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Knowledge Needs of Parents of Infants with Congenital Abnormalities

Kristin Adler

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When you're going to have a baby, it's like you're planning a vacation to Italy. You're all excited. You get a whole bunch of guidebooks, you learn a few phrases so you can get around, and then it comes time to pack your bags and head for the airport.

Only when you land, the stewardess says, "WELCOME TO HOLLAND."

You look at one another in disbelief and shock, saying, "HOLLAND? WHAT ARE YOU TALKING ABOUT? I SIGNED UP FOR ITALY."

But they explain that there's been a change of plan, that you've landed in Holland and there you must stay.

"BUT I DON'T KNOW ANYTHING ABOUT HOLLAND!" you say. 'I DON'T WANT TO STAY!"

But stay you do. You go out and buy some new guidebooks, you learn some new phrases, and you meet people you never knew existed. The important thing is that you are not in a bad place filled with despair. You're simply in a different place than you had planned. It's slower paced than Italy, less flashy than Italy, but after you've been there a little while and you have a chance to catch your breath, you begin to discover that Holland has windmills. Holland has tulips. Holland has Rembrandts.

But everyone else you know is busy coming and going from Italy. They're all bragging about what a great time they had there, and for the rest of your life, you'll say, "YES, THAT'S WHAT I HAD PLANNED."

The pain of that will never go away. You have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very significant loss. But if you spend your life mourning the fact that you didn't get to go to Italy, you will never be free to enjoy the very special, the very lovely things about Holland.

Emily Perl Kingsley

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KRISTIN ADLER: Knowledge Needs of Parents of Infants with Congenital Abnormalities
Doctoral Dissertation, 169 pp.
Doctoral Programme in Nursing Science

ABSTRACT

Parents of a child suffering from a congenital abnormality face multiple challenges in the first months of the life of their baby. Besides managing the fact that their child is not "normal" they have to learn about many treatments and specialised care-giving tasks for their infant. They need to learn numerous new skills and need lot of information and knowledge to be ready to care for their child after being discharged from hospital.

The purpose of this three-phased study was to assess the knowledge of parents of a child with a congenital abnormality, during and after the first hospitalisation.

In phase I, an integrative literature review was conducted to review current instruments for the assessment of knowledge needs and what knowledge needs parents with a child with special health care needs have. In addition, three interviews with parents and two focus group interviews with nurses and social care counsellors were conducted. To strengthen the methodological approach in focus group interviews with this special population, a methodological review about focus group interviews in child, youth and parent research was conducted.

In phase II, the data of the literature review and the extracted data of the focus group interviews and the interviews with the parents was used to develop an instrument to assess these knowledge needs. The items were reduced through estimating the content validity index. A content validity index of 0.80 was set for the items of the instrument.

In phase III, the instrument was tested on three wards, one ward in every University Hospital (two in Switzerland, one in Germany) and the knowledge needs of the parents were collected. The feasibility was confirmed by the users of the instrument.

Results: Parents of a child with special health care needs, need knowledge about the diagnosis, the treatment and care of their child, the therapy and the short- and long-term prognosis. The information must be in a terminology adapted to the parents' language and cognitive skills. Conclusion: The needed knowledge should be given recurrently and adapted to existing level of the parents' knowledge. To assess the level of the parents' knowledge, an instrument like the one developed and used in this study is helpful.

KEYWORDS: Congenital abnormality, special health care needs, knowledge needs, assessment, interviews, focus groups

TURUN YLIOPISTO
Lääketieteellinen tiedekunta
Hoitotieteenlaitos
Hoitotiede
KRISTIN ADLER: Synnynnäisiä poikkeavuuksia sairastavien pikkulasten vanhempien tietotarpeet
Doctoral Dissertation, 169 pp.
Doctoral Programme in Nursing Science

TIIVISTELMÄ

Synnynnäisiä poikkeavuuksia sairastavien lasten vanhemmat kohtaavat haasteita lapsensa ensimmäisten elinkuukausien aikana. Sen lisäksi, että he joutuvat selviytymään siitä, että heidän lapsensa ei ole ”normaali”, heidän on tutustuttava moniin hoitoihin, joita heidän lapsensa tarvitsee. Heidän on opeteltava lukuisia uusia taitoja, ja he tarvitsevat paljon tietoa voidakseen hoitaa lastaan sairaalasta kotiutumisen jälkeen.

Tämän kolmivaiheisen tutkimuksen tarkoituksena oli arvioida synnynnäisiä poikkeavuuksia sairastavien vastasyntyneiden vanhempien tietoja ensimmäisen sairaalahoitojakson aikana ja sen jälkeen.

Vaiheessa I tehtiin integroiva kirjallisuuskatsaus, jossa tarkasteltiin nykyisiä välineitä tietotarpeiden arvioimiseksi ja sitä, millaisia tietotarpeita on vanhemmilla, joilla on synnynnäisiä poikkeavuuksia sairastava lapsi. Lisäksi tehtiin kolme vanhempien haastattelua ja kaksi fokusryhmähaastattelua sairaanhoitajien ja sosiaalihuollon ammattilaisten kanssa. Fokusryhmähaastattelujen metodologisen lähestymistavan vahvistamiseksi tehtiin metodologinen katsaus fokusryhmähaastatteluista lasten, nuorten ja heidän vanhempiensa tutkimuksessa.

Vaiheessa II kirjallisuuskatsauksen tietoja sekä fokusryhmähaastattelujen ja vanhempien haastattelujen tietoja käytettiin kehittämään arviointityökalu näiden tietotarpeiden arvioimiseksi. Väittämiä vähennettiin testaamalla aineistoa sisällön validiteetti-indeksin avulla. Arviointityökalun väittämien sisällön validiteetti-indeksiksi asetettiin tasolle 0,80.

Vaiheessa III arviointityökalu testattiin kolmella osastolla, yksi osasto kustakin tutkimukseen osallistuneesta yliopistosairaalasta (kaksi Sveitsissä, yksi Saksassa), sekä kerättiin vanhempien tiedontarpeet. Arviointityökalun käyttäjät vahvistivat sen käytettävyyden.

Tulokset: Synnynnäisiä poikkeavuuksia sairastavien lasten vanhemmat tarvitsevat tietoa lapsensa diagnoosista, hoidosta, terapiasta sekä lyhyen ja pitkän aikavälin ennusteesta. Tietojen esittämisessä tulee käyttää vanhempien kielellisiin ja kognitiivisiin taitoihin mukautettua käsitteistöä.

Johtopäätökset: Tarvittavaa tietoa olisi annettava toistuvasti ja se olisi mukautettava vanhempien nykyiseen tietämystasoon. Vanhempien tietämyksen tason arvioimiseksi on hyödyllistä käyttää tässä tutkimuksessa kehitetyn ja käytetyn kaltaista työkalua.

AVAINSANAT: Synnynnäinen epämuodostuma, terveydenhuollon erityistarpeet, tiedontarpeet, arviointi, haastattelut, fokusryhmät.

Table of Contents

Abbreviations

CINAHL	Cumulative Index to Nursing & Allied Health Literature
CVI	Content Validity Index
EMBASE	Biomedical literature database
ERIC	Online library of education research and information, sponsored by the Institute of Education Sciences (IES) of the U.S. Department of Education
EUROCAT	European network of population-based registries for the epidemiological surveillance of congenital anomalies
LOE	Level of Evidence
PubMed	the National Library of Medicine's® (NLM) free, searchable bibliographic database supporting scientific and medical research
MINI I, II	Mothers' Information Needs Instrument
OECD	Organisation for Economic Co-operation and Development
PEG	Percutaneous endoscopic gastrostomy
PsycINFO	Library of psychological science of the American Psychological Association
WHO	World Health Organization

List Of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Adler, K., Salanterä, S., Leino-Kilpi, H., Grädel, B.. An Integrated Literature Review of the Knowledge Needs of Parents with Children with Special Health Care Needs and of Instruments to Assess These Needs. *Infants & Young Children*, 2015; 1: 46-71.

II Adler, K., Salanterä, S. Zumstein-Shaha M.. Focus Group Interviews in Child Youth and Parent Research – an integrated literature review. *International Journal of Qualitative Methods*, 2019; 18: 1-15.

III Adler, K., Salanterä, S. Zumstein-Shaha M.. Wissensbedürfnisse von Eltern eines Kindes mit einer angeborenen Fehlbildung und erhöhtem Pflegebedarf vor der Entlassung vom ersten Krankenhausaufenthalt nach der Geburt. *Pflegewissenschaft*, 2021; 1: 32-44.

IV Adler, K., Salanterä, S. Zumstein-Shaha M.. Developing and Testing an Instrument to Assess Knowledge Needs of Parents with a Child with Congenital Abnormality and Special Health Care Needs, (manuscript).

1 Introduction

In the penultimate decade the number of children which died because of congenital abnormalities decreased in Europe (Europäische Gemeinschaften, 2008, 2010; OECD, 2008). Since 2010 the number of deaths caused by congenital abnormalities has remained more or less the same (WHO, 2018). With a better prenatal screening fewer babies are born with congenital abnormalities such as Spina bifida, Laparoschisis / Gastroschisis and heart defects. Due to rapid progress in pediatric surgical specialities and neonatal intensive care, most abnormalities lead not to death but sometimes to long-term disability with the need of additional specialised care.

Parents of a child suffering from a congenital abnormality face multiple tasks in the first months of the life of their baby. Besides coping with the fact that their child is "not normal" they must be taught several treatments and specialised care-giving tasks of their infant e.g., care for a stoma, a shunt after developing a hydrocephalus, catheterisation or intensive physiotherapy. The baby may also have feeding problems or develop not normally and she or he has to spend the first weeks or months in hospital. This can be a challenging phase for the parents (McCorkell, McCarron, Blair, & Coates, 2012; Reeder & Morris, 2021).

Perceived importance of needs, expressed by the parents is significantly and positively correlated with their perception of how their needs are being met and with their request for help from the hospital to fulfil them. The items related to parents' needs to trust nurses and doctors are consistently rated as very important (Kristjansdottir, 1995; Lundberg, Lindström, Roen, & Hegarty, 2016; Seliner, Latal, & Spirig, 2016; Umar et al., 2021) .

In their study Jackson et al., (2008) analysed parents' informational needs and psychological experiences when supporting their children with health care needs. In the qualitative analysis they grouped the findings into four themes: delivery of information, levels of support, relationships between the family and professionals, and management of events.

Similarly, "receiving information" and "mutual trust" were the two factors of particular importance in the relationship between parents and health care personnel. (Halvorsen et al., 2020; Jiang, Sun, Zhou, & Feng, 2021; Nuutila & Salanterä, 2006). As the needs for support and information change, they ought to be assessed on a

continuous basis (Boyse, Gardner, Marvicsin, & Sandberg, 2014; Nuutila & Salanterä, 2006).

From experience, taking home a baby for the first time or an older child after a first or repeated hospitalisation may be a very stressful, anxiety-provoking experience for the parents (Hurley, Kiernan, & Price, 2021; Nayeri, Roddehghan, Mahmoodi, & Mahmoodi, 2021). Anxiety is often the result of perceptions of lack of preparedness and doubts about competence to manage their child's care at home (Weiss et al., 2008). Because of insufficient information about their child's health condition, parents felt insecure when it was time to seek help for their children. They felt, that the families were weakened in making decisions about their child's care if they were not involved in discharge planning (Altman, Zurynski, Breen, Hoffmann, & Woolfenden, 2018).

Often there is no agreed pathway for the discharge planning of children with complex care needs, the information is mostly provided on an ad hoc basis (Brenner et al., 2015; Mannarino, Michelson, Jackson, Paquette, & McBride, 2020). A good discharge-management of these children is very complex but also very important to enable / empower the parents to a good start in their new life with their baby (Altman et al., 2018; Bhansali et al., 2016; Bowles, Jnah, Newberry, Hubbard, & Roberston, 2016; Brenner et al., 2015; Goes & Cabral, 2017; Lewis & Noyes, 2007; L. Smith & Daughtrey, 2000).

Several studies have been conducted assessing the needs of parents of children that are long-term ill or suffer of a congenital abnormality (Aite et al., 2006; Alsem et al., 2014; Brenner et al., 2015; Çınar, Ay, Boztepe, & Gürlen, 2021; Hummelinck & Pollock, 2006; R. Jackson et al., 2008; Ragan, Duffett-Leger, Laing, & Boctor, 2021; Reeder & Morris, 2021; Siebes, Ketelaar, Gorter, Alsem, & Jongmans, 2012; Starke & Moller, 2002; Stinson & McKeever, 1995; Umar et al., 2021; Young, O'Riordan, Goldstein, & Robin, 2001).

They show, that the parents need information about the diagnosis of the child, description of the anomaly and the prognosis in terms of survival chances of the baby before surgery and after surgery, the cause of the anomaly, the steps of the recovery process as well as the quality of their baby's life (Aite et al., 2006; Çınar et al., 2021). Further information is needed about their child's condition, symptoms, tests, treatment and medication (Gold et al., 2020; Jachimiec, Obrecht, & Kavanaugh, 2015). They needed information about services that are available for their child about financial resources and how to access them, about insurance plans. They also wanted more training with the therapy techniques (Alsem et al., 2014). They need opportunities to practice homecare skills (Desai, Durkin, Jacob-Files, & Mangione-Smith, 2016) and how to administer the child's medication (Boyse et al., 2014; Gold et al., 2020; Lundberg et al., 2016).

Where the family can obtain support and having personal needs satisfied are further described needs in literature (Alsem et al., 2014; Douma et al., 2020; Hallstrom & Elander, 2007). If parents were not sure when and where to seek help for their child this could result in a delay before bringing the child to hospital. This could result in worsening of the child's condition or the need to bring the child to the emergency department instead of the health care providers in the community (Altman et al., 2018).

These studies show that assessing the needs of parents of a child with an illness or a congenital abnormality and the relationship between the families and the health care personnel is very complex but also very important. This is not restricted to the needs during hospitalisation it also includes what parents need to be able to get on in everyday life after the hospitalisation and how they can cope with the situation. Parents want to participate in "planning of the child's care", "the child's care and rehabilitation" and in "decisions concerning their child's care and treatment" (Balling & McCubbin, 2001; Barone, Boss, Raisanen, Shepard, & Donohue, 2020; Hallstrom & Elander, 2007; Umar et al., 2021).

Parents get many information from nurses through their regular exchange (Goes & Cabral, 2017; Miles, Carlson, & Brunssen, 1999), so nurses are in a key role to assess what knowledge parents need to be able to care for their sick baby (Lundblad, Byrne, & Hellstrom, 2001). The perception of health care staff about the needs of parents does not always match the perceived needs of parents. Some needs were seen as more important to health care staff than to parents, others were seen as more important to parents than to the health care stuff (Mannarino et al., 2020; Shields, Kristensson-Hallstrom, & O'Callaghan, 2003).

Research in the paediatric setting looking at parents' knowledge needs to be able to care for their handicapped or ill baby is increasing. The population is small and neglected. There is still little research in specialised settings and there is a lack of instruments that support nurses to assess knowledge needs of parents having a child with a congenital abnormality.

The purpose of this three-phased study was to assess the knowledge needs of parents of a child with a congenital abnormality, during and following the time of the first hospitalisation directly after birth. For this purpose, an instrument was developed for nurses to assess these needs.

2 Review of the Literature

To analyse the existing evidence to the knowledge and information needs of parents with a child with a congenital abnormality, a search of literature published over 10 years (1998-2008) in the PubMed Database was conducted. Keywords used were "information", "knowledge", "information needs", "parents*", "congenital abnormalities*", birth defect, sick baby, needs assessment*, nursing care*, instrument, and questionnaires*, "patient education*", "empowerment" and "nursing*" in different combinations (* = Mesh-Terms).

First the search was done without limits and then, because of the amount of literature found, they were limited to "publications of the last 5 years" to get the most recent literature and "child 0-18 years" to fit the target group and language was set to "publications in English and German". For this summary and the interpretation of the results the literature was updated 2019 and 2022 to cover the years 2009-2022. As information- and knowledge needs are sometimes referred to synonymously in literature, both expressions were used in the search.

In the first part of the literature review the underlying concepts are defined. In the second part the literature about the needs of parents with hospitalised children or children with special needs and instruments to assess theses needs are presented.

