

Information needs of families of children undergoing ventricular shunt surgery

Necessidades de informação de familiares de crianças submetidas à derivação ventricular

Necesidades de información de las familias de niños sometidos a derivación ventricular

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Abstract

Objective: To identify the information needs of family members regarding the care of children undergoing ventricular shunt.

Methods: This survey-type study was carried out at a university hospital in the city of São Paulo from May 2022 to July 2023. Data collection included information on the indication of the device, signs of complications, surgical procedure, care, and guidance received.

Results: Thirteen family members participated in the study. Around half (53.8%) of the participants were able to explain the indication for using a valve, but only 30.8% were able to report the signs of malfunction. The vast majority (76.9%) were unable to report complications related to the use of the device, and 61.5% denied having received guidance on how the system worked. The moment of placing the device was marked by urgency, lack of information, and incomprehensible language.

Conclusion: Caregivers have little understanding of ventricular shunt, indicating to health professionals the importance of strengthening health literacy in this population.

Keywords

Hydrocephalus; Chronic disease; Health education; Family; Pediatric nursing

Resumo

Objetivo: Identificar necessidades de informação de familiares sobre o cuidado de crianças submetidas à derivação ventricular.

Métodos: Estudo tipo *survey* realizado em um hospital universitário na cidade de São Paulo de maio de 2022 a julho de 2023. A coleta de dados contemplou informações sobre indicação do dispositivo, sinais de complicação, procedimento cirúrgico, cuidados, e orientações recebidas.

Resultados: Treze familiares participaram no estudo. Cerca de metade (53,8%) dos participantes soube explicar a indicação de usar válvula, mas apenas 30,8% soube relatar os sinais de mau funcionamento. A grande maioria (76,9%) não soube referir as complicações relacionadas ao uso do dispositivo, e 61,5% negaram ter recebido orientação sobre o funcionamento do sistema. O momento de colocar o dispositivo foi marcado por urgência, déficit de informação, e linguagem incompreensível.

Conclusão: Os cuidadores têm pouca compreensão sobre derivação ventricular, indicando aos profissionais de saúde a importância de fortalecer a literacia em saúde dessa população.

Descritores

Hidrocefalia; Doença crônica; Educação em saúde; Família; Enfermagem pediátrica

Resumen

Objetivo: Identificar las necesidades de información de los familiares respecto al cuidado de niños sometidos a derivaciones ventriculares.

Métodos: Estudio tipo encuesta realizado en un hospital universitario de la ciudad de São Paulo, de mayo de 2022 a julio de 2023. La recolección de datos incluyó cuestiones relacionadas con la indicación del dispositivo, señales de complicaciones, procedimiento quirúrgico, cuidados y orientaciones recibidas.

Resultados: Participaron 13 familiares, el 53,8% de los participantes pudo explicar la indicación del uso de la válvula, pero solo el 30,8% sabía identificar los signos de mal funcionamiento. El 76,9% del grupo no supo referir las complicaciones relacionadas con el uso del dispositivo, y el 61,5% negó haber recibido orientaciones sobre el funcionamiento del sistema. El momento de la colocación del dispositivo se caracteriza por la urgencia, la falta de información y un lenguaje incomprensible.

Conclusión: Los cuidadores tienen una comprensión limitada sobre la derivación ventricular, revelando a los profesionales de salud la importancia de fortalecer la alfabetización en salud de esta población.

Descriptorios

Hidrocefalia; Enfermedad crónica; Educación en salud; Família; Enfermería pediátrica

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Introduction

Hydrocephalus is highlighted as one of the most frequent neurological conditions in the context of clinical practice in pediatrics. It significantly contributes to increasing child morbidity and mortality, directly and indirectly affecting family members, caregivers, and health professionals involved in caring for children. In Brazil, the prevalence of congenital hydrocephalus is 0.3 for every 100,000 inhabitants; in the global scenario, 80 cases of the disease per 100,000 children were estimated with a higher incidence in Africa and South America.^(1,2)

