



Kassel School of Medicine

Gesundheit
Nordhessen

Faculty of Medicine

Neurosurgery

Exploring Life with a Shunt

—

Qualitative Interviews with Hydrocephalic Patients with a
CSF-Shunt

David Köditz

ID: 30589908

January 2020

Lay Abstract

Exploring Life with a Shunt – Qualitative Interviews with Hydrocephalic Patients with a CSF-Shunt

Background: Hydrocephalus is a condition characterised by abnormal quantities of cerebrospinal fluid in the brain. Until now, a shunt surgery is still the main treatment for most forms of this condition. The shunt is a lifelong implant which has a big impact on patients' Quality of Life (QoL). Hydrocephalic patients report QoL as the most important outcome after treatment. This and the lack of literature in this field requires further research.

Aims: The primary aim of this study was to explore different areas of life affected by shunt treatment. Additionally, these topics will form the foundation of a standardised QoL questionnaire in future research.

Methods: 20 patients from the prospective hydrocephalus database of the Klinikum Kassel were contacted via letter. After giving consent, 14 face-to-face interviews were conducted and recorded using a semi-structured interview guide. The raw interview data were transcribed and analysed according to Mayring's qualitative content analysis with the help of the NVivo software. In the end, a category system was devised which grouped the interview data.

Results: The interview data revealed a big variety of topics which affect QoL of hydrocephalic patients with a shunt like travel, sports, physical and psychological health, communication, occupation, social life, self-image, perception by others and many more.

Conclusion: This study has shown that there are plenty of topics which affect the life of hydrocephalic patients with a shunt. Although responses varied to a certain degree, exploration of this participant group revealed a need for information and guidance regarding life with a shunt. By addressing this need, overall treatment, and satisfaction of hydrocephalic patients with a shunt could be improved in the future.

Word count:

Title: 13 words

Body of Abstract: 271 words

Key Words

Hydrocephalus

Cerebrospinal Fluid

Shunt

Quality of Life

Interview

Acknowledgements

I would like to thank my supervisor Dr Stefanie Kästner for her guidance and support throughout the whole project period. I really appreciated her ingenuity and help when questions came up.

Additionally, I enjoyed the practical application of my research project which illustrated the clinical relevance to me, and which contributed to my path of becoming a good doctor. Special thanks also go to Dr Manuela Pötschke as well for her interview training and methodical support. Finally, I want to express my gratitude to Dr Anja Timm who helped me throughout the ethics application.

My Contribution

From September to January this research project went through different phases. My contribution to each phase will be explained in the following.

Ethics application

This research project required ethical assessment by the Faculty of Medicine Ethics Committee (FOMEC) and Landesärztekammer Hessen (LÄKH). To get this project approved I prepared an application in English and German stating all required ethical measures. I added a participant information sheet, consent form, semi-structured interview guide and a recruitment letter in both languages, respectively. On the 14th of August LÄKH approval (2020-1823-evBO) was granted while FOMEC was confirmed on the 1st of September (ERGO 55778). All documents were reviewed by my supervisor Dr Stefanie Kästner.

Preparatory work

This project is a pilot study and as such I contributed to the original design and conduction of this study. In the first few weeks, 20 patients were selected from a database from the Klinikum Kassel with the help of my supervisor. I organised all the relevant documents, printed them and sent them off to the patients. Concurrently, I read a lot of research about hydrocephalus, the underlying pathology, QoL and shunts as preparation for the interviews. Mid-September I contacted 14 patients via phone who gave consent after receiving the relevant documents. During the phone calls, I explained what the study was about and arranged a meeting for a face-to-face interview at the Klinikum Kassel.

Data collection

Although beforehand I had to carry out a pretest interview to confirm the practical application of my interview guide. Afterwards, I met the participants at the neurosurgery department at the Klinikum Kassel and conducted the interviews independently in a separate room. Organising these appointments, calling out participants in the waiting room and talking to them for up to two hours

was an incredible, practical experience in the course of this project. I had to be flexible with my time as some participants could only come after work or at the weekend. Most interviews were recorded, and I transcribed all of them using Microsoft Word. After I familiarised myself with the NVivo software, analysis of the interview transcripts could begin. During this phase, I had two Q&A sessions with Dr Manuela Pötschke who answered my questions about my qualitative methodology. In the end, I created a category system from my analysis in NVivo which I presented to my supervisor for review. Besides, this project taught me how a doctor can use qualitative methodology to conduct medical research.

Writing the report

While I was working on the analysis, the early chapters of my project report were finalised as well and reviewed by Dr Stefanie Kästner. I am the sole author of this report and gathered all the relevant information. Beyond the scope of this research project, my supervisor gave me the opportunity to shadow her during her work at the Klinikum Kassel where I could learn the practical application of shunt treatment and the relevance of my project.

Word count: 485 words

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1. Literature Review

This literature review explores the background of all four aspects of the research question. First of all, the anatomy and the physiology are presented which are necessary in understanding how and why hydrocephalus develops in the first place. Secondly, a closer look at hydrocephalus, the different types, symptoms and diagnosing techniques is taken, followed by a variety of shunt treatment options. The fourth aspect is QoL and how it has developed its current role in medicine and

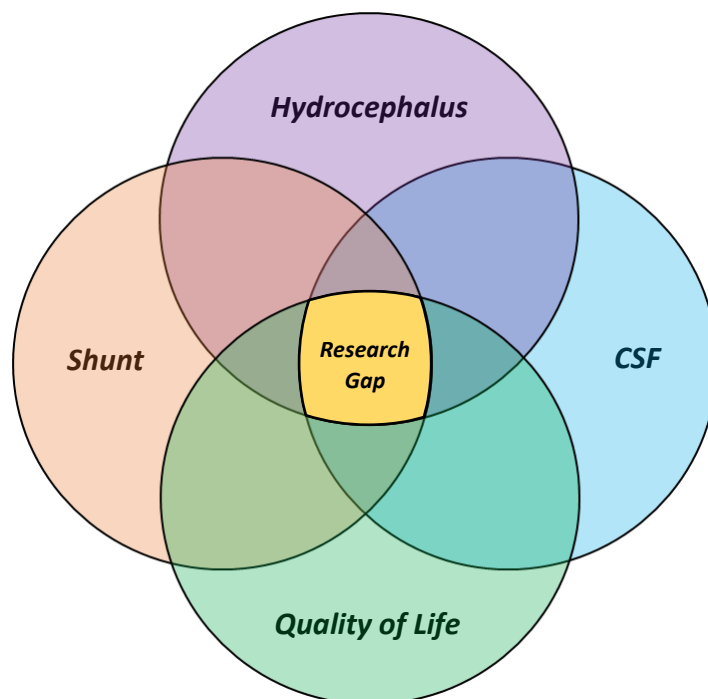


Figure 1: Research Gap (own image)

health science research. The final part will look at the research gap and how all four previous aspects come together to justify the need for this research project. A visualization of this can be seen in *figure 1*.

1.1 CSF Anatomy and Physiology

Cerebrospinal fluid (CSF) circulates between the ventricles of the brain, the cisterns, and the subarachnoid space. Thus, the brain is surrounded in this fluid which is indicative of its functions.¹

CSF protects the brain from mechanical injury by neutralising gravitation and it creates a balanced environment for neural tissue which allows for the transport of nutrients and waste products.²

Although 500ml of CFS is produced, mainly by the choroid plexus in the lateral ventricles, the average

CSF volume in adults is 150ml. This is due to reabsorption.¹ The colourless and clear fluid composition is similar to plasma but with less potassium and glucose and slightly more chloride. This is a result of active ion transport and osmosis.³ The flow of CSF has a distinct pattern; it runs from the lateral ventricles into the third ventricle before it enters the fourth ventricle via the cerebral aqueduct. From here, the fluid passes the Foramina of Magendie and Luschka towards the Cisterna Magna which segues into the subarachnoid space. Drainage takes place through spinal nerve roots and the brain parenchyma.⁴ The pressure in the CSF system can vary and normally shifts from around 5 - 10 mm Hg in a lying position and around -5 - (-10) mm Hg while standing. It is also dependent on factors such as coughing, sneezing, singing or other forms of Valsalva manoeuvre. The maintenance of an acceptable pressure within the cerebrospinal system and the cranial cavity itself is essential for a normal and healthy life. However, disturbances in CSF circulation or absorption can lead to increases in Intracranial Pressure (ICP) and can sometimes result in different forms of pathologies such as hydrocephalus.²

1.2 Hydrocephalus

Hydrocephalus is a pathological condition characterised by an accumulation of abnormal quantities of CSF in the ventricles of the brain.⁴ A broad distinction divides this condition into the two types; *communicating hydrocephalus* and *noncommunicating hydrocephalus*. The former affects the flow and absorption of CSF after exiting the ventricles, leading to an enlargement of the whole ventricular system. *Noncommunicating hydrocephalus* on the other hand is caused by an obstruction in specific locations between the ventricles, which affect the circulation of CSF, commonly in the cerebral aqueduct. This causes only distinct affected areas of the ventricular system to increase in size.^{3,5} The widening of the ventricles can put pressure on the brain and cause symptoms, which differ substantially from person to person. Common primary symptoms are nausea and vomiting or headaches due to the increase in ICP. Further unspecific symptoms can be reduced vigilance, coma, or seizures. If this condition arises in newborns, a common sign is an increase in head size because the cranial sutures have not closed yet.

