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Home enteral tube feeding - from patients', relatives' and nurses' perspectives

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Abstract

Home enteral tube feeding – from patients', relatives' and nurses' perspectives

Aim: The overall aim of this thesis was to describe and explore home enteral tube feeding (HETF) care and treatment from patients', relatives' and nurses' perspectives. **Methods:** Qualitative studies were carried out according to the Grounded Theory methodology (I, III) and phenomenography (IV). Eleven patients (I) were interviewed twice with focus on their experiences of HETF care and what it means to live with HETF. Twelve relatives were interviewed twice (III) with focus on experiences of HETF care and what it means to live close to a HETF-patient. Ten registered nurses working at hospital or in community home care were interviewed about their conceptions of planning, daily care and follow-up procedures of HETF. In a quantitative study (II) data was collected by a study specific questionnaire with questions concerning daily care of HETF, route of tube feeding, feeding methods, side effects, information and support from the health care. Health related quality of life and general health were also measured by using the Short-Form 12 (SF-12) and the Health Index (HI). **Findings:** The HETF treatment and care had an impact on daily life for both patients (I, II) and their relatives (III) and implied many practical, emotional and social problems in their daily life, which they strived to *manage*. The patients also experienced *restrictions and distress* due to side effects, impaired physical function, and time-consuming and awkward tube feeding (I). The patients' HRQL and general health were negatively affected (II). The relatives experienced loneliness and worrying to a high extent, they took on a great responsibility and had to adjust their daily life to the HETF (III). The amount and quality of received *guidance and support* from the health care turned out to have impact on the patients' and relatives' daily life and how they could manage their situation. Adequate guidance and support meant being calm and reassured, while lack of guidance and support meant insecurity, worries and distress (I, III). According to the nurses, *cooperation in the care trajectory* was decisive for how well the care was running (IV). Cooperation meant information transfer and a mutual understanding between nurses, and also other professionals. Nurses' knowledge about tube feeding and discharge planning procedures, their commitment to the patients' care, as well as clarity regarding responsibility of HETF care were of crucial importance of how the cooperation worked, and the quality of the HETF care (IV). **Conclusions:** HETF treatment had a negative impact on daily life for patients and their relatives implying practical, emotional and social problems. Received information and support varied but was often expressed as insufficient, and cooperation in the care trajectory was decisive for the quality of care. Improvements are needed regarding cooperation and discharge planning, the nurses' level of knowledge and responsibility distribution, as well as guidance and support to patients and relatives both before and after discharge.

Keywords: home enteral tube feeding, home care, side effects, quality of life, care trajectory, discharge planning, support, patients, relatives, nurses

Svensk sammanfattning

Sondmatning i hemmet – från patienters, närståendes och sjuksköterskors perspektiv

Syfte: Det övergripande syftet med avhandlingen var att beskriva och undersöka sondmatning i hemmet (HETF) utifrån patienters, anhörigas och sjuksköterskors perspektiv. **Metoder:** Kvalitativa studier genomfördes enligt Grounded Theory (I, III) och fenomenografi (IV). Elva patienter intervjuades två gånger med fokus på deras upplevelser av HETF och vad det innebär att leva med HETF (I). Tolv närstående intervjuades med fokus på upplevelser av HETF vård och vad det innebär att leva nära någon som behandlas med HETF (III). Tio sjuksköterskor som arbetade på sjukhus eller i hemsjukvård intervjuades om deras uppfattningar av planering, daglig vård och uppföljning av HETF (IV). I en enkätstudie (II) riktad till patienter samlades data in med ett studiespecifikt frågeformulär angående vården av HETF, infart, matningsmetoder, biverkningar, information samt stöd från hälso- och sjukvården. Hälsorelaterad livskvalitet och allmän hälsa mättes med hjälp av Short-Form 12 (SF-12) och Hälsoindex (HI). **Resultat:** Avhandlingens resultat visade att HETF behandling och vård inverkade på det dagliga livet för både patienter (I, II) och deras närstående (III) och medförde många praktiska, emotionella och sociala problem i vardagen, som de kämpade med att hantera. Patienterna upplevde också begränsningar och obehag på grund av biverkningar, nedsatt fysisk funktion samt tidsödande och besvärlig sondmatning (I, II). Dessutom var patienternas hälsorelaterade livskvalitet och allmänna hälsa påverkad i negativ riktning (II). Närstående till patienter med HETF tog på sig ett stort ansvar och kände sig tvungna att anpassa sin vardag efter sondmatningen. De oroade sig för hur framtiden skulle bli och kände sig ensamma i sin roll som närstående (III). Omfattning och kvalitet på information, vägledning och stöd från hälso- och sjukvården visade sig påverka patienternas och de närståendes dagliga liv och deras förmåga att hantera situationen. Adekvat information, vägledning och stöd medförde lugn och trygghet i vardagen, medan bristande information och stöd innebar osäkerhet, oro och stress (I, III). Enligt sjuksköterskorna var samarbetet och informationsöverföringen mellan sjuksköterskor och andra yrkesgrupper i vårdkedjan avgörande för hur väl vården fungerade. Sjuksköterskors kunskap om sondmatning och utskrivningsplanering, engagemang i patienternas vård, liksom tydlighet i ansvarsfördelning angående HETF var avgörande faktorer för hur samarbetet fungerade och för vårdens kvalitet (IV). **Konklusion:** Behandling med HETF hade en negativ inverkan på det dagliga livet för patienter och deras anhöriga och innebar praktiska, emotionella och sociala problem. Stödet de fick från hälso- och sjukvården varierade och ibland saknades stöd helt. Samarbetet i vårdkedjan hade enligt sjuksköterskorna betydelse för vårdens kvalitet. Förbättringar behövs inom vården angående bedömning av patienters behov, vägledning och stöd till patienter och närstående både före och efter utskrivning. Även sjuksköterskors kunskaper om vårdplanering och sondmatning samt om ansvarsfördelning behöver förbättras.

Nyckelord: sondmatning i hemmet, vård i hemmet, biverkningar, livskvalitet, vårdkedjan, utskrivningsplanering, stöd, patienter, närstående, sjuksköterskor

To the participating patients and relatives

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Abbreviations

EWB	Emotional Well-Being
HETF	Home Enteral Tube Feeding
HI	Health Index
HRQL	Health-Related Quality of Life
MCS	Mental Component Summary
NG	Nasogastric Tube
PEG	Percutaneous Endoscopic Gastrostomy
PCS	Physical Component Summary
PWB	Physical Well-Being
SF-12	Short Form 12

Original papers

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Bjuresäter, K., Larsson, M. & Athlin, E. Management of restrictions and distress - patients' perspective on home enteral tube feeding. *Submitted.*
- II. Bjuresäter, K., Larsson, M., Athlin, E. & Nordström, G. Patients Living with Home Enteral Tube Feeding: Nutritional Care, Side Effects and Health-Related Quality of Life. *Submitted.*
- III. Bjuresäter, K., Larsson, M. & Athlin, E. Struggling in an inescapable life situation: being a close relative of a person dependent on home enteral tube feeding. *Accepted for publication in Journal of Clinical Nursing*
- IV. Bjuresäter, K., Larsson, M., Nordström, G. & Athlin, E. (2008). Cooperation in the care for patients with home enteral tube feeding throughout the care trajectory: nurses' perspectives. *Journal of Clinical Nursing*, 17, 3021-3029.

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Introduction

In my work as a registered nurse at a county hospital, I have met patients with eating disabilities and many of them treated with tube feeding. The patients often described problems related to home enteral tube feeding (HETF), which made me wonder about how the HETF-care really worked.

When searching in the scientific literature, I found out that a number of studies described how HETF-care *should be* performed, but few studies explored how the care *really* worked, and the HETF-patients experiences of their situation at home and support was scarcely explored.

Therefore the focus in this thesis is patients', relatives', and nurses' experiences of HETF in order to facilitate a care of as high quality as possible.

Background

Eating problems and malnutrition

Eating is essential for human beings, both from a biological and a social perspective (Rolfes *et al.* 2006). When being affected by a disease, the ability and pleasure of eating can be reduced or impaired. Eating problems related to chewing and/or swallowing are commonly associated with neurological-, and gastrointestinal diseases, cancer and brain injury. For patients who are unable to eat and take in their daily need for nourishment, the risk of being malnourished is apparent. Malnutrition implies deviations from normal nutrition (Rolfes *et al.* 2006), but there is no consensus about a uniform definition (Stratton *et al.* 2003). In this thesis, the term *malnutrition* is used for undernutrition. It is well known that protein- and energy malnutrition (PEM), the most common form of undernutrition in western countries (Lochs *et al.* 2006, Stratton *et al.* 2003), is common both in the hospital setting (prevalence between 11-41%) and in community care (prevalence between 4-60%) (National Board of Health and Welfare 2000). The causes of malnutrition have been frequently studied, concluding that both an inadequate food intake and biological physical responses cause the state of malnutrition (Rolfes *et al.* 2006, Stratton *et al.* 2003). Malnutrition is connected with physical complications and increased mortality (National Board of Health and Welfare 2000, Stratton *et al.* 2003) and has a negative impact on the patients concerning feebleness, exhaustion, decreased appetite, apathy and impaired quality of life (Stratton *et al.* 2003). Although malnutrition and its consequences are well-known in the health care, there are still a lot of malnourished patients never identified and treated for malnutrition (Edington *et al.* 2003).

Treatment of malnutrition implies oral support including food fortification and oral supplements as a first step (Lochs *et al.* 2006). For patients unable to meet their nutritional needs orally - i.e. patients with eating problems having their gut preserved - enteral tube feeding is the preferred mode for delivery of nourishments (van Gossum, 2005).

Tube feeding

As early as in 1790, nourishment was given through an early kind of feeding tube. A mixture of jellies, milk, eggs and wine were given through a whale bone covered with eel skin, but the outcome of this treatment for the patient was not reported (DeLegge 2005). Treatment with feeding tubes continued during the 1800s until the early 1900s, when guidelines for gastric feeding were provided to medical practitioners. In 1921, a flexible nasogastric tube in rubber was introduced. During the 1950s and 1960s, attention was paid to the development of feeding formulas, containing complete nutrition, which were shown to have a positive impact on the patient's well-being (DeLegge 2005, Phillips 2006).

In several countries, enteral nutrition is considered to be the act of providing nourishment through the gut, orally or through an enteral access device (DeLegge 2005). In Sweden, enteral nutrition is referred to as *tube feeding* (Kondrup 2001). There are several routes for delivery of tube feeding. Most common routes for HETF patients are via nasogastric tube (NG), percutaneous endoscopic gastrostomy (PEG), low profile gastrostomy device - sometimes called 'a button' - and jejunostomy (Van Gossum 2005). The advantages and disadvantages of different routes for delivery, above all NG and PEG, have been discussed in several studies. Although NG has been pointed out as the preferable option for short-term treatment and PEG as suitable for long-term treatment (Crosby & Duerksen 2007, Dwolatzky *et al.* 2001, Ehrsson *et al.* 2004, Elpern 1998, Löser *et al.* 2005), consensus is still lacking with regards to this issue. According to guidelines from the European Society for Clinical Nutrition and Metabolism (ESPEN), PEG is a safe and comfortable method for long-term enteral feeding for patients who are considered appropriate for PEG (Löser *et al.* 2005), but there are still different routines at hospitals for the choice of route for the tube feeding.

Feeding methods for tube feeding can be described as intermittent feeding (allocated in shorter or longer periods of time throughout the day), continuous feeding (at all hours), which can both be given using a gravity drip method or an infusion pump (Elpern 1998), and bolus feeding (given as a meal for 20-40 minutes using a syringe) (Rolfes *et al.* 2006). Feeding methods are evaluated in a few studies, but mainly concerning one condition or complication at time, e.g. diarrhoea or loss of appetite (Crosby & Duerksen 2005, Shun Wah Lee & Auyeung 2003). All methods are reported to have both advantages and

disadvantages (DeLegge 2002) but no consensus is found in the literature for which method is preferable.

