



Parent perception of telemetric intracranial pressure monitoring in children - A qualitative case study

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ABSTRACT

Introduction: Telemetric monitoring of intracranial pressure (ICP) in children with a complex cerebrospinal disorder might help parents distinguish acute and potential life-threatening symptoms of hydrocephalus from other illnesses.

Research question: What is patient and parent perceptions of system utility of telemetric ICP monitoring, and how does a long-term telemetric implant influence daily life of both patients and their families?

Material and methods: A qualitative case study design with a focus group interview including parents of children with a complex cerebrospinal fluid disorder and an implanted telemetric ICP sensor.

Results: Three parents participated. Based on thematic analysis, three themes were created: 'Daily living with telemetric ICP monitoring', 'Parenting a child with a CSF disorder', and 'The healthy sibling'. The ICP sensor provided the parents with security and made them trust their intuition, while the possibility of home monitoring ensured stability for the entire family and had a calming effect on healthy siblings. Home monitoring was seen as the system's greatest advantages, whereas size, weight, and functionality of the external monitoring equipment were highlighted as disadvantages.

Discussion and conclusion: All parents supported the telemetric ICP sensor as a valued tool in treatment guidance of their child and stated that advantages exceeded disadvantages. It was stated that the possibility of conducting ICP measurements at home reduced the need for acute hospital admissions, which consequently led to a more stable daily life for the entire family. Suggestions regarding technical improvements with focus on more compatible external monitoring equipment were raised by all parents included.

The three parents are referred to as P1, P2, and P3.

1. Introduction

Hydrocephalus is a complex cerebrospinal fluid (CSF) disorder, affecting both children and adults. In Denmark, the prevalence of infantile hydrocephalus is reported to be 1.08 in 1000 live-born children (from 1977 to 2015) (Schmidt et al., 2018). It is a life-long chronic condition, with a risk of both structural brain damage and repetitive hospital admissions and surgeries due to treatment failure. Hence, having a child with hydrocephalus will potentially impact daily life as well as family structure (Knecht et al., 2015; Smith et al., 2015), including the relationship between the affected child and its parents (Pinquart, 2013; Smith et al., 2015) and siblings (Fullerton et al., 2017; Gan et al., 2017; Haukeland et al., 2015; Knecht et al., 2015).

The standard treatment of hydrocephalus is shunting of CSF from the

ventricles to another body cavity - the peritoneum being the most common. The symptoms of hydrocephalus and thus treatment failure vary and depend on the child's age and the underlying cause of the disease. Symptoms can present as an abnormal growth of the head and lack of development, too acute headache, vomiting, visual complaints, and a decreasing level of consciousness (Kahle et al., 2016; Di Rocco and Frassanito, 2020). Parents of children with hydrocephalus live with the responsibility to distinguish these signs of hydrocephalus from other childhood illnesses (Smith et al., 2015).

Measurement of intracranial pressure (ICP) can be used as guidance in the treatment of hydrocephalus, and long-term ICP monitoring with a telemetric ICP sensor is found to be a valid and useful tool in the clinical management of paediatric patients with a complex CSF disorder (Pedersen et al., 2020). It may be of particular value in those paediatric patients with reduced ability to express themselves (e.g., toddlers or children without a language). The telemetric ICP sensor allows home

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Abbreviations

ICP	intracranial pressure
CSF	cerebrospinal fluid
FGI	focus group interview

monitoring, which provides a more accurate picture of the child's everyday life; hence, a child admitted to the hospital is often more inactive than a child in its habitual environment. Further, repetitive home monitoring sessions can be used to adjust ICP lowering medical treatment (acetazolamide) or shunt valve settings and help educate parents about the child's CSF disorder. A long-term implant requires, however, a high level of collaboration and compliance from patients as well as parents. Where the child is forced to live with a foreign body implant, the parents must be familiar with equipment design and management to conduct home monitoring.

In European centers, the most frequently used telemetric ICP sensor have been Raumedic Neurovent-P-tel (Raumedic AG, Helmbrechts, Germany) and Miethke Sensor Reservoir (Christoph Miethke GmbH & Co. KG, Potsdam, Germany) (Omidbeigi et al., 2021). The telemetric ICP sensor examined in this interview was the Neurovent-P-tel, which is no longer commercially available. However, this project is designed to address the general aspect of implanted telemetric ICP sensors, regardless of the precise commercial product.