The condition is characterized by an imbalance between the production and distribution of cerebrospinal fluid (CSF). This leads to an increase in cerebral ventricles and changes in intracranial pressure (ICP), which may be associated with congenital malformations or acquired after injury. Regarding classification, hydrocephalus can be non-communicating (when there is an obstruction in the passage of CSF between ventricles) or communicating (when the absorption of CSF in the subarachnoid space is altered).⁽²⁾

Ventricular shunt is a unidirectional valve device and is one of the main treatment options for children with congenital or acquired hydrocephalus. Ventriculoperitoneal shunt (VPS) consists of silicone catheters that drain CSF into the peritoneal cavity (more conventional treatment). When the system drains CSF into an external collection bag, it is called an external ventricular shunt (EVS), acting as both a drainage valve and an ICP monitoring device.^(2,3)

Since their initial development, bypass valve systems have seen several advancements to reduce complications and the number of revision procedures. Complications related to its use are frequent (highlighting infections, obstruction, and displacement), implying high rates of system revision and other complications. Device failures are commonly caused by mechanical obstruction. They occur in ~40% of children in the first two years after original implantation, requiring intervention and having continued risk. Infections are described in 5-9% of procedures, occurring mainly in the first three months after surgery. They present with fever, irritability, hyponatremia, catheter extrusion, presence of CSF fistulas in the wound or erythema, and symptoms of system mal-

function.⁽⁴⁻⁶⁾ Subdural collection and hemorrhage may also occur after the procedure resulting from excessive CSF drainage.⁽⁷⁾

Given their frequent occurrence, the recognition of dysfunctions and complications by family members and caregivers in the daily care of children using ventricular shunts requires knowledge about the disease and treatment.

In chronic and complex conditions (such as hydrocephalus), the involvement of patients and families is necessary so that they can identify and monitor signs and symptoms related to complications. To achieve this, health professionals must establish effective communication, informing and validating the knowledge of family members to make informed decisions and achieve good results.⁽⁸⁾ The specific needs in the daily care of children with chronic health conditions (such as a high number of consultations and examinations, frequent hospitalizations and surgical interventions, and daily restrictions) generate a demand for support and guidance from family members and caregivers.⁽⁹⁾ Furthermore, lack of knowledge and guidance about childcare can be a direct source of stress and poor adherence to treatment.

In this scenario, the importance of effective communication between health professionals and family members is highlighted and the discussion on parental literacy is relevant. At an individual level, literacy can be defined as the ability of individuals to find, understand, and use information and services to make health decisions.⁽¹⁰⁾ Highlighting the association between parental literacy level and children's health outcomes is important, including its relationship with the number of emergency care unit visits, hospitalization rates, and medication errors.⁽¹¹⁾

Nurses, as health educators, have a fundamental role in directing family members to clear, individualized, and meaningful information, promoting their health literacy and consequent autonomy. Thus, nurses must know the family members and their demands and need to establish effective interventions in the care of children using ventricular shunts.⁽¹²⁾

Given the complexity of care and the importance of understanding the chronic condition presented above, the objective of this study was to identify the information needs of family members regarding the care of children undergoing ventricular shunt.

Methods

This survey-type study with a quantitative approach was carried out in the surgical pediatrics unit of a tertiary-care-level university hospital in São Paulo. It has a referral service for the treatment of children with congenital malformations and serious chronic conditions, among which neurological diseases are highlighted. The surgical pediatrics unit consists of 11 beds for the hospitalization of children undergoing surgical procedures in different specialties. The mean number of hospitalizations for neurosurgical treatment is 9.5 children per month. In 2022, 2.3 children with a ventricular shunt on average were admitted per month.

The non-probabilistic sample was conveniently composed of 13 participants. They met the inclusion criteria of being a family member or caregiver of the child hospitalized in the pre- or post-operative periods of VPS or EVS, or for the intervention of secondary conditions. All participants signed the free and informed consent form (FICF). Two family members refused to participate in the research.

The instrument used in the interviews was developed after reading several studies on care for children undergoing ventricular shunt.⁽¹³⁻¹⁵⁾

The elaborated questions addressed knowledge about diagnosis, devices, procedures, and care, in addition to the perception of the support and guidance received. The form consisted of 10 questions on socio-demographic characterization, knowledge about indication, functioning, and care of the device, information needed about the care of children with ventricular shunt, and information received about this procedure.