Transition from hospital to home

When patients have received preparatory guidance at hospital they can be discharged to their home (Gorski 2005). Preparation includes information, education and establishment of contact with the home care if needed. A well-working cooperation between the care givers has been reported to increase the options for a smooth transition from hospital to home for the patient (Arrowsmith 1994, Costello & Todd-Magel 1997, Goff 1998, Gorski 2005). A growing body of research has illuminated problems with information transfer regarding patients in general across organisational boundaries (Armitage & Kavannah 1995, Clare & Hofmeyer 1998, Hansen *et al.* 1998, Lundh & Williams 1997, Payne *et al.* 2002) and a lack of understanding and respect from other professionals, e.g. between hospital and home-care personnel (Atwal 2002, Payne *et al.* 2002). Studies exploring the discharge process concerning patients in need for HETF are limited and the results are contradictory. Some studies have reported that patients and relatives were satisfied with the preparation including training at hospital and sufficient time for preparation (L'Estrange 1997), while others have reported deficiencies in the preparation before discharge concerning HETF patients (Liley & Manthorpe, 2003). Thus, more research is needed concerning preparation and the transition from hospital to home of HETF patients since this still is a scarcely explored area in nursing.

Home care and HETF

The changes in the health-care system during the past decades have in several European countries led to an increased transfer of the health care to the home environment (Schneider *et al.* 2000). Together with changes in technology and equipment as well as in attitudes to tube feeding this has expanded the use of HETF (DeLegge 2002). Due to shorter time at the hospital, the patients' training and familiarising with tube feeding is to an increasing extent taking place in the home environment (Crosby & Duerksen 2007, Van Gossum 2005), and many patients are cared for at home with limited or with no help and support from professionals in the home care.

Home care can be defined in different ways. What the different definitions have in common is that they includes care of ill persons in their own home (Fitzpatrick 1998), but can also include nursing homes/sheltered institutions (van Bilsen *et al.* 2008). Home health care is performed by professionals, while home care can be performed also by an informal caregiver e.g. a family member. Opportunities to get home health care vary between and within countries (McNamara *et al.* 2000) and is dependent on what is valued and the organisation of the nursing care system (Adams *et al.* 1998). In Sweden, home health care is governed by the National Board of Health and Welfare and are available for all patients in need of this service after individual assessment by professionals (Socialstyrelsen 2008). The municipalities, together with county councils, are responsible for providing home health care for patients unable to handle or carry out the care by themselves (Condelius *et al.* 2007, Lundh & Williams 1997). Home health care includes home care technologies, medical care, rehabilitation and nursing care, and is aided by Registered Nurses or district nurses, together with other health-care professionals around the clock (Gustafsson *et al.* 2009, Socialstyrelsen 2008, SOSFS 1997:14 1997). In addition, medical and nursing care for patients with severe illness, such as cancer patients, can be provided by advanced home-care teams with nurses and physicians specialised in oncology or pain relief (Higginson & Sen-Gupta 2000, Wennman-Larsen & Tishelman 2002). In this thesis the term *home care* will be used for both professional home health care and informal home care in patient's own homes (nursing homes/sheltered institutions excluded).

Patients with HETF care

The HETF patient group have been described in a limited number of studies. The most common indication for the use of HETF in the literature is dysphagia due to swallowing disorders, cancer and motility disorders (DeLegge 2005, Van Gossum 2005). Diagnoses among adult patients using HETF are neurologic disorders 35-44% (mainly cerebral vascular disorders e.g. stroke, amyotrophic lateral sclerosis (ALS), digestive disorders 10-18%, and head and neck cancer 15-30% (Schneider *et al.* 2001, Van Gossum 2005). The mean age among adult HETF patients is in most of the available studies 60-65 years (Van Gossum 2005). There are a limited number of surveys concerning the care and administration of HETF (Crosby & Duerksen 2005, Elia *et al.* 2001, Hebuterne *et al.* 2003, McNamara *et al.* 2000, Schneider *et al.* 2000). These surveys describe the patient group, quality of life and outcome of HETF treatment. There are

also a few qualitative studies concerning patients' contacts with the professional home care (Brotherton & Lyons 2002, Evans *et al.* 2004, Liley & Manthorpe 2003). Research about patients' situation with HETF is scarce and consequently, further research is needed in order to gain more knowledge about HETF treatment and care.

Patients experiences of HETF

Daily life at home

Daily life is a broad concept. In the nursing domain, daily life, also referred to as daily living, is of particular concern and should according to Carnevali and Reiner (1990) be related to the functional health status of a person. Activities in daily life concern anything that the patients do and often follow a usual pattern, which is relevant to their current health situation. Events and demands, internal or external, are also relevant in daily life (Carnevali & Reiner 1990). Any change in daily life, e.g. transition from hospital to home, will affect the health status interchangeably (Carnevali 1983). There is a growing body of nursing research concerning daily life for patients with different diagnoses cared for at home for a shorter or longer period. These patients have illuminated the importance of being able to stay at home, as home is the place where they prefer to be, where they can pursue their interests and have their family around them (Ballangrud *et al.* 2008, Carlsson *et al.* 2004, Lindahl *et al.* 2003). According to Lindahl (2003), being able to stay at home was experienced as positive as the home was seen as a safe and comfortable place. However, home care could also mean dependence to others (Carlsson *et al.* 2004), or experiences of being tied to the home (Lindahl *et al.* 2003). Studies exploring patients' daily life with HETF and what support is needed are very limited (Brotherton *et al.* 2006, Brotherton & Lyons 2002, Liley & Manthorpe 2003) but the few studies found have described HETF as inconvenient and causing practical problems. It is therefore of interest to gain more knowledge about what it means to live with HETF.

Side effects related to HETF

Tube-related complications and side effects to tube feeding are well known. Leakage around the tube site, abdominal pain, and tube dislodgment are common tube-related complications (Crosby & Duerksen 2005, Mercer &

Mungara 1996). The literature about side effects related to tube feeding has almost entirely concerned gastrointestinal side effects. Flatulence, diarrhoea, constipation, nausea and acid reflux are associated with tube feeding (Crosby & Duerksen 2005, Crosby & Duerksen 2007, Koulentaki *et al.* 2002, L'Estrange 1997, Reddy & Malone 1998, Rolfes *et al.* 2006) and can be related to feeding route, type of formula and feeding methods (Rolfes *et al.* 2006). Side effects related to tube feeding have mostly been studied in hospital settings (Homann *et al.* 1994, Pancorbo-Hidalgo *et al.* 2001, Shang *et al.* 2003, Whelan *et al.* 2006) but frequencies of side effects and how these affect the patient's daily life after discharge is still scarcely described. Only one study has been found evaluating side effects for patients treated with HETF over time, showing that gastrointestinal side effects were common and had not decreased over the period of three weeks (Roberge *et al.* 2000). Since side effects do not only arise when the patients are in the hospital this must be a crucial research question.

Health and quality of life

An important aspect when searching for knowledge about daily life is to measure patients' opinion of their own health. The concept of health is described in various ways, depending on what paradigm is represented. One definition commonly cited is that of the World Health Organisation (WHO), which has manifested health as '*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*' (WHO 1946). This definition has been criticised due to its biomedical perspective of human being. In addition, the criticism pointed at the connection between health and disease (Willman, 2009). Nowadays, the early WHO definition has been extended (Ejlertsson & Andersson 2009), moving towards a more holistic perspective including such things as the person's ability to act towards goals, coping ability and wellness (Willman 2009). In nursing, the American Nurses Association (American Nurses Association 1980) defined health as a dynamic state of having the potential to develop mental and behavioural well-being. This definition includes the individual striving for an optimal functioning, which is in congruence with several nursing theories (Meleis 2007). Borgenhammar (1982) stated that health '*not only is difficult to catch as a concept but also relative*' (p.18), pointing out the important interaction of physical, psychological, social and cultural dimensions of health, which is in line with the nursing perspective. This means that the biological-medical and humanistic perspectives are not excluding but

complementary to each other (Willman 2009) but most instruments for measuring health are based on a biomedical definition (Bowling 2001). Hence, as health is an individual experience (Kozier *et al.* 2004), both nurses and researchers must be aware about the use of the concept and what it may mean to different people.

Quality of life has been paid a major interest in health care research during the last 30 years as an outcome measure of health. There is no consensus about the term *quality of life* (Bowling 1997, Bowling 2001), but WHO have defined it as *“Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”* (WHO 1998, p.551). Health is considered both as a dimension of and a prerequisite for quality of life (Borglin 2005). When interested in research of the health status, health-related quality of life (HRQL) can be measured. The concept of HRQL must rest on the concept of health as well as the concept of quality of life. HRQL refers to the physical, emotional and social well-being of patients following treatment and to the impact of disease and treatment on disability and daily functioning (Bowling 2001).

Due to the fast development of techniques and equipment for tube feeding, it can be assumed that the patients’ HRQL when being treated with HETF can be affected in both a positive and a negative direction (Schneider *et al.* 2000). Studies have shown that patients with HETF had poor HRQL and experienced psychological distress (Malone 2002, Schneider *et al.* 2000). However, studies exploring HRQL related to special areas, e.g. feeding methods or route of HETF, or studies measuring general health for patients treated with HETF have not been found. Longitudinal studies concerning this group of patients are very few. The studies found have reported a poor HRQL which slightly improved over time (Loeser *et al.* 2003, Roberge *et al.* 2000) but these studies had their limitations in very few respondents or use of informal caregivers as respondents for non-competent patients. It is notable that some studies measuring HRQL for HETF patients have included patients both with and without cognitive impairments, using relatives or professional caregivers as respondents on behalf of the patient when the patients were unable to respond to the questions (Loeser *et al.* 2003, Schneider *et al.* 2000). When exploring a patient’s health and HRQL, it is necessary to make sure that the information is grounded in the patient’s own experiences. Thus, it is of great interest to gain

knowledge about this group of patients' own views of their HRQL and general health.

The relatives' experiences of HETF

When a family member is stricken by illness the family life often will be affected and the relatives involved (Östlinder 2004). Therefore, experiences of relatives of patients in home care have been paid more attention in research during recent years. Different terms for relatives are used in research: *partner, spouse, close relative, family member and next of kin*. Since the relatives in this thesis can be both partners, adult children, children in law and siblings, the term *relative* is chosen. Various experiences of home care have been found among relatives. Some studies have reported about experiences of happiness at having the patient at home instead of in hospital, more opportunities to spend time together, and to participate in social life together, but there are also many experiences of burden, frustration, lack of control and anxiety (Nijboer *et al.* 1998, Smeenk *et al.* 1998, Winkler *et al.* 2006, Öhman & Söderberg 2004). Despite of if the patient could run the care by themselves or not, the relative took part in the care to some extent and they often experienced the home care as a burden being preoccupied with practical matters (Winterling *et al.* 2004). Relatives' situation related to HETF care and what role they play is however scarcely described in the literature. The few studies found described the relatives' experiences of distress, vague responsibility and lacking preparation of the care (Liley & Manthorpe 2003, Silver & Wellman 2002, Silver *et al.* 2004). As relatives seem to be quite invisible in the care of HETF so far, more studies are needed in order to explore what support is needed.

The nurses' role in HETF care

Registered nurses play a key role in the care of HETF. As the treatment with tube feeding usually starts during the patient's hospital stay and is ongoing after discharge to home, both hospital and home care nurses will be involved. After a prescription from the physician about initiating tube feeding, the type of feeding formula, amount and speed, and feeding method are tried out and adjusted at the hospital based on the patient's individual needs (DeLegge 2002, Malone 2002). The ward nurses play an important role in this step concerning the design of appropriate care for the patient (Arrowsmith 1994, Malone 2002).

Before discharge, patients and relatives need preparation in form of education and training about daily care of tube feeding as well as prescription of feeding formula and appropriate equipment (Howard & Bowen 2001, Malone 2002). This is tasks in which ward nurses also should be involved (Gorski 2005). The nurses are also responsible for the transfer of information throughout the care trajectory (SOSFS 2005:27 2005).

There are several organisations concerning home care worldwide, and in Sweden district nurses are responsible for coordinating and performing the professional home care (Distriktssköterskeförningen i Sverige 2008). Home-care nurses meet a great variety of patients suffering from different forms of illnesses with various and complex demands (Kihlgren 2005). This means that the nurses must have comprehensive medical and nursing knowledge to be able to meet the patients' needs (Tunedal & Fagerberg 2001). Several studies describe how nurses should carry out planning and preparation before discharge where tube feeding is concerned (Arrowsmith 1994, Loan *et al.* 1997, Russel & Rollins 2002, Stratton 2002). However, few studies have explored the nurses' work in this process (Todd *et al.* 2005). Furthermore, no study has been found about the home-care nurses' role in the care of HETF patients. This brings a need for gaining knowledge about how care of HETF is carried out and the nurses' situation related to HETF.

