



Universitätsklinikum
Hamburg-Eppendorf



Hamburg University of Applied Sciences
Department Life Sciences
Course of Study Health Sciences

Bachelor Thesis

Esophageal Atresia – Quality of Life in children, adolescents and their families

– The EA-QoL Study –

Pilot testing of a condition-specific Health related Quality of Life instrument

Name: Charline Jedro

ID number: 2158145

First Adviser: Prof. Dr. Christine Adis (Hamburg University of Applied Sciences)

Second Adviser: Dr. Rachel Sommer, MPH (University Medical Center Hamburg-Eppendorf)

Date: 23rd August 2016

Acknowledgments

I wish to record my gratitude to those, who made it possible to create this Bachelor's thesis. I owe sincere acknowledgment to the Health related Quality of Life working group at the University Medical Centre Hamburg-Eppendorf that conducted the EA-QoL study in cooperation with scientists from the Queen Silvia Children's Hospital in Gothenburg and provided their data for this Bachelor's thesis. Further, I also show appreciation to the Medical School Hanover for recruiting children and adolescents with esophageal atresia as well as their parents. In addition, I want to address special thanks to the participants for being open-minded in sharing their experiences about living with a chronic health condition.

I also wish to extend special thanks to Dr. Rachel Sommer and Prof. Dr. Christine Adis for their advice and constantly support in creating this Bachelor's thesis.

Table of Contents

List of Figures	IV
List of Tables.....	IV
List of Abbreviations	IV
Zusammenfassung	V
Abstract.....	VII
1. Introduction.....	1
2. Theoretical Background	2
2.1 Health related Quality of Life (HrQoL).....	3
2.1.1 The concept of QoL and HrQoL.....	3
2.1.2 HrQoL in children and adolescents with a chronic disease	4
2.1.3 Instruments to measure HrQoL in children and adolescents	5
2.2 Esophageal atresia.....	7
2.2.1 Facts on esophageal atresia	7
2.2.2 Classification and Detection	8
2.3 Impact of EA among children and adolescents on their HrQoL.....	12
2.4 Development of the EA-QoL questionnaire.....	13
2.4.1 Aims of the project.....	13
2.4.2 Research group	13
3. Methods.....	14
3.1 Description of post project phases	14
3.1.1 The Swedish EA-QoL study.....	14
3.1.2 The German EA-QoL study.....	15
3.2 Study design.....	15
3.3 Sample recruitment.....	17
3.4 Analysis	17
3.4.1 Descriptive analysis on item level	17
3.4.2 Non parametric test (Mann-Whitney-U Test).....	18
3.4.3 Cognitive Debriefing on item level	18
4. Results.....	19
4.1 Sample description	19
4.2 Descriptive analysis on item level.....	20
4.3 Non parametric test (Mann-Whitney-U test)	23
4.4. Cognitive debriefing on item level	25
4.5 Item selection	27
5. Discussion.....	34
6. Conclusion and outlook	40
References	42
Eidesstattliche Erklärung.....	47
Appendix.....	48

List of Figures

Figure 1: Classification of EA after Vogt.....	8
Figure 2: Classification of non-syndromic MCA by organ system (n=21).....	11
Figure 3: Example of one item from EA questionnaire (translated into English)	16

List of Tables

Table 1: Sample description including gender and age	20
Table 2: Mann-Whitney-U test for parents of children aged 2-7	24
Table 3: Mann-Whitney-U test for parents of children/adolescents aged 8-17.....	24
Table 4: Mann-Whitney-U test for children/adolescents aged 8-17	25
Table 5: Item selection for parents of children aged 2-7	28
Table 6: Item selection for parents of children/adolescents aged 8-17	31
Table 7: Item selection for children/adolescents aged 8-17.....	34
Table 8: Results of parents of children aged 2-7	653
Table 9: Results of parents of children/adolescents aged 8-17	684
Table 10: Results of children/adolescents aged 8-17	707

List of Abbreviations

DISABKIDS	Condition specific module to measure HrQoL in children/adolescents
EA	Esophageal atresia
GER	Gastroesophageal reflux
GIQLI	Gastrointestinal Quality of Life Index
HrQoL	Health related Quality of Life
KEKS	German patient support group for children and adults with a disease of the esophagus
KIDSCREEN	HrQoL Questionnaire for Children and Young People
KIGGS	German Health Interview and Examination Survey for Children and Adolescents
PedsQL	Pediatric Quality of Life Inventory
SF-8	(Short Form)-8 Health Survey
TEF	Tracheoesophageal fistula
QoL	Quality of life
WHO	World Health Organization
WHO-5	WHO-Five Well-being Index

Zusammenfassung

Hintergrund: In den letzten Jahren gab es einen Paradigmenwechsel in der pädiatrischen Medizin, während früher primär die Behandlung infektiöser Erkrankungen im Zentrum stand, ist es heutzutage der Umgang mit chronischen Erkrankungen. Ein Beispiel hierfür ist Ösophagusatresie (ÖA), eine angeborene Anomalie, die zu einer Unterbrechung der Speiseröhre führt und statistisch gesehen 2,44 Kinder pro 10.000 Geburten betrifft. Bedingt durch mögliche chronische (Co-) Morbiditäten und zusätzliche Anomalien besteht ein individuelles Risiko für langfristige gesundheitliche Beeinträchtigungen, die die gesundheitsbezogene Lebensqualität (HrQoL) beeinflussen. Es gibt aktuell nur fünf Studien, die den Einfluss von ÖA auf die HrQoL im Kindes- und Jugendalter untersuchten, mit uneinheitlichen Ergebnissen. Keine dieser Studien hat jedoch einen krankheitsspezifischen Fragebogen zur Erfassung der HrQoL genutzt. Aus diesem Grund haben schwedische und deutsche Wissenschaftler/innen die EA-QoL Studie konstituiert, wodurch der erste ÖA spezifische Fragebogen für 2-17 Jährige entwickelt wurde. Das Erhebungsinstrument ist als Selbstbericht und Elternfragebogen in zwei Altersversionen verfügbar. Der Pilottest fand in Schweden und in Deutschland statt, um Items für die Feld- und Retest Version auszuwählen und diese weiter zu prüfen.

Methoden: In der deutschen EA-QoL Studie wurde der ÖA Fragebogen von Eltern von 2-7 Jährigen (30 Items), Eltern 8-17 Jährigen (50 Items) und von den 8-17 Jährigen (50 Items) selbst ausgefüllt. Alle Items wurden auf Item-Ebene analysiert, inklusive einer Analyse des kognitiv Debriefings und des Mann-Whitney-U Tests. Basierend auf speziell definierten Kriterien wurden Items für die Feld- und Retest Version selektiert.

Ergebnisse: In der deutschen EA-QoL Studie nahmen 32 Familien (10 Eltern von 2-7 Jährigen, 11 Eltern von 8-17 Jährigen, 11 Kinder/Jugendliche zwischen 8-17 Jahren) teil, die in acht Fokusgruppen den ÖA Fragebogen ausfüllten. Die Analyse der Daten hat ergeben, dass 24 Items in den Elternfragebogen für Kinder zwischen 2-7 Jahren und 42 Items in der Selbst- und Elternfragebogenversion für die 8-17 Jährigen inkludiert werden sollten.

Fazit: Basierend auf den deutschen und schwedischen Ergebnissen des Pilottests wird eine Feld- und Retest Version des ÖA Fragebogens für Eltern von 2-7 Jährigen sowie der Selbst- und Elternfragebogen für Kinder/Jugendliche zwischen 8-17 Jahren erstellt. Diese Versionen werden psychometrisch getestet, um so ein valides Instrument zu gewinnen, welches die HrQoL bei Kindern/Jugendlichen mit ÖA misst. Es kann dadurch die Bürde dieser Erkrankung besser verstanden werden, um darauf basierend Maßnahmen zu ent-

wickeln, die die Gesundheitsversorgung der Betroffenen optimieren und die HrQoL erhöhen.

Abstract

Background: In pediatric medicine, there has been a shift from treating infectious diseases to managing chronic health conditions. One rare chronic health condition is esophageal atresia (EA) which is a congenital anomaly that causes an interruption of the esophagus and affects 2.44 children per 10,000 births. Due to possible chronic (co-) morbidities and additional anomalies, patients with EA have individual risks for long-term health issues that affect their Health related Quality of Life (HrQoL). For children/adolescents with EA, only five studies assessed the influence of EA on HrQoL with incoherent results. However, none of them used a condition-specific instrument for the assessment of HrQoL. As a consequence, a German and Swedish expert panel developed the first EA specific questionnaire for children and adolescents between 2 and 17 years. The questionnaire is available as self- and parent proxy report version for two age-groups. A pilot testing of this instrument took place in Sweden and Germany in order to select items that should be included in the field- and retest version for further testing.

Methods: In the German EA-QoL study, the EA questionnaire was completed by parents of children between 2 and 7 years (30 items), parents of children between 8 and 17 years (50 items) and children/adolescents between 8 and 17 years (50 items). All items were analyzed on item level including a cognitive debriefing and Mann-Whitney-U test in order to select items for the field- and retest version based on specific criteria that have been defined by the expert panel.

Results: In the German EA-QoL study, 32 families (10 parents of 2-7 year-old children, 11 parents of 8-17 year-old children/adolescents, 11 children/adolescents between 8 and 17 years) participated in eight focus groups discussions and completed the EA pilot questionnaire. Based on the German results, 24 items will remain in the field- and retest version for parents of 2-7 year-old children whereas 42 items remain in the field- and retest version for children/adolescents' self- and proxy report.

Conclusions: Based on the German and Swedish results of the pilot testing, a field- and retest version of the EA questionnaire for parents of children aged 2-7, parents of children/adolescents aged 8-17 and children/adolescents aged 8-17 years will be developed to psychometric test this instrument that measures HrQoL in children and adolescents with EA. As a result, it is possible to learn more about the burden of this disease in order to develop strategies and optimize their health care and increase their HrQoL.

1. Introduction

„You were given this life because you're strong enough to live it”
(Amber Spencer, a mother of a son affected by EA (Spencer, 2014)).

Health is more than just the absence of a disease; it includes physical, mental and social well-being (World Health Organization, 1948). Due to this broad concept, it was possible to take the concepts Quality of Life (QoL) and Health related Quality of Life (HrQoL) into consideration while treating a patient (Bullinger & Quitmann, 2014, p. 137; World Health Organization, 1995, p. 1403f). Since medical advances delayed mortality and improved treatment options, there has been a shift towards measuring health outcomes to improve the QoL of a patient (National Center for Chronic Disease Prevention and Health Promotion, 2016). The specific measurements of HrQoL provide knowledge about the daily life of patients with various diseases and this information can be used to develop proper treatments that increase HrQoL of these patients (Kirch, 2008, p. 646).

In (pediatric) medicine, a shift from treating infectious health conditions to managing chronic diseases took place (Petersen et al., 2005, p. 1065). In Germany, 16% of children and adolescents between 0 and 17 years are diagnosed with a chronic health condition. As a result, the affected have to deal with psychological, physical and social consequences (Eiser & Morse, 2001, p. 5ff; Petersen et al., 2005, p. 1065). One example of a chronic disease is esophageal atresia (EA), which is a rare congenital anomaly that causes an interruption of the continuity of the esophagus (Nassar et al., 2012, p. 2; Spitz, 2007, p. 1). The total prevalence of EA is 2.44 children per 10,000 births (Nassar et al., 2012, p. 4). Patients with EA have an individual risk for long-term health issues, depending on the complexity, congenital malformations as well as the treatment progress. For that reason, the morbidity among survivors' remains frequent and complicated (Deutsche Gesellschaft für Kinderchirurgie, 2012, p. 9). It is a major task for medical research to assess consequences as well as effects of chronic diseases of children and adolescents in order to implement strategies to improve HrQoL (Eiser & Morse, 2001, p. 9ff; Petersen et al., 2005, p. 1065).

Until today, the number of studies that measure the HrQoL in children and adolescents with EA is limited (n=5), especially when it comes to a cross-culturally approach (Dellenmark-Blom et al., 2016, p. 563). Two studies showed that HrQoL of children and adolescents with EA is unimpaired or excellent (Dingemann et al., 2014, p. 631; Ludman & Spitz, 2003, p. 53), whereas three studies presented that the HrQoL is good but still lower compared to healthy references (Legrand et al., 2012, p. 808; Lepeyre et al., 2013, p. 1096; Peetsold et al., 2010, p. 417). However, none of these studies used a disease-

specific questionnaire to assess HrQoL in children and adolescents with EA (Dellenmark-Blom et al., 2015, p. 563). Disease-specific HrQoL instruments are important in order to provide a broader understanding of a particular condition that might not be captured by other generic instruments (Preedy & Watson, 2010, p. 4193). Therefore, a Swedish and German expert panel conducted the EA-QoL study including the first condition-specific questionnaire that measures the HrQoL in children and adolescents born with EA. With the help of this HrQoL questionnaire, the knowledge about HrQoL of patients with EA will increase by exploring it through the child's and parents' perspective (EA-QoL Group, 2015, p. 6).

This thesis is based on the EA-QoL study while focusing on the German pilot test of the new EA HrQoL questionnaire. The aim of the thesis is to make a recommendation which items should be included in the field- and retest version of this instrument from the German perspective. Since the EA HrQoL questionnaire is available for parents of children between 2 and 7 years, parents of children/adolescents aged 8-17 and children/adolescents between 8 and 17 years, an age-related recommendation for each target group will be provided.

Therefore, chapter two introduces the concepts of QoL and HrQoL followed by HrQoL in children and adolescents with a chronic disease and instruments to measure HrQoL. Further, EA will be explained including chronic morbidities and additional anomalies that can occur. Afterwards, the impact on EA among children and adolescents on their HrQoL will be analyzed with the help of five studies. At the end of this chapter, the development of the EA-QoL questionnaire will be presented.

The third chapter shows the methods that have been used in this thesis by firstly focusing on the study design and sample recruitment. Further, the analyzing process will be explained which includes the descriptive analysis on item level, non-parametric test (Mann-Whitney-U Test) and the cognitive debriefing on item level.

The fourth section of this thesis presents the results of the pilot test regarding the new EA questionnaire. Therefore, a sample description will be made followed by the results of the descriptive analysis on item level, non-parametric test (Mann-Whitney-U test), cognitive debriefing and item selection.

The fifth chapter discusses the results critically and the thesis finishes with a conclusion and outlook for the field- and retest.

2. Theoretical Background

The theoretical background provides information on the concept of Health related Quality of Life as well as on the rare condition esophageal atresia. This is followed by the impact of esophageal atresia among children and adolescents on their Health related Quality of Life and at the end of this paragraph, the development of the EA-QoL questionnaire from the Swedish and German perspective will be presented.

2.1 Health related Quality of Life (HrQoL)

The following paragraph focusses on the Health related Quality of Life. At the beginning, the concept of Quality of Life and Health related Quality of Life will be explained followed by transferring this concept to children and adolescents with a chronic condition and at the end, an overview on instruments to measure Health related Quality of Life will be provided.

2.1.1 The concept of QoL and HrQoL

The World Health Organization (WHO) included in their definition of health physical, mental (emotional and cognitive) and social well-being (World Health Organization, 1948). Due to this broad concept, it was possible to take the concepts of QoL and HrQoL into consideration while treating a patient (Bullinger & Quitmann, 2014, p. 137; World Health Organization, 1995, p. 1403f).

In Public Health, QoL is widely known and has not been defined consistently yet (Brown et al., 2014, p. 302). The WHO defines it as the “[...] *individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*”. Additionally, the following subdomains which affect QoL have been identified: “[...] *A person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment*” (World Health Organization, 1997, p. 1). A review by Oleson showed that the QoL construct has two main components namely “happiness and satisfaction” with the following subcomponents “[...] *physical and mental health socio-economic stability, fulfilling activities and ability to function, connections with other people, positive self-concept, and overall satisfaction*” (Brown et al., 2014, p. 302). Measurements of QoL are considerate to provide information with regard to the success of preventive strategies, health care delivery and treatment options for patients (Kirch, 2008, p. 1224f). HrQoL is defined as the subjective QoL that is related to a patient’s health (Preedy & Watson, 2010, p. 4222). It is a concept, which “[...] *refers to a person or group’s perceived physical and mental health over time*” (Kirch, 2008, p. 646). The specific measurements of HrQoL provide knowledge about a patient’s daily life with various diseases which are ei-

ther acute or chronic. With the help of HrQoL, a patient's condition can be assessed in order to focus on the functional effects of this particular disease and use this to develop a proper treatment for these patients (ibid). Instruments to assess HrQoL will be further explained in chapter 2.1.3.

2.1.2 HrQoL in children and adolescents with a chronic disease

Due to medical advancements, the focus of pediatric medicine has shifted from treating infectious health conditions to managing chronic diseases (Petersen et al., 2005, p. 1065). In Mokkink et al.'s review, a national consensus was held in order to define chronic health conditions in childhood, based on a systematic review and theoretical framework of determinants of health conditions. As a result, the following four criteria have been established: *"A disease or condition is considered to be a chronic condition in childhood if:*

(1) It occurs in children aged 0 up to 18 years

(2) The diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods or instruments according to professional standards

(3) It is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment

(4) It has been present for longer than three months or it will, very probably, last longer than

three months, or it has occurred three times or more during the past year and will probably reoccur" (Mokkink et al., 2008, p. 1441).

Since the prevalence of pediatric chronic diseases is increasing, a significant number of children and adolescents suffer from a chronic condition (Perrin, Shonkoff, 2000 as cited in Petersen et al., 2005, p.1065). In Germany, the German Health Interview and Examination Survey for Children and Adolescents (KIGGS) conducted a follow-up telephone interview between 2009 and 2012. The study included 12,368 participants. Parent reports showed that 16% of children and adolescents between 0 and 17 years have a chronic health condition. However, studies that have been conducted to evaluate the influence of a chronic condition on children/adolescents daily life show incoherent results. For instance, the KIGGS study found out that only one of five children/adolescents were affected in their daily life because of a chronic condition (Neuhauser & Poethko-Muller, 2014, p. 781). In contrast, Eiser and Morse as well as Petersen et al. revealed that children and adolescents in general have to deal with psychological, physical and social consequences due to the chronic condition (Eiser & Morse, 2001, p. 5ff; Petersen et al., 2005, p. 1065).

