Retrospective and prospective analysis of ICD-10 and ZTT DC:0-3R diagnoses in a population of tube dependent toddlers and young children

eingereicht von

Lisa del Negro

Mat.Nr.: 0311479

und

Elisabeth Thierrichter

Mat.Nr.: 0310264

zur Erlangung des akademischen Grades

Doktorin der gesamten Heilkunde

(Dr. med. univ.)

an der

Medizinischen Universität Graz

ausgeführt an der

Universitätsklinik für Kinder- und Jugendheilkunde

Klinische Abteilung für Allgemeine Pädiatrie

unter der Anleitung von

Ao. Univ.-Prof. Dr. Marguerite Dunitz-Scheer

Graz, 10.07.2009 (Unterschrift)

Eidesstattliche Erklärung

Ich erkläre ehrenwörtlich, dass ich die vorliegende Arbeit selbstständig und ohne fremde Hilfe verfasst habe, andere als die angegebenen Quellen nicht verwendet habe und die den benutzten Quellen wörtlich oder inhaltlich entnommenen Stellen als solche kenntlich gemacht habe.

Graz, am 10.07.2009

(Lisa del Negro)

Eidesstattliche Erklärung

Ich erkläre ehrenwörtlich, dass ich die vorliegende Arbeit selbstständig und ohne fremde Hilfe verfasst habe, andere als die angegebenen Quellen nicht verwendet habe und die den benutzten Quellen wörtlich oder inhaltlich entnommenen Stellen als solche kenntlich gemacht habe.

Graz, am 10.07.2009

(Elisabeth Thierrichter)

DANKSAGUNG

An dieser Stelle möchten wir uns bei den zahlreichen Personen, die uns im Laufe unseres Studiums und während der Erstellung unserer Diplomarbeit tatkräftig unterstützt haben, herzlich bedanken!

Ein besonderer Dank geht an unsere Betreuerin, Frau Ao. Univ.-Prof. Dr. Marguerite Dunitz-Scheer, die uns in den letzten Monaten stets mit Rat und Tat zur Seite stand und uns ermöglichte, eine besondere Gruppe von Kindern näher kennenzulernen.

Wir möchten uns beim gesamten Team des Instituts für Medizinische Informatik, Statistik und Dokumentation unter der Leitung von Frau Univ.-Prof. Dipl.-Ing. Dr. Andrea Berghold bedanken. Ein herzlicher Dank geht insbesondere an Herrn Dr. Gerhard Bachmaier für die Hilfe in statistischen Fragen und die Auswertung unserer Daten.

Herrn Univ.-Prof. Dr. Peter Scheer danken wir für die Unterstützung bei der Entstehung dieser Arbeit.

Ein herzliches Dankeschön sei an Frau Mag. Petra Kaimbacher gerichtet, die uns in wochenlanger Arbeit ermöglichte, auf die Daten zurückzugreifen und uns immer mit praktischen Tipps zur Seite stand.

Herr Mag. Hannes Beckenbach war maßgeblich an der Aussendung der Fragebögen beteiligt – hierfür sei ihm herzlich gedankt.

Wir danken außerdem Herrn Dr. Thomas Traby, der immer ein offenes Ohr für unsere Fragen hatte.

Vielen Dank möchten wir Frau MMag. Maria Thierrichter für die Geduld und die Gewissenhaftigkeit beim Korrekturlesen unserer Arbeit und die sprachliche Unterstützung aussprechen.

Unseren Eltern, gebührt besonderer Dank. Sie haben uns nicht nur das Studium ermöglicht, sondern sind uns sowohl in den Höhen, als auch Tiefen des Studiums stets zur Seite gestanden. Vielen, vielen Dank für eure liebevolle Unterstützung!

ZUSAMMENFASSUNG

Hintergrund: Sondenabhängige Kinder sind eine seit noch nicht allzu langer Zeit bestehende, spezielle Population in der Pädiatrie. Sondendependenz wird als unbeabsichtigte Notwendigkeit, ausschließlich über eine Sonde ernährt zu werden definiert und ist durch die Ablehnung von oraler Nahrung und das Fehlen einer medizinischen Ursache charakterisiert. Die Station für Psychosomatik und Psychotherapie an der Universitätsklinik für Kinder- und Jugendheilkunde Graz hat langjährige Erfahrung in der Behandlung sondendependenter Kinder und verfügt über die weltweit größte Datensammlung dieser Inanspruchnahmepopulation. Ziel dieser Studie war, diese Datensammlung bezüglich epidemiologischer Faktoren zu analysieren. Eine vergleichbare Analyse existierte unserem Wissen nach bisher nicht. Der Schwerpunkt dieser Arbeit wurde auf die retrospektive und prospektive Analyse der ZTT DC:0-3R- und ICD-10-Diagnosen in dieser internationalen Population sondendependenter Kleinkinder gesetzt.

Methoden: Die Datenauswertung wurde mittels des Statistikprogramms ARCHIMED durchgeführt, das sowohl biometrische als auch epidemiologische Daten sondendependenter Kinder erfasst. Die Studienpopulation bestand aus 302 sondenernährten Kindern im Alter zwischen 0 und 3,99 Jahren – 168 weiblich, 134 männlich – die zwischen 1998 und Juni 2009 am Sondentwöhnungsprogramm teilnahmen. Zusätzlich wurde in einem Pilotprojekt ein Fragebogen entwickelt, der zum Ziel hat, die Ansichten der Eltern über die Essprobleme ihres Kindes zu untersuchen.

Ergebnisse: Eine wichtige Tatsache war die Erkenntnis der Schwere und Komplexität der zugrunde liegenden Diagnosen dieser speziellen Inanspruchnahmepopulation. Die Sondenernährung begann in den meisten Fällen früh nach der Geburt und wurde während des kritischen Zustandes des Kindes und der dadurch notwendigen medizinischen Interventionen fortgesetzt. Ein weiterer interessanter Aspekt war das häufige Auftreten von schweren Nebenwirkungen durch Langzeit-Sondenernährung.

Konklusion: Die fehlende Unterstützung von Kindern und Eltern nach der Sondenimplantation sowie das Fehlen von adäquater Nachsorge müssen als Versagen angesehen werden, Therapie, Kraft und Fachwissen in die post-intensivmedizinische Versorgung zu investieren.

ABSTRACT

Background: Tube dependent children are a new and special population in paediatrics. The condition of tube dependency is defined by the ongoing unintended need to be exclusively tube-fed and is characterized by food refusal and the lack of any medical cause. The Psychosomatic Unit of the Children's Hospital in Graz, Austria, has a long tradition and many years of experience in the treatment of tube dependent children. Furthermore, the world's largest data collection on this specific clinical population has been established in Graz. The aim of our study was to analyse this unique data collection. The emphasis was set on the retrospective and prospective analysis of the ZTT DC:0-3R and ICD-10 diagnoses in a large sample of tube dependent children.

Methods: The data collection was performed by using the ARCHIMED program, which records biometric and epidemiological data of tube dependent children. Our sample consisted of 302 children aged 0 to 3.99 years – 168 females, 134 males – who had been treated in the Graz Model weaning program between 1998 and June 2009. The sample is only focused on exclusively tube-fed children who were referred to the program for the sole reason of needing weaning from their tube dependency. Additionally, a pilot questionnaire was developed with the aim of investigating the parents' perspective of their child's eating problems.

Results: A sticking fact was the recognition of the severity and complexity of the underlying medical diagnoses of these infants. Tube feeding was in most cases started after birth and was continued throughout a series of severe medical conditions and interventions. Another interesting finding was the high occurrence of severe and distressing negative side effects of long-term enteral feeding.

Conclusion: The total lack of child and parental support after tube insertion and the lack of adequate aftercare must be considered as a shameful institutional failure to invest therapy, energy and know-how into the last phase of ex-intensive care.

TABLE OF CONTENTS

DISTRIBUTION OF WORK

This diploma thesis was composed together by us, Lisa del Negro and Elisabeth Thierrichter. The following list represents the distribution of work.

1. Introduction

1.1 Enteral nutrition	ELISABETH THIERRICHTER
1.2 The Graz Model weaning program	LISA DEL NEGRO
1.3 Two selected classification systems	ELISABETH THIERRICHTER
1.4 Case reports	LISA DEL NEGRO

2. Methods — LISA DEL NEGRO
3. Results

3.1 up until 3.1.2.12	THIERRICHTER ELISABETH
3.1.2.13 up until and including 3.2	LISA DEL NEGRO

4. Discussion

Classification systems	THIERRICHTER ELISABETH
Parents of tube dependent children, Multimorbidity, Questionnaire, Literature	LISA DEL NEGRO

ABBREVIATIONS

a.m.	ante meridiem
DSM	The Diagnostic and Statistical Manual of Mental Disorders
DSM-III-R	The Diagnostic and Statistical Manual of Mental Disorders, Third Revision, Revised
DSM-IV	The Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association, Fourth Revision
e.g.	exempli gratia, for example
EPJ	endoscopic percutaneous jejunostomy
et al.	et aliud
etc.	et cetera
fig.	figure
GIT	gastrointestinal tract
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
incl.	including
JET-PEG	jejunal tube through percutaneous endoscopic gastrostomy
MS	Microsoft
NASA	National Astronautics and Space Administration
NGT	nasogastric tube
no.	number
NEC	necrotizing enterocolitis
p.m.	post meridiem
PEG	percutaneous endoscopic gastrostomy
PVC	polyvinyl chloride
RDC-PA	Research Diagnostic Criteria-Preschool Age
U.K.	United Kingdom
USA	United States of America
WHO	World Health Organisation
ZTT DC:0-3	Zero to three's Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, 1987
ZTT DC:0-3R	Zero to three's Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood: Revised edition, 2005

TABLE OF FIGURES

TABLE OF PHOTOS

TABLE OF CHARTS

PREFACE

We decided to write our diploma thesis at the Psychosomatic Unit at the Children's Hospital in Graz, Austria, because this unit has been very successfully treating a graving international sample of tube dependent children during the last 12 years. These children form an extraordinary population in the world of medicine up to this point.

No study of a comparable extent has been conducted yet and therefore, the epidemiological situation of this special group of children is more or less unexplored and open for experimental interventions of all kinds. Worldwide, there is neither knowledge about the number of children who are nourished by tube on a long-term basis nor data about how many of these patients develop a tube dependency in the course of time. Besides, only few data about the diagnoses and indications in the group of tube dependent children can be found.

Tube dependency has obviously been regarded as unimportant. This can be confirmed on the level of a medical perspective. Quite in contrast, there is a vast amount of awareness and desperation on the side of the parents and caregivers of the affected children. This fact is reflected in the numerous parent-forums on the internet. Parents of tube dependent children mostly run into encounters of being told that they should not "produce" or "invent" a problem which is not officially recognized as being an unintended but clearly initiated side effect of medical treatment. So the phenomenon of tube dependency must be defined to be an absolutely unrecognized morbidity. Analogies to premature children, who were treated with high doses of oxygen and then lost their ability to see, can be made. Children, who would not have survived because of their extreme prematurity or other severe disorders, are treated with high tech medicine in order to keep them alive. But it has to be considered, that this treatment also holds unintended complications like the development of tube dependency. This population of surviving patients is left alone with their tube and often left to solve the issue on their own. In the future, the problem of tube dependency in childhood will expectedly increase massively, since the possibilities of medicine will develop further and further.

This paper deals with the largest ever published population of tube dependent children, who all have been treated by the interdisciplinary tube weaning team of the Psychosomatic Unit in Graz.

1 Introduction

1.1 Enteral nutrition

1.1.1 General

Children with eating and feeding disorders can suffer from various organic, surgical, metabolic, psychological and interaction disorders, which can be associated with insufficient oral intake, impossibility to swallow and therefore lead to a failure to thrive. To avoid these consequences and to supply vital nutriments to the child, tube feeding is used in all areas of neonatal and childhood medicine. A feeding tube is a thin tube made of plastic or soft rubber, which is inserted through the nostril into the stomach or the small intestine. Tube feeding means that fluid nutrition is applied directly into the gastrointestinal tract; it is referred to as enteral nutrition (1).

1.1.2 History

The term “enteral nutrition” derives from the Greek word “enteron” and means nutrition via the gastrointestinal tract with special nutriments made of natural eatables. It is important to mention that enteral nutrition can either be drunk or applied via a tube (2).

The old scripts of the Israelites, Egyptians and Persians already contained detailed recommendations for the utilization of food and drinks in connection with health or the treatment of diseases (2).

Around 3400 before Christ, food was applied into the rectum. Doctors used amongst others sheep-milk, honey, lard, breast milk or wine. It took a very long time, before they found out that nutrition was only reabsorbed if it passed the anatomic barrier between colon and small intestine. Nevertheless, this procedure was used until the 1930s (2).

In the 12th century, patients were fed via a silver-tube which was inserted into the pharynx (2).

In 1570, oral nutrition with a tube was described for the first time. Doctors used a “tube” made out of lamb-intestine, which was inserted via the nose into the oesophagus (2).

In the early 1970s, many patients who could have been nourished enterally were fed parenterally, because neither the technique of application nor adequate nutrient solutions were available. The development of balanced nutrient solutions had its origin in the

astronautics as the NASA developed the so-called astronaut food. At the same time, nutrient solutions which were similar to the astronaut food, were developed for pre- and postsurgical use. These solutions consisted of elementary, synthetic nutrients which led to two main problems: (i) the bitter taste which derived from free amino acids and (ii) the high osmotic pressure which led to diarrhoea (2).

In medical facilities, enteral feeding was even more complicated. Additionally to the above mentioned problems with nutrient solutions, the technique of tube feeding was hardly feasible. Tubes consisted of PVC which became solid after some days and therefore led to injuries of the mucosa and gastrointestinal bleeding (2).

Up until now, feeds and tubes have ameliorated and today, there are various kinds of tubes as well as different feed preparations according to each patient's needs (2).

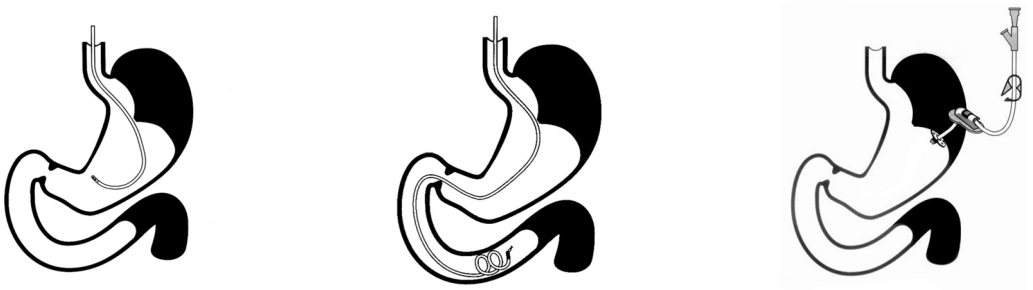
1.1.3 Indications for enteral nutrition

There is a range of indications for enteral nutrition in different (medicinal) departments. In paediatrics, enteral nutrition is used to assure the supply of vital nutriments for:

I. Patients with inborn malformations, cleavage or atresia.
II. Extreme premature babies who are too weak to eat sufficiently.
III. Patients in a reduced general condition, for example patients with cardiac problems.
IV. Food-supply after accidents, craniocerebral trauma or other medical conditions which have to be treated in the intensive care unit.
V. Controlled feeding of patients with metabolic diseases.
VI. Controlled feeding of patients with consuming diseases, for example oncologic patients (3).

1.1.4 Tube systems

Depending on the individual needs of the patient and the expected period of tube feeding, two different types of tube feeding systems are available: transnasal tubes (via the nasopharynx into the stomach or into the jejunum) or percutaneous tubes (through the abdominal wall) (4).



1.1 Nasogastric tube 1.2 Nasojejunal tube 1.3 Percutaneous tube

Figure 1. **1: Nasogastric tube.** Taken from http://htma.info/uploads/RTEmagicC_Gastrale_Sondenlage_01.jpg
2: Nasojejunal tube. Taken from http://htma.info/uploads/RTEmagicC_Jejunale_Sondenlage_01.jpg
3: Percutaneous tube. Taken from http://htma.info/uploads/RTEmagicC_PEG_Sonde_Zeichnung.jpg

1.1.4.1 Transnasal tubes

A transnasal tube is inserted through the nose, passes the throat and is pushed forward into the stomach (nasogastric tube) or into the small intestine (nasointestinal or nasojejunal tube). The second option is used if there is a high risk of aspiration. Thereby it is important to distinguish between tubes for adults and children, respectively between tubes with a small or a large diameter (5).

As Dunitz-Scheer et al. stated, "the need for short-term tube feeding is the main reason for nasogastric tube placement. Although the recommended length of tube feeding is arbitrary, by short-term, we suggest a period up to 2 months; this would apply to premature infants, surgical corrections of inborn anomalies, and treatment of infants suffering from prolonged diarrhoea." (6)

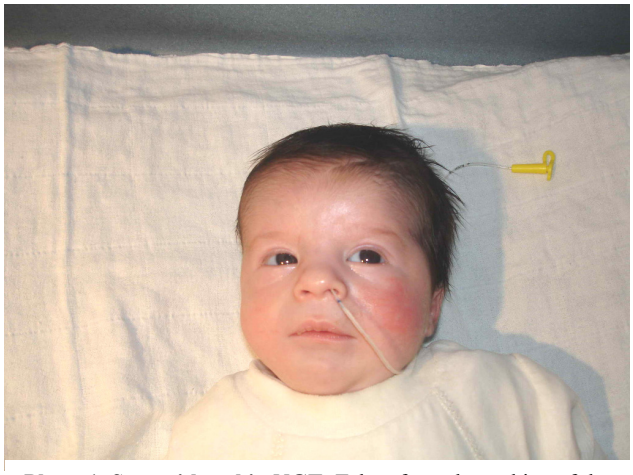


Photo 1. Sam with a thin NGT. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Another indication for nasogastric tube placement is an unpredictable course of disease (5).

1.1.4.1.1 Advantages of transnasal tubes

The following advantages of transnasal tubes can be observed:

I. There is no need for anaesthesia when a transnasal tube is placed.

II. It is mostly non invasive and atraumatic, especially when the infant is very young.

III. The tube is very easy to remove as it just has to be pulled out via the nose.

IV. Transnasal tubes are ideal for short-term enteral feeding because of the above named advantages (7).

1.1.4.1.2 Disadvantages of transnasal tubes

During the developmental phase of individuation (sixth to ninth month of age), nasogastric tube placement may become increasingly difficult due to the child's growing sense of its basically invasive character. Some parents describe a feeling of abuse and suffer greatly from needing to overcome the growing resistance of their toddler. Further disadvantages of transnasal tubes are, on the one hand, some acute complications like pharyngeal and oesophageal perforation and accidental intracranial or bronchial insertion. These complications are very rare, but can be fatal. On the other hand, transnasal tube feeding can lead to nasopharyngeal discomfort, nasal erosion, abscesses or sinusitis as well as oesophagitis, oesophageal ulceration or stricture if the tubes are used for a longer period of time than recommended (8).

Furthermore, transnasal tubes can lead to irritations of the skin, are difficult to fix and can easily be removed by the child itself (7).

1.1.4.1.3 Technique of tube insertion

It is essential to diagnose a passable gastrointestinal tract before the tube is inserted.

I. Defining the tube length: The appropriate tube length is defined by the distance between ear and nose plus the distance between nose and the pit of the stomach. The length should be marked on the tube for the further procedure (9).

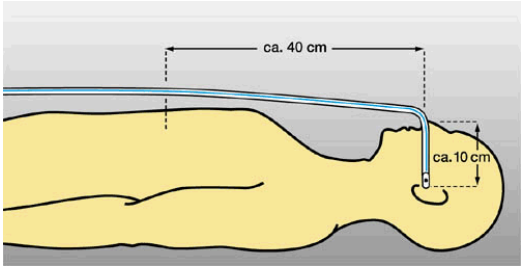


Figure 2. Defining the tube length of transnasal tubes. Taken from http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Abmessen+der+Sondenl%C3%A4nge

II. Insertion of the nasogastric tube: The tube is placed into the nostril and pushed forward for approximately 10 centimetres. The patient is requested to bend his/her head and to swallow. As the patient swallows, the tube is pushed forward. If the

patient starts coughing heavily, the insertion has to be interrupted, because the tube probably lies in the trachea. If the tube is inserted up to the marking, it can be expected that it is situated at the gastro-oesophageal transition and should be pushed forward for another 10-20 centimetres (10).

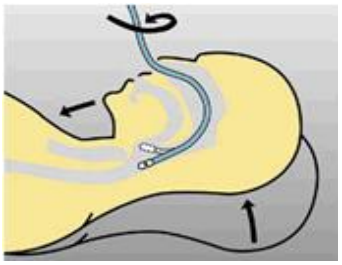


Figure 3. Insertion of the nasogastric tube. Taken from http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Das+Anlegen+und+Plazieren+der+transnasalen+Sonde+-+nasogastral

III. Insertion of the nasojejunal tube: For tube placement of a nasojejunal tube the same procedure as for the nasogastric tube is used. The only difference is that it is pushed forward for approximately 50 centimetres. For unconscious patients, an endoscope or the Seldinger technique can be used (11).

IV. After insertion, the tube is fixed on the patient's cheek. This fixation has to be checked regularly.

V. To verify the correct position of the tube, an X-ray control is performed (12).

1.1.4.2 Percutaneous tubes

A percutaneous tube is inserted through the abdominal wall and attached to it with sutures.

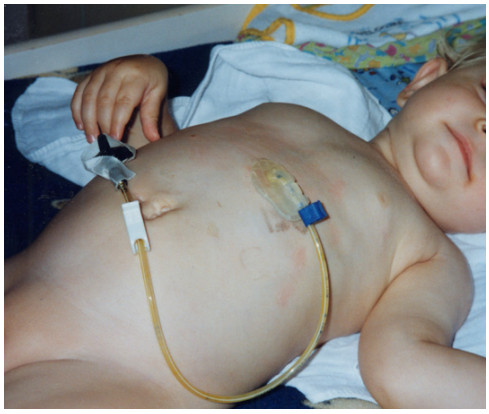


Photo 2. Sue with a lying PEG. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

There are different types of such tubes, out of which the best according to the patient's needs can be chosen: gastral PEG, EPJ or JET-PEG (a PEG with added enteral feeding tube placed in the jejunum) (13).

Percutaneous tubes are indicated in cases with an "expected phase of prolonged insufficiency of oral intake (e.g., lasting more than 2 months) – as seen in children with severe neuromuscular diseases, neurodegenerative diseases, metabolic disorders,

regression of developmental milestones, recurrent aspirations, chronic lung disease, and so on." (6) In such cases, it might be far-sighted to start enteral feeding with a nasogastric tube in order to certify feeding tolerance (6).

A special type of percutaneous tubes is the so-called button. It is attached to the abdominal wall by a balloon and can therefore easily be changed or removed. Buttons are the more modern kind of percutaneous tubes. They are not suitable if a child has to be fed several times a day. For long-term nutrition, buttons are better than "normal" percutaneous tubes, because the children are not limited in their physical activity (7).

1.1.4.2.1 Advantages of percutaneous tubes

There are several advantages of percutaneous compared to nasogastric tubes.

Firstly, there are no facial irritations, nasal adhesions, oral or nasal irritations. Secondly, the risk of aspiration is minimized because the percutaneous tube cannot migrate into the oesophagus (6). Thirdly, the percutaneous tube is not visible for other people and the tube is not interfering with daily activities, which is an important advantage for the child and the parents. In addition to that, feeding takes less time than with nasogastric tubes (14). The psychological and developmental impacts are different from child to child and caregiver to caregiver and have a great influence on the acceptance of the device as a long-term feeding technique (7).

1.1.4.2.2 Disadvantages of percutaneous tubes

The disadvantages of percutaneous tubes are that the placement is an invasive procedure for which the patient needs to be anaesthetized. Furthermore, the tube can cause irritations or infections of the stoma area, leaking and malfunction. Additionally, percutaneous tubes can dislocate or fall out (7).

1.1.4.2.3 Technique of tube insertion

There are various techniques to insert a percutaneous tube.

I. Suture pull-through method: The abdominal wall is anaesthetized and then penetrated by a hollow needle. A guide suture is pushed through the hollow needle and then grabbed by the waiting endoscopy-forceps. Then the guide wire is pulled out through the oesophagus. Afterwards, the tube is inserted through the mouth and pushed down along the guide suture into the stomach, where it is attached to the abdominal wall from the in- and outside (1).

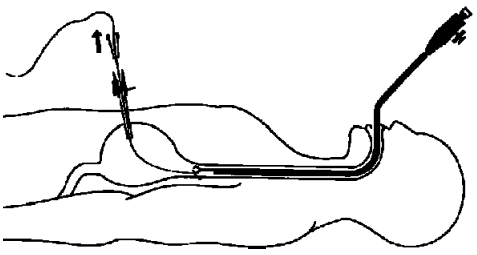


Figure 4. PEG – suture pull-through method. Taken from http://www.clunes.de/etp/images/peg05.gif

II. Direct centesis: The direct centesis is used if there is any stenosis in the oesophagus or the stomach. When using this method, the abdominal wall is anaesthetized and the tube is inserted via a hollow needle, before it is attached to the gastric wall by a balloon. An endoscopic control of the right location follows (1).

1.1.5 Tube nutrition

1.1.5.1 Tube feeding strategy

Enteral feeds can be given as bolus, intermittently or continuously.

Bolus feeds are applied by pressure and drop by gravity (7). They are very simple and require minimal equipment, but at the same time increase the risk of gastrointestinal symptoms (15). Bolus feeds are given four to twenty-four times a day – depending on the child's age and nutritional condition (1). The advantage of bolus feeding is that the patient is not limited in his/her mobility, while the disadvantages are the above-named gastrointestinal symptoms like nausea, diarrhoea and meteorism (16).

Intermittent feeds are applied either by hand or pump (7). The advantages are the unlimited mobility of the patient as well as the fact that "real" meals are imitated. On the other hand intermittent feeds can lead to gastrointestinal complications like nausea, vomiting (associated with the risk of aspiration), abdominal convulsions and diarrhoea (16).

Continuous feeds use a pump system (7). Here, the rate of gastrointestinal symptoms is reduced, the subjective and metabolic tolerance is relatively good (16). Another advantage of continuous feeds is the high calory intake, which can be reached by this method (1). On the other hand, it has to be considered that the patient is connected to the system most of the time, which limits his/her mobility (16). Continuous feeds are

recommended, if the child suffers from any gastrointestinal diseases with malabsorption, passage barrier, Crohn's disease or severe dystrophies. In addition to that, this kind of application is used for duodenal tubes (1).

Dunitz-Scheer et al. pointed out that "as a general rule, oral feeding followed by bolus supplementation, or nocturnal tube feeding with oral intake by day has the additional benefit of preserving oral activity and feeding habits, as well as hunger and satiety cycles. Patients intolerant to bolus feeding, or with severe malabsorption, may benefit from continuous feeding." (6)

1.1.5.2 Feed preparation

There are several nutritionally complete pre-packaged feeds on the market (8).

Standard enteral feeds contain all the carbohydrate, fat, protein, water, electrolytes, fibre and micronutrients (vitamins and trace elements) which are required by a stable patient (8). They can either be isocaloric or high caloric, if needed (17).

In addition to the standard enteral feeds, there are special formulas for patients according to age and/or the specific underlying disease (1).

"Pre-digested" feeds improve the nutrient absorption and are used in patients with pancreatic insufficiency or inflammatory bowel disease. They contain nitrogen as short peptides or free amino acids as well as a variable amount of fibre and possibly vitamin K, if needed (8).

Special feeds for diabetics contain amylum and fructosis instead of maltodextrin. Additionally, they are high in unsaturated fatty acids – an energy source which does not affect the blood sugar (18).

Besides, feeds especially produced for patients with liver or renal insufficiency can be found(18).

1.1.6 Complications in tube-fed children

Tube feeding is a good option to supply patients with vital nutriments for a transitory or permanent period of time, but there are also several risks which have to be considered, since they can lead to new problems and impaired development. Therefore, indications for tube feeding in childhood have to be examined very strictly.

Firstly, tube feeding can lead to resorptive and functional disorders like villous atrophy, reflux, gagging, vomiting, rumination and diarrhoea (19). However, tube feeding can also lead to constipation, which is caused by reduced gut motility and absorption. Normally, gut motility and absorption are promoted by hormones which are released during visual contact with food, oral licking, tasting and mastication. To avoid constipation, feed administration rates should be decreased; continuous feeding and adding of prokinetic agents are recommended (8). Due to all these gastrointestinal reasons, the child's thriving is affected and growth might not develop age-appropriately, although the child receives enough calories by tube feeding (19).

Secondly, the oral cavity is not stimulated sufficiently. Due to this condition, licking, biting, sucking, swallowing and chewing patterns may not develop age-appropriately. Also, the pre-stages of preverbal communication like making sounds, oral imitation, babbling, and mimic differentiation may be retarded. In addition to that, children who are long-term tube-fed can have problems with the differentiation of flavour (19).

Thirdly, tube feeding has an immense influence on intra-familial relationships. This can lead to severe disturbances both in the parents-child-relationship and the parental partnership. Several stages in the parents' emotional life can be observed: (20)

> In the beginning, parents are glad that their child is supported, grows and puts on weight. They accept that their child has to be nourished by tube, because its medical condition requires this kind of feeding. If the child needs long-term tube feeding, the tube becomes a distracting and limiting factor in the family's life. In addition to that, the long-term implications become more and more present and can become potentially harmful to the child. Another very important consequence of tube feeding is that the parents lack the emotional and social endorsement they normally get through feeding their child. Tube feeding means that the child is fed according to a strict time schedule and has nothing to do with the emotional and intuitive character of a normal feeding. Furthermore, the child does not experience eating with relish because it is forced to be the passive acceptor and not the active demander (20).