In the following, the term 'nurse' is used for registered nurses working in hospitals and registered nurses specialized in district nursing working in the community.

Rationale for the thesis

As shown in the literature review research is scarce about how HETF care is functioning in the care trajectory. Knowledge is lacking regarding what it means to live with HETF and what it means to be a relative of a person dependent on HETF. Outcome studies of HETF treatment and care and exploring studies of HETF-patients daily life including side-effects and health-related quality of life are few, both at any given point of time and over time. Furthermore, studies measuring HETF-patients experiences of their own health have not been found at all. Patients with their cognitive function preserved often run the HETF care at home on their own or with support from relatives to a varying extent. It is therefore of great interest to gain knowledge regarding the care trajectory related to HETF, and what support patients and relatives need and receive from the health-care system. This thesis is an attempt to contribute to the knowledge and understanding of HETF from patients', relatives' and nurses' point of views.

Overall and specific aims

The overall aim of this thesis was to describe and explore HETF care and treatment from patients', relatives' and nurses' perspectives.

The specific aims were to:

- explore what it means to live with HETF (I) and to be a close relative to a person dependent on HETF (III), and how the situation can be managed (I, III).
- examine side effects, health-related quality of life, general health and nutritional care among patients receiving HETF after discharge from hospital (II).
- explore how the planning, daily care and follow-up procedures work in the care trajectory for patients treated with HETF, seen from the perspective of hospital and community care nurses (IV).

Methods

Design

The overall design in this thesis was descriptive and explorative. In order to elucidate and describe different aspects of the research questions, multiple triangulation has been used (Denzin 1989, Polit & Beck 2008). Triangulation can refer to data triangulation, investigator triangulation, theory triangulation, and method triangulation (Thurmond 2001, Williamson 2005). In this thesis method triangulation was carried out both as within-method triangulation, since the qualitative studies involved both grounded theory and phenomenography, and as between-method triangulation, since three qualitative and one quantitative studies were performed (Carr 1994). The methods complement each other, providing detailed descriptions and deep understanding which would not be possible using one method alone (Foss & Ellefsen 2002, Polit & Beck 2008). Furthermore, data triangulation was carried out as sources for data were interviews with patients, relatives and nurses, and questionnaires answered by patients (Denzin 1989, Polit & Beck 2008). For an overview of the design, see Table 1.

Table 1. Overview of the studies

Study	Design	Methodological approach	Data collection	Participants
I	Explorative	Grounded theory	Individual interviews x 2 January 2008-June 2010	11 patients ^{a)}
II	Descriptive	Prospective study	Questionnaires x 2 March 2006-June 2009	40 patients
III	Explorative	Grounded theory	Individual interviews x 2 April 2007-January 2009	12 relatives
IV	Descriptive	Phenomenography	Individual interviews x 1 Apr-May 2003	10 nurses

a) The patients in study I were not included in study II

Qualitative methodology

Grounded theory (I, III)

Grounded theory is a methodology originally developed by the two sociologists Barney Glaser and Anselm Strauss (Glaser & Strauss 1967). The focus in grounded theory studies is the meaning given to events and the actions or emotions expressed by the informants, along with in which context the events and actions happen (Morse *et al.* 2009). Grounded theory has its roots in symbolic interactionism (Morse *et al.* 2009) which states that meaning is constructed through interactions between people, and that people interpret their experiences on the basis of their actual situation (Blumer 1969, Mead 1934). The aim of grounded theory is to generate concepts, models or theories grounded in empirical data and further to provide a meaningful guide to actions. Simultaneous sampling, data collection and analysis, constant comparison, sensitivity and theoretical saturation are basic principles of grounded theory (Glaser & Strauss 1967, Strauss & Corbin 1998).

Strauss, influenced by interactionism and pragmatic writing, developed the methodology further together with Juliet Corbin (1986), while Glaser continued developing his thoughts in what he called the *classic grounded theory*. Later on, the methodology was developed in several directions where Kathy Charmaz' constructivist way of grounded theory (Charmaz 2006) is one of them (Morse *et al.* 2009). In this thesis, grounded theory as described by Strauss and Corbin (1998) is used (I, III). Strauss and Corbin commonly used in nursing research (Morse *et al.* 2009), have stated that grounded theory is theory derived from data, systematically gathered and simultaneously analyzed throughout the research process. According to Strauss and Corbin (1998) it is not given that analysis will result in a theory. Conceptual ordering can end up in a model elucidating the categories and their properties and dimensions (Strauss & Corbin 1998). Grounded theory was considered a suitable approach for study I and III, since HETF-dependent patients and their close relatives interact with each other as well as with the ambient society, in which the health-care system is an important part. Furthermore, the methodology was useful in order to explore the hitherto sparsely investigated area of the life situation of patients living with HETF (I) and their relatives (III).

Phenomenography (IV)

A qualitative method with a phenomenographic approach was used in study IV. Phenomenography has its roots in the pedagogical research about learning carried out by Ference Marton and colleagues, and has been developed since the 1980s (Marton & Booth 2000). Phenomenography makes a distinction between what something is and how something is conceived to be. Attention on reality, what things objectively are, is called the first order perspective. The focus in phenomenography is the second order perspective, which is concerned with a person's view of reality; *how* people experience and conceive a phenomenon (Marton 1994, Marton & Booth 2000). Within phenomenography it is assumed that whatever phenomenon or situation people encounter, it is possible to identify the limited numbers of qualitatively different ways in which people experience, conceptualize, perceive, and understand different aspects of the world (Barnard *et al.* 1999, Marton 1981, Marton & Booth 2000). People have various conceptions of phenomena in the world around us, since people have various relations to the surrounding world. Therefore, different people make different experiences of the world. In the analysis common meanings in data represent the various meanings a phenomenon has among different individuals (Barnard *et al.* 1999, Marton 1981). The result is called the outcome space, which covers the different categories and their logical relationships. These categories in the outcome space represent descriptions of variations at a collective level (Barnard *et al.* 1999, Marton 1981, Marton 1994, Marton & Booth 2000). Phenomenography is more and more commonly used in nursing research (Sjöström & Dahlgren 2002), and this approach was chosen as the variations in which nurses conceive how planning, daily care and follow-up procedures in the care trajectory work for patients with HETF were sought for.

Quantitative methodology

A descriptive, prospective design with a consecutive sample (Field 2005) was used in study II. The design was chosen in order to examine HRQL, general health, occurrence of side-effects and nutritional care among a group of patients treated with HETF. Data was collected twice in order to describe the patients' situation over a period of time.

Participants and procedure

The participants in this thesis consisted of four different samples, as shown in Table 2.

Table 2. Characteristics of the participants in study I-IV

Study	Study I	Study II	Study III	Study IV
	N=11 ^a	N=40	N=12	N=10
Participants	Patients	Patients	Relatives	Nurses
Gender				
Male	6	25	2	0
Female	5	15	10	10
Age				
Median	58	64	58	-
Range	37-79	30-86	23-94	-
Civil status				
Single	2	9	1	-
Married/cohabitant	9	31	11	-
Support at home from				
Home health care	3	8	4	-
Advanced home-care team	0	0	1	-
Patients' disease				
Cancer	9	27	7	-
Neurological disease	0	11	4	-
Gastrointestinal disease	2	2	1	-
Delivery of HETF				
Nasogastric	7	16	-	-
Percutaneous Endoscopic Gastrostomy	3	24	-	-
Jejunostomy	1	0	-	-
Feeding method				
Intermittent feeding	7	22	-	-
Bolusfeeding	4	18	-	-

a) The patients in study I were not included in study II

After signed agreement from the Heads of Departments at hospitals and the Medically Responsible Nurse (MRN) in municipalities, contacts were taken with the chief nurses at the hospitals and the MRNs (I-IV).

The chief nurses mediated contact with ward nurses responsible for nutritional care and these nurses were informed about the study procedures (I, II, III). Thereafter they identified patients responding to the inclusion criteria and asked them to participate in the study (I, II). Inclusion criteria in study I were being treated with HETF, or recently had been treated with HETF, in the own home, age 18 years or older and ability to speak Swedish. The patients were recruited

from five wards/units in oncologic care, medical care, ear-nose-throat care and the endoscopic unit at one regional university hospital and two county hospitals and also from twelve municipalities in central Sweden. After the patients' approval to participate in the study they were contacted via telephone to further be informed about the study and for arranging time and place for the interview (I).

In study II the inclusion criteria were being 18 years or older, able to read and write Swedish and going to be discharged to their own home for treatment with HETF. The included patients were identified at ten hospitals from four county councils in central Sweden; two regional university hospitals and eight county hospitals. In total 28 units/wards of medicine, neurology, endoscopy, oncology, ear-nose-throat and surgical care were used. The patients in study I were not included in study II. After agreement from the patients their names and addresses were given to the author who two weeks after discharge sent an invitation letter and the first packages of questionnaires to the patients. Reminders were sent twice (II). Sixty-two patients agreed to participate, of which 40 patients (65%) responded to the questionnaires. For the 22 non-responding patients, information was obtained from the discharging unit about age and diagnosis. Out of these, six patients were dying or had recently died, five patients had a difficult time at home and also had impaired general condition. For the remaining eleven non-responding patients the reasons for not responding were unknown. Twenty-nine patients also responded two months later, i.e. about ten weeks after discharge. Of those not responding at the second occasion eight patients had head and neck cancer, and three had a neurological disease. The cause for not responding at the second occasion is unknown, but when checking with the discharging clinics most of these patients were shown to have impaired general condition.

The relatives in study III were identified via included patients in the quantitative study (II). About one month after the patients had returned their questionnaires at the second occasion (II), an invitation letter was sent to the patients asking for their consent for their relative to participate in an interview study (III). If the patient agreed, he/she returned a signed agreement including name and address of the person they considered as their closest relative. Thereafter, the relatives were contacted and invited to participate in an interview study (III). Relatives were also recruited by contact with district nurses in the twelve municipalities, who, after verbal agreement from the relatives gave their names

and addresses to the author. Thereafter contacts were taken with the relatives in order to further inform about the study and to arrange for the interview. The inclusion criteria were being a close relative to a person treated with HETF in their own home (not in a nursing home or sheltered institution), aged over 18 years and able to speak Swedish. All the relatives were considered by the patients to be their closest relative, but the opposite was not automatically the case. The relatives were spouses, siblings or adult children of the patient. All spouses and one sibling lived together with the patients, and all other relatives lived separated from the patient.

In study IV, the chief nurses at hospital wards and the MRNs in the municipalities asked nurses at the units who corresponded to the inclusion criteria to participate in the study. After agreement from the nurses, their names were given to the author who thereafter contacted them to further inform about the study and arrange time and place for the interview. In order to get as great a variation of concepts as possible, the informants were purposively selected from different areas and levels in the health-care system. Registered Nurses/district nurses with experience of patients in need of HETF during the previous six months were included. Four nurses worked in wards for surgical care, two worked in endoscopic units at hospital and four in community home care. All participants had worked as nurses between four and 30 years (Median 23 years).

Care context

All patients (I-IV) started their tube-feeding treatment as inpatients at hospital and returned to their own home after discharge. After discharge, all patients were followed up regarding their disease by physicians at the discharging clinic but few patients had return visits regarding their tube feeding.

The organisation and follow-up concerning HETF varied both within and between the county councils and municipalities. Patients received tube-feeding equipment from the discharging clinic, the local primary health care or the community home care. Organised support and guidance regarding the tube feeding from the health care varied. Some patients who had contact with district nurses in the home care for their underlying illness also received help and support concerning the tube feeding. For these patients the amount of care varied from limited help bi-weekly to visits from the health-care personnel

several times every day. At one of the ten hospitals there was a nurse-led clinic for patients with head and neck cancer, where some of the patients in study I and II were cared at. Some of the relatives (III) were related to patients who also were cared for at this clinic. At this clinic patients could receive support and guidance about tube feeding, be provided with equipment, and when needed the nurses also could establish contact with the community home care.