2.1 Definition of key concepts

In the study three key concepts were addressed. That was the concept of children with special health care needs, the concept of knowledge and information and the concept of empowerment.

2.1.1 Child with special health care needs

Babies born with a congenital abnormality are mostly children with special health care needs. Children and youths with special health care needs (CSHCN) are defines as "those who have or are at risk for a chronic physical, developmental, behavioural or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998)(p.

138). Even though this definition is over 20 years old, it is still widely used (Alliance, 2013).

Children with special health care needs require more care as a cause of their developmental, physical, emotional or behavioural differences as other children at the same age do. They often require additional health services and support. These vary from e.g. financial support to complex medical equipment like for example home ventilation (Alliance, 2013). Caring for a child with special health care needs is a big challenge for the affected family (Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Nayeri et al., 2021; Paajanen, Annerstedt, & Atkins, 2021).

2.1.2 Knowledge and information

Knowledge is an abstract concept but there is no clear definition. Many philosophers have tried to defined what they understood as knowledge (Bolisani & Bratianu, 2018). Knowledge is defined by the International Classification for Nursing Practice (ICNP) as ”Status with the specific characteristics: Specific content of thinking based upon acquired wisdom or learned information or skills, cognisance and recognition of information” (ICNP). This means that people have to understand the information that is provided to them and they have to be able to use it together with the learned skills.

Information- and knowledge needs are sometimes referred to synonymously in literature. In this study the concept of knowledge needs is used for the bio-physiological (i.e. illness, symptoms, treatment and complications), functional (i.e. individual needs, mobility, rest, nutrition and body hygiene), experiential (i.e. emotions and hospital experiences), ethical (i.e. rights, duties, participation in decision-making and confidentiality), social (i.e. families, other patients and patient unions) and financial (i.e. costs and financial benefits) dimensions (Rankinen et al., 2007). Having knowledge and / or gaining knowledge requires, that information exist. and it includes information needs. Having access to and getting information is an important part in the process of gaining knowledge and empowerment. Folkman & Lazarus (1988) described information-seeking is as one of many problem-solving strategies and information is acknowledged as a vital component in understanding the practical implications of the disability and in facilitating adjustment to it (Pain, 1999).

Within patient education, information, training and counselling can be distinguished whereas information-giving and training can overlap (Abt-Zegelin, 2002). Information was provided to assist in the process of adjusting emotionally to their child’s disabilities, to enable parents’ access to services and benefits, and to improve their management of their child’s behaviour. Parents’ comments indicated that information was usually useful, but occasionally of mixed benefit (Pain, 1999).

Parents most frequently reported professionals as their source of information, but other parents and voluntary organizations were also mentioned (Pain, 1999).

2.1.3 Patient / parent empowerment

Patient / parent empowerment through knowledge and the nurses' role in this process has become a worldwide important topic in clinical nursing and nursing research (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Cerezo, Juve-Udina, & Delgado-Hito, 2016; Christensen & Hewitt-Taylor, 2006; Gibson, 1991; Kuokkanen & Leino-Kilpi, 2000; Lau, 2002; Nyatanga & Dann, 2002; Perestelo-Perez et al., 2017; Virtanen, Leino-Kilpi, & Salanterä, 2007).

The concept of empowerment has been widely discussed. Health policy programs and interventions have been established to promote patient empowerment (Bravo et al., 2015; Yeh, Wu, & Tung, 2018). Empowerment has its origin in the Latin verb for power "*potere"*, which means "to be able". Its prefix "em" means "cause to be or provide with". Therefore, empowerment is the process and result of a person or a group being able to control important events in their life by themselves through their own power. Well-being is the ultimate objective of empowerment (Nyatanga & Dann, 2002).

Several authors have made definitions of the concept of empowerment (Acuna Mora, Sparud-Lundin, Moons, & Bratt, 2022; Pekonen, Eloranta, Stolt, Virolainen, & Leino-Kilpi, 2020) and the concept is continuously being analysed to get a better understanding of it (Halvorsen et al., 2020). But so far, no widely agreed definition or model exists (Fumagalli, Radaelli, Lettieri, Bertele, & Masella, 2015).

Lau defines it as "an enabling process, through which individuals or communities take control of their lives and their environment" (2002), Gibson (1991) defines empowerment as "a social process of recognizing, promoting, and enhancing people's ability to meet their own needs, solve their own problems, and mobilise necessary resources to take control of their own lives". She describes empowerment as "a process of helping people assert control over factors that affect their health". Kuokkanen and Leino-Kilpi (2000) define empowerment as an action of empowering and the state of being empowered.

Empowerment in patient education involves "enabling patients to enhance their social, problem-solving and communication skills raising their consciousness about health values, needs and goals and so facilitating their ability to manage their health problems" (Virtanen et al., 2007). If family carers are involved, it is important, that their level and type of involvement is determined (Funk et al., 2019). Their well-being and capacity to care for the family member has to be considered (Funk et al., 2019). For this study the definition of Lau (2002) and Virtanen et al. (2007) are used.

The target group is the parents/mothers of children with a congenital abnormality and not the patients as such.

Newer studies suggest new models of patient empowerment. Schneider-Kamp & Askegaard (2020) elaborated four dimensions of patient empowerment: Patient control (the perceived control of patients over their condition), patient participation (the degree of medical decision-making through the patient), patient education (the degree of medical knowledge gained by the patient) and patient autonomy (how independent of health care providers the patient acts).

Besides the definitions, four theoretical approaches are described for the concepts of power and empowerment (Bradbury-Jones, Sambrook, & Irvine, 2008; Kuokkanen & Leino-Kilpi, 2000). The first of the three categories described by Kuokkanen & Leino-Kilpi (2000) is the critical social theory, the second category looks at the organizational theories and the third is concerned with the social psychological theory.

A fourth theoretical approach was described by Bradbury-Jones et al. (2008). She describes the concept of empowerment as disciplinary power / knowledge relationships. When empowering patients, nurses support the parent's empowering process through the transfer of their power and knowledge to the patient. The patients should be empowered to become experts in their own care. These patients will ask questions and want to be actively involved in decision-making. They should be seen as experts or becoming experts and not as "difficult" patients.

This theoretical approach described by Bradbury-Jones et al. (2008) has to be considered in the context of babies born with a congenital disorder. When the newborn babies are admitted after birth the nurses mainly have more knowledge and power to care for the baby than the parents, but over time, the parents learn a lot about their baby and how to take care of it. At this time nurses have to be able to change their attitude and focus on leaving the control to the parents to care for their child. In this study a combined perspective based on social psychology and the post-structural approach described by Bradbury-Jones (2008) is used.

2.2 Needs of parents with a child with a congenital abnormality and special health care needs.

Children born with a congenital abnormality are classified as "children with special health care needs". The prevalence of children with special health care needs was approximately 14 million in the United States in 2018-2019 (Initiative, 2019). In Europe the prevalence of children born with a congenital abnormality from 2011 to 2018 was between 244 and 267 per 10'000 births per year (EUROCAT, 2019), in 2020 the overall prevalence in Europe was 253 / 10`000 births (EUROCAT, 2020).

The latest available prevalence from England is 222 per 10`000 births (National Disease Registration Service, 2020).

Birth of a child with a congenital abnormality

Becoming parents of a child with a congenital abnormality is very challenging and troublesome. Parents are confronted with a situation they didn't expect and are very insecure about the future. They are also sad about the loss of a desired healthy baby (Bevilacqua et al., 2013; Di Grazia, Pellizzoni, Tonegatti, & Rigamonti, 2017). Many parents are in a state of an emotional shock and need psychosocial support (Allen, 2014; Bevilacqua et al., 2013; Geense, van Gaal, Knoll, Cornelissen, & van Achterberg, 2017; Jessup, Douglas, Priddis, Branch-Smith, & Shields, 2016; Reid & Gaskin, 2018).

Besides the numerous abnormalities that can be classified, there are children whose diagnosis are not clear when they are born. It sometimes takes months or even years before the abnormality or syndrome of their child gets a name (Wallis et al., 2019). Knowing the diagnosis of their child as soon as possible is very important for the parents, as they crave to know what is wrong with their child. Even though the parents are longing to get a diagnosis, it is very important that this information is provided in a very subtle manner.

The delivery of the diagnosis is a very sensitive task and should be provided in a very subtle manner. The families are in a traumatic situation and have difficulties understanding the information they get (Allen, 2014; Bevilacqua et al., 2013; Jessup et al., 2016; Reid & Gaskin, 2018). At this point, the parents are torn between getting as much information as possible and the fact, that they cannot handle it all (Di Grazia et al., 2017). This is one of the most important phases for the parents and it is essential that the person who explains the diagnosis to the parents is aware of the role he or she has.

The parents need a lot of information but also psychosocial support. Many parents felt that they did not get enough support when receiving the diagnosis. If the diagnosis is clear prenatally, counselling should start before the child is born (Bevilacqua et al., 2013; Stoffel et al., 2017). Many parents state, that they would have needed the opportunity to discuss the questions that arise repeatedly until they understood everything (Bevilacqua et al., 2013; R. Jackson et al., 2008; Reid & Gaskin, 2018). They wanted to know what life their child will have, what it will be living with a child with a diagnosis as their baby has (Alsem et al., 2014). Of these children many require long-term care from their parents (Lundblad et al., 2001) and they have many questions to everyday care skills they needed to learn to be able to care for their child. Knowing, that their child could be successfully treated was a big relief for parents (Williams et al., 2019).

Information and Support

In order for the parents to be empowered they need information that is understandable. The parents wish to get the information and the child's health record in a written form to be able to keep it up to date and to read it over and over again. (Allen, 2014; Boyse et al., 2014; Bragadottir, 1999; Desai et al., 2016; Diehl, Moffitt, & Wade, 1991; Kendall, Sloper, Lewin, & Parsons, 2003; Kristjansdottir, 1991, 1995; Kyritsi, Matziou, Perdikaris, & Evagelou, 2005; Lundberg et al., 2016; Nightingale, Friedl, & Swallow, 2015; Pye & Green, 2003; Shields, Hunter, & Hall, 2004; Shields & Kristensson-Hallstrom, 2004; Shields et al., 2003; Wray & Maynard, 2006; Young et al., 2001).

They get most of the information from health care professionals during the first hospitalisation after birth. But they also seek support from other parents in the same situation personally or in support groups (Agrawal et al., 2017; Alsem et al., 2017; Alsem et al., 2014; Boyse et al., 2014; Hammarberg, Sartore, Cann, & Fisher, 2014; Johnson, Johnson, Heyhoe, Fielder, & Dunning, 2018; Lundberg et al., 2016; Nicholl, Tracey, Begley, King, & Lynch, 2017; Wallis et al., 2019).

As time goes by, the parents become experts in the care of their child (Brenner et al., 2015; Kirk & Glendinning, 2002). This sometimes leads to conflicts with nurses if they don't accept the parents as the child's health care specialist (Kirk & Glendinning, 2002). At the beginning, the nurses and other health care providers have an advantage in knowledge about the care of the child. Though the parents should always be seen as partners who are learning a lot about their child and are preparing to take over the management and care (Fixter, Butler, Daniels, & Phillips, 2017; Gramszlo et al., 2020; J. D. Lotz, Daxer, Jox, Borasio, & Fuhrer, 2017; J. Smith, Cheater, & Bekker, 2015; J. Smith, Swallow, & Coyne, 2015).

They develop to be the experts of their child and want to be taken seriously in that role. They want to be supported by experienced nurses (Seliner et al., 2016). Nurses have a big responsibility to support the empowering of the parents to be able to take care for their child. Their relationship to the families is the most important in the discharge preparation of the child (Bevilacqua et al., 2013; Bowles et al., 2016; Brenner et al., 2015; Goes & Cabral, 2017; Korukcu, Deliktas, & Kukulu, 2017; Kruijsen-Terpstra et al., 2016; Ronan, Brown, & Marsh, 2020). The nurses change to the role of educators and counsellors (Goes & Cabral, 2017).

Families with children with a disability have many needs. Even though the parents receive a lot of information about their child's condition, its cause, treatment and prognosis, some information is missing. Especially about psychosocial issues, the social development and research about the condition (Douglas, Redley, & Ottmann, 2016; Geense et al., 2017; Nightingale et al., 2015; Pelentsov, Fielder, Laws, & Esterman, 2016; Pelentsov, Laws, & Esterman, 2015). In the end-phase of the stay in hospital they need training about home therapy techniques, information

about services, about financial resources and special treatments for their child (Alsem et al., 2014; Desai et al., 2016; Jachimiec et al., 2015).

Transition to home

When the parents leave the hospital for the first time, they are mostly anxious (Brenner et al., 2015; Lundberg et al., 2016; Ronan et al., 2020). The parents are looking forward to the time at home but at the same time they fear the responsibility they have as soon as they are at home alone with their child. The transition from hospital to home of children with complex needs is very challenging. Early education and preparation increases family empowerment (Ronan et al., 2020). There is a need for assessments and protocols to improve negotiation between parents and health service providers (Brenner et al., 2015; Ronan et al., 2020). When parents receive multidisciplinary teaching from a discharge coordinator, the nurse and if needed a dietician, parents feel secure to take their child home. In the study of Schuh et al. (2016) 96 % of the questioned parents felt ready to take their child home. Over 90 % of the parents rated their knowledge about medical needs, problems to watch for, when and who to call if problems occur, what their child is allowed and what not and when the next follow-up was planned very high (8+ out of a range of 0-10). The possibility of rooming-in prior to discharge and the coordination of outpatient community services support the parents in the discharge process (Bowles et al., 2016). Some parents valued the possibility of taking their child home for a day and later for a day and night and then go back to hospital before leaving for good (Brenner et al., 2015).

Support and Care Team at Home

After discharge, the families need a stable team of health care providers for their support and the care of their child. The family's capacity to coordinate and navigate the system has an impact on the provider's ability to manage the care of children with complex needs (Altman et al., 2018; L. Smith & Daughtrey, 2000). Health care providers see to a wide range of children with medical complex care. These children are often medically fragile and can become seriously unwell very quick. They often have a combination of neurodevelopmental disability with behavioural issues and mental health issues and physical problems like feeding difficulties, needing nasogastric tubes. Some children need mobility devices which need maintenance and sometimes emergency replacement (Altman et al., 2018).

Many families have problems successfully navigating the system due to financial, cultural or language barriers (Altman et al., 2018). Another challenge is the variability of parental health literacy around the child's health condition and the

knowledge which services should be accessed for which medical issue (Altman et al., 2018). Most parents only understand some of the information they get during their time in hospital (Dol, Delahunty-Pike, Anwar Siani, & Campbell-Yeo, 2017).

Children with multisystem conditions often see many subspecialty teams which can lead to fragmentation of the health system with the danger that the children could "slip through the cracks". If parents don't get adequate information when and where to seek help for their children this could result in lengthy delays before the children are brought to the Emergency Department when the condition gets worse (Altman et al., 2018). Written care plans with standardized templates are very useful in the interdisciplinary care of a medical complex child. Beside the child's name they should include all contact information of the parents, the hospital, the community-based care provider, the child's diagnoses, the emergency management, an overview of the medical issues, the diet, technical supports and a social history (Adams et al., 2013; Boyse et al., 2014; Bragadottir, 1999; J. D. Lotz et al., 2017; Tregay et al., 2016).

Physicians, nurses and care coordinators have to understand the situation of the families and support them in navigating the health care system. They should plan, track and monitor the support and care of families with a child with special health care needs (Ranade-Kharkar et al., 2017). Care coordinators can be special paid personnel like the primary health care provider but also all other people who interact with the patients and families (Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014; Van Speybroeck et al., 2020).

Even though many health care personnel can take over the role of a care coordinator, primary care structures are probably the most efficient to coordinate the care of the patient throughout the health care system (WHO, 2011). Sometimes dedicated care coordinators e.g. clinical nurse specialists coordinate health care for people with intellectual impairment in the United Kingdom (WHO, 2011).

Families often feel that their child's care was not delivered or coordinated by the primary health care provider. They had to take over that part themselves (Boyse et al., 2014). A patient-centred medical home for patients with a complex disease can result in an improved clinical outcome. It can be an anchor for the healthcare team and enables the coordination of care (Fernandes & Sanders, 2015). Online support is increasing but parents sometimes have more problems understanding the virtual information than the information they got through the hospital staff (Dol et al., 2017). Parents often use the internet and social media to get information about their child's condition (Agrawal et al., 2017; Alsem et al., 2017; Nicholl et al., 2017; Wallis et al., 2019). In one study, parents in Ireland reported that the information they got supported them in decision making, care and management of their child's condition (Nicholl et al., 2017).