Further classifications of hydrocephalus are *congenital, acquired or acute* and *chronic*.⁶ An increased ICP is no requirement for developing hydrocephalus as a specific form of hydrocephalus such as *normal pressure hydrocephalus* (NPH) indicates. This distinct form of hydrocephalus is most commonly seen in the elderly. Actually, this type is no real hydrocephalus but a form of brain atrophy which can also be treated with a shunt. The typical symptoms in NPH are problems with gait, urinary incontinence, and dementia, commonly known as *Hakim's Triad*. Thus, this form of hydrocephalus is often mistaken for Alzheimer's or Parkinson's disease.⁷ Infections during pregnancy or congenital malformations can lead to babies born with hydrocephalus. Furthermore, factors like stroke, meningitis, head injuries or brain tumours can promote the development of hydrocephalus at every age.⁸ This condition is normally diagnosed using neurological examinations and radiological imaging such as magnetic resonance imaging (MRI), computed tomography (CT) or ultrasound imaging in infants. To analyse the CSF itself, a lumbar puncture is used as well, especially in NPH.⁴ Apart from NPH, untreated hydrocephalus is a potentially lethal condition.^{7,9} Endoscopic Third Ventriculostomy (ETV) can also be used to treat hydrocephalus but so far, shunt surgery is still the main treatment for most forms.¹⁰

1.3 Shunt

Procedures which divert CSF are one of the most neurosurgical surgeries performed around the world.¹¹ A shunt channels the CSF from e.g. the ventricles to a body region where absorption is

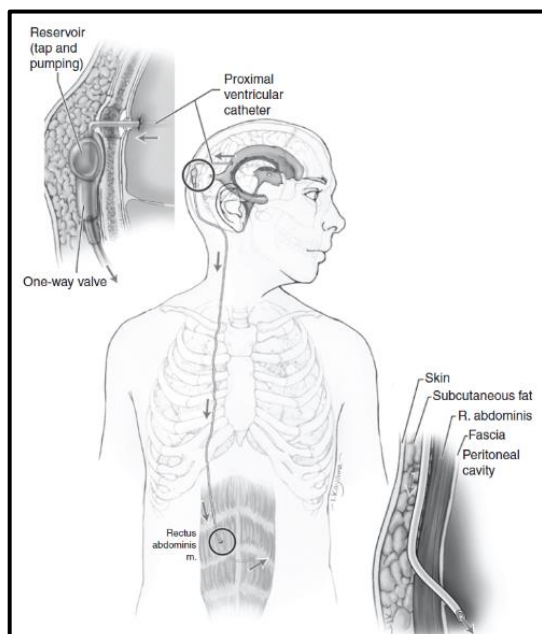


Figure 2: Ventriculoperitoneal shunt¹¹

possible. In many cases, a shunt can improve patients' symptoms and ultimately their Quality of Life (QoL). Morbidity and mortality associated with hydrocephalus could be reduced substantially through this surgical procedure.¹² There are different types of shunts but the two most commonly performed are ventriculoperitoneal (VP) shunts and ventriculoatrial (VA) shunts. An example of a VP shunt can be seen in *figure 2*.¹³ They channel the accumulated CSF to the peritoneal cavity or the right

atrium where it can be reabsorbed. There are many different shunt models in production, but they normally consist of 3 basic components. An inflow which is responsible for the CSF drainage, a valve system which can compensate abnormal pressures of CSF and an outflow catheter which channels the CSF to a body region where it can be absorbed. A broad distinction of shunt valves can be made between *resistance valves* (single-value setting) and *variable resistance valve* (programmable) which relies on an external device for pressure adjustments. However, shunt treatment is not risk-free. There are many problems which arise during and after the procedure but current literature is lacking a standard classification of shunt complications.^{14,15} The failure rates of shunts vary and can be as high as 45% in the first year after surgery and it decreases for every following year.¹⁰ Paulsen et al. state that most people require one or more shunt revisions across their lifetime.¹⁶ Typical shunt complications can be infections, over and under drainage of CSF, mechanical failure of the hardware or problems with the tube e.g. in the peritoneal region which can lead to further complications such as haemorrhages, headaches, or neurological impairments. In 2010 Korinek and colleagues investigated shunt complications in 720 adult patients and concluded, that the most common

complication of shunts was shunt obstruction, in 15.9% of cases and catheter malposition, in 7.1% of cases.¹⁷ Shunt dysfunction can be life-threatening and urgent intervention, such as surgical revision is needed.¹⁸ Shunts are lifelong implants and they often require adjustments and long-term follow-ups. Their presence can be felt and sometimes even be heard by the shunt owner.¹⁹ Complications, failure rates and follow-ups significantly influence a patient's wellbeing and ultimately their QoL.²⁰

1.4 Quality of Life

Over the past years, the term QoL has become very popular in medicine and health science research and is used very frequently now to assess the impact of health conditions or treatment on a patient's life. However, in the current literature, QoL still seems to be an umbrella term covering all sorts of aspects of peoples' lives such as health, happiness, work and others with no clear consensus or definition. Additionally, it appears that the quality of patients' lives has a strong subjective component because people weigh the various elements of their lives very differently. In this context, the term Health-related Quality of Life (HRQoL) plays a major role as well because it condenses QoL into the sphere of health, diseases, and special conditions of patients. However, focusing only on health-related aspects while neglecting other QoL elements can significantly overestimate the influence of health on overall QoL. Even for the individual, it can be hard to distinguish between aspects of life that are influenced by health from those that are not. Thus, health should be included in QoL assessments, but other spheres of life should also be taken into account to gain a holistic view of a patient's QoL.²¹ The outcome measures of treatments are no longer only the survival or the reduction of symptoms but also patient-oriented outcomes which include psychological and social dimensions as well.²² The World Health Organisation's (WHO) definition of QoL also outlines that subjective goals, expectations, concerns and the culture surrounding the individual play an important role.²³ Additionally, an ageing population has increased the demand for QoL measurements because nowadays diagnoses of chronic diseases rise continuously and this will affect patients throughout their lives rather than acute illnesses.²¹ Furthermore, we see a strong increase in psychological or psychosomatic diseases which mirror the need for holistic QoL outcome measurements even more.²²

Another aspect which is often discussed in QoL research is the question of whether proxies can give valid information about people they care for. Studies show that results between self-reported and proxy-reported information differ substantially and thus patients should report independently whenever possible.²⁴ In the literature it is accepted that QoL is not static, remaining the same throughout an individual's life, but it is a highly dynamic concept. As individuals develop with time, the aspects which are important in their lives change too. This can be due to relationships, accidents, illness progression and many other influential factors.^{25,26} Over time, researcher have come up with many different measures to assess QoL which often involve SF-36, EQ-5D, WHOQOL-BREF from the WHO or other tools like PedsQL for children. Those questionnaires cover dimensions such as physical and emotional functioning, health perception, social role functioning but also vision, hearing, mobility and sexual activity.^{27,28} Current literature tries to develop more disease-specific measurement tools of QoL such as in the case of hydrocephalus.²⁹

