



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

Nora Lize¹ · Vera IJmker-Hemink² · Rianne van Lieshout³ · Yvonne Wijnholds-Roeters³ · Manon van den Berg² · Maggy Youssef-El Soud³ · Sandra Beijer¹ · Natasja Raijmakers^{1,4}

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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.

Keywords Cancer · Caregivers · Eating · Patients focused care · Psycho-oncology · Qualitative research

Introduction

Patients with cancer often experience nutritional problems such as anorexia, taste and smell changes, dry mouth,

swallowing problems, and nausea [8, 21] that can lead to insufficient nutritional intake, unintended weight loss, and ultimately cancer cachexia [2]. 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 5 years [30]. Some tumour types are known for their high prevalence of nutritional impact symptoms, e.g. (gastro)oesophageal, pancreatic, head and neck, and lung tumours [18]. 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 [7]. The prevalence of nutritional impact symptoms in patients with lung cancer is between 67 and 88%, due to the treatment but also due to systemic inflammation caused by the tumour [10, 12].

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

✉ Nora Lize
nlize@iknl.nl

¹ Research & Development, Netherlands Comprehensive Cancer Organisation, PO-box 19079, 3501 DB Utrecht, The Netherlands

² Department of Gastroenterology and Hepatology – Dietetics and Intestinal Failure, Radboud University Medical Centre, Nijmegen, The Netherlands

³ Department of Dietetics, Maxima MC, Veldhoven, Veldhoven, The Netherlands

⁴ Netherlands Association for Palliative Care, Utrecht, The Netherlands

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 [13]. 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 ([33], p. 6).

Standard nutritional screening is recommended in international guidelines [1] 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 wellbeing are 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 information [6], or a lack of attention [20] from HCPs in relation to psychosocial consequences of their nutritional problems. In a systematic literature review of Wheelwright et al. [33], the authors concluded that professional care should not only address the physical aspects of cachexia but also patients' emotions and relationships [33]. Other studies in patients with head and neck cancer and hematologic cancer and patients receiving parenteral home feeding showed that patients want their HCPs to recognize their distress provoked by their nutritional complaints, while their HCPs tend to focus on physical aspects of their condition [11, 15, 16, 22, 23]. 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 [26, 28, 29]. 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

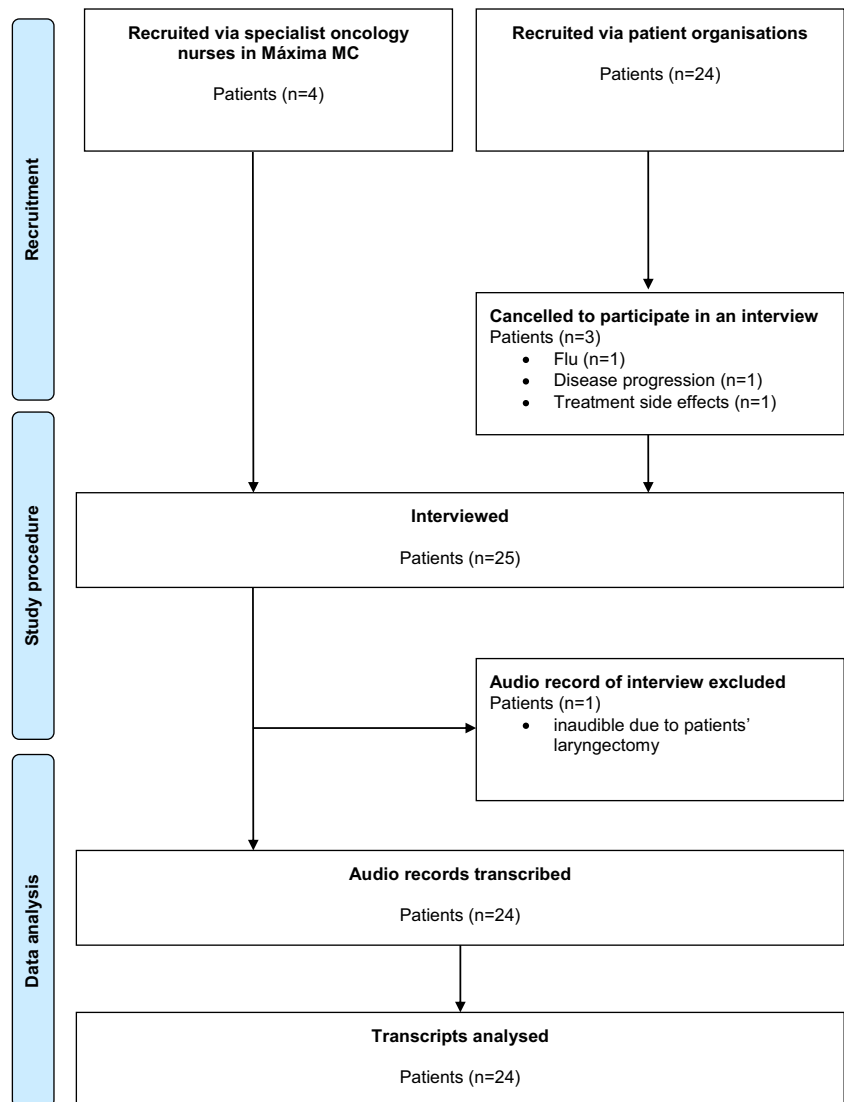
Patients were eligible for inclusion if they were over 18 years of age, diagnosed with head and neck cancer, lung cancer, or lymphoma, and (had) experienced nutritional problems due to their cancer or treatment. The presence of nutritional problems was self-reported. Patients were recruited via patient 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 (Fig. 1).

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

Fig. 1 Flow diagram respondents



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.). 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)

[4]. 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 [5, 27, 31]. 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 [4] 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 [4]. 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 [7, 12]. 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, online recruitment via patient organisations may result in a selection bias favouring patients with a relatively good health status and active information-seeking behaviour [9]. 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 design [4], 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 was used for reporting and writing [32].

Results

Most patients were male (62.5%) and the mean age was 63 years (Table 1). Most patients (71%) were in recovery or remission, and almost half (46%) of the population was diagnosed 1 to 5 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 dietitians 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, dietitians who were only engaged with patients' nutritional intake, physicians who did not provide patients adequate information about reduced

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	<1 year	5 (21%)
		1–5 years	11 (46%)
		>5 years	8 (33%)
Recruitment	Oncology ward	3 (12.5%)	
	Online	21 (87.5%)	

^aLow 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

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 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 programme, 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 physician’s expertise is in line with results from previous studies [15, 22]. 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, 22]. 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 [11]. 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 [6, 20, 24, 33].

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 [3, 11, 14, 15]. 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 unbeneficial [14], unreachable [11], or insufficient and confusing [3]. 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, 23, 25]. 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, and shame [13]. 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 [9]. Patients included in the present study were higher educated and relatively younger compared to the general cancer population [19]. 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 physicians' 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 guidelines [1], 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 caregivers [13], 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.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-021-06217-6>.

Code availability Not applicable.

Author contribution 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.

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Data availability The corresponding author has full control to all primary data and allows the journal to review the data upon request.

Declarations

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.

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

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