

DOCTORAL THESIS



Ordinary mealtimes under extraordinary circumstances

Routines and rituals of nutrition, feeding and eating in children with a gastrostomy and their families

Ellen Backman



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Halmstad University Dissertations no. 78

ISBN 978-91-88749-64-2 (printed)

ISBN 978-91-88749-65-9 (pdf)

Publisher: Halmstad University Press, 2021 | www.hh.se/hup

Printer: Media-Tryck, Lund

Photos front cover: Rasmus Backman

*Principium erit mirari omnia,
etiam tritissima.
Medium est calamo committere
visa & utilia.
Finis erit naturam adcuratius delineare,
quam alius (si possumus).*

The beginning will be to wonder at all things,
even the most commonplace ones.

The middle is to commit to writing things
seen and found useful.

The end will be to depict nature more
carefully than any other (if we can).

*Carl Linnaeus,
Philosophia Botanica, 1751*

Preface

Asking someone, “*What’s eating you?*” is a way to learn what is consuming, or ‘eating,’ their thoughts, time, and energy (Talkenglish.com, n.d.). The question is a worthy start to any thesis, since a thesis develops out of a lingering curiosity, a question or problem waiting to be, if not solved, at least elaborated on and thoroughly discussed. The question “What’s eating you?” as a starting point of this thesis also pinpoints the imprint food makes on our language and social re-lations. Food and the activity of eating fills not only the biological needs of the individual, but serves to mark times of the day, life-cycle changes, and social belonging. Furthermore, mealtimes in families as reoccurring everyday routines play a vital role for development and health in children.

Over the years, I have in my work as a speech-language therapist met children with developmental or early acquired disorders where food and feeding-related issues have major consequences for families’ everyday life. I have found myself captivated by the challenges faced by these families in general, but more specif-ically the families of children using alternative modes of nutrition, for example feeding via gastrostomy tube (G-tube). Alongside the benefits associated with the introduction of a G-tube, which include the improved nutritional status of the child, or the relief of pressure to feed orally, I have noticed the demands of main-taining a shared mealtime, risks of being excluded from family traditions, and frequent contacts with various healthcare services.

At times, my thoughts still return to the teenage boy with a chromosomal deletion syndrome whom I met many years ago at the clinic where I was working. He had been using a G-tube since a young age, due to oral-motor impairment and low internal drive to eat. He confused me, since during our training sessions he showed severe difficulties with oral sensory and motor functions combined with no motivation to increase the amount of food eaten by mouth, yet neverthe-less spoke with great enthusiasm of the cinnamon rolls he ate with his friends after school. My thoughts also return to the mother of a child with a congenital craniofacial anomaly, and a G-tube, whom I met more recently. She explained how happy she was about the many things that worked so well for her child, but spoke sadly of how gatherings with friends and family became occasions she dreaded or avoided, due to the focus on food accompanying traditional celebra-tions and social events. In these, and many other encounters, I have been dissat-ified with the lack of guidelines and research informing me as a healthcare pro-fessional in supporting families of children with feeding disorders, beyond

nutritional advice and oral sensory-motor exercises. What was ‘eating me’ was the insight that I knew so little of the everyday challenges of the children using G-tubes, and that only by knowing more, could healthcare practices be tailored to really meet the complex needs of these children and their families. The work presented here is my contribution to expand on the knowledge of everyday life following a G-tube placement.

I have written this thesis within my frame of reference, and it thereby reflects the culture and society in which I was raised, live, and work. In a way, it reflects my childhood, where food has always played an important part of my family’s social interactions, routines, and rituals. It reflects the trials of family mealtimes in my own daily life and, lastly, it reflects the challenges of eating that I encounter in my clinical work as a speech-language therapist. Although the world is bigger than Sweden, Europe, Australia, and North America, this thesis is predominately influenced by ideas and research stemming from these places. It reveals a ‘Western’ conception of food, eating, and mealtimes, and is seen through the lens of my upbringing and life-history. Nevertheless, telling the story of this project allows me to share some of the pieces that make up the everyday life of children living with gastrostomy and their families.

A handwritten signature in black ink, appearing to read 'Emma Bäck', followed by a small asterisk symbol.

Västra Frölunda, April 12th, 2021.

Abstract

The aim of this thesis is to explore routines and rituals related to feeding, eating, and mealtimes in families that have a child with a gastrostomy tube (G-tube), from the perspectives of healthcare professionals, the children, and their parents. The thesis is based on four empirical studies. **Study I** is a longitudinal, quantitative study with the aim to describe children with developmental or acquired disorders receiving a G-tube, and to compare characteristics, contacts with healthcare professionals, and longitudinal eating outcomes. Findings from **Study I** demonstrated that children with developmental disorders needed G-tube feeding for longer than children with acquired disorders. Children with developmental disorders were also younger at G-tube placement, and had more multidisciplinary healthcare. These findings led to the subsequent studies focused specifically on children with developmental disorders.

Study II applies mixed methods and explores everyday life, health care, and intervention goals during the first year following G-tube placement through the documentation in medical records. In **Studies III** and **IV**, the experiences of family mealtimes for children with a G-tube and their parents are collected through individual interviews that are analysed qualitatively. Triangulation of methods, participants, researchers, and data across the four studies is applied to search for confirmation between findings, as well as to identify areas of discrepancy. Ecocultural theory, the WHO framework ICF, and the concept of participation form the conceptual framework of the thesis. Taken together, findings from the studies describe how the main experiences of feeding, eating, and mealtime relate to specific impairments of the child, the collective value attached to family mealtimes, and the parental responsibility to harmonise competing interests and conflicts among family members and/or healthcare professionals.

This thesis extends previous research by focusing on the ecocultural context of the child in combination with a dimensional understanding of health. The findings shed light on measures taken by the families themselves to adjust to and handle their daily lives, as well as spell out areas where more support is needed. Furthermore, this thesis suggests that an expanded focus on children's participation in everyday mealtimes, and in the healthcare follow-up of G-tube feeding, is important in enhancing intervention outcomes.

Keywords: AAC; ecocultural theory; enteral nutrition; ICF; participation; pediatric; health

List of scientific papers

- I. Backman, E., Karlsson, A-K. & Sjögreen, L. (2018). Gastrostomy tube feeding in children with developmental or acquired disorders: A longitudinal comparison on health care provision, and eating outcomes four years after gastrostomy. *Nutrition in Clinical Practice*, 33(4), 576-583. doi: 10.1002/ncp.10056.
- II. Backman, E., Granlund, M., & Karlsson, A.-K. (2020). Documentation of Everyday Life and Health Care following Gastrostomy Tube Placement in Children: A Content Analysis of Medical Records. *Disability and Rehabilitation*, 42(19), 2747-2757. doi: 10.1080/09638288.2019.1573383.
- III. Backman, E. & Karlsson, A-K. (2021). Children's perspectives on mealtimes when living with a gastrostomy tube: A qualitative study. *Journal of Pediatric Nursing*, 58, 53-59. doi: 10.1016/j.pedn.2020.11.018
- IV. Backman, E., Granlund, M., & Karlsson, A.-K. (2021). Parental perspectives of family mealtimes when having a child using a gastrostomy tube. *Qualitative Health Research*. Advance online publication. doi: 10.1177/1049732321997133

The papers are referred to in the text by their Roman numerals and have been reprinted with the permission of the respective publishers.

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Abbreviations

The following abbreviations are used in the thesis and in the four sub-studies:

AAC	Augmentative and Alternative Communication
fPRC	The Family of Participation Related Constructs
GDPR	The General Data Protection Regulation
G-tube	Gastrostomy tube feeding
GT	Gastrostomy tube feeding (abbreviation used in Study I)
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health - Children and Youth
ICD-10	International Statistical Classification of Diseases and Related Health Problems – 10th revision
LSS	The Swedish Act Concerning Support and Services for Persons with Certain Functional Impairments
NOMESCO	Nordic Medico-Statistical Committee
UN	United Nations
WHO	World Health Organization

Definitions in short

In this thesis

Acquired disorder	Denoting a disease, condition, or abnormality that is contracted after birth.
Developmental disorder	Include congenital limitations in function in one or multiple domains, including cognition, motor performance, vision, hearing, speech, or behaviour, manifesting as delays in reaching developmental milestones.
Disability	The umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (WHO, 2011b).
Eating	Including actions of eating food that has been served, bringing it to the mouth, and consuming it in culturally acceptable ways (WHO, 2001) .
Feeding	Defined as 'give food to' and relates to nutrition in order to sustain vital bodily functions.
Functioning	An umbrella term referring to physiological and psychological functions of body systems, a person's capacity to execute a task or an action, and what a person does in his or her current environment (WHO, 2001).

Impairment	Problems in body function or structure such as significant deviation or loss (WHO, 2001).
Mealtime	A situation where two or more persons share time and space for one or multiple of the following food-related activities: preparation, consuming food, communicating and/ or cleaning up
Paediatric feeding disorder	Impaired oral intake for more than 2 weeks that is not age-appropriate, and is associated with medical, nutritional, feeding skill and/or psychosocial dysfunction (Goday et al., 2019).
Participation	A feeling of belonging and engagement, experienced by the individual in relation to being active in an certain context (Eriksson & Granlund, 2004).
Rituals	A set of fixed actions or sometimes words performed regularly, especially as part of a ceremony (Cambridge Dictionary, 2018).
Routines	A usual or fixed way of doing things (Cambridge Dictionary, 2018).

1. Introduction

This thesis, written within the scientific field of health and lifestyle with a specialisation in disability studies, concerns children with a gastrostomy tube (G-tube). The overall aim is to explore routines and rituals related to feeding, eating, and mealtimes in families that have a child with a G-tube. Participation, everyday family mealtimes, and healthcare support are central themes of the thesis, together with an explicit focus on children with developmental disorders. The themes are studied through the words of healthcare professionals using medical records, through the words of the children themselves, and the words of their parents (referring herein to biological parents, legal guardians, or other caregivers with medical decision-making responsibilities who brings up and cares for a child).

The interdisciplinary research field of health and lifestyle aims to explore individual as well as structural aspects of the concepts of lifestyle and health, disparities in health, and health promotion. Similarly, the research field of disability studies is placed at the intersection of many overlapping disciplines including sociology, medicine, psychology, economics, and history, with the common goal of developing theoretical and practical knowledge about the meaning, nature, and consequences of disability. The thesis adheres to the definition by WHO (2011b) of disability as an “umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors” (p. 4). By placing the thesis in this cross-sectional theoretical context, my aspiration has been to expand earlier, medically-focused research on children with G-tubes by bringing attention to the condition’s consequences for family mealtimes and child participation in everyday life. Thus, this thesis will explore the concept of lifestyle through examining how mealtime-related routines and rituals in family life are maintained, adjusted, or abandoned when faced with childhood disability.

Concerning the concept of health, and disability, the present thesis applies a dimensional understanding, where objective observations together with personal perceptions of the activities and encounters in daily life contribute to the understanding of a person’s health. From a child health perspective, participation in everyday activities provides opportunities for acquiring

important skills and socialising in the family's cultural context. During mealtimes, for example, children encounter what is regarded as food in the family, or how and with whom food consumption is usually carried out. Furthermore, family mealtimes influence children's motor and language skills by calling for both physical and communicative actions (Ferm et al., 2012; Sameroff, 2009). The family mealtime is also a moment for social interaction and familial bonding through the sharing of past, present, and future events, the exchange of ideas, engagement in problem-solving, and discussion of issues that are sensitive and emotionally laden (Denham, 2003; Fiese et al., 2006; Skeer et al., 2018). As such, mealtimes also contribute to a positive parent-child relationship, and promote parental health and family cohesion, in addition to supporting child health.

The studies included in this thesis were carried out between 2015 and 2020. During this period, mealtimes for children with developmental disorders have been a burning question in Swedish society, since the issue of how to define 'a mealtime' became a matter of the Swedish court system. In December 2016, the Administrative Court of Appeal stated that an eight-year old girl receiving nutrition through a G-tube had the legal right to personal assistance, according to the Swedish Act Concerning Support and Services for Persons with Certain Functional Impairments, LSS (The Swedish Parliament, 1993): "Mealtimes are a basic need given the wording of the act. According to the court, the concept of mealtime must therefore also include tube feeding" (*author translation*, Administrative Court of Appeal, 2016). The verdict of an appeal made to the Supreme Administrative Court followed the same line of reasoning, and stated: "Thus, other means of satisfying a person's nutritional needs than bringing food to the mouth should be included in the term mealtime. The Supreme Administrative Court believes that tube feeding should be equated with mealtime in that manner ..." (*author translation*, The Supreme Administrative Court, 2018). These formal statements mirror a growing awareness in society of the importance and value in understanding childhood disability through a holistic point of view, where biological, psychological, and social aspects are given equal consideration. Correspondingly, this thesis adheres to a relational model, where disability is seen as an interplay between reduced function in a person and barriers in the environment. It is my wish that this thesis will contribute new insights concerning the feeding, eating, and everyday mealtimes of children using a G-tube and their families.

2. Background

This chapter provides background information regarding the use of G-tubes in children, and the current knowledge of outcomes after G-tube placement. It presents the concept of health to illustrate various dimensions comprising this concept, and how health can be understood. Furthermore, the chapter introduces the distinct yet interrelated concepts of feeding, eating, and mealtime, as well as an overview of current research. The final section presents routines and rituals, in order to provide a deeper exploration of the structure and content of family mealtimes.

2.1 Gastrostomy tube feeding

A G-tube is a surgically placed device used to give direct access to a person's stomach for supplemental feeding, hydration, or medication (Fröhlich et al., 2009; Gauderer et al., 1980, 2001). The G-tube may be used in both adults and children to occasionally administer supplementary feeding as part of a nutrition support regimen, or may be the sole route of nutritional intake. For children, the practice of G-tube feeding is indicated for prolonged inadequate oral in-take following developmental or acquired disorders, most commonly neuro-logical impairments, congenital malformations, or oncologic disease (Glasson et al., 2018; Heuschkel et al., 2015; Wong et al., 2019). In contrast to G-tube feeding commenced in adulthood, children require purposeful activities related to food and eating in combination with the nutrition provided by the G-tube to stimulate their immature, developing body structures and functions (Arvedson et al., 2020; Edwards et al., 2016).

Depending on underlying disorders, the need for G-tube feeding can be short- or long-term. Differences in the length of necessary G-tube programmes among children with neurological impairment or transient organ failure has been noted, with neurological impairments representing the main indication for prolonged G-tube feeding, defined as exceeding 8 months in Diamanti et al. (2013) and 2.3 years in Lalanne et al. (2014). However, outcome differences have only been briefly explored in relation to demographic characteristics.

A number of European studies show an increase in the use of G-tubes in children (Backman & Sjögreen, 2020; Cuerda et al., 2009; Daveluy et al., 2006; Diamanti et al., 2013). In Sweden, G-tube placements increased by 130 percent from 1998 to 2014, and approximately 300 G-tube placements are currently performed on children every year (Backman & Sjögreen, 2020; Swedish National Board of Health and Welfare, 2019). The growing number of G-tube placements have been explained by improved survival rates among children presenting with complex medical conditions or congenital malformations, and by the increased recognition of the clinical efficacy of nutritional support in improving treatment success and reducing family frustration during intensive medical therapies (Backman & Sjögreen, 2020; Daveluy et al., 2006; McGrath & Hardikar, 2019; Wong et al., 2019). The combination of the increased number of G-tube placements with the long-term need for this nutritional support in many children means that everyday mealtime activities will be deeply affected for a considerable period of time for such children and their families. Therefore, research exploring the long-term outcomes in children's everyday activities following G-tube placement is imperative in order to provide families with adequate information. More information on underlying disorders is of specific interest when anticipating and communicating expected eating outcomes after G-tube placement, as well as when establishing guidelines and planning subsequent healthcare.

2.2 Health in children with G-tubes

Previous outcome research demonstrates improved nutrition and growth status following the insertion of a G-tube (Lalanne et al., 2014; Ricciuto et al., 2015; Åvitsland et al., 2006). Frequently described complications are abdominal pain, dislocation of the tube, and skin infections (Duncan et al., 2018; Lalanne et al., 2014; McSweeney et al., 2013; Pars & Çavuşoğlu, 2019; Wu et al., 2013). Taken together, measurable data provide empirical support for the use of a G-tube as a safe and successful alternative mode of nutrition with tolerable complications. However, in a systematic review of 104 studies assessing G-tube feeding in children with neurologic impairment, Kapadia et al. (2016) found a large degree of heterogeneity and irregularities in outcome selection. Anatomical and physiological conditions were found to be the most frequently reported outcomes, corresponding to 79 percent of the 120 unique studied outcomes (Kapadia et al., 2016). A notable paucity of outcomes assessing families' social functioning, child satisfaction, and healthcare resource use was exposed, suggesting that all stakeholder interests, including affected children and their families, are not being collected and subsequently

addressed. Thus, knowledge regarding G-tubes in children is currently dominated by a medical research tradition focussed on physiological outcomes.

In Sweden, healthcare professionals attending to children with a G-tube are guided by the primary goal of the health care system, that is “good health” (The Swedish Parliament, 2017). When striving for “good health”, an operational definition is imperative, as it directs clinical management, outcome measures, and policies, as well as guiding research questions (Huber et al., 2011). Boorse (1977) defines health as “the absence of disease”, while the World Health Organization, WHO, (1948) defines health as “a state of complete physical, mental, and social well-being”. Children relate health to being able to perform wanted activities and being engaged in everyday contexts (Almqvist et al., 2006; Willis et al., 2017). Savage and Callery (2005) explored how parents and children with cystic fibrosis differed in what they regarded as important in the meaning of being healthy, and found weight gain being the priority for parents, whereas children prioritised having energy for physical activities. The study elucidated how children took an active role in deciding whether to implement dietary advice, and so their perspective needed to be considered in the dietary management of cystic fibrosis.

The use of G-tube feeding is a compensatory strategy for malnutrition and is not to be seen as a curative treatment. This calls for a working definition of health that is different from both Boorse (1977) and WHO (1948). In keeping with either of these two definitions, no one living with a long-term health condition, such as one requiring G-tube feeding, could be regarded as having health. Instead, a definition of health must take into consideration subjective experiences from daily life, i.e., what is personally encountered, undergone, or lived through, in combination with what can be objectively observed from an outside perspective (Nazli, 2012). Tengland (2007) proposes a two-dimensional theory of health combining functional ability with subjective well-being, which underpins the present thesis. Following the theory, the definition of “good health” is:

“ (1) to have acquired the basic abilities and dispositions that people in her society typically acquire, usually in childhood and youth, and be able to use these abilities, given that the circumstances are acceptable, and (2) to experience health-related (subjective) well-being.” (Tengland, 2010, p. 332).

According to this definition of health, healthcare professionals that attend to a child with a G-tube and the child’s family are therefore to handle both basic abilities *and* aspects of health-related well-being. One example of impaired basic abilities negatively affecting nutritional status is an acquired difficulty in the ability to chew and swallow safely following a traumatic brain injury.

Another example is a developmental deficit in processing sensory information of food due to a neuropsychiatric disorder. Both can result in reduced health if not treated accordingly, for example by the placement of a G-tube. However, negative experiences in the child related to the intake of food, such as nausea, pain, or anxiety, may persist despite commencing G-tube feeding, and will therefore need additional healthcare strategies.

2.3 Health care for children with G-tubes

In Sweden, a majority of G-tube placements are carried out at one of four national clinics in paediatric surgery by a paediatric surgeon or a paediatric gastroenterologist (Danielsson et al., 2018). After discharge, regional paediatric health care has the responsibility to fund and follow up on care of the stoma, provision of feeding equipment, and training of parents in the daily administration of tube feeding, following published guidelines (Heuschkel et al., 2015; Swedish Pediatric Surgical Association, 2018). The healthcare contact will be organised, depending on the underlying disorder of the child, at a children's clinic at the local hospital, at an outpatient children's clinics, or at a child and youth habilitation service centre, for example.

A multidisciplinary approach has been advised in the care of children with G-tubes, together with a cooperation between healthcare professionals and parents (Edwards et al., 2016; Heuschkel et al., 2015; Sharp et al., 2017). Communicative, social, and emotional aspects, as well as strategies enabling participation in everyday life, should be incorporated into clinical practice in order to improve child health and family mealtimes, and increase the overall success of G-tubes (Brotherton et al., 2007a; Wilken, 2012). Sharp et al. (2017) recommend that all children with severe feeding disorders should be treated by a healthcare team that includes expertise in medicine, psychology, nutrition, and speech-language/occupational therapy. Such a team would offer the necessary oversight and guidance to address both individual and relational aspects. However, research describes a lack of professional guidance for families adapting to everyday life with a G-tube (Craig, 2013; Edwards et al., 2016; Russell et al., 2017). A comparison of parental and healthcare professionals' perceptions of the information given, parental involvement in decision making, and the adequacy of support, demonstrated a clear difference, with parents calling for greater involvement in their child's care (Brotherton et al., 2007b). In an analysis of the content of informational brochures provided to parents of children with newly-placed G-tubes, Syrmis et al. (2019) noted a predominance of information regarding practical management. Information on goal setting, oral stimulation for the child to prevent tube

dependency, and socio-emotional issues of the family was less evident. More research is needed to understand how follow-up for children with G-tubes is planned and implemented in order to highlight areas of improvement.

2.4 Feeding, eating, and mealtimes

In a study exploring the view of parents who care for children with G-tube feeding due to a neurological impairment, Petersen, et al. (2006) concluded that “eating and feeding are not the same” (p. 713), and that healthcare professionals and researchers needed to widen the scope of outcome measures for understanding life with a G-tube. Although the provision of basic nutrition is the primary focus when placing a G-tube, the study by Petersen et al., (2006) as well as other studies, have highlighted that the use of a G-tube also affects feeding, eating, and cultural values connected to mealtimes, thus covering biological, psychological, and social dimensions (Heuschkel et al., 2015; Nelson et al., 2015).

In a paper from 1993, Crotty wrote that “the act of swallowing divides nutrition’s ‘two cultures’, the post-swallowing world of biology, physiology, biochemistry, and pathology, and the pre-swallowing domain of behaviour, culture, society and experience” (p. 109). Crotty’s aim was to illuminate the dimensional aspects, or levels, of food intake and the need for acknowledging these multiple ‘cultures’ to improve and balance public health practices related to nutrition. In the present thesis, I approach Crotty’s concept of two cultures by using three distinct, yet interrelated concepts: *feeding*, *eating*, and *mealtime*. For some children with a G-tube, it can be assumed that these three may coincide in the same situation, whereas for other children, the three may be separated due to circumstances of the individual child or the family (Brotherton et al. 2007a; Russell et al., 2017).

Feeding is defined as “to give food to” (Oxford Dictionaries, 2017) and fills biological needs for nutrition in order to sustain vital physiological functions and enable development of the growing child (Agostoni et al., 2005; Engle & Huffman, 2010). With G-tube feeding, the provision of adequate energy and nutrients is made possible through a stoma in the abdominal wall directly into the gastric tract. The nutrition through the G-tube can be in the form of home-blenderised or pre-fabricated formulas, delivered as continuous formula infusion or intermittent bolus feeding using a pump or a syringe (Bobo, 2016; Braegger et al., 2010).

Eating is defined according to the International Classification of Functioning, Disability and Health (ICF), as a multifaceted activity including actions of handling food that has been served, bringing it to the mouth, and

consuming it in culturally acceptable ways (WHO, 2001), thus indicating that actions connected to food and eating need to be assessed and classified in relation to a person's specific context. As such, the concept of eating can be seen as a bridge between Crotty's two cultures. For children with a G-tube, continued eating by mouth and participation in food-related activities should be encouraged according to their physical abilities to stimulate oral sensorimotor development and other skills related to eating (Arvedson et al., 2020; Edwards et al., 2016).

A mealtime is yet a broader concept, comprising food choices and combinations, social interaction, and the structure of the activity. In the words of Ochs and Shohet (2006), mealtimes are cultural sites that "are historically durable yet transformable, socially organized and organizing and tempo-spatially situated arenas, which are laden with symbolic meanings and mediated by material artefacts" (p. 35). Accordingly, a mealtime in the present thesis is seen as a social practice whereby culture becomes visible through the dynamics of actions, strategies, artefacts, and roles that vary within and across social groups but share an underlying value of signalling group belonging. Thereby, mealtimes offer researchers and clinicians an opportunity to explore patterns of social interaction and communication reflecting family lifestyle, the roles that family members play, and the deeper symbolic meanings of the event (Fiese et al., 2006; Ochs & Shohet, 2006).