1.5 Research Gap

Bringing together all four previous topics while looking at the research so far, it can clearly be said that there is very little information about QoL assessment in hydrocephalic patients who underwent shunt therapy.³⁰ Of the few papers which are available the majority use predetermined QoL measurement tools such as SF-36 or 15-D but nothing specialised in hydrocephalus.^{27,28,31-34} A handful of studies use a QoL questionnaire specified for hydrocephalus, the so-called Hydrocephalus Outcome Questionnaire (HOQ) which was developed by Kulkarni A. V. et al. Those disease-specific measurement tools of QoL appear to be more effective in collecting patients' subjective views concerning their shunt therapy.³⁵ However, the HOQ was developed only for children with hydrocephalus but in the current literature, there is no equivalent for adults with hydrocephalus.³⁵⁻⁴⁰ This research project tries to fill that gap by interviewing hydrocephalic adults with shunt therapy. The aim is to find out how the life of people with hydrocephalus changes due to a shunt and thus creating the basis for a QoL measurement tool for the hydrocephalic patient of adult age with a shunt in future research. This topic is highly relevant because patients with hydrocephalus view QoL

as the most important outcome after treatment.⁴¹ In addition to that, the subjective component of interviews, i.e. from patients' perspectives, seem to be really important because standard QoL measurement tools try to quantify QoL by preset questions. In these studies, the patients do not get a chance to talk freely about elements which are especially important to them and must find an answer to a question which approximately fits their situation. This seems contradictory as QoL is all about a patient's perspective and subjective experiences as mentioned previously.^{28,31} To the knowledge of the authors, this study is the first to try to fill this gap by using semi-structured interviews which allow the patients to talk freely about things which matter most in their lives with regards to their shunt. The results shall help to improve patients' treatment in the future. They can be used to explain long term effects of a shunt treatment, identify problems, allow physicians to better understand patients, help patients to see the consequence of these lifelong implants and ultimately increase patients' satisfaction.^{20,29}

Literature Review word count: 2011 words

2. Aims

This explorative research project is conducted in cooperation with the Klinikum Kassel and the University of Kassel and provides the basis for a follow-up study led by Dr Stefanie Kästner and Dr Manuela Pötschke.

The primary aim of this research project is to explore how the life of people with hydrocephalus changes due to a shunt. The secondary aim is to form the foundation of a standardised QoL questionnaire for adults with hydrocephalus and a shunt in the follow-up study by creating a category system. In the course of this mixed-method approach, the results shall help to improve holistic treatment and satisfaction in this patient target group.

3. Methods

This chapter focuses on how the data was gathered and worked with during the different phases of the research project. Firstly, recruitment of patients is explained. In the course of this, the inclusion and exclusion criteria will be presented before a closer look is taken on interview conduction itself. The final part of this chapter is marked by describing the transcription and analysis process.

Ethical approval for this study was granted by the “Landesärztekammer Hessen” (2020-1823-evBO) in Germany on the 14th of August and by the Faculty of Medicine Ethics Committee (ERGO 55778) in the UK on the 1st of September. As part of a mixed-method approach, this explorative research project and a similar study from the fellow student Anne-Modwen Ehle from the Kassel School of Medicine provide a foundation for a follow-up study led by Dr Stefanie Kästner and Dr Manuela Pötschke. The project was conducted in German, but all the relevant data was translated into English afterwards.

3.1 Recruitment

To address the research question of this study, patients were contacted from the prospective hydrocephalus database of Klinikum Kassel. This database was created by supervisor Dr Stefanie Kästner and includes all shunt patients from the Klinikum Kassel since 2007. As qualitative research does not focus on developing generalisable statements for the population, this study does not aim for representativeness either.⁴² However the research team tried to maximize variance by selecting a heterogeneous group of patients from the hydrocephalus database of the Klinikum Kassel.^{43,44} This sampling process followed a deductive approach where study participants were selected based on previously determined selection criteria.^{45,46} With the help of Dr Stefanie Kästner’s expert judgement, different criteria from the hydrocephalus database such as age, gender, date of shunt surgery, hydrocephalus origin, number of revision surgeries and shunt type were taken into account when participants were selected for this research.

As there is already a hydrocephalic specific QoL measurement tool for children, this study only focused on people of the age of 18 or older. Participants needed life experience with a shunt and therefore only people were included who had their shunt for a year or more. Another aspect was

neurological impairments. Participants were only included if they had no impairments such as aphasia which would have prevented them from effectively taking part in an interview setting. Patients were excluded from the selection if they were stationarily situated at the Klinikum Kassel because of their shunt as this may negatively impact their responses during an interview. An overview of the inclusion and exclusion criteria can be seen in the following table:

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
Patients with hydrocephalus and shunt treatment	Patients with other health conditions and no hydrocephalus or shunt
Patients without severe neurological impairment	Patients with severe neurological impairment
First shunt treatment >1 year ago	First shunt treatment <1 year ago
Adult patients >18 years of age	Patients <18 years of age
Patients who come to the Klinikum Kassel for their regular check-up	Patients who are stationarily situated because of their shunt

Table 1: Inclusion and exclusion criteria (own image)

In the end, 20 patients were approached by mail with a recruitment letter, a patient information sheet, a written consent form and a return envelope. If patients decided to take part in the study, they could sign the consent form and return it. After giving consent, these patients were contacted via phone to arrange an appointment for a face-to-face interview at the Klinikum Kassel. The

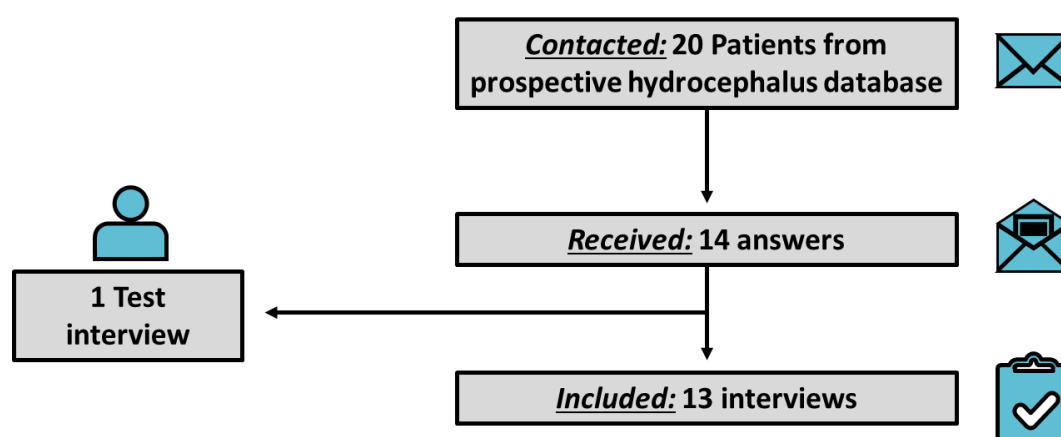


Figure 3: Patient Flow Chart (own image)

response rate and the recruitment process can be seen in the patient flow chart in figure 3. Of the 20 patients who were contacted, 14 answered.

3.2 Interviews

One of the participants who gave consent was used as a pre-test to determine the approximate length and conduct of the interview. Furthermore, a pre-test is important to determine if participants can understand the interview questions and respond accordingly. Before the actual interviews, the interviewer took part in a special interview training led by a professional from the University of Kassel. The participant group showed a variety of age between 23 and 57. Ten of them were females while only four participants were males. After arranging an appointment most of the interviews were conducted in a separate meeting room in the Klinikum Kassel, while one interview was done via telephone due to the second wave of the SARS-COV2. If consent was given previously the interviews were recorded with an Olympus LS-P1 audio recorder from the University of Kassel. To direct the interviews, a semi-structured interview guide was used. The complete guide can be found in the appendix. Giving the explorative nature of this project, a semi-structured interview only gives a rough framework of topics, but the respondent has also the opportunity to mention new topics.⁴⁷ This relatively free model, but within a certain scope, fits well to this kind of project as it allows the introduction of subjective experiences by the participant which is emphasised in the literature.^{21,23,28,34} The structure and preset categories were developed based on the current literature by e.g. analysing different QoL measurement tools so far. Afterwards, the interview guide was discussed and finalised with a group of experts. The different categories can be seen in *figure 4*, but of course participants could come up with new categories by themselves. Categories from the interview guide were shown to the participants as icons during the interview to stimulate the conversation.