During the diagnosis, children, adolescents and their parents are confronted with acute stress which often turns into chronic stress (Compas et al., 2012, p. 457). For instance, chronic health conditions can have various effects on adolescents since this is a *"[...] time*

of rapid growth and physiological changes accompanied by important individuation and socialization process" (World Health Organization, 2007, p. V i). They may influence growth and puberty, psychosocial development and the course and management of the condition. While any long-term disease can have an impact on developmental processes, these processes can also influence the chronic condition. Depending on which chronic condition an adolescent suffers from and what kind of medications are necessary, puberty, growth and the maturation of all biological systems might be delayed (World Health Organization, 2007, p. 2ff). Moreover, the well-being can be determined largely, depending on the severity level and treatment procedures as well as by social and psychological complications that might result (Engstrom, 1999, p. 29ff; World Health Organization, 2007, p. 3). Another factor is that chronic diseases might have a significant impact on the school attendance of an adolescent as well as on his/her achievements (World Health Organization, 2007, p. 4). Further, parents of chronically ill children and adolescence have an increased burden due to managing it and they can also experience restrictions in their daily life (Cadman et al., 1991, p. 884ff; Eiser & Berrenberg, 1995, p. 109ff; World Health Organization, 2007, p. 5). Therefore, it is a major task for medical research to asses these consequences as well as the effects on HrQoL of children and adolescent for specific chronic conditions in order to implement strategies to improve HrQoL (Eiser & Morse, 2001, p. 9ff; Petersen et al., 2005, p. 1065).

2.1.3 Instruments to measure HrQoL in children and adolescents

With regard to outcome assessment, a shift from clinical indicators towards the patients' perception of the disease and its related treatment took place over the past years (Bullinger & Quitmann, 2014, p. 137). Since the prevalence of chronic diseases, which require adequate long-term treatment and care, increased, the development in the field of HrQoL assessments was constantly promoted (Schipper et al., 1996 as cited in Bullinger & Quitmann, 2014, p.137). Therefore, patient-reported outcomes (PROs) have been established including "[...] *the patient's perspective in epidemiological, clinical, health economics, and health services research* (Fayers & Machin, 2007; Patrick & Erickson, 1993 as cited in Bullinger & Quitmann, 2014, p.137). Nowadays, due to the research and advances that have been made with regard to QoL and HrQoL, they can be assessed with the help of specific tools. The inclusion of findings benefit research and practice worldwide since they mainly promote a patient's health status (Bullinger, 1991 as cited in Bullinger & Quitmann, 2014, p.138).

Instruments to measure HrQoL are either generic, chronic generic or disease-specific (Bullinger, 2014, p. 99; Patrick & Deyo, 1989). Generic HrQoL measurements are devel-

oped to assess information on healthy and ill children either within the population or in clinical practice. As a result, it is possible to compare healthy and ill children regarding various conditions and settings (Fayers & Machin, 2000 as cited in Solans et al., 2008, p.743). Chronic generic instruments measure experiences with chronic conditions in general, regardless of the particular diagnosis (Bullinger, 2014, p. 99; P.M. Fayers & Machin, 2007). In contrast, disease-specific instruments assess data on symptoms or health problems that are related to a specific disease and only in populations affected by this particular disease (Fayers & Machin, 2000 as cited in Solans et al., 2008, p.743). They are designed to estimate the function of an affected organ, symptoms that are related to the organ and its functional limitations as well as the resulting morbidity affecting the HrQoL of a patient. They have been developed in order to provide a broader understanding of a particular disease that makes it possible to conduct specific interventions which are needed by the affected and might not be captured by other generic instruments (Preedy & Watson, 2010, p. 4193).

In order to develop and pilot testing a condition-specific instrument that measures HrQoL, Bullinger established the following guidelines:

- (1) *Literature review and expert interviews*
- (2) *Focus groups with patients including recordings and transcription*
- (3) *Statement coding which focus on QoL with development conceptual models and item identification*
- (4) *Item generation with answer scales*
- (5) *In case of international studies, back- and forth translation with harmonization*
- (6) *Cognitive interviews or group discussions to gain information about clearness and acceptance of questionnaire*
- (7) *Pilot testing with first psychometric data*
- (8) *Field test with bigger sample for psychometric examination, with assessing reliability, validity and responsiveness*
- (9) *Assessment of population-based or clinical reference values and further establish a manual including analysis procedures* (Bullinger, 2014, p. 99f).

This has the advantage that patients themselves can be included in the process of developing new assessment tools for a specific health condition measurement instrument and therefore, generate new domains. This is mostly done by conducting qualitative interviews with patients, who discuss the main topics of well-being and functioning with this disease from their expert perspective and as a result, a conceptual model including those dimension can be created. At least the core domains physical, mental (emotional and cognitive), and social well-being are included. Moreover, dimension with regard to patients' behavior

or their physical function in order to meet everyday life roles are also part of the questionnaire (Bullinger & Quitmann, 2014, p. 138).

There are two types of self-reported instruments, the proxy-reported assessments in order to represent QoL from an external person's point of view and the individual assessment. Since the HrQoL construct is based on subjective assessments, it is necessary to obtain self-report. The proxy-report assessments are used as independent information so they do not represent the patient's perspective. Using proxy-report and patients ratings is very important when it comes to assess HrQoL of a child/adolescent. Due to the fact that childhood and adolescence show rapid changes with regard to their development, their QoL is influenced by quantitative and qualitative changes. As a result, age-related differences regarding HrQoL have to be considered (Petersen et al., 2005, p. 1066). Usually, children aged 8 years and older receive a self-report version whereas their parents get the proxy-form. Both perspectives will be treated as independent sources of information (Bullinger & Quitmann, 2014, p. 138).

2.2 Esophageal atresia

The following paragraph provides information on esophageal atresia, a rare health condition. First of all, facts on esophageal atresia will be explained followed by classification and detection of this disease and finally chronic morbidities and additional anomalies will be explained.

2.2.1 Facts on esophageal atresia

The medical term "esophageal atresia" (EA) describes a rare congenital anomaly affecting the esophagus (Nassar et al., 2012, p. 2). The European Union defines a disease or condition as rare if no more than 5 out of 10,000 people in the EU are affected by it. It is estimated that four million Germans suffer from one of 8,000 rare diseases, with regard to the entire EU, about 30 million people are affected. The group of rare conditions is very heterogeneous with mostly very complex diseases. However, nearly all of them are chronic, lower the QoL and can already cause symptoms in childhood (Bundesministerium für Gesundheit, 2016).

Congenital anomalies, as part of rare diseases, are "[...] *structural or functional anomalies (e.g. metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life*" (World Health Organization, 2015). One example of a congenital anomaly is EA, which causes an interruption of the continuity of the esophagus in combination with or without a connection to the trachea (Spitz, 2007, p. 1). There are two different main types of EA, the newborn has either the short or long gap form with several sub-

types and occurrences (A.D.A.M. Medical Encyclopedia, 2013). In more than 90% of the cases, EA occurs in combination with a tracheoesophageal fistula (TEF) but other malformations are also possible (Schleusner, 2016).

The total prevalence of EA varies in different countries and therefore Nassar et al. conducted a study, using an international surveillance system, and estimated that the total prevalence of EA is 2.44 children per 10,000 births. As a result, EA is categorized as a rare condition (Nassar et al., 2012, p. 4). Until today, the cause of EA seems to be multifactorial but is still unknown. However, less than 1% of all cases are associated with genetically disorders whereas the vast majority of EA occurs non-syndromic/non-familial (Spitz, 2007, p. 4).

Until the 1929's, EA was 100% fatal (Vogt, 1929, p. 465) but over the years, the survival rate continuously increased up to 90% due to the overall improvements in neonatal intensive care with regard to diagnosis, surgical interventions, treatment and technical advances (Goyal et al., 2006, p. F381f; Spitz, 2007, p. 6).

2.2.2 Classification and Detection

The first person who classified EA was Vogt in 1929 and his system is still used nowadays. It is stated in Spitz's review that Ladd (1944) and Gross (1953) adjusted Vogt's system whereas Kluth (1976) defined ten major types of EA which are also based on Vogt's system (Spitz, 2007, p. 2). In order to classify EA in detail, a distinction between the isolated type (without further malformations), associated type (with further malformations) and the syndromic form (with a genetic component) has to be made (Deutsche Gesellschaft für Kinderchirurgie, 2012, p. 3).

Figure 1 presents the classification of EA and shows that EA can be divided in four main types and three subtypes for type III. Further, it also includes the prevalence of each type.

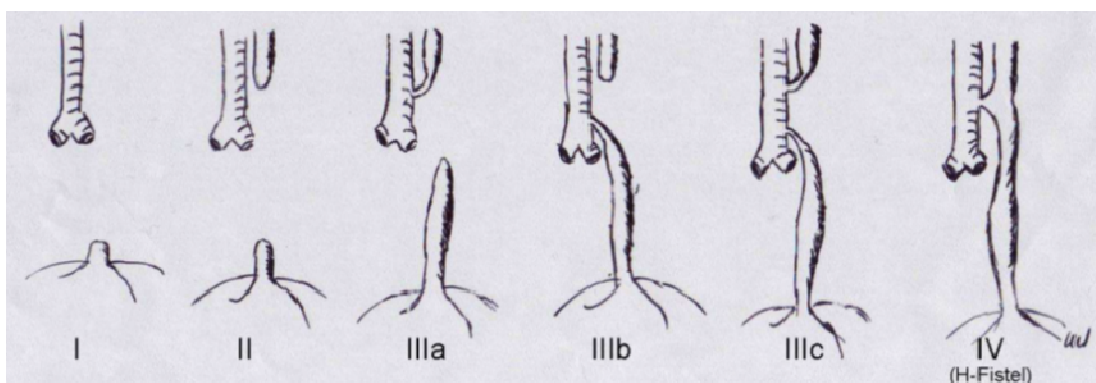


Figure 1: Classification of EA after Vogt
Source: Vogt, 1929, p.465

- Type I: Esophagus is to a great extent missing, no TEF (1%)
- Type II: Isolated EA without a TEF (3%)

- Type III:
 - Type III a: EA with proximal TEF (1%)
 - Type III b: EA with distal TEF (94%)
 - Type III c: EA with both proximal and distal TEF (1%)
- Type IV (H-fistula): esophagus is continuously with a short proximal TEF h-shaped between windpipe and esophagus (1%) (Schleusner, 2016).

The exact prenatal detection of EA is difficult to make (Houben & Curry, 2008, p. 667ff). However, immediately after the child is born, a dyspnea or foamy saliva in front of the child's mouth or nose can occur (Deutsche Gesellschaft für Kinderchirurgie, 2012, p. 2). Additionally, the child has rattling sounds in the lungs or even suffocation (Schleusner, 2016). For that reason, a small feeding tube needs to be insert but it is not possible to pass it to the stomach because of EA (A.D.A.M. Medical Encyclopedia, 2013). As a result, the newborn needs surgery within 48 hours after delivery. The main target of a surgical intervention is to close the TEF and to establish a continuously esophagus. In severe cases, for example a very low birth weight with pneumonia, it is necessary to delay the primary surgery (Deutsche Gesellschaft für Kinderchirurgie, 2012, p. 5).

2.2.3 Chronic morbidities and additional anomalies in children and adolescents

Patients with EA have individual risk for long-term health issues, depending on the complexity and of the congenital malformations as well as the treatment progress. For that reason, the morbidity among survivors' remains frequent and complicated (Deutsche Gesellschaft für Kinderchirurgie, 2012, p. 9).

Studies demonstrate that patients with EA can suffer from complications due to repair of their esophagus or the disease itself. Early complications for patients with EA are anastomotic leakage or stricture and recurrent fistula (Spitz, 2007, p. 9) whereas late complications are dysphagia, gastroesophageal reflux (GER), chest wall deformities, esophageal anastomosis, esophageal motility, esophagitis, epithelial metaplasia, cancer and pulmonary function impairment (Rintala et al., 2009, p. 50ff).

Already for children and adolescents with EA, chronic comorbidities are typical. These morbidities range from GER, dysphagia and respiratory disorders (Malmstrom et al., 2008, p. 399; Pedersen et al., 2013, p. 2489; Puntis et al., 1990, p. 87) to growth retardation (Dellenmark-Blom et al., 2015, p. 1; Puntis et al., 1990, p. 84). In the following, these complications will be briefly described in order to understand EA more in depth and analyze its impact on the life of affected children and adolescents.

A study by Pedersen et al. with 59 children and adolescents between 5 and 15 years showed that 55.9% of them are affected by GER (Pedersen et al., 2013, p. 2489). Similar

results are shown in Rintala et al.'s review, where GER has an incidence ranging from 27-75% in older children and adults. However, the incidence of GER in the general population is only a bit lower and cannot be statistically proofed. For patients with a repaired esophagus, the symptoms seem not as severe so that an intervention in their daily life is not necessary. The variation of 45% could be caused by several factors, like confusion between dysphagia derived symptoms and symptoms that are caused by GER (Rintala et al., 2009, p. 51f). It is stated that a significant number of patients suffer from long-standing GER which can cause chronic esophageal inflammation and can lead to recurrent pulmonary infections and abnormalities of pulmonary function (Kovesi & Rubin, 2004 as cited in Rintala et al., 2009, p.51f). In case medical treatment is not successful, EA patients with GER need surgical antireflux treatments (Bergmeijer et al., 2000, p. 573; Kloek et al., 2006, p. 71ff; Lindahl et al., 1989, p. 986).

A further comorbidity in all age groups is dysphagia, which is defined as a difficulty in swallowing (Rintala et al., 2009, p. 51). In the study by Pedersen et al., 69.5% of children and adolescents between 5 and 15 experienced dysphagia every month whereas 15.3% of them suffer from it every day (Pedersen et al., 2013, p. 2489). However, Rintala et al. did an institutional review considering dysphagia, their result showed that 80% of EA patients had to use liquids while their eating or even avoid specific food in order to avert that it gets stuck in their esophagus (Rintala et al., 2009, p. 51).

Another comorbidity of EA are continuously pulmonary dysfunctions, which are very common for children and adults with EA and a significant number of them even suffer from persisting respiratory symptoms. Symptoms of pulmonary dysfunctions can vary from wheezing or daily coughing to recurrent episodes of bronchitis or pneumonia (Rintala et al., 2009, p. 54). Pedersen et al.'s study showed that 55.9% of children and adolescents with EA experience respiratory symptoms (Pedersen et al., 2013, p. 2489).

A typical association of EA with proximal fistula is Tracheomalacia. In a study by Malmstrom et al., 21 of 27 (78%) of adolescents with EA were diagnosed with Tracheomalacia (Malmstrom et al., 2008, p. 399). Symptoms are barking and brassy cough or wheezing (Chetcuti et al., 1988, p. 345; Rintala et al., 2009, p. 54). Nowadays, it seems as if Tracheomalacia improves with age. Further, there is no association between symptoms of GER with persisting respiratory symptoms (Chetcuti et al., 1988, p. 345f). These facts lead to the conclusion that the repeated and in early childhood caused permanent airway and lung damages. However, in general, most of the reported pulmonary dysfunctions are not severe (Rintala et al., 2009, p. 54).

Moreover, another chronic comorbidity in children and adolescents with EA is growth retardation. In a study by Puntis et al. nearly one third of the participating children with EA were decelerated in their growth (Puntis et al., 1990, p. 87).

Since only one child with an esophageal replacement is included in the conducted study, the long-term outcomes will only be shortly discussed in the following. With the help of today's medical advancements, there are many esophageal replacement techniques in order to fix long-gap defects or repair failed primary anastomosis. However, there is a lack of prospective controlled studies which focus on long-term function and outcomes of esophageal replacement (Rintala et al., 2009, p. 54).

Besides these morbidities, children and adolescents can also be affected by additional anomalies. Stoll et al. conducted a study with 99 patients with EA and in their research, 46.5% had an associated malformation. Whereas only a few (n=8) of these patients were affected by chromosomal abnormalities and non-chromosomal conditions (n=17), 22 patients were affected by multiple congenital anomalies (MCA) affecting the following systems (Stoll et al., 2009, p. 288):

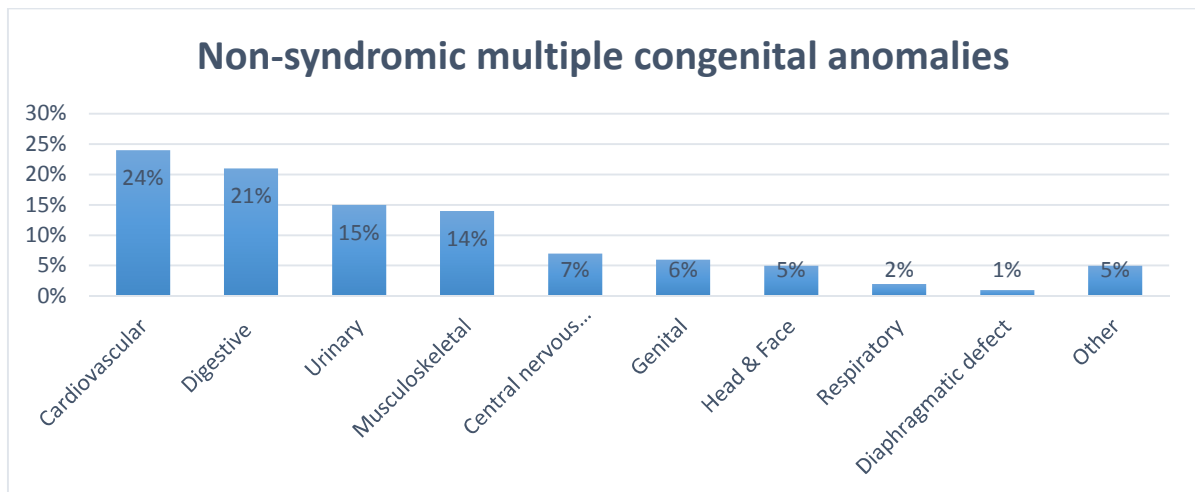


Figure 2: Classification of non-syndromic MCA by organ system (n=21)
Source: Stoll et al., 2009, p.288

Shaw-Smith even stated in his review that up to 57.3% of newborns with EA or TEF have more anomalies (Shaw-Smith, 2006, p. 546). Moreover, infants with H-type fistula have an incidence of only 10% for associated anomalies whereas the incidence in isolated atresia is 65% (Spitz, 2007, p. 4).