Mealtimes are often defined by one or a combination of the following criteria: 1) time of day (e.g., breakfast 6 AM-10 AM), 2) energy content (e.g., a minimum of 375 kcal), 3) social interaction (requiring more than one person to be present), and 4) food combinations (meals consist of more than one food and a beverage; Meiselman, 2008). Larson, Branscomb and Wiley (2006) conceptualise mealtimes as involving "a coordinated arc of activities: shopping or gathering food, meal preparation, a prayer in some families, eating, conversation, and cleaning up" (p. 2). This definition illuminates both value-laden activities and social interaction connected to eating, but is on the other hand very broad when also including shopping or gathering food. The definition of mealtime in the present thesis is instead derived from literature exploring mealtimes as a recurring everyday activity in families with children (Adolfsson et al., 2013; Evans & Rodger, 2008; Spagnola & Fiese, 2007), and is defined as a situation where two or more persons share time and space for one or multiple of the following food-related activities: preparation, consuming food, communicating, and/ or cleaning up. It is viewed as a situation where the sociality of food is recognised through the customs and meanings expressed through commensality.

2.5 Family mealtimes influence on health

Frequent shared family mealtimes are valuable moments to promote healthy feeding and eating practises in children (Hammons & Fiese, 2011; Verhage et al., 2018) and are associated with positive psychosocial outcomes, self-esteem, and commitment to learning in children (Harrison et al., 2015). Mechanisms connected with the beneficial outcomes of family mealtimes are suggested to be communication, routines, and rituals, as well as values attached to commensality (Skeer et al., 2018). On the other hand, mealtimes in families have also been described as a declining event, contributing to dietary problems such as obesity or disordered eating (Hunt et al., 2011). Some examples of studies that explore various aspects of mealtimes are presented below to give the reader a picture of the multifaceted nature of the family mealtime and its relation to health.

2.5.1 Nutrition, communication and family identity

One example of how mealtimes affect child health was demonstrated in an American survey study involving 1,923 parents of adolescents (Neumark-Sztainer et al., 2014). In the study, the authors explored associations between types of foods being served at family dinner and variables such as household income, parental education, work-life stress, and the perceived importance of family meals. The analyses revealed that high levels of work-life stress, the presences of depressive symptoms, and low levels of family functioning were all strongly associated with serving less nutritious food at dinner. On the other hand, more time for food preparations, perceiving family mealtimes as important, and enjoying cooking were all positively associated with serving healthy foods. The findings by Neumark-Sztainer et al. (2014) point to how nutritional intake in children is greatly influenced by both parental well-being and the value attached to mealtimes.

In a study by Lawrence and Plisco (2017), 50 children together with a parent answered separate questionnaires to explore the correlation between frequency of family mealtimes and family communication. The analysis showed that as frequency of mealtimes increased, the levels of communication increased; in addition, as frequency of mealtimes increased, the levels of life satisfaction increased. Their findings suggested that the frequency of shared mealtimes promotes increased levels of positive feelings and attitudes about one's life, as well as family connectedness in both children and their parents.

Another example adopts the perspective of children. In a Swedish study, 112 children described their perceptions of family mealtimes with regards to what, where, and with whom meals are made and eaten (Persson Osowski & Mattson Sydner, 2019). Descriptions were in many ways given of an idealised

family dinner, where family members shared a “proper meal at home” in a nice atmosphere and good conversation. The children appreciated helping out with food-related tasks, not only the activity of eating together. The interpretation of the children’s narratives suggested that mealtimes functioned as a way to construct the family and as an opportunity for children to actively acquire customs and values related to family mealtimes, but the children also contributed to change the activity by breaking rules and challenging norms (Persson Osowski & Mattson Sydner, 2019).

2.5.2 Mealtimes for children with developmental disorders

Mealtimes in families where a child has a developmental disorder have been the focal point in several studies. A study exploring the results from the American National Survey of Children’s Health for children with disabilities included 4,336 children and illuminated the value of shared family mealtimes for children with various disorders (DeGrace et al., 2016). Increased frequency of family mealtimes was associated with increased likelihood for positive social skills and engagement in school. Frequency of family mealtimes was not associated with parental aggravation with children or with problematic social behaviour. On the other hand, mealtime observations of families of children with developmental disorders have demonstrated that mealtimes tend to focus on feeding, rather than social and learning opportunities (Totterdell, 2016). Veness and Reilly (2008) observed mealtime interaction between mothers and their young children with cerebral palsy. The results revealed that interactions were maternally dominated and directive communicative functions, for example “open [your mouth]” or “eat it all up now”, were the phrases most commonly used by mothers. Child communication was dominated by protest. Another study of interaction between a child with severe speech and physical impairments and her mother explored how goals of communication and feeding were accomplished during mealtime (Ferm et al., 2012). The authors concluded that the dyad’s pattern of interaction efficiently met the goals of both satisfactory food intake and social interaction, but interaction mainly related to immediate mealtime issues. The authors raised concerns about the lack of conversation topics associated with past and present events, which is important for linguistic, cognitive, and social development. Mothers of children with autism have described mealtimes as stressful, chaotic, and energy depleting (Suarez et al., 2014). Separate mealtimes were described as one of the strategies for families to avoid exhausting mealtime events, together with being mindful about the mealtime environment and the food served.

Remijn et al., (2019) conducted an interview study of adolescents and young adults with cerebral palsy. The aim of the study was to get insight into the experiences of eating and drinking in social activities. According to the authors, this study showed that young people with cerebral palsy encounter several limitations involving eating and drinking, such as difficulties handling various food textures or utensils, the need for assistance at mealtimes, and time restrictions. These difficulties led to negative feelings and lower participation levels, yet little attention from healthcare professionals was directed towards these difficulties.

With this overview, I want to highlight the role that both the quality and quantity of family mealtimes plays in promoting health in children and their parents, and the active partaking of children. Furthermore, for children who have developmental disorders that impact feeding ability mealtimes tend to become a disease-specific task for both affected children and their parents, rather than a typical activity of daily life. As such, focus is on adhering to dietary recommendations and ensuring individualised assistance, not on commensality and social interaction beyond the present activity. The findings from the reviewed studies raise questions regarding how children with a G-tube and their parents perceive mealtimes and if support is provided to establish and maintain beneficial family mealtime habits.

2.6 Understanding family mealtimes

Mealtimes in families are not static but evolving, for example due to the age and maturity of the children in the family. At first, infants rely on innate reflexes to coordinate sucking, swallowing, and breathing. Infants have an anatomy of oral and pharyngeal structures that facilitates nipple feeding and the intake of fluid foods (Arvedson & Lefton-Greif, 2020). Mealtimes are an intimate interaction between the infant and the parents during which the infant gains awareness of its body signalling hunger and satiety, and depends on people in the immediate environment to provide basic needs (Arvedson & Lefton-Greif, 2020; Satter, 1986, 1990). Following anatomical changes, the fading of reflexes, and general motor development, the growing child gains the ability to handle various food textures and utensils (Arvedson & Lefton-Greif, 2020). As children become increasingly independent, mealtimes also become an arena for testing out limits, for example, regarding quantity or food preferences, as well as a situation to interact with others and learn new skills (Carruth et al., 2004). This brief overview of eating development illustrates why future eating abilities in a child with a G-tube will be affected by, for example, the period in a child's eating development when the G-tube

feeding is commenced, and by the intervention strategies implemented parallel to the alternative feeding regime.

2.6.1 A shared responsibility

“The feeding relationship” (Satter, 1986, 1990) demarcates the complex interaction that takes place between children and parents as they engage in food selection, eating, and regulatory behaviours. A positive feeding relationship is founded on an allocation of responsibility where parents choose food that is safe and appropriate for children, offering it in a positive and supportive setting. Children are responsible for deciding the amount and pacing based on an intrinsic drive to eat (Satter, 1986; Schwartz et al., 2011).

Establishing and maintaining a positive feeding relationship is a challenging task in any family, however, the relationship between parents and a child with a paediatric feeding disorder is particularly vulnerable (Davies et al., 2006; Satter, 1986). Pahsini et al., (2016) demonstrated that parents vary in their responses to the feeding situation of their child with a G-tube. A total of 416 caregivers were asked to think of a typical feeding situation with their child, and describe their attitude using the options “I am feeling: relaxed/ not relaxed/ anxious/ intrusive”. Only 41 percent were relaxed during the feeding situation with their child. A total of 36 percent were not relaxed, 19 percent were anxious, and 4 percent felt intrusive. Thus, interventions with feeding in childhood, such as nutrition via a G-tube, must be made with an awareness of the overall impact on the feeding relationship (Mason et al., 2005). Also, awareness is needed of typical eating development in order to optimally support and stimulate the child’s eating abilities in relation to the underlying disorder. A child with a degenerative muscular dystrophy with little likelihood of recommencing oral eating will need different intervention approaches than a child with a congenital heart defect who most likely will have the physical resources to develop typical eating abilities after surgery.

Recognising family mealtimes as a shared responsibility between children and parents raises practical ethical considerations, balancing the principle of autonomy for the child with the responsibility of parents (Craig & Scambler, 2006; Schwartz et al., 2011). Ethical considerations involve parents providing children with sufficient food and liquid (orally or by G-tube) in order to grow and develop, yet remaining responsive to the communicative cues of the child. Considerations also involve the evaluation of available clinical evidence about risks and benefits around suitable intervention strategies. For example, when implementing oral tastes for children with G-tubes, the potential risk of aspirating food into the airways needs to be weighed against the

potential benefits of stimulating basic oral sensorimotor abilities and the pleasure of tasting preferred foods (Chadwick, 2014).

Denham (2003) suggested that enhanced understanding of how daily activities such as family mealtimes are organised and adjusted to distinct health care needs, for example G-tube feeding, is an important step in order to develop deeper understanding of how families manage long-term health conditions. Consequently, it is imperative to increase the knowledge of everyday mealtimes following G-tube placement in children and the type of health care offered to these families. Studying mealtimes implies studying the routines and rituals connected to the situation to further understand what lies behind maintaining, adjusting, or abandoning specific activities. The following section will discuss the concepts of routines and rituals.

2.6.2 Routines and rituals during mealtimes

Daily lifestyle activities, such as gathering food for shared mealtimes, child-rearing practices, and ceremonies marking life-cycle transitions, hold important purposes for families in providing a predictable structure to guide individual or group behaviour (Spagnola & Fiese, 2007; Weisner et al., 2005). During mealtimes, instrumental activities without any emotional meaning take place alongside symbolic practices reflecting family identity. Mealtimes are universal daily activities, existing in every society, culture, and social class, yet their symbolic meanings and structural organisation differ across families and groups (Fjellström, 2008; Meiselman, 2008).

According to the Cambridge Dictionary (2018), a *routine* is “a usual or fixed way of doing things”, and a *ritual* is “a set of fixed actions or sometimes words performed regularly, especially as part of a ceremony”. These two concepts are thus similar in terms of recurrence but differ in their symbolic meaning. Routines and rituals can be contrasted along the dimensions of communication, commitment, and continuity (Fiese et al., 2002). Routines typically involve instrumental communication relating to what must be done during specific, reoccurring activities, and involve a momentary time commitment. Mealtime routines are activities with focus on the task itself including preparation, setting the table, the organisation of how food is served, or exchange of information (Evans & Rodger, 2008). Once the activity is completed, there is little afterthought. Rituals serve to create and reinforce family identity, conveying messages of cultural belonging and social inclusion through affective commitment in activities (Fiese et al., 2002). Rituals also provide continuity in meaning across generations. Rituals can include preparing the mealtime setting with traditional decorations or eating special food to celebrate important events or festivals, such as the American custom of eating turkey for

Thanksgiving, or the Swedish Midsummer tradition of eating pickled herring. The emotional involvement in rituals contributes to a sense of stability, family belonging, and meaningfulness. Given the difference between routines and rituals, disruption of either will affect the family differently. Fiese et al. (2002) proposes that when routines are disrupted, it is a hassle, but when rituals are disrupted, there is a threat to group cohesion.

Spagnola and Fiese (2007) suggest that routines and rituals, for example during mealtimes, form a foundation to return to in times of stress or change. However, previous research in families of children with long-term health disorders suggest that routines and rituals can be difficult and stressful to maintain depending on the child's particular condition (Crespo et al., 2013; Santos et al., 2018). One such example is the study by Axelsson and Wilder (2014) that compared the frequency of family activities and child presence between families of children with profound intellectual and multiple disabilities to families of typically developing children in Sweden. Family activities, for example playing a board game, visiting friends or relatives who have children, or playing with siblings, occurred less often in families of children with disabilities, and the children with disabilities were less often present during family activities compared to the typically developing children.

2.6.3 Contemporary mealtimes

The construction and maintenance of daily routines are recognised as major adaptive tasks through which all families organise and shape their children's activities and development (Gallimore et al., 1993). Arranging mealtimes involves challenges, including time and work, which can elicit conflicts in any family. Both media and researchers have questioned whether the occurrence and value of shared mealtimes are changing towards favouring individual snacking and fast food (Fieldhouse, 2015; Ochs & Shohet, 2006). However, through studying contemporary Scandinavian mealtime patterns, Fjellström (2009) and Holm et al. (2012, 2016) concluded that eating is still a shared social activity, although with changes related to the organisation of working life, food distribution systems, and the family institution.

One notable change is the increased use of computers, tablets, and mobile phones during mealtimes between 1997 and 2012 (Holm et al., 2016). However, the changes did not seem to apply evenly across the day's different mealtimes. Dinners were the event most often eaten together with others, and most seldom accompanied by technology. In a British study exploring mealtime patterns from 1975 to 2000, the total time of eating at home had decreased in favour of time eating at restaurants (Cheng et al., 2007). However, the study showed that the time allocated to eating at home had increased

in families with children. In a study of six Western cultures, Harkness et al. (2011) found family mealtimes to be valued routine activities enabling shared family time. In a more recent Australian study of 992 caregivers, 92 percent stated the family mealtime was important, and 77 percent of the included children shared five or more evening meals per week together with at least one caregiver (Litterbach et al., 2017). In accordance with these findings from various countries, the value of shared mealtimes in contemporary families seems to persist, and this thesis is based on the assumption that the value and meaning of the routines and rituals of family mealtimes will be no different for families of children with G-tubes, albeit coupled with specific challenges.

In conclusion, children with G-tubes are growing in number but knowledge is lacking regarding how underlying disorders affect long-term outcomes. Furthermore, the dominant focus of previous studies on quantitative analysis of growth and complication rates is insufficient when striving to understand how a G-tube placement affects daily mealtimes for children and their parents. In order to illuminate various aspects of food intake and how these relate to a person's health, a holistic approach is recommended ranging from an individual, physiological level to a broad cultural level. In the present thesis, the concepts of feeding, eating, and mealtime are chosen to reflect this understanding. Furthermore, mealtimes are understood as comprising routine and ritual elements that both challenge and contribute to family life. The next chapter will give a deeper explanation of the present thesis' conceptual framework.

3. Conceptual framework

This chapter includes the ontological and epistemological underpinnings of the thesis to clarify my theoretical and conceptual point of departure. It summarises models used for exploring disability, focusing on childhood disability and systems theory. The chapter gives a description of the ICF, a presentation of the participation concept, and of ecocultural theory, all tools used within the present thesis to explore everyday mealtimes for children with G-tubes.

3.1 Ontological and epistemological underpinnings

Within the clinical field of paediatric feeding disorders, a multi-level, systemic approach is useful because it acknowledges that impairments in a child's physical and psychological functioning are intertwined with the social characteristics of the family system (Davies et al., 2006). For a child with a G-tube, feeding and eating impairments can derive from a dysfunction in the motor system involved in the act of swallowing due to cerebral palsy, for example. This corresponds to an impairment on the biological level. On a psychological level, a child's internal motivation, attention, or planning functions can negatively affect eating. On a social level, parental challenges in managing daily mealtime routines or lack of professional support may negatively influence children's possibility to take part in communicative interaction and cultural events connected to commensality. In addition, there may also be vertical effects working between these levels, for example, biological mechanisms leading to nausea may hinder the social experiences of sharing a meal.

One meta-theory merging analytical levels is critical realism. In short, critical realism is described as ontologically inclusive, claiming that the real world cannot be observed or exist independently from human perceptions, theories, and constructions (Bhaskar & Danermark, 2006). Epistemologically it combines the observable, manifest phenomena with the unobservable structures and mechanisms that produce them (Maxwell & Mittapalli, 2010). The world as we understand it is built upon our observations and experiences, but there are also parts of reality that we cannot observe (Bhaskar et al., 2018). In other words, some things in the world are objectively "out there",

independent of our views or claims about them. However, knowledge about reality is culture-bound and dependent on human representations. Methodologically, critical realism endorses the mixing of qualitative with quantitative approaches to create a dialogue and emergence between diverse levels and perspectives (Bhaskar & Danermark, 2006; Maxwell & Mittapalli, 2010). In the present thesis, critical realism guided the formulation of research questions and the choice to use various data collection methods. Critical realism also functioned as the point of reference when reviewing previous research.

3.2 Models to explore disability

Several models to describe and understand disability exist, accentuating various aspects of disability, such as medical, financial, social and cultural. According to Article 1 of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006), persons with disabilities include “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Thus, disability is seen as a result of the interaction between a person (with a health condition) and that person’s contextual factors. A child with a G-tube due to an acquired or developmental disorder would be defined as a person with a disability if in consequence of the impairment the child was restricted from participating with others, due to lack of opportunities to be active, or discrimination from society, for example, by failing to provide necessary aids or support.

The UN definition follows a relational model of disability, suggesting that impairments as well as social and environmental barriers can operate simultaneously (Martin, 2013; Reindal, 2008) and are of equal importance in the reality of living with a health condition. The relational model was found logical to support the work of this thesis for two major reasons. First, the relational model is the prevalent perspective for disability legislation in Sweden, as well as other Scandinavian countries (Traustadóttir et al., 2015) and should therefore guide the support given to affected families. Secondly, feeding and eating depend, as I have shown in previous sections, on an interaction between the basic abilities of the child with a G-tube and the people and objects in the environment. Considering these elements together will improve the understanding of the family mealtimes for children with G-tubes and their families.

3.2.1 Childhood disability

Theoretical paradigms searching to describe and understand disability generally illuminate experiences and goals of adults, failing to capture the specific circumstances of childhood disability (Bricout et al., 2004; Hammel et al., 2008; Priestly, 1998). Children with impairments face challenges different from adults because of their growing bodies, their dependence on their environment, and the need for special support for them as well as for their family (Bricout et al., 2004). As sketched out in the background section, necessary and suitable intervention strategies following a G-tube placement will depend, for example, on the underlying disorder and on the age of the child at placement. Also, the quality of the feeding relationship and the socio-cultural context of the family affect the potential experience of disability.

Compared to disability in adulthood, children with impairments and their families also face the developmental challenges experience by any other family. A theoretical framework valuable in understanding childhood disability would therefore need an integrated point of view, and to include consideration of the individual child, aspects of child development, and social-ecological forces (Rosenbaum & Gorter, 2012). It would need a focus on the transitional processes between the child and the environment, viewing disability as dynamic, occurring over time, and within certain social contexts. It is also imperative that researchers using such a theoretical framework include the perspective of the affected children.

Children's perspective representing their own experiences has often been excluded from research on childhood disability, which instead has been dominated by a focus on a 'child perspective' developed by adults (Nilsson et al., 2015; Ytterhus et al., 2015). Children in general, and children with developmental disorders in particular, have often been "protected" from research. In their place, information has been collected from people in their surroundings (Alderson & Morrow, 2011). However, in order to capture the subjective dimension of health and disability, obtaining the views of children is imperative. It is also in line with the UN Convention of the Rights of the Child (United Nations, 1990), underlining that children have the right to express their views freely and are to be provided with the opportunity to be heard in matters affecting them in relation to their age and maturity. Hence, for researchers claiming to explore childhood disability, children need to be viewed as actors by collecting and respecting their own views, feelings, and requests. This line of reasoning is why the perspectives of children using G-tubes were also included in the thesis.

3.3 Systems theory and transactional models

Systems theory conceptualises living organisms as active agents. It provides a framework for looking at how units operate when they are dependent on each other, and it is a promising theoretical approach when exploring childhood disability (Bornman & Granlund, 2007). The term *system* indicates a collection of parts, functioning as a whole, influenced by environmental, complex, and dynamic interactions (Molenaar et al., 2014). With systems theory comes an understanding that a diversity of interactions within and between various systems can lead to the same outcome (equifinality) just as the same interactions can lead to many outcomes (multifinality; Bornman & Granlund, 2007).

The family can be seen as a system that is dynamic and transactional, meaning that the parents' functioning has an effect on their children's functioning, and vice versa (Yan & Ansari, 2016). Parents and children continuously adapt to each other's behaviours, and co-regulation occurs whenever individuals' joint actions blend together to achieve a unique and mutually created set of social actions (Sameroff, 2009). As seen in the previous section on the feeding relationship, a child's eating and mealtimes skills develop, not as the result of an exchange of discrete communicative or physical signals, but as a part of a continuous, "looping" process of interaction between the child and the child's parents occurring over time (Sameroff, 2009).

Deriving from systems theory, Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979, 1995; Bronfenbrenner & Morris, 2006) conceptualises how children are affected by the micro-system (e.g., parents, peers, mentors), meso-systems (e.g., the interaction between microsystems influencing the child), exo-systems (e.g., organisation of day-care, community, economics), as well as the macro-systems (e.g., government policies, ethics, socio-economic climate).

Michailakis (2003) argues that it is beyond the scope of any researcher to explore all possible systems or all aspects of a person's reality. Rather, by differentiating systems and splitting up reality, certain views are made visible, while concealing others. Approaching childhood disability research with systems theory suggests that prior to an observation, the system to be observed, as well as the system from which an observation is carried out, must be defined, thereby differentiating the researcher from what is to be observed (Michailakis (2003)). The present thesis is concerned with children living with a G-tube, and the family mealtime experience from the perspectives of healthcare, children, and parents, as captured by me, a clinically experienced researcher. The primary point of departure is the micro-system including the close family, but also contact between parents and healthcare services,

representing the meso-system. However, this outset did not rule out that the empirical material could also include aspects of the exo- and macro-systems, such as narratives of socioeconomic status, school organisation, community-based respite care, or national laws and regulations related to disability and children's rights. These systems can have a direct impact on how families organise their daily life, contributing to enable or hinder the child's and the child's family's participation in society.

My focus in this thesis was on deepening the knowledge of the everyday mealtime of children with a G-tube and their parents, which required more focused theoretical and conceptual tools than ecological systems theory. The drawback with Bronfenbrenner's comprehensive theory has been put forward by Gallimore et al. (1989), arguing that the plausibility of how everything is connected within systems theory gives little guidance in how various mechanisms or levels are organised or influence each other. In addition to its breadth, another disadvantage is the theory's emphasis on development. In the field of childhood disability, traditional developmental measures and concepts do not offer suitable tools to explore functional performance in daily life activities or family experiences (Haley et al., 2010). Rather, a theoretical and conceptual approach to aid the understanding of health and disability in children will need to focus on how to support child autonomy and the child's participation in everyday activities despite not following a typical progression in physical, psychological, or social functioning.

3.4 Seeing health and disability by using the ICF

A conceptual framework and classification system that reflects a dimensional theory of health and disability is the International Classification of Functioning, Disability and Health (ICF), later updated with a version for children and youth, ICF-CY (WHO, 2001; 2007). The ICF supplements international diagnostic classification systems and is based on a biopsychosocial model of health where a person's functioning is conceived as a dynamic interaction between structures and functions of the body, activities, and participation in the context of environmental and personal factors. In the ICF these are referred to as domains. This dynamic interaction between domains can be seen as related to systems theory, and suggests that changes in any part of the ICF domains may potentially have influences elsewhere (Rosenbaum & Gorter, 2012). The ICF can provide a framework of thought for assessment, intervention, and monitoring child progress and outcomes, as well as a classification system with a hierarchical structure of chapters and codes within each domain. To exemplify, an anomaly in the anatomical structures of the

oesophagus (s520) may also impact purposeful sensing and exploration of objects by mouthing, touching, and tasting (d120), as well as the child's immediate family (e310). The ICF aids clinicians and researchers to distinguish various influential aspects from each other as well as to operationalise a relational model of disability. For instance, the personal experience in a child with an oesophageal anomaly will vary depending on other bodily functions, motivation, context, and attitudes of people in the immediate environment.

The framework has been suggested as a useful tool for assessing feeding- and eating-related impairments, and in planning intervention, as it encompasses basic abilities such as swallowing and growth, participation in everyday life, and important environmental factors (Berlin et al., 2009; Lefton-Greif & Arvedson, 2007; Mahant et al., 2018; Threats, 2007). Furthermore, using the ICF domains within a healthcare setting can guide professionals when collaborating, documenting, and communicating a more dimensional and structured picture of a child's functioning and health (Martinuzzi et al., 2015; Simeonsson, 2009).

