

University of Southampton

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Field: Neurosurgery

Life with a Shunt - Exploring the Experience of Parents of Hydrocephalic Children with a CSF- Shunt - A Qualitative Study

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Lay Abstract

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Background: Hydrocephalus is one of the most common neurological disorders in children with few treatment options. It is characterised by rising intracranial pressure and is often life threatening. A shunt is the most common treatment that is required throughout life with high complication and failure rates. Main symptoms associated with shunt failure are headaches, regurgitation, impaired consciousness, and nausea. Those symptoms are similar to common childhood illnesses that complicates identification for parents.

Aims: To explore and evaluate the impact a shunt has on the lives of children's parents and their family.

Methods: 17 Interviews following a semi-structured guideline with parents of children who have a shunt for at least one year were conducted. The interviews covered questions regarding everyday life, perception, social environment, appearance, medical complications, vacation, hobbies, routines, education and family. Further topics subjectively important to the participant could be addressed. The transcripts were analysed using a thematic approach to find patterns.

Results: The 17 interviews exceeded the expected length, which exemplifies the impact of a shunt on parent's lives. Most participants repeatedly mentioned concerns about shunt function and insecurities differentiating symptoms. Restrictions were brought up when talking about vacations, activities that might lead to injuries in the head and neck region and transferring responsibility for their child. Few had a routine controlling the shunt. Having the same practitioner was reported as reassuring.

Conclusion: Shunts have a major impact with parents continually worrying about their child's health and shunt malfunctions. Adaptation in everyday life is possible, but difficult,

and parents need experience discerning symptoms and reassurance on safe, 'normal' activities. Continuity of the attending physician is vital for parents to feel adequately supported. Further support and hearing past experiences of other parents could help them cope and adapt better to the constant worry.

Lay Abstract Body Word Count 294

Key words: Hydrocephalus, VP Shunt, Paediatric hydrocephalus, Quality of Life, Life with a shunt, Parental concerns

Acknowledgements

I want to thank my supervisor Dr Stefanie Kästner for guiding me through this research project from beginning to start, would also like to thank Dr Manuela Pötschke for teaching me how to conduct interviews and helped me with the qualitative analysis.

A further thank you to my fellow student David Köditz with whom I could always discuss our projects and problems since we had similar topics.

And finally, I would like to thank the nurses from E91 and Ms Von der Wall for letting me use their rooms to conduct interviews.

My Contribution

Ethics approval

This project required ethical approval from the Faculty of Medicine Ethics Committee (FOMEC) and the Landesärztekammer Hessen (LÄKH). To acquire full approval an application including the interview framework, recruitment letter, participant information sheet and a consent form were submitted in German and English language via the ERGO-2 systems (ERGO reference 56268) and the LÄKH after conditional approval was granted by FOMEC. The application to the LÄKH further included a cover page and study protocol. Approval was granted on 14th of August (LAEKH) and then full approval on the 1st of September by the FOMEC.

Preparatory Work

To this pilot study, I contributed the interview guideline that was adapted using feedback from Dr Kästner and suggestions based on her expert knowledge as a neurosurgeon looking after many children with a shunt and their families. Further feedback by Dr Pötschke was taken into account, especially on the interview setting and planning the amount of questions. Before the project was initiated, background research was undertaken to understand the underlying condition hydrocephalus, available treatments and research about patients' lives, through psychological studies and quality of life. In preparation for the interviews, teaching for conduction of interviews was carried out by Dr Pötschke. This caused another change in the interview guideline due to changed expectations regarding the interview process. The topics were gathered more broadly, and prepared questions were not planned in a schedule-like manner.

Data collection

The interviews were conducted and transcribed by myself. I shadowed Dr Kästner for three days during this project and witnessed two operations in which children had a shunt implanted or shunt control appointments. This increased my knowledge surrounding this

condition which helped me relate better to the participants' explanations and gain context to the surrounding literature.

The analysis was done using NVivo, a program for qualitative research. Some graphical figures were created by myself using Pages.

I am the sole author of this project report.

My Contribution Word Count: 319

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Abbreviations

CSF - Cerebrospinal fluid

VP Shunt - Ventriculoperitoneal shunt

QOL - Quality of life

EVD - External Ventricular Drainage

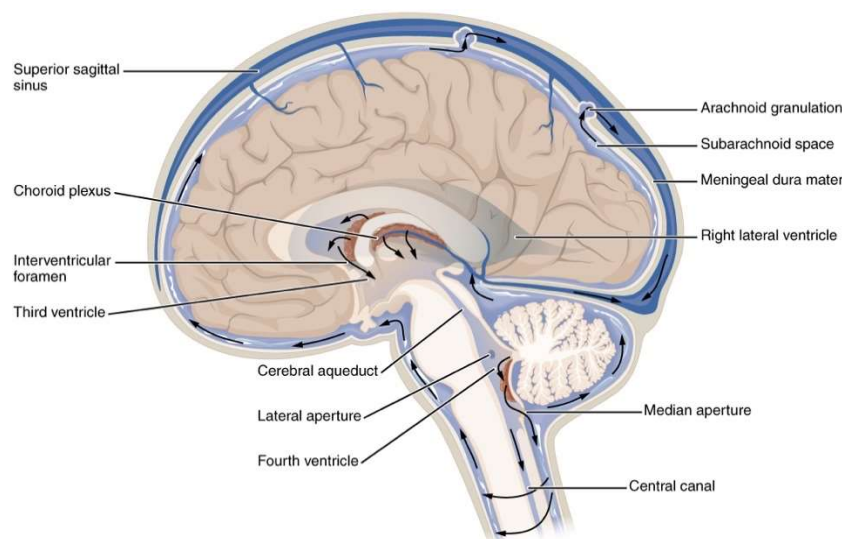
ETV - Endoscopic third ventriculostomy

Introduction: Literature Review

Basic Anatomy and Physiology of Hydrocephalus

The human brain is one of the most important organs for human beings with reglementary functions and the origin of our conscience. It is a very fragile organ that often reacts drastically to changes of internal or external stimuli. It is protected by the surrounding skull and cerebrospinal fluid (CSF), which cushions the brain and neutralises gravity to ensure mobility. CSF is produced in the choroid plexus in the lateral, third and fourth ventricles. Demonstrated in *Figure 1*, CSF flows through the ventricular system and moves from the fourth ventricle into the subarachnoid space, where it is absorbed and drains into the venous sinuses.¹⁻³

An adult has approximately 150 ml of CSF with an average production of 450-500ml per day. The volume of CSF in the brain increases with growth, a neonate possesses approximately 50ml of CSF.³ Meanwhile, a child between 4-13 years has an average of 90 ml of CSF.^{4,5} Normally, the same volume of produced CSF is absorbed, with three times the body level of CSF produced each day³, changes in absorption or occlusion affect intracerebral pressure drastically.



*Figure 1: Ventricles and Circulation*⁶

Hydrocephalus

Hydrocephalus is defined as an accumulation of CSF. With an incidence of 80-110 per 100.000 live births in Europe infantile hydrocephalus is one of the most common neurological disorders in children.⁷

Hydrocephalus may be classified as communicating or non-communicating. In communicating hydrocephalus, the absorption of CSF is decreased. The CSF flows through the ventricular system without obstruction but the amount of CSF increases since CSF production exceeds absorption.^{8,9}

Noncommunicating or occlusive hydrocephalus is caused by an obstruction that leads to impaired CSF circulation which has an enlarged ventricular system prior to the obstruction and narrowed system distal to it. Common causes are aqueductal stenosis, colloid cysts blocking a foramen of Monro and tumours.^{2,3} 20% of paediatric hydrocephalus is caused by obstruction. In preterm babies the most common cause of hydrocephalus is intraventricular haemorrhage mainly due to the preterm birth. Some children have a congenital hydrocephalus with varying causes as Chiari malformations, aqueduct stenosis and atresia of the foramen of Monroi.¹⁰

The main symptoms of hydrocephalus are impaired consciousness, headaches and regurgitation caused by the rising intracranial pressure (ICP).¹¹ In chronic hydrocephalus the patients often have significantly enlarged ventricles and may present with other symptoms such as deceleration, somnolence, lack of strength and energy, regurgitation and disinhibited reflexes.²

In infants hydrocephalus presents with apnoea, bradycardia, hypertension, macrocephaly and bulging anterior fontanelle due to open skull sutures, irritability and lethargy. The condition can be recognised in routine appointments with rapidly increasing head size and a bulging fontanelle when they are not closed yet, which normally happens approximately one year after birth. Older children with closed sutures present with headaches, visual

abnormalities, nausea, vomiting and decreased level of consciousness with altered behaviour.¹²

Diagnostics

CT and MRI are the common methods to establish the diagnosis of hydrocephalus and might establish the underlying cause. Lumbar measurements of CSF pressure is not routinely performed anymore.² In infants ultrasound can be used to detect hydrocephalus if the fontanelle has not closed yet.^{10,12}

Treatment

Current treatment for hydrocephalus is ventriculoperitoneal (VP) shunting through implantation of a shunt into the lateral ventricle. The VP shunt drains excess CSF into the peritoneal space, where it can be absorbed. Ventriculoatrial (VA) shunts are draining into the right atrium. The procedure normally takes 45-60 minutes and has very low risks during the surgery.^{3,13-15} But a high probability of recurrent shunt failures puts the patient at risk throughout their lifetime.