1.1.7 Contraindications for tube feeding

The American Gastroenterological Association pointed out that "tube feeding should be considered when the patient cannot or will not eat, the patient has a functional gut, and a method of access can be safely obtained. Mechanical obstruction is the only absolute

contraindication to enteral feeding. Severe diarrhoea, protracted vomiting, enteric fistulae, and intestinal dysmotility may provide special challenges to tube feeding but are not necessarily contraindications. However, it must be determined clinically what is safest and most efficacious for an individual patient." (21)

1.1.8 Tube dependency

Dunitz-Scheer et al. definded that "tube dependency is a distressing and unintended result of tube feeding in infancy. The condition of tube dependency can be defined as active refusal to eat and drink, lack of will to learn or the inability, and lack of motivation to show any kind of precursors of eating development and eating and drinking skills after a period of gastric feeding. It is characterized by overt disinterest, food avoidance and active refusal, gagging, vomiting, oversensitivity, fussiness, and other oppositional and aversive behaviour. It may influence the quality of life of the affected infants and their families to such a degree that all other troubles fade into insignificance besides the nightmare of a child who will not eat or drink." (6)

Although tube dependency is a distressing and unintended result of tube feeding in infancy, it seems to be an inescapable consequence and can occur as early as one week after tube placement. Interestingly, Dunitz-Scheer et al. observed that tube dependency can appear in every child independent of age and underlying disorder (6).

1.2 The Graz Model weaning program

1.2.1 General

The comprehensive tube weaning program of the Psychosomatic Unit of the Children's Hospital in Graz, Austria, was developed in 1987 on the basis of clinical experience and encounters with more than 430 tube dependent children referred not only from Austria, but from countries all over the world (USA, U.K., Israel, Canada, New Zealand, Australia, Switzerland, etc.) (6).

Trabi et al. explained that "the Graz Model weaning program is a multidisciplinary method excluding any kind of force feeding. The principle of the program is the establishment of self-regulated oral intake by supervised hunger due to rapid reduction of food intake by tube. Additionally, parents are counselled not to pressure children to eat and are coached to recognize and read their child's hunger cues." (22)

1.2.2 Indications and contraindications for tube weaning

Tube feeding has, like every medical intervention, positive as well as negative consequences and therefore, the indication needs to be re-evaluated on a regular basis. It is only reasonable to feed a child per tube if it ameliorates the child's life quality (23).

Most often, tube weaning happens without any problems. If not, it is necessary to evaluate, if there is a medical indication for ongoing tube feeding. This indication could for example be a vital health threat, high risk of aspiration or no benefit for the child from tube weaning. It is always an individual decision if the child profits by the tube or not (23).

Generally, tube weaning is indicated, if the child (i) is able to ingest orally without aspirating, (ii) can perceive and signalize his/her needs so that the attachment person will understand them, and/or if (iii) the child's general condition is stable enough so that tube weaning will not lead to medical complications (23).

By contrast, transition from tube to oral feeding is not possible, (i) if the child suffers from organic acidopathy, (ii) in the presence of pathologies of swallowing functions, (iii) if there is a high risk of aspiration, (iv) if the child did not learn to regulate his/her hunger and satiety cycles and (v) if tube weaning would lead to a reduction of the child's life quality (24).

Tube weaning is amongst others not recommended in children in a bad general condition, with acute infections or insecure health condition. Furthermore, children with Dumping Syndrome, Prader-Willi Syndrome and Short Bowel Syndrome should not be weaned from tube feeding (24).

There are also some no-go criteria, which should be considered in the process of tube weaning: gastrointestinal infections, clinical exsiccosis, anxiety states of the parents, etc (24).

1.2.3 Procedure of tube weaning

1.2.3.1 Type of program

The Psychosomatic Unit of the Children's Hospital in Graz offers three different possibilities to take part in the tube weaning program: (i) the inpatient program, (ii) the outpatient program and the (iii) net-patient program (7).

Whether a child (and his/her parents) take(s) part in either the inpatient or outpatient program depends on several factors.

First, the Psychosomatic Unit has three mother-infant-units to offer, where one of the parents can stay in the same room as the child. The intention of the weaning team is to preferably occupy these rooms, because the inpatient treatment of the child offers a very intensive care around-the-clock. This care contains medical support as well as nursing and all other possibilities the hospital can offer.

Second, some of the patients taking part in the weaning program are severely ill and have to be treated as an inpatient in order to observe the child's medical condition all the time and to intervene whenever necessary.

Third, children from European countries are entitled to apply for the E112, a form for medical cases of extreme specificity. In these cases the child's own insurance covers the full fee of inpatient treatment, which comes up to about 7000 Euro per week including all fees of the specific program (in the year 2008).

The program itself is the same for in- as for outpatients. The particular therapies as physiotherapy, occupational therapy, speech therapy, etc. take place from Monday to Friday 8 a.m. to 2 p.m. for all patients. In addition to that, the play picnic is performed from Monday to Friday at mid-day. Furthermore, the child is weighed every day and the parents can ask any time for a medical check-up.

Families taking part in the program as inpatients stay in the hospital as long as the child needs to be weaned, which is approximately three weeks. In this time, they take part in the daily programs and have amongst others the advantage of ward rounds also on week-ends.

Outpatients stay outside of the hospital and take part in the same daily therapies as the inpatients. Normally, the tube weaning team recommends that the families plan a stay of four to five weeks in order not to get into time-troubles if the weaning process takes longer than expected. The parents of outpatients also have the opportunity to have their child medically checked at any time, even in the night or on week-ends, where they can address to the outpatient clinic of the Children's Hospital Graz. If the medical condition of the child requires inpatient support, the child can be admitted at any time. The outpatient program costs about 600 to 1000 Euro per week (in the year 2008), but needs external accommodation.

The third group of patients are the so-called net-patients. This group is composed of parents who ask for help with tube weaning their children via e-mail. In these cases, the parents send all information about their child's problem, including data about the type of tube, date of insertion, the child's underlying disease(s), biometric data like weight, height and head circumference, etc. Then they get clear defined instructions about how to help their child to get rid of the tube. These instructions base on the same concept as weaning in Graz is performed, meaning that the parents reduce the daily intake per tube gradually while offering attractive drinks and food to their child all day. In addition to that, the parents need to have a paediatrician close-by to control the child's general condition. If the weaning at home does not succeed, there is still the possibility to admit the child as an in- or outpatient in Graz.

1.2.3.2 Clinical diagnostics

Before tube weaning can start, a detailed diagnostic investigation has to be performed. This means that the medical biography including surgical reports and the results of all performed radiological examinations are of prime importance. After the joint definition of the aim of treatment, parents and children undergo a standardised clinical investigation. The clinical diagnostics consists of (i) paediatric diagnostics, (ii) interactive and interactional diagnostics and (iii) a classification of the feeding behaviour disorder (25).

(i) Paediatric diagnostics is mainly based on previous reports and investigations. It is performed by a group of experienced professionals consisting of paediatricians, logopaedics, occupational and physical therapists. Thereby, it is essential not to perform any invasive examinations to avoid iatrogenic traumata, which can lead to a retraction of the child in the phase where the child-parent-relationship should re-stabilize (25).

(ii) In the interactive and interactional diagnostics, video-documentation is used to observe the interaction between child and parents. The child-parent-relationship is then assessed by using the diagnostic manual of ZTT-DC:0-3R (see chapter 3.3 – ZTT DC:0-3R) (25).

(iii) For the classification of feeding behaviour disorders, also ZTT-DC:0-3R is used (25).

1.2.3.3 Phases of weaning

The following phases are passed through in the Graz Model weaning program:

I. Adaption phase

Depending on the occurrence of pre-weaning oral abilities, the Graz tube weaning protocol reduces the tube-fed volume by 20-40% on day one, 40-60% on day two and – regulated by the child's physical state and exploratory oral behaviour – reduces the remaining 40-60% either completely on day three or gradually over the following days (25). During this phase of reduction, children receiving continuous or bolus feeding should change over to continuous feeding during night, while provoking hunger-periods during day time, where the children are not fed at all (6).

The child's medical condition is monitored via the general condition, the nappies' weight and in special cases by measuring of the urine specific gravity. Taking of blood samples should only be performed if absolutely necessary (25).

The goal is the occurrence of hunger during daytime (25).

During this period the child must be exposed to a world of attractive food and drinks, all served in small and colourful dishes during all therapeutic sessions but not offered by anyone specifically (6).

This is to achieve an advancement of age-appropriate interest in food without any pressure (25).

II. Tube-explantation / Defined end of tube feeding

As mentioned above, the presence of hunger is essential for tube weaning. A child who is satiated will not show any oral activities. In the moment the child experiences hunger, oral activity will develop. This activity can range from babbling to sucking, licking or tasting. As soon as any of these activities occur, nasogastric tubes should at least be removed during daytime, while feeding via percutaneous tubes should only be performed in the night in order to create more hunger and provoke even more oral activity. If the child is capable of drinking enough to maintain a stable condition and if the parents and the weaning team feel comfortable with the idea of continuing without the tube, tube-explantation should be performed (6).

After tube-explantation, a considerable weight-loss of 5-12% of the original weight will follow in the next 12-72 hours. Due to the increasing hunger, the child will get dehydrated and bad-tempered (25). In this stage, sufficient support is crucial. Parents must be able to have the child checked at any time, if they have any concerns about insufficient intake or potential harm. Monitoring takes place via daily measuring of the body weight (6).

Photo 3. Daily measuring of the body weight. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

III. Plateau-phase

If the child is in a good general condition, a weight loss of up to 10-12% is tolerated. In this stage, the child can choose autonomically when, what and how to eat and drink. During the next one to three weeks, the child will gradually gain weight until the same weight as before weaning will be reached again (25).

The child should learn to self-regulate the hunger-satiation-rhythm (25).

IV. Education- and readaption-phase

In this phase, the aim is to re-establish an age-appropriate food intake in the cultural and familiar environment with defined rules (25). Two rules have to be considered by the parents:

I. "Offer the infant food if and only if a hunger cue has been shown.

II. Stop feeding immediately after any hint of refusal of food." (26)

In this regard, it is very important to teach the parents how to interpret their child's cues. As Dunitz-Scheer et al. states "if the food comes too fast, it may provoke the impression of intrusiveness, leading to facial aversion and food avoidance. If the food comes too late, the infant will not make the link between cue and answer and will not learn its own role in the food-seeking and food-offering dialogue." (6)

The goal is to establish the newly acquired feeding-eating-rhythm in the familiar environment (25).

After these four phases are passed through, it is crucial to trust in the ability of the child to self-regulate drinking and eating in order to maintain his/her biological needs. In the first two to three weeks after weaning, the child is likely to loose weight, before it starts gaining weight in the next two to three months. When the child begins to develop greater motor skills and to use more energy, weight may maintain on a stable level for four to five months, as seen in healthy children around twelve months, before it gains weight again (6).

As the child gains weight, oral skills develop and the child's interest in new food grows. In this time, the parents' expectations and control concerning the weight-gain of their child should further decrease. Table manners and other eating rules, such as structured mealtimes and preselected food, must not be adopted before the feeding situation has become unstressed and the child has become more confident (6).

The child and his/her parents will need further support by the weaning team, because short-term food refusal is likely to occur. For this and other reasons, it is important that the caring doctors are available (via e-mail or telephone) to answer questions concerning the child's development and the parent-child-relationship as well as the ideal amount of food-intake for the individual child (20).

1.2.3.4 Duration

The duration of tube weaning depends on several parameters.

First, tube weaning in children under the age of twelve months is easier than in older children (6). In addition to that, there is "an inverse correlation between gestational age and chance for weaning; preterm born children can be weaned more easily." (22)

Second, children with nasogastric tubes are weaned faster than children with percutaneous tubes (22).

Third, tube weaning in children with congenital heart diseases happens fastest. By contrast, children with inborn metabolic disorders take a long time to be weaned. A reason for this could be that it is not possible to provoke hunger in these patients, since these children must not starve due to the underlying metabolic disease (22).

Finally, there is a correlation between the severity of illness and the period of weaning. This may be due to the fact that severely ill children can only be discharged after they have gained full stabilization (22).

Generally, the Graz Model weaning program has shown that weaning is most often possible in a period of one to three weeks (25). Thereby, two kinds of weaning can be distinguished:

Primary weaning means that the child is successfully weaned during the program and leaves the hospital without a tube and with sufficient food-intake (22).

Secondary weaning means that the tube cannot be explanted until the time of discharge, because the child does not eat sufficiently and still needs supplemental feeds at night. Complete weaning happens during the aftercare phase in which the parents and their child stay in close contact with the medical attendant and his/her team (22).

1.2.4 Characteristics of the Graz Model weaning program

Trabi et al. pointed out that “learning to eat can happen only in a clinical environment with a high level of knowledge and expertise about normal eating, feeding development, failure to thrive, starvation, malnutrition and other medical, developmental or psychological conditions associated with food refusal.” (22)

1.2.4.1 Interdisciplinarity

The Graz Model weaning program is based on the interdisciplinary nature of the involved team. Thereby, every professional category has its special and important tasks in the weaning process. Only if these professional groups cooperate and communicate well, successful weaning is possible.

The following domains are involved:

1.2.4.1.1 Paediatric team

The paediatric team is responsible for coordinating diagnostic and therapeutic procedures and for monitoring the child’s weight and medical condition. Here, it has to be considered

that all invasive interventions have to be evaluated very strictly and that a weight loss of 6-11% of the original weight is and must be tolerated to provoke a hungry feeling (19).

1.2.4.1.2 Nursing team

The nursing team is very important in the weaning process because they have the closest contact to the parents and are responsible for observing the child's and the parent's physical and mental health condition. Paediatric nurses communicate a feeling of security to the parents who have to handle many difficult and stressful situations (19). Furthermore, the nurses take care that the children stay in permanent, but unforced contact with food (1).

1.2.4.1.3 Eating therapy

Eating therapy is the key-element in the Graz Model weaning program. Every day, a play picnic, where the children get the opportunity to approach food playfully, is performed. Three to eight infants or toddlers and at least one of their attachment figures take part in this one-hour lasting therapy, which is about not to force the children to eat, but to arouse their interest in the especially prepared and colourful finger food which is offered at the picnic. Every preoccupation with food like playing, touching, feeding the parents or the other participants is allowed (7). Thereby, parents are told only to interfere on strict demand for help of their child (22). If hungry enough and not disturbed or feeling in danger, any child will want to start to eat.

Apart from the play picnic, the child can see, smell and touch food at nearly all times of the day (22).

Photo 4. The play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the children's parents

Photo 5. The play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the children's parents

1.2.4.1.4 Video analysis

Video analysis is performed to examine the interaction between parents and child repeatedly (19). Parents are often surprised at their verbal and non-verbal communication patterns which can influence the eating and feeding disorder of their child both in a positive and negative way (1). Pathological behaviour patterns can be identified via video analysis and used to develop a strategy of modification (19).

1.2.4.1.5 Developmental psychologist

The aim of the developmental psychologist is to assist both, the child's and the parents' development, which in the majority of cases is disturbed in the functional-emotional sector due to tube feeding (19).

1.2.4.1.6 Interaction-focused guidance

Interaction-focused guidance is performed in an unstructured, undemanding and non-directive way by all members of the team (22) to establish a balanced relationship between parents and child, which is not only focused on the feeding or eating process (19). Such a focusing can pressure the parents as well as the child and hinder the weaning process massively (1).

1.2.4.1.7 Psychoanalytic oriented psychotherapy

Psychoanalytic oriented psychotherapy is performed to work on traumatic events in the child's and parents' history (22). Tube feeding can lead to severe disturbance of the parental self-esteem because the parents cannot fulfil their task to nourish their child (19).

1.2.4.1.8 Speech language pathologist

Speech therapy/logopaedics is performed to stimulate the oro-facial area in a non traumatic way to correct earlier traumatic oral experiences (22). Here, it is very important that the stimulation is not performed with any kind of food, so that the child does not get under pressure, which could lead to a total refusal of the child to get into contact with food as well as it can impair the traumatic experiences (1).

1.2.4.1.9 Occupational therapy

Occupational therapy is on the one hand used to improve the child's tactile perception. In doing so, "biological" textures are offered, "since most tube-fed children are often oversensitive toward tactile stimulation of materials other than plastics." (22)

On the other hand, occupational therapy sessions are used to stimulate the vestibular system which is essential for the sensomotoric perception. Parents are told to sit down in a rocking chair with the child and to seesaw in an intensity the child feels comfortable with. In addition to that, the occupational therapist teaches the parents easy exercises which can be performed independently (1).

1.2.4.1.10 Physiotherapy

Many tube dependent children show developmental deficits concerning the musculoskeletal system. Physiotherapy uses craniosacral methods and influences motor tone, mobility and coordination in a positive way (1). The therapy is performed three to six times weekly and may include the parents, who are encouraged to support their child in becoming more independent (22).

1.2.4.1.11 Nutritional counselling

Nutritional counselling is carried out to inform and enlighten the parents about age-appropriate nutrition or special diets if needed. It is also important to ensure the parents that their child can self-regulate his/her food intake (25).

1.2.4.2 The role of parents and siblings in the weaning process

Tube feeding can lead to severe disorders in the parent-child-triad respectively in the mother-child-dyad.

Therefore, the child normally is admitted together with at least one parent; normally the mother stays in hospital with her child. If this is not possible, the parents have to be available from 8 a.m. to 8 p.m. to take part in the various therapy sessions. It is advantageous if the siblings also can be integrated in the weaning process (25).

Most of the children taking part in the Graz Model weaning program have already been in hospital for many weeks and have undergone several ineffective weaning attempts. Since the mother often is more involved in the happenings concerning the child's health, she is extremely burdened and easily gets ill especially in the phase of weaning where the child is no longer fed by tube in order to provoke hunger. Here, the father is essential. His task is on the one hand to support his wife and on the other hand to be a more relaxed and less anxious attachment figure. Furthermore, he may take over the part of feeding (3).

1.2.4.3 Criteria for successful weaning and success rate

Wilken defined long- and short-term criteria for successful weaning.

> Short-term criteria for successful weaning are that the child shows signals of hunger and thirst. Further signs for successful weaning are if the child has regular urination and defecation and the urine and the faeces are of normal colour, smell and consistence. In addition to that, the child has the same playful activity as before weaning and does not show any aversive behaviour to the feeding situation or food (24).

Long-term criteria for successful weaning are stabilization of the eating behaviour, age-appropriate growth and increase of the head circumference. Another very important criterion is the removal of the tube (24).

The Graz Model weaning program can show a success rate of 96% in 2007 – 78 out of 81 patients were weaned successfully – and a success rate of 94% in 2008, when 79 out of 84 children were weaned (6).

1.3 Two selected classification systems

1.3.1 General

Classification is the disposition of items, terms and attributes, which have some characters in common, but differ in others. In medicine, classification systems are a method to systemise and categorise diseases and health related problems. They help to define patterns of disorders and to group related diseases (27).

Classification systems are an important instrument to define the aetiology and the course of a disorder, as well as the efficiency of therapies (28).

The aims of classification systems are amongst others:

I. Facilitation of communication between scientists and/or clinicians (27). By using classification systems, both the national and the international exchange of information are possible, even if the users do not have the same cultural and/or linguistic background.

II. Classification systems are the basis of national and international statistics of morbidity and mortality. They allow making observations about the incidence and prevalence, as well as the health status of a population.

III. In many countries, classification systems are used to standardise reimbursement in health facilities.

1.3.1.1 History

It was not before the beginning of the 19th century and the appearance of natural science that psychic disorders were accepted as diseases of the brain or psyche. Before that, psychic disorders were ascribed to witches, devils, magic or divine powers and people presenting aberrant behaviour were treated like prostitutes, thieves or vagabonds. This

means they were put into jail instead of being treated for their disease. After the acceptance of psychic disorders, natural scientists tried to define these disorders – something which can be seen as the beginning of classifying psychiatric disorders (29).

The difficulty of systemising and attaching psychopathological phenomena to standardized entities of diseases has accompanied child and adolescent psychiatry since the beginnings of the 19th century. Every classification of disorders in child and adolescent psychiatry has to be geared to certain standards or new standards must be defined (30).

1.3.1.2 Quality criteria of classification systems

1.3.1.2.1 Clarity

Classification systems should be clearly structured. This means that they either should be structured according to the clinical symptoms or that the structure should follow a defined system which is easy and quickly to understand. To reach a certain level of clarity can be an extraordinary problem.

Regarding children and adolescent psychiatry, most of the classification systems are not entirely clear. One has to mention that many psychiatric disorders in childhood and adolescence cannot be found in the chapter of paediatric disorders, but due to the phenomenological structure are listed in the particular chapter of disorders in adults. In order to maintain a level of clarity and uniformity, there are not even special subchapters for children and adolescence, because this would cause subcategories in nearly every single code of disease (30).

1.3.1.2.2 Operationalization

Operationalization means that classification systems have to define symptoms and especially psychopathological phenomena as clearly as possible, so that the user can set a diagnosis according to this description. It must be possible to use this description as a checklist in order to assign the patient to a certain disorder. The more precise the operationalization is done, the easier it is to set a diagnosis for the patient (30).

1.3.1.2.3 Selectivity

Selectivity is a crucial quality criterion. It means that classification systems have to differentiate between disorders in order to avoid overlapping. One way to increase

selectivity is to define exclusion-criteria. In addition to that, decision- and alliance-standards determine the number and combination of symptoms in a selected period (30).

1.3.1.2.4 Validity

Validity answers the questions: Does the test measure what should be measured?

It is difficult to reach a certain level of validity in classification systems. Disorders in child and adolescent psychiatry normally offer face validity (30).

“Face validity is concerned with how a measure or procedure appears. Does it seem like a reasonable way to gain the information the researchers are attempting to obtain? Does it seem well designed? Does it seem as though it will work reliably? Unlike content validity, face validity does not depend on established theories for support.” (31)

Since diagnostic marks are often missing in classification systems, the clinical assessment is essential. A high validity can finally only be reached via an adequate “case relation” (30).

1.3.1.2.5 Reliability

Reliability is the degree of precision of measurements of a test, independent of what is measured with regard to the contents (31).

In classification systems, different kinds of reliability play an important role: (i) interrater reliability, which is the only way to allow clinical and scientifical comparison and which therefore is a very important goal of international classification systems; (ii) test-retest reliability, which can be insufficient in psychiatric diagnosis in children and adolescents, if the psychopathological condition changes quickly (30); (iii) internal consistence, which measures internal correlations (31).

Reliability gives answer to the question: Is the measurement repeatable?

This quality criterion is especially important in international classification systems.

1.3.1.2.6 Practicability

Classification systems have to be practicable in the clinical daily routine. Practicability is defined by (i) a clearly arranged layout, (ii) the traceability of the logical structure, (iii) the overall extent and (iv) the differentiation of the particular criteria.

It will always be necessary to compromise between the requirement of precision and the application in the clinical daily routine (30).

1.3.1.2.7 Directions for use

The more differentiated and self-explanatory the directions for use of classification systems are, the more they will influence the other quality criteria in a positive way. In many systems, decision trees are used to make it easier for the clinician to use them (30).

1.3.1.2.8 Distribution rate

A main goal of classification systems is to be as widespread as possible. To reach this goal, it is crucial that a classification system is developed on the basis of national and/or international consensus. The final aim should be to use only one uniform classification system worldwide (30).

1.3.2 International Classification of Diseases (ICD)

1.3.2.1 Definition

The International Classification of Diseases of the *World Health Organization* serves the worldwide codification of diagnoses and represents the basis of the international comparable causes of death statistics (32). It is "the global standard to report and categorize diseases, health-related conditions and external causes of disease and injury in order to compile useful health information related to deaths, illness and injury (mortality and morbidity)." (33)

1.3.2.2 Progression of ICD

The origins of ICD date back to the 1850s, with the first official edition in 1893 (34). In 1948, the WHO took over the task to develop international classification systems and, within the framework of this task, to administrate and review the *International Classification of Diseases* (29).

In 1955 already, the 7th revision of ICD (ICD-7) was finalised. In the years 1967 and 1979, the next revisions followed, trying to complete the classification system in order to get a higher acceptance around the globe (29).

The eighth revision of ICD was published in 1967 (29) and retained the basic structure of classification and the general way to classify diseases. This was achieved by classifying

diseases according to their aetiology rather than a particular manifestation, whenever possible (35). The revision was not as complete as it was expected to be and showed for example deficits in the sector of psychiatry where the diagnoses, although almost listed in their entirety, were not sufficiently differentiated (29).

More than ten years later, in 1979, the ninth revision of the *International Classification of Diseases* (ICD-9) was completed as a further advancement of former revisions. The system was categorically arranged and nosologically respectively aetiologically orientated. A defect to criticise was the absence of operationalization (see chapter 1.3.1.2 – Quality criteria of classification systems) (29).

Even before the conference for the ninth revision, the *World Health Organisation* had realized that the *International Classification of Diseases* needed a systematic rethinking of its structure in order to create a classification system which would not require a fundamental revision for many years (35).

In the following years, evaluation of ICD-9 was performed all around the world, for example through a survey organized at headquarters and meetings held by some of the WHO Regional Offices (35). Researchers and clinicians in more than 40 countries of the world participated in the development of ICD-10 (29) which "was endorsed by the *World Health Assembly* in 1990 and came into use in WHO Member States as from 1994." (34)

The *World Health Organisation* schedules to review the *International Classification of Diseases* every ten years and to complement these revisions with annual updates in order to keep scientific evidence and to reflect the advances in medicine and all health sciences.

1.3.2.3 ICD-10

ICD-10 is currently the international standard of classification systems and the result of one of the biggest trials ever performed (more than 700 clinicians and researchers in 110 institutions in 40 countries) (29). This trial led to some fundamental changes in the structure of the *International Classification of Diseases* such as the alphanumeric notation which implicates more than twice as many codes than in ICD-9. Thus, a more detailed differentiation in the categories of diseases can be performed. Furthermore, new and international verified classifications were given thought to in the tenth revision (36).

A very important attribute of ICD in general and ICD-10 in particular is that it has to satisfy preferably all member countries of the *World Health Organisation* – at the moment

190 countries are using ICD-10 – (29) by paying regard to linguistic and cultural differences. This goal is reached by using codes which are independent of language. These codes permit transnational statistics and studies. In addition to that, a continuous monitoring of the population's health status is possible via coding diagnoses (36). By monitoring the health status in the member states of the WHO, ICD represents the basis for recording national and international mortality and morbidity statistics. Furthermore, the classification system serves "the monitoring of the incidence and prevalence of diseases and other health problems." (34)

It is important to mention that the "design of ICD has direct impact on health care. It influences public health programmes, prevention, reimbursement and treatment." (37)

The structure of ICD-10 with its alphanumeric notation bases on 3-digit codes with 4-digit subcategories (38). The Roman numbers I to XXI represent the 21 chapters of ICD-10. Each chapter is then provided with a letter, which is the first digit of the code. For example, K is the first digit in chapter XI (eleven). The second digit indicates the main category, while the third designates the main group. For the classification of the disorder itself, the fourth digit is used (29). Here a short example: K35.1 – K stands for chapter XI *Diseases of the digestive system*, 3 represents *Diseases of appendix*, 5 stands for *Acute appendicitis* and 1 represents *Acute appendicitis with peritoneal abscess* (39).

In the following paragraph, we want to dwell on ICD-10 chapter V, *Mental and behavioural disorders*, coded with F00-F99. The main part of diagnoses of chapter V is adopted from adult psychiatry and therefore not appropriate for children. There are two main categories with psychiatric diseases which occur during childhood: F80-89, *Disorders of psychological development*, and F90-98, *Behavioural and emotional disorders with onset usually occurring in childhood and adolescence*. The main category F80-89 includes amongst others diagnoses noted below specific developmental disorders of speech and language, specific developmental disorders of scholastic skills or pervasive developmental disorders. In the main category F90-98, one can find main groups like hyperkinetic disorders, conduct disorders or emotional disorders with onset specific to childhood. In addition to that, other behavioural and emotional disorders with onset usually occurring in childhood and adolescence are coded with F98. This main group contains the diagnosis *Feeding disorder of infancy and childhood* coded with F98.2. The definition of this diagnosis is "a feeding disorder of varying manifestations usually specific to infancy and early childhood. It generally involves food refusal and extreme faddiness in the

presence of an adequate food supply, a reasonably competent caregiver, and the absence of organic disease. There may or may not be associated rumination (repeated regurgitation without nausea or gastrointestinal illness).” (39)

1.3.3 ZTT DC:0-3

1.3.3.1 Definition

ZTT DC:0-3R is a classification system especially for infants and toddlers aged zero to three years.

ZTT stands for *Zero to three*, a nonprofit organisation which represents interdisciplinary professional leadership in mental health and infant development (40). They inform, train and support professionals, policymakers and parents in their efforts to improve the lives of infants and toddlers (41). DC:0-3R means *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood: Revised edition* (40).

The goal of the developers of DC:0-3 was to advance professional communication, clinical formulation and research by providing classification criteria (40).

1.3.3.2 History of ZTT DC:0-3

The first edition of Zero to three’s DC:0-3 was published in 1987 as the first attempt ever to formulate a useful scheme to complement existing frameworks like DSM-III-R (*The Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association*) from 1987 and the World Health Organisation’s ICD-9 (*International Classification of Diseases*) (40).

The developers of DC:0-3 recognised “the need for a systemic, developmentally based approach to the classification of mental health and developmental difficulties in the first four years of life” and wanted to include new knowledge about the meaning of individual differences in infancy and “factors that contribute to adaptive and maladaptive patterns of development in this new classification system”. (40)

Researchers and clinicians from infant mental health centres in Europe and North America took part in the open process to create DC:0-3 by analyzing case reports, identifying recurring patterns of behavioural problems and describing categories of disorders. The result was a multidisciplinary descriptive classification system based on five axes (40).