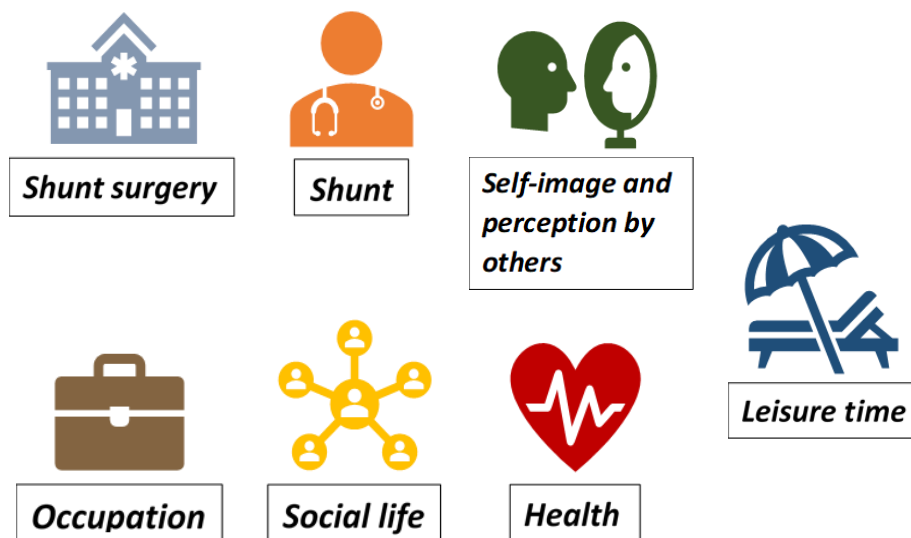


Figure 4: Interview categories (own image)

The length of the interviews varied between approximately 20 minutes and 1 hour and 30 minutes, depending on time and responsiveness of the participants. To avoid bias attributed to the interviewer's attention, only 2 interviews were conducted per day maximally. Conduction of further interviews was stopped after reaching theoretical saturation. This means that new knowledge was not expected by increasing the number of interviews because data from the last few interviews corresponded to what has already been said in previous interviews.⁴⁸

3.3 Transcription & Analysis

From the interviews, 61157 words of interview text could be gathered. The text was then grouped into P = Participant, C = Caretaker and I = Interviewer. In the next step, these data were transcribed using Microsoft Word and the semantic-content-related transcription system (German: Semantisch-inhaltliches Transkriptionssystem) by Kuckartz et al.⁴⁹ A detailed listing of this system can be found in the appendix. Line numbers were added to the interview transcript to allow appropriate quotation and referencing. The analysis of the raw interview data was done with NVivo, a qualitative data analysis software by QSR international which is commonly used by qualitative researchers, especially in a setting as in this research project.⁵⁰ The analysis itself was carried out according to Mayring's qualitative content analysis (German: Qualitative Inhaltsanalyse). This approach works well with the research project setup as the few categories from *figure 4* were already brought into the interview and from this point, further categories could be explored by the participants. Consequently,

Mayring's concept allowed the researchers the combination of an inductive and deductive approach during the analysis process.⁵¹ The interview transcripts were analysed in multiple run-throughs by categorising the different topics in a mind map like structure. In the end, a category system was created which groups the interview data into overall categories, subcategories, further subcategories with a definition and a prime example for each.

4. Findings

In the course of this study, 13 hydrocephalic participants were interviewed to explore how their life has changed due to a shunt. After analysing the interview data, a category system was developed which can be seen in the form of a mind-map in *figure 5*. A black plus on a subcategory indicates that there are further subcategories. A more detailed breakdown with all further subcategories, definitions and prime examples can be found in the appendix. The following chapter will present the different categories with the help of interview quotations which were emphasised most.

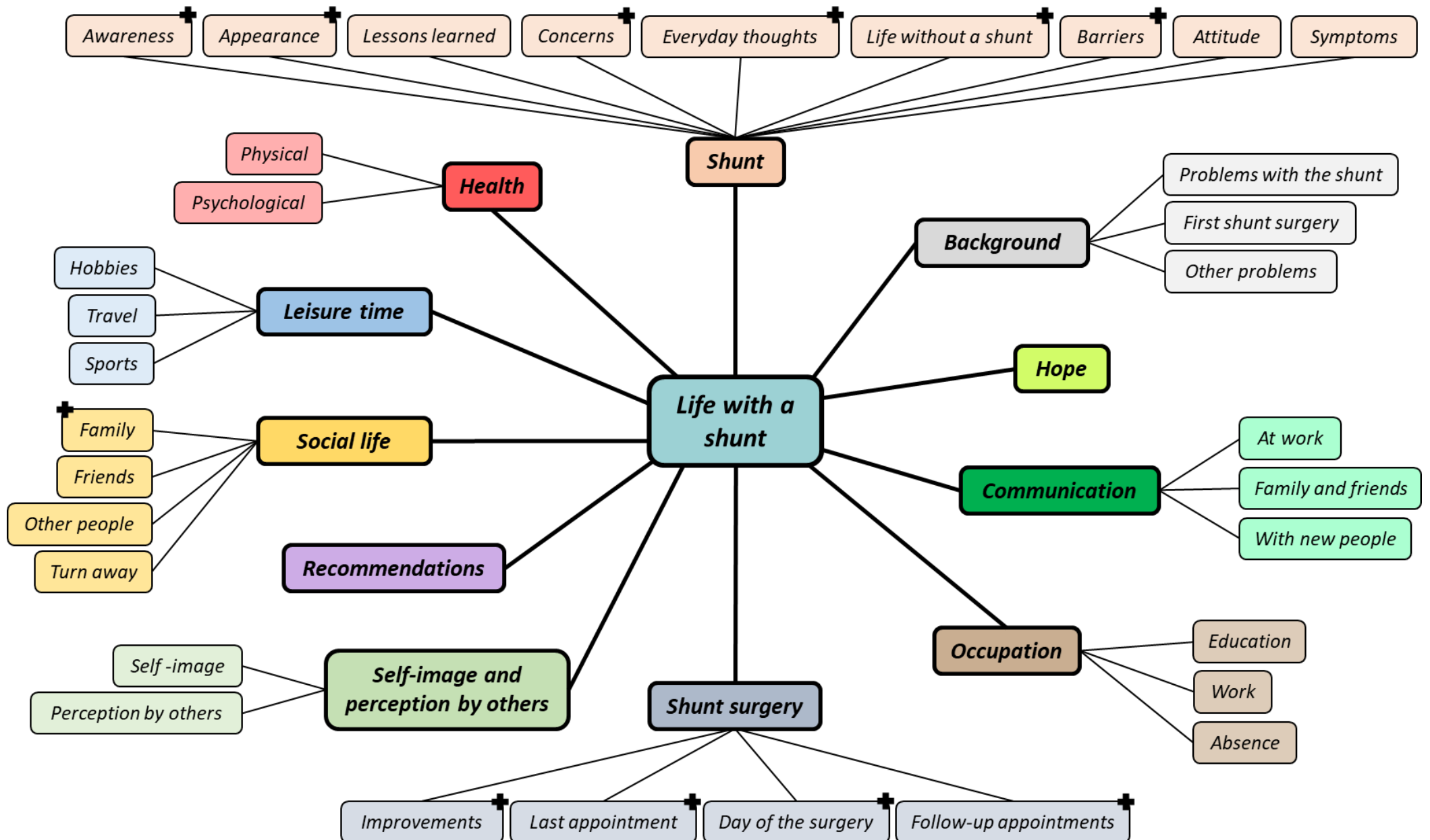


Figure 5: Category system (own image)

4.1 Background

The first interview questions were mostly about the background and how events led to shunt surgery. Participants also described problems which occurred after the shunt surgery and difficulties where they see no link to the shunt itself. Common topics were shunt infections, multiple surgeries, and adhesions of the shunt tube (e.g., interviews 10, 2, 6).

P: "Then, it was discovered that the shunt has grown together [points towards the abdomen]. ... doctors have said, that because of adhesions it [the shunt] is not intact anymore." (Interview 1, line 10-14)

P: "... with the help of lumbar punctures, they have tried to get a grip on it, but the brain tumour was back so quickly that we have decided to place the shunt." (Interview 6, line 13-15)

4.2 Shunt surgery

When participants explicitly talked about the shunt surgery itself, the following subcategories were explored: "Day of the surgery", "Follow-up appointments", "Last appointment" and "Improvements". Concerning the "Day of the surgery" different responses were given. Some participants described that they have no memory of the day of the shunt surgery while others seemed to still have specific impressions in mind. Especially in this category participants talked a lot about their emotions regarding the day of the shunt surgery. The most present emotion around shunt surgery was fear.