Patient and family feedback has been reported once for the Neurovent-P-tel. Barber et al. briefly described four families' practical experience as 'reasonable unobtrusive and hassle-free', with no difficulties in fixing the external equipment to the head or carrying the equipment for an extended period (Barber et al., 2016). According to our clinical experience, the telemetric ICP sensor is a valued tool, but with limitations in both equipment design and management. Further, some children report discomfort in relation to the implant itself. This study aimed to create a bridge between the clinician's idea of the telemetric ICP sensor and the patient and parents' personal perceptions of living with the implanted sensor, and thus systematically clarify patient and parent perceptions of system utility and how a long-term implant influence daily life of the patient and family.

2. Material and methods

2.1. Design

A qualitative case study design was chosen with a focus group interview (FGI) to gain concrete, contextual, high-quality data (Baxter and Jack, 2008) and understand the daily life experiences of parents with a child with a CSF disorder and an implanted telemetric ICP sensor. The FGI was followed by a thematic analysis inspired by Graneheim et al. (Graneheim and Lundman, 2004). The study was part of a longitudinal study in which data from the thematic analysis of the FGI was used to supplement clinical experience and construct a questionnaire evaluating patient and parent perceptions of the telemetric ICP sensor in a national questionnaire study (Pedersen et al., 2024).

A FGI encourages active engagement among participants, fostering opportunities for the exchange of both conscious and not conscious experiences and beliefs (Morgan, 2010). The synergy of the focus group interaction generates additional perspectives and theoretically a more comprehensive dataset, e.g., compared to single-based interviews (Rabiee, 2004). Further, a FGI has proved to be an efficient method for uncovering insights into thoughts and emotions, thereby illuminating differences in perspective (Morgan, 2010). It provides the participant's honest and spontaneous information about a range of ideas and feelings, including the verbal communication used to describe the telemetric ICP sensor (Rabiee, 2004). Since the FGI aimed to clarify sensitive

perspectives and the total eligible patient population in Denmark consists of only ten children, we chose to only include a small number of participants. Further, the study did not strive to achieve representativity and generalizability but aimed to examine the in-depth knowledge and understanding of the telemetric ICP sensor that the parents presented (Kazdin, 2003).

2.2. Participants and setting

Parents met the inclusion criteria if their child 1) had an implanted telemetric ICP sensor, 2) had been treated at the Neurosurgical Department, Rigshospitalet, Copenhagen within a timeframe of five years (January 2014 to December 2019), 3) at the time of the interview were under the age of 18 years, and 4) the parent spoke fluent Danish. There were no other exclusion criteria. At the time of the study, we identified 10 Danish children aged 0 to <18 years with a present telemetric ICP sensor. The hydrocephalus nurse (a nurse care coordinator specialised in hydrocephalus) at the Neurosurgical Department is the primary contact person for patients with a CSF disorder and a telemetric ICP sensor and for their families, and thus has in-depth knowledge on this patient group. Parents were chosen from a concept of applicability in which they were included based on their particular knowledge within the field (Rabiee, 2004), and versatility in demographics and educational level. In Denmark, an online social network for patients with hydrocephalus and the relatives of those patients exists. It was assumed that being part of the online social network could create an extended trust among the participants, encouraging them to freely express their views and relate to each other's comments (Rabiee, 2004). Last, we aimed that the children differed in age, sex, diagnosis, and thus ICP history.

Eligible patients and parents were identified, and four parents were invited and accepted to participate. One parent dropped out on the day of the interview due to acute illness of the child. The three participating parents will be referred to as P1, P2 and P3. The participants were both male and female, with different social statuses (married or divorced), educational level (lower secondary school, short-cycle higher education or medium-cycle higher education), and employment status (family leave or self-employed). The children differed in sex, age (range 5–11 years) and ICP history, see case characteristics in Table 1. Hence, some had experienced years of ICP-lowering treatment, including ICP monitoring sessions and acute hospital admissions due to treatment failure, while others had not. All children had a telemetric ICP sensor at the time of the interview, but only two sensors were functioning. One child had the telemetric ICP sensor for more than five years, while the remaining two sensors had been implanted for less than a year. For one child, this was the second telemetric ICP sensor. Further clinical information and the relationship between child A-C and P1-3 are omitted for anonymization purposes.