The presented chronic morbidities and additional anomalies in children and adolescents can lead to different severity level regarding EA. Dellenmark-Blom et al. developed criteria to assign patients with EA to two different levels of severity. They either are categorized to have a mild to moderate EA or severe EA. In case one or more of the following criteria are met, the EA will be categorized as severe:

- 1) *Primary anastomosis was delayed and/or EA replacement had to be done*
- 2) *An open surgery of the EA correction had to be performed because of recurrent TEF or anastomotic leakage*

3) *Presence of severe tracheomalacia*

4) *Presence of at least one other congenital condition and/or associated malformation which*

leads to disability according to the ICF-CY (Dellenmark-Blom et al., 2016, p. 564).

In a review of 135 medical records, 73 children (54%) were affected by the severe form of EA according to these criteria (ibid).

2.3 Impact of EA among children and adolescents on their HrQoL

Dellenmark-Blom et al. reviewed literature that focused on HrQoL among children and adolescents born with EA. In total, they found five studies concerning this topic (Dellenmark-Blom et al., 2016, p. 563). These studies will be briefly described in the following in chronological order.

The first study dealing with QoL after gastric transposition for EA by Ludman et al., measured the HrQoL of 28 patients (aged 2-22). To assess HrQoL, Ludman et al. used the Gastrointestinal Quality of Life Index (GIQLI). The results showed that HrQoL of children and adolescents, who had gastric transposition, was in general unimpaired. Nevertheless, patients who had gastric transposition as a primary procedure experienced less EA specific symptoms compared to patients who had previous unsuccessful attempts (Ludman & Spitz, 2003, p. 53).

A further study measuring HrQoL and its determinants in children and adolescents was conducted by Peetsold et al. including parents of 24 children and 37 children themselves. They used the child health questionnaire as well as the reflux questionnaire to measure HrQoL. The results presented an impaired general health compared to the healthy reference population. This is caused by the high number of concomitant anomalies and reflux symptoms (Peetsold et al., 2010, p. 417).

Another study by Legrand et al. assessed the long-term outcome of children with esophageal atresia type III. They used the Pediatric Quality of Life Inventory (PedsQL) 4.0 questionnaire to measure HrQoL of 57 children. The results implicated that these children have a good quality of life but still it is lower compared to the healthy control group and also lower in patients who experience symptoms of gastroesophageal reflux disease and barking cough (Legrand et al., 2012, p. 808).

The study by Lepeytre et al. measured the QoL in children who were treated for EA type III. Parents completed a questionnaire assessing the health of their children regarding the previous year and PedsQL 4.0 was completed by children who were older than eight years (n=43). The results showed that the QoL in children with EA is good, similar to

healthy controls. Nevertheless, their QoL is negatively influenced by respiratory and/or digestive symptoms (Lepeyre et al., 2013, p. 1096).

The latest study, by Dingemann et al., used GIQLI, WHO-Five Well-being index (WHO-5) and a HrQoL Questionnaire for Children and Young People (KIDSCREEN-27) to assess HrQoL in children and adults (n=92) born with complex or complicated EA and registered in the German patient support group database (KEKS). Based on their results, they concluded that HrQoL is excellent among these children (Dingemann et al., 2014, p. 631).

In conclusion, researchers are divided over the effect of EA on HrQoL. Two studies showed that HrQoL of children and adolescents with EA is unimpaired or excellent (Dingemann et al., 2014, p. 631; Ludman & Spitz, 2003, p. 53), whereas three studies presented that the HrQoL is good but still lower compared to healthy reference groups (Legrand et al., 2012, p. 808; Lepeyre et al., 2013, p. 1096; Peetsold et al., 2010, p. 417). Nevertheless, it has been reported, that no study has included a condition-specific HrQoL questionnaire in their research. As a consequence, Dellenmark-Blom et al. developed the first EA specific questionnaire for pediatric patients (Dellenmark-Blom et al., 2016, p. 563).

2.4 Development of the EA-QoL questionnaire

The next section explains the development of the EA-QoL questionnaire by focusing on the aims of the project and scientists that are involved in the EA-QoL study.

2.4.1 Aims of the project

The comprehensive aim of the study is to improve HrQoL and the independence of children and adolescents who were born with EA as well as their families. This should be achieved with the help of developing a condition-specific questionnaire which increases the knowledge of EA by exploring it through the child's and parents' perspective. This also gives children/adolescents with EA and their parents a voice in health care. The information obtained can be used by health professionals in order to understand EA in more detail and the burden that are connected to the disease. As a result, the health care of patients with EA can be improved by considering condition-specific aspects and needs that influence HrQoL. Additionally, the condition-specific instrument for EA can be used in clinical studies and further research and this cooperation project can serve as a role model for researchers in other countries in order to provide the questionnaire cross-culturally (EA-QoL Group, 2015, p. 6).

2.4.2 Research group

The EA-QoL study is a cooperation project of a Swedish and German expert panel. The Swedish experts MSc Pediatric Nurse, PhD-Student Michaela Dellenmark-Blom, Dr. John Eric Chaplin and Prof. Dr. Kate Abrahamsson are from the Institute of Clinical Sciences in the Department of Pediatric Surgery at the Queen Silvia Children's Hospital. The German expert team consists of Prof. Dr. Monika Bullinger, Dr. Julia Quitmann, Dr. Rachel Sommer and MA Stefanie Witt from the University Medical Centre Hamburg-Eppendorf, Department of Medical Psychology as well as Prof. Dr. Benno M. Ure, PD Dr. Jens Dingemann and Dr. Carmen Dingemann from the Medical School Hanover, Pediatric Surgical Center (EA-QoL Group, 2015, p. 3ff).

3. Methods

In the following section, a description of post project phases as well as the study design and sample recruitment will be explained. Subsequently, the analysis of the new condition-specific instrument for measuring the HrQoL in children and adolescents with EA will be presented including specific criteria for descriptive analysis on item level, non-parametric test (Mann-Whitney-U test) and cognitive debriefing on item level in order to select items for the field- and retest.

3.1 Description of post project phases

The following section provides information on the post project phases of the Swedish EA-QoL study and the German EA-QoL study.

3.1.1 The Swedish EA-QoL study

The Swedish team recruited 30 families, 18 children and 32 parents. They were stratified for age (0-7, 8-12, 13-17 years), gender and severity level of EA, resulting in ten focus groups. One (psychological) trained moderator led the discussions and additional, one research assistant supported the moderator during the focus groups with children. The obtained data were transcribed and content wise analyzed concerning more than 1,300 statements. HrQoL domains in children and adolescents with EA include social, emotional and physical aspects. Mostly HrQoL experiences with EA concerned categories such as physical activity, stigma and social exclusion as well as food and the eating process. As a result, two age related versions of the pilot questionnaire were implemented: a proxy version for parents of children under 8 years and a self-completion as well as a proxy version for children/adolescents aged 8-17 years (Dellenmark-Blom et al., 2016, p. 563ff; EA-QoL

Group, 2015, p. 6f). The results of the focus group discussions provided rich material in order to conduct a pilot and field-testing in Sweden. The HrQoL dimensions, which were based on the methodology outlined by the U.S. Food and Drug Administration, have not been reported in previous literature (EA-QoL Group, 2015, p. 6f).

3.1.2 The German EA-QoL study

The German EA-QoL study started with a back and forth translation of the Swedish version into German in order to secure a cultural adaptation and validation of EA HrQoL instrument in Germany. Furthermore, the main procedures of the Swedish project were also applied to the German project. This included focus group discussions, pilot testing of the EA questionnaire and later on a field- and retest of the questionnaire in Germany with children and adolescents who were born with EA and their parents. The German EA-QoL team also included further questionnaires to gain a broader knowledge of EA. For children/adolescents (8-17 years) the following questionnaires have been used during the focus group discussion: EA questionnaire, KIDSCREEN, DISABKIDS and PedsQL™. For parents of children and adolescents aged 2-17, the EA questionnaire, KIDSCREEN, condition specific module to measure HrQoL in children/adolescents (DISABKIDS), PedsQL™, Family Impact Module and (Short Form)-8 Health Survey (SF-8) have been used (EA-QoL Group, 2015, p. 7f).

3.2 Study design

The EA-QoL study followed the focus group methodology that were established by the U.S. Food and Drug Administration in their guidelines for instrument development on patient reported outcome measures (EA-QoL Group, 2015, p. 6f; U.S. Department of Health and Human Services et al., 2009, p. 1ff). The main aspect is that a “bottom-up” approach has been used for developing and testing the EA questionnaire. This secures that the patient’s perspective is included (ibid; Turner et al., 2007, p. 87). Additionally, the study was also guided by the well-established methodology of the European DISABKIDS project for children with a chronic health condition. Furthermore, the Regional Ethics Committee obtained approval to conduct the EA-QoL study (Dellenmark-Blom et al., 2015, p. 1f).

The focus group discussions took place at the Hanover Medical School on 19th and 25th February 2016 and the patient population consisted of 21 families. During the first part of the two-hour focus groups, the participants discussed aspects and experiences of living with EA. In the second part, they completed the different questionnaires and gave feed-

back with regard to the perception of the questions and the level of understanding afterwards (EA-QoL Group, 2015, p. 8).

Since this thesis focusses on the new EA questionnaire and its pilot testing in Germany, the other instruments and processes will be described separately.

The EA questionnaires were distributed to the children, adolescents and their parents during the focus group sessions. They were completed separately by parents of children aged 2-7, parents of children aged 8-17 and children/adolescents aged 8-17. These questionnaires were returned to the German team after the participants completed them. Informed consent and the permission to use clinical data have been obtained before in order to be able to use the collected data for research purposes. All aspects of the procedure were approved by the Ethics Committees of the Hanover Medical School for the German sample.

For all age groups, the EA questionnaires included items that cover different HrQoL domains which have been previously identified by the Swedish team. Every item had a five point likert-scale where the participants could choose the best answer for themselves or for their child. The scale ranged from complete disagreement to complete agreement (Preedy & Watson, 2010, p. 4248). The categories are “never”, “rarely”, “sometimes”, “often” and “always”. Participants also had the option to answer an item with “not applicable”. Moreover, they were asked to answer the cognitive debriefing questions since this is a pilot testing for a new instrument. For each item, they were asked to answer the following questions with “yes” or “no”: “Is the question relevant?”, “Is the question clear?”, “Is the question important” and “Does the question need to be reworded”. The following figure shows an example of one item with its answer options.

		never	rarely	sometimes	often	always	Not applicable	The question...			
								is relevant?	is clear?	is important?	needs to be reworded?
1.	Is it a problem for your child that he/she vomits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

Figure 3: Example of one item from EA questionnaire (translated into English)
Source: Own source

The parent proxy version for children between the ages of 2 to 7 years contains 30 items and is only available as parent-report since the children are too young to complete a questionnaire by themselves. Examples for items are “Does eating stress your child?”, “Do people stare at your child?” or “Is your child ashamed of his/her scar?”.

The self-report version and the proxy-report version for children/adolescents aged 8-17 consists of 50 items, including the same questions. Questions for parents are for example “Does your child find it difficult to play sports because of his/her health condition?”, “Is your child afraid when he/she chokes?” or “Does it bother your child that he/she gets acid

reflux/heart burn (day and/or night)?". The questionnaire for children/adolescents included the same items but asked from their perspective, for instance "Do you find it difficult to play sports because of your health condition?".

All three versions can be found in the appendix (p.47-62) but each item will be also presented more detailed within the Item selection in chapter 4.5.

3.3 Sample recruitment

All families were enlisted and recruited from the Pediatric Surgical Center of the Medical School Hanover by the clinical project coordinator PD Dr. J. Dingemann. Potential participants received a patient information letter, study material and informed consent via mail and returned them, if participated, in postpaid envelopes to the Medical School Hanover. The patient material was then coded and researchers of the Institute of Medical Psychology received the anonymized questionnaires for data entry and analysis. All research materials that have been collected within the EA-QoL study will remain until one year after completion of the study (EA-QoL Group, 2015, p. 12).

The inclusion and exclusion criteria for patient recruitment were defined by the expert panel. All children between 2 to 17 years diagnosed with different severity level of EA were included as well as one parent. In addition, the affected children and their parents needed to have sufficient German skills. No further exclusion criteria were implemented (EA-QoL Group, 2015, p. 8).

3.4 Analysis

The quantitative data analysis was conducted using SPSS v. 20.0 (SPSS Inc, 2008). Therefore, a descriptive analysis on item level separately for age group as well as self- and parent-report have been made and a descriptive analysis of the cognitive debriefing. The aim is to decide for each item separately, whether to retain, reject or discuss it for the field- and retest version. The procedure in order to evaluate and interpret the data of the descriptive analysis on item level, non-parametric test (Mann-Whitney-U test) and cognitive debriefing on item level will be described in the following.

3.4.1 Descriptive analysis on item level

The descriptive analysis on item level comprises the number of valid answers, mean, standard deviation, skewness and kurtosis.

Since the participants could answer the EA questionnaire on a 5-point-likert scale, all items that have been negative formulated were recoded. As a consequence, it is valid for all items that the higher the value is, the higher is the HrQoL regarding this specific item.

The mean and standard deviation provide a preliminary overview on the HrQoL of children and adolescents with EA from their own and from their parents' perspective. However, since this condition-specific questionnaire is used to optimize the pilot test version, it is more important to focus on indicators that give a hint regarding the selection of items for the field- and retest.

A further indicator that has been analyzed is skewness, which outcome provides information whether the data are normally distributed or skewed left or right. If the skewness is exactly zero, the distribution is exactly symmetrical. In case the skewness value differs highly from 0, it indicates that the data are skewed left (negative values) or right (positives values) (Schäfer & Schöttker-Königer, 2015, p. 51f). In this study, it is a criterion to reject an item, in case the data are not normally distributed. The skewness is considered to be high in case the value is above 2.0 or lower than -2.0 due to the fact that the number of respondents is low.

The same value is also applicable to kurtosis (ibid) which means, if the kurtosis exceed 2.0 or -2.0, the item will be rejected.

3.4.2 Non parametric test (Mann-Whitney-U Test)

The nonparametric Mann-Whitney-U test has been conducted for all age groups in order to detect significant differences within these groups. The aim of this questionnaire is to include some items that measure differences regarding the level of EA but not distinguish between males and females. Therefore, all items that distinguishes between child gender will be rejected.

3.4.3 Cognitive Debriefing on item level

The cognitive debriefing on item level is the main aspect that provides information whether to retain, reject or discuss an item. In order to decide whether an item is relevant, clear, important or if it needs to be reworded, a specific value was set by the EA-QoL Group.

For the first cognitive debriefing question "Is the question relevant?", at least 70% needed to be answered with yes in order to retain the item. However, due to the data and further discussions, the German research group decided to disregard "relevance" since this is associated with one's own child and cannot be related to other children who also suffer from EA. Therefore, the focus was on the second question "Is the question important?" because it reflects whether an item is in general important for children with EA or their

parents. The total agreement needs to be above 70%. The value of the third cognitive debriefing question "Is the question clear?" is 80%, which means that at least for 80% the question is understandable. The last question "Does the question needs to be reworded" needs to score below 20% in order to retain the item. In case it reached a total score above and all other values are not exceeding their values, the items are retained and further tested in the field- and retest.

As a result, an item should be retained in the questionnaire in case the following inclusion criteria are met:

- Absolute value of skewness or kurtosis does not exceed 2.0 or -2.0
- Clearness >80%
- Importance >70%
- Wording \leq 20%

If one of the criteria is not fulfilled, the item will be rejected unless the reason is "wording", then the item will be discussed but still remains in the EA questionnaire for further testing.

4. Results

In the following, the results of the pilot test regarding the new EA questionnaire will be presented. First of all, the sample will be described. This section is followed by the analysis, which is subdivided in parents of children aged 2-7, parents of children/adolescents aged 8-17 and children/adolescents aged 8-17. The results of the descriptive analysis on item level, Mann-Whitney-U test and the cognitive debriefing on item level will be presented. Finally, taking the previous analysis in consideration, the item selection will be explained.

4.1 Sample description

In total, eight focus group discussions with 32 participants were conducted at the Medical School Hanover on 19th and 25th February 2016.

Two discussion groups included 10 parents of children with EA between the ages of 2 to 7 years. Nine parents were representing their sons and one parent was representing his/her daughter.

Additionally, two focus group discussions included children from 8-12 years as well as two group sessions with their parents in parallel have been conducted. The focus group of children aged 8-12 in total consisted of four girls as well as four boys.

The last two focus groups included adolescents from 13-17 years and their parents have had a separate discussion. The adolescents' focus group consisted of one male and two females.

2-7 years		8-12 years				13-17 years					
<i>Parents</i>		<i>Children</i>		<i>Parents</i>		<i>Children</i>		<i>Parents</i>		<i>Children</i>	
♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀
9	1	0	0	4	4	4	4	1	2	1	2
10		0		8		8		3		3	
10				16				6			
N total=32											

Table 1: Sample description including gender and age
Source: Own source

However, the children/adolescents between 8 and 12 years as well as the adolescents between 13 and 17 years received the same EA questionnaire for children/adolescents between 8 and 17 years and therefore, they will be analyzed together although they were in separate focus group discussions.

In fact, 19 children and adolescents have been diagnosed with EA with distal TEF whereas only 2 children/adolescents suffer from isolated EA. Moreover, 12 children/adolescents were classified to have a mild or moderate form of EA, 7 children/adolescents have a severe form of EA and for 2 children/adolescents, there are no information provided.

4.2 Descriptive analysis on item level

The descriptive analysis on item level comprises the number of valid answers, mean, standard deviation, skewness and kurtosis. These analysis will be presented separately for parents of children aged 2-7, parents of children/adolescents aged 8-17 and children/adolescents aged 8-17.

Parents of children aged 2-7

The number of parents who gave valid responses ranged between seven and ten, however, for more than 50% of the questions, ten valid responses were provided.

The mean ranged between 2.12 (SD +/- 1.81) and 4.44 (SD +/- 1.33). The lowest mean could be found in item 28 ("Is it hard for your child to explain to others what he/she can and cannot do?"). This indicates that it was, on average, often a problem for their child to explain to others what he/she can and cannot do. The highest mean on the other hand could be found in item 22 ("Does your child feel that teachers in the preschool/school give help when needed?") which means that the average of the parents thought that their child receives often or always help from their teachers in case they need it.

Another important factor of descriptive analysis is the standard deviation, which ranged from 0.87 (Mean 4.33) in item 29 ("Is it a problem for your child to eat food at a party or when he/she is out with friends?") up to 2.11 (Mean 3.22) in item 18 ("Does your child avoid eating because he/she is afraid of choking?").