Data were collected from May 2022 to July 2023, when hospitalizations were monitored daily by researchers. After identifying the children who met the inclusion criteria, one of the researchers introduced himself to the family members, explained the purpose of the study and ethical aspects, and asked them for their agreement to participate.

After the FICF was signed, the interview was conducted by applying the instrument; the interview was recorded and then transcribed. Family members were approached in a space close to the children's beds, specifically designated for companions, preserving their privacy. For the sociodemographic characterization of family members, data related to sex, relationship, and/

or degree of kinship with the children, age, education, occupation, and marital status were obtained. To characterize the children, the institution's electronic medical record was used and the following information was extracted: sex, age, skin color and/or race, medical diagnosis, type of shunt (VPS or EVS), and number of surgical approaches for ventricular shunt.

The data obtained were stored in an electronic database and subjected to descriptive analysis. Thus, categorical variables were described using absolute and relative frequencies. At all stages of the study, the determinations of the National Health Council (Resolution: 466/12) were complied with, and the research was conducted after the project was approved by the Research Ethics Committee of the proposing academic institution (Opinion: 600/2022; CAAE: 60076522.0.0000.5505).

Results

Among the 13 participants, 76.9% were mothers with a mean age of 38.5 years. Most of them had completed secondary education (46.2%), were married (53.8%) and unemployed (76.9%) (Table 1).

Regarding children, the mean age was 6.4 years (min.-max.: 0.2-13.5) and the distribution by sex was similar. Myelomeningocele (53.8%) was the neurological diagnosis predominantly related to hydrocephalus, and VPS was the most commonly used type of system (92.3%) (Table 2). The mean number of surgical approaches related to ventricular shunt was 2.1 per child (min-max: 1-4). We highlight that five (55.5%) of the nine school-age children did not attend school (33.3%) or were away from the school environment (22.2%) during the research period.

As shown in Table 3, 53.8% of participants were able to explain the indication for valve use. Analysis of the primary data indicated that the remaining participants (46.2%) had difficulty answering the question, citing reasons such as smaller head size, an increase in head circumference, and drainage of "liquid" or "water".

Regarding how the device works, only one (7.7%) family member was able to describe the mechanism in detail. Other participants mentioned 'fluid drainage', but without specifying basic aspects such as insertion

Table 1. Sociodemographic characterization of family members participating in the study

Variables	n (%)
Sex	
Female	12 (92.3)
Male	1 (7.7)
Relationship with the child and/or degree of kinship	
Mother	10 (76.9)
Father	1 (7.7)
Caregiver	1 (7.7)
Grandmother	1 (7.7)
Age (years)	
31-35	4 (30.8)
36-40	4 (30.8)
41-45	5 (38.4)
Education	
Completed elementary education	5 (38.4)
Incomplete elementary education	1 (7.7)
Completed high school	6 (46.2)
Incomplete higher education	1 (7.7)
Occupation	
Unemployed	10 (76.9)
Employed	3 (23.1)
Marital status	
Married	7 (53.8)
Divorced	2 (15.4)
Single	4 (30.8)

Table 2. Sociodemographic characterization of children participating in the study

Variables	n (%)
Sex	
Female	6 (46.2)
Male	7 (53.8)
Age (years)	
< 1	2 (15.4)
1-5	4 (30.8)
6-10	5 (38.4)
11-15	2 (15.4)
Medical diagnosis	
Arachnoid cyst	2 (15.4)
Chronic non-progressive encephalopathy	2 (15.4)
Arteriovenous malformation	1 (7.7)
Arnold-Chiari malformation	1 (7.7)
Myelomeningocele	7 (53.8)
Type of ventricular shunt	
Ventriculoperitoneal	12 (92.3)
External ventricular	1 (7.7)

site, flow, and system composition. Signs of malfunction of the ventricular shunt system were adequately reported by only 30.8% of respondents. We highlight that 76.9% of the group did not know how to report which complications were related to the use of the device, including those responsible for children who had

