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## Outpatients' experiences with unintended weight loss during treatment of disease

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**Outpatients' experiences with unintended weight loss during treatment of disease: A qualitative study**

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**Abstract:****Introduction:**

Disease-related malnutrition is known to be negatively associated to clinical outcomes. Patients are key actors in order to maintain sufficient nutrition intake, to avoid malnutrition during disease. A recent study in five Danish outpatient clinics found that 26% of the outpatients had an unintended weight loss within the last three months. The aim of this study is to investigate the patients' perspective on how Unintended weight loss has been prevented and treated during their outpatient care, and how this knowledge may be used in optimizing future outpatient care.

**Methods:**

Individual semi-structured interviews were conducted in seven patients suffering from unintended weight loss in three different outpatient clinics. A thematic analysis was performed inductively and interpreted based on the motivational theory; Self-Determination Theory.

**Results:**

Three themes are identified as related to the patients' experiences with unintended weight loss during disease. Each theme has two sub-themes. The first main theme is 'Knowledge and understanding of causes and nutritional care' with the sub-themes 'Physicians and nurses' and 'Patients'. The second main theme is 'Generalized nutritional advice or actual counseling' with the sub-themes 'Nutritional advice in general terms' and 'Individualized nutritional counseling' and the third theme is 'Nutritional counseling - when and how?' with the sub-themes 'When should nutritional counseling be given?' and 'How should nutritional counseling be given?'.

**Conclusion:**

In general, the patients experience that the treatment of their unintended weight loss has not met their needs. They are left with a lack of knowledge and without individualized nutritional counseling.

**Keywords:** Malnutrition, nutritional counseling, outpatients, interviews, qualitative study, unintended weight loss

## Introduction

Malnutrition during disease and treatment may cause complications, infections or increased mortality (1–6). During disease, requirements for energy and protein are increased because of elevated metabolism. Malnutrition is a consequence of nutritional intake less than recommended and/or failure to absorb nutrients, which will lead to weight loss (2,7). Risk of malnutrition in the hospital setting is found by nutritional screening, including two of the following scenarios: Body Mass Index (BMI) <18,5 kg/m<sup>2</sup>, combination of weight loss and reduced BMI or reduced gender-dependent fat-free mass (2). Malnutrition affects mental and physical capacity, which will impact the response to treatment (8).

Risk of malnutrition often occurs when the process of the disease, including elevated cytokines, affects appetite and the disease as well as treatment affect nutritional intake e.g. because of nausea, changed sense of taste and smell or mucositis (2,8–13). The European Society of Clinical Nutrition and Metabolism (ESPEN) recommends that all patients in both the primary and secondary care are screened for malnutrition or risk of malnutrition (14). ESPEN has also developed evidence-based recommendations for clinical nutrition (2,15). In Denmark, The National Board of Health has developed national recommendations for screening of medical inpatients as well as nursing home residents (16). Even though the proportion of outpatients treated in Denmark increased by 24% from 2008 to 2018 (17), no recommendations for nutritional caretaking are made for the ambulatory setting. Thus, more and more patients, including the increasing proportion of elderly patients, are treated in the ambulatory setting without any nutritional screening or care plan. This study is based on a recent study conducted at five outpatient clinics at a Danish University Hospital. The study found that 26% of the outpatients had an unintended weight loss (UWL) within the last three months and 21% had reduced food intake (RFI) within the past week (18). In a qualitative study of health professionals' perspectives on nutritional efforts in the pulmonary ambulatory setting, the nurses and physicians found their own nutritional practices sparse and unstructured. Common wishes from nurses and physicians were;

priority from leaders, well-organized structure for working with good nutritional practice (GNP), as well as local and national guidelines that would stimulate priority to nutritional efforts (19). In the acknowledgement of time limits in the ambulatory setting, the association between UWL and RFI was investigated in a logistic model, showing an odds ratio (OR) 7.684 (5.147;11.472) for experiencing UWL compared with patients who had no RFI (18). These results indicate that asking the patients about UWL may be sufficient as a first screening in the ambulatory setting. However, as the patients and relatives are their own carers as to actually handle nutritional care on a daily basis outside hospital, the patient's perspective on how UWL has been and should be managed in the outpatient setting has to be investigated. The aim of this study is to investigate the patients' perspective on how UWL has been prevented and treated during their outpatient care, and how this knowledge may be used in optimizing future outpatient care.

## Methods

This study was designed as a qualitative interview study using a semi-structured interview guide in a hermeneutic approach to obtain nuanced descriptions of patients' experiences with UWL during outpatient care at a Danish Hospital (20).