The parents were initially informed about the study purpose when first contacted by the hydrocephalus nurse and subsequently informed about participation and the FGI method by the first author. The FGI was conducted in Danish at the Neurosurgical Department at Copenhagen University Hospital in December 2019 in a neutral hospital meeting room in a familiar setting for the participants.

2.3. Data collection

Prior to the interview, the participants were asked to complete a short survey, covering their educational level and current work situation, along with daily activities for their sick child and healthy siblings. Two of the authors participated in the FGI, the last author as moderator and the first author as an observer. Neither the last nor the first author knew the participants before the interview or were involved in the treatment of their children. The last author explained the objective of the study, including the four topics of the FGI 1) patient history with focus on the telemetric ICP sensor, 2) everyday life of the patient, 3)

Table 1
Diagnostic and ICP related characteristics of included children.

	Child A	Child B	Child C
Childs age at time of diagnosis	Postnatal 6–10 years	Pre- or perinatal	Postnatal 0–5 years
Diagnosis	DQ070 DG950B DR519	DQ038	DQ038B DG910 DR519
Mental disability	None	None	None
Childs age at time of first ICP lowering treatment	8 years	2 months	3 years
Surgical ICP lowering treatment 1 year prior to implantation of telemetric ICP sensor	Occipitocervical decompression ×2, postoperative CSF leak, treated with lumbar drain	None, one adjustment of valve settings of initial VP shunt	Initial VP shunt implantation, one shunt revision
Reason for implantation	Satisfactory postoperative imaging after the second operation. Five months post surgery continuous complaints of posture related headache, CTc without hydrocephalus. Implantation to evaluate ICP.	Adjustable VP shunt. Episodic symptoms where the child needs to lay down for 2–3 days, accompanied by explosive vomiting. Diagnostic evaluation for epilepsy, unknown if the seizures are ICP related. CTc without hydrocephalus. Implantation to evaluate ICP during episodic symptoms/ seizures.	Fixed VP shunt. CTc could indicate overdrainage. Both good and bad days. Active and well on good days; preferred to sleep/lay down on bad days. Implantation of a telemetric ICP sensor and an adjustable VP shunt, to evaluate if the symptoms were ICP related and to assess future valve settings.
Age at time of first telemetric ICP sensor	9 years	3 years	3 years

everyday life of healthy sibling(s) and 4) everyday life of the parent(s). Last, the participants were asked to introduce themselves.

To explore the participants’ experiences, and yet ensure relevance for the study, a semi-structured interview guide was constructed. The guide was inspired by literature (Barber et al., 2016; Pedersen et al.,

Table 2
Examples of questions from the interview guide.

Questions
How do you experience your contact to the hospital?
Does your child’s diagnose affects institutional life (kindergarten/school)?
Does your child feel different compared with his/her friends?
How is the relationship between the sick child and its healthy siblings?
Does it affect your healthy child(ren) to have a sick sibling?
How do you include your healthy child(ren) when your sick child is hospitalized?
What is your role in management and treatment of your sick child?

2020) and clinical experience with the telemetric ICP sensor. It was reviewed and revised by the last and the first author until consensus on the content was reached. Examples of questions are listed in Table 2. In addition to the interview guide, a prompting technique was used to ensure flow in the conversation to make the participants feel at ease. The interview guide included open-ended questions and started with the question: How long have your child experienced pressure related symptoms?

The interview lasted approximately 120 min and was conducted with digital audio recording. The first author took notes on non-verbal interactions and the impact of the group dynamic to support the oral text (Rabiee, 2004), and both the last and the first author provided observational notes immediately after the interview. The interview was transcribed verbatim by the first author.

2.4. Analysis

The analysis of the FGI was conducted systematically and verifiably, corresponding to the concepts described by Graneheim et al. (Graneheim and Lundman, 2004). This analytic approach aims to condense the transcript into different categories and themes.

The transcribed text was read thoroughly and several times by the first author. It was sorted into content areas addressing specific topics, and the text within each content area was extracted from the transcript and gathered in a separate document. All text was separated into meaning units, which were subsequently condensed without losing relevant content and given a code. The codes were once again reviewed and re-coded if needed. Based on differences and similarities, the codes were sorted into categories, and a theme for each set of categories was formed. At last, themes as well as categories were reassessed to ensure that they reflected the overall data. Throughout the process, meaning units, categories, and themes were reviewed and revised by the last and the first author. To ensure credibility, themes and categories are supported by verbatim quotes.

