Oral nutritional supplements within the nutrition therapy

*Prescription and adherence from a dietetic practice perspective*

EVELINA LILJEBERG
Abstract

The overall aim of this thesis was to increase knowledge and deepen understanding on prescription of and adherence to oral nutritional supplements (ONS). In Paper I, the reporting quality of interventions with ONS in publications of randomised controlled trials was explored. In Paper II, adherence to ONS prescriptions from dietitians to hospital outpatients in clinical practice was assessed. Further, an evaluation of the population characteristics and ONS prescription characteristics was performed. In Papers III and IV, dietitian and patient experiences of prescribing or being prescribed and using ONS were explored through qualitative interviews.

The reporting quality of ONS interventions was found to be incomplete, making it hard to interpret trial findings and replicate them in clinical practice. The articles mainly lacked a description of intervention procedures, provider and location(s), but an improvement was observed in articles published after 2011. Adherence to ONS was found to be high (> 75%) among hospital outpatients prescribed ONS in clinical practice. The population was relatively young (mean age 67 years), and the two most common medical diagnoses were cancer and gastrointestinal disease. The prescriptions were individually tailored by dietitians, usually encompassing several flavours (mean 4.2) and 1–3 bottles/day. In the dietitian interview study, shared tailoring of the ONS prescription and provision of behaviour change support were identified as important aspects when dietitians prescribe ONS. In the patient interview study, ONS were described as a one-dimensional remedy: contributing with nutrients, but unable to resolve the situation of altered eating. Additionally, ONS usage was described as regulated autonomously based on the priority given to nutrition in everyday life.

In conclusion, this thesis shows that prescription of and adherence to ONS are complex processes, which tend to be underestimated in the ONS literature. Adherence to ONS was high, which might be explained by population characteristics and the dietitian-tailored prescriptions fulfilling criteria for appropriate ONS prescriptions. The interview studies provided insights into nutrition therapy with ONS from both the dietitian and the patient perspective. The findings indicated that ONS should be prescribed using a person-centred care approach, with patients viewed as an active part in nutrition therapy.

Keywords: oral nutritional supplements, dietitian, prescription, adherence, dietetic practice, nutrition therapy, malnutrition

Evelina Liljeberg, Department of food studies, nutrition and dietetics, Box 560, Uppsala University, SE-751 22 UPPSALA, Sweden.

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To my family
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


IV Liljeberg, E., Nydahl, M., Lövestam, E., Andersson, A. ‘I take the amount I need to feel good’: a qualitative exploration of patient experiences of the meaning and usage of oral nutritional supplements. *Manuscript.*

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Contribution of authors

**Paper I**
Evelina Liljeberg, Margaretha Nydahl and Agneta Andersson were actively involved in the conception and design of the study. Evelina Liljeberg performed the search for articles. All four authors were involved in drafting the manual for article review. Evelina Liljeberg and Elin Lövestam performed the review of reporting quality. Evelina Liljeberg conducted the statistical analyses under supervision of co-authors and drafted and revised the manuscript in collaboration with co-authors.

**Paper II**
Evelina Liljeberg, Margaretha Nydahl and Agneta Andersson were actively involved in the conception and design of the study. Karin Blom Malmberg contributed to the design of the study. Evelina Liljeberg and Karin Blom Malmberg contributed to the data acquisition. Evelina Liljeberg was responsible for data collection and conducted the statistical analyses. All authors contributed to the interpretation of the data. Evelina Liljeberg drafted and revised the manuscript, which was critically revised by co-authors.

**Papers III–IV**
All four authors were actively involved in the conception and design of the studies. Evelina Liljeberg was responsible for data collection and transcription. All authors were involved in the thematic analysis, and Evelina Liljeberg took a leading role in the analysis process and did the principal coding. Evelina Liljeberg had the main responsibility for writing and revising the manuscripts, in collaboration with co-authors.
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Abbreviations

AND  Academy of Nutrition and Dietetics
BCW  Behaviour Change Wheel
BMI  Body Mass Index
COM-B system  Capability Opportunity Motivation – Behaviour system
EN   Enteral Nutrition
FFQ  Food Frequency Questionnaire
ITT  Intention-To-Treat
MPR  Medication Possession Ratio
MUST  Malnutrition Universal Screening Tool
NCP  Nutrition Care Process
NCPT  Nutrition Care Process Terminology
ONS  Oral Nutritional Supplements
PN   Parenteral Nutrition
PP   Per-Protocol
RCT  Randomised Controlled Trial
SDM  Shared Decision-Making
STC  Systematic Text Condensation
TIDieR  Template for Intervention Descriptions and Replication
WHO  World Health Organization
24-h recall  Twenty-Four-Hour Dietary Recall
Preface

Before this PhD journey started, I worked as a clinical dietitian at Karolinska University Hospital, primarily at the gastrointestinal surgery unit and the oncology unit. The nutrition therapy focused on increasing patients’ energy and nutrient intake through food-based strategies, oral nutritional supplements, enteral nutrition and/or parenteral nutrition. The clinical work was inspiring, and I had the opportunity to follow patients at the ward as well as in the hospital outpatient setting. To me, the conversations with patients were especially interesting when I was striving to finding a balance between my own interests (dietetically focused) and the patients’ interests concerning their food and eating. At follow-ups, we discussed changes made and not made, and I was often thinking about my role as a dietitian and in what way I could be of greater help to patients. When a PhD position within the communication of dietetics was available, I applied – since I was curious and felt that more research performed from a dietitian’s viewpoint was needed. Hopefully, the contents of this thesis will be of value for both dietitians and other healthcare professionals, and ultimately also for the persons at the centre of the care: the patients.
Background

Introduction
In this thesis, nutrition therapy with oral nutritional supplements (ONS) is explored from a dietetic practice perspective in order to inform future management of disease-related malnutrition. This work acknowledges the importance of patient adherence to ONS prescriptions and challenges related thereto, and also explores adherence to this nutrition intervention from the viewpoints of behavioural change theory and person-centred care. I have performed the work with this thesis at the Department of Food Studies, Nutrition and Dietetics at Uppsala University, where research and teaching are focused on food and eating from interdisciplinary perspectives. The studies included in this thesis can be placed within the field of dietetics and the applied healthcare sciences, and have contributed to the growing research area on the dietetic profession and nutrition therapy for malnutrition.

Dietetic professionals’ working process when providing nutrition therapy is called the Nutrition Care Process (NCP) and includes four steps. Those are the nutrition assessment, diagnosis, intervention and, lastly, monitoring and evaluation (1, 2). This thesis focuses on the third step, the nutrition intervention, for patients with malnutrition or at nutritional risk. Focus is also on the change of eating behaviour, sometimes acknowledged as adherence to therapy, which within dietetic practice can be assessed during the monitoring and evaluation phase. Adherence to treatment is in general closely connected to treatment outcomes, and is often described as challenging (3, 4). This is true also for adherence to nutrition therapy (5, 6).

Instead of having the medical diagnosis or medical treatment as a starting point, the studies included in this thesis started with the nutrition therapy with ONS in focus. Though dietitians are suggested as most suitable in choosing which ONS to prescribe (7), the accredited healthcare professional who prescribes ONS differs between countries and settings (8-10). In Sweden, this task is primarily performed by dietitians (10).
Nutrition therapy for malnutrition

Nutrition therapy for patients with malnutrition or at nutritional risk consists of food-based strategies to increase food intake and/or the energy density of food, ONS, enteral nutrition (EN) or parenteral nutrition (PN) (11-13). In Sweden, as in other European countries (14, 15), the first-line nutrition intervention for malnutrition involves food-based strategies to increase oral intake through changes in ordinary food. Examples of food-based strategies are fortification of food, adding extra snacks, modification of food texture or provision of meal assistance (14, 15). If food-based changes are not enough, adding ONS is recommended. Commonly, a combination of food-based strategies and ONS is applied. EN is recommended if oral nutrition support (food-based strategies + ONS) is not enough or not safe, and the gastrointestinal tract is functioning. PN is the final solution if the other strategies do not ensure a safe and satisfactory energy and nutrient intake (12-15). In Figure 1, a summary of the basic principles of nutrition therapy for malnutrition, as described by the Swedish National Board of Health and Welfare, is presented (14). Those principles are similar to other European guidelines (16).

![Figure 1](image.png)

**Figure 1** Basic principles of nutrition therapy for malnutrition as described by the Swedish National Board of Health and Welfare (14). Translated from Swedish.

Oral nutritional supplements

ONS belong to the category ‘Foods for special medical purposes' and are intended for dietary management in patients with limited intake of ordinary food due to a disease or medical condition (17). ONS can be in the form of ready-to-drink liquids, puddings, energy modules, or powders to be mixed with flu-
ids. The products contribute with energy and nutrients through their fat, carbohydrate, protein, vitamin and/or mineral contents (18, 19). Occasionally, ONS are referred to as sip feeds.

ONS have been shown to be clinically effective and associated with an increased energy and nutrient intake, weight gain, lower risk of complications (11, 20-27), improved quality of life (24, 28-31), decreased length of hospital stay (32) and cost savings (33-36). In a meta-analysis performed by the National Collaborating Centre for Acute Care in United Kingdom in 2006 (11) and in subgroups of patients in other meta-analyses (20, 21, 37), ONS usage has been associated with lower mortality risk. ONS as a treatment approach for malnutrition is therefore endorsed in several international guidelines as a complement when food-based strategies are not enough (12, 13, 38-40). Nevertheless, randomised controlled trials (RCTs) are frequently requested in order to establish solidly evidence-based guidelines regarding the best malnutrition therapy (24, 32, 41).

ONS prescription

Within healthcare, ONS are often being prescribed to patients. The definition of a drug prescription is 'Directions written for the obtaining and use of drugs’ according to the Medical Subject Headings database (42). In the literature on ONS, a prescription tends to describe the number of bottles to be consumed per day. Key aspects of appropriate ONS prescription have, by Cadogan and colleagues, been suggested to involve the following (8):

\[P\]atient screening and assessment to ensure that a clinical indication for nutrition support exists, global assessment of the underlying causes of malnutrition, setting goals in terms of nutrition support treatment, providing food first advice and regular monitoring of patients subsequently prescribed ONS to assess continued need.

In many European countries, ONS are prescribed by healthcare professionals and subsidised by the government. However, the primary healthcare professional responsible for ONS prescription varies between countries and settings (8-10, 43, 44). When studying interventions to improve appropriate ONS prescription, involving dietitians was found to be the most common intervention component (8). The dietetic professional has also been suggested as best suited for choosing which ONS to prescribe (7). Moreover, prescribing healthcare professionals who are not dietitians have expressed a lack of confidence when prescribing ONS (45) and in choosing the ONS that are most appropriate (46).
The Swedish context
In Sweden, the system of medicine prescriptions, including aspects like subsidisation and which professional is responsible for prescription, is nationally governed (47). However, the system of prescriptions of foods for special medical purposes (including ONS and EN) is governed locally in the 21 Swedish regions. Consequently, the degree of subsidisation, product selection, responsible prescribers and ONS distribution procedures vary with geographic location (10). Also, the number of registered dietitians in relation to population size varies between the 21 regions (48). In total, there are approximately 1,800 dietitians working in Sweden (49). As mentioned before, dietitians serve as the primary prescribers of ONS to free-living non-institutional patients (i.e., hospital outpatients and primary healthcare patients) in a majority of the Swedish regions. Doctors and, in one out of 21 regions, district nurses also have prescription rights (10). A dietitian-performed prescription typically involves communicating a recommended intake of ONS as well as arranging a subsidised distribution of ONS to the patient. Examples of different distribution procedures are home delivery or collection at a healthcare unit or pharmacy.

In Sweden, free-living non-institutionalised patients represent the principal group of ONS users (60%), followed by nursing home residents (25%) and, lastly, hospitalised patients (15%) (50). Within nursing homes and hospitals, various healthcare professionals are responsible for the initiation and monitoring of ONS usage as part of the nutrition care. During 2012, 3 million litres of ONS were sold in the country, corresponding to a cost of approximately 150 million SEK (≈ 15 million EUR) (50).