P: "... because from the moment I entered the hospital until I was transported to Bad Wildungen [rehab], the whole period of time is gone, thank god!" (Interview 4, line 296-298)

P: "... everything seemed like a dream. You wake up after the surgery and my wife was there immediately, but it is strange ..., I think I got off at the wrong station ..." (Interview 11, line 258-260)

The "Follow-up appointments" and "Last appointment" subcategories describe which aspects were important for the participants concerning the routinely and the last appointments in relation to the shunt. The most common topic was that participants mentioned emotions towards these appointments. E.g., that they have concerns or fear and they think about the shunt and their past surgeries when they have to go to an appointment shortly (e.g., interview 15). However, some participants indicated that they had no emotions whatsoever concerning these appointments (e.g.,

interview 8). The final subcategory explored potential improvements in the context of the shunt surgery and yielded five further subcategories. Participants described that doctors often have no time and too little knowledge to answer their questions. Furthermore, the lack of follow-up appointments, the language and the communication itself were criticised.

C: "They explain it in a very complicated way. ... Especially when they talk in technical language." (Interview 10, line 573-575)

P: "Personally, I think that doctors do not tell a lot about the whole thing." (Interview 12, line 431-432)

4.3 Shunt

The category "Shunt" revealed a lot of subcategories and further subcategories. Participants' appearance was addressed very often. While some participants seemed to have no problems, others explained that the scars from the shunt surgery and the shunt itself influenced their appearance. Especially during childhood this topic appeared to be problematic.

P: "... and I thought I would rather cover myself than hearing that [comments about appearance] and then nobody will see it [the shunt] ..." (Interview 8, line 265-266)

P: "... and that my hair got shaved off of course. And especially with 13-14 this is somehow strange ... (Interview 6, line 48-49)

Furthermore, participants described many symptoms which they related to their shunts such as problems with hearing, headaches, and balance problems (e.g., interviews 10, 13, 15) and it was mentioned that they live more conscious now because of their shunt (e.g., interview 7). Another question explored participants' overall attitude towards the shunt and most of them appreciate the lifesaving function of this implant.

P: "Actually very good. I am happy that I have it [the shunt], because otherwise they could not get a grip on it." (Interview 6, line 313-314)

Further subcategories explored how aware participants are of their shunt. Most of them said that the shunt is not perceptible, though some participants explained that they could hear their shunt (e.g., interviews 12, 13, 15, 8). Awareness of the tube and the shunt itself as a foreign object was quite rare

in this group of participants (e.g., interviews 11, 9). During the interviews, participants described many barriers which prevented them from doing things they like. Common responses were about sports like boxing (e.g., interview 10) or skydiving (e.g., interview 12). Other barriers comprised of roller coasters (e.g., interview 12), diving and altitudes (e.g., interview 2). Despite that, some participants seemed to live a normal life without any barriers (e.g., interviews 12, 15, 3).

P: "There is nothing that I don't do because of my shunt ..." (Interview 4, line 148)

During everyday life, a lot of thoughts run through the participants' minds. They described that perceived symptoms such as headaches made them think about their shunt more often (e.g., interviews 10, 12). Position changes with related pressure compensation and destiny were other common topics which came up during the interviews. However, most participants explained that they do not think about the shunt at all.

P: "... not at all. No, no, no. It [the shunt] is there, but I do not think of it. (Interview 13, line 332-333)

Of those participants who mentioned concerns about their shunt, the most common categories were the fear of mechanical impacts, hardware failure or physical work.

P: "Let us say e.g. carry some heavy things ... That is heavy for me so I am not allowed to do it." (Interview 8, line 177-180)

P: "I fear that it [the shunt] bursts or something else goes wrong ..." (Interview 13, line 260)

The last topic under the category "Shunt" asked for participants' thoughts on how a life without their shunt would look like. Participants recognised that there would be no life without a shunt and that such an implant improves the health of most people with hydrocephalus.

P: "As I said before, brain fluid would not drain off and at some point, I would be destined to die." (Interview 12, line 463-464)

4.4 Self-image and perception by others

Responses to topics such as self-image and perception by others were quite mixed. While some participants did not see any differences (e.g., interviews 4, 7, 2), others said for example that they see themselves as different individuals after the shunt surgery. Equally, people from their social environment confirm that they perceive the participants differently after the shunt surgery.

P: "... after the shunt I felt much better and people from my social environment said I am myself again ..." (Interview 13, line 89-90)

4.5 Social life

During the interview, participants explained that a shunt did indeed have a big influence on family and friends. Some participants were treated differently (e.g., interviews 13, 6) while others saw no influence (e.g., interview 15). Overall, participants highly appreciated the support from family and friends during the difficult time of the shunt surgery (e.g., interview 10). In this context, it was mentioned multiple times that close people turned away because of the difficult time, the hospitalisation and even because of the physical barriers due to the shunt.

P: "... and later I told them, when we wanted to do sports together, that I could not join and then they said they don't want to hang out with me anymore ... and then the friends left me alone." (Interview 8, line 197-202)

4.6 Occupation

While hospitalisation and shunt surgery hindered some education careers such as studies (e.g., interviews 6, 10), most participants explained that the shunt had no influence on their work (e.g., interview 11). Even absence due to routine follow-up appointments did not seem to have a negative impact on occupation overall (e.g., interview 7).

4.7 Leisure time

Another big category was leisure time. It comprised subcategories such as travel, sports, or hobbies in general. For most participants, hobbies were not impaired and even improved by a shunt (e.g., interview 13). The activities which involved contact sports were often dropped because of fear that there could be some mechanical impact on the shunt. A few participants mentioned that travel in

other countries is now a problem, because they fear that foreign medical care would not be sufficient enough if problems with the shunt occur abroad.

P: "I haven't dared to go far away ever again." (Interview 12, line 239)

4.8 Health

In the course of this category, participants were questioned about their physical and psychological health. Although participants were aware that shunt surgery and an implant bears some potential to develop negative psychological conditions, most of them did not experience anything like that so far (e.g., interviews 11, 13, 15, 2). A few participants mentioned that they got psychological counselling, but this was due to other health problems and not because of the shunt itself (e.g., interview 8, 9). Equally, a shunt did not seem to impair physical health in the participant group because such issues were attributed to the underlying hydrocephalus but not to the shunt implant.

P: "... this [the shunt] is no health aspect because it is not present. For me it is not present. As and additional part of my body which does not belong there. And consequently, this is neither health wise nor psychologically a topic." (Interview 2, line 193-195)

4.9 Other categories

Further categories comprised "Communication", "Hope" and "Recommendations". Participants handled communication about the shunt very differently. Some informed family, friends, and colleagues at work (e.g., interviews 11, 8) while others kept it more confidential (e.g., interview 2). As with a lot of the categories, the picture was quite mixed. One interviewee responded that the thought of hope is very important as this could be the only option to improve the current situation with the shunt (Interview 10). In the context of the interviews, participants gave recommendations to other patients who think about potential shunt surgery in the future. The overall message was to go along and to not think too much about it. From the patients' point of view, the shunt is a very positive thing (e.g., interviews 11, 13, 4).

P: "It is just a nice way to survive and for this reason I can only advice ... to put yourself in the hands of the doctors and trust them ..." (Interview 4, line 361-363)

5. Discussion & Conclusion

To answer the research questions the following chapter will discuss the findings from this project.

Because interview responses were sometimes quite mixed, the discussion is broken down in two main parts about QoL. Firstly, the most common topics which appear to decrease QoL in this participant group will be explained and potential opportunities for improvement will be provided.

Afterwards, the main categories which already have increased QoL in this study group will be mentioned. This is followed by study limitations which may affect validity. Finally, a conclusion with an outlook for future research is given.

