed that appetite loss, nausea, vomiting and constipation were significantly associated with a lower QoL.^{7,8,19} Compared to our results, the severity of these gastrointestinal problems (mean scores ranging from 7-14 for nausea and vomiting,²³⁻⁴³ for appetite loss,¹³⁻³² for constipation and⁶⁻¹⁹ for diarrhea) were in line for nausea/vomiting and diarrhea but higher for appetite loss and constipation then in our study.²⁰⁻²³ Moreover, QoL was also lower when appetite loss and nausea/vomiting occurred concurrently, compared to patients unaffected by these symptoms.^{24, 25}

In our study, nutritional care needs were also associated with lower QoL which is in line with the results of 18 qualitative studies described in the review of Wheelwright et al.²⁶ A study in patients with advanced cancer showed that these patients often seek information regarding nutrition hoping to restore their QoL.²⁷ Moreover, a study performed in cancer patients undergoing chemotherapy further affirm our findings²⁸ showing a lower QoL in patients needing nutritional counselling compared to patients who did not need it.

Only preliminary studies have shown that nutritional support may be associated with beneficial effects, i.e., prevented bedsores¹², improved performance status¹³ in the very advanced cancer patients but these studies have not specifically looked at QoL. The intervention consisted of providing individualized and tailored nutritional support to meet or exceed the energy and protein re-

quirements. Besides nutritional advice to improve nutritional intake, dietitians may also play an important role in supporting psychosocial consequences of nutritional problems of patients and their informal caregivers especially when emotions lead to conflicts in the patient-informal caregiver relationship. In a pilot randomized controlled trial²⁹, advanced cancer patients and family caregivers were randomized either to receive 2–3 h of direct dietitian contact time over a 4–6-week period, or to the control group receiving only usual care. During the intervention, issues with nutrition impact symptoms and food or eating-related psychosocial concerns were addressed through nutrition counselling, with a focus on improving nutrition-related communication between the dyads. Results showed improvement in quality of life, eating-related distress and eating-related enjoyment in a subgroup of patients. However, these preliminary results should be interpreted with caution because compliance in this pilot study was poor; of the 89 eligible patients, 42 were randomized and only 20 finished the 5-week assessment.

Although in our study we found that nutritional care was associated with lower QoL, we think this may be explained by reverse causality: Patients with more and more severe gastrointestinal symptoms (and associated lower QoL) are more often referred to a dietitian. This reverse causation is also present with the other healthcare professionals, in other words patients receiving care of other healthcare professionals have a lower QoL than patients who did not receive care (data not shown).



The present work covers a novel topic of research showing that gastrointestinal problems (both severe and less severe) and nutritional care needs are independently associated with lower QoL. These findings highlight the importance of addressing gastrointestinal problems as a standard part of daily care for advanced cancer patients in order to optimize symptom management probably by a combination of nutritional care, pharmacological and psychosocial interventions.

Some limitations of this study need to be addressed. First, due to the cross-sectional character of the study, this study cannot investigate causality. It is possible that the observed associations of gastrointestinal problems, lack of nutritional care and nutritional care needs with QoL might be bidirectional. Second, selection bias might exist. It is well-known that patients with a low QoL are less likely to participate in a study³⁰, resulting in a study population with a relatively high QoL compared to the source population. This type of bias could have led to an underestimation of the associations. Third, some residual confounding is to be expected. Studies show that weight loss, physical function, physical activity and systemic inflammatory response in patients with advanced cancer may have an effect on QoL and be associated with gastrointestinal problems.^{31, 32} Unfortunately, no information about these factors was available.

Future research should further investigate the relationship between gastrointestinal problems, nutritional care and nutritional care needs with QoL in a longitudinal setting, including all relevant information. Next, specifically the effect of symptom management strategies for gastrointestinal problems such as nutritional care (e.g. diet modifications), but also pharmacological and psychosocial interventions for nutritional issues, should be investigated in prospective randomized trials, as these problems are of paramount importance for the QoL of patients with advanced cancer.

Conclusion

More than half of all patients with advanced cancer experience gastrointestinal problems, while only few patients receive nutritional care. These gastrointestinal problems, nutritional care needs and received nutritional care are associated with lower quality of life. More prospective cohort studies and randomized studies are needed to clarify the role of nutritional counselling on gastro-intestinal problems, psychosocial well-being and QoL in patients with incurable cancer.

DECLARATIONS

FUNDING The eQuiPe study is funded by the Roparun Foundation.

DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST The authors have no conflicts of interest to declare that are relevant to the content of this article.

ETHICAL APPROVAL This study was performed in line with the principles of the Declaration of Helsinki. The study was reviewed by the Medical Research Ethics Committee of the Antoni van Leeuwenhoek hospital in the Netherlands (METC17.1491).

CONSENT TO PARTICIPATE Written informed consent was obtained from all individual participants included in the study.

CONSENT FOR PUBLICATION Written informed consent was obtained from all individual participants included in the study.

AVAILABILITY OF DATA AND MATERIAL (DATA TRANSPARENCY) Since 2011, PROFILES registry data is freely available according to the FAIR (Findable, Accessible, Interoperable, Reusable) data principles for non-commercial (international) scientific research, subject only to privacy and confidentiality restrictions. The datasets analyzed during the current study are available through Questacy (DDI 3.x XML) and can be accessed by our website (www.profilesregistry.nl). In order to arrange optimal long-term data warehousing and dissemination, we follow the quality guidelines that are formulated in the ‘Data Seal of Approval’ (www.datasealofapproval.org) document, developed by Data Archiving and Networked Services (DANS). The data reported in this manuscript will be made available when the eQuiPe study is completed.

AUTHORS’ CONTRIBUTIONS SP, NL, SE, SB, LP and NR were involved in the study design. SP drafted the manuscript and performed the statistical analysis. All authors reviewed the manuscript and gave final approval of the manuscript.

ACKNOWLEDGEMENT We thank all patients for their time and effort in participating in our study while being in an uncertain situation. We also want to thank the participating hospitals for recruiting and informing patients and relatives about the eQuiPe study.

REFERENCES

1. Cancer today. <http://gco.iarc.fr/today/home>. Accessed 10 Feb 2021
2. IKNL, Incidence, Number. Available from: <https://iknl.nl/nkr-cijfers> [Accessed 2021 Mar 15]
3. Franssen H., Advanced Cancer in Numbers “Uitgezaaide kanker in beeld”. Utrecht: IKNL; 2020
4. Haun MW, Estel S, Rücker G, et al (2017) Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev* 6:CD011129. <https://doi.org/10.1002/14651858.CD011129.pub2>
5. Kaasa S, Loge JH, Aapro M, et al (2018) Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol* 19:e588–e653. [https://doi.org/10.1016/S1470-2045\(18\)30415-7](https://doi.org/10.1016/S1470-2045(18)30415-7)
6. Teunissen SCCM, Wesker W, Kruitwagen C, et al (2007) Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 34:94–104. <https://doi.org/10.1016/j.jpainsymman.2006.10.015>
7. Cramarossa G, Chow E, Zhang L, et al (2013) Predictive factors for overall quality of life in patients with advanced cancer. *Support Care Cancer Off J Multinat Assoc Support Care Cancer* 21:1709–1716. <https://doi.org/10.1007/s00520-013-1717-7>
8. van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, et al (2009) Quality of life and non-pain symptoms in patients with cancer. *J Pain Symptom Manage* 38:216–233. <https://doi.org/10.1016/j.jpainsymman.2008.08.014>
9. Amano K, Maeda I, Morita T, et al (2016) Need for nutritional support, eating-related distress and experience of terminally ill patients with cancer: a survey in an inpatient hospice. *BMJ Support Palliat Care* 6:373–376. <https://doi.org/10.1136/bmjspcare-2014-000783>
10. Tchekmedyian NS, Zahyna D, Halpert C, Heber D (1992) Clinical aspects of nutrition in advanced cancer. *Oncology* 49 Suppl 2:3–7. <https://doi.org/10.1159/000227118>
11. Amano K, Baracos VE, Hopkinson JB (2019) Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Crit Rev Oncol Hematol* 143:117–123. <https://doi.org/10.1016/j.critrevonc.2019.08.006>
12. Amano K, Morita T, Baba M, et al (2013) Effect of nutritional support on terminally ill patients with cancer in a palliative care unit. *Am J Hosp Palliat Care* 30:730–733. <https://doi.org/10.1177/1049909112469273>
13. Amano K, Maeda I, Ishiki H, et al (2016) A Feasibility Study to Investigate the Effect of Nutritional Support for Advanced Cancer Patients in an Inpatient Hospice in Japan. *Palliat Med Hosp Care - Open J* 2:37–45
14. van Roij J, Zijlstra M, Ham L, et al (2020) Prospective cohort study of patients with advanced cancer and their relatives on the experienced quality of care and life (eQuiPe study): a study protocol. *BMC Palliat Care* 19:139. <https://doi.org/10.1186/s12904-020-00642-w>

15. van de Poll-Franse LV, Horevoorts N, van Eenbergen M, et al (2011) The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer Oxf Engl* 1990 47:2188–2194. <https://doi.org/10.1016/j.ejca.2011.04.034>
16. Aaronson NK, Ahmedzai S, Bergman B, et al (1993) The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 85:365–376. <https://doi.org/10.1093/jnci/85.5.365>
17. Giesinger JM, Loth FLC, Aaronson NK, et al (2020) Thresholds for clinical importance were established to improve interpretation of the EORTC QLQ-C30 in clinical practice and research. *J Clin Epidemiol* 118:1–8. <https://doi.org/10.1016/j.jclinepi.2019.10.003>
18. Osse BHP, Vernooij MJFJ, Schadé E, Grol RPTM (2004) Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. *J Pain Symptom Manage* 28:329–341. <https://doi.org/10.1016/j.jpainsymman.2004.01.010>
19. Cramarossa G, Zeng L, Zhang L, et al (2014) Predictive factors of overall quality of life in advanced cancer patients using EORTC QLQ-C30. *Expert Rev Pharmacoecon Outcomes Res* 14:139–146. <https://doi.org/10.1586/14737167.2014.864560>
20. Augustussen M, Pedersen ML, Hounsgaard L, et al (2018) Development of health-related quality of life and symptoms in patients with advanced cancer in Greenland. *Eur J Cancer Care (Engl)* 27:e12843. <https://doi.org/10.1111/ecc.12843>
21. Iwase S, Kawaguchi T, Tokoro A, et al (2015) Assessment of Cancer-Related Fatigue, Pain, and Quality of Life in Cancer Patients at Palliative Care Team Referral: A Multicenter Observational Study (JORTC PAL-09). *PLoS One* 10:e0134022. <https://doi.org/10.1371/journal.pone.0134022>
22. Lee CK, Novello S, Rydén A, et al (2018) Patient-Reported Symptoms and Impact of Treatment With Osimertinib Versus Chemotherapy in Advanced Non-Small-Cell Lung Cancer: The AURA3 Trial. *J Clin Oncol Off J Am Soc Clin Oncol* 36:1853–1860. <https://doi.org/10.1200/JCO.2017.77.2293>
23. Leighl NB, Karaseva N, Nakagawa K, et al (2020) Patient-reported outcomes from FLAURA: Osimertinib versus erlotinib or gefitinib in patients with EGFR-mutated advanced non-small-cell lung cancer. *Eur J Cancer Oxf Engl* 1990 125:49–57. <https://doi.org/10.1016/j.ejca.2019.11.006>
24. Barajas Galindo DE, Vidal-Casariago A, Calleja-Fernández A, et al (2017) Appetite disorders in cancer patients: Impact on nutritional status and quality of life. *Appetite* 114:23–27. <https://doi.org/10.1016/j.appet.2017.03.020>
25. Pirri C, Bayliss E, Trotter J, et al (2013) Nausea still the poor relation in antiemetic therapy? The impact on cancer patients' quality of life and psychological adjustment of nausea, vomiting and appetite loss, individually and concurrently as part of a symptom cluster. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer* 21:735–748. <https://doi.org/10.1007/s00520-012-1574-9>
26. Wheelwright SJ, Darlington A-S, Hopkinson JB, et al (2016) A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 6:307–314. <https://doi.org/10.1136/bmjspcare-2014-000680>
27. Pyo J, Ock M, Lee M, et al (2021) Unmet needs related to the quality of life of advanced cancer patients in Korea: a qualitative study. *BMC Palliat Care* 20:58. <https://doi.org/10.1186/s12904-021-00749-8>
28. Prevost V, Grach M-C (2012) Nutritional support and quality of life in cancer patients undergoing palliative care. *Eur J Cancer Care (Engl)* 21:581–590. <https://doi.org/10.1111/j.1365-2354.2012.01363.x>
29. Molassiotis A, Brown T, Cheng HL, et al (2021) The effects of a family-centered psychosocial-based nutrition intervention in patients with advanced cancer: the PiCNIC2 pilot randomised controlled trial. *Nutr J* 20:. <https://doi.org/10.1186/s12937-020-00657-2>
30. de Rooij BH, Ezendam NPM, Mols F, et al (2018) Cancer survivors not participating in observational patient-reported outcome studies have a lower survival compared to participants: the population-based PROFILES registry. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil* 27:3313–3324. <https://doi.org/10.1007/s11136-018-1979-0>
31. Daly LE, Dolan RD, Power DG, et al (2020) Determinants of quality of life in patients with incurable cancer. *Cancer* 126:2872–2882. <https://doi.org/10.1002/cncr.32824>
32. Dittus KL, Gramling RE, Ades PA (2017) Exercise interventions for individuals with advanced cancer: A systematic review. *Prev Med* 104:124–132. <https://doi.org/10.1016/j.ypmed.2017.07.015>

CHAPTER 6

Experiences of patients with cancer with information and support for psychosocial consequences of reduced ability to eat: a qualitative interview study

Lize N, IJmker-Hemink V, van Lieshout R, Wijnholds-Roeters Y, van den Berg M, Youssef-El Soud M, Beijer S, Raijmakers N

Supportive Care in Cancer 2021;
29; 6343–6352



ABSTRACT

PURPOSE Patients with cancer may experience emotions such as anger or sadness due to tumour- or treatment-related reduced ability to eat. These emotions can be provoked by patients' own struggle with eating, by misunderstanding of their struggle by others, or by less pleasure in social activities. Literature indicates that patients with cancer may experience a lack of information and support regarding psychosocial consequences of reduced ability to eat. The aim of this qualitative study is to gain insights into experiences with this information and support.

METHOD Transcripts of semi-structured interviews with 24 patients with cancer who experience(d) psychosocial consequences of reduced ability to eat were thematically analysed. Interviews were recorded, transcribed verbatim and analysed using Atlas.ti.

RESULTS Patients expressed positive experiences with information and support for psychosocial consequences of reduced ability to eat while receiving multidisciplinary recognition and personalised care. Patients expressed negative experiences when healthcare professionals only assessed topics within their own expertise, or when healthcare professionals mainly focused on their nutritional intake. Informal support for reduced ability to eat was positively evaluated when informal caregivers tried to understand their situation. Evaluation of informal practical support varied among patients.

CONCLUSION Patients with cancer who experience psychosocial consequences of reduced ability to eat both need professional and informal support. Recognition of these consequences from healthcare professionals is important, as well as understanding from informal caregivers.

INTRODUCTION

Patients with cancer often experience nutritional problems such as anorexia, taste and smell changes, dry mouth, swallowing problems and nausea^{1,2} that can lead to insufficient nutritional intake, unintended weight loss and ultimately cancer cachexia.³ Overall, diet-related problems were reported by 45% and weight loss was experienced by 44% of cancer survivors diagnosed and/or treated within the past five years.⁴ Some tumour types are known for their high prevalence of nutritional impact symptoms e.g. (gastro)oesophageal, pancreatic, head and neck, and lung tumours.⁵ For example, in patients with head and neck cancer the prevalence of nutritional impact symptoms is >90%, mainly as a result of the tumour location and treatment.⁶ The prevalence of nutritional impact symptoms in patients with lung cancer is between 67-88%, due to the treatment but also due to systemic inflammation caused by the tumour.^{7,8} Cancer or treatment related reduced ability to eat can also have psychosocial consequences. A recent qualitative study showed that patients with cancer experienced a broad range of emotions such as anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame. These emotions were induced by patients' own struggle with eating and by misunderstanding of their struggle by others. Furthermore, patients experienced less pleasure in their social activities. Informal caregivers experienced similar emotions due to their high sense of responsibility for the patients' wellbeing. This study also indicated that psychosocial consequences of reduced ability to eat may occur during the entire disease trajectory and can persist during recovery and remission.⁹ These recent findings are in line with the results of earlier studies conducted among patients with advanced cancer and cancer cachexia. These patients experienced a range of emotions such as depression, fear and frustration in relation to their nutritional complaints.¹⁰

Standard nutritional screening is recommended in international guidelines¹¹ and is mainly performed by nurses. Current nutritional screening however, only targets weight loss and the presence of nutritional impact symptoms. In case of a positive screening, guidelines recommend referral to a dietician. How patients experience reduced ability to eat and how nutritional problems impact their emotional and social well-being is not formally assessed.

Assessing the need and wishes for psychosocial support regarding reduced ability to eat by healthcare professionals (HCPs) might be necessary, considering past research that showed these needs are often not met. Results of qualitative studies among patients with advanced cancer and cancer cachexia showed these patients consistently report a lack of recognition and information¹², or a lack of attention¹³ from HCPs in relation to psychosocial consequences of their nutritional problems. In a systematic literature review of Wheelwright et



al.¹⁰, the authors concluded that professional care should not only address the physical aspects of cachexia, but also patients' emotions and relationships. Other studies in patients with head and neck cancer, hematologic cancer and patients receiving parenteral home feeding showed that patients want their HCPs to recognise their distress provoked by their nutritional complaints, while their HCPs tend to focus on physical aspects of their condition.¹⁴⁻¹⁸ However, these studies only touched upon the topic what patients need regarding their reduced ability to eat, but they did not study this topic in-depth as a central research question itself. More research is needed to gain insights in what patients really need from their HCPs and their informal caregivers regarding psychosocial consequences of reduced ability to eat.

It is a well-known phenomenon both in research and clinical practice that many patients receive nutritional and emotional support from informal caregivers.¹⁹⁻²¹ Whether this informal support for reduced ability to eat contributes to patients' wellbeing has not yet been studied. The aim of the present study is to gain insights into patients' experiences with information and support for psychosocial consequences of reduced ability to eat due to cancer or treatment. Based on these experiences, recommendations to improve future information and support can be formulated.



METHODS

Design

A qualitative interview study design was used to gain a deeper understanding of patients' experiences with received information and support. Semi-structured interviews were performed with patients who experienced reduced ability to eat due to their cancer or treatment.