3.4.1 Benefits and drawbacks of the ICF

Some scholars claim that the ICF has had profound impact on broadening the view of health and disability. The framework resolves the split between a medical and a social model of disability by including perspectives other than the purely biomedical (Björck-Åkesson, 2018; Vargus-Adams & Majnemer, 2014). However, the ICF has been criticised. The ICF provides elaborated concepts and definitions for body structures and functions, yet less is understood about what distinguishes and characterises the concepts of activity and participation (Badley, 2008; Granlund 2013). Critical disability researchers have also addressed that disability is primarily considered an individual problem in contrast to a political or a social problem. Another critique is the focus on classification based on objective numbers. Within the ICF, assessment and treatment measures are described in relation to generally accepted population standards (Bricout et al., 2004; Nordenfelt, 2006). Although an assessment relative to population standards can contribute to classify a person's level of functioning in relation to normative expectations, it tells little about their everyday experience. The numerical focus is said to clearly de-politicalise the issue of disability, failing to describe the plentiful geographical, cultural, and social contexts a person with a disease or a disorder relates to (Hammel et al., 2008; Snyder & Mitchell, 2005).

3.4.1 ICF as an analytical tool

Despite the critique directed at the ICF, the framework was included in the present thesis as it was thought valuable to bring attention to various levels of reality following a G-tube placement: body, activity, and participation in everyday mealtimes in relation to the child's environment and personal factors. The framework was also included as it is widely recognised within paediatric rehabilitation services (Martinuzzi et al., 2015; Vargus-Adams & Majnemer, 2014), and is recommended by the Swedish National Board of Health and Welfare as a clinical tool to assess, follow-up, and document health conditions in a structured manner, as well as to support goal-setting. The domains of the ICF served as tools for data analysis. The ICF was also used as a means to discuss the everyday functioning in children with G-tube from a biopsychosocial perspective, thus including both the dimensions of health proposed by Tengel (2007) together with social elements of the child's environment. One strategy to address the issue of ICF's potential failure to recognise subjective experiences was to complement the objective framework with an inner perspective of children with G-tubes and their families. To address the critique related to 'normality', and the lack of consideration for various cultural and social contexts, ecocultural theory complemented the ICF. This theory will be presented below, but first, the concept of participation is specifically elaborated on.

3.5 The concept of participation

Taking part in daily activities, such as family mealtimes, is positively related to subjective well-being (De Winter et al., 1999; Law, 2002; Weisner, 2002) and offers primary learning opportunities for the development of communication, social interaction, and other important skills in children (Bronfenbrenner & Morris, 2006; Dunst et al., 2000). In the ICF, the concept of participation is defined as "involvement in a life situation" and is operationalised as "the execution of a task in a current environment" (WHO, 2001; 2007). Related to feeding, eating, and mealtimes, child participation could thereby comprise bringing food to the mouth, handling utensils, or being active in cooking. However, as mentioned above, there is uncertainty within the ICF regarding what characterises participation and failure to recognise the subjective experience of the individual. Therefore, a thorough reflection of the concept of participation, reaching beyond the ICF definition, was deemed important to include in the present thesis, since this concept was thought valuable when exploring how feeding, eating, and mealtimes are interrelated for children with a G-tube.

The Oxford Dictionary (2017) defines ‘participation’ as the act of taking part in an activity or event, synonymous with attendance and presence. In a much-cited essay (Hart, 1992), child participation is referred to as the process of sharing decisions that affect one’s life, and is depicted as a ladder with steps marking increased degrees of participation and active citizenship. These two references illustrate how participation reflects being physically present as well as an individual’s commitment and partnership during an activity. In a study by Erikson and Granlund (2004), the concept of participation was described by students with disabilities of all ages, their parents, teachers, and special education consultants, resulting in a definition as a feeling of belonging and engagement, experienced by the individual in relation to being active in a certain context. This definition will be used in the present thesis. The definition proposes that participation comprises three components: feelings of participation, activity, and context. These components and influencing factors will be described below.

3.5.1 A dimensional concept

Participation as a dimensional concept is discussed in a framework proposed by Imms et al. (2017): The Family of Participation-Related Constructs, (fPRC). In the fPRC, two components are proposed to constitute participation: ‘Attendance’ and ‘Involvement’. Attendance corresponds to physically being present, and can be objectively measured in terms of frequency of attendance and/or the range or diversity of activities where a person is present (Imms et al., 2017). The attendance dimension relates to the components of ‘activity’ and ‘context’ in the above-mentioned definition, mirroring a person’s opportunities for participation, for example, through accessible physical environments or prerequisites for taking part in activities (Eriksson & Granlund, 2004). One aspect of attendance is the acknowledgement that persons can attend separate parts of the same activity, motivated by different goals. Gillen and Hancock (2006) suggest that children and their parents, despite attending the same activity, approach mealtimes from different perspectives, with adults having a more distinct focus on nutrition, whereas children integrate play into their eating. Attendance is necessary, albeit not sufficient, for participation. Involvement refers to the person’s own feelings while attending and can be operationalised as the perceived importance assigned to a certain activity or the intensity of engagement. The dimension relates to the components of ‘activity’ and ‘feelings of participation’, in that it includes a person’s sense of self, being able take part in activities that one is interested in, and the experience of being part of a group (Eriksson & Granlund, 2004; Imms et al., 2017).

3.5.2 Participation and child autonomy

Arvedson (2008) proposes that children with feeding disorders and their parents are vulnerable to social exclusion, emphasising participation as the first consideration when evaluating feeding disorders in children. Imms et al. (2017) suggested that participating in meaningful activities should be an essential intervention goal in order to achieve healthy growth and development in children with disabilities. These statements relate to the ethical principle of respect for autonomy.

To respect a child's autonomy is to acknowledge that a child has the right to hold views, to make choices, and to take actions based on personal values and beliefs (Beauchamp & Childress, 2001; United Nations, 1990), going beyond functionally independent performance, physical accessibility, and attendance. Such respect for a child's autonomy involves both respectful attitudes and actions. Thus, parents, researchers and healthcare professionals have an ethical duty to empower others for whom they are responsible, for example by providing children with personally adjusted aids, including them in daily activities, and being attentive to communicative signals and initiatives from the child. In the context of paediatric feeding disorders, a child may not have the physical ability to independently bring food to the mouth, but may well have the communicative ability to request and reject specific food textures or tastes. In such cases, participation for the child may entail being present during mealtimes and engaged by taking initiatives, despite not being able to eat independently. Providing children who have developmental disorders with participation opportunities has proven challenging for families, healthcare professionals, and childhood disability researchers (Cavet & Sloper, 2004; Coyne, 2008; Jordan et al., 2018), but research is scarce regarding mealtime participation for children with G-tubes.

3.5.3 Participation as an analytical tool

The concept of participation relates both to objective and subjective aspects, and can be an analytic tool to vertically combine various levels of reality. In the present thesis, the concept of participation was considered when exploring children's attendance and involvement during family mealtimes, and the inclusion of children in the research process. The concept also relates to issues of power relationships and communication, thus it is imperative when exploring children's and parents' involvement in healthcare related to the G-tube. Although the empirical material and data collection methods varied between the studies, the children's and parents' feelings of belonging and engagement in relation to being active in a certain context formed a thread running throughout.

3.6 Ecocultural theory

Ecocultural theory evolved from a series of studies conducted at the University of California in the 1980s and 1990s, with Ronald Gallimore, Thomas S. Wiesner and Lucinda P. Bernheimer as leading figures. They combined knowledge in culture and human development; medical, psychological, and cultural studies of families and children at risk; mixed methods; and evidence-informed policy, to develop ecocultural theory. The theory merges ecology, interpreted as the relationship between persons, and their environment, as well as their resources and constraints, with culture, in an attempt to deepen the understanding of how families create and maintain everyday routines (Weisner, 2002; Weisner et al., 1997). For example, important aspects of ecology when understanding childhood disability would be the geographic setting or the monetary resources of the family. Cultural aspects relate to routines and rituals of life, how and which artefacts are used, and what goals and values give activities meaning. Parallel to critical realism and systems theory, ecocultural theory encourages an understanding of children and their families within multiple levels of systems, and permits seeing that children both actively shape, and are shaped by, the environments in which they participate.

Ecocultural theory emphasises that a major task for families of children with a health condition, as well as any other family, is constructing and maintaining the everyday routines through which families' lives are organised (Gallimore et al., 1993, 1999; McConnell & Savage, 2017). The theory moves away from a view in which families of children with developmental disorders only manage individual crises. Instead, ecocultural theory takes the perspective of the family by focusing on family specific goals, resources, and needs, and strives to explore and understand the activities and factors influencing and shaping their lifestyle. The theory poses that families with the ability to find meaning in routines and rituals, and the ability to balance competing interests, needs, and resources among family members, will be more likely to perceive a sense of well-being, and support optimal development for their children (Weisner et al., 2005).

3.6.1 Central elements of ecocultural theory

Central elements in ecocultural theory are the concepts of *family schema*, *activity settings*, and *accommodation*. The broad concept of *family schema* is a product of culture and experience (McConnell & Savage, 2017) and is the global view of the family system. It includes beliefs about who family members are, ideas about what children need, goals and expectations for the family as a whole, and the family's approach to problem solving (Weisner, 2002).

The family schema is the atlas that assists families in what actions to take, it provides direction and motivational force (McConnell & Savage, 2017).

The concept of *activity settings* is more tangible than the family schema, and is suggested to be the structure through which ecological effects are mediated (Gallimore et al., 1989). Activity settings include both intentionally constructed learning activities (such as playing a game or reading together) and naturally occurring routines and rituals where family interaction is embedded (such as family dinners or celebrations of anniversaries). Activity settings offer opportunities for children to develop and learn through modelling, joint participation, and other forms of social learning within goal-directed interactions (Gallimore et al., 1989). Activity settings are the core unit of analysis for ecocultural theory and comprise five components. These components are: the people present, the cultural values and goals, the tasks being performed, scripts for conduct, and the participants' motives and engagement in the activity.

The third concept, *accommodation*, refers to a process through which all families in various ways, intentionally or non-intentionally, respond to conflicting interests and daily hassles. Accommodation is defined as a family's functional responses or adjustments to the demands of daily life (Gallimore et al., 1993). Accommodations encompass adaptive strategies, including actions taken, avoided, or delayed in response to serious concerns or mundane daily problems (Gallimore et al., 1996). Accommodations become visible in the organisation of domestic chores, marital role relationships, or childcare activities, for example. The accommodations made vary as a function of the family schema and depend on many factors, including ecological constraints, family resources, and cultural beliefs.

I now return to the study exploring mothers' perceptions of mealtimes for children with autism (Suarez et al., 2014) to exemplify. The decision to forego shared family mealtimes in order to focus on individual nutritional intake in the child and limit conflict, was an accommodation experienced as necessary for mothers to reach manageable everyday activities yet greatly disappointing, as well as coupled with feelings of guilt. In this example, the family ecology (e.g., limited time, no accessible professional assistance for the child) was pitted against sociocultural values (e.g., traditional food choices and shared family dinners), which affected the experience of the family's routines. Accommodations per se are neither positive nor negative. The valance of an accommodation could be judged as positive for the child, but negative for the parent or a sibling (Gallimore et al., 1993), as seen in the example above. Only long-term outcome assessments for children and parents can conclude the goodness of an accommodation. One outcome measure of accommodations is the sustainability of activity settings (Gallimore et al.,

1989). Sustainability in this case relates to activities that can be continued across times and multiple situations.

3.6.2 Ecocultural theory as an analytical tool

Ecocultural theory was considered valuable in the present thesis because the theory considers the meaning of everyday activities for children with developmental or acquired disorders and their families, merged with how daily activities influence the health of family members as well as intentional and non-intentional lifestyle choices. Thereby ecocultural theory complements the more individual, objective focus of the ICF. Ecocultural theory has also been a promising point of departure when exploring young children's experiences, for example, in pre-school care (Grace & Bowes, 2011), as the theory brings attention to details of everyday life and how these form a child's practical knowledge and perceptions of daily activities, by staying close to the concreteness of day-to-day in the style and content of data collection methods. Applying ecocultural theory offers a way to explore how children using a G-tube and their parents construct and participate in everyday routines and rituals. The activity setting of family mealtimes manifested the concrete representation of the family's ecological, social, and cultural context. The theory was used when designing interview concepts (Studies III and IV) and when discussing findings (Studies II, III, and IV).

In conclusion, this thesis is based on critical realism and departures from a systems theory approach to explore mealtimes of children with a G-tube and their families. Physiological, psychological, and social elements are viewed as interwoven and interdependent in the experiences and encounters of these children and their parents. This view directs the research to be conducted as close as possible to the families, and emphasises the importance of real-life contexts. Ecocultural theory in combination with the ICF, connected by the elaborated concept of participation, were chosen as the analytical tools to explore how feeding, eating, and family mealtime routines and rituals are influenced by the presence of G-tube in a child.

4. Previous research

The following chapter presents previous research that is relevant to the topic of family mealtimes for children with G-tube. First, family outcomes following G-tube placement, not specifically related to mealtimes, are reviewed. Thereafter follows a review of current research on family mealtimes and paediatric G-tube feeding.

4.1 Family outcomes following G-tube placement

Research examining family outcomes following a G-tube placement in a child is mixed. Improvements of the daily life have been reported, with reduction in feeding times, parents expressing less concern about their child's nutritional status, and improvement in parents' own social functioning and quality of life (Matuszczak et al., 2014; Åvitsland et al., 2013). The parents interviewed by Mahant et al., (2011) also described how siblings had an active role in the G-tube care, and how they appeared to gain maturity and intrafamily respect.

However, a review by Sullivan (2014) put forward how negative perceptions coexists with the improvements following G-tube placement. Mothers describe feelings of guilt about their child's poor growth, high levels of stress, and that the G-tube confirms the child's disability, marking parental failure of nurturing. Parental challenges also include practical limitations related to carrying and sterilizing equipment (Craig & Scambler, 2006), dilemmas relating to maintaining participation in everyday activities (Mahant et al., 2011), the management of comments from others to the use of tube-feeding, and difficulty knowing what is right for their child (Edwards & Leafman, 2019; Hopwood et al., 2020). Parents report the G-tube as an additional burden, restricting mobility which negatively impacts family vacations and social interaction with relatives (Edwards et al., 2016; Mahant et al., 2011), as well as feelings of professionals having control over family life (Sleigh, 2005). The studies reviewed above indicate that G-tube feeding can affect an entire family system physically, emotionally, and socially.

In an interview study of how parents learn to overcome challenges related to tube feeding, Hopwood et al. (2020) demonstrated four kinds of tools parents used to adapt: memory aids and readiness tools, metaphors and narratives, repurposed everyday objects, and personalised routines and materials. Yet, the question remains of how the activity of family mealtimes is affected and adjusted in families of children with a G-tube.

4.2 Family mealtimes in children with G-tubes

Several literature searches were conducted to explore current knowledge in family mealtimes for children with a G-tube. The final search was performed January 2021, in the electronic databases PsycInfo, Scopus, MEDLINE, and CINAHL. These databases were chosen to capture the interdisciplinary nature of paediatric G-tube and mealtimes. All empirical studies that investigated family mealtimes for children with G-tube feeding published between 2000 and 2020 were considered. This time frame was chosen because it was assumed to cover the contemporary scientific discourse of family mealtimes and paediatric G-tube feeding.

4.2.1 Key descriptive data

An initial analysis of key descriptive data from each study shed light on the dominant areas of the research in terms of methodologies and participants, consequently identifying significant gaps.

A total of 12 papers were identified, and the countries represented were: USA (3), United Kingdom (4), Australia (4) and Norway (1). The reviewed papers were published in 9 journals, encompassing the research areas of nutrition, health, occupational therapy, medicine, and child development. Three journals included multiple publications: *Child: Care, Health, and Development* (2), *Nutrition in Clinical Practice* (2), and *Australian Occupational Therapy Journal* (2). The number of participants range from 5 to 140. In one study, healthcare professionals were informants. In another study, adults with childhood G-tube placement were interviewed. In the remaining ten studies, parents provided information. Regarding represented health conditions, the children's underlying disorder was cerebral palsy in 3 studies. Other disorders included intellectual disability, Rett syndrome, Epidermolysis bullosa, and Ataxia Telangiectasia. Qualitative (6), quantitative (4), and mixed methodologies (2) were used. No study reported using a theoretical framework to inform design or analysis. A total of 3 studies had the specific aim of exploring aspects of mealtimes following paediatric G-tube placement. The other 9

studies examined for example level of parental stress, child and parent quality of life, and overall satisfaction after G-tube placement with mealtimes being one explored area, among others.

4.2.2 Increased mealtime satisfaction

Several studies, representing both qualitative and quantitative methodologies, reported parental satisfaction with children's feeding regimen and reduced time as well as pressure at mealtimes (Brotherton et al., 2007a; Downs et al., 2014; Glasson et al., 2020; Hubbard & Mayre-Chilton, 2015; Russell et al., 2017). Significant improvements were reported with easier, more enjoyable mealtimes for parents and children (Lefton-Greif et al., 2011; Åvitsland et al., 2013). Åvitsland et al. (2013) also reported a significantly improved parent-child communication during mealtimes 18 months after G-tube placement.

Other positive outcomes were the possibility to combine oral feeding with nutrition through the G-tube, and increased opportunities for the child to socially interact during mealtimes (Downs et al., 2014; Glasson et al., 2020). The young adults interviewed by Hubbard and Mayre-Chilton (2015) recalled how the G-tube placement for them as children had meant that food could be eaten just for pleasure or curiosity, rather than as physical necessity, and that the G-tube had given back the social aspects of eating. Another example of child influence following G-tube placement was given in Glasson et al. (2020), where some parents described how their child made choices to feed orally or return to G-tube feeding.

4.2.3 Emotional, social and practical challenges

Although family mealtimes overall improve after G-tube placement, practical, emotional, and social barriers were also evident in the reviewed studies. A survey study on parent perceptions of mealtime behaviours in children with tube-feeding demonstrated elevated levels of behavioural problems in the included children, compared to normative data (Burklow et al., 2002). The findings also suggested that despite commencing tube feeding, parents have concerns about whether their child gets enough to eat, and feel that their child's eating pattern hurts the child's general health. This concern can lead parents to engage in maladaptive feeding behaviours such as coaxing and force feeding. Behavioural issues were also raised in Franklin and Rodger (2003). Mothers expressed difficulties bonding with their infants because of disrupted early feeding. Similarly, parents interviewed by Petersen et al. (2006) described that mealtimes tended to centre around providing tube feedings for their child with cerebral palsy, and in the study by Rouse et al. (2002)

mealtimes were described as a mechanical function rather than a natural bonding time.

A number of studies highlighted the emotional value attached to eating orally, and that in many cases food consumed by mouth was attributed higher worth than G-tube feeding. Mealtimes were for some families of specific importance since other opportunities for social interaction were reduced in children with profound developmental disabilities. Parents reported a sense of loss with the elimination of oral feeding (Glasson et al., 2020; Petersen et al., 2006; Sleigh, 2005) and did not want their children to lose the gratification of eating, or a time of close contact. Many parents saw oral feeding as distinguished from G-tube feeding, and the provision of food as very important for their children to the point that parents insisted on feeding the children by mouth, despite medical complications or even when many of the children did not seem to enjoy it (Petersen et al., 2006; Rouse et al., 2002; Russell et al., 2017).

G-tube feeding was also associated with several practical mealtime challenges, for example adapting family schedule to fit the child's feeding regime (Russell et al., 2017; Sleigh, 2005), the child's G-tube restricting mealtimes outside of home, and that food-related social interaction with family and friends required extra organisation (Brotherton et al., 2007). In the study by Russel et al. (2017), only 9 of 36 parents (26 %) reported eating together with their child at shared family mealtimes. Although parents thought of the mealtime as a special time, and a source of family bonding, practical challenges led to parents feeling that the children's inability to be fed by mouth caused the children, but at times also parents, to feel "left out" or isolated.

4.2.4 Strategies to adjust family mealtimes

Learning to handle life with a child using a G-tube, and the impact of this feeding regime on the family mealtime routine, is not a linear process, yet only one study Russel et al. (2017) reported on the development of strategies to adjust. Parents in the interviews emphasised that coping with having a child with a G-tube and problem-solving were closely linked, and were both a consistent part of the mealtime experience, for example, "moving dining rooms into the living-room space; joining the child on the floor, propped on pillows; and using lamps or hanging plants to hook equipment were some of the adaptations that caregivers contrived to adjust their dining environments" (Russel et al., 2017, p. 6). This excerpt demonstrates that parents' ability to adapt, notice environmental barriers, and think beyond what comprises a typical mealtime may be a key to increase positive outcomes of G-tube feeding in the family setting.

The study participants reported a need for support when developing new routines and rituals, to maintain a sense of “normalcy” in the family. Parents also expressed frustration with healthcare professionals as “being removed from the realities of what is going on in the home” (Russel, et al., 2017, p. 7). The authors concluded that in order to enhance the success of home-based interventions such as G-tube feeding, more research is needed to explore parents’ abilities to implement and adapt to these interventions. The value attached to oral feeding for many parents also suggests that support for oral feeding should be given high priority.

4.2.5 Summary of findings

The quantitative data in the reviewed studies demonstrate high overall levels of satisfaction with G-tube feedings, yet qualitative data suggest that quantitative data is blunt and insufficient when exploring more complex events such as family mealtimes. Qualitative data provide information on personal experiences and emotional dilemmas not captured in a more standardised format. From these reviewed studies, it is clear that the family mealtime is an activity where biological, psychological, and social aspects are all present and inter-related. Many similarities were found between mealtimes for children with G-tubes and for children with other long-term health conditions without G-tubes, for example, the focus on oral intake and diminished attention to the cultural context of the family by researchers and healthcare professionals. Furthermore, this review illuminates the lack of children’s own perspectives, and the meaning they attach to feeding, eating, and mealtimes.

4.3 Concluding remarks

The importance of family mealtimes for child health and cultural learning and social interaction is well-recognised. Key strengths in prior studies focusing on G-tubes in children are the findings of positive effects on nutrition, growth and parental relief, as well as the elucidation of challenges in managing complications, practicalities, swallowing difficulties, and behavioural issues. These challenges form potential barriers for children to participate in family mealtimes and for parents to establish sustainable daily routines. However, little is known about how family mealtimes are organised, or families’ accommodations to meet the needs of the child with a G-tube as well as other family members’ needs. Furthermore, there is a lack of research exploring how healthcare professionals support these children and their families in finding and maintaining daily routines related to feeding, eating, and mealtime.

Also, research of long-term outcomes for children with G-tubes is scarce, thus limiting healthcare professionals in providing families with relevant information before and after G-tube placement, in developing treatment programmes, selecting functional outcome measures, and communicating across disciplines.

To address these gaps in the literature, this thesis built on existing research in childhood disability and paediatric G-tube use when setting out to explore what is specific about food and eating in families of children with a G-tube, but also what is universal in their thoughts and management of family mealtimes. The interest was directed towards the experiences of children and their parents, along with the picture captured in medical records by healthcare professionals, in order to provide a more complex picture of the health and the day-to-day food practices of children with G-tubes.

5. Aim

The overall aim of this thesis is to explore routines and rituals related to feeding, eating, and mealtimes in families that have a child with a gastrostomy tube, from the perspectives of healthcare professionals, children, and their parents.

The research questions for this thesis are:

- How do children with G-tubes and their parents experience and describe the activity setting of family mealtimes, and accommodate to food-related challenges?
- What kind of support related to feeding, eating, and mealtime is provided to children with G-tubes and their families?

The objectives for the four sub-studies were:

- To describe children with developmental or acquired disorders receiving gastrostomy tube feeding, and to compare longitudinal eating, feeding outcomes, and health-care provision related to eating and feeding. *(Study I)*
- To explore healthcare professionals' documentation of child health and everyday life related to nutrition, feeding, and eating following gastrostomy tube placement in children. *(Study II)*
- To explore children's experiences of mealtimes when living with a G-tube. *(Study III)*
- To explore parents' descriptions of family mealtimes and food-related challenges when living with a child using a G-tube. *(Study IV)*

6. Methodology

The topic of this thesis, everyday mealtimes for children with G-tubes, relates to both observable, countable measures as well as personal perceptions, making the research questions difficult to answer using one single approach. Therefore, this thesis applied a mixed method design that will be described in this chapter along with the materials, participants, and procedures included in the studies. The final section of the chapter summarises reflections on my own preconceptions and the ethical considerations made in the research project.

