

Congenital portosystemic shunts: To close or not to close? Ethical stakeholders' perspectives

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Abstract

The Clinical Ethics Center was asked to discuss the “ethics” of the prophylactic treatment of portosystemic shunts (CPSS). In order to meet this demand, semi-structured interviews were conducted with patients, parents, and doctors by a multidisciplinary team including laypersons. Doctors' perspectives seem opposed to patients' and parents' perspectives. Doctors wonder if they operate on CPSS too much or too early. Their questions arise from medical uncertainty. Patients and especially parents trust doctors but want to understand the situation to be able to take the best decision. They prefer CPSS to be cured in order to be relieved of the sword of Damocles. If international collegiality can help practitioners discuss therapeutic alternatives, the ethical reflection should take place more locally. In practice, ethics acting as a third party can help reflect on particular situations, taking into account psycho-socio-familial factors to decide whether to operate or not, now or later.

Keywords: CPSS, ethics, uncertainty, decision, collegiality.

Introduction

Congenital portosystemic shunts (CPSS) are rare congenital, abnormal venous communications between the portal venous system and the systemic circulation. Their prevalence is estimated at 1:30,000 to 1:50,000 newborns. They are accepted to be the consequence of incomplete vascular remodeling between the sym-



metric embryonic and asymmetric fetal hepatic and perihepatic circulations.¹ CPSS can lead to multiple systemic complications: neurological, cardiopulmonary, hepatic, endocrine, hematological, renal, and infectious complications. Liver malignancy and cardiopulmonary manifestations such as hepatopulmonary syndrome, porto-pulmonary hypertension, and high-output heart failure are among the most severe complications and can be life threatening [1]. The severity of these multisystemic repercussions varies from one individual to another. Some neuropsychiatric symptoms such as school difficulties, unexplained mental retardation or neurocognitive delay, attention deficit disorder, and other psychiatric diseases can be underestimated.

Nowadays, CPSS are often identified through prenatal ultrasound. Therefore, it can be diagnosed at any age. Some individuals can live a normal life for years; their shunt going unnoticed and be revealed by complications later in life. It can also be discovered fortuitously.

The management of CPSS consists in shunt closure, using either a surgical or endovascular approach. This latter option is preferred as it is less invasive.² The benefits of shunt closure include regression of liver nodules, resolution of hyperammonemia and improvement of neurocognitive symptoms, resolution of glomerulonephritis, reversal of hepatopulmonary syndrome, and stabilization of pulmonary hypertension. However, closure can also lead to major complications such as thrombosis, occlusion device migration, and portal hypertension.

To date, several questions remain unanswered: which patients are at risk of developing which complications? In which patients will the shunt close spontaneously? Which patients have multiple shunts or will open new shunts in response to surgical or interventional treatment? Confronted with these medical uncertainties, specialists ask themselves if the shunt should be closed preventively, despite the risks involved, in patients whose outcome without intervention is unpredictable and varies from no symptoms to severe symptoms.

Ethics, especially through a bottom-up approach,³ has emerged as an additional tool for helping specialists reflect and discuss. It is in this context that our clinical ethics team was solicited by clinicians involved in the care of patients with CPSS.

1 Because of abnormal venous communications, blood goes directly from the intestines to the heart without passing through the liver for filtration. <http://ircpss.com/shunts.html>

2 The approach for closure depends on anatomy and portosystemic (PS) pressure measuring during an occlusion test. The interventional radiological procedure consists in endovascular closure thanks to prosthesis. If an occlusion device impinges on neighboring vessels or PS gradient is too high, a two-step surgical procedure is preferred [1].

3 Bottom-up approaches take into account the specific local circumstances of the case itself, often using empirical data, lived experience, and personal accounts.