A skewness below the value of -2.0 was present in item 17 ("Is your child worried when he/she chokes on food?") with a skewness of -2.38 as well as in item 22 ("Does your child feel that teachers in the preschool/school give help when needed?") with a value of -2.69. The data are therefore expected to be left skewed.

In total, in five items, the kurtosis was below or above the value 2.0 or -2.0. Four items had a lower kurtosis than -2.0, ranging from -2.02 to -2.57, namely item 4 ("Can your child eat at the pace he/she wants?"), item 12 ("Does it bother your child that people nearby get frightened when your child makes more noise than other children (e.g. breathing, clearing his/her throat, coughing)?"), item 15 ("Does your child's health condition make it difficult for your child to sleep at night?") and item 18 ("Does your child avoid eating because he/she is afraid of choking?"). Only one item had a higher kurtosis than 2, item 22 ("Does your child feel that teachers in the preschool/school give help when needed?") has a kurtosis of 7.42. Since the data value is below -2.0 for four items, they are left skewed whereas item 22 is right skewed.

Parents of children/adolescents aged 8-17

The number of parents of children/adolescents aged 8-17, who gave valid responses ranged between nine and eleven, but in 60% of the cases eleven valid responses were counted.

The mean ranged between 1.54 (SD +/- 0.82) and 4.36 (SD +/- 1.03). The lowest mean could be found in item 37 ("Does your child feel it is a positive thing that he/she was born with esophageal atresia?"). This indicates that, from the parents' point of view, the majority of their children never or rarely think that it is a positive thing that they were born with EA. The highest mean could be found in item 7 ("Does your child gets teased about things in school?") and item 11 ("Is it a problem for your child if he/she drinks a lot when he/she

eats?"). It means that parents thought, that their children, on average, never or rarely get teased in school and it is also never or rarely a problem for their child if he/she drinks a lot when he/she eats.

Furthermore, the standard deviation ranged from 0.82 (Mean 1.54) in item 37 ("Does your child feel it is a positive thing that he/she was born with esophageal atresia?") up to 2 (Mean 3) in item 50 ("Does esophageal atresia make your child feels uncertain when it comes to boys/girls?"). Here, the mean as well as the standard deviation was lowest for item 37 (Does your child feel it is a positive thing that he/she was born with esophageal atresia?).

In only one item, the skewness was below the critical value -2.0 since item 11 ("Is it a problem for your child if he/she drinks a lot when he/she eats?") had a skewness of -2.22. For that reason, this is the only item which is not normally distributed regarding the skewness.

Additionally, considering the same critical value for kurtosis, 7 items were not normally distributed, ranging from -2.33 to -2.02 and from 3.38 to 4.73. This is the case for item 11 ("Is it a problem for your child if he/she drinks a lot when he/she eats?"), item 32 ("Is your child careful about what he/she wears because of his/her scar/scars?"), item 39 ("Is it hard for your child having to take medications?"), item 43 ("Does your child feel small compared to his/her friends?"), item 44 ("Is it hard for your child to find clothes because of his/her height or body size?"), item 46 ("Do you feel that teachers in your child's school understand that some things are difficult for your child because of his/her health condition (e.g. sports)?") and item 50 ("Does esophageal atresia make your child feels uncertain when it comes to boys/girls?"). This indicates that for these items, a normal distribution is not present.

Children/adolescents aged 8-17

The number of children/adolescents who gave valid responses was eleven, however one item, item 26 ("Are you stressed by having to finish your meal in time in the school cafeteria?") only has ten valid responses.

The mean ranged between 2.18 (SD +/- 1.72) and 4.54 (SD +/- 1.21). The lowest mean could be found in item 37 ("Do you feel it is a positive thing that you were born with esophageal atresia?"). This indicates that the majority of the affected children/adolescents rarely think that it is a positive thing that they were born with EA which is also applicable to their parents' response. The highest mean could be found in item 32 ("Are you careful about what you wear because of your scar /scars?") which means that child-

ren/adolescents, on average, were never or rarely careful about what they wear because of their scar/scars.

Furthermore, the standard deviation ranged from 0.82 (Mean 4.45) in item 6 (“Do others say mean things about you?”) up to 2.09 (Mean 3.18) in item 28 (“It is hard for you to find peace and quiet when you eat in the school cafeteria”) and in item 43 (Mean 3.18) (“Do you feel small compared to your friends?”).

In four items, the skewness is below the critical value -2.0, ranging between -2.03 and -3. For that reason, the following items are not normally distributed with regard to the skewness: item 5 (“Do others call you names (e.g. because you are small, have an unusual cough, eat slowly, or because you have a surgical scar?”), item 14 (“Does it bother you that it takes longer to eat for you than for your friends?”), item 29 (“Do you choke or vomit when eating in the school cafeteria?”) and item 32 (“Are you careful about what you wear because of your scar /scars?”).

Additionally, considering the same critical value for kurtosis, eleven items are not normally distributed, ranging from -2.44 to -2.12 and from 2.04 to 9.23. This is the case for item 5 (“Do others call you names (e.g. because you are small, have an unusual cough, eat slowly, or because you have a surgical scar?”), item 9 (“Do you have to think about avoiding certain foods because of your health condition (e.g. because of choking, acid reflux or heart burn?”), item 10 (“Does your health condition restrict you from eating any food?”), item 14 (“Does it bother you that it takes longer to eat for you than for your friends?”), item 18 (“Do you worry about choking in front of others?”), item 28 (“Is it hard for you to find peace and quiet when you eat in the school cafeteria?”), item 29 (“Do you choke or vomit when eating in the school cafeteria?”), item 32 (“Are you careful about what you wear because of your scar /scars?”), item 42 (“Do you feel that there are other children like you?”), item 43 (“Do you feel small compared to your friends?”) and item 50 (“Does esophageal atresia make you feel uncertain when it comes to boys/girls?”). Hence, item 32, 43 and 50 are also above or below the critical value of kurtosis with regard to their parents.

4.3 Non parametric test (Mann-Whitney-U test)

The Mann-Whitney-U test has been conducted for child gender and severity level of EA to detect significant differences within these groups. For the two age groups, no significant differences regarding gender have been shown. With regard to the severity level of EA, significant differences were found.

Parents of children aged 2-7

The result of the Mann-Whitney-U test showed a significant differences for the severity level of EA in one item. Children with mild to moderate EA showed significant lower HrQoL with regard to item 4 (Can your child eat at the pace he/she wants?) than children with severe EA.

	<i>4. Can your child eat at the pace he / she wants?</i>
N	9
Mann-Whitney-U	0.00
Z	-2.62
Exact significance [2*(1-tailed Sig.)]	0,02*

Table 2: Mann-Whitney-U test for parents of children aged 2-7
Source: Own source

Parents of children/adolescents aged 8-17

Within the EA questionnaire for parents of children/adolescents aged 8-17, significant differences could be detected with regard to two items. Children/adolescents with mild to moderate EA showed significant lower HrQoL regarding item 16 and 50 than children with severe EA.

	<i>16. Can your child eat at the pace he/she wants?</i>	<i>50. Does esophageal atresia make your child feel uncertain when it comes to boys/girls?</i>
N	9	10
Mann-Whitney-U	0.5	1.50
Z	-2.26	-2.27
Exact significance [2*(1-tailed Sig.)]	0,02*	0,03*

Table 3: Mann-Whitney-U test for parents of children/adolescents aged 8-17
Source: Own source

Children/adolescents aged 8-17

For children/adolescents aged 8-17 with EA, one item showed a significant difference with regard to the severity level. In this case, children/adolescents with mild to moderate EA showed a significantly higher HrQoL regarding item 22 than children/adolescents with severe EA.

	<i>22. Is it easy for you to be open with others about esophageal atresia?</i>
N	10
Mann-Whitney-U	1.5
Z	-2.14

Exact significance [2*(1-tailed Sig.)]	0,03*
---	--------------

Table 4: Mann-Whitney-U test for children/adolescents aged 8-17
Source: Own source

4.4. Cognitive debriefing on item level

In the next paragraph, the results of the cognitive debriefing will be described. Therefore, the four categories “relevant”, “clear”, “important” and “wording” will be discussed with regard to the already described critical values (chapter 3.3: Analysis).

Parents of children aged 2-7

All 30 items that have been used in the EA questionnaire seem to be relevant for parents of children aged 2-7. However, one item scored below 70%. Only 60% of parents’ thought that item 2 (“Does your child have to eat particular/special foods (e.g. puréed food, peeled or grated food, or food given via a gastrostomy button) because of his/her health condition?”) is a relevant question.

Moreover, all 30 items are considered to be clear since they scored more than 80%, mostly 100%. This can also be transferred to the category “importance”, which ranged between 87.5% and 100%.

As mentioned earlier, an item that scored 20% or even more should be reworded in order to secure that the participants understood the question properly. This is the case for seven items, where the percentage ranged from 20% up to 22.2%. It is applicable for item 1 (“Is it a problem for your child that he/she vomits?”), item 4 (“Can your child eat at the pace he/she wants?”), item 5 (“Does eating stress your child?”), item 6 (“Is it difficult for your child to eat a full meal?”), item 7 (“Is your child worried about choking?”), item 8 (“Does your child's health condition cause him/her to eat slowly?”) and item 11 (“Do people make comments to your child because of his/her health condition?”).

Parents of children/adolescents aged 8-17

For parents of children/adolescents aged 8-17, 35 items of this questionnaire were relevant, whereas 15 items scored less than 70%, ranging between 22.2% and 66.7%. The following items were not relevant: Item 7 (“Does your child gets teased about things in school?”), item 11 (“Is it a problem for your child if he/she drinks a lot when he/she eats?”), item 14 (“Does it bother your child that it takes longer to eat for him/her than for his/her friends?”), item 17 (“Does it bother your child if he/she gets other food in school than his/her friends?”), item 18 (“Does your child worry about choking in front of others?”), item 20 (“Does your child feel that it is a problem for him/her that he/she must have specialized/particular food (e.g. puréed food, nutritional drink, or food through a gastrostomy

button)?”), item 21 (“Is your child afraid when he/she chokes?”), item 27 (“Does it feel like your child is always the last one to finish when he/she eats in the school cafeteria?”), item 39 (“Is it hard for your child having to take medications?”), item 43 (“Does your child feel small compared to his/her friends?”), item 44 (“Is it hard for your child to find clothes because of his/her height or body size?”), item 45 (“Does it bother your child that he/she gets acid reflux/heart burn (day and/or night)?”), item 47 (“Is your child bothered by that he/she has a different kind of cough?”), item 49 (“Does your child think about how his/her future will be because of his/her esophageal atresia?”) and item 50 (“Does esophageal atresia make your child feels uncertain when it comes to boys/girls?”).

However, all items were clear to the parents because they scored nearly always 100% except in item 28 (“Is it hard for your child to find peace and quiet when he/she eats in the school cafeteria?”) 90.9% and in item 42 (“Does your child feel that there are other children like him/her?”) 88.9% but they are still higher than 80% and therefore all items were understandable for these parents.

Furthermore, 48 items are rated as important for parents of children/adolescents aged 8-17 with EA with all scores 70% or above. Only item 17 (“Does it bother your child if he/she gets other food in school than his/her friends?”) and item 44 (“Is it hard for your child to find clothes because of his/her height or body size?”) are scored below 70%, respectively 66.7% and 62.5%.

Additionally, parents rated that 48 out of 50 items do not need to be reworded. It is only necessary for item 30 (“Is it easy for your child to fit in and make friends?”) and item 42 (“Does your child feel that there are other children like him/her?”) because these items are equal or above 20%.

Children/adolescents aged 8-17

Only four out of 50 items scored at least 70% in the category “relevant”, ranging from 70% up to 81.8%. For children aged 8-17 these items are relevant: item 3 (“Do you participate in physical demanding activities (such as running, playing football, handball)?”), item 16 (“Can you eat at the pace you want?”), item 22 (“Is it easy for you to be open with others about esophageal atresia?”) and item 42 (“Do you feel that there are other children like you?”).

However, only four items were not considered to be clear since they scored less than 80%, namely item 18 (“Do you worry about choking in front of others?”), item 26 (“Are you stressed by having to finish your meal in time in the school cafeteria?”), item 37 (“Do you feel it is a positive thing that you were born with esophageal atresia?”) and item 50 (“Does esophageal atresia make you feel uncertain when it comes to boys/girls?”).

For children/adolescents aged 8-17, only 28 items were important for these affected. These percentages vary between 36.4% in item 27 (“Does it feel like you are always the last one to finish when you eat in the school cafeteria?”) and 50 (“Does esophageal atresia make you feel uncertain when it comes to boys/girls?”) up to 63.6% in nine items, for instance item 5 (“Do others call you names (e.g. because you are small, have an unusual cough, eat slowly, or because you have a surgical scar)?”).

For the affected children, nearly every item was written appropriately so that only item 34 (“Do you feel that you are not perfect because you have scars?”) was scored as “needs to be reworded” (27.3%).

4.5 Item selection

Considering the results of descriptive statistics and cognitive debriefing, a recommendation can be made whether an item should be retained, rejected or discussed (chapter 3.3) in the field- and retest version from the German perspective. On basis of these guidelines, the following tables for parents of children aged 2-7, parents of children/adolescents aged 8-17 and children/adolescents aged 8-17 have been created. They present an evaluation of every single item considering if it should be retained, rejected or discussed and also mentions the reason for it. In case an item should be discussed, it will still remain in the field- and retest version for further testing.

Parents of children aged 2-7

No.	Item	Retain	Reject	Discuss	Reason
1.	Is it a problem for your child that he/she vomits?			X	Wording (20%)
2.	Does your child have to eat particular/special foods (e.g. puréed food, peeled or grated food, or food given via a gastrostomy button) because of his/her health condition?	X			
3.	Does your child find it boring to get different food than other people eat?	X			
4.	Can your child eat at the pace he/she wants?		X		Kurtosis (-2.02) Wording (22.2%)
5.	Does eating stress your child?			X	Wording (20%)
6.	Is it difficult for your child to eat a full meal?			X	Wording (20%)
7.	Is your child worried about choking?			X	Wording (20%)
8.	Does your child's health condition cause him/her to eat slowly?			X	Wording (22.2%)
9.	Does your child have less strength than other children during physically demanding activities?	X			
10.	Does your child get tired easily when he/she plays games or sports?	X			

11.	Do people make comments to your child because of his/her health condition?			X	Wording (20%)
12.	Does it bother your child that people nearby get frightened when your child makes more noise than other children (e.g. breathing, clearing his/her throat, coughing)?		X		Kurtosis (-2.23)
13.	Do people stare at your child?	X			
14.	Does it bother your child that people make comments about him/her?	X			
15.	Does your child's health condition make it difficult for your child to sleep at night?		X		Kurtosis (-2.43)
16.	Is it hard for your child to eat because food sticks in his/her throat?	X			
17.	Is your child worried when he/she chokes on food?		X		Skewness (-2.38)
18.	Does your child avoid eating because he/she is afraid of choking?		X		Kurtosis (-2.57)
19.	Is your child ashamed of his/her scar?	X			
20.	Can your child go to other children's homes after preschool/school without careful planning?	X			
21.	Does your child feel that other children at the preschool/school understand him/her?	X			
22.	Does your child feel that teachers in the preschool/school give help when needed?		X		Skewness (-2.69) Kurtosis (7.42)
23.	Does your child feel different than other children because of his/her health condition?	X			
24.	Is it a problem for your child that he/she gets respiratory infections easily?	X			
25.	Do your child feel self-conscious about his/her problems with restricted airways (e.g. coughing, phlegm, or difficulty breathing)?	X			
26.	Is it hard for your child being small compared to other children of the same age?	X			
27.	Does your child hate taking medicine?	X			
28.	Is it hard for your child to explain to others what he/she can and cannot do?	X			
29.	Is it a problem for your child to eat food at a party or when he/she is out with friends?	X			
30.	Is it a problem for your child that his/her health condition involves absence from preschool/school?	X			

Table 5: Item selection for parents of children aged 2-7
Source: Own source

Parents of children/adolescents aged 8-17

No.	Item	Retain	Reject	Discuss	Reason
1.	Does your child has the strength to play sports (e.g. running, playing football) and play as his/her friends do?	X			
2.	Is your child bothered by breathing	X			

	difficulties when he/she exercises and plays?				
3.	Does your child participate in physical demanding activities (such as running, playing football, handball)?	X			
4.	Does your child find it difficult to play sports because of his/her health condition?	X			
5.	Do others call your child names (e.g. because he/she is small, has an unusual cough, eats slowly, or because he/she has a surgical scar)?	X			
6.	Do others say mean things about your child?	X			
7.	Does your child gets teased about things in school?	X			
8.	Does your child has the feeling that others are staring at him/her (e.g. when coughing, choking, dressing in the locker room)?	x			
9.	Does your child has to think about avoiding certain foods because of his/her health condition (e.g. because of choking, acid reflux or heart burn)?	X			
10.	Does your child's health condition restrict him/her from eating any food?	X			
11.	Is it a problem for your child if he/she drinks a lot when he/she eats?		X		Skewness (-2.22) Kurtosis (4.73)
12.	Is it/does it feel hard for your child to eat because he/she chokes?	X			
13.	Does your child feel it is a problem that he/she gets food stuck in his/her throat when he/she eats?	X			
14.	Does it bother your child that it takes longer to eat for him/her than for his/her friends?	X			
15.	Does your child get any pain when he/she eats because of his/her health condition (e.g. when food gets stuck in his/her throat, heartburn, stomach ache)?	X			
16.	Can your child eat at the pace he/she wants?	X			
17.	Does it bother your child if he/she gets other food in school than his/her friends?		X		Importance (66.7%)
18.	Does your child worry about choking in front of others?	X			
19.	Is it a problem that your child vomit food after eating?	X			
20.	Does your child feel that it is a problem for him/her that he/she must have specialized/particular food (e.g. puréed food, nutritional drink, or food through a gastrostomy button)?	X			
21.	Is your child afraid when he/she chokes?	X			
22.	Is it easy for your child to be open with others about esophageal atresia?	X			
23.	Does it feel awkward for your child	X			

	when others ask him/her about esophageal atresia?				
24.	Is it complicated for your child to explain to others what esophageal atresia is?	X			
25.	Does your child get tired of people asking about the scar/scars?	X			
26.	Is your child stressed by having to finish his/her meal in time in the school cafeteria?	X			
27.	Does it feel like your child is always the last one to finish when he/she eats in the school cafeteria?	X			
28.	Is it hard for your child to find peace and quiet when he/she eats in the school cafeteria?	X			
29.	Does your child choke or vomit when eating in the school cafeteria?	X			
30.	Is it easy for your child to fit in and make friends?			X	Wording (20%)
31.	Does your child feel different because he/she has scars?	X			
32.	Is your child careful about what he/she wears because of his/her scar/scars?		X		Kurtosis (-2.02)
33.	Does your child feel awkward when his/her scar/scars are visible to others (e.g. strangers, new people, boyfriend/girlfriend, friends or classmates in the locker room, people in the swimming pool)?	X			
34.	Does your child feel that he/she is not perfect because he/she has scars?	X			
35.	Does your child have trouble sleeping at night because of his/her health condition (e.g. acid reflux, heartburn, or respiratory problems)?	X			
36.	Does your child's health condition mean that he/she has to think about, for example, what he/she eats, taking medicines on time, sleeping in a raised position (extra pillows) to sleep well?	X			
37.	Does your child feel it is a positive thing that he/she was born with esophageal atresia?	X			
38.	Does your child feel sad that he/she was born with esophageal atresia?	X			
39.	Is it hard for your child having to take medications?		X		Kurtosis (-2.12)
40.	Does your child feel he/she can talk to you as parents about esophageal atresia?	X			
41.	Does your child feel like the only one who was born with esophageal atresia?	X			
42.	Does your child feel that there are other children like him/her?			X	Wording (22.2%)
43.	Does your child feel small compared to his/her friends?		X		Kurtosis (3.38)
44.	Is it hard for your child to find clothes because of his/her height or body size?		X		Kurtosis (-2.13) Importance