6.1 Study design

The conceptual framework of this thesis comprising the ICF, the concept of participation, and ecocultural theory, sought to balance the focus between the child, the child's contexts, and the interaction between the two. With this approach came a challenge to take multiple aspects of reality into consideration, and elaborate on a wide range of scientific concepts, as well as staying close to the mundane happenings of family mealtimes. A mixed-methods approach was chosen in the present thesis, since the combination of qualitative and quantitative techniques is suggested to provide informative, balanced, and useful research results (Nastasi et al., 2010) and was thought suitable to capture various aspects of the mealtime activity setting. Mixed methods can be applied within a single study with data integrated at some stage, or sequentially across studies (Creswell & Plano Clark, 2017). In this thesis, a convergent parallel mixed-methods design (Fetters et al., 2013) was applied in Study II with the quantitative and qualitative data collected concurrently, and sequentially across the four included studies.

At first, an introductory study (Study I) with a retrospective quantitative research design was conducted based on medical records. The study was designed to describe children with G-tubes in a structured and consistent manner regarding demographics, healthcare contacts, and longitudinal eating outcomes, and to examine connections between variables on group level. The findings guided the design of the following studies when it came to

participant focus, methods of data collection, and analysis tools. An overview of the study design and included studies is presented in Figure 1. Study II examined everyday life and health care during the first year following G-tube placement through the words of healthcare professionals, returning to the documentation in medical records. A mixed methods approach was applied to explore variations between the descriptions of daily family life and health status of the child, with the documented healthcare goals for the children with a G-tube. An inductive qualitative content analysis of the medical records was integrated with a deductive quantitative component following the domains of the ICF.

In order to contrast what was depicted in the medical records, the focal point of the two subsequent studies was on personal experiences and daily challenges facing affected children (Study III) and their parents (Study IV). A qualitative descriptive design was applied (Sandelowski, 2000) in both studies. This qualitative study design was thought appropriate considering the thesis aim, as the design entails the presentation of accounts in everyday language, as opposed to the more interpretive language of phenomenology or grounded theory, for example (Sandelowski, 2000). Qualitative, descriptive studies have been suggested as valuable in obtaining accounts of a phenomena concerning the *who*, *what*, and *where* of events, and can be of special relevance to practitioners (Sandelowski, 2000). The final integration of findings across the four studies occurred at the level of interpretation using triangulation (Fetters et al., 2013), Figure 1.

6.2 Study population and materials

The target groups in this thesis are children with G-tube and their parents. Study I was a cohort-study, including all children with a G-tube within one Swedish administrative region. The results of the study revealed the need for nutrition via a G-tube lasting over several years for children with developmental disorders, suggesting that everyday mealtimes will be deeply affected for a considerable period of time for such children. Therefore, the subsequent studies (Studies II, III, and IV) focused explicitly on children with developmental disorders and their parents.

The empirical material of the thesis consists of medical records and individual interviews. Medical records served as the basis of Studies I and II, as naturally occurring documents can be seen to represent what is actually happening in the world, independent of specific research activities (Bowen, 2009). In Studies III and IV, data collection through interviews was selected, as interviews are especially suitable for describing and exploring people's

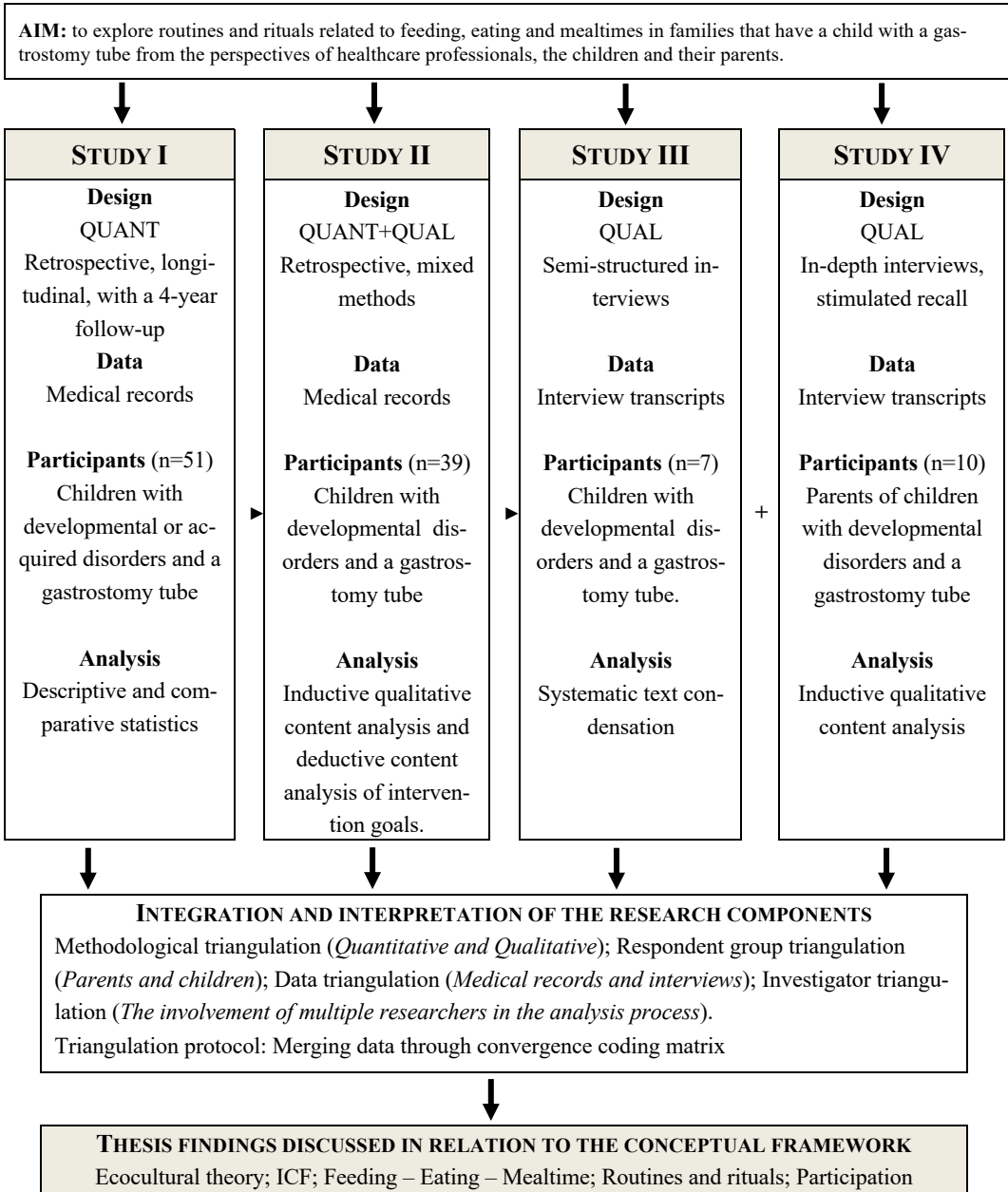


Figure 1. Flowchart showing the mixed-model design of the thesis, including the research aim, the included studies, the triangulation of methods, data and respondent group, and the integration of findings.

experiences, studying their understanding of the meaning of their lived world, and clarifying and elaborating their viewpoints (Kvale, 2007). In-depth interviews are also suggested as a valuable tool for unexplored research areas (Creswell & Poth, 2018).

6.2.1 Study I

As described in the background of this thesis, a child with a G-tube is prescribed care based on cooperation between a network of healthcare professionals, as well as between healthcare professionals and parents. One of the main tools for organising and documenting this cooperation is the medical record. Healthcare professionals are obliged to document healthcare measures in the patient's medical record. The record should contain information regarding a patient's state, the aim of the health care event, assessments, findings, and medical diagnoses, as well as information given to the patient and relatives (The Swedish Parliament, 2008). The aim of the medical record is primarily to contribute to safe care of the patient and good quality of documentation to improve the quality of patient care (Härinen et al., 2008). In the present thesis, the medical record was assumed to provide information concerning a child's health condition, assessments, interventions, and healthcare contacts.

Study I included the medical records of 51 children, 28 boys and 23 girls, with developmental (n=38) or acquired (n=13) disorders. The medical records were collected from secondary and tertiary healthcare providers in one Swedish administrative region with approximately 320,000 inhabitants. All children with a G-tube were eligible for inclusion, and inclusion criteria were (a) age at G-tube placement <19 years, (b) G-tube regime >1 month, and (c) a G-tube placement between 2005 and 2012. Within the region, specialised paediatric medical care is provided at one inpatient children's clinic at the major municipal hospital, three outpatient children's clinics, children's psychiatric outpatient clinics, and at child and youth habilitation service centres. Eligible children were identified through a search in the region's medical record system using the NOMESCO code JDB, Gastrostomy (Nordic Medico-Statistical Committee (NOMESCO), 2010) and the ICD-10 code Z43.1, Encounter for attention to gastrostomy (The International Statistical Classification of Diseases and Related Health Problems – 10th revision; WHO, 2011a). The primary diagnostic code from the ICD-10, as stated in the medical record by the paediatrician in charge of referring to G-tube surgery, was used to classify the underlying condition. The primary diagnoses were classified as 'developmental', relating to neurodevelopmental disorders or congenital

malformations, for example, or ‘acquired’, relating to conditions contracted after birth (Adams et al., 2014).

Data collection and analysis, Study I

The clinics involved in specialised paediatric medical care share the same system of electronic medical records, which allows several professionals to consult and edit patient records and easily access records made by colleagues. Data from the medical records were collected retrospectively, beginning at twelve months prior to the child’s G-tube placement through year four after G-tube placement. The medical records were accessed through the region’s electronic medical records system in December 2016, using an extraction protocol, Appendix 1.

Data were analysed using descriptive statistics and expressed as medians, min-max, and percentages. Non-parametric statistical tests were used to analyse differences between children with developmental disorders and children with acquired disorders, as the data was non-normally distributed. Comparison of categorical data was performed using Fisher’s exact test. Group differences in continuous variables were analysed using the Mann-Whitney U test for two independent samples. The quantitative analyses were performed using the SPSS software, version 23.0 (IBM Corp., 2015). A p-value <0.05 was considered statistically significant.

6.2.2 Study II

Documents like medical records do serve as informants, but can more properly be considered as actors in their own right (Prior, 2003). Medical records function as a distributing and collecting device where “all tasks concerning a patient’s trajectories must begin and end” (Berg, 1996, p. 510), and by reading and writing the record, tasks of how and what to do are mediated. However, a medical record will never include all that was dealt with during a telephone call, a healthcare visit, or a planning meeting. One of the values of the medical record is the very fact that it is selective, forcing its author to select, summarise, and transfer the current issues into manageable, defined problems within the healthcare provider’s working routines (Berg, 1996). The selection of precisely what type of information is recorded, and what links between data are considered more relevant than others, can be of particular scientific interest, as this will probably lead to the measures taken. Thus, in Study II, the medical records were assumed to reflect what healthcare professionals judged as important to document regarding the everyday challenges for children with G-tube and their families, as well as the efforts needed to approach these challenges.

Study II was conducted within the same administrative region as Study I and included the medical records of 39 children, 21 boys and 18 girls. Inclusion criteria were a) developmental physical, sensory, and /or intellectual disorders, b) age 1–18 years, c) G-tube regime >1 month, and d) G-tube placement between January 1, 2005 and December 31, 2015. Because one year of age is typically when children begin to play a more independent role in family mealtimes, due to the development of gross and fine motor skills, psychosocial development, and oral motor functioning (Arvedson & Lefton-Greif, 2020), it was chosen as an appropriate lower age limit.

Data collection and analysis, Study II

In September 2017, the complete medical records of all eligible children were searched systematically for notes covering areas of the G-tube, nutrition, feeding, eating, and/ or mealtimes, in the healthcare context of assessment, individual service plans, intervention; or follow-up within the first twelve months following the G-tube placement. In some instances, feeding or eating was the focus throughout an entire documented healthcare event. Sometimes, feeding or eating was mentioned or partially presented. The length of the texts from one healthcare event varied from short notifications, using standard phrases, to a couple of pages of free text categorised according to key words.

The medical records were analysed using inductive qualitative content analysis focusing on the manifest content (Graneheim & Lundman, 2004). This method was chosen because it is a systematic method to qualitatively analyse various kinds of empirical material (Graneheim et al., 2017), which was thought valuable, as the content of the medical records were anticipated to differ depending on the background of the healthcare professional. Meaning units from the selected texts were identified and extracted. A meaning unit was considered a phrase or paragraph that reflected the objective of the study through its content and context, followed and preceded by a shift of meaning in the text. The meaning units were condensed and abstracted into codes as understood in relation to the context. Similar codes were grouped into subcategories and categories. The coding and tentative categories were conferred upon and revised to ensure the credibility of the findings. Consensus was high throughout the analysis and only a few modifications were made following the discussions. The categories were illustrated by quotes taken from the original material. Lastly, an overall theme was formulated that encompassed the recurring regularities within and across the categories.

For the deductive quantitative analysis, documented intervention goals relating to the aim of the study were extracted from the individual service plans or when clearly stated as an intervention goal within another context of the medical record. Established linking rules (Cieza et al, 2005; 2016) were used

when assigning relevant codes to the intervention goals following the second level of classification in the ICF. A procedure of identifying meaningful concepts from the goals was performed prior to the linking process (Klang Ibrahimova et al., 2011). One limitation with using the ICF is the complexity of the classification, with over 1,500 categories relevant for describing functioning. Depending on the level of classification, an intervention goal such as “The child has developed her eating ability” (ID 37) could be coded as either d210 (Undertaking a single task) or b510 (Functions for eating and drinking). Steps were taken to follow published linking guidelines, yet the codes linked to the documented interventions goals in Study II might not be comparable across studies, depending on the training and the profession of the researcher.

Finally, the two data sets were merged together in a side-by-side comparison using a mixing matrix (O’Cathain, Murphy, & Nicholl, 2010) in order to identify similarities and differences in how categories from the qualitative content analysis were reflected in the documented intervention goals and vice versa. The software package NVivo (QSR International, 2020) was used to organise the text extracts.

6.2.3 Studies III and IV

The second half of the research project included children with a G-tube and their parents. The families were recruited by healthcare professionals working at clinics responsible for the routine follow-up of paediatric G-tubes within three administrative regions in Sweden. In total, seven children aged 6 to 12 years (median 8 years) participated, Table 1. The parents were given the option to be interviewed individually or together. Three parent interviews were with mother and father together, and four interviews were with the mother alone. This rendered a sample of ten interviewed parents. All participating families had Swedish as their first language, and lived in towns and rural areas in southern Sweden.

The child with the G-tube had to fulfil the following inclusion criteria: a) developmental physical, sensory, and /or intellectual disorders, b) age 6–12 years, c) G-tube regime >1 month, and d) a level of communication that enabled them to convey descriptions using speech or other modes of communication (e.g., using sign language or graphic communication boards) with or without support from a familiar communication partner. Exclusion criteria were malignancy or traumatic brain injury, and a communicative ability seldom effective even with familiar partners.

Table 1. *Participants in Studies III and IV with demographic characteristics for the interviewed children.*

Participating child	Participating parent	Time since gastrostomy tube placement (in years)	Feeding habits ¹	Level of communication ²
Alice	Mother and father	7	Most in tube	I
Cindy	Mother	12	All in tube	IV
David	Mother	5	All in tube	II
Gustav	Mother and father	8	Mostly orally	III
Karl	Mother	0.5	Most in tube	II
Lisa	Mother and father	8	Most in tube	I
Teo	Mother	5	All orally	III

¹Feeding habits were estimated using a 4-point scale: all in tube, most in tube, mostly orally, or all orally. “Most in tube” was defined as more than 50 percent of total intake in the tube, and “mostly orally” was defined as more than 50 percent of total nutritional intake from liquids and solid food orally (Åvitsland et al., 2006).

²Level of communication was classified using the “Communication Function Classification System” (Hidecker et al., 2011) ranging from Level I (a person independently and effectively alternates between being a sender and receiver of information with most people in most environments) to Level V (a person is seldom able to communicate effectively even with familiar people). All modes of communication were considered.

Children aged 6 to 12 years were selected, as they have a greater linguistic and cognitive competence to reflect on their experiences than younger children, yet have specific needs adapted to interviewing methodology compared to older children (Kortessluoma et al., 2003). The intention was to obtain a varied sample of gender, age, time since G-tube placement, and amount of food taken by mouth. In total, 21 families were contacted and given thorough oral, written, and pictorial information about the study. Thirteen families agreed to take part in the study, of which six later withdrew prior to data collection. Reasons for declining involvement included parents not having enough time, children not wishing to take part in an interview, and the health conditions preventing participation.

Interview procedure

The interview procedures applied in the present thesis were developed based on ecocultural theory, and the five components of an activity setting: the people present, cultural values and goals, the tasks being performed, scripts for conduct and the participants' motives and engagement, as well as professional clinical experience in families of children with developmental disorders. The questions were designed to explore children's and parents' experiences of everyday mealtimes and G-tube feeding, as well as the support they received. Although the interview procedures were developed based on previous research, careful attention was given to formulating broad questions open to discovering new areas of importance. One demanding choice in qualitative interviewing is the type of questions used. Generalised and abstract questions can be difficult for participants, especially children, to reflect upon and for interviewers to make sense of (Bauman et al., 2002; Einarsdóttir, 2007), yet too practical and exact questions will give little room for exploration of participants' meaning and understanding of the research topic. Another choice is between structured or unstructured questions (Bauman et al., 2002; Kvale, 2007). A structured interview may be perceived as rigid and lacking in flexibility if all questions are prepared before-hand, yet aid the researcher in posing the same questions to all participants. An unstructured interview may be more open to the personal narratives and associations of the participants, yet the accounts may more easily diverge from the topic.

Study III had a theoretical focus on the children's perspective and situated practices related to the G-tube, food, eating, and mealtimes. A semi-structured, flexible approach was assumed, suitable to enquire into children's experiences. Also, modes of communication and the order of the interview activities could be adapted with a flexible approach, thereby making it possible to include children who would be unable to participate in a more standardised format. The point of departure was the belief that children differ from adults in how they view and reflect upon their own lives. Thus, to gain understanding of children's unique reality, methods that suit their competence, interest, and context are required (Alderson & Morrow, 2011). Alternative and augmentative communication (AAC) strategies were used throughout the research process to prepare the children before the interviews; when explaining the aim and data collection; during the interviews to aid the children in understanding the questions and in expressing themselves; and, when ending the visit, for the children to evaluate the interview process. Play-based, structured activities supported the conversation with the children, as play activities are more familiar and more relaxed for them than regular interviews (Clark, 2005). These activities, further described below, included drawing a picture, playing a board game, and picture-supported interview questions.

Study IV explored parent's descriptions and experiences of everyday mealtimes with individual in-depth interviews including a stimulated recall methodology using video-recorded family mealtimes. A combination of generalised, practical, structured, and unstructured questions was used, Appendix 2. Stimulated recall involves video-recording an activity, then replaying the recording to the participants so that they can comment on matters of interest (Lyle, 2003). Stimulated recall can deepen the understanding of a person's perception of an activity and the meaning attached to activities and tasks (Dempsey, 2010). Stimulated recall presents participants with an opportunity to discuss strategies for interaction while they are directly faced with examples of themselves engaging in interaction, thereby complementing more commonplace interview procedures where participants are asked to remember actions that they have taken or the values and strategies that they use in general (Dempsey, 2010). In the research context of childhood disability, Wilder (2008) showed that using video recordings of everyday interactions when interviewing parents supplemented other methods of data collection and added greater depth to the material. In Study IV, watching a recorded family mealtime together with the parents was chosen to make possible a conversation about intentional, sub-intentional, or unintentional performed actions and accommodations. The events in the recordings were to serve as a stimulus to help parents recall and develop their ideas about routines and rituals of everyday mealtimes. A pilot study was conducted to check the feasibility of the data collection and the interview procedures. The pilot study resulted in minor changes in picture choice for the child interviews and in the interviewer's preparation before the parent interviews.

Data collection: Studies III and IV

Data were collected from December 2018 through November 2019, and organised according to Figure 2. For families willing to participate in Studies III and IV, a preparatory home visit (Visit #1) was scheduled to talk the study through, answer questions, and receive proper informed consent. The preparatory home visit also included gathering demographic information about the child, a period of initial rapport building, and providing the child with a picture-supported letter explaining the content of the coming interview. Talking to the parents and the child during this first home visit provided basic understanding of the child's feeding, eating, and communication. The child interviews could thereby proceed more smoothly, as activities and communication materials could be tailored according to the explicit needs of the child. At this visit, a video camera was left with the family, with instructions to record three ordinary family mealtimes over the course of a two-week period. The parents

were then to choose one of these recordings that they felt captured a typical family mealtime, and which they felt comfortable to share.

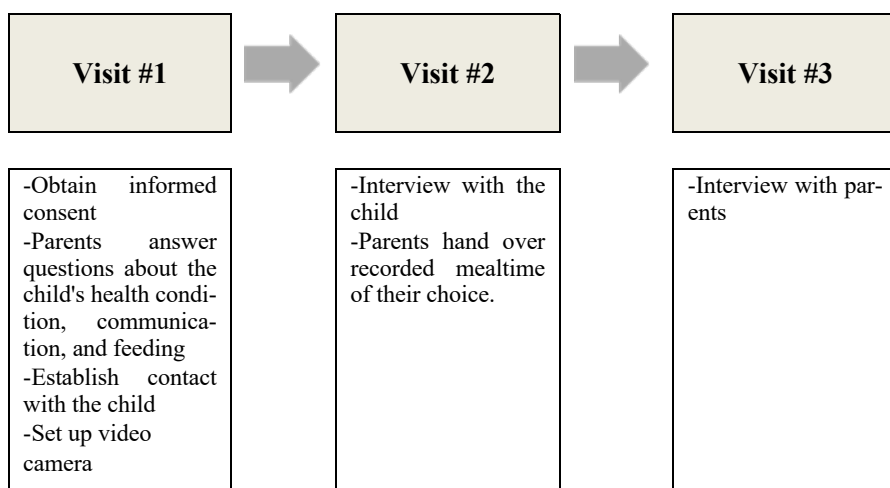


Figure 2. Description of data collection in Studies III and IV.

Approximately two weeks after the preparatory home visit, the child interview took place at a venue of the child's choice (Visit #2). Six interviews were conducted in the home of the children, and the interview of one child was performed at a local hospital. The children chose whether a support person would be present during the visit. One child asked for the mother to be present, and one child asked for the mother and a personal assistant to be present. All children were asked if there was anything they wanted to do together with the researcher prior to the interview. Typically, the children wanted to show the interviewer some toys or games.

The child interviews began with an explanation of the research project, to clarify the purpose of the study activities for the child. Information about the study was explained using verbal language in combination with a visual scheme of the interview activities and a graphic communication board, in order to aid children in talking about concepts new to them, for example, 'confidentiality', Appendix 3. The level of AAC depended on the linguistic and cognitive abilities of the child.

After the introductory activities, the child was asked to draw a picture of the family's typical mealtime. The drawings themselves did not serve as data, but as a means of facilitating conversation with the child and to serve as a joint referent (Greene & Hogan, 2005). Drawing a picture has been suggested as an effective and respectful method to enhance conversation with children, as it is not controlled by the interviewer, but rather comes from the child and

provides a reprieve from the pressure of making eye contact (Dockett & Perry, 2007). A limitation may be that not all children like to draw, or have physical impairments that make drawing difficult. Hence, children in the study were offered a choice between drawing with pen and paper, on a tablet, or providing descriptions to the interviewer, who drew in the child's place. Next, questions and unfinished sentences relating to food, eating, mealtimes, and interests of the child were entangled into the context of a specially created board game. Examples of prompts were "In the kitchen I like to ...", or "My favourite dish is...". One advantage of the board game is the counterbalance the activity provides to the asymmetry of power between 'child' and 'researcher', making them two equal collaborators.

The last part of the visit included a semi-structured interview. The interviews were based on thematic questions about everyday mealtimes with additional picture-support to facilitate the child's understanding and expression. The questions were designed as concretely as possible, with clear connections to what the children actually do in everyday life (Grace & Bowes, 2011), for example, "Tell me about a really bad food memory", or "Describe how your family eats dinner". Topics were introduced using open-ended questions to elicit spontaneous narratives, then complemented with direct questions and picture-based support to follow up on vague, confusing, or even contradictory information. Other interview techniques were rephrasing questions, paraphrasing and summarising responses, using hypothetical questions, and providing interviewer-supplied examples (Bedoin & Scelles, 2015). Ending the visit, the interview activities were evaluated by the child using Talking Mats. Talking Mats is a visual framework that allows individuals with communicative and cognitive disabilities to reflect upon and express their views on various issues (Murphy et al., 2013). Talking Mats is used by placing a picture representing a conversational topic at the bottom of a mat, while pictures illustrating an evaluation scale are placed on the top of the mat by the interviewer. In the study, one picture for each of the activities during the visit was then placed below the top scale by the child as an answer to open-ended questions like, "What did you think about drawing a picture?". The purpose of this last activity was to sum up the visit, assess how the interview approach was perceived by the child, and to obtain improvement proposals for future interviews. The interviews were video recorded digitally and lasted between 35 and 70 minutes (mean length 52 minutes).