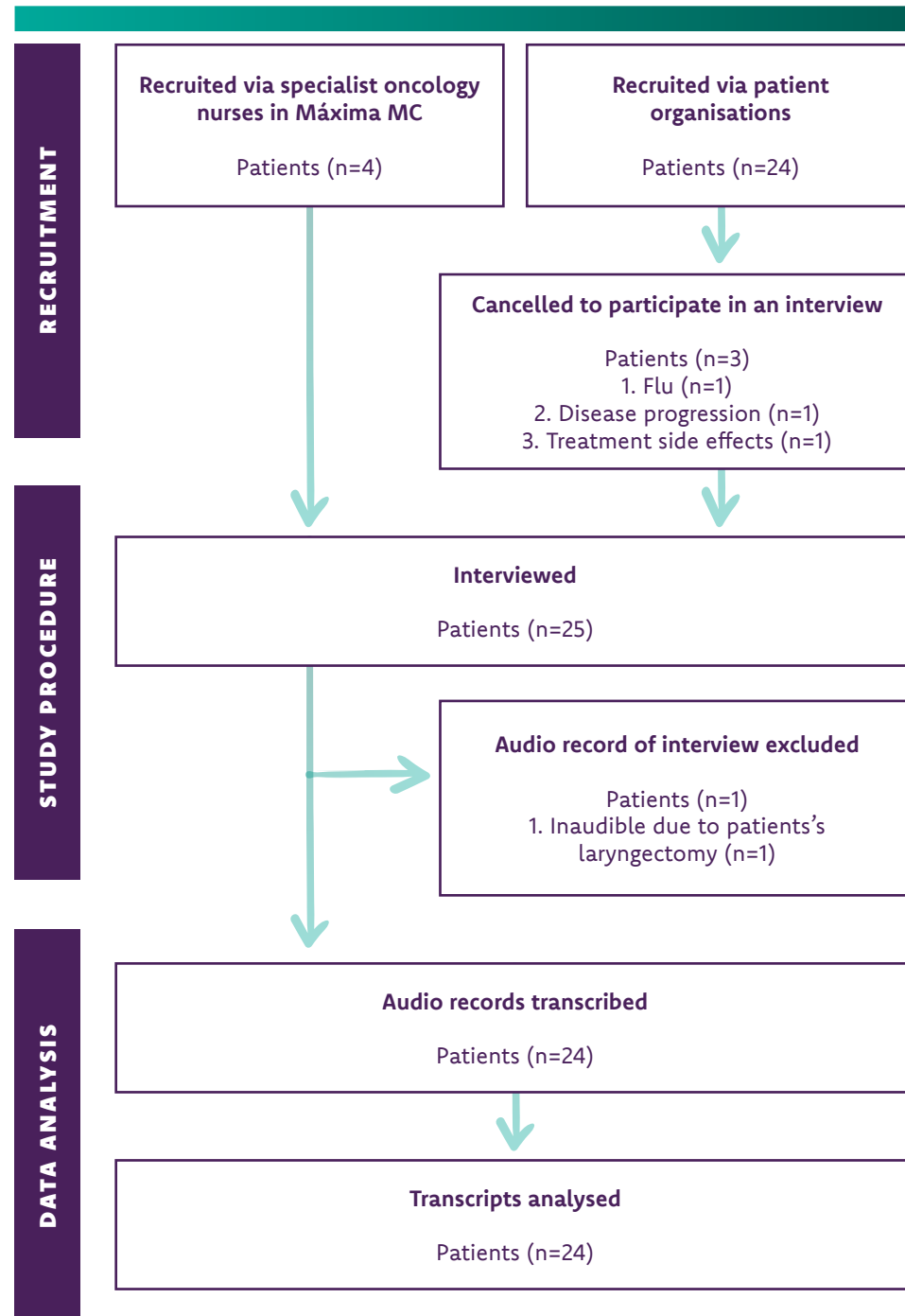
Sampling and sample

Patients were eligible for inclusion if they were over eighteen years of age, diagnosed with head and neck cancer, lung cancer or lymphoma and (had) experienced nutritional problems due to their cancer or treatment. The presence of nutritional problems was self-reported. Patients were recruited via patient organisations for head and neck cancer (Hoofd/hals), Lymphoma (Hematon) and lung cancer (Stichting longkanker Nederland). The research population was supplemented by recruitment via specialist oncology nurses at Maxima MC in Veldhoven, The Netherlands.

Data collection

The participating patient organisations posted calls on their websites and (social) media channels to invite their members to participate in the interview study. In this invitation call, patients were asked whether they experienced reduced ability to eat and were invited to participate in an interview about its consequences on their daily and social lives. When patients were interested to participate in the study they were asked to subscribe for an interview by completing an online form. Nurses in the participating hospital assessed whether patients with lung cancer were eligible for inclusion according to the study inclusion criteria. When they considered patients eligible for inclusion, the nurses informed these patients about the study and asked consent to be approached by a member of the research team for further information. Patients who subscribed via the online form or patients who consented to the nurses were contacted by phone. They received detailed information about the study and were invited to participate in an interview. In total, 25 patients were interviewed (Figure 1.).

FIGURE 1 Flow Diagram Respondents



All semi-structured interviews were conducted from February to May 2018 (NL). One interview was conducted with a patient at their office at work. All other interviews were conducted at patients' homes. Informal caregivers were included when the patient wanted an (adult) informal caregiver to be present, and when both patient and informal caregiver consented to their participation. Informal caregivers participated in twelve interviews. All interviews were conducted following a semi-structured topic list (Online Resource 1.).

ONLINE RESOURCE 1 Topic List

1. When did you get your diagnosis?
 - 1.1. Secondaries/metastases
 - 1.2. Treatments
 - 1.3. How are you doing now?
2. Are you getting dietary care?
 - 2.1 Nutritional drinks
 - 2.2. Tube feeding
 - 2.3. Intravenous feeding
3. Did you ever ask for help when eating became more difficult?
 - 3.1. Care professional
 - 3.2. Other
 - 3.3. What did you think about it?
 - 3.4. Was there anything missing? /Were you satisfied with the help you were given?
4. Did you ever look for information about eating?
 - 4.1. What did you think about it?
 - 4.2. Was there anything missing? /Were you satisfied with the information you were given?

Sociodemographic data and clinical data were self-reported by patients and were collected prior to the interview. The semi-structured topic list was developed in collaboration with an expert group consisting of two dieticians specialised in oncology care, one psychologist and four representatives of patient organisations and patient information platforms. The input of this expert group ensured that the questions in the topic list were appropriate for patients who experienced reduced ability to eat. The interviewer started by asking 'When did you get your diagnosis/treatment?' to encourage patients to talk. The second question 'How are you doing now?' meant to establish trust and connection by showing interest in the patients' current condition, (i.e. building rapport).²² Disease phase was interpreted from patients answers to these first two questions and the interview context. It was considered that questions about impending death might be too confronting for patients.

Data analysis

The interviews were audiotaped, and records were transcribed verbatim. A descriptive phenomenological approach was used to code the transcripts and to analyse the emerging themes.²³⁻²⁵ One interview was neither transcribed nor analysed because it was inaudible due to the patients' laryngectomy. The field notes of this interview were used as additional input for the thematic analysis. Transcripts of interviews with 24 patients were operable for thematic analysis. First, fourteen transcripts were open coded by three independently coding researchers (NL, SB, NR). After coding a transcript, the codes were compared and discussed to develop a code tree (NL, SB, NR). This procedure was repeated until the first point of data saturation was reached, after coding fourteen transcripts. Data saturation is the point when no new themes emerge from the data.²² The following ten transcripts were coded by the (then established) code tree by two researchers (NL, ZN). The code tree was established by discussing and comparing the independently coded transcripts during continuous group discussions to achieve consensus on the code tree. Four researchers clustered the open codes to identify themes in the data (NL, NR, SB, ZN). Initial findings were discussed with the aforementioned expert group to ensure rigour in the data analysis

Study procedure

To maximise insights into the diversity of experiences with support for psychosocial consequences of reduced ability to eat, we choose patients with head and neck cancer, lung cancer or lymphoma, cancer types with a high prevalence of nutritional impact symptoms. For patients with head and neck cancer and lung cancer these symptoms are well described.^{6,8} However, for malignant lymphoma, a general percentage of nutritional symptoms is not described in the literature, probably because the occurrence of nutritional impact symptoms mainly depends on the location of the lymphoma (more symptoms in patients with lymphoma in the gastrointestinal tract) and the intensity of the treatment (varying from wait and see till very intensive treatments like stem cell transplant). In addition, patients with one of these three cancer types differ in age, prognosis, onset and cause of the nutritional impact symptoms and perspectives for recovery. These differences may influence the need for psychosocial support. It was decided to recruit via patient organisations as it was possible to reach many self-reported patients within a relatively short time frame. However, on-line recruitment via patient organisations may result in a selection bias favouring patients with a relatively good health status and active information seeking behaviour.²⁶ Therefore, the research population was supplemented with patients with lung cancer in an early stage of advanced disease and currently under anti-cancer treatment. These patients were assessed as applicable for inclusion by the specialist oncology nurses of the Maxima MC.

Ethical considerations

The study design was informed by ethics in qualitative research design²², and was conducted according to the declaration of Helsinki. The study protocol was reviewed by the Maxima MC in Veldhoven (METC N18.032) and was exempted from ethical review according to the Dutch Medical Research Involving Human Subjects Act (WMO). During data collection and analysis, the rules of the European Personal Data Protection Act were followed. A written informed consent was signed by all patients prior to the interview. The transcripts were checked, and personal details were deleted to ensure patients' privacy. Critical appraisal of qualitative research (COREQ) reporting guidelines were used for reporting and writing.²⁷

RESULTS

Most patients were male (62,5%) and the mean age was 63 years (Table 1.)

TABLE 1 Patients' clinical and sociodemographic characteristics

		Patients (n=24)
Gender	Male	15 (62,5%)
	Female	9 (37,5%)
Age	Mean age in years (range)	63 (31-79)
Education ^a	Low	4 (17%)
	Middle	4 (17%)
	High	13 (54%)
	Unknown	3 (12%)
Marital status	Living together	17 (71%)
	Living alone	7 (29%)
Primary cancer site	Head and neck	9 (37,5%)
	Lymphoma	9 (37,5%)
	Lung	6 (25%)
Disease phases	Recovery or remission	17 (71%)
	Early advanced disease	7 (29%)
Time since diagnosis	<1year	5 (21%)
	1-5 years	11 (46%)
	>5 years	8 (33%)

^a low educational level = no education or primary school, intermediate educational level = lower general secondary education, vocational training or equivalent, high educational level = pre-university education, high vocational training, university

Most patients (71%) were in recovery or remission, and almost half (46%) of the population was diagnosed one to five years prior to the interview. Nine patients were diagnosed with head and neck cancer (37,5%), nine patients with lymphoma (37,5%), and six patients (25%) with lung cancer.

Four themes emerged from the data underlying patients' experiences with information and support for psychosocial consequences of reduced ability to eat. Two themes related to information and support provided by healthcare professionals (HCPs): 1) multidisciplinary recognition 2) personalised care. Two themes related to patients' experiences with informal support: 3) understanding 4) practical support.

Patients' experiences with information and support provided by healthcare professionals

Multidisciplinary recognition

Patients mentioned they had mainly received information and support from dieticians and physicians. Patients evaluated this information and support as positive when they felt a team of HCPs recognised and addressed their needs. Especially, the physicians' recognition of patients' reduced ability to eat and its psychosocial impact was regarded as valuable by patients. Patients expressed trust in their physician's expertise. Patients who were referred to a dietician considered this as an integral part of their healthcare team and treatment plan. Patients expressed positive experiences when they felt HCPs from different fields of expertise worked together and communicated with each other:

[the dietician] "always kept in touch with me and she also had conversations with the oncologist, at one point she also brought in a speech therapist [...] yes, that is a small hospital and only for cancer, you will be so well helped and supported there" (patient no. 10., head and neck cancer, recovery or remission)

Patients mentioned negative experiences with information and support when they felt HCPs only assessed topics within their own field of expertise. For example, dieticians who were only engaged with patients nutritional intake, physicians who did not provide patients adequate information about reduced ability to eat or neglected the topic completely. Furthermore, patients mentioned negative experiences when physicians had not referred them to other HCPs such as for example a dietician or a psychologist when they felt this might have been beneficial for them. Those patients felt they had to stand up for themselves to receive adequate information and support. Patients started searching for their own information and expressed it was hard to find adequate and reliable information:

"I started, on my own initiative, to look for what more I could do because the pain [when eating] was not acceptable and therefore I did not eat. Then, thanks to myself, via my contacts with the pain team, I ended up with a speech therapist and a physiotherapist. Nobody, not even the oncologist, for example referred me to these treatments, which is strange" (patient no 7. head and neck cancer, recovery or remission)

Personalised care

Patients expressed positive experiences with information and support from HCPs, when they felt care was tailored to their personal goals. Personal goals patients expressed in relation to their eating were: to change lifestyle, diminish treatment side-effects, prevent (further) disease progression and to learn to eat normal and to enjoy food. Patients expressed they wanted information and support from HCPs because they had confidence in HCPs expertise. Patients expressed positive experiences with information and support from HCPs when they felt HCPs acknowledged their eating inabilities and simultaneously supported them to focus on their eating abilities:

"When I said to my former dear haematologist that the only thing I still liked to eat sometimes were burgers or greasy Chinese food, he said good job, you should do that! [...] I really appreciated that and it felt as a big relief when he said: you are doing this well, at least you eat something, and life must also remain worth living" (patient no. 25., lymphoma, early advanced disease)

Patients expressed negative experiences when they felt HCPs did not acknowledge their personal goals regarding eating. For example, when patients felt HCPs were mainly focused on improving their nutritional intake while this was not one of their goals. Patients expressed this made them feel misunderstood and they felt that HCPs did not listen to them. Furthermore, when patients perceived the given nutritional advice as unrealistic or inadequate this advice was discarded:

"at some point in the oncology program, you will of course have to deal with the dietician and then you will get a piece of paper that says what you must eat, I was thinking – you know what I do with that this piece of paper? I throw it in the bin. I was thinking, go ahead and eat it yourself if you are sick, there is so much food on that list, even a normal [healthy] person cannot digest it in one day!" (patient no. 17., lymphoma, early advanced disease)

Patients' experiences with informal support

Understanding

Patients mentioned several informal caregivers who supported them regarding psychosocial consequences of reduced ability to eat. Informal caregivers mentioned were: spouses, relatives, friends, and peers. Patients evaluated informal support as positive when they felt their informal caregivers tried to understand their reduced ability to eat, and showed consideration for their eating inabilities and simultaneously supported them by adjusting food to their eating abilities:

[my family] "takes into account, what I can and can't eat, and they also take into account what I like, so my brother only gets herring for me and the rest gets a bowl with meatballs and a bowl of chicken legs" (patient no. 7., head and neck cancer, recovery or remission)

Patients who felt that informal caregivers did not take their eating inabilities into account or pushed them to eat when patients felt not able to, expressed negative experiences with informal support. This was especially important when patients' nutritional complaints were not visible and when reduced ability to eat persisted in the phases of recovery or remission:

"my daughter, she has also stopped trying things, for example to prepare some soft food, because it usually does not work and because that makes me sad, but the oldest [daughter], when she comes during the weekends, she keeps coming with all kind of recipes and then I have to try things again" (patient no. 2., head and neck cancer, recovery or remission)

Understanding for their reduced ability to eat was an important reason for patients to search for peer support. Whether peer support was evaluated as positive varied among patients. Patients mentioned positive experiences with peer support when they felt their peers had gone through similar experiences which made them feel less alone. In addition, peer support empowered them and provided them with valuable information to learn to cope with reduced ability to eat. Other patients expressed negative experiences with peer support because they felt their personal situation was so unique that nobody could help them. Other patients felt confronted by their peers' struggle or felt that peers complained too much about their own reduced ability to eat.

Practical support

Patients received a broad range of practical support regarding reduced ability to eat from their informal caregivers. Whether this practical support was perceived as supportive or as burdensome varied among patients. Some patients expressed happiness or relief that others supported them by organising daily meals at times they did not feel able to do groceries or prepare their own food:

"When I would say: I really really don't want to eat anything, please leave me alone I really don't want to eat anything, then she would walk downstairs with the attitude: aha, we will see my little man, yes and then she would finally come back up with something and I would think ah! I really feel like it [this food/meal] ... I thanked her explicitly for that later, yes" (patient no. 28., lung cancer, early advanced disease)

Other patients mentioned that they did not want to receive any practical support for various reasons. Some patients expressed that they want to discover themselves what their eating abilities and inabilities were. Others were not willing to accept practical support because they wanted to maintain their autonomy as much as possible despite their disease or found it burdensome or confronting to decline the meals that informal caregivers prepared for them with love and good intentions:

"The moments when I really felt very sick then everything just passes you by, it just takes energy every time to reject [the food] or to say it is not wanted now, could you leave me in peace [...] everyone around you is supportive and wants to do something for you, but all I wanted to do at that time was to rest, so they should not be nagging" (patient no. 16., lymphoma, recovery or remission)

Another aspect of not accepting practical support from informal caregivers was that some patients were concerned about their informal caregiver's wellbeing. Patients were worried that their reduced ability to eat would lead to high burden for their informal caregivers. Furthermore, some patients missed caring for their partner or other relatives as they used to do before they got ill:

"But I don't approve that because you [husband] also need vegetables, you also have to eat healthy, vegetables and everything, so then I think, I'll cook for him [husband] again because he enjoys it so much" (patient no. 15., lung cancer, early advanced disease)

DISCUSSION

The aim of this study was to gain insights into patients' experiences with information and support for psychosocial consequences of reduced ability to eat due to cancer or treatment. Patients with cancer who experience psychosocial consequences of reduced ability to eat receive information and support of both HCPs and informal caregivers. HCPs' recognition of psychosocial consequences of reduced ability to eat seems important, as well as personalised support and understanding from informal caregivers. Patients had positive experiences with information and support especially when this recognition came from their physicians. Furthermore, patients had positive experiences when a team of HCPs from diverse disciplines assessed their nutritional problems and collaborated and communicated well with each other about these problems. Patients had negative experiences when HCPs mainly targeted at improving nutritional intake instead of tailoring nutritional care to their personal goals. Patients expressed positive experiences with informal support when their informal caregivers understood their reduced ability to eat and its psychosocial consequences. Whether practical support of their informal caregivers was evaluated as positive varied among patients.