Families with children with special health care needs are often confronted with financial burdens in two ways. Many children need medical equipment and more home health services as other children but through the special health care needs of their children, parents can only work fewer hours and miss out on work when they have medical appointments (Di Grazia et al., 2017; McClung, Glidewell, & Farr, 2018). The parents often don't have enough information how to access services and benefits. They have the need to see a social worker to get information about financial assistance (Bragadottir, 1999; Diehl et al., 1991; R. Jackson et al., 2008; Kristjansdottir, 1991, 1995; Kyritsi et al., 2005; Pain, 1999; Shields et al., 2004; Shields et al., 2003; Shields, Young, & McCann, 2008; Stinson & McKeever, 1995; Wray & Maynard, 2006).

2.3 Instruments assessing needs of parents with a hospitalised child or a child with special health care needs

As there was only little literature to instruments assessing needs of parents with children with special health care needs, literature of instruments assessing needs of parents with hospitalised children was included. Several instruments assessing needs of parents with a hospitalised child or a child with special health care needs were found in the literature (Alsem et al., 2014; Armstrong & Kerns, 2002; Austin, Dunn, Huster, & Rose, 1998; Bailey & Simeonsson, 1988; Bevilacqua et al., 2013; Buran, Sawin, Grayson, & Criss, 2009; Coleman, Maltby, Kristjanson, & Robinson, 2001; Kristjansdottir, 1991; Lundblad et al., 2001; Stein & Riessman, 1980; Stinson & McKeever, 1995; Wray & Maynard, 2006; Young et al., 2001). The needs of parent's questionnaire (NPQ) is an instrument that occurred several times in studies about the needs of parents of hospitalised children. It was developed in 1991 by Kristjansdottir (1991) and used in several studies (Bragadottir, 1999; Kristjansdottir, 1995; Kyritsi et al., 2005; Shields et al., 2004; Shields & Kristensson-Hallstrom, 2004; Shields et al., 2003; Shields et al., 2008). The NPQ was designed to measure parents' perception of the importance and fulfilment of their needs. Additionally, the need for services to fulfil these needs was assessed. It contains 51 statements of needs responded to by their level of importance on a five-point Likert Scale, the level of perceived fulfilment on a five-point Likert Scale, and the need for services to fulfil these needs on a two-point scale (Yes=1). 16 of these needs were needs referring to knowledge.

Lundblad et al. (2001) used a questionnaire that was administrated to nurses and not to parents. Wray and Maynard (2006) assessed the perceived needs of children with heart diseases, of their parents and siblings and the support and services the families were receiving. The questions covered a broad spectrum of topics. They

were focused on the support of the family and not on the information needs of the parents during and following the first hospitalisation after birth. Young et al. (2001) conducted a retrospective study where the parents filled out a questionnaire in which they recalled the meeting when they were informed about the malformation of their child. They were asked if they had been informed about issues concerning the abnormality of their child.

In 2014 Alsem et al. (2014) developed an inventory to assess family needs in children with a physical disability (Family needs inventory in Paediatric Rehabilitation (FNI-PR). It was developed through interviews with families of children with a physical disability and a literature review about family needs (Siebes et al., 2012). Some questions of the Family Needs Survey (Bailey & Simeonsson, 1988) and the Family Needs Assessment Tool (Buran et al., 2009), were also used to develop the FNI-PR . Additionally interviews with health care professionals were conducted (Alsem et al., 2014).

All these instruments cover a part of the knowledge needs of parents after the birth of their child with a congenital abnormality, but none of the covers all needs. More details to the instruments are presented in chapter 5.3.

2.4 Summary of the literature review

In summary the review of previous literature shows that parents of children with congenital disorders have several needs, mainly knowledge needs that change over time. However, we lack ways to assess these knowledge needs systematically. Most of the existing instruments were developed for research purposes and not, to assess the knowledge needs of parents systematically in clinical practice. The needs presented in this literature review were mostly assessed with interviews or questionnaires retrospectively and not at the time when they occurred.

There are currently no valid assessment tools or instruments available that could be used by health care professionals to assess the knowledge needs of parents after their child's birth before going home for the first time. An instrument assessing the knowledge needs of parents could support nursing personnel in offering parents such knowledge that they need and support the empowerment of the parents in the care process of their child. For this purpose, a new instrument to assess knowledge needs of parents of a child with a congenital abnormality and special health care needs was developed to be used before the first discharge from hospital after birth of the child. This instrument should be integrated into protocols for discharge planning of children with a congenital abnormality and special health care needs (Brenner et al., 2015; Siebes et al., 2012).

3 Aims

The ultimate goal of this study is to improve the knowledge of parents with a child with a congenital abnormality to enable them to care for their child when leaving the hospital with their child for the first time after the birth.

The purpose of this three-phase study was to assess the knowledge of parents of a child with a congenital abnormality, during and following the time of the first hospitalisation directly after birth. For this purpose, an instrument was developed for nurses to assess these needs.

More specifically, the research tasks of this study were as follows:

1. To explore the knowledge needs of parents with a child with a congenital abnormality and special health care needs and assess instruments assessing these knowledge needs
2. To describe the use and the relevant factors related to conducting focus group interviews with children, youths, and parents.
3. To develop an instrument for nurses to assess the knowledge needs of parents with a child with a congenital abnormality and special health care needs during the first hospitalisation after birth
4. To explore the knowledge needs of parents with a child with a congenital abnormality and special health care needs with the new instrument during the time of the first hospitalisation after birth

4 Materials and Methods

Different designs, samples, settings and methods of data collection and analysis were used throughout the study. This chapter describes the study samples, data collection, analysis and ethical questions for each of the three phases of the study (phase I, II and III).

A multimethod study design (Anguera, Blanco-Villaseñor, Losada, Sánchez-Algarra, & Onwuegbuzie, 2018) using the methodological framework for developing measurement scales described by Streiner and Norman (2003) was used to develop the instrument. The framework is a guide to develop and validate measurement scales. It covers the development of the individual items (e.g. through literature reviews or focus groups), how to select the best items, how to combine them into the scale, and how to determine the reliability and validity of the scale.

4.1 Design, setting and sampling

In the first part an overview of the designs, settings and samples of each phase of the study are presented. First the theoretical background and the search for the items of the instrument, second the development of the instrument and third the data collection and testing of the instrument.

<table>
<tr><th colspan="3">Phase I (2009-2011; papers I - IV)
THEORETICAL BACKGROUND; LITERATURE SEARCH FOR ITEMS FOR THE INSTRUMENT</th></tr>
<tr><td colspan="3">Purpose: to identify knowledge needs of parents of a child with special health care needs and to evaluate instruments to assess these needs</td></tr>
<tr><td>Literature review about knowledge needs of parents with children with special health care needs and instruments to assess these needs (Paper I)
Sample:
48 articles
Design:
Explorative design, Integrative literature review</td><td>Methodological review about Focus Group Interviews in Child, Youth and Parents research (Paper II)
Sample:
120 articles
Design:
Explorative design, Integrative literature review
In preparation for the focus group interviews</td><td>Interviews (n=3)
Sample:
Interview 1: mother
Interview 2: mother, father
Interview 3: mother, father
Design:
Explorative design, semi structured interview

Focus group interviews (n=2)
Sample:
Interview 1: 4 nurses, 2 social care counsellors
Interview 2: 2 nurses
Design:
Explorative design, focus group interview</td></tr>
</table>

<table>
<tr><th colspan="2">Phase II (2011-2013; papers III, IV)
DEVELOPMENT OF THE INSTRUMENT</th></tr>
<tr><td colspan="2">Purpose: to develop an instrument for nurses to assess the knowledge needs of parents with a child with a congenital abnormality before first discharge from hospital</td></tr>
<tr><td>Sample:
Transcripts of the interviews and focus group interviews from phase I
Data of integrative literature review from phase I</td><td>Design:
Content analyses inductive and deductive to devise the items for the instrument</td></tr>
<tr><td colspan="2">Purpose: to assess the content validity index of the developed instrument</td></tr>
<tr><td>Sample:
2 parents
4 nurse experts</td><td>Design:
Descriptive design, calculation of content validity index</td></tr>
</table>

<table>
<tr><th colspan="2">Phase III (2014-2016; papers III, IV)
DATA COLLECTION AND TESTING OF THE INSTRUMENT</th></tr>
<tr><td colspan="2">Purpose: to assess the knowledge needs of parents with a child with a congenital abnormality before first discharge from hospital and to explore the comprehensiveness of the developed instrument</td></tr>
<tr><th>Assessment of the knowledge needs</th><th>Exploration of the comprehensiveness</th></tr>
<tr><td>Sample:
16 parents
Design:
Descriptive and explorative design
Instrument:
Developed instrument to assess knowledge needs</td><td>Sample:
2 interviews
Interview 1: mother
Interview 2: mother
Design:
Explorative design, semi structured interview</td></tr>
</table>

Figure 1. Phases of the study.

In **Phase I**, the items of the instrument were generated through a literature review, three interviews and two focus group interviews. Additionally, a Methodological review about focus group interviews in child, youth and parent research was conducted to prepare the focus group interviews.

Integrative Literature Review (Paper I)

The integrative literature review about knowledge needs of parents with children with special health care needs and of instruments to assess these needs, was conducted. The questions guiding the integrative literature review were:

1 What are the knowledge needs of parents with a child with special health care needs?

2 What instruments were used to assess these knowledge needs?

The search followed the steps described by Whittemore and Knafl (2005): 1. identification of the problem, 2. literature search, 3. evaluation, analysis and presentation of the found data. As the aim of the literature review was a qualitative collection of the existing literature all types of studies were included (Paper I) (Adler, Salanterä, Leino-Kilpi, & Grädel, 2015). The search was conducted in PubMed, CINAHL, EMBASE and PsycINFO with articles published from 1999 to 2010 (Paper I). Search words used in the literature search were:
"Nursing AND empowerment", "parents AND information needs" "information AND patient education AND knowledge", "congenital abnormality AND information needs" birth defect, sick baby, needs assessment*, nursing care*, instrument, and questionnaires*.

The initial search strategy identified a total of 8329 articles, after the duplicates were removed. Firstly, the title and abstract (if available) were inspected. If the inclusion were met, the full article was read. If the article met the criteria, it was included in the review. Using the preliminary inclusion criteria, the article screening yielded 48 articles. The following data were extracted from these 48 studies: author(s), year, data collection method or instrument/scales used in the study, knowledge needs described, subtopics, and LOE of the studies.

In addition, the references of the found literature were manually searched. After abstract reading, 111 publications were chosen for further analysis. Besides determining and assessing the knowledge needs of parents of a child with special health care needs, the review also explored the instruments used to assess these needs. The most recent research literature at that time of the study was included. In addition, primary literature referred to in the articles was used when relevant to the topic.

All studies that provided information regarding the knowledge needs of parents of children (0–18 years old) with special health care needs were included, regardless of whether they were written in English or German. Studies were disqualified at this point, if the parents' perspectives was not the main source of the knowledge needs or if the study's quality was extremely low (i.e., the contents' source was not stated and there was hardly any literature cited). After this first selection, the studies included in the review were analysed with different appraisal tools (see chapter 4.2.)

The literature search was limited to the PubMed Limitations "publications of the last 10 years" to get the most recent literature and "child: 0-18 years" years to fit the target group and the language was set to "publications in English and German". This age group was used since it covered the whole lifespan from birth to adulthood.

Methodological review about Focus Group Interviews in Child, Youth and Parents research (Paper II)

To identify the knowledge needs of parents with a child with a congenital abnormality it was planned to do focus group interviews with concerned parents. When planning these focus group interviews only little information about how to plan and conduct focus group interviews with children, youth and parents was found. Therefore, an additional methodological integrative literature review to that topic was done (Paper II). The purpose of this integrative literature review was to describe the use and the relevant factors related to conducting focus group interviews with children, youths, and parents.

The literature search was conducted in PubMed Central, ERIC, and PsycINFO with the search terms "focus groups/methods" or "focus groups/utilization." Additionally, terms such as "child," "youth," "adolescent," "parents," "child health research," "pediatric research," "paediatric research," "analysis," and "child development" were used. The limits included publication dates within the last 10 years and English and German language publications. The initial search identified 1971 articles. Additionally, reference lists, bibliographies and books were hand searched. Books about child development were included as the developmental stage of the children or youths is a very important factor when preparing focus group interviews with children and youths. After excluding duplicates and studies that didn't contain a description of how focus groups with children, youths and parents were conducted there were 54 articles left from that search. The reference lists added another 66 articles. In the end, 120 articles and book sections were included using an inductive analysis.

Focus Group Interviews (Paper III)

The focus group interviews were held with nurses (n=6) and social care counsellors (n=2) in two University Hospitals in Switzerland and three interviews with parents of one University Hospital in Switzerland were done at the family's home. The potential participants for the focus group interviews were contacted with a letter containing the information to the study and the date and time of the focus group interview. The willing participants returned their contact data and an informed consent form. The interview was conducted following a guideline. It started with opening questions like the ward the participants were working on, the length of time they had been working there, which congenital abnormalities the patients had on the ward they were working. Following there were questions to what the participants think, the parents need to learn to be able to care for their child, what information the parents need and at what time they need this information. They were asked on the basis of which guidelines/standards/guidelines the parents were informed and instructed. At the end the participants were asked if they would change something in the way parents are taught and informed or if there was anything that wasn`t mentioned that would be important for the parents during the time in hospital or before they take their child home. For the interviews, eligible parents of children that had been on the ward in the concerned University Hospital in Switzerland were contacted a few weeks after discharge of their baby. The interviews were conducted with the help of questions about the care needs of the child, which information they needed to be able to care for their child at home, which information they got in regard of the congenital abnormality and care of their child. They were asked, if they had to learn any special care procedures or activities due to their child's congenital abnormality, when they realised what they had to learn those procedures and by whom or where they learned these activities and received the information. The next questions were, if something was missing and what advice they would give to nurses on the wards in terms of the information they needed/would have needed and the care/actions or activities they needed to learn. They were asked about their advice what should be changed, so that they could experience and learn everything they need to be able to look after their child well at home. The last question was, if there was anything that has not been addressed that would be important in terms of information provision and training by nurses? The focus groups and interviews were taped and transcribed.

In **phase II** (2011-2013) the instrument was developed from the items that had been generated with the data of the literature review and the extracted data of the focus group interviews and interviews with the parents.

The items were reduced through estimating the content validity index. To test if there are any items that are not necessary or not understandable the developed

instrument was rated (Streiner & Normann, 2003) by two parents with a child with a congenital abnormality and four nurse experts. The parents were selected from the parents that had been contacted for the interviews in phase I. The nurse experts worked on a ward in one of the University Hospitals in Switzerland where children with congenital abnormalities were treated and cared for (Paper III, Paper IV).

In **phase III** (2013-2016) the instrument was used on three different wards of three University Hospitals (two in Switzerland, one in Germany) and the knowledge needs of the parents were collected. One of the two wards in Switzerland was a ward with mainly surgical patients of all age. The other one was a mixed ward for patients of all age and the ward in Germany was an intensive care for newborn babies with health problems and premature born babies that were stable enough to survive without an incubator. The data was collected over two years (between April 2014 and September 2016). The study started as soon as the study assistant was identified and all the concerned health care professionals were informed orally and in writing about the study. The study assistant identified potential parents from the children that were admitted to the participating ward. All parents with a newborn with a congenital abnormality were classed as potential parents. The parents were approached as soon as their child was stable enough that the discharge process could start. First the study and instrument were described to the parents and written informed consent was obtained. The first part of the instrument (the questionnaire) was handed over about two weeks before the estimated discharge of the baby. The second part (the discharge-checklist) was handed over about two days before discharge. In both University Hospitals in Switzerland a study assistant collected the data. In the one University Hospital in Switzerland a nurse expert approached the eligible parents in the other University Hospital it was a nurse of another ward at the beginning of the study. As that nurse left the hospital during the data collection a head nurse of took over. The targeted sample size was 100 questionnaires in one year (Paper IV).