DC:0-3 was very well accepted by clinicians working with mental health problems of young children and they regarded it as useful for their clinical daily routine (40).

In 2003, DC:0-3 needed to be reviewed out of several reasons: Firstly, every diagnostic systems should be reviewed after 10 years. Secondly, limitations of the usefulness of DC:0-3 occurred and classification criteria needed more specification. Thirdly, DC:0-3 turned out to be useful for clinical formulation and treatment planning and thus needed new criteria and guidelines for these topics. Furthermore, a revision was strongly needed since only two out of the five trials published in the *Infant Mental Health Journal* reported reliability – a fact which was caused by the lack of specificity of DC:0-3's criteria. Last but not least, a review of the existing edition was a possibility to pay regard to new knowledge and clinical experience (40).

1.3.3.3 ZTT DC:0-3R

In 2005, after 2 years of work, the revised edition of ZTT DC:0-3, ZTT DC:0-3R was published to provide "a revision that updates criteria for classifications, incorporates new knowledge from clinical experience and attempts to clarify areas of persistent ambiguity." (40)It was based on the review of clinical literature and other diagnostic systems, as well as on two surveys of users worldwide and the feedback from experts using DC:0-3 (40).

Like its previous edition, ZTT DC:0-3R was intended to complement existing classification systems for mental health and developmental disorders in infancy and early childhood. This was necessary, because for example *The Diagnostic and Statistical Manual of Mental Disorders* was neither sufficiently covering syndromes of early childhood that needed clinical attention nor did it sufficiently consider developmental features of early disorders (40).

It is interesting that clinicians have always used the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* in the first four years of life and not only in the first three years. Many of them found the classification system to be useful up into the preschool age period. This led to (i) an integration with DSM-IV criteria for older children as well as (ii) an incorporation of criteria of the *Research Diagnostic Criteria-Preschool Age* (RDC-PA) into DC:0-3R. RDC-PA was developed from 2001 to 2002 by *The American Academy of Child and Adolescent Psychiatry* and defines psychiatric criteria for disorders experienced in preschoolers. As an

example, ZTT DC:0-3R adopted sub-classifications for *Feeding Behavior Disorders* from RDC-PA (40).

The five axes of ZTT DC:0-3R

Zero to three's *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, revised edition* is a multiaxial classification system, based on five axes, whereof the first three axes deal with the classification of disorders, while the fourth and fifth reflect the assessment of individuals in context (40).

Axis I: Clinical Disorders

Axis I contains different psychiatric disorders in children, of which feeding behaviour disorders are going to be discussed in this paper.

Feeding Behavior Disorders are coded with the number 600 in DC:0-3R and include six different subtypes. They can occur at any moment in infancy and early childhood and have to be considered, when an infant or young child has problems to establish regular feeding patterns. This means that the child has difficulty to regulate his/her feeding according to physiological feelings of hunger or satiety (40). A feeding behaviour disorder should be considered if the parents report feeding problems which last longer than one month. In children older than three months, the following objective cues can be observed: a mean feeding-duration of more than forty-five minutes and/or a feeding-interval of less than three hours. In addition to that, parents tell about amongst others rumination, vomiting and food-refusal (30). A primary feeding disorder should be considered, if the problems occur during the absence of hunger and/or interpersonal problems such as negativism, separation or trauma (40). On the other hand, a few things have to be taken into account: Firstly, the diagnosis of *Feeding Behavior Disorders* is not to be used when an infant's or young child's feeding problem is primarily due to *Disorders of Affect*, *Adjustment Disorder*, *Posttraumatic Stress Disorder*, *Deprivation/Maltreatment Disorder*, or a *Relationship Disorder*. Secondly, the clinician should not use *Feeding Behavior Disorders* as a primary diagnosis if organic or structural problems, like cleft palate or reflux, affect the child's ability to eat or digest food. In such cases, the appropriate medical diagnosis should be listed under Axis III. If the feeding disorder persists after the organic or structural problems have been resolved, on of the following diagnoses of *Feeding Behavior Disorders* has to be considered (40).

"601. Feeding Disorder of State Regulation

This diagnosis requires all three of the following criteria be met:

(1) The infant has difficulty reaching and maintaining a calm state during feeding (e.g., the infant is too sleepy, too agitated, and/or too distressed to feed).

(2) Feeding difficulties start in the newborn period.

(3) The infant fails to gain weight or loses weight.

602. Feeding Disorder of Caregiver-Infant Reciprocity

The diagnosis of Feeding Disorder of Caregiver-Infant Reciprocity requires that all three of the following criteria be met:

(1) The infant or young child does not display developmentally appropriate signs of social reciprocity (e.g., visual engagement, smiling, or babbling) with the primary caregiver during feeding.

(2) The infant or young child shows significant growth deficiency.

(3) The growth deficiency and lack of relatedness are not due solely to a physical disorder or a pervasive developmental disorder.

603. Infantile Anorexia

The diagnosis of Infantile Anorexia requires that all six of the following criteria be met:

(1) The infant or young child refuses to eat adequate amounts of food for at least 1 month.

(2) Onset of the food refusal occurs before the child is 3 years old.

(3) The infant or young child does not communicate hunger and lacks interest in food but shows strong interest in exploration, interaction with caregiver, or both.

(4) The child shows significantly growth deficiency.

(5) The food refusal does not follow a traumatic event.

(6) The food refusal is not due to an underlying medical illness.

604. Sensory Food Aversions

This diagnosis requires that all four of the following criteria be met:

(1) The child consistently refuses to eat specific food with specific tastes, textures, and/or smells.

(2) Onset of the food refusal occurs during the introduction of a novel type of food (e.g., the child may drink one type of milk but refuse another, may eat carrots but refuse green beans, may drink milk but refuse baby food).

(3) The child eats without difficulty when offered preferred foods.

(4) The food refusal causes specific nutritional deficiencies or delay of oral motor development.

605. Feeding Disorder Associated with Concurrent Medical Condition

The diagnosis of Feeding Disorder Associated with Concurrent Medical Condition requires that all four of the following criteria be met:

(1) The infant or young child readily initiates feeding, but shows distress over the course of feeding and refuses to continue feeding.

(2) The child has a concurrent medical condition that the clinician judges to be the cause of the distress.

(3) Medical management improves but does not fully alleviate the feeding problem.

(4) The child fails to gain adequate weight or may even lose weight.

606. Feeding Disorder Associated with Insults to the Gastrointestinal Tract

This diagnosis requires that all four of the following criteria be met:

(1) Food refusal follows a major aversive event or repeated noxious insults to the oropharynx or gastrointestinal tract (e.g., choking, severe vomiting, reflux, insertion of nasogastric or endotracheal tubes, suctioning) that trigger intense distress in the infant or young child.

(2) The infant or young child's consistent refusal to eat takes one of the following forms:

(a) The infant or young child refuses to drink from the bottle but may accept food offered by a spoon. (Although the child may consistently refuse to drink from the bottle when awake, he/she may drink from the bottle when sleepy or asleep.)

(b) The infant or young child refuses solid food but may accept the bottle.

(c) The child refuses all oral feedings.

(3) Reminders of the traumatic event(s) cause distress, as manifested by one or more of the following:

(a) The infant shows anticipatory distress when positioned for feeding.

(b) The infant or young child resists intensely when a caregiver approaches with a bottle or food.

(c) The infant or young child shows intense resistance to swallowing food placed in his/her mouth.

(4) The food refusal poses an acute or long-term threat to the child's nutrition." (40)

Axis II: Relationship Classification

The relationship classifications of Axis II identify the types of relationship disorders that clinicians may discover in specific relationships respectively in interactions between child and parents. In doing so, it has to be considered that relationship disorders are always specific to a relationship (40).

It is essential to understand the quality of the parent-infant relationship if developing a diagnostic profile for infants and young children. Here, relationships between a child and a few familiar adults who take responsibility for the child's care and well-being – so-called primary relationships – play a very important role since the adults support the child to have a healthy development. In relationships the child learns skills, develops social initiation, reciprocity and cooperation and "begins to develop the capacity for autonomous emotional regulation and self-control." (40)

In rating the infant-parent-relationship, the clinician has to consider multiple aspects of the relationship dynamic, including:

I. “Overall functional level of both the child and the parent.

II. Level of distress in both the child and the parent.

III. Adaptive flexibility of both the child and the parent.

IV. Level of conflict and resolution between the child and the parent.

V. Effect of the quality of the relationship on the child’s developmental progress.” (40)

Axis II serves the classification of relationships between parents and children. In ZTT’s DC:0-3R, each quality is described in terms of (i) characteristic behavioural quality, (ii) affective tone and (iii) psychological involvement. The following five relationship qualities are distinguished:

Overinvolved

This relationship is characterised by parents who often interfere with the infant’s or young child’s desires, who dominate their child, but on the other hand may have periods of depression, anxiety or anger which results in a lack of continuance in the parent-child-relationship. Furthermore, the infant or young child is not seen as an independent person with individual needs.

The infant in this type of relationship may show submissive or, conversely, defiant behaviours. It may seem to be delayed in motor skills, expressive language, or both, as well as it may be very constricted in its range of affective expression. When separating the child from the parents, it may vehemently resist (40).

Underinvolved

To the observer, the child-parent interaction shows lifelessness and an absence of pleasure as well as a sad, constricted, withdrawn and flat affect in both parents and child. It is characterised by parents who seem not to know what their child needs or wants, who do not appropriately protect and/or support it and who are noticed to be uninvolved with little eye contact or physical closeness. One reason for underinvolvement can be that a parent may have experienced physical neglect or deprivation him- or herself (40).

Anxious/Tense

"Interactions in this parent-child relationship are tense and constricted, with little sense of relaxed enjoyment or mutuality." (40) The characteristics of this relationship are overprotective parents who are very sensitive to the infant's or young child's cues and infants who do not fulfil their parents' expectations concerning their temperament or developmental capacities. Both children and parents show an anxious mood which can be seen in motor tension, agitation, facial expression and apprehension (40).

Angry/Hostile

Interactions in this kind of relationship are harsh and abrupt and often lack in emotional mutuality. The child may appear frightened, impulsive, inhibited or diffusely aggressive as well as it may show resistant or defiant, demanding and/or aggressive behaviour with the parent. Furthermore, it may exhibit fearful and avoidant behaviour. The parents' rule is characterised by (i) insensitivity to the infant's or young child's cues, especially when he or she views the child as demanding, (ii) abrupt handling of the child and (iii) teasing or taunting the child (40).

Abusive (verbally/physically/sexually)

According to *Zero to three's Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* one has to differentiate between three types of abuse: (i) verbal abuse, (ii) physical abuse and (iii) sexual abuse. If a clinician diagnoses any kind of abuse, he or she should use it as the primary relationship diagnosis.

A verbally abusive relationship is characterised by parents who are intended to severely blame, attack, belittle, overcontrol and/or reject the infant or young child, whose reaction can vary from constriction and vigilance to severe acting-out behaviours. Parents often have had previous critical relationships and therefore may interpret the infant's cries as a negative reaction towards themselves.

Physically abusive relationship "involves severe physical abuse, unclear boundaries, and overcontrol by the parent." (40) The following characteristics can be found: (i) parents who physically harm the infant or child, (ii) parents who fail

to supply the child with food, medical care, and so on, and (iii) potential periods of verbal and/or sexual abuse.

In sexually abusive relationships, parents lose the perception of physical boundaries and show a sexual intrusive behaviour towards the infant or young child. Children may appear aggressive or anxious, as well as tense. Sexual abuse is often combined with physically or verbally abusive behaviour. In addition to sexual assaults, parents fail to respond to the child's needs and cues, because of preoccupation with their own needs for narcissistic self-gratification (40).

Axis III: Medical and Developmental Disorders and Conditions

As stated in ZTT DC:0-3R "Axis III should be used to note any physical (including medical and neurological) and/or developmental diagnoses made using other diagnostic and classification systems. These systems include the *American Psychiatric Association's Diagnostic and Statistical Manual* (DSM-IV-TR, 2000), *International Classification of Diseases* (ICD-9, 1977, or ICD-10, 1992), and specific classifications used by speech/language pathologists, occupational therapists, physical therapists, special educators, and primary health care providers." (40)

It is important to note that if the child complies with criteria for a DSM-IV-TR or ICD-10 psychiatric disorder, this disorder should be coded on Axis I among *800. Other Disorders* (40).

Furthermore, it has to be considered that psychiatric symptoms can be provoked by medical illnesses. Out of this reason, a paediatric or other medical examination, such as laboratory tests, should be performed in children with psychiatric disorders. Thus, a mood disorder with symptoms like lethargy, hypersomnia, low arousability, and poor feeding may be caused by hypothyroidism (40).

Axis IV: Psychosocial Stressors

Psychosocial stress may have a consequential influence on the child's development. Here, one needs to distinguish between (i) acute and permanent psychosocial stressors, (ii) stressors that are attributable to a single source and multiple cumulative stressors as well as (iii) direct and indirect stressors. Direct stressors are events that affect the child directly, such as an illness requiring a child's hospitalization, while indirect stressors do not affect the child directly – for example a sudden illness of a parent that results in separation from the child (40).

In addition to these distinctions, a child may experience psychosocial stress in situations that are part of normal experience in the family's culture, like the birth of a sibling, a family move or entry into child care or school (40).

While some children may be very sensitive to psychosocial stressors, others will not react at all. In this context, caregivers are very important since they may protect the child, but can also reinforce the negative effect of psychosocial stress through the effect of negative attitudes and/or anxiety (40). "The ultimate impact of a stressful event or enduring stress depends on three factors:

1. The severity of the stressor.
2. The developmental level of the infant or the young child.
3. The availability and capacity of adults in the caregiving environment to serve as a protective buffer and to help the child understand and cope with the stressor." (40)

ZTT DC:0-3R offers a checklist for psychosocial and environmental stressors to (i) identify the multiple sources of stress, that an infant or young child and the family experienced and to (ii) note the duration and severity of stressors (40).

Axis V: Emotional and Social Functioning

Axis V is used to assess the emotional and social functioning of an infant or young child. Already at birth, some emotional and social capacities are present. In the ensuing months and years, these capacities grow, as the child physically and neurologically develops further (40).

DC:0-3R provides the *Capacities for Emotional and Social Functioning Rating Scale* to help clinicians to state a diagnosis. In this rating scale, six capacities are distinguished:

1. "Attention and regulation;
2. Forming relationships or mutual engagement;
3. Intentional two-way communication;
4. Complex gestures and problem solving;
5. Use of symbols to express thoughts and feelings; and
6. Connecting symbols logically and abstract thinking." (40)

Each of these capacities is assessed separately and age-accordingly. Here, six different ratings from 1 (functions at an age-appropriate level under all conditions and with a full range of affect states) to 6 (has not achieved this capacity) are used. In addition to that, "the clinician should use a rating of "not applicable" (n/a) when a child is below the age at which he or she would typically be expected to have the capacity in question". (40)

1.4 Case reports

Case report 1: Maria, 5 months old, 601: Feeding Disorder of State Regulation

Maria was the second child after five pregnancies of her mother. The pregnancy was uncomplicated besides premature contractions in the third month. Maria was born in the 41st week of gestation with a birth weight of 3.670 grams, a birth length of 55 centimetres and a head circumference of 34 centimetres. Although the umbilical cord was wrapped around her neck, she had an Apgar Score of 7/8 and no postnatal problems occurred.

During the first month of life, Maria was fully breast-fed. Sucking worked well; Maria was drinking enough and gained about 600 grams of weight. However, from the beginning on, Maria spat and vomited frequently. From the second month of life onwards, the situation worsened. The spitting problems aggravated, Maria started to drink less and always cried after feeding. Due to very low intake of food, Maria was admitted to a hospital in Russia at the age of one and a half months. In hospital, she completely stopped drinking and therefore received the NGT after one week. A five week stay in hospital revealed no pathological findings and Maria was transferred to Berlin, because her mother was not content with the treatment in Russia. In Berlin, many diagnostic investigations were performed: blood tests, metabolic tests, bacteriological tests, a cranial MRT in anaesthesia, a scintigraphy to assess Maria's gastro-oesophageal reflux, an X-ray examination for the same reason, abdominal sonographies, cranial sonography, electroencephalography, long-time ph measurement and histo-pathologic diagnostic of the GIT. No pathological findings were found in these investigations. The clinicians in Berlin noted that the child did neither seem fundamentally limited during drinking, nor seemed to have any pain, but stopped abruptly to drink after some successful acts of sucking. The NGT was removed in Berlin after a total period of 2 months. Sucking worked quite well at that time but Maria always stopped drinking abruptly after some sucking episodes. Therefore, Maria was mostly fed during sleep and gained weight properly despite the feeding difficulties. The child's

developmental status was excellent. Social anamnesis: four persons in the household; mother, father, a four year-old brother and Maria.

When admitted at the Psychosomatic Unit in Graz, Maria was in a very good general condition. Her weight was 5.670 g (25th percentile); she showed a friendly and interested behaviour. In the physical status no pathological findings were detected. Treatment at the Psychosomatic Unit involved daily sessions of physiotherapy, speech therapy, occupational therapy, individual and interactive psychological counselling and eating play therapy. Since the physiotherapist determined a malposition of the cervical spine, an X-ray was performed. It revealed a left-convex malposition of the cervical spine. The paediatric orthopaedist stated a tonus asymmetry syndrome and performed chiropractise of the cervical spine. After this treatment, the posture of the head during feeding improved immediately. Maria made rapid progress concerning her eating behaviour. After some days, she started to drink sufficient amounts of fluid and it was possible to feed her also during wakefulness. In the play picnics, Maria started to eat supplementary food by spoon. Vomiting did not occur any more, Maria gained weight day after day.

Picture 6. Case report 1. Maria approximately 2 months after tube weaning. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Maria was discharged after a bit more than two weeks, with a weight of 6.010 g and a satisfying eating behaviour. It was recommended to feed her with a normal infant formula as well as to add supplementary food according to her age.

	ZTT DC:0-3R
I	601: Feeding Disorder of State Regulation
II	900: Balanced relationship
III	K21.9 Mild gastro-oesophageal reflux, A08.0 St.p. rotavirus-gastroenteritis, F98.2 St.p. transitory tube feeding
IV	Psychosocial stress: 3-4
V	Age-appropriate development

Chart 1. Case report 1. ZTT DC:0-3R diagnoses.

Case report 2: Alex, 3 years and 8 months old, 602: Feeding Disorder of Caregiver-Infant Reciprocity

Alex came to Graz after his mother had contacted the Psychosomatic Unit at the Children's Hospital in Graz by e-mail. He has a non-hereditary condition Mowat Wilson Syndrome. This autosomal dominant disorder is characterized by a number of health defects including Hirschsprung's disease, mental retardation, seizure disorder, delayed growth and motor development, congenital heart disease, genitourinary anomalies and absence of the corpus callosum. Because of this syndrome, he is delayed in his mental and physical development. From birth on, he was breast-fed and later on, he was eating pureed solid and drinking from a cup until he was 2 and a half years old. At that time, he became ill and developed mouth ulcers and a sore throat; and stopped eating and drinking. His mother mentioned that Alex was separated from her in this period, because she was taking care of her ill father and stayed in hospital overnight. She believed that this separation in connection with his illness might have contributed to his food refusal. As a consequence of the food refusal, Alex started to be exclusively fed by NGT. Since then, he refused to eat and turned his head away whenever his parents offered him any kind of food.

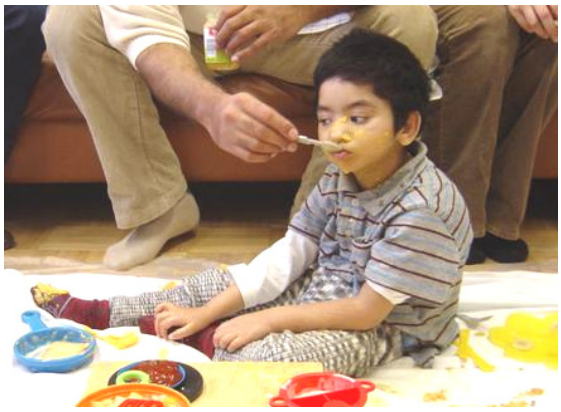


Photo 7. Case report 2. Alex at the play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

When he was admitted at Graz, Alex weighed 15.6 kg with a height of 90.2 cm. This means he was below the 30th percentile regarding height and at the 25th percentile regarding weight. He was a cheerful, nice, sometimes very happy, sometimes absolutely overregulated 3 year-old boy. The status revealed a cognitive and motor developmental delay. In addition to that, Alex had multiple severe food allergies.

Alex took part in the Graz Model tube weaning program as an inpatient. In addition to the standard therapies, a psychological counselling for his mother was performed. Alex's daily intake per tube was reduced. In the beginning, he started to eat in a very cautious way, but unfortunately he became very weak and showed no more motivation for eating. Out of these reasons, the NGT had to be re-inserted. This procedure was very traumatising for him and led to a total stop of self-regulation which caused a new start from the beginning. Alex was a very complex child and the relationship between him and his environment was

sometimes very difficult, because of his strong crying attacks. These attacks made the mother feel very guilty of his situation, because she believed that they are associated with pain. In the coaching the interdisciplinary weaning team tried to make the mother more confident and to explain to her that Alex's crying was not always associated with pain. A main goal of the team was to release the pressure from this mother-child interaction; any kind of emotional stress should be reduced.

Alex was discharged after three weeks with remaining nocturnal feeds. His discharge weight was 14.1 kg, with a weight loss of 1.5 kg, which is still in the expected range.

	ZTT DC:0-3R
I	602: Feeding Disorder of Caregiver-Infant Reciprocity
II	901: Overregulated mother-son relationship
III	Q99.9 Mowat-Wilson Syndrome, T78.1 Multiple food allergies, F98.2 NGT-dependency
IV	Psychosocial stress: 3-4
V	Severe developmental delay

Chart 2. Case report 2. ZTT DC:0-3R diagnoses.

Case report 3: Lenny, 9 months old, 603: Infantile Anorexia

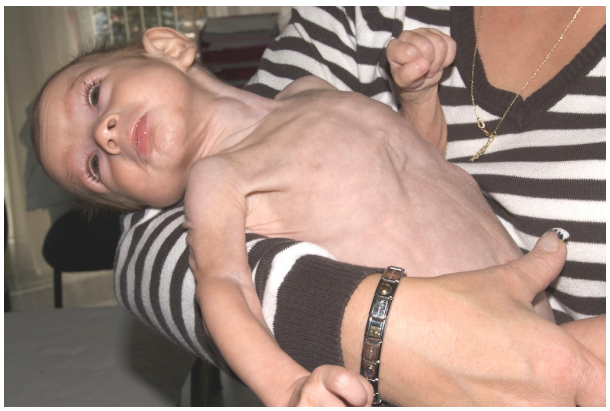


Photo 8. Case report 3. Lenny at his admission in Graz. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Lenny was born in the 40th gestational week with a birth weight of 3.500 g. His mother had six miscarriages before he was born and suffered from a severe depression. In the beginning, Lenny was a typical case of Feeding Disorder of Caregiver-Infant Reciprocity (602), but in a period of three months, he developed an Infantile Anorexia (603). He took in too little fluid from the beginning on and began to refuse actively.

Lenny was admitted in Graz, when he was nine months old. At that time, he weighed only 4.8 kg and although exclusively tube-fed for nearly 6 months, he was severely malnourished. He was directly transferred to the intensive care unit, because of severe vomiting and liver and renal failure. Ten days later, Lenny's tube weaning program could start. He took part in all therapies. In addition to that, an intensive interaction therapy and

Photo 9. Case report 3. Lenny 2 months after tube weaning. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

psychiatric counselling of hsi mother were performed. Lenny started to eat right away, so that his NGT could be removed after one week, in which he gained about 1 kg of weight.

The boy was discharged after 4 weeks without a tube and a weight of 7 kg.

	ZTT DC:0-3R
I	603: Infantile Anorexia
II	905: Mixed relationship disorder
III	R63.8 Severe malnutrition, N19 Renal failure, E45 Retarded development following protein-energy malnutrition K90.9 Intestinal malabsorption, R63.3 Feeding difficulties, F98.2 NGT-dependency
IV	Psychosocial stress: 6
V	Almost age-appropriate development

Chart 3. Case report 3. ZTT DC:0-3R diagnoses.

Case report 4: Kevin, 4 years old, 604: Sensory Food Aversions, Picky Eater

Kevin was born in the 37th gestational week with a birth weight of 2.500 g. An atrial septal defect was diagnosed. In addition to that, a hypomyelination syndrome was suspected. Kevin was severely retarded and suffered from spastic quadriplegic cerebral palsy.

Photo 10. Case report 4. Kevin at the play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

At the admission, Kevin had been tube-fed via PEG for 12 months, because of too little intake of fluid and a failure to thrive. His bodyweight at admission was 10.2 kg at a height of 90 cm; his body mass index is 12.6, which means underweight even though he was exclusively tube-fed. Kevin showed no signs of internal disease. A motor developmental delay was diagnosed. The boy showed good contact with his family. He was moderately disabled with various levels of cognitive, emotional, sensory and motor impairment and global developmental delay. Kevin took part in the tube weaning program as an inpatient

and was involved in the standardised therapies like physiotherapy, speech therapy, occupational therapy and so on. Also an interactive psychological counselling was performed. The program was very successful in Kevin's case – he was weaned without any complications. He accepted very well not to be tube-fed and started to eat and drink.

The patient was discharged after a bit more than two weeks. During his stay, he lost about 1000 g, which was about 10% of his body weight. This weight loss is absolutely within the normal and expectable range after weaning. The PEG was not removed during his stay. It was recommended to take out the tube within 6 months of weight stabilisation.

ZTT DC:0-3R	
I	604: Sensory Food Aversions, Picky Eater
II	900: Balanced relationship
III	Q21.1 Atrial septal defect, Q14.8 Right optic nerv coloboma, H91.8 Hearing impairment, K21.9 Gastro-oesophageal reflux, Q55.8 Sliding testis on both sides, Q89.9 Dysmorphic features, G80 Spastic quadriplegic cerebral palsy, F79 Mental retardation, F 98.2 PEG-dependency
IV	Psychosocial stress: 3
V	Severe developmental delay

Chart 4. Case report 4. ZTT DC:0-3R diagnoses.

Case report 5: Lucia, 3 ½ years old, 605: Feeding Disorder Associated with Concurrent Medical Condition

Lucia was born prematurely in the 36th gestational week by emergency Caesarean section with a birth weight of 2.608 g. She required oxygenation and developed septicaemia. Lucia suffers from a Netherton's Syndrome with ichthyosiform dermatosis. The Netherton's Syndrome is a severe, autosomal recessive form of ichthyosis. Most patients are "scalded-looking" at birth and are very slow to gain weight. The cracking/scaling of their skin causes them to lose water, heat and proteins. Patients with Netherton's Syndrome also tend to have fragile and spiky hair, which often grows very slowly.

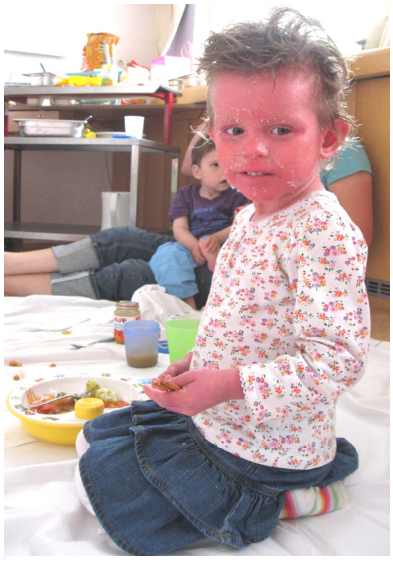


Photo 11. Case report 5. Lucia at the play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Lucia required a daily bath and application of cream to cleanse and manage her skin condition. In addition to that, she had a history of multiple gastrointestinal problems like chronic severe vomiting, and a history of difficulties

establishing oral feeding during infancy, chronic severe refusal to feed and eat and difficulties gaining weight. She was fed via NGT from birth onwards and never established oral feeding. So, a PEG was implanted, when she was about 7 months old. Her only oral intake was water.

At admission, Lucia was in a good general condition, her weight was 11.1 kg. She had skin irritations on the whole integument. Lucia took part in the weaning program as an out-patient. She attended all kinds of therapies. After seven days, she was no longer fed via the PEG, because her oral intake of fluids and food was sufficient to maintain weight.

Lucia was discharged after three weeks in a very good condition. She left the Psychosomatic Unit with 11.34 kg, a weight gain of 200 g. The tube was not removed, but it was recommended to do this within the next two to six months.

	ZTT DC:0-3R
I	605: Feeding Disorder Associated with Concurrent Medical Condition
II	900: Balanced relationship
III	E72.8 Netherton Syndrome, K20 Eosinophilic oesophagitis, P07.2 St. p. prematurity, F98.2 PEG-dependency
IV	Psychosocial stress: 3
V	Mild developmental delay

Chart 5. Case report 5. ZTT DC:0-3R diagnoses.

Case report 6: Julia, 2 years old, 606: Feeding Disorder Associated with Insults to the Gastrointestinal Tract

Julia was born as the first child of her parents in the 28th gestational week with a birth weight of 1.460 g. She was delivered by Caesarean section due to abruption of placenta. On the third day of life, Julia sustained an intraventricular hemorrhage. In addition to that, she suffered from a necrotizing enterocolitis and was operated nine times.

Photo 12. Case report 6. Julia laughing. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J., Deutsch, with friendly permission of the child's parents

At her admission in Graz, Julia was fed partially parenterally, partially enterally via NGT and weighed 9.4 kg. She had a severe developmental delay and showed traumatised behaviour towards the hospital's medical stuff.

