‘Between foods and medicines’: A qualitative interview study of patient experiences of the meaning and usage of oral nutritional supplements

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ABSTRACT

The aim of this study was to deepen the understanding of what oral nutritional supplements mean to patients and how this meaning connects to supplement usage, by exploring patient experiences of such supplements. Qualitative interviews were conducted in June 2019–March 2020 with ten patients with malnutrition or at nutritional risk, prescribed oral nutritional supplements by dietitians. Data were thematically analysed using systematic text condensation. Two final categories were identified: ‘Oral nutritional supplements are a one-dimensional remedy’ and ‘Everyday oral nutritional supplement usage is regulated autonomously’. The patients described the meaning of oral nutritional supplements as nutrition. While the supplements could compensate for nutrients not eaten or be part of a helpful compensation strategy, they could not lessen the burden of altered eating. Supplement usage was described as dependent on the acceptance of taste and the priority given to nutrition in everyday life. Usage was greater when nutrients were perceived as needed, such as when striving for higher bodyweight or disease recovery. Usage was lower when a patient’s own goals were not increased nutrient intake or bodyweight or when other activities were perceived as more important. Patient experiences indicated that oral nutritional supplements could serve as a remedy for malnutrition, but not for a situation of altered eating. Supplement usage was described as being regulated autonomously based on patient views on the importance of nutrition. Those views were diverse, highlighting the importance of supplement prescribers discussing treatment goals with each patient. A deeper understanding of the meaning of oral nutritional supplements and reasons for their usage from a patient perspective is crucial in order for healthcare to provide appropriate, effective nutrition therapy for malnutrition.

1. Introduction

Although disease-related malnutrition is highly prevalent within healthcare in Western societies (Cereda et al., 2016; Norman et al., 2008), patient experiences of malnutrition therapy remain understudied. The patient perspective is especially crucial as patient adherence (or compliance) to malnutrition therapy is acknowledged as a challenge by healthcare professionals and researchers (Beelen et al., 2017; de van der Schueren et al., 2018; Wan et al., 2021). The underlying causes of malnutrition are described as multifactorial and might consist of an acute or chronic inflammation state, malabsorption and/or a reduced food intake due to for example anorexia, dysphagia or gastrointestinal problems (Cederholm et al., 2019; Stratton et al., 2003). In addition to physiological features affecting food intake during disease, changes in behavioural, cognitive and social dimensions of eating are also important from a patient perspective (Burges Watson et al., 2018). This aspect has received less focus in previous literature on malnutrition and nutrition therapy. A framework including the aforementioned dimensions has been operationalised by Burges Watson and colleagues when studying head and neck cancer survivors, with reference made to the term ‘altered eating’. Altered eating is defined as ‘a changed state of any combination of physical, emotional and social interactions with food and eating that has a negative impact on health and wellbeing’ (Burges Watson et al., 2018, p. 8). Their framework can be
useful across a range of medical diagnoses and valuable to consider in treatments of altered eating in order to improve patients’ food-related quality of life (Burges Watson et al., 2018).

1.1. Background

Nutrition therapy for patients with malnutrition who can take in food orally consists of dietary counselling, combined with oral nutritional supplements (ONS) when ordinary food is not enough (Arends et al., 2017; Gandy, 2019; Socialstyrelsen, 2020). ONS are nutritional products in liquid, powder or pudding form, which are classified as foods but managed as medicines, since they are prescribed and monitored by healthcare and often subsidised (Cadogan et al., 2020; European Parliament and Council, 2013; Stratton & Elia, 2010). In meta-analyses, ONS have been shown to be clinically effective (National Collaborating Centre for Acute Care, 2006; Ferreira et al., 2012; Koretz et al., 2007; Milne et al., 2009; Stratton et al., 2003). However, the effectiveness of ONS varies because of varying patient prescription adherence (Bauer et al., 2005; Jobse et al., 2015; Seguy et al., 2020). Although adherence to ONS can be problematic (Ginzburg et al., 2018; Gosney, 2003; Grass et al., 2015; McMurdo et al., 2009; Milne et al., 2009), a high average adherence rate to ONS was found in a systematic review by Hubbard and colleagues in 2012 (Hubbard et al., 2012). Five years later, those high adherence rates were confirmed in our study of hospital outpatients in a Swedish clinical setting (Liljeberg et al., 2019). However, we also found low consistency between the patient-reported prescribed ONS amount and the prescribed ONS amount documented by the dietitian in the medical records, for almost half the population (n = 31/78) (Liljeberg et al., 2019). One potential explanation for this inconsistency might be that the dietitians applied a person-centred care approach – sharing the decision on the prescription content with the patient, instead of recommending a fixed amount (Liljeberg et al., 2021). A non-prescriptive approach, serving as guidance instead of instruction, is appreciated by patients (Hancock et al., 2012), and adherence to dietetic therapy is better when a person-centred care approach is used (Endevet & Gesser-Edelberg, 2014). Person-centred care has been established as a new norm for healthcare and emphasises equal distribution of power between a healthcare provider and patient by recognising patient context, values and preferences (Ekman et al., 2011; Nolte & Merkur, 2020).