The studies in Papers II and IV were conducted in Region Uppsala, which is one of the most dietitian-dense regions in Sweden (48). The region has close to 390,000 inhabitants and a university hospital which is one of the largest hospitals in Sweden, with 850 hospital beds and 8,500 employees (51). The clinical dietitian unit serving adult patients at the hospital has 25 dietitians employed (the number has increased in recent years). A majority of the public (n = 25) and private (n ≈ 20) primary healthcare units in the region have a dietitian employed. Furthermore, Uppsala University is one of three universities in the country offering a dietetics program (180 credits). When ONS are prescribed as a complement to the ordinary diet (e.g., 1–3 bottles/day) in Region Uppsala, the subsidy is generous and the patient pays only a fee of 250 SEK (≈ 25 EUR) per month. If the energy and nutrient intake comes solely from ONS or EN, the patient pays a fee of 1,500 SEK (≈ 150 EUR) per month (52, 53). In Paper III, the dietitians interviewed were recruited nationally and represented 7 out of 21 regions. Those regions were diverse with regard to dietitian density per 100,000 inhabitants, ONS subsidy level, product selection and ONS distribution.
Adherence to nutrition therapy with ONS

Definition of adherence

The potential beneficial effect of a therapy depends on patient adherence (or compliance) to the treatment. Several different definitions and terms have been used over time to describe this phenomenon (54). An early and widely cited definition of compliance was presented by Sackett and Haynes in 1976 (55):

*Compliance is the extent to which the patient’s behaviour (in terms of taking medications, following diets or executing other lifestyle changes) coincides with the clinical prescription.*

Since the term compliance reflects a passive patient who receives advice from a healthcare professional, the term adherence has been suggested as more suitable. The argument for this is that it frames the patient as an active party in the treatment process. In 2003, the World Health Organization (WHO) presented a merged definition of adherence to long-term therapy (3):

*[T]he extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.*

The WHO adherence definition includes the word *agreed* and emphasises a desirable patient and healthcare professional relationship based on equality and cooperation (3). In the majority of studies cited in this thesis that include data or discussions on adherence (or compliance), it is not clear if the suggested recommendations were agreed upon. When the phenomenon is discussed in this thesis, the term adherence is used. However, when citing other publications, the respective authors’ terminology is used.

Measuring ONS adherence in studies

Adherence to dietary advice is usually measured using traditional dietary assessment methods such as weighed or estimated food records, food frequency questionnaires (FFQs), 24-hour dietary recalls (24-h recalls), food diaries and, sometimes, biomarkers (5). When it comes to measures of adherence to dietary supplements or specific food items like ONS, common methods for assessing adherence are patient interviews, dietary records, and collection of consumed or unconsumed packages/cans (56, 57). Occasionally, measurement of biomarkers in plasma or serum, or the direct measure of supervising ONS consumption, have been used (30, 56, 58). Adherence or compliance to ONS is often reported as a ratio of the consumed amount in relation to the
prescribed amount (intake/prescription), where 100% is the maximum adherence level (57). An adherence rate over 80% is generally considered as satisfactory within the literature on treatment adherence (4). In two different ONS trials, 73–75% have been suggested as cut-offs to separate compliance from non-compliance (59, 60). In another trial, ≤ 30% of provided ONS actually being consumed was defined as low compliance and ≥ 80% as high compliance (61).

Adherence to ONS

Higher adherence to ONS has been associated with beneficial treatment effects regarding nutrition intake (57), nutritional status (59, 61-63), reduced risk of hospitalisation (43) and improved liver function and survival in chronic liver disease (64). Though adherence (or compliance) to ONS has been acknowledged as problematic (20, 60, 64-67), a high average compliance rate (78%) was identified in a literature review of compliance to ONS published by Hubbard and colleagues in 2012 (57). Studies included in this review were mainly RCTs (n = 32/46), followed by non-randomised trials (n = 9/46) and cross-sectional studies performed in routine clinical practice (n = 5/46). When comparing ONS compliance between different study types, it was found to be lower in cross-sectional studies (61%) than in clinical trials (77–79%), which according to the review authors could be an effect of trial conditions (e.g., more encouragement, number of visits and reinforcement) (57). All cross-sectional studies included in this review (66, 68-71) were performed within institutions like nursing homes and hospitals. In a study of ONS usage in an Irish community setting (n = 76, of whom 64% were non-institutionalised), half of the population answered that they did not follow the prescription on most days of the week (72).

Factors influencing adherence to ONS

A number of factors have been suggested as influencing ONS adherence. High compliance has been positively associated with higher ONS energy density, and negatively associated with age (57). Low acceptance of the taste, texture or volume and lack of choice of ONS have been suggested as barriers to ONS adherence (20, 60, 61, 65, 73). On the other hand, variation in flavours, texture and serving formats have been suggested as beneficial (18, 74, 75). Other factors suggested to be of importance for adherence to ONS are if the prescription is individually tailored (18), how the supplement is taken (57, 76), if the patient is informed of the purpose of taking supplements (18, 77), social support (67) and the duration of ONS usage (64, 67). However, in the review by Hubbard and colleagues, compliance to ONS and duration of treatment were unrelated (57). Also, factors associated with the disease and the treatment of the disease may play a role. For example, compliance to ONS has been shown to
be higher before gastrointestinal surgery than after, and postoperative bloating and early satiety are suggested as affecting ONS intake (75, 78). Though there was no correlation between body mass index (BMI) and compliance to ONS (at baseline) in the Hubbard review (57), malnutrition status was associated with compliance in a study on nursing home residents (61). In the latter study, those assessed as malnourished had a higher compliance rate than those assessed as non-malnourished (61). Thus, it appears that nutritional status may play an important role in the adherence to ONS.

**Trial reporting as a means to improve ONS prescription and adherence**

The differing compliance to ONS between the trial setting and routine clinical practice suggests that elements of the ONS interventions in RCTs are of importance to achieve high adherence (57). In order to identify those elements, adequate trial reporting is of importance. Review authors investigating the effects of dietary advice with or without ONS have commented on the pronounced absence of reporting of the nature, intensity and content of nutrition interventions in clinical trials (79). Further, a large number of studies on ONS (174/288) had to be excluded from the review by Hubbard and colleagues due to inadequate reporting of compliance (57). Trial reporting is an area that has received greater interest in recent years and several reporting guidelines have been published in order to enable replication and avoid research waste (e.g. 80-82). Since the delivery of evidence-based interventions is a core goal of healthcare, the quality of intervention reporting is of great importance for the implementation of evidence into clinical practice (81). For the dietitian in clinical practice, well-described methods of nutrition interventions and data on adherence enable correct interpretation of trial results and replication.

**Dietetic practice**

Dietetics is a core subject for practicing dietitians, and is by the Academy of Nutrition and Dietetics (AND) in the US defined as (83, 84):

> The integration, application and communication of practice principles derived from food, nutrition, social, business and basic sciences, to achieve and maintain optimal nutrition status of individuals and groups.

The subject can thus be understood as interdisciplinary and influenced by the traditions in several fields. Nowadays, the scope of dietetic practice is broad and the occupational roles, working environments, specialities and client
groups of dietitians vary (84, 85). In most countries, dietitians are found within the hospital setting, food service, food production and manufacturing companies, and in academia/research (86). In Sweden, dietitians are also often found in the primary healthcare and community settings. Dietetic practice shares the general healthcare goal of having a basis in scientific evidence. Therefore, the standards of evidence-based medicine apply also to dietitian-provided nutrition therapy (85, 87). Within different evidence grading systems, the RCT (preferably double-blinded) is generally viewed as providing the highest degree of evidential support for practice (88).

Dietitians are in many countries, including Sweden, endorsed by dietetic organisations to work and document in accordance with the NCP and NCP terminology (NCPT) (84, 89). The aim of the NCP and NCPT is to support dietitians’ critical thinking and problem-solving skills when addressing practice-related tasks, and also to move dietetic practice towards becoming more evidence-based, rather than experience-based (1, 2, 90). The four steps of the NCP are interrelated and connected, and each step informs the next one. The nutrition assessment (step 1) involves collection of relevant data, and is followed by the nutrition diagnosis (step 2), which includes the identification and labelling of an existing nutrition problem that the dietitian is responsible for treating. The nutrition intervention (step 3) includes actions aiming to resolve the nutrition diagnosis. In the final step, nutrition monitoring and evaluation (step 4), the dietitian identifies the amount of progress made and determines if the expected outcomes have been achieved (1). The NCP can be used when working with individuals, groups or communities within the clinical or public health setting. The focus of this thesis has been on individual nutrition therapy within the clinical setting.

Malnutrition – definition and criteria

Described as one of the major healthcare challenges in Western societies (91, 92), malnutrition is an area suggested to be addressed and managed by dietitians (93). Within clinical trials, dietitians are often responsible for malnutrition therapy (31, 94-96). Malnutrition is very common in high-risk groups in the Western world and is prevalent among 20–50% of patients admitted to hospital (97), 20% of hospital outpatients (98), 14–18% of nursing home residents (99, 100), and 3–6% of older adults living in their own home (100). Malnutrition has consequences for the patient as well as for society through its associations with decreased quality of life (21, 101), increased length of hospital stay, morbidity, mortality (97, 102, 103), and cost of care (102, 104). The underlying causes of malnutrition are often multifactorial and include reduced food intake, malabsorption, and increased metabolism and catabolism (21). Reduced food intake may be caused by, for example, eating difficulties,
gastrointestinal problems and/or depression (21, 105). Medical diagnoses or conditions where disease-related malnutrition is common include cancer, gastrointestinal disease, kidney disease, lung disease, neurological disease and multimorbidity in geriatric patients (21). Consequently, those patients are found in a majority of medical specialist areas and healthcare settings.

In this thesis, the term malnutrition is used to refer to undernutrition. This is in line with the European Society for Clinical Nutrition and Metabolism’s definition of malnutrition as (16):

\[
\text{[A] state resulting from lack of intake or uptake of nutrition that leads to altered body composition (decreased fat free mass) and body cell mass leading to diminished physical and mental function and impaired clinical outcome from disease.}
\]

A challenge for researchers, clinicians and stakeholders within the field of malnutrition is the absence of consensus regarding the diagnostic criteria for the condition. In 2019, a new consensus approach named the Global Leadership Initiative of Malnutrition (GLIM) was published (105). The initiative suggests a two-step model when diagnosing malnutrition, where the first step is to perform a risk screening with a validated malnutrition screening tool. Examples of such tools are the Malnutrition Universal Screening Tool (MUST) (106, 107), the Short-Form Mini Nutritional Assessment (108) and the Subjective Global Assessment of Nutritional Status (109). In the second step, malnutrition is diagnosed if a patient presents with at least one phenotypic criterion (non-volitional weight loss, low BMI or reduced muscle mass) and one etiologic criterion (reduced food intake/assimilation or inflammatory condition) (105). In Sweden, the National Board of Health and Welfare recommends nutritional risk screening within healthcare to include an appraisal of non-volitional weight loss, eating difficulties and low BMI. If one of those three criteria is present, a more thorough nutrition assessment is recommended to be performed by a healthcare professional skilled in malnutrition aetiology and interventions (14). In the cited literature in this thesis, including the articles reviewed in Paper I, a wide variety of malnutrition screening tools and criteria have been used. In Papers II and IV, patients who had been referred to and prescribed ONS by a dietitian were included. Consequently, the participants were assessed by a nutrition professional as at risk of malnutrition or as presenting with a malnutrition diagnosis. In Paper II, MUST was also used to describe the nutritional status of the studied population.
Theoretical framework

The research questions in this thesis were developed from a clinical dietitian standpoint, aiming at extending the knowledge base for the improvement of nutrition therapy for malnutrition. Analyses were data-driven, rather than theoretically informed. However, theory and frameworks were applied in a later phase in order to deepen the understanding of the findings, particularly in Papers III–IV. The research methods used in the included studies stem from different research traditions. I believe that a combined approach, using methods from a biomedical positivistic tradition (Papers I and II) as well as an interpretative tradition (Papers III and IV), is the most fruitful one for gaining or producing new knowledge for the improvement of healthcare. Consequently, the work with this thesis started from a biomedical, non-critical view on the concepts of prescription and adherence and the later studies have added additional perspectives on how to interpret and approach those phenomena.