Data collection

Interviews (I, III, IV)

Data was collected by means of qualitative interviews carried out by the author (I, III) and the author and a research assistant (IV). Each informant was interviewed twice with about one month in-between (I, III) and once in study IV. The purpose of qualitative interviews is to gain descriptions of the informants' experiences that can be used to interpret the meaning of the phenomenon under study (Streubert Speziale & Carpenter 2003). Qualitative interviews are focused on certain themes and an interview guide with a few entry questions is used rather than a rigid schedule of questions (Streubert Speziale & Carpenter 2003). This meant that the interviews (I, III, IV) were carried out in a dialogue between the interviewer and the informants, who were encouraged to talk freely. In study I and III an interview guide was used initially, which was further developed during the data collection and analysis. In study IV a thematic interview guide was used during the data collection. The interview guides covered the themes *daily life, practical care, support* and *contacts with the health care* in study I. In study III the themes were about the same as in study I but with the focus on the relative, and with the addition of *role as a relative*. The themes in study IV were *discharge planning, information transfer, daily care, follow-up procedures* and *competence*. In order to further illuminate the phenomenon and achieve as rich descriptions as possible the interviewers also used follow-up questions and asked for examples and clarifications. All interviews (I, III, IV) were digitally recorded and transcribed verbatim by the author with exceptions for six interviews in study III and five interviews in study IV which were transcribed verbatim by an assistant. Thereafter the transcriptions were carefully scrutinised by the author. Only minor changes regarding verbal ambiguities were carried out.

Questionnaires (II)

Three questionnaires were used for data collection, a study-specific questionnaire, the Short Form 12 (SF-12) and the Health Index (HI).

Study-specific questionnaire

A study-specific questionnaire was developed with the purpose to examine daily care of HETF, route of tube feeding, feeding methods, side effects related to tube feeding, information, guidance and support from the health-care system regarding HETF. The questionnaire included 31 questions with clinical and demographic data included. Most questions were measured on an ordinal scale with four to seven alternatives depending on the question. Some of them also included open-ended follow-up question. Due to a very low response rate these were not analysed and consequently not included in this thesis. For a comprehensive overview of the content of the questionnaire, see Appendix 1.

Short-Form 12 (SF-12)

The generic instrument 12-Item Short-Form Health Survey (SF-12) was used to measure HRQL. The SF-12 is a shorter version of SF-36, which represents the most commonly used health concepts in surveys; physical, social and role functioning, and mental health (Ware & Sherbourne 1992). The SF-12 contains eight scales concerning physical capacity, physical functioning, emotional functioning, pain, social functioning, vitality and perception of general and mental health, covering a physical component summary score (PSC) and a mental component summary score (MCS). The scale scores range from 0 to 100, with 100 representing the highest level of physical and mental health status (Ware *et al.* 1996). The SF-12 was considered appropriate to use as several patients were likely to have difficulties filling out a form that is too comprehensive.

Health Index (HI)

The HI, consisting of ten items, measuring general health, was first published by Nordström et al (1992) and has been used in several studies (Barthelsson 2009, Eriksson *et al.* 2000, Sjöström *et al.* 2004). Participants were asked to rate their health status during the previous week on a four-graded Lickert scale, ranging from 1 to 4 (very poor to very good) for each item. The scores are summarized into a Health Index ranging from 10 (the lowest self-rated health) to 40 (the highest self-rated health). Nordström et al (1992) performed a factor analysis and defined two factors, emotional well-being (EWB) consisting of the items energy, temper, fatigue and loneliness, and physical well-being (PWB) consisting of the items mobility, sleep, vertigo, bowel function and pain. HI was used as it was considered to provide important information about the respondents' estimated health.

Data analysis

Grounded theory (I, III)

The analysis (I, III) were performed simultaneously with the data collection, and was carried out with open coding, axial coding and selective coding, as described by Strauss and Corbin (1998). The analysis was carried out in close collaboration between the researchers in the research group. After reading through the entire transcribed interview, open coding was performed. The open codes were both written down as expressed by the informant (in-vivo codes) and also named in a more abstract concept (in-vitro codes). Concepts and codes were constantly compared and contrasted and grouped into preliminary categories, which were discussed and further compared in the research group. Emerging codes and concepts were then grouped together into more abstract categories, which were labelled. In the axial coding, connections between categories were sought and each category was further developed by identifying properties and dimensions. In the selective coding process, each category was saturated with information from new interviews or from earlier assessed data, and a core category was identified. At this stage of the process, the understanding of the relationship between categories and the core category was explored in order to create a conceptual model. During the whole process of analysis, memos were written in order to capture thoughts, ideas and

reflections, helping the author to focus and understand the phenomena under study (Corbin 1986).

Phenomenography (IV)

When using a phenomenographic approach, a series of analytic steps are followed (Barnard *et al.* 1999) even if they nowadays are described in various ways (Barnard *et al.* 1999, Dahlgren & Fallsberg 1991, Hyrkäs *et al.* 2003, Marton 1994, Sjöström & Dahlgren 2002, Uljens 1993). The analysis (IV) was carried out from the point of view of professional nursing of the actual group of patients and seven steps were used inspired by Hyrkäs *et al.* (2003): 1) All the interviews were read through in order to receive an overall picture. 2) Significant statements were selected from the interviews. 3) Comparison of statements was performed. 4) Pools of meanings were formed by grouping the statements from the previous stage. 5) Similarities and differences between pools of meanings were analysed and further tested through comparison to the original material. 6) Categories of descriptions and system of interrelationships were generated. 7) The categories were finally named by using concepts to emphasize their content. The analysis was carried out as a continuous movement back and forth between the parts and the whole of the interviews, and between the steps of analysis. During this process the researchers collaborated in critical reflections and discussions.

Statistics (II)

For statistical analysis (II) The Statistical Package for Social Sciences (SPSS), version 17.0 and 18.0 for Windows, was used. SF-12 data was processed by means of a program provided by the HRQL group at the University of Gothenburg, Sweden (Sullivan *et al.* 1997). Descriptive statistics were presented as frequencies and percentages in variables at nominal level and as arithmetic means, standard deviation and range for variables at ratio scale. Median was used when appropriate. Inferential statistics with non-parametric tests were carried out. To examine differences between two independent groups, the two-tailed Kolmogorov Smirnov Z test was used. Differences in proportions between two unrelated groups were tested using Pearson's Chi-square test (one degree of freedom) and in the case of small expected frequencies, the Fisher's Exact test was used. Wilcoxon signed-rank test was conducted to examine differences between two related groups. The tests were two-tailed, and a value of $p < 0.05$ was considered to be statistically significant (Field 2005).

Trustworthiness, reliability and validity

The combination of qualitative and quantitative methods and different data sources strengthens the trustworthiness of the research findings as they complement each others' strengths and weaknesses and provide a richer and deeper understanding of the area under study (Polit & Beck 2008).

Study I, III and IV

In study I and III, trustworthiness, which is a qualitative term for scientific rigour, was taken into consideration as described by Strauss and Corbin (1998) who do not use the commonly used terms connected to trustworthiness; *credibility*, *dependability*, *confirmability* and *transferability* (Lincoln & Guba 1985). Instead Strauss and Corbin (1998) pointed out the necessity of being true and transparent in the methodological description. They have suggested several criteria for evaluation of the quality of studies carried out by means of a grounded theory methodology, which are in accordance to the terms suggested by Lincoln and Guba (1985). These are divided into two areas: 'The research process' and 'Empirical grounding of a study', and contain clear descriptions of sampling procedure, use of theoretical sampling, generation of concepts, emerging of categories, created variation in the theory and significance of theoretical findings. These criteria have been taken into consideration when describing the studies (I, III) aiming to elucidate them throughout the methodological section.

In study IV, the terms for trustworthiness described by Lincoln and Guba were used (Hamberg *et al.* 1994, Lincoln & Guba 1985). In order to receive a strong credibility two test interviews were performed, which confirmed that the themes in the interview guide were relevant to the aim of the study. During the interviews, open-ended questions with follow-up questions were used to invite the informants to deepen and develop their conceptions and thoughts. Quotes were used to illustrate and validate the findings. In order to enhance the dependability of the study, the selection of the informants and the process used for choosing the informants were clearly described, as well as the methods for data collection and analysis. All the researchers cooperated continuously during the data analysis and discussed statements from the transcripts, pools of meaning and description categories, which refers to confirmability. The pre-understanding of the researchers was also continuously discussed. The characteristics of the informants, the context of the study, the interviews and

process of data analysis were described as clearly as possible in order to facilitate transferability.

Study II

Validity refers to the degree to which an instrument measures what it is supposed to measure (American Educational Research Association & American Psychological Association 2004, Polit & Beck 2008). *Reliability* refers to the consistency of measurements when the testing procedure is repeated on a group of individuals (American Educational Research Association & American Psychological Association 2004). One way of testing the reliability of an instrument is to check the internal consistency which rests on inter correlations among all the items in an instrument (Polit & Beck 2008).

The questions in the study-specific questionnaire used were developed on the basis of scientific literature in the area and the authors' professional experience of advanced nursing. Prior to the data collection, a pilot test of the questionnaire was performed. Five nurse lecturers with clinical experience of nutritional care and tube feeding completed and commented on the questionnaire, resulting in minor vocabulary adjustments. Thereafter, five patients with a history of HETF treated at an ear, nose and throat clinic answered and commented on the revised questionnaire. No further adjustments were made. This was considered as demonstrating validity (American Educational Research Association & American Psychological Association 2004). The five patients were not included in the main study.

The SF-12 had previously demonstrated both validity and reliability in the English version (Franks *et al.* 2003, Jenkinson & Layte 1997, Pickard *et al.* 1999, Ware *et al.* 1996) as well as reliability in the Swedish version (Cronbach's α 0.83-0.85) (Stenzelius 2005). Reference values for a Swedish normal population are reported (Sullivan *et al.* 1997). The HI have been tested for reliability in different patient populations in Swedish settings with satisfactory results (Cronbach's α 0.77-0.85) (Forsberg & Björvell 1993, Langius *et al.* 1993, Nordström *et al.* 1992) and have also demonstrated validity (Nordström *et al.* 1992).

Ethical considerations

All studies were carried out in accordance with ethical principles and guidelines (Northern Nurses' Federation 2003). Ethical considerations were applied to voluntary participation, confidentiality and integrity. The studies were approved by the Committee on Research Ethics, Karlstad University, Sweden. Permission to carry out the studies (I-IV) was given by the chief physician at the respective hospital departments and by the medical responsible nurse (MRN) in the respective municipality where the studies were performed. When the chief nurses (IV) or nurses (I-III) had identified appropriate informants, these were given an information letter about the aim and nature of the study, and a request to participate in the study. The informants in study IV (nurses) gave their consent to the chief nurses, and informants in study I-III gave their consent to the nurses, who gave the name and address of the informants to the author, who thereafter contacted the informants. The informants in study III (relatives) were also identified through participating patients in study II. These patients gave their written permission to the researcher to send an invitation letter to the person they considered as their closest relative, together with information and requests to participate in study III. Thus, some patients in study II and some relatives in study III were connected to each other. When including patients in study I no patients in study II were included due to the risk of threatening the persons' integrity if patients and relatives related to each other had been included in two similar interview studies. Hence, the patients and the relatives in study I and III did not have a relation to each other though this delayed the period of inclusion. The informants (I, III, IV) were further informed about the study and voluntary participation in connection with the data collection. They were also told about confidentiality and their opportunity to decline participation at any time without it affecting on their care. All consents were given verbally to the author.

There was a risk of experiencing violation of integrity or that the questions would be perceived as sensitive, but this risk was estimated as low. When designing the questions, account was taken of this issue. When participating in research, there is always a risk of the informants feeling omitted or experiencing questions as sensitive or inconvenient to answer. For the informant, the usefulness of being listened to was estimated as important and the risk of feelings of violation of integrity as limited. Participation in a study could bring positive feelings among the informants knowing they have contributed to research and development in an area of concern for them. In order to further

reduce the risk of complications of participants, interviews were carried out twice (I, III) with about one month in-between. This was done in order to establish a relationship between the interviewer and the informant before venturing into questions that might be regarded as more sensitive and difficult. Four separate lists of codes, one for each study (I-IV), were established by the author as informants were included. All transcribed interviews were given a code number for transcription as well as all questionnaires prior to dispatch. Code lists and the collected data were kept separate and locked up according to regulations at Karlstad University. Only the author had access to the collected data material. In compiling the results after completion of the analysis code numbers will not be included, this means that the results may not be related to specific research subjects.