Most studies on ONS adherence are performed from a healthcare perspective and there is a lack of studies on patients’ ONS usage in everyday life. Reasons for drinking or not drinking ONS have been explored to a certain extent, and while acceptability of taste is often highlighted as central (Beelen et al., 2017; de Luis et al., 2015; den Uijl et al., 2015; Milne et al., 2009), a desire to prolong independence and trusting the advice of the doctor or dietitian have both also been suggested as important factors (den Uijl et al., 2015). However, it has been argued that the doctor-patient relationship receives too much focus in compliance discussions and is less central from a patient perspective, at least when it comes to medication (Conrad, 1985). Adding to those results, a discrepancy has been identified between the healthcare perspective and the patient perspective on negative health consequences of malnutrition (Beelen et al., 2017; Bullock et al., 2021). Patients seem to underestimate the malnutrition risk, which might counteract behaviour change and affect therapy success (Beelen et al., 2017; Bullock et al., 2021; Castro et al., 2021). In order to build a better understanding of how patients experience a ONS prescription and translate it into their everyday life, a qualitative scientific approach is suitable. Since ONS are widely used, are costly for society and/or the patient, and adherence is suggested to be challenging, a focus on patient experiences can provide valuable insights into nutrition therapy with ONS.

2. The study

2.1. Aim

The aim of this study was to deepen the understanding of what ONS mean to patients and how this meaning connects to ONS usage.

2.2. Study design

This was a qualitative interview study with free-living outpatients, asked about their experiences of being prescribed and using ONS in everyday life. The study was made from a pragmatic epistemological position (Patton, 2014), but was inspired by phenomenology, where people’s lived experiences and lifeworld are in focus (Kvale & Brinkmann, 2014; Malterud, 2012). This was in line with the chosen analysis procedure: systematic text condensation (STC) (Malterud, 2012).

2.3. Participants

Study participants were recruited by dietitians working within the hospital or primary healthcare setting in Region Uppsala, Sweden. Recruitment was also performed from three local patient organisations with members among whom malnutrition and ONS prescriptions were frequent: the Head and Neck Cancer Association, the Breast Cancer Association and the Gastrointestinal Association. Purposive sampling was employed (Patton, 2014) and eligible patients met the following criteria: adult (>18 years old), prescribed ONS (with ≥2 macronutrients and micronutrients) by a dietitian for more than one month, free-living (non-institutionalised), free from dementia or cognitive impairment, not receiving enteral or parenteral nutrition, and able to communicate verbally in Swedish. Broad recruitment, across different medical diagnoses and healthcare settings, was applied to achieve a maximum variation sample (Patton, 2014) and include a diverse range of experiences connected to being prescribed and using ONS. Eligible patients received verbal and written study information from the dietitians. If interested in participating, they were encouraged to contact the research team or their contact details were forwarded to the team by the dietitians (n = 7). Participants recruited by the patient associations (n = 3) made contact themselves, after receiving information through member channels such as e-mails or member meetings. In all, ten patients were recruited. A limited number of up to ten individuals is suggested as suitable when performing an STC analysis where the focus is on experiences of a phenomenon (Malterud, 2012). The decision on terminating the recruitment process was guided by the concept of information power rather than saturation, and occurred when the interview material was found to be rich enough in information to achieve the study aim (Malterud et al., 2016).