Another treatment method is endoscopic third ventriculostomy (ETV), which is only successful in obstructive hydrocephalus. An endoscope is inserted into the third ventricle through a burr hole and creates a hole in the floor of the third ventricle. This allows the CSF to directly drain into the subarachnoid cisterns, thereby bypassing the obstruction.^{12,16,17}

Shunting and ETV have similar success rates in studies. However their use in conditions is not interchangeable; shunting can be performed in all cases of hydrocephalus while ETV may only be used in obstructive hydrocephalus.^{15,18,19}

In acute hydrocephalus CSF is drained externally by external ventricular drainage (EVD). A shunt is further required if the cause cannot be eliminated and additional treatment is necessary.²

In children below 2000g bodyweight shunts are not recommended, so a Rickham reservoir is installed to gain access to the ventricular system repeatedly to drain excess CSF when required or EVD is performed until a shunt can be placed.^{2,10,14}

VP shunt complications

Shunt surgery has been the gold standard in hydrocephalus treatment since the 1960s. When the procedure arose, mortality in the first two years was as high as 24%. Recent studies have shown that in 2016 the all-cause mortality in the first two years has dropped to 8%.²⁰ Different studies demonstrate shunt failure rates up to 45% within the first year and revision rates between 37% and 82%.^{13,21-26} It has to be noted that complications and shunt malfunctions increase morbidity. Shunt failures are caused by infection, obstruction, mechanical failure, over- and underdrainage, distal catheter-specific failures, mispositioning, shortening of catheters, catheter fracture or slippage.^{23,27-29}

The majority of patients require at least one revision surgery.^{23,30,31} Most patients have a lifelong dependency on their shunt. Regular shunt control is vital to ensure proper functioning and most patients have between 1-3 check-up appointments per year.^{4,12,18,23,32-36} Other failures cannot be checked pre-emptively and will present to medical professionals when the patient notices symptoms. Shunt failures are a potentially life-threatening event and can present with the typical symptoms of raised ICP or with diffuse symptoms.³⁷

Risk factors

Stevens *et al.* defined risk factors influencing a child's health in 2006 and concluded that multiple risk factors stacking on top of each other create a higher risk profile and increase the likelihood for a lower health status.³⁸ Factors found to impact a child's health status include non-white ethnicity, lower social class, no insurance and poor maternal health. Some factors found to influence outcome in hydrocephalus patients are listed in *Table 1*. Lower socioeconomic status decreases access to healthcare, with children in this group often having more risk factors associated with poorer health. This means shunted children might not have access to the needed healthcare and will develop more urgent malfunctions since they are not detected as early. This impact is most prominent in countries without universal healthcare. However, there is still some influence in countries with universal healthcare, as Germany.³⁸

Table 1 Factors influencing shunt outcome

Risk factors	Beneficial factors
Age under 6 months at first shunt insertion ^{19,26,29,33,39,40}	Shunt with antibiotic or silver coat (only early infection decreased) ^{29,41}
Cardiac comorbidity ²⁶	Universal health care ^{42,43}
Endoscopic placement ²⁶	Living in high-income family ^{42,43}
Emergency shunt failure ⁴⁴	Experienced surgeon ^{*32,44}
No free healthcare access ^{42,43,45}	Parental concern ⁴⁵
Low socioeconomic status ^{42,43} or lower family income ^{16,45}	
Complexity of shunt ⁴⁶	
Longer stay in hospital ¹⁶	
Epilepsy and seizures ¹⁶	
History of Myelomeningocele ^{29,33,35}	
Previous revision surgeries ^{23,31}	
History of shunt infection ²⁹	
Shunt origin ^{23,29,47}	
Prematurity ^{24,29}	

*Controversial since some studies showed no correlation²⁶

Shunt malfunctions often lead to revision surgeries to assess the shunt function and possibly exchange it.³⁷

General Outcome

A study from Kulkarni *et al.* found that the aetiology of the hydrocephalus mainly affects the physical outcome in children with a shunt.¹⁶ A similar study by Beez *et al.* found similar results⁴⁸, which indicates the origin of the hydrocephalus affects the patients' lives more than the treatment type.⁴

Multiple studies were done on long-term outcome of participants that received their shunts in early childhood. By the age of 30 all patients had undergone revision surgery. Some only required a longer catheter and had pre-established revision to install a longer device.^{25,30,49,50} Additional surgery always has infection risks, stress for the patient and their family. This interruption was reported as a factor that withheld the patients and their families from normalising their life and gave them a strong feeling of uncertainty and dependence. They could not find a correlation between cause of hydrocephalus and cognitive outcome but shunt infections, epilepsy and a high number of shunt operations negatively impacted the outcome.⁵⁰

Kulkarni underlined the importance in differentiating between what a patient actually could do and what they perceived to be able to do when assessing quality of life (QOL). Stating that studies about patients' QOL have to include the patients' abilities and their perception of their ability.¹⁶

The Hydrocephalus Outcome Questionnaire measures clinical outcome and the impact on a child's physical, emotional, cognitive and social health in 51 questions each with five possible answers ranging from never to always.⁵¹

The following is a summary of some of the research on VP shunts and impact on the patient's life in a categorised form.

Physical health

A study using questionnaire-guided interviews and examination to assess the QOL of adults who had received a shunt within their first year of life found that physical health and perceived health were diminished in the hydrocephalic group compared to an age-matched cohort.⁴⁹ Patients report headaches, vomiting and impaired consciousness as symptoms of shunt failure. In studies, about a third of patients have epilepsy and 20% report regular headaches.^{4,25,49} Zimmerman *et al.* found that generally, patients reported a better health

status and less headaches since they have the shunt but that recent surgeries increased the occurrence of headaches.⁵²

A study done by Prakash *et al.* found that living with a shunt impacted children's QOL differently. The symptoms with most occurrence were headaches, general pain and fatigue.⁵³ Further, VP Shunts are associated with abdominal complications as infections and pseudocysts. Research on abdominal complications related to the shunt show rates between 5-47%.^{13,54} Other rare complications are deafness in over-shunted patients⁵⁵ and the perforation of internal organs following migration of the shunt.⁵⁶

Mental and Emotional Health

In a study children with a shunt reported lower self-esteem, social isolation and psychological wellbeing compared to the general population.⁵⁷ On the other hand a study by Zimmerman *et al.* found that children with a shunted hydrocephalus had no increased burden of anxiety, depression and fatigue.⁵²

About 87% of adults that grew up with a shunt when asked about their shunt report that they are generally content and satisfied, 66% did not feel that the shunt was relevant in their day to day life but some were occasionally ashamed because of experiences relating to harassment because of skin appearance and visibility. 80% of participants requested improved reliability and better shunt valves which malfunction less.⁴

A few patients reported hearing noises caused by the shunt but 76% of them did not feel negatively affected by the noises. Some actually felt like that assured them the shunt was functioning.³⁶

Education and Social functioning

Multiple studies showed 40% of the patients with a shunt attended school on a regular basis and merely 10% were restricted from going to school, mainly due to underlying conditions. 45% lived independently, 35% depend on their family and 20% lived in a facilitated home.^{25,30,50} More than half work on open labour market with 10% never having worked.⁵⁰

It was found that epilepsy, shunt infections and the number of operations had influence on the patients' intelligence and mental ability.⁵⁰ There seems to be an impact on social functioning since more than 50% of patients have never had a partner and feel severely socially restricted.⁵⁰

Parents

Complications are a regular concern for patients and families living with a shunt. Parents of children with a shunt often express worries about the uncertainty of a threatening malfunction that could happen suddenly. A common complication is underdrainage that presents with the typical hydrocephalus symptoms: headaches, nausea, regurgitation and cognitive impairment.^{4,32,58} Those are similar to symptoms caused by common illnesses in childhood. Differentiation between common ailments or shunt-related symptoms is a big burden and responsibility for parents.