5.1 Decreased QoL

The relevant literature states that currently there is no QoL measurement tool specifically for adults with hydrocephalus and a shunt. The interview data from this research project has shown that there are plenty of topics about which the participants want to talk and which affect their QoL.³⁵⁻⁴⁰ This need to communicate is underpinned by the high response rate of 65% in comparison to other studies with similar settings.⁵²⁻⁵⁴ In this context, the subcategory “Improvements” has demonstrated not only the need to talk about topics concerning life with a shunt but also for information from healthcare professionals. A statement from interview 12 emphasises this point: *“... that is true, you have to ask yourself ... Personally, I think that doctors do not tell a lot about the whole thing.”* (Interview 12, line 430-432). Of course, this is not particular for patients with hydrocephalus and a shunt but lack of time during appointments was mentioned most.⁵⁵ Additionally, the technical language and the shortage of information was criticised. Those aspects fit well into the overall picture that there is a need for information and support regarding life with a shunt. However, most participants reported that follow-up appointments were seen as positive and as an opportunity to ask questions. Although patients with hydrocephalus and a shunt receive basic information in diverse briefing and debriefing meetings, there is general misunderstanding due to the large amount of information being delivered at once. This becomes even more problematic when patients are under emotional stress.^{56,57} This was mentioned a few times in this study group as well e.g., *“... Shortly before the check-ups ... around a week before I start to get anxiety and concerns ...”* (Interview 8, line

314-317). Anxiety is not only limited to the appointments themselves but also seems to accompany patients throughout their life with a shunt. Clearly, worrying thoughts and fears were not topics for all participants in this study but it still seems to be relevant for some e.g. “More concerns, that something goes wrong or that it [the shunt] does not work anymore” (Interview 11, line 341-342), “... first of all you have the fear that this thing is blocked again ...” (Interview 12, line 76-77) or “... you always have this bad feeling and fear that you potentially have another surgery.” (Interview 8, line 323-324). Fear and anxiety seem to be common problems in patients with hydrocephalus and a shunt as related literature suggests.²⁰ This fear of shunt malfunction and related complications should be tackled by providing enough information and guidance which addresses patients’ concerns and questions. The two subcategories “Concerns” and “Barriers” are especially important because there seemed to be a lot of misinformation and beliefs regarding the shunt. For example, some participants experienced audible noises from the shunt and interpreted that the working shunt makes a buzzing sound. However, when those noises started to subside, they were frightened (e.g., interviews 12, 13). Others stated that it would cause great distress if they could hear their shunt (e.g., interview 2). Further examples where patients had questions regarding what a shunt can and cannot do were: Security checks, roller coasters, diving, altitude, physical work, and different types of sports such as soccer or skydiving. Clear advice on these topics and addressing misinformation could prevent patients from making unnecessary sacrifices and thus decreasing their QoL. The same goes for perceived symptoms which was also a subcategory mentioned most. The participants seemed to be unsure which signs they should attribute to the shunt and when to seek medical advice: “... *in the early days I was here in the emergency department three or four times ... you have to get a feeling for this first ... you do not know if these are just normal headaches or if there is a problem.*” (Interview, line 118-122). Common problems were headaches, audible noises from the shunt, problems with hearing, pain, vomiting, balance disturbances or problems with sleep. The current literature suggests that a variety of perceived symptoms concerning the shunt could be due to multiple other underlying conditions which are often present in patients with hydrocephalus.²⁰ Information about common

signs and symptoms of a shunt could be helpful for patients because this would potentially reduce their worries about shunt problems and thus improve QoL. Forms of interventions to address this demand for information were explicitly mentioned by the participants e.g., via information material such as flyers or group meetings with other hydrocephalic patients with a shunt. Concerning appearance, participants described that this is not affected by the shunt itself but more by the shaving and scars due to the shunt surgery. Some used headscarves, caps, or wigs to cover these up. Often the local hospital hairdresser could help with these problems, but such opportunities should be communicated to patients. Additionally, shunt treatment appears to have a big impact on patients' social life as well, because participants reported that people treat them differently or even turn away because of the shunt. In the context of hydrocephalus and a shunt treatment, a caretaker is often involved. Provision of information as mentioned multiple times previously should also be accessible to caretakers as they are in close contact with the patients. This is suggested by the current literature as well.²⁰ Concerning occupation, it is good to see that the shunt itself did not really influence participants' working lives. However, long periods of absence due to revision surgeries or problems with the shunt, in general, can impair work and education progress. Although employers seemed to be cooperative, participants felt guilty when they could not attend work for longer periods of time. When looking at leisure time, a major problem for participants from this study group was travel. The fear of travelling to other countries because of the perceived lack of sufficient medical care was mentioned several times e.g. *"I haven't dared to go far away ever again."* (Interview 12, line 239). There is obvious potential here for attending physicians to explain the pros and cons of travel and whether or not all countries bear the same risk. This could take some fear from this group of patients and potentially improve their QoL.

5.2 Increased QoL

Although a shunt influences multiple facets of patients with hydrocephalus as seen above, it also exhibits some potential to improve QoL. Some participants have mentioned that they live more consciously now and have an overall positive mindset. They were thankful for small things and one

participant could even follow their own career aspiration because of the shunt. Therefore, the overall picture is not only shaped by problems, barriers, or concerns, but is also underpinned by the overall positive attitude towards the shunt. Participants recognised the shunt as a life-saving implant and were thankful for it: “I think, I cannot imagine what a life without it [the shunt] would look like ... it is an important thing ... it protects me from too much water in the head.” (Interview 4, line 353-355). The mixed responses and the fact that some participants had no problems with the shunt at all indicate that the need for information and guidance mentioned initially does not apply to all patients with hydrocephalus and a shunt. The interview data gave the impression that those patients with more shunt complications had an increased demand for information and guidance. To investigate this in detail, further research should be done in this field.

5.3 Limitations

It has to be mentioned that this research project has only interviewed patients at a single institution and therefore transferability of results to patients treated at other institutions is questionable. Furthermore, there is a certain selection bias, because patients with a negative attitude towards the shunt could be less likely to participate in this project. Reporting bias cannot be fully excluded as well because most participants were treated by Dr Stefanie Kästner and they could potentially fear that negative responses could affect their current treatment, even though they were informed via the study documents that this would not be the case. Lastly, the difficulty to determine QoL should be emphasised as this concept is highly subjective and the impact of one single factor, such as the shunt, is problematic to identify, especially when the patient has multiple health conditions which influence QoL together.

5.4 Conclusion

To our knowledge, this study is the first to explore the impact of a shunt on QoL in hydrocephalic, adult patients by using a semi-structured interview approach to allow a more detailed look at patients' subjective experiences. Referring back to the primary and secondary research questions of this project, it can be said that there are plenty of topics which affect the life of patients with hydrocephalus and a shunt as seen in *figure 5*. Although responses varied to a certain degree,

exploration of this participant group revealed a need for information and guidance regarding life with a shunt. This need should be thought about in future medical care. However, the participant number of N = 13 in this research project allows no generalisable assumptions about patients with hydrocephalus and a shunt in general. Therefore, this study is only the basis of a mixed-method approach in the course of which a follow-up study of larger scale shall determine whether the assumptions from this study hold true. In this context, a standardised QoL questionnaire for adults will be developed to improve holistic treatment and satisfaction of patients with hydrocephalus and a shunt in the future.

Word count: 5969 words

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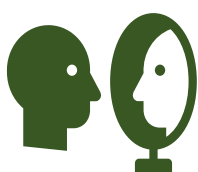
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7. Appendix

This chapter is a collection of additional resources which were used during the different phases of this research project.

7.1 Interview guide

This document is the final semi-structured interview guide which was used during all of the interviews (translated to English). It is important to mention that these were just guiding questions if the interviewee could not talk much about the different topics.



Self-image and perception

How did you perceive yourself before the shunt surgery?

How do you think have others perceived you before the shunt surgery?

How do you perceive yourself now after the shunt surgery?

Does the impact of the shunt on your appearance bother you?

Do you think other people notice the shunt immediately?

How do you think do others perceive you now after the shunt surgery?



Leisure time

What did you do during your leisure time before the shunt surgery?

Did you enjoy doing sports before your shunt surgery? If yes, what sort of sports?

What do you do now during your leisure time after the shunt surgery?

Is there any kind of sports or hobbies now which you did not do before the shunt surgery?

Has your holiday planning changed due to the shunt?



Social life

Would you describe yourself as a person who socialized a lot before the shunt surgery?

How was your family situation before the shunt surgery?

Have you noticed that relationship to people in your close environment did change after the shunt surgery?



Occupation

What was your occupation before the shunt surgery?

Has your work routine changed due to the shunt?