Our findings show that multidisciplinary recognition of reduced ability to eat and its psychosocial impact is important for patients, especially the physicians' recognition. The finding that patients in general greatly trust on their physicians' expertise is in line with results from previous studies.^{15,18} These studies were conducted in specific cancer populations known for their severe eating problems (i.e. hospitalised patients receiving haematological treatment, advanced cancer patients receiving home parental nutrition), and reported that patients value greatly the advice of their physician regarding their eating problems.^{15,18} When physicians did not address patients' nutritional issues it caused distress.¹⁵ Furthermore, a previous study conducted among patients with head and neck cancer showed that some patients felt abandoned by HCPs regarding the eating problems they encountered during and after radiotherapy. This feeling of abandonment was less pronounced when physicians and nurses had referred patients to other HCPs, for example a psychosocial counsellor or a dental hygienist.¹⁴ Other studies in patients with cachexia also addressed patients' needs for HCPs to assess the importance of their eating problems and its severe psychosocial impact.^{10,12,13,28}

In the present study, patients positively assessed information and support from HCPs when care was tailored to their personal goals, opposed to the negative assessment of HCPs providing patients general advices mainly targeted at nutritional intake. This finding is in concordance with previous studies.^{14,15,29,30}

In a study among hospitalised patients receiving haematological treatment, patients also expressed needing personalised nutritional counselling tailored to their nutritional complaints, financial restraints and individual preferences.¹⁵ Other studies showed that patients with reduced ability to eat experienced general nutritional advice as unbeneficial³⁰, unreachable¹⁴ or insufficient and confusing²⁹. Patients' experiences with peer support varied, in general most patients who sought and found peer support were positive about this support. However, this may be biased due to the recruitment via patient organisations, since patients often become a member of a patient organisation because they specifically have a need for peer support. Some patients expressed that they felt that their situation was so unique that nobody could support them, not even peers

Besides professional information and support, patients also received practical support for the daily meals from informal caregivers. Their experiences with this informal support varied. Patients positively assessed this practical support when they felt relieved from the burden of taking care of the meals. This is also observed in several studies among patients receiving anti-cancer treatment. These patients, from different cancer populations and receiving various (curative) treatments, unanimously reported to feel relieved that their informal caregivers took care of the practical aspects of the daily meals.^{17,31,32} On the other hand, our findings also showed that some patients experienced practical support provided by their informal caregivers as a burden, because they felt a loss of autonomy or felt troubled when they were not able to eat the meals prepared by their informal caregivers. Our previous study showed that misunderstanding of psychosocial consequences of reduced ability to eat by the patient's social surrounding can provoke a wide variety of emotions, such as anger, anxiety, disappointment, grief and sadness, guilt, powerlessness, shame.⁹ Findings of the present study indicate that understanding for psychosocial consequences of reduced ability to eat underlies patients' positive experiences with informal support.

To our knowledge, this is the first study that focused on patients' experiences with information and support for psychosocial consequences of reduced ability to eat due to cancer or treatment. Other studies touched upon this topic, but this phenomenon has not yet been studied in-depth as a central research question. Therefore, qualitative research methods were the appropriate choice of conduct. Our study also has limitations. Recruitment via patient organisations might have led to a selection bias favouring patients with a relatively good health status. The aim of this study was to recruit patients in all stages of the disease trajectory, thus in recovery and remission and under active anti-cancer treatment. Therefore, the research population was supplemented by patients recruited via oncology nurses in the participating hospital. Both the

background variable time since diagnosis and the number of patients recruited via the oncology nurses (n=3) show that patients' experiences with information and support during active anti-cancer treatment might be underreported in this study. Furthermore, recruitment via an online call may lead to a selection bias favouring more empowered patients with active information seeking behaviour.²⁶ Patients included in the present study were higher educated and relatively younger compared to the general cancer population.³³ Most patients were recruited by a call via patient organisations that asked for respondents who experienced psychosocial consequences of reduced ability to eat. This might have led to a selection bias for patients with psychosocial consequences of reduced ability to eat left unaddressed by HCPs. Furthermore, all interviews except one were conducted in patients and informal caregivers simultaneously, which might have led to socially desired answers and the underreporting of conflicts regarding patients' reduced ability to eat. However, interviewing patients and informal caregivers together also contributed to the study, as one of the research questions concerned patients' experiences with informal support. Despite these limitations this study provides new insights that can serve as a starting point for future research.

Implications

- HCPs recognise psychosocial consequences of reduced ability to eat
- Especially physicians recognition is important
- Assess patients' wishes and preferences regarding reduced ability to eat
- Emphasise multidisciplinary collaboration in patient communication
- Include informal caregivers in nutritional support to generate mutual understanding

Patients value the multidisciplinary recognition of the impact of reduced ability to eat from HCPs. Considering patients' trust in their physician's expertise regarding reduced ability to eat the physician would be suitable to refer patients to other HCPs when needed. It is important that HCPs emphasise that they are part of a multidisciplinary team. Furthermore, this study highlights the importance of personalised care. For patients it is important that HCPs assess patients' wishes and preferences regarding reduced ability to eat.

Standard nutritional screening, as suggested by international ESPEN guidelines¹¹, might be a good opportunity to also assess the psychosocial impact of patients' reduced ability to eat, and what patients need regarding supportive and informal care. Currently, nutritional screening is mainly aimed at physical problems i.e. weight loss and nutritional impact symptoms. However, food is more than nutritional requirements and eating is an important part of patients' daily and social lives. HCPs should be aware that eating is more than the intake of

nutrition and should support patients on all domains of quality of life that relate to reduced ability to eat. Patients need understanding of reduced ability to eat from their informal caregivers⁹, and their varied experiences with practical support from informal caregivers addresses the importance of including informal caregivers in (nutritional) support. Therefore, HCPs should support patients and informal caregivers to achieve mutual understanding and normalise emotions that can be provoked by patients' reduced ability to eat.

In conclusion, patients with cancer who experience psychosocial consequences of reduced ability to eat value HCPs multidisciplinary recognition of their experience and personalised care. Patients acknowledge receiving practical support from informal caregivers, with mixed experiences of how effective this was in helping them to cope with their reduced inability to eat. Patients valued informal caregivers' understanding for psychosocial consequences of reduced ability to eat. Therefore, it is important to include informal caregivers in (nutritional) care.

DECLARATIONS

FUNDING this study was funded by Zorg Instituut Nederland, 'Transparantie over de kwaliteit van zorg bij ernstige somatische aandoeningen', Grant 2017.

CONFLICTS OF INTERESTS the authors have no relevant financial or non-financial interests to disclose.

ETHICS APPROVAL Approval was obtained from the ethics committee of Maxima MC in Veldhoven (METC N18.032). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

CONSENT TO PARTICIPATE informed consent was obtained from all individual participants included in the study.

CONSENT FOR PUBLICATION not applicable.

AVAILABILITY OF DATA AND MATERIAL the corresponding author has full control to all primary data and allows the journal to review the data upon request.

CODE AVAILABILITY not applicable.

AUTHORS' CONTRIBUTIONS all authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Nora Lize, Natasja Raijmakers and Sandra Beijer. The first draft of the manuscript was written by Nora Lize and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

REFERENCES

1. de Pinho NB, Martucci RB, Rodrigues VD, D'Almeida CA, Thuler LCS, Saunders C, et al. Malnutrition associated with nutrition impact symptoms and localization of the disease: Results of a multicentric research on oncological nutrition. *Clinical Nutrition* 2019;38(3):1274-9.
2. Omlin A, Blum D, Wierecky J, Haile SR, Ottery FD, Strasser F. Nutrition impact symptoms in advanced cancer patients: frequency and specific interventions, a case-control study. *Journal of cachexia, sarcopenia and muscle* 2013;4(1):55-61.
3. Baracos V, Martin L, Korc M, Guttridge D, Fearon K. Cancer-associated cachexia. *Nat Rev Dis Primers* 2018;4:17105.
4. Sullivan ES, Rice N, Kingston E, Kelly A, Reynolds JV, Feighan J, et al. A national survey of oncology survivors examining nutrition attitudes, problems and behaviours, and access to dietetic care throughout the cancer journey. *Clin Nutr ESPEN* 2021;41:331-9.
5. Muscaritoli M, Lucia S, Farcomeni A, Lorusso V, Saracino V, Barone C, et al. Prevalence of malnutrition in patients at first medical oncology visit: the PreMiO study. *Oncotarget* 2017;8(45):79884.
6. Crowder SL, Douglas KG, Yanina Pepino M, Sarma KP, Arthur AE. Nutrition impact symptoms and associated outcomes in post-chemoradiotherapy head and neck cancer survivors: a systematic review. *Journal of Cancer Survivorship* 2018;12(4):479-94.
7. Fearon K, Arends J, Baracos V. Understanding the mechanisms and treatment options in cancer cachexia. *Nature reviews Clinical oncology* 2013;10(2):90.
8. Lin T, Yang J, Hong X, Yang Z, Ge T, Wang M. Nutritional status in patients with advanced lung cancer undergoing chemotherapy: a prospective observational study. *Nutr Cancer* 2020;72(7):1225-30.
9. Lize N, Raijmakers N, van Lieshout R, Youssef-El Soud M, van Limpt A, van der Linden M, et al. Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study. *European Journal of Oncology Nursing* 2020.
10. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2014;6(3):307-14.
11. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2016;36(1):11-48.
12. Cooper C, Burden ST, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. *Journal of Cachexia, Sarcopenia and Muscle* 2015;6(1):99-111.
13. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
14. Larsson M, Hedelin B, Athlin E. Needing a hand to hold: lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs* 2007;30(4):324-34.
15. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
16. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European journal of oncology nursing* 2011;15(2):145-51.
17. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 2013;22(7-8):1034-43.
18. Orrevall Y, Tishelman C, Herrington M, 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. *Clinical Nutrition* 2004;23(6):1280-7.
19. Schaller A, Liedberg GM, Larsson B. How relatives of patients with head and neck cancer experience pain, disease progression and treatment: a qualitative interview study. *European journal of oncology nursing* 2014;18(4):405-10.
20. Stenberg U, Cvancarova M, Ekstedt M, Olsson M, Ruland C. Family caregivers of cancer patients: perceived burden and symptoms during the early phases of cancer treatment. *Soc Work Health Care* 2014;53(3):289-309.
21. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2010;19(10):1013-25.
22. Boeije H. Analysis in qualitative research. Sage publications Ltd; 2009.
23. Sundler AJ, Lindberg E, Nilsson C, Palmér L. Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open* 2019;6(3):733-9.
24. Starks H, Brown Trinidad S. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research* 2007;17(10):1372-80.
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101.
26. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. *Journal of medical Internet research* 2002;4(2):e13.
27. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 2007;19(6):349-57.
28. Porter S, Millar C, Reid J. Cancer cachexia care: the contribution of qualitative research to evidence-based practice. *Cancer Nurs* 2012;35(6):E30-8.
29. Beeken R, Williams K, Wardle J, Croker H. "What about diet?" A qualitative study of cancer survivors' views on diet and cancer and their sources of information. *European journal of cancer care* 2016;25(5):774-83.
30. Locher JL, Robinson CO, Bailey FA, Carroll WR, Heimburger DC, Magnuson JS, et al. The contribution of social factors to under-eating in older adults with cancer. *J Support Oncol* 2009;7(5):168-73.
31. Salihah N, Mazlan N, Lua PL. Chemotherapy-induced nausea and vomiting: exploring patients' subjective experience. *J Multidiscip Healthc* 2016;9:145-51.
32. Molassiotis A, Stricker CT, Eaby B, Velders L, Coventry PA. Understanding the concept of chemotherapy-related nausea: the patient experience. *Eur J Cancer Care (Engl)* 2008;17(5):444-53.
33. Netherlands Cancer Registry (NCR). In.: Netherlands Comprehensive Cancer Organisation (IKNL); 2020 [cited 13-10-2020]. Available from: <https://www.cijfersoverkanker.nl>.



CHAPTER 7

Experiences of primary healthcare professionals with psychosocial support for reduced ability to eat in patients with advanced cancer: a qualitative interview study

Lize N, Beijer S, Bergman T, ten Have H, Kennis M, Kodde A, van de Poll–Franse L, Putman R, Schweitzer B, Veldhoven C, Raijmakers N

ABSTRACT

PURPOSE Primary healthcare professionals (HCPs) are often involved in care for patients with advanced cancer who experience a reduced ability to eat. In addition to nutritional support, these patients also need psychosocial support which is often not met. This study aims to gain insights into the experiences of primary HCPs with providing psychosocial support for reduced ability to eat in patients with advanced cancer.

METHODS A qualitative interview study was conducted among 40 primary HCPs. All interviews were recorded, transcribed verbatim and thematically analysed using ATLAS.ti 9.0.22.0.

RESULTS The extent to which HCPs discussed the psychosocial consequences of a reduced ability to eat varied from always to ad hoc. Some HCPs did not address these issues because they did not recognise them, experienced cultural differences or they considered it a private matter. HCPs mentioned that patients and informal caregivers had multiple reasons not to talk about these issues and often initiated the conversation by expressing non-verbal signals or by talking indirectly about these problems. HCPs mentioned regular or multiple home visits and multidisciplinary collaboration as facilitators for providing this support. All barriers related to the absence of multidisciplinary collaboration.

CONCLUSION Primary HCPs have an important role in psychosocial support for reduced ability to eat for patients with advanced cancer. Multidisciplinary collaboration is key in providing this type of support. Awareness about the psychosocial consequences of a reduced ability to eat needs to be raised by increasing knowledge and exchanging expertise between HCPs.



INTRODUCTION

Patients with advanced cancer experience nutritional problems, such as anorexia, early satiety, changes in smell and taste, food aversion, nausea and vomiting, and difficulty swallowing.¹ These complaints can result in diminished nutritional intake and weight loss. When the disease progresses, nutritional problems and weight loss become worse and can eventually contribute to (refractory) cancer cachexia, a process that is often irreversible. An estimated 85% of patients with advanced cancer develop cancer cachexia during the end stage of the disease.²⁻⁴

Additionally to these physical problems, nutritional problems due to cancer or its treatments can also influence the emotional and social well-being of patients with advanced cancer. Patients with cancer and their informal caregivers can experience a broad range of emotions related to the patient's disease or treatment related reduced ability to eat.⁵⁻⁷ Patients mentioned feelings of anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame. These emotions were evoked in patients by their own struggle with eating or by the misunderstanding of this struggle by others. Among informal caregivers these emotions were evoked by their high sense of responsibility for the patient's well-being.⁷ A large body of mainly qualitative studies explored these psychosocial consequences in patients with advanced cancer and their informal caregivers. In general, these studies showed that patients and informal caregivers want and need healthcare professionals' (HCPs) support for these psychosocial consequences.^{5,6,8,9} These needs may not always be met, as patients with cancer expressed both positive and negative experiences with the psychosocial support of HCPs.¹⁰

Primary care is important for patients with advanced cancer, as home is the most preferred place of end-of-life care and death.^{11,12} Over one thirds of all patients die at home in the Netherlands.¹³ As a result, primary HCPs are often confronted with patients with advanced cancer and their informal care givers struggling with reduced ability to eat. There is a paucity of literature regarding the experiences of primary HCPs with providing psychosocial support for reduced ability to eat. The few studies available are mainly focused on HCPs' management of weight loss in advanced cancer and cancer cachexia patients. These studies indicate that primary HCPs are reluctant to discuss the patient's weight loss, and subsequently are reluctant to discuss the psychosocial consequences related to this weight loss.¹⁴⁻¹⁷

Therefore, the aim of this study is to gain insights into the experiences of primary HCPs with psychosocial support for patients with advanced cancer who experience a reduced ability to eat, and their informal caregivers. Based on these insights, this study aims to draft recommendations for a better alignment between the psychosocial support provided by primary HCPs and the needs of patients and informal caregivers.

METHODS

Design

A semi-structured interview-study was conducted with primary HCPs to gain insight into their experiences with psychosocial support for reduced ability to eat for patients with advanced cancer and their informal caregivers.

Sampling and sample

Primary HCPs were: assistant practitioners (for critical, elderly, mental and somatic care), dietitians, district nurses, and general practitioners (GPs). It was anticipated that HCPs working in these four disciplines would be the main providers of psychosocial support for reduced ability to eat for patients with advanced cancer. Purposive sampling methods¹⁸ were used to recruit forty HCPs, ten of each working in one of these four primary care disciplines. The study population was supplemented with participants recruited by snowball sampling.¹⁸

Study procedure

An advisory board was set up to support the study procedure and recruitment; one assistant practitioner for mental healthcare (RP), one assistant practitioner for healthcare who also worked as an oncology dietitian (MK), two GPs specialised in palliative care (BS, CV), one medical advisor primary palliative care (AK), and one dietitian specialised in primary oncology care (HTH). Primary HCPs were also recruited via websites and social media channels of professional organisations including: the Netherlands Association for Palliative Care (PZNL), Palliative home care (PaTz), Palliative expert team of GPs (PalHag), the Dutch Association of Nurses and Carers (V&VN) and the Dutch Dietitians Oncology Group (LWDO).

Data collection

Primary HCPs were informed about the study by the members of the advisory board face to face or by emailing a digital information leaflet that provided information about the research aim, population, methods and the privacy protocol. Primary HCPs were invited to participate in an online interview of 30 to 45 minutes. In total, 47 primary HCPs were recruited, and 40 participants were interviewed by one researcher (NL, female, MSc. in Cultural Anthropology) from November 2020 to May 2021. Three primary HCPs who had applied were not interviewed because there were more than ten applications within that primary healthcare discipline (two district nurses and one GP). Two primary HCPs cancelled the interview owing to the corona lockdown and the related increase in workload or family circumstances and two primary HCPs did not respond after application. Prior to the interviews a semi-structured topic list was developed in collaboration with the members of the advisory board (Online resource 1).

ONLINE RESOURCE 1

Topic list
Study number:
Date:
Time:

Introduction

First of all, I'd like to thank you for participating in this interview. I'm Nora Lize, researcher at the Netherlands Comprehensive Cancer Centre. IKNL is a research institute with the aim of improving the quality of oncological care.

It's known from previous research that reduced ability to eat in cancer patients can have psychosocial consequences. Patients with cancer also indicate that the professional support they receive from their healthcare professionals does not always match their needs. With this study we want to gain insights into the experiences of primary care healthcare professionals with providing psychosocial support for reduced ability to eat for patients with advanced cancer.

Based on the results of this research, an information leaflet is made and an existing e-learning for healthcare professionals is further developed. In addition, the results of this study are published in professional and scientific journals.

What you tell me will be treated confidentially and the data will be processed anonymously.

The interview will last about half an hour to 45 minutes. You can indicate that you want to end the interview at any time. Do you have any questions?

I'd like to record the interview so that this can be transcribed. After transcribing, the record will be destroyed. Do you give permission to record this conversation?

This is record number [number], it's [date, time]. Do I have your permission to record this interview?

Sociodemographic and professional characteristics

I'd like to start with asking you a few general questions.

Where are you

At home

At work

How did you hear about this research?

Age

Gender

Profession

Assistant practitioner healthcare

Dietitian

District nurse

General practitioner

Contract

Part-time

Fulltime

Weekly working hours

Years of experience in current profession

Oncological or palliative care education

Yes, namely

No

Psychosocial support for reduced ability eat for patients/informal care givers

I'd like to start with the first topic of the interview.

Patients with advanced cancer can experience reduced ability to eat. Due to their struggle with eating they can experience emotions such as anger and sadness.

They may also experience misunderstanding for this struggle from others, or have less pleasure in social activities.

Informal caregivers of patients with advanced cancer can experience emotions provoked by the patients' reduced ability to eat, due to high feelings of responsibility for the patient's well-being, and their desire to take good care of the patient.

Do you discuss these psychosocial consequences of reduced ability to eat with patients/informal caregivers?

[YES]

I'd like to ask you some questions about your experiences when you discuss this subject with patients/informal caregivers

How does this conversation come about?

Who starts this conversation?

you

patients

informal caregivers

protocol or guidelines

What are your reasons to start this conversation?

concerned informal caregivers

powerlessness in informal caregivers

associations with impending death

Can you describe the course of this conversation?