It was planned to test the test-retest reliability with 10 % of the questionnaires. Due to the small amount of completed questionnaires (n=16) and the fact, that many children were discharged much earlier than planned (often on the day the discharge-checklist was filled out) this test could not be carried out. Instead, two Interviews with parents who had been at home for at least half a year were conducted to verify if the knowledge needs in the questionnaire matched the experience of the parents some months after discharge of their child. One of the interviews was done in the University Hospital in Germany and one at the family's home.

The age of the children at time of the interview was 9, resp. 21 months. Both interviews were done with the mothers of the children. They were selected, because both of the children had a very complex congenital abnormality with a lot of special

health care needs. Both mothers had also filled out the questionnaire before their baby was discharged and they were included in the main study. Both participants stated at the time of discharge, that they perceived to be well prepared to take their children home. In the open interview they were asked, if that perception was confirmed or if anything had occurred after discharge that they should have needed to know before they left the hospital. They were asked if any information was missing and if the time when they got the information was appropriate in retrospect. They were also asked where they got their information or knowledge from since they were discharged.

4.2 Data analysis

Phase I

Integrative literature review about knowledge needs of parents with children with special health care needs and instruments to assess these needs

The methodological quality of the included studies from the literature search used for the generation of the items of the instrument was appraised with three different appraisal tools. For qualitative studies, the Critical Review Form for Qualitative Studies (Version 2.0) developed at the McMaster University in Hamilton, Ontario, Canada was used. For quantitative studies, the Guide for Quantitative Research (Law, et al., 1998), and for literature reviews, the Critical Appraisal Tool developed by Engberg (2008) was applied.

The NPQ questionnaire by Kristjansdottir (1991) was used as the basis for the instrument developed for this study. This questionnaire was developed for parents of hospitalised 2-6 year old children (Kristjansdottir, 1991) and has been used in many studies (Kristjansdottir, 1995; Kyritsi et al., 2005; Shields et al., 2004; Shields & Kristensson-Hallstrom, 2004; Shields et al., 2003; Shields et al., 2008). It contains 51 statements of needs responded to by their level of importance on a five-point Likert Scale, the level of perceived fulfilment on a five-point Likert Scale, and the need for services to fulfil these needs on a two-point scale (Yes=1). 16 of these needs were needs referring to knowledge. These knowledge needs were used as the basis of the literature search for the items of the new instrument. Additionally some questions of the Family Needs Survey (Bailey & Simeonsson, 1988) and the Family Needs Assessment Tool (Buran et al., 2009), were also used for the development of the instrument in this thesis.

The themes in our study were distinguished using a constant comparison method to the knowledge needs of the NPQ. Additional knowledge needs found in the analysed literature were listed. Extracted data were compared item by item, and similar data

were categorized and grouped together. The review also examined the instruments that have been used to assess these needs.
The data from the literature review were analysed following the qualitative content analysis framework of Mayring (2003). They were identified, coded and categorised (Paper I).

Methodological review about Focus Group Interviews in Child, Youth and Parents research

The articles from the literature search about focus group interviews in child, youth and parents research were grouped into three categories (Paper II):

A. Articles with focus groups or analysis of focus groups as main issue.

B. Articles where focus groups were used for data collection and details about the use of the method were described and discussed.

C. Articles where focus groups were used for data collection and at least one detail about the use of the method was described but not discussed.

Analysis of the Focus Group Interviews

The data from the focus groups and interviews were analysed deductively following the approach of text analysis by Crabtree and Miller (1992) and then inductively following the qualitative content analysis framework of Mayring (2003).

Crabtree and Miller's approach to text analysis, particularly outlined in their 1992 work "A Template Approach to Text Analysis: Developing and Using Codebooks", is a qualitative method used to systematically analyse textual data. Here's a summary of what their method involves:

1. Using a Codebook: Researchers develop a set of codes (a codebook) that represent themes or categories relevant to the research question. These codes can be predefined (a priori) or emerge during the analysis.
2. Applying the Template: The codebook is used as a “template” to guide the analysis of textual data (e.g., interview transcripts, field notes). The researcher applies these codes to segments of text that match the themes.
3. Iterative Refinement: The template is not fixed. As the researcher engages with the data, the codebook can be revised—codes can be added, removed, or redefined to better capture the meaning in the data.
4. Interpretive and Structured: This method balances structure (through the use of a codebook) with interpretive flexibility, allowing researchers to explore meaning while maintaining consistency in analysis.

This approach is particularly useful in health research and other fields where understanding complex human experiences and behaviors is essential.

In the inductive phase all categories of the interviews were extracted. The deductive approach was chosen to analyse if the categories derived from the literature review were confirmed in the interviews. These two approaches were chosen to confirm the categories from the literature reviews but still keeping the analysis open to new categories which might not have been covered in the literature review.

Phase II

In phase II a quantitative content analysis was conducted inductively and deductively form the contents of the literature review, parents' interviews and focus group interview to generate the items of the instrument. The focus groups and interviews were taped, transcribed and analysed inductively following the qualitative content analysis framework of Mayring (2003) and then deductively following the approach of text analysis by Crabtree and Miller (1992). The two methods were chosen to see if the categories derived from the literature review were confirmed in the interviews but still keeping the analysis open to new categories which might not have been covered in the literature review. A constant comparison method was used to distinguish themes. Extracted data were compared item by item, and similar data were categorized and grouped together. For the reduction of generated items, the Content Validity Index was calculated (Paper IV). The parents and nurse experts rated the importance of all items using a 4-point Likert-scale: 1) not at all relevant, 2) slightly relevant, 3) quite relevant, 4) very relevant. Additionally, the comprehensibility and clarity of the items were rated with "yes" or "no". The raters also had the possibility to add comments to their statements. Content Validity Index (CVI) on Scale-level Index (S-CVI) and Item-level (I-CVI), was calculated. All questions below the I-CVI index of 0,80 were deleted (Streiner & Normann, 2003).

Phase III

In phase III, the data with the instrument were collected. The instrument consists of two parts. One is a questionnaire consisting of two parallel 10 cm visual analogue scales. On one visual analogue scale, the parents rate the amount of knowledge they need to a certain statement and on the second, they rate their current knowledge about the statement (Table 5). It was developed to assess the knowledge needs of parents about two weeks before discharge of their child from hospital.

Of the data derived from the questionnaires, the potential difference between the knowledge needs and the self-assessed current knowledge of the parents for each statement was calculated.

Then the results were converted into percentages and divided into five groups.

1. More knowledge than needed.
2. As much knowledge as needed
3. Less knowledge than needed (up to 5 points less).
4. Much less knowledge than need (more than 5 points less).
5. “Does not apply”

The cut-off of five points was chosen as it was interpreted to mean that parents had up to half as much knowledge, they felt they needed. The parents with “much less knowledge” had less than halve of the knowledge that they felt they needed. This means they were missing a substantial amount of knowledge, which could lead to a considerable uncertainty in the care of their child (Paper III).

The second part of the instrument is a discharge checklist containing 12 general statements to the knowledge of the parents. Some of the statements are divided into more detailed sub-statements (Table 6). It was developed to check the knowledge of the parents short before discharge of their child. The parent’s rate on a 10 cm visual analogue scale, to what extent they agreed with the statement. In the discharge checklist the average value of the 10 cm visual analogue scale of every main statement was calculated to assess to what extent the statement was fulfilled.

To test the instrument, the data from interviews in phase III were analysed inductively following the qualitative content analysis framework of Mayring (2003) and then following the approach of text analysis by Crabtree and Miller (1992). The deduction was based on the knowledge needs covered by the instrument. The results were then compared with the analysis of the first interviews that were conducted at the beginning of the study. The intention was to see, if the knowledge needs described in the interviews in the first phase (which had been included in the instrument) were the ones the parents had experienced when leaving the hospital or if some knowledge needs had come up, that had not been covered by the questionnaire.

4.3 Ethical considerations

With humans as study participants – all “the rights of those humans have to be protected” (Polit & Tatano Beck, 2008; WMA, 2013). The first weeks and months of parents is vulnerable time in their lives (M. Lotz, 2017). Parents whose child is

born with a congenital abnormality are even more vulnerable to the impact of the birth of their child on their live (Koch & Jones, 2018). In respect to the difficult situation in which the parents are, a very careful approach had to be planned. The ethical codes of the Swiss professional nursing organisation (SBK Geschäftsstelle, 2000, 2006) and scientific research (Polit & Tatano Beck, 2008) were followed.
The ethical approvals and permissions to conduct the study were obtained according to each organization's practice (283/13 (Hospital 1), 070/214SNCTP 898 (Hospital 2), 323/13 (Hospital 3)). All medical and nursing directors of the participating clinics gave their permission for the study.

Oral and written information on the research's objectives, voluntary nature of participation, guarantees of confidentiality and anonymity, and the option to withdraw from the study at any moment was provided to participants at each step. Throughout every stage of the trial, parents' and nurses' written informed consent was acquired. The original documents are stored in a safe place. The answers of the questionnaires were anonymised in the documents that were used for further calculations. All documents were saved with a safe password.

In phase III all parents who were asked to participate in the data collection were given time to understand the information and, if needed, to discuss the study with the researcher via telephone or email. Based on the received information, the participants voluntarily made the decision to participate in or decline participation in the study. The parents were assured that the option of declining to participate would have no effect on the care of their child. To avoid that the parents felt under pressure a study assistant was chosen that didn't work on the same ward as the children were hospitalised.

5 Results

The results are reported according to the research phases. First the development of the instrument, second the results of the data collection with the developed instrument and third the results of the interviews that were conducted to test the developed instrument for its feasibility and completeness are described.

<table>
<tr><th colspan="4">Results Phase I</th></tr>
<tr><td colspan="4">Purpose: to explore the knowledge needs of parents of a child with a congenital abnormality and special health care needs and to assess instruments assessing these needs.
To describe the use and the relevant factors related to conducting focus group interviews with children, youths, and parents.</td></tr>
<tr><td>Literature review
- Knowledge needs of parents with a child with special health care needs
- Research Instruments used to assess knowledge needs of parents with a child with special health care needs</td><td>Methodological review
Focus group interviews in child, youth and parent research</td><td>Interviews with parents</td><td>Focus group interviews with health care professionals</td></tr>
<tr><th colspan="4">Results Phase II</th></tr>
<tr><td colspan="4">Purpose: To develop an instrument for nurses to assess the knowledge needs of parents with a child with a congenital abnormality and special health care needs during the first hospitalisation after birth</td></tr>
<tr><td colspan="4">Developed Instrument</td></tr>
<tr><td colspan="2">Questionnaire</td><td colspan="2">Discharge Checklist</td></tr>
<tr><th colspan="4">Results Phase III</th></tr>
<tr><td colspan="4">Purpose: To explore the knowledge needs of parents with a child with a congenital abnormality and special health care needs with the new instrument during the time of the first hospitalisation after birth and to explore the comprehensiveness of the developed instrument</td></tr>
<tr><td colspan="2">Data collection with the developed instrument
- Results of the questionnaire
- Results of the discharge checklist</td><td colspan="2">Testing of the instrument
- Interviews with parents 6 months after discharge</td></tr>
</table>

Figure 2. Diagram of the presented results in the different phases of the study.

5.1 Results Phase I

In this section the results of the first phase of the study are presented. First, the literature review to analyse the knowledge needs of parents of children with special health care needs and the questionnaires used to assess these needs. Second, the results of the integrative literature review to the use and the relevant factors related to conducting focus group interviews with children, youths, and parents and third, the results of the interviews with the parents and the focus group interviews with the health care providers.

5.1.1 Knowledge needs of parents with children with a congenital abnormality and special health care needs and instruments to assess these needs based on literature and interviews (Phase I, Paper I)

A literature review was done in order to analyse the knowledge needs of parents of children with a congenital abnormality and special health care needs and the questionnaires used to assess these needs (Paper I). Out of the 48 papers that were analysed, 36 of them described the information needs of parents of children with special health care needs and had a qualitative design (LOE Level VI, single descriptive/qualitative/physiological research) according to Polit and Tatano Beck (2008). Ten of the studies were correlational studies (LOE Level IV, single correlational/observational research), one was a literature review (LOE Level V, systematic review of descriptive, qualitative, and physiological studies), and one seemed to be a literature review but was not named as such. The research was carried out in a number of nations (Australia, Canada, China, England, Finland, Germany, Holland, Hong Kong, Italy, North America, Scotland, South Africa, South America, Switzerland, and Thailand). The data collection of the included studies was performed by questionnaires/tools (n=25), interviews (n = 12), focus groups (n=5), online survey (n = 1), literature review (n = 1), or a combination (n = 3). In one study, data collection was unclear.

5.1.1.1 Knowledge needs of parents with a child with a congenital abnormality and special health care needs (Paper I)

Parents of a child with special health care needs have a variety of knowledge needs. 37 different knowledge needs were described in the articles. These were categorized into nine categories (Paper I):

Knowledge about the condition or illness
Knowledge about treatment
Knowledge about daily care of the child

Knowledge about equipment
Knowledge about the future
Knowledge about organizational issues
Knowledge about the effect of the illness on the family
Knowledge about support
Knowledge about how to explain the illness to others

Category "Knowledge about the condition or illness"
Parents wanted knowledge about the diagnosis of their child, the aetiology of the condition or disability, how it is described and the expected duration of the problem (Aite et al., 2006; Austin et al., 1998; Collier, Pattison, Watson, & Sheard, 2001; Fisher, 2001; Hall & Graff, 2010; Henley & Hill, 1990; Hummelinck & Pollock, 2006; Kendall et al., 2003; McWilliam & Scott, 2001; Miller, Colligan, & Colver, 2003; Thon & Ullrich, 2010; Wiberg, Heidenreich, Springer, & Noterdaeme, 2007; Wong et al., 2004; Young et al., 2001; Zhao & Cheng, 2009). It is very important for the parents to get a diagnosis referring to the problems of their child. They then could start getting adapted to the challenge and start their new life with all the required adaptations (Fisher, 2001).

Category "Knowledge about treatment"
They wanted to know everything about the treatment of their child's diagnosis, about the treatment plan, tests that had to be done, the results of the tests, medication including side-effects and which operation techniques were available (Armstrong & Kerns, 2002; Collier et al., 2001; Creedy et al., 2005; Deis, Spiro, Jenkins, Buckles, & Arnold, 2010; Diehl et al., 1991; Henley & Hill, 1990; Huber, Dietrich, Cugini, & Burke, 2005; Hummelinck & Pollock, 2006; Jackson, Cheater, & Reid, 2008; R. Jackson et al., 2008; Shore, Buelow, Austin, & Johnson, 2009; Snowdon & Kane, 1995; Stinson & McKeever, 1995; Thon & Ullrich, 2010; Toye, Kristjanson, Coleman, Maltby, & Jackson, 2004; Wong et al., 2004).

Category "Knowledge about daily care of the child"
Parents wanted knowledge about the daily care of their child. How and what to feed their child, especially if their child needed a special diet or had to be tube-fed (Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009; Collier et al., 2001; Diehl et al., 1991; Henley & Hill, 1990; Kuttenberger, Ohmer, & Polska, 2010; Snowdon & Kane, 1995; Stinson & McKeever, 1995).

How to transport their child was another knowledge need of the parents (Diehl et al., 1991; Stinson & McKeever, 1995) and what had to be organised for the discharge of their child (Pain, 1999) and how to administer the medication of their child (Creedy et al., 2005; Hummelinck & Pollock, 2006).

They wanted to know how to care for injection or incision sites (Stinson & McKeever, 1995). How to face, the child, how to talk and play with their child were other knowledge needs parents expressed in the studies (Lanners & Lamert, 1999; Wong et al., 2004).

Category "Knowledge about equipment"
As many children with special health care needs need special equipment like e.g. ventilators, nebulizers, surveillance monitors and other aids or orthopaedic splints parents need the knowledge where to get and how to handle the equipment for their child (Chow, 2001; Diehl et al., 1991; Henley & Hill, 1990; Miller et al., 2003).