Smith *et al.* interviewed parents about their life with a child that has a shunt. The main aspects reported were wishing for a normal life, uncertainty and developing expertise. Normalisation was especially affected when the child had unexpected revisions that abruptly changed the families' lives again and restricted them from finding their new normal. It was also found that many parents felt less uncertain with growing expertise in recognising and differentiating their child's symptoms. Some parents felt that their observations were not considered appropriately in the hospital and that their knowledge of their child's symptoms and wellbeing should be more important for the practitioners.⁵⁸

Many parents reported that they were planning their vacations differently by researching shunt clinics in the area and that they monitored their child's fluid intake and sun exposure.⁴ Most stated that with growing expertise they felt more confident and secure. They still regularly worry because shunt failures are a common side effect, but their life was no longer defined by the shunt.⁵⁸

A recent study found that parental concern positively influenced a child's health, especially in long-term illnesses.⁴⁵

More than 80% of parents inform themselves about their child's condition and treatment.

Research found that of the internet using parents nearly 30% use this tool to find hydrocephalus support groups and over half want social support.⁵⁹ This highlights that parents need to be informed about their child's health, development, outlook and treatment and how beneficial credible sources are. Professionals could gather relevant and trustworthy sources and thereby help parents distinguish the helpful from unreliable content.

Furthermore, this demonstrates how support from other individuals with similar experience is important for families. Hospitals could consider creating a local support group or database for parents.

Some studies report large differences between a parent's evaluation of the child's physical health compared against the child's account.^{52,60} However, the evaluation of the child's mental and social situation was more similar.⁶¹

When researching children's QOL, the actual child in question is often forgotten and the parent's or carer's perspective is mainly questioned.

Aims

The overall aim of this qualitative study is the exploration and evaluation of the effects a VP shunt has on the patients' and their families' lives. This will be achieved through the gathering of subjective experiences from 10-20 parents whose child is living with a VP shunt.

Material and Methods

Interview Guideline

As part of the Ethics application in the UK and Germany the preliminary interview guideline was created. To find general areas that might be affected in the patients' and their families' lives a mind map was created, then augmented using papers and journals. Additionally, the professional experience of Dr Kästner was drawn upon. A questionnaire was created based on these areas and possible questions for the interviews formulated. This led to the interview guidelines that are rather hypothetical since the actual interview was not planned as strictly. The full ERGO2 approval (ID: 56268) was received on the 1st of September 2020 after the translated LAEKH approval from the 14th of August was handed in with all documents (consent form, interview guideline, participant information sheet, recruitment letter). In preparation an interview training was done by Dr Pötschke, who is a sociology professor at Kassel university.

Patient Recruitment and Interview Arrangements

In September 2020 the project officially began, the information and contact sheets were made accessible to the patients on the neurological wards and the outpatient clinics. The first responses arrived by the end of September. The potential participants were contacted to arrange a date and time for the interview.

Inclusion Criteria	Exclusion criteria
Parent of child with a VP/VA shunt to treat hydrocephalus	Shunt implantation surgery within one year prior to the start of project
Child's age <18 years	Language barrier

Table 2: Inclusion and exclusion criteria

Interview Setting

The interviews took place between the last week of September and the end of November. For the interviews, the researcher met the parents at the Klinikum Kassel,

Mönchebergstraße 41-43 34125 Kassel, and led them to a prepared room with a table, chairs, recording device and cards stating the main topics, shown in *Figure 3*. The participants had signed the consent form beforehand and were asked again if they felt comfortable with being recorded. No participant did not want to be recorded. The cards were used as a guiding thread to ensure all topics were covered in each interview. The interviews were directed depending on the conversation. In some cases parents thought of additional topics they wanted to address. This led to an additional topic, 'family' being added to the themes after two interviews.

In total 17 interviews were conducted with a planned duration of 30-60 minutes per interview.

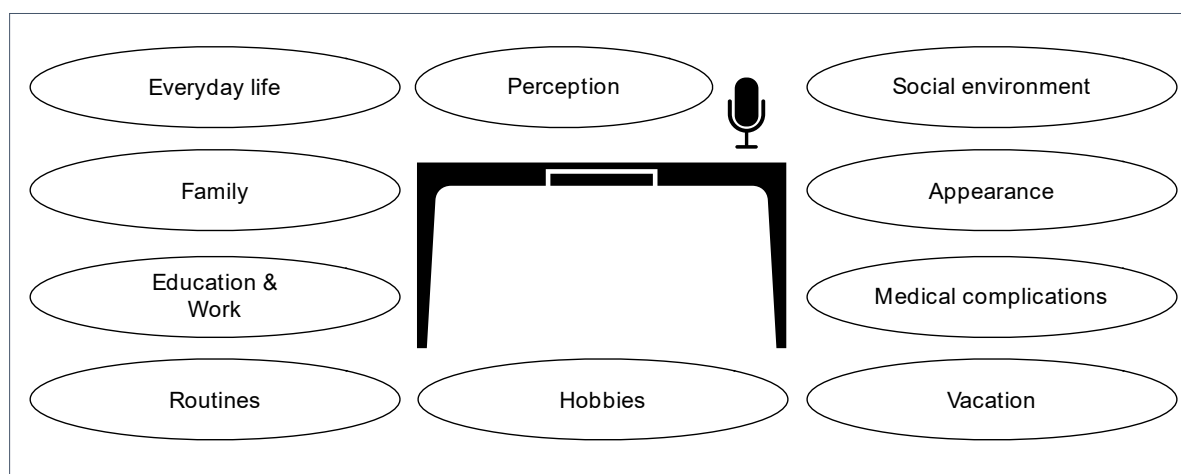


Figure 2: Interview setting

Data processing and analysis

The transcription was done by the researcher. In the transcription process, the patients' data were anonymised, and names and places were shortened to one letter, the participants could not be traced back afterwards.

In the thematic analysis a qualitative systematic approach according to Mayring was used.⁶²

This was done in multiple steps. References were assigned codes and then grouped to themes depending on their content. In the coding phase the interviews were read multiple times. The codes were compiled to themes and subthemes, shown in *Table 3*. The codes were then checked for clarity and whether they fit the category distinctly. The process was a

combination of inductive category formation and deductive category assignment.^{62,63} The researcher decided that one reference could fit multiple themes and did not exclude the possibility of coding a reference into multiple categories. This was done using NVivo, a program for qualitative analysis, which was then used to compare answers within a theme and to find patterns.

Results / Findings

General Findings

17 interviews were conducted during the study period, three with both parents, one with the father and 13 with the mother present. Difficulties arose when organising the interviews due to working schedule, medical appointments and family commitments. The parents' willingness to participate indicates that they felt research on living with a shunt was important and might be helpful to them. The duration of the interviews exceeded the expectations and multiple interviews took longer than one hour with an average interview length of 58 minutes, which shows how many topics the participants wanted to discuss. Multiple participants thanked the researcher afterwards for the conversation and stated that it helped them to talk about their life and struggles. This shows the importance of the shunt in their daily life and that they might wish for additional support.

Table 3 shows the coding system with themes (T), subthemes, their definition and examples translated analogously from the German interviews by the researcher.