What issues are of concern to patients/informal caregivers?

How much time do you spent discussing this subject?

compared to nutritional intake?

How do you support patients/informal caregivers?

listening and acknowledging advice

referral to other healthcare professionals

other best practices

Do you feel well equipped to provide this psychosocial support?

If yes, where and how did you acquire this knowledge/skill?

If not, what do you need to acquire this?

[NO/SOMETIMES]

You indicated that you (sometimes) do not discuss this subject with patients/informal caregivers?

What are the reasons that you do not discuss this subject with patients/informal caregivers?

doesn't occur in daily practice

no need for patient/informal caregiver

not enough time

no experience/education

no possibilities/resources

not my task

I can't help with these issues

Would you like to discuss this subject more often with patients/informal caregivers?

If so, what could help you with this?



Multidisciplinary collaboration

Patients indicate that they need multidisciplinary recognition and support for psychosocial consequences of reduced ability to eat.

Do you collaborate with other primary care healthcare professionals for providing psychosocial support for reduced ability to eat for patients with advanced cancer?

If yes, with whom?

assistant healthcare practitioners

dietitians

district nurses

general practitioners

other healthcare professionals

Do you refer patients/informal caregivers to other disciplines of healthcare?

If so, to whom do you refer?

If so, when do you refer?

If so, how do you refer?

Do you conduct multidisciplinary consultations about patients with advanced cancer?

If so, with whom, when and how?

Do you discuss reduced ability to eat in these multidisciplinary consultations?

If so, do you inform patients about this ?

Closure of the interview

This is the end of the interview. Are there any issues related to this subject that we didn't discuss?

I'll end the record.

Thank you very much for your time.

We're still looking for primary healthcare professionals who like to participate in this study. In particular, we're still looking for [profession, level of experience].

Do you know a eligible colleague?

Could you approach him/her for an interview?

Do you want to be informed about the results of this study?

Participants were interviewed via the online channel of Microsoft Teams (n=36, video records), or by phone owing to a request of the primary HCP, or owing to technical problems (n=4, audio records). All interviews were transcribed verbatim by a professional transcribing service. One interview was only partly recorded and transcribed due to technical failure.

Data analysis

A descriptive phenomenological approach was used to code the transcripts and analyse the emerging themes in the data.¹⁹⁻²¹ For the analysis ATLAS.ti version 9.0.22.0 was used.²² First, three researchers individually open coded²³ eight transcripts (NL, NR, SB). Each coded transcript was compared in group discussions to achieve consensus on the code tree and reach the first point of data saturation. Two independent coding researchers (NL, TB) recoded and discussed the following sixteen transcripts and finalised the code tree, the second point of data saturation. The remaining 24 transcripts were coded by one inde-

pendently working researcher (NL, TB), and five randomly selected transcripts were discussed to test consensus. After open coding, quotes in the code tree were discussed (NL, TB) who then clustered the codes into categories (i.e. axial coding).²³ A thematic analysis¹⁹ was conducted (NL, NR, SB, TB) to identify the main themes in the data. The open coding started in January 2021 and the thematic analysis was conducted in June 2021.

Ethical considerations

The study protocol was reviewed by the Medical Ethics Committee Brabant (METC NEW-2020-93) and was exempted from ethical review according to the Dutch Medical Research Involving Human Subjects Act (WMO). The study design was performed according to the declaration of Helsinki. During data collection and analysis, the rules of the European Personal Data Protection Act were followed. At the start of each interview, primary HCPs provided verbal consent for recording the interview. Furthermore, a digital informed consent was signed by all primary HCPs prior to the interview. The transcripts were checked, and personal details were deleted to ensure the privacy of the primary HCPs. Consolidated criteria for reporting qualitative research (COREQ) were used to ensure correct and explicit reporting upon this study.¹⁸



RESULTS

In total, 40 primary HCPs were interviewed including: ten assistant practitioners for healthcare, ten dietitians, ten district nurses, and ten GPs. The majority of these primary HCPs (90%) were female and the mean age was 48 years. More than two-thirds of the HCPs were educated or specialised in oncology or palliative care, and half of the HCPs had \geq ten years of experience in their current profession. (Table 1).

TABLE 1 Characteristics of Primary Healthcare Professionals (2021)

		Primary HCPs (n=40)
Age	Mean in yrs. (range)	48 (25-64)
		n (%)
Gender	Female	36 (90)
	Male	4 (10)
Educated/specialised in oncology/palliative care	Yes	27 (67.5)
	No	13 (32.5)
Years of experience in current profession	<5 yrs.	11 (27.5)
	5-10 yrs.	9 (22.5)
	\geq 10 yrs.	20 (50)
Employment	Part-time	29 (72.5)
	Full-time	11 (27.5)

Conversations about the psychosocial consequences of a reduced ability to eat

The extent to which the HCPs took the initiative differed from always to ad hoc. HCPs who always took the initiative often used an assessment tool (for example the Dutch 'Lastmeter') or started an open conversation about eating. HCPs who addressed these issues ad hoc mentioned mental lists and checks or signs in the communication between patient and informal caregiver as a trigger to initiate the conversation:

"sometimes when you enter the room, you see there's a roll, a plate of porridge and a piece of fruit, for when he [the patient] wants to eat something. And then he looks at me and says: 'Yes, but I'm not hungry

at all'. And then... yes, I'll talk to both of them [patient and informal caregiver] about it" (HCP no. 35, district nurse)

Some HCPs mentioned not to recognise these psychosocial consequences. Other HCPs mentioned that they deliberately did not address these issues because they experienced cultural differences. These HCPs indicated that they did not want to raise the issue of the patient's reduced ability to eat with these families because they felt that the end of life and the death of the patient are taboo that cannot be discussed. Finally, some HCPs expressed not to initiate the conversation because they considered it a private issue between patients and their informal caregivers.

According to HCPs, patients and their informal caregivers also initiated a conversation but less frequently than HCPs who initiated it. HCPs mentioned that when patients or informal caregivers initiated this conversation they often introduced the topic by expressing non-verbal signals related to the topic or by talking about it indirectly. Patients often introduced the topic by mentioning their physical or nutritional complaints. HCPs indicated that informal caregivers also often indirectly discussed the psychosocial consequences of a reduced ability to eat, by mentioning the reduced intake of the patient. Sometimes informal caregivers expressed frustration related to this reduced intake, or they related the reduced intake to the patient's impending death.

HCPs described several reasons that kept patients and informal caregivers away from initiating the conversation; patients being too ill to talk, patients having multiple other (and more severe) disease-related issues, or patients avoiding all healthcare. HCPs also mentioned that some patients and informal caregivers did not want to talk about the patient's reduced ability to eat in the presence of each other because they did not want to hurt each other. Moreover, some HCPs told that informal caregivers sometimes expressed their worries about the patient's reduced intake when they were alone with the HCP, for example at the front door:

"it often happens that when you leave and the partner walks you to the door, then the partner will ask you questions like: 'what do you think, he is not eating, why?'. So in this way you sometimes speak to the partner separately [...] the last conversation with the patient's partner is often not about what shall I prescribe for the patient, but it is usually about the partners anxiety or fear, that's the real problem" (HCP no. 10, district nurse)

Psychosocial support for reduced ability to eat

Primary HCPs provided psychosocial support for reduced ability to eat by listening to patient's and informal caregivers' problems, by normalising emotions evoked by reduced ability to eat of patients, and by explaining what patients and informal caregivers could expect regarding nutritional complaints when the disease progresses. Furthermore, HCPs gave practical (nutritional) advice regarding eating and disease stage, for example they advised the patient to eat whatever they still enjoyed and focus on what was still possible for them to eat. Subsequently, HCPs mentioned that they involved informal caregivers in (nutritional) care for the patient, and that they think this is an important element of psychosocial support for reduced ability to eat. In general, HCPs talked with patients and informal caregivers as dyads. They expressed that it is equally important to provide psychosocial support to the patient as to their informal caregiver. HCPs indicated that this would benefit patients' wellbeing importantly:

"I often wonder what is the purpose of all that food? What do they want to achieve? And that's what we talk about, also with those who are closest to the patient, of course, because if you don't include them in the decision-making it won't work [...] and then of course you make a plan that is supported by all parties. Because that plan has the best chance of succeeding" (HCP no. 22, GP)

HCPs sometimes initiated the conversation with the informal caregivers alone to gather knowledge about the seriousness of the complaints and physical condition of the patient. Most HCPs however, preferred to discuss all issues in the presence of both the patient and the informal caregiver.

Facilitators for psychosocial support for reduced ability to eat

HCPs mentioned that regular and multiple home visits were an important facilitator for providing psychosocial support for reduced ability to eat. According to HCPs, by visiting patients in the safety and comfort of their homes, they were able to build a good relationship that leads to the confidence and trust needed to talk to patients and informal caregivers about difficult and sensitive topics such as the decline of nutritional intake and the associated impending death:

"I think every problem that you recognise you should try to discuss. My only consideration is how well I know someone. You have to be able to gauge how you say things to some people. Because you do want the message to get through and you don't want to scare people off by playing the role of the highly educated nurse. So I have to be able to consider how I can convey the message in such a way that people

understand what I mean and that it also will be accepted" (HCP no. 27, district nurse)

HCPs also explained that visiting patients and informal caregivers repeatedly at their homes enabled them to address other, at that moment more important disease related issues first. These HCPs discussed the patient's problems later, or introduced the topic of the psychosocial consequences of a reduced ability to eat and get back at it during a follow up visit. HCPs mentioned that the presence of informal caregivers (who were almost always present) at the homes of patients was beneficial.

Another facilitator mentioned by HCPs regarding psychosocial support for reduced ability to eat was multidisciplinary collaboration. Several HCPs from diverse disciplines are often involved in primary care for patients with advanced cancer at home. This enabled HCPs to consult their colleagues and ensure that the same message about patients' reduced ability to eat was discussed by all HCPs involved in care. HCPs felt this made their message more powerful:

"they [district nurses] see the patient more often, so they are the ones who build a relationship with the patient. Consider when someone takes care of you, sees you naked, I think that all matters. Often patients listen very well to the district nurse. So we try to communicate the same message [...] and I noticed that it helps if the GP repeats it again" (HCP no. 40, assistant healthcare practitioner)

Additionally, some HCPs scheduled their visits to encounter the patient's GP or other HCPs at the patient's home. Most HCPs considered it as an important part of their work to refer patients and informal caregivers to other relevant disciplines of healthcare when necessary:

"but I also like it that I have a lot of contact with a couple of assistant practitioners for mental healthcare, because I work in a general practice office, I like the fact that I know them well, I can easily refer them by name and when I think it's OK with the patient and their relatives. I like that. Because, of course, I'm not equipped for everything, but then it's important to know the right way to refer patients" (HCP no. 15, dietitian)

Other ways to enable multidisciplinary collaboration were working in the same primary healthcare centre, maintaining personal networks of colleagues, and organising multidisciplinary meetings. Organising multidisciplinary meet-

ings was considered as a very productive and useful practice, but also as very time-consuming and expensive to get everyone at the same place.

Barriers of psychosocial support for reduced ability to eat

HCPs mentioned several barriers for providing psychosocial support for reduced ability to eat in patients with advanced cancer. These barriers were all related to the absence of multidisciplinary collaboration. HCPs mentioned as barriers; limited knowledge (of their own and their colleagues), limited exchange of information and professional expertise, limited access to other HCPs from different disciplines of healthcare, and limited involvement in care. HCPs who did not feel sufficiently equipped expressed the desire to acquire more knowledge about the subject. Often colleagues made decisions about the patient's reduced ability to eat that the HCPs was critical of because of their knowledge of the potential psychosocial consequences:

“I have experienced several times that a dying patient came home [from the hospital] with tube feeding, then I think to myself: ‘that shouldn't have happened’ [...] when this happens, we as GPs have to say: ‘it's not useful anymore’, and you can get into conflicts with relatives and with the patient [...] I think where it goes wrong is in the cooperation [with other HCPs], so that there is no earlier discussion with that family or with that patient that it's finite, that we're doing what we can, but that at some point that disease is going to win anyhow” (HCP no. 7, GP)

Sometimes, HCPs wanted to consult their colleagues, or refer patients or informal caregivers to other disciplines of healthcare, but were unsure whether these colleagues were sufficiently equipped. Other HCPs expressed that they did not consider psychosocial support as their field of expertise or they did not consider it was one of their tasks. This was only mentioned as a problem by HCPs when they felt unable to consult their colleagues about these issues, or when they did not know how to refer their patients to other disciplines of healthcare. Of all interviewed primary HCPs, dietitians most often expressed that they felt to be involved too late in the care. Because of this dietitians mentioned that it was hard for them to provide good psychosocial support for reduced ability to eat.

DISCUSSION

This interview study provides insights into primary HCPs' experiences with psychosocial support for reduced ability to eat in patients with advanced cancer. The extent to which HCPs initiated the discussion about these issues varied from always to ad hoc. Some HCPs did not address these issues because; they did not recognise them, they considered it a private matter or experienced cultural differences. Patients and informal caregivers often mentioned these psychosocial consequences by expressing non-verbal signals or by talking about it indirectly. Reasons for patients and informal caregivers not to discuss these issues were being too ill to talk, having multiple other issues, avoiding all healthcare or fear of hurting each other. Regular or multiple home visits and multidisciplinary collaboration were important facilitators for providing this psychosocial support. Barriers related to the absence of multidisciplinary collaboration; limited knowledge, limited exchange of professional expertise, limited access to other HCPs, and limited involvement in care.

This current study demonstrates that not all HCPs recognise the psychosocial consequences of a reduced ability to eat among patients with advanced cancer or deliberately did not address them. The primary focus of the few available studies that investigated this topic was on the management of advanced cancer-related weight loss.¹⁴⁻¹⁷ In concordance with our study, these studies also indicated that primary HCPs were reluctant to discuss patients' weight loss and the related issue of impending death, owing to the irreversible nature of weight loss in advanced cancer.^{14,16} Furthermore, HCPs tended to avoid the subject because of the fear to give patients false hope regarding the effect of nutritional interventions.¹⁵

We found that patients with advanced cancer and their informal caregivers initiate the conversation about the psychosocial consequences of a reduced ability to eat with their primary HCPs by talking about it indirectly or by expressing non-verbal signs. These indirect referrals were also described in previous research.¹⁴ The few available studies showed that most primary HCPs seemed to wait until patients or informal caregivers raised the issue of weight loss and eating problems.^{14,17} One study demonstrated that although nurses specialised in cancer care were aware of the need for an ongoing dialogue about the patient's weight loss and their eating problems, there was little evidence that this dialogue also occurred in practice.¹⁷ The combination of the wait-and-see attitude of HCPs described in the literature (but not found in our study), and the finding of our study that patients and informal caregivers tend to raise these issues indirectly or by expressing non-verbal signs, might result in HCPs not recognising these issues and providing too little of this type of psychosocial

support. Therefore, this study demonstrates the importance of HCPs being alert to indirect communication or non-verbal signals and being proactive in providing psychosocial support for reduced ability to eat.

The facilitators and barriers for providing psychosocial support for reduced ability to eat mentioned by HCPs in this study are in concordance with the findings of previous research conducted among primary HCPs providing home care for patients with advanced cancer. The barrier limited access to other HCPs was also mentioned by nurses who found it difficult to contact dietitians regarding the nutritional care of patients with advanced cancer.¹⁶ In another study, nurses expressed that they never or only occasionally referred patients to the dietitian, despite the fact that they believed that nutritional care was important for these patients. These nurses explained that they did not refer patients to dietitians because they thought that dietitians were too busy and not able to attend patients with advanced cancer at their homes. Nurses who did regularly refer patients to the dietitian did so because of their regular informal contacts with these dietitians.¹⁴ The findings of this study underline the findings of our study, that multidisciplinary collaboration is an important facilitator for providing psychosocial support for reduced ability to eat.

To our knowledge, this is the first study that focused on primary HCPs experiences with providing psychosocial support for reduced ability to eat for patients with advanced cancer. Our study also has some limitations. Despite the snowball sampling method in addition to the recruitment through the network of primary HCPs experienced in oncology or palliative care, most of the HCPs included in the study were trained or specialised in oncology and palliative primary care. This might have resulted in a selection bias of HCPs being more than average experienced and educated within these disciplines of healthcare. There may also be a selection bias within the population of not specialised HCPs interviewed in this study. These HCPs may have a higher than average interest in the subject. Therefore, the results of this study must be interpreted with caution. In daily practice, the psychosocial consequences of a reduced ability to eat may be less recognised and assessed in primary care than the results of this study suggest.

Implications

First, all primary HCPs need to recognise the psychosocial consequences of a reduced ability to eat. Second, HCPs need to be aware that patients and informal caregivers tend to discuss these issues indirectly, and therefore HCPs need to be aware of clinical observations, indirect communication and non-verbal signs. Third, multidisciplinary collaboration is the key for providing adequate psychosocial support for reduced ability to eat. Thus peer-to-peer coaching, consulting and exchange of expertise between colleagues from different disciplines of primary healthcare needs to be facilitated. Fourth, it is important to increase awareness about and the topic should be included in the formal education of HCPs working in all disciplines of primary healthcare. Finally, it is recommended to involve informal caregivers in the psychosocial support for reduced ability to eat.

Primary HCPs play an important role in the psychosocial support for reduced ability to eat in patients with advanced cancer. However, awareness about the psychosocial consequences of a reduced ability to eat needs to be increased. Multidisciplinary collaboration, peer-to-peer coaching, consulting and exchange of expertise between colleagues from different disciplines of primary healthcare can serve as important methods to increase awareness about these issues.



REFERENCES

1. Orrevall Y. Nutritional support at the end of life. *Nutrition*. 2015;31(4):615–6.
2. Fearon K, Arends J, Baracos V. Understanding the mechanisms and treatment options in cancer cachexia. *Nature reviews Clinical oncology*. 2013;10(2):90.
3. Fearon K, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, et al. Definition and classification of cancer cachexia: an international consensus. *The lancet oncology*. 2011;12(5):489–95.
4. Vogel J, Beijer S, Delsink P, Doornink N, ten Have H, van Lieshout R. *Handboek Voeding bij kanker: De Tijdstroom*; 2016.
5. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ supportive & palliative care*. 2014;6(3):307–14.
6. Wheelwright S, Darlington AS, Hopkinson JB, Fitzsimmons D, Johnson C. A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia. *Palliative medicine*. 2016;30(2):149–60.
7. Lize N, Raijmakers N, van Lieshout R, Youssef-El Soud M, van Limpt A, van der Linden M, et al. Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study. *European Journal of Oncology Nursing*. 2020.
8. Amano K, Baracos V, Hopkinson J. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Critical reviews in oncology/hematology*. 2019;143:117–23.
9. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *Journal of pain and symptom management*. 2013;46(1):77–95.
10. Lize N, Ijmker-Hemink V, van Lieshout R, Wijnholds-Roeters Y, van den Berg M, Soud MY, et al. Experiences of patients with cancer with information and support for psychosocial consequences of reduced ability to eat: a qualitative interview study. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 2021.
11. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*. 2013;12:7.
12. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of oncology : official journal of the European Society for Medical Oncology*. 2012;23(8):2006–15.
13. Pivodic L, Pardon K, Morin L, Addington-Hall J, Miccinesi G, Cardenas-Turanza M, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *Journal of Epidemiology and Community Health*. 2016;70(1):17–24.
14. Dewey A, Dean T. Assessment and monitoring of nutritional status in patients with advanced cancer: part 1. *International journal of palliative nursing*. 2007;13(6):258–65.
15. Dewey A, Dean T. Nurses' management of patients with advanced cancer and weight loss: part 2. *International journal of palliative nursing*. 2008;14(3):132–8.
16. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *Journal of pain and symptom management*. 2006;31(4):293–305.
17. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *Journal of advanced nursing*. 2006;54(3):304–12.
18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*. 2007;19(6):349–57.
19. Sundler AJ, Lindberg E, Nilsson C, Palmér L. Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open*. 2019;6(3):733–9.
20. Starks H, Brown Trinidad S. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research*. 2007;17(10):1372–80.
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
22. Friese S. *Qualitative data analysis with ATLAS. ti*: Sage; 2014.
23. Boeije H. *Analysis in qualitative research*: Sage publications Ltd; 2009.