The girl took part in the weaning program as an inpatient. In the first week of therapy, she got a noro- and rotavirus infection. Due to that infection, the weaning program had to be suspended until the 3rd week of her stay. In the therapies which where performed, Julia showed clear, but slow progress regarding the interest in and the acceptance of oral food. A simultaneous weaning of the NGT and the parenteral nutrition was not possible, because of Julia's complicated gastrointestinal situation. Therefore, the focus was set on the reduction of the parenteral nutrition for the benefit of oral intake of food respectively an augmentation of the nutrition she received via the NGT. During the stay, Julia showed a low to moderate loss of weight. Furthermore, a clear decrease of recurrent vomiting was noticed.

Julia was discharged after four weeks with a weight of 9.200 g. It was recommended to continue the oral food supply to get her further cautiously used to oral intake of food and to reduce the parenteral nutrition.

	ZTT DC:0-3R
I	606: Feeding Disorder Associated with Insults to the Gastrointestinal Tract
II	901: Reactively overinvolved
III	K91.8 Short bowel syndrome, Z98.8 St.p. 9 surgeries due to NEC, P07.3 St.p. prematurity, P52.9 St.p. intraventricular hemorrhage, F98.2 NGT-dependency and parenteral feeding via Hickman-catheter
IV	Psychosocial stress: 4
V	Severe developmental delay

Chart 6. Case report 6. ZTT DC:0-3R diagnoses.

2 Methods

We used data from the data base EAT-DOC *(Early Autonomy Training-Documentation)* of the Psychosomatic Unit of the Children's Hospital in Graz, Austria for this study.

The study was approved by the local ethics commission, the parents were asked for consent concerning the analysis and publication of the data.

2.1 Data collection

The data collection system was created to record, collect and evaluate significant variables and facts of the specific population of tube dependent children. This task has to our knowledge been performed for the first time ever. The interdisciplinary team of the Psychosomatic Unit defined a collection of important questions, which were merged into a questionnaire which the parents sometimes receive before admission and sometimes at admission (7).

The need for a basic data collection arose from the fact, that neither epidemiology on tube-fed children in general existed nor specifically on tube dependent children. Even though Austria is a small country (with about 8.3 millions inhabitants), comparable in standard of medicine and population with Switzerland or Israel, the clinical impression – derived from frequent encounters with colleagues in international conferences – is that enormous regional differences and very diverse fashions of tube indication are in existence. More research will be needed to achieve a general evaluation of the phenomenon of tube dependency in children (7).

The data base was developed, because the worldwide largest population of tube dependent children has been treated in Graz since 1987. It is the headstone to make scientific evaluation possible, a fact which is of great importance, since the epidemiological data records in this special population of tube dependent children is very poor (7).

Its origins date back to 2006, when the *International Feeding Intervention Group* published guidelines for tube weaning and at the same time recognised the need for a professional registration of tube dependent children in order to be able to make statements about epidemiological data in this special population (7).

The first data base was established in 2007 in Graz and gradually improved in the following years. It recorded data of tube dependent children until the end of 2008, when a

revision was regarded as necessary. This revision led to a completely new software and design, the ARCHIMED-program. ARCHIMED was developed in the late 1990s by the *Institute for Medical Statistics and Informatics* in Vienna. In 1998, the new software was tested in Graz for the first time. The aim of ARCHIMED is to provide an integrated documentation and evaluation system for scientific intentions. Its characteristics are (i) different screens for different purposes like a study documentation screen where data is anonymized, (ii) statistical functions like interpretation of different variables and graphical illustration of data, which are pre-assigned in ARCHIMED and (iii) the possibility to import and export data from other programs like MS Excel, MS Word, and so on (42), (43).

2.1.1 Configuration

It is important to mention that the data base of the Psychosomatic Unit does not only record tube dependent children, but also patients with other eating disorders like anorexia, bulimia and obesity.

Concerning patients with tube dependency, one can find four main sectors: (i) Basic claim data, (ii) Admission, (iii) Check-up and (iv) Discharge.

The Basic claim data sector contains data like address, kind of program (inpatient/outpatient/net-patient) and year of admission.

In the Admission sector, a lot of different data about the patient and his/her feeding behaviour are noted. The *General data* sheet contains general information about the child like name, age at admission, sex, contact details, the reason for admission and the country of origin. In the *Biometric data* sheet, information concerning the child's weight, birth and important earlier interventions is noted. On the sheet for *Tube related issues*, reasons for tube implantation, information about former weaning therapies as well as information about what kind of tube currently is implanted, are registered. The *Oral motor competence* sheet gives information about the oral motor skills of the child. Another sheet gives information about the *Feeding situation* itself. Here, the parents are interviewed about their perception of their child's behaviour while feeding. The last sheet tells about the *Parents' food habits* like dietary information and food characteristics. Furthermore, parents are asked, if any of them suffers from an eating disorder.

The *Diagnosis* sheet (Fig. 5), which we used for this study, encloses all information about the child's diagnoses mostly according to Zero to three's DC:0-3R.

Axis I describes the type of eating behaviour disorder. Possible selections are:

601. Feeding Disorder of State Regulation

602. Feeding Disorder of Caregiver-Infant Reciprocity

603. Infantile Anorexia

604. Sensory Food Aversions, Picky Eater

605. Feeding Disorder Associated with Concurrent Medical Condition

606. Feeding Disorder Associated with Insults to the Gastrointestinal Tract

Axis II gives information about the type of parent-infant relationship, which is assessed by observance carried out by experienced clinicians. The following relationship qualities can be observed:

900. balanced

901. overinvolved

902. underinvolved

903. anxious/tense

904. angry/hostile

905. mixed relationship disorder

906. abusive

Axis III corresponds to the child's ICD-10 diagnoses. The assessment of these diagnoses results from using (i) the ICD-10 catalogue, which is included in the data base, or (ii) a special ICD-10 coding software called *DIACOS®*. *DIACOS®* is a coding-system, which facilitates the documentation of clinical services. It is available in many different languages and has amongst others been used in Germany, Austria, Switzerland, Luxembourg and Slovenia for several years (44).

Axis IV serves the evaluation of the child's psychosocial stress referring to WHO's *International Classification of Functioning, Disability and Health, Part 1 and 2*. The ICF serves as a set uniform language in different countries and different areas to describe the functional state of health, impairment, social disturbance and relevant factors surrounding a person (45).

Psychosocial stress has a cumulative effect on children. The sum of stressors affects the child depending on their period and intensity in different ways. The evaluation of each child's psychosocial stress is performed by the interdisciplinary team of the Graz weaning program. Here, values from zero to seven are used, whereas zero stands for no psychosocial stress while seven represents the highest level of psychosocial stress.

0 – There is no psychosocial stress assessable.

2 – The child shows slight effects of psychosocial stress like excitability, time-limited outbursts of fury, changes in sleeping habits and so on.

5 – One can find medium-heavy effects in the child such as impulsive behaviour, sleeping disorders and separation anxiety (e.g., the child does not want to leave the mother to go to school).

7 – Severe effects of psychosocial stress are diagnosed if the child backs out of interactional relationships, appears depressive, can not be calmed when crying or if it can not communicate age-appropriately (1).

In Axis V, the child's developmental status is assessed by the paediatric team of the Psychosomatic Unit. There are three levels to distinguish:

age-appropriate development	The child does not show any pathology in his/her development.
mild developmental delay	The child is delayed in his/her development for about one quarter of his/her life time. That means that a four year-old child is at the developmental level of a three year-old.
severe developmental delay	The child has not reached the developmental milestones for the first year of life. That means, for example that the child is not able to sit freely and can not walk.

The last information which is collected is the Severeness of disease. It is assessed by at least two senior resident paediatricians within the diagnostic work-up every patient receives. Here, seven levels can be differentiated:

0 – none

1 – minimal

2 – mild

3 – moderate

4 – average

5 – overaverage

6 – severe

7 – extreme

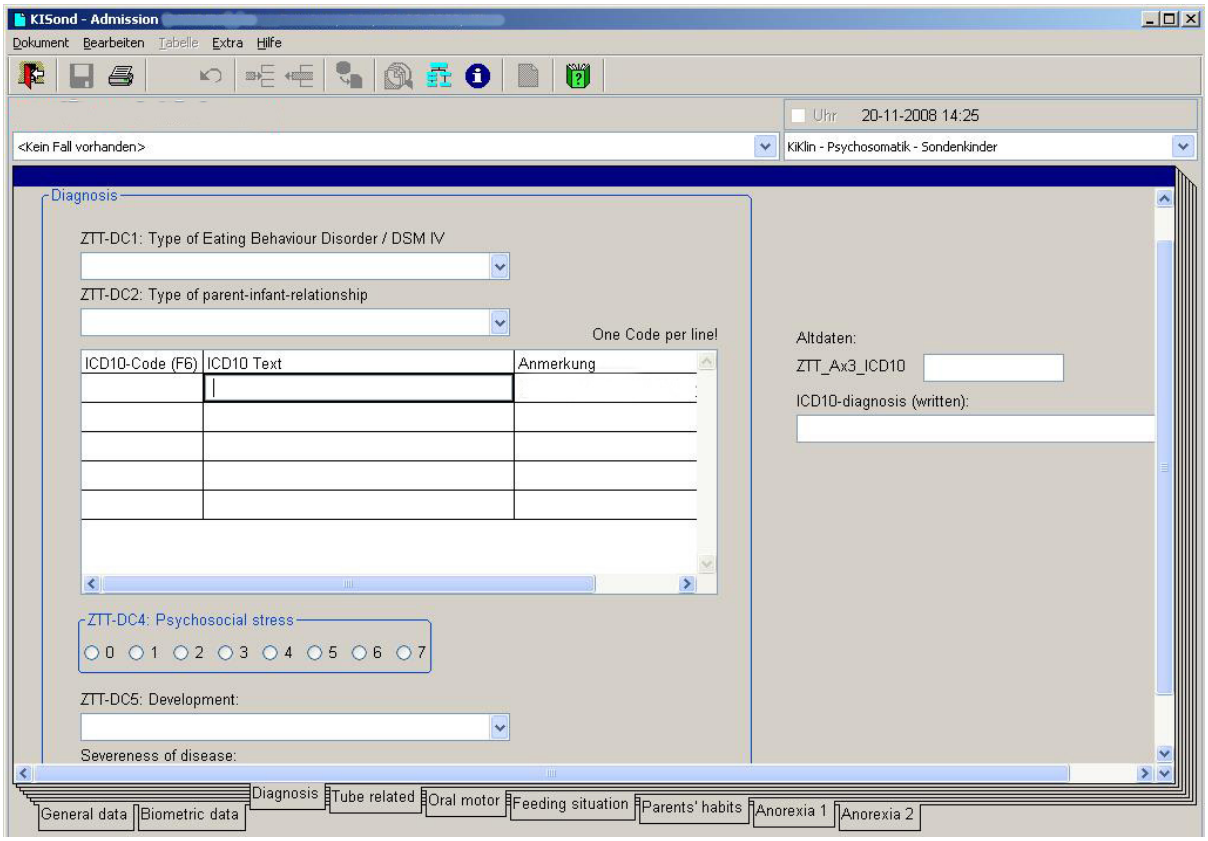


Figure 5. The Diagnosis sheet in the Admission sector. Admitted from ARCHIMED.

The *Check-up* sector is used to regularly update information about the child's medical condition during the weaning process in Graz as well as after discharge. It contains information about the actual type of nutrition, type of food, time of nutrition, the amount of food per 24 hours, the technique of feeding, the child's reaction to food, etc.

The *Discharge* sector includes general data about the discharge diagnosis, recommendations concerning aftercare and drugs the child possibly has to take. Furthermore, the discharge sector gives information about the feeding situation, like the

date of the last tube feed and if the child is solely eating him-/herself or if partial tube feeding is necessary.

2.1.2 Questionnaire

Besides these different sheets, self-designed questionnaires can be integrated in ARCHIMED. We designed a tube-questionnaire to investigat the parents' perspective of the specific eating problems of their child. This questionnaire was sent per e-mail before the tube weaning program in Graz started. Those, who didn't answer, were personally asked to fill out the questionnaire during their stay.

The questionnaire exists in German and English. It consists of eight questions, which are easy to answer and analyse. Professional help is not necessary and it takes only a short time to fill in the questionnaire. Answers can be either yes, no or not filled in (stated as unspecified in the following results) in five out of eight questions. In one question, the parents have to fill in, in which month and year their child's eating disorder has been diagnosed, if it was diagnosed, and if so, by whom. Here, they can choose between five different professions (general practitioner, paediatrician, neonatologist, physiotherapist, occupational therapist). If none of these is appropriate, a sixth answer offers the possibility to fill in another profession. The two last questions ask about the number of months the parents have considered the tube to be a good and effective intervention respectively for how many months they have felt it is not fulfilling the needs.

2.2 Study population

2.2.1 Data base study

The data base includes a unique population of 353 tube dependent children aged 43 days to 14 years and 7 months. This population recorded in Graz is the largest worldwide. Here, one has to mention that the amount of tube dependent children worldwide is not known. Therefore, the data base in Graz is extremely important, since it allows epidemiological statements concerning this special group of children, for the first time.

From all tube patients patients recorded in the data base (353), 188 were female, while 165 were male.

302 patients were included in the study population. The following inclusion criteria had to be fulfilled:

(i.) patients younger than 4 years (0 to 3.99 years),

(ii.) tube dependency at admission,

(iii.) patients who took part in the weaning program either as an in-, out- or net-patient,

(iv.) children, who were looked after by the Psychsomatic Unit of the Children's Hospital in Graz in the time from January 1998 to June 3, 2009.

The reason why we excluded patients older than 3.99 years from this study population is that *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, revised edition* is used for children below 4 years.

The study group of 302 children consisted of 168 female and 134 male patients. The age ranged from 0.12 to 3.98 years, a mean of 1.70 years was calculated.

2.2.2 Questionnaire

The questionnaire was sent out to the parents of all patients referred to the tube weaning program in the period from March 1, 2009 to June 15, 2009. 19 out of 19 (100%) questionnaires were filled out either before the children were admitted in Graz or while the tube weaning program took place. Amongst the 19 patients, whose parents filled out the questionnaire, 8 were male, 11 were female.

The age of the patients recorded in the questionnaires ranged between 0.38 and 10.49 years.

3 Results

3.1 Data base study

3.1.1 Collectivity of all tube dependent children in the data base

In the beginning, a brief overview of all tube dependent children included in the data base (353) will be provided, since this registration is unique in the world.

3.1.1.1 Gender distribution of all tube dependent patients registered in the data base

Amongst the 353 patients, 188 (53.26%) female and 165 (46.74%) male children were recorded, as shown in Fig. 6.

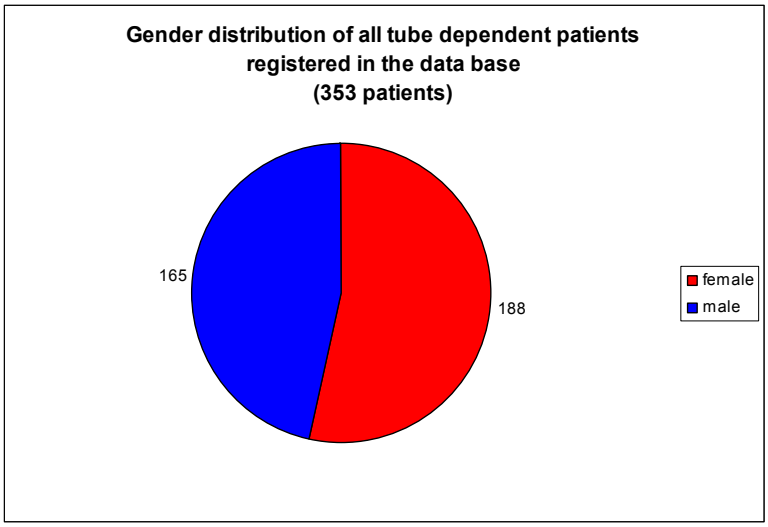


Figure 6. Gender distribution of all patients registered in the data base.

3.1.1.2 Age distribution of all tube dependent patients registered in the data base

Chart 7 and Fig. 7 show the age distribution of all 353 children registered in the data base. We decided to analyse the age at the date of collection of the basic claim data. The age ranged between 43 days (0.12 years) and 14 years and 7 months (14.6 years). Chart 7 apportions the number of patients for each year of life. The calculated mean of age is 2.34 years.

Year of life	Number of patients
0	82
1	123
2	59
3	38
4	20
5	14
6	3
7	6
8	2
9	2
10	2
11	0
12	1
13	0
14	1
	353

Chart 7. Number of patients in relation to each year of life (0 to 14 years).

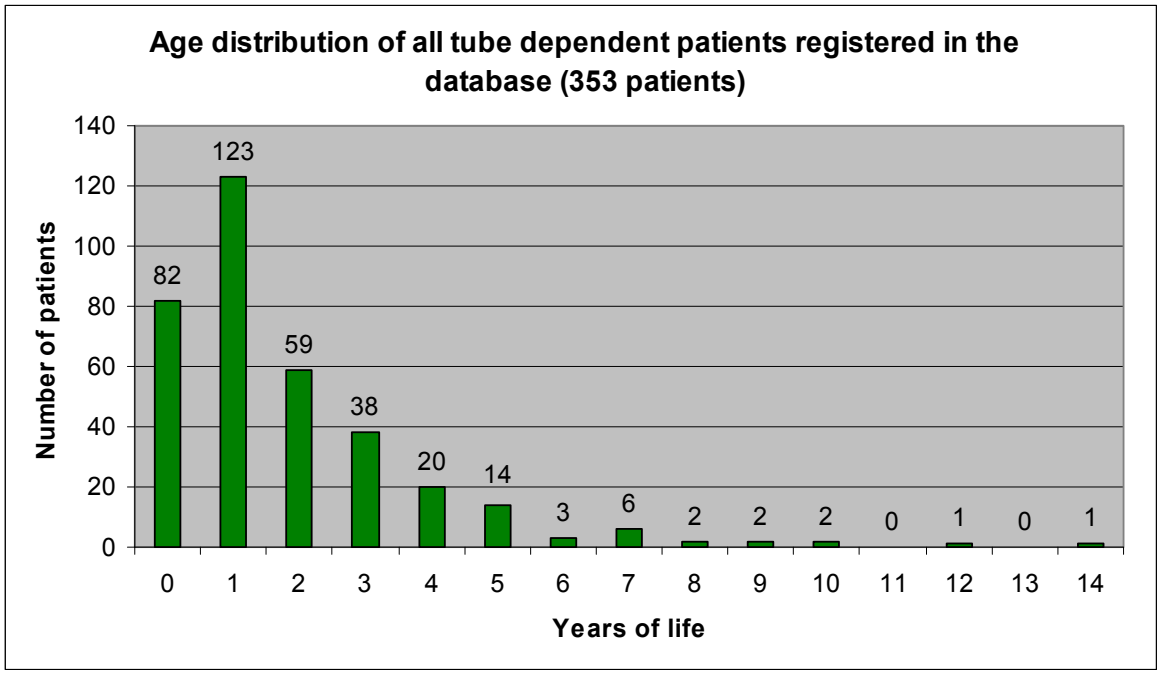


Figure 7. Age distribution of all patients registered in the data base.

3.1.2 The study population

All following results refer to our sample, which consisted of 302 patients. These 302 patients fulfilled all required inclusion criteria named above.

3.1.2.1 Gender distribution of the 302 patients included in the sample

As mentioned in chapter 2.2.1, the study population included 168 female patients (55.63%) and 134 male patients, equivalent to 44.37%. This result is shown in Fig. 8.

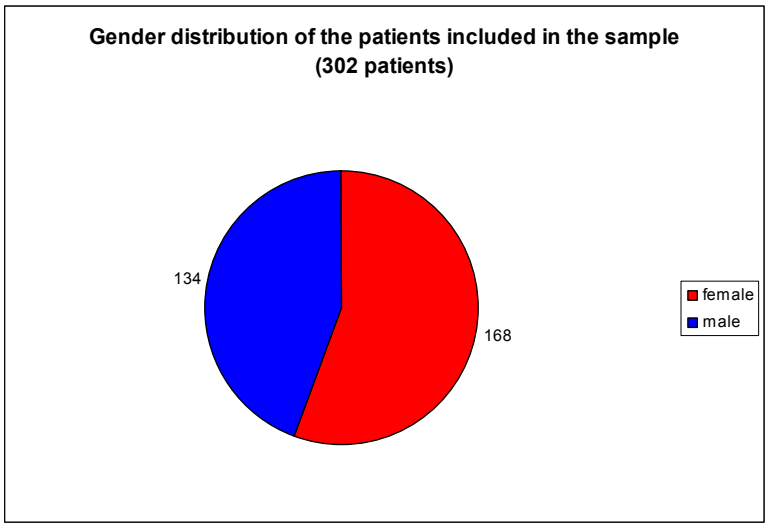


Figure 8. Gender distribution of the study population.

3.1.2.2 Age distribution of the 302 patients included in the sample

Fig. 9 illustrates the age distribution of the study population. In order to state the age distribution as precisely as possible, we decided to divide the years of life into months. As mentioned above, we used the age at the date of collection of the basic claim data.

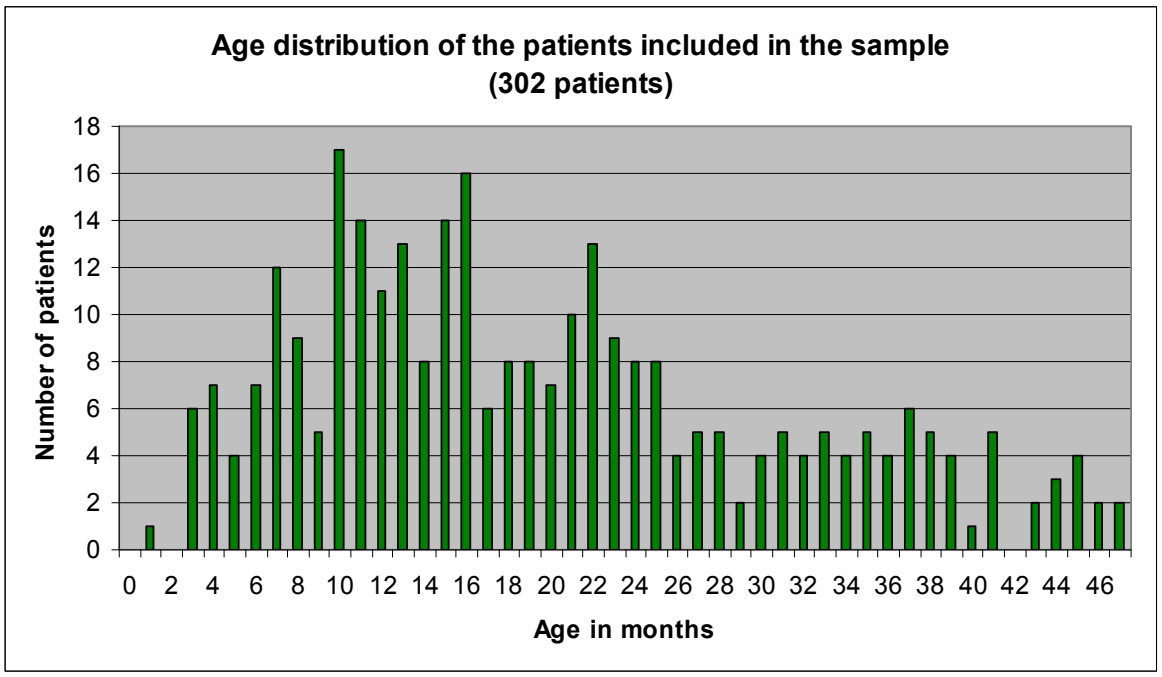


Figure 9. Age distribution of the study population.

3.1.2.3 Admissions per year

All 302 patients included in the study population had been treated by the interdisciplinary tube weaning team of the Psychosomatic Unit of the Children's Hospital in Graz, over a period of 12 years (1998 to 2009. It is important to mention that only patients, who were admitted before June 3, 2009, are analysed in this study. Fig. 10 illustrates the number of admissions per year in this period.

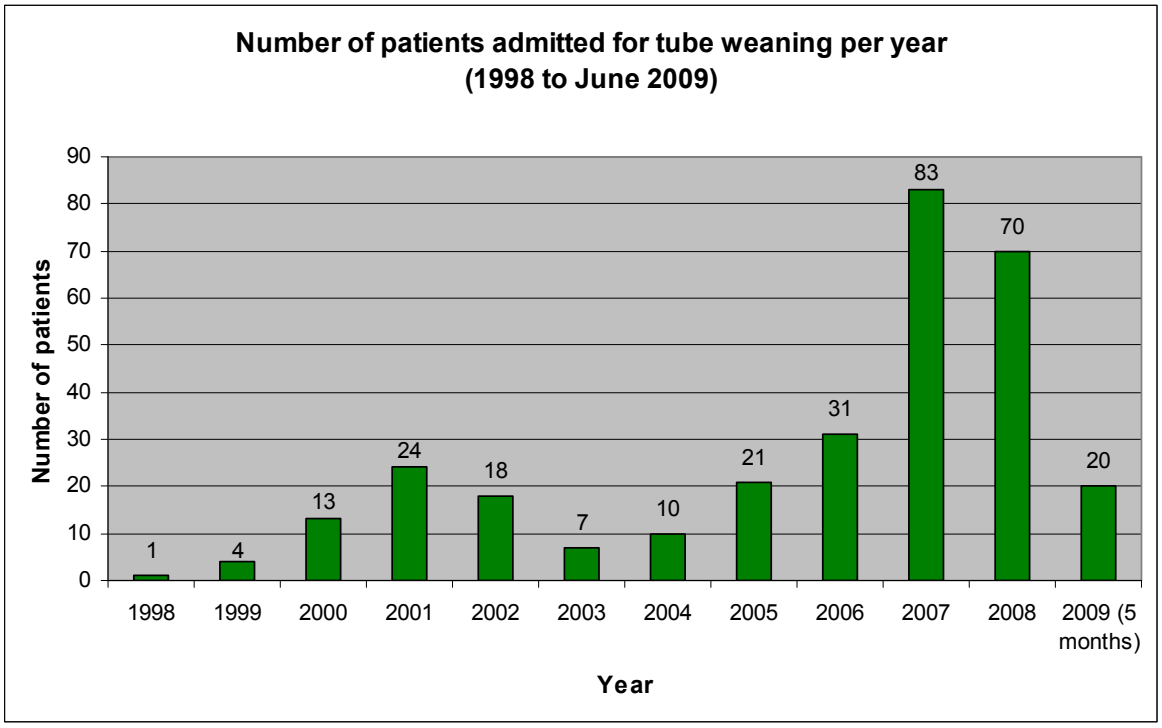


Figure 10. Number of patients included in the sample admitted between 1998 and June 2009.

3.1.2.4 Nationality of the patients included in the sample

Since children from all over the world are treated in the Graz Model weaning program, we analyzed the distribution of nationalities in our study population of 302 children. This analysis showed the following nations: Algeria, Australia, Austria, Belgium, Canada, Croatia, Denmark, England/Great Britain, France, Germany, Guatemala, Hungary, Iran, Ireland, Israel, Italy, Japan, Liechtenstein, New Zealand, Poland, Romania, Russia, Serbia, Slovenia, South Africa, Sweden, Switzerland, Turkey and United States of America.

Chart 8 shows the number of patients per nation admitted to the Psychosomatic Unit. The nations are arranged according to the number of patients from each country, in order to easily distinguish from which country most patients were treated by the interdisciplinary weaning team.

Nation	Number of patients
Germany	92
Austria	88
England/GB	42
Denmark	9
Ireland	9
USA	9
Australia	8
Switzerland	6
New Zealand	5
France	4
Israel	3
Italy	3
Poland	3
Turkey	3
Canada	2

Nation	Number of patients
Hungary	2
Slovenia	2
Algeria	1
Belgium	1
Croatia	1
Guatemala	1
Iran	1
Japan	1
Liechtenstein	1
Romania	1
Russia	1
Serbia	1
South Africa	1
Sweden	1
	302

Chart 8. Number of patients per nation.

Since children from 29 nations were treated in Graz in the time period between 1998 and June 2009, we decided not to visualize each country, but to show the distribution of the study population according to the continents (see Fig. 11). Here, Europe is represented with 269 patients (89.07%), Oceania with 13 children (4.30%), from America 12 patients (3.97%) were treated by the interdisciplinary weaning team, 6 children (1.99%) were from Asia and 2 African patients (0.66%) were included in the study population.

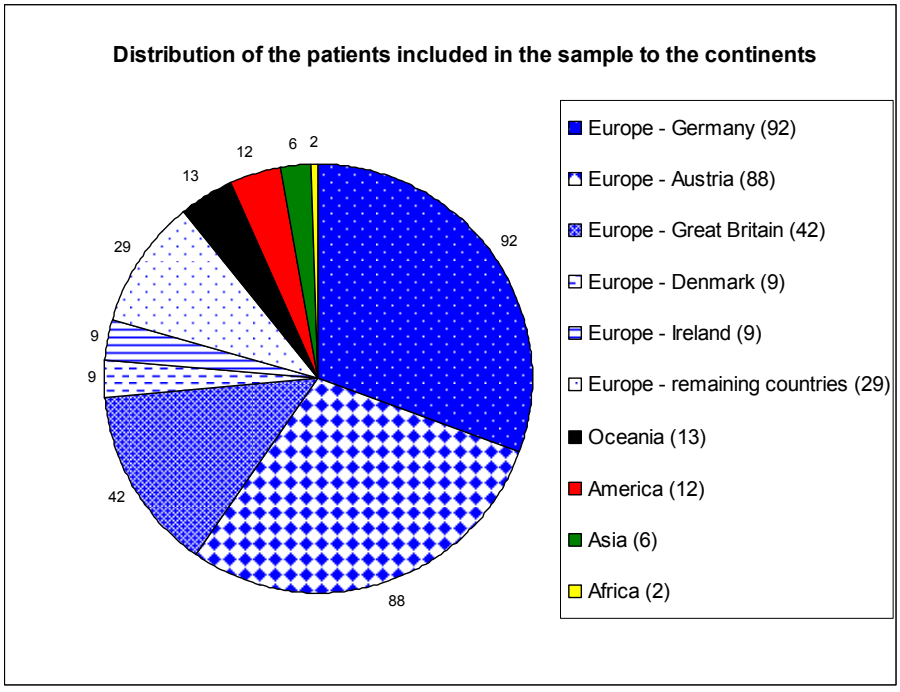


Figure 11. Distribution of the 302 patients included in the sample to the continents.