Adherence to treatment from different perspectives

The biomedical perspective

The biomedical perspective dominates many healthcare settings and organisations (3). This means that the importance of adherence is understood from a healthcare point of view. Information gained using a biomedical approach can include statistical associations between adherence and various factors. WHO has categorised all factors identified as associated with adherence to therapy into five interactive dimensions, which are: (i) social and economic factors; (ii) health care team- and system-related factors; (iii) condition-related factors; (iv) therapy-related factors, and (v) patient-related factors (3). The WHO model guided the planning of the study described in Paper II and has also been used in the discussion in this thesis.

The five dimensions of adherence and examples are presented in Figure 2. For a long time, a large focus was placed on patient-related factors as barriers to high adherence. However, the other dimensions are advocated to receive more attention, since they are suggested to be equally or maybe even more important (3, 110). In a literature meta-review of systematic reviews on factors affecting treatment adherence, 771 individual factors were identified. The factors were categorised in accordance with WHO’s five dimensions and the main results from this meta-review are presented below (111):

- **Social and economic factors** – Social support was shown to increase patient adherence, while a lack of social support was connected to lower adherence. Social stigma connected to conditions such as HIV and psychological diseases was associated with low adherence. Economic factors such as unemployment,
poverty, lack of healthcare insurance, et cetera, were associated with low treatment adherence.

- **Health care team- and system-related factors** – a lower patient adherence was shown when information on medication prescriptions was inadequate, if follow-up was lacking or if the patient-provider relationship was weak. Easy access to healthcare facilities was shown to be of importance for achieving adherence.

- **Condition-related factors** – if a disease or condition was asymptomatic, adherence tended to be lower. Also, intake of medicines was shown to be lower when one’s condition had improved. Adherence was higher if the disease was severe and lower if the disease was milder.

- **Therapy-related factors** – if the treatment regimen was complicated (e.g., frequent doses, combination of many medicines), long-term, or if side effects were pronounced, adherence was generally lower. If the medicine was effective (objective or perceived effectiveness), adherence tended to be higher.

- **Patient-related factors** – demographic characteristics show a varying connection to treatment adherence. For example, age and gender were differently associated with adherence depending on population and type of treatment. A higher education level was connected with higher treatment adherence. Individual belief systems and psychological profiles/personality traits have been connected to both higher and lower adherence rates depending on the areas of investigation.
**Figure 2** The World Health Organization’s five dimensions of adherence to therapy, with examples (3, 111).

* According to WHO, demographic variables such as age are categorised as social and economic factors, but in the review by Kardas et al. they are categorised as patient-related factors, which I also find more suitable.

**A behavioural change theory perspective**

A biomedical perspective has been suggested as insufficient to fully understand something as complex as treatment adherence (3, 112). One suggestion for extending knowledge is to bridge the gap between biomedicine and behavioural science (112). A behaviour can be defined as *'Anything a person does in response to internal or external events'* (113), and adherence or non-adherence can thus be understood as a health-related behaviour. Therefore, adherence to treatment can be studied through and explained by well-known psychological models and theories such as the Health Belief Model, Protection Motivation Theory, Theories of Reasoned Action/Planned Behavior, and Social Cognition Theory. These are classified as either cognition or social cognition models, where individual core beliefs, motivations, intentions and representations in the social world are components described as affecting behaviour (112, 114).

In 2011, a new framework for characterising and designing behaviour change interventions, the Behaviour Change Wheel (BCW), was published by Michie...
The BCW model is presented in Figure 3. This framework was based on previously existing behaviour change models and theories, and brought those together in a model applicable to any behaviour in any setting (113). At the core of the BCW, we find the sources of a behaviour, representing a person’s capability, opportunity and motivation (COM), which interact to generate behaviour (B). This inner hub of the wheel (in green) is also called the COM-B system, and has – as a framework of its own – been suggested as superior to other theories in explaining treatment adherence (116). Capability refers to a person’s psychological (e.g., knowledge) and physical (e.g., physical skills) capacity to perform a behaviour. Opportunity refers to factors lying outside of the person and can be physical (e.g., environmental resources) and social (e.g., cultural norms). Motivation consists of reflective (e.g., analytical decision-making) or automatic (e.g., emotional responding) brain processes that energise and direct behaviour. Each component can influence behaviour directly, but capability and opportunity can also influence behaviour indirectly through a person’s motivation (113, 115). In the next circle of the wheel (in red), nine intervention functions are presented and categorised into different activities aimed at changing a behaviour. The definitions of the intervention functions are presented in Table 1. Through an intervention function, an activity or strategy is understood as affecting patient capability, opportunity and/or motivation, which enables behaviour change (115). It should be noted that a strategy can have more than one function. For example, a message on health consequences can function as education, but can also go beyond this to persuasion if information that evokes emotions is included (113). The specific activities/strategies available to aid behaviour change are not included in the wheel, but have been systematically operationalised in the Behaviour Change Technique Taxonomy (117). The outer, grey circle of the wheel consists of seven policy categories. These constitute actions implemented by authorities that enable or support behaviour change through the intervention functions (115). In Paper III, the BCW was used to deepen the understanding of the findings.
Figure 3 The Behaviour Change Wheel. Published by Michie with colleagues in 2011 (115) and adapted with permission (licenced under CC BY 2.0).
<table>
<thead>
<tr>
<th>Intervention function</th>
<th>Definition</th>
<th>Example of intervention function</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td>Increasing knowledge or understanding</td>
<td>Providing information to promote healthy eating</td>
</tr>
<tr>
<td><strong>Persuasion</strong></td>
<td>Using communication to induce positive or negative feelings or stimulate action</td>
<td>Using imagery to motivate increases in physical activity</td>
</tr>
<tr>
<td><strong>Incentivisation</strong></td>
<td>Creating expectation of reward</td>
<td>Using prize draws to induce attempts to stop smoking</td>
</tr>
<tr>
<td><strong>Coercion</strong></td>
<td>Creating expectation of punishment or cost</td>
<td>Raising the financial cost to reduce excessive alcohol consumption</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td>Imparting skills</td>
<td>Advanced driver training to increase safe driving</td>
</tr>
<tr>
<td><strong>Restriction</strong></td>
<td>Using rules to reduce the opportunity to engage in the target behaviour (or to increase the target behaviour by reducing the opportunity to engage in competing behaviour)</td>
<td>Prohibiting sales of solvents to people under 18 to reduce use for intoxication</td>
</tr>
<tr>
<td><strong>Environmental restructuring</strong></td>
<td>Changing the physical or social context</td>
<td>Providing on-screen prompts for GPs to ask about smoking behaviour</td>
</tr>
<tr>
<td><strong>Modelling</strong></td>
<td>Providing an example for people to aspire to or imitate</td>
<td>Using TV drama scenes involving safe-sex practices to increase condom use</td>
</tr>
<tr>
<td><strong>Enablement</strong></td>
<td>Increasing means/reducing barriers to increase capability or opportunity(^1)</td>
<td>Behavioural support for smoking cessation, medication for cognitive deficits, surgery to reduce obesity, prostheses to promote physical activity</td>
</tr>
</tbody>
</table>

\(^1\) Capability beyond education and training; opportunity beyond environmental restructuring.
Person-centred care and a critical perspective

As a reaction to the biomedically focused care, where people are often reduced to a disease, person-centred care has been introduced as a new holistic norm for healthcare (118). A person-centred care approach has been described as a form of applicable ethics where the patient narrative, shared decision-making (SDM) and narrative documentation are in focus (119, 120). The arguments for the implementation of person-centred care have been referred to as either ethical or instrumental. The ethical argument stresses that a person’s participation and authorisation in their own care has a value in itself, while the instrumental argument stresses that the quality of care or people’s health should be improved by implementing person-centred care (118, 121). In Sweden, a transition from picturing person-centred care as a means to achieve better care outcomes (instrumental argument) towards becoming a goal in itself (ethical argument) has been identified (122).

Person-centred care adopts a humanistic view of people and advocates a power shift from the healthcare professional towards the patient (120, 123). When care is person-centred, the patient is viewed as a person with experiences, preferences and values and those aspects are seen as equally important as the healthcare professional’s knowledge on disease and therapy. Both perspectives should be included when decisions on care are made, and decisions should be made in collaboration between the patient and the healthcare professional. Therefore, SDM is a main feature of person-centred care (120). Many different SDM models/definitions exist and a majority of them contain components such as ‘Describe treatment options’, ‘Make the decision’, ‘Patient preferences’ and ‘Tailor information’ (124). One widely used early definition was introduced by Charles and colleagues in 1997 and included four characteristics of SDM (125). Firstly (i), SDM involves two parties, the healthcare professional and the patient, and (ii) both parties take steps to participate in the decision-making process for the patient’s care and treatment. Further (iii), SDM implies that both parties share information, e.g., about treatment alternatives (healthcare professional) and illness narratives and values (patient). Lastly (iv), a decision is made based on both parties’ involvement and agreement (125). Since person-centred care is based on values endorsing partnership and equally distributed power between the patient and healthcare professional, terms such as compliance and adherence have been argued to be non-applicable within a person-centred care approach (119).

In line with person-centred care values, the terms compliance and adherence have received a lot of critique over the years, especially from researchers within the social sciences. This is because the terms communicate certain values, such as an explicit hierarchy between a superior healthcare professional and a patient (126-128). It also classifies the healthcare professional as the
active part, giving recommendations, while the patient is passive, receiving recommendations and being expected to go home and follow them (128, 129). The critique has been addressed by elaborating on the definition of adherence/compliance and for example adding phrases such as ‘agreed recommendation’ (3), and also by creating new terms such as ‘concordance’ where the definition includes ‘...the primacy of the patient’s decision is recognized’ (130). Though the purpose of the compliance-adherence shift was to reduce the blame placed on the patient when not achieving the right degree of behaviour change, the terms compliance and adherence have been found to be used synonymously (129). The concordance shift, with an emphasis on SDM, has also been critiqued as a strategy that shares the same ideology as compliance – the aim is still to persuade people to do what the doctor says (128). Since dietetic practice is similarly encouraged to become more person-centred (131), this more critical perspective on healthcare values was considered in Papers III and IV when investigating dietitian and patient experiences of the nutrition therapy with ONS.

Giorgi’s descriptive phenomenological method in psychology

If person-centred care can be seen as an answer to a too narrowly focused paternalistic biomedical care, phenomenological philosophy can be seen as an answer to a too narrow theory of science. At least according to Amadeo Giorgi, a psychologist who claimed that the methods within the natural sciences were unable to give all the answers to the research questions within his field (132). Therefore, he introduced a phenomenological analysis method, grounded on a Husserlian perspective, applicable within a psychological framework. The method is framed as generic enough to be applicable also for other human sciences, and has been adopted within a range of fields. In Papers III and IV in this thesis, systematic text condensation (STC), which is based on Giorgi’s descriptive phenomenological method in psychology (132, 133), was used for analysis.

In phenomenological philosophy, a person’s lifeworld and phenomena – anything that presents itself to human consciousness – are in focus. The actual existence of an object is not perceived as relevant, as in the natural sciences. Instead, the focus is on the experience of an object. Alongside the focus on human experiences, other central themes within phenomenology are to look for the essence of a phenomenon and the bracketing of past knowledge about the object in focus (132). Bracketing means that past knowledge is set aside so as not to influence the views on the mode and content of the experienced object.

In line with Giorgi’s phenomenological method, STC shares the view of human lifeworld experiences as valid knowledge (133). However, STC is not
considered to be a fully committed phenomenological method, but rather inspired by phenomenology and useful for medical researchers when exploring for example patient or carer experiences of different phenomena (133, 134).

**Identified research gaps**

Although there is an extensive amount of literature on the effect or effectiveness of ONS, less focus has been placed on *how* the ONS prescription is or should be constructed.