					(62.5%)
45.	Does it bother your child that he/she gets acid reflux/heart burn (day and/or night)?	X			
46.	Do you feel that teachers in your child's school understand that some things are difficult for your child because of his/her health condition (e.g. sports)?		X		Kurtosis (-2.25)
47.	Is your child bothered by that he/she has a different kind of cough?	X			
48.	Is it worse for your child than for others when he/she catches a cold?	X			
49.	Does your child think about how his/her future will be because of his/her esophageal atresia?	X			
50.	Does esophageal atresia make your child feel uncertain when it comes to boys/girls?		X		Kurtosis (-2.33)

Table 6: Item selection for parents of children/adolescents aged 8-17

Source: Own source

Children/adolescents aged 8-17

No.	Item	Retain	Reject	Discuss	Reason
1.	Do you have the strength to play sports (e.g. running, playing football) and play as your friends do?	X			
2.	Are you bothered by breathing difficulties when you exercise and play?	X			
3.	Do you participate in physical demanding activities (such as running, playing football, handball)?		X		Importance (54.5%)
4.	Do you find it difficult to play sports because of your health condition?	X			
5.	Do others call you names (e.g. because you are small, have an unusual cough, eat slowly, or because you have a surgical scar)?		X		Skewness (-2.74) Kurtosis (7.94) Importance (63.6%)
6.	Do others say mean things about you?		X		Importance (63.3%)
7.	Do you get teased about things in school?		X		Importance (54.5%)
8.	Do you feel that others are staring at you (e.g. when coughing, choking, dressing in the locker room)?	X			
9.	Do you have to think about avoiding certain foods because of your health condition (e.g. because of choking, acid reflux or heart burn)?		X		Kurtosis (2.32)
10.	Does your health condition restrict you from eating any food?		X		Kurtosis (2.32)
11.	Is it a problem if you drink a lot when you eat?	X			
12.	Is it/does it feel hard for you to eat because you choke?	X			

13.	Do you feel it is a problem that you get food stuck in your throat when you eat?	X			
14.	Does it bother you that it takes longer to eat for you than for your friends?		X		Skewness (-2.03) Kurtosis (2.81)
15.	Do you get any pain when eat because of your health condition? (e.g. when food gets stuck in your throat, heart-burn, stomach ache?)	X			
16.	Can you eat at the pace you want?	X			
17.	Does it bother you if you get other food in school than your friends?		X		Importance (45.5%)
18.	Do you worry about choking in front of others?		X		Kurtosis (-2.12) Clearness (72.7%) Importance (63.6%)
19.	Is it a problem that food you vomit after eating?	X			
20.	Do you feel that it is a problem for you that you must have specialized/particular food (e.g. puréed food, nutritional drink, or food through a gastrostomy button)?		X		Importance (63.6%)
21.	Are you afraid when you choke?	X			
22.	Is it easy for you to be open with others about esophageal atresia?		X		Importance (54.5%)
23.	Does it feel awkward when others ask you about esophageal atresia?		X		Importance (63.6%)
24.	Is it complicated to explain to others what esophageal atresia is?		X		Importance (63.6%)
25.	Do you get tired of people asking about the scar/scars?	X			
26.	Are you stressed by having to finish your meal in time in the school cafeteria?		X		Clearness Importance (45.5%)
27.	Does it feel like you are always the last one to finish when you eat in the school cafeteria?		X		Importance (36.4%)
28.	Is it hard for you to find peace and quiet when you eat in the school cafeteria?		X		Kurtosis (2.44) Importance (45.5%)
29.	Do you choke or vomit when eating in the school cafeteria?		X		Skewness (-2.42)
30.	Is it easy for you to fit in and make friends?		X		Importance (54.5%)
31.	Do you feel different because you have scars?	X			

32.	Are you careful about what you wear because of your scar /scars?		X		Skewness (-3) Kurtosis (9.23) Importance (54.5%)
33.	Do you feel awkward when your scar/scars are visible to others (e.g. strangers, new people, boy-friend/girlfriend, friends or classmates in the locker room, people in the swimming pool)?		X		Importance (54.5%)
34.	Do you feel that you are not perfect because you have scars?			X	Wording (27.3%)
35.	Do you have trouble sleeping at night because of your health condition (e.g. acid reflux, heartburn, or respiratory problems)?	X			
36.	Does your health condition mean that you have to think about, for example, what you eat, taking medicines on time, sleeping in a raised position (extra pillows) to sleep well?	X			
37.	Do you feel it is a positive thing that you were born with esophageal atresia?		X		Clearness (63.6%) Importance (63.6%)
38.	Do you feel sad that you were born with esophageal atresia?	X			
39.	Is it hard having to take medications?	X			
40.	Do you feel you can talk to your parents about esophageal atresia?		X		Importance (63.6%)
41.	Do you feel like the only one who was born with esophageal atresia?	X			
42.	Do you feel that there are other children like you?		X		Kurtosis (3.87)
43.	Do you feel small compared to your friends?		X		Kurtosis (- 2.44) Importance (54.5%)
44.	Is it hard for you to find clothes because of your height or body size?		X		Importance (45.5%)
45.	Does it bother you that you get acid reflux/heart burn (day and/or night)?	X			
46.	Do you feel that teachers in the school understand that some things are difficult for you because of your health condition (e.g. sports)?		X		Importance (63.6%)
47.	Are you bothered by that you have a different kind of cough?	X			
48.	Is it worse for you than for others when you catch a cold?	X			
49.	Do you think about how your future will be because of your esophageal atresia?	X			
50.	Does esophageal atresia make you feel		X		Kurtosis (2.04)

	uncertain when it comes to boys/girls?				Clearness (72.7%) Importance (36.4%)
--	--	--	--	--	---

Table 7: Item selection for children/adolescents aged 8-17
Source: Own source

In conclusion, for parents of children aged 2-7, 24 items will remain in the field- and retest version from the German perspective, including 18 items that met all criteria and the six items (item 1, 5, 6, 7, 8, 11) that should be discussed but still remain for further testing. However, six items should be rejected (item 4, 12, 15, 17, 18, 22).

For parents of children/adolescents between 8 and 17 years, in total 42 items should be retained in the field- and retest because 40 fulfill the criteria and two items (item 30, 42) should be tested further. As a consequence, eight items (item 11, 17, 32, 39, 43, 44, 46, 50) need to be rejected. The final result for children/adolescents between 8 and 17 years showed that 23 items should retain in the field- and retest, since 22 items met all criteria and one item (item 34) should be further tested. However, 27 items should be rejected (item 3, 5, 6, 7, 9, 10, 14, 17, 18, 20, 22, 23, 24, 26, 27, 28, 29, 30, 32, 33, 37, 40, 42, 43, 44, 46, 50).

Nevertheless, since children/adolescents 8-17 years and their parents have to have the same version of the EA questionnaire, the parents' version is the one that will be included in the field- and retest.

5. Discussion

The thesis focused on the German EA-QoL study by analyzing the presented data and selecting items from the German point of view for the field- and retest. The results that have been explained in chapter 4 will be critically discussed and they will be related to previous findings from other studies. Further, limitations regarding the EA-QoL study will be also presented. First of all, the results will be briefly summarized followed by a discussion of all results in relation to previous findings. At the end of this chapter, limitations will be presented.

With the help of the EA-QoL study, conducted by a Swedish and German expert panel, the first condition-specific questionnaire that assess the HrQoL in children and adolescents between 2 and 17 years via self- and proxy-report has been developed, based on the international guidelines for instrument development on patient reported outcome measures. The pilot test of the instrument in Germany included 32 participants, 21 children and adolescents diagnosed with EA as well as their parents. Two age-related versions

of the EA questionnaire have been tested: Parent proxy version for children aged 2-7 and diagnosed with EA (30 items), parent proxy version for children/adolescents between 8 and 17 years (50 items) and self-report version for children/adolescents between 8 and 17 years (50 items). Each item has a five point likert-scale ranging from complete disagreement to complete agreement. Further, participants could also choose “not applicable” as an answer. Additionally, a cognitive debriefing with four questions was included, assessing whether the question is important, clear, relevant and if it needs to be reworded. In order to decide which items should be retained, rejected or discussed for the field- and retest, the expert panel developed specific criteria for analyzing the Swedish and German data sets. An item should be retained in the questionnaire in case the following inclusion criteria are met: Absolute value of skewness or kurtosis does not exceed 2.0 or -2.0, clearness >80%, importance >70%, wording \leq 20%. If one of the criteria was not fulfilled, the item was rejected unless the reason is “wording”, then the item was discussed but still remained in the EA questionnaire for further testing. As a consequence, the German data for parents of children between 2 and 7 years showed that 24 items should be retained in the field- and retest for further testing. For parents of 8-17 year-old children/adolescents as well as for the children/adolescents themselves, 42 items should be retained in the field- and retest version based on the parents’ version. The reason for choosing the parents’ version is due to the critical results of the children/adolescents as already described in chapter 5.4. Moreover, to include the items that should be further discussed is a good opportunity to test them again since the only reason for them being not directly included is due to the category “wording”. In case there are still misunderstandings regarding these items within a bigger sample, they can be still reworded. However, the field- and retest version of the EA questionnaire will be based on the Swedish and German data sets together.

The German sample included 19 children and adolescents who were diagnosed with EA with distal TEF whereas only two children/adolescents suffer from isolated EA. Compared to the frequencies that have been described in previous published literature, the German sample nearly is congruent with it. Schleusner estimated that 94% of patients are affected by EA with distal TEF, in the German sample, 90.48% suffer from type III b (EA with distal TEF). Moreover, the second most common type of EA is type II (isolated EA without TEF), which has been estimated to affect 3% (Schleusner, 2016). In the German sample, 9.52% are affected by this type. One reason for the deviation can be the small sample size of EA patients (n=21).

Additionally, the categorization of severity level is complex and just has been developed by Dellenmark-Blom et al. briefly (Dellenmark-Blom et al., 2016, p. 564ff). In the German

EA-QoL study, 12 children/adolescents are classified to have a mild or moderate form of EA, 7 children/adolescents have a severe form of EA and for two children/adolescents, there are no information provided. In case the two children with an undefined severity level are disregarded in the German EA-QoL study, 63.16% of children/adolescents have a mild or moderate EA whereas 36.84% are affected by the severe form of EA. These results are not congruent with the results of Dellenmark-Blom et al. study where the severe form was more common with 54% than the mild to moderate form with 46% (Dellenmark-Blom et al., 2016, p. 564). As mentioned earlier, the deviation in the German sample might be again caused by the small sample size (n=21). Further, an interesting aspect is that the two children/adolescents who have been diagnosed with the isolated type of EA, both suffer from severe forms of EA. These results can be related to Spitz's findings, who found that the incidence of children/adolescents with the isolated type of EA have further associated anomalies is relatively high with 65% (Spitz, 2007, p. 4).

Further, based on my literature research, the EA-QoL study is the only instrument that differentiates between age groups in children and adolescents with EA. The advantage is, that the measurements are more sensitive and might capture age-related differences better. This should be considered since childhood and adolescence are a time of rapid changes (Petersen et al., 2005, p. 1066). For instance, a two-year-old child has a completely different life-style than a 17-year-old adolescent and cannot provide information on his/her own and therefore, only a proxy-report is possible since the child is too young (Varni et al., 2007, p. 2). Children and adolescents between the age of 8 to 17 years can report about their condition by themselves but it is also important to include parent-proxy-report as well (Bullinger & Quitmann, 2014, p. 138).

Moreover, the completion of the EA questionnaire during the focus group discussion made it possible to discuss the questionnaire with all participants and to notice which items might be unclear or not as important and the reasons for it. This provided additional information regarding the cognitive debriefing.

Within the descriptive analysis on item level, the items with the highest and lowest HrQoL were described for children aged 2-7 and children/adolescents aged 8-17 via self- and parent-proxy-report. Thus, it is important to keep the small sample size in mind, since the number of valid answers per questions ranged between seven and eleven and therefore these answers are not representative.

For parents of children aged 2-7, the lowest HrQoL (Mean 2.12) was in item 28 ("Is it hard for your child to explain to others what he/she can and cannot do?"). The reason might be due to the young age of the children that it is, on average, often a problem for children to explain to others what they can and cannot do. EA is a complex disease with various

chronic morbidities and additional anomalies. As a result, understanding and even explaining for a child between 2 and 7 years what he/she can and cannot do is difficult.

In the version for children/adolescents aged 8-17 and their parents, this question is asked more precisely in several questions. For instance, item 24 ("Is it complicated for you/ your child to explain to others what esophageal atresia is?"). The mean for children /adolescents is 3.36 and for parents 3.6, so it seems like HrQoL regarding explaining to others what EA is and what one can and cannot do seems to improve by age but still remains an issue. The highest mean (4.44) for parents of children between 2 and 7 years could be found in the item 22 ("Does your child feel that teachers in the preschool/school give help when needed?") which means that the average of the parents think that their child receives often or always help from their teachers in case they need it. For children/adolescents between 8 and 17 years and their parents, item 46 ("Do you feel that teachers in the school/ your child's school understand that some things are difficult for you/ your child because of your/his/her health condition (e.g. sports)?"), the mean is 3.27 and for their parents, the mean is 3.18. This indicates, that on average, teachers did not always understand that some things are difficult for a child/adolescent with EA. Compared to younger children, the HrQoL might decrease by age and school type.

For children/adolescents between 8 and 17 years, the lowest HrQoL (Mean 2.18) could be found in item 37 ("Do you feel it is a positive thing that you were born with esophageal atresia?"). This is also applicable to their parents since the mean is 1.54. This indicates that EA negatively influences the HrQoL in children and adolescents because they never or rarely thought that it is a positive thing that they were born with EA. The highest HrQoL (Mean 4.54) for children and adolescents in item 32 ("Are you careful about what you wear because of your scar/scars?") implicates that they were never or rarely careful about what they wear because of their scar/s. It seems like they did not care about whether someone saw their scar/s or not and this implicates that they accepted their scar/s as a part of themselves. Their parents replied a bit differently because the mean here is 2.8 and therefore significantly lower. These disparities might be caused by different perceptions regarding the child's/adolescent's behavior. Since parents might be more worried and concerned when it comes to their child's chronic condition, they might have a more "negative" perspective. This can be also seen in a study by White-Koning et al. who compared the child's QoL through self-reports to parent proxy reports of 500 children (8-12 years), suffering from a chronic condition named Cerebral Palsy. The results showed that parents are rating their child's QoL lower than the children themselves. One reason that the researchers found out is that parenting of a child with a chronic condition leads to high levels of stress which influences the parents' perception regarding their child's health negatively (White-Koning et al., 2007, p. 804). Further, parents of chronically ill children and

adolescents also have an increased burden due to managing it and they can also experience restrictions in their daily life (Cadman et al., 1991, p. 884f; Eiser & Berrenberg, 1995, p. 109ff; World Health Organization, 2007, p. 5).

In general, the results of the Mann-Whitney-U test regarding the severity level for parents of children between 2 and 7 years, parents of children/adolescent between 8 and 17 years and children/adolescents between 8 and 17 years need to be critically discussed and interpreted with cautions because the sample size here ranges between nine and ten and is therefore very small.

Nevertheless, four items that measure differences with regard to the severity level of EA could be detected. It is interesting to see that in the questionnaire for parents of children aged 2-7 and 8-17, the same item (item 4/item 16) detected differences. From the parents' results, children with mild to moderate EA show significant lower HrQoL with regard to item 4/ item 16 ("Can your child eat at the pace he/she wants?") than children with severe EA. However, the expected result would be, that children/adolescents with severe EA have a significant lower HrQoL than children with mild to moderate EA. It was also the case for item 50 ("Does esophageal atresia make your child feel uncertain when it comes to boys/girls?") in the parent proxy report for children/ adolescents aged 8-17 years. A possible explanation could be that in case children/adolescents suffer from the severe form of EA, they have further health conditions which cause restrictions in their daily life so that maybe the consequences of EA seem less important.

For children/adolescents between 8 and 17 years, in item 22 ("Is it easy for you to be open with others about esophageal atresia?"), it is the opposite way. Children and adolescents with mild to moderate EA show significant higher HrQoL than children with severe EA. In conclusion, the EA questionnaire is supposed to include items that detect significant differences regarding severity level of EA. For that reason, the described items should be retained in the field- and retest.

The results of the cognitive debriefing showed that parents understood the four questions properly whereas for children/adolescents, they might lead to confusion.

For parents of children between 2 and 7 years, the results of the cognitive debriefing questions demonstrate a high level of agreement in total. This indicates that the used questions are widely accepted. Only one item was not considered to be relevant. Further, all 30 items were clear and important for these parents. The reason could be due to the fact that the most critical time for children with EA is right after they were born due to surgical treatment and adjustment to the health condition. However, seven items need to be reworded. The reason could be due to the fact that the instrument was developed in Swe-

dish, has then been translated into English and afterwards into German. During this process and in order to secure similarity, these seven items might be expressed differently. As a consequence, they need to be reworded in order to secure that parents in the field- and retest understand them properly.