Table 3. Assessment of the information needs of family members and/or caregivers

Questions asked to family members	Yes n (%)	No n (%)
Can you explain why your child uses a valve?	7 (53.8)	6 (46.2)
Can you describe and/or say how the valve works?	1 (7.7)	12 (92.3)
Do you know how to indicate signs of valve malfunction?	4 (30.8)	9 (69.2)
Você sabe indicar as possíveis complicações relacionadas ao uso da válvula?	3 (23.1)	10 (76.9)
Can you tell me if there are any restrictions and/or prohibitions on the child's daily activities due to the valve? (e.g.: school, games, sports)?	7 (53.8)	6 (46.2)
Do you have questions about the surgical procedure (pre-, trans-, or post-operative) for valve placement and/or revision? Which ones?	7 (53.8)	6 (46.2)
In your everyday life, do you come across situations involving the valve that you cannot deal with? Which ones?	2 (15.4)	11 (84.6)
Did you and your family receive guidance on how the valve works before the procedure?	5 (38.5)	8 (61.5)
Have you had any experience with other educational initiatives on hydrocephalus and the use of the valve? Which ones?	-	13 (100)
Have you ever looked for information about hydrocephalus and valves in places such as the internet and books? Which ones? Was the information useful?	10 (76.9)	3 (23.1)

already undergone review due to malfunction or with a history of procedure-related complications. Regarding daily activities, 46.2% of participants responded that they did not know any restrictions related to the use of the valve. Other family members mentioned being careful with activities that could have a strong impact on the valve insertion area, without necessarily listing them as restrictions.

But the only thing recommended is not to hit the head because of the valve. So, when he convulses and I'm not close, I always advise at school, if he convulses, turn him opposite the valve so he doesn't hit. F3

The majority (58.3%) of those interviewed also indicated that they had doubts about the surgical procedure of placement and revision of the device (e.g. the type of valve material, whether the valve accompanies the child's growth, whether revisions involve changing the entire system, what are the signs of improvement in the postoperative period, etc). Among the participants who did not report any doubts, ~46.2% pointed out that the more surgical approaches the child is subjected to, the more understanding about the 'device and care' they acquire.

Regarding the question about the children's routine, 15.4% of family members reinforced their concern about activities with risk of impact.

I just have one thing... I just feel really sorry that he has to avoid some things, like I told you... running around because of the valve... like, this concern is constant. F11

The majority (61.5%) of participants denied having received guidance on how the ventricular shunt system works before the surgical procedure.

Because on the day I was supposed to do it, the doctor just said that I would simply have to do it, put in a valve. F2

Family members pointed out that the decision to place the device was marked by urgency, lack of information, and incomprehensible language. Furthermore, they consider the reason for placement, risks of the procedure, valve operating mechanism, and benefits of its use as essential aspects to be clarified.

All participants denied any contact with other educational initiatives on hydrocephalus and valve use, other than the guidance received from the health team directly involved.

The use of research tools and books to seek information about hydrocephalus and valve use was reported by 76.9% of family members. However, it was observed that such a strategy sometimes intensified feelings of anguish and stress.

I looked for it, but then I went crazy. I preferred to stop. When you go looking, you better stop looking. F11

The difficulty in understanding the text and fear regarding what might be found were highlighted by the other participants (23.1%) as reasons for not seeking information.

Discussion

This study identified that family members of children undergoing ventricular shunt did not have sufficient information to manage their care. Failures in communication among health professionals and little information given to family members contribute to the profile of people who are not informed, catalyzing anguish and demand.

Understanding the information needs and experiences of families in the context of chronic disease makes it possible to outline interventions that expand their resources to experience this condition, promoting more effective and qualified care.⁽¹⁶⁾ Thus, effective communication is the main tool for building knowledge among family members of children undergoing ventricular shunt, helping them acquire the skills necessary to manage specific care.

Children undergoing ventricular shunt require specific care due to the chronicity of the disease and technological dependence. The quality of this care depends on adequate preparation of family members by health professionals, with information that can provide security to caregivers concerning both the disease and the device.⁽¹⁷⁾ In this sense, participants in the present study did not receive information about the functioning of the ventricular shunt system, signs of malfunction, and restrictions imposed by it, ignoring its impact on the children's quality of life.