2.5. Methodological rigor

To ensure trustworthiness, we aimed to follow the criteria for qualitative studies suggested by Lincoln et Guba (Lincoln and Guba, 1985); credibility, transferability, dependability, and confirmability. *Credibility* was assured both by including participants with various experiences and through method selection (focus group interview). Further, raw data and data analysis were shared between the last and the first author, and agreement on findings was reached through discussion. *Transferability* was reached by providing contextual data on the study setting and data collection. *Dependability* was assured by a solid research design and the involvement of the entire research group in developing the research question and conducting the study. Inconsistency in data collection was limited since only one interview was conducted. Finally, *confirmability* was assured by the last and the first author checking and rechecking the data. Further, the research group consisted of different medical professionals (nurses, medical doctors) with different levels of experience and knowledge within the research field.

2.6. The telemetric ICP sensor

Fig. 1 shows the telemetric ICP sensor. The parenchymal sensor is implanted during general anaesthesia, usually through a frontal burr hole and contralateral to a pre-existing shunt. The parenchymal sensor is activated by an external reader unit, a so-called reader ring (Reader TDT1 readP). During measurement, the reader ring is placed on the skin above the telemetric ICP sensor and fixated by a bandage or a headband, and data is transferred continuously by a cable (length 203.0 mm) from the ICP sensor/reader ring to a storage unit, a so-called datalogger (weight 950 g). Hence, the datalogger must be carried by the child or a parent if the child is moving during measurement (Fig. 1).

The device was CE approved with a recommended implantation time of 3 months due to signal durability. We are, however, not obligated by Danish law to remove the device after this period, and to avoid unnecessary surgical risks, our policy is therefore to explant telemetric ICP sensors only due to patient safety and comfort (e.g., local pain, skin erosion, infection) or on request from the child or the parent.

2.7. Ethics

Approval from the Danish Data Protection Agency (P-2019-754) was obtained, and the study was conducted according to the principles of the Declaration of Helsinki. Oral and written consent was given before study participation. The participants were informed about the study aim and the voluntary nature of the study, and that withdrawal from the study was possible at any time, without any consequence for the treatment of their child. They also agreed to the confidentiality of project information.

Data was stored in a closed folder according to the data projection rules, and all participants' names were changed for anonymization purpose. To ensure complete patient anonymity, limited details on diagnosis, demographics, and family relations are provided in the paper.

3. Results

Based on the FGI, one main theme 'Daily living with telemetric ICP monitoring', and two subthemes 'Parenting a child with a CSF disorder' and 'The healthy sibling' emerged from analysis of the parents' reflections. All themes and associated categories are listed in Table 3. As this paper mainly focuses on the telemetric ICP sensor, the first section describes the parents' experiences and perceptions of the telemetric ICP monitoring system, including reflections on implantation and

Table 3

Associated themes and categories emerged in the thematically analysis.

Theme	Category	Subcategories
Daily living with telemetric ICP monitoring	Implantation and explantation	Involvement
		Reason and decision
	Functionality	Practical use
		Home monitoring sessions
Parenting a child with a CSF disorder	Part of the toolbox	Technical challenges
		Suggestions to improvements
	Pros and cons	Treatment guidance
		Parent intuition
The healthy sibling	Sensations related to the telemetric ICP sensor	Practical utility
		Home monitoring vs hospital admission
	Sensations and family constellations	Security and stability
		Of the child
The healthy sibling	Handling the sick child	Of the parents
		Feelings of the parents
	Sensations and relationship	Priorities
		Coping strategies
Daily life	Sensations and relationship	Precautions in daily life
		Defying daily limitations
	Daily life	Feelings of the sibling
		Intra-sibling relationship
Daily life	Sensations and relationship	Parent-sibling relationship
		Challenges
	Daily life	School

ICP, intracranial pressure.

explantation, system utility, and the child's experience with the telemetric sensor. However, due to the emerged themes, the last section describes the perspectives of parenting a child with a CSF disorder and healthy siblings.