The large difference between adherence to ONS in clinical trials and routine clinical practice implies that elements of the ONS interventions in clinical trials might be of importance for achieving high adherence to ONS prescriptions (57). A prerequisite to enable transfer of knowledge about successful/unsuccesful interventions is adequate reporting. If active component(s) of interventions can be identified, this information can serve as guidance for clinical practice and new interventions. There are indications of suboptimal reporting of nutrition interventions for malnutrition in trials (57, 79), but the reporting of ONS interventions has not been studied systematically before.

In the Swedish context, where this thesis originates, the primary prescribers of ONS are dietitians and the largest consumer group of ONS is non-institutionalised patients (10, 50). However, there is a lack of studies on the adherence to ONS in this population when ONS are prescribed within routine clinical care. Though there is a large amount of research on treatment adherence in general, it has been emphasised that adherence to a large degree depends upon the specific requirements and characteristics of a treatment (112). Adherence is occasionally discussed in studies on ONS and malnutrition, but often treated as a secondary finding and seldom investigated as the primary focus. In addition to a lack of data on the dietitian-led prescription and patient adherence to ONS in clinical practice, experiences of this nutrition therapy from a dietitian and patient perspective remain understudied. For example, it remains unexplored how dietitians with ONS prescribing rights experience the performance of this professional task. Additionally, most studies on ONS are made from a healthcare perspective, but how patients experience this nutrition therapy is not well-known. Such explorations could provide insights that allow for a deepened understanding of aspects that are important for ONS therapy, from multiple perspectives.
Aims

The overall aim of this thesis was to increase knowledge on and deepen understanding of ONS prescription and adherence.

The specific aims of Papers I–IV were:

I. To assess the quality of reporting of interventions in publications describing randomised controlled trials of ONS in populations with malnutrition or at risk of malnutrition.

II. To assess adherence to ONS among hospital outpatients. The secondary aim was to evaluate patient characteristics, including patient experiences of ONS, and characteristics of ONS prescriptions in clinical practice.

III. To obtain a deeper understanding of specific aspects that are of importance for dietitians when providing nutrition therapy including ONS.

IV. To deepen the understanding of what ONS mean to patients and how this meaning connects to their ONS usage.
Methods

Overview

The work with this thesis started in late 2014. The design of the two initial studies (Papers I–II) was quantitative, while the two later studies (Papers III–IV) were performed with a qualitative design. An overview of the studies is presented in Table 2.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Focus</th>
<th>Material</th>
<th>Study period</th>
<th>Design and method</th>
<th>Analysis</th>
</tr>
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<tbody>
<tr>
<td>I</td>
<td>Reporting quality of interventions with ONS</td>
<td>76 publications/trial reports</td>
<td>Final search performed in January 2016</td>
<td>Quantitative, literature study</td>
<td>Quantitative content analysis, inter-rater reliability test, chi-square test</td>
</tr>
<tr>
<td>II</td>
<td>Adherence to ONS</td>
<td>N = 96 patients</td>
<td>September 2016–February 2017</td>
<td>Quantitative, cross-sectional survey</td>
<td>Descriptive statistics, Spearman’s rho</td>
</tr>
<tr>
<td>III</td>
<td>Experiences of prescribing ONS</td>
<td>N = 13 dietitians</td>
<td>October 2019–March 2020</td>
<td>Qualitative, interview study</td>
<td>Thematic cross-case analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Experiences of ONS prescription and usage</td>
<td>N = 10 patients</td>
<td>June 2019–March 2020</td>
<td>Qualitative, interview study</td>
<td>Thematic cross-case analysis</td>
</tr>
</tbody>
</table>

ONS, oral nutritional supplements.

Evaluation of reporting quality of interventions with ONS (Paper I)

Included publications

For Paper I, a quantitative content analysis was performed to assess the reporting quality of ONS interventions in RCTs. The 76 publications included were
retrieved through a literature search in PubMed using a search strategy developed for the purpose of this study. The search strategy was intended to capture terms relating to (i) malnutrition or risk of malnutrition, (ii) ONS, and (iii) RCTs. The search was conducted in January 2016 with a publication year restriction applied (2002–2015). For an article to be included, all of the participants in one of the intervention arms or control group had to be prescribed multi-nutrient ONS (≥ 2 macronutrients and added micronutrients) alone or in combination with other intervention elements. The population had to be ≥ 18 years old and the duration of the intervention ≥ 28 days. If ONS were part of a combined intervention (e.g., ONS and dietary advice), only the reporting of the ONS intervention was evaluated.

Assessment of the quality of reporting and inter-rater reliability

Reporting quality was assessed using the Template for Intervention Description and Replication (TIDieR) checklist and guide, which contains twelve items (81). The TIDieR checklist and guide was published in 2014 to serve as an extension of item number 5 in the Consolidated Standards for the Reporting of Trials (CONSORT) statement (80), and is a guiding document on how to report upon an intervention and intervention adherence in clinical trials. The completeness of reporting of the ONS trials was assessed for each of the twelve items and rated as either ‘YES’ or ‘NO’. A manual was developed with the aim of facilitating the use of the TIDieR checklist and guide, as an instrument for assessment of the quality of ONS intervention reporting (see Appendix 2 in Paper I). All four authors participated in training sessions and in development of the manual.

Two independent reviewers (ELi and ELö) rated 40 of the 76 articles. Disagreements were resolved through consensus discussions. For the 36 remaining articles, TIDieR items with sufficient inter-rater reliability were rated by a single reviewer (ELi) and TIDieR items with insufficient inter-rater reliability by both reviewers. Inter-rater reliability was measured using Krippendorff’s alpha (K α), and a value above 0.67 was required for an item among the remaining articles to be rated by only one reviewer (135). The proportions of YES ratings in articles published before and after 2011 were compared using the chi-square test (χ²). This comparison was made since a new update of the CONSORT reporting guideline for clinical trials was published in 2010 (80).

Assessment of adherence to ONS (Paper II)

For Paper II, a cross-sectional study of adherence to dietitian-prescribed ONS among hospital outpatients was performed.
Study participants
The study population consisted of adult outpatients (≥ 18 years old) who had received a prescription of ONS from a dietitian working at Uppsala University Hospital in Sweden. The local prescription guidelines stated that, to be prescribed ONS, a patient had to be at risk of malnutrition and have a medical diagnosis where ONS had a documented scientifically positive effect. Also, ordinary food intake had to be evaluated as insufficient (52). Eligible patients were free-living, without dementia or cognitive impairment, able to communicate verbally in Swedish and should not receive EN or PN. Recruitment was performed by 18 hospital dietitians working in all areas of care, except the gerontology department which were not able to participate in the study. Of 218 patients fulfilling the inclusion criteria, 96 were included in the study. The primary reasons for not participating were that patients were never asked about the study by the dietitian due to e.g. time constraints or that they declined study participation.

Data collection and statistical analysis
Data were collected through structured telephone interviews, electronic medical records and a register of delivered nutritional products. When deciding which variables to include in the data collection, the WHO model describing the five dimensions of adherence was taken into consideration, focusing mainly on the therapy-related factors (ONS-related) (3). The telephone interview survey was constructed for this specific study. The preliminary telephone interview questions were tested in five cognitive interviews, before the final version of the questions was compiled. This was done to detect sources of response errors such as problems with comprehension or recall (136).

Adherence to ONS was assessed through three different measures. Two of them consisted of dividing self-reported intake by the prescribed amount and the third was a medication refill adherence measure called medication possession ratio (MPR). Self-reported ONS intake was determined by posing a 24-h recall question and a frequency question. Information about prescribed amount was gathered from the dietetic notes in the patients’ medical records. The 24-h recall question was supported using the automated multiple pass method in order to aid patients to remember all bottles consumed (137). MPR was calculated using the following formula ‘Number of days’ supply obtained during observation period divided by Number of days in observation period times 100’ (138). Scores for the adherence rates determined using the three measures ranged between 0 and 100%. If a patient reported a higher consumption than the prescribed amount, the adherence rate was truncated at 100%.
Descriptive statistics were used to describe adherence measures, patient and prescription characteristics, and experiences of ONS. Wilcoxon’s signed-rank test was used when comparing differences between the adherence measures and Spearman’s rho was used to assess relationships between them.

Interview studies (Papers III and IV)

Study participants

A purposive sampling technique was used in the interview studies (139), and 13 dietitians and 10 patients, respectively, were recruited. Eligible dietitians had to regularly, at least once a month, prescribe ONS to adult patients, and could work in any healthcare setting and region of Sweden. The dietitians were recruited through an invitation published on the Swedish Association of Clinical Dietitians’ homepage, included in its newsletter and sent out to its Facebook group. In a second step of the recruitment process, managers of dietetic departments in geographic areas not yet covered were contacted and asked to spread the word about the study among their employees.

Eligible patients met the following criteria: adult (≥ 18 years old), prescribed ONS (with ≥ 2 macronutrients and micronutrients) for more than one month by a dietitian, free-living (non-institutionalised), absence of dementia or cognitive impairment, not receiving EN or PN, and able to communicate verbally in Swedish. The patients were recruited by hospital and primary healthcare dietitians, and also through local patient organisations, in one region in Sweden, Region Uppsala. In line with the concept of adequate information power (instead of saturation), recruitment of dietitians and patients ceased when the research team found the interviewees’ descriptions to fulfil the aim of gaining new insights and understanding connected to the nutrition therapy with ONS (140). A limited sample size is suggested as beneficial when performing an analysis using STC (133).

Data collection and analysis

Individual qualitative interviews about experiences of nutrition therapy with ONS were performed with both dietitians and patients. Two different interview guides were used with questions focusing on lived experiences of prescribing or being prescribed and using ONS. The questions were open-ended and follow-up questions were used when appropriate, in line with the performance of a lifeworld interview (141). Interviews lasted between 25 and 68 minutes (mean 50 minutes) and were transcribed verbatim. The data were analysed using STC, which is a procedure for cross-case thematic analysis (133).
The STC analysis is based on Giorgi’s descriptive phenomenological psychological method and follows four steps (132, 133). Analyses were performed on the dietitian and patient data separately, starting with the dietitian interviews. Both analysis processes began with (step 1) getting a general overview of the interview material and reaching agreement between the four authors about preliminary themes. In the following step (2), meaning units were identified and the material was sorted into code groups. In the third step (3), the material in each code group was further divided into subgroups. Subsequently, each subgroup was rewritten into a condensate, which is an artificial quote that encompasses the material of the subgroup and is written in the first person. In the final step (4), the condensates were used as a starting point for synthesis and an analytical text presented as final categories (133). The analyses were data-driven and theoretical perspectives were included in a later phase to deepen the understanding of the findings (133, 139). In Paper III, the BCW and the concept of SDM were used (115, 125), and in Paper IV, the altered eating framework was used when interpreting the findings (142).

Ethical considerations

In Paper I, the collected data consisted of published reports of RCTs with ONS. No human material or data were used, meaning that no ethical approval was required for this study. Ethical approval for the study on adherence to ONS (Paper II) was sought and received from the Regional Ethical Review Board of Medical Sciences in Uppsala (Reference No. 2015/55 and 2015/55/1) and for the interview studies (Papers III and IV) from the Swedish Ethical Review Authority (Reference No. 2019-01198). Throughout the project, the ethical principles of the declaration of Helsinki were followed (143). Written informed consent was collected from all study participants (Paper II–IV), and they were informed of their rights to discontinue participation at any time, without explanation.

Study participants in the study on adherence to ONS (Paper II) were compensated with a gift certificate for flowers corresponding to 100 SEK (approximately 10 EUR) or could choose to donate the money to Médecins Sans Frontières (Doctors Without Borders). The sum was considered reasonable to compensate for the inconvenience of participating in a telephone interview, and not likely to persuade patients to participate against free will. The majority chose to donate the money. During the inclusion period for the study on adherence to ONS (Paper II), I worked part-time as a clinical dietitian at the surgery unit at the hospital where the patient recruitment was performed. Hence, there was one case where I was the ONS-prescribing dietitian. Therefore, another researcher in the research team performed the telephone inter-
view with this patient. This was done to avoid the risk of impacting the professional relationship with the patient and also to avoid an exaggerated risk of social desirability bias (e.g., having the prescribing dietitian asking about amount consumed).