## Participants

Participants were recruited from three different outpatient clinics at Aalborg University Hospital, Denmark. The outpatient clinics were: Gastroenterology (G), Hematology (H) and Pulmonary Medicine (PM). An e-mail with an information letter was sent to the head nurses at the outpatient clinics. The letter contained information about the purpose of the investigation and inclusion criteria. Then the head nurses had the responsibility to invite patients who experienced UWL to participate, which was the only inclusion criteria in this study. The head nurses then provided the patients phone numbers to the investigators. Seven patients were getting information about the study and invited to participate. All patients were willing to participate in the study and after supplemental oral information, all the patients gave written consent for participation. The study was

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conducted according to the rules of the Helsinki Declaration of 2002. The patients differed regarding age, reason for visit, disease, side-effects whether they have got food delivery,

nutrition supplement or talked to a dietitian. Characteristics of the participants are shown in Table 1.

Table 1: Characteristics of the participants. M: man. W: woman. H: Hematology. PM: Pulmonary medicine. and G: Gastroenterology.

ID	Age	Sex	Reason for visit	Outpatient clinic	Civil status	Food delivery	Nutrition supplement	Talked to a dietitian
I1	60-70	M	Treatment	H	Alone	No	No	Yes
I2	60-70	M	Treatment	H	Married	No	No	No
I3	60-70	W	Treatment	H	Married	Yes – of the family	No	Yes
I4	70-80	W	Control	PM	Widow	Yes – of a company	Oral nutrition supplement	Yes
I5	60-70	W	Control	PM	Alone	No	No	Yes
I6	20-30	M	Treatment	G	Cohabiting	No	No	No
I7	60-70	M	Control	H	Married	No	Tube-feeding	No

### Data collection

The seven patients' experiences were examined through individual, semi-structured interviews. The intention with the interviews was to get insight into the patients' experiences of, how UWL has been prevented and treated. An interview guide was developed to ensure consistency. The interview guide was based on the three phases of GNP; "Identification", "Nutrition plan" and "Monitoring, evaluating and adjusting" (2,21). According to Kvale & Brinkmann the interview guide contained preliminary questions, exploratory questions and direct questions. Furthermore, it consisted of briefing and debriefing (20).

Prior to the interviews one pilot interview was conducted with a patient who met the inclusion criteria. As no changes, except the order of the questions, were made, the interview was included in the investigation. All interviews were conducted by the same investigator and one assistant. The role of assistant shifted among two other investigators, between interviews. The interviews took place either at the hospital or in the patient's home in accordance to the need of the individual patient. The estimated duration of each interview was 30 minutes, varying from 20 to 40 minutes excluding briefing and debriefing. The interviews were recorded on a digital dictaphone, Olympus Voice Recorder WS-811, and afterwards transferred to a computer and encrypted using the software program Encrypto 1.3.3. The interviews were all transcribed verbatim by the

investigator that wasn't assistant at the particular interview. The transcribed material was not sent back to the participants, so they could comment on the transcribed material based on their interview. A brief summary was made at the end of each interview so that the patient could tell if he/she agreed or disagreed and thus validate it.

### Data analysis

Data were analyzed in the Nvivo 12.2.0 software program. A thematic analysis was conducted to identify themes across the interviews (20). First, all the transcribed material was read separately by two different investigators and each of whom selected and pre-coded quotations of meaning. Subsequently the two investigators compared and discussed their pre-codes to agree on final codes. Patterns across the codes were then collected in sub-themes, and main themes were then identified based on the sub-themes. Some parts in the quotations were marked with [...], if something without meaning was left out. Other parts were marked with [a word] if the investigators added a word to increase the understanding of the quotation. the quotation is marked with (Informant) and a number according to their personal ID which indicate the participant who said the quotation. Finally, the themes were analyzed based on an interpretation of the quotations based on the motivation theory; Self-Determination Theory (SDT). SDT describes factors that promote motivation and behavioral functioning. According to SDT autonomy, competence and relatedness

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s are three basic psychological needs. Autonomy is the sense of control over life, competence is the sense of capability to act or interact and relatedness is a sense of belonging and connecting with others (22). According to SDT, the level of motivation is dependent by the extent to which, these needs are satisfied. In addition, an action can be motivated intrinsic or extrinsic. Intrinsic motivation is driven by internal rewards such as the joy of performing an action, the opportunity to learn or explore. Extrinsic motivation is driven by external influences such as punishment, rewards or recognition. If a person doesn't act or act with no intention, it is a result of not valuing the act or not feeling

competent to act. In that case a person will be amotivated (22). The interpretation-based on SDT was conducted to identify and understand the patients' experiences of dealing with malnutrition.