For parents of children/adolescents between 8 and 17 years, the results of the cognitive debriefing showed that nearly all items are important, clear and understandable but not all items are considered to be relevant for one owns child. For instance, item 11 (“Is it a problem for your child if he/she drinks a lot when he/she eats?”), it might not be a problem for these children who were included in the pilot test that they drink a lot when they eat but it is still an important question which should be included in the field- and retest.

The self-report of children/adolescents between 8 and 17 years regarding the cognitive debriefing showed debatable results since the vast majority of items are neither relevant nor important for them. The results showed that only 4 out of 50 items are relevant for these children/adolescents whereas 28 items are considered to be important for children/adolescents in general with EA. Reason for it cannot be related to the “clearness” or “understanding” of these items, since only 4 out of 50 items are not clear and only one item needs to be reworded. Therefore, reasons for these results are can be only guessed. It might be due to the fact that the focus group discussions took place in the late afternoon, after these children/adolescents already went to school and might also have a long approach to come to the Medical School Hanover. Further, the EA questionnaire was completed at the end of the discussion. As a result, the level of concentration might be even lower. Additionally, the differences between the cognitive debriefing question “Is the question relevant” and “Is the question important” might not be understood properly and lead to confusion. Another aspect could be that they rated these items like this because, on average, they have a good quality of life and therefore, these items are neither relevant nor important for them because they are not affected.

If all the results are taken into consideration, a generalization of the results is limited due to the fact that the German EA-QoL study only included a small sample size of children and adolescents with EA and the study used the single-center design. The German EA-QoL study included 21 children and adolescents with EA as well as their parents. The sample size with $n=32$ is relatively small since compared to other studies since the other studies included between 28 and 92 participants (Dingemann et al., 2014, p. 631; Legrand et al., 2012, p. 808; Lepeytre et al., 2013, p. 1096; Ludman & Spitz, 2003, p. 53; Peetsold et al., 2010, p. 417). However, the German EA-QoL study is a pilot study with qualitative and quantitative phases. The primary aim here was not to measure HrQoL in children and adolescents born with EA but to include the patients’ perspective in developing an EA-

questionnaire (pilot version). Since this is the first study developing a condition-specific instrument for children and adolescents born with EA, a comparison to other studies is not possible (Dellenmark-Blom et al., 2016, p. 563).

6. Conclusion and outlook

Due to the shift from treating infectious disease to managing chronic conditions in pediatric medicine, HrQoL in children and adolescents became more in focus of research. Since EA is a rare congenital anomaly that can lead to chronic morbidities and additional anomalies, children and adolescents can experience physical, psychological and social consequences. However, the influence of EA on HrQoL in children and adolescents has only been targeted in five studies while none of these used a condition-specific questionnaire to measure HrQoL. With the help of the EA study, the first condition-specific HrQoL questionnaire, available for children and adolescents between 2-17 years via self- and proxy report, was developed and pilot tested in Sweden and Germany. The pilot testing of the instrument included a cognitive debriefing in order to evaluate each item. In order to select items for the field- and retest version, specific criteria have been set. The German EA-QoL study with 32 participants showed that for parents of children between 2 and 7 years, 24 items should be retained in the field- and retest and 42 items should be retained in the questionnaire for children/adolescents between 8 and 17 years and their parents. This is due to the fact that the parent proxy version and the self-report needs to be the same and the parent version should be included in the field- and retest from the German perspective since most items were neither important nor relevant for children/adolescents.

The Swedish expert team will also analyze the data of their pilot testing according to the same criteria that have been used for the German analysis. Additionally, they will make a DIF analysis for child gender (male/female) controlled for severity of EA as well as an item inter-correlation. Subsequently, the German and Swedish data sets will be matched in order to create a condition-specific instrument for children/adolescents with EA based on both pilot testing results.

A field test will be conducted in Sweden and Germany in order to psychometrically examine the EA questionnaire. For the German field-test, at least 50 children/adolescents and 75 parents will be recruited from four different organizations, namely KEKS, Medical School Hanover, University Hospital Hamburg-Eppendorf and Altona Children's Hospital. The field test version will be distributed to the participants either per mail or directly from the clinic/organization. For validation purpose, the PedsQL™, KIDSCREEN and DISAB-KIDS questionnaires will be distributed to the participants as well. In order to psychometri-

cally test the EA-questionnaire, a retest will be conducted with 10% of the participants of the field test. The retest questionnaire, which is the same as the field test questionnaire, will be send out to the families two weeks after the field test questionnaire arrived back at the clinic (EA-QoL, 2015, p.10). Subsequently, the collected data will be analyzed with the aim to achieve a valid and reliable instrument that can be further used in research, clinical trials as well as for medical decision making purposes. Moreover, the valid EA HrQoL questionnaire can be used in other countries as well after a respective culturally adaptation and validation. This allows, although EA is a rare condition, that many patients can provide information on their HrQoL and the condition can be understand more in depth. As a result, strategies, e.g. psychosocial interventions to improve the HrQoL in children and adolescents with EA can be developed, tested and implemented. With the help of those interventions, it is possible to increase the HrQoL of children and adolescents born with EA further support them in their future.

References

- A.D.A.M. Medical Encyclopedia. (2013). Esophageal Atresia. Retrieved from <https://www.nlm.nih.gov/medlineplus/ency/article/000961.htm> (05/10/2016)
- Bergmeijer, J. H. L. J., Tibboel, D., & Hazebroek, F. W. J. (2000). Nissen Fundoplication in the Management of Gastroesophageal Reflux Occurring After Repair of Esophageal Atresia. *Journal of Pediatric Surgery*, 35(4), 573-576.
- Brown, R. I., Faragher, R. M., & Merrick, J. (2014). Special Issue: Quality of life in a social context. *International Public Health Journal*, 6(4).
- Bullinger, M. (1991). Quality of Life- definition, conceptualization and implications: a methodologist's view. *Theoretical Surgery*, 6, 143-148.
- Bullinger, M. (2014). [The concept of quality of life in medicine: its history and current relevance]. *Z Evid Fortbild Qual Gesundheitswes*, 108(2-3), 97-103. doi:10.1016/j.zefq.2014.02.006
- Bullinger, M., & Quitmann, J. (2014). Quality of life as patient-reported outcomes: principles of assessment. *Dialogues Clin Neurosci*, 16(2), 137-145.
- Bundesministerium für Gesundheit. (2016). Gesundheitsgefahren - Seltene Erkrankungen. Retrieved from <http://www.bmg.bund.de/themen/praevention/gesundheitsgefahren/seltene-erkrankungen.html> (04/12/2016)
- Cadman, D., Rosenbaum, P., Boyle, M., & Offord, D. R. (1991). Children with chronic illness: family and parent demographic characteristics and psychosocial adjustment. *Pediatrics*, 87(6), 884-889.
- Chetcuti, P., Myers, N. A., Phelan, P. D., & Beasley, S. W. (1988). Adults who survived repair of congenital oesophageal atresia and tracheo-oesophageal fistula. *Bmj*, 297(6644), 344-346.
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol*, 8, 455-480. doi:10.1146/annurev-clinpsy-032511-143108
- Dellenmark-Blom, M., Chaplin, J. E., Gatzinsky, V., Jonsson, L., & Abrahamson, K. (2015). Health-related quality of life among children, young people and adults with esophageal atresia: a review of the literature and recommendations for future research. *Qual Life Res*, 24(10), 2433-2445. doi:10.1007/s11136-015-0975-x
- Dellenmark-Blom, M., Chaplin, J. E., Gatzinsky, V., Jonsson, L., Wigert, H., Apell, J., . . . Abrahamsson, K. (2016). Health-related quality of life experiences among children and adolescents born with esophageal atresia: Development of a condition-specific questionnaire for pediatric patients. *J Pediatr Surg*, 51(4), 563-569. doi:10.1016/j.jpedsurg.2015.09.023
- Deutsche Gesellschaft für Kinderchirurgie. (2012). Leitlinien der Deutschen Gesellschaft für Kinderchirurgie *Kurzstreckige Ösophagusatresie* (pp. 1-15): AWMF online - Das Portal der wissenschaftlichen Medizin.

- Dingemann, C., Meyer, A., Kircher, G., Boemers, T. M., Vaske, B., Till, H., & Ure, B. M. (2014). Long-term health-related quality of life after complex and/or complicated esophageal atresia in adults and children registered in a German patient support group. *J Pediatr Surg*, *49*(4), 631-638. doi:10.1016/j.jpedsurg.2013.11.068
- EA-QoL Group. (2015). *Study Protocol*. Department of Medical Psychology. University Medical Center Hamburg-Eppendorf, Hamburg, Germany.
- Eiser, C., & Berrenberg, J. L. (1995). Assessing the impact of chronic disease on the relationship between parents and their adolescents. *J Psychosom Res*, *39*(2), 109-114.
- Eiser, C., & Morse, R. (2001). Quality-of-life measures in chronic diseases of childhood. *Health Technol Assess*, *5*(4), 1-157.
- Engstrom, I. (1999). Inflammatory bowel disease in children and adolescents: mental health and family functioning. *J Pediatr Gastroenterol Nutr*, *28*(4), S28-33.
- Fayers, P. M., & Machin, D. (2000). *Quality of Life. Assessment, Analysis and Interpretation*. UK: John Wiley & Sons Ltd,.
- Fayers, P. M., & Machin, D. (2007). *Quality of Life: The assessment, analysis and interpretation of patient-reported outcome* (Second ed.): John Wiley & Sons.
- Goyal, A., Jones, M. O., Couriel, J. M., & Losty, P. D. (2006). Oesophageal atresia and tracheo-oesophageal fistula. *Arch Dis Child Fetal Neonatal Ed*, *91*(5), F381-384. doi:10.1136/adc.2005.086157
- Houben, C. H., & Curry, J. I. (2008). Current status of prenatal diagnosis, operative management and outcome of esophageal atresia/tracheo-esophageal fistula. *Prenat Diagn*, *28*(7), 667-675. doi:10.1002/pd.1938
- Kirch, W. (2008). Health-Related Quality of Life (HRQOL)Health-related quality of life (HRQOL). In W. Kirch (Ed.), *Encyclopedia of Public Health* (pp. 646-646). Dordrecht: Springer Netherlands.
- Kloek, J. J., van de Laar, G. A., Deurloo, J. A., Aronson, D. C., Benninga, M. A., Taminiau, J. A., & Heij, H. A. (2006). Long-term results of boerema anterior gastropexy in children. *J Pediatr Gastroenterol Nutr*, *43*(1), 71-76. doi:10.1097/01.mpg.0000215313.72826.bc
- Kovesi, T., & Rubin, S. (2004). Long-term complications of congenital esophageal atresia and/or tracheoesophageal fistula. *Chest*, *126*(3), 915-925. doi:10.1378/chest.126.3.915
- Legrand, C., Michaud, L., Salleron, J., Neut, D., Sfeir, R., Thumerelle, C., . . . Gottrand, F. (2012). Long-term outcome of children with oesophageal atresia type III. *Arch Dis Child*, *97*(9), 808-811. doi:10.1136/archdischild-2012-301730
- Lepeyre, C., De Lagausie, P., Merrot, T., Baumstarck, K., Oudyi, M., & Dubus, J. C. (2013). [Medium-term outcome, follow-up, and quality of life in children treated for type III esophageal atresia]. *Arch Pediatr*, *20*(10), 1096-1104. doi:10.1016/j.arcped.2013.06.035

- Lindahl, H., Rintala, R., & Louhimo, I. (1989). Failure of the Nissen fundoplication to control gastroesophageal reflux in esophageal atresia patients. *J Pediatr Surg*, *24*(10), 985-987.
- Lindahl, H., Rintala, R., & Sariola, H. (1993). Chronic esophagitis and gastric metaplasia are frequent late complications of esophageal atresia. *J Pediatr Surg*, *28*(9), 1178-1180.
- Ludman, L., & Spitz, L. (2003). Quality of life after gastric transposition for oesophageal atresia. *J Pediatr Surg*, *38*(1), 53-57; discussion 53-57. doi:10.1053/jpsu.2003.50009
- Malmstrom, K., Lohi, J., Lindahl, H., Pelkonen, A., Kajosaari, M., Sarna, S., . . . Makela, M. J. (2008). Longitudinal follow-up of bronchial inflammation, respiratory symptoms, and pulmonary function in adolescents after repair of esophageal atresia with tracheoesophageal fistula. *J Pediatr*, *153*(3), 396-401. doi:10.1016/j.jpeds.2008.03.034
- Mokkink, L. B., van der Lee, J. H., Grootenhuis, M. A., Offringa, M., & Heymans, H. S. (2008). Defining chronic diseases and health conditions in childhood (0-18 years of age): national consensus in the Netherlands. *Eur J Pediatr*, *167*(12), 1441-1447. doi:10.1007/s00431-008-0697-y
- Nassar, N., Leoncini, E., Amar, E., Arteaga-Vazquez, J., Bakker, M. K., Bower, C., . . . Mastroiacovo, P. (2012). Prevalence of esophageal atresia among 18 international birth defects surveillance programs. *Birth Defects Res A Clin Mol Teratol*, *94*(11), 893-899. doi:10.1002/bdra.23067
- National Center for Chronic Disease Prevention and Health Promotion. (2016). Health-Related Quality of Life - HRQOL Concepts.
- Neuhauser, H., & Poethko-Muller, C. (2014). [Chronic and vaccine-preventable diseases in children and adolescents in Germany: results of the KiGGS study: first follow up (KiGGS wave 1)]. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*, *57*(7), 779-788. doi:10.1007/s00103-014-1976-6
- Patrick, D. L., & Deyo, R. A. (1989). Generic and disease-specific measures in assessing health status and quality of life. *Med Care*, *27*(3 Suppl), S217-232.
- Patrick, D. L., & Erickson, P. (1993). Health status and health policy: Quality of life in health care evaluation and resource allocation. *Oxford University Press*.
- Pedersen, R. N., Markow, S., Kruse-Andersen, S., Qvist, N., Hansen, T. P., Gerke, O., . . . Husby, S. (2013). Esophageal atresia: gastroesophageal functional follow-up in 5-15 year old children. *J Pediatr Surg*, *48*(12), 2487-2495. doi:10.1016/j.jpedsurg.2013.07.019
- Peetsold, M. G., Heij, H. A., Deurloo, J. A., & Gemke, R. J. (2010). Health-related quality of life and its determinants in children and adolescents born with oesophageal atresia. *Acta Paediatr*, *99*(3), 411-417. doi:10.1111/j.1651-2227.2009.01579.x
- Perrin, J. M., & Shonkoff, J. P. (2000). Developmental disabilities and chronic illness: An overview. In R. E. Behrman, R. M. Kliegman, & H. B. Jenson (Eds.), *Textbook of Pediatrics* (pp. 121-129). Philadelphia: WB Saunders Company.

- Petersen, C., Schmidt, S., Power, M., & Bullinger, M. (2005). Development and pilot-testing of a health-related quality of life chronic generic module for children and adolescents with chronic health conditions: a European perspective. *Qual Life Res*, 14(4), 1065-1077.
- Preedy, V. R., & Watson, R. R. (2010). *Handbook of Disease Burdens and Quality of Life Measures*: Springer New York.
- Puntis, J. W., Ritson, D. G., Holden, C. E., & Buick, R. G. (1990). Growth and feeding problems after repair of oesophageal atresia. *Arch Dis Child*, 65(1), 84-88.
- Rintala, R. J., Sistonen, S., & Pakarinen, M. P. (2009). Outcome of esophageal atresia beyond childhood. *Semin Pediatr Surg*, 18(1), 50-56. doi:10.1053/j.sempedsurg.2008.10.010
- Schäfer, A., & Schöttker-Königer, T. (2015). *Statistik und quantitative Methoden für Gesundheitsfachberufe*: Springer Verlag.
- Schipper, H., Clinch, J. J., & Olweny, C. (1996). Quality of life studies: Definitions and conceptual issues. In B. Spilker (Ed.), *Quality of Life and Pharmacoeconomics in Clinical Trials* (pp. 11-24). Philadelphia: Lippincott-Raven.
- Schleusner, E. (2016). Ösophagusatresie *Klinisches Wörterbuch*. Berlin Boston: De Gruyter.
- Shaw-Smith, C. (2006). Oesophageal atresia, tracheo-oesophageal fistula, and the VACTERL association: review of genetics and epidemiology. *J Med Genet*, 43(7), 545-554. doi:10.1136/jmg.2005.038158
- Solans, M., Pane, S., Estrada, M. D., Serra-Sutton, V., Berra, S., Herdman, M., . . . Rajmil, L. (2008). Health-related quality of life measurement in children and adolescents: a systematic review of generic and disease-specific instruments. *Value Health*, 11(4), 742-764. doi:10.1111/j.1524-4733.2007.00293.x
- Spencer, A. (2014). For my son. Unbouncepages.com. <https://de.pinterest.com/pin/64528207135794936/> (07/07/2016).
- Spitz, L. (2007). Oesophageal atresia. *Orphanet J Rare Dis*, 2, 24. doi:10.1186/1750-1172-2-24
- SPSS Inc. (2008). SPSS Statistics for Windows, Version 17.0. Chicago: SPSS Inc.
- Stoll, C., Alembik, Y., Dott, B., & Roth, M. P. (2009). Associated malformations in patients with esophageal atresia. *Eur J Med Genet*, 52(5), 287-290. doi:10.1016/j.ejmg.2009.04.004
- Turner, R. R., Quittner, A. L., Parasuraman, B. M., Kallich, J. D., & Cleeland, C. S. (2007). Patient-reported outcomes: instrument development and selection issues. *Value Health*, 10 Suppl 2, S86-93. doi:10.1111/j.1524-4733.2007.00271.x
- U.S. Department of Health and Human Services, Food and Drug Administration, Center for Drug Evaluation and Research (CDER), Center for Biologics Evaluation and Research (CBER), Center for Devices and Radiological Health (CDRH). (2009). Guidance for Industry - Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. Retrieved from

<http://www.google.de/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUK Ewic5OWI1rHOAhVLEywKHRyzCplQFggfMAA&url=http%3A%2F%2Fwww.fda.gov%2Fdownloads%2FDrugs%2F...%2FGuidances%2FUcm193282.pdf&usq=AFQjCNG-mITIV0exgys5dSBepTt7IEhIlg&bvm=bv.129391328,d.bGg> (06/22/2016)

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 Generic Core Scales. *Health Qual Life Outcomes*, 5, 2. doi:10.1186/1477-7525-5-2

Vogt, E. (1929). Congenital Esophageal Atresia. *American Journal of Roentgenology*, 22(5), 463-465.