The interviews with the parents (Visit #3) were scheduled to allow for me to review the family's mealtime recording in advance. The recordings were reviewed using an observation template organised according to the five components of an activity setting. Sequences that evoked questions related to mealtime accommodations, routines, and rituals were selected to present at

the coming interview. Thus, the recordings did not serve as data, but served as a joint referent and as means of facilitating conversation with the parents.

The interviews started with a broad question about the family's everyday meals, and parents were asked to describe their day-to-day lives in relation to food, eating, and mealtimes. Thereafter the interview deepened, and the parents were encouraged to respond freely about areas introduced by the researcher, Appendix 2. Following the thematic questions, sequences from the recorded mealtime were presented and discussed. I introduced the sequences and encouraged the parents to reflect upon what they saw happening during the recorded mealtime. The goal of the interview was to create a climate that supported an organised conversation yet avoided question-answer collaboration, or asking leading questions that might prompt the parents to respond in a desired way. The interviews were audio-recorded and lasted between 42 and 111 minutes (median 77 min) of which 27 to 50 minutes (median 36 min) were based on stimulated recall.

Data analysis: Studies III and IV

The child and the parent interviews were transcribed orthographically following the guidelines suggested by Guendouzi and Müller (2006). Spoken language is not like written language, neither in what words are used nor how they are assembled into connected speech. Transcribing children's speech is even more challenging, as the linguistic system is under development, and the researcher must consciously choose how to map spoken forms as they were said by the child or the standard lexical item used in adult language. Transcripts were prepared with the coming analysis in mind, with focus on the participants' experiences, and included verbal utterances as well as non-verbal aspects of the interaction (e.g., gestures, pauses, overlapping speech, pointing on communication board, or sign language usage), but did not include details that might obscure the overall accessibility of the transcript (e.g., the interviewer's repetitive encouraging *hm*'s and *yeah*'s). Focus was on content, rather than phonology or linguistic patterns. The software package NVivo (QSR International, 2020) was used to organise the transcripts.

The child interviews were analysed by means of systematic text condensation (Malterud, 2012). Systematic text condensation presents a methodical approach for thematic analysis of qualitative data and was chosen as it has been proven valuable for analysing small sample sizes (Malterud, 2012) and accounts of participants with communicative disabilities (Buchholz et al., 2018). The procedure of condensation, specific for this method of qualitative analysis, ensures an elaborated review of sorted meaning units and prevents the researcher from favouring meaning units supporting preconceptions (Malterud, 2012). The analysis was carried out stepwise to 1) establish a

general impression of the data and define initial themes, 2) identify and code meaning units, 3) abstract and condense the content, and 4) synthesise and summarise the content into categories and subcategories.

The parent interviews were analysed following the steps of inductive qualitative content analysis (Graneheim et al., 2017; Graneheim & Lundman, 2004; Lindgren et al, 2020). This analysis method was selected because it comprises both phenomenological descriptions of the manifest concrete content, close to the text, as well as hermeneutic interpretations of the latent abstracted message. Qualitative content analysis offers a systematic approach to analyse qualitative data through described concepts and tools such as meaning units, codes, and categories. Furthermore, the process of decontextualisation and abstraction of the material aids a cross-case comparison and integration of findings.

6.2.4 Integration of the findings

To interpret the main findings of this thesis, the results and discussions from the four inter-related studies were triangulated (O'Cathain et al., 2010) after finishing the separate analyses. The integration was assumed to lead to both a confirmation of the results when comparing the included studies, an expansion of the results when various perspectives on G-tube feeding and family mealtimes were explored, and an illumination of any discrepancy between results.

As suggested by Farmer et al., (2006), the process followed a triangulation protocol to increase transparency and provide insight into how the analysis was carried out. First, the results and the discussions from the four studies were reviewed thoroughly to get a sense of the whole. Second was a phase of sorting, and all information relevant to the thesis aim and the research questions was identified and extracted into the NVivo software to aid the organisation of excerpts. Third, the excerpts were sorted, interpreted into meta-themes cutting across the studies, and organised in a convergence coding matrix to facilitate comparison between the studies, Table 2. Fourth, the content within each meta-theme was assessed and evaluated concerning the coherence of the findings. This step involved denoting any *convergence* (agreement), *complementarity* (partial agreement), *silence* (a finding in one data set and not another) or *dissonance* between the studies. O'Cathain et al., (2010) articulates explicitly that looking for disagreements across findings is of particular importance and is not to be seen as a methodological flaw but as leading to a better understanding of the research question. Also, surprise silences might lead to an increased understanding or a discovery of areas in need for further investigation. However, silence can also be expected due to

differences in data collection methods. Fifth, the merged findings from the four studies were reported through a narrative weaving approach (Fetters et al., 2013).

Table 2. *Examples of a convergence coding matrix, meta-theme 1.*

Meta-theme 1: The Child's Feeding Disorder		
Study I (Health care perspective)	The median age at the time of G-tube placement was 35 months. Four years after placement of the G-tube, two thirds of the studied children still required the G-tube. Only 16% children with developmental disorders transferred to eating all orally, as opposed to 91% children with acquired disorders.	Convergence
Study II (Health care perspective)	The median age of the study participants was 38 months. No description of change over time or notes on prospects for the future were found in the medical records.	
Study III (The perspective of the children)	The children differed in how they viewed their future need for the G-tube, ranging from 'will need', 'might need' to 'won't need' when older. The children viewed the G-tube as a natural part of themselves, and clearly communicated a previous lack of interest in food.	
Study IV (The perspective of the parents)	The parents described their children as never liking food, never showing interest in food, or never being able to breast-feed. Unsure about the child's eating in the future, always in need of nutritional supplements, but improvement of family mealtimes, accepting to sit at the table, and increased interest for food.	

6.3 Reflexivity

A researcher's self-reflection is an essential part of all research, as the researcher's background and position will affect the research questions asked, the perspective of the investigation, the methods chosen, and the conclusions drawn (Malterud, 2001). The present thesis is based on critical realism, which recognises that knowledge about what constitutes reality is context-bound and dependent on human representation. Therefore, empirical data and research findings are not be seen as something that "emerge" or are objectively "out there" waiting to be assembled. Knowledge is rather constructed in co-operation between the researcher and the study participants (Bauman et al., 2002). The knowledge construction applied in the present thesis is dependent on the combined efforts of myself, as a researcher, the children, and the parents. For example, the quality of the empirical material from the interviews depended on the type of questions asked, the interviewees' ability to

formulate thoughts into verbal accounts, and the interviewer's way of listening and interpreting the answers.

My background as a trained speech-language therapist with over ten years of professional experience was advantageous when completing the review of the medial records, in facilitating family recruitment, and in planning and executing the interviews. Familiarity with the documentation process, multidisciplinary teamwork, and with the electronic medical records system made a comprehensive assessment possible in Studies I and II. This assessment might not have been possible without this clinical experience. The knowledge of main characteristics in children with developmental disorders but also their inter-individual variations, along with training in family-centred health care, was essential in how the data collection was organised and completed. Also, the experience of interacting with children on various communicative levels, in using AAC and being accredited in the Talking Mats procedure, was imperative in planning and executing the child interviews. Concerning the parent interviews, my clinical experience contributed to an overarching understanding of the healthcare process for children with G-tubes and their families.

Even though my previous experience in many ways was beneficial, it was sometimes difficult to maintain distance and balance already existing knowledge. The combination of my clinical experience with my active role in the data collection and analysis may have resulted in taking things for granted, or overlooking areas of importance. One way to evade this was the use of the ICF and ecocultural theory. However, a challenge with ecocultural theory is that researchers who are not members of the same cultural context as the participants often have limited understanding of the unique ecocultural niche in question, whereas researchers who are members of the same cultural context may have pre-understandings that hinder an open reflection of the empirical data. Therefore, the research design must allow for an open and flexible approach, valuing the balance of power and pre-conceptions between the professional researcher and the participants. One example of this openness within the present studies was that families were provided the space and opportunity to film their own family mealtimes, thereby counteracting possible prior beliefs of the researcher (Study IV). A second example of how the importance of context familiarity was taken into consideration was the allocation of data collection responsibility to one researcher regarding the medical records (Studies I and II) because of previous experience with the clinical population.

Another strategy to illuminate the influence of prior knowledge was bracketing. Bracketing is a procedure in which a researcher's preconceptions are made visible (Tufford & Newman, 2012), and was accomplished

throughout the research process by writing observational memos as a means of examining and reflecting upon my course of action and methodological choices as well as the empirical material.

The ambition of this thesis is to be descriptive and stay close to the wording of the participants, yet all enquiry entails interpretation (Lindgren et al., 2020; Malterud, 2001). The qualitative analysis included abstracting and de-contextualising the notes in the medical records and the participants' accounts in a process moving away from the original text. As a text can involve multiple meanings and change meaning depending on how meaning units are selected or coded, this process is dependent on subjective interpretation (Graneheim & Lundman, 2004). Continuous reflection took place throughout the data collection regarding what and how much from the medical records to include to ensure trustworthiness of the document sampling. There was a strict methodological adherence and thorough explanation of the steps taken to organise and interpret the collected data. Representative quotes from the medical records and the interviews were included to demonstrate the connection between the data and the findings.

Re-contextualisation in qualitative analysis is a co-creation of the researcher and the text, involving interpretation of both the manifest and the latent content of the text (Graneheim et al., 2017). The influence of my preconceptions on the findings was taken into consideration during the research process through continuous discussions with my supervisors, in order to view the empirical material from various perspectives. As suggested by Sandelowski (2000), interpretations in all steps, such as selecting meaning units, coding, and formulating categories, were continuously discussed. The research group comprised different professions and levels of experience, including clinical and theoretical expertise in child development, childhood disability, and family-centred care, as well as the field of health and lifestyle. This breadth was a strength throughout all phases of the studies, design, data collection, analysis, and reporting of the findings. It permitted various perspectives on the medical documentation and the interviews deriving from both clinical and theoretical experience, making the data collection and interpretation less vulnerable to individual notions.

6.4 Ethical considerations

The project was reviewed and ethically approved by the Regional Ethics Committee in Lund (Approval No. 2016/93) and by the Swedish Ethical Review Authority (Approval No. 2019-02714). In order to gain access to the medical records, the head of the clinics and the controller of the hospital as

well as the university responsible for questions related to the General Data Protection Regulation (GDPR; European Union, 2018) were informed, and they approved the review.

The included studies adhere to the ethical guidelines of the Declaration of Helsinki (World Medical Association, 2013) and the ethical principles described in the Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). The practical applications of these ethical principles lead to consideration of the following: the selection of participants, informed consent, and risk/benefit assessment.

6.4.1 The selection of participants

Children with developmental disorders are a vulnerable group, and taking part in an interview situation might be demanding in various ways. On the other hand, children are supposedly the best source of knowledge about their own life. Resting on the principle of justice described in the Belmont Report (1978), and on children's rights (United Nations, 1990), the healthcare of children with G-tubes cannot be evaluated and improved if the affected children themselves, and their families, are excluded from research. The present thesis was concerned with making the research as comprehensible as possible for both children and parents. For example, this meant being flexible and open to any desires of individual families regarding timing of home visits, in order to facilitate study participation. Another example was the adaptable interview concept, which provided the children with possibilities to describe their own experience tailored to their individual prerequisites and abilities.

6.4.2 Informed consent

Studies conducted with children differ from studies involving adults with regard to the informed consent of a third person, who decides whether children are to be given the choice of participating (Einarsdóttir, 2007). In Studies I and II, parents of the eligible children received written information and were given the possibility to withdraw from the medical review at any point in time. For Study III, the children's parents gave informed written consent. The children themselves did not sign informed consent. The child's informed consent was understood as the willingness to provide information during the interview and could thus be withdrawn at any time (Einarsdóttir, 2007). It was seen as an on-going achievement through the interviews, rather than an agreement beforehand (Mukherji & Albon, 2010). No child withdrew from the study during the interview. Occasionally, children demonstrated

unwillingness to continue discussing a specific issue, asking to move on to the next activity.

Detailed information was given regarding the voluntary participation, confidentiality, and the possibility to withdraw from the studies at any point in time. All participants were fully informed about how the collected material would be kept and their right to receive information about stored personal data following the GDPR.

6.4.3 Risk/benefit assessment

In research involving people, it is central to weigh benefits against the risks that participation may entail. The benefits for the participants of this thesis were the possibility of giving voice to children living with G-tubes and their parents, making their individual insights visible and meaningful. In doing so, healthcare could in the future be better tailored to meet the needs of affected families.

Considering potential harm, none of the studies was of such a nature that they themselves caused physical pain or injury. However, taking part in research studies always poses a risk of experiencing being monitored during the collection of data. The aspect of disclosing material from medical records may feel inconvenient, as the information was once collected and shared within the context of professional secrecy. Therefore, the families in Studies I and II received written information regarding the purpose of the research and how the material was to be handled. Regarding the use of interviews and video recordings, both methods can cause psychological distress when participants come close to their own actions and feelings, perhaps becoming aware of aspects in everyday life that they previously may not have been aware of. Detailed information was given in advance about why and how the data collection would be executed. During the interviews, space was given for participants to reflect upon any emotions that surfaced.

The data material was anonymised and only related to a given code (Studies I and II) or pseudonym (Studies III and IV) to protect the privacy of the participants. The material was stored separately from the code key and only available to researchers involved in the studies. When reporting the findings, caution was taken to balance the use of descriptive examples, while maintaining anonymity, despite small patient groups and rare disorders. With this awareness and preparation, the benefits of conducting the studies within the thesis were considered to outweigh the potential harm.

7. Findings

This chapter presents a summary of the findings from the thesis' four sub-studies, each with a specific aim for which data were initially collected, analysed, and reported separately. Thereafter the integrated findings are reported in relation to the two overarching research questions posed in the thesis. Together the studies aim to explore routines and rituals related to feeding, eating, and mealtimes in families that have a child with a G-tube from the perspectives of healthcare professionals, the children, and their parents.

7.1 Main findings: Study I

In Study I, the medical records of 51 children within one administrative region of Sweden were used to describe and compare characteristics, healthcare contacts, and eating outcomes according to whether the children's primary diagnosis was "developmental" ($n=38$) or "acquired" ($n=13$). Children with developmental disorders had a median age of 24 months at the time of G-tube placement, whereas children with acquired disorders had a median age of 109 months ($P=.041$). In comparison, children with developmental disorders displayed a longer duration of the G-tube feeding regime. Discontinuation of G-tube feeding due to eating sufficiently orally occurred after a median of 16 months (min-max: 2-43 months) after placement and was more often seen in children with acquired disorders ($P<.001$). Four years after the G-tube placement, 6 of 37 (16%) children with developmental disorders had transferred to eating all-orally, as opposed to 10 of 11 (91%) of children with acquired disorders. Three children died during the study period, all attributed to causes other than G-tube placement. The analysis of involved healthcare professionals demonstrated that the children with developmental disorders had contact with a greater number and variety of healthcare professionals both before and after placement, compared to children with acquired disorders.

The discrepancies in age at G-tube placement and in duration of G-tube feeding regime between children with developmental disorders and children with acquired disorders anticipates different prerequisites for eating development dependent on the underlying disorder, as well as how the G-tube and

associated difficulties will affect the children's family. Therefore, the succeeding studies focused on children with developmental disorders.

7.2 Main findings: Study II

In Study II, the medical records of 39 children with developmental disorders and a G-tube were searched for notes related to feeding, eating, and mealtimes to explore healthcare professionals' documentation of child health and everyday mealtimes following G-tube placement. The inductive content analysis resulted in one overall theme, "Seeking a balance", reflecting how children's curiosity and opportunities for development, as well as parental values and desires, had to be weighed against safety and medical aspects. This demanded flexibility from all people involved in the care for the child on a day-to-day basis, and a constant adjustment of daily routines in order to meet the specific needs of the child. Two main categories, with seven subcategories, captured the key aspects of the documentation. The main category "Striving for physical health" outlined the collective effort of parents, and professionals in the child's environment for improved physical child health following G-tube placement. Actions were predominantly directed towards providing nutrition, attaining satisfactory growth, and caring for the gastrostomy stoma. The main category "Depicting everyday life" covered the use of the child's G-tube and the daily nutrition, feeding, eating, and mealtimes. The documentation provided a description of the current status but did not result in any intervention or other healthcare measures. The notes in the medical records provided substantial information about the child's health status and nutritional intake. The actions were fewer and more generally described when they concerned emotional, social, or environmental aspects.

The inductive content analysis was followed by a focused deductive analysis of the documented healthcare goals. Twenty-one children (54%) had intervention goals related to the G-tube, and these goals primarily focused on the ICF domain "Body structure and functions". The most common topics of the goals were found to be related to ingestion functions, ICF code b510 (n=9; 24%), and growth, ICF code b530 (n=8; 22%). Connecting the inductive and the deductive analysis emphasised the predominant focus on biological aspects in the medical records. Another similarity between the two data sets was the focus on the individual child rather than the activities or contexts in which the child was situated. The medical records were sparse on examples related to participation in food-related activities, or how caregivers could promote a supportive environment during mealtimes.

7.3 Main findings: Study III

The third study explored children's experiences of mealtimes when living with a G-tube. The analysis of the interviews with seven children using a G-tube resulted in four main categories and eight subcategories. The following main categories comprise the findings of the children's mealtimes experiences: "Stable in form, open to variation", "An individual, and a shared activity", "An object that needs to be dealt with", and "A part of me". A complex picture emerged, where the children described nutrition, whether through the G-tube or orally, as necessary for a healthy body, although this did not suffice to make the mealtime a positive experience. For some children, eating was associated with undesirable effects, such as difficulty processing specific food textures, stomach-ache, nausea, and choking. However, the value of eating together with the rest of the family was expressed by all children, even those with very little oral intake.

The children voiced ambiguous feelings about having a G-tube. It was spoken of as a natural part of their body, and as something positive and necessary for their health, combined with feelings of difference from their peers. The children rarely perceived that the G-tube restricted them, even though their accounts illustrated adaptive strategies to make certain activities possible.

7.4 Main results: Study IV

The fourth study explored parents' descriptions of family mealtimes and food-related challenges when living with a child who has a G-tube. The parents' descriptions were summarised in four main categories reflecting the manifest content: "One situation, different functions", "On the child's terms", "Doing something to me", and "An unpredictable pattern". An overarching theme was interpreted as mealtimes being "An everchanging kaleidoscopic experience", corresponding to the latent content of the interviews. One aspect of the kaleidoscope metaphor was how mealtimes were assembled from smaller parts that were not always of interest on their own, but taken together, created a fascinating, complex representation. Another aspect of the kaleidoscope metaphor was how a small alteration in perspective or compilation could change the image entirely, even though the basic components of the mealtime remained the same. Mealtimes were experienced as closely related to physical abilities and behaviours of the child with a G-tube, but at the same time were referred to as a collective event, essential for social interaction and the creation of family identity. The analysis showed that parents of children with a G-tube found joy in and strived for establishing mealtime routines and rituals in line with their social and cultural context, while struggling to reach

a point of satisfaction and sustainability. The parents experienced little interest from healthcare professionals in understanding or providing support beyond the practical handling of the G-tube or the nutritional intake of the child.

7.5 Integration of findings

The integration of the studies focused on the *convergence*, *complementarity*, *silence*, and *dissonance* (Farmer et al., 2006) between the healthcare perspective, the children's perspective, and the parents' perspective, and was guided by the overarching research questions of the thesis. A total of five meta-themes were interpreted, Table 3.

Table 3. Overview of the overarching research questions and meta-themes integrating the findings.

Research question	Meta-themes
How do children with G-tubes and their parents experience and describe the activity setting of family mealtimes, and accommodate to food-related challenges?	The child's feeding disorder A situation full of meaning Daily challenges with the G-tube
What kind of support is provided to children with G-tubes and their families related to feeding, eating, and mealtime?	Parents' responsibility An array of care actions

7.5.1 The child's feeding disorder

This first meta-theme covers how the feeding and eating difficulties of the child were evident at an early age, at present, and expected to continue to affect future family mealtimes. The numerical data from the medical records, the children's narratives, and the children's health history as described by their parents were convergent in viewing the feeding disorder as evident from early on in the children's life, specifically for children with developmental disorders. The median ages of the children at the time of G-tube placement were 35 months in Study I and 38 months in Study II. Combined with the fact that several children had prior nutritional supplementation through a nasogastric tube, this suggest that the children struggled to attain adequate nutrition from a very young age. In the children's own accounts, these results were mirrored in how they talked of the G-tube as a natural part of their body, and recall never being interested in food. The early feeding disorders were also apparent in how parents spoke of nutritional challenges with their children, for example, children being unable to breast-feed, and mealtimes differing completely from parents' experience with siblings.

At present, the perspectives complemented each other in what the difficulties were and how they were accommodated for in everyday life. The interviewed children were very aware of how their feeding and eating differed from family members and peers. They mentioned having access to preferred foods, as well as being given sufficient time, as helpful accommodation strategies to feel engaged in mealtimes despite the difficulties. The parents talked of how the children's feeding and eating affected various aspects of the family mealtime. One aspect was how family dinners were planned according to the child's food preferences to counteract negative mealtime experiences. This resulted in less variety and less experimental cooking than would have been the case in the absence of the child's disorder. For example, Alice's parents described:

FATHER: You have to give in ((laughter))

MOTHER: Yes, Alice is the one who decides ... yes, as long as she eats
(Parent interview, Alice)

This extract exemplifies how family mealtimes were constantly centring around the needs and resources of the child with the G-tube. There was convergence between the healthcare perspective, the children's perspective, and the parents' perspective in that the G-tube, an accommodation per se to the child's feeding disorder, was perceived as necessary for growth and overall energy levels. Other positive aspects of the G-tube mentioned across the studies were the benefits of the skin-level device that could be hidden under clothing, practical aspects of pump feeding contributing to making time for other activities, and the relieved pressure on family mealtimes and oral eating to secure nutritional intake.

There was convergence between the three studied perspectives regarding the future and the long-term need for nutritional supplementation through the G-tube. The results in Study I revealed that four years after placement, two-thirds of the studied children still required the G-tube. Six of the seven interviewed children, presenting various developmental disorders, had had the G-tube for over four years. The parents felt unsure about their child's future eating, and expected nutritional supplements to be required for a long time, although they also described improvements, for example, the child more often accepted to sit at the table, or displayed an increased tolerance of tastes and textures. The mother of Gustav speculated: "I think that he will maybe never, he will always need ... nutritional supplements to get extra energy". Her account echoes a view of the need for nutritional supplements as being indefinite. Similarly, Study I demonstrated that children with developmental disorders receiving nutrition via the G-tube were not likely to progress to manage

all nutrition orally over the four years studied, but could in some cases increase the oral intake.

7.5.2 A situation full of meaning

This second meta-theme comprises the numerous functions and values attached to mealtimes for the included families. The family mealtime was described as an activity with a clear organisation that provided opportunities for adequate nutritional intake, for acquiring new skills related to eating, for socialising among family members, and for taking part in cultural events.

The interviews with the children and their parents complemented the data collected from the medical records with examples of how daily mealtimes were arranged. For example, in Karl's family it was always the mother who supported the child with the tube feeding during family mealtimes, whereas in Cindy's family this task rotated depending on who had the role of personal assistant that day. Other aspects of mealtime structure were accounts of formal and informal rules, for example, related to use of mobile phones or tablets, and rules of conduct. There was convergence across the three perspectives in descriptions of routine elements that the child participated in, such as setting the table, cooking, or handling the cutlery, although the medical records only noted such activities to a limited degree. Some children indicated reluctance to play an active part during mealtimes, using expressions such as "if I have to", or "not doing it voluntarily", whereas other children were more positive, and used words such as "enjoy" or "love to". Food-related activities were mentioned by parents as valuable to stimulate the child's abilities connected to eating. Both the children and their parents also talked appreciatively of such activities as constituting a mutual event with a shared goal, for example, nicely decorating the table or making a birthday cake.