CHAPTER 8

General discussion



GENERAL DISCUSSION

The studies described in the first part of this thesis concern the psychosocial consequences of a reduced ability to eat in patients with cancer and their informal caregivers. The second part is related to the experiences of patients and their healthcare professionals (HCPs) with the provided psychosocial support for these psychosocial consequences. Most research that investigates the psychosocial consequences of a reduced ability to eat is conducted among patients with advanced cancer or in patients with (end-stage) cancer cachexia (e.g., patients with end-stage cancer). These studies consistently show that both patients and their informal caregivers experienced distress or negative emotions such as fear and frustration in response of the patient's reduced ability to eat. In addition, eating-related conflicts between patients and their informal caregivers are often reported.¹⁻⁴ Regarding psychosocial support, these studies continuously report a lack of recognition, attention and information from HCPs for the psychosocial consequences of weight loss in the end-stage of cancer.^{2,3} The few studies about HCPs' experiences with providing psychosocial support for a reduced ability to eat are also focused on HCPs' experiences with patients weight loss in end-stage cancer settings. These studies indicate that HCPs were reluctant to discuss patients weight loss and the related psychosocial consequences because HCPs felt there was little to do about the patient losing weight. Furthermore, HCPs feared patients unrealistic expectations regarding the available nutritional interventions.⁵⁻⁸

Little is known about the psychosocial consequences of a reduced ability to eat and patients' experiences with psychosocial support during the whole cancer trajectory (including treatment, recovery and remission). Some studies touched upon this subject but did not study the topic in-depth. In addition, HCPs' experiences with providing psychosocial support for patients' reduced ability to eat are barely investigated. Insights in HCPs' experiences may provide us ideas about how we can help HCPs with providing adequate psychosocial support for reduced ability to eat and better align with patients' needs in the future.

Mapping the problem of the psychosocial consequences of a reduced ability to eat

The results of this thesis indicate that patients with cancer often suffer from psychosocial consequences of a reduced ability to eat, not only in the end-stage of the disease but during the whole cancer trajectory. Eating-related emotions mentioned by patients were; anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame and it was demonstrated that these emotional consequences can have a high negative impact on patients' well-being. A re-

duced ability to eat can also have social consequences for patients with cancer. The results demonstrate that patients experienced a decreased pleasure in their social activities and either changed, searched for alternative or avoided their social activities. Furthermore, the results demonstrate that a reduced ability to eat can affect the patient-informal caregiver relationship.

Psychosocial consequences of a reduced ability to eat

The results of this thesis show that patients may experience a broad range of emotions related to their reduced ability to eat which can have a high impact on patients' wellbeing during the whole cancer trajectory. In addition, patients indicated that they also experienced social consequences due to their reduced ability to eat. Patients and informal caregivers appear to have less enjoyment in social life because much of it revolves around eating. These results are in line with previous research into the psychosocial consequences of a reduced ability to eat and its impact, although this research was largely performed among patients with end-stage cancer.^{4,7-23} Wheelwright et al.⁴ reviewed this branch of literature and conclude that patients with end-stage cancer often experienced eating as an enduring task rather than an enjoyable activity, and that this possibly provokes eating-related "negative emotions such as depression, fear and frustration".^{4(p6)} Opsomer et al.²³ conclude that a reduced ability to eat can lead to strong emotions in some patients with end-stage cancer such as "feelings of despair and incomprehension or feeling miserable"^{23(p495)}.

Informal caregivers

The results of this thesis indicate that informal caregivers of patients with reduced ability to eat feel highly responsible for the overall well-being of the patient. Patients mentioned several informal caregivers; spouses, relatives, friends, and peers. The finding that informal caregivers feel highly responsible for patients' well-being is in line with previous research conducted among informal caregivers caring for patients with end-stage cancer. Several studies show that informal caregivers felt a great responsibility for and were alert on patients' nutritional intake.^{16,18,31,32} Furthermore, informal caregivers spend a lot of time thinking about how to optimise the meals, preparing food, and improving the nutritional intake of the patient.^{13,18,21} Informal caregivers' focus on improving patients' nutritional intake is also described in this thesis. The results of this thesis also describe how this may lead to conflicts about eating between informal caregivers and patients feeling pushed to eat. The results of this thesis suggest that a possible dynamic underlying these conflicts is the clash between informal caregivers feeling highly responsible for patients' well-being, while at the same time patients feel misunderstood in their struggle with eating. Wheelwright et al.¹, came to a similar conclusion although they use other words to

explain this dynamic between patients and informal caregivers. According to Wheelwright et al. the conflicts about patients' reduced ability to eat during the end-stage of cancer can be seen as a clash between patients' autonomy and informal caregivers' desire for control over the situation and desire to counteract feelings of powerlessness.

In concordance with findings in previous research, the studies in this thesis also demonstrate that even when there are no manifest conflicts about eating, the relationship between patients and informal caregivers can silently be affected patients' reduced ability to eat. In this thesis, primary HCPs caring for patients with end-stage cancer mentioned that patients and informal caregivers often avoided talking about reduced ability to eat because they did not want to hurt each other. Previous research shows that some patients did not talk about their nutrition-related problems with their partners because they wanted to hide their reduced ability to eat.²³ In another study conducted among bereaved informal caregivers it was found that they sometimes avoided the subject of the patient's reduced ability to eat because they did not want to hurt the patient, because they felt it was not useful to talk about it, or to avoid conflicts.³³

On the other hand, it is often the informal caregiver who cares for the patient's diet and provides practical support for the daily meals. The results of this thesis indicate that patients have both positive and negative experiences with this informal support for their reduced ability to eat. Whether patients felt supported by their informal caregivers depended on how much understanding they received for their struggle with eating. The literature also indicates that patients have varying experiences with informal support, depending on the patient's disease stage. Studies conducted among patients who received curative treatments unanimously describe patients who felt relieved because their informal caregivers took over the practical aspects of preparing the daily meals.^{28,34,35} Whereas studies conducted among patients with end-stage cancer describe how these patients often felt to be controlled by their dominant informal caregivers regarding their eating.¹

To gain insights into the provided psychosocial support for a reduced ability to eat

Patients' experiences with professional support for a reduced ability to eat

The findings in this thesis show that patients with cancer want HCPs to recognise and assess their reduced ability to eat throughout the whole cancer trajectory, and that these needs are often unmet. Furthermore, unmet nutritional support needs are associated with a lower quality of life and were present in 17% of our population of patients with end-stage cancer suffering from gastrointestinal problems. In addition, it is shown that when more time passed

since diagnosis, patients felt less satisfied with HCPs' support for their reduced ability to eat. Patients expressed positive experiences with HCPs' support for their reduced ability to eat when they received multidisciplinary support that was tailored to their personal goals.

The finding that patients with a reduced ability to eat have unmet support needs is confirmed by a large body of research conducted among heterogeneous groups of patients. Most studies describe how HCPs tend to be overtly focused on the physical aspects of the patient's inadequate nutritional intake^{2,4,18,26-28,36} This is particularly an unwanted situation, considering the conclusion of Oberholzer et al.² that patients may suffer from the increase of psychosocial consequences of their cancer cachexia when their HCPs have a lack of attention, are reluctant to discuss these psychosocial consequences, or give wrong information about patients' reduced ability to eat. Looking at the literature, the percentage of patients with unmet needs may further increase significantly as the disease progresses. According to a study conducted by Amano et al.²⁹, 76% of the hospice patients and cancer cachexia had nutritional support needs that were not met by HCPs. This group of patients wanted special attention for their eating-related distress and needed more information about their anorexia and weight loss. Consistent with our results, Koshimoto et al.³⁷ also found associations between the need for nutritional counselling and lower QoL scores on the domains of global health status, emotional, cognitive and social functioning. The findings of this thesis show that patients' satisfaction with HCPs support for reduced ability to eat seems to be lower when the period after their diagnosis is longer. This may indicate a lead for improvement in aftercare for those patients whose reduced ability to eat persist in the stages of recovery and remission, or for patients who never fully recover from their ability to eat. This can be patients who finished their curative anti-cancer treatments, but also patients who are discharged because they will receive palliative care at their homes. This finding is in line with previous studies reporting that patients with a reduced ability to eat seem to feel unsupported by their HCPs regarding their reduced ability to eat in the aftercare.³⁸⁻⁴² Especially patients with head and neck cancer, a patient group for whom the social disruption sometimes lasts years after treatments^{39,40,42}, report little support from their HCPs for this social disruption after their discharge from the hospital.³⁹

Organisation of nutritional and psychosocial support

Psychosocial support for reduced ability to eat needs to be integrated in nutritional care. It is demonstrated in this thesis that patients who received intensive AML treatments experienced emotional distress as a result of their reduced ability to eat. This emotional distress was alleviated when they received adequate nutritional support. In a similar way, the need to integrate psychosocial

support for a reduced ability to eat within nutritional support is described in studies conducted among patients with end-stage cancer. Koshimoto et al.³⁷ demonstrate that patients with end-stage cancer and a demand and a need for nutritional counselling suffered more from eating-related distress compared to patients without a demand and a need for nutritional counselling. Patients who had a demand for nutritional counselling suffered more from conflicts with others about eating, worried more about their eating, and had more problems with their self-motivation regarding the daily nutritional intake. Amano et al.²⁴ appeal for an integration of palliative, supportive, and nutritional support to ease eating-related distress among patients with end-stage cancer.

The results in this thesis show that patients expressed positive experiences when they received multidisciplinary support for their reduced ability to eat from a team of HCPs. This is in line with the current literature. A study conducted among patients with head and neck cancer shows that patients felt abandoned by HCPs regarding their reduced ability to eat during and after radiotherapy. This feeling was less pronounced when HCPs referred patients to other disciplines of healthcare, for example to a psychosocial counsellor or a dental hygienist²⁶. Furthermore, Amano et al.²⁵, suggest that eating-related distress among patients with end-stage cancer can be counteracted by a multimodal treatment.

Besides multidisciplinary support, the results of the thesis also demonstrate that patients expressed positive experiences when HCPs' support for their reduced ability to eat was tailored to their personal goals. Personal goals patients expressed in relation to their reduced ability to eat were to change lifestyle, to diminish treatment side-effects, to prevent (further) disease progression, to learn to eat like before, and learn to enjoy food again. Patients expressed negative experiences when HCPs provided them general advices that mainly targeted their nutritional intake. These findings are supported by studies conducted among patients with a wide variety of diagnoses, showing that patients perceived general information and advice about nutrition and cancer as unbeneficial²², unfeasible²⁶, insufficient, and confusing⁴³. In a study conducted among hospitalised patients receiving haematological treatments, patients also mentioned their need for personalised nutritional counselling tailored to their nutrition-related problems, financial constraints and individual preferences²⁷.

Healthcare professionals' experiences with psychosocial support for reduced ability to eat

The results of this thesis demonstrate that not all *primary HCPs* (assistant practitioners, dietitians, district nurses, and general practitioners) recognised or assessed the psychosocial consequences of a reduced ability to eat among patients with end-stage cancer. Furthermore, HCPs expressed that patients and

informal caregivers were reluctant to initiate conversations regarding these psychosocial issues. HCPs mentioned several explanations for this reluctance such as; patients who were too ill to talk at all, patients with multiple other issues that needed to be discussed, patients avoiding all healthcare and patients and informal caregivers who were afraid to hurt each other by discussing patients' reduced ability to eat in each other's presence. HCPs indicated that when patients or informal caregivers initiated discussions regarding the patient's reduced ability to eat, they often expressed this by non-verbal signals (e.g. visible emotions, or social interaction), or by talking about these problems indirectly. In addition, HCPs found it equally important to provide psychosocial support to both patients and informal caregivers with regard to the patient's wellbeing. Multidisciplinary collaboration is seen by HCPs as an important facilitator for providing psychosocial support for the patient's reduced ability to eat.

Recognition and assessment

The findings in this thesis show that *not all* primary HCPs recognised and assessed the psychosocial consequences of a reduced ability to eat. This finding is in concordance with the findings of past research, although there are only a few studies focused on HCPs' experiences with providing psychosocial support for patients with end-stage cancer and a reduced ability to eat. These studies show that HCPs avoided the conversation about patients' weight loss and the psychosocial consequences because they felt that the weight loss was irreversible and were unsure about how to provide support.⁵⁻⁷ A study conducted among physicians, nurses and dietitians in a teaching hospital shows that physicians expressed not to discuss patients' weight loss and subsequently the psychosocial consequences due to; lack of time, because they did not want to take away the patient's hope, or because they did not consider psychosocial support to be part of their professional role. Nurses in the same study expressed uncertainty to talk about patients' weight loss due to lack of education about cancer cachexia. Nurses and dietitians both expressed to avoid the topic because they were afraid to cause distress in patients.⁴⁴

Involving the informal caregivers

The results of this thesis demonstrate that primary HCPs caring for patients with end-stage cancer at their homes experienced it as equally important to provide psychosocial support to patients as to informal caregivers. Including informal caregivers in psychosocial support will most likely unburden both informal caregivers and patient. Patients were often concerned about the informal caregiver's wellbeing, and they worried that their reduced ability to eat caused too much stress in informal caregivers. Studies conducted among HCPs caring for patients in palliative care settings also unanimously demonstrate HCPs' awareness of the importance of

including informal caregivers. HCPs on the palliative ward of a teaching hospital reported that when informal caregivers were not included in nutritional support they sometimes started “fighting back”⁴⁵ the patient’s weight loss and in the worst cases even forced the patient to eat.^{45–47} In another study, HCPs from a specialised palliative care staff stressed the importance to initiate conversations about the patient’s reduced ability to eat with patients and informal caregivers together.⁴⁸

Multidisciplinary collaboration

In this thesis, HCPs mentioned multidisciplinary collaboration as an important facilitator for providing psychosocial support for the patient’s reduced ability to eat. There are no studies that specifically investigated HCPs’ experiences with multidisciplinary collaboration and psychosocial support for patients with cancer and a reduced ability to eat. However, studies that relate to the topic give reason to argue that the absence of multidisciplinary communication may lead to inadequate psychosocial support. Especially the absence of communication between dietitians and other HCPs caring for patients with end-stage cancer seems to lead to problems. One study describes how nurses did not refer patients with end-stage cancer to dietitians even when they considered it necessary, because they did not know how to get in touch with dietitians⁷, or because they assumed that dietitians were not able to visit patients at home⁵. The literature indicates that nurses seem to experience a barrier to refer patients with end-stage cancer to a dietitian. This may lead to suboptimal psychosocial support for reduced ability to eat; as one study conducted among European dietitians shows that they consider providing basic psychosocial care an integral part of their work. However, these dietitians also reported that they felt they were often involved too little or too late in the care for patients with end-stage cancer to still be able to provide adequate psychosocial support.⁴⁹ These findings are consistent with the results described in this thesis showing that dietitians felt they were involved too late in the care of patients with end-stage cancer by their colleagues.

Implications

Implications for daily clinical practice

Everyone acknowledges that for healthy people eating means more than meeting nutrient requirements. However, we tend to forget this when we talk with people with cancer. We tend to forget that they also want to enjoy their meals together with their loved ones, and if they are not able to do this it may lead to high levels of emotional distress and in some cases to social problems. From the results of this thesis we can formulate some recommendations to help HCPs provide psychosocial support to patients who experience a reduced ability to eat.

1. Recognise and assess the psychosocial consequences of a reduced ability to eat
2. Provide basic psychosocial support for a reduced ability to eat
3. Involve informal caregivers in support for a reduced ability to eat
4. Inform patients about the various informal support options for their reduced ability to eat
5. Identify patients who need personalised support for a reduced ability to eat
6. Arrange multidisciplinary support for a reduced ability to eat

Recognise and assess the psychosocial consequences of a reduced ability to eat

The results of this thesis suggest that the psychosocial consequences of a reduced ability to eat are not always recognised by HCPs and that patients find it difficult to start talking about it. As a result HCPs can easily overlook these issues. In addition, emotions that can accompany nutrition-related problems may change over time. It is not hard to imagine that if the patient is experiencing a reduced ability to eat for a few weeks, for example during chemotherapy, both patients and informal caregivers have little concern about this. It becomes a different story when the disease progresses and the patient starts to lose weight rapidly, when taste is not coming back, remains changed or when patients realise that eating may never be completely normal again. Therefore, it is important that screening for these psychosocial consequences receives more attention throughout the whole cancer trajectory. This can be arranged by complementing already existing screening tools used in clinical practice to identify nutrition-related problems or (risk of) malnutrition by adding a question about the psychosocial consequences of these problems.

The findings of this thesis also show that patients and informal caregivers seem to find it difficult to talk about the psychosocial consequences of a reduced ability to eat, and may downplay their problems with the patient’s reduced ability to eat out of concern for each other. HCPs caring for patients with end-stage cancer in the home setting mentioned that their repeated home visits enabled them to build a trusting relationship to discuss these problems. Furthermore, these HCPs expressed that by visiting patients at their homes they could use nonverbal communication and social interaction as prompts to discuss patients’ reduced ability to eat. Home visits are especially useful for HCPs caring for patients with cancer who are known to suffer from high impact nutrition-related problems such as patients with end-stage disease and patients receiving tube feeding or parenteral feeding at their homes.

However, a lot of HCPs treat patients clinically or on outpatient basis and do not have the opportunity to visit patients at home. For these HCPs it is import-

ant to keep in mind that the psychosocial consequences of a reduced ability to eat are easily overlooked if there is less time to get to know the patient and their informal caregivers or understand the patient's social situation.

Provide basic psychosocial support for a reduced ability to eat

The results of this thesis show that some of the psychosocial consequences of a reduced ability to eat stem from the misunderstanding that patients experience for their daily struggle with eating. For patients, acknowledgement of HCPs that their reduced ability to eat has not only physical but also emotional and social consequences can already reduce their perceived lack of understanding. HCPs can acknowledge psychosocial consequences of a reduced ability to eat by providing basic psychosocial support. Providing basic psychosocial support entails; listening to patients' and informal caregivers' stories, normalising emotions of patients and informal caregivers and properly informing patients and informal caregivers about the possible development of nutrition-related problems during the cancer trajectory. It is plausible to argue that in many cases, providing basic psychosocial support will be sufficient to prevent the development of more serious psychosocial consequences of the patient's reduced ability to eat, and that not every patient needs to be referred to a medical social worker, occupational therapist or psychologist.