White-Koning, M., Arnaud, C., Dickinson, H. O., Thyen, U., Beckung, E., Fauconnier, J., . . . Colver, A. (2007). Determinants of child-parent agreement in quality-of-life reports: a European study of children with cerebral palsy. *Pediatrics*, 120(4), e804-814. doi:10.1542/peds.2006-3272

World Health Organization. (1948). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

World Health Organization. (1995). The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med*, 41(10), 1403-1409.

World Health Organization. (1997). Measuring Quality of Life - The World Health Organization Quality of Life Instruments (The WHOQOL-100 and the WHOQOL BREF) Retrieved from http://www.google.de/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUK Ewi1n9jG1LHOAhVCFiwKHbHfA2YQFgqeMAA&url=http%3A%2F%2Fwww.who.int%2Fmental_health%2Fmedia%2F68.pdf&usq=AFQjCNGS32RQ71xCOxWo7DL LvNjoN7rI7A&bvm=bv.129391328,d.bGg (06/19/2016)

World Health Organization. (2007). The Adolescent with a Chronic Condition: Epidemiology, developmental issues and health care provision, 1-52. Retrieved from http://www.google.de/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUK EwiEI7LVILTOAhXjPZoKHfRwApMQFgghMAA&url=http%3A%2F%2Fwhqlibdoc.who.int%2Fpublications%2F2007%2F9789241595704_eng.pdf&usq=AFQjCNGL 1 YjUf5vQ3uYYWI7vm3 Wu5zEw&bvm=bv.129389765,d.bGs (07/03/2016)

World Health Organization. (2015). Fact sheet - Congenital anomalies. Retrieved from <http://www.who.int/mediacentre/factsheets/fs370/en/> (05/20/2016)

Eidesstattliche Erklärung

„Ich versichere hiermit, dass ich die vorliegende Bachelor-Thesis zu dem Thema

Esophageal Atresia – Quality of Life in children, adolescents and their families

– The EA-QoL Study –

Pilot testing of a condition-specific Health related Quality of Life instrument

ohne fremde Hilfe selbständig verfasst und nur die angegebenen Hilfsmittel benutzt habe. Wörtlich oder dem Sinn nach aus anderen Werken entnommene Stellen sind unter Angabe der Quelle kenntlich gemacht.“

Hamburg, den 23.08.2016

Charline Jedro

Appendix

German EA questionnaire for parents of 2-7 year-old children

Denken Sie an **die letzten 4 Wochen**.

		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
								Zutreffend?	Verständlich?	wichtig?	anders zu formulieren?
1.	Ist es für ihr Kind ein Problem sich erbrechen zu müssen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
2.	Muss Ihr Kind spezielle Nahrungsmittel (z.B. püriertes, geschältes, feingeriebenes Essen oder Essen via Magensonde) zu sich nehmen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
3.	Langweilt es Ihr Kind, dass es anderes Essen bekommt als andere?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
4.	Kann Ihr Kind so schnell essen wie es möchte?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
5.	Stresst das Essen Ihr Kind?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
6.	Ist es schwierig für Ihr Kind, eine vollständige Mahlzeit zu essen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
7.	Hat Ihr Kind Angst vor dem Würgen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
8.	Muss Ihr Kind aufgrund seiner Krankheit langsam essen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
9.	Ist Ihr Kind kräftig genug, um zu spielen und Sport zu machen wie seine Freunde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
10.	Ermüdet Ihr Kind schnell, während es spielt oder Sport macht?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
11.	Wird Ihr Kind aufgrund seiner Krankheit von anderen Personen angesprochen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
12.	Stört es Ihr Kind, dass umstehende Personen Angst bekommen, sobald es mehr Geräusche (z.B. beim Atmen, Räuspern und/oder Husten) macht als andere Kinder?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
13.	Starren andere Ihr Kind an?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
14.	Stört es Ihr Kind, dass andere Bemerkungen über es machen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
15.	Erschwert die Krankheit Ihres Kindes ihm, nachts zu schlafen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
16.	Ist die Nahrungsaufnahme belastend für Ihr Kind, weil Essen in seinem Hals stecken bleibt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



	nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
							Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
17. Hat Ihr Kind Angst davor, beim Essen zu würgen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
18. Vermeidet es Ihr Kind zu essen, weil es Angst davor hat, zu würgen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
19. Schämt sich Ihr Kind, weil es Narben hat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
20. Kann Ihr Kind nach der Kita/Schule ohne vorherige sorgfältige Planung zu Freunden gehen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
21. Hat Ihr Kind das Gefühl, dass andere in der Kita/Schule es verstehen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
22. Hat Ihr Kind das Gefühl, dass die Erzieher/Lehrer in der Kita/Schule ihm helfen, falls es nötig ist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
23. Fühlt Ihr Kind sich aufgrund seiner Krankheit anders als andere Kinder?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
24.	Ist es ein Problem für Ihr Kind, dass es leichter Atemwegsinfektionen bekommt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
25.	Ist Ihr Kind sich selbst über seine Probleme mit den eingeschränkten Atemwegen bewusst (z.B. Husten, Verschleimtsen, Atemprobleme)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
26.	Ist es ein Problem für Ihr Kind, dass es im Vergleich zu gleichaltrigen Kindern kleiner ist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
27.	Hasst es Ihr Kind, Medikamente zu nehmen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
28.	Ist es für Ihr Kind schwierig, anderen zu erklären, was es kann und was nicht?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
29.	Ist es ein Problem für Ihr Kind, auf Feiern oder unterwegs mit Freunden etwas zu essen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
30.	Ist es ein Problem für Ihr Kind, dass es aufgrund seiner Krankheit in der Kita/Schule fehlt ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	

German EA questionnaire for parents of 8-17 year-old children/adolescents

Denken Sie an **die letzten 4 Wochen**.



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
1.	Ist ihr Kind kräftig genug, um genauso zu spielen und Sport zu machen wie seine Freunde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
2.	Stört es Ihr Kind, dass es schnell Atemprobleme bekommt, während es spielt oder Sport treibt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
3.	Macht Ihr Kind körperlich anstrengenden Sport (z.B. Joggen, Fußball, Handball)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
4.	Fällt es Ihrem Kind wegen seiner Krankheit schwer Sport zu machen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
5.	Ärgern andere Ihr Kind (z.B. weil es kleiner ist, viel hustet, langsamer isst oder wegen der Operationsnarbe/n)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
6.	Sagen andere gemeine Dinge über Ihr Kind?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
7.	Wird/wurde Ihr Kind in der Schule gehänselt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
8.	Hat Ihr Kind das Gefühl von anderen angestarrt zu werden (z.B. wegen des Hustens, Würgens oder wegen der Narben)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
9.	Muss Ihr Kind aufgrund seiner Krankheit bestimmtes Essen meiden (weil es sonst würgen muss oder unter Sodbrennen leidet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
10.	Ist Ihr Kind aufgrund seiner Krankheit beim Essen eingeschränkt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
11.	Bekommt Ihr Kind Probleme, wenn es zum Essen viel trinkt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
12.	Ist es für Ihr Kind belastend zu Essen aufgrund des Würgens?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
13.	Ist es ein Problem für Ihr Kind, dass es beim Essen würgen muss?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
14.	Stört es Ihr Kind, dass es langsamer isst als seine Freunde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
15.	Hast Ihr Kind aufgrund seiner Krankheit Schmerzen beim Essen (z.B. weil es sich verschluckt, würgt oder Sodbrennen bekommt)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
16.	Kann Ihr Kind so schnell essen wie es möchte?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
17.	Stört es Ihr Kind, wenn es etwas anderes Essen muss als seine Freunde (z.B. in der Schule)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
18.	Macht Ihr Kind sich Sorgen darüber, in Gegenwart anderer würgen zu müssen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
19.	Ist es ein Problem für Ihr Kind, dass es nach dem Essen erbrechen muss?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
20.	Stört es Ihr Kind, dass es spezielle Nahrung zu sich nehmen muss (z.B. püriertes, geschältes, feingeriebenes Essen oder Essen via Magensonde)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja	<input type="radio"/> Ja	<input type="radio"/> Ja	<input type="radio"/> Ja
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Nein	<input type="radio"/> Nein	<input type="radio"/> Nein	<input type="radio"/> Nein
21.	Hat Ihr Kind Angst, wenn es würgt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
22.	Fällt es Ihrem Kind leicht mit anderen über seine Krankheit zu sprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
23.	Ist es unangenehm für Ihr Kind, wenn andere es auf seine Krankheit ansprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
24.	Ist es schwierig für Ihr Kind, anderen zu erklären, was Ösophagusatresie ist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
25.	Nervt es Ihr Kind, wenn andere es auf seine Narben ansprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
26.	Stresst es Ihr Kind, wenn es sich beim Essen (in der Schule) beeilen muss?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
27.	Stört es Ihr Kind, wenn es immer der Letzte beim Essen (in der Schule) ist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
28.	Fällt es Ihrem Kind schwer (in der Schule) Ruhe zum Essen zu finden?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
29.	Muss Ihr Kind während des Essens (in der Schule) würgen oder erbrechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
30.	Fällt es Ihrem Kind leicht, sich anzupassen und Freunde zu finden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
31.	Fühlt sich Ihr Kind anders als andere aufgrund seiner Narben?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
32.	Achtet Ihr Kind darauf wegen seiner Narben, sich in einer besonderen Art und Weise anzuziehen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
33.	Findet Ihr Kind es unangenehm, wenn andere seine Narben sehen können (z.B. Fremde, Freunde, Partner)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
34.	Hat Ihr Kind das Gefühl wegen seiner Narben nicht perfekt zu sein?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
35.	Hat Ihr Kind aufgrund seiner Krankheit Schwierigkeiten nachts zu schlafen (wegen Sodbrennens, Atemprobleme, ...)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
36.	Muss Ihr Kind wegen seiner Krankheit besondere Dinge beachten, (z.B. Nahrung, Medikamente, Schlafposition, ...)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
37.	Findet Ihr Kind, dass es positive Aspekte daran gibt, dass es mit einer Ösophagusatresie geboren wurde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
38.	Ist Ihr Kind traurig darüber mit einer Ösophagusatresie geboren worden zu sein?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
39.	Ist es schlimm für Ihr Kind, Medikamente zu nehmen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
40.	Kann Ihr Kind mit Ihnen über seine Krankheit sprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
41.	Hat Ihr Kind das Gefühl, die/der Einzige zu sein, der/die mit Ösophagusatresie geboren wurde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
42.	Glaubt Ihr Kind, dass es auch andere wie ihn/sie gibt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



nie
selten
manchmal
oft
immer

Trifft nicht zu

Die Frage ist...

							Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
43.	Fühlt Ihr Kind sich klein im Vergleich zu Gleichaltrigen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
44.	Ist es schwer für Ihr Kind, Kleidung in seiner Größe zu finden?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
45.	Stört es Ihr Kind, dass es manchmal Aufstoßen muss oder Sodbrennen hat (nachts/tagsüber)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
46.	Haben/Hatten die Lehrer in der Schule Verständnis dafür, dass für Ihr Kind manche Dinge aufgrund seiner Krankheit schwierig sind/waren (z.B. Sport)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
47.	Stört es Ihr Kind, dass es anders husten muss als andere?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
48.	Ist es für Ihr Kind schlimmer als für andere, wenn es sich erkältet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
49.	Denkt Ihr Kind darüber nach, wie seine Zukunft aufgrund seiner Krankheit sein wird?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
50.	Verunsichert die Krankheit Ihres Kindes es, wenn es um Mädchen/Jungen (als Partner) geht?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein

German EA questionnaire for 8-17 year-old children/adolescents

Denke an **die letzten 4 Wochen.**



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
1.	Bist du kräftig genug, um genauso zu spielen und Sport zu machen wie deine Freunde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
2.	Stört es dich, dass du schnell Atemprobleme bekommst, wenn du spielst oder Sport treibst?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
3.	Machst du körperlich anstrengenden Sport (z.B. Joggen, Fußball, Handball)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
4.	Fällt es dir wegen deiner Krankheit schwer Sport zu machen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
5.	Ärgern dich andere (z.B. weil du kleiner bist, viel hustest, langsamer isst oder wegen deiner Operationsnarbe/n)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
6.	Sagen andere gemeine Dinge über dich?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
7.	Wirst/wurdest du in der Schule gehänselt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
8.	Hast du das Gefühl von anderen angestarrt zu werden (z.B. wegen des Hustens, Würgens oder wegen deiner Narben) ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
9.	Musst du wegen deiner Krankheit bestimmtes Essen meiden (weil du sonst würgen musst oder unter Sodbrennen leidest)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
10.	Bist du aufgrund deiner Krankheit beim Essen eingeschränkt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
11.	Bekommst du Probleme, wenn du zum Essen viel trinkst?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
12.	Ist es belastend für dich zu Essen aufgrund des Würgens?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
13.	Ist es ein Problem für dich, dass du beim Essen würgen musst?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
14.	Stört es dich, dass du langsamer isst als deine Freunde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
15.	Hast du aufgrund deiner Krankheit Schmerzen beim Essen (weil du dich verschluckst, würgst oder Sodbrennen bekommst)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
16.	Kannst du so schnell essen, wie du möchtest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
17.	Stört es dich, wenn du etwas anderes Essen musst als deine Freunde (z.B. in der Schule)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...			
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?
18.	Machst du dir Sorgen darüber, in Gegenwart anderer würgen zu müssen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
19.	Ist es ein Problem, nach dem Essen erbrechen zu müssen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
20.	Stört es dich, dass du spezielle Nahrung zu dir nehmen musst (z.B. püriertes, geschältes, feingeriebenes Essen via Magensonde)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
21.	Hast du Angst, wenn du dich verschluckst/würgst?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
22.	Fällt es dir leicht mit anderen über deine Krankheit zu sprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
23.	Ist es dir unangenehm, wenn andere dich auf deine Krankheit ansprechen ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
24.	Ist es schwierig, anderen zu erklären, was Ösophagusatresie ist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
25.	Nervt es dich, wenn andere dich auf deine Narben ansprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein
26.	Stresst es dich, wenn du dich beim Essen (in der Schule) beeilen musst?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
27.	Stört es dich, wenn du immer der Letzte beim Essen (in der Schule) bist?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
28.	Fällt es dir schwer, (in der Schule) Ruhe zum Essen zu finden?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
29.	Musst du während des Essens (in der Schule) würgen oder erbrechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
30.	Fällt es dir leicht, dich anzupassen und Freunde zu finden?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
31.	Fühlst du dich anders als andere aufgrund deiner Narben?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
32.	Achtest du darauf wegen deiner Narben, dich in einer besonderen Art und Weise anzuziehen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
33.	Findest du es unangenehm, wenn andere deine Narben sehen können (z.B. Fremde, Freunde, Partner)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
34.	Hast du das Gefühl wegen deiner Narben nicht perfekt zu sein?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
35.	Hast du aufgrund deiner Krankheit Schwierigkeiten nachts zu schlafen (wegen Sodbrennens , Atemprobleme, ...)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
36.	Musst du wegen deiner Krankheit besondere Dinge beachten,(z.B. Nahrung, Medikamente, Schlafposition, ...)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
37.	Findest du, dass es positive Aspekte daran gibt, dass du mit einer Ösophagusatresie geboren wurdest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
38.	Bist du traurig darüber mit einer Ösophagusatresie geboren worden zu sein ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
39.	Ist es schlimm für dich, Medikamente zu nehmen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
40.	Kannst du mit deinen Eltern über deine Krankheit sprechen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
41.	Hast du das Gefühl, die/der Einzige zu sein, der/die mit Ösophagusatresie geboren wurde?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
42.	Glaubst du, dass es andere wie dich gibt?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	



		nie	selten	manchmal	oft	immer	Trifft nicht zu	Die Frage ist...				
								Zutreffend?	Verständlich?	Wichtig?	anders zu formulieren?	
43.	Fühlst du dich klein im Vergleich zu Gleichaltrigen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
44.	Ist es schwer für dich, Kleidung in deiner Größe zu finden?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
45.	Stört es dich, dass du manchmal Aufstoßen musst oder Sodbrennen hast (nachts/tagsüber)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
46.	Haben/Hatten die Lehrer in der Schule Verständnis dafür, dass manche Dinge aufgrund deiner Krankheit schwierig für dich sind/waren (z.B. Sport)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
47.	Stört es dich, dass du anders husten musst als andere?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
48.	Ist es für dich schlimmer als für andere, wenn du dich erkältetest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
49.	Denkst du darüber nach, wie deine Zukunft aufgrund deiner Krankheit sein wird?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	
50.	Verunsichert dich die Krankheit, wenn es um Mädchen/Jungen (als Partner) geht?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	<input type="radio"/> Ja <input type="radio"/> Nein	

Quantitative analysis and cognitive debriefing data (parents of children aged 2-7)