Self-reported patient characteristics are presented in Table 1 (with pseudonyms used). All but one patient were long-term (>1 year) users of ONS. In the results section, quotes are followed by the patient pseudonym, information on age range, medical disease and whether the patient lives alone (LA) or together with others (LO). In Sweden, dietitians are the primary healthcare prescribers of ONS and the products are subsidised for patients with malnutrition or at nutritional risk (Läkemedelsverket, 2012). In Region Uppsala, patients pay a fee of around 29 USD per month when getting ONS as a supplement to ordinary food (exchange rate in January 2022). The prescribed ONS are delivered to a patient’s home by a designated distribution company and each delivery contains products for one month. The interviewees like most patients within the region and country, were mainly prescribed ONS that are ready-made, multi-nutrient liquids. Some also had experiences of puddings and/or powders. All participants except one had a current ONS prescription monitored by their dietitian. One of the participants had stopped using ONS 1.5 years earlier and their dietitian-led nutrition therapy had ended.
provided valuable information connected to the study aim. Minor line with how a lifeworld interview is performed (Kvale, 2014). The interviews were held in Swedish, and quotes have been translated into English. Two of the interviews were initially conducted during two interviews (a personal assistant and a spouse, respectively), depending on participant preferences. Non-participants were present but were not active in the conversations. A semi-structured interview guide was used (Table 2). The questions were open-ended and suitable prompts and follow-up questions were used when found appropriate, in line with how a lifeworld interview is performed (Evale & Brinkmann, 2014). The interviews were held in Swedish, and quotes have been translated into English. Two of the interviews were initially conducted as pilot interviews, but were included in the analysis since their contents provided valuable information connected to the study aim. Minor changes to the interview guide followed the pilot interviews, such as starting each interview by focusing on ONS usage in everyday life before the prescription and re-phrasing a few questions so they were more open ended. All interviews were audio-recorded and transcribed verbatim. The mean length of the interviews was 43 min (range 25–66 min). Field notes were taken during or after the interviews.

### 2.4. Data collection

Semi-structured interviews were conducted between June 2019 and March 2020. The interviews were undertaken by the first author (ELI), who is a registered dietitian with experience from dietary counselling in cancer care. The interviews took place in the homes of participants (n = 5), at the Department of Food Studies, Nutrition and Dietetics at Uppsala University (n = 3) or through a telephone/video phone call (n = 2), depending on participant preferences. Non-participants were present during two interviews (a personal assistant and a spouse, respectively), but were not active in the conversations. A semi-structured interview guide was used (Table 2). The questions were open-ended and suitable prompts and follow-up questions were used when found appropriate, in line with how a lifeworld interview is performed (Evale & Brinkmann, 2014). The interviews were held in Swedish, and quotes have been translated into English. Two of the interviews were initially conducted as pilot interviews, but were included in the analysis since their contents provided valuable information connected to the study aim. Minor changes to the interview guide followed the pilot interviews, such as starting each interview by focusing on ONS usage in everyday life before the prescription and re-phrasing a few questions so they were more open ended. All interviews were audio-recorded and transcribed verbatim. The mean length of the interviews was 43 min (range 25–66 min). Field notes were taken during or after the interviews.

| Pseudonym | Gender | Age (years) | Occupation | Medical diagnosis | Duration ONS use (months) | Living alone |
|-----------|--------|-------------|------------|-------------------|--------------------------|-------------|
| Anna      | Female | 70–79       | Retired    | Rheumatic disease | 12–23                    | Yes         |
| Christina | Female | 50–59       | Working    | Cancer            | 12–23 (stopped 1.5 years ago) | No          |
| Elisabeth | Female | 60–69       | On part-time retirement and part-time sick leave | Cancer | 12–23 | No |
| Eva       | Female | 60–69       | On sick leave | Gastrointestinal disease | >24 | No |
| Harry     | Male   | 60–69       | Retired    | Cancer            | 0–11                      | Yes         |
| Margrethe | Female | 70–79       | Retired    | Neurological disease | >24 | No |
| Mary      | Female | 50–59       | On sick leave | Cancer | >24 | No |
| Roger     | Male   | 70–79       | Retired    | Neurological disease | 12–23 | No |
| Ruth      | Female | 70–79       | Retired    | Surgery rehabilitation | >24 | Yes |
| Vera      | Female | 80–89       | Retired    |                  |                          |             |

ONS, Oral Nutritional Supplements.

### 2.5. Ethical considerations

Approval of the study protocol was given by the Swedish Ethical Review Authority (Reference No. 2019-01198) and all study participants gave verbal and written informed consent. All participants were informed of their rights to discontinue study participation at any time or not answer any specific question, without explanation. To protect the identities of the participants, we chose to use pseudonym and present ages and durations of ONS usage as ranges. In the study information, patients were told that their name would be replaced with a fictional name and that the results would be presented in a way that would ensure they could not be identified by anyone un-authorized. Since their dietitian took part in the recruitment process, the risk that the dietitian might have knowledge of their study participation was mentioned. Throughout the study, the ethical principles of the Declaration of Helsinki were followed (World Medical Association, 2013).