Involve informal caregivers in support for a reduced ability to eat

When HCPs provide this basic psychosocial support, they can also directly address the misunderstanding for the struggle with eating patients may experience from their informal caregivers. Informal caregivers provide an important part of nutritional and psychosocial support for patients with cancer and a reduced ability to eat. When informal caregivers' high sense of responsibility and the emotions evoked by patients' reduced ability to eat remain unspoken, the likelihood of relationship problems between patients and informal caregivers is high. Therefore it is important to identify the social situation and care system of the patient. Who takes care of the patients diet? Have tensions arisen in the relationship with informal caregivers because of the patient's reduced ability to eat? Asking these questions kills two birds with one stone. On the one hand, patients are encouraged to articulate any psychosocial consequences of their reduced ability to eat, and this opens doors to seek appropriate support if necessary. At the same time, by talking about the social problems that may arise in the patient's social environment, it will also become clear how the informal caregivers experience the patient's reduced ability to eat and how this affects them emotionally and socially. Again, if necessary, appropriate support can then be provided for informal caregivers, to emotionally support them with their high sense of responsibility and feelings they may be experiencing due to

the patient's reduced ability to eat. The support for informal caregivers seems to be a gap in the current health system, while supporting informal caregivers with the patient's reduced ability to eat will greatly benefit both informal caregivers and patients. Besides talking with patients *and* informal caregivers simultaneously during patient consultation, it might also be of benefit to speak to informal caregivers separately.

Inform patients about the various informal support options for their reduced ability to eat

An important complement to formal care for patients with cancer is informal care.⁵⁰ Informal care for patients with cancer in the Netherland often takes place in low-threshold centres where patients can find a listening ear, peer support and activities that help with relaxation, coping and building resilience during and after the disease.⁵¹ Patients can connect with each other and share their experiences with reduced ability to eat via centres to support living with and after cancer (i.e. IPSO centra voor leven met en na kanker).⁵² In addition, patients and informal caregivers can find science based information about nutrition and cancer (i.e. voedingenkankerinfo.nl)⁵³ or join moderated online platforms with information about cancer and peer-to-peer forums (i.e. kanker.nl)⁵⁴. The psychosocial consequences of a reduced ability to eat are particularly well suited for informal support. After all, eating is something that preferably takes place in informal and personal situations rather than in the medical sphere or in institutions. To help patients cope with their reduced ability to eat, numerous initiatives have taken off in recent years. A shining example comes from the patient organisation for head and neck cancer in the Netherlands.⁵⁵ To help patients cope with their reduced ability to eat this patient organisation organises activities where people meet each other and eat together. Similar initiatives are also developed for other groups of patients with cancer, for example cooking workshops for cancer patients with (permanent) taste changes due to treatments as chemotherapy.^{56,57} During these workshops patients can get practical advices with regard to their reduced ability to eat. During the interviews conducted for this thesis, so many patients said something like: no one can really understand what it is like unless you experience it yourself. While cooking or eating together people can share their experiences with others who go through the same process.

Informing patients about the informal support options with regard to their reduced ability to eat is also important from a broader societal perspective. The number of patients diagnosed with cancer is expected to rise to 156,000 per year over the next decade.⁵⁸ With such an increase in the number of cancer diagnoses, solutions need to be explored to lower the burden on the national healthcare system.

Identify patients who need personalised support for a reduced ability to eat

The results of this thesis demonstrate that some patients who experience more severe psychosocial consequences of a reduced ability to eat need personalised and professional support in addition to both basic psychosocial and informal support. It is important that HCPs identify patients who are in need of extra or specialised support for their reduced ability to eat. In the Netherlands, the Distress Thermometer⁵⁹ is considered to be the most appropriate instrument for identifying distress in adults with cancer⁶⁰. The Distress Thermometer is a short questionnaire that patients can complete at home and thereafter discuss with their nurse or physician. On the Distress Thermometer the patient scores the level of distress of their disease-related problems, including family/social problems, emotional problems and problems with eating. When the patient scores a level of distress related to their reduced ability to eat, HCPs can use this as a starting point to further assess the psychosocial consequences of a reduced ability to eat. Furthermore, the Distress Thermometer includes a question about the patient's wish for referral. This makes the distress thermometer well suited for HCPs to initiate the process of Shared Decision Making. Shared Decision Making was implemented in 2006 in the Netherlands as a healthcare reform framework. The basic premise is that healthcare should match the patient's situation and needs as much as possible. In daily practice, it is the process in which HCPs and patients jointly discuss which healthcare best suits the values and wishes of the patient.⁶¹ This discussion is initiated by HCPs and is guided by four steps. In the first and second step the patient is informed about the option to choose and the medical and technical options with regard to the possible treatments. In the third and fourth step HCPs and patients jointly explore the patient's preferences and engage in Shared Decision Making.⁶² An important component in Shared Decision Making is that the patient is also informed about the option to refrain from treatments. For example, Shared Decision Making allows patients and dietitians to decide together not to aim for a certain protein or calorie intake because it is considered too stressful for the patient.

Arrange multidisciplinary support for a reduced ability to eat

In this thesis it is indicated that there is a group of patients who want to be informed about the existence of and referred to the healthcare disciplines that can support them to cope with their reduced ability to eat. In addition, results of this thesis showed how HCPs feel empowered when they work together in a multidisciplinary team or have a strong network of colleagues supporting patients and informal caregivers with a reduced ability to eat. When HCPs involved in all relevant disciplines of healthcare recognise and assess the psychosocial consequences of a reduced ability to eat, multidisciplinary collaboration

will be more easily to establish. To support multidisciplinary collaboration it is common practice in hospitals in the Netherlands to organise multidisciplinary consultations. Most of these multidisciplinary consultations already include dietitians and other HCPs that engage in support for patients with a reduced ability to eat. Multidisciplinary consultations are less frequently organised in primary care in the Netherlands because it is complex, time-consuming and cost-intensive to bring all relevant disciplines together. In daily practice, HCPs are often not paid for their participation in multidisciplinary consultations in primary care. In order to improve future primary care in the Netherlands, it is important that insurers recognise the added value of multidisciplinary consultation in primary care and make budget available for this. There are already working groups aimed at facilitating multidisciplinary consultation and collaboration in primary care that have already succeeded in bringing insurance companies to the table.⁶³

Furthermore, the upcoming healthcare centres and primary care oncology care networks will continue to facilitate collaboration between different healthcare disciplines within primary care. In the healthcare centres, HCPs from different disciplines work under one roof. In this way, multidisciplinary collaboration is facilitated because HCPs can easily visit each other. Communication between HCPs has become safer but not easier since the introduction of the European general data protection regulation in 2018.⁶⁴ Although patient privacy is significantly better safeguarded by this European legislation, it has proven to be a barrier with regard to the communication between healthcare disciplines, within primary care but also across the lines of care. There are already technological developments that partially solve this problem of limiting data sharing such as secured apps and secured email.

Existing best practices

- These practical clinical implications were informed by the many 'best practices' I encountered;
- A haematologist who recognises and acknowledges the psychosocial problems surrounding the reduced ability to eat in his patients: "Just eat what you like, life must still be worth living".
- A general practitioner who involves the dietitian early on in the palliative care of a patient, and together with the dietitian brings the difficult news that eating will probably never improve.
- A nurse who sees opportunities in improving the mouth opening of a patient with head and neck cancer and refers him or her to a specialist physiotherapist so that she might again have the chance to enjoy eating a little more.
- An assistant practitioner who refers an informal caregiver who is overly insistent on eating to a spiritual caregiver.

Implications for future research

Not every patient who develops chronic or permanent nutrition-related problems will experience psychosocial consequences of a reduced ability to eat and some patients with low impact nutrition-related problems will develop severe psychosocial consequences. The results of this thesis indicate that the experiences with a reduced ability to eat is dynamic, and food and eating seem to have different meanings in different disease stages throughout the cancer trajectory. Therefore, more research is needed to investigate *when* patients with a reduced ability to eat develop (severe) psychosocial consequences of a reduced ability to eat and how these psychosocial consequences *evolve* during the cancer trajectory.

To investigate these questions it is best to identify research populations with high impact of nutrition-related problems. It might be useful to use the infrastructure provided by nation-wide oncological cohort studies because this is the most efficient way to recruit large numbers of patients known to experience high-impact nutrition-related problems. In the Netherlands, one of the suitable cohorts to reach patients with high-impact nutrition-related problems seems the POCOP cohort for oesophageal and gastric cancer (Prospective Observational Cohort Study of Oesophageal-gastric cancer Patients).⁶⁵ Within the questionnaires used in this cohort study one or two questions can be added to assess the presence of psychosocial consequences of a reduced ability to eat and the related unmet supportive care needs throughout the cancer trajectory. In addition, patients recruited in this cohort studies can also be selected for a semi structured interview study. Purposive sampling methods^{66,67} can be used to include patients who develop psychosocial consequences of a reduced ability to eat in different stages of their disease. Patients selected for this interview study will be interviewed several times throughout their cancer trajectory. This mixed method study will provide insights in the questions *when and why* patients develop these psychosocial consequences and how these issues *evolve* over time.

Furthermore, more research is needed to gain insights in the clinical relevance of the psychosocial consequences of a reduced ability to eat. This can be done by investigating the relation between these psychosocial consequences and patients' outcomes, such as quality of life (QoL). Currently, the association between the psychosocial consequences of a reduced ability to eat and QoL is being investigated, using the data from the survey study presented in chapter 3 of this thesis.⁶⁸ The survey study was limited to patients with head and neck, lung cancer and lymphoma. To investigate these associations among a broader and more representative group of patients with cancer, it is recommended to use population based cohorts such as PROFILES (Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship).⁶⁹

Last, one of the questions not investigated in this thesis is *how many* patients experience psychosocial consequences of a reduced ability to eat. To investigate this, it is efficient to use the Netherlands Cancer Registry (NCR)⁷⁰. This national database consisting of all newly diagnosed cancer patients can be used to select patients diagnosed with cancer in a specific period. These patients can be asked to participate in a survey, that queries the incidence of the psychosocial consequences of a reduced ability to eat and related care needs, to a representative historical cohort of the general cancer population.

Together, these studies will provide a risk profile for developing psychosocial consequences of a reduced ability to eat, with patients' clinical characteristics and risk factors related to disease and disease stage. This risk profile together with data on the impact of the psychosocial consequences of a reduced ability to eat on the patient's QoL, will sufficiently inform both HCPs and patients to engage in shared decision making and jointly decide over treatment options and referral to other disciplines of healthcare.

Implications for education

All HCPs can encounter patients with psychosocial consequences of a reduced ability to eat. Therefore, it is important to ensure that this topic is included in the education of HCPs who care for patients with cancer. The main aim is to create awareness for these problems among all HCPs and to incorporate it in daily practice. As the starting point for support for patients with a reduced ability to eat will often be the physician and oncology nurses it is especially recommended to incorporate education about the psychosocial consequences of a reduced ability to eat in their basic medical training. For example, based on the results of this thesis, recommendations for HCPs on psychosocial consequences are included in the national guideline for general nutrition and dietary treatment.⁷¹ It is a recommendation to support adherence to this guideline. Furthermore, an e-learning has been developed based on the research presented in this thesis. This e-learning aims to increase awareness about these psychosocial consequence and informs about the support options in various disciplines of healthcare.⁷² It is recommended to integrate this free available e-learning into continuing training of all HCPs who care for patients with cancer. Also scientific articles about this subject in professional and academic journals will increase awareness among HCPs.

Methodological considerations

Little was known about the psychosocial consequences of and the psychosocial support for patients' reduced ability to eat during the whole cancer trajectory. Qualitative research methods are appropriate when little is known about a subject and when the aim is to capture the widest possible range of participants

experiences. Therefore, the qualitative research methods used in several chapters of this thesis are the appropriate choice of conduct. Qualitative research involves the recruitment of small numbers of participants which limits the generalisability of the results. To enrich the qualitative results, a cross sectional survey was conducted, based on the qualitative data. In this cross sectional survey study, a larger sample size was included, which partly compensated the limited generalisability of the qualitative results. This improved the external validity of the results among patient populations with the same primary cancer type.

For the interview studies and one of the survey studies patients were recruited via an online call posted via patient organisations and via the participating hospitals. However, most of the patients were included via patient organisations. This might have led to a selection bias favouring a patient population relatively younger and higher educated when compared to the general cancer population⁷⁰. Furthermore, participation in an interview or survey depends on the physical state of the patient and patients with a low QoL are less likely to participate in a study. On the other hand, patients who experience severe psychosocial consequences of a reduced ability to eat may be motivated to participate in a study that enquires the topic because they want to call attention to it. Therefore, the results of the studies should be interpreted with caution and should not be generalised to the larger population of patients with cancer. Furthermore, HCPs were recruited via a network of HCPs experienced in oncological, palliative or nutritional support. This may have led to a selection bias of HCPs interested, educated or specialised in these fields of healthcare. Consequently, in daily practice the psychosocial consequences of a reduced ability to eat may be less frequently recognised and assessed in primary care than the results of this thesis may suggest.

For the interview studies, all patients and informal caregivers except one were interviewed together. This may have resulted in giving socially acceptable answers and it is possible that conflicts about eating were more serious or occurred more frequently than the results of these chapters suggest, because patients and informal caregivers did not want to hurt each other. Some participants were interviewed or filled in a questionnaire one to five years or more after diagnosis. These participants might not have remembered the psychosocial consequences of a reduced ability to eat accurately (recall bias) possibly resulting in an underestimation of the psychosocial consequences. Due to the cross sectional character of the studies no conclusions about causality can be made. It is possible that the observed associations might be bidirectional.

Conclusions

The psychosocial consequences of a reduced ability to eat occur throughout the whole cancer trajectory and may have a high impact on patients' well-being and quality of life. Currently, patients may have unmet needs regarding support for their reduced ability to eat. All HCPs caring for patients with cancer need to be aware of the psychosocial consequences of a reduced ability to eat. Recognition by HCPs and providing basic psychosocial support for these issues is critical. Multidisciplinary collaboration is key for providing adequate support for reduced ability to eat. Screening for the psychosocial consequences of a reduced ability to eat requires more attention in all phases of treatments and especially in follow-up care. HCPs need to inform patients about informal support options and involve informal care givers in nutritional and psychosocial counselling. Furthermore, HCPs should explore together with the patient the need for referral to multidisciplinary and personalised support for a reduced ability to eat.



REFERENCES

1. Wheelwright S, Darlington AS, Hopkinson JB, Fitzsimmons D, Johnson C. A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia. *Palliat Med* 2016;30(2):149-60.
2. Oberholzer R, Hopkinson J, Baumann K, Omlin A, Kaasa S, Fearon K, et al. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;46(1):77-95.
3. Cooper C, Burden S, Cheng H, Molassiotis A. Understanding and managing cancer-related weight loss and anorexia: insights from a systematic review of qualitative research. *Journal of Cachexia, Sarcopenia and Muscle* 2015;6(1):99-111.
4. Wheelwright S, Darlington A, Hopkinson J, Fitzsimmons D, White A, Johnson C. A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care* 2014;6(3):307-14.
5. Dewey A, Dean T. Assessment and monitoring of nutritional status in patients with advanced cancer: part 1. *Int J Palliat Nurs* 2007;13(6):258-65.
6. Dewey A, Dean T. Nurses' management of patients with advanced cancer and weight loss: part 2. *Int J Palliat Nurs* 2008;14(3):132-8.
7. Hopkinson J, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care professionals. *J Pain Symptom Manage* 2006;31(4):293-305.
8. Hopkinson J, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs* 2006;54(3):304-12.
9. Hopkinson JB. The emotional aspects of cancer anorexia. *Curr Opin Support Palliat Care* 2010;4(4):254-8.
10. Hopkinson J. How people with advanced cancer manage changing eating habits. *J Adv Nurs* 2007;59(5):454-62.
11. Hopkinson JB. Carers' Influence On Diets Of People With Advanced Cancer. *Nursing Times* 2008;104(12):28-9.
12. Reid J, McKenna H, Fitzsimons D, McCance T. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer Care (Engl)* 2010;19(5):682-9.
13. Holden C. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. *Hosp J* 1991;7(3):73-84.
14. Muir CI, Linklater GT. A qualitative analysis of the nutritional requirements of palliative care patients. *J Hum Nutr Diet* 2011;24(5):470-8.
15. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *Journal of Human Nutrition and Dietetics* 2000;13(2):113-7.
16. Souter J. Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences. *Int J Palliat Nurs* 2005;11(10):524-32.
17. Hopkinson J. Investigation of the family approach to weight and eating for families affected by cancer cachexia. *BMJ Supportive & Palliative Care* 2012;2(Suppl 1):A51-A.
18. Orrevall Y, Tishelman C, Herrington M, 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. *Clinical Nutrition* 2004;23(6):1280-7.
19. Hinsley R, Hughes R. 'The reflections you get': an exploration of body image and cachexia. *Int J Palliat Nurs* 2007;13(2):84-9.
20. Shragge J, Wismer W, Olson K, Baracos V. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med* 2007;21(3):227-33.
21. Strasser F, Binswanger J, Cerny T, Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliat Med* 2007;21(2):129-37.
22. Locher JL, Robinson CO, Bailey FA, Carroll WR, Heimbürger DC, Magnuson JS, et al. The contribution of social factors to under-eating in older adults with cancer. *J Support Oncol* 2009;7(5):168-73.
23. Opsomer S, Joossens S, De Wit C, Lauwerier E, Pype P. Losing Health Symbols Because of Nutrition-Related Problems in Advanced Cancer: An Interpretative Phenomenological Analysis. *Journal of Hospice & Palliative Nursing* 2018;20(5):492-9.
24. Amano K, Baracos V, Hopkinson J. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Critical Reviews in Oncology/Hematology* 2019;143:117-23.
25. Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Supportive Care in Cancer* 2018;27(8):2869-76.
26. Larsson M, Hedelin B, Athlin E. Needing a hand to hold: lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nurs* 2007;30(4):324-34.
27. McGrath P. Reflections on nutritional issues associated with cancer therapy. *Cancer Pract* 2002;10(2):94-101.
28. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 2013;22(7-8):1034-43.
29. Amano K, Maeda I, Morita T, Tatara R, Katayama H, Uno T, et al. Need for nutritional support, eating-related distress and experience of terminally ill patients with cancer: a survey in an inpatient hospice. *BMJ supportive & palliative care* 2016;6(3):373-6.
30. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;36(4):439-45.
31. Hopkinson J. The Nourishing Role: Exploratory Qualitative Research Revealing Unmet Support Needs in Family Carers of Patients With Advanced Cancer and Eating Problems. *Cancer Nursing* 2018;41(2):131-8.
32. Meares CJ. Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncol Nurs Forum* 1997;24(10):1751-7.