Findings

The main findings concerning care and treatment of HETF will be presented under the headings, *Patients' perspectives of HETF*, *Relatives' perspectives of HETF* and *Nurses' perspectives of HETF*. The findings from the qualitative studies illuminate patients' (I), relatives' (III) and nurses' (IV) experiences of HETF care and what it means to live with HETF and further what it means to be a close relative to a person dependent on HETF. The findings from the quantitative study (II) describe occurrence of side effects, HRQL, general health and perceptions of the HETF care.

Patients' perspectives of HETF

HETF care and daily life (I, II)

Most patients managed their day-to-day care by themselves with varying degrees of help and support from relatives or from the health-care system (I, II). The findings from the qualitative study (I) were described in one core category: *Management of restrictions and distress in daily life* and the categories: *Ambivalence and worries*, *Reduced capacity*, *Time-consuming and awkward feeding*, *Social isolation* and *Need for knowledge and support*. The patients daily life often were full of restrictions and distress which they struggled to manage, but the severity and extent of problems varied. Reduced capacity due to side effects and impaired physical functions brought on difficulties to carry out daily activities. The time-consuming feeding contributed further to feelings of being restricted and limited time for other activities. The tube feeding could also be experienced as awkward and hassle often occurred concerning practical administration of the tube feeding, e.g. lack of adequate equipment. The hassle was experienced as very distressing and became an additional burden for the patients in their already impaired daily life. When they were hindered in daily activities, the ability and options to socialize with others became limited and experiences of social isolation were found. The patients could experience how friends and acquaintances avoided being together with them due to their inability to eat, which was difficult to manage (I). Also patients in study II expressed being restricted in mobility due to time-consuming feeding, mostly stated by the patients using intermittent feeding (59% n=13) compared to the patients using bolus feeding (28% n=5) (non significant).

Ambivalence about the tube was found (I). The patients were grateful as the tube meant survival and gave relief from the pressure of painful oral eating. Using the tube also meant that the patients could stay at home, but all patients longed to remove the tube, which was seen as a necessary evil. As information about the duration of the HETF treatment seldom was given from the health care, this caused uncertainty and worries among the patients. Worries were also expressed concerning the management of practical problems and the amount of feeding formula they could consume, which often was less than the prescribed amount. Moreover, there was an uncertainty about what was to come. The transition from tube feeding to start eating orally was seen as difficult and frightening. Fears and uncertainty were expressed concerning choking or inability to chew and swallow (I).

How the patients' daily life turned out could be related to their ability to manage the restrictions and distress which were connected with the HETF (I). The patients' strategies varied from being active searching for knowledge, trying to solve problems that arose, to being passive, which meant waiting for things to get better by themselves or waiting for someone else to initiate actions. Their ability to handle the situation seemed to be related to their internal resources but mostly to the amount and quality of information and support they got. When patients received the guidance and information they needed from the health care and felt supported both by the health care personnel and by the relatives, this meant calm and reassured daily life and that they could better manage the restrictions and distress in their daily life (I). However, information and support from the health care were often experienced as vague. When the preparation before discharge was deficient which often happened, this made the patients insecure and worried about how to handle the tube feeding. Contradictory information could also be given from the health care personnel which confused the patients. Sometimes they did not know where to turn to when they needed help. When the patients sought for support from the health-care system they could feel ignored or even marginalised from the personnel which made them very disappointed (I).

The findings in study II are somewhat contradictory to the findings in study I regarding experiences of received information and support. A majority of the patients (II) reported two weeks after discharge (n=40) that they had participated in the decision making concerning HETF care (85%, n=34), and knew entirely how to handle the HETF care (83%, n=33). Most patients

reported that they had received enough information (70%, n=28) and support (75%, n=30) from the health care and that they felt entirely safe with their HETF care (80%, n=32) (II). A few patients reported that they had received information to a low extent (3%, n=1) or no information at all (5%, n=2), and two patients (5%) scored that they had received support only to a low extent. Two thirds of the patients reported that their daily life with HETF functioned very well (68%, n=27) while 32% (n=13) considered that their daily life functioned rather well. Similar proportions were reported two months later.

Side effects related to HETF (I, II)

Side effects related to HETF were commonly reported both at two weeks after discharge and two months thereafter (II) (Figure 1). No statistically significant differences were seen between the two points of data collection.

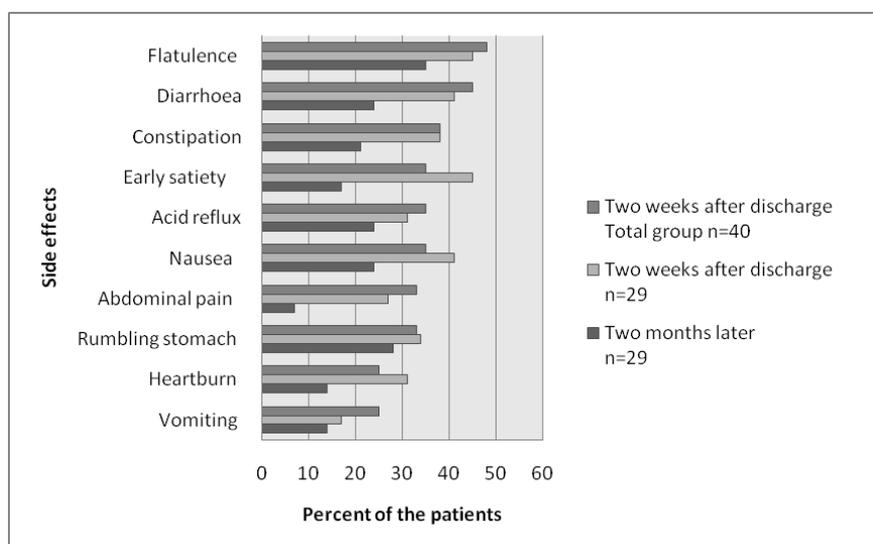


Figure 1. Self-reported side effects related to HETF for the total group (n=40) two weeks after discharge and for those responding at both two weeks after discharge and two months later (n=29).

When comparing route of HETF (PEG and NG) no statistically significant differences were found with regards to side effects (n=40). Regarding feeding methods, two weeks after discharge the patients using intermittent feeding (n=22) more frequently reported diarrhoea (64%, n=14 vs 22%, n=4, p=0.012) and acid reflux (50%, n=11 vs 17%, n=3, p=0.046) compared to the bolus

feeding group. When comparing feeding methods after two months (n=29), there were still differences between the intermittent fed group and the bolus fed group. At this occasion, the intermittent feeding patients (n=16) to a greater extent reported early satiety (36%, n=5 vs 0% p=0.017) and rumbling stomach (29%, n=4 vs 0%; p=0.042) compared with the bolus fed group (II). In the qualitative study (I) the patients described how side effects such as nausea and diarrhoea reduced their capacity to carry out daily activities which was experienced as distressing to various extents depending on the severity of problems. Side effects were experienced as distressing as they were unpleasant and gave rise to discomfort. The severity of side effects and restrictions varied but always affected the daily life (I).

Health-related quality of life and general health (II)

Health-related quality of life (HRQL) and general health for all patients responding two weeks after discharge (n=40) and for those who responded both two weeks after discharge and two months thereafter (n=29) are presented in Figure 2. HRQL and general health did not differ significantly between the two points of time (n=29).

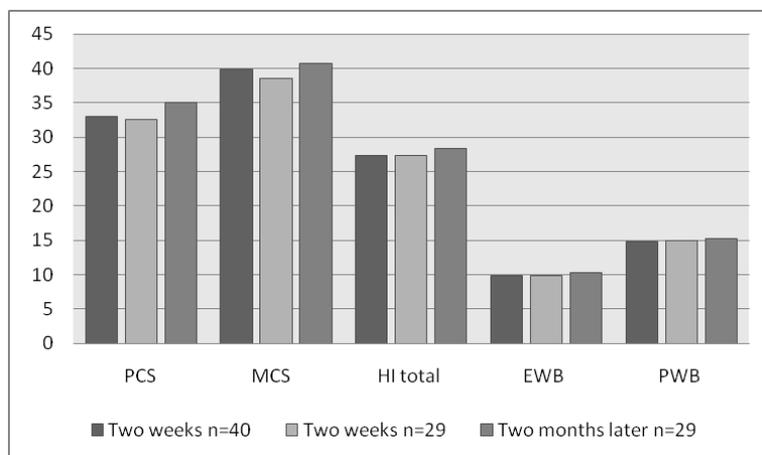


Figure 2. Mean values for the Short Form 12 (PCS=Physical Component Summary, MCS=Mental Component Summary) and the Health Index (HI) (EWB=Emotional Well-Being, PWB=Physical Well-Being) for the HETF patients two weeks after discharge and two months later.

a) one questionnaire missing for total HI, EWB and PWB i.e. n=28

As regards route of HETF (i.e. PEG and NG) no statistically significant differences were seen in relation to HRQL and HI. When comparing the groups of patients using intermittent feeding and bolus feeding, the intermittent group reported significantly lower scores on physical HRQL (PCS 30.1 vs 34.7; $p=0.026$) and emotional health (EWB 9.0 vs 10.6; $p=0.022$) two weeks after discharge.

Relatives' perspectives of HETF (III)

In the relatives' perspectives of HETF, the core category '*Struggling in an inescapable life situation*' was the central phenomenon, which eight categories were related to, and on which the conceptual model was built. Two processes '*Experiences and interpretations of the new life situation*' and '*Consequences and actions in the new life situation*' were discovered and built up the model. These processes contain the categories '*Loss of togetherness and pleasure*', '*Loneliness in a new role*', '*Worrying about the future*', '*Participation in the care*', '*Taking responsibility*', '*Adjusting own life to tube feeding*', '*Striving for closeness*', and '*Enduring the new life situation*'. The categories describe how the close relatives were struggling to understand and manage the new life situation which had occurred due to the fact that the patient could not eat normally and was dependent on HETF, and their new situation was experienced as inescapable. In the beginning, the situation was experienced as chaotic, but as time went by, things settled down and own routines were established. Although a positive attitude towards the HETF treatment by means of survival for the patient, this was overshadowed by the burdens the relatives experienced. Being a relative to a person dependent of HETF meant that their own life had involuntarily become ruled by HETF. Eating alone and participating in social events alone without the patient brought on experienced loss of togetherness and pleasure. Feelings of loneliness were common and there were also worries about how the future would turn out.

The organisation and structure of the health-care system was unclear to the relatives and they experienced difficulties in receiving proper help when problems occurred. As guidance, including information, and support from the health care often was experienced as vague, the relatives chose to participate in the care and took on a great responsibility. The unwillingness to abandon the patient meant that the situation became inescapable and the relatives felt forced to adjust their own daily life to the tube feeding. They struggled to get the daily

life to work, both for the patient and for themselves. In order to manage their changed daily life several strategies were used. To hope for the patient to get better and to wait and put their trust in the process of time were strategies used, and when feeling lonely they strived to reach affinity with the patient. The amount and quality of support from the professional home care, the hospital care and other family members as well as openness in the relationship between the patients and their relatives, was shown to be of importance for how the relatives' daily life turned out and for how they managed.

Nurses' perspectives of HETF (IV)

In study IV, nurses working at hospital and in community care described their perspectives of HETF care. The findings were captured in one main category: '*Cooperation*' which had a hierarchical relationship to three description categories: '*Nurses' knowledge*', '*Nurses' view of responsibility*', and '*Nurses' professional awareness and commitment*'. The nurses considered that cooperation in the care trajectory had an imperative impact on how well the HETF care was carried out. The cooperation was described as both satisfying and unsatisfying and concerned mainly the nurses working at hospital and in community care, but sometimes also other health care personnel. The nurses' knowledge, responsibility and professional awareness and commitment had an impact on how the cooperation turned out, and ranged from having knowledge to lacking knowledge, from explicitness to vagueness in responsibility, and from patient-related to task-related care.