Health

How was your health before the shunt surgery?

→ How did you feel?

How is your health now after the shunt surgery?



Shunt surgery

If you visualise the day of the shunt surgery now, how did you feel?

You had some briefings and debriefings around your shunt surgery, how did you experience them?

→ Is there something you would improve the next time?

If you visualise the last appointment because of the shunt now, how did you feel?



Shunt

Do you think of your shunt during a normal day a lot?

→ Which moments specifically?

Can you feel the shunt at the moment and in general?

Do you have concerns that something could go wrong in regard to the shunt?

→ If yes, which moments specifically?

How would your life look like if you did not decide to have the shunt surgery?

7.2 Transcription guide

This transcription guide based on Kuckartz's semantic-content-related transcription system (German: Semantisch-inhaltliches Transkriptionssystem) was used during the analysis of the interview data. The following rules were applied:

- Use literal transcription
- Keep grammar even if it includes mistakes
- Keep duplications of words
- Use punctuation for readability
- Interviewer = "I"
- Participant = "P"
- Caretaker = "C"
- Add line numbers for referencing
- New paragraph for each interview participant
- Present emotional, nonverbal expressions such as laughter in brackets
- Rewrite dialects
- Ignore stuttering and unfinished words
- Mark clauses and unfinished sentences with a "/"
- Mark breaks longer than 3 seconds with "(...)"
- Mark incomprehensible words with "(unv.)"

7.3 Category System

In the course of the analysis, the data were grouped into categories, subcategories and further subcategories with a definition and prime example for each. By means of this category system and the raw NVivo data, the mind map from the finding chapter was developed.

Category	Subcategory	Further subcategory	Definition	Prime example
Background	First shunt surgery		Participants describe the events which have led to the first shunt surgery	P: "... with the help of lumbar punctures, they have tried to get a grip on it, but the brain tumour was back so quickly that we have decided to place the shunt." (Interview 6)
	Problems with the shunt		Participants describe problems which occurred after the first shunt surgery	P: "Then, it was discovered that the shunt has grown together [points towards the abdomen]. ... doctors have said, that because of adhesions it [the shunt] is not intact anymore." (Interview 1)
	Other problems		Participants describe problems which are not directly linked to the shunt	P: "Five years ago, I was here too, and a calcified brain tumour was removed which could be identified on the MRT images." (Interview 7)
Shunt surgery	Day of the surgery	No memory	Participants describe that they have no memory of the day of the shunt surgery	P: "... because from the moment I entered the hospital until I was transported to Bad Wildungen [rehab], the whole period of time is gone, thank god!" (Interview 4)
		Emotions	Participants describe their emotions in regard to the day of the shunt surgery	P: "The first few surgeries were bad, and I was scared because of the high risk and I did not know what to do and there were a lot of emotions." (Interview 8)
		Impressions	Participants describe their impressions of the day of the shunt surgery	P: "... everything seemed like a dream. You wake up after the surgery and my wife was there immediately, but it is strange ..., I think I got off at the wrong station ..." (Interview 11)
	Follow-up appointments	Impressions	Participants describe how follow-up appointments in	P: "It was positive, completely normal. I was examined and CT and other things regularly." (Interview 13)

			relation to the shunt were perceived	
		Missed appointments	Participants explain why they missed follow-up appointments	<i>P: "... I let the annual meetings slip to check if this thing [shunt] still works, due to increasing self-knowledge." (Interview 2)</i>
		Emotions before appointments	Participants describe how they feel before appointments in relation to the shunt	<i>P: "... Shortly before the check-ups ... around a week before I start to get anxiety and concerns ..." (Interview 8)</i>
	Last appointment		Participants describe how the last appointment in relation to the shunt was perceived	<i>P: "... exactly as it should be. A casual conversation about off-topic and private things. In sum a nice but professional chat ..." (Interview 2)</i>
	Improvements	No time	Participants describe the lack of time during appointments related to the shunt	<i>P: "... and nothing happened, and I got a bit angry and at 3:30 pm still nothing." (Interview 11)</i>
		No knowledge	Participants describe the lack of knowledge during shunt appointments	<i>C: "... it was the case again, that some random persons were there who had no time and who did not really know anything." (Interview 10)</i>
		No follow-up appointment	Participants describe that several appointments did not take place	<i>P: "I do not know if they actually took place ..." (Interview 10)</i>
		Language	Participants describe the use of technical language during the appointments	<i>C: "They explain it in a very complicated way. ... Especially when they talk in technical language." (Interview 10)</i>
		Communication	Participants describe the lack of communication between themselves and the doctor during appointments	<i>P: "Personally, I think that doctors do not tell a lot about the whole thing." (Interview 12)</i>
Recommendations			Participants give recommendations to other patients who think about	<i>P: "It is just a nice way to survive and for this reason I can only advice ... to put yourself in the hands of the</i>

			their shunt or a shunt surgery	<i>doctors and trust them ..."</i> (Interview 4)
Shunt	Appearance	Scars	Participants describe the influence of the scars from the shunt surgery	<i>P: "Yes. Since I got married, I feel that it [scars] bother me more than before." (Interview 8)</i>
		No problem	Participants explain that they have no problems concerning their appearance in regard to the shunt	<i>P: "No, nothing. You can hardly see it." (Interview 13)</i>
		Coverage	Participants describe that they covered the shunt or the area of the shunt surgery	<i>P: "... and I thought I would rather cover myself than hearing that [comments about appearance] and then nobody will see it [the shunt] ..."</i> (Interview 8)
		Childhood	Participants describe their childhood experience in relation to their appearance influenced by the shunt	<i>P: "... and that my hair got shaved off of course. And especially with 13-14, this is somehow strange ... (Interview 6)</i>
		Bodyweight	Participants describe how bodyweight changes affect their appearance in relation to the shunt	<i>P: "If I had lost weight then I could see it [tube] how far it goes. That bothered me a lot because I could see how long the shunt actually is." (Interview 8)</i>
	Lessons learned		Participants describe what they have learned from the whole situation with the shunt	<i>P: "You live more consciously." (Interview 7)</i>
	Symptoms		Participants describe different symptoms which they link to their shunt	<i>P: "And I get asked very often if I am sick, because my nose sounds like it like I have caught a cold. No, that is because of the shunt valve." (Interview 10)</i>
	Attitude		Participants rate the attitude	<i>P: "Actually very good. I am happy that I have it [the shunt] because otherwise, they could</i>

			towards the shunt	<i>not get a grip on it.” (Interview 6)</i>
	Awareness	Tube	Participants describe how they are aware of the shunt tube	<i>P: “... I had problems sometimes because the tube, which runs along the costal arch, can be felt.” (Interview 11)</i>
		Pain	Participants describe how they are aware of pain due to the shunt	<i>P: “Unfortunately. This is approximately here and here [shows points on the body] and this really really hurts.” (Interview 5)</i>
		Not perceptible	Participants describe that they cannot perceive the shunt in any way	<i>I: “Can you feel the shunt at all? E.g., if you are at rest now when we sit here?” P: “No.” (Interview 8)</i>
		Hearing	Participants describe that they are aware of the shunt because of the audible noises	<i>P: “No, but once in a while it beeps, but it is not bad.” (Interview 13)</i>
		Foreign object	Participants describe how they perceive the shunt as a foreign object	<i>P: “... and oh I have bumps on my head, this is really bad especially when I wash my hair.” (Interview 9)</i>
		Change of position	Participants describe that position change makes them aware of the shunt	<i>P: “For me, it is more when I stand up, i.e., position change.” (Interview 10)</i>
	Barriers		Participants describe things which cannot be done because of the shunt	<i>P: “Skydiving, such a tandem jump. This has always been my childhood dream ...” (Interview 12)</i>
		Sports	Participants describe sports which they cannot do because of the shunt	<i>P: “And boxing or such things, this is not possible. Especially blows to my head, I would not try this anymore.” (Interview 10)</i>
		Security check	Participants describe that they avoid security checks because of the shunt	<i>P: “I would be especially careful at the airport with these things. Through such a magnet or so ...” (Interview 3)</i>
		Roller coaster	Participants describe that they avoid roller	<i>P: “I continued to do everything similarly except fast</i>