### 2.6. Data analysis

STC, described by Malterud, was used for cross-case thematic analysis; it has its origin in Giorgi’s descriptive phenomenological method in psychology (Giorgi, 2009; Malterud, 2012). NVivo Plus 11 software was used for data organisation (QRS International Pty Ltd, 2015). The analysis consisted of four steps, which are presented in a schematic overview in Table 3. In the initial step (1), all four authors read parts of the transcripts in order to get a general impression of the material and agree upon preliminary themes. In the second step (2), the first author (ELI) identified meaning units representing statements about being prescribed and using ONS and sorted them into code groups. In the third step (3), the descriptions in each code group were further divided into subgroups. The contents of each subgroup were then rewritten into a condensate, summarising the meaning units into ‘an artificial quotation maintaining the original terminology applied by the participants’, grounded in the empirical data (Malterud, 2012, p. 799). The analysis process was performed step-wise in an iterative way, reviewing the sorting and labelling of code groups and subgroups several times. All four authors discussed the contents and labels of code groups, subgroups and written condensates during regular analysis meetings. Lastly (step 4), the condensates were used as starting points for synthesis and an analytical text describing patients’ experiences of being prescribed and using ONS. STC steps 1–3 were performed for parts of the material while interviews were still being held. During the interviews and the beginning of the analysis process (steps 1–3), our ambition was to bracket our preconceptions and keep the voices of the patients in focus, in line with a phenomenological attitude and a data-driven study approach (Patton, 2014). Later in the analysis process, we searched for literature and theoretical perspectives connected to our findings, and the altered eating framework was used in step 4 of the analysis to cover the wide spectrum of the patients’ different altered relationships to food and eating (Burges Watson et al., 2018). This framework comprises three domains with seven features in total: 1. Patient physiology (anatomical, functional and sensory); 2.
anyone in the research group and had not met any of the researchers. The first author (ELi), who interviewed all the participants, had previous experience from performing therapeutic clinical interviews and was trained in qualitative interviewing. Since all authors were dietitians and performed dietetic research, reflexivity was employed to keep of a project diary and use of a decision trail (Malterud, 2014). The ONS were described as a convenient solution for nutrient intake. The patients described this changed relationship to food and eating in negative terms and referred to eating as ‘hard’, ‘tiresome’ or ‘boring’. The problems described were very diverse and ranged from cancer-related nausea and difficulties swallowing to increased energy requirements due to involuntary spasticity and also worry and grief for a dying or deceased spouse. Below, Ruth and Vera share a glimpse into a life with altered eating.

‘Some days, it might be harder to swallow than others. I don’t really know, I can’t really say, but when you feel like it’s too difficult to eat, then I don’t want food and since I’ve lost my sense of taste, it’s hard to eat, hard to inspire yourself to want to eat’

Ruth (70–79 y, neurological disease, LO)

‘He (spouse) didn’t have the will to live anymore. He was done with his life, he felt, and he didn’t eat and it was a really big step for us to leave our house and move here, right, but as it turned out, we had time to make the move before (he died). I cooked for him and he ate maybe one spoonful and nothing more, so at the same time I lost all my desire to cook and do everything’

Vera (80–89 y, surgery rehabilitation, LA)

The ONS were described to be nutrient-rich and to affect bodyweight, and could thus compensate for food. Many patients shared positive experiences of using ONS, such as increased strength and alertness. ONS were also described by some as a lifesaver and a form of ‘insurance’, providing their body with the right nutrients, which could be harder to achieve with ordinary food. In general, when describing the aim of the products, a nutrient-focused language was used – such as that ONS contributed with calories, proteins, minerals or vitamins. Harry described, in an ironic voice, how he imagined himself eating a nice meal at a restaurant when drinking the ONS. In doing so, he highlighted that ONS only fulfilled the need for nutrients, contrasting this with a more multidimensional, pleasurable meal experience:

‘Now I’m at the Operakällaren [a fancy restaurant at the opera house in Stockholm] and I’m eating an exquisite meal (ironically) and get all my proteins and carbohydrates and minerals and everything that you’re supposed to eat’

Harry (60–69 y, gastrointestinal disease, LO)

The one-dimensional meaning of ONS, as a nutrient carrier, was also described in positive terms. Since food preparation and eating could be burdensome in a situation characterised by disease and altered eating, the ONS were described as a convenient solution for nutrient intake.

‘I would probably feel much worse without because I can’t really say, but when you feel like it’s too difficult to eat, then I don’t want food and since I’ve lost my sense of taste, it’s hard to eat, hard to inspire yourself to want to eat’

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have to prepare and eat as many meals without having company, which was described as depressing. Anna, who had recently lost her spouse and life companion, described the value of ONS in those terms:

‘When I have guests and we are eating, then I eat a whole lot, almost like before […] but I guess I would be forced to manage (with ordinary foods) if I wouldn’t receive it anymore (ONS prescriptions), but it’s much easier to have it, a supplement, it really is’

Anna (70–79 y, rheumatic disease, LA)

When they felt better and eating was not altered anymore, which some patients had experienced, the ONS could still be perceived as a more convenient solution for getting a sufficient nutrient intake, compared with preparing and eating ordinary food.