To protect the identities of included participants in the interview studies, the personal information revealed was carefully deliberated on. For example, we avoided presenting any specific geographic locations of the dietitians’ workplaces, since the dietetic force in Sweden is small. Further, we chose to present the patients’ age and duration of ONS use as ranges and used pseudonyms. This was done since the patients were recruited in only one region of Sweden.
Results

Paper I

Of 76 articles identified, only two (3%) reported all TIDieR items in sufficient detail according to the TIDieR checklist and manual criteria. Figure 4 shows the proportions of articles that met the criteria for each TIDieR item. The most frequently missing element was a description of the intervention procedures, i.e., how the ONS were to be taken and if participants were given a choice of flavours, which was adequately presented in only 26% of the articles. Less than half of the articles included a description of the intervention provider and sufficient information about the location(s) for the intervention. Information about how the interventions were delivered and adherence was reported in 60–65% of the articles. Most frequently reported, in > 70% of the articles, were items regarding the brief name of the intervention, the rationale for the intervention and the materials used, i.e., information about the specific ONS product(s) administered. The reporting quality for the TIDieR item materials (item 3) and provider (item 5) was higher in articles published after 2011.

In the sub-sample of 30 articles rated by two reviewers, inter-rater agreement was sufficient (Kα ≥ 0.67) for half of the TIDieR items (items 2, 4, 5, 10, 11 and 12). Subsequently, items 1, 3 and 6–9 of the remaining 36 articles were rated by two reviewers. For example, the reason for a low inter-rater reliability for item 1 was a low number of ‘NO’ ratings, and disagreement when one of the authors rated a ‘YES’. Further, disagreements on item 8 occurred due to different interpretations of scheduled visits/contacts. Disagreements were resolved through consensus discussions.
Proportions of articles (n = 76) meeting the criteria for each TIDieR (Template for Intervention Descriptions and Replication) item (81) (Paper I).

* N/A = Not applicable.

Paper II

Among the 96 study participants, complete data were available for 78, since the others declined participating in the telephone interview. The mean age of the participants was 67.4 years and 52% were men. The two most common medical diagnoses were malignancy and digestive system disease. The majority of the patients (83%) were prescribed 1–3 bottles of ONS per day and the average number of flavours was 4.2. Duration of ONS usage was less than 1 month for 33%, 1–6 months for 40% and ≥ 7 months for 27% of the population.

Mean adherence to ONS was 93% (SD 18) measured with the frequency question, 87% (SD 28) measured with the 24-h recall question and 76% (SD 21) measured with MPR (see Figure 5). All pairwise comparisons of the distribution of the adherence rate, measured with the three methods, differed significantly. Spearman’s rho test showed a significant positive correlation between adherence rates measured with the 24-h recall question and with the frequency question, respectively ($r_s 0.79$, $p 0.000$). No correlation was found between MPR and the two other measures. Out of 78 patients participating in the telephone interview, 100% answered that they usually drank the whole bottle when consuming ONS. The patient-reported prescribed amount deviated from the dietitian-documented prescribed amount for 40% ($n = 31/78$) of the participants.
The majority of the patients participating in the telephone interview agreed to a large extent with the statements ‘I like the taste of the ONS’ (76%), and ‘The ONS are good for my health’ (88%). Only 17% agreed to a large extent with the statement ‘Support from others helps me drink ONS’. Fifty-four percent regarded ONS as foods rather than medicine and 28% regarded them as medicines rather than foods. The remaining 18% could not choose between the two alternatives. Most commonly, the ONS were consumed in between meals.

**Figure 5** Adherence to oral nutrition supplements (Paper II).

* Significant at 0.05 level.
24-h, 24-hour; MPR, medication possession ratio.

**Paper III**

The analysis of the interviews with the 13 dietitians resulted in two main categories which were labelled ‘Shared tailoring of the ONS prescription’ and ‘Supporting and facilitating ONS use’. A shared tailoring process (category 1) was described by the dietitians when emphasising the importance of patient acceptance and involvement in prescribing ONS. Since patients had their own preferences, the dietitians expressed being very flexible regarding products and amounts prescribed, and tailoring the prescription together with the patient.

*I usually say yes, you can drink between two or three per day, that’s not a problem. So I don’t know, maybe it confuses them, gets a bit grey
but typically the patient says him or herself that yes, I can drink one per day, and then I say yes, then we have one per day and that’s the prescription then’ (D8, hospital)

If a patient expressed resistance to being prescribed ONS, the dietitians described respecting the patient’s choice and instead negotiated other solutions. The dietitians also shared many descriptions of supporting patients in order to facilitate ONS use (category 2). This support occurred in the dialogues with patients by using various communication strategies, and also by organising practical issues such as ONS delivery and support from others.

‘It feels as if our prescriptions aren’t taken seriously. But then, if you say that this is like a medicine for you…, then I feel that they might take it a bit more seriously’ (D3, primary healthcare)

‘For those who suffer from the most severe dementia, I have put in a notification in my calendar to order a delivery every month because it’s no idea to even let them try. Then, I do it for them because then I know they’ll drink it’ (D13, primary healthcare)

In summary, the dietetic-performed ONS prescription can be understood as a professional process characterised by shared tailoring and providing support to facilitate ONS usage.

Understanding the findings through the BCW and the concept of shared decision-making

In the discussion in Paper III, the findings were further elaborated on using the BCW framework (113, 115) and the concept of SDM (125). The dietitians stressed the importance of patient involvement in the tailoring process, and the sharing of information such as treatment alternatives (dietitian) and acceptance and preferences (patient), which are part of the SDM definition (125). Further, the decisions on prescribing ONS and on the contents of the prescription were described as being made together with the patient. The study findings were implemented into the BCW model, and examples of specific strategies employed by the dietitians were included (see Figure 6). Those strategies can be understood as enabling behaviour change by affecting patient capability, opportunity and/or motivation through an intervention function. Of the nine intervention functions, examples were identified in the interviews for seven. Two of the seven policy categories were identified as of importance for the ONS prescription. The connection between specific strategies (or behaviour change techniques) employed by the dietitians, the intervention functions and the policy categories are described in Figure 6.
Figure 6 Implementing the findings of dietitians’ experiences of prescribing oral nutritional supplements (ONS) in the Behaviour Change Wheel (BCW). Including the patient and the dietitian in the study core of the wheel, together with the term ‘shared tailoring’, reflects the importance of a shared decision-making process in tailoring and prescribing ONS (or not). The original BCW figure was published by Michie et al. (115), and is adapted with permission (licenced under CC BY 2.0). The modifications we made in this figure are as follows: in the green hub of the wheel, we removed the different types of Capability (i.e., Psychological and Physical), Motivation (i.e., Automatic and Reflective) and Opportunity (i.e., Social and Physical) and added the patient, the dietitian, the shared tailoring term and the behaviour in focus for change. Further, we have added numbers 1–9 on the Intervention functions and Policy categories, which are also represented by examples found in the study findings (Paper III).
Paper IV

The analysis of the 10 patient interviews resulted in two final categories which were labelled ‘ONS is a one-dimensional remedy’ and ‘Everyday ONS usage is regulated autonomously’. The patients described a painful loss of normal eating, and the ONS as a one-dimensional remedy (category 1) for this loss. The ONS was described as compensating for low nutrient intake and as affecting bodyweight, but being unable to compensate for the lost pleasure of normal 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’s 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 tiresome sometimes actually, but living on supplements is not all that great either’ Harry

However, this one-dimensionality was also described as positive, since the ONS could work as a simplifying solution for nutrient intake. Specifically, this could be helpful in situations when preparing and eating a meal was burdensome or depressing due to the disease and altered eating. ONS usage was described as regulated autonomously depending on the acceptance of ONS taste and the priority placed on nutrition in a patient’s everyday life (category 2). The dietitian-recommended amount to be consumed was perceived as a suggestion, not an exact prescription.

‘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

The patients described taste as having to be at least acceptable in order for the ONS to be consumed. Further, a very diverse picture with regard to ONS flavours preferred and strategies to facilitate ONS consumption was described. ONS usage was expressed as being prioritised when nutrients were perceived as needed, for example when food intake was low or when striving for a higher bodyweight or disease recovery. On the other hand, drinking ONS was described as non-prioritised when the intake of nutrients was not a patient’s main focus, for example when a higher bodyweight was not wanted or when a competing activity was prioritised instead of ONS usage.
'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

In summary, the meaning of ONS was nutrition, and usage was regulated autonomously based on the priority given to nutrition in patient’s everyday life. The overall goal of taking ONS or not seemed to be to ‘feel good’ in a life context, where ONS could not resolve the painful altered eating.
Discussion

The ONS prescription – more complex than ‘prescribing a pill’

In Paper I, the reporting of ONS interventions in RCTs was found to be incomplete in most cases. Especially the procedures of the intervention, the intervention provider and the location of the intervention were inadequately described. In a scoping review on interventions to improve appropriate ONS prescribing, intervention details were also found to be scarcely reported upon (8). Inadequate intervention descriptions of RCTs have been framed as a general problem within several healthcare disciplines (144-146), and hinder the replication of trials in clinical practice or research (81). From the findings in the later studies in this thesis (Papers II–IV), an ONS prescription can be understood as a more complex process than simply providing ONS bottles ‘as pills’ to patients. However, this complexity seems to be underestimated, since ONS intervention reporting is poor (Paper I) and fixed amounts of prescribed ONS are often used in RCTs (61, 95, 147, 148).

Two out of the 76 articles reviewed in Paper I reported all TIDieR items in sufficient detail (61, 149). As an example of what we can learn from an article with high-quality reporting, the one published by Miller and colleagues in 2006 will now be presented (149). In this article, a description of an RCT with ONS and resistance training among older adults following lower limb fracture was provided. The primary findings were that all participants experienced weight loss, but those receiving the combined approach with ONS plus resistance training lost less weight than those receiving only resistance training (149). Since the article contained all relevant ONS intervention details, one can read that the intervention started at the hospital and continued in each patient’s home after discharge (item 7). The participants were prescribed Fortisip (Nutricia Australia Ptd Ltd) (item 3) for 6 weeks (item 8) and the volume was individually adapted based on calculated energy requirements (between 580 and 800 ml/day) (items 8 and 9). Participants could choose from among six flavours and the ONS were administered as four doses, at institutions (item 4). Those living at home were recommended to take ONS twice per day or sometimes more often, based on discussions with the patient (item 4). Nursing staff delivered the intervention at the hospital, and a study dietitian was responsible for the intervention in the home environment (item 5). The intervention was
delivered individually and face-to-face (item 6). Adherence was registered by staff at the hospital and by counting cans and keeping a diary for those at home (monitored by research staff) (item 11). Median adherence rate was 67% (item 12). Items 1, 2 and 10 were also adequately described. In summary, when the intervention description is complete, important information is shared which allows for a correct interpretation of the results and intervention replication. Reading this study by Miller and colleagues (149), it is clear that an ONS intervention is very different from conducting an RCT where participants are allocated to receive a therapeutic or placebo pill.

In this thesis, the focus has primarily been on the ONS prescription, and not on food-based strategies to increase energy and nutrient intake. However, the study findings strengthen arguments given for having skilled nutrition professionals as ONS prescribers, since the prescription in clinical practice is closely intertwined with patients’ changeable food intake in a context of disease and altered eating. In a recent systematic review, a combined approach of dietitian-provided dietary counselling and ONS was shown as the most effective nutrition intervention for older adults at risk of malnutrition (150). The discussion on which intervention – food-based strategies, ONS or a combined approach (food-based strategies + ONS) – is most effective in treating malnutrition has been ongoing for the last two decades (21, 29, 79, 151, 152). Even if a ‘food first’ approach (i.e., food-based strategies before other components such as ONS) is recommended (14, 15), a survey of dietetic practice in the UK showed that the dietitians most commonly used a combined one (food-based strategies + ONS). This was the case, even though the dietitians reported that they favoured a food-based approach (153). This treatment dilemma was also visible in the dietitian interviews (Paper III), since the dietitians emphasised food-based changes as a first treatment approach, but also described ONS as simpler for the patients and therefore more effective. In the patient interviews, the ONS were described as contributing with nutrients, but not being connected to other aspects related to preparing and eating a meal. This one-dimensionality could in some situations be understood as positive, since food preparation and eating can be hard and burdensome in the context of disease and altered eating (Paper IV) (142). The findings from this thesis cannot answer the question of which treatment approach is best. However, the findings (Papers III–IV) showed that ONS need and usage were described by both dietitians and patients as closely connected to ordinary food intake. Additionally, a nutrition intervention with ONS could be understood as preferably being performed with a person-centred approach, including shared tailoring of the prescription in combination with food-based strategies and behaviour change support (Paper III). To summarise, the ONS prescription can be seen as one part of a bigger whole when it comes to nutrition therapy for malnutrition within dietetic practice.
Adherence to ONS in dietetic practice from different perspectives

To deepen understanding, the findings of the studies in Papers II–IV will now be discussed in relation to the different theoretical frameworks presented in the introduction.