T e	Subthem	Definition	Example
E V E R Y D A Y L I F E	Hobbies and how they are impacted by the shunt	Hobbies the children perform and how it might be influenced by a shunt. This ranged from normal engagement to complete inability to perform a hobby. Includes parents' thoughts or worries about hobbies. Football and diving were hobbies parents worry about.	"He was able to do everything, but I honestly don't feel well when I see him doing headers. Have you read any studies about too many headers? I'd rather he would not become a professional soccer player. The Dr told us he could do whatever he wanted apart from deep diving maybe. We will see what he wants to do later." (13)
	Restrictions	Restrictions on family's lives' due to shunt and medical treatment directly and indirectly; including hobbies, problems scheduling due to shunt appointments, shunt setting.	"Not by the shunt itself but it wasn't set correctly and we know now, he suddenly developed much quicker since the shunt was adjusted. He couldn't play with his brother for more than ten minutes and now he can go on long walks or run around. That definitely restricted him." (07)
	General daily life and Routines	Regular activities by child and family and how they are impacted by the shunt. Routines to check the shunt. Can be due to	"Yes, when I change his diaper, I always have a look at his scars and belly. Mainly to remind myself of the incredible child we have. How lucky we are. And I would notice it if anything was red

		medical reasons, as recent surgery or complication, or a general routine.	and inflamed. But generally, he is just incredible, and everything is normal.” (13) “In the beginning we measured his head. But after a bit I stopped because it drove me crazy. The Dr always measures it differently and it just drove us both mad. I threw the measuring tape away and we’re all better now. The clinicians will find it. But for now we need to live our lives.” (01)
	Social environment	Participants statements describing their social interactions, friends of child, their social environment before and after shunt, possible changes by shunt and stays in hospital.	“It’s difficult to meet people. Either you are working or with your child and I honestly cannot give him to someone else. I would be worried about what could happen. And some friends without children don’t understand that constant worry. Keeping friends once you have a child is hard but even harder when you can’t leave it with someone else.” (04) “We have friends from the neuro ward, they were there with us and their child has a shunt as well. It is comforting to talk about it with someone who understands.” (07)
PART	Relationship to health-care professionals	How parents describe healthcare professionals (physicians, nurses and other) and their sentiment towards them, especially experiences made in	“Our opinion about the hospital and physicians has changed drastically. Before our child was treated, we heard a lot of negative experiences in the past from family and friends. Now we see how our little one is treated, and they are working well as a team and it works again. A lot has improved.” (02)

S A N D		regard to hydrocephalus treatment and shunt operations. Including the communication with them.	"It is difficult. Some have great communication skills and know something about their patients, others tell you something contrary to what you've heard before, then you ask and they don't know anymore. And with a longer hospital stay you see a lot of Drs..." (12)
H E A L T H C A R E	Additional burden and strains	Worries and negative impact shunt has had indirectly on the family, e.g. therapy, hospital stays etc.	"The doctors used many big words and we are not in the medical field and don't know what a shunt or hydrocephalus is. For normal people operations on someone's head sound so dangerous but on a child, it is worse... They didn't think about how we were feeling." (09) "When I know I'll go to the clinic, I raise my hackles. Much has happened there..." (16)
R E S E C T O R	Medical Care	How do they perceive the medical care, do they feel supported and taken care of?	"Dr showed us a diagram of a shunt and hydrocephalus and that helped me understand the procedure. I didn't know what they wanted to do before." (09) "We used to go once a year but since nothing has happened for so long, we talked to the practitioner and decided together." (11) "It is important for me to go to a specific person when something is wrong, they know our history and won't have to ask the same questions again and again. That continuity is important in general and even more with the shunt." (03)

	Help & Questions	How parents' questions are handled and how they can ask for help.	"When we had the first appointment, we were told to always contact our practitioner if we had a question or were unsure about something. We have contacted them a few times and always got an answer promptly. This helps dealing with our insecurities." (13)
	Shunt explanation	How was the conversation before shunt was inserted? Did the parents get an explanation about the hydrocephalus, the shunt and outlook?	"One practitioner said there was no time and we needed to sign a consent form now and then get him into the operation room immediately. We felt overwhelmed. For the second operation a different doctor took some time and explained the procedure to us, the risks and what would happen afterwards. That was really helpful. But the first operation was very drastic. We didn't even know how long it would take." (05)
EDUCATIONAL	Child's education and possible prospect in professional field. How were nursery and school chosen, specific requirements because of shunt		<p>"She goes to the same school as her older sister. Everything is the same, she can get the same education, the shunt doesn't change that. We asked her teachers to be considerate of some symptoms. They notice if something is wrong, but nothing happened so far." (02)</p> <p>"To ensure I don't worry, I need trained hands with medical background. I wouldn't be able to focus on the things I have to do if I wasn't trusting the teachers." (08)</p>

C O S M E T I C	Reports about the outer appearance of the shunt, influence on child's self-esteem, thoughts they have, scenarios the shunt influences as hairdresser appointments, at the beach etc.		<p>"It is very important to him that his hair is long enough to completely cover the shunt. Luckily my parents are hairdresser and he doesn't have to tell anyone else about the shunt. That makes it a lot easier for him." (11)</p> <p>"We always enjoyed doing her hair especially after an operation, so I don't think she worries about her appearance." (06)</p>
	Parents' work	Description of the parents working situation and possible adjustments caused by shunt.	"I planned a promotion and wanted to adjust to a new position, but I took a step back. My child and being with her is my priority so it's just rational to pause my career. I have a good job and that's enough for now." (02)
	F A M I L I A L M I L I E U	How is the family's structure, communication, interaction and is the shunt affecting their life as a family? Is the shunt an important topic for them?	<p>"Our older daughter has severe fears. It has happened three times that I have brought her to school in the morning planning to see her in the evening but then did not come back. That afflicts us gravely." (09)</p> <p>"I personally think that I neglect E (daughter without shunt). I know that I am not there for her. The situation with H in the hospital is difficult for us." (02)</p>
	Worries	Do the parents worry about their child, especially regarding the shunt?	"I worry what would've happened if we had not gone to the hospital. Our paediatrist didn't see the hydrocephalus and didn't transfer us, it was pure

			<p>luck that it was found. What if that happens again?" (09)</p> <p>"Every year right before the shunt check-up appointment I get really worried and think about all the things that could go wrong. At other times it's okay but that week is a nightmare." (11)</p>
M E D I C A L H I S T O R Y	Medical history regarding shunt	Participants reproduction of their child's medical history regarding the shunt. Includes diagnostics, operations, hospital stays and development.	<p>"My child was diagnosed at a few months old. The hydrocephalus was found late because she has a genetic illness that took all the attention. Our Dr did not do the ultrasound and missed it." (09)</p> <p>"She first got diagnosed when she was a few months old as a preterm baby and then she had her first shunt, we could go home a few days later. She had an EVD when the shunt had to be taken out and a new one implanted. It worked well." (14)</p>
	Own research	How parents researched additional information, which topics and if it helped them cope.	<p>"I read both scientific facts and experiences. Survival chances often appeared and that was horrible for me to read about. But collecting knowledge and background was helpful." (13)</p> <p>"We know a person that has lived with a shunt for years and asked him loads of questions. Hearing his experience gave me hope for the future and that our child won't be restricted." (17)</p>
	Complications	What kind of complications has the child had regarding the shunt? How	"Once in Kindergarten a ball hit his head and at first nothing happened but after a few weeks, he was very sleepy and drowsy and started vomiting.

		have they developed and what were associated symptoms?	<p>We thought it was a GI infection at first but when it didn't improve after a few days we went to our GP and then to the hospital. It turned out the shunt had ruptured." (11)</p> <p>"He had an infection and the shunt had to be taken out to then implant a new one. That was a lot for his little body. Luckily everything went well afterwards." (07)</p>
S Y M P T O M S	Symp- toms in general	The symptoms participants associate with shunt failure and complications and the signs they are aware of	<p>"In the beginning we were told those symptoms are important: nausea, vomiting, disorientation, no interest in anything and headaches. Especially if it starts abruptly." (14)</p> <p>"Only when she says she has a headache. Otherwise we don't think the shunt is causing problems." (16)</p>
	Estima- tion of symp- toms	<p>Do participants feel confident differentiating between symptoms that are caused by the shunt and might indicate a complication? Do they know what to look out for?</p> <p>When would they seek professional advice? Has their expertise</p>	<p>"We pay attention to how long his headaches last. He drinks some water and rests if he feels like it and if he still has a headache then, is floppy we consider going to the hospital. In the beginning we were on edge as soon as he had the slightest headache. But that went away eventually." (10)</p> <p>"We try to find a reason for his symptoms. It's normal that he feels sick after eating a whole chocolate bar. When he seems off and is apathic and silent we start to worry. He is a very active child. But he started describing how he is feeling</p>

		differentiating symptoms developed?	now so we know better when to worry. And we have observed what the practitioners observe, so we know a few of those tests and questions.” (13)
V A C A T I O N	Any comments about travelling, taking a vacation, planning it and possible reasons not to and constraints, precautions taken, destinations, past and future trips, includes school trips of child alone		“The father won’t fly anywhere. He’d rather be in a car for some hours because he knows it would be under his control when, where and how we’d get back. We have not flown anywhere since then. And that’s very sad. We really enjoyed flying and seeing the world.” (06)
G R O U P & T H E R E S	Did participants use any further support to deal with the situation? Have they looked for or are part of a support group? Would they want to contact other parents of child with a shunt to talk about their experience? Would they want to be contacted? Do they wish for additional (holistic) treatment?		<p>“I would’ve wanted to contact someone to hear experiences and would offer it. I would’ve really appreciated it but unfortunately that was not offered to us.” (11)</p> <p>“Yes and no. I talk about the shunt very openly and I think it might have helped me. But on the other hand, I don’t know how I would’ve handled a negative experience and hearing of complications. I am not sure that you can actually compare the situations. That’s why I’d be cautious.” (13)</p> <p>“I think therapy to cope with the trauma would be really helpful for me and my child. Like a family therapy. But when we came back home, I completely forgot and I am not sure if it’s too late now.” (05)</p>