3.1. The telemetric ICP monitoring system

The decision on implantation and explantation (or lack of explantation) of the telemetric ICP sensor was discussed, and while implantation of the sensor was the neurosurgeon's suggestion, all parents supported the decision and felt involved in the decision-making. One parent explained it as:

"I never asked questions, I thought the telemetric ICP sensor was the right decision" (P1)



Fig. 1. The telemetric ICP sensor

The figure shows the telemetric ICP sensor and two different monitoring sessions, in which it is seen how the external reader ring is fixated by a bandage and to what extent the child's moving range is limited by the length of the cable between the reader ring and the datalogger. The right picture shows the child biking while carrying the datalogger in a backpack.

Only the 9-year-old child was partly involved in the decision, whereas the two younger children were not presented to the telemetric ICP sensor before the decision was made. Further, none of the parents would reject the idea of implantation of a new telemetric ICP sensor if needed, e.g.:

“If none of the other examinations clarifies the symptoms, it is not unthinkable that we ask for a new sensor” (P1)

In the case where the child had a total of two sensors, the parents themselves suggested the implantation of a new sensor. All parents emphasised that the sensor should only be explanted if complications occur.

Although ICP monitoring sessions did not necessarily lead to an altered treatment strategy, the telemetric ICP sensor provided the parents with extra security. It was stated that the telemetric ICP sensor helped clarify unusual symptoms and ensure the right diagnosis, with two parent stating:

“If the telemetric ICP sensor had been implanted six months earlier, it could probably have saved us from 27 different diagnoses, 45 examinations, and 100 days of sick leave” (P1)

“The telemetric ICP sensor helps us to distinguish whether the symptoms are pressure-related or caused by something-else” (P2)

All parents saw home monitoring with the child in its everyday environment as the monitoring system’s greatest advantage. All parents claimed that the size, weight, and functionality of the datalogger, including the placement of the reader ring above the telemetric ICP sensor and the wire connecting the reader ring to the datalogger, were clear disadvantages, explained as follows:

“I had to force the child to wear it at school. He/she was afraid that the other kids would tease him/her. But the most annoying thing was that the reader ring kept failing of, which started the alarm and interrupted the hole class” (P3)

“The reader ring has to be fastened to the skin, and it hurts. It even hurts without the reader ring” (P2)

The implanted sensor itself was only reported to be a cosmetic challenge in one patient, another parent explaining:

“There is no cosmetic issue, it is nothing compared to all the other surgeries” (P1)

When asked, the parents’ perception was that none of the three children felt embarrassed by the telemetric ICP sensor itself, one even wanted to share experiences and knowledge with friends. One parent did, however, report that the child feared getting teased with ‘the bump’ and being forced to talk about the telemetric ICP sensor, thus aiming to hide it in public:

“If the hair is too short, he/she will ask to wear a cap. He/she doesn’t want the other kids to ask questions” (P2)

Though all parents saw the telemetric ICP sensor as an important tool, in which advantages exceeded disadvantages, the interview revealed mixed sensations towards the telemetric ICP sensor. While the parent to the child with the defect sensor wished it was still functional, another parent stated a hate/love relationship to the sensor, explaining that it had a calming effect and was an essential tool in treatment of the child, but also kept the parents awake during overnight measurements, fearing that the child would get strangled in the wire:

“My child wakes up with the wire wrapped three times around the neck, one day things will go wrong” (P2)

Based on the above-mentioned advantages and disadvantages of the monitoring system, several suggestions for improvement were raised, with focus on reducing the size of the telemetric ICP sensor and the size and weight of the datalogger and creating a more compatible system

using a magnetic reader ring or a wireless connection from the sensor to the datalogger. One parent stated:

“It would be a dream scenario if the sensor was an integrated part of the shunt system” (P1)

All agreed that managing a child with a CSF disorder requires a combination of neurosurgical knowledge and parent intuition. Adding the telemetric ICP sensor to the equation helps distinguish symptoms and diagnoses, though ICP values are within the normal range. Two of the parents used the telemetric ICP sensor to support their parent intuition:

“When my intuition tells me something is wrong, I borrow a datalogger to confirm or disprove my child’s symptoms” (P2)

3.2. The healthy siblings

In two out of three, the telemetric ICP sensor was reported to ensure stability to the entire family, with one parent explaining:

“I use the measurements to calm the older sibling, to show that the situation is stable and that the pressure is within reasonable limits” (P2)

This ‘family stability’ was, according to the parents, partly caused by a reduction in acute hospital admissions and surgical shunt revisions.