Category "Knowledge about the future"
Many parents were concerned about the future of their child and wanted to know how their child will develop (Kerr & McIntosh, 2000; Lam & Mackenzie, 2002; Lanners & Lamert, 1999; van den Borne et al., 1999; Wong et al., 2004; Wray & Maynard, 2006) and if it will be able to talk (Chuacharoen et al., 2009). Many parents had knowledge needs to the intellectual needs their child, how it can be educated or which school it will able to go to (Anderson, Loughlin, Goldberg, & Laffel, 2001; Bailey, Blasco, & Simeonsson, 1992; Buran et al., 2009; Creedy et al., 2005; Ellis et al., 2002; Finfer, 2007; Graves & Hayes, 1996; Huber et al., 2005; Lanners & Lamert, 1999; Thyen, Sperner, Morfeld, Meyer, & Ravens-Sieberer, 2003; van den Borne et al., 1999; Wong et al., 2004). How the illness might affect the child's career and social life and if the child will be able to have own children in the future was another knowledge need expressed by the parents (Collier et al., 2001). In a study conducted by Henley & Hill (1990), 67.9% of the fathers and 60% of the mothers stated, that they needed a great deal more knowledge about how the illness of their child might affect it's career, social life and marriage. Some parents wanted to know about the development of medical and surgical procedures that might help their child in future (Wray & Maynard, 2006).

Category "Knowledge about organizational issues"
The parents wanted to know when their child had to go for check-ups and how long the waiting time will be (Buran et al., 2009; R. Jackson et al., 2008; Stinson & McKeever, 1995).

Category "Knowledge about the effect of the illness on the family"
Having a child with special health care needs always has an impact on the whole family. Parents wanted to know how the disability of their child could affect the siblings (Miller et al., 2003) and how the family could cope with the stress of the illness (Anderson et al., 2001).

Category "Knowledge about support"
To be able to cope with the situation the parents had many knowledge needs where to get support and how to access the services (Armstrong & Kerns, 2002; Chow, 2001; Creedy et al., 2005; Diehl et al., 1991; Ellis et al., 2002; Graves & Hayes, 1996; Hummelinck & Pollock, 2006; R. Jackson et al., 2008; Koshti-Richman, 2009; Lanners & Lamert, 1999; McWilliam & Scott, 2001; Muggli, Collins, & Marraffa, 2009; Nuutila & Salanterä, 2006; Pain, 1999; Stinson & McKeever, 1995; Thyen et al., 2003; Toye et al., 2004; Wray & Maynard, 2006; Young et al., 2001), what support groups there are (Andrews, Williams, Vandecreek, & Allen, 2009; Huber et al., 2005; R. Jackson et al., 2008; Miller et al., 2003; Muggli et al., 2009; Stinson & McKeever, 1995; Thyen et al., 2003; Young et al., 2001). 76% of the participants reported that they found peer-to-peer parent support to be the most helpful in coping with their child`s CLD (Andrews et al., 2009). They wanted to know how they would find time for themselves and how to cope with the situation emotionally (Ellis et al., 2002; Henley & Hill, 1990; Pain, 1999; Stinson & McKeever, 1995). How to get financial support (Thon & Ullrich, 2010), what insurance they need and what benefits and financial services there are and how they can be accessed was another knowledge need mentioned in the studies (Chuacharoen et al., 2009; Diehl et al., 1991; Hall & Graff, 2010; Hummelinck & Pollock, 2006; Pain, 1999; Toye et al., 2004). In the focus groups carried out by Hall (2010), the parents felt devastated trying to find money to pay for the therapy and special classes for their child.

Category "Knowledge about how to explain the illness to others"
The parents wanted to know how they could explain the illness to the concerned child (Anderson et al., 2001; Collier et al., 2001; Henley & Hill, 1990; Toye et al., 2004), the siblings, the babysitter or the schools (Austin et al., 1998; R. Jackson et al., 2008; Kendall et al., 2003; Stinson & McKeever, 1995; Toye et al., 2004).

In seven of the eight studies of the literature review conducted by Fisher (2001), parents were not satisfied with the information they had received. They had difficulties obtaining information, getting sufficient information or receiving too much information at a time, especially at the time of the diagnosis (Fisher, 2001; Hummelinck & Pollock, 2006). Most parents expressed that professional communication and the provision of information was deficient (Hummelinck & Pollock, 2006; Kendall et al., 2003; Miller et al., 2003).

5.1.1.2 Research instruments used to assess knowledge needs of parents with a child with a congenital abnormality and special health care needs

The thorough literature search in phase I (Paper I) revealed 26 studies in which questionnaires were used to assess the knowledge needs of parents, eleven studies used pre-existing instruments, and 15 studies developed or used purposive instruments in their study.

There were seven pre-existing instruments used in the studies (Table 1).

Table 1. Research instruments to assess knowledge needs of parents.

Name of the Instrument	Author, year	Developed by	Country
Family Needs Assessment Tool	Buran et al., 2009	(Rawlins, Rawlins, & Horner, 1990)	USA
Parent Report of Psychosocial Care Scale	Austin et al., 1998; Shore et al., 2009	Austin et al., 1998	USA
Support Needs Inventory for Parents of Asthmatic Children	Toye et al., 204	Coleman, Maltby, Kristjanson, & Robinson, 2001	Australia
Impact on Family Scale German version called “Familien-Belastungsskala” (FABEL)	Thyen et al., 2003	Stein & Riessman, 1980	Germany
Paediatric version of the “Family Needs Questionnaire”	Armstrong & Kerns, 2002	(Kreuzer, 2000)	Canada
“Family Needs Survey”	Bailey et al., 1992; Ellis et al., 2002; Graves & Hayes, 1996; Lanners & Lamert, 1999		USA
“MINI I and II”	Stinson & McKeever, 1995	Stinson & McKeever, 1995, based on the patients learning needs scale of Bubela et al., 1989.	Canada

The different instruments covered different knowledge needs. These are presented in the following table.

Table 2. Knowledge needs covered by the instruments.

	Contents covered by the scale	**Contents missing**	**Remarks**
Family needs assessment		Purpose: Assessment of needs of families with a child with cerebral palsy receiving services at the CP clinic.	
	Knowledge about the future Knowledge about support Knowledge about the condition or illness Knowledge about daily care of the child Knowledge about organizational issues Knowledge about equipment	Knowledge about treatment Knowledge about how to explain the illness to others	Nearly all knowledge needs covered. Knowledge needs described specific for children with cerebral palsy
Parent Report of Psychosocial Care Scale		Purpose: Information about their child's seizure condition	
	Knowledge about the condition or illness Knowledge about treatment Knowledge about how to explain the illness to others Knowledge about the future Knowledge about support Knowledge about daily care of the child	Knowledge about equipment Knowledge about organizational issues Knowledge about the effect of the illness on the family	Many knowledge needs covered. Knowledge needs described specific for children with a seizure condition.
Support Needs Inventory for Parents of Asthmatic Children		Purpose: Support needs of parents of asthmatic children	
	Knowledge about the condition or illness Knowledge about support Knowledge about treatment Knowledge about the future Knowledge about daily care of the child Knowledge about how to explain the illness to others Knowledge about the effect of the illness on the family	Knowledge about equipment Knowledge about organizational issues	Most knowledge needs covered. Knowledge needs described specific for children with asthma.
Impact on Family Scale, German version called "*Familien-Belastungsskala*" (FABEL)		Purpose: Assessment of the social disruption affecting parents. Personal strains, financial impact, problems in coping with the disease and concerns for siblings.	
	The needs were not described as needs but as items that have an impact on the family.		
Family needs questionnaire (paediatric version)		Purpose: To assess family members' perceived needs following the brain injury of a relative throughout the patient's recovery period.	
	Knowledge about support Knowledge about treatment	Knowledge about daily care of the child	Only few of the needs described but many other

	Contents covered by the scale	Contents missing	Remarks
	Knowledge about the condition or illness	Knowledge about the future Knowledge about how to explain the illness to others Knowledge about equipment Knowledge about organizational issues Knowledge about the effect of the illness on the family	needs that were not knowledge needs.
Family Needs Survey		Purpose: Documentation family needs for the purpose of planning an early intervention program.	
	Knowledge about the condition or illness Knowledge about support Knowledge about daily care of the child Knowledge about the future Knowledge about how to explain the illness to others	Knowledge about treatment Knowledge about equipment Knowledge about organizational issues Knowledge about the effect of the illness on the family	Most needs described as support needs, not as knowledge needs.
MINI I and II		Purpose: Assessment of the information that mothers of children after cardiac surgery perceived as important to know and the extent to which they thought they understood the information.	
	Knowledge about the condition or illness Knowledge about support Knowledge about treatment Knowledge about daily care of the child Knowledge about the future Knowledge about how to explain the illness to others Knowledge about equipment Knowledge about organizational issues Knowledge about the effect of the illness on the family		All needs covered but very detailed and specifically for children with heart problems

There were other instruments that were developed for the study in which they were administered. They contained specific questions for the respective study with ratings on Likert scales or numeric scales. Some also contained knowledge needs, which

were included in the developed instrument. No psychometric testing was described for these instruments.

None of the instruments covered all knowledge needs that were described in the literature, the interviews and focus group interviews. Some questionnaires were not suitable to use for the development of the instrument described in this thesis. They were developed and used for research and not to assess the needs of parents of hospitalised children or children with special health care needs in clinical practice. They were also not designed and tested to be used in that early stage of the child`s live.

5.1.2 Focus group interviews as research method in child, youth and parent research (Paper II)

To plan the focus group interviews with parents a literature review about focus group interviews in child, youth and parents research was conducted. The 120 included articles were all expert opinions (Polit & Tatano Beck, 2008). The experts were people concerned (e.g. parents) or health care professionals. The articles were grouped into three categories. A - articles written about the construction or conduction of focus groups or analysis of focus groups as main issue, B - article where focus groups were used for data collection and details about the use of the method were described and discussed and C - article where focus groups were used for data collection and at least one detail about the use of the method was described but not discussed. Most of the included articles were in category A. Only 27 were category B and nine in category C. For the following basic points, the special contents to the preparation and conduction of focus group interviews with children, youths and parents were extracted:

Table 3. Basic points in planning and conducting focus group interviews.

Preparation of focus groups	Conducting focus group interviews with children, youths and parents	Data analysis
- Selection of participants - Questioning strategies - Timing of the interview - Setting, in which the interviews take place - Length and quantity of interviews - Ethical issues that have to be considered	- Role of the moderator - Seating the participants - Introduction arrangements	- Transcription - Data analysis

The literature review showed, that focus group interviews are a suitable way for data collection in child, youth and parent research. Parents usually welcome the possibility to share their story and talk with other affected parents. When focus group interviews are planned with parents of children with special health care needs it is important to take into account that this might need special arrangements. Parents need time to arrange the care of their child while they are taking part in the interview or they might need to take their child with them. Then additional assistance might have to be planned to occupy the children during the interviews. If the children are in school, the parents might prefer to attend the focus groups during school time. Parents prefer a location that is known to them. This could be the premises of the school or also a place in a shopping mall or a church. To start the focus group interviews it is recommended to let the parents share the story about their child.

When conducting focus group interviews with children the age and stage of development have to be considered. Children need additional assistance during the focus group interview. It is important that they trust the moderator and the assistants. The length of focus group interviews is shorter than with adult participants and timing should be adapted to the school schedule.

Irrespective of the age of the participants the moderator has to be able to empathise with the participants of the focus group. He or she needs a lot of knowledge about the living environment of the participants.

5.1.3 Focus group interviews with the health care professionals (Phase I, Paper III, IV)

To identify the knowledge needs of parents of a child with a congenital abnormality and special health care needs two focus groups with health care professionals. In one focus group interview there were four nurse and two social care counsellors, in the other focus group, 2 nurses (n=6 / n=2). The knowledge needs identified by the health care professionals were very similar to the ones found in the literature research but they were mostly on a more detailed level. For the instrument, the knowledge needs identified by the health care professionals were combined with the knowledge needs of the literature review (Table 4).

Table 4. Categorization of knowledge needs from the interviews with health care professionals.

Knowledge need identified by health care professionals	Category from the literature review in which it was grouped
Tube feeding, insertion of tube, handling of enteral nutrition	Knowledge about everyday care of the child
Catheterisation, bowel irrigation	Knowledge about everyday care of the child
Care of a stoma	Knowledge about everyday care of the child
Skincare in general and round the stoma	Knowledge about everyday care of the child
Handling of devices like feeding pump, monitoring system, suction machine, indwelling subcutaneous cannula	Knowledge about handling of technical equipment
Who is responsible for the child on the ward of the physicians, senior physician, nurses	Knowledge about organisational issues
Problems in handling the altered body image of their child	Knowledge about support
Family members; who should be trained in caring for the child	Knowledge about support
Telephone numbers of the Emergency Department or the Hospital	Knowledge about support
Normal anatomy, physiology and pathophysiology	Knowledge about the condition or illness
What has to be observed like breathing, aspiration, complication with the stoma, diarrhoea, fever, pain	Knowledge about the condition or illness
What internet sites were available and understandable	Knowledge about the condition or illness

5.1.4 Interviews with parents (Phase I, Paper III, Paper IV)

As third source of knowledge needs of parents with a child with a congenital abnormality and special health care needs, three interviews with parents of a child with a congenital abnormality and special health care needs were conducted. The knowledge needs of the parents coincided with those of the literature and the focus group interviews. They stated that they needed to know how to organise themselves and needed details to the time required for the care of their child and the management of the material. They wanted to know who will write the prescription for the material and medication and where they can get the material and medication. One parent needed more details on how to administer the parenteral nutrition and to change the dressing of the parenteral catheter. They also wanted detailed instructions on the problems that may occur at home and about situations where they have to make decisions like e.g. what to do if they dropped something on the floor or if the insertions site of the central catheter was becoming red. The contact numbers of all important people were important for the parents too. One parent wanted to know

how many other children have the same diagnosis and would have liked to compare their child with others with the same illness. The parents said that it needed a lot of initiative of them as parents to get all the information they needed (paper III, paper IV).

5.2 Results of phase II, developed instrument (Paper I, IV)

From the findings of the literature review, the focus group interviews with health care professionals and the interviews with parents the items for the instrument for nurses to assess knowledge needs of parents with a child with a congenital abnormality before first discharge from hospital was were generated. The instrument consists of a questionnaire and a discharge checklist. The knowledge needs that were derived from the literature review were completed with the results from the focus group interviews and the interviews with parents. For the questionnaire, these knowledge needs were summarised in seven categories. More details to the categories are described in chapter 5.1.

1. Knowledge about the condition or illness (15 items)
2. Knowledge about what decisions should be made (2 items)
3. Knowledge about treatment and results (6 items)
4. Knowledge about everyday situations and the care of the child (14 items)
5. Knowledge about how to operate technical equipment (4 items)
6. Knowledge about organizational things (10 items)
7. Knowledge about where to get support (15 items)

The first part of the instrument is a structured questionnaire. It contains a number of different statements. On one side, the parents rate how much they need to know about the statement to be able to care for their child. On the other side, they rate, if they have enough knowledge to that statement. They rank their answers on a 10 cm visual analogue scale with the endpoints “I don`t agree” and “I strongly agree” (Table 5). This rating system was used in the “Support needs inventory” (Coleman et al., 2001; Toye et al., 2004) and the “Mini I and MINI II” (Stinson & McKeever, 1995). As the instrument was developed for children with different health problems and parents with different levels of knowledge needs this seemed to be a suitable way to assess the perceived need of knowledge first, before assessing the existing knowledge of the parents.

Table 5. Example of questions and answer options in the questionnaire.

To be able to care for my child I have to know:	**Does not apply**	**At the moment I know enough**
How a gastrointestinal tract works Not important very important		don`t agree strongly agree
What is different with my child Not important very important	☐	I don`t agree I strongly agree
What consequences that has for its feeding Not important very important	☐	I don`t agree I strongly agree

Seven additional points at the end of the questionnaire recorded the knowledge about the responsible senior physicians and nurses and whether they had been included in the decisions on therapy and treatment of their child. There were also two questions to identify an excessive burden and to the knowledge about helpful coping strategies. In addition, the demographic data of the parents were collected. The demographic data also contained the questions to the diagnosis of the child, how many operations the child had, if there were any complications, how the child was fed, what therapies they had and if homecare support after discharge was planned. Additionally, the patient charts were used to complete missing answers.

The second part of the instrument consists of a checklist issued shortly before discharge. The discharge checklist consists of 12 key messages and up to 4 additional statements detailing the main message, where parents, depending on the question / statement assess their knowledge on 10 cm visual analogue scale (Table 6). The response options depend on the statement. Right at the end of the checklist they estimate on a 10 cm Visual analogue scale, how confident they feel taking their child home.