O T H E R	Any comments about living with a shunt that does not fit into other codes but was not mentioned repeatedly and didn't lead to a new category.		<p>"My Christian faith and the community really helped me accept it and deal with it. It was like psychological help." (11)</p> <p>"I would wish for shunt patients to be contacted as soon as there is a new therapy developed." (05)</p>
	P E R C E	Child	<p>Reports of parents about how their child perceives themselves with the shunt, the shunt itself and thoughts about it.</p> <p>"I don't think that he sees the positive sides. It helps him. Sometimes he is annoyed by it and asks why him and not a different child but that happens rarely. He only thinks about the shunt when the hairdresser touches the shunt." (05)</p> <p>"She processes a lot right now and tells people everything about the shunt, operation and our practitioners. It is her way of coping." (2)</p>
	P T I O N	Parents & Siblings	<p>Comments that exemplify the participants' perception of the shunt, their thoughts about it and</p> <p>"I learned listening to her about what she can and cannot endure. She knows best when something might be wrong with her body and that includes the shunt." (08)</p> <p>"I forget the shunt sometimes and when I diaper him, I actively stroke the skin where the shunt and tube are to get the feedback that it is there and what we went through. It grounds me and I am thankful for the child I have." (13)</p>

Table 3: Coding Framework

Everyday life

The theme 'everyday life' included hobbies and activities, restrictions, routines involving the shunt and the social environment. Reported restrictions could either be led back to possible

mechanical destruction of the shunt, as headers in football or altered pressure in deep sea diving, or were caused by other medical conditions and not the shunt itself. Overall few limitations and restrictions for the children were named. Participants did report problems planning and managing time due to unforeseen complications. Some with long hospital stays had difficulties maintaining a social life.

When asked for any routines involving the shunt, some had kept a diary with symptoms and observations in the past but stopped. Those routines were associated with more stress by the participants and led to worries. Others liked to actively remind themselves of the shunt by touching it while diapering their infant to remind them of their gratitude.

Relationship to healthcare professionals

In the interviews the different experiences with healthcare professionals became clear quickly. Comparing them showed the beneficial influence a good relationship between practitioners and parents could have. The participants refer to the pre-operation information talk as a deciding factor for their worries and trust in the medical team. When the practitioners took the time to sit down with the parents and explain the procedure, situation, complications and outlook the parents overall seemed less troubled by the shunt. In comparison parents whose first experience with the shunt was abrupt and hectic and when parents had to sign a consent form without proper explanation, they were more anxious and feared complications in their everyday life. It was reported that practitioners told the parents about possible outcome in a rather unempathetic way which led the parents to feel like they could not rely on the practitioner. Some parents actually asked for a different practitioner or went to a different hospital entirely because they did not feel well cared for. Especially when dealing with worried parents, communication is vital.

Another factor important to the participants is consistency in doctors treating their child. A more constant and sometimes nearly personal connection helped them rely on the doctor and feel less anxious. Regularly changing doctors, as common in clinical care, felt less safe for them since they felt medical professionals did not know their child's habits and history

and thereby questioned their ability to assess their child's medical status. Specifically, since a common symptom caused by shunt failures is altered consciousness and mental state, knowing how a child behaves normally is important. This can be taken into account for clinicians to listen to the parents more and believe them when they say that their child is behaving abnormally. After they have found a doctor by whom they felt well taken care of, they reported a more stable connection and less worries due to better consultation. This also caused fewer hospital visits because other causes could be identified better. This further strengthens the point raised above that interpersonal relations between parents and practitioners affect the child's treatment.

Education

Most children were able to go to the nursery or school and be part of their age group. Children who needed special care and went to a school for children with disabilities seemed to be the ones with other medical conditions. The parents did not report that the shunt itself influenced their child's education and their choice of school or nursery. Most reported that they informed teachers about the child's condition and some symptoms to be aware of. It was important to the participants that their child had the chance to grow up as normally as possible.

Cosmetic and Appearance

Individual participants reported worry about their child's appearance being affected by the shunt. This was due to scars or the visible bulge. Some mentioned that they asked the hairdresser to be particularly careful when going over that part of the child's head. Overall, they classified this topic rather unimportant.

Family dynamics and influence of the shunt on the family as a whole

In general, the participants claimed their family's life did not change drastically due to the shunt. Other medical factors that influenced mobility and mental capacity were named and seemed to affect it more than the shunt. A common theme was that they explained the shunt

and symptoms to their relatives and asked them to be aware of it. They generally wanted the shunt to have as minimal attention as possible to ensure a normal life.

Some parents gave account of worries they might neglect their other child when they give additional attention to the child with a shunt to make up for their traumatic experiences in the hospital. The individuals reported worry that they might not be impartial and just towards their children. Notably, the parents whose children had spent a long time in the hospital were affected greatly by that experience and reported they transferred their worries and experiences into everyday life.

Quote from Interview 8:

"I can compare my worries in the past with them right now: Back then I felt like the hospital was our home. We were here at least every other day and now we actually settled in at our actual home. The disease is not as notable anymore. Right now, we actually live and the shunt exists."

Symptoms

All participants reported that some symptoms made them worry about shunt malfunctions. The ones commonly mentioned were nausea and regurgitation, headaches, tiredness, changed vision, altered mental state, confusion and lethargy. They were worried about differentiating benign causes from possibly dangerous shunt malfunctions. The participants who had lived with the shunt for longer or who had witnessed shunt malfunction stated that their experience made them feel more secure in recognising an actual problem with the shunt. They still worried regularly when their child had any of those symptoms but felt more able in differentiating.

Vacation

The participants reported impaired ability to go on vacation because of the shunt. They worried about possible treatment in other countries due to the continual possibility that the shunt could malfunction and would need immediate control by a professional. This led to

fewer vacations and the majority of the participants have not gone on holiday further away. Most stayed in Germany and planned to come back to their main hospital if something with the shunt seemed to be wrong. This affected the family's plans especially for those who liked to travel. Some planned to try an airplane trip in the future but others felt like plane rides were not possible for them.

Their main worry was the inability to reach a specific practitioner that knows their child's history. Having all the information in an online patient file might help them rely on other doctors. Additionally, a list with experienced neurosurgeons regularly dealing with shunts could help ease their worries.

Additional support

Participants stated they would appreciate having the opportunity to contact parents that have lived with a child with a shunt for longer. Especially shortly after the first insertion they had questions exceeding the medical aspects, as worries and problems that might occur. Some on the other hand vehemently opposed the idea of hearing other experiences. This highlights the vulnerable state they are in and how individual optimal support would need to be.

Additionally, parents wished for resources when their child is being treated at the hospital, for example a room to spend alone time with their child and a bed for a parent. This is an important factor for parents that can only see their child outside of their working hours and would like to spend time with their child outside of its hospital room.

Other

In this category single comments without a recurring theme were gathered. Examples are religious observations, the wish to be contacted if another treatment was found in the future and the reminder that sometimes the easiest solution, as a basic shunt without newer technology, works best.

Perception

Most participants described their perception of the shunt as neutral and rather unimportant and more as a part of their child. The same was reported about the child's perception of the shunt. Two participants disclosed their child sometimes had wished the shunt was not there. A few participants stated they had been shocked to think about the shunt being necessary for the child's whole life but reported they had gotten used to it and did not see it as a problem anymore.

What would be different if your child did not have a shunt?

The last interview question was close to the overall research question and responses from each interview are shown in *Figure 4*. The responses can be categorised into groups: no effect, less or different worries, vacations, less medical appointments, changed priorities and their assessment of illnesses. Even though they reported about their life with a shunt for an average of an hour many still felt not having a shunt would not change their life. This confirms that they have adapted to their life with a child with a shunt. The points raised show their personal preference and relevance of a specific topic to them. Their situation was affected by other factors, as other medical conditions and family structure, which has an impact on their perception of the shunt as well. Not all families were affected in the same way and these interviews only show some examples. Overall, the shunt seems to be secondary in the participants' lives apart from specific areas, as vacation and worries about illnesses.