			coasters because of the shunt	<i>rides at the fairground.” (Interview 12)</i>
		No barriers	Participants describe that they have no barriers because of the shunt	<i>P: “There is nothing that I don’t do because of my shunt ...” (Interview 4)</i>
		Independency	Participants describe that the shunt hinders their independence	<i>I: “... on the other hand would it be cool to be more independent?” P: “Yes [laughs], yes. Yes, this is exactly it.” (Interview 10)</i>
		Diving	Participants describe that they avoid diving because of the shunt	<i>P: “I would if I could or if somebody could assure me that I can try it, I would immediately sign up for a diving course. This is such a thing, where I say, what a shame ...” (Interview 2)</i>
		Altitude	Participants describe that they avoid higher altitudes because of the shunt	<i>P: “Traveling, ...for a longer period of time in higher altitudes ...” (Interview 2)</i>
	Concerns	Physical work	Participants explain concerns about their physical activity in relation to the shunt	<i>P: “Let us say e.g. carry some heavy things ... That is heavy for me so I am not allowed to do it.” (Interview 8)</i>
		No concerns	Participants describe that they have no concerns regarding the shunt	<i>P: “No, not at all ... I am not scared the whole day that something could happen, no.” (Interview 6)</i>
		Mechanical impact	Participants explain concerns about mechanical impacts on shunt	<i>P: “It happened to me with the trunk lid of my car, then you immediately panic and think hopefully nothing happened that something is broken off or so ...” (Interview 11)</i>
		Hardware failure	Participants explain concerns about hardware failure of the shunt	<i>P: “I fear that it [the shunt] bursts or something else goes wrong ...” (Interview 13)</i>
		Emotions	Participants describe their emotions regarding their concerns about the shunt	<i>P: “Well, sometimes you are scared that this thing is blocked again ...” (Interview 12)</i>

		Another surgery	Participants describe their concerns about another shunt surgery	<i>P: "Yes, she thought that the shunt was broken eventually due to a surgery. I do not know if I would do it a second time. I mean, I am not 20 anymore." (Interview 9)</i>
	Everyday thoughts	Symptom related	Participants describe that their perceived symptoms make them think about their shunt	<i>P: "... As I have said before you do not think about the shunt all the time but if you are not well, such as this morning, then I stand up and think oh no, this cannot be true ..." (Interview 12)</i>
		Change of position	Participants describe the change of position makes them think about their shunt	<i>I: "Are these the moments which remind you of this [shunt] especially?" P: "Exactly, this pressure exchange." (Interview 1)</i>
		Description	Participants describe other factors which make them think about their shunt	<i>P: "There are moments, let's say when I am alone and when I sit on my terrace with a cup of coffee, then I think what if ..." (Interview 7)</i>
		No thoughts	Participants describe that they do not think about their shunt regularly	<i>P: "... not at all. No, no, no. It [the shunt] is there, but I do not think of it. (Interview 13)</i>
		Destiny	Participants describe that they how they handle the thought about their shunt	<i>P: "... Everything what should come will come. That is how I live now. I think, if this thing [shunt] should be blocked tomorrow then it is how it is, and I cannot change it. Therefore, it is not necessary to think about it every day." (Interview 12)</i>
	Life without a shunt	No thoughts	Participants explain that they have no thoughts regarding life without a shunt	<i>P: "I do not ask myself the question what would be if had no shunt. Would it be different? Would something be worse?" (Interview 2)</i>
		No life without a shunt	Participants recognise that there would be no life without a shunt	<i>P: "As I said before, brain fluid would not drain off and at some point, I would be destined to die." (Interview 12)</i>
		Education	Participants acknowledge the impact of the shunt on the	<i>P: "Yes, I would not have become a nurse ..." (Interview 6)</i>

			individual educational path	
		Better life	Participants describe that their life would be better without a shunt	<i>I: "And can you imagine how a life without a shunt would look like?" P: "More simple, just because of the whole thing with my hearing, this is a substantial limitation." (Interview 10)</i>
Self-image and perception by others	Self - image		Participants describe how they perceive themselves	<i>P: "Well, I think that I am more satisfied now, but I see that I could to everything before and now I have some limitations." (Interview 12)</i>
	Perception by others		Participants describe how they think they are perceived by others	<i>P: "... after the shunt, I felt much better and people from my social environment said I am myself again ..." (Interview 13)</i>
Social life	Family	Treat differently	Participants describe how their family treat them differently because of the shunt	<i>P: "Before the shunt they treated me like a sick human, and I did not want this. I do not want to be sick; I want to be normal again and healthy and after the shunt, they said good." (Interview 13)</i>
		Support	Participants acknowledge the support from the family in relation to the whole shunt topic	<i>P: "I just have so much luck that my father takes care of it ..." (Interview 10)</i>
		No impact from shunt	Participants explain that the whole shunt topic has no impact on their families	<i>The family is not influenced by the shunt (Interview 15)</i>
		Mothering	Participants describe that they are being mothered by members of the family because of the shunt	<i>P: "Especially in the close family circle everyone is worried. For example, when I complain about headaches everyone thinks the worst, oh no another surgery ..." (Interview 6)</i>
		Hospitalisation	Participants describe that hospitalisation due to the shunt has influenced the family	<i>P: "Well, I would say that I needed to stay on this ward for about 3 weeks and I was only allowed to get visitors at specific times ..." (Interview 12)</i>

	Friends		Participants describe the influence of the shunt on friends	<i>C: „This is no problem at all. He/she is integrated into the neighbourhood. They do not treat him/her like a disabled.” (Interview 3)</i>
	Other People		Participants describe the influence of the shunt on other people	<i>P: “I regularly go to the hairdresser, but my current hairdresser is sick ... and he asked, what is this? And I say, I have a shunt and then he said ok we have to be careful here ...” (Interview 13)</i>
	Turn away		Participants describe how people turn away from them because of the shunt	<i>P: “... and later I told them, when we wanted to do sports together, that I could not join and then they said they don’t want to hang out with me anymore ... and then the friends left me alone.” (Interview 8)</i>
Communication	At work		Participants describe how they communicate at work that they have a shunt	<i>P: “Yes, they know about my disease and about the shunt.” (Interview 8)</i>
	With new people		Participants describe how they communicate with new people that they have a shunt	<i>P: “No, I do not talk about the shunt.” (Interview 3)</i>
	Family and friends		Participants describe how they communication with family and friends that they have a shunt	<i>C: “... I do not know if many people know that he has a shunt, but in our family or neighbourhood they know.” (Interview 3)</i>
Hope			Participants describe how they can improve their situation in the future in relation to the shunt	<i>C: “There is this ray of hope that they develop a new thing. Many currently develop new systems. But these are dreams of the future ...” (Interview 10)</i>
Occupation	Education		Participants describe the effect of the shunt during education	<i>P: “... I do not want to spend 4,5,6 weeks in rehabilitation and idle away the year and then I will start my apprenticeship one year later. I</i>

				<i>have started my education, but my mind was head was really delayed in the beginning ..."</i> (Interview 6)
	Work		Participants describe how work is affected by the shunt	<i>P: "Well, no. I have no problems. As I said, after adjusting the system it works well." (Interview 11)</i>
	Absence		Participants describe how absence due to appointments and stays in relation to their shunt influences their life	<i>I: "Did you miss out on content in school?" P: "No, that was fine. It worked. I had good friends from school who brought all the material that I could continue learning." (Interview 7)</i>
Leisure time	Travel		Participants describe what impact the shunt has on travel	<i>P: "I haven't dared to go far away ever again." (Interview 12)</i>
	Sports		Participants describe the influence of shunt on sports	<i>P: "Yes, I have played a lot of soccer in the past. Of course, I could not play it anymore because of headers and body contact and so on." (Interview 11)</i>
	Hobbies		Participants describe the influence of shunt on hobbies	<i>P: "Before, I did not have the shunt and I could not bicycle ... Afterwards I started to learn it again and now it works well again." (Interview 13)</i>
Health	Physical		Participants describe how the shunt impacts individual physical health	<i>P: "... this [the shunt] is no health aspect because it is not present. For me, it is not present. As an additional part of my body which does not belong there. And consequently, this is neither health wise nor psychologically a topic." (Interview 2)</i>
	Psychological		Participants describe how the shunt impacts individual psychological health	<i>P: "Nothing at all. I have to say that I am not a negative human, but mostly positive. I see the good in everything first ..." (Interview 7)</i>

Table 2: Category system (own image)