33. Raijmakers N. End of Life Care and Decision Making: Opinions and experiences of the general public, bereaved relatives, and professionals. 2013.
34. Molassiotis A, Stricker CT, Eaby B, Velders L, Coventry PA. Understanding the concept of chemotherapy-related nausea: the patient experience. *Eur J Cancer Care (Engl)* 2008;17(5):444-53.
35. Salihah N, Mazlan N, Lua PL. Chemotherapy-induced nausea and vomiting: exploring patients' subjective experience. *J Multidiscip Healthc* 2016;9:145-51.
36. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European journal of oncology nursing* 2011;15(2):145-51.
37. Koshimoto S, Arimoto M, Saitou K, Uchibori M, Hashizume A, Honda A, et al. Need and demand for nutritional counselling and their association with quality of life, nutritional status and eating-related distress among patients with cancer receiving outpatient chemotherapy: a cross-sectional study. *Supportive Care in Cancer* 2019.
38. Wilson K, Pateman B, Beaver K, Luker KA. Patient and carer needs following a cancer-related hospital admission: the importance of referral to the district nursing service. *Journal of Advanced Nursing* 2002;38(3):245-53.
39. van Overveld LF, Takes RP, Turan AS, Braspenning JC, Smeele LE, Merckx M, et al. Needs and preferences of patients with head and neck cancer in integrated care. *Clinical Otolaryngology* 2018;43(2):553-61.
40. Crowder SL, Douglas KG, Yanina Pepino M, Sarma KP, Arthur AE. Nutrition impact symptoms and associated outcomes in post-chemoradiotherapy head and neck cancer survivors: a systematic review. *J Cancer Surviv* 2018;12(4):479-94.
41. Crowder S, Najam N, Sarma K, Fiese B, Arthur A. Head and Neck Cancer Survivors' Experiences with Chronic Nutrition Impact Symptom Burden after Radiation: A Qualitative Study. *J Acad Nutr Diet* 2020;120(10):1643-53.
42. Einarsson S, Laurell G, Tiblom Ehrsson Y. Experiences and coping strategies related to food and eating up to two years after the termination of treatment in patients with head and neck cancer. *Eur J Cancer Care (Engl)* 2019;28(2):e12964.
43. Beeken R, Williams K, Wardle J, Croker H. "What about diet?" A qualitative study of cancer survivors' views on diet and cancer and their sources of information. *European journal of cancer care* 2016;25(5):774-83.
44. Millar C, Reid J, Porter S. Refractory cachexia and truth-telling about terminal prognosis: a qualitative study. *Eur J Cancer Care (Engl)* 2013;22(3):326-33.
45. 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.
46. 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.
47. McClement SE, Harlos M. When advanced cancer patients won't eat: family responses. *Int J Palliat Nurs* 2008;14(4):182-8.
48. Clark J, Raijmakers NJ, Allan S, Zuylen Lv, Heide Avd. Declining oral intake towards the end of life: how to talk about it? A qualitative study. *International journal of palliative nursing* 2017;23(2):74-82.
49. Pinto I, Pereira J, Campos C, Thompson J. The dietitian's role in palliative care: a qualitative study exploring the scope and emerging competencies for dietitians in palliative care. *J Palliat Care Med* 2016;6(2):253.
50. Hamelhuys. Onderzoek bewijst meerwaarde informele zorg bij kanker. 2019 [January 3, 2023]. Available from: <https://hamelhuys.nl/onderzoek-bewijst-meerwaarde-informele-zorg-bij-kanker/>
51. De Juiste Zorg op de Juiste Plek. Informele psychosociale zorg voor mensen met kanker. 2023 [January 3, 2023]. Available from: <https://www.dejuistezorgopdejuisteplek.nl/praktijkvoorbeelden/informele-psychosociale-zorg-voor-mensen-met-kanker/>
52. IPSO Centra voor leven met en na kanker. n.d. [November 11, 2022]. Available from: <https://ipso.nl/>
53. Wereld Kanker Onderzoek Fonds. 2022 [11 November, 2022]. Available from: <https://www.voedingenkankerinfo.nl/>
54. Kanker.nl. Kanker.nl we zijn er voor je. n.d. [January 3, 2023]. Available from: <https://www.kanker.nl/>
55. Patientenvereniging Hoofd-Hals. 2023 [January 3, 2023]. Available from: <https://pvhh.nl/>
56. Eric-Jan Wissink. Kennis, kunde en kruiden. n.d. [December 22, 2022]. Available from: <https://www.ericjandesmaakman.nl/>
57. Eten+Welzijn. Kookworkshops 'Eet goed voor jezelf' verdienen vervolg. n.d. [03 January 2023]. Available from: <https://www.etenwelzijn.nl/kookworkshops>



58. Integraal Kanker Centrum Nederland (IKNL). Kanker in Nederland trends & prognoses tot en met 2032. 2022 [January 3, 2023]. Available from: <https://iknlsawebprod.blob.core.windows.net/mediacontainer/iknl/media/pdfs/kanker%20in%20beeld/trendrapport-kanker-in-nl-digitale-versie.pdf>
59. Tuinman M, Gazendam-Donofrio S, Hoekstra-Weebers J. Screening and referral for psychosocial distress in oncologic practice: use of the Distress Thermometer. *Cancer* 2008;113(4):870-8.
60. Federatie Medisch Specialisten. Detecteren behoefte psychosociale zorg. n.d. [January 3, 2022]. Available from: https://richtlijndatabase.nl/richtlijn/detecteren_behoefte_psychosociale_zorg/meest_geschikte_instrument/psychometrische_eigenschappen.html
61. van der Weijden T, van Veenendaal H, Drenthen T, Versluijs M, Stalmeier P, Koelewijn-van Loon M, et al. Shared decision making in the Netherlands, is the time ripe for nationwide, structural implementation? *Z Evid Fortbild Qual Gesundheitswes* 2011;105(4):283-8.
62. Nederlandse Federatie van Kanker Patientens Organisaties (NFK). Tools bij Samen Beslissen. 2022 [January 3, 2023]. Available from: <https://nfk.nl/themas/samen-beslissen/tools-bij-samen-beslissen>
63. Integraal Kanker Centrum Nederland (IKNL). Netwerkvorming Oncologie: ook voor de gevolgen van kanker. n.d.
64. European Commission. Data protection in the EU. n.d. [December 12, 2023]. Available from: https://commission.europa.eu/law/law-topic/data-protection/data-protection-eu_en
65. Dutch Upper GI Cancer Group. POCOP biedt een platform voor het verzamelen van gegevens van patiënten met slokdarm- en maagkanker. n.d. [January 3, 2022]. Available from: <https://pocop.nl/>
66. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 2007;19(6):349-57.
67. Boeije H. *Analysis in qualitative research*. Sage publications Ltd; 2009.
68. Nijholt S, Lize N, van Lieshout R, van den Berg M, Kok A, Beijer S, et al. The association between psychosocial consequences of a reduced ability to eat and QoL in patients with cancer. [Unpublished manuscript]. In press 2022.
69. Profiles Registry. The PROFILES registry. 2023 [January 3, 2023]. Available from: <https://www.profilesregistry.nl/>
70. Nederlandse Kankerregistratie (NKR) IKNL. NKR Cijfers. 2022 [January 11, 2023]. Available from: iknl.nl/nkr-cijfers
71. Landelijke Werkgroep Dietisten Oncologie (LWDO). Algemene Voedings- en dieetbehandeling Landelijke richtlijn, Versie: 3.0. 2017 [January 3, 2023]. Available from: https://nvdietist.nl/app/uploads/2021/03/Algemene_Voedings-en_dieetbehandeling.pdf
72. Wereld Kanker Onderzoek Fonds (WKOF). Informatie voor professionals. 2022 [November 15, 2022]. Available from: <https://www.voedingenkankerinfo.nl/professionals/>



CHAPTER 9

Summary

(in English and Dutch)



SUMMARY

Cancer and its treatments often lead to nutrition-related problems resulting in a reduced ability to eat. Unfortunately, little is known about the psychosocial consequences of a reduced ability to eat in patients with cancer. Previous research has been primarily conducted in patients with end-stage cancer and in patients with cancers which are known to cause severe nutrition-related problems. Research in patients with end-stage cancer shows that a reduced ability to eat in the final stage of the disease can often lead to negative emotions for both patients and their informal caregivers. The relationship between patients and their informal caregivers can also be strained by a reduced ability to eat. In addition, little is known about the impact of these psychosocial consequences on patients' well-being and quality of life. Patients report that healthcare professionals (HCPs) pay little attention to the psychosocial consequences of a reduced ability to eat. However, there is little knowledge about what kind of professional supportive care needs patients and their informal caregivers have. Also, little research has been done on the experiences of HCPs with providing psychosocial support for patients with cancer and a reduced ability to eat. Therefore, the objective of this thesis is twofold:

1. to map the psychosocial consequences of a reduced ability to eat in patients with cancer and their informal caregivers and,
2. to gain insight into the psychosocial support provided for patients with cancer and a reduced ability to eat, as experienced by patients and HCPs

Psychosocial consequences of a reduced ability to eat

Chapter 2 presents the results of an exploratory qualitative interview study. The aim is to map the psychosocial consequences of a reduced ability to eat in patients with cancer and their informal caregivers. Interviews were held with 24 patients with head and neck cancer, lung cancer or lymphoma and twelve informal caregivers. These patients and informal caregivers express that they experience psychosocial consequences of a reduced ability to eat in all stages of the disease. The main themes that emerge are: the struggle with eating, the experienced misunderstanding for this struggle and the high sense of responsibility in informal caregivers. These three themes lead to emotional consequences for patients and informal caregivers such as; anger, anxiety, disappointment, guilt, grief or sadness, powerlessness and shame. Arguments about eating can occur between patients and informal caregivers, but these appear to be less serious compared to the results of research conducted in end-stage cancer settings. When these arguments occur this is often due to informal caregivers' efforts to get the patient to eat more or better. The patient's reduced ability to eat seems

to have little impact on the relationships with family and friends. However, a reduced ability to eat does have social consequences for patients and informal caregivers, such as experiencing a reduced pleasure in social activities. As a result, patients and informal caregivers adjust their social activities, seek other activities, or avoid certain social activities.

Chapter 3 describes an interview study conducted in 23 patients with acute myeloid leukemia (AML) who recently received intense anti-cancer treatments. In the interviews patients were asked about their experiences with nutritional support in the hospital during treatments. These interviews show that nutritional support in the hospital can both alleviate and exacerbate emotional distress. Patients experience the nutrition-related problems caused by the intensive AML treatments in different ways. Their experiences range from experiencing severe emotional distress to acceptance. On the one hand, adequate nutritional support provides peace of mind for patients. On the other hand, some patients experience loss of independence, limited mobility, problems with feeding equipment and/or fear of unwanted weight gain (from enteral or parenteral feeding). Patients also express that when they experienced large variations in nutritional support practices between different hospitals, this lead to severe emotional distress, confusion and reduced confidence in general healthcare practices for patients with cancer. The continuity of nutritional support practices is important to patients who receive anti-cancer treatments in different hospitals.

Psychosocial support for a reduced ability to eat

Chapter 4 describes the emotional impact of a reduced ability to eat in patients with cancer and patients' satisfaction with HCPs support for these issues. This questionnaire study was conducted in 98 patients with head and neck cancer, lung cancer or lymphoma. It shows that a reduced ability to eat has a high emotional impact. The emotional consequences with the highest impact score are disappointment, sadness and anger. The most commonly reported emotional consequences are less enjoyment, longing for certain foods and powerlessness. The majority of patients who received support for a reduced ability to eat and its emotional consequences received this support from a dietitian (89%). Of the patients who did not receive this support, one in five indicated a need for it. Most patients who received support for a reduced ability to eat are satisfied with this support (66%). Patients who have been diagnosed longer ago are less satisfied with HCPs support for a reduced ability to eat than patients diagnosed less than a year ago. In addition, patients who do not expect their reduced ability to eat to improve are less satisfied with HCPs support than patients who expect to eat better in the future.

Chapter 5 describes the association between gastrointestinal nutrition-related problems, received nutritional support, and nutritional care needs with quality of life in patients with end-stage cancer. The nutrition-related outcomes from a baseline questionnaire are analysed. The data comes from the prospective cohort study eQuipe on quality of life and quality of care. The questionnaire was administered to 1080 patients with advanced cancer. The analysis shows that nearly half of these patients experience clinically relevant gastrointestinal problems, while only 14% receives nutritional support. Having gastrointestinal problems, received nutritional support and having nutritional care needs, are associated with lower quality of life within this patient population. The lower quality of life reported by patients in this study is probably due to reversed causality or the irreversible nature of nutrition-related problems in the palliative phase.

Chapter 6 describes patients' experiences with psychosocial support for a reduced ability to eat. For this qualitative interview study, interviews were conducted with 24 patients with head and neck cancer, lung cancer or lymphoma. Patients are positive about the professional support they receive when a team of HCPs from different disciplines acknowledge their reduced ability to eat throughout the whole disease trajectory. Patients also find it important that HCPs collaborate with each other and communicate well with their colleagues about these issues. Patients have negative experiences when HCPs are primarily focused on improving their nutritional intake, rather than tailoring nutritional support to their personal goals. Patients have positive experiences with informal support when informal caregivers show understanding for their reduced ability to eat and the psychosocial consequences. Whether informal caregivers' practical support for the daily mails is perceived as positive varies from patient to patient.



Chapter 7 provides insights into HCPs' experiences with giving psychosocial support for a reduced ability to eat to patients with end-stage cancer. For this qualitative interview study, 40 primary HCPs were interviewed including; ten assistant practitioners for healthcare, ten dietitians, ten district nurses, and ten general practitioners. This interview study shows that not all HCPs discuss the psychosocial consequences of a reduced ability to eat. Healthcare providers mention a number of reasons not initiate the conversation; they do not recognise the issue, they perceive it as a private matter, or they perceive cultural differences to be too great to initiate the conversation. HCPs perceive that patients and informal caregivers find it difficult to express their concerns about the patient's reduced ability to eat, and when they express themselves they often do so non-verbally or by talking about it indirectly. HCPs emphasise the importance of involving informal caregivers in psychosocial support for a reduced ability to eat. Multidisciplinary collaboration is the most important facilitator for HCPs to provide this type of psychosocial support. HCPs mention the following barriers; having too little knowledge, experiencing too limited exchange of professional expertise between colleagues, having limited access to other HCPs and the limited involvement in homecare for patients with advanced cancer.

Chapter 8 summarises the main findings of this thesis, the methodological considerations of the different studies, suggestions for future research, education and clinical practice. In conclusion one can state that, the psychosocial support for a reduced ability to eat should be an integral part of nutritional care for patients with cancer, *and* their informal caregivers. From the results of this thesis the following recommendations for HCPs' daily practice are formulated:

1. Recognise and acknowledge the psychosocial consequences of a reduced ability to eat during the entire disease trajectory
2. Provide basic psychosocial support for a reduced ability to eat
3. Involve informal caregivers in psychosocial support for a reduced ability to eat
4. Inform patients and informal caregivers about informal support options
5. Recognise patients who need personalised support for a reduced ability to eat
6. If necessary, organise multidisciplinary support for patients with a reduced ability to eat

SAMENVATTING

Kanker en de behandeling daarvan leiden vaak tot voedingsklachten die het eten bemoeilijken. Er is helaas nog weinig bekend over de psychosociale gevolgen van het moeilijker eten door kanker. Het onderzoek dat naar deze problematiek gedaan is, is voornamelijk uitgevoerd bij patiënten met gevorderde kanker en bij patiënten met vormen van kanker die bekend staan om ernstige voedingsproblematiek. Uit het onderzoek bij patiënten met gevorderde kanker blijkt dat het moeilijker eten in het laatste stadium van de ziekte vaak tot negatieve emoties voor zowel de patiënt als diens naasten kan leiden. Ook de relatie tussen patiënten en naasten kan door het moeilijker eten onder druk komen te staan. Daarnaast is er weinig bekend over de impact van deze psychosociale gevolgen op het welzijn en de kwaliteit van leven van de patiënt. Patiënten geven aan dat er weinig aandacht is van zorgverleners voor de psychosociale gevolgen van problemen met eten. Echter, er is weinig kennis over wat voor psychosociale ondersteuning de patiënt en diens naasten willen krijgen. Ook is er nog nauwelijks onderzoek gedaan naar de ervaringen van zorgverleners met het geven van psychosociale ondersteuning aan patiënten met kanker die moeilijker eten. De doelstelling van dit proefschrift is dan ook tweeledig:

1. het in kaart brengen van de psychosociale gevolgen van het moeilijker eten van patiënten met kanker en hun naasten en,
2. inzicht verkrijgen in de geboden psychosociale ondersteuning bij het moeilijker eten door kanker, zoals ervaren door patiënten én zorgverleners.

Psychosociale gevolgen van het moeilijker eten

Hoofdstuk 2 presenteert de resultaten van een exploratieve kwalitatieve interviewstudie waarin de psychosociale gevolgen van het moeilijker eten in kaart wordt gebracht. Uit de interviews met 24 patiënten met hoofd-hals kanker, longkanker of lymfoom en twaalf naasten blijkt dat zij in alle stadia van de ziekte psychosociale gevolgen van het moeilijker eten ervaren. Enkele belangrijke thema's die naar voren komen zijn; de worsteling met het eten, het ervaren onbegrip voor deze worsteling en het grote verantwoordelijkheidsgevoel van de naasten. Deze drie thema's leiden tot emotionele gevolgen voor patiënten en naasten zoals; angst, boosheid, machteloosheid, schaamte, schuld, teleurstelling en verdriet. Wanneer er conflicten over het eten ontstaan tussen patiënten en naasten lijken deze mild te verlopen vergeleken met het onderzoek gedaan in de context van gevorderde kanker. Als deze conflicten ontstaan komt dit vaak voort uit de moeite die naasten doen om de patiënt meer of beter te laten eten. Het moeilijker eten lijkt weinig invloed te hebben op de relatie met familie en vrienden. Wel heeft het moeilijker eten sociale gevolgen voor patiënten

en naasten, zoals het ervaren van minder plezier in sociale activiteiten. Het gevolg is dat patiënten en naasten hun sociale activiteiten aanpassen, op zoek gaan naar andere activiteiten, of sociale activiteiten vermijden.

Hoofdstuk 3 beschrijft een interview studie met 23 patiënten met acute myeloïde leukemie (AML) die recent intensieve behandelingen hebben ondergaan. In de interviews wordt patiënten gevraagd naar hun ervaringen met de voedingszorg in het ziekenhuis tijdens de behandelingen. Uit deze interviews komt naar voren dat de voedingszorg in het ziekenhuis emotionele distress zowel kan verlichten als versterken. Patiënten ervaren de voedingsproblemen veroorzaakt door de intensieve AML behandelingen verschillend. Waarbij hun ervaringen variëren van hevige emotionele distress tot acceptatie. Aan de ene kant geeft adequate ondersteunende voedingszorg patiënten mentale rust. Aan de andere kant ervaren sommige patiënten een verlies aan zelfstandigheid, beperkte mobiliteit, problemen met voedingsapparatuur en/of angst voor ongewenste gewichtstoename (bij enterale of parenterale voedingsondersteuning). Patiënten geven ook aan dat wanneer zij in verschillende ziekenhuizen grote verschillen in de ondersteunende voedingszorg ervaren dit resulteert in ernstige emotionele distress, verwarring en een verminderd vertrouwen de gehele zorg voor patiënten met kanker in het algemeen. De continuïteit van voedingszorg is belangrijk voor patiënten die worden behandeld in verschillende ziekenhuizen.