The findings in relation to the five dimensions of adherence

In contrast to other studies on adherence to ONS in clinical practice (57, 64, 72, 154), the adherence rate was high in the studied Swedish hospital outpatient setting (Paper II). With guidance from the WHO model of the five dimensions of adherence, possible factors of importance for this high adherence rate will now be discussed (3).

Firstly (social and economic factors), the ONS were generously subsidised and cost of ONS has previously been acknowledged as a barrier to this treatment approach (77). Secondly (health care team- and system-related factors), the healthcare professionals prescribing the ONS and monitoring the therapy were dietitians. Dietitians have been suggested as best suited for choosing which ONS to prescribe (7), and the inclusion of the dietetic profession was also the most common intervention component in a scoping review of interventions aiming to improve appropriate ONS prescription (8). The dietetic professional can be assumed to have a different set of knowledge and skills than other healthcare professionals, which probably affects management of ONS prescriptions. In Paper III, shared tailoring of the prescription and providing behavioural change support were identified as important aspects when the interviewed dietitians prescribed ONS. This relates to the therapy dimension (therapy-related factors), since the nutrition therapy and prescription characteristics in Paper II were in line with recommendations for appropriate ONS prescription (8, 15, 18). More specifically, the ONS were prescribed in combination with nutrition counselling, and patients were allowed to taste the ONS before prescription and to participate in choice of flavours. Additionally, a variety of flavours were prescribed (Paper II). The majority liked the taste of their prescribed ONS, which has been suggested as central to achieve ONS adherence (20). The findings from the interview studies (Papers III and IV) confirmed that taste acceptance is a prerequisite for ONS usage and therefore for ONS prescription, from both a dietetic and a patient perspective. The challenging acceptance of ONS has been widely discussed in previous quantitative and qualitative literature (20, 60, 64, 73, 75, 155). From the findings in Paper III, ONS prescription can be understood as requiring a large effort on the part of the prescriber in order to manage the challenging ONS acceptance. Fourthly (patient-related factors), the gerontology department was not able to participate in the study (Paper II). Consequently, a major
group of the oldest hospital outpatients prescribed ONS was not included, and
the studied population was relatively young (mean age 67 years). This might
have affected the adherence rate, since higher age has previously been associ-
ated with lower ONS adherence (57). Also, patient attitudes are suggested as
being related to ONS adherence (67). A majority of the patients in this study
(Paper II), agreed with the statement ‘ONS are good for my health’, which can
be a potential influencing factor for the high adherence rate identified. This
connects to the fifth dimension (condition-related factors), and perceived dis-
ease severity. In several qualitative studies, older adults have expressed a view
of not perceiving malnutrition as a harmful health risk for them (73, 155, 156).
Also, in the interview study with patients (Paper IV), the perceived benefit of
nutrients was described as affecting ONS usage. Severity of disease and per-
ceived severity of disease have, in several studies, been associated with adher-
ence to treatment. A milder, or perceived milder, disease does in general lead
to a lower adherence rate (111), and might serve as one explanation for the
correlation between adherence to ONS and age found previously (57). Addi-
tionally, a majority of the study participants had cancer (Paper II), which can
generally be classified as a severe disease, and might therefore increase the
ONS adherence rate.

The findings in relation to the Behaviour Change Wheel

In Paper III, the interviews with dietitians provided insights into the ONS pre-
scription process from a dietitian perspective. In this study, adherence was
chosen to be acknowledged from a behaviour change theoretical standpoint,
and drinking ONS was thus framed as a behaviour change problem. By using
the BCW model (115), different strategies applied by the dietitians, such as
referring to ONS as medicines or organising social support to enhance ONS
consumption, were connected to behaviour change constructs (see Figure 6).
Examples of dietetic strategies connected to seven out of nine intervention
functions were identified in the interview material. Also, two policy catego-
ries, namely fiscal measures and service provision, were identified as of im-
portance for the behaviour change of drinking ONS (113, 115). Using the
BCW highlights the role of the dietitian as a behaviour change facilitator. It
also strengthens previous findings of patients and dietitians viewing counsel-
ling and support, beyond education, as important to improve adherence to nu-
trition therapy (157, 158). Further, use of this model adds to the understanding
of why a particular strategy or context-specific entity enables behaviour
change.

An example of the connection between a dietitian-applied strategy in Paper III
and the behavioural change constructs will now be discussed. Several dieti-
tians described that they, during the patient encounter, often suggested or dis-
cussed when and how the patient should take the prescribed ONS, in order to
facilitate ONS usage. Such a strategy can be classified as action planning, according to the behaviour change technique taxonomy and is defined as ‘Prompt detailed planning of performance of the behaviour’ (117). Action planning can deliver the intervention function enablement, which can be understood as aiding behaviour change through the COM-B system constructs reflexive motivation and psychological capability. More specifically, self-conscious planning (reflexive motivation) and increased knowledge and psychological skills (psychological capability) to perform the behaviour, may become enhanced by this strategy (113, 115). Another example of using the BCW to aid the understanding of how the price subsidy might support the behaviour of drinking ONS will now be discussed. Tax subsidies belong to the policy category named fiscal measures, and could enable the behaviour change of drinking ONS by supporting the intervention functions enablement and incentivisation (see Table 1 for definitions). Low ONS cost could enable behaviour change by affecting the physical opportunity when reducing the price barrier (enablement). Additionally, the low cost could create an expectation of reward among patients, thanks to their saving money (incentivisation), which could affect their reflective motivation (113). This could occur among patients who had previously bought ONS at full price in a pharmacy, or for those who were aware of the relatively high cost without a subsidy (e.g., 20–30 SEK/2–3 EUR per bottle). Since this behavioural change theoretical lens was applied in the later phase of the analysis of the dietitian interviews, the BCW was used in a backward mode. The framework is originally intended for use in the planning and designing phase of an intervention, but is also suggested to be useful for evaluating interventions (113). Possibly, other examples would have been described by the dietitians if a deductive study approach had been used. Based on the findings in Paper III, future clinical trials or other studies on ONS might benefit from using the BCW in order to expand the knowledge on which strategies to use when facilitating the behaviour change of drinking ONS.

The findings in relation to person-centred care concepts

Within a person-centred care approach and a large amount of social science research, the terms compliance and adherence have been questioned. This because they mirror a paternalistic professional-focused healthcare (119, 126-128). Some of the findings in the qualitative interviews (Papers III and IV) can add to those discussions on the adherence phenomenon. According to WHO, adherence is defined as the ‘extent to which a person’s behavior [...] corresponds with agreed recommendations from a health care provider’ (3). However, in the interviews, the dietitians described and endorsed the ONS prescription to be performed in a shared tailoring process (Paper III), which included elements of SDM (125). Additionally, the patients described being prescribed autonomy with regard to the amount to be consumed (Paper IV).
Patients have previously been found to appreciate a nonprescriptive, patient-led and humanistic approach in dietetic consultations (159, 160). Correspondingly, a person-centred care approach within dietetics has been identified to include a redistribution of power to the patient, and individualising care, based on the patient’s needs and desires (131). From this perspective, a question can be raised on whether it is possible to combine the desirable person-centred care approach and the biomedically stemming term adherence (or compliance) when prescribing ONS in dietetic practice. In the international NCP terminology of nutrition diagnoses, a diagnosis called ‘Limited adherence to nutrition-related recommendations’ (previously ‘Lack of adherence to […]’) can be found, and is suggested to be used by dietitians when expected outcomes are not achieved or when the treatment plan is not adhered to (161). In a Swedish focus group study, Lövestam and colleagues identified dietitians as struggling between a system and lifeworld perspective when using the standardised NCP terminology. In this study, the adherence diagnosis came up as an example of a harsh and offensive diagnosis, and was expressed to be avoided by many of the dietitians out of respect for the patients (162). Clearly, the applicability of using the adherence term can be questioned when the ONS prescription is performed in a person-centred care context.

In line with the pragmatic approach of this thesis when it comes to the usage of mixed methods stemming from different research traditions, I think the focus for dietetic practice should be on optimising nutritional care. What is important is for the ONS prescription to be tailored together with the patient in a collaborative treatment process (Paper III), which can be done irrespectively of usage of the term adherence (or compliance). However, it is also important to reflect upon the biomedical heritage, with norms still influencing healthcare to a large extent. The natural scientific and biomedical approach has contributed with great success to the field of nutrition and malnutrition therapy. However, the biomedical perspective also needs to be challenged, since a too reductionistic focus might create a gap between the views of healthcare and those of the people needing care. From the included studies in this thesis, it is clear that the idea of the paternalistic healthcare system is challenged, since giving power to the patient is endorsed. This is in line with a person-centred care approach (118, 119). However, more research is warranted to verify the implementation of those dietitian- and patient-expressed ideals of a nutrition care based on equality. For example, contradictory results of a suboptimal level of patient involvement have previously been found in diet-related decision-making during the dietetic encounter (163). Also, a gap between patients’ and dietitians’ perceptions of person-centred care in dietetic practice has been identified in a past Australian cross-sectional study (164).
Adherence in clinical trials versus dietetic practice

Through studies of the nutrition therapy with ONS in dietetic practice, different meanings of patient adherence depending on context have become more visible. In a clinical trial, adherence (or compliance) is of importance to enable comparison of treatment effects. In dietetic clinical practice, adherence is of importance to make an individual treatment goal more attainable. Within RCTs, low adherence is problematic since it reduces the power to detect effects of the treatment in focus, and makes a comparison between two or more approaches difficult (56). This is the reason why reporting the adherence rate is considered to be of importance in the description of an RCT (81). In the study on reporting quality of ONS interventions (Paper I), 36% of the articles lacked information on treatment adherence, which counteracts a correct interpretation of the results in those studies. In Paper I, statistical principles used by trial authors, such as intention-to-treat (ITT) or per-protocol (PP), or whether the study was framed as an ‘efficacy’ or ‘effectiveness’ trial, were not considered. However, those aspects of RCT study design are tightly connected to the concept of adherence (or compliance). An ‘efficacy’ trial intends to investigate the effect of an intervention under the most optimal conditions possible (including high adherence), while an ‘effectiveness’ trial intends to investigate the effect in a ‘real-world’ healthcare system (165). Correspondingly, an ITT analysis is suggested to be performed when evaluating treatment effects in RCTs (56, 166). In an ITT analysis, all study participants will be included in the analysis, regardless of their level of compliance to the intervention (56). Using this approach might serve as an explanation for the lack of adherence reporting in one third of the reviewed trials in Paper I. A PP analysis includes only the subset of participants who did not deviate from the treatment protocol, and hence those who were compliant to the intervention (56). Whatever analysis principle is used, reporting the adherence level is recommended (81).

In dietetic clinical practice, adherence to a nutrition intervention has by Myers and Orrevall been presented as one level in a ‘cascade of nutrition outcomes’ (167). In this model, a change in patient attitudes/values is expected to influence the behaviour (adherence), which influences food intake. This, in turn, influences anthropometric measures or biomedical measures, which is suggested to lead to improvements in nutrition-related patient-centred measures. Such measures are therefore framed as the main goal with a nutrition intervention (167). In the interviews with dietitians and patients (Papers III and IV), changing bodyweight was often talked about as being the goal of taking ONS, alongside the overall wellbeing of the patient. The patients stated they consumed the amount of ONS that made them feel good. This could relate to taking ONS to ingest nutrients or not taking ONS to participate in a valued
activity instead (Paper IV). Similarly, autonomous self-regulation of medication usage (asthma and epilepsy) has been described within other fields (127, 168). Also, the interviewed dietitians for Paper III, endorsed patients being involved in the decision to prescribe ONS or not, and the amount to be prescribed. Patient adherence or compliance therewith have different meanings depending on the setting.