3.1.2.5 Tube systems in the sample

In the study population, 2 different types of tube were distinguished: nasogastric tubes and percutaneous tubes. The group with percutaneous tubes also included children with a button. Here it is important to mention, that a child could have different kinds of tube systems as well as it is possible that a child had the same tube systems two or more times with a period in between.

In Fig. 12, we visualized each child's first tube. 227 out of 302 children (75.17%) had an NGT as their first tube, while the first tube of 64 patients (21.19%) was a PEG. In 11 cases (3.64%), no specified information about the first tube was registered in the data base.

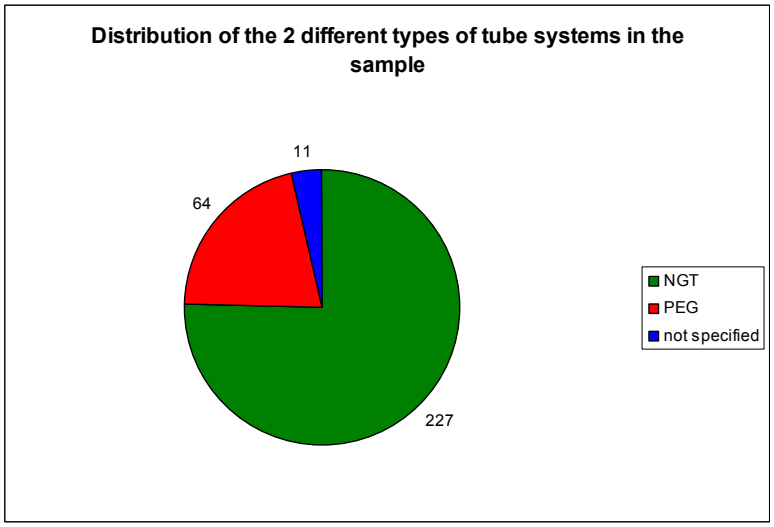


Figure 12. Distribution of each child's first tube in relation to the 2 different tube systems.

3.1.2.6 Multimorbidity in the sample

Fig. 13 deals with the multimorbidity in our study population. In order to make the visualisation more clearly, we formed 5 groups. The first group consisted of 11 out of 302 children (3.31%), who had no diagnosis registered in the data base. 149 patients (49.67%) had between 1 and 5 diagnoses. In 115 patients (38.08%) we found 6 to 10 diagnoses, while 21 patients (6.95%) offered between 11 and 15 diagnoses. The last group is made up of 6 patients (1.99%), of whom we could find between 16 and 20 diagnoses registered in the data base.

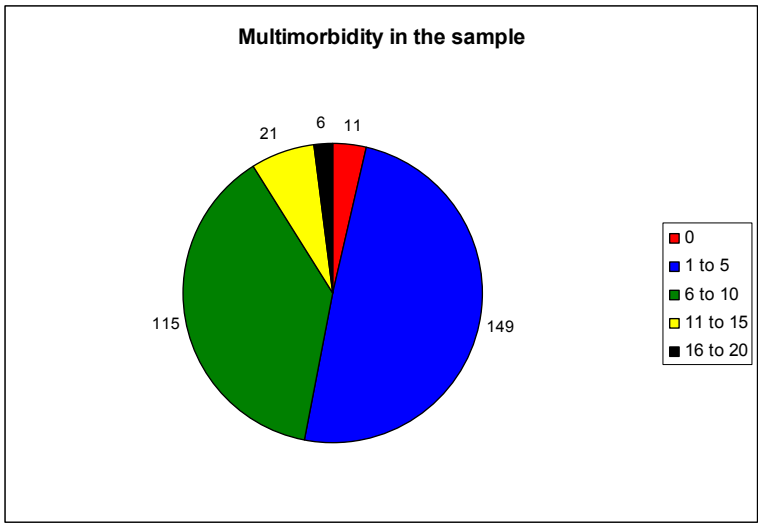


Figure 13. Multimorbidity in the study population. Division in subcategories of 0 diagnosis, 1 to 5, 6 to 10, 11 to 15 and 16 to 20 diagnoses.

As shown in Fig. 14, most of the patients had between 2 and 8 diagnoses (231 out of 302 patients, 76.49%). The most common number of diagnoses per person was 4 (41 children, 13.58%). 9 patients (2.98%) had exactly 1 diagnosis noted in the data base, while we could find 1 patient (0.33%) with 20 diagnoses.

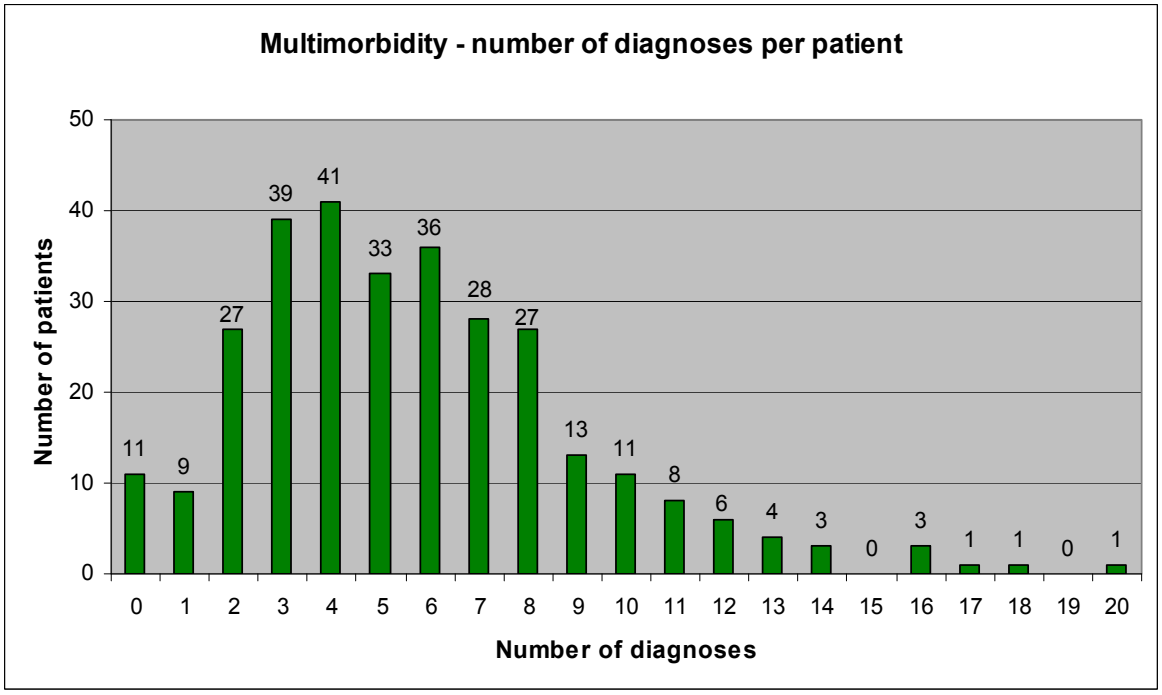


Figure 14. Multimorbidity in the sample. Number of diagnoses per patient.

3.1.2.7 ZTT DC:0-3R Axis I diagnoses in the sample

According to the classification of ZTT DC:0-3R, Fig. 15 shows the frequency of each subgroup of eating behaviour disorders in the study population.

In 40 cases (13.25%), a Feeding Disorder of State Regulation (601) was diagnosed. 18 children (5.96%) suffered from a Feeding Disorder of Caregiver-Infant-Reciprocity (602), while an Infantile Anorexia (603) was stated as diagnosis in 4 cases (1.32%). 30 children (9.93%) received the diagnosis 604: Sensory Food Aversions, Picky Eater. The interdisciplinary weaning team diagnosed a Feeding Disorder associated with Concurrent Medical Condition (605) in more than one-third of the cases (130 out of 302; 43.05%). 66 patients (21.85%) suffered from a Feeding Disorder associated with Insults to the GIT (607). In 14 cases (4.64%), no diagnosis was registered in the data base.

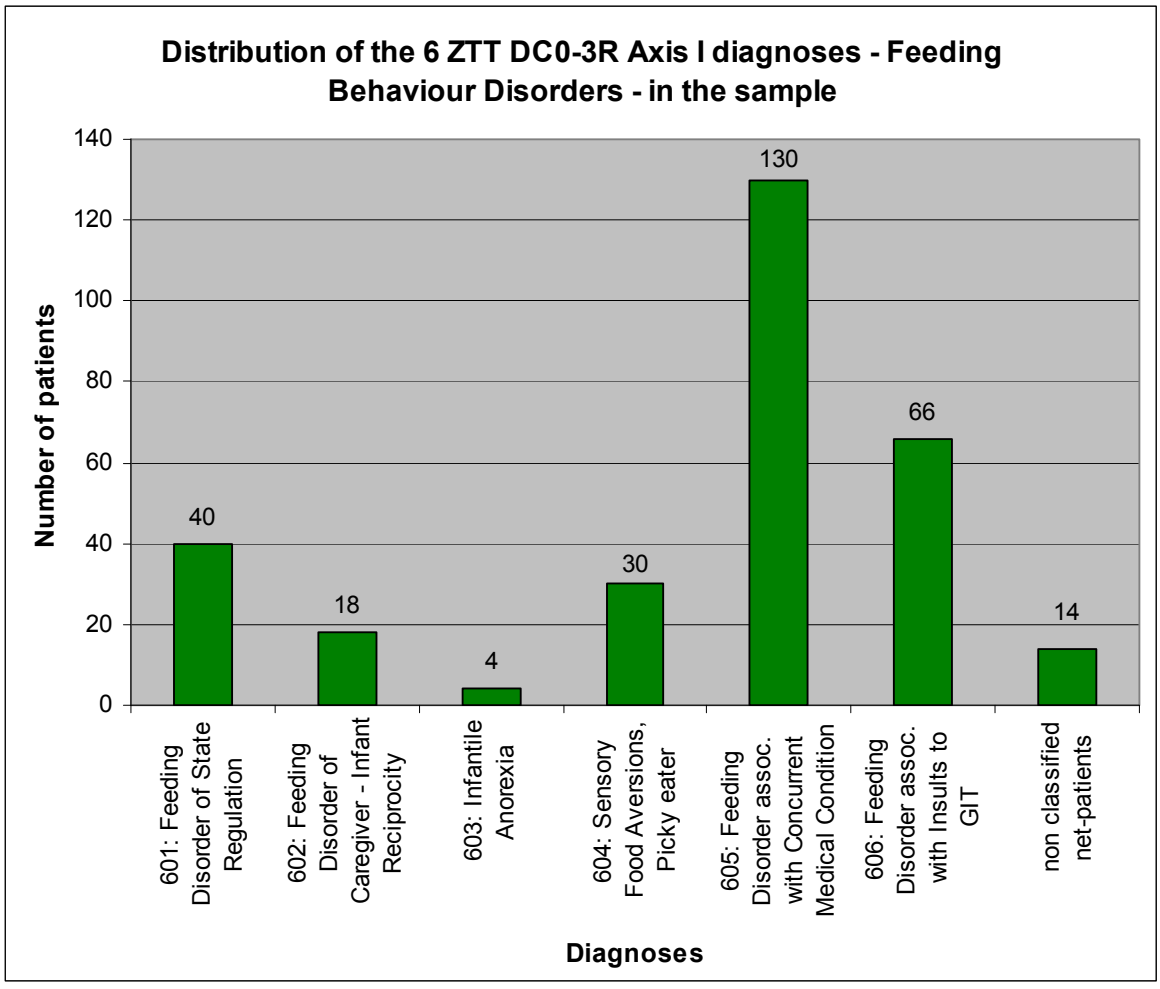


Figure 15. ZTT DC:0-3R Axis I diagnoses in relation to the number of patients.

3.1.2.8 ZTT DC:0-3R Axis II diagnoses in the sample

Axis II diagnoses are dealing with relationship disorders.

In our study population, we found the following values (Fig. 16): most of the 302 patients, namely 176 (58.28%) had no disorder concerning relationships; the relationship between child and caregivers was balanced (900). In 56 cases (18.54%), an overinvolved relationship (901) was diagnosed, whereas 8 cases (2.65%) showed an underinvolved relationship. An anxious/tense relationship (903) was found in 39 children (12.91%). No angry/hostile relationship (904) was detected. The so-called mixed relationship disorder (905) was diagnosed in 10 cases (3.31%). In 2 (0.66%) cases, the relationship between child and caregivers was assessed as abusive (906). In 11 children (3.64%), we didn't find any information about the Axis II diagnoses in the data base.

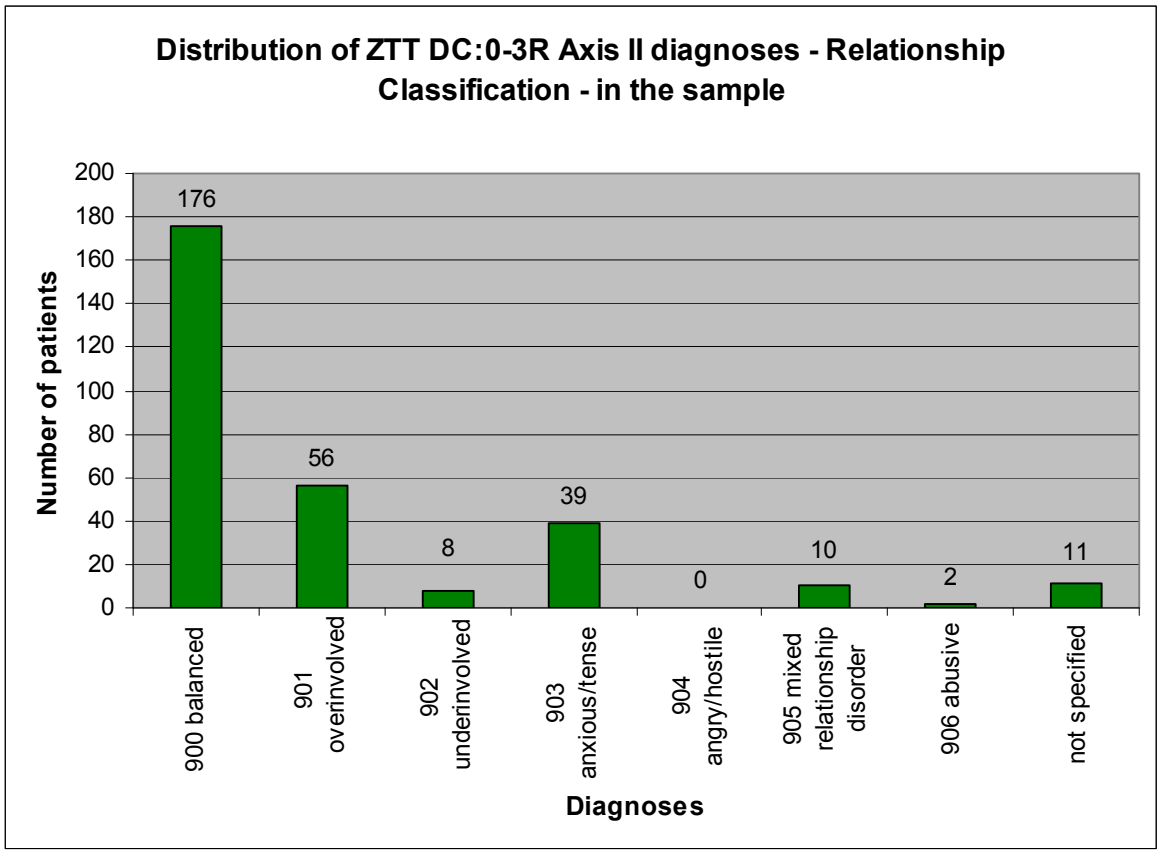


Figure 16. ZTT DC:0-3R Axis II diagnoses in relation to the number of patients.

3.1.2.9 ZTT DC:0-3R Axis IV diagnoses in the sample

The diagnoses of Axis IV contain information about the child's psychosocial stress and are assessed by the interdisciplinary weaning team of the Psychosomatic Unit in the Children's Hospital in Graz.

Fig. 17 shows the collected results: In 20 out of 302 children (6.62%) no psychosocial stress was assessable (psychosocial stress: 0). 27 patients (8.94%) showed a very low level

of psychosocial stress (psychosocial stress: 1). Further 42 out of 302 (13.91%) showed slight effects of psychosocial stress like excitability and changes in sleeping habits (psychosocial stress: 2). In 73 patients (24.17%), the interdisciplinary team assessed a psychosocial stress level of 3, another 59 children (19.54%) were diagnosed to have a psychosocial stress level of 4. Furthermore, 36 patients suffered from a psychosocial stress level of 5. We found 26 children (8.61%) with a registered psychosocial stress of 6 in the analysis. Severe effects of psychosocial stress (psychosocial stress: 7) were diagnosed in 3 patients (0.99%). In the remaining 16 cases (5.30%), no description of the child's psychosocial stress was found.

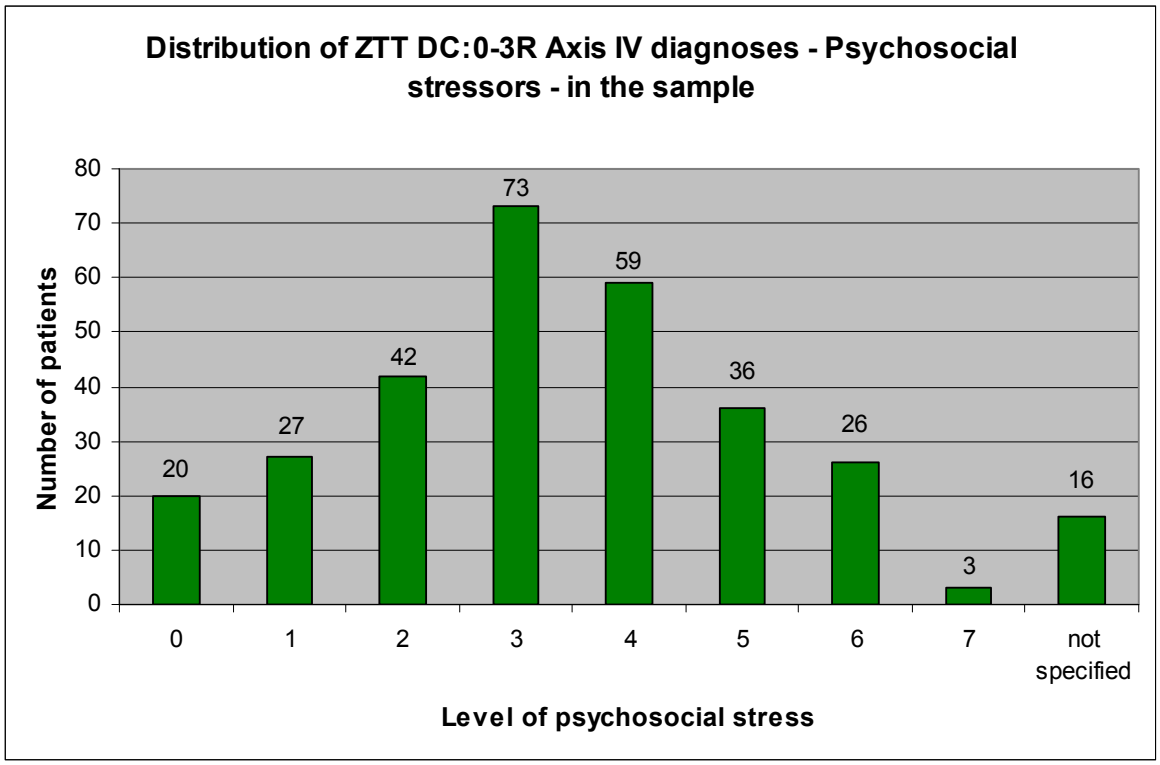


Figure 17. ZTT DC:0-3R Axis IV diagnoses in relation to the number of patients.

3.1.2.10 ZTT DC:0-3R Axis V diagnoses in the sample

In Axis V, the paediatric team assesses the child's development.

There are 3 different categories of development in the data base: 86 patients (28.47%) showed an age-appropriate development, while in 132 cases (43.71%) a mild developmental delay was diagnosed. A severe developmental delay was found in 73 patients (24.17%). In another 11 cases (3.64%) no data about the child's development was recorded. The results are shown in Fig. 18.

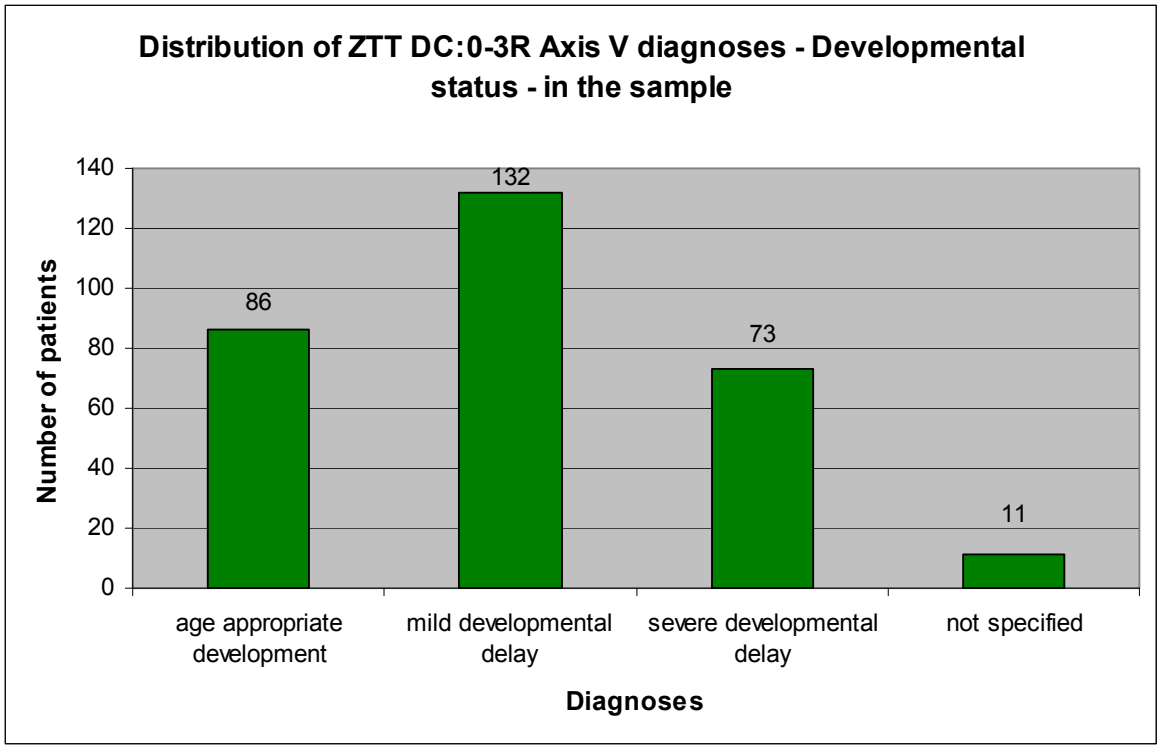


Figure 18. ZTT DC:0-3R Axis V diagnoses in relation to the number of patients.

3.1.2.11 Severeness of disease

The severeness of disease is assessed with 8 different values ranged from 0 to 7, whereas 0 stands for none and 7 for extreme severity.

Chart 9 shows the distribution of the number of patients in relation to the particular values of the severeness of disease.

Severeness of disease	Number of patients
0 - none	6
1 - minimal	9
2 - mild	35
3 - moderate	62
4 - average	68
5 - overaverage	29
6 - severe	63
7 - extreme	16
not specified	14
	302

Chart 9. Number of patients in relation to the severeness of disease.

As shown in Fig. 19, most of the patients were either diagnosed with a moderate (62 out of 302; 20.53%) or an average level of severeness of disease (68 out of 302; 22.52%).

Another 63 (20.86%) suffered from a severe disease, while 16 (5.30%) reached the highest level ("extreme") in the severeness of disease score.

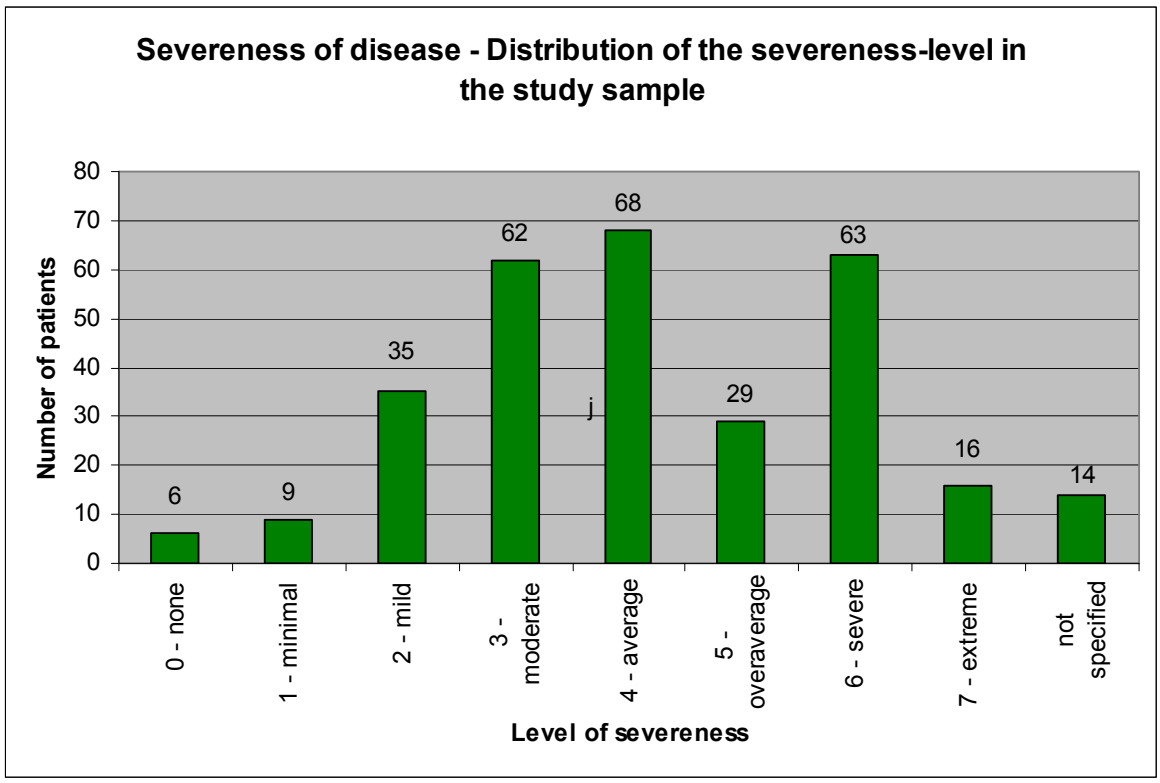


Figure 19. Level of severeness of disease in relation to the number of patients.

3.1.2.12 Distribution of the 21 chapters of ICD-10 in the sample

As most of the patients in the study population had more than one diagnosis (see chapter 3.1.2.6), we decided to form groups according to the 21 chapters of ICD-10 and distributed a main diagnosis to each child.

Fig. 20 shows the distribution of the patients in the study population to these 21 chapters. In 4 cases (1.32%), a chapter I diagnosis, according to *Certain infectious and parasitic diseases* was assessed as the main diagnosis, while 4 patients (1.32%) suffered from a *Neoplasm* (chapter II diagnosis). Another 4 patients (1.32%) had a chapter III diagnoses: *Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism*. In 12 cases (3.97%) some kind of *Endocrine, nutritional and metabolic disease* (chapter IV) was diagnosed. 8 patients (2.65%) could be allocated to chapter V (*Mental and behavioural disorders*). A group of 14 patients (4.64%) was formed in chapter VI *Diseases of the nervous system*, while only 1 patient (0.33%) suffered from a chapter VII (*Diseases of the eye and adnexa*) diagnosis. Again we found only 1 patient (0.33%) with his/her main diagnosis in one of the subsequent chapters: IX *Diseases of the*

circulatory system, XIII *Diseases of the musculoskeletal system and connective tissue*, XIV *Diseases of the genitourinary system*, XV *Pregnancy, childbirth and the puerperium*, XIX *Injury, poisoning and certain other consequences of external causes* and XXI *Factors influencing health status and contact with health services*. 10 patients (3.31%) were assessed to have their main diagnosis in chapter XI, *Diseases of the digestive system*. A group of 55 children (18.21%) suffered from *Certain conditions originating in the perinatal period* (chapter XVI). The largest group in our study population consisted of 146 patients (48.34%), who were distributed to chapter XVII *Congenital malformations, deformations and chromosomal abnormalities*. 27 patients (8.94%) had a main diagnosis which belongs to chapter XVIII, *Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified*. In this chapter, we detected 16 patients with a lack of expected normal physiological development, 6 children with dysphagia, 1 patient with chronic dystrophia, 1 with diaphragmatic elevation and 3 children with convulsions. We did not detect any patients to have their main diagnosis in the following chapters: VIII *(Diseases of the ear and mastoid process)*, X *(Diseases of the respiratory system)*, XII *(Diseases of the skin and subcutaneous tissue)* and XX *(External causes of morbidity and mortality)*. In 11 patients, no main diagnosis could be assessed with the available data.