## Results

Three themes are identified as related to the patients' experiences with UWL during disease. Each theme has two sub-themes. Themes and sub-themes are listed in Table 2. The table includes selected quotations with associated codes and affected components of SDT from the interpretation.

Table 2: Example of thematic analysis with interpretation based on SDT.

Main themes	Participants reflected the theme	Sub-themes	Selected quotations	Codes	Affected components of SDT
<b>Knowledge and understanding of causes and nutritional care</b>	All the participants have reflected this theme	Physicians and nurses	15: "The physician has told me that I should gain weight. But then he says; of course, you do what you can. And yes, I do."	Guidance from physicians and nurses	<b>Competence:</b> The patient's lack information affects her competence to handle her weight loss.
		Patients	16: "They have only pointed it [the weight loss] out each time and asked me why. And I don't know why it happened. I think, it would be easier to maintain the weight, if I know why and how."	Lack of knowledge and understanding of causes and treatment of weight loss	<b>Competence:</b> The patients lack information affects her competence to handle her weight loss.
<b>Generalized nutritional advice or actual counseling</b>	All the participants have reflected this theme	Nutritional advice in general terms	11: "They can only tell me to eat well. Then I say; what do I do, if I can't eat well [...] Worst case scenario, you can get tube feeded and that is not funny. [...] It's just survival medication."	Generalized nutritional advice from physicians and nurses	<b>Competence:</b> The patient is not given any alternatives, which may affect his ability to motivation to act on his weight loss.  <b>Autonomy:</b> The patient does not have the autonomy to choose for himself
			15: "The times I have said; what can I do to increase the weight, they have just said; well you know what is fattening"	Generalized nutritional advice from physicians and nurses	<b>Competence:</b> The professionals think that the patient has the competences and knowledges to act on her weight loss, even though she asks them for help.  <b>Autonomy:</b> The patient has the autonomy to act on her own, but she needs the professionals to help her, which they fail to do.
		Individualized nutritional counseling	16: "I think it [nutritional care plan] must be a little flexible. Cause I don't eat at home every day, and I can't always control what to eat. So, it must be a little flexible."	Individualized nutritional care plan.	<b>Autonomy:</b> The patient wants a nutritional care plan, but he wants the autonomy to choose what to eat.  <b>Competence:</b> A flexible nutritional care plan can be adapted to his competences.
			11: "Recently, I have not been talking to a dietitian. I only talk to the nurses and physicians about it. The fact that I do not like meat has emerged within the past year. So, it has not been taken into account."	Ongoing meetings with dietitian.	<b>Competence:</b> Ongoing meetings with a dietitian can accommodate changes in the patient's competences.
<b>Nutritional counseling - when and how?</b>	All the participants have reflected this theme	When should nutritional counseling be given?	11: "I think, it's too early at the first conversation. Because you get so much information. It should probably come later [...]. At the first conversation you're not ready, because you think, you have to die."	Initially focus on diet and weight loss	<b>Competence:</b> The patient does not have the ability to act on diet and the weight loss at the beginning. <b>Autonomy:</b> The patient wants the autonomy to decide when to initiate focus on weight loss.
		How should nutritional counseling be given?	15: "I think it would have been nice, if someone had [kept an eye on the weight]. When I am here for control or something. Or you could write down what you eat and then they could tell you if it's not enough and you have to double or something."	Monitoring of diet and weight loss	<b>Relatedness:</b> The patient wants to have relatedness to the professionals and to handle the weight loss in collaboration with the hospital. <b>Competence:</b> The patient wants to know, if she is doing it right or wrong regarding her diet.



## Knowledge and understanding of causes and nutritional care

The analysis of the interviews shows that patients' as well as physicians' and nurses' knowledge and understanding of causes and treatment of UWL during disease, respectively, can have an impact on patients' motivation to act on the problem.

### Physicians and nurses

Patients' experiences with physicians' and nurses' knowledge and understanding of causes and nutritional care of UWL are characterized by frustration.

*"The physician has told me that I should gain weight. But then he says; of course, you do what you can. And yes, I do."*(15)

The quotation indicates that the patient doesn't have the necessary competences to act on the UWL and physicians and nurses don't handle the problem. Thus, there is no relatedness between the patient and professionals in handling UWL. Patients may therefore experience to stand alone with the problem, which may affect their intrinsic motivation. Even though the professionals give the patient autonomy to act on their own, action is required based on the patients' knowledge and competences.