The ONS – in between foods and medicines

Along with EN and PN, ONS are defined as medical nutrition products. In the U.S., the term medical foods is also used (19). The ONS can be considered to be food items which are managed like medicines when for example being prescribed to people with diseases and monitored by healthcare. In contrast to ‘taking a pill’, the palatability of ONS cannot be neglected when prescribing or using them (Papers II–IV). Only the ONS nutrition profile is legally required to fulfil a set of standards (17), while the flavour, texture or context of taking them are not mentioned in law and hence are viewed as secondary concerns. Also, the tendency to report on the specific ONS given, but not on intervention procedures, such as if patients were allowed to choose between different flavours in clinical trials, confirms a narrow focus on this nutrition therapy in the literature (Paper I). From the results presented in this thesis, it is clear that an approach broader than considering ONS bottles as pills is warranted in future prospective ONS studies.

In the patient interviews (Paper IV), it became evident that their experiences of a changed relation to food and eating was painful, and affected a central part of their lives. In their stories, the ONS were framed as counteracting only one part of their loss of normal eating, namely nutrient delivery. By exploring patient experiences, the ONS can thus be understood to serve as a remedy for malnutrition, but not for altered eating. Altered eating is a framework developed by Burges Watson and colleagues when studying head and neck cancer survivors with ethnographic methods, and addresses food-related quality of life. Seven areas of life (physical-anatomical, physical-functional, sensory, behavioural, cognitive, cultural/social and emotional) are suggested as affecting or affected by altered eating, which 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’ (142). The use of this framework in Paper IV revealed the impact of the patients’ described loss of normal eating, regardless of if it was a consequence of a lost oesophagus function or of lost shared meals due to the death of a spouse. The identified patient view of nutrition as representing only a small part of the multidimensional meaning of food and eating is nothing new, and has been widely discussed before, sometimes from critical perspectives (169-171). For dietetic practice,
the results from the patient interview study (Paper IV) underline the importance of discussing the goal of the nutrition therapy with a patient, while at the same time acknowledging that ONS might serve as a one-dimensional remedy to a painful loss of normal eating. Nutrition might or might not be the primary focus for the patient, even if it is central for the practicing dietitian.

Methodological considerations

Paper I

To reduce selection bias, a systematic literature review of high quality should capture all relevant literature by searching several databases. Additionally, the study selection is recommended to be performed by at least two persons (172). In Paper I, we used a single database (PubMed) and only one person performed the abstract screening (ELi), which can be considered to be methodological weaknesses. However, articles at the borderline for inclusion were discussed within the author group. We chose not to use the term ‘Systematic review’ due to those deviations from the guidelines, even though this paper is more of a systematic review than a narrative one. The articles reviewed were not blinded with regard to trial author names or locations. This might have affected the ratings. However, the project did not have resources to assign different people to perform the screening/blinding and the reviewing. For Cochrane reviewers, blinding of trial author names is not recommended, since there is a lack of evidence that the decisions are affected thereby (172).

The low inter-rater reliability scores for 6 out of 12 TIDieR checklist and guide items makes visible the subjective nature of deciding upon adequate reporting quality of intervention details. Low inter-rater reliability was also identified in a similar study investigating physiotherapy intervention reporting (144). In order to counteract this challenge and strengthen the reliability of the study, two independent raters were used for items considered difficult to assess. A higher inter-rater reliability might have been achieved if the primary purpose of the checklist was the assessment of reporting quality, rather than reporting guidance. Even if the TIDieR checklist and guide is also suggested as suitable to be used for the assessment of intervention descriptions (81), a study published in 2020 by Dijkers and Millis found it to be a weak instrument for intervention reporting quality (173).

Paper II

There are several challenges in performing a cross-sectional study within routine clinical practice. Selection bias has to be discussed from several angles as regards the study on adherence to ONS among hospital outpatients. Firstly,
the gerontology department was not included, which might have affected the findings, since older patients make up a group pointed out as struggling with ONS acceptance and adherence (20, 65, 73, 155). Secondly, having many people, i.e., 18 dietitians, involved in the recruitment in a clinical environment characterised by high workload might have resulted in missing some patients fulfilling the inclusion criteria. Additionally, since recruitment was made by the ONS-prescribing dietitian, the patients being asked to participate might have been those who were using ONS to a greater extent, since they were in contact with their dietitian. Recent contact with a dietitian might also have affected the adherence rates. A ‘white coat adherence’ phenomenon was acknowledged already in the 1990s and suggests there are higher adherence rates close in time to a healthcare encounter (174, 175).

The telephone interview consisted of survey questions, and was created by the authors for the purpose of this study. No validated instrument or tool was used. Use of a validated self-reported adherence scale for medications (e.g., The Eight-Item Medication Adherence Scale) was considered in the planning phase, but no suitable scale was identified and of course none was validated for ONS (176, 177). However, face and content validity of the telephone interview were strengthened by the professional backgrounds of the four authors who were all registered dietitians, acquainted with the procedure of prescribing ONS in clinical practice. The 24-h dietary recall interview and the FFQ are two well-established dietary assessment methods (178). In contrast to the original purpose of the methods – to capture the whole food intake – the focus of our study was to capture the intake of only one food item. Limitations with retrospective dietary assessment methods are the reliability of people’s memories and the risk of receiving ‘socially desirable’ answers (178). Self-reported measures on adherence to medicines also tend to give overrated adherence scores, due to overestimated intake reports (174). In addition, the 24-h recall interview is recommended to be repeated in order to give a valid measure on the usual intake of a specific food item (178). Even if MPR data seem to give a more objective measure of adherence than those based on self-reports, MPR has its drawbacks. A prescription refill does not translate to the actual ingestion of previously delivered medicines (or ONS) (174). Additionally, we used different observation times – for some patients only one refill interval – which is not an optimal approach (138). In summary, we considered the adherence measure with the frequency question as most valid, and the use of three different adherence measures in combination to be a general methodological strength (179).

Papers III and IV
A sample size of 10 and 13 participants, respectively, in the qualitative interview studies could be criticised as being too small. However, being guided by
Malterud’s concept of information power, and the recommendation of avoiding too many participants in a STC analysis, we found the interviewees’ stories on their experiences as sufficiently rich to answer the research questions (133, 140). Also, Patton stresses the lack of sample size rules within qualitative methods, and endorses flexibility in relation to what and whom is being studied (139).

We aimed for a breadth of experiences connected to prescribing, being prescribed and using ONS in dietitians’ and patients’ life worlds. The dietitians were primarily recruited through the Swedish Association of Clinical Dietitians (DRF), which has around 70% of the dietetic workforce in Sweden as members (180). Also, all interviewed dietitians were female. Whether experiences of prescribing ONS would deviate between DRF members and non-members or between females and males is unknown. Beyond those characteristics, the dietitians represented different medical specialties and geographic areas, which is positive with regard to capturing a broad spectrum of experiences. The patients were recruited from different healthcare settings and medical specialist areas, and their experiences of being prescribed ONS and everyday usage were found to be broad and information-rich. Context features to consider are that all participants except one were long-term users of ONS, and the price subsidy was generous in this region.

The participants received verbal and written information on the interviewer’s background as a clinical dietitian, in line with ethical principles of revealing relevant study information. This may have affected what was shared and focused on for the interviewed dietitians and patients. According to Thorne, interviewees are inclined to focus on what they think the interviewer will understand instead of, for example, the complexity of their experiences (181).

Since I have a background as a clinical dietitian and this thesis has an applied research focus, it is important to reflect upon how this might have affected the studies. Of course, this have influenced everything from study aims to the concluding words in this thesis. Regarding Papers III and IV, qualitative research methodology points out researcher reflexivity as increasing the credibility of performed studies (139). Within phenomenology, and when performing a STC analysis, the ‘bracketing’ of past knowledge is aimed for during interviews and analysis (132, 133). This was especially challenging in the patient interviews, and the initial interviews contained more therapeutic elements than what is warranted in a research interview, such as a lot of mirroring and nutritional assessment-inspired questions. To help make my preconceptions and hidden values more visible, I kept a project diary from the start. Additionally, interview techniques and the dietitian and patient perspectives were discussed during regular study meetings including all four authors of Papers III–IV.
Conclusions

The studies included in this thesis focused on the nutrition therapy with ONS from a dietetic practice perspective. In particular, ONS prescriptions and prescription adherence have been explored from different angles using both quantitative and qualitative research methods.

In the first paper (Paper I), ONS interventions in RCTs were found to be incompletely described, which hinders intervention replication and result interpretation. In the second paper (Paper II), adherence to ONS prescribed by dietitians was found to be high among hospital outpatients. Beyond potential explanatory factors, such as a relatively young population with severe diseases, the individually dietitian-tailored prescriptions encompassing a range of flavours might serve as an explanation to this finding. In the third and fourth papers (Papers III and IV), dietitians’ and patients’ experiences of ONS as part of the nutrition therapy were explored. Patient involvement in a shared tailoring process and the role of dietitians as behaviour change facilitators were identified as two important aspects when dietitians prescribe ONS (Paper III). In the patient interviews, ONS were identified as serving as a one-dimensional remedy, compensating for nutrients, but not for the painful loss of normal eating. However, this one-dimensionality could also be understood as positive, since ONS could serve as an effective way of ingesting nutrients without expectations of being social or bringing pleasure, in the way a meal does. Additionally, ONS usage was described as being regulated autonomously based on the priority given to nutrition in a patient’s everyday life (Paper IV).

Overall, this thesis shows that prescription of and adherence to ONS are complex processes (Papers I–IV). This complexity seems to be underestimated in the literature, since the descriptions of ONS interventions are inadequate (Paper I). The included studies suggest that adherence to dietitian-prescribed ONS is high, and the behaviour change of taking ONS is enabled by supporting the patient and involving them in treatment decisions, in line with a care that is person-centred. Lastly, prescribers should acknowledge that nutritional status may or may not be prioritised by the patients, and this might affect ONS usage.
Clinical implications

Based on the results from the studies included in this thesis, performed from a dietetic practice perspective, Table 3 includes some suggestions on how to prescribe ONS.

**Table 3 Clinical implications of the thesis findings**

<table>
<thead>
<tr>
<th>Clinical implication</th>
<th>Supporting thesis findings</th>
</tr>
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<tbody>
<tr>
<td>ONS should not be prescribed in a standardised manner – ‘like a pill’.</td>
<td>In Papers II–IV, the findings supported an individualised treatment, since adherence was high with a dietetic-tailored prescription, and dietitians and patients expressed individual differences in treatment preferences.</td>
</tr>
<tr>
<td>The patient should be given the opportunity to taste the ONS before a prescription is made.</td>
<td>In Paper II, where patient adherence to ONS was high, the majority was allowed to taste the ONS before prescription. Also, dietitians emphasised trial tasting as an important part of the shared tailoring process (Paper III), and patients described a variety of individual preferences regarding flavours and serving styles (Paper IV).</td>
</tr>
<tr>
<td>The prescriber and the patient should decide together if and what to prescribe, in line with a person-centred care approach.</td>
<td>In Paper II, the majority of the patients participated in the choice of flavours. In Paper III, the dietitians expressed the shared tailoring process as important to achieve a successful treatment. Additionally, patients expressed acceptance of taste as a prerequisite for using ONS, and also appreciated being able to manage the amount to be consumed in an autonomous way (Paper IV).</td>
</tr>
<tr>
<td>The prescriber and the patient should discuss the goals with the ONS therapy.</td>
<td>In Paper IV, the patients expressed the importance of nutrient intake and body-weight as affecting their ONS usage. This perceived importance varied greatly among the interviewed patients and was also described as situation-dependent. The prescriber must remember that nutritional status is not always</td>
</tr>
</tbody>
</table>
Feeling good could mean being able to go to the cinema or prioritising fluid intake from ‘coffee with a friend’ instead of from an ONS bottle.