Main statements of the discharge checklist

1. I am informed about the medication that my child needs to take
2. I feel safe in the drug medication administration of my child
3. I know about my child’s diet
4. I feel safe in my child’s diet

5. I know about the personal hygiene of my child
6. I feel safe in the care of my child
7. I know how much time I need for the care and nutrition of my child
8. I know what signals of my child I have to pay attention to
9. I know what materials I need for my child
10. I know what assistant devices I need for my child
11. I am informed about the further treatment of my child
12. I know what kind of support exists

Table 6. Example of statements and answer possibilities in the discharge checklist.

	Does not apply		
What do I know about the personal hygiene of my child?	☐	I know nothing	I know everything
I know how to take care of the stoma	☐	I know nothing	I know everything
I know how to take care of my child's skin	☐	I know nothing	I know everything
I feel secure in the personal hygiene of my child	☐	Not secure	Secure
What do I know about the warning signals I have to observe with my child?	☐	I know nothing	I know everything
I know what to do if my child vomits	☐	I don`t know	I know
I know what to do if my child has diarrhoea	☐	I don`t know	I know
I know what to do if my child has a fewer	☐	I don`t know	I know

The questionnaire and the discharge checklist contain a column "does not apply" as they were developed for children with different health care needs so it's possible that some questions or statements don't apply for every child.

5.3 Results phase III, exploration of the knowledge needs of parents with a child with a congenital abnormality and special health care needs with the new instrument (Paper III) and exploration of the comprehensiveness of the instrument (Paper IV)

The aim of Phase III was, to assess the knowledge needs of parents with a child with a congenital abnormality before first discharge from hospital. In the following two sections the results of the questionnaire and the discharge checklist and the results of the interviews to assess the comprehensiveness of the instrument are reported.

5.3.1 Exploration of the knowledge needs of parents with a child with a congenital abnormality and special health care needs with the new instrument

In the course of the two years, 35 parents were approached to fill out the questionnaire and discharge checklist. All together 16 (n=16) questionnaires and discharge checklists were filled out by the parents. 19 (n=19) of the requested parents did not want to participate in the survey or the children were released so quickly after the first contact that there was no time to complete the questionnaire. The data was collected over two years (between April 2014 and September 2016).

The children of the parents who took part in the study had various malformations of the abdominal wall, the gastrointestinal tract, the genitourinary tract, the liver, the heart, the spine and the brain. They were in need for following additional care: parenteral nutrition via central long-term catheter, percutaneous endoscopic gastrostomy (PEG), ileostomy, respiratory support (at night), bladder catheter or intermittent catheterization, very frequent skin care through the aggressive stool created by a short bowel and intensive physiotherapy. Almost all children were connected to a home monitor for monitoring oxygen saturation and heart rate. In addition, the needed an infusion pump for parenteral nutrition or the pump for enteral nutrition via the PEG. Some of the children were on regular medication.

The knowledge needs and the perceived needs of parents to a certain statement were assessed with the questionnaire. Of the answers, the difference between the knowledge needs and the self-assessed knowledge for each category of the questionnaire was calculated. Thereafter, the results were converted into percentages and divided into five groups (Table 7) (n=16).

1. More knowledge present than need
2. As much knowledge as needed
3. Less knowledge present than needed (up to 5 points less)

4. Much less knowledge present than need (more than 5 points less)
5. "Does not apply"

In the following table the percentage of the four groups (more knowledge present than needed, less knowledge present than needed, much less knowledge present than needed or "does not apply") is presented for the seven categories of the questionnaire. The percentage shows how many % of the answers were in the according group.

Table 7. Percentage of perceived knowledge needs.

Category ↓	More knowledge present than needed	As much knowledge as needed	Less knowledge present than needed (up to 5 points less)	Much less knowledge than needed (more than 5 points less)	„Does not apply"
Knowledge about the condition or illness (15 items)	16% (n=38/240*; min.: 0,1; max.:5,9)	8% (n=19/240)	40% (n=96/240; min.-5,00; max.-0,1)	15% (n=36/240 min.-10; max.-5,1)	14% (n=34/240)
Knowledge about what decisions should be made (2 items)	72% (n= 23/32; min. 0,2; max. 8,2)	19% (n=6/32)	9% (n= 3/32; min. -1,2; max. -0,3)	0%	0%
Knowledge about treatment and results (6 items)	18% (n= 17/96; min. 0,1; max. 8,4)	7% (n= 7/96)	50% (n= 48/96; min. -4,7; max.-0,2)	20% (n= 19/96; min. -10; max.-5,3)	4% (n=4/96)
Knowledge about everyday situations and the care of the child (14 items)	3% (n=7/224; min.0,1; max.6,6)	8% (n= 18/224)	38% (n=84/224; min. -4,7; max.-0,2)	13% (n=30/224; min. -9,6; max.-5,1)	33% (n=73/224)
Knowledge about how to operate technical equipment (4 items)	5% (n=3/64; min. 0,2; max. 0,3)	8% (n= 5/64)	16% (n=10/64; min.-5,0; max.-0,1)	5% (n=3/64; min. -7,7; max.-6,8)	64% (n=41/64)
Knowledge about organizational things (10 items)	24% (n=38/160; min. 0,1; max. 9,8)	14% (n= 23/160)	44% (n=71/160; min. -5,0; max. -0,1)	15% (n=24/160; min. -10; max.-5,3)	2% (n=3/160)
Knowledge about where to get support (15 items)	27% (n=64/240; min. 0,1; max. 9,7)	17% (n= 41/240)	35% (n=84/240; min. -5,0; max. -0,1)	15% (n=35/240; min. 9,9; max. -5,1)	5% (n=13/240)

*Explanation to n=xx/yy: Every category had a different number of items. So, the number of possible answers varied.
E.g. in the category 1 there were 15 items and 16 questionnaires so there were 240 possible answers. The "n = 38/240" means that 38 of the possible 240 answers were in that group.

This Table shows, that the parents mostly had more knowledge than needed concerning the decisions that should be made and 5%-27% had more knowledge in the other categories. Knowledge about the condition or illness of the child was lacking in 55% of the parents. And 70% respectively 51% had less knowledge than needed concerning the treatment and results of the treatment and about everyday situations in the care of their child. Knowledge about where to get support was lacking in 50% of the parents. Much less knowledge than needed was stated by up to 20% of the parents in the different categories.

The second part of the instrument is a checklist issued shortly before discharge Papers III and IV) to assess, if the parents had all knowledge they needed and felt safe to take their child home. It consists of 12 key messages and up to 4 additional statements detailing the main message, where parents, depending on the question / statement assess their amount of knowledge on 10 cm visual analogue scale The response options depended on the statement. (Table 6). The average values of the 10 cm Visual analogue scale of the main statements were calculated to what extent the statement to be assessed was perceived as correct. The categories are presented from the highest to the lowest value (Table 8).

Table 8. Values of the 12 categories.

Nr. of main category	Main category	Average value on 10 cm VAS
4	I feel safe in my child's diet	8,74
9	I know what materials I need for my child	8,61
7	I know how much time I need for the care and nutrition of my child	8,46
1	I am informed about the medication that my child needs to take	8,22
5	I know about the personal hygiene of my child	8,22
6	I feel safe in the care of my child	8,10
2	I feel safe in the drug administration of my child	8,01
8	I know what signals of my child I have to pay attention to	7,64
10	I know what assistant devices I need for my child	7,53
12	I know what kind of support exists	7,50
11	I am informed about the further treatment of my child	7,07
3	I know about my child's diet	7,00

To have an overview on the statements in regard to how many percent of the parents perceived the statements on the discharge checklist as correct, partly correct or rather not correct, the results of the individual statements in the discharge checklist were additionally divided into five groups.

1. The statement is approximately correct (over 8 on the 10 cm Likert scale) 42.88%
2. The statement is partly correct (between 3 and 8 on the 10 cm Visual analogue scale) 26.56%
3. The statement is rather not correct (below 3 on the 10 cm Likert scale) 6.60%
4. Does not apply 3.82%
5. Missing 20.14%

In average the parents rated the statements of the discharge checklist between 7,0 and 8,74. Looking at the individual assessments, the smallest score counted was 0, the maximum score was 10. 67% of the parents felt that the statements were correct or partly correct. Only 6,6 % felt they were not correct.

The last question was a 10 cm visual analogue scale on which the parents rated if they felt confident enough to take their child home. The calculated average was 8.09 on the visual analogue scale of 0 to 10 (0 = No, I'm not sure 10 = Yes, I feel sure). The smallest score was 2.5, the largest was 10. Three parents rated their readiness to take their child home in the range of 3 and 8, all others over 8 (n=16).

5.3.2 Exploration of the developed instrument

It was planned to test the test-retest reliability with 10% of the questionnaires. Due to the small amount of completed questionnaires and the fact that many children were discharged much earlier than planned (often on the day the discharge-checklist was filled out) this test could not be carried out.

Instead, two Interviews with parents who had been at home for at least 6 months were done to assess the experiences of mothers at home after discharge with the use of the developed instrument to see, if they had any knowledge needs which came up after discharge that were not covered by the questionnaire. These two parents were chosen, as they were still coming for regular check-ups in one of the University hospitals and could be approached without violating the duty of confidentiality. The age of their children at time of the interview was nine, resp. 21 months. Both interviews were done with the mothers of the children. The results of these interviews are presented in chapter 5.9.1. They both said that overall, they were well prepared before they left the hospital. The instrument helped them in the preparation for discharge but they still felt very anxious the first days at home with their baby. Both mothers said that they would have liked to use their own equipment for monitoring and feeding the child more often before they left the hospital as it was difficult to learn it all in the last days before discharge. One child went into a shared

apartment where three children with intensive care lived with their families but there were nurses there to support the families if they needed help. So, they could practice using their own equipment before they went home definitely. There were some problems like the plate of the stoma that wouldn't stick or information about homecare support that didn't occur until a few weeks or months after discharge. One child needed an operation for his kidney problem where the parents needed more information a few months after discharge. Both mothers knew where to get support and information for their new problems (paper III).

5.3.3 Results of the Interviews with the parents to evaluate the instrument

In this section the results of the interviews that were conducted to test the developed instrument for its feasibility and completeness are described.

Time at which the parents became aware of what knowledge needs they had.
The time when the parents became aware of what knowledge they needed depended on the time of diagnosis. They became aware of many knowledge needs in the course of the hospital stay, especially about everyday care such as the care of a stoma or the attachment of parenteral nutrition.

Information / training received and time of information giving / training.
The parents were quickly involved in the care and gradually learned to take care of the children and pay attention to signs where they have to act.

Origin of the information
The information about the diagnosis has mostly come from the medical field, and information about every day care from nurses / nursing experts and via the Internet.

Time spent on daily care
The parents had a high additional time effort due to the increased care needs of their child.

Support from homecare
One parent had support from home care, one did not.

The parents were torn between the need for support on the one hand and the restrictions on the other hand due to frequent changes in caregivers or the loss of privacy if a stranger was working in the household for 24 hours a day, 7 days a week.

Dealing with consumable care material
The children sometimes needed a lot of care material, especially if they were fed parenterally or had a stoma. This was a big challenge for the parents because they were confronted with other materials at home than they knew from the hospital. This

was sometimes a relief, but it also led to uncertainty. Obtaining the care material could also lead to problems.

Contact with other concerned parents
One parent wanted to get in contact with other concerned parents, one did not. The one who would have liked to have contact, wanted to know how other children with the same or similar illness developed and what quality of life they had. For the one who did not want a contact mostly on the grounds that each child was different and they did not want to compare their child with others. Especially before birth, they did not know what their child's limitations would be and that they did not want to worry more than necessary when they met other people. They stated that they simply did not have the time to care for or maintain contact.

What was helpful, positive feedback
In one of the hospitals there was a case manager who took care of everything before discharge. In another hospital, the parents could take their child home for a weekend or a few days "on trial" before they were finally discharged. They then came back to the ward for a few days before they were discharged definitely. This was appreciated by the parents.

What was missing or should have been different
Although the parents stated in the interviews that they had received enough information, there were still some points mentioned where there was room for improvement or where they would have wished for a different way of informing or dealing with them. There was also a lack of written information on contacts or guidelines on care duties.

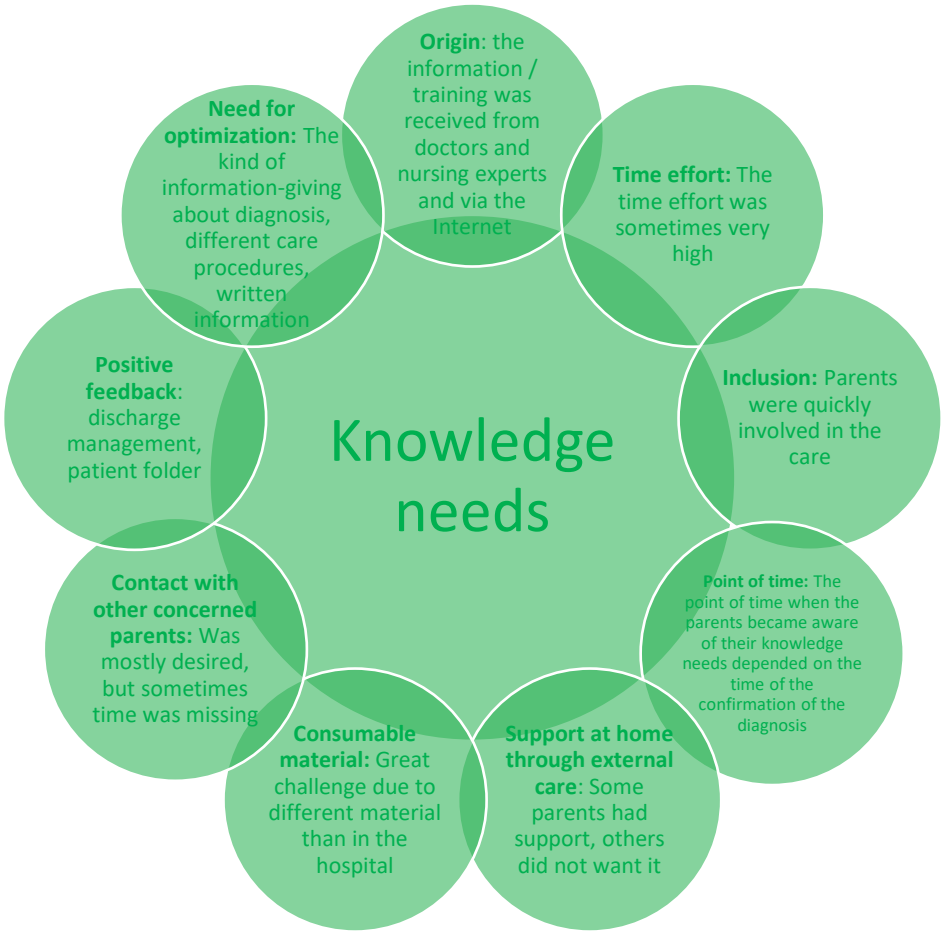

Figure 3. Summary of the results of the interviews to evaluate the instrument - Parents needs after discharge.

5.4 Summary of the results

Based on this three-phase study parents of children with a congenital abnormality and special health care needs have different knowledge needs at different at different points in time. In order to satisfy these needs nurses should assess these needs systematically. For this reason, an instrument consisting out of a questionnaire and a discharge checklist was developed in this study. The administration of the instrument shows that at the time of discharge the parents mostly feel, that they have enough knowledge about their child's condition and care to care for their child at home. In the course of the study a methodological review of the use of focus group interviews in child and parent research was conducted. The results show, that focus group interviews are a useful way to gather data in child- and parent research. The

interviews have to be planned and conducted carefully according to the age of the participants.

The results of the different phases of the study are summarized here.

Table 9. Summary of the results in the different phases.