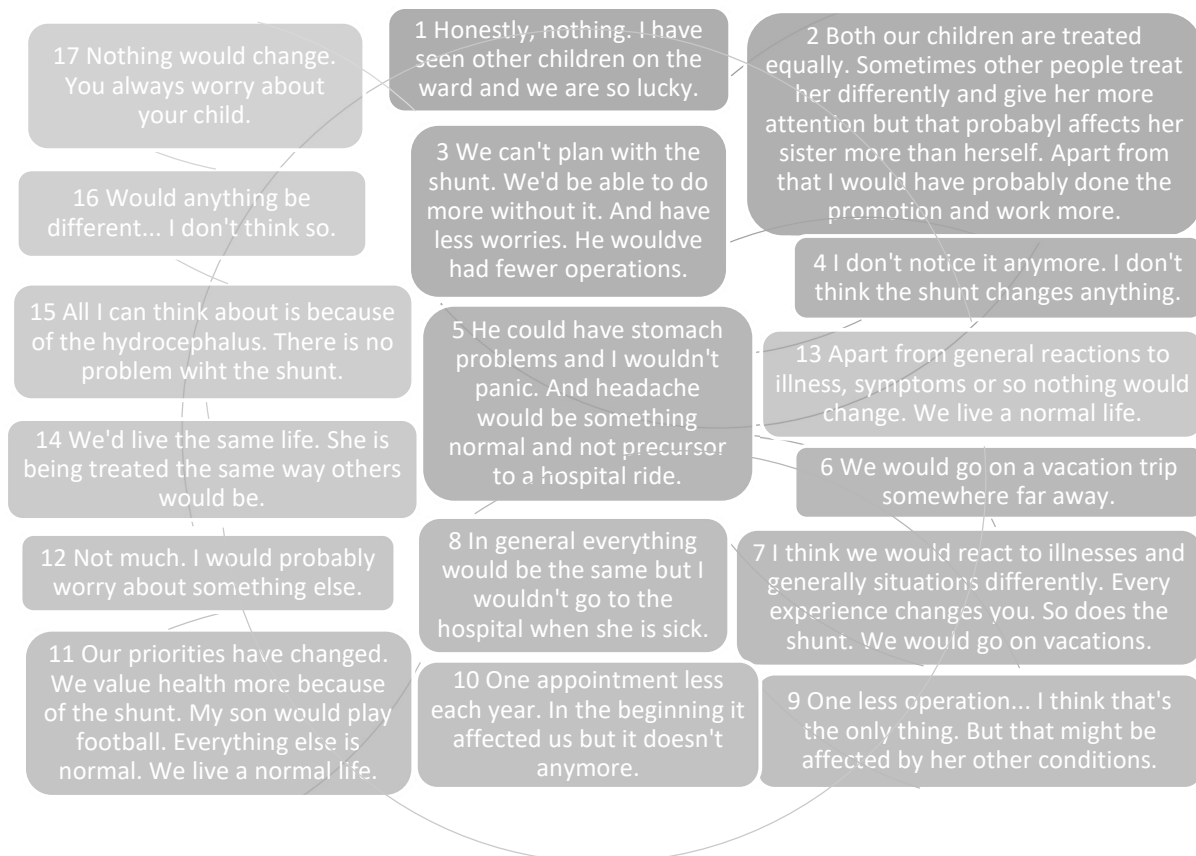


Figure 4: Would life change if there was no shunt?

Discussion and Conclusion

The purpose of this study was the exploration of the life of parents with children with a shunt from the parents' perspective. The answers on the topics were as varied as could be expected from literature and research status on shunts and other long-term treatments.^{4,16,30,34,49,53,57,58,60,64} As other studies have shown, multiple variables such as child age, treatment history and hydrocephalus aetiology influence the patients' reported QOL⁶⁰. Since the participants were not sorted by any of those criteria, a range of answers was to be expected. It would be interesting to set the answers into perspective using recent interventions, number of malfunctions and frequency of changing hospital or practitioner. Parents' social life was impacted by their time in the hospital and worries about leaving their child alone or transferring responsibility to someone else. This improved over time since their experience helped them rely on the shunt. The findings about children's daily life showed an active participation in public life including education, hobbies and social function. They were however influenced by neurological impairments. The results found in this study are similar to other studies.^{25,49,64} Parents of children with other neurological disorders were not excluded and participants reported impact by the other disorders that often surpassed the influence the shunt has. Usually, the origin could not be differentiated. To ensure precise results about the impact a shunt has, exclusion criteria could be altered. It could be expected that families that have lived with a child with a shunt for years have adapted to the situation due to experience. Recent unexpected complications might have an additional effect on their assessment of shunt symptoms⁵⁸, which could be researched in future studies. Similar to the other studies this research found parents' education on shunt and possible symptoms caused by a malfunction were important for their assessment of shunt function which influenced their trust in the shunt and overall worries.^{21,65} Children of more engaged parents showed a better overall health score⁴⁵, which could be applied by educating parents of hydrocephalus and shunts. The participants' wish for a more holistic

approach which has shown significance in research, especially for patients who have had multiple revisions.⁵³ This could include further therapy or help groups in their local hospital. To reduce fears and restrictions surrounding vacations electronic shunt records could improve parents' lives.⁶⁶ Practitioners could easily access the treatment history and relevant information via a specific cloud-based system used in healthcare in any hospital. This would increase independence from their known practitioner, as is shown with the shunt pass used in Germany. Another approach could be smartphone applications which are currently studied. They are especially well perceived by children⁶⁷ and might improve the patients' and their families' outlook on future medical treatment and observations.

Similar to other studies the participants in this study reported they often did not feel taken seriously when reporting worries to healthcare professionals.⁵⁸ This should be improved. Professionals should take the carer's observations seriously since their awareness to changes in the child's behaviour is often more accurate and can improve outcome and quality of life.²¹

The setting of this paper and its maximum word count did not facilitate the analysis and discussion of all the data. For future projects a narrower research question might help focusing on a specific theme in more depth. There was only one interview conducted per participant, which can only reflect their experience and perspective at that point in time, thus no future development. Asking the participants to do another interview after one or two years would enable the researcher to recognise changing sentiments and processes.

Conclusion

This study found that some parents wish for support shortly after the initial shunt implantation in form of contact to other parents that have lived with a child with a shunt for longer and would be equally willing to offer support.

A wide variety of topics were covered. Specifically vacations, recognising relevant symptoms, worries and continuity in healthcare professionals seemed important.

Strengths

In general, the main strength of qualitative research is a rich data set, which can show similarities and differences to underline personal experiences. Using Lincoln and Guba's evaluative criteria this data is assessed as trustworthy in its credibility, transferability, dependability and confirmability.⁶⁸

The interviews did not limit the participants' reports. All topics could be addressed. This reduced bias since the participants had the chance to give account on any topic. The interview guideline was created using an experienced professional's accounts. Relevant topics mentioned by patients in the past were included.

In the setting various perspectives were heard due to different general and medical backgrounds, family constellations and length of shunt treatment. This enabled this research to have perspectives from different levels of experience on living with a shunt.

All interviews were conducted, transcribed and analysed by the same researcher, which makes the interviews and answers more comparable.

The researcher kept a reflective diary to ensure process evaluation, as well as to stay aware and limit bias on the results.

Limitations:

This study does not aim to show all the topics that might be affected in a family's life but rather show some areas that are mentioned by these specific families. These experiences are highly subjective, and this paper does not claim to be complete. Sympathy and other interpersonal factors influence any interview.

The participants included might not be representative for the cohort, as the inclusion relies on interest to take part and was not controlled for any factors. Families with less time or resources might have been unknowingly excluded. Additionally, all of them access the German healthcare system. In a private healthcare system other worries would arise.

It has to be noted that the researcher did not ask the children.

Outlook

The data generated in this pilot study will be used to create a standardised questionnaire to further the research on living with a child with a shunt by Dr Kästner and Dr Pötschke.

This research shows how individual the experiences of living with a shunt are, as well as the problems that come with it.

Word count: 5436

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Appendix

Search strategy:

When researching for the literature background, an online search using the Ovid Medline was performed. The key words used were VP shunt, hydroceph*, paediatr*, QOL, impact, therapy and parents. Some papers were cross referenced. Further some anatomy and physiology books from the Kassel School of Medicine library were used.

Quotes in the order they appear in the thesis beginning in *Table 3*.

13 Hobbies C: Er kann alles machen, aber Kopfbälle mit der Wölbung und so muss nicht sein. Was sind die wissenschaftlichen Diagnosen bei zu vielen Kopfbällen? Theoretisch kann er machen, was er will. Aber professioneller Fußballer muss eigentlich nicht sein. Ja, wir werden gucken, was er machen will. Und wenn es ihm gut geht, ist alles gut. Uns wurde gesagt, dass Tiefseetauchen nicht so ist, weil es nicht erprobt ist.