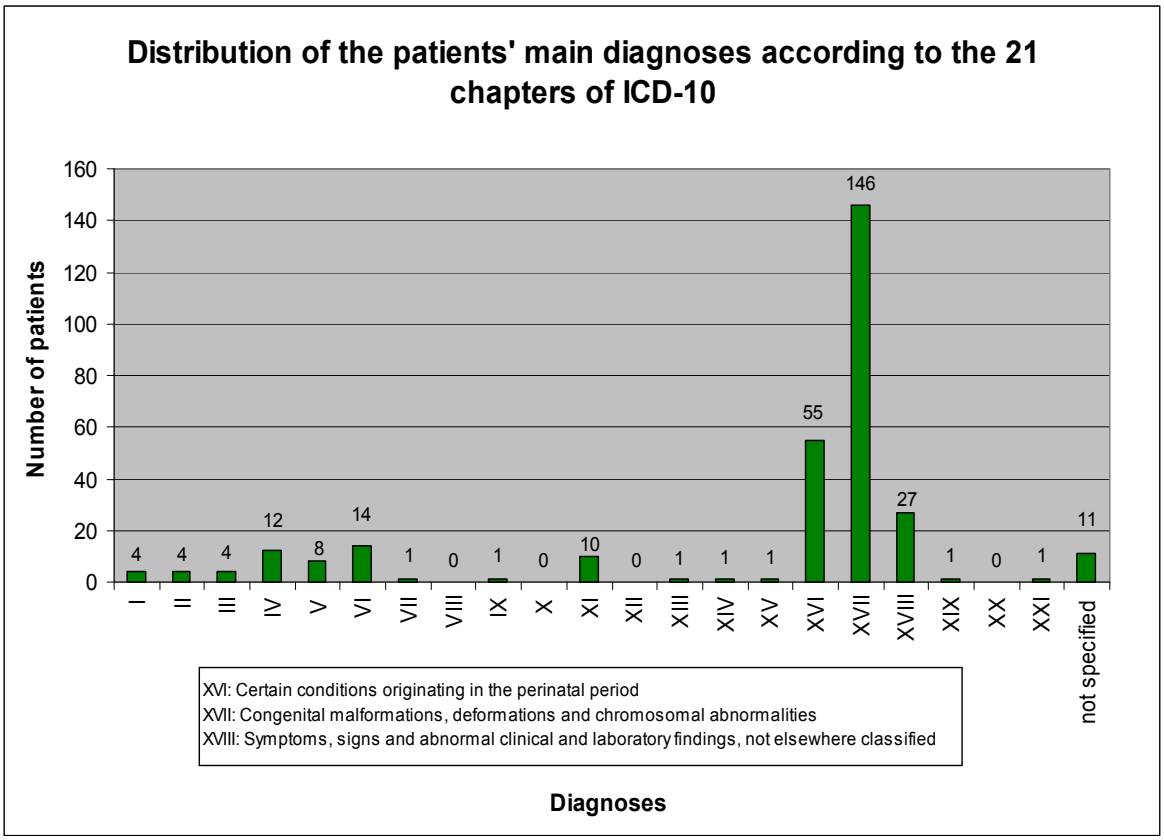


Figure 20. Main diagnoses in the sample according to the 21 chapters of ICD-10 in relation to the number of patients.

Since the bigger part of the 302 patients, namely 146 (48.34%), fell into chapter XVII, we analysed this group more precisely in order to detect the distribution of these patients in relation to the main groups of chapter XVII. Chapter XVII includes congenital malformations, deformations and chromosomal abnormalities. The main groups serve the differentiation of the disorders according to the system, in which the malformations, deformations or abnormalities occur.

As obvious in Fig. 21, 11 main groups are distinguished in chapter XVII:

6 out of 146 patients (4.11%) suffered from a congenital malformation of the nervous system. In 2 of these patients, a Dandy Walker Syndrome was diagnosed; the others revealed the following diagnoses: meningoencephalocele, Catch 22 Syndrome, congenital malformation of brain, unknown neurological syndrome (each 1 patient).

In 1 patient (0.68%) a congenital malformation of eye, ear, face and neck was detected; in this case, the main diagnosis was hemifacial microsomia.

In 29 cases (19.86%), a congenital malformation of the circulatory system was diagnosed. This main group includes amongst others the following malformations, arranged according to their frequency: hypoplastic left heart syndrome (6 patients), ventricular septal defect (4 patients), coarctation of the aorta (4 patients), double inlet ventricle, atrial septal defect, tretralogy of Fallot, Scimitar syndrome (each 2 patients), double outlet right ventricle, transposition of the great arteries, hypoplastic right ventricle, atrioventricular septal defect, aortic stenosis, complex congenital heart disease and pulmonary stenosis (each 1 patient).

3 patients (2.05%) were assessed to the group of congenital malformations of the respiratory system; 1 child with a floppy larynx, 1 with a hypoplasia and dysplasia of the lung and 1 with a congenital laryngo tracheo malacia.

We did not classify any of the 146 patients to have either a lip and cleft palate or a malformation of the genital organs as their main diagnosis.

20 patients (13.70%) showed a congenital malformation of the digestive system like atresia of oesophagus without fistula (8 patients), congenital malformations of intestinal fixation (3 patients), other congenital malformations of oesophagus (2 patients), Hirschsprung's disease (2 patients), atresia of oesophagus with tracheo-oesophageal fistula, congenital hiatus hernia, congenital malformation of stomach, congenital malformation of intestine, atresia of bile ducts (each 1 patient).

1 patient (0.68%) suffered from a congenital malformation of the urinary system. An exstrophy of urinary bladder was diagnosed in this case.

Another 8 patients (5.48%) belonged to the group of congenital malformations of the musculoskeletal system. Here, the following diagnoses were detected: omphalocele (4 patients), arthrogryposis multiplex congenital, mandibulofacial dysostosis (Franceschetti Syndrome), congenital diaphragmatic hernia, other congenital malformations of musculoskeletal system (each 1 patient).

42 out of 146 patients (28.77%) are noted in the group Q80-89 *Other congenital malformations*. The more detailed description of this group is visualized in Fig. 22. The most frequently used ICD-10 code in this group was Q87.8 which includes the following diagnoses: Charge Syndrome (9 patients), Cantrell Syndrome, Alagille Syndrome (each 1 patient). In addition to that, 2 patients were coded with Q87.8, but in the text description, a Goldenhar Syndrome was noted (properly coded with Q87.0). 9 patients showed a Q87.0 diagnosis, whereof 5 patients suffered from a Pierre-Robin Syndrome and 4 patients from a Goldenhar Syndrome. In 6 patients, a Q87.1 diagnosis was set as main diagnosis: 4 with Smith-Lemli-Opitz Syndrome and each 1 with Cat Eye Syndrome and Cornelia de Lange Syndrome. 4 patients had the diagnoses Q87.2; in 2 cases the main diagnosis was a VACTERL Syndrome, in 2 cases a VATER Syndrome. The diagnosis Q89.7 was assessed as the main diagnosis in 3 cases: 2 cases of complex malformation syndrome, 1 case of dysmorphia. Another 2 cases of dysmorphic syndromes and 1 case of malformation syndrome were coded with Q89.9. In 2 patients we found a Q87 diagnosis: 1 patient suffered from a Charge Syndrome, 1 from a cardio-facial-cutaneous syndrome. In 1 case, a congenital ichthyosis (Q80.9) was the main diagnosis, in 1 case the main diagnoses was a fetal alcohol syndrome (Q86.0).

Amongst the 36 patients with chromosomal abnormalities, the most frequent diagnosis was Down Syndrome (13 patients). These 13 patients were classified with the following codes: Q90.0, Q90.2, Q90.9. In 7 patients, the main diagnosis was coded with Q99.9. Amongst these patients, we found the subsequent disorders: Castello Syndrome, undefined chromosomal aberration, Klippel-Feil Syndrome, deletion of chromosome 10 and Mowat Wilson Syndrome. 6 cases of Wolff Hirschhorn Syndrome were detected. Further 2 children suffered from a DiGeorge Syndrome, while another 2 patients were coded under other deletions of part of a chromosome. In 2 cases, the code

Q99.8 was used (1 patient with Midas Syndrome, 1 with an unspecified chromosomal aberration). The remaining patients had the following diagnoses (1 patient per diagnosis): Edwards Syndrome, partial trisomy 22, partial trisomy 3 and De Grouchy Syndrome.

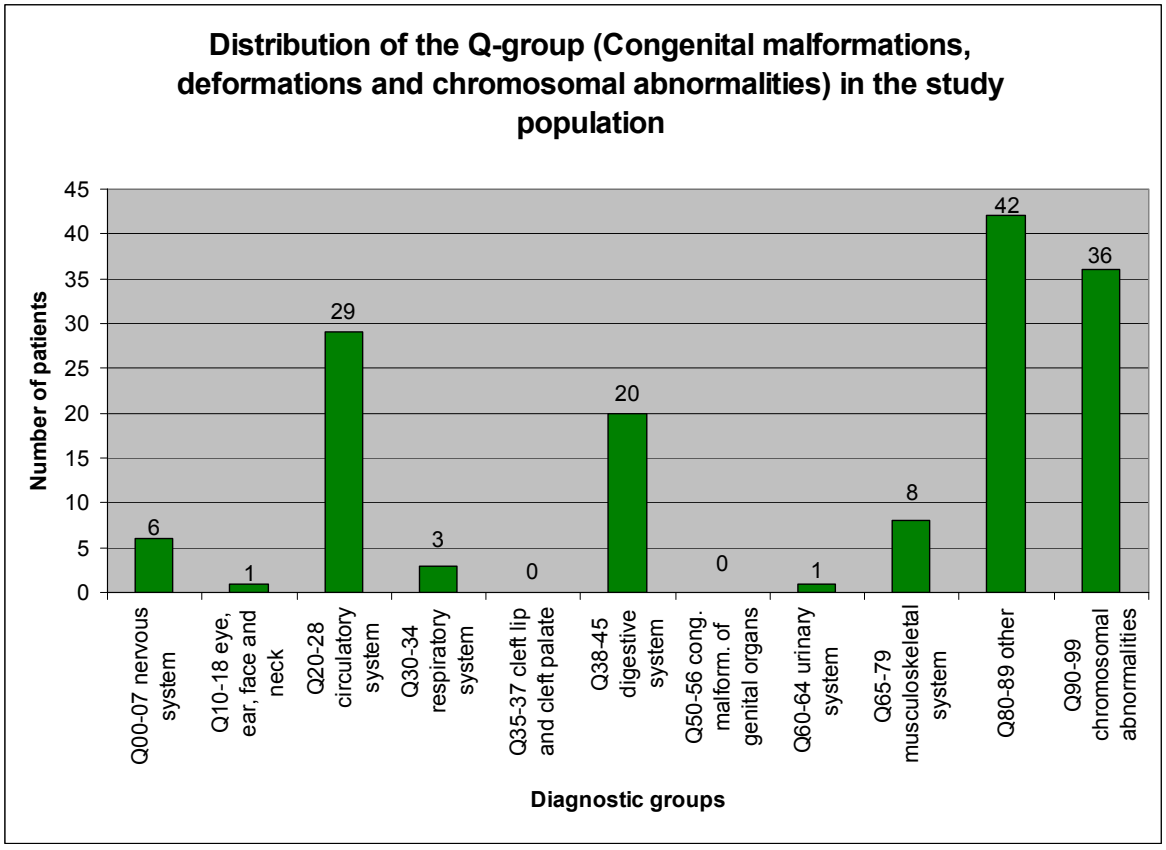


Figure 21. The 11 main groups of ICD-10 chapter XVII diagnoses in relation to the number of patients.

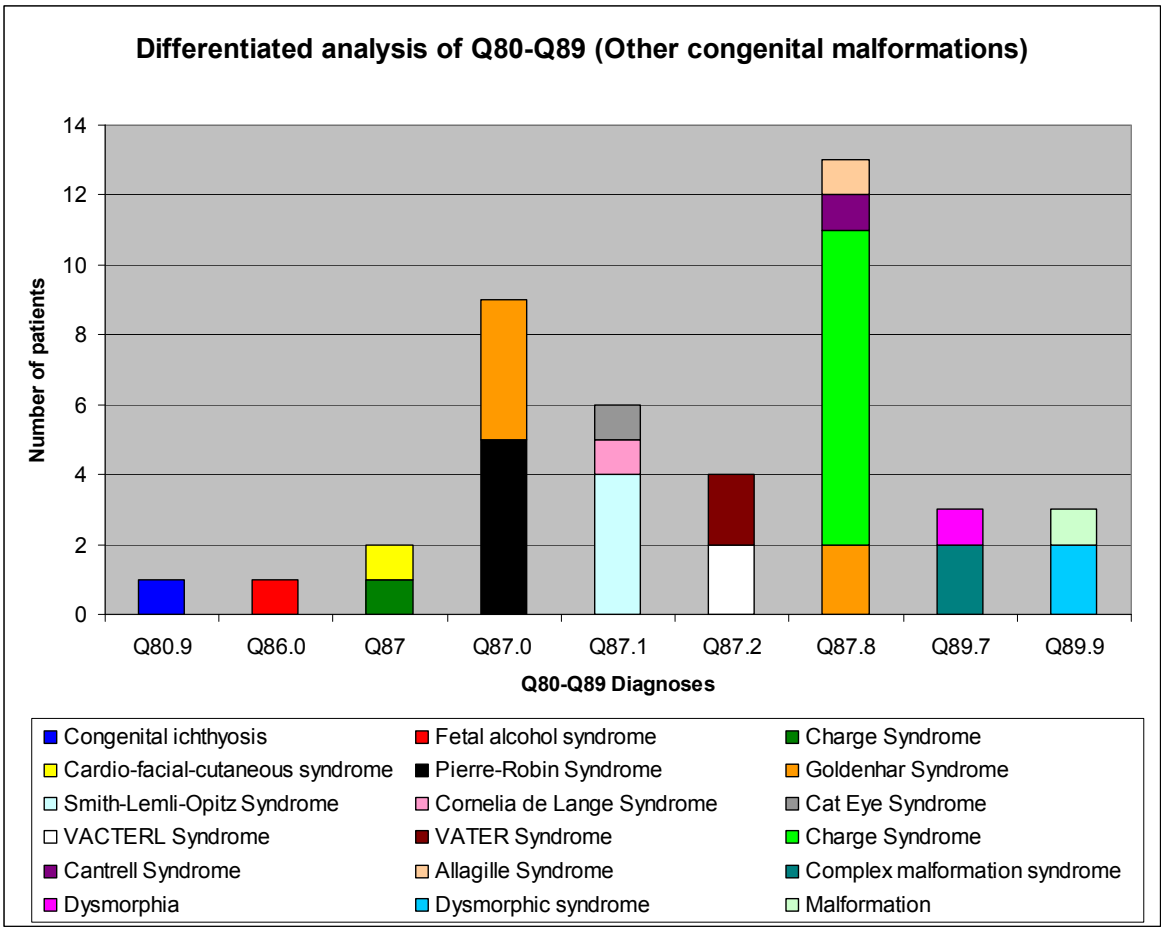


Figure 22. Differentiated analysis of the diagnosis "Other congenital malformations" (Q80-Q89)

3.1.2.13 Reducing the 21 chapters of ICD-10 to 12 main diagnostic groups

We built 12 main diagnostic groups out of the 21 chapters of ICD-10. Each of the 21 chapters is divided by the 4-digit-system. As explained in chapter 1.3.2.3, roman numbers represent the chapters. The first digit of the ICD-10 code is a letter and stands for the main category. Chart 10 illustrates the composition of the 12 main diagnostic groups out of the 21 chapters of ICD-10.

Group 1 includes diseases of the nervous system as declared in ICD-10 by the letter G (chapter VI). We added 1 patient who suffered from a Brown Syndrome, coded as H50.6 and therefore registered in chapter VII in ICD-10. In addition to that, 7 patients from chapter XVII (letter Q) were included; 6 of these patients suffered from a congenital malformation of the nervous system (Q00-Q07), 1 patient had the main diagnosis of a floppy larynx (Q31.8). Furthermore, patients with dysphagia (R 13) and patients with convulsions (R56) were included. Lastly, we added 1 patient with neonatal hyperekplexia, coded with Z82.0 to group 1.

Group 2 consists of 1 patient with dilated cardiomyopathy, originally coded in chapter IX and 29 patients with congenital malformation of the circulatory system (Q20-Q28).

In group 3, we summarized patients with intestinal infectious diseases (coded with A00-A09), patients with diseases of the digestive system (K00-K93), children with necrotizing enterocolitis (P77) and cases, in which a congenital malformation of the digestive system (Q38-Q45) was set as the main diagnosis.

Chromosomal anomalies were noted in group 4. Here, 1 patient with Hajdu-Cheney Syndrome (M35.8), 2 patients with congenital malformations and deformations of the musculoskeletal system (Q65-Q79) and all patients with chromosomal abnormalities like Trisomy 21, Trisomy 18 or Wolff-Hirschhorn Syndrome (Q90-Q99) were included.

39 premature infants form group 5. All these patients are registered with the code P07 as their main diagnosis.

Group 6 includes neoplasms (C00-D48) and diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89).

Conditions which are combined with a complicated perinatal period, are summarized in group 7. Here, 1 case of sepsis due to an infection during labour (O75.3) is noted. In addition to that, we included patients with their main diagnosis in the group P00-P04 fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery, patients with respiratory and cardiovascular disorders specific to the perinatal period (P20-P29) and children with other disorders originating in the perinatal period, like convulsions of the newborn, congenital hypotonia and neonatal cerebral leukomalacia. Furthermore, 5 patients with their main diagnosis in group Q65-Q79 are summarized below complicated perinatal period, since they have diseases like congenital diaphragmatic hernia and omphalocele.

In group 8, psychiatric diseases of the child or his/her parents were registered. It includes all diagnoses coded with F00-F99. In addition to that, 1 case of psychic abuse (code T74.3) was adjoined.

Metabolic diseases form group 9. They are all coded with E00-E90. It is important to mention that patients with cystic fibrosis (E84.0) are also included in this group.

Children suffering from unspecified developmental delay are summarized in group 10. The main diagnoses of these patients are either coded as R62 or R63.

Group 11 is called other and rare congenital malformations. This group contains 1 case of tubular acidosis (N25.8), 1 patient with the main diagnosis Q18.8 (hemifacial microsomia), 2 patients of group Q30-Q34 – 1 suffering from hypoplasia and dysplasia of the lung, 1 from laryngotrachomalacia – and 1 patient with the main diagnosis of exstrophy of the urinary bladder (Q64.1). Besides, 1 patient with the diagnosis Q79.8 (other congenital malformations of musculoskeletal system), 42 patients of the group Q80-Q89 (see chapter 3.1.2.12) and 1 patient with the diagnosis R93.5, diaphragmatic elevation, were noted in group 11.

The last group consists of non classified net-patients, who have no main diagnosis registered in the data base.

12 main groups	Name	Composition of the group						
Group 1	Diseases of the nervous system	VI G00-G99	VII H60-H95	XVII Q00-Q07	XVII Q30-Q34	XVIII R10-R19	XVIII R50-R69	XXI Z00-Z99
Group 2	Diseases of the cardiovascular system	IX I00-I99	XVII Q20-Q28					
Group 3	Diseases of the gastrointestinal system	I A00-B99	XI K00-K93	XVI P75-P78	XVII Q38-Q45			
Group 4	Chromosomal anomalies	XIII M00-M99	XVII Q65-Q79	XVII Q90-Q99				
Group 5	Prematurity	XVI P05-P08						
Group 6	Neoplasms, diseases of blood, blood-forming organs + disorders of the immune mechanism	II C00-D48	III D50-D89					
Group 7	Complicated perinatal period	XV O00-O99	XVI P00-P04	XVI P20-P29	XVI P90-P96	XVII Q65-Q79		
Group 8	Psychiatric diseases of child or parents	V F00-F99	XIX T66-T78					
Group 9	Metabolic diseases	IV E00-E90						
Group 10	Unspecified developmental delay	XVIII R50-R69						
Group 11	Other and rare congenital malformations	XIV N00-N99	XVII Q10-Q18	XVII Q30-Q34	XVII Q60-Q64	XVII Q65-Q79	XVII Q80-Q89	XVIII R90-R94
Group 12	non classified net-patients							

Chart 10. The 12 main diagnostic groups.

3.1.2.14 ZTT DC:0-3R Axis I diagnoses in relation to the 12 main diagnostic groups of ICD-10

In Fig. 23, the relation between ZTT DC:0-3R Axis I and the 12 main diagnostic groups of ICD-10 is visualized.

As mentioned in chapter 3.1.2.7, the most common Axis I diagnosis is 605. Feeding Disorder Associated with Concurrent Medical Condition. This diagnosis builds the largest fraction in all 12 main diagnostic groups of ICD-10, except of group 3, Diseases of the gastrointestinal system, where the diagnosis 606. Feeding Disorder Associated with Insults to the Gastrointestinal Tract dominates. The 4 children with the Axis I diagnosis 603. Infantile Anorexia are split up into 4 different ICD-10 main groups: psychiatric disease of child or parents, metabolic diseases, unspecified developmental delay and other and rare congenital malformations. In the diagnostic main group of prematurity, 1/3 of the patients has the Axis I diagnoses 601. Feeding Disorder of State Regulation, 1/3 is diagnosed as 605. Feeding Disorder Associated with Concurrent Medical Condition, while the last third consists of 602. Feeding Disorder of Caregiver-Infant Reciprocity, 604. Sensory Food Aversions and 606. Feeding Disorder with Insults to the GIT.

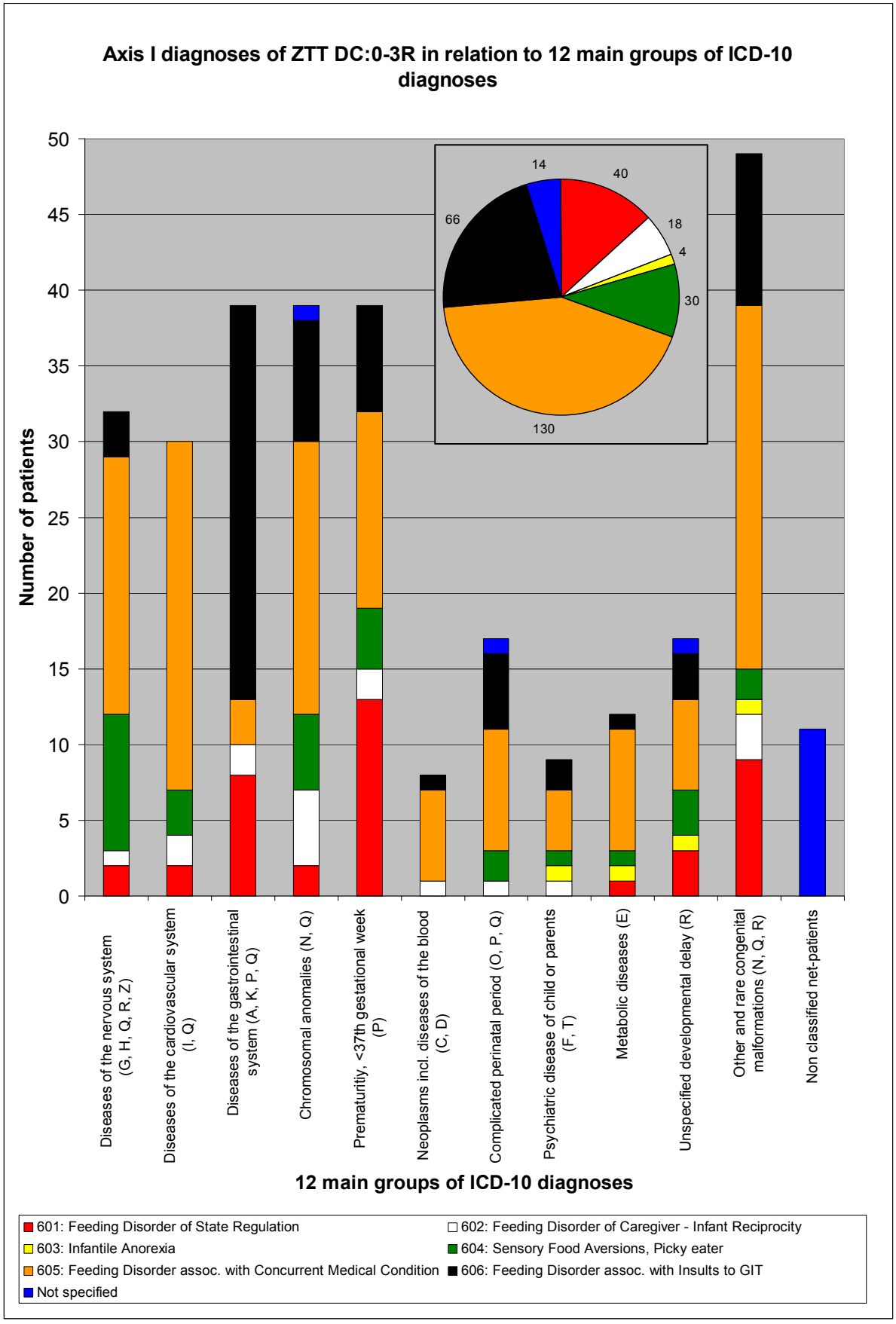


Figure 23. ZTT DC:0-3R Axis I diagnoses in relation to the 12 main diagnostic groups of ICD-10 diagnoses.

3.1.2.15 Age distribution of the study population in relation to the 12 main diagnostic groups of ICD-10 diagnoses

We analyzed the patients' age at the collection of basic claim data in relation to the 12 main diagnostic groups of ICD-10 diagnoses. The result is visualised in Fig. 24. Here, the 81 patients (26.82%) noted with 0 years are between 42 days and 11 months old. The group of the 1 year-old patients (41.05%) includes all children between 12 and 23 months of age. 59 patients (19.54%) were between 24 and 35 months old, when the basic claim data was collected. The age of the oldest children (38 patients; 12.58%) in the study population ranged between 36 and 47 months of age.

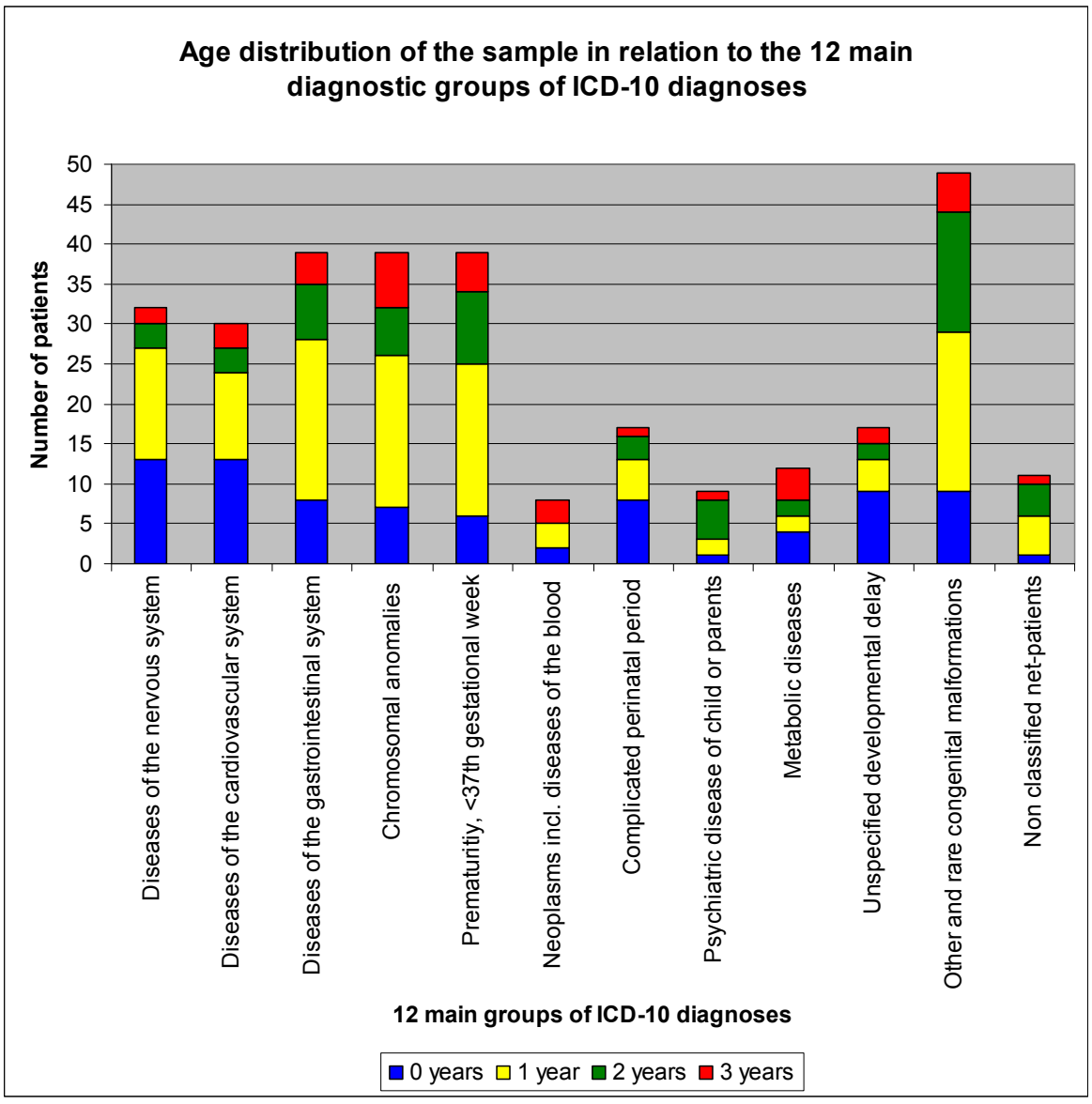


Figure 24. Age distribution of the study population in relation to the 12 main diagnostic groups of ICD-10 diagnoses.

3.1.2.16 Gender in relation to the 12 main diagnostic groups of ICD-10 diagnoses

Fig. 25 illustrates the distribution of the study population concerning the patients' gender in relation to the 12 main diagnostic groups of ICD-10 diagnoses.