<table>
<thead>
<tr>
<th>When ONS are included in the malnutrition therapy, they should be considered as one part of a multifactorial nutrition intervention.</th>
<th>In Paper II, where adherence to ONS was high, all patients received nutrition counselling from a dietitian in combination with the prescription of ONS. In Paper III, the dietitians stressed the importance of using food-based strategies in combination with ONS. Additionally, using behaviour change strategies was identified as an important aspect for achieving a successful ONS treatment. The patients expressed their food intake as tightly connected to their perceived need for ONS and their ONS usage (Paper IV).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitians are suitable ONS prescribers (or should be involved in the prescription) since they are trained in providing nutrition therapy involving also food-based and behavioural change strategies as medical nutrition products.</td>
<td></td>
</tr>
</tbody>
</table>

ONS, oral nutritional supplements.

Lastly, the results from this thesis would benefit from confirmation through studies performed with an experimental design. Thus, more research in this area is warranted.
Future perspectives

I believe that future research within dietetic practice and the malnutrition field would benefit most from the continued usage of mixed methods and perspectives. I consider the following research areas as relevant for further exploration, building on the findings of this thesis:

- In order to investigate if the strategies applied by the dietitians in this thesis are successful, clinical trials with adherence to ONS (or behaviour changes in taking ONS) as the primary outcome measure are warranted.

- The shared tailoring process of the ONS prescription needs to be explored further. For example, conversation analysis of dietitian-patient encounters or interviews with patients, focusing on shared-decision making, would shed more light on this finding.

- The pros and cons of having dietitians as primary prescribers of ONS also require further study. Interesting outcomes in focus could be patient satisfaction or quality of life, nutritional status, adherence, cost effectiveness, time invested in managing ONS, et cetera.

- The question of whether to use a ‘food first’ approach or a combined one, with food-based strategies plus ONS, needs to be studied further from both a physiological and a phenomenological viewpoint. This would serve to guide clinical practice as to the best malnutrition treatment approach.

- The goals of malnutrition therapy should be explored further from the patient and the healthcare perspective. The altered eating framework could potentially be a helpful aid in such a study.

- In general, the field of malnutrition and malnutrition therapy would benefit from including more of the perspectives from behavioural change theory and person-centred care philosophy. This is the case since the literature currently found within this area tends to be very biomedically focused and nutrition therapy is often managed as a drug therapy.
Svensk sammanfattning

Bakgrund
I den här avhandlingen har förskrivning av och följsamhet till ordination av kosttillägg undersökt. Arbetet har tagit sitt avstamp i dietistens kliniska vardag när rapporteringskvalitet, patientföljsamhet samt dietisters och patienters erfarenheter av kosttillägg som en del av nutritionsbehandlingen har utforskats.


Användning av kosttillägg har visats ge fördelaktiga behandlingseffekter såsom ökat energi- och näringsintag, ökad kroppsvikt, förbättrad livskvalitet, god kostnadseffektivitet samt, i ett fåtal meta-analysen minskad dödlighet (11, 24, 36, 101). I många länder förskrivs kosttillägg till patienter inom häls- och sjukvården till ett subventionerat pris. Dietister har med sin kompetens beskrivits som bäst lämpade för att bestämma vilket kosttillägg patienter bör förskrivas (7), men olika hälso- och sjukvårdsprofessioner ansvarar för detta beroende på vilken kontext och vilket land man befinner sig i (8-10, 43). I Sverige är det i huvudsak dietister som ansvarar för förskrivningen av kosttillägg till patienter i ordinärt boende (10).

Följsamheten till ordination av kosttillägg påverkar nutritionsbehandlingens effekt (43, 59, 61, 62) och beskrivs ofta i litteraturen som bristfällig (20, 60, 61, 64). I en systematisk litteraturöversikt gällande just följsamhet till ordination av kosttillägg var dock den genomsnittliga följsamheten hög (78 % in- tag/ordination) (57). Litteraturgenomgången visade också att följsamheten var högre för patienter i kliniska prövningar än i tvårsnittsstudier utförda i den.
kliniska vardagen. Författarna till översikten föreslår att detta kan bero på att patienter får mer uppmuntran och stöd till att dricka kosttillägg om de ingår i en klinisk prövning (57). I Sverige är patienter i ordinärt boende den största användargruppen av kosttillägg (50), men det saknas studier av denna population som fått kosttillägg förskrivet i den kliniska vardagen och ej deltar i en klinisk prövning.

Trots att det förekommer en relativt stor andel vetenskapliga studier kring effekten av kosttillägg, så saknas det studier som har följsamhet till denna behandling som sitt primära fokus. Forskningsfrågorna har tidigare i huvudsak gällt huruvida kosttillägg har en effekt, menad väljligt lite fokus lagts på hur en förskrivning faktiskt går till eller borde konstrueras. Mot bakgrund av detta fokuserar denna avhandling på att utveckla kunskapen om förskrivning av och följsamhet till kosttillägg som en del av nutritionsbehandlingen vid undernäring eller risk för undernäring.

Syfte

Det övergripande syftet med denna avhandling var att öka kunskapen om och förståelse för förskrivning av kosttillägg och följsamhet till denna behandling. Specificering av syftet för delarbete I-IV följer.

Delarbete I: att undersöka rapporteringskvalitén gällande kosttilläggsinterventioner. Detta i publikationer som beskriver randomiserade kliniska prövningar med kosttillägg, i populationer med undernäring, eller risk för undernäring.

Delarbete II: att undersöka följsamhet till ordination av kosttillägg bland öppenvårdspatienter på sjukhus. Det sekundära syftet var att undersöka sammanhängen på populationen som förskrivs kosttillägg i den kliniska vardagen samt att undersöka förskrivningarnas innehåll.

Delarbete III: att få en djupare förståelse för vilka aspekter dietister anser är viktiga när de förskriver kosttillägg som en del av nutritionsbehandlingen.

Delarbete IV: att fördjupa förståelsen för vilken mening kosttilläggen har för patienter och hur detta relaterar till deras användning av kosttillägg.

Metod

För delarbete I genomfördes en granskning av rapporteringskvalitén i artiklar beskrivandes kliniska prövningar med kosttillägg. En rapporteringsriktlinje

**Resultat**

I delarbete I granskades totalt 76 artiklar med kosttilläggsinterventioner och av dessa var det endast två stycken som rapporterade samtliga 12 punkter i rapporteringsguiden tillräckligt väl. Två tredjedelar av artiklarna saknade information om föreslaget tillvägagångssätt för intag av kosttillägg samt om deltagarna fick välja smak. Däremot innehöll en majoritet av artiklarna information om vilket kosttillägg som användes i studien. Information om följsamhet till interventionen saknades i en tredjedel av artiklarna. Rapporteringskvalitén var bättre i artiklar publicerade efter 2011.

I delarbete II deltog 96 öppenvårdspatienter med en medelålder på 67 år. De flesta hade en cancer- eller magtarmsjukdom. Den genomsnittliga följsamheten till ordination av kosttillägg, uppmätt med tre olika metoder, var hög (> 75 %). En majoritet av patienterna hade förskrivits mellan en till tre flaskor kosttillägg per dag (83 %) och var delaktiga i val av smak (92 %). Över två tredjedelar (69 %) hade fått smaka på kosttilläggen innan förskrivning och i genomsnitt hade patienterna förskrivits drygt fyra olika smaker. Majoriteten (> 75 %) tyckte om smaken på sina kosttillägg och ansåg att de var bra för deras hälsa.

För delarbete III genomfördes intervjuer med 13 dietister. Analysen ledeck fram till två slutgiltiga kategorier som benämndes ”Att skräddarsy kosttilläggsförskrivningen tillsammans med patienten” och ”Att stöta och underlätta användningen av kosttillägg”. För det första beskrev dietisterna att patientens smakacceptans var en förutsättning för att kosttillägg skulle förskrivas och de framhöll vikten av att erbjuda smakprovning. Dietisterna uttryckte också att det var viktigt att patienten involverades i förskrivningen av kosttillägg och var delaktig i beslut gällande val av produkt och förskrivningsmängd. För det andra beskrev dietisterna att de stöttade patienterna och underlättade för deras användning av kosttillägg på olika sätt. Detta dels genom att kommunicera olika aspekter kring kosttilläggen i samtalet med patienten och dels genom att
ordna med praktiska detaljer kring kosttilläggen som exempelvis organisering av hemleverans.

För delarbete IV genomfördes intervjuer med tio patienter. Analysen ledde fram till två slutgiltiga kategorior som benämndes ”Näringsdrycken är en en-dimensionell gottgörelse” och ”Den dagliga användningen av kosttillägg regleras autonomt”. För det första beskrevs meningen med näringsdrycken (kosttilläggen) att kompensera med näringsämnen, samtidigt som patientens förändrade relation till mat och ätande inte kunde botas av den. I vissa situatiorer beskrevs denna en-dimensionella mening som positivt. Detta då näringsdrycken kunde fungera som ett enklare sätt att få i sig näring i jämförelse med att tillaga och äta en betungande måltid. För det andra beskrev patienterna att deras användning av näringsdryckerna påverkades av smaken samt betydelsen de lade vid sitt näringsintag. Om näringsintaget ansågs vara viktigt och en högre kroppsvikt önskvärd, beskrevs intaget av näringsdrycken som prioriterat. Om en högre kroppsvikt inte uppfattades som viktigt eller om patienten ansåg att en konkurrerande aktivitet var viktigare än drickandet av näringsdryck uttryckte de att användningen var nedprioriterad. Därtill beskrev patienterna att de uppfattade dietistens rekommendation om intagsmängd som ett förslag snarare än en ordination.

Diskussion och slutsats

Rapporteringskvalitén gällande interventioner med kosttillägg i kliniska prövningar visade sig vara låg (delarbete I), vilket är i enlighet med liknande studier utförda inom andra hälso- och sjukvårdsdiscipliner (144-146). Detta försvårar tolkningen av studiers resultat samt upprepning av lyckade kliniska förövningar i den kliniska vardagen (81). I delarbete II var följsamheten till ordination av kosttillägg hög. Potentiella förklaringar till detta kan vara populationens relativt låga ålder och svåra sjukdomstillstånd. Ålder samt sjukdomars svårighetsgrad sammankopplas ofta med patientföljksamhet i litteraturen (3, 111). Den äldre populationens bristande följsamhet till ordination av kosttillägg har beskrivits som särskilt utmanande och problematisk (57, 65). Den höga följksamheten i delarbete II kan också förklaras av att förskrivningarna skräddarsyddes till patienterna av dietist. Individanpassning rekommenderas i förskrivningsriktlinjer (18) och förskrivningen av kosttillägg föreslås bli bättre när dietistprofessionen är involverad (7, 8, 45).

I intervjustudien med dietister (delarbete III) identifierades en delad beslutfattningsprocess kring förskrivningens innehåll samt dietistens roll som ett stöd till beteendeförändring som två viktiga aspekter för att uppnå en lyckad nutritionsbehandling med kosttillägg. Detta rimmar väl med värdegrunden i

I intervjustudien med patienter (delarbete IV) kan drickande av näringsdryck förstås som en hälso-inriktad aktivitet. Detta till skillnad från en måltid som ofta är en njutbar och social aktivitet, åtminstone när man är frisk (171). Därtill beskrev patienterna att deras användning av kosttillägg påverkades av betydelsen de lade vid ett högt energi- och näringsintag snarare än att följa en strikt given rekommendation från dietisten. En autonom reglering av medicin-användning har tidigare beskrivits gällande patienter med epilepsi och astma (127, 168). Även i denna grupp av patienter som fått kosttillägg förskrivet verkar användningen självständigt regleras med målsättningen att må så bra som möjligt.

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References


167. Myers EO, Orrevall Y. Using the nutrition care process - Critical thinking from eight clinical cases. Publisher: Esther Myers and Ylva Orrevall; 2016.


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