‘Then you might like, yeah, I’ll skip that snack, skip a meal here and there, and take the supplement instead […] It’s probably easy to take one, if you think it’s hard to cook or do something, or are in a hurry, I’ll take one of those (ONS) instead’

Eva (60–69 y, cancer, LO)

Though several of the patients expressed gratitude at receiving the ONS and perceived them as effective in increasing nutrient intake and bodyweight, the ONS could not compensate for the lost pleasure of normal eating. The ONS could not be a remedy for a lost sense of taste, a lost appetite, a lost hand function or a non-functioning oesophagus. Nor could they compensate for lost shared meals. In summary, a life where one was not able to eat as before was described as painful and depressing, and the ONS served as a one-dimensional remedy to a situation of altered eating.

‘Sometimes it feels quite meaningless to eat since I could just as well take the plate from the table and dump it into the toilet, if you see what I mean. It’s actually what it’s like sometimes, you might think it sounds drastic but that’s my reality […] I imagine that those supplements stick better, right. If nothing else, at least they are energy-dense, right, so it’s easier to get nutrients from them, if you see what I mean, but as I said, the whole thing with food is tiring sometimes actually, but living on supplements is not all that great either’

Harry (60–69 y, gastrointestinal disease, LO)

3.2. Everyday ONS usage is regulated autonomously

According to the patients, acceptance of taste was a prerequisite for consuming ONS and different individual strategies were applied to improve ONS acceptance. In all interviews, the taste of the ONS was described and discussed in both positive and negative terms. All patients was described as depressing. Anna, who had recently lost her spouse and seemed to fit all.

‘Think they’re all (the ONS) very sweet and I understand why they are, but I have never used sugar on my sourd milk and no sugar in tea or coffee and stuff like that, so, I perceive them as very sweet but I don’t think it’s hard to drink them. I can easily get one of the drinks down, but it’s not so […] I mean, you feel like it (…) it gets boring or I don’t know how to put it, but it’s like that with all the flours, like with anything that you have eaten. You can get bored with food in different ways but this gets boring quite quickly’

Ruth (70–79 y, neurological disease, LO)

According to the patients, ONS usage was affected by the priority given to nutrition in everyday life – they did not follow a strict prescription. The patients presented a very diverse picture of how the dietitians recommended the amount of ONS that should be consumed. Some dietitians were described as having recommended a very specific amount (e.g., ‘drink three bottles per day’), while others had not given any recommendations on amount. Some patients described being recommended an interval (e.g., ‘one to two bottles per day’) or that the recommendation changed frequently. For those whose recommendation was constantly changing, frequent follow-ups were held by the dietitian and adjustments were described as being negotiated and agreed upon together with the dietitian. All patients stated, when talking about the recommended amount in relation to the amount consumed, that they perceived the dietitian recommendation on ONS intake to be a suggestion rather than a strict prescription. They viewed it as being prescribed a freedom of choice – a prescribed ONS autonomy.

‘Of course, she recommended that I take two per day but I didn’t agree so I haven’t done that […] I know what I should eat but in reality, you don’t always do […] and that’s because I don’t want to get fat […] I’m prescribed heart medicines but I’m not prescribed the supplements. It’s a suggestion and there’s a slight difference’

Vera (80–89 y, surgery rehabilitation, LA)

‘No, there was no prescription at all. Or maybe there was “take as much as you want” I don’t know, but there was no real prescription, but I tried this out and I think it works’

Margrethe (70–79 y, cancer, LA)

‘Interviewer asks about the recommended amount’ No, it’s more, what should I say, it’s simply the amount that I myself think I need to feel good’

Harry (60–69 y, gastrointestinal disease, LO)

According to the patients, ONS usage was affected by their current situation in everyday life and depended on the perceived importance of nutrition and the ease of nutrient intake. If a higher nutrient intake and/or bodyweight was expressed as desirable, a striving for a higher ONS usage was described. The opposite situation, where a high nutrient intake and/or bodyweight was not desirable, was also described. For example, as seen in Vera’s quote above, one reason for not consuming more than one ONS per day was that she didn’t want to ‘get fat’. On the other hand, Anna welcomed a higher bodyweight and Elisabeth, who had recently been recommended by the dietitian to replace the afternoon ONS bottle with a fruit, expressed a slight reluctance to make this change since she really wanted to secure her nutrient intake. To her, nutrition was something that she was in control over, and a way of improving her chances to recover from cancer and stay alive.