No.	Item	N	Mean	SD	Skew	Kurtosis	Relevant %	Clear %	Important %	Wording %
1.	Is it a problem for your child that he/she vomits?	10	3.3	1.7	-0.58	-1.49	100	100	100	20
2.	Does your child have to eat particular/special foods (e.g. puréed food, peeled or grated food, or food given via a gastrostomy button) because of his/her health condition?	10	3.9	1.66	-1.25	-0.04	60	88.9	88.9	10
3.	Does your child find it boring to get different food than other people eat?	10	2.3	1.49	0.61	-0.99	77.8	87.5	87.5	10
4.	Can your child eat at the pace he/she wants?	10	3.6	1.35	-0.09	-2.02	100	100	100	22.2
5.	Does eating stress your child?	10	3.9	1.59	-1.03	-0.78	80	100	100	20
6.	Is it difficult for your child to eat a full meal?	10	3.3	1.64	-0.22	-1.53	100	100	100	20
7.	Is your child worried about choking?	10	3.5	1.43	-1.1	0.24	90	100	100	20
8.	Does your child's health condition cause him/her to eat slowly?	10	2.4	1.58	0.87	-0.57	100	100	100	22.2
9.	Does your child have less strength than other children during physically demanding activities?	10	2.2	0.92	-0.47	-1.8	100	100	100	10
10.	Does your child get tired easily when he/she plays games or sports?	10	3.6	1.17	-0.04	-1.46	90	100	100	0
11.	Do people make comments to your child because of his/her health condition?	10	3.6	1.26	-0.62	0.59	90	90	88.9	20
12.	Does it bother your child that people nearby get frightened when your child makes more noise than other children (e.g. breathing, clearing his/her throat, coughing)?	8	3.37	1.99	-0.55	-2.23	88.9	100	90	10
13.	Do people stare at your child?	9	3.33	1.58	-0.46	-1.03	77.8	100	88.9	11.1
14.	Does it bother your child that people make comments about him/her?	10	2.7	1.64	0.22	-1.53	88.9	100	100	0
15.	Does your child's health condition make it difficult for your child to sleep at night?	9	4	1	0	-2.43	100	100	90	0
16.	Is it hard for your child to eat because food sticks in his/her throat?	10	2.6	1.50	0.13	-1.49	88.9	100	100	0
17.	Is your child worried when he/she chokes on food?	9	2.67	2.00	-2.38	0.18	88.9	100	100	11.1
18.	Does your child avoid eating because he/she is afraid of choking?	9	3.22	2.11	0.27	-2.57	88.9	100	100	0
19.	Is your child ashamed of his/her scar?	8	4	1.85	-1.44	0.00	100	100	100	12.5

20.	Can your child go to other children's homes after preschool/school without careful planning?	10	2.3	1.70	0.93	-0.99	90	100	100	0
21.	Does your child feel that other children at the preschool/school understand him/her?	7	2.43	1.90	0.76	-1.69	100	88.9	100	11.1
22.	Does your child feel that teachers in the preschool/school give help when needed?	9	4.44	1.33	-2.69	7.42	100	100	100	0
23.	Does your child feel different than other children because of his/her health condition?	8	4.37	1.19	-1.65	1.35	100	100	100	0
24.	Is it a problem for your child that he/she gets respiratory infections easily?	10	3.6	1.17	-1.07	1.85	100	100	100	0
25.	Do your child feel self-conscious about his/her problems with restricted airways (e.g. coughing, phlegm, or difficulty breathing)?	9	3	1.66	-0.21	-1.67	100	100	100	0
26.	Is it hard for your child being small compared to other children of the same age?	8	3.62	1.6	-0.58	-1.27	90	100	100	0
27.	Does your child hate taking medicine?	10	3.3	1.16	-0.19	1.09	100	100	100	0
28.	Is it hard for your child to explain to others what he/she can and cannot do?	8	2.12	1.81	1.3	-0.26	75	100	100	11.1
29.	Is it a problem for your child to eat food at a party or when he/she is out with friends?	9	4.33	0.87	-0.82	-1.08	100	100	90	0
30.	Is it a problem for your child that his/her health condition involves absence from preschool/school?	8	2.37	1.6	0.58	-1.27	77.8	100	100	11.1

Table 8: Results of parents of children aged 2-7

Source: Own source

Quantitative analysis and cognitive debriefing data (parents of children/adolescents aged 8-17)

No.	Item	N	Mean	SD	Skew	Kurtosis	Relevant %	Clear %	Important %	Wording %
1.	Does your child has the strength to play sports (e.g. running, playing football) and play as his/her friends do?	11	4	1.18	-0.88	-0.61	90	100	100	0
2.	Is your child bothered by breathing difficulties when he/she exercises and plays?	11	2.73	1.42	0.07	-1.38	100	100	100	0
3.	Does your child participate in physical demanding activities (such as running, playing football, handball)?	11	3.82	1.54	-1.25	0.31	100	100	80	11.1
4.	Does your child find it difficult to play sports because of his/her health condition?	11	3.27	1.62	-0.19	-1.64	100	100	100	14.3
5.	Do others call your child names (e.g. because he/she is small, has an un-	11	3.54	1.29	-0.97	-0.6	81.8	100	88.9	0

	usual cough, eats slowly, or because he/she has a surgical scar)?									
6.	Do others say mean things about your child?	11	3.54	1.37	-0.69	-0.66	72.7	100	70	0
7.	Does your child gets teased about things in school?	11	4.36	1.03	-1.58	1.74	63.3	100	77.8	0
8.	Does your child has the feeling that others are staring at him/her (e.g. when coughing, choking, dressing in the locker room)?	11	3.27	1.01	0.05	-1	90.9	100	100	0
9.	Does your child has to think about avoiding certain foods because of his/her health condition (e.g. because of choking, acid reflux or heart burn)?	11	3.18	1.33	-0.09	-1.12	90.9	100	100	0
10.	Does your child's health condition restrict him/her from eating any food?	11	3.09	1.3	0.13	-0.88	88.9	100	100	0
11.	Is it a problem for your child if he/she drinks a lot when he/she eats?	11	4.36	1.29	-2.22	4.73	60	100	77.8	0
12.	Is it/does it feel hard for your child to eat because he/she chokes?	11	3.82	1.08	-0.15	-1.39	90.9	100	100	0
13.	Does your child feel it is a problem that he/she gets food stuck in his/her throat when he/she eats?	11	3.45	1.37	-0.46	-0.89	90	100	100	0
14.	Does it bother your child that it takes longer to eat for him/her than for his/her friends?	11	2.45	1.75	0.77	-1.28	60	100	77.8	0
15.	Does your child get any pain when he/she eats because of his/her health condition (e.g. when food gets stuck in his/her throat, heartburn, stomach ache)?	11	3.82	1.33	-1.16	0.68	70	100	100	0
16.	Can your child eat at the pace he/she wants?	10	2.9	1.37	-0.1	-1.17	90	100	77.8	12.5
17.	Does it bother your child if he/she gets other food in school than his/her friends?	11	2.09	1.45	1.02	-0.19	44.4	100	66.7	12.5
18.	Does your child worry about choking in front of others?	11	2.54	1.44	0.26	-1.25	66.7	100	77.8	0
19.	Is it a problem that your child vomit food after eating?	11	2.73	1.42	-0.44	-1.97	77.8	100	88.9	0
20.	Does your child feel that it is a problem for him/her that he/she must have specialized/particular food (e.g. puréed food, nutritional drink, or food through a gastrostomy button)?	11	2	1.73	1.27	-0.38	22.2	100	100	0
21.	Is your child afraid when he/she chokes?	11	2.73	1.79	0.24	-1.91	66.7	100	88.9	0
22.	Is it easy for your child to be open with others about esophageal atresia?	9	3.22	1.3	-0.08	-0.19	100	100	81.8	0
23.	Does it feel awkward for your child when others ask him/her about esophageal atresia?	10	3.3	1.49	-0.39	-0.78	88.9	100	70	0
24.	Is it complicated for your child to explain to others what esophageal atresia is?	10	3.6	1.71	-0.71	-1.36	75	100	90	0
25.	Does your child get tired of people asking about the scar/scars?	10	2.7	1.34	0.33	-0.85	87.5	100	70	0

26.	Is your child stressed by having to finish his/her meal in time in the school cafeteria?	10	2.1	1.59	1.44	0.68	88.9	100	77.8	0
27.	Does it feel like your child is always the last one to finish when he/she eats in the school cafeteria?	10	1.8	1.32	1.18	-0.58	62.5	100	75	0
28.	Is it hard for your child to find peace and quiet when he/she eats in the school cafeteria?	11	2.36	1.36	0.93	-0.27	77.8	90.9	77.8	11.1
29.	Does your child choke or vomit when eating in the school cafeteria?	10	3.2	1.69	-0.39	-1.57	87.5	100	77.8	0
30.	Is it easy for your child to fit in and make friends?	10	3.1	1.52	0.03	-1.12	100	100	75	20
31.	Does your child feel different because he/she has scars?	11	3.45	1.44	0.75	-0.32	88.9	100	70	0
32.	Is your child careful about what he/she wears because of his/her scar/scars?	10	2.8	1.81	0.23	-2.02	75	100	72.2	0
33.	Does your child feel awkward when his/her scar/scars are visible to others (e.g. strangers, new people, boyfriend/girlfriend, friends or classmates in the locker room, people in the swimming pool)?	11	2.91	1.51	-0.03	-1.32	77.8	100	77.8	0
34.	Does your child feel that he/she is not perfect because he/she has scars?	11	3.27	1.74	-0.37	-1.77	77.8	100	70	0
35.	Does your child have trouble sleeping at night because of his/her health condition (e.g. acid reflux, heartburn, or respiratory problems)?	11	2.64	1.36	0.23	-0.97	88.9	100	80	10
36.	Does your child's health condition mean that he/she has to think about, for example, what he/she eats, taking medicines on time, sleeping in a raised position (extra pillows) to sleep well?	11	1.82	1.6	1.79	1.65	77.8	100	100	0
37.	Does your child feel it is a positive thing that he/she was born with esophageal atresia?	11	1.54	0.82	1.15	-0.25	77.8	100	88.9	0
38.	Does your child feel sad that he/she was born with esophageal atresia?	11	3.27	1.68	-0.37	-1.49	75	100	81.8	0
39.	Is it hard for your child having to take medications?	11	2.82	1.83	0.09	-2.12	55.6	100	100	0
40.	Does your child feel he/she can talk to you as parents about esophageal atresia?	11	3.82	1.33	-1.16	0.68	88.9	100	100	0
41.	Does your child feel like the only one who was born with esophageal atresia?	10	2.6	1.65	0.43	-1.47	75	100	80	0
42.	Does your child feel that there are other children like him/her?	9	3.56	1.59	-0.97	-0.44	87.5	88.9	75	22.2
43.	Does your child feel small compared to his/her friends?	9	1.78	1.39	1.92	3.38	62.5	100	71.4	12.5
44.	Is it hard for your child to find clothes because of his/her height or body size?	11	2.73	1.85	0.25	-2.13	44.4	100	62.5	0
45.	Does it bother your child that he/she gets acid reflux/heart burn (day and/or night)?	11	2.18	1.25	1.01	-1.25	60	100	80	0
46.	Do you feel that teachers in your child's school understand that some things are difficult for your child because of his/her health condition (e.g. sports)?	11	3.18	1.94	-0.21	-2.25	77.8	100	100	0

47.	Is your child bothered by that he/she has a different kind of cough?	11	2.64	1.75	0.55	-1.69	66.7	100	100	0
48.	Is it worse for your child than for others when he/she catches a cold?	11	2.64	1.5	0.55	-1	100	100	100	0
49.	Does your child think about how his/her future will be because of his/her esophageal atresia?	11	3.91	1.7	-1.17	-0.52	66.7	100	70	0
50.	Does esophageal atresia make your child feels uncertain when it comes to boys/girls?	11	3	2	0	-2.33	50	100	71.4	12.5

Table 9: Results of parents of children/adolescents aged 8-17
Source: Own source

Quantitative analysis and cognitive debriefing data (children/adolescents aged 8-17)

No.	Item	N	Mean	SD	Skew	Kurtosis	Relevant %	Clear %	Important %	Wording %
1.	Do you have the strength to play sports (e.g. running, playing football) and play as your friends do?	11	3.64	1.36	-0.64	-0.44	63.3	81.8	72.7	9.1
2.	Are you bothered by breathing difficulties when you exercise and play?	11	2.36	1.36	0.64	-0.44	60	100	90.9	0
3.	Do you participate in physical demanding activities (such as running, playing football, handball)?	11	4.27	1.01	-1.37	1.31	81.8	90.9	54.5	9.1
4.	Do you find it difficult to play sports because of your health condition?	11	3.54	1.44	-0.48	-1.11	36.4	90.9	81.8	0
5.	Do others call you names (e.g. because you are small, have an unusual cough, eat slowly, or because you have a surgical scar)?	11	4.45	1.21	-2.74	7.94	20	100	63.6	0
6.	Do others say mean things about you?	11	4.45	0.82	-1.15	-0.25	27.3	100	63.6	0
7.	Do you get teased about things in school?	11	4.09	1.64	-1.5	0.63	30	81.8	54.5	9.1
8.	Do you feel that others are staring at you (e.g. when coughing, choking, dressing in the locker room)?	11	3.36	1.69	-0.55	-1.41	36.4	81.8	72.2	0
9.	Do you have to think about avoiding certain foods because of your health condition (e.g. because of choking, acid reflux or heart burn)?	11	3.91	1.22	-1.4	2.32	45.5	90.9	90.9	9.1
10.	Does your health condition restrict you from eating any food?	11	3.91	1.22	-1.4	2.32	36.4	90.9	90.9	0
11.	Is it a problem if you drink a lot when you eat?	11	4.09	1.64	-1.5	0.63	9.1	90.9	90.9	0
12.	Is it/does it feel hard for you to eat because you choke?	11	3.82	1.6	-1.07	-0.3	18.2	90.9	90.9	9.1
13.	Do you feel it is a problem that you get food stuck in your throat when you eat?	11	3.64	1.57	-0.78	-0.68	45.5	90.9	81.8	9.1

14.	Does it bother you that it takes longer to eat for you than for your friends?	11	4.36	1.43	-2.03	2.81	20	90.9	72.7	0
15.	Do you get any pain when eat because of your health condition? (e.g. when food gets stuck in your throat, heartburn, stomach ache?)	11	3.64	1.57	-0.78	-0.68	36.4	100	90.9	0
16.	Can you eat at the pace you want?	11	3.27	1.62	-0.19	-1.64	72.7	100	81.8	0
17.	Does it bother you if you get other food in school than your friends?	11	3.91	1.87	-1.19	-0.76	20	100	45.5	0
18.	Do you worry about choking in front of others?	11	3.18	1.83	-0.09	-2.12	27.3	72.7	63.6	0
19.	Is it a problem that food you vomit after eating?	11	3.54	1.81	-0.65	-1.55	30	81.8	90.9	0
20.	Do you feel that it is a problem for you that you must have specialized/particular food (e.g. pureed food, nutritional drink, or food through a gastrostomy button)?	11	3.91	1.87	-1.19	-0.76	30	90.9	63.6	0
21.	Are you afraid when you choke?	11	3.82	1.47	-0.77	-0.76	45.5	100	72.7	0
22.	Is it easy for you to be open with others about esophageal atresia?	11	3	1.73	-0.14	-1.84	80	81.8	54.5	9.1
23.	Does it feel awkward when others ask you about esophageal atresia?	11	3.82	1.33	-0.85	0.23	60	100	63.6	9.1
24.	Is it complicated to explain to others what esophageal atresia is?	11	3.36	1.57	-0.36	-1.28	54.5	81.8	63.6	9.1
25.	Do you get tired of people asking about the scar/scars?	11	3.45	1.69	-0.43	-1.72	63.6	90.9	72.7	9.1
26.	Are you stressed by having to finish your meal in time in the school cafeteria?	10	3.9	1.66	-1.25	-0.04	27.3	72.7	45.5	0
27.	Does it feel like you are always the last one to finish when you eat in the school cafeteria?	11	4	1.61	-1.4	0.44	10	81.8	36.4	9.1
28.	Is it hard for you to find peace and quiet when you eat in the school cafeteria?	11	3.18	2.09	-0.21	2.44	18.2	90.9	45.5	0
29.	Do you choke or vomit when eating in the school cafeteria?	11	4.45	1.29	-2.42	5.51	27.3	90.9	81.8	9.1
30.	Is it easy for you to fit in and make friends?	11	3.09	1.97	0.13	-1.87	36.4	81.8	54.5	9.1
31.	Do you feel different because you have scars?	11	4.09	1.37	-1.32	0.98	18.2	100	72.7	0
32.	Are you careful about what you wear because of your scar /scars?	11	4.54	1.21	-3	9.23	18.2	90.9	54.5	0
33.	Do you feel awkward when your scar/scars are visible to others (e.g. strangers, new people, boyfriend/girlfriend, friends or classmates in the locker room, people in the swimming pool)?	11	4	1.34	-1.21	0.93	27.3	81.8	54.5	0
34.	Do you feel that you are not perfect because you have scars?	11	4	1.61	-1.4	0.44	27.3	100	72.7	27.3
35.	Do you have trouble sleeping at night because of your health condition (e.g. acid reflux, heartburn, or respiratory problems)?	11	3.64	1.69	-0.67	-1.36	27.3	90.9	90.9	0
36.	Does your health condition mean that you have to think about, for example,	11	3.91	1.58	-0.94	-0.95	27.3	90.9	90.9	0

	what you eat, taking medicines on time, sleeping in a raised position (extra pillows) to sleep well?									
37.	Do you feel it is a positive thing that you were born with esophageal atresia?	11	2.18	1.72	0.95	-1.01	36.4	63.6	63.6	18.2
38.	Do you feel sad that you were born with esophageal atresia?	11	4	1.34	-1.21	-0.93	30	81.8	90.9	0
39.	Is it hard having to take medications?	11	3.45	1.86	-0.48	-1.92	18.2	100	81.8	0
40.	Do you feel you can talk to your parents about esophageal atresia?	11	4.09	1.64	-1.5	0.63	54.5	90.9	63.6	0
41.	Do you feel like the only one who was born with esophageal atresia?	11	2.91	1.81	0.16	-1.96	33.3	100	90	0
42.	Do you feel that there are other children like you?	11	4.18	1.25	-1.91	3.87	70	90.9	72.7	9.1
43.	Do you feel small compared to your friends?	11	3.18	2.09	-0.21	-2.44	27.3	81.8	54.5	0
44.	Is it hard for you to find clothes because of your height or body size?	11	3.54	1.75	-0.77	-1.28	45.5	81.8	45.5	0
45.	Does it bother you that you get acid reflux/heart burn (day and/or night)?	11	3.82	1.4	-0.94	-0.14	54.5	90.9	90	0
46.	Do you feel that teachers in the school understand that some things are difficult for you because of your health condition (e.g. sports)?	11	3.27	1.85	-0.49	-1.92	36.4	81.8	63.6	0
47.	Are you bothered by that you have a different kind of cough?	11	3.54	1.81	-0.65	-1.55	27.3	90.9	90.9	0
48.	Is it worse for you than for others when you catch a cold?	11	3.73	1.85	-0.9	-1.27	54.5	81.8	81.8	0
49.	Do you think about how your future will be because of your esophageal atresia?	11	3.73	1.62	-0.85	-0.76	36.4	81.8	72.7	0
50.	Does esophageal atresia make you feel uncertain when it comes to boys/girls?	11	4.27	1.62	-1.92	2.04	18.2	72.7	36.4	0

Table 10: Results of children/adolescents aged 8-17

Source: Own source