Phase I	**Literature review to the knowledge needs of parents with a child with a congenital abnormality and special health care needs (Paper I)**	37 different knowledge needs were described in the articles. These were categorized into nine categories: knowledge about the condition or illness, knowledge about support, knowledge about treatment, knowledge about daily care of the child, knowledge about the future, knowledge about how to explain the illness to others, knowledge about equipment, knowledge about organizational issues and knowledge about the effect of the illness on the family. In the 26 studies in which questionnaires were used to assess the knowledge needs of parents, eleven studies used pre-existing instruments, and fifteen studies developed or used purposive instruments in their study. None of the instruments covered all knowledge needs that were described in the literature.
	Methodological review about focus group interviews with children, youths and adults (Paper II)	Focus group interviews are a suitable way for data collection in child, youth and parent research, when well designed. The special situation of parents with a child with special health care needs has to be considered when planning and conducting a focus group interview. Children's age and developmental stage play a big part in the conduction of focus group interviews. Children need additional assistance during the focus group interview.
	Focus group interviews (Paper I)	The knowledge needs identified by the health care professionals were found in the literature research but they were mostly on a more detailed level: • Normal anatomy, physiology and pathophysiology • What has to be observed like breathing, aspiration, complication with the stoma, diarrhoea, fever, pain • Tube feeding, insertion of tube, handling of enteral nutrition • Catheterisation, bowel irrigation • Care of a stoma • Skincare in general and round the stoma • Handling of devices like feeding pump, monitoring system, suction machine, indwelling subcutaneous cannula • Problems in handling the altered body image of their child • Who is responsible for the child on the ward of the physicians, senior physician, nurses • Family members; who should be trained in caring for the child • What internet sites were available and understandable
	Interviews (Paper I)	The knowledge needs of the parents (n=16) coincided with those of the literature and the focus group interviews. Additionally, they stated that they needed to know how to

		organise themselves and needed details to the time required for the care of their child and the management of the material. They also wanted detailed instructions on the problems that may occur at home and about situations where they had to make decisions like e.g. what to do if they dropped something on the floor or if the insertions site of the central catheter was becoming red.
Phase II	**Instrument development (Papers I, IV)**	Questionnaire: The knowledge needs that were derived from the literature review were completed with the results from the focus group interviews and the interviews with parents. All these knowledge needs were summarised in seven categories. 1. Knowledge about the condition or illness 2. Knowledge about what decisions should be made 3. Knowledge about treatment and results 4. Knowledge about everyday situations and the care of the child 5. Knowledge about how to operate technical equipment 6. Knowledge about organizational things 7. Knowledge about where to get support Discharge Checklist: The discharge checklist consists of 12 key messages and up to 4 additional statements detailing the main message.
Phase III	**Data collection (Paper III)**	The results of the questionnaire showed that they had more knowledge needs than knowledge available at the time when the questionnaire was filled out (about two weeks before discharge). In the discharge checklist that was filled out shortly before discharge of the child the parents rated their knowledge higher and stated that they felt secure to take their child home.
	Interviews to evaluate the instrument (Paper IV)	In the interviews that took place between three months to a year after discharge of the child, it became apparent that the parents felt well prepared to leave the hospital, but after some time at home things occurred where they noticed that some knowledge was missing, especially contact numbers and written information to the care plan of their child.

6 Discussion

In this chapter, firstly, the results will be discussed in light of previous research results according to the research aims. Secondly, the validity and reliability of the study will be discussed.

6.1 Discussion of the results

In this section firstly the knowledge needs of parents with a child with a congenital abnormality assessed with the developed instrument and out of the literature are discussed. Secondly the developed instrument with its advantages and disadvantages is discussed.

6.1.1 Knowledge needs of parents with a child with a congenital abnormality in general and during the first hospitalisation after birth

The study revealed that parents needed a lot of knowledge to care for their child with a congenital abnormality and special health care needs. The results of the questionnaire showed that they mostly had more knowledge needs than knowledge at the time when the questionnaire was filled out (about two weeks before discharge). Especially in the categories “knowledge about the condition or illness”, “knowledge about treatment and results”, “knowledge about everyday situations and the care of the child” and “knowledge about where to get support”.

Only in the category “knowledge about what decisions should be made” the parents had more knowledge than needed. In the discharge checklist that was filled out shortly before discharge of the child the parents rated their knowledge higher and stated that they felt secure to take their child home. These results could be an indication that the training of the parents in the care of their child and the supply of information takes part in the last two weeks before the child leaves the hospital.

Maybe the questionnaire helped the parents to be aware of all the information and skills that are missing and they could actively inform themselves. In the interviews that took place between three months to a year after discharge of the child, it became apparent that the parents felt well prepared to leave the hospital, but after

some time at home, things occurred where they noticed that some knowledge was missing. A discharge checklist was one support tool parents described in the study of Ronan et al. (2020) Even though the parents felt well prepared to go home, they felt very anxious in the first days and weeks after the discharge. These results were confirmed by parents who were interviewed about their experience in transition to home with their technology dependent child (Brenner et al., 2015) and by parents taking their child home from a cardiology unit (Schuh et al., 2016).

Written documents were one of the main missing needs of parents. This statement was also expressed by parents in one of the hospitals, where a folder was given to the parents with all the important information and phone numbers of all responsible contact persons. Thus, the parents do not seem to perceive this folder in a form that was helpful. This finding is also consistent with statements in the literature describing the need for written information and care plans in older studies (Aite et al., 2006; Kendall et al., 2003) and in more recent articles (Adams et al., 2013; Al-Daihani & Al-Ateeqi, 2015; Jachimiec et al., 2015; Jessup et al., 2016; J. D. Lotz et al., 2017; Lundberg et al., 2016; Reid & Gaskin, 2018).

Parents also wanted information and contact details from all the people who can help. In the literature it is described that parents would like an interdisciplinary team that stays constant and knows them and their child, as well as their medical history and treatment and treatment plan, and who can always be contacted if they have any questions (Alsem et al., 2014) Fernandes & Sanders, 2015). Especially children with multisystem conditions who see many subspecialty teams are vulnerable to fragmentation of the health care system and to “falling through the cracks” (Altmann et al., 2018, p 6).

As described in other studies, it was found that parents need a lot of knowledge at the time of diagnosis (Allen, 2014). However, they are torn between the desire to get as much information as possible and the flood of information that they can hardly classify and manage (Jessup et al., 2016; Kendall et al., 2003). Parents stated they wanted “easy-to-digest” information, just the facts, because they couldn’t handle anything else (Boyse et al., 2014). Parents frequently use the internet to gather information on their child’s condition (Nicholl et al., 2017). It might be helpful if the parents could retrieve specific information virtually and / or online over and over again to be able to handle them gradually and according to their own needs (Dol et al., 2017; Kendall et al., 2003). Still the parents need support to understand everything they read online (Dol et al., 2017). The parent’s ability to manage their medical complex child is influenced by the complexity of the child’s condition, the psychosocial structure of the family and the health literacy of the parents (Altman et al., 2018; Sørensen et al., 2012).

The way they were informed about the diagnosis and its consequences was also one of the points in which the parents would have wanted a different approach. The

diagnosis and the way in which it is communicated is also described as a major challenge in the literature and requires a good education of the doctors (Boss et al., 2017). The parents would have wanted more empathy and more information about the consequences and possibilities that the malformation or disability has on the future life of their child (Alsem et al., 2014).

The statements of the parents to be able to exchange experiences with other affected parents only partially coincided with those described in the literature. In the interviews, not all parents considered contact with other people to be helpful. One mother even consciously avoided this. In the literature, these contacts and support groups are perceived as very helpful and highly desirable (Agrawal et al., 2017; Alsem et al., 2014; Hammarberg et al., 2014; Lundberg et al., 2016; Wynter, Hammarberg, Sartore, Cann, & Fisher, 2015).

In more recent literature, electronic sources and mobile applications with reliable information were wished by parents in addition to the face-to-face contact (Baumann, Jaks, Robin, Juvalta, & Dratva, 2020; Jaks, Baumann, Juvalta, & Dratva, 2019; Kubb & Foran, 2020; Mannarino et al., 2020; Reeder & Morris, 2021). As it is difficult for the parents to know in what information they can believe in, they like to discuss their findings with the paediatrician (Baumann et al., 2020; Jaks et al., 2019; Kubb & Foran, 2020).

6.1.2 Developed instrument for nurses to assess these knowledge needs

The second task of the study was to develop an instrument to assess these needs. The instruments that were found in the literature (phase I) didn't cover all the knowledge needs that parents might have during and following the first hospitalisation after birth of their child with a congenital abnormality and they were not developed to be used at that stage of the child's life. Therefore, a new instrument was developed and used to assess the knowledge needs of the parents.

The numbers of items in each category of the instrument varied as they were developed from the literature review and the interviews with health care professionals and parents. Some areas of knowledge have been studied more and thus there are more items about one topic than others.

When reflecting the missing knowledge needs of parents that had been at home with their children for some months it became evident, that written information and the contact to other affected parents were two important issues that were not covered in the developed questionnaire and should be added to the instrument. These are two important issues also described in literature in many studies (Alsem et al., 2017; Desai et al., 2016; Geense et al., 2017; Lundberg et al., 2016; Nightingale et al., 2015; Reid & Gaskin, 2018; Wallis et al., 2019).

The instrument was useful to detect the knowledge needs of the parents before their child was discharged from hospital. It seems that the parents mostly had no trouble understanding the questionnaire and answering the questions. One mother asked for support while filling out the questions as she was not a German native speaker and she was unsure if she would understand all the questions. All other parents didn't need any support. The data collection with the instrument through a person who wasn't working on the ward where the patients were hospitalised proved to be a problem. It was difficult to find the right time to approach the parents. A nurse working on the ward would probably be able to address the parents at the most suitable time. On one ward the nurses seemed to fear that the questionnaire could reveal unmet knowledge needs which should have been covered by them. If the questionnaire was administered on a routine basis, this fear might decrease.

This study was conducted to assess the knowledge needs of parents of a child with a congenital abnormality and special health care needs. Even if the satisfaction of these needs is very important one should not forget that there are many other needs of the parents too. Parents of a child with a congenital abnormality are often grieving the loss of the desired healthy baby. Especially if the diagnosis was not made prenatally the parents are often in a state of shock and denial. They are dealing with a traumatic situation and might have difficulties understanding the information they get at that moment (Bevilacqua et al., 2013; Di Grazia et al., 2017; Reid & Gaskin, 2018). To be prepared for possible stressful situations and problems that might arise the parents need to be provided with psychosocial and emotional support (Stoffel, 2014).

6.2 Validity and reliability of the study

In this section the validity and reliability of the data, the research process and the used instrument will be discussed.

This three-phase Study started with the theoretical background to evaluate studies that focus on the knowledge needs of parents of a child who has a congenital abnormality and special health care needs and to examine instruments that were used to assess these needs.

The theoretical background as basis for the planned instrument (phase I) included two parts: An integrative literature review following the steps described by (Whittemore & Knafl, 2005) was conducted. The literature search was conducted in PubMed, CINAHL, EMBASE, and PsycINFO, with articles published from 1999 to 2010. These databases were selected as they are essential and comprehensive databases in the field of nursing and health sciences. To provide analytical evaluations of the quality of the study, especially to minimize bias in research,

different critical appraisal tools were used. For qualitative studies, the Critical Review Form for Qualitative Studies, Version 2.0 (Letts et al., 2007), developed at McMaster University, Hamilton, Ontario, Canada. For quantitative studies the Guide for Quantitative Research (Law et al., 1998) and for literature reviews the Critical Appraisal Tool from Engberg (2008). The first author of the literature review (Paper I) assessed the majority of the articles. As a reliability check, 10% of the articles were also assessed by a second reviewer for their methodological quality. Diverse ratings were discussed until a consensus was reached on the quality of the content and its suitability to the research questions.

The second part of the theoretical background in phase I included focus group interviews held with nurses and social care counsellors and three interviews with parents. As basis for the focus group interviews a methodological review on focus group interviews in child and parent research was conducted. A constant comparison method was used to distinguish themes from the literature and the interviews. Extracted data were compared item by item, and similar data were categorized and grouped together. A limitation here is that the categorization of the data was conducted by only one person.

In the second phase the instrument was developed and the content validity index of the items was estimated. The instrument was critically reviewed by experts which were selected on their expertise with children with a congenital abnormality and special health care needs. Four nurse experts and two mothers of a child with a congenital abnormality and special health care needs rated on a scale of one to four, how important every single question is and, if it is understandable. One question was deleted as the calculated CVI was below 0,80. Only one question was marked as not being understandable by one evaluator. All other questions were marked as being understandable.

In the third phase the instrument was used and the reliability of the instrument was evaluated. It was planned to test the test-retest reliability with 10 % of the questionnaires. Due to the small amount of completed questionnaires (n=16) and the fact, that many children were discharged much earlier than planned this test could not be carried out. Instead, two Interviews with parents who had been at home with their child with a congenital abnormality and special health care needs for at least half a year were done to verify if the knowledge needs in the questionnaire matched the experience of the parents after some time since discharge from hospital.

This and the low number of completed questionnaires is a clear limitation of the study. It was planned to get 100 questionnaires over a period of one year. This goal had changed dramatically in the period up to the beginning of the study. This number was determined by the number of patients that usually were referred to the participating wards in one year. The real number of expected patients was about 200 and we hoped to have halve of the parents taking part in the study. In the end there

were much less children whose parents could be included in the study. This was partly due to the availability of new treatment guidelines and methods for certain conditions (e.g. large abdominal wall lesions, children with post-necrotizing enterocolitis bowel obstruction). These children could go home without additional care needs. In addition, one large clinic that had confirmed its participation suddenly declined to participate in the study just at the beginning of the trial. The period of data collection was prolonged to two years but even though there were not more parents who took part in the study.

It was also very difficult to find the right time to inform the parents about the study and ask them if they wanted to participate. Some children were very unstable in their first weeks after birth. One never knew if and when they might need surgery again or sometimes it was even unclear if they would survive. The parents were not addressed until the situation had stabilised. When the more stable phase came, it was difficult to reach the parents because they were already organising a lot at home and did not spend so much time at the ward anymore. The time before discharge is very stressful for parents and the last thing they can face, is taking part in a research project (Ward, 2010). Often, the planned dismissal was then suddenly brought forward, so that there was no time left to fill in the questionnaire. There were also some parents who promised to fill out the questionnaire and discharge-checklist but did not want to participate in the study after all. They were not asked why they did not want to participate, but some parents expressed that they were too busy at the time with the discharge planning and organisation of all medical aids and products to complete the questionnaire.

It might have been easier if the person who approached the parents to ask for their participation had worked on the same ward. The time of discharge would have been easier to estimate, as one would not have been dependent on the information of others and the parents could have been approached easier when they came to visit their child. However, this was intentionally avoided as we did not want to put the parents under pressure to participate in the study. Brenner et al. (2017) faced the same problems and conducted interviews with parents using a confidential telephone system. Despite these problems recruiting parents in this vulnerable phase, we think it is very important to involve them in research projects. An online survey might have helped approaching parents who preferred to fill out a questionnaire online instead of a paper form.

6.3 Implications for future research

According to the results of the study, the following suggestions for future research in the care of children with congenital abnormalities and special health care needs are proposed:

1. Parents of children with a congenital abnormality and special health care needs have different knowledge needs at different times during and after the hospitalisation of their child. Especially at the time of diagnosis and before discharge many questions erase. Later in the life of the child other questions occur. Specific instruments to assess these knowledge needs at different times (during and after the hospitalisation and ongoing during the different stages of their life) should be developed.
2. Parents of children with a congenital abnormality and special health care needs have difficulties obtaining information, getting sufficient information or receiving too much information at a time, especially at the time of the diagnosis. More knowledge is needed, when and in what form, information should be presented to the parents.
3. The developed instrument should be further tested for validity and reliability with a larger sample of questionnaires. This could be easier if the questionnaire would be administered before discharge with all parents of children with a congenital abnormality.
4. Focus group interviews with children, adolescents and parents need further methodological development. Especially a guideline for the appropriate way to summarise focus group interviews with (small) children should be developed. Additionally, the evaluation and detailed reporting of the research method should be enhanced.

6.4 Implications for practice

According to the results of the study, the following suggestions for the care of children with congenital abnormalities and special health care needs are proposed:

1. Parents of children with a congenital abnormality and special health care needs feel very insecure when leaving the hospital with their child for the first time. More knowledge is needed about the factors that lead to this insecurity and what could help the parents in this crucial phase. The parents want a lot of information about the diagnosis of their child but they are often overstrained with all the information they get. The knowledge needs of the parents should be assessed at different stages during the whole life of the child and parents should get a possibility to discuss the information they find in the internet with a health care professional. Parents of children with a congenital abnormality and special health care needs would like written information about the condition, treatment and care of their child. This can be in paper format or online information that can be addressed whenever needed. Little films for treatment procedures, e.g. change of a dressing, tube feeding, etc. made available by the specialist clinics,

would be helpful. Secure internet sites, provided by the specialist clinics with tailored information for their specific problems would be helpful for the parents.