‘It has become a force of habit for me to take the supplement in the afternoon but it’s a bit unnecessary since I could just as well have a
sandwich or two or something, but it’s just (sounding sigh) I’ve wanted to get all the nutrients [...] I really rely on the supplements because I know that the ingredients in it are well-balanced. And that’s what I need’

Elisabeth (60–69 y, cancer, LO)

Some patients also described adjusting their ONS consumption based on their intake of ordinary food. For example, Vera described not needing the ONS when spending time with relatives and sharing birthday meals, as this resulted in her eating more. Ruth described doing a daily evaluation and compensating with ONS when her food intake was too low. She also described situations where ONS was simpler to take than ordinary food, since she could not eat everything due to difficulties swallowing.

‘It’s probably how much I perceive I have eaten of other foods (that determine how many ONS she takes) [...] and then sometimes it happens that I feel like no, now it’s too hard, then I’ll take one of those instead (embarrassed laugh) of eating [...] For example there have been many times now when I’ve been to the hospital to undergo examinations and then I bring them (ONS) because it’s much easier than buying something to eat’

Ruth (70–79 y, neurological disease, LO)

Some patients described consuming ONS in order to increase alertness in connection with activities like sports shooting or golfing, while Ruth avoided taking them in the afternoon or evening since she found they made it hard to fall asleep. Sometimes, other activities counter-acting ONS consumption were prioritised, even though a higher ONS intake was expressed as important from a nutritional perspective. For example, Harry stated that he did not want his disease to decide intake was expressed as important from a nutritional perspective. For

‘I have to try (sounding sigh) to spread those occasions across the time that I’m awake, so to speak, but it doesn’t always work out that well. It depends on what I’m doing, like yesterday was chaos since I and a friend went to the movies at half past twelve and then I had no, I had breakfast, but no real lunch, and when I got home I was supposed to have dinner and then, yeah I know that it was bad and I think I had one supplement so yesterday was a catastrophe from a nutrition point of view’

Harry (60–69 y, gastrointestinal disease, LO)

Mary described decreasing her ONS intake in order to prioritise fluids from coffee and other meals, since needing assistance to move from her wheelchair to the toilet was tiresome.

‘Right now, I have a urinary tract infection. Then it’s really good to drink a lot but it’s not that easy to drink a lot when you are in a wheelchair and have to move over to a (toilet). It’s just too much. It’s too burdensome. It’s hard enough anyway, so then I reduce the intake of these (ONS) for example in order to be able to drink coffee, to have dinner and lunch [...] Sometimes you have to sacrifice one thing for another’

Mary (50–59, neurological disease, LO)

When the two categories are taken together, the meaning of ONS was nutrition, and usage was described as dependent on the acceptance of taste and the priority given to nutrition in everyday life. ONS could not bring normal eating back, but were described to work as a convenient solution for nutrition intake in a situation of altered eating. Usage was expressed as prioritised when nutrients were perceived as needed, such as when compensating for low food intake or when striving for higher bodyweight or disease recovery. On the other hand, usage was described as consciously lowered when a patient’s own goal was not increased nutrient intake or bodyweight or when other activities were perceived as more important than drinking ONS.

4. Discussion

This study provided a number of insights concerning malnutrition therapy with ONS from a patient perspective. The overarching message identified was that ONS usage is regulated autonomously, based on how each patient prioritises nutrition in everyday life.

4.1. The ONS – in between foods and medicines

The patients described the meaning of ONS as being to compensate for nutrient deficiencies and eliminate burdensome food-related tasks. This meaning was expressed as affecting the patients’ consumption of ONS in different ways, adding to the discussion on ONS adherence being challenging. Our study findings confirm the multidimensional meaning of food and eating and that provision of nutrients is just one small part thereof (Meiselman, 2020). The patients described ONS as nutrient carriers, unable to provide the same pleasure or feeling of social belonging that eating food together with others does. Drinking ONS thus seems to be disconnected from commensality (eating together) (Fischler, 2011) and can be understood as a health-promoting act, rather than a pleasurable and social act. The meaning of eating being reduced to an act only for achieving good health has been proposed to be an effect of a medicalisation of foods (Mayes, 2014). Since ONS are classified as foods (European Parliament and Council, 2013; Weenen et al., 2014), but in many ways are managed as medicines (being prescribed, dispensed by pharmacies etc.), they constitute an illustrative example of what food becomes when only the biological aims of eating – nourishing the body and survival – are considered. ONS are food products that from a medico-legal perspective must contain a perfect nutrient combination for the malnourished human body, while flavour, texture and context of consumption are not mentioned in law (European Parliament and Council, 2013) and hence are viewed as secondary. However, from a patient perspective, these aspects are central, and one important contribution of this study was the insight that ONS serve as a one-dimensional remedy to a situation of altered eating. One should acknowledge that this one-dimensionality could also be understood as positive, since the ONS gave the patients an opportunity to ingest nutrients without having to prepare or participate in a socially and culturally connected meal, thus limiting interference with daily routines. This insight is important, since there is an ongoing discussion on the most suitable malnutrition intervention: food-based strategies (‘food first’), ONS or a combination thereof (food-based strategies plus ONS) (Baldwin, de van der Schueren, et al., 2021; Baldwin, Smith, et al., 2021; Parsons et al., 2017). Our findings can promote the understanding of why ONS might, for some patients, work better than food-based changes. When eating is altered, food intake can be difficult and ONS provide a solution that does not represent a meal: they contribute only with nutrients. This means that taking an ONS might be a strategy for ingesting nutrients preferable to eating a meal when you have no appetite, distorted taste perceptions or lack pleasant company. Also, in contrast to taking a pill, and in line with previous literature, we found that the taste acceptance or palatability of ONS could not be neglected in this nutrition therapy (Beelen et al., 2017; Enríquez-Fernandez et al., 2019; Milne et al., 2009; Stratton & Elia, 2010).