07 Restriction: Vom Shunt eigentlihc nein. Davon, dass der Shunt lange nicht gut eingestellt war. Dass es H eben zeitweise nicht so gut gnig, wie es ihm hätte gehen können. Das merkt man jetzt auch an den sportlichen Sachen. Seit der letzten OP ist er so viel leistungsfähiger und das ist natürlich echt schade. Er hat sich immer unwohl gefühlt, war duselig und wie soll man da wirklich was können und sich entwickeln. Dass ihn das doll in der Entwicklung beeinträchtigt, glaube ich nicht. E hat ja auch seine Probleme. Weiß man auch nicht, ob das anders wäre wenn sie später geboren wären. Aber sie sind 12 Wochen zu früh geboren und dürfen ihre WehWehchen haben. Und dafür stöhnen wir finde ich auf einem hohen Niveau. Ich glaube, dass ihn der Shunt jetzt gerade nicht beeinflusst.

13 Routines: Ich sehe den mehrmals am Tag und gucke explizit an die Stelle und sehe, ob es rot ist oder nicht. Beim Wickeln gucke ich mir die Narben am Bauch an. Oft streichle ich ihm über den Shunt, das ist für mich ein Feedback. Dieses klasse Kind, das wir haben, dem

es gerade so gut geht und trotzdem, dass er besonders ist und wir das mitgetragen haben.

Es ist einfach da Er kriegt zwar eine Mütze auf, früher war das zum Verstecken, auch wenn ich eher denke zeig was du hast

01 Routines : Nein, am Anfang haben wir immer den Kopf gemessen jede Woche. Und dann habe ich irgendwann entschieden, dass wir das nicht mehr machen. Und dann habe ich das Ding weggeschmissen. Da habe ich gesagt, dass mich das wahnsinnig macht. Nicht nur mich, sondern meinen Mann vor allem. Und dann habe ich gesagt, das kommt weg. Die in der Praxis messen ganz anders als ich und auch wenn sie mir das zeigen ist das dann ne andere Stelle und bei Schwankungen, ne. Dann haben die das immer bei den Kontrollen gemacht und das hat mir gereicht. Ja das macht einen selber kirre. Und da sagen wir ne, wir gehen so viel zur Kontrolle und gehen da und da hin da können die das machen. Aber zu Hause hören wir damit auf. Das habe ich ganz schnell gelassen. Und Fieber messen alles gar nicht. Was den Shunt angeht, haben wir keine Routine.

04 social environment: Naja, ich habe keinen Mann und kann hier nicht weg. Ich kann nicht mal einfach so eine Stunde, einen Nachmittag, eine Nacht oder sogar länger weg sein. Ich kann etwas planen, aber wenn etwas ist, muss und werde ich das dann kurzfristig absagen. Und dann bin ich besorgt, was passieren kann. Ich kann sie auch nicht weggeben.

07 Social environment: B: Ja, tatsächlich zu der einen Familie. Die kennen wir von der Station. Es hilft, auch mal mit Eltern zu sprechen, die das nachempfinden können.

02 Opinion healthcare: sehr positiv. Man hat in der Vergangenheit einfach so 20 Jahre zurück nichts Gutes über das Klinikum Kassel sprechen können. Es gab öfter negative Berichte in der Öffentlichkeit. Das hat man immer gelesen und aufgeschnappt und wenn ich jetzt sehe, wie meine Tochter in der Kinderchirurgie und Neurochirurgie versorgt wird und wie gut Schwestern und Ärzte arbeiten. Es ist ein gutes System. Es ist viel getan worden und daher ist es mit den Jahren eher positiver geworden, ja.

12 Opinion Healthcare: Die Ärzte haben sich unterschiedlich viel Zeit genommen für die Erklärungen, manche haben schon gleich mit den Ärzten kommuniziert. Aber was ich

schlimm finde, ist, dass jeden Tag ein anderer Arzt reinkommt, wenn er stationär war. Alle erzählen was anderes und wenn man dann nachfragt wissen sie nicht Bescheid und wollen nachgucken und kommen nie wieder. Das war sehr unglücklich.

09 Healthcare: Nicht mit Schlagworten um sich werfen. Mein Mann und ich sind beide nicht aus der Medizin, wir wissen beide nicht, was ein Hydrozephalus ist. Mit dem Shunt und zu sagen, dass ein Schlauch in den Kopf gelegt wird. Alleine Kopfoperation ist für einen außenstehenden schon Horror. Für die Mediziner ist das nicht klar, was da außenstehende denken und fühle

16 Healthcare: Als ich wusste, dass ich heute in die Klinik muss, haben sich mir die Nackenhaare aufgestellt.

09 Medical Care: Ja, es wurde relativiert und einfach durch die Erklärung und so. Schaubilder, Erklärungen und diese Angst wurde uns genommen, dass es doch nicht zu spät ist, vorher wussten wir nicht was passiert.

11 Medical Care: Bis vor ein, zwei Jahren waren wir auch immer im SBZ, aber unter Absprache haben wir das erstmal beendet, weil er sich so gut entwickelt

03 Medical Care : Ja, genau, immer bei der Dr K Ich bin auch am liebsten immer bei ihr. Sie kennt ihn auch von den Ärzten am Besten. Wir hatten durchaus auch schon mal das Problem, dass wir in die Notaufnahme immer wieder das gleiche erzählen mussten. Das geht einfach schneller wenn die das schon alles wissen.

13 Help and Questions: Sie hat sich Zeit genommen, uns alles erklärt und immer wieder gesagt, wenn wir Fragen haben, unsicher sind oder so, ist auch heute noch so. Wenn irgendwas unklar ist, sollen wir uns melden und nachfragen und dann kommt recht schnell eine Antwort.

05 Shunt explanation: Aufklärung war da nicht mehr möglich, es kam einfach ein Arzt und sagte ich muss Ihrem Kind den Shunt setzen, keine Möglichkeit und wir können nicht warten. Dann hat er mir ein Blatt Papier hingehalten, das ich unterschreiben sollte. Ich hab mir das nicht mal durchgelesen und musste einfach einen Strich drauf machen. Ja, das war

diese Op. Was ich mir vielleicht vorher gewünscht hätte und was mir nicht bewusst war, als er die zweite OP hatte.

02 Education: War alles von Anfang an klar, die gleiche Kita und die gleiche Schule wie ihre große Schwester. Da haben wir keine Sorgen. Ja, wir haben das mit den Betreuern besprochen. Sie wissen Bescheid und achten auf Eintrübungen und Übelkeit, wissen, dass sie einen Shunt hat und achten da ein bisschen drauf. Aber das ist bisher alles nie eingetreten. Sonst behandeln sie sie wie jedes Kind, keine Extrawünsche wie alle anderen.

08: da brauche ich medizinisch ausgebildete Hände. Bei der Zeit, die sie da ist, da sind mir vertraute Hände wichtig, sonst kann ich mich nicht auf meine Uni konzentrieren, da Sorge ich mich nur.

11 Cosmetics: Nein, er will das so haben, dass die Haare lang genug sind, damit der Shunt verdeckt ist. Meine Eltern sind Friseure und die schneiden ihm die Haare, das macht es besser für ihn, weil er das so auch keinem extra sagen muss.

06: Und wir hatten schon immer Spaß auch wenn eine Revision war und was abrasiert wurde, haben wir mit den Haaren was ausprobiert und hier und da was zu machen. Egal ob kurz oder lang, sie entscheidet und wir machen das. Sie sieht den Shunt auch nicht negativ. Andere sehen das, aber sie ist damit okay. Ist auch ne ganz schöne Narbe geworden.

02 Work: war bis vor kurzem in der Meisterentwicklung, bin dann einen Schritt zurückgetreten, weil ich mir gedacht habe, die Priorität ist mein Kind und habe die Meisterentwicklung bis aufs Weitere abgebrochen. Ich arbeite in drei Schichten und bin für die Elektroantriebe zuständig

09 Familial Milieu: Die große Schwester hat starke Verlustängste. Drei mal habe ich sie morgens in die Schule gebracht habe und meinte ich komme nachmittags wieder und kam dann einfach nicht wieder. Diese Situation belastet uns sehr.