Psychosociale ondersteuning bij het moeilijker eten

Hoofdstuk 4 beschrijft de emotionele impact van het moeilijker eten voor patiënten met kanker en de patiënt tevredenheid met de ondersteuning van zorgverleners bij deze problemen. Deze vragenlijststudie is afgenomen bij 98 patiënten met hoofd-hals kanker, longkanker of lymfoom. Hieruit komt naar voren dat het moeilijker eten een grote emotionele impact heeft. De emotionele gevolgen met de hoogste impact score zijn teleurstelling, verdriet en boosheid. De emotionele gevolgen die het vaakst genoemd worden zijn minder genot, het verlangen naar bepaalde voedingsmiddelen en machteloosheid. De meerderheid van de patiënten die steun ontvangt bij het moeilijker eten en de emotionele gevolgen hiervan ontvangt dit van een diëtist (89%). Van de patiënten die deze steun niet ontvangt geeft een op de vijf aan hier behoefte aan te hebben. De meeste patiënten die ondersteuning krijgen bij het moeilijker eten zijn tevreden met deze ondersteuning (66%). Patiënten zijn langer na de diagnose minder tevreden over de steun van zorgverleners voor het moeilijker eten dan patiënten die minder dan een jaar geleden zijn gediagnosticeerd. Bovendien zijn patiënten die niet verwachten dat het moeilijker eten nog verbetert minder tevreden over de ondersteuning van zorgverleners dan patiënten die verwachten dat het eten makkelijker zal gaan in de toekomst

Hoofdstuk 5 beschrijft het verband tussen gastro-intestinale voedingsklachten, ontvangen voedingszorg en voedingszorgbehoeften, met kwaliteit van leven bij patiënten met gevorderde kanker. In deze vragenlijst studie worden de voedings-gerelateerde uitkomsten geanalyseerd van een baseline vragenlijst. De vragenlijst is afkomstig uit een prospectieve cohort studie (eQuipe) naar kwaliteit van leven en kwaliteit van zorg. De vragenlijst werd afgenomen onder 1080 patiënten met gevorderde kanker. De analyse laat zien bijna de helft van de patiënten klinisch relevante gastro-intestinale klachten ervaren, terwijl slechts 14% voedingszorg ontvangt. Het hebben van gastro-intestinale voedingsklachten, ontvangen voedingszorg en voedingszorgbehoeften hangen samen met een lagere kwaliteit van leven in deze groep patiënten. Deze lagere kwaliteit van leven wordt waarschijnlijk veroorzaakt door omgekeerde causaliteit of de onomkeerbaarheid van voedingsklachten in de palliatieve fase.

Hoofdstuk 6 beschrijft de ervaringen van patiënten met de psychosociale ondersteuning die zij ontvingen voor het moeilijker eten. Voor deze kwalitatieve interviewstudie zijn interviews afgenomen bij 24 patiënten met hoofd-hals kanker, longkanker of lymfoom. Patiënten zijn positief over de ontvangen professionele zorg wanneer een team van zorgverleners uit verschillende disciplines hun voedingsproblemen erkennen gedurende het gehele ziekteverloop. Ook vinden patiënten het belangrijk dat zorgverleners goed met elkaar samenwerken en onderling goed communiceren over deze problemen. Patiënten hebben negatieve ervaringen wanneer zorgverleners zich vooral richtten op het verbeteren van de voedingsinname, in plaats van de voedingszorg af te stemmen op de persoonlijke doelen van de patiënt. Patiënten hebben positieve ervaringen met de informele ondersteuning wanneer de naasten begrip tonen voor het moeilijker eten en de psychosociale gevolgen. Of de praktische steun van de naasten bij het eten als positief wordt beoordeeld verschilt per patiënt.

Hoofdstuk 7 biedt inzicht in de ervaringen van zorgverleners met het geven van psychosociale ondersteuning bij het moeilijker eten aan patiënten met gevorderde kanker. Voor deze kwalitatieve interviewstudie zijn 40 zorgverleners uit de eerste lijn geïnterviewd, tien diëtisten, tien huisartsen, tien praktijkondersteuners en tien wijkverpleegkundigen. Uit deze interviewstudie blijkt dat de zorgverleners niet altijd het gesprek starten met patiënten en naasten over de psychosociale gevolgen van het moeilijker eten. Zorgverleners noemen een aantal redenen om het onderwerp niet aan te kaarten; ze herkennen de problematiek niet, ze beschouwen het als een privéaangelegenheid, of ze ervaren te veel culturele verschillen om het gesprek aan te gaan. Zorgverleners zien dat patiënten en naasten hun zorgen over het moeilijker eten van de patiënt moeilijk uitten, en als zij zich uitten dit vaak doen via non-verbale signalen of door er indirect over te praten. Zorgverleners benadrukken het belang van het betrekken van de naasten bij de psychosociale ondersteuning voor het moeilijker eten. Multidisciplinaire samenwerking is de belangrijkste faciliterende factor voor zorgverleners om deze psychosociale ondersteuning te geven. Zorgverleners noemen als barrières; het hebben van te weinig kennis, het ervaren van een beperkte uitwisseling van professionele expertise met collega's, het hebben van beperkte toegang tot andere zorgverleners en beperkte betrokkenheid bij de thuiszorg voor patiënten met gevorderde kanker.

Hoofdstuk 8 bevat een samenvatting van de belangrijkste bevindingen van dit proefschrift, de methodologische overwegingen van de verschillende studies, suggesties voor toekomstig onderzoek, onderwijs en de klinische praktijk. Concluderend kan men stellen dat de psychosociale ondersteuning voor het moeilijker eten een integraal onderdeel zou moeten zijn van de voedingszorg voor patiënten met kanker, én voor hun naasten. Vanuit de resultaten van dit proefschrift worden de volgende aanbevelingen voor de dagelijkse zorgpraktijk geformuleerd:

1. Herken en erken de psychosociale gevolgen van het moeilijker eten gedurende het gehele ziekteproces
2. Geef basale psychosociale ondersteuning bij het moeilijker eten
3. Betrek de naasten bij de psychosociale ondersteuning voor het moeilijker eten
4. Informeer patiënten en naasten over informele ondersteuningsmogelijkheden
5. Herken de patiënten die gepersonaliseerde ondersteuning nodig hebben bij het moeilijker eten
6. Organiseer indien nodig multidisciplinaire ondersteuning voor het moeilijker eten



APPENDICES

Words of Appreciation

List of Publications

About the Author

WORDS OF APPRECIATION

DANKWOORD

Om te beginnen wil ik de patiënten en naasten bedanken die mee hebben gewerkt aan het onderzoek. Ik heb mij er altijd over verbaasd dat mensen die zoiets heftigs meemaken als een kankerdiagnose hun – vaak spaarzame – tijd en energie investeren in het deelnemen aan een interview, of het invullen van een vragenlijst. Hun drijfveer was bijna altijd dat zij anderen in eenzelfde situatie wilde helpen. Deze wens werd een belangrijke drijfveer voor mij gedurende dit promotietraject. Ook wil ik de zorgverleners bedanken die tijd vrij hebben gemaakt voor een interview, zelfs tijdens de coronapandemie.

Het was een drietrapsraket die mij dit promotietraject in slingerde. Gina, dankjewel dat je zag dat ik – ondanks dat ik het naar mijn zin had als je directe collega en gastvrouw – behoefte had aan het verzilveren van mijn ‘verse’ universitaire diploma. Melanie, dankjewel voor je doortastendheid, voor ik het wist zat ik (beduusd) bij Peter op de kamer. En natuurlijk Peter, bedankt voor je wijsheid, je open- en onbevooroordeelde blik en je enthousiasme om mij het zetje – of moet ik zeggen enorme duw – te geven die ik op dat moment nodig had. Bedankt dat je de koppeling maakte tussen voeding en kwalitatief onderzoek, dit is de basis voor alles wat in dit boekje is beschreven. De kans die jij mij hebt gegeven, heeft mijn hele carrière op een spoor gezet waar ik tot aan mijn pensioen de vruchten van zal plukken. Lourens, ik heb je leren kennen als een bevlogen en attente directeur van FoodforCare en ik kreeg vanaf dag één energie van jouw visie op eten in de zorg. Ik wens je toe dat je op een dag al je inspirerende plannen kan uitvoeren. En Ine bedankt voor je advies en voor je goede zorgen, toen ik nog als uitzendkracht werkte bij IKNL.

Sandra en Natasja, waar moet ik beginnen? Starten met een promotietraject, ik vond het razend spannend en werd soms onzeker van wat ik allemaal nog te leren had. Jullie waren als een warm bad. Ik ben er heel trots op hoe wij als projectgroep zijn gegroeid. Ik ben er dankbaar voor dat ik heb mogen meemaken hoe onze relatie zich ontwikkelde, veranderde en opbloede. Onze gezamenlijke inspanningen lopen ten einde – en ik ga jullie missen – maar ik neem deze ervaring de rest van mijn carrière mee. Sandra, ik heb zo vaak met bewondering gekeken naar hoe jij kalm en doelgericht bergen werk verzette waar ik gillend van zou zijn weg gerend. Nog meer inspirerend was voor mij hoe vriendelijk en behulpzaam je bent in zowel het contact met je pupillen, als met bestuurders op het hoogste niveau. Hoe jij met oprechte vriendelijkheid de moeilijkste zaken voor elkaar weet te krijgen, heeft mij vanaf dag één geïnspireerd. Natasja, jouw deskundigheid en doelgerichtheid waren – en zijn – nog steeds een leer-

school voor mij. Ik wil je bedanken voor het geven van richting als we dreigden af te dwalen in het promotietraject. Bedankt dat je me altijd midden in de onderzoeksgroep palliatieve zorg plaatste, wanneer ik dreigde weg te dobberen naar mijn eigen eilandje. Lonneke, ik weet hoe druk je bent en toch had ik altijd het gevoel dat ik je kon benaderen als het nodig was. Een fantastische eigenschap voor een professor. Bedankt ook dat je als je het gebrek aan tijd of mijn stemming in mijn werk aanvoelde dit zonder oordeel benoemde. Dit inspireerde mij om het beste uit mijzelf te halen.

Ik wil de leden van de beoordelingscommissie, Prof. dr. Lia van Zuylen, Prof. dr. Marieke Schuurmans, Prof. dr. Henk Schers, Prof. dr. Emiel Kraemer, Dr. Jacqueline Langius, Dr. Meeke Hoedjes bedanken voor de tijd en moeite om mijn proefschrift te lezen en te beoordelen. Ik zie uit naar het debat dat we over de resultaten gaan voeren.

Rianne, het is ongelooflijk met hoeveel energie jij mensen hebt geïncludeerd voor meerdere van onze studies, dank daarvoor. Ook dank voor je vriendelijke en oprechte interesse in mij als persoon en student. Daarnaast wil ik Annemieke, Marlies, Anouk en Yvonne speciaal bedanken voor hun hulp bij de inclusie. Het is zo fijn als mensen je zo goed helpen bij een onderzoeksproject. Germund, Cécile, Lidia, Peter, Petra, bedankt dat we via jullie organisaties mochten werven. Ik wil alle coauteurs bedanken voor hun waardevolle bijdrage aan de artikelen, ik heb hen niet allemaal persoonlijk leren kennen, maar ik heb zoveel geleerd van het verwerken van jullie feedback. Zola en Tessa, ik vond het erg leuk om jullie stagebegeleider te zijn. Jullie waren beiden enthousiaste studenten, bedankt voor de gezelligheid. Savvas, σε ευχαριστώ που ηγήθηκες του πέμπτου κεφαλαίου. Η δουλειά σου ήταν υψηλής ποιότητας και είναι πολύ ευχάριστο να συνεργάζεσαι μαζί σου, σε ευχαριστώ γι' αυτό.

Van mijn collega's bij IKNL wil ik als eerste Janneke bedanken. We zijn bijna gelijktijdig de achtbaan in gestapt en dat maakte onze vriendschap extra waardevol. Janneke, bedankt voor je doorlopende steun, je inspirerende drive om jezelf te ontwikkelen en je intelligente blik op dingen. Linda, bedankt voor je oprechte interesse, niet alleen in mijn promotietraject. Heidi, bedankt voor je vrolijkheid en je gezellige opbeurende vlotte babbel. Carly, jij begon net toen ik aan het afronden was, ik had je graag langer als collega gezien. Ik vond onze gesprekken over promoveren erg leuk. Belle, bedankt voor je input, ik werd altijd geïnspireerd door jouw ideeën over en het enthousiasme voor het onderzoek. Carla – mijn mede Thirty Seconds Troela – bedankt voor de gezelligheid. Ook wil ik mijn nieuwe collega's bij het Trimbos instituut bedanken, voor het warme welkom en de interesse voor mijn laatste loodjes.

Bas en Mieke (BaMi), ik weet dat jullie trots op mij zijn, ook zonder mijn promotie, dank daarvoor. Ik weet ook dat jullie oprecht geïnteresseerd zijn in het onderwerp, ik hoop dat het eindproduct jullie nieuwsgierigheid bevredigd. En natuurlijk ook dank voor alle uren oppassen, ik had dit proefschrift niet kunnen afronden zonder jullie steun. Judith, idem dito, ik had dit niet af kunnen ronden zonder jouw steun. Bedankt dat je altijd voor me klaar staat en paranimf wilt zijn. Irene en Renske, bedankt dat ik weet dat ik jullie altijd kan bellen als ik hulp nodig heb. Isis, bedankt voor je steun met name rondom de geboorte van Mika, onmisbaar. David, bedankt voor je interesse in mijn proefschrift en de leuke gesprekken over onderzoek doen. Tyche, bedankt voor je steun, ik ben blij dat je mijn paranimf wilt zijn. De Jantjes, bedankt voor de fantastische tijd in India, vlak voor het ‘echt zwaar’ werd, ik heb er lang energie uit kunnen putten. En dank voor alle boottochtjes op de Fubar, voor een onmisbare dosis lol. Lorella, we hebben het niet veel over mijn proefschrift gehad tijdens deze sessies, en dat geeft juist aan hoeveel goed werk we hebben gedaan. Zonder jouw begeleiding was ik nooit zo ver gekomen, het is moeilijk om het belang van onze gesprekken te overschatten, dankjewel daarvoor.

Rico, jij bent degene die het bloed, het zweet en de tranen bij tijd en wijle mag opdweilen ;-). Jouw steun en geloof in mij, zijn al zestien jaar lang het fundament waarop alles gestoeld is, zonder jou had ik de eindstreep niet gehaald. Als laatste wil ik jou bedanken Mika. Je ben een spook en een boef, en je bent het beste wat mij ooit is overkomen. Ik hoop dat je trots bent op je moeder.

Nora, mei 2023



LIST OF PUBLICATIONS

This Thesis

Lize N, Raijmakers N, van Lieshout R, Youssef-El Soud M, van Limpt A, van der Linden M, Beijer S. Psychosocial consequences of a reduced ability to eat for patients with cancer and their informal caregivers: a qualitative study. *European Journal of Oncology Nursing*, 2020.

Lize N, IJmker-Hemink V, van Lieshout R, Wijnholds-Roeters Y, van den Berg M, Youssef-El Soud M, Beijer S, Raijmakers N. Experiences of patients with cancer with information and support for psychosocial consequences of reduced ability to eat: a qualitative interview study. *Supportive Care in Cancer*, 2021.

van Lieshout R, Lize N, Tick L, Deursen J, Driessen E, Janssen T, Custers S, Kranenburg S, van der Lee B, Koene H, Beckers E, Schouten H, Beijer S. Nutrition-related problems, nutritional support practices and barriers to adherence to nutritional guidelines during intensive treatment for acute myeloid leukemia: patients' and hematology nurses' perspectives and experiences. *Clinical Nutrition ESPEN*, 2022.

Lize N, Raijmakers N, van den Berg M, Emmaneel L, Kok A, Lagendijk M, van Leeuwen-Bouwhuis K, Lieshout R, Nagel Z, Beijer S. Patients with cancer experience high impact of emotional consequences of reduced ability to eat: A cross sectional survey study. *European Journal of Cancer Care*, 2022.

Paschos S, Lize N, Eussen S, van der Padt-Pruijsten A, van den Beuken-van Everdingen M, van Laarhoven H, den Boer M, de Graeff A, van den Borne B, ten Have H, Kennis M, Beijer S, Raijmakers N, van de Poll-Franse L. Are gastrointestinal problems, nutritional care and nutritional care needs associated with quality of life in patients with advanced cancer? Results of the observational eQuiPe study. *Supportive Care in Cancer*, 2023.

Lize N, Beijer S, Bergman T, ten Have H, Kennis M, Kodde A, van de Poll – Franse L, Putman R, Schweitzer B, Veldhoven C, Raijmakers N. Experiences of primary healthcare professionals with psychosocial support for reduced ability to eat in patients with advanced cancer: a qualitative interview study. (submitted)

Other publications

Ijker-Hemink V, Lize N, Beijer S, Raijmakers N, Wanten G, van den Berg M. Lessons learned from a randomized controlled trial on a home delivered meal service in advanced cancer patients undergoing chemotherapy: a pilot study. *BMC Nutrition*, 2021.

Bergman T, Lize N, Beijer S, Raijmakers N, Metselaar S. A care ethics approach to a reduced ability to eat. (submitted)

Nijholt, S, Lize, N, van Lieshout, R, van den Berg M, Kok A, Beijer S, Raijmakers N. The association between psychosocial consequences of a reduced ability to eat and QoL in patients with cancer. (submitted)

Becker M, Veldhoven C, Kodde A, Lize N, Beijer S, Raijmakers N. Verborgen verdriet en boosheid door eetproblemen bij kanker. Grote behoefte aan erkenning en ondersteuning bij psychosociale gevolgen van het onvermogen tot eten bij patiënten met kanker en hun naasten. (ingediend)

ABOUT THE AUTHOR



Nora Lize was born on 14 September 1986 in Utrecht, the Netherlands. After graduating from intermediate general secondary school in 2002, she attended culinary school and worked as a chef. She continued her education and graduated from higher general secondary education in 2006. In 2010 she passed the university entrance exam, Colloquium Doctum, and started a Bachelor's degree in Cultural Anthropology and Development Sociology at the Utrecht University, the Netherlands. After finishing her bachelor in 2015, she started a master Cultural Anthropology: Sustainable Citizenship at Utrecht University, the Netherlands. She graduated in 2017. Subsequently, she started her Ph.D. research at the Netherlands Comprehensive Cancer Organisation (IKNL) in 2017. Her research focused on the psychosocial consequences of a reduced ability to eat in patients with cancer. She currently works as a scientific research associate tobacco control at the Trimbos Institute, Netherlands Institute of Mental Health and Addiction.