### Patients

Several patients experience lack of knowledge and understanding regarding the causes of weight loss. Although the weight is monitored each time at the hospital, only a few patients experience to get the necessary knowledge of causes and handling. In this regard a patient says:

*"They have only pointed it [the weight loss] out each time and asked me why. And I don't know why it happened. I think, it would be easier to maintain the weight, if I know why and how."* (16)

Other patients do not understand that it is a problem to lose weight during disease.

*"I think, I get the food I need [...] and I'm fine with this weight. It's other people*

*who have a problem with my weight"*(14)

It seems that the patient does not value the handling of weight loss. Therefore, she experiences amotivation to act on the problem. That may indicate that she has not received the necessary information about the potential risks. Therefore, she lacks the competences to understand and act. Several patients find it beneficial to bring along relatives when they are given a lot of information.

*"Every time we have met the physician, she [the wife] has been writing in a little black book. She did it before I had surgery, after I had surgery and during the other treatments I've gone through. She has been with me every time and written down, because I may have heard something she hasn't or maybe she heard something different."* (17)

This suggests that relatives may increase the patient's knowledge and competences to handle UWL during other treatment. If the patient cannot accommodate all the information himself, the relative may remember and understand some other things and then they support each other. Thus, both the patients' sense of competences and relatedness increases, which may support the patients' intrinsic motivation.

## Nutritional advice in general terms or actual counseling

The interviews reveal that most patients have been given nutritional advice in general terms rather than actual counseling.

### Nutritional advice in general terms

Several patients experience a lack of focus on UWL including dietary advice and counseling. In this regard a patient says:

*"I don't think that it should be necessary to ask to talk to a dietitian. They should really offer that."* (13)

The quotation shows that the patient has initiated a meeting with a dietitian herself. It indicates that she experiences a lack of focus on her needs. She experiences not to have the necessary competences and takes responsibility for seeking help herself. However, she later

adds that the meeting with a dietitian did not improve her knowledge and competences. The general experience among the patients who have been in contact with a dietitian, is that they have not been given adequate advice and tools for them to take charge of their UWL.

*“When they [dietitians] go through my diet, the only thing I am told is; add some more sugar, drink cocoa instead of milk, drink juice instead of water and stuff like that, but it doesn’t help.” (15)*

The quotation indicates that the patient has received general advice regarding her diet, and it has not been helpful. It seems that there is a lack of focus on the individuals’ need and nutritional problems to provide sufficient counseling. Besides dietitians also physicians and nurses advice the patient regarding diet.

*“They can only tell me to eat well. Then I say; what do I do, if I can’t eat well [...]? Worst case scenario, you can get tube feeded and that is not funny. [...] It’s just survival medication.” (11)*

It seems that the patient has not been introduced to specific dietary advice. He has only been told that he should eat well, but not what and how. Moreover, it indicates that the patient experiences tube feeding as the last option and he needs alternatives. The patient loses his autonomy and the motivation decreases. On the other hand, patients may need the professionals to handle the situation as they expect them to have another knowledge.

*“The times I have said; what can I do to increase the weight, they have just said; well you know what is fattening” (15)*

The quotation indicates that physicians and nurses assume that the patient has the necessary knowledge regarding eating the right things to increase weight. If the patient experiences not to get useful advices it may affect the motivation to continue. To increase intrinsic motivation advice and counseling should accommodate the patient’s autonomy and competences. Thus, they should jointly develop a plan, which increases the patient’s sense of relatedness. That may create a foundation of learning

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through intrinsic motivation.

### Individualized nutritional counseling

Although most patients have only received general advice regarding diet, several patients indicate that they would like individual counseling.

*“You have to eat something you like [...]. What got me going again was a wiener schnitzel.” (12)*

It seems that the patient needs to have an influence on his diet. When the appetite is lacking it may be important to focus on the patient’s preferences. This would accommodate the patient’s autonomy and opportunity to meet his competences. The patients’ ability to eat food they like may influence their intrinsic motivation. This indicates that nutritional care and nutritional care plans must be adapted to the individual patient.

*“I think it [nutritional care plan] must be a little flexible. Cause I don’t eat at home every day, and I can’t always control what to eat. So, it must be a little flexible.” (16)*

The patient wants a nutritional care plan, that is individual and flexible. It indicates that the patient wants autonomy in planning his daily diet, but he needs counseling regarding what and how to do it. In this way the patient can be motivated intrinsically if an individual nutrition care plan accommodates the patient’s competences and condition. Thus, the nutritional care plan should be flexible and constantly adjusted.