02 Familial Milieu: Ich persönlich würde beurteilen, dass ich meine Tochter E vernachlässige. Vielleicht sagt meine Frau was anderes. Es ist jetzt eine besondere Situation, sie ist bei Freunden untergebracht, aber ich weiß, dass ich gerade nicht wirklich

für sie da bin. Das ist würde ich sagen das Einzige, dass sie jetzt manchmal alleine ist. Aber man freut sich dann besonders auf zu Hause wenn sie da ist. Jetzt ist es halt doof.

09 Fam, Worries : Wenn wir nicht in H gewesen wären, was wäre mit ihr passiert? Hätte der Kinderarzt es irgendwann entdeckt oder ja... Vielleicht wäre es auch irgendwann zu spät gewesen.

11 Fam Worries: Ja, über die Ängste und so. Vor allem jetzt, da der Termin näher kommt. Da reden wir viel drüber und beruhigen uns. Ich weiß nicht, ob ich mit Ärzten darüber reden könnte und ich glaube nicht, dass da was helfen würde. Es sind einfach mütterliche Sorgen.

09 Med History: Der kam mit einem dreiviertel Jahr. Bei ihr ist er spät gefunden worden, da sie nicht nur eine Shuntanlage hat, sondern auch eine genetische Vorerkrankung hat, die PBS. Und da waren wir oft bei Ärzten zu Kontrollen. Bei ihm ist das aber untergegangen.

14 Med History: Angefangen hat es, weil sie ein ehemaliges Frühchen ist. Sie hatte keinen einfachen Start. Der Shunt stellte sich dann zwei Monate nach der Geburt heraus und einen Monat später hat sie ihren ersten Shunt bekommen. Dann durfte sie etwas später nach Hause. Dann mit einem halben Jahr musste der raus, dann hat sie eine EVD bekommen, dann wieder einen Shunt und ja...

13 Med Own Research: Ich habe beides gelesen. Die Überlebenschancen kommen schnell, auch wenn man nicht danach sucht und das fand ich ätzend.

17 Med Own Research: Bekannte von uns haben auch ein Kind mit einem Shunt und die haben wir ganz viel gefragt. Die haben da ja schon alles durch, haha, nach so vielen Jahren. Zu hören, wie gut das alles gehen kann und dass es funktioniert, hat uns Hoffnung gegeben.

11 Med Complications: Im Kindergarten haben sie Fußball gespielt und ihm wurde so seitlich an den Hals der Ball gespielt. Der Kindergarten hat etwas schlecht kommuniziert. Es hat dann auch zwei Wochen gedauert, bis es ihm schlecht ging. Und dann haben wir daran auch gar nicht mehr gedacht. Er hat sich ständig übergeben und da dachten wir dann an Magen-Darm. Dann waren wir beim Kinderarzt als das nicht aufhörte, dann sind wir gleich ins Klinikum. Da kam dann raus, dass der Shunt gerissen war.

07 Med Complications: Er hatte eine Infektion und der Shunt wurde rausgenommen und dann nach der Heilung ein neuer rein. Das war viel und man hat gesehen, dass es fast zu viel für seinen kleinen Körper war. Zum Glück hat es gereicht.

14 Symptoms: Wir hatten von Anfang an gesagt bekommen, dass folgende Symptome wichtig sind: Übelkeit, Erbrechen, Desorientiertheit, niedriges Interesse, Kopfschmerzen. Und vor allem wenn es plötzlich kommt.

16 Symptoms General: Wenn sie plötzlich Kopfschmerzen hat, werden wir hellhörig. Sonst denken wir nicht an den Shunt.

10 Estimation Symptoms: Wir achten darauf, wie lange die Kopfschmerzen anhalten. Meistens wenn er dann genug getrunken hat oder kurz hingelegt und ausgeruht ist, dann ist es auch wieder okay. Wenn es mal einen ganzen oder zwei Tage andauern würde, würde ich mir mehr Gedanken machen.

13 Est Symptoms: Also wenn er eine Tafel Schokolade gegessen hat, kein Wunder. Wenn er komisch ist. Er ist eigentlich aufgeweckt und redet viel und wenn er apathisch und taumelig ist. Wir fangen auch langsam an zu sagen, dass er uns sagen kann, wenn sein Kopf weh tut. Wir als Eltern haben beobachtet, was die Ärzte kontrollieren.

06 Vacation: Er weigert sich seit den schlimmen gesundheitlichen Schicksalen in den Urlaub zu fliegen. Er sagt er kann sich in ein Auto setzen und wo hin fahren, weil ich mich dann auch wieder in mein Auto setzen kann, um nach Hause zu fahren, wenn was ist. Ich werde mich aber nicht von einem Flugzeug abhängig machen. Und wir sind vorher sehr gern geflogen und ich habe ihm tausend Mal gesagt, dass es egal ist und sie mit dem Shunt fliegen darf und er sagt Nur ja, darf sie, aber wenn da was ist, was dann? Dann kann ich nichts tun und aus dem Krankenhaus kriege ich sie nicht zurück. Da weigert er sich strikt und das ist seine Art damit umzugehen. Seitdem fliegen wir nicht mehr. Sind im Umkreis von Deutschland unterwegs. Es ist so schade.

11 Group Therapy: Ich hätte gern wen kontaktiert und Fragen gestellt, was über ihr Leben mit dem Shunt gehört. Ich würde das auch jedem anbieten. Leider wurde uns das nicht angeboten.

13 Group Therapy: Ja und Nein. Ich selbst würde es jetzt jedem erzählen. Ich drücke es nicht jedem auf die Nase, würde mich aber einer Gruppe anbieten, weil ich finde, dass die Meinung oder Erfahrung helfen kann. Andererseits ist es meine Erfahrung und nur unsere Erfahrung, von der wir reden können. Wir haben ein sensationelles Kind, das wir auch von anderen Seiten bestätigt bekommen, wo man anderen vielleicht zu viel Hoffnung macht. In jeder Phase im Krankenhaus, teilweise auch hier übernachtet wenn es ging, habe ich viel gesehen und erlebt und was meiner Meinung nach anders, manchmal sagt man schlimmer oder einfach anders, wo ich nicht wüsste, ob ich mit meinen Erfahrungen nicht zu euphorisch wäre. Wir haben eine stabile Familie aus jeder Richtung. Dass wir da eigentlich keinen Rückhalt brauchen.

05 Group Therapy: Abgesehen davon, dass das in einer Traumabewältigung für uns gut wäre, das als Familie aufzuarbeiten. Als wir wieder nach Hause gekommen sind, habe ich das einfach komplett vergessen. Aber auch etzt würde ich sagen, dass uns diese Mutter Kind Kur gut tun könnte.

11 Other: Mein Glaube, der christliche Glaube, ist da auch wichtig. Das war für mich wie psychologische Hilfe. Der Glauben und die Gemeinschaft hat mir geholfen

5 Other: Ich würde gern kontaktiert werden, wenn es eine neue Therapie und eine Alternative zum Shunt gibt.

5 Perception Child: Er sieht die guten Seiten nicht. Erst fand er das doof, dass er jemand ist, der was hat. Und fragte auch dieses ganz blöde Warum ich und nicht wer anders? Darauf ich: Für andere ist das genau so blöd und sei froh, dass man da was machen konnte. Er denkt jetzt aber nur noch daran, wenn er dem Friseur sagt, da bitte nicht doll drüber zu gehen.

02 Perception Child: Nein, bei H habe ich das Gefühl, dass sie verarbeitet. Weil sie viel über ihren Shunt erzählt, erzählt sie werde am Kopf operiert und ich denke das ist viel zum Verarbeiten.

08 Perception Parent: Ich habe gelernt, ihr zuzuhören und ihr zu vertrauen, dass sie merkt, wenn etwas ist. Das ist nicht nur der Shunt, sondern generell ihr Körper. Ich vertraue ihr da auch mit dem Shunt.

13 Perception Parent: Ich sehe den mehrmals am Tag und gucke explizit an die Stelle und sehe, ob es rot ist oder nicht. Beim Wickeln gucke ich mir die Narben am Bauch an. Oft streichle ich ihm über den Shunt, das ist für mich ein Feedback, dass er da ist und seine Arbeit tut und was wir alles schon geschafft haben. Wir haben so ein großartiges Kind, dafür bin ich dankbar.

Quote Int 8:

Ich kann es nur so vergleichen. Früher war mein zu Hause das Krankenhaus, weil ich gefühlt jeden zweiten Tag im Krankenhaus war und jetzt bin ich mit ihr zu Hause angekommen. Wir haben den Alltag und es steht nicht die Erkrankung im Vordergrund. Das war früher anders, wir waren immer besorgt und angespannt. Aber das ist nicht mehr so.