Satisfying cooperation was found when the discharge planning process was well-functioning and initiated at an early stage, giving nurses in the community care options to plan for the care as well as for follow-up visits. Relevant information was transferred in the care trajectory and there was a mutual understanding with the other caregivers. The nurses in both settings had relevant knowledge about discharge planning procedures and care of tube feeding, and they were up-to-date with new devices and equipment. They knew their area of responsibility, took on the expected responsibility and worked according to a patient-related perspective.

When the cooperation was described as unsatisfying deficiencies in the information transfer and the communication between the nurses occurred. Neither setting of nurses was fully aware of the limitations, pressures and needs

of the other nurses. Nurses at hospitals conceived the discharge planning and given information as adequate, while the community nurses conceived the opposite. The community nurses lacked time for internal planning and appropriate information and sought for written information about the tube feeding and the current devices. Furthermore, care of HETF patients could be affected negatively when the nurses lacked relevant knowledge, when they were not aware of their area of responsibility and had a more task-related perspective of the care.

Comprehensive understanding of the findings

When analysing the four studies in the thesis as a whole, the understanding of the findings was deepened. The four studies showed that the HETF treatment had a great impact on daily life for both patients (I, II) and their relatives (III) as HETF treatment and care implied many practical, emotional and social problems in daily life. Experiences of restrictions, *distress and losses* were found both among patients and relatives, which they strived to manage. The patients experienced restrictions and distress due to side effects, impaired physical function, and time-consuming and awkward tube feeding, and experienced also social isolation (I, II). All patients longed for removal of the tube even though start eating was seen as difficult and frightening (I). Furthermore, the patients' HRQL and general health were negatively affected (II). Study I and II had in common that daily life seemed easier for patients using bolus feeding. These patients experienced fewer side effects (II), less impaired HRQL and general health (II) and experiences of restrictions were less pronounced (I, II). Relatives to patients with HETF experienced loneliness and worrying to a great extent. Demands and vulnerability were embedded in the role of being a relative, and they often lacked support both from other family members and the health care system in their struggling to manage their new daily life (III). How the patients' and relatives' could manage restrictions and distress varied and seemed partly to be related to inner resources and personality (I, III). However, mostly the *management* was related to the amount and quality of *guidance and support* they received. Lack of sufficient guidance and support from the health care system caused worries, insecurity and distress. When adequate guidance and support were given, both patients and relatives achieved a *balance in daily life* and felt calm and reassured (I, III). *Cooperation* in the care trajectory between different parties involved seemed to be decisive for how well the care was running (IV). Cooperation included discharge planning, mutual understanding and information transfer between nurses and other professionals in the care trajectory. Nurses' knowledge about tube feeding and discharge planning procedures, their commitment to the patients' care, as well as clarity regarding responsibility of HETF care were factors of crucial importance of how the cooperation worked, and the quality of the HETF care (IV).

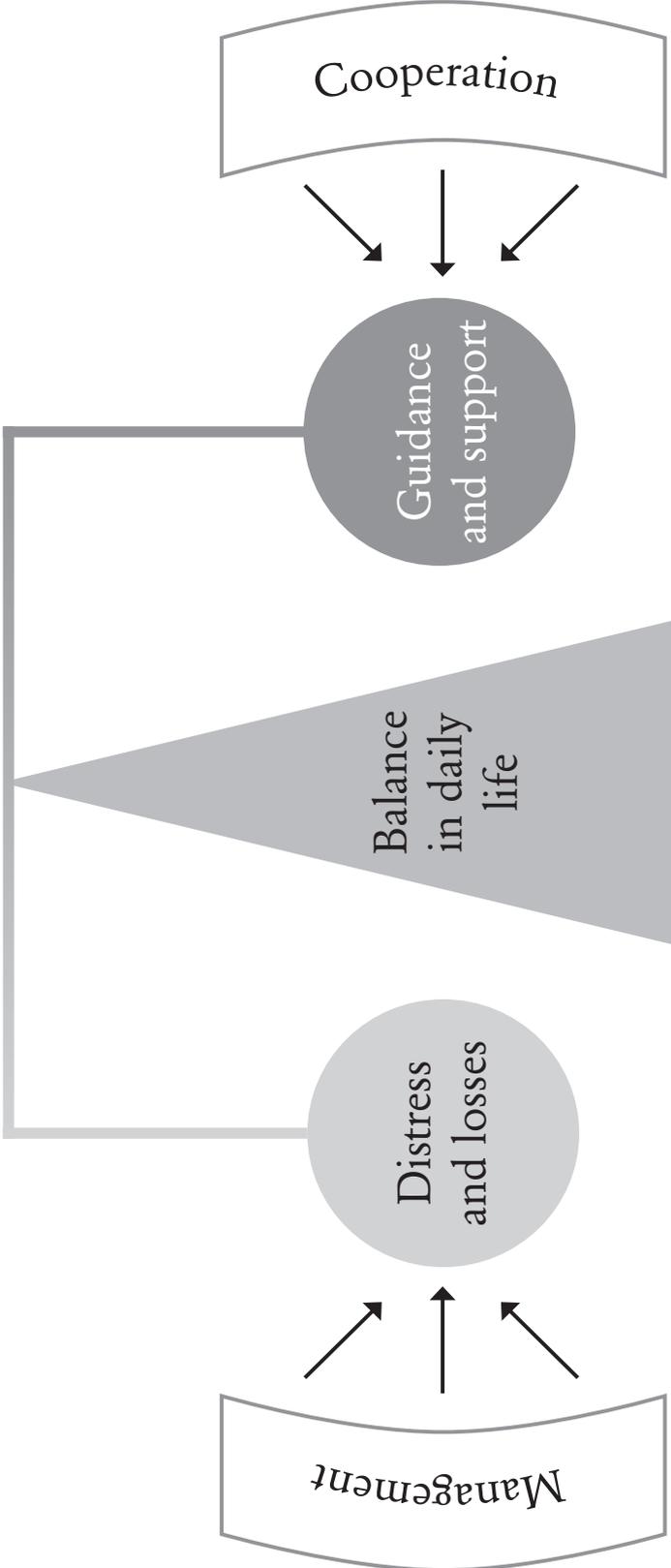


Figure 3. Comprehensive understanding of the findings.

Discussion

The four studies showed that the HETF care had an impact on patients' and relatives' daily life, which was often filled with restrictions and difficulties. Many patients suffered from side-effects and reported their HRQL and health as low, and the relatives had faced a new role of being informal caregivers, in which they often took on a great responsibility. How their daily life turned out seemed to be related to patients' and relatives' internal resources and personality and the guidance and support provided in the care trajectory by health care personnel and family. The support from the health care sector was related to the organisation of HETF care, in which nurses' knowledge, view of responsibility and commitment were found to play a crucial role. Received information, guidance and support, which were described as insufficient by many patients in the interview study, was mainly scored as satisfactory in the quantitative study.

The patients' perspectives

The health care system has undergone considerable changes during recent decades due to financial reductions and the developments of medical techniques and treatments (Bevan 2010, Taylor 2005, Williamson & Talbert 2008) which entail shorter periods of in-patient care. Positive effects from this have been highlighted (Taylor 2005) but structured evaluations concerning the quality of home care for different groups of patients are still lacking. The findings in this thesis have provided new knowledge about how HETF patients experience their care and daily life. An important finding was the varying degree of preparation of the patients before discharge, which was shown to have a great impact on how the care worked and how the daily life turned out for them (I). The few studies concerning the transition of HETF patients in the care trajectory support these findings (Brotherton *et al.* 2006, L'Estrange 1997, Liley & Manthorpe 2003) in which insufficient preparation and support before discharge were found. According to Hildingh *et al.* (2007) is the period after discharge a vulnerable period where difficulties in problem solving and feelings of helplessness and powerlessness are common. The patients (I) were found to have a great need of help and support with regards to HETF. This need was however often unidentified by the health care personnel. The lacking identification of patients' needs might be related to the fact that many of the patients (I) had cancer and had retained the ability to conduct activities in daily

life (ADL) on their own. The discharge nurses might have included the ability to take care of HETF in ordinary daily self-care. As the findings (I) showed that many HETF patients indeed are in need of support at home and that their needs are unidentified, this illustrates the need for improvement of nurses' assessment of patients' strengths and weaknesses before discharge from hospital (Carnevali 1983). This must be the starting point for professional support in home care. The findings also highlight the need for great vigilance among nurses, who should be responsible over time for assessing the patients' needs at home (I).

The patients in this thesis experienced the care of HETF as difficult and inconvenient, and their daily life could be restricted by lack of energy and discomfort both due to the illness, side-effects of the treatment and the time-consuming feeding (I, II). These problems are in line with previous studies describing HETF patients' problems (Brotherton *et al.* 2006, Jordan & Philpin 2006, Liley & Manthorpe 2003). Similar findings are also found regarding other groups of patients dependent on medical technology at home (Fex *et al.* 2009, Sandelowski 1993, Winkler *et al.* 2006). The patients (I) expressed ambivalence concerning the tube, as it meant survival and made it possible for them to stay at home, but was also seen as inconvenient and a necessary evil. They longed for the tube feeding treatment to end, so they could return to what they called 'a normal life'. An important finding was the distress the patients also experienced during the transitional phase from getting nourishment by tube feeding formula to starting to eat orally again. Fears of choking or inability to chew and swallow were expressed, and this finding has not been found elsewhere. As such fears could be very threatening and may delay the return to oral eating, our finding emphasise the need for more attention to these patients during the transitional phase. This may be especially important since several HETF patients are cancer patients who are expected to start eating orally again. The patients also described how their social life was affected due to reduced capacity, eating disabilities and use of tube feeding (I), which also have been reported previously (Brotherton *et al.* 2006, Roberge *et al.* 2000). Experiences of being kept out of social life, being misunderstood, ignored or not taken seriously (I) highlight the necessity of also focusing on the patients' socio-psychological needs in the assessment over time. Accordingly, our findings about patients' experiences of daily life and HETF (I) were well in accordance with other studies reporting that being dependent on medical technology at home is accompanied with many negative experiences, but may also have

positive dimensions (Winkler *et al.* 2006). This states the need for care and support based on the patients' individual need.

This finding revealed somewhat contradictory findings regarding the patients' satisfaction with their daily life and the information and support they received from health care. In study I (interview study) a clear pattern of distress and problems in patients' daily life was found as well as a great need of support, which often was lacking. In study II (quantitative study) on the contrary, a majority of the patients reported that their daily life was well functioning, they knew how to handle their tube feeding, that they felt entirely safe and that the received information and support was sufficient. However, these findings also displayed that a number of patients actually had problems in their daily life with HETF, and had not received enough information and support. Notable is also that the majority of the patients in study II reported that they felt restricted to some extent, which may negatively impact on the daily life. These differences might be related to variations among individuals concerning their needs, preferences, wishes and expectations. It is well-known that patients answering questionnaires about satisfaction of care often score high (Jenkinson *et al.* 2002). The variations of findings (I, II) underline the need for more studies in this area.

Another interesting finding was that the group of patients using intermittent feeding reported significantly lower physical HRQL and emotional health than the patients using bolus feeding, and the intermittent fed group also more frequently reported diarrhoea and acid reflux (II). Studies evaluating and comparing feeding methods are still scarce, but the few studies found have reported contradictory results concerning advantages and disadvantages, focusing on mainly one side effect at a time, e.g. diarrhoea (Ciocon *et al.* 1992, Lee *et al.* 2010, Shang *et al.* 2003, Shun Wah Lee & Auyeung 2003). The use of bolus feeding has been questioned in recent years related to risk of complications (Bowling *et al.* 2008). Our findings (I, II) support use of bolus feeding in the home environment for patients with preserved cognitive function, as this method may reduce the restricted time and improve the opportunity to live as normal as possible. This also is supported by findings in a review by Raykher *et al.* (2007). However, in the debate about bolus feeding it is important to stress the imperative need to identify suitable patients without medical obstacles for bolus feeding to avoid complications. Based on the

findings in this thesis it is important to argue for initiation of bolus feeding in the discharge planning process.