In group 1, 62.5% of the patients were female, 37.5% male. These patients suffered from a disease of the neurological system. Group 2, diseases of the cardiovascular system included as many female as male patients (each 15). The dominant gender in group 3, diseases of the GIT, was the group of girls with 58.97% in contrast to the boys who made up 41.03%. Chromosomal anomalies, summarized in group 4 were found more often in girls (61.54%) than in boys (38.46%). In group 5, nearly as many boys as girls (48.72% to 51.28%) were found. These patients were born prematurely. Group 6 consisted of neoplasms (coded with the letter C and D00-D48 in ICD-10) and diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (coded with D50-D89 in ICD-10). The patients who had a diagnoses coded with C were all female (50%); 2 had a brain tumour, 1 a rhabdomyosarkoma and 1 girl suffered from an acute lymphoblastic leukaemia. In contrast to that, we detected only boys (4 patients; 50%) with diseases of the blood. A complicated perinatal period, respectively a main diagnosis in group 7, was registered in 9 boys (52.94%) and 8 girls (47.06%). In group 8, psychiatric disease of child or parents, the girls dominated with 2/3 of all the patients. Group 9, metabolic diseases, included as many female as male patients, while the girls dominate in group 10, unspecified developmental delay (70.59% females; 29.41% males). The largest group, other and rare congenital malformations, included slightly more boys (53.06%) than girls (46.94%). In the group of non classified net-patients, we found 7 girls (63.63%) and 4 boys (36.36%).

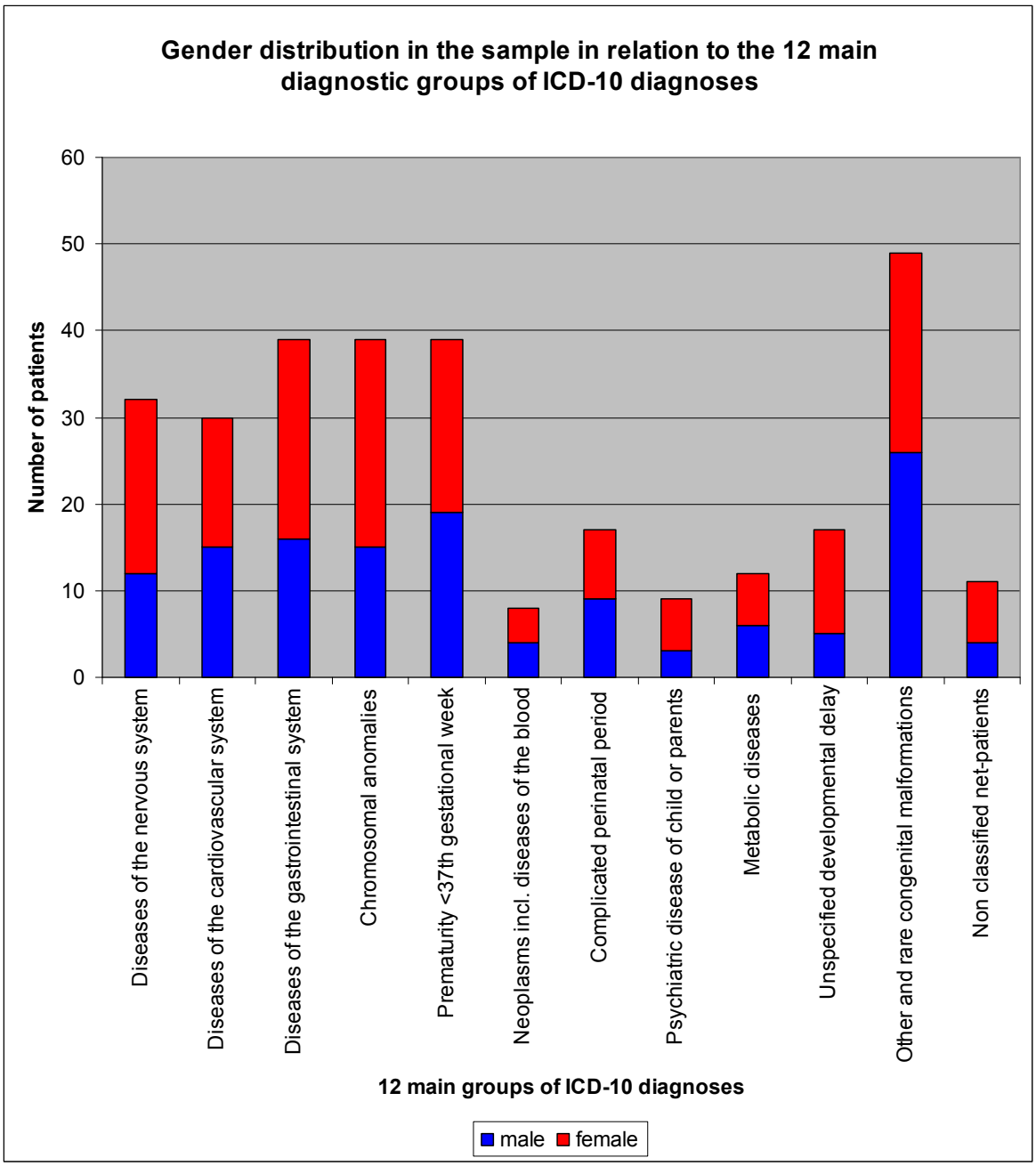


Figure 25. Gender in relation to the 12 main diagnostic groups of ICD-10 diagnoses.

3.1.2.17 Nationalities in relation to the years of age

Fig. 26 illustrates the relation between the children's country of origin and their years of age. The main part of children younger than 1 year (75.61%) was from the German-speaking countries Austria, Germany and Switzerland. The remaining 24.39% disperse to the other countries, whereas Great Britain has the biggest proportion (45%) of these countries. Within Austria, we found nearly as many children younger than 1 year as children between 1 and 1.99 years (36.36% to 35.23%). In Great Britain, the dominant group was children aged 1 to 1.99 years (42.85%). The same statement is valid for

Germany, where this group accounted for 42.39% and Ireland with 55.56% children between 1 and 1.99 years of age. The only nation, where children with an age of 2 to 2.99 years were the most frequent, was Denmark (44.44% of all Danish patients).

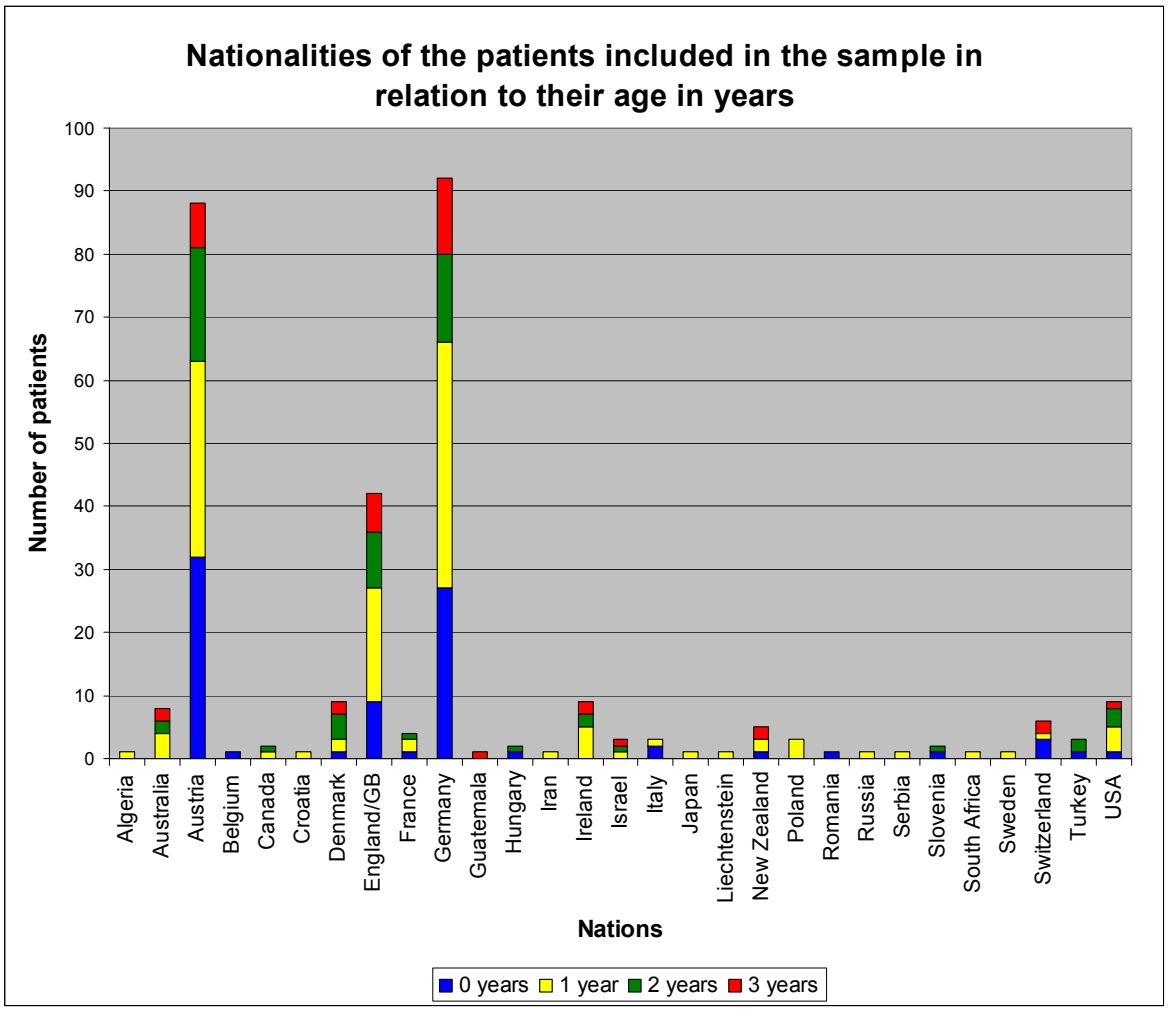


Figure 26. Distribution of 4 age cohorts to the participating nations in the weaning program.

3.1.2.18 German-speaking children and the success of weaning them

Since children from the German-speaking countries Austria, Germany and Switzerland form the largest group of patients, we analysed these patients in more detail and looked at the status of weaning in this group. The status of weaning can be divided into totally weaned children, partially weaned children and children, who are impossible to wean. Partial weaning means that the child is able to orally intake fluids or food, but still needs additional nutrition via the tube.

Chart 11 and Fig. 27 show this analysis for the 186 German-speaking children between 0 and 3.99 years, who were divided into 4 age cohorts.

Status of weaning	Years of age			
	0-0.99 years	1-1.99 years	2-2.99 years	3-3.99 years
weaned	88,71%	90,14%	87,50%	90,48%
partially weaned	4,84%	5,63%	9,38%	9,52%
impossible to wean	6,45%	4,23%	3,13%	0%

Chart 11. Status of weaning of the German-speaking children in relation to their age in years.

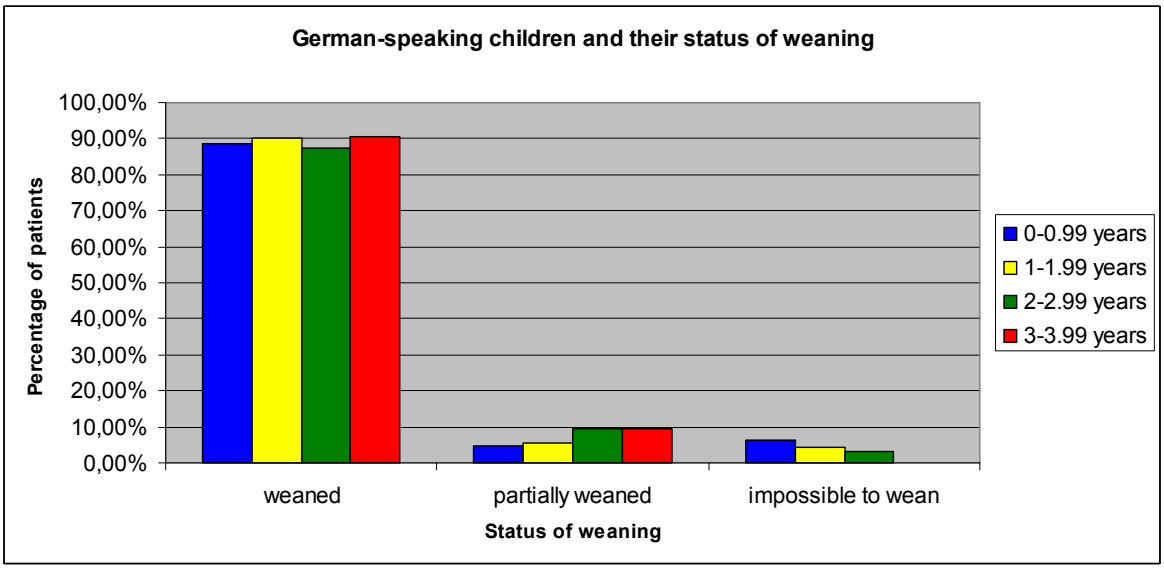


Figure 27. Percentage of German-speaking children in 4 age cohorts in relation to their status of weaning.

The group of 0 to 3.99 year-old children who were impossible to wean (8 children; 13.81%) was assessed in more detail:

A 3 month-old girl, who was born prematurely in the 34th gestational week, with severe neonatal asphyxia, necrotizing enterocolitis, dysphagia and microcephaly.

A girl aged 10 months, with severe neonatal asphyxia, dysphagia, severe cerebral palsy, tracheostomy and a disorder of gastric emptying.

A girl, 11 months old with post-haemorrhagic encephalopathy, severe bulbar dysphagia, hypoxic thalamus-lesion, missing cerebral myelination and severe statomotoric retardation. In addition to that, the girl was diagnosed as a floppy infant.

A 15 month-old boy with a cerebral disorder of the suck- and swallowing-coordination, severe mental retardation, cerebral haemorrhage, hyperventilation syndrome, left-side hemiplegia, an atrial septal defect, hypothyroidism and muscular hypotonia.

A girl aged 22 months, born prematurely in the 34th gestational week with oesophageal-, duodenal- and anal atresia, right descending aorta, dysphagia, Cockayne Syndrome and a multiple dysmorphic syndrome.

A boy, 22 months, after Toxic Shock Syndrome, with recurrent vomiting, dysphagia, skoliosis, severe muscular hypotonia and blind.

A 29 month-old boy who suffered from an apallic syndrome, cerebral convulsions and severe bulbar dysphagia.

The main common symptom of these 7 infants impossible to wean, was a severe degree of dysfunctional swallow-coordination with definite signs of recurrent aspiration and therefore unsafe swallowing.

Additionally, in an 11 month-old boy with a disorder of the amino-acid metabolism, hepatomegaly, hepatopathy, adiposogigantism and global developmental delay, the tube weaning had to be stopped due to an acute gastroenteritis which caused the transfer to the intensive care unit.

3.1.2.19 ZTT DC:0-3R Axis I diagnoses in relation to gender

Chart 12 and Fig. 28 visualize the percentage of boys and girls in every Axis I diagnosis of ZTT DC:0-3R. In most of the Axis I diagnoses, the boys are slightly more frequently represented than the girls. This dominance is most noticeable in Axis I diagnosis 602. Feeding Disorder of Caregiver-Infant Reciprocity. In contrast to that, the female patients form the main part in Axis I diagnosis 606. Feeding Disorders associated with Insults to the Gastrointestinal Tract.

ZTT DC:0-3R Axis I diagnoses	% male patients	% female patients
601: Feeding Disorder of State Regulation	11,94%	14,29%
602: Feeding Disorder of Caregiver - Infant Reciprocity	8,96%	3,57%
603: Infantile Anorexia	1,49%	1,19%
604: Sensory Food Aversions, Picky Eater	11,94%	8,33%
605: Feeding Disorder assoc. with Concurrent Medical Condition	45,52%	41,07%
606: Feeding Disorder assoc. with Insults to GIT	16,42%	26,19%
not specified	3,73%	5,36%
	100,00%	100,00%

Chart 12. ZTT DC:0-3R Axis I diagnoses in relation to the percentage of male and female patients.

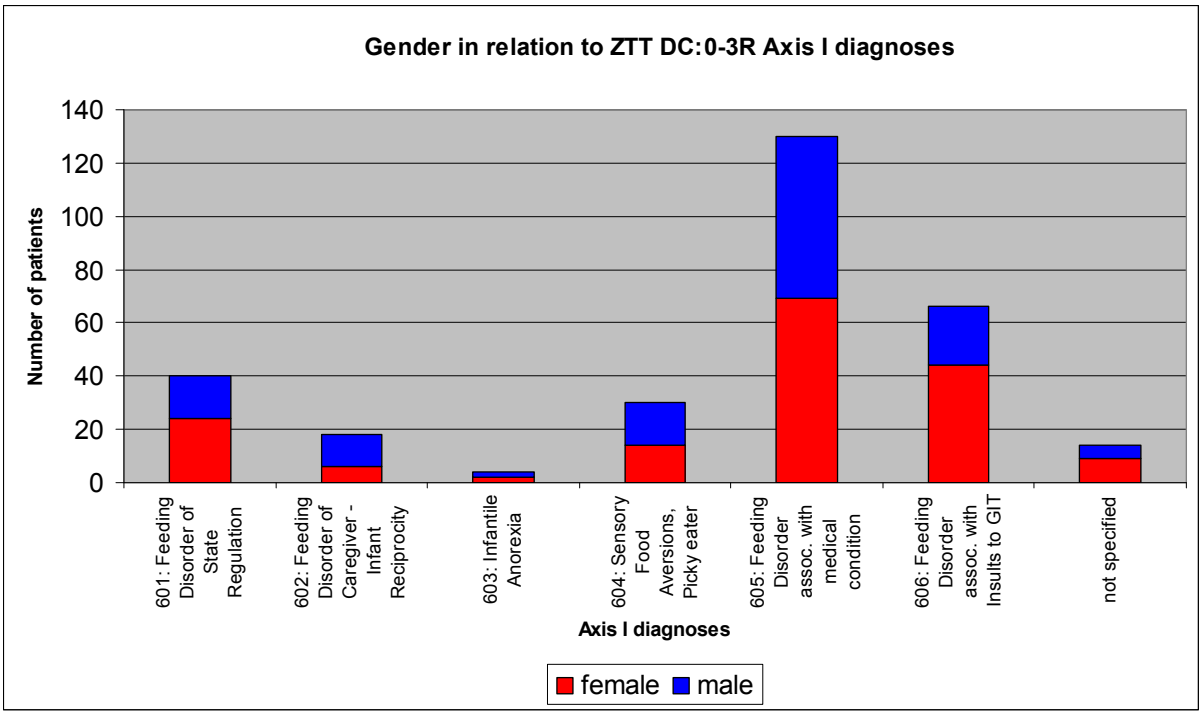


Figure 28. Gender in relation to ZTT DC:0-3R Axis I diagnoses.

3.2 Questionnaire

As pilot of this study, a questionnaire was developed with the aim of investigating the parents' perspective of the specific eating problems of their child. Since such a questionnaire does not exist in literature, we suggest accepting this chapter as experimental part without scientific significance.

The answers of the 19 questionnaires included in this study were evaluated with the ARCHIMED-program.

Fig. 29 illustrates the age distribution of the questionnaire population of 19 children. The main part (68.42%) was aged between 1.5 and 4 years. The age of 2 children, 10.49 years and 9.85 years, topped the age of the other children for several years.

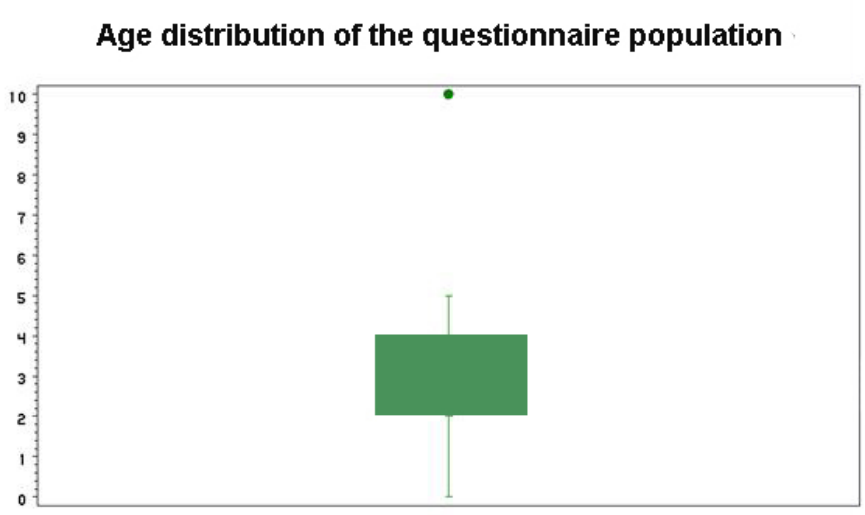


Figure 29. Age distribution of the questionnaire population.

In question no. 1, the parents were asked if they would call their child's problem an eating disorder. This question was answered with yes by 14 parents (73.68%). 4 parents (21.05%) answered with no and 1 person (5.26%) did not answer this question.

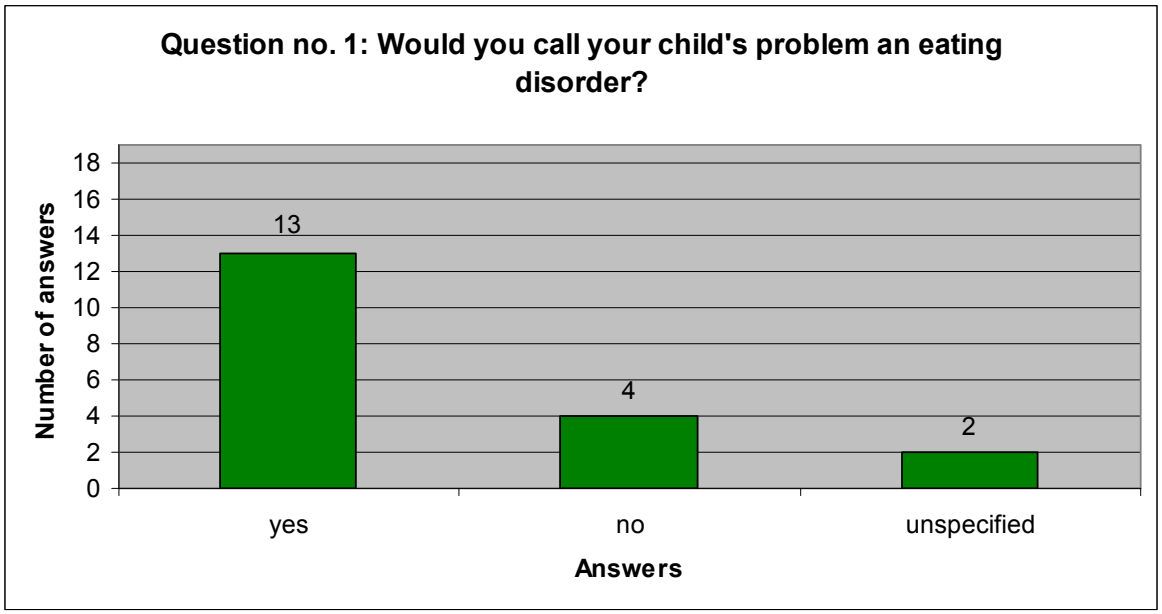


Figure 30. Question no. 1. Would you call your child's problem an eating disorder?

Question no. 2 consisted of two parts and referred to question no. 1. It was only to consider by parents who answered question no. 1 in the affirmative. In the first part, we wanted to evaluate when the questionable eating disorder was diagnosed. The parents were asked to fill in the date of diagnosis as accurately as possible. In order to gain standardised data we wanted them to notify the month and year. With a statistical inaccuracy of 2 weeks, the children's age at the time of diagnosis ranged between right after birth and 71 weeks.

The second part of question no. 2 asked about the person who diagnosed the eating disorder. Here, 3 parents (15.79%) pointed out that a neonatologist had diagnosed their child's disorder, while 6 (31.58%) stated the paediatrician, 5 (26.32%) declared other persons and further 5 parents (26.32%) did not answer this part of the question.

In the category "other", the parents could decide on their own who to name. The following 5 answers were given: gastroenterologist, speech therapist, cardiologist, surgeon and hepatologist.

Amongst the 5 parents who did not give us any information to the second part of question no. 2, we could evaluate 3 parents who had answered question no. 1 with no and therefore did not answer question no. 2 at all.

We also found 1 case, in which the parents negated question no. 1, but answered question no. 2, part 2 with "paediatrician".

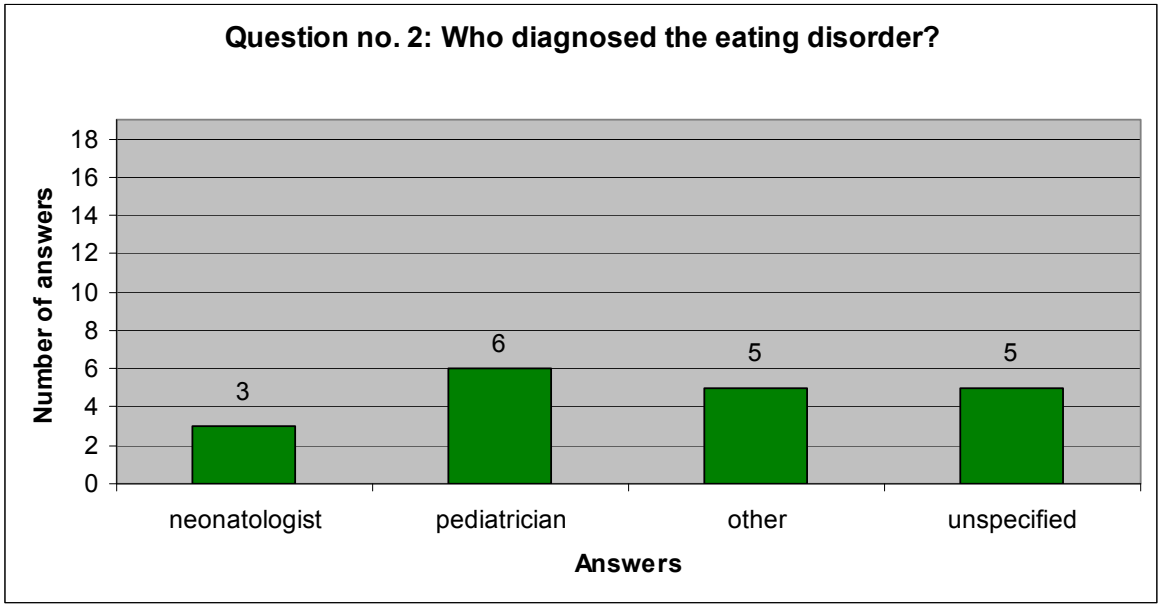


Figure 31. Question no. 2. Who diagnosed the eating disorder?

Furthermore, we asked the parents "Were you informed about the placement of the tube before it was placed?" (question no. 3). The answers are illustrated in Fig. 32. This question was answered in all 19 questionnaires; 17 parents (89.47%) replied that they were informed about the tube placement, while 2 parents (10.53%) declared that they were not informed.

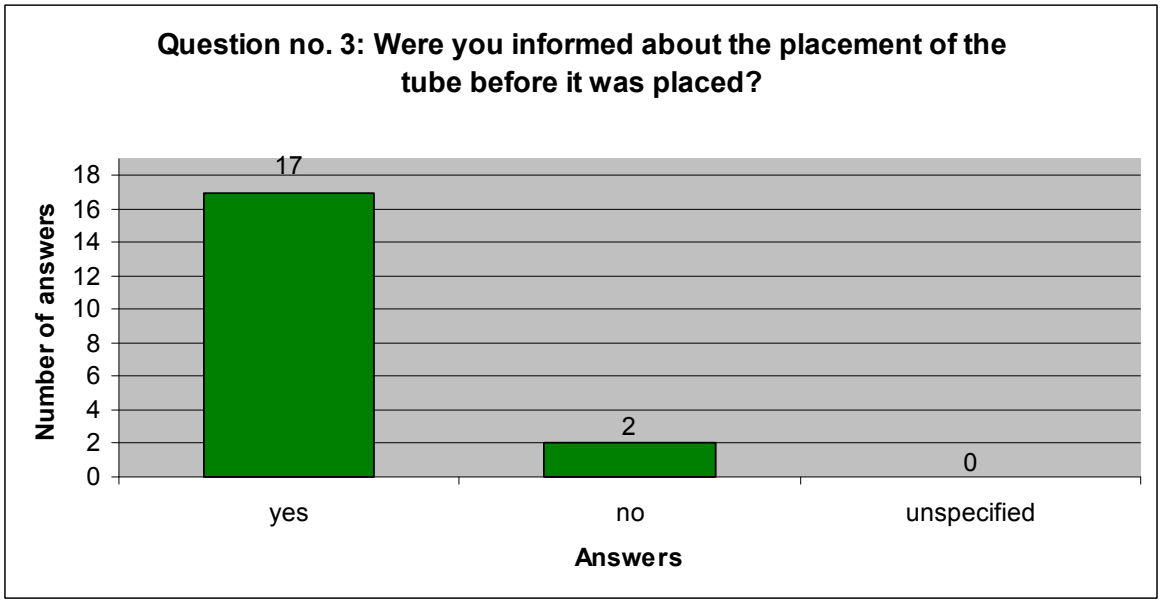


Figure 32. Question no. 3. Were you informed about the placement of the tube before it was placed?

In question no. 4 we collected data concerning the question if the parents were asked for consent regarding tube implantation. We didn't have any unspecified answers in this question. 17 parents (89.47%) were asked for consent, while 2 (10.53%) negated this question.