Although mealtimes were spoken of as having a recurring organisation, the parents also mentioned never being sure how the next mealtime would develop, given the uncertainty about what the child with the G-tube was going to eat or how long it would take, something that tested the whole family. The multiple meanings of the mealtime also elucidated conflicting interest and functions. A speech-language therapist wrote: "[The child] wants to eat by herself with a spoon, but the mother doesn't approve since, according to her, the child then eats less" (ID 21). This excerpt shows how the feeding relationship between the child and the parent was tested when the amount of oral intake was placed against respecting the child's autonomy. One part of family mealtimes spoken of as challenging for parents was how to provide optimal level of support and demands for the child with the G-tube while being fair

towards siblings. There was silence in the medical records regarding such dilemmas.

Dinner was spoken of as a shared family event in both child and parent interviews, whereas for example breakfasts were more typically completed individually. In David's family, he described breakfasts as often eaten alone or with his mother alone. Dinner was described as usually eaten together with both his parents and his siblings. When asked if he liked eating on his own or in the company of his family better, David replied:

- DAVID: [I like] eating together.
INTERVIEWER: Why is that?
DAVID: Because then you don't have to be alone
INTERVIEWER: ((nodding)) How does it feel to be alone?
DAVID: Mm, a bit boring.

(Child interview, David)

His account reflects the value of eating together with others, which was also seen in the parent interviews. Cindy's mother described dinner as "the shared meal of the day and it's important to us ... and something that all the sisters talk of as positive". In another interview, Karl's mother recounted "I think [dinner] is a rather cosy moment of the day, even if it's a bit chaotic ((laughter)) it's rather nice just to (...) sit down, all of us for a while". She further described that despite spilled food, the ringing of mobile phones, or the children wanting to run about, dinner was seen as a natural part of the evening routine that gathered the whole family. These accounts mirror how shared mealtimes reinforced family identity, promoted family cohesion, and provide an opportunity for recreation.

The experiences of the children and the parents were convergent in their expressions of the significance of family mealtimes as an arena for communication, and complemented notes in the medical records. Again, dinners were explicitly referred to as an event looked forward to because of the opportunity for small talk, telling jokes, exchanging information, or just to sitting quietly together. However, descriptions from both parents and children reflected mealtime communication as often being dominated by coaxing and negotiation related to amount of food and pace of eating. Parents also mentioned how they mindfully avoided certain conversation topics in order to prevent tantrums negatively affecting the intake of food for the child with a G-tube and the social climate in the family. The communicative value and challenges during mealtimes were only briefly mentioned in the medical records and were primarily denoted in the context of providing the child with

modes of AAC to request or comment on food, but silent in relation to social interaction in a broader sense.

Mealtime rituals were mentioned in both child and parent interviews. Rituals included seemingly commonplace procedures such as lighting a candle or decorating the table on weekends with nice napkins, as well as traditions taking place more seldom, for example Halloween parties and Christmas festivities. The children and parents also spoke of food-related rituals connected to the cultural Swedish context that were abandoned, adjusted, or left unchanged. These aspects were not visible in the documentation of the medical records. One example of abandoned traditions was not attending festive gatherings with extended family, due to serious food aversion in the child. Parents expressed that they felt sorry for the child not being able to take part in food-related traditions, and therefore it was easier not to attend. Another reason was logistic challenges for parents to bring feeding equipment and food that the child tolerated, yet still being unsure if the child could accept to be fed or eat in an unfamiliar environment. One example of adjusted traditions was how Christmas dishes were modified according to the child's food preferences and eating abilities. It was seen as more important to have something for the child to eat during celebrations, than that the food was strictly traditional. Regardless of the child's difficulties, some rituals remained unchanged: the option to choose food on one's birthday, despite only eating a limited amount, for example. Some parents also shared the creation of new family rituals, such as one family ending the school week with going to a particular bakery to buy a chocolate pastry desired by the child.

The children and the parents reported how accommodations such as abandoning, adjusting, or creating new family mealtime rituals had positive consequences for the rhythm of life and family cohesion, by giving all family members something to collectively look forward to, plan, and talk about. On the other hand, disruption of mealtime rituals related to complications of the G-tube, the child's feeding disorder, and the emotional climate of the family had negative implications. Such disruptions threatened the sense of predictability and compromised the respite associated with family mealtimes.

7.5.3 Daily challenges with the G-tube

This third meta-theme describes everyday obstacles related to the child's G-tube and illuminates some of the accommodations made to address these obstacles. There was complementarity in the descriptions of adverse effects from the G-tube, including complications from the feeding method, not being free in what food to give to the child, and the G-tube being a social hindrance. For example, a habilitation nurse noted a parent's disappointment with not

being able to give Omega-3 fish oil through the G-tube, as this created blockage in the G-tube vault (ID 15). This exemplifies how the use of a G-tube gave rise to a clash between what nutrition is technically possible to give to the child, and what the parent ideally would want to give to the child. The children talked about accommodations to approach G-tube challenges, such as strategies to handle pain coming from the stoma or the stomach, independently adjusting the speed of the feeding pump to avoid feeling nauseous, and choosing swimwear that conceals the G-tube to avoid questions from others.

There was also convergence and complementarity between the medical records, the interviews with the children, and with their parents regarding accommodations related to the organisation of mealtimes to facilitate G-tube feeding. Accommodations included relocating the child from the table to a couch or a pram to aid the use of a feeding pump, scheduling mealtimes corresponding to the child's enteral feeding scheme, and replacing recommended prefabricated enteral formulas with home-blenderised feedings better suited to family values. The data material also included several mealtime accommodations aimed at engaging children who did not eat orally by allowing alternative activities. A speech-language therapist wrote "[The child] sits at the table when tube-fed [using a pump], is engaged in playing on a toy-piano, seems happy and content, seeks eye-contact, and shows interest in the environment" (ID 3). The statement exemplifies how a play-activity aided to make the mealtime enjoyable for the child unable to eat. Similarly, children and parents mentioned drawing a picture or playing a game on a mobile phone as activities facilitating the child to sit at the table together with the rest of the family, despite not sharing the activity of eating.

There was convergence between the three perspectives in how mealtimes gave opportunities for the child to experience many aspects of food and social interaction in addition to necessary nutritional intake, but also the difficulties in involving the child in shared family mealtimes. A paediatrician wrote "The child prefers not to sit at meals, can sit for a few minutes, but then wants to run and play" (ID10). The interviews and the medical records gave examples of how providing the child with adequate nutrition was at times accomplished detached from the rest of the family, by administrating the G-tube feeding as the child was using a tablet or watching a film individually. Several parents spoke sadly of the child being unable or unwilling to participate in food-related events, which separated the child from the rest of the family.

In summary, there was complementarity between the three perspectives, in that the medical records reported the presence of difficulties integrating the G-tube feeding into daily life, but included little information about what way this guided healthcare actions. The interviews gave insight into various daily

aspects affected by the G-tube, including medical, relational, and practical, and a pronounced need for professional support in these areas.

7.5.4 Parents' responsibility

This fourth meta-theme concerns healthcare support and how care actions for children with a G-tube related to feeding, eating, and mealtimes were coordinated and initiated. For some families, optimal health care was smoothly accomplished through initial guidance and routine check-ups. For others, it was a distressing journey characterised by disappointments, setbacks, and frustration. There was convergence between parents and the documentation made by healthcare professionals regarding a frustration voiced by parents with disorganised and unsatisfying health care. Examples included how children were sent between numerous clinics, irregular follow-up, and the recommendation of treatment options considered unrealistic by parents. Gustav's mother said: "We've received a lot of advice, but it hasn't always been ... possible to implement everything ... in everyday life, you know, with work and school and everything". Such gaps between the healthcare perspective and the challenges described by parents and children suggests the lack of a broad family-centred perspective among healthcare professionals.

The medical records and the parents' accounts were convergent in the descriptions of how nutrition demanded a great level of attention from people involved in the child's daily care. However, there was dissonance between the parental perspective and the healthcare perspective regarding the responsibility to cover and coordinate all areas possibly affected in a child with a G-tube. The medical records reflected a collective effort by parents, healthcare professionals, and school staff for improving the health of the child following the G-tube placement. Parents, on the other hand, noted a lack of support from health care, school, relatives, and friends, resulting in families managing life on their own. Parents experienced a great responsibility for asserting and organising best possible support for their child related to feeding, eating, and mealtime. One example of this was documented by a habilitation nurse:

"The parents have contacted the Centre of Assistive Technology by themselves to get a feeding pump. According to the father, at the time for the G-tube surgery they heard that a pump can be used to give the child feeding. The parents have now come to the conclusion that they want to try this." (ID 9)

This passage demonstrates that parents take on a great responsibility even with healthcare measures requiring expert knowledge in the health technology itself, but also in navigating organisational institutions. A lack of support in organising daily challenges was also apparent when linking ICF domains

to the intervention goals. Goals within the ICF domain “Environmental factors” corresponded to 24 percent, yet two-thirds of these goals related to types of food, e110. Only one intervention goal was linked to support for immediate family, e310. In practice, this suggests that in the absence of external support parents and children need to rely on their personal resources and find solutions on their own to make everyday life work.

Regarding the role children take in managing the G-tube, the children’s interviews gave examples of children who viewed the G-tube maintenance and the tube feeding as a task managed by adults, while others provided examples of being independent in the care for the G-tube and in the feeding procedure. Being able to manage the care of the stoma and feeding procedures was noted among both younger and older children. This indicates that age is not a significant factor in including children in their own health care; factors such as interest, physical ability, cognitive level, and motivation are of greater importance.

7.5.5 An array of care actions

This fifth and last meta-theme encompasses the type of healthcare actions and people involved in the care for children with a G-tube. The healthcare professionals, the children, and the parents were convergent in the description of implemented care actions. These included monitoring weight, control for amount and type of tube feeds, as well as maintenance of the G-tube and the stoma. The children and parents both described in detail regular healthcare visits to the hospital to follow up on growth and the recurrent change of the G-tube button every three months.

There was convergence in the range of professionals involved in the child’s health care. These professionals included paediatricians, registered nurses, registered dietitians, speech-language therapists, paediatric dentists, occupational therapists, physiotherapists, social workers in medical and healthcare, clinical psychologists, and special needs educators. A high degree of multidisciplinary care, understood as including areas of psychology, nutrition, speech-language therapy, and medicine, was noted among the children with developmental disorders both prior to and after G-tube placement in the medical records as well as in the parent interviews. However, comparing the notes in the medical records with the lived experiences of children and parents raises questions regarding the collective aim of the multidisciplinary teamwork. Lisa’s parents described how the family over the years had contact with numerous hospitals and healthcare professionals responsible for their child. Nevertheless, Lisa’s father spelled out with resignation, “We went to a clinical psychologist [with Lisa] ... I don’t really know if it gave that much ... it

felt more like ‘now we can put a check in that box’.” His statement can be interpreted as limited integration of teamwork around the child, despite the involvement of several healthcare professionals. This dissonance was also demonstrated in the contradictory analyses of healthcare contacts and intervention goals, indicating a preponderance of actions related to individual aspects of the child such as medical status, nutrition, and growth, not aspects of the environment or participation. Among the intervention goals, no goals related to the ICF domain of participation, for example, taking part in food-related activities or in mealtimes without eating.

There was dissonance and silence across the studies related to the children’s involvement in care. In the children’s interviews, their accounts reflected an understanding of the healthcare actions needed to care for the G-tube, and the necessity of food to nourish the body, grow, and feel well. When Lisa described the G-tube care at the hospital, she said:

“Every three months I go and change the button-device and at times I [go to the hospital] to get weighed, measured, and to talk. That is the most boring part! I don’t like to talk about it, they just ((changing to a high pitched, childish voice)) ‘How are you now?’ and ‘How old are you now?’ ... It’s good that they tell me how much I have grown and if I have gained or lost weight. I think that’s good to know” (Child interview, Lisa)

In her description, she gives examples of how the healthcare professionals have tried to include her in the conversation, but apparently have misjudged how this could be done in a successful way.

In many situations, the children could describe very precisely what they did and did not need, what they liked and disliked related to the G-tube and to feeding, eating, and mealtimes. Examples from the children’s narratives were accommodations such as the use of compresses between the stoma and the G-tube button device to avoid pain when playing, taking a shower to decrease unpleasant itching from the stoma, and strategies to cope with the distress coupled with changing the button-device. The children also voiced the importance of healthcare professionals informing them about the practical aspects of having a G-tube, including managing the tube feeding and tending to the device. Despite this, active attempts to capture the children’s opinions regarding the G-tube, eating, or mealtimes during healthcare visits were only rarely mentioned in the medical records or in the parent interviews. Child participation was not mentioned during goal setting. The children’s thoughts were generally interpreted by the people who cared for the child, which did not give the child an opportunity to speak for him/herself, as in this example where the habilitation nurse wrote “the child’s responsible teacher states that the child has been offered to drink the milk during the morning snack, but

firmly says no” (ID 36). The excerpt points to how the nurse has used the teacher as the primary informant to get a picture of the child’s mealtime and food intake, but describes no attempt to capture the insights of the child. One reason for children not being involved in the follow-up of the G-tube, or in goal setting, could be that many children with G-tube feeding have multiple developmental disorders with impaired ability to communicate experiences and desires. Another reason could be a lack of knowledge in how to involve children in their own health care.

The absence of child participation in planning and evaluating the G-tube use could be viewed in the light of the experience of involving children in the present thesis. In the context of evaluating the interview process of Study III, the children stated that it was good that they were given the opportunity to express what they thought about having a G-tube. The children’s evaluation using Talking Mats demonstrated that they appreciated making a drawing of their family mealtime and playing the board game, but that they were ambiguous towards structured questions. One child thought more toys would have been fun. Another child found the part with structured questions too lengthy, but otherwise the children did not mention particular parts they wanted to change in the research concept. In all interviews, the children shared their experiences willingly and were perceived as taking the research situation seriously.

8. Discussion

This chapter will address how the integrated findings from Studies I, II, III, and IV contribute to the understanding of routines and rituals related to feeding, eating, and mealtimes in families that have a child with a G-tube. The empirical findings are addressed in relation to the conceptual framework of the thesis, as well as to previous research. The chapter concludes with an outline of methodological limitations and future research.

8.1 A biopsychosocial understanding of G-tube feeding

One major finding of this thesis is the diverse effects of G-tube feeding on mealtimes among the involved children and their families. Some families found G-tube feeding to be a well-functioning, alternative mode of nutrition, with improvements in individual as well as social aspects. Other families expressed that the G-tube was a demanding part of daily life, with challenges in nursing, optimising nutrition, and arranging sustainable family mealtimes. This disparity of outcomes challenges previous predominantly positive outcome research on paediatric G-tube placement and, similar to Kapadia et al. (2016), provides justification for the need to continue to explore life-impact outcomes in a broader sense. The present thesis depicts how different primary diagnoses resulting in a need for G-tube feeding lead to similar positive, as well as negative, outcomes, representing the systems theory concept of equifinality. However, there were also examples of how similar medical history resulted in very diverse outcomes for the child and their parents, representing multifinality. Examining and acknowledging various levels of functioning can be one approach to more fully understand what influences G-tube outcome.

8.1.1 Effects on body structure and function

Using the framework of the ICF, the G-tube was demonstrated to support body structure and function, in that it aided nutritional intake and satisfactory growth. The G-tube also gave opportunities to develop basic oral sensory and

motor abilities, due to children not requiring a nasogastric tube, which was recalled from both parents and children as distressing and hindering eating by mouth. Negative outcome aspects of the G-tube within the domain of body structure and function were related to complications from the stoma and vomiting due to increased volumes of food in an immature gastrointestinal system, for example.

The long-term need for G-tube feeding in children with developmental disorders, beginning at early age, suggests that these children have primary physiological impairments negatively affecting their ability to develop safe and functional eating. The agreement among healthcare, children's, and parental perspectives relating to the long-term need of G-tube feeding for children with developmental disorders was comparable to the results in Diamanti et al. (2013) and Lalanne et al. (2014). In contrast, the children with acquired disorders were more likely to return to oral feeding after completion of intensive chemotherapy or rehabilitation training, as the difficulties of these children in obtaining adequate nutrition were secondary in nature. In both cases, however, the use of a G-tube provided nutritional support for children who otherwise could be at risk of forced feeding or severe malnutrition.

8.1.2 Effects on activity and participation

Within the ICF domain of "Activity and participation", the findings from the medical records, as well as in the children's and parents' narratives, suggest that the G-tube enabled children to take part in food-related activities, eating, and family mealtimes. Several children displayed an increased interest in trying out new tastes and handling foods when free from the demands of oral intake, which contributed to developing skills related to eating. Participation in everyday mealtimes without the pressure of oral intake also provided the children with increased opportunities for communication. This finding confirms previous research in how the G-tube can counteract strained child-parent interaction during mealtimes (Wilken, 2012) and exemplifies how an environmental factor, such as a feeding aid, can facilitate both attendance and engagement during mealtimes. Aspects of child attendance included being present at different parts of the mealtime activity as well as at several mealtime contexts. There were also examples of feelings of involvement and meaning attached to mealtimes, the G-tube care and feeding procedure. In accordance with Willis et al. (2017), having fun and experiencing success were components expressed by the children, signalling a meaningful participatory experience during mealtimes and G-tube care. In contrast, the G-tube restricted participation for some children, and in some contexts. One example was how the scheduling and organisation of the G-tube feeding at school

hindered the child's participation in lunches with peers, yet at home simplified playing with friends, since the G-tube feeding could be postponed to a more convenient time. These findings mirror a relational understanding of disability, demonstrating that despite the eating impairment and the need for G-tube feeding in the child remaining the same, environmental conditions affected the possibility to successfully participate.

8.1.3 Environmental factors and social effects

Connected to the ICF and environmental factors, interaction during mealtimes following a G-tube placement was described as less focused on promoting nutritional intake than before the placement. Thereby mealtime conversations could instead touch upon happenings from all family members' daily lives and plans for the future. Corresponding to Willis et al. (2017), the family mealtime communicated a sense of belonging in the child's family, and social connectedness was developed through shared mealtime experiences. For some children, the administration of nutrition through the G-tube was accomplished using a feeding pump. In line with findings from Matuszczak et al. (2014), and Wilken (2012), this G-tube practise was mentioned as simplifying family mealtimes for parents, as they were not required to handle the child's nutritional intake simultaneously with their own eating. Attention could instead be turned to interacting with family members and enjoying their own food.

However, the placement of a G-tube seems not to entirely resolve the challenges following paediatric feeding disorders. The parents had still to manage how the child's different eating routines affected them and the spectrum of emotions that evoked. Their narratives included accounts of handling others' negative attitudes, questioning one's own abilities as a parent, feelings of inadequacy in terms of how to best support the child's eating development and the tiring struggle to ensure the best possible mealtime assistance at school and through healthcare services. The G-tube was also coupled with feelings of estrangement from peers and other families, in both children and parents, which led to avoiding certain events or contexts. One example was parents describing the G-tube as facilitating shared dinners at home, but restricting the options for eating out at restaurants or with family friends.

In light of the relational model of disability, the G-tube and the child's feeding disorder gave rise to disability when the interaction of the child's health condition with environmental factors became a barrier to full and effective participation on an equal basis with others, not only for the child, but also for parents and siblings. The findings are in line with previous studies on the impact of childhood disability on family dynamics, suggesting that family

systems including a child with impairments or critical medical needs are better explained by a child-driven model than a transactional model (Keogh et al., 2000; Wilder & Granlund, 2015).

The findings from this thesis demonstrate the necessity of including biological, psychological and social levels in order to understand the consequences in everyday life for children with a G-tube and their parents. Furthermore, the findings emphasise that supporting good health requires attention to both objective measures and subjective experiences. Restricting follow up to growth and complications in a child will neglect personal incentives and family values that affect the implementation of a new feeding regime and the outcome experience. On the other hand, by only addressing parental anxiety with talk of typical child development and, for example, assuring that all children vomit, treatment providers will overlook concrete, physical impairments that can require intervention.

8.2 An ecocultural understanding of G-tube feeding

A second major finding of this thesis is how the value of food and family mealtimes persisted, despite the challenges connected to feeding, eating, and mealtimes, and the placement of a G-tube. Ecocultural theory applies to all families, regardless of cultural background or health conditions. This universality was advantageous because it was not assumed, prior to analysing the findings, that the values and activities of family mealtimes were necessarily different for children with a G-tube and their parents compared to typically-developing children or children without a health condition.

Several similarities are found when comparing the findings of this thesis with previous research on family mealtimes in general. Both children and parents referred to mealtimes, especially dinner, and food-related activities, for instance baking and cooking, as valued collective events, essential for the social interaction and the creation of family identity, similar to the meaning mealtimes have in any other family (Harkness et al., 2011; Lawrence & Plisco, 2017). Specific types of foods and food-related traditions were explicitly spoken of as linking present and past generations. Yet, as in any other family, mealtimes were culturally changeable as regards the use of artefacts, the creation of new rituals, and the adjustment of routines to fit contemporary organisation of working life and the roles of family members. The children's and parents' accounts also reflected communication as defining their family and socially constructing their relationships. Below, the findings are discussed in relation to the central concepts of ecocultural theory: family schema, activity settings, and accommodations.

8.2.1 The family schema of commensality

The organisation of the included families' mealtimes was interpreted to derive from deeply rooted family traditions valuing the collective experience of mealtimes, together with an idealised picture of parenthood providing optimal moral and practical guidance to one's children. Accounts of rules, foods for celebrations, and descriptions of dinner as the daily opportunity to take part in each other's daily life were examples of how the family schema became observable in the empirical material. The examples illustrated how the family schema provided direction and motivational force for family members, although they were not always conscious of the assumptions or beliefs that guided their actions. Both children and parents spoke with warmth of small and large traditions related to mealtimes, such as symbolisms in food choices or the commitment to uphold celebrations, yet there was silence concerning the presence of ritual elements in the medical records. This discrepancy between the healthcare perspective and the personal meaning assigned to rituals has been noted previously (Denham, 2003) and could reflect the still-dominating medical tradition in the healthcare for children with G-tubes.

For children with typical development and no health conditions, feeding, eating, and mealtimes mostly occur concomitantly within the same activity setting. The present findings demonstrate that the children with a G-tube included in this thesis also often attended family mealtimes, and that all parents sought to include children in food-related routines and rituals. These findings stand in contrast to previous research suggesting that children with developmental disorders are less often present during family activities (Axelsson & Wilder, 2014; Russell et al., 2017; Suarez et al., 2014). However, there were also examples of children whose feeding and eating took place separate from shared mealtimes, instead receiving tube feeding while watching a film, since parents found that such activities increased the child's nutritional intake.

The integrated findings of the thesis showed that children were given opportunities to participate in family mealtimes through engaging in alternative activities, such as drawing or playing a game on a mobile phone. Similar to Santos et al., (2018), this indicates that a ritual event can have both open and closed parts. The former refers to aspects that can be changed without altering the meaning of the interaction, while the latter refers to core elements that cannot be changed. Thus, the children with a G-tube were seen as participating in family mealtimes albeit drawing a picture while the rest of the family ate. In this case, communication and presence, not the food itself, seemed to be core elements in what constituted a mealtime. This finding contrasts with previous research emphasising the value of oral eating (Petersen et al., 2006; Rouse et al., 2002; Russell et al., 2017). Alternative activities for the child can be interpreted as working strategies to balance competing interests among

family members, and reflect the value attached to gathering around the table, despite being involved in various aspects of the same activity. These findings add to previous research on the importance of how parents provide children with the space and opportunity to participate in daily activities, based on a child's individual abilities, thereby playing a significant role in supporting the child's access to and engagement in activities (Axelsson et al., 2013; Wilcox & Woods, 2011).

8.2.2 The mealtime activity setting

The findings demonstrate that the activity setting of family mealtimes aims to ensure bodily needs, and improve a child's eating abilities, alongside the value of gathering family members and the serving of specific dishes, irrespective of whether food was eaten. The descriptions of routine elements were consistent and common across the perspectives studied. Both the children's and the parents' descriptions depicted mealtimes as having clear borders and recurring elements relating to structure, type of meal, and content, as well as people's roles and actions. This coherence implies that continuity and predictability characterise the typical mealtime setting, and indicate that the parents had constructed coherent and sustainable daily activities valued by themselves and their children, despite challenges connected to food and eating.

However, motives and goals of the mealtime differed between parents and children. Children valued being present, the social interaction between family members, and the handling of food and cutlery. Parents emphasised the importance of nutritional intake during mealtimes, social interaction, and traditional aspects of food. This discrepancy is similar to what Savage and Callery (2005) noted among children with cystic fibrosis and their parents. Future studies comparing family mealtimes for children with G-tubes with other paediatric long-term health conditions affecting food and eating, such as diabetes, asthma and food allergy, would be beneficial to explore similarities and differences in the mealtime activity setting and its components.