A high frequency of side effects related to HETF was also reported over time. Even if a slight decrease was seen over time, the problems remained for most patients (II). Roberge *et al.* (2000) reported similar findings about side effects one to four weeks after discharge from hospital, such as diarrhoea, constipation and nausea, which illuminates that side effects may appear also after a while at home. It is therefore important to repeatedly assess patients receiving HETF for a longer period of time after discharge so side effects or other complications can be identified.

The patients reported low physical as well as mental HRQL two weeks after discharge as well as two months thereafter (II). These findings are supported by the few studies found regarding HRQL for HETF patients (Jordan & Philpin 2006, Malone 2002, Roberge *et al.* 2000, Schneider *et al.* 2000). Also other groups of patients with long-term illnesses (Franzén 2007, Mystakidou *et al.* 2009, Naughton *et al.* 2002, Pickard *et al.* 1999) have reported low HRQL, which might be a sign of that long-term care *per se* affects HRQL. The hardships the patients expressed (I, II), were related to the HETF treatment but one should bear in mind that all patients also suffered from a severe disease. It may be difficult to distinguish the experiences of being treated with HETF from the experience of having a serious disease. The literature reveals different standpoints in this issue. Forsberg (1996) and Wengström *et al.* (1999) have stated in their studies concerning cancer patients that the patients experiences of living might be affected by their serious disease. Liley and Manthorpe (2003) on the other hand have stated that it was possible for the patients in their study to distinguish the experiences of tube feeding from the experiences of having a serious illness. Hence, it may be difficult when measuring health and HRQL to know exactly what the respondents have responded on (McMahon *et al.* 2005), as quality of life means different things to different persons (McMahon *et al.* 2005, Testa & Simonson 1996). However, patients' experiences in this thesis imply a need for preparation before discharge as well as need for support in order to increase their well-being, no matter of the cause for distress.

The relatives' perspectives

Also the relatives experienced restrictions in their daily life due to the HETF treatment and they struggled to manage the new situation. The relatives (III) experienced their situation as inescapable since they did not want to abandon the patient but being present. They participated in the daily care to various extents and felt forced to put on a great responsibility which often became burdensome and overwhelming. Nevertheless, feeling committed to the patient increased relatives' sense of well-being and the ability to manage the situation (III), which is in line with the findings of Perreault *et al.* (2004). Similar findings have also been described in previous research, reporting that treatment with artificial nutrition could bring social and psychological consequences for the relatives (Orrevall *et al.* 2005, Stern 2006). It is well known that a heavy burden may fall on relatives in home care to patients with various diagnoses (Kellett & Mannion 1999, Samuelsson *et al.* 2001, Wennman-Larsen & Tishelman 2002). Hence, our findings further stress the need for support from the health care also to the relatives. Most relatives stated that they lacked information both in connection to discharge and thereafter which added to the already troublesome situation (III). This is congruent with previous studies (Carlander *et al.* 2005, Funk *et al.* 2009, Stajduhar 2003, Stenberg *et al.* 2009) which concluded that relatives of cancer patients in home care participated in the care on own initiative and put on major responsibilities, although they lacked information and support from the health care. Information is normally given to the patient, who can choose if they want to pass over information to their relatives or not (Östlinder 2004). This routine which is aimed at preserving the patients' integrity might however be a threat to the quality of care. The relatives, who participate in the day-to-day care at home when the patients for some reason are lacking energy or capacity to carry out the care by them self, should be allowed to get the same information about HETF as the patient. According to Palmore Gilliland and Bush (2001), relatives are in great need of information and support to be able to function in their role as informal caregivers. The relatives seem to often be forgotten and quite unseen from the health care system which highlights the importance of improvements in this area. Relatives need to be actively involved in the discharge planning process in order to gain relevant information and guidance before the patients' transition to the home. Further, support is also needed in the role of being a informal care giver at home, which is supported by previous studies (Gaugler *et al.* 2009, Silver & Wellman 2002, Silver *et al.* 2004, Stajduhar 2003).

Guidance and support

Accordingly, the findings in this thesis illuminated unmet needs of guidance and support among the HETF patients and the relatives (I, III), which indicates that there are room for improvements in this area. Guidance includes information and practical training, and support includes follow-ups over time. Thus, guidance and support are of utmost importance and should be provided continuously before discharge from hospital and throughout the period of HETF care in the patients' home, to facilitate care of HETF and the daily life. An ongoing dialogue between the patients and the health care personnel, preferable the nurses, is important to identify possible difficulties or problems in time, in order to prescribe and carry out interventions needed (Carlson & Bultz 2003, Perreault *et al.* 2004, Richardson 2004). There is also a need for follow-up routines regarding appropriate feeding, identification and prevention of problems, and monitoring the nutritional status, which also has been pointed out by McNamara *et al.* (2000).

There are several guidelines and legislations stating that elderly patients with multiple diseases are justified for professional home care (From 2007). Our findings have highlighted the need for such guidelines and legislations also for HETF patients, even if they not have multiple diseases and can run their ADL by themselves (I, II). Adequate guidance about tube feeding is needed in the discharge process, including verbal and written information given repeatedly based on the patient's ability to understand and retain information. Furthermore, patients need guidance about adequate interventions related to the tube feeding care to decrease side effects, prevent eventual problems and to increase their well-being.

Our findings also illuminated the necessity to provide emotional support to patients and relatives in order to help them endure and manage their changed daily life (I, III), a task which is included in nurses' professional role (Skilbeck & Payne 2003). In order to be successful in providing emotional support, a caring relation must be established which requires a continuous contact between the parties involved (Iranmanesh *et al.* 2009, Larsson *et al.* 2007, McMahon *et al.* 2005). Such continuity seemed to be lacking in our studies (I, III). Continuous contact via personal visits and/or telephone calls have previously been reported to decrease the burdensome experiences in home care (Strawn *et al.* 1998), result in fewer and briefer readmissions and shorter duration of tube feeding (Scott *et al.* 2005). Hence, it should be time for improvement of

continuity in home care in general and HETF care in particular. In order to meet patients' and relatives' needs, health care personnel, nurse managers and policy-makers must increase their awareness of areas in HETF-care that should be improved (Algera *et al.* 2004). Our findings provide imperative information about such areas.

Based on the findings in this thesis, it is important to stress that nurses in HETF care must extend their knowledge about the various forms of support. According to Palmore Gilliland and Bush (2001) the area of support is multiple and includes physical and psychological support, instructional support, evaluation support and emotional support. This means that support to HETF-patients and their relatives should include help with day-to-day care if needed, ensure use of appropriate equipment, teaching, counseling and advice, feedback, and help with coping of losses, distress and worries. Hence, the skills of all nurses should include all these dimensions (McIntosh 1996, Skilbeck & Payne 2003, Spitzer *et al.* 1995).

The nurses in our findings were found to be uncertain about the management of tube feeding and experienced limited knowledge in the area (IV). It is important that nurses as well as other health care personnel have appropriate and sufficient knowledge concerning discharge planning and tube feeding and are up to date with new materials and methods in the area, in order to provide guidance and support with a high quality to patients and relatives (Arvanitakis *et al.* 2009, Goff 1998, McIntosh 1996, Tilus 2002, Winkler *et al.* 2006).

Organisation of HETF care

This thesis highlighted that the amount and quality of guidance and support before and after discharge could be a matter related to organisational aspects and cooperation in the care trajectory. Cooperation in the care trajectory was described by the nurses to impact on how well the HETF care was carried out (IV). Deficiencies in the cooperation was expressed as it could negatively impact on the care (I, III, IV) which is in accordance with previous studies (Propp *et al.* 2010, Watts & Gardner 2005), reporting that cooperation based on communication regarding the patients' care was necessary in order to provide quality in the care. Furthermore, our findings showed that knowledge about tube feeding and discharge planning, clarity concerning the distribution of responsibility and the nurses' commitment to the care were important factors,

and deficiencies were found regarding all these factors (IV). These findings are in accordance to Watts and Gardener (2005) who found that nurses considered that they had total control of the discharge planning, but lacked knowledge about what discharge planning meant and their own responsibility in this process. Both our studies (I, III) and others (Wilson *et al.* 2002) have emphasised that deficiencies in cooperation and communicating may lead to a risk of patients falling between the two health care providers, resulting in unnecessary suffering and difficulties in their daily life. This put the light on the urgent need for development of collaboration in the care trajectory to reach quality of care.

Preparation before discharge was shown in this thesis to be crucial for the daily life of patients and relatives (I, III). The discharge planning process requires multidisciplinary cooperation (Anthony & Hudson-Barr 1998) where nurses play a prominent role, as they have a holistic perspective of care and are privy to the patients' various abilities and needs (Lowenstein & Hoff 1994, Watts & Gardner 2005). The discharge planning requires special skills in conducting an assessment of the patients, not only with respect to the patients' physical status and level of care required, but also to the patients' and the relatives' ability, readiness and motivation to be involved in the care (McGinley *et al.* 1996, Watts & Gardner 2005). Nurses in the health care system nowadays work in an environment with a lot of stress and pressure. According to Kihlgren, a heavy workload and lack of time make great demands of nurses' competence and their responsibility can often be experienced as a burden (Kihlgren *et al.* 2003). Although this, it is of utmost importance that nurses carry out appropriate interventions according to their responsibilities, and are committed to the patients' care (I).

The organisation of the health care sector may vary, and there are several differences between and within countries, not least in Sweden. What is important is not who and what organisation which support the patients, but that the guidance and support really will be provided and meet patients' and relatives' needs. District nurses working in community home care are suitably placed to support these patients, as they can visit them and relatives at home (Gustafsson 2009, Socialstyrelsen 2008). They also have a great opportunity to establish a trustful relationship with the patient and relatives (Berterö 2002, Luker *et al.* 2000). Guidance and support can also be provided by means of nurse-led clinics, a form of supportive nursing care inspired from primary

nursing (Larsson *et al.* 2007). Nurse-led clinics as a complement to regular care have been highlighted during the last decade, and are most often organised from the hospital setting, where nurses in the departments maintain their contact established in the hospital with the patients even after discharge (Larson *et al.* 2005, Larsson *et al.* 2007, Lewis *et al.* 2009). Nurse-led follow-ups, by telephone or personal visits to the clinic, have been shown to have a positive impact on patients' emotional well-being (Larsson *et al.* 2007, Moore *et al.* 2002). However, continuous contacts with patients and relatives, regardless of what care giver, should evaluate the tube feeding care and provide information, guidance, practical and emotional support, with the intention to increase the patients' and relatives' well-being and feelings of security and safeness.

Methodological considerations

Triangulation by means of data triangulation and method triangulation was used in order to describe and explore the phenomenon HETF from different perspectives. The combination of questionnaires and interviews with patients, relatives and nurses was considered to strengthen the findings (Polit & Beck 2008).

The qualitative studies

Trustworthiness can be described in various ways (Beck 1993, Lincoln & Guba 1985, Sandelowski 1986) and refers to the methodological soundness and adequacy. When doing qualitative research, the researcher must continuously reflect upon methodological aspects (Holloway & Wheeler 2002). It is important to be trustworthy and reliable throughout the research process and when writing the methodological descriptions, so the findings can be believable for others (Holloway 2005). One important aspect when doing qualitative studies is the *sample*. Taylor and Bogdan (1998) argue that the sample size should be determined at the end of the study because only then does the researcher know how many participants are needed in order to find out what was attempted. This argumentation is in line with the principles of Grounded Theory (Glaser & Strauss 1967, Strauss & Corbin 1998) where it is stated that in theoretical sampling the actual number of informants is less important. In study I and III a purposive sampling was used initially, and as the data collection and analysis proceeded, theoretical sampling was used. The sample sizes in this thesis might be considered as small, which can be seen as a weak

point. Repstad (2007) have stated that deep-going analysis of a few interviews brings better quality to the studies than doing analysis on the surface of many interviews. In two of our studies (I, III) two interviews were performed with each informant with the intention of getting as rich data as possible. Twenty two interviews were carried out with eleven patients (I) and 24 interviews with 12 relative (III), and saturation in the categories were considered to be reached after eight (I) and ten (III) informants respectively. However, further inclusion of informants might have impacted on the findings.