*“Recently, I have not been talking to a dietitian. I only talk to the nurses and physicians about it. The fact that I do not like meat has emerged within the past year. So, it has not been considered.” (11)*

The patient indicates that he needs more ongoing appointments with a dietitian. As his condition and medication changes, his taste changes too. This means that his competences provided by the help of dietitians beforehand, are no longer sufficient.

Failure to meet these changes may cause that the patient gets demotivated to handle his UWL. Nutrition care plans and nutritional efforts should therefore continually align with the patients' challenges, autonomy and competences. Thus, the handling must be prepared in collaboration with the patient.

*"So, I wouldn't think; oh no, you don't have the energy [to cook], I then get nothing. Since I get food delivered, it comes every day." (14)*

The quotation indicates that the patient has had autonomy and competences to plan her own nutritional effort. However, the delivered food is not adapted to the patient, which means that she does not always eat it all. It seems that the lack of autonomy can affect the patient's motivation to eat. Furthermore, it indicates that the nutritional effort and nutritional care plan must be tailored to the individual patients, if they should be motivated to change habits and follow a nutritional care plan.

#### **Nutritional care - when and how?**

The patients have different experiences with when and how their UWL has been handled. Depending on their course of disease it is different whether there has been a focus on UWL or the risk of it from the beginning, ongoing or not at all.

#### **When should nutritional counseling be given?**

Most of the patients express that they would like the hospital to focus on their diet and UWL in parallel with their treatment.

*"I think it's easiest if the hospital takes care of it, every time I'm here." (16)*

The quotation indicates that the patient experiences relatedness with the hospital, if the professionals show interest in his diet and weight. If the professionals at the hospital keep close focus on diet and weight continually, it may increase the patient's intrinsic motivation to act on it.

*"I think, it's too early at the first conversation. Because you get so much information. It should probably come later [...]. At the first conversation you're not ready, because you think, you have to die." (11)*

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Several patients indicate that they cannot handle UWL at the same time as other treatment at the beginning of their disease. It seems that intrinsic motivation is weakened in the beginning due to lack of competences to act on UWL. Patients receive an overload of information in the beginning of treatment; thus, it can be difficult to deal with UWL too. There may be a need to motivate patients extrinsically at the beginning of treatment, before they can even take part in the handling of UWL.

#### **How should nutritional counseling be given?**

Several patients get weighed regarding medication dosage and treatment at the hospital. However, if a weight loss is detected, it is not always acted upon. Most patients state that they want counseling in their nutritional status in regard to treatment or meetings in the outpatient clinic.

*"I think it would have been nice, if someone had [kept an eye on the weight]. When I am here for control or something. Or you could write down what you eat and then they could tell you if it's not enough and you have to double or something." (15)*

The patient seeks the professionals to monitor her diet and weight. Therefore, she would like ongoing feedback on her nutritional status, so she can adjust her diet accordingly. Feedback from professionals can probably motivate the patient extrinsically to continue following her nutritional efforts. Ongoing feedback will most likely increase her competences in adapting to the situation, which may create a relatedness between the patient and professionals too. Thus, the patient's intrinsic motivation will increase. Another patient used a mobile application (app) where he could monitor diet and weight and get feedback. At the same time professionals at the hospital could keep an eye on his monitoring and provide personal feedback based on his data, when he met in the outpatient clinic.

*"It was that [the app], I think, that helped visualize the progress and then, of course, the bathroom scale too. But I could see that I was getting the calories that my body needed, and then I could look at the scale. I could also feel it in my mood, that now there's progress." (17)*



The patient tells that he was motivated by the app, that could visualize his progress. At the same time the visualization could contribute a competition with the patient himself. It seems that the patient finds this competition giving. Therefore, the app may have motivated him intrinsically to continue his effort. He could also get feedback from professionals, which may have created extrinsic motivation to continue.