In a study to evaluate the circumstances related to the sudden death of children with ventricular shunt, it was observed that signs of increased intracranial pressure (such as nausea, vomiting, and headaches) preceded death, and were not recognized or valued by the main caregivers as warning signs.⁽¹⁸⁾ Most dysfunctions as well as the evolution of the signs and symptoms presented are progressive, except in rare cases of catheter fracture, which could potentially be associated with sudden and complete shunt dysfunction. Thus, early recognition of a worsening clinical condition is essential before irreversible neurological damage occurs, enabling rapid surgical intervention.⁽¹⁸⁾ In this context, guidance from nurses to children and families to early identify warning signs can contribute greatly to achieving better results.

The information given to family members and carers is considered insufficient, especially when language that is difficult to understand is used. For health education of family members of children with special care needs, studies recommend that health professionals use strategies such as: informing with simplified language, using educational materials, and validating the information given to family members by indicating sources of reliable content.^(19,20) A care plan contextualized to the clinical situation and the knowledge of caregivers can help prevent complications, thus im-

proving the quality of life of children with ventricular shunt.

To empower family members of children undergoing ventricular shunt, nurses should promote health literacy, enabling these family members to acquire knowledge through information about health-promoting care. Thus, with information about the health care these children need, they will be able to make decisions about managing complications.⁽²¹⁾ More than half of the participants reported not having received guidance about both the device and the surgical procedure before surgery. Furthermore, most of them stated that they still have doubts, again indicating a failure in the communication process. Effective communication involves ensuring that the information has been correctly interpreted by the recipients. The identified failures highlight assistance that did not link the professional to the patient and his family. This makes it impossible to have effective dialogues about the needs of caregivers and, therefore, their care and can increase the feeling of anguish generated when learning a new diagnosis using a device.

The creation of a context in which there is interaction between the multidisciplinary team and caregivers, with open dialogue and based on the 'experiences and needs' of family members, can be an essential tool for building concrete knowledge. Technical and formal communication can prevent family members from feeling welcomed by the team, making it difficult for them to verbalize their doubts, needs, and fears.⁽²²⁾ The relationship between the multidisciplinary team and family members is also important for effective communication and, thus, for the health education process. The bond between team and family is directly affected by the deficit in interaction between professionals. This causes failures to inform about needs in both discussion about the therapeutic plan and team awareness concerning the individuality of family demands. Effective multidisciplinary interaction broadens the vision of patients and families, making it possible to better understand their real needs and identify the failures that prevent the construction of concrete knowledge.⁽²³⁾ Just as communication between professionals must be horizontal, the construction of health knowledge of family members and patients must also be stripped of the concept of deposit education, as caregivers must be seen as potentially active subjects in the health-dis-

ease process of children.⁽²⁴⁾ The knowledge brought by family members normally comes from observing the health team's (especially the nursing team) handling of children and devices, in which the lack of dialogue instructs the practice of care only superficially. It was shown that there is a distance between family members and professionals regarding health education. It often results from professionals who are not available and family members who (due to fear and lack of understanding) are unable to verbalize their doubts and demands.⁽²³⁾ Shared knowledge cannot be just technical-scientific. It must consider the experience and knowledge brought by family members and caregivers, as this is the only way that health education becomes accessible and effective.⁽²⁵⁾ The study revealed that family members of children undergoing ventricular shunt have little information about the device which is the main treatment option in cases of hydrocephalus. Therefore, it contributed information that makes it possible to build educational material to promote more qualified and safe assistance based on real needs.

As a limitation of the research, we highlight the reduced number of participants due to institutional changes regarding the admission of patients to the service during the data collection period.

Conclusion

Family members of children undergoing ventricular shunt have little information about the system, including indication, operating mechanism, signs of malfunction, possible complications, and daily care. They have doubts about the surgical procedures to place and revise the valve and have difficulty understanding the instructions received, especially due to the language used.

Contributions

Silva KS, Ferreira ES, Santos LG, Kusahara DM, and Belega-Anacleto ASC declare that they contributed to the design of the study, collection, analysis, and interpretation of data, writing of the manuscript, critical and relevant review of the intellectual content, and approval of the final version to be published.

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