4.2. Understanding self-regulation of ONS intake

In line with previous findings regarding self-regulation of medication for epilepsy and asthma, the patients in this study seemed to regulate their ONS usage autonomously (Conrad, 1985; Farnesi et al., 2019). Such active, self-determined ONS regulation can be interpreted as patients expressing a sense of self-agency, rather than being passive agents who go home and follow a carer’s advice (Jeannerod, 2003; Morin, 2017). It also clearly relates to concepts such as empowerment and self-management, where healthcare desires an active patient who solves problems, makes independent decisions and acts upon them (Cerezo et al., 2016; Lorig & Holman, 2003). When the taste of ONS was acceptable, their usage was described as being affected by patients’ own views regarding the need for nutrients and to what extent the activity of
drinking ONS was prioritised or fit into their daily schedule. For example, drinking ONS was described as central, even as a lifesaver, when recovering from a life-threatening disease like cancer, but not as important for a patient not wanting to gain weight. Disease severity and perceived disease severity have in several systematic reviews been shown to influence adherence to treatment (Kardas et al., 2013). Perceived severity is suggested to affect behaviour change and is a central concept in some behaviour change theories, such as the Health Belief Model (Rosenstock, 1974). A life-threatening disease like cancer might therefore lead to higher ONS adherence than a milder disease or condition. However, in a systematic review on compliance to ONS, very little variation was shown based on medical diagnosis — but a negative association between compliance and age was found (Hubbard et al., 2012). Older people with malnutrition constitute a group in which acceptance of taste and adherence to ONS seem to be especially challenging (Hubbard et al., 2012; McMurdo et al., 2009; Milne et al., 2009). A scoping review of older adults, including those at risk of malnutrition, concluded that this group considered weight loss a positive outcome and viewed what was considered a healthy diet for the general population (high in fruits and vegetables and low in fat and sugar) to be suitable for them (Castro et al., 2021). Our results confirmed that such views were expressed by some patients who were prescribed ONS in clinical practice. However, the opposite situation was also exemplified in our findings, since a strong belief in the beneficial effects of the ONS led to a reluctance to decrease ONS intake. From a healthcare perspective, struggles with discontinuation of long-term ONS prescriptions have previously been described as a practical barrier for this malnutrition treatment (Harris et al., 2019). The findings of our study highlighted the need for bridging the gap between the healthcare and patient perspectives on the goal of malnutrition therapy. The patients’ goals seemed to vary: for some, they were about an optimal nutrient intake and for others they stretched beyond the nutritional status, towards what made them feel good from a more holistic viewpoint.

### 4.3. Clinical implications and future perspectives

This study implies that there is a need for a ONS prescriber and patient to discuss the goals with the ONS therapy. For the patient, an improved nutritional status might or might not be central. ‘Feeling good’ could mean being able to go to the movies or prioritising fluid intake from coffee over that from an ONS bottle. Therefore, it is also very important for a prescriber to discuss together with the patient not only **what** changes that are suitable (food-based changes, ONS, etc.), but also **why** a certain nutrition therapy would be beneficial for the patient and **how** it could be implemented in their life. The study findings also imply that nutrition therapy with ONS does not serve as a remedy for altered eating, which is an aspect that prescribers should be aware of. From a person-centred care approach, understanding what it is like for patients who are not able to eat as usual is an important task for nutrition professionals. This is in addition to striving for a higher energy and nutrient intake by patients. In order to learn if the suggested implications benefit patients, experimental studies are needed. For such studies, an intervention could for example focus on self-regulated versus strictly prescribed ONS amounts or setting goals together with each patient. Most importantly, outcome measures of meaning for the patients should be included in future trials on nutrition therapy for malnutrition. The altered eating framework could be helpful for this purpose.