8.2.3 Accommodations

The findings from Studies II, III, and IV depicted how the health condition of the child and food-related challenges, for example the unpredictability of the child's physical symptoms, eating ability, and parents' close attention to the child's nutritional intake had a negative impact on the routines and rituals of daily life for many of the families. There were examples of how the child's medical status required parents to be on 24-hour alert to handle any possible

difficulties and demands. These findings correspond to the results of Mahant et al. (2011), who delineated a constant concern for the child's physical health as one dominant theme in the daily life of parents who had a child with a neurological impairment and G-tube feeding. However, the medical records and the interviews captured necessary, but not always desirable, compromises and choices to approach these challenges and create a more predictable daily mealtime, exemplifying minor and major accommodations. Consistent with the thesis' focus on family mealtimes, accommodations related to domestic chores and tasks were most evident, such as adjusting mealtime content and environment. However, parents also gave examples of accommodations in childcare tasks, marital roles, and healthcare services, mirroring previous studies describing a broad range of accommodations in families of children with long-term health conditions (Crespo et al., 2013; McConnell & Savage, 2017).

Some aspects of the children's body structures and functions were shown to be important in understanding the accommodations made to the family mealtime. These included anatomical structures of the mouth, gastrointestinal functioning, sensory functions, and abilities to sustain, shift, and divide attention. A challenge of the ICF is that the framework suggests a bidirectional relationship across domains, depicted with arrows running in both directions between, for example the domain, "Body structure and function", and the domain, "Activity", yet little guidance is given in the ICF manual regarding how this relationship can be understood or classified. Combining the accommodation concept from ecocultural theory with ICF offered an insight into families' processes to establish sustainable daily routines, and how the domains of ICF influence each other. This combination demonstrates that accommodations appear on various levels. Accommodations on a physiological level comprised using texture modification on served foods in agreement with the child's oral abilities, or changing types of tube-fed foods to support gastrointestinal function. There were also examples of how the use of a feeding pump increased child autonomy, by making it possible for the child to independently adapt the speed of enteral formula, or choose the time and place for feeding. Accommodations on a psychological level included parental strategies to increase child interest in food, reduce pressure on oral eating, and prepare the child before mealtimes using pictures or weekly menus. Social accommodations encompassed parents postponing returning to work after parental leave, in order to facilitate caregiving, serving food "buffet style" to ensure that all family members had something they favoured, or choosing conversational topics that engaged the whole family.

The range of accommodations suggests that having a child with a G-tube affects everyday life far beyond establishing basic nutritional needs and the

mealtime routine. Accommodations as such are not prevalent in families of children with long-term health conditions or developmental disorders alone. The findings of this thesis depict multiple intertwined and changing accommodation processes within families, driven by various motivational forces. One example was how mealtime scheduling was adjusted according to the needs of a family member with diabetes. Another example was the arrangement of childcare tasks, with siblings being the primary focus and the child with the G-tube being secondary focus. Thus, accommodations were not processes exclusively centred around the child with a G-tube.

Similar to the exploration of accommodation quality described in Galimore et al. (1993), the accommodations described in the present findings were not found deviant, strange, or surprising, but were perceived as culturally familiar and resembled actions other families of children would take, albeit to a greater extent. This finding supports prior research suggesting that routines and rituals provide a sense of security and stability for families of children with health conditions (Crespo et al., 2013; Santos et al., 2018; Spagnola & Fiese, 2007). On the other hand, one could question whether the families' endeavour to uphold traditions and culturally normative routines also creates stress and could thereby evoke feelings of differentness.

8.3 Family mealtimes under extraordinary circumstances

A third major finding of this thesis is how mealtimes in families that include a child with a G-tube were demonstrated to be multifaceted and holding several interrelated, but also incompatible dimensions. Crotty's two cultures, the pre-swallowing culture, dominated by society and experiences, and the post-swallowing culture, dominated by physiology and biochemistry (Crotty, 1993), at times were in conflict. This opposition required parents to negotiate conflicting interests within themselves, and among family members, related to the values of feeding, eating, and mealtime. One example was how parents put forward the necessity of providing their child with adequate nutrition and practice developing skills required for eating, motivated by the parental responsibility to care for one's child. In some cases, this meant the children's interests and right to express their views were disregarded. Values at stake here are parental obligations to ensure child nutrition, set against the autonomy of the child, an ethical conflict previously identified (Craig & Scambler, 2006). Similar to previous research, this thesis also elucidates that parents of children with G-tube feeding face dilemmas concerning parental obligations towards the child with impairments, i.e., searching for and providing the best possible care and prioritising time to support the child, contrasted against the

needs of siblings and “normal parenting” (Hopwood et al., 2020; McConnell & Savage, 2017). This exposition of dilemmas elucidates that addressing and giving room for reflections concerning various values connected to feeding, eating, and mealtimes following the placement of a G-tube in a child, is crucial in the process of establishing sustainable routines and for supporting the health of children and their parents.

The children’s compliance with eating their meal and parental strategies to increase the child’s interest in food was described to dominate the interaction in several families. Communicative functions were used both as tools to develop eating abilities as well as to handle and prevent mealtime hassles. Such focus on the present activity may impede children from participating in conversations reflecting social and cultural frameworks for understanding past and future events (Ochs & Shohet, 2006). Findings from this thesis expand previous research on mealtime communication in families of children with long-term health conditions (Ferm et al., 2012; Totterdell, 2016; Veness & Reilly, 2008) by including the perspective of children, and support the dual obligation facing parents during mealtimes, involving both general parenting responsibilities and such disease-specific tasks as managing the feeding-pump, adjusting the mealtime environment to ensure optimal conditions, and constantly evaluating the amount of nutrition taken by the child.

Considered from a life-course perspective, this thesis expands previous research on G-tube feeding in children by directing attention to both the immediate and long-term outcomes of G-tube placement, through examining the interacting forces on the individual child and the child’s family. In the short term, tube feeding through a syringe was a relief to parents and seen as an effective way to provide the child with nutrition compared to force feeding and drawn-out mealtimes filled with coaxing and conflicts. However, in the long run, sustainable mealtime routines and rituals seem not to be accomplished by a feeding syringe. Instead, a combination of actions targeting nutrition, the child’s eating abilities, feeding aids, child and parent emotions, and the social interaction within the family must be implemented in order to establish sustainable mealtimes despite extraordinary circumstances.

8.4 Healthcare support

This thesis explored the challenges encountered by children with G-tubes and their parents during mealtimes and the support they receive from healthcare professionals. A fourth major finding is the gap identified between family needs and implemented healthcare measures. Initially, the reviewed medical

records did elucidate numerous healthcare professionals being involved in the assessment, treatment, and follow up related to G-tube feeding in children. Furthermore, the medical records reflected aspects of nutrition, feeding, eating, and mealtimes, thus representing a biopsychosocial understanding of G-tube feeding. Thereby, the documentation in the medical records included all themes raised by Nelson et al. (2015) and all domains of the ICF that ought to form the clinical conversation after G-tube placement in children. However, the entries in the medical records were, in many cases, uneven, with extensive information on the biological aspects of children's health status, and scant information relating to psychological, social, and environmental aspects. Coding the intervention goals in the medical records following the ICF illuminated that despite the ICF's establishment in 2001, and its important role in research and the clinical field of rehabilitation and disability over twenty years, not all domains of the ICF were shown to be addressed in the clinical work with children with G-tubes.

The findings in the medical records were confirmed and complemented by the interviews with children and parents, reflecting a primary focus on care of the stoma and monitoring child growth. These findings correspond to earlier research which suggest that health care for children with G-tubes mainly derives from a medical research tradition with focus on growth, nursing, and supporting nutrition (Edwards et al., 2016; Kapadia et al., 2016). One interpretation of the emphasis on physical aspects of the child could be a lack of formal instruments to assess social aspects of eating and mealtimes, something that has previously been pointed out as an area in need of improvement (Sharp et al., 2017). It is also imperative to point out that many of the children with G-tubes have numerous disorders and healthcare needs to be considered, which affects the measures taken by parents and by healthcare professionals. The emphasis on physical rather than social aspects could mirror how the importance of accommodating medical issues overshadows other aspects of family life, in situations in which healthcare actions targeting infections and nutritional requirements are given higher priority in respect to other life areas.

The medical records and the interviews illustrated that multiple institutions were involved in the G-tube care of the children, including healthcare clinics, school personnel, and social services. In addition to institutions, several healthcare professions were also involved in the care of the children, which was contrasted with the narrow range of healthcare actions provided. This contradictory finding suggests that multidisciplinary care does not necessarily guarantee an integration of knowledge about a child and the situation of the child's family. The medical records and interviews illustrated how practical aspects, assessments, and recommended interventions for some children were at odds, and called for a functional cooperation between healthcare

professionals and families in order to find the most optimal level of care. The collaboration reflected a *multidisciplinary* team, where members functioned as independent specialists, rather than an *interdisciplinary* team, where treatment goals are set collaboratively and there is a high degree of communication (Körner, 2010). This reflects that these families are part of numerous systems that interrelate and require coordination. What the thesis demonstrates is that in most cases these systems are coordinated by parents and that the implementation of healthcare measures on a daily basis were left to parents. Such responsibility demands great resources of, for example, parental time and energy and can affect their health, marital relationship, and possibilities to provide support to siblings.

Connecting the present findings to ecocultural theory adds an understanding of the goals and meanings of everyday activities in individual families, and how these will influence implementation of intervention strategies and accommodations in each household. If healthcare measures are to be meaningful, assessments and interventions must target various levels of a health condition, and resources must be allocated to allow for emergence of the collected information. Furthermore, support must be tailored to meet the goals and values of each family (Bernheimer et al., 1990; Denham, 2003). The benefits of family-centred early childhood intervention services are nothing new (Hanna & Rodger, 2002). Considering the family schema with its routines and rituals can be helpful in assessing functioning within all domains of the ICF, and when implementing healthcare actions, yet the present findings indicate that barriers to appraising family routines and rituals are still present. Such barriers could comprise lack of knowledge in family-centred care, power relationships between healthcare professionals and parents (where healthcare professionals are given interpretive precedence), or the organisation of healthcare hindering an interdisciplinary teamwork.

Ending this discussion of the thesis findings, I want to emphasise children's participation, or lack thereof, in health care. The insights provided by the children regarding their functioning and their everyday life situations demonstrated that their knowledge should to a greater extent be taken into consideration by healthcare professionals when planning follow-up and intervention. Yet children's own accounts of their G-tube experiences seldom guided the healthcare planning. The work presented herein elucidates how creative methods based on knowledge in AAC, communicative development in children, and flexible interview techniques can support children as agents in their own healthcare and in research. The UN Convention on the Rights of the Child became Swedish law in January 2020. The thesis findings emphasise how Swedish healthcare professionals, now more than ever, must adjust their clinical work to involve children in matters that affect them.

8.5 Methodological limitations

The mixing of methods both within and across included studies provided knowledge that would not be gained by using one single method, illuminating a complex image of mealtimes in families of children with G-tubes. Nevertheless, the findings from the thesis need to be considered in the light of some limitations related to sample characteristics, data collection, and methods for analyses. These are further discussed below.

8.5.1 Medical records

The medical records were collected within one administrative region of Sweden, reflecting that particular demographic, geographic, and health care setting. This may have affected the transferability of the findings (Graneheim & Lundman, 2004) but it had two major advantages: (1) the possibility to use personal contacts to identify children who were not correctly registered and coded in the medical records' system, thus contributing to a richer data material, and (2) my previous familiarity with the medical record system, which in combination with knowledge in the clinical population ensured dependability of the data. A challenge with using medical records is the language use, which proved to be uneven in quality, incomplete, and scarce in the use of standardised classifications. In certain cases, this demanded, not condensation, but expansion and interpretation of a given statement. For example, descriptions of feeding habits in Study I were at times estimated based on expressions like "seldom uses the G-tube" or "eats some meals by mouth". Nevertheless, medical records represent legislated, professional documentation that carry an active, constitutive role in setting objectives, planning, and implementing healthcare measures. Hence, the benefits of using the medical records were regarded as compensating for described drawbacks.

An advantage with using the whole medical record was the inclusion of all possible healthcare professionals in contact with the child related to the G-tube and feeding-related issues. Using the medical record as the empirical material to reflect the professional perspective of health and everyday life for children with G-tubes presented a possibility to include excerpts based on its content, rather than on explicit healthcare professions. Thereby any of my personal preconceptions, as a researcher and a clinician, could be set aside concerning which healthcare professionals are usually involved in the care of a child with a G-tube. A previously noted limitation with using medical records is their insufficiency to fully reflect the care provided or the quality of the complex interplay between patients and healthcare professionals (Karls-son et al., 2013). Interviews with healthcare professionals or observations of healthcare visits might have contributed to a more nuanced picture of how

children and their families are given opportunities to describe their everyday life, and how these descriptions are coupled to assessments and intervention. In future research, these methods are an area worthy of enquiry to expand on the picture given by this thesis.

8.5.2 Interviews

The thesis confirms the utility of interviews conducted and analysed within a qualitative descriptive design in providing an expressive summary of participants' accounts, valuable as end-products, but also as entry points for further study (Sandelowski, 2000). In contrast to standardised quantitative investigations, the qualitative methodology allowed for an individual freedom of expression and for the research activities to be adjusted for specific wishes or prerequisites of the participants.

The interview concept in Study III opened a communicative space that encouraged children to engage in a dialogue, rather than taking part in an adult-controlled interview situation. For one child, the use of unfinished sentences led to the telling of personal experiences, whereas for another child, this was not a helpful strategy. Drawing the family mealtime elicited revealing descriptions from some children, but was completed swiftly by others. Thus, the interview concept and the resulting data material were a function of the abilities and interests of both the interviewed child and the interviewer. As discussed in Nilsson et al. (2015), this meant that a great degree of interpretation and adaptation was needed by the interviewer as part of the ongoing research process. One way of validating the children's narratives was by triangulating issues raised in the different activities during the visit, for example, by returning to a problem raised during the board game in the activity of the structured questions. Such triangulation certified that the interpretations of the children's experiences derived from the children themselves, and were not construed by me as the researcher. In Study IV, the stimulated recall method was proven valuable in obtaining rich insight into the parents' reasoning of family mealtimes and food-related challenges of having a child with a G-tube. Nevertheless, video recordings are fractional, capturing only part of an event, depending on where the camera is directed, the duration of the film, and how the camera is operated. Furthermore, the recording only reflects that specific mealtime, which might be different from the family's usual mealtime. Another limitation with using recordings is the possibility that the camera affects family members' natural behaviour and interaction. To address these limitations, the families were asked to record three shared mealtimes and choose the recording they felt best reflected their typical family mealtime.

The design of this thesis did not attempt to provide findings transferrable to a whole population, but rather to describe variations, and conduct thorough analyses within limited samples. Yet, when evaluating the interview findings, the sample size of seven children and ten parents needs to be considered. The number of families involved was a compromise between providing enough depth and breadth in the empirical material, and being feasible given resources for identifying eligible children and carrying out a careful analysis of the collected material. The combination of a highly specific study sample, the support of an established theory, and a strong interview dialogue, was deemed to provide sufficient informational power in the data material (Malterud et al., 2016). Another strength was that both mothers and fathers were interviewed, as previous studies have been dominated by a maternal perspective (Craig & Scambler, 2006; Glasson et al., 2020; Petersen et al., 2006; Wilken, 2012).

8.5.3 The synthesis of the findings

In the current thesis, numeric data and excerpts from the medical records were merged with personal accounts from children and parents, and interpreted into overriding meta-themes that cut across the studies. Triangulating various data sources, methods, and researcher perspectives enhanced the credibility and the transferability of the thesis. However, triangulation is a complex process not without challenges and limitations (Farmer et al., 2006). One challenge is that silence or dissonance in meta-themes between studies might be due to inherently different content or qualities in the data sets, or the methods themselves. This was apparent regarding how the situation of siblings during family mealtimes were described. Both children and parents mentioned siblings in their interviews. However, a medical record is by its form and function focused on the individual patient, which could explain why sibling situations were not covered in Studies I or II. Another challenge with triangulation is that some data sets might be suited to address a specific research question better than others, resulting in findings from one data set that are weighted more than those of another data set (Farmer et al., 2006). For instance, in the current thesis, interview questions probed the description and value of food-related traditions, whereas the condensed language of the medical records was lacking in such reflections. Following the aim of the thesis to explore mealtimes in families, the meaning and value of rituals described by the children and their parents were considered to be of great importance to the overall findings, albeit unmentioned by the medical records.

In conclusion, the triangulation of methods, participants, researchers, and data made it possible to obtain a mutual confirmation of some of the findings as well as identifying areas of discrepancy. Furthermore, using a protocol

when interpreting the findings provided insight into how the research was carried out, thereby increasing the trustworthiness of conclusions reached.

8.6 Future research

Longitudinal studies with several data points would be valuable to investigate mealtime sustainability and accommodations over time in families affected by paediatric feeding disorders. Future studies may also address causal relationships between family functioning and communicative patterns, or between child participation during mealtime and eating development for children with a G-tube. Moreover, future studies are needed to explore the interaction between children and healthcare professionals to identify tools and strategies promoting this therapeutic relationship. Finally, this thesis focused on family mealtimes for children with G-tube feeding in a Swedish context, which might differ from other parts of the world. Hence, research from other cultural contexts would broaden the understanding of family mealtimes following a G-tube placement in a child.

9. Conclusion

The overall aim of this thesis is to explore routines and rituals related to feeding, eating, and mealtimes in families that have a child with a G-tube, from the perspectives of healthcare professionals, the children, and their parents. This was done in four different studies combining documentation in medical records with individual interviews. In conclusion, a developmental disorder in a child was shown to be associated with lower age at placement and longer duration of the need for G-tube feeding. This finding elucidates how mealtimes will be affected for a long time for such children and their families. Another major finding is the diverse effects of G-tube feeding on mealtimes among the involved children and their families. Some families found G-tube feeding to be a well-functioning, alternative mode of nutrition, while others considered the G-tube to be a demanding part of daily life, with challenges in nursing, optimising nutrition, and arranging sustainable family mealtimes. In addition, this thesis shows how the value for children and their parents of food and shared family mealtimes persists despite challenges connected to feeding, eating, and mealtimes, and the placement of a G-tube.

The thesis findings demonstrate how families actively take measures to adjust to and handle the demands of daily lives with paediatric feeding disorders. A broad range of accommodations across biological, psychological, and social levels of functioning were noted, suggesting that having a child with a G-tube affects everyday life reaching beyond establishing basic nutrition. However, the findings indicate remaining barriers in health care to appraising family routines and rituals, despite the helpfulness of such elements in assessing functioning within all domains of the ICF, and when implementing intervention actions. The thesis confirms prior studies as well as my motivation to commence this research project, given that current research and health care focus mainly on growth, nursing, and supporting nutrition.

Lastly, children's perspectives were seldom reported in the medical records and children were not involved in goal setting. Yet, this thesis demonstrates how flexible and carefully designed communication material can promote child agency, even in the presence of communicative or cognitive disorders.

10. Clinical implications

Building on the findings from this thesis, the following recommendations for clinical practice are made:

- Healthcare professionals need education in strategies and resources to involve children in the planning, provision, and follow-up of assessments and interventions related to health conditions. The results from the present thesis demonstrate that, given adequate support, children at various cognitive and communicative levels can provide valuable knowledge about their own situation and healthcare needs.
- Healthcare professionals need to more regularly ask parents how they perceive and manage family mealtimes, and what aspects they struggle with at home. A systematic and coherent use of multidimensional assessment instruments can aid such conversation and lead to interdisciplinary intervention strategies tailored accordingly.
- Family-centred intervention plans must build on the child's and the parents' perceptions of health and what the parents already are doing in daily life. Attention to a family's daily routine increases the likelihood that more precise treatment plans can be developed and carried out, and that the given support suits with the whole family's situation.
- Healthcare professionals should consider encouraging the use of enteral feeding pumps, as the results from this thesis indicate increased child autonomy and overall parent satisfaction following the introduction of a feeding pump.
- Healthcare professionals should discuss the content of the medical record with the child and the child's family, as well as within the multi-professional healthcare team, to establish what is beneficial for a fruitful mutual healthcare cooperation.

11. Sammanfattning på svenska

Den här avhandlingen, med den svenska titeln ”Vanliga måltider, ovanliga förutsättningar – rutiner och ritualer relaterade till intag av föda och ätande i familjer där ett barn har en gastrostomi,” är skriven inom ramen för forskarutbildningen i hälsa och livsstil med inriktning handikappvetenskap på Högskolan i Halmstad. Avhandlingen består av fyra delstudier och en ramberättelse, en så kallad ”kappa”. Följande kapitel ger en sammanfattning av bakgrund, konceptuellt ramverk, undersökningsmetoder och resultat. Kapitlet avslutas med att sätta resultaten i relation till tidigare forskning och det konceptuella ramverket, hur resultaten kan användas i praktiken samt möjlig framtida forskning.

11.1 Bakgrund

När en person har svårt att få i sig tillräckligt med näring, medicin eller vätska bör man överväga en gastrostomi. Gastrostomi är en port i bukväggen som leder direkt in i magsäcken och har använts sedan 1980-talet (Gauderer, 2001). Det kan finnas olika orsaker till att en person behöver en gastrostomi, exempelvis mag-/tarmsjukdomar som påverkar kroppens förmåga att ta upp näringsämnen, funktionsnedsättningar som begränsar förmågan att tugga och/eller svälja, samt sjukdomar som ger ökat behov av specifika näringsämnen (Colomb et al., 1998). I Sverige sker cirka 300 gastrostomi-insättningar på barn varje år.

Bakomliggande orsaker har visat sig ha betydelse för hur länge ett barn är i behov av en gastrostomi. Neurologiska funktionsnedsättningar är förknippade med långvarig användning av gastrostomi (Diamanti et al., 2013; Lallanne et al., 2014), men mer kunskap behövs om hur bakomliggande orsaker och tidigare erfarenheter av ätande påverkar användningen av en gastrostomi hos barn. Annan kunskap som saknas är hur familjer anpassar sitt vardagsliv utifrån gastrostomin och hur barn görs delaktiga under måltider. Sådan kunskap är viktig för att kunna ge barn och deras familjer värdefull information inför en gastrostomi-insättning samt rätt uppföljning efteråt. Avhandlingen syftar därför till att utforska rutiner och ritualer för barnets intag av föda och

ätande samt familjemåltider när ett barn har en gastrostomi, utifrån vårdpersonals, barns och deras föräldrars perspektiv.

11.2 Tidigare forskning

Studier om följderna av en gastrostomi-insättning hos barn fokuserar ofta på näringsintag, biverkningar, operationsmetoder och tillväxt. Aktuell forskning visar att en gastrostomi är ett säkert och tillförlitligt nutritionssätt som bland annat leder till positiv viktuppgång och minskat antal allvarliga infektioner hos barn (Fröhlich et al., 2009; Lalanne et al., 2014; Ricciuto et al., 2015). Studier som undersöker familjens situation, barns upplevelse av att ha en gastrostomi och hur hälso- och sjukvårdsresurser används för berörda barn och deras familjer är inte lika vanliga (Kapadia et al., 2016).

Den forskning som finns av hur en gastrostomi hos ett barn påverkar familjers vardag visar på exempelvis lugnare och mer harmoniska måltider, förbättrad kommunikation mellan barn och föräldrar samt ökad livskvalitet för föräldrar efter insättande jämfört med innan (Matuszczak et al., 2014; Åvitsland et al., 2013). Föräldrar berättar dock om negativa aspekter av sitt barns gastrostomi också. I intervjustudier med föräldrar har gastrostomin beskrivits tydliggöra barnets funktionsnedsättning och gastrostomin ses som ett misslyckande i föräldrarollen att ge sitt barn mat (Petersen et al., 2006; Sullivan, 2014). Utmaningar i vardagen innefattar praktiska aspekter med hantering av matningshjälpmedel (Craig & Scambler, 2006 och kommentarer från personer i omgivningen (Edwards & Leafman, 2019).