An important finding, however, not related to the telemetric ICP sensor itself, was the impairment of family life from living with a child with a complex CSF disorder. In our three cases, a CSF disorder with a late onset did not seem to influence family life, to the same extent as an early onset. Irritation and a lack of understanding from the healthy siblings were reported in the late-onset-case:

“The healthy siblings thought the sick child was faking symptoms, trying to attract the attention from the parent” (P3)

In the cases with an early onset, a long-term psychological affection of the healthy siblings was reported. It was described how the birth of the sick child altered the healthy sibling’s life significantly:

“The healthy sibling had been looking forward to a younger sibling, and then came this, and everything changed, my family got pulled apart” (P1)

“All of the sudden the healthy sibling felt neglected and sad, what was this, and how do you explain this to a child” (P2)

The parents reported how the healthy sibling feels excluded and left alone, but also how, in one case, the sibling has a highly (almost extreme) developed sense of empathy.

‘Stability’ and ‘involvement’ of the healthy sibling were listed as main priorities when admitted to the hospital with the sick child, e.g., only one parent is co-admitted with the sick child, while the spouse is at home with the healthy sibling, explained as:

“If both mom and dad are co-admitted the healthy sibling’s world crumbles” (P2)

The parents of the children with an early onset CSF disorder aimed to involve the healthy siblings in the non-acute phase of the sick child’s admission, stating:

“As the healthy sibling grew older, we have increased the involvement (...) so the healthy sibling as a minimum takes part in the discharge-process” (P1)

“It calms the healthy sibling to be co-admitted for 24 hr., it ensures the sibling that the world is not falling apart” (P2)

This reduces the concern for the sick child and enables the healthy sibling to demystify hospital admission and ensure that the healthy sibling does not feel left out. One of the parents further chose to explain the severity of the disease, e.g., the reason for hospital admission, since this has a calming effect on the healthy sibling.

Numerous, long, and severe hospital admissions throughout the two early-onset-cases' life were reported, and the unpredictable illness caused the healthy sibling to be on constant high alert. In both cases, the extreme awareness has led to psychiatric affection with one consulting a psychologist due to severe anxiety, and the other presenting stress-related symptoms. As a result, both healthy siblings have been partly absent from school, and one is now on a half-time-schedule. We can speculate if an implanted telemetric ICP sensor may reduce the family/sibling anxiety level.

4. Discussion

Our study illustrates different aspects of parent perception of a long-term cerebral monitoring implant in children with a complex CSF disorder. We clarify different perspectives on system utility and the impact a long-term telemetric ICP sensor has on management of a complex CSF disorder, as well as on family stability. A CSF disorder is associated with uncertainties related to treatment strategy, complications, treatment effectiveness/shunt revision rates, long-term outcome, and influences on daily life, e.g., family activities and structure. Parents develop different strategies to cope with these uncertainties, and despite its disadvantages, a telemetric ICP sensor might be helpful in this process.

Telemetric ICP monitoring has been available for more than a decade. Previous publications provide detailed *technical* descriptions and comparisons of the different telemetric systems (Norager et al., 2018, 2019; Omidbeigi et al., 2021; Pedersen et al., 2020), while *practical utility issues* like the size and weight of the datalogger and reader ring have been highlighted as limitations in equipment design (Antes et al., 2016; Pedersen et al., 2020). In 2016, Barber et al. reported the first, and only, patient and family feedback on telemetric ICP monitoring in children (Barber et al., 2016). Though described as unobtrusive, the lack of aesthetics when the child must wear a headbandage and carry the heavy datalogger around by hand is highlighted as a disadvantage. Further, the system was described as easy to use and tolerable for the child. The 'feedback information' was, however, not systematically obtained and does not include further information on advantages and disadvantages perceived by patients and relatives.

The parents in our focus group interview all agreed that *home monitoring* is the telemetric ICP monitoring system's greatest advantage. While the size and weight of the datalogger and reader ring once again were stated as disadvantages, with suggestions of reducing the size of the telemetric ICP sensor itself and *creating a wireless external system*. The children did not feel embarrassed by the telemetric ICP sensor, but neither did they want to conduct monitoring sessions in public, e.g., in kindergarten or school.