### 4.4. Strengths and limitations

In reviewing the study findings, one must consider that the majority of the participants were over 60 years old, non-working, Swedish-speaking, long-term users of ONS (primarily ready-made, liquid ones) living in a country with very generous subsidies on medical nutrition products. However, the sample was very diverse with regard to the phenomenon in focus – experiences of being prescribed ONS and ONS usage – which is desirable in an experience-focused inquiry (Malterud, 2012). The inclusion of patients using other types of ONS, such as soups and other more ‘food-like’ products, might perhaps have enriched the findings even further. However, such ONS are not prescribed to any great extent in Sweden. Future qualitative studies from other countries where they are used could provide further knowledge in this area.

One of the questions in the interview guide, ‘Do you view the ONS as food or medicine’, was not phrased in a life-world interview fashion, where open questions on experiences of a phenomenon are recommended (Kvale & Brinkmann, 2014). This question was included due to the interesting results presented by den Uijl et al. (2015), where a majority of ONS users considered ONS to be food rather than medicine. In our interviews, this question was more or less redundant, since it was hard for the patients to answer and they tended to reflect on this topic in other parts of the interview anyway.

The altered eating framework stems from a study of head and neck cancer survivors (Burnes Watson et al., 2018). Our participants were a mixed group as regards medical diagnoses (cancer of different types, neurological diseases, rheumatic disease and gastrointestinal disease). However, we found the framework to be very helpful when interpreting the changed relationships to food and eating. Therefore, we agree with the creators of the altered eating framework; altered eating seems to be an entity applicable to several medical diagnoses where malnutrition is common (Burnes Watson et al., 2018). The majority of the study participants were recruited by their ONS-prescribing dietitian and they were also informed of the interviewer’s background as a clinical dietitian. This might have affected what was shared, and some descriptions of the role of their dietitian or their ONS or eating practices might have been positively exaggerated. According to Thorne, people might focus their stories on what they think the interviewer will understand, rather than giving a complex description of their experiences (Thorne, 2008). However, many of the interviewees also shared experiences of views or behaviours which were not in line with healthcare recommendations.

One limitation of this study is the lack of a triangulation of data sources, which is recommended to increase the credibility of a qualitative study (Patton, 2014). However, in a previous study by our research team, Swedish dietitians also described the prescription of ONS to be performed in a flexible manner based on patient acceptance and preferences (Liljeberg et al., 2021). This alignment of the dietitian and patient descriptions on the ONS prescription process in a Swedish outpatient context strengthens the findings of this study.

### 5. Conclusions

Patient experiences indicated that ONS can be understood as a one-dimensional remedy which compensates for low nutrient intake, but cannot lessen the burden of altered eating. However, they can serve as a helpful strategy for ingesting nutrients when the relationship to food and eating is altered. By comparing the multidimensional meaning of food and eating to the one-dimensional meaning of ONS, one factor contributing to the difference between malnutrition interventions comprising only food-based strategies and those comprising only ONS becomes clearer. The patients described their ONS usage as being regulated autonomously based on their own views of the importance of nutrition in general and in specific everyday situations. Those views varied, and ONS was described both as a ‘lifesaver’ and as just a calorific drink leading to unwanted fatness. The patients described having a mandate to independently decide upon the amount to consume — and did so in order to feel good. Feeling good could relate to both nutritional status and to participating in a valued activity that negatively affected ONS intake. One implication for healthcare from this study is the insight that ONS are unable to bring normal eating back, something that is central for patients. Another noteworthy aspect is that the perceived importance of nutrient intake and weight gain varied in this group of ONS users and was indicated to affect their ONS usage. This highlights
the need for a discussion between the healthcare professional and the patient on the goal of nutrition therapy for malnutrition, which from a patient perspective can go beyond nutritional status.

Ethical statement

Approval of the study protocol was given by the Swedish Ethical Review Authority (Reference No. 2019-01198) and all study participants gave verbal and written informed consent. All participants were informed of their rights to discontinue study participation at any time or not answer any specific question, without explanation. Throughout the study, the ethical principles of the Declaration of Helsinki were followed.

Author contributions

All four authors were actively involved in the conception and design of the study. ELi was responsible for data collection and transcription. All authors were involved in the thematic analysis, and ELi took a leading role in the analysis process. ELi had the main responsibility for writing the manuscript, in collaboration with co-authors. All authors have approved the final manuscript.

Declaration of competing interest

None of the authors has any conflicts of interest to declare.

Data availability

The data that has been used is confidential.

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