As variations in experiences were sought for, which strengthen the dependability, informants were chosen on basis of variations in study IV. In study I and III, this principle also guided the selection of informants in the purposive phase. There were difficulties to obtain an optimal variation of informants which partly may be related to the patients' serious illnesses. Very few patients or relatives of patients with neurological illness e.g. stroke and amyotrophic lateral sclerosis (ALS) were included, compared to other studies with HETF patients (Brotherton *et al.* 2006, Hebuterne *et al.* 2003, Paccagnella *et al.* 2008, Schneider *et al.* 2001). Departments of neurology were part of the departments which included patients and five patients with neurologic diseases were asked for participation. Out of these, three had ALS and two had had a stroke and all five declined to participate due to inability to speak and impaired general condition. These patients may have contributed with valuable information especially related to these groups of patients. For practical and ethical reasons, e.g. to maintain confidentiality, identification of the informants was carried out by nurses at the different units serving as gate keepers. This was the preferable way to handle the identification but may have affected the choice of informants. The use of gate keepers to protect the informants and to support the informants' confidentiality, but give the persons who serve as gate keepers' control of which informants to include in the study (Iphofen 2005). This meant that identification of informants (I, III, IV) could have turned out differently if other nurses had served as gatekeepers, ending up with a different sample which could have impacted of the findings.

Data collection was carried out by means of qualitative interviews (I, III, IV). To further ensure the credibility, two test interviews were performed, which confirmed that the themes in the interview guide were relevant (IV). In order to strive for truthful findings the interviews were carried out in dialogue where the informants were encouraged to talk freely. The author used open-ended

questions followed by probing questions to deepen the informants' conceptions and thoughts. The interview situation is a social interaction where peoples' statements may vary depending on who they are talking to and how this person is perceived (Taylor & Bogdan 1998) which may be a weak point in qualitative studies, also in this thesis (I, III, IV). This may impact on the findings of the study and its credibility, whether the findings can be understood as truthful or not (Hamberg *et al.* 1994). To minimize this risk, several informants were included, and their experiences provided congruent data which strengthens the findings. Interviewing the informants twice (I, III) also contributed to the credibility. In the first interview, the informant and the researcher got acquainted with each other and could talk about issues related to the aim of the study. In the second interview contact between the two had already been established, and the interview climate was more open and relaxed, which provided possibilities to widen and deepen the interview.

The second interview aimed to deepen the understanding and clarify vagueness, and also give the opportunity to validate data from the first interview (Sandelowski 1986). In study IV only one interview with each informant was carried out, which must be seen as a weakness. As these informants were in the same profession as the interviewer (registered nurses) and shared experiences from the topic under study, it was however possible to create a safe and trustful atmosphere in the interviews and the data obtained was rich. However, use of a second interview also in study IV could of course have further developed the findings. Digital recorder was used in all interviews (I, III, IV) and field notes were written about the impressions immediately after the interviews (I, III) which contributed to dependability.

To further strengthen the credibility, the researchers discussed their pre-understanding both before the data collection and in the *data analysis* process (I, III, IV). The author's belief is that the pre-understanding is impossible to completely put aside but is integrated in the persons' experiences of the past, beliefs, thoughts and culture. However, to be able to discover something new and understand the collected data it is necessary to be aware of own pre-understanding and to be critical in the reflections upon the findings throughout the whole process. This was strived for by the author. In addition, memos were written continuously about the author's thoughts, ideas and reflections (I, III). All the researchers in the research group cooperated continuously during the data analysis and discussed statements from the transcripts, pools of meaning

(IV) and codes (I, III) and the emerging categories (I, III, IV) which also contributes to dependability. In presentation of the findings, quotes were used to illustrate and validate the findings which also enhanced the credibility. As transferability refers to the possibility of application of the findings to other groups of patients, it is necessary to describe the context and the characteristics of the informants, the context of the study, the interviews and process of data analysis as clearly as possible. All this issues were taken in consideration during the research process. All known characteristics of the informants were also presented for achieve clearness. The findings were presented as rich as possible with quotations to further enhance transferability.

The quantitative study

Identification of patients to the study *sample* was conducted with assistance from nurses serving as gate keepers, as described previously. Thirty three patients were estimated as not appropriate to ask for participation due to weakness or impaired general condition. There might be patients suitable for participation who never was asked as well. Out of 62 HETF patients who had agreed to participate in the quantitative study (II), 40 patients (65%) recruited from 28 units at ten hospitals in central Sweden responded to the questionnaires. More than half of the patients suffered from malignant disease i.e. head and neck cancer. This means that this group of patients may be fragile and may have impaired general condition, which also was mirrored by means of the response rate. As low response rates may threaten the validity (Polit & Beck 2008), a large number of units and hospitals were included to recruit patients. Further to increase the response rate, stamped addressed return envelopes were used and reminders were sent twice. For the 22 non-responding patients information about the patients' status was received from the hospital units. The reason for not responding was that most of these patients were shown to have impaired general condition and some patients had died. In total 29 patients also responded at the second occasion for measurement. Too impaired general condition was also at this point of data collection the major reason for eleven the non-responding patients. A majority of the respondents had head and neck cancer, as mentioned above. These patients are known to have a reduced five-year survival rate, varying between 30 % for patients diagnosed with large tumors with lymph node metastasis and up to 70 to 90 % for patients with small tumors (Hakulinen *et al.* 2010, Tromp 2005). One might judge the number of respondents (n=40) to be limited. However, taken the seriousness of

the disease and the patients' general condition is into consideration, the number of patients is considered to be acceptable. Other reported studies in the area have similar or less number of respondents (Crosby & Duerksen 2007, Elia & Stratton 2008, L'Estrange 1997, Schneider *et al.* 2000). Strength of this study is that patients were recruited from a great number of units from a large geographic area of Sweden and that the patients have responded to questionnaires at two occasions with two months in between. As longitudinal studies including patients receiving HETF are scarce (Roberge *et al.* 2000) this is an important area for future studies.

The questions in the study specific questionnaire used in the *data collection* were developed from scientific literature in the area, previous research and professional experience in advanced nursing care. A pilot study was performed to test if the questionnaire was constructed to measure what was intended. Nurse lecturers with experience of tube feeding and home care and patients with a history of HETF commented on the questionnaire and minor changes were made. The questions were considered to show validity regarding test content (American Educational Research Association & American Psychological Association 2004). The two instruments SF-12 and HI were used for measuring HRQL and general health. The SF-12 has been tested in several studies (Franks *et al.* 2003, Jenkinson & Layte 1997, Pickard *et al.* 1999, Ware *et al.* 1996) and demonstrated good validity and reliability, also the Swedish version (Sullivan *et al.* 1997). The Swedish version of HI has been tested for validity (Nordström *et al.* 1992) and reliability in studies of surgical patients and healthy adult individuals (Forsberg & Björvell 1993, Nordström *et al.* 1992) with satisfactory results. The combination of a quantitative and a qualitative study (I, II) was intended to increase the validity, but the findings were partly contradictory. There might be several causes of this. The used questions might not be sensitive or clear enough, or the patients had a tendency of being positive to health care when scoring. This have been found previously (Jenkinson *et al.* 2002). Another explanation might be that several questions in the study specific questionnaire asked the patient to score their experiences 'during the last week' while the qualitative interviews highlighted the total period of time for HETF treatment. It can also be questioned whether the two samples differed with healthier patients with fewer restrictions responding in study II, and patients with more impaired general condition in study I. This demonstrates the need for further studies in this area.

Conclusions

This thesis has provided knowledge which is important for nurses, nurse managers, and others in the health care team, who may be involved in patients with HETF and their families in the care trajectory. The following conclusions can be drawn:

- HETF treatment had a great negative impact on daily life for many patients (I) and relatives (III) implying practical, emotional and social problems. Living with or close to a person treated with HETF meant restrictions, distress and losses, which patients and relatives strived to manage (I, III). Impaired physical function (I, II), time-consuming eating (I, II) and awkward feeding (I), and feelings of social isolation (I) hindered the patients' daily life.
- The patients' HRQL and general health were negatively affected by HETF, yet most of them reported that their daily life functioned rather or very well (II).
- Bolus feeding was connected with fewer side effects (II), less impaired HRQL and general health (II), and experiences of restrictions were less pronounced (I, II) than among patients using intermittent feeding.
- The relatives' lives had involuntarily become ruled by HETF and demands and loneliness were embedded in the role of being an informal caregiver. They often took on a heavy responsibility for the HETF care, despite lacking information (III).
- How the patients' and relatives' could manage restrictions and distress varied and seemed partly to be related to inner resources and personality but mostly to the amount and quality of guidance and support they received (I, III).

- A prominent lack of support was found among patients (I) and relatives (III) regarding practical and emotional problems. Contradictive findings were reported in study II, where a majority of the patients felt safe and satisfied with received information and support.
- Cooperation in the care trajectory between different parties involved seemed to be decisive for how well the care was running (IV). Cooperation meant information transfer and a mutual understanding about the other care giver between nurses and other professionals in the care trajectory (IV).
- Nurses' knowledge about tube feeding and discharge planning procedures, their commitment to the patients' care, as well as clarity regarding responsibility of HETF care were described as factors of crucial importance of how the cooperation worked, and the quality of the HETF care (IV).
- There is a great need of improvements regarding the cooperation in the care trajectory, including planning in the discharge process, nurses' level of knowledge and clarification of the responsibility for HETF care. The findings also demonstrated the necessity of improvements regarding information, guidance and support to patients and relatives throughout the care trajectory.

Further research

The findings in the thesis provide important knowledge about HETF care. However, several areas are still vague and unknown, which are important to further study.

Quantitative studies over time are lacking. Therefore it is important to explore and describe the group of patients over time to gain knowledge about the patients' situation for a longer period than ten weeks, as in our study. A special attention should be paid to side effects, HRQL and perceived health and factors of importance for patients' appraisal of them. Evidence concerning feeding methods and use of bolus feeding is needed, preferably by means of randomised controlled studies.

The qualitative and quantitative study provided somewhat contradictory results concerning the patients' knowledge about care and administration of tube feeding, received support, and daily life. This highlights the importance of more qualitative studies to capture the patients experiences of received and needed support and their daily life. As a complement to this quantitative studies with several questions regarding functioning in daily life and received guidance and support could be useful, but with questions put in other ways, clearer and more comprehensive, and from different views.

Both patients and relatives expressed a difficult situation. Intervention studies with a programme for support to the patients and relatives would be of great interest. Such an intervention could include nurses' responsibility and skills, and continuity in the organisation and care.

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Appendix 1

Questions in the questionnaire

- 1) Age
- 2) Gender
- 3) Marital status
- 4) Housing
- 5) Which disease and/or disorder is the cause that you need tube feeding at home?
- 6) At which clinic/department/unit did your tube feeding start?
- 7) By which route have you received your tube feeding the last three days?
- 8) What kind of feeding formula have you had the last few days?
- 9) How many bags of feeding formula do you consume per day?
- 10) Who handle most of your practical tube feeding care at home?
- 11) Which tube feeding method did you use the last three days?
- 12) What advantages do you find that your present tube feeding method has?
- 13) What disadvantages do you find that your present tube feeding method has?
- 14) Have you tried some other feeding method previously?
- 15) In that case, for what reason were the feeding method changed?
- 16) What advantages do you find that your previous tube feeding method had?
- 17) What disadvantages do you find that your previous tube feeding method had?
- 18) Who decided which feeding method you would have when you went home from the hospital?
- 19) Did you feel a part in the decision-making with regards to feeding method?
- 20) Do you know exactly why that method was chosen?
- 21) Did you consider that account was taken of your daily life and your situation in the choice of feeding method?
- 22) Do you have any side effects you put in connection with your feeding?

- 23) If you have any of the side effects mentioned above, does it affect you so that you do not take the feeding formula any part of the day?
- 24) My daily life with tube feeding at home functions...
- 25) I think I am restricted in my daily life due to the tube feeding...
- 26) I know how to handle all aspects of my tube feeding care...
- 27) I received the information/knowledge I need to run my tube feeding care...
- 28) I know where to turn to in order to get the material I need for my tube feeding...
- 29) I know who is responsible for my tube feeding in the health care system...
- 30) I feel that I get the support I need from the health care system concerning my tube feeding...
- 31) I feel that the tube feeding is handled in a secure and correct way...
- 32) I feel safe at home with the tube feeding treatment...