## Discussion

In this study we aimed to investigate how malnutrition in outpatients was prevented and treated in the perspective of patients suffering from UWL during outpatient care, and how this knowledge may be used in optimizing future outpatient care. The interviews with seven patients show that patients have many similar as well as different experiences with knowledge and treatment of UWL. The first recommendations in the newest guideline from ESPEN are that nutritional counseling should be individually adjusted (15). The results of this study indicate that several patients have not received individual nutritional counseling, but that is what they actually want and need to be able to handle their situation. At the same time, they indicate a desire and need for more and ongoing meetings with trained dietitians, which is also one of the recommendations in the ESPEN guideline. However, several patients experience that they have not been offered either the number of meetings, they needed or trained expertise from the dietitians they may have met. They experience that they do not get the amount of information, they need to take charge of their situation. ESPEN also recommends that causes of malnutrition should be detected as early as possible (15). However, several patients express that they cannot cope handling UWL initially. On the other hand, some patients have not had their causes of UWL identified, which frustrates them. Thus, there is a need to focus on the causes, but maybe not initially for all patients. This emphasizes the need for individual counseling tailored the condition and competences of the individual patients at the particular time. In addition, several patients express that they do not understand how to act on UWL. That indicates that they need education and information about their situation, which also is a recommendation from ESPEN. ESPEN also recommends that

patients must be offered delivered food, if they need it (15). However, a Danish study showed that patients who got food delivered, did not increase their nutritional intake and body weight, even though the food was tailored the individual patient (23). In this study, a patient gets food delivered too, but she tells that she does not always eat it all, because she does not always like the food. This indicates that food-delivery must be adapted to the individual patient's wishes and needs on the particular day, if the patient should be motivated to eat and follow the nutritional care plan. Two of the patients have been offered tube-feeding; one did not want it, while the other received it. The patient that did not take up the offer may not have had sufficient competences to take the decision, or offered sufficient counseling and other nutritional care options, since he is still asking for help with his weight loss. In ESPEN guidelines it is recommended that patients are offered tube-feeding, if nutritional guidance is not enough (15). However, the results from this study show, that only sparse and superficial counseling was provided, and that one of the patients was offered no alternatives but tube-feeding.

Furthermore, ESPEN recommends focusing on physical activity in the treatment of malnutrition. In this study, none of the patients mentioned a focus on physical activity during their treatment. It may be a result of the interview guide used, or there has been really no focus on physical activity during their treatment. In addition, this may indicate that data saturation has not been received through the interviews.

Two of the interviewed patients have used apps regarding their handling of UWL, with which they had good experiences. The use of apps has also been investigated in several studies - also with a positive effect (24,25). The studies as well as the quotations of patients indicate that the use of an app is positive, because it is individualized, overview generating and can provide feedback, which can motivate patients to continue their efforts. At the same time an app can save the professionals some time, as the patients register their data themselves. Thus, the use of an app can be positive for both patients and professionals.

The discussion of the results of this study and the ESPEN guidelines emphasize the

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importance and need to individualize several aspects of nutritional care. The patients are heterogeneous according to course of disease, relatives, competences as well as wishes and needs regarding frequency of meetings and food preferences.

The positive effect of an individualized approach is supported by several studies on this area of research (26–29). A Danish study showed that some nurses and physicians lack knowledge, time and understanding of nutritional care (19). That might be the reason why, the patients feel that they do not get the counseling they need.

Patients included in this study are affiliated to different outpatient clinics, are different places in their course of treatment and have different ages. This variation may affect the transferability of the results. However, it provides a broad insight to the problem. Quotations and interpretations depend on the particular informants, the investigators and applied theory. Therefore, the results of this study are not replicable. To increase the credibility of the results the analysis and interpretation were conducted in collaboration and agreement between the investigators.

## Conclusion

In general, the patients experience that the treatment of their UWL has not met their needs. They are left with a lack of knowledge and without individualized nutritional counseling. It seems that malnutrition is not prioritized in the outpatient clinics in accordance with published guidelines. Thus, there is a need of increased focus on handling of malnutrition in outpatients. If patients should be motivated to handle their UWL, the nutritional care should be individualized and tailored the individual patient's needs and competences. However, the lack of satisfaction with the nutritional care may be due to the fact that the professionals lack knowledge in the field, do not prioritize it or do not have the time. Thus, there is a need to further investigation of why and how the professionals can integrate nutritional care in accordance with ESPEN guidelines.

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## Author contributions

All authors were responsible for the conceptualization of this study. MH recruited the participants in collaboration with the head nurses in the respective outpatient clinics.

NZ, TØ and SM collected the data. TØ and SM performed the data analysis and drafted the manuscript and all authors revised and wrote the final edition. Mette Holst supervised the overall process.

## Ethical approval

This study was performed in compliance with ethical standards. Participation was voluntary and with consent. The regional ethics committee had no comments to the application, ID: 2018-146.

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## Conflict of Interest

The authors have no conflicts of interest to declare for this study.

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