2. The information about the diagnosis of a child with a congenital abnormality should be given to the parents through an expert with great empathy. The parents should be informed about the consequences that the abnormality has on the life of their child but also about the chances the child has.
3. Parents of children with a congenital abnormality should get the opportunity to talk to other concerned parents or they should be offered addresses of support groups.

7 Conclusions

Many studies show, that parents of a child with additional health care needs need a lot of information concerning the diagnosis, the short- and long-term prognosis, and about the therapy and treatment of their child. They show that the information must be in a terminology adapted to the parents' language and intellectual capability, it should be adapted to the parents' level of knowledge and it should be accessible at any time. The parents prefer written information or internet sites where they can recall the information whenever they needed it. The information and knowledge needs should be assessed at different times during the life of the child.

In this study, a new instrument was developed, to assess the knowledge needs of parents before first discharge from hospital after birth of their baby. Such an instrument is helpful for nurses to assess the knowledge needs of parents before they leave the hospital for the first time. A standardised approach to assess the needs of the child and the family in preparation for discharge should be addressed with clear timelines and criteria for reassessment of the needs once the child is at home.

For the parents of children with additional health care needs it is very important that the care for their child is provided by a highly qualified team of nurses, physicians, therapists and counsellors who bring in a lot of experience and empathy. A good discharge preparation should include the help for parents to make contacts outside the hospital, to build up a network that supports them in the step to start their new life at home with their child. It is helpful for parents to exchange information with other affected parents. Future research should be conducted on what help parents would need to reduce the burden they have after the birth of a child with a congenital abnormality and special health care needs and especially in the last weeks before discharge and what support helps them after discharge of their child.

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List of Figures, Tables and Appendices

Figures

Tables

Appendices

Appendices

Appendix 1. Instrument German version (Copyright: Kristin Adler).

Appendix 1. Instrument German version (Copyright: Kristin Adler).

Studie: Wissensbedarf von Eltern eines Kindes mit einer angeborenen Fehlbildung
Abgabe ca. 2-3 Wochen vor Austritt

Briefkopf Klinik

Fragebogen zu den Wissensbedürfnissen für Eltern von Kindern mit einer angeborenen Fehlbildung

Registernummer: _____ **Datum:** _____

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiss ich genug darüber
1.	**Wie ein normaler Magendarmtrakt aufgebaut ist und funktioniert** Nicht wichtig — Sehr wichtig		trifft gar nicht zu — trifft voll und ganz zu
2.	**Wie ein normales Herz aufgebaut ist und funktioniert** Nicht wichtig — Sehr wichtig		trifft gar nicht zu — trifft voll und ganz zu
3.	**Wie normale Nieren und ableitende Harnwege aufgebaut sind und funktionieren** Nicht wichtig — Sehr wichtig		trifft gar nicht zu — trifft voll und ganz zu
4.	**Was bei meinem Kind anders ist** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
5.	**Welche Konsequenzen dies für die Ernährung hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
6.	**Welche Konsequenzen dies für den Kreislauf hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
5.	**Welche Konsequenzen dies für die Ernährung hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
6.	**Welche Konsequenzen dies für den Kreislauf hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
7.	**Welche Konsequenzen dies für die Urinausscheidung hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
8.	**Welche Operationen durchgeführt wurden** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
9.	**Wie der Zustand meines Kindes ist** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
10.	**Welches die Symptome einer Herzinsuffizienz (Herzschwäche) sind** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
11.	**Welche Medikamente mein Kind bekommt** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
12.	**Wie die Medikamente gelagert werden müssen** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
13.	**Wie die Medikamente verabreicht werden** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

2

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
14.	Welche Wirkung und Nebenwirkungen die Medikamente haben Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
15.	Wie das Inhalieren geht Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
16.	Welche anderen Therapien mein Kind hat (z.B. Krankengymnastik, Ergotherapie, Logopädie) Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
17.	Welche Übungen ich selber machen kann Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
18.	Wie man Sauerstoff verabreicht Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
19.	Welche Komplikationen es dabei geben kann Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
20.	Welche Untersuchungen und Tests bei meinem Kind durchgeführt werden Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
21.	Die Resultate der Untersuchungen und Tests die bei meinem Kind durchgeführt wurden Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
22.	Welche Säuglingsmilch / Ernährung mein Kind bekommt Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

3

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
23.	Wie ich diese Säuglingsmilc / Ernährung herstellen muss Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
24.	Wie die Säuglingsmilc / Ernährung gelagert wird Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
25.	Wie ich mein Kind sondieren muss Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
26.	Wie ich das Stoma versorgen muss Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
27.	Welche Komplikationen es beim Stoma geben kann Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
28.	Wie ich die Haut unter der Sonde, am Gesäss, beim Stoma pflegen muss Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
29.	Wie der Überwachungsmonitor meines Kindes funktioniert Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
30.	Wie der Sondomat funktioniert und wie er eingesetzt wird Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
31.	Wie das Absauggerät funktioniert und wie es eingesetzt wird Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

4

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
32.	**Wie ich mit dem venösen oder subkutanen Katheter umgehen muss** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
33.	**Wie lange mein Kind etwa im Krankenhaus bleiben muss** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
34.	**Welche Voraussetzungen erfüllt sein müssen, damit ich mein Kind nach Hause nehmen kann** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
35.	**Wie oft ich nach dem Austritt zur Nachkontrolle gehen muss** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
36.	**Wann die nächste Nachkontrolle stattfindet** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
37.	**Wo die nächste Nachkontrolle stattfindet** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
38.	**Wie ich zusätzliche Erkrankungen vorbeugen kann** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
39.	**Wie ich im Falle einer Nebenwirkung eines Medikamentes reagieren muss** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
40.	**Wie ich reagieren muss wenn mein Kind Fieber hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

5

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
41.	**Wie ich reagieren muss wenn mein Kind Erbricht** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
42.	**Wie ich reagieren muss wenn mein Kind Durchfall hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
43.	**Was Ödeme sind und wie ich reagieren muss wenn mein Kind Ödeme hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
44.	**Wie ich reagieren muss wenn mein Kind Schmerzen hat** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
45.	**Wo ich das Material für die Pflege meines Kinder her bekomme** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
46.	**Wie viel Zeit ich für die Pflege meines Kindes brauche** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
47.	**Wen ich in die Pflege meines Kindes miteinbeziehen kann** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
48.	**Wer mir Unterstützung geben kann** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
49.	**Wer mein Kind beaufsichtigen kann, damit ich zwischendurch ein paar Stunden freie Zeit habe** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

6

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
50.	**An wen ich mich wenden kann, wenn mir die Situation zu viel wird** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
51.	**Wem ich anrufen kann, wenn ich nach dem Austritt aus dem Krankenhaus noch Fragen habe** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
52.	**Telefonnummer der häuslichen (Kinder-) Krankenpflege** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
53.	**Telefonnummer der Mütterberatungsstelle** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
54.	**Welche Selbsthilfeorganisationen es gibt** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
55.	**Kontaktadresse einer Selbsthilfeorganisation** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
56.	**Wer die Kosten des Krankenhausaufenthaltes bezahlt** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
57.	**Wer alle zusätzlichen Aufwendungen die durch die Fehlbildung entstehen bezahlt** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu
58.	**Wo ich finanzielle Unterstützung bekomme** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

7

	Um für mein Kind sorgen zu können muss ich folgendes wissen:	Hat / braucht mein Kind nicht	Im Moment weiß ich genug darüber
59.	**Auf welchen Internetseiten ich Informationen nachschauen kann** Nicht wichtig — Sehr wichtig	☐	trifft gar nicht zu — trifft voll und ganz zu

	Zusätzliche Fragen / Punkte	Wie wichtig ist dies für mich
60.	**Ich weiss, welcher Oberarzt für mein Kind zuständig ist** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
61.	**Ich weiss, welche Krankenschwester für mein Kind zuständig ist** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
62.	**Ich habe genug Informationen um über die Behandlung und Therapie meines Kindes mitentscheiden zu können** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
63.	**Ich werden in die Entscheide zur Behandlung und Therapie meines Kindes miteinbezogen** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
64.	**Ich habe genügend schriftliche und mündliche Informationen über den Gesundheitszustand, die Behandlung und Therapien meines Kindes** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
65.	**Ich kenne die Anzeichen einer persönlichen Überlastung** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig
66.	**Ich kenne hilfreiche Bewältigungsstrategien** trifft gar nicht zu — trifft voll und ganz zu	Nicht wichtig — Sehr wichtig

8

Demographische Daten

Geschlecht Kind: ☐ ♂ ☐ ♀ ☐ unklar
Name, Vorname Mutter: _____ Alter Mutter: _____
Name, Vorname Vater: _____ Alter Vater: _____
Zivilstand (Mutter): ☐ Verheiratet ☐ Eingetragene Partnerschaft ☐ in Beziehung
☐ geschieden ☐ verwitwet
Zivilstand (Vater): ☐ Verheiratet ☐ Eingetragene Partnerschaft ☐ in Beziehung
☐ geschieden ☐ verwitwet
Wie viele gemeinsame Kinder haben Sie (neben dem hospitalisierten Kind): _____
Geburt: ☐ Spontangeburt ☐ Kaiserschnitt
Diagnose des Kindes: _____
Wie viele Operationen hatte das Kind? _____
Komplikationen ☐ Ja - Welche? _____ ☐ Nein
Ernährung des Kindes: ☐ gestillt ☐ Fläschchen ☐ Gestillt und Fläschchen
☐ sondiert (○ Intervall ○ über mehrere Std.) ☐ parenteral Ernährt
Hat Ihr Kind Therapien: ☐ Physiotherapie ☐ Ergotherapie ☐ Logopädie ☐ _____
Hat das Kind ein Stoma? ☐ Ja – Wo? ☐ Nein
War das Kind auf der Intensivstation? ☐ Ja – wie lange? _____ ☐ Nein
War das Kind auf der Neonatologie? ☐ Ja – wie lange? _____ ☐ Nein
Welches war die letzte Schulbildung (Mutter): ☐ Hauptschule, ☐ Realschule ☐ Gymnasium
☐ Fachhochschule ☐ Universität
Welches war die letzte Schulbildung (Vater): ☐ Hauptschule, ☐ Realschule ☐ Gymnasium
☐ Fachhochschule ☐ Universität
Haben Sie eine Lehre gemacht (Mutter)? ☐ Ja – Welche? _____ ☐ Nein
Haben Sie eine Lehre gemacht (Vater)? ☐ Ja – Welche? _____ ☐ Nein
Arbeiten Sie (Mutter)? ☐ Ja – wie viele Prozent? _____ ☐ Nein
Arbeiten Sie (Vater)? ☐ Ja – wie viele Prozent? _____ ☐ Nein
Werden Sie wieder arbeiten wenn Ihr Kind entlassen wird (Mutter)?
☐ Ja – wie viele Prozent? _____ ☐ Nein
Werden Sie wieder arbeiten wenn Ihr Kind entlassen wird (Vater)?
☐ Ja – wie viele Prozent? _____ ☐ Nein
Mussten Sie während der Schwangerschaft liegen? ☐ Ja – wie lange? _____ ☐ Nein
Welche Nationalität haben Sie (Mutter)? _____
Welche Nationalität haben Sie (Vater)? _____
Ist zu Hause eine Unterstützung durch häusliche (Kinder-) Krankenpflege geplant?
☐ Ja (○ häusliche Kinderkrankenpflege ○ häusliche Krankenpflege) ☐ Nein
Bemerkungen
_____
_____
_____
_____

☐ Ich/wir möchte/n über die Studienresultate informiert werden

Name, Adresse:

_____
_____
_____
_____

Appendix 2 Discharge checklist German version (Copyright: Kristin Adler)

Briefkopf Klinik

Studie: Wissensbedarf von Eltern eines Kindes mit einer angeborenen Fehlbildung
Abgabe an die teilnehmenden Eltern kurz vor Austritt.

Austrittscheckliste für Eltern von Kindern mit einer angeborenen Fehlbildung

Registernummer: _____ **Datum:** _____

	Hat / braucht mein Kind nicht	
Was weiss ich über die Medikamente die mein Kind einnehmen muss?	☐	Ich weiss nichts ____ ich weiss alles
Ich kenne die Wirkung und Nebenwirkungen der Medikamente	☐	Weiss ich nicht ____ weiss ich
Ich weiss, wie ich mich im Fall einer Medikamentennebenwirkung verhalten soll	☐	Weiss ich nicht ____ weiss ich
Ich weiss, wie ich die Medikamente lagern muss	☐	Weiss ich nicht ____ weiss ich
Ich weiss, wie ich meinem Kind die Medikamente geben kann	☐	Weiss ich nicht ____ weiss ich
Ich fühle mich sicher in der Medikamentenverabreichung bei meinem Kind	☐	Nicht sicher ____ sicher
Was wissen Sie über die Ernährung meines Kindes?	☐	Ich weiss nichts ____ ich weiss alles
Ich weiss, was und wie viel mein Kind trinken darf	☐	Weiss ich nicht ____ weiss ich
Ich weiss, wie ich dir Ernährung herstelle	☐	Weiss ich nicht ____ weiss ich
Ich weiss, wie ich die Ernährung verabreiche	☐	Weiss ich nicht ____ weiss ich
Ich fühle mich sicher in der Ernährung meines Kindes	☐	Nicht sicher ____ sicher

	Hat / braucht mein Kind nicht	
Ich weiß, was und wie viel mein Kind trinken darf	☐	Weiß ich nicht ____ weiß ich
Ich weiß, wie ich dir Ernährung herstelle	☐	Weiß ich nicht ____ weiß ich
Ich weiß, wie ich die Ernährung verabreiche	☐	Weiß ich nicht ____ weiß ich
Ich fühle mich sicher in der Ernährung meines Kindes	☐	Nicht sicher ____ sicher
Was weiß ich über die Körperpflege bei meinem Kind?	☐	Ich weiß nichts ____ ich weiß alles
Ich weiß, wie ich die Körperpflege meines Kindes durchführen kann	☐	Weiß ich nicht ____ weiß ich
Ich weiß, wie ich das Stoma bei meinem Kind pflege	☐	Weiß ich nicht ____ weiß ich
Ich weiß, wie ich die Haut bei meinem Kind pflege	☐	Weiß ich nicht ____ weiß ich
Ich fühle mich sicher in der Pflege meines Kindes	☐	Nicht sicher ____ sicher
Ich weiß wie viel Zeit ich für die Pflege und Ernährung meines Kindes brauche	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu
Ich weiß auf welche Gefahrensignale ich bei meinem Kind achten muss	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu
Ich weiß, was ich bei der Atmung beachten muss	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu
Ich weiß, was ich tun muss, wenn mein Kind erbricht	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu
Ich weiß, was ich tun muss wenn mein Kind Durchfall hat	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu
Ich weiß, was ich tun muss wenn mein Kind Fieber hat	☐	Stimme der Aussage nicht zu ____ ich stimme der Aussage zu

2

	Hat / braucht mein Kind nicht	
Ich weiß welche Materialien ich für mein Kind benötige	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wo ich sie beziehen kann	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß welche Hilfsmittel ich für mein Kind benötige	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wo ich sie beziehen kann	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wie ich mit den Hilfsmitteln umgehen muss (Funktionen, Bedienung)	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich bin informiert über die weitere Betreuung meines Kindes	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wann die nächste Kontrolle stattfindet	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wo die nächste Kontrolle stattfindet	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, bei wem die nächste Kontrolle stattfindet	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, welche Unterstützungsmöglichkeiten es gibt	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, an wen ich mich im Notfall wenden kann	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wem ich anrufen kann wenn ich Fragen zur Pflege oder Behandlung meines Kindes habe	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich kenne die Telefonnummer der häuslichen Kinderkrankenpflege	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu
Ich weiß, wer mich in meinem Freundeskreis und oder Familie unterstützen kann	☐	Stimme der Aussage nicht zu ——— ich stimme der Aussage zu

Fühlen Sie sich sicher, Ihr Kind nach Hause zu nehmen?

Nein, ich fühle mich nicht sicher ——— Ja, ich fühle mich ganz sicher

3

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