Måltider i familjer är dagligt återkommande aktiviteter som ger vardagen en struktur och utvecklar barns motoriska förmågor kopplade till ätandet. Måltider är också ett socialt sammanhang som stimulerar språkförmågan samt visar på familjers sociala värderingar och kulturella tillhörighet (Spagnola & Fiese, 2007). För familjer med ett barn som har en gastrostomi kan det vara utmanande att skapa och anpassa måltidsrutiner som är hållbara över tid och som gör barn delaktiga utifrån sina förmågor. I en studie av Russell och medarbetare (2017) beskrevs att endast en fjärdedel av barnen med en gastrostomi ofta eller alltid fick mat tillsammans med övriga familjen under gemensamma måltider. Barnets inställning till mat samt svårigheter för föräldrar att anpassa barnets matschema med familjens måltider beskrevs hindra barnets delaktighet under måltiden. Resultaten är i linje med tidigare forskning som visar att barn med funktionsnedsättningar mer sällan deltar i familjegemensamma vardagssituationer än barn utan funktionsnedsättningar (Axelsson & Wilder, 2014). Det gör att barn med en gastrostomi riskerar att

gå miste om en av vardagslivets betydelsefulla aktiviteter under lång tid vilket kan få en negativ påverkan på deras utveckling och hälsa.

11.3 Konceptuellt ramverk

Avhandlingen bygger på en miljörelativ syn på funktionshinder (Martin, 2013; Reindal, 2008). Enligt denna syn behöver inte en funktionsnedsättning i sig innebära ett funktionshinder. Ett funktionshinder uppstår när en person med funktionsnedsättning möter en bristfällig omgivning. För att planera tillvägagångssätt samt analysera och diskutera studiernas resultat användes Världshälsoorganisationens ramverk ICF: Klassifikation av funktionstillstånd, funktionshinder och hälsa, (WHO, 2001) tillsammans med en teoretisering av begreppet delaktighet samt ekokulturell teori. Tillsammans bidrar detta konceptuella ramverk till att både beskriva specifika individuella faktorer och en förståelse för det sammanhang som barnet är en del av.

ICF är ett internationellt överenskommet ramverk för att beskriva och klassificera hälsa och hälsorelaterade tillstånd. ICF inkluderades i avhandlingen eftersom ramverket ansågs värdefullt för att uppmärksamma och beskriva olika delar av vardagen för ett barn med en gastrostomi: kroppens fungerande, mat-relaterade aktiviteter, delaktighet i vardagliga måltider i relation till personliga faktorer som ålder och motivation. Även faktorer i omgivningen, exempelvis familj, hjälpmedel och hälso- och sjukvårdssystemet inkluderas i ICF. I ICF ingår begreppet *delaktighet*, men det är otydligt hur begreppet ska förstås och undersökas. I den här avhandlingen definieras delaktighet i enlighet med Eriksson and Granlund (2004) som en känsla av tillhörighet och engagemang, upplevt av en person i relation till att vara aktiv i ett givet sammanhang.

Avhandlingens teoretiska ram är hämtad från ekokulturell teori. Teorin fokuserar på att förstå de sätt som familjer agerar och förhåller sig till faktorer i omgivningen som inte går att kontrollera (Gallimore et al., 1993, 1999; Weisner, 2002). Ekokulturell teori ger redskap för att utforska hur familjer skapar och finner mening i rutiner, ritualer, balanserar familjemedlemmars mål och in-tressen, samt söker stabilitet mellan behov och resurser.

11.4 Metod

I avhandlingen kombinerades kvantitativa metoder, som att undersöka antal och statistiskt beräkna gruppskillnader, med kvalitativa metoder för att samla in fördjupande beskrivningar och personliga erfarenheter. Kombinationen av

metoder förväntades förstärka det slutliga resultatet genom att belysa olika aspekter av vardagliga måltider för barn med en gastrostomi.

Studie I och II utgick från ett vårdperspektiv. I den första studien inhämtades information från patientjournaler inom en svensk region för att statistiskt beskriva barn med en gastrostomi i fråga om ålder, kön, bakomliggande diagnos, vårdkontakter och förändring i ätande över tid genom en fyraårsuppföljning. Barn i åldrarna 0 till 18 år med förvärvade diagnoser (n=13) jämfördes med barn som hade utvecklingsrelaterade diagnoser (n=38). Barnen var gastrostomi-opererade mellan 2005 och 2012. De efterföljande tre studier fokuserade på barn med utvecklingsrelaterade diagnoser. I studie II analyserades journaler tillhörande 39 barn (21 pojkar, 18 flickor) från första året efter gastrostomi-operationen. Barnen hade opererats mellan 2005 och 2015. Syftet var att undersöka vårdinsatser samt hur vardagliga aspekter av familjens måltid var dokumenterade i barnets journal. Avsnitt ur journalerna som innehöll information relaterad till näringstillförsel, ätande, gastrostomin och måltid analyserades med hjälp av kvalitativ innehållsanalys (Graneheim & Lundman, 2004). Ytterligare en analys gjordes på materialet och den innefattade de behandlingsmål som fanns dokumenterade i barnens journaler. Dessa kategoriserades utifrån ICF.

Studie III och IV syftade till att fånga barns och deras föräldrars erfarenheter och upplevelser av gastrostomi, ätande och måltid. Enskilda intervjuer genomfördes med barn (4 pojkar, 3 flickor) i åldrarna 6 till 12 år med hjälp av en flexibel intervjumetodik anpassad efter barnens fysiska, mentala och kommunikativa förmågor. Barnen fick rita, spela ett specialutformat brädspel och delta i ett strukturerat samtal med hjälp av bildstöd. Intervjuerna analyserades med systematisk textkondensering (Malterud, 2012). Föräldrarna (3 pappor, 7 mammor) intervjuades med öppna frågor om måltider och barnets gastrostomi samt med metoden "stimulated recall" (Lyle, 2003). Föräldrarna filmade tre vardagliga måltider och delade en av dem med mig. Inför intervjun tittade jag igenom deras film och valde ut sekvenser som väckte frågor om gastrostomin, rutiner, ritualer och barnets delaktighet under måltid. Genom att titta på utvalda sekvenser ihop med föräldrarna gavs möjlighet att få deras syn på vad som skedde under den specifika, filmade måltiden, men öppnade också upp för fördjupande frågor om familjens måltid i allmänhet. Föräldrantervjuerna analyserades med kvalitativ innehållsanalys (Graneheim & Lundman, 2004).

11.5 Resultat

Studie I visade att fyra år efter gastrostomi-insättningen fick 67 procent av barnen fortfarande näring via gastrostomin. Bara sex av 37 barn (16%) med en utvecklingsrelaterad diagnos hade övergått till att äta all mat via munnen, jämfört med 10 av 11 barn (91%) med en förvärvad diagnos. Barnen med utvecklingsrelaterade diagnoser var yngre vid operationstillfället och hade en längre behandlingstid med gastrostomin jämfört med barnen med förvärvade diagnoser. Trots att många olika vårdprofessioner var involverade hade insatserna övervägande fokus på näringstillförsel, medicinsk hälsostatus och tillväxt.

I studie II visade journalerna under det första året efter gastrostomi-insättningen på behov av avvägningar mellan önskningar, krav, säkerhet och utforskande som både familj och vårdpersonal ständigt behövde göra i barnets vård. Det här tolkas in i det övergripande temat "Att söka efter balans". Två huvudkategorier sammanfattade beskrivningarna i dokumentationen: "En strävan mot hälsa" och "Åskådliggörande av vardagslivet". Den första kategorin beskriver de insatser som gjordes för att åstadkomma förbättrad hälsa och hade ett tydligt fokus på fysiska aspekter. Den andra kategorin samlar generella beskrivningar av vardagslivet, men journalnotaten var inte kopplade till specifika åtgärder eller vårdinsatser. Analysen av dokumenterade behandlingsmål visade att 21 barn (54%) hade mål relaterade till gastrostomin, mat och måltid. Dessa mål fokuserade främst på ICF-domänen "Kroppsstruktur och kroppsfunktion".

Barnens upplevelser av måltider och att ha en gastrostomi undersöktes i studie III och sammanfattades i fyra huvudkategorier: "Stabil i sin form, öppen för variation", "En individuell och en gemensam aktivitet", "Ett föremål som måste hanteras" samt "En del av mig". För en del barn var ätandet kopplat till negativa upplevelser av illamående, krav och svårigheter att motoriskt hantera vissa konsistenser. Oavsett hur mycket barnen åt via munnen eller hur de upplevde själva ätandet så var dock familjens måltid ett uppskattat tillfälle till gemenskap. Barnen var ambivalenta till sin gastrostomi. De benämnde gastrostomin som en naturlig del av kroppen och som nödvändig för att växa och må bra. Samtidigt beskrev de också känslor av att vara annorlunda och utanför på grund av sitt ovanliga ätande.

I studie IV tolkades föräldrarnas beskrivningar av familjens måltid som en kalejdoskopisk upplevelse där många små delar bildade en föränderlig helhet. Fyra huvudkategorier utgjorde resultatet: "En situation, olika funktioner", "På barnets villkor", "Gör något med mig" samt "Ett oberäkneligt mönster". Analysen visade att föräldrarna värdesatte rutiner och ritualer kopplade till måltiden samt familjens sociala och kulturella sammanhang, men att det var

utmanande att balansera mellan vad som var bäst för barnet och vad som var bäst för övriga familjemedlemmar. Föräldrarna beskrev att de fick god hjälp från sjukvården när det gällde barnets sårvård, hjälpmedel och näringstillförsel, men saknade stöd gällande andra delar av vardagen som också påverkas av en gastrostomi.

När de fyra studiernas resultat slogs samman noterades både likheter, skillnader och kompletterande fynd mellan de olika undersökta perspektiven. Det fanns tydliga likheter i hur barnets ätsvårigheter upplevdes inverka på familjens måltider och i beskrivningarna av anpassningar som gjorts för att få en hållbar vardag. Det handlade om anpassningar i miljön, vilken mat som serverades och vad som förväntades av barnet. Resultaten från studierna visar att måltiden var en situation med flera betydelser och funktioner. Måltiderna beskrevs ha en tydlig struktur som hjälpte till att organisera vardagen, men måltiderna synliggjorde också dilemman där olika personers mål med aktiviteten ställdes mot varandra. Exempelvis såg föräldrar ofta måltiden som en möjlighet för barnet att få i sig den näring som barnet behövde, medan barnen lyfte fram värdet av att vara tillsammans oavsett om de åt något eller inte. Dagliga utmaningar som beskrevs handlade om smärta kopplat till gastrostomin, hantering av matningspump, och att få barnet delaktigt under måltiden. Ett tema som återkom i det samlade materialet var hur föräldrarna tog stort ansvar för planering och koordinering av barnets vård. En skillnad som blev tydlig mellan studierna vad barnets delaktighet i vården av sin gastrostomi. I journalerna rapporterades inga barn vara delaktiga i målsättning och barnens egen röst var ofta osynlig i dokumentationen. I intervjuerna med barnen själva framkom dock att de tog stort ansvar för att sköta sin gastrostomi och hade utarbetat flera strategier och knep för att få gastrostomin att fungera så smidigt som möjligt.

11.6 Diskussion

Avhandlingen visar att barn med utvecklingsrelaterade diagnoser har långvariga behov av näring via en gastrostomi vilket betyder att måltider för dessa barn och deras familjer kommer att påverkas under lång tid. Användningen av ICF i diskussionen av resultaten visar på att en gastrostomi påverkar barnet både positivt och negativt vad gäller kroppsstrukturer och -funktioner, vilka aktiviteter barnet gör samt sammanhang som barnet är delaktigt i. Utifrån ekokulturell teori sågs att samtliga tre undersökta perspektiv – vårdpersonals, barnens och föräldrarnas – beskriver förändringar som gjorts för att skapa vardagsrutiner anpassade till värderingar och förutsättningar i familjen. Barnen och deras föräldrar åskådliggör en ständig avvägning mellan å ena

sidan specifika behov kopplade till näringstillförsel och fysiska förutsättningar, å andra sidan värdet av gemensamma måltider och att vara en del av familjen. Genom förankring i handikappvetenskap, ICF och ekokulturell teori bidrar avhandlingen med kunskap om hur användningen av en gastrostomi hos ett barn inverkar på vardagliga måltider i familjen. Avhandlingens resultat överensstämmer med tidigare forskning som påtalar ett fortsatt stort behov av ökad medvetenheten och kunskap hos vårdpersonal som innefattar att sammanväga fysiologiska, psykologiska och sociala aspekter i uppföljningen av hälsan hos barn med en gastrostomi. Vidare belyser avhandlingen brister i hur barn inkluderas i frågor som rör dem själva.

11.7 Implikationer och framtida forskning

Avhandlingen avslutas med förslag på hur vården för barn med gastrostomi kan förbättras. Ett förbättringsområde är kunskapsnivån hos personal gällande arbetssätt som involverar barn i planering, genomförande och uppföljning av behandlingsåtgärder. Andra förbättringsområden är samarbetet mellan olika yrkesprofessioner, journalföring samt att regelbundet fråga föräldrar hur de hanterar vardagliga måltider och sina känslor kopplade till barnets gastrostomi, exempelvis genom användning av strukturerade frågeformulär.

Den här avhandlingen ger en bild av hur måltider fungerar i familjer där ett barn har en gastrostomi. Framtida studier skulle kunna undersöka orsaksförhållanden mellan fungerande i familjer och ätande hos barn med en gastrostomi, eller mellan barns delaktighet under måltid och fortsatt ät-utveckling. Studier som systematiskt undersöker familjers anpassning till ett barns gastrostomi över tid skulle också vara värdefulla för att öka kunskapen om processer som leder till hållbara familjerutiner. I det sammanhanget behöver familjer från varierande kulturella bakgrunder inkluderas. Slutligen finns behov av att utforska måltider för barn med en gastrostomi i andra sammanhang än i hemmet, exempelvis i förskola, skolan eller hos vänner och släktingar.

12. Acknowledgments

The work of this thesis was made possible by the financial support of the Linnea and Josef Carlsson's foundation, the foundation *Sparbanksstiftelsen Varberg*, regional research- & development grants from Region Halland and the *Majblomman* research foundation.

To do research is to cooperate, and be open and humble to the knowledge of others, while developing one's own knowledge. It is about concentrating on the uniqueness of the present task while keeping focus on the bigger picture. Also, it is more often about refining or complementing the research of others than developing innovative, new ideas. It is impossible to mention all those to whom I owe a big, warm "Thank you!" for sharing their knowledge, keeping me on track, and scrutinising my writings. Nevertheless, I seize this opportunity to express my appreciation and gratitude to some of them especially:

First and foremost, **all the participating families** involved in the project who bravely and generously shared medical records, time, everyday life, and valuable experiences with me. This thesis is, after all, about them, and I thank them deeply. Thank you also to **Ebba Sundin**, my main supervisor, for your ceaseless encouragement and interest in my work, your sense of language, and for helping me to never lose sight of the social sciences when I occasionally wandered towards a more medical focus. **Ann-Kristin Karlsson**, my assistant supervisor, for your warm support, careful attention to analytic details, and honesty. **Mats Granlund**, my assistant supervisor, for the respect you have shown me during the work of this thesis, and for sharing your invaluable, deep scientific knowledge and network within the field of childhood disability and participation research. **Lotta Sjögreen**, my role model and co-author who guided me from the very beginning of this journey, and helped me sort out the information for what would become Study I.

Thank you to **all my colleagues at Region Halland's Child and Youth Habilitation Service Centres**, for being my foundation and safe haven, providing energy and support when life as a doctoral student was burdensome

or lonely. Specifically, I thank **Margareta Niklasson**, head of the Child and Youth Habilitation Service Centre in Kungsbacka, and **Anna Ingemansson**, head of the Child and Youth Habilitation Service Centres in Region Halland, for believing in me and being positive, interested, and supportive during these past years.

My warmest gratitude to the always helpful and supportive **staff at the Research and Development Department, FOU, Region Halland**. I am also grateful for the help of **all secretaries and health professionals within and outside Region Halland** who helped me identify and recruit families for the project.

I have not forgotten **all of you who** gave of your time to read my work, giving valuable feedback on the thesis and included papers, making me reflect, reconsider and develop. My **colleagues at the School of Health and Welfare, Halmstad University**, for providing a stimulating atmosphere and for all the encouragement during these years. A special thanks to **past and present fellow doctoral students** for offering valuable comments on my manuscripts and discussing with me various aspects of the project, as well as life in general, on numerous occasions. **Renee Luthra** and **Helena Taubner**, precious companions on the endeavour of becoming disability scholars, thanks for all the laughs, moans, thoughts, and invaluable conversations I have shared with you during our time as doctoral students. A warm thank you also to **the CHILD research group at Jönköping University**, for letting me be part of your inspiring team. **Margret Buchholz**, **Ingrid Mattson Müller**, and **Eva Holmqvist**, DART centre for AAC and AT, Sahlgrenska University Hospital, Gothenburg: many thanks for your professional and friendly assistance in the design of the supportive communication strategies used in the second part of this project.

My very dear friends and neighbours, thank you for food and talks, for vacations and weekdays, for running and skiing, for sailing and just being. Finally, a special, sincere “Thank you” goes to **my close as well as extended family** for your emotional and material support during these years, and for being the most passionate, severe, and constructive critics of them all. Your knowledge, guidance, and intuition regarding when to be professional and when to be my family has been most valuable. **Petter, Rasmus** and **Frida**, my source of energy and happiness, a constant reminder of what I value most. Thank you for letting me do this, for being interested in my work, and for making me smile when I need it the most. I am so very grateful that you are part of my everyday life ♥

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14. Appendix

- Appendix 1.** *Protocol for data extraction from medical records*
- Appendix 2.** *Parental interview guide*
- Appendix 3.** *Graphic communication board used to inform the children about the study aim and procedure.*

Appendix 1. *Protocol for data extraction from medical records*

Prior to gastrostomy placement

1. Demographics (sex, date of birth)
2. Date of gastrostomy placement
3. Primary medical diagnosis according to the ICD-10 (WHO, 2011a). Diagnoses were further grouped as “acquired” or “developmental”. Neoplasms (ICD-10 Chapters C and D) and Intracranial injuries (ICD-10 Chapter S) were classified as acquired disorders.
4. Indication for gastrostomy according to the ICD-10.
5. Nutritional support (oral nutritional supplements, nasogastric tube, parenteral nutrition and/or nutritional advice)
6. Eating assessments (The medical records were scanned for the occurrence of formal or informal assessments or descriptions of the child’s eating ability. Formal assessments were to be based on a named test or checklist, and informal assessments were to be based on mealtime observations or oral motor assessments, with the results systematically noted in the child’s medical record.)
7. Medications (Medications were grouped according to the aim of the treatment: intestinal regulator, antibiotic, anticonvulsant, respiratory medication, gastroesophageal reflux disease, treatment, chemotherapy, other, or no medication.)
8. Healthcare professionals in contact with the child related to feeding and eating.

After gastrostomy placement

1. Date and reason for gastrostomy discontinuation
2. Feeding habits (Feeding habits were estimated using a 4-point scale: all in tube, most in tube, mostly orally, or all orally. “Most in tube” was defined as more than 50 per cent of total intake in the tube, and “mostly orally” was defined as more than 50 per cent of total nutritional intake from liquids and solid food orally; Åvitsland et al., 2006)
3. Eating assessments
4. Source of nutrition (categorised as “homemade”, i.e. mother’s milk or blenderised food, or “commercially manufactured enteral products”)
5. The occurrence of “Oral stimulation using different tastes” (defined as minor amounts of food given orally to stimulate sensory input in the mouth, improve saliva production and gastro-intestinal processes, as recommended to children with all nutrition in tube)
6. Healthcare professionals in contact with the child related to feeding and eating.

Appendix 2. Parental interview guide

Questions without video

(follow-up questions to explore the where, who, what, how, feelings)

1. Initial question: "Tell me about mealtimes in general for your family."
2. Tell me about a meal you had in the family that you experienced as particularly successful or enjoyable.
3. At times, all families experience pressure and stress over various things. Tell me about a meal that you remember as affected by stress or that you experienced as less successful?
4. Families vary in what special habits and traditions related to food they have. Tell me how it is for you.
5. Tell me about the food and mealtimes for [your child with gastrostomy].
6. What are your thoughts about your child's eating in the future?
7. What support have you received related to your child's eating from family, friends, or healthcare professionals?

Questions without video

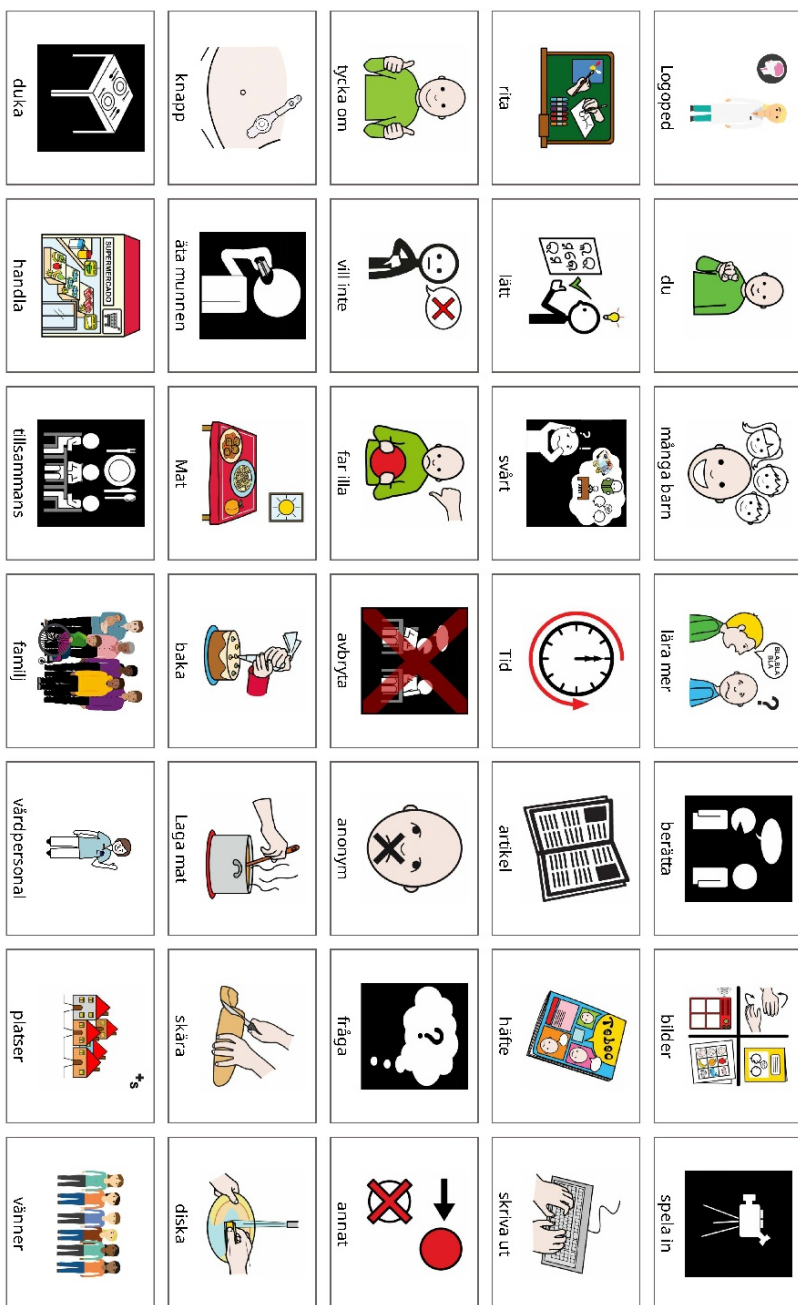
(follow-up questions to explore the where, who, what, how, feelings)

1. Start by telling me why you chose this particular recording. In what way is this a typical mealtime for your family?
2. (Present examples of sequences, such as the participants' various roles and tasks, topics of conversation, interaction, adjustments during the meal, presence and involvement of the child with gastrostomy, activities).

Closing the interview

1. How did the camera affect your mealtime?
2. How did you feel about looking at your recorded mealtime and discussing it?
3. Now we've talked and looked at your recorded mealtime. I have no more questions. Is there anything else regarding your situation around eating and mealtimes that you want to talk about?

Appendix 3. Graphic communication board used to inform the children about the study aim and procedure.



For info om symbollicenser: <http://www.dart-gbg.org/licenser>
 Detta bildstöd är skapat via www.bildstod.se



Ellen Backman

Ellen Backman is a clinical specialist in speech-language therapy. This is her doctoral thesis in the field of health and lifestyle with a specialisation in disability studies conducted at Halmstad University in collaboration with Region Halland.

The thesis explores routines and rituals related to nutrition, feeding, eating and mealtimes in families that have a child with a gastrostomy tube. The thesis consists of four separate studies, and includes documentation from medical records, individual interviews with affected children as well as with their parents. Eco-cultural theory, the International Classification of Functioning, Disability and Health (ICF), and the concept of participation form the conceptual framework of the thesis.

School of Health and Welfare

978-91-88749-64-2 (printed)
Halmstad University Dissertations, 2021