A chronic illness of unpredictable nature, such as a CSF disorder, demands family members to adjust and live with the requirements and consequences of the condition. It can increase family stress levels, cause depression, clinical burnout (e.g., emotional, physical, and cognitive fatigue) (Lindström et al., 2010; Pinquart, 2013; Smith et al., 2015), and cause family members to refocus their needs (Newby, 1996). The parents in this focus group interview highlighted that a telemetric ICP sensor provides an extra security in symptom management and treatment decisions and shift potentially acute hospital admissions into home monitoring sessions. Though parents develop an extraordinary level of expertise in recognizing and responding to signs of hydrocephalus (Smith et al., 2015), and thus treatment failure, the telemetric ICP sensor was reported to support parent intuition and help distinguish symptoms. This can potentially lead to a lower stress level and reduce the risk of burnout. Healthy siblings may be particularly affected by a child with a chronic illness (Fullerton et al., 2017; Gan et al., 2017; Haukeland et al., 2015; Knecht et al., 2015), as was seen in both our early-onset-cases. In both cases, the telemetric ICP sensor was reported to ensure stability and calm the healthy siblings.

The role of parenting consists of three main themes, responsiveness (e.g., warmth and support), demandingness (e.g., supervision and rule-

setting), and promotion of autonomy (instead of overprotecting the child) (Pinquart, 2013). Challenges in balancing overprotection and supportiveness of the child's autonomy have previously been reported by parents to children with hydrocephalus (Smith et al., 2015). A meta-analysis comparing parenting a sick child and a healthy child indicated that the parent-child relationship between a parent and a sick child is less warm, more controlling, and overprotective (Pinquart, 2013). It is further reported that more experience with a disease is correlated with greater adaption, and thus less influence on the parent-child relationship, while many stress-related factors, e.g., acute hospital admission, are suggested to have a negative impact on the parent-child relationship (Pinquart, 2013). Our data suggest that parenting a child with a chronic illness with recurrent acute episodes leads to a more controlling and overprotecting relationship, despite years of experience with the disease (early onset vs. late onset). It is likely that a telemetric ICP sensor with home monitoring capability can give the parents an opportunity to ease up and rely more safely on their experience and intuition.

4.1. Study limitations

Though the number of cases in this focus group interview is small, the study design allows for intersubjective validation and exploration of narratives. By including a small number of participants, we can obtain in-depth, high-quality data from each participant and thus provide a thorough understanding of the investigated subject. As this is a case study, the included participants' experiences do not represent all families living with a complex CSF disorder. Families living in other municipalities, using other coping strategies, or having children with other diagnoses might have answered differently to the questions asked during the interview. Further, it is important to state, that the included children are children with a complex CSF disorder, who due to inconsistency in symptoms and diagnostic findings had a telemetric ICP sensor implanted. The obtained data can therefore not be generalised to children with a less complex CSF disorder.

5. Conclusion

Through a focus group interview, we collected spontaneous information from parents of children with a CSF disorder and a long-term telemetric ICP sensor unbiased by the clinician's perspective. This paper illustrates three parents' perceptions of a telemetric sensor and its external monitoring system. The clear advantages of home monitoring and positive influence on daily family life and the well-being of healthy siblings were stated by all participating parents. The utility difficulties and limitations provide important information for manufacturers of future long-term telemetric ICP sensors.

Further, we illustrate the complexity of living with a CSF disorder – with the parents and healthy siblings in focus. While the three parents included developed different coping strategies to manage daily life with a sick child, the healthy siblings were left with a mix of negative and positive feelings towards the sick child, resulting in psychiatric affection with lower self-esteem and quality of life. This knowledge might help, e.g., healthcare professionals to guide parents of children with a CSF disorder and thereby help them achieve the information needed to accommodate the needs of healthy siblings.

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Availability of data and material

The audio recorded interview as well as the verbatim transcribed interview are available. This also applies all thematic analysis.

Authors' contributions

All authors have contributed to designing the study and writing the manuscript. RG was the moderator of the interview, while SHP was an observer. SHP further verbatim transcribed and analysed data. Findings (meaning units, categories, and themes) were reviewed and revised by RG and SHP.

Ethics approval

Approval from the Danish Data Protection Agency (P-2019-754) was obtained, and the study was conducted according to the Principles of the Declaration of Helsinki.

Consent to participate

Oral and written consent was given before study participation. Consent included participation and publication.

Declaration of competing interest

None of the authors have any conflict of interest to declare.

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