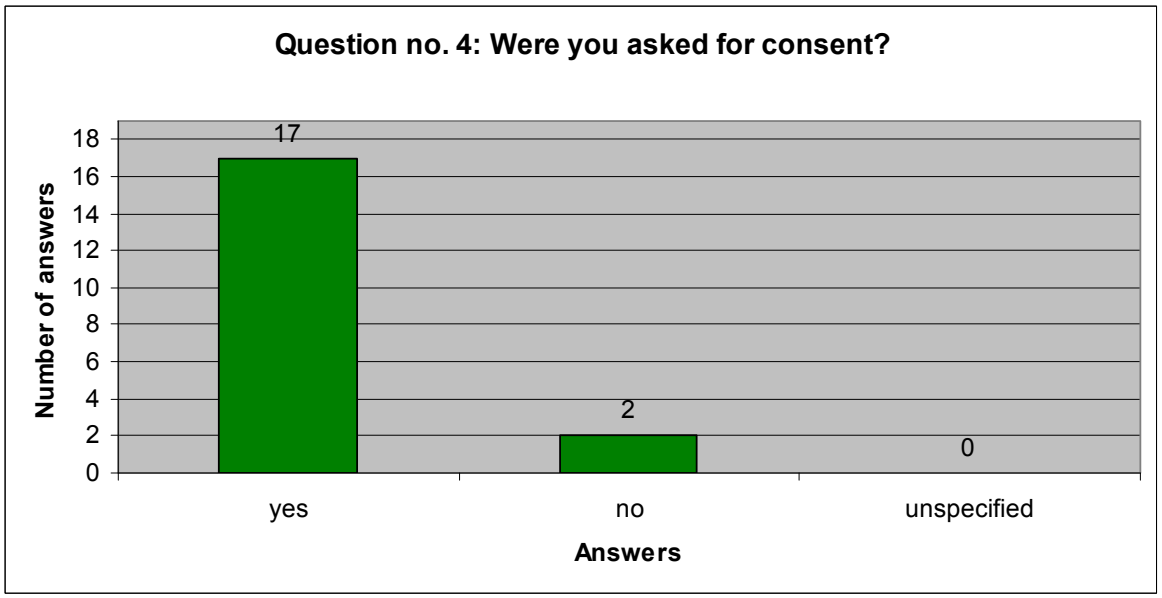


Figure 33. Question no. 4. Were you asked for consent?

Question no. 5 dealt with the problem if the parents were "talked into" accepting a feeding tube. In Fig. 34 the following result is visualized: 6 parents (31.58%) answered this question with yes, while 13 caregivers (68.42%) did not feel pressed to accept the tube.

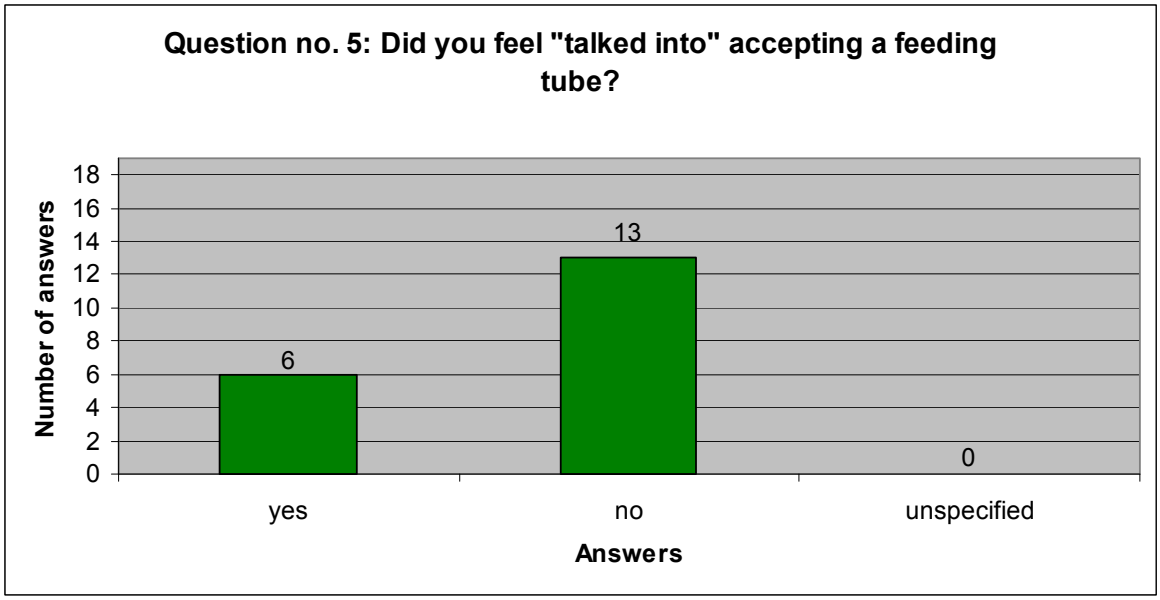


Figure 34. Question no. 5. Did you feel "talked into" accepting a feeding tube?

We wanted to assess if the parents were informed about the possibility of the development of a tube dependency in question no. 6. In the evaluation, it is identifiable that 8 parents (42.11%) had been informed about a possible tube dependency. By contrast, 10 parents (52.63%) did not receive any information about the possibility of the development of a tube dependency before the tube was implanted. The evaluation showed only 1 (5.26%) unspecified answer to this question.

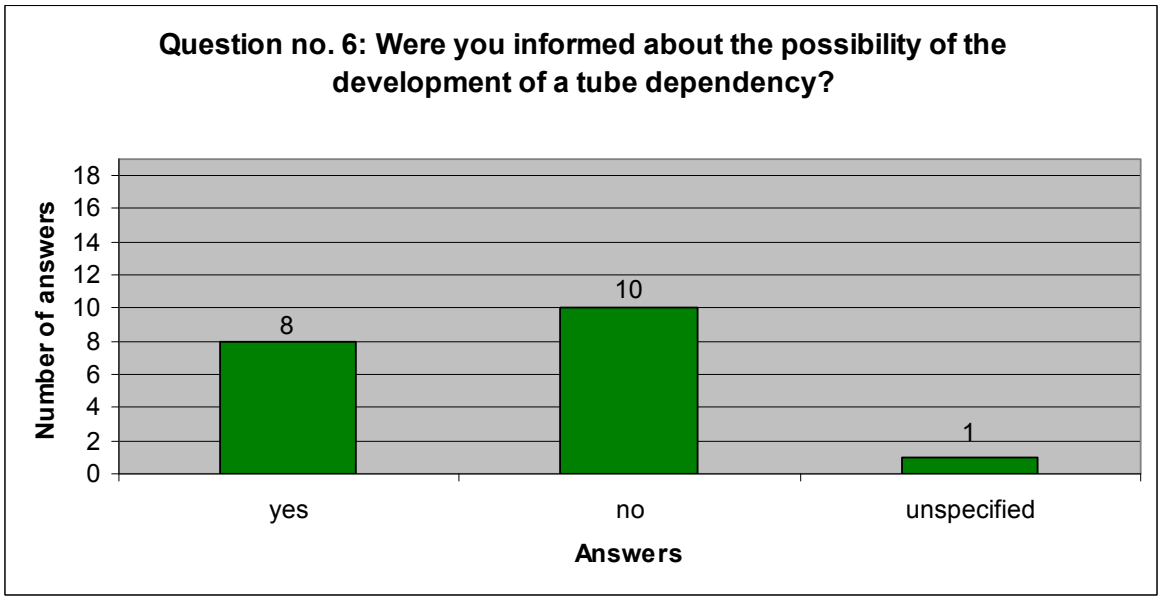


Figure 35. Question no. 6. Were you informed about the possibility of the development of a tube dependency?

The next question (no. 7) asked for how long the parents think that the tube had been a good and effective intervention. The parents were asked to fill in the appropriate number of

months. Here, 2 questionnaires did not include any answer to this question. Concerning the remaining 17 questionnaires, the minimum months of a tube being regarded as a good intervention was 0, while the maximum was stated with 138 months.

In the last question (no. 8), we evaluated the parent's opinion about the period of time they felt that the tube was not fulfilling its goal any longer. The answers were given as number of months. 8 out of 19 parents (42.11%) did not answer this question at all, while 11 parents (57.89%) gave wide-spread answers. The stated range of months in which the tube was esteemed as not fulfilling its goal reached from 0 to 24 months.

4 Discussion

Classification systems

In the analysis of our study population we found out that a reduction of the 21 chapters of ICD-10 to 12 main diagnostic groups results in higher benefits for our special population. The 12 main diagnostic groups are more suitable, because the most frequent diagnoses in our population can be summed up more logically in 12 instead of 21 groups.

The study revealed that ICD-10 as the worldwide largest and most used classification system does not have any specific diagnoses for the large range of eating behaviour disorders in infancy and early childhood on the one hand nor for tube dependency on the other hand, a problem which is well-known by paediatricians. This situation shows to have more than one negative implications for the affected children. Firstly, eating behaviour disorders and tube dependency are not perceived as problems. Secondly, parents are incorrectly seen as barraters. Thirdly, children with eating behaviour disorders or tube dependency do not receive any therapy. Currently, the only possibility to code this diagnosis is to use F98.2. This possibility is very unsatisfying and in fact incorrect since the definition of F98.2 (see chapter 1.3.2.3) does neither include tube feeding in general nor tube dependency in particular. Furthermore, the definition determines the absence of organic disease. In our study population – which represents the largest number of tube dependent children in the world – the case of a tube dependent child without any organic disease did not occur at all. Based on the analysis of our sample, we strongly recommend adding a new diagnosis to the main group F89 *Unspecified disorder of psychological development*, which would justify the specific disease of tube dependency in childhood. We expect that the inclusion of such a diagnosis in ICD-10, which nowadays is severely underestimated in the world of medicine, would increase the awareness and sensitivity of clinicians to this special population of children and their tube related problems to a great extent.

Due to the insufficient classification of tube dependency in ICD-10, we are glad being able to revert to ZTT DC:0-3R. The Psychosomatic Unit Graz has used this system since the early 1990s, since the two leading paediatricians of this unit, MD Scheer and MD Dunitz-Scheer, were the only paediatric European task force members of the NCCIP (National Center for Clinical Infant Programs), which developed the ZTT DC:0-3 in 1987. The first edition of this classification system contained only one code for eating behaviour disorders

in childhood. In the revised edition of 2005, six sub-classifications of these disorders were included, based on the work of Irene Chatoor, one of the worldwide leading specialists in the diagnosis of eating behaviour disorders in early childhood. The six subgroups 601 to 606 are very helpful to describe the patients' diagnoses better and to open new doors to specific intervention. But even these subgroups are not ideal for the special population of tube dependent children, which we analysed in this paper. Due to the multimorbidity and certain complex syndromes of our patients, an explicit classification was very difficult and often not satisfying; compromises had to be found to classify these patients as good as possible. The same problem appeared in the group of premature children, whose tube dependency was an unintended side effect of the necessary high tech medicine, which made survival possible. Out of these reasons, we suggest the implementation of a seventh subgroup, 607. "Acquired Tube Dependency" as well as the option of enabling to classify co-morbidities. A child admitted specifically for tube weaning would be able to be on the one hand classified as 607. Acquired Tube Dependency, and on the other hand, it might be useful to also classify the child according to the six existing groups of ZTT DC:0-3R Axis I diagnoses.

Summing up our conclusions about diagnostic classification of tube dependent children, we came to the result, that only a detailed classification of an eating or feeding behaviour disorder can lead to an increased sensibility amongst clinicians and therefore allows a better prevention of this condition. Additionally, any differentiated diagnoses will again lead to a more specified and individual therapy specific to each patient's problems. We hope to make a contribution to a therapy according to State of the Art in the field of preventing long-term harm in tube-fed children.

Parents of tube dependent children

It is important for us to bring up a few statements about the parents of tube dependent children. They are often regarded as being difficult personalities or even hysterical and not taken seriously when they search for help for their tube dependent child. Many clinicians do not know about the problems of tube dependency or think that the parents invent a problem. So the caregivers often even get the feedback that they are mentally ill and responsible for their child's eating problems. In reality, the parents are mostly deeply frustrated and desperate, but generally not mentally ill. Tube dependency is devastating for the parents and the longer the child is depending on tube feeding the worse the situation gets. Additionally, the whole family life is restricted due to the tube dependency; they

avoid social contacts because they fear further discrimination, especially with the NGT. Furthermore, the parents live in permanent anxiety for their child and become oversensitive to smallest happenings. The main problem for the affected family is often that they are left alone with their tube-fed child. In the beginning, they appreciate that their child is fed by tube to be sufficiently nourished. The problem begins, when they leave hospital with a tube-fed child and no further aftercare is offered. They are often left on their own with no contact person for any tube related questions, because the support of parents with a tube dependent child is often not seen as important. This fact is also discussed in "Prevention and Treatment of Tube Dependency in Infancy and Early Childhood" by Dunitz-Scheer et al. in ICAN, 2009.

The group of patients who was impossible to wean consists of severely ill children, who in fact do not fulfil the inclusion criteria for taking part in the Graz Model tube weaning program, since safe swallowing is not possible, a high risk of aspiration is present or tube weaning would lead to a reduction of the child's life quality. The parents of these children are desperate and hope for a medical wonder when they come to Graz. It is hard to convey to the parents that in some cases weaning is not possible and that their children will have to be tube-fed their whole live, but it is important to accept the medical limitations.

Multimorbidity

The expectation that in ZTT DC:0-3R Axis I the diagnosis 605. Feeding Disorder of Medical Condition associated with Concurrent Medical Condition would be most frequent, proved true. This frequency is due to the fact that most children in our sample suffered from severe diseases. Besides, the main part of our study population was affected with multiple diseases and multiple co-morbidities, which as a whole influence the child's ability to eat and drink.

Questionnaire

The analysis of the questionnaire as the experimental part is to be seen as a survey of the opinion of 19 parents with tube dependent children. It is alarming that more than half of the parents had not been informed about the possibility of the development of a tube dependency. In our opinion, this missing information can be attributed to either the above named fact of ignorance of tube dependency amongst clinicians or to the fact that the parents' education is not seen as important and/or unorganised. Since long-term tube feeding can cause severe side-effects as far as an increased mortality, this issue is crucial.

Another fact which is worrying is that one third of the parents felt talked into accepting a feeding tube for their child. In our opinion it is essential to take the time to speak very calmly with parents about their child's medical condition and the reasons why he/she needs the tube. In two cases, the parents had not been asked for consent before the tube was implanted, which must be considered as inacceptable. From an ethical and human perspective, this should not happen these days. Additionally, such an act is legally not correct, since today's medicine bases on informed consent which means that the last decision is made by the parents.

Literature

Due to the small number of publications about the topics of eating behaviour disorders, tube dependency and tube weaning, we want to refer to the following papers: (i) Chatoor I. Feeding and other disorders in infancy. In: Tasman A, Kay J, Lieberman J (eds). Psychiatry. Philadelphia: WB Saunders; 1997. pp. 683-701, (ii) Chatoor I, Egan J. Non organic failure to thrive and dwarfism due to food refusal. A separation disorder. J Am Acad Child Adolesc Psychiatr 1983; 22: 294-301. and (iii) Benoit D, Wand EE, Zlotkin SH. Discontinuation of enterostomy tube feeding by behavioural treatment in early childhood: a randomized controlled trial. J Pediatr 2000; 137: 498-503.

5 References

(1) Krasnovsky A. Qualitative Therapieevaluation nach erfolgter Sondenentwöhnung bei frühkindlichen Ess- und Fütterungsstörungen. 2004.

(2) Fresenius Kabi AG. Wie alles begann. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Wie+alles+begann. Accessed 08.03., 2009.

(3) Dunitz-Scheer M, Hauer A, Wilken M, Krasnovsky A, Lassnig A, Pöcherstorfer H, et al. "Essen oder nicht Essen, das ist hier die Frage". Pädiatrie und Pädologie 2004(6):1-11.

(4) Fresenius Kabi AG. Sondensysteme. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Sondensysteme. Accessed 08.03., 2009.

(5) Fresenius Kabi AG. Transnasale Sonden. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Transnasale+Sonden. Accessed 08.03., 2009.

(6) Dunitz-Scheer M, Levine A, Roth Y, Kratky E, Beckenbach H. Prevention and Treatment of Tube Dependency in Infancy and Early Childhood. ICAN 2009;1(2):73-82.

(7) Dunitz-Scheer M. [Discussion of the diploma thesis *Comparative analysis of ICD-10 and ZTT DC0-3R diagnoses in a large international population of tube-dependent infants referred for tube weaning*]. 2009.

(8) Kenny T, Kenny B. Enteral Feeding. 2009; Available at: http://www.patient.co.uk/showdoc/40000482/. Accessed 08.03., 2009.

(9) Fresenius Kabi AG. Abmessen der Sondenlänge. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Abmessen+der+Sondenl%C3%A4nge. Accessed 08.03., 2009.

(10) Fresenius Kabi AG. Das Anlegen und Platzieren der transnasalen Sonde - nasogastral. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Das+Anlegen+und+Plazieren+der+transnasalen+Sonde+-+nasogastral. Accessed 08.03., 2009.

(11) Fresenius Kabi AG. Das Anlegen und Platzieren der transnasalen Sonde - nasojejunal. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Das+Anlegen+und+Plazieren+der+transnasalen+Sonde+-+nasojenunal. Accessed 08.03., 2009.

(12) Fresenius Kabi AG. Fixieren der Sonde. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Fixieren+der+Sonde. Accessed 08.03., 2009.

(13) Fresenius Kabi AG. Endoskopische Anlage nach der Fadendurchzugsmethode. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Endoskopische+Anlage+nach+der+Fadendurchzugsmethode. Accessed 08.03., 2009.

(14) Texas Pediatric Surgical Associates. Tube feeding for children. 2007; Available at: http://www.pedisurg.com/PtEduc/Tube_Feeding.htm. Accessed 08.03., 2009.

(15) Kenny T, Kenny B. Nasogastric (Ryles) Tubes
. 2009; Available at: http://www.patient.co.uk/showdoc/40000186/. Accessed 08.03., 2009.

(16) Suter PM. Checkliste Ernährung. 3. ed. Stuttgart/New York: Georg Thieme Verlag; 2008.

(17) Fresenius Kabi AG. Hochmolekulare Standarddiäten. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Hochmolekulare+Standarddi%C3%A4ten. Accessed 08.03., 2009.

(18) Fresenius Kabi AG. Stoffwechseladaptierte Spezialdiäten. 2008; Available at: http://www.enterale-ernaehrung.de/internet/kabi/enteral/entern.nsf/Content/Stoffwechseladaptierte+Spezialdi%C3%A4ten. Accessed 08.03., 2009.

(19) Dunitz-Scheer M, Wilken M, Walch G, Schein A, Scheer P. Wie kommen wir von der Sonde los?! Kinderkrankenschwester 2000;19(11):448-456.

(20) Wilken M. Warum willst du denn nicht essen? Krümelchen 2003:18-21.

(21) American Gastroenterological Association. Guidelines for the Use of Enteral Nutrition. Gastroenterology 1995(108):1280-1281.

(22) Trabi T, Dunitz-Scheer M, Tappauf M, Burmucic K, Kratky E, Scheer P. Inpatient tube weaning in children with long term feeding tube dependency: Restrospective analysis of 221 patients. JIMH in press (2009).

(23) Wilken M, Jotzo M. Sondenentwöhnung bei Kindern. Heilberufe 2004:38-39.

(24) Wilken M. Kann es auch ohne gehen? Praxis und Evaluation der ambulanten Sondenentwöhnung. In: Teeffelen A, Jacobs P, editors. Ernährung auf eine andere Art - Behandlungskonzepte bei gestörter Nahrungsaufnahme Heilbronn: SPS Verlagsgesellschaft; 2006. p. 65-104.

(25) Dunitz-Scheer M, Wilken M, Lamm B, Scheitenberger S, Stadler B, Schein A, et al. Sondenentwöhnung in der frühen Kindheit. Monatsschrift Kinderheilkunde 2001;149:1348-1359.

(26) Dunitz-Scheer M, Scheer P, Trojovsky A, Kaschnitz W, Kvas E, Macari S. Changes in psychopathology of parents of NOFT (non-organic failure to thrive) infants during treatment. ECAP 1996;5(2):93-100.

(27) Remschmidt H. Psychiatrie in der Adoleszenz. Stuttgart/New York: Georg Thieme Verlag; 1992.

(28) Chatoor I. Feeding disorders in infants and toddlers: diagnosis and treatment. Child and Adolescent Psychiatric Clinics of North America 2002;11(2):163-183.

(29) Paulitsch K. Praxis der ICD-10-Diagnostik. Wien: Facultas; 2004.

(30) Herpertz-Dahlmann B, Resch F, Schulte-Markwort M, Warnke A. Entwicklungspsychiatrische Grundlagen von Diagnostik, Klassifikation, Therapie und Ethik. In: Herpertz-Dahlmann B, Resch F, Schulte-Markwort M, Warnke A, editors. Entwicklungspsychiatrie. 2. ed. Stuttgart, New York: Schattauer; 2008. p. 331-351.

(31) Walter de Gruyter GmbH & Co. KG editor. Pschyrembel Sozialmedizin. 1. ed. Berlin/New York: de Gruyter; 2008.

(32) Deutsches Institut für Medizinische Dokumentation und Information. Klassifikationen, Nomenklaturen und Thesauri. 2009; Available at: http://www.dimdi.de/static/de/klassi/basisinfo-klassi.pdf. Accessed 07.04., 2009.

(33) World Health Organization (WHO). Revision of the International Classification of Diseases (ICD). 2009; Available at: http://www.who.int/classifications/icd/ICDRevision/en/index.html. Accessed 05.05., 2009.

(34) World Health Organization (WHO). International Classification of Diseases (ICD). 2009; Available at: http://www.who.int/classifications/icd/en/. Accessed 07.04., 2009.

(35) World Health Organization (WHO). History of the development of the ICD. 2009; Available at: http://www.who.int/classifications/icd/en/HistoryOfICD.pdf. Accessed 06.04., 2009.

(36) Schopen M. Die Einführung der International Classification of Diseases (ICD-10) in Deutschland. Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz 1999;42:827-833.

(37) World Health Organization (WHO). Revision of the International Classification of Diseases (ICD). 2009; Available at: http://www.who.int/classifications/icd/ICDRevision/en/index.html. Accessed 07.04., 2009.

(38) Deutsches Institut für Medizinische Dokumentation und Information. Familie der internationalen gesundheitsrelevanten Klassifikationen. 2009; Available at: http://www.dimdi.de/static/de/klassi/diagnosen/icd10/familie.htm. Accessed 07.04., 2009.

(39) World Health Organization (WHO). ICD Version 2007. 2006; Available at: http://apps.who.int/classifications/apps/icd/icd10online/. Accessed 05.05., 2009.

(40) ZERO TO THREE. Diagnostic classification of mental health and developmental disorders of infancy and early childhood: Revised edition (DC:0-3R). Washington, DC: ZERO TO THREE Press; 2005.

(41) Melmed M, Lieberman A. About us. 2009; Available at: http://www.zerotothree.org/site/PageServer?pagename=abt_aboutus. Accessed 20.04, 2009.

(42) Dorda W, Wrba T, Duftschmid G, Sachs P, Gall W, Rehnelt C, et al. Archimed: A Medical Information and Retrievel System. Meth. Inform. Med. 1999;38:16-24.

(43) Bachmaier G. [Discussion of the diploma thesis *Comparative analysis of ICD-10 and ZTT DC0-3R diagnoses in a large international population of tube-dependent infants referred for tube weaning*]. 2009.

(44) ID - Information und Dokumentation im Gesundheitswesen GmbH. Simply coding clinical services correctly. 2008; Available at: http://www.id-berlin.de/engl/_2produkte/diacos.php?sid. Accessed 09.06., 2009.

(45) Deutsches Institut für Medizinische Dokumentation und Information. ICF - Internationale Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit. 2008; Available at: http://www.dimdi.de/static/de/klassi/icf/index.htm. Accessed 18.06., 2009.

Appendix

Forschungsfragebogen zur Sondenentwöhnung

Abteilung Psychosomatik, Department für Allgemeine Pädiatrie

Universitätsklinik für Kinder- Jugendheilkunde, A - 8036 Graz

Fragebogen (bitte die nicht zutreffenden Antworten löschen) – bitte an elisabeth.thierrichter@medunigraz.at schicken!

1.) Würden Sie sagen, dass Ihr Kind an einer Essstörung leidet? ja/nein

2.) Falls ja, wann wurde die Essstörung diagnostiziert? ……. (Monat/Jahr)

Wer diagnostizierte die Essstörung? - Hausarzt
- Kinderarzt
- Neonatologe
- Physiotherapeut
- Ergotherapeut
- jemand anderes – falls ja, wer?

3.) Bekamen Sie Informationen, bevor Ihrem Kind eine Sonde gesetzt wurde? ja/nein

4.) Wurde Ihr Einverständnis eingeholt? ja/nein

5.) Hatten Sie das Gefühl überredet zu werden, die Sonde zu akzeptieren? ja/nein

6.) Wurden Sie über die Möglichkeit informiert, dass Ihr Kind eine Sondenabhängigkeit entwickeln könnte? ja/nein

7.) Wie lange war die Sonde eine gute und sinnvolle Intervention/Möglichkeit, Ihr Kind zu ernähren? …. (Anzahl der Monate)

8.) Seit wann haben Sie das Gefühl, dass die Sonde ihre Aufgabe nicht mehr erfüllt? …. (Anzahl der Monate)

Tube-questionnaire

Department of Paediatric Psychosomatics

University Children's Hospital, 8036 Graz

Questionnaire (please erase the answers which are not appropriate) – please return to elisabeth.thierrichter@stud.meduni-graz.at

1.) Would you call your child's problem an eating disorder? yes/no

2.) If so, when was it diagnosed? ..... (month/year)

By whom?
- general practitioner
- pediatrician
- neonatologist
- physiotherapist
- occupational therapist
- other - if another person - who?

3.) Were you informed about the placement of the tube before it was placed? yes/no

4.) Were you asked for consent? yes/no

5.) Did you feel "talked into" accepting a feeding tube? yes/no

6.) Were you informed about the possibility of the development of a tube dependency? yes/no

7.) For how many months has the tube been a good and effective intervention? …(number of months)

8.) For how many months do you feel it is not fulfilling? …(number of months)

Photo 33. Paula and her mother with a part of the tube weaning team. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Photo 44. Paula eating chocolate. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Photo 15. Paula making friends with Sarah. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

Photo 26. Marc having fun at the play picnic. Taken from the archive of the Psychosomatic Unit of the Children's Hospital Graz, Austria, © J. Deutsch; with friendly permission of the child's parents

CURRICULUM VITAE

Lisa del Negro

Persönliche Daten

Geburtstag: 01.03.1985

Geburtsort: Graz, Österreich

Schulische und universitäre Ausbildung

09/2008	2. Diplomprüfung
07/2004	1. Diplomprüfung
10/2003	Beginn des Diplomstudiums Humanmedizin an der Medizinischen Universität Graz
06/2003	Matura am Bundesgymnasium und Bundesrealgymnasium Carnerigasse, Graz

Famulaturen

06/2008	Abteilung für Innere Medizin, Krankenhaus der Elisabethinen, Graz, 4 Wochen
08/2007	Abteilung für Allgemeine Pädiatrie, Univ.-Klinik für Kinder- und Jugendheilkunde, LKH Graz, 2 Wochen
	Abteilung für Allgemeine Pädiatrie, Kinderpsychosomatik, Univ.-Klinik für Kinder- und Jugendheilkunde, LKH Graz, 2 Wochen
07/2006	Abteilung für Innere Medizin, Krankenhaus der Elisabethinen, Graz, 4 Wochen
07/2005	Abteilung für Innere Medizin, Krankenhaus der Elisabethinen, Graz, 4 Wochen

Praktisches Jahr

10/2008	Abteilung für Onkologie, universitäre palliativmedizinische Einrichtung, Univ.-Klinik für Innere Medizin, LKH Graz, 10 Wochen
12/2008	Univ.-Klinik für Dermatologie und Venerologie, LKH Graz, 5 Wochen
03/2009	Allgemeinmedizin bei Dr. M. Laure, Bruck/Mur, 5 Wochen
04/2009	Abteilung für Chirurgie, LKH Leoben, 10 Wochen

CURRICULUM VITAE

Elisabeth Thierrichter

Persönliche Daten

Geburtstag: 14.01.1985

Geburtsort: Graz, Österreich

Schulische und universitäre Ausbildung

02/2009	2. Diplomprüfung
2007/08	1-jähriger Erasmus-Studienaufenthalt in Trondheim, Norwegen
07/2004	1. Diplomprüfung
10/2003	Beginn des Diplomstudiums Humanmedizin an der Medizinischen Universität Graz
06/2003	Matura am Bundesgymnasium und Bundesrealgymnasium Carnerigasse, Graz

Famulaturen

08/2007	Abteilung für Gynäkologie und Geburtshilfe / St. Olavs Hospital, Trondheim (Norwegen), 6 Wochen
04/2007	Abteilung für Allgemeine Pädiatrie / Univ.-Klinik für Kinder- und Jugendheilkunde, LKH Graz, 2 Wochen
09/2006	Abteilung für Innere Medizin / Krankenhaus der Elisabethinen, Graz, 4 Wochen
07/2005	Abteilung für Innere Medizin / Krankenhaus der Elisabethinen, Graz, 4 Wochen

Praktisches Jahr

03/2009	Abteilung für Pädiatrie, LKH Leoben, 5 Wochen
04/2009	Abteilung für Chirurgie, LKH Leoben, 10 Wochen
10/2009	Allgemeinmedizin, 5 Wochen
11/2009	Abteilung für Innere Medizin, Klinik Friedrichshafen, akademisches Lehrkrankenhaus der Universität Tübingen, 10 Wochen