Processing the ethical request

The Clinical Ethics Center of the Greater Paris University Hospitals, Assistance Publique-Hôpitaux de Paris (Cec), was created in 2002 following the first law on patients 'rights'.⁴ It is inspired by the MacLean Center for clinical medical ethics [2]. Cec's main activity is clinical ethics consultations. It is interested in complex medical decisions in specific cases; in particular when the patient or relative is in an ethical conflict with the doctor or the medical team concerned [3]. Cec's fundamental principles are based on: 1) meeting with all the protagonists involved, including patients and relatives; 2) a broad multidisciplinary team that includes healthcare professionals and laypersons such as researchers in humanities and social sciences; 3) an approach based on Beauchamp and Childress' principles of biomedical ethics: respect for autonomy, beneficence, non-maleficence, and justice [4].

The request regarding CPSS closure was different from the Cec's routine activity as it concerned a recurrent ethical question in a given medical practice. It is what we call an organizational ethics issue [5]. In this case, without wanting or being able to elaborate a research protocol in order to answer the question posed, Cec tries to investigate the request and to examine it as usual in particular cases. In order to best respect Cec's fundamental principles and explore ethical questions from all points of view, a team of consultants composed of a doctor and a reporter trained in clinical ethics interviewed the first people concerned, i. e. patients ($n = 3$: 1 post-operative adult and 2 post-operative children) and parents of affected children ($n = 8$: 2 mothers and 2 couples of post-operative children and 1 couple before their child was operated on). They were recruited through medical teams specialized in CPSS management at Kremlin-Bicêtre, Beaujon, Necker, and the Swiss Pediatric Liver Center. There were no inclusion criteria as this was not a research study. The clinical ethics consultants interviewed the few patients/relatives that the teams were able to solicit to answer some questions. Among them, one mother of a pre-operative child refused the interview. Also, one post-operative adult and the parents of a patient with severe post-operative complications did not respond to our request. Healthcare professionals were also interviewed ($n = 6$: hepatologists including 2 pediatric, 1 pediatric radiologist and 1 pediatric surgeon).

First, interviews were conducted in order to understand the approach to medical decision-making among professionals, patients, and families in this specific medical situation. Strictly speaking, there was no interview guideline. Interviewees were asked about the following aspects of the CPSS: presentation, diagnostic methods, and timing of management. Furthermore, some of the interview questions were dedicated to the quality and quantity of medical information re-

4 <https://ethique-clinique.aphp.fr>

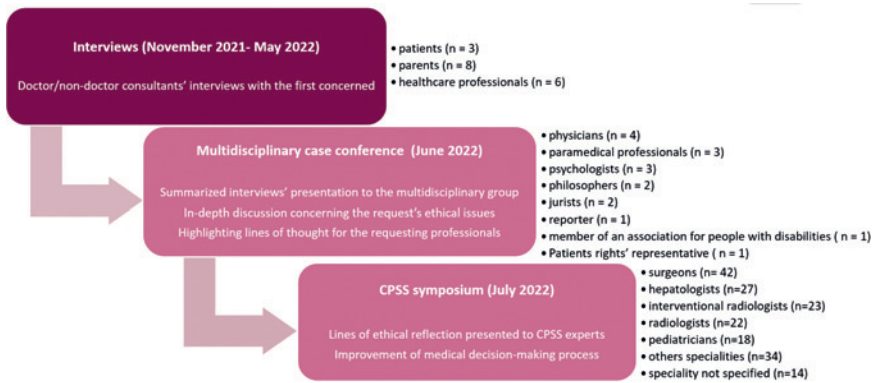


Figure 1: Ethical reflection process

ceived by patients and parents; the medical, psychological, and social arguments which contributed to the decision to close the CPSS or not. Finally, interviewees were questioned about the roles of medicine and collegiality in this particular situation. All except one family-and-patient interview were performed by video-conferencing, the exception was a mother and her daughter who were seen in person. Professionals were also interviewed in person, except for the Swiss medical team. The interviews were not coded nor were they analyzed by sequential thematization (a method used at the Cec when conducting research protocols [6]). They were synthesized by the consultants and problematized according to the principles of biomedical ethics.

Subsequently, the organizational ethics dilemma was discussed in the Cec's multidisciplinary case conference (n = 17: 4 doctors, 3 paramedical professionals, 3 psychologists, 2 philosophers, 2 jurists, 1 journalist, 1 member of an association for people with disabilities, and 1 patients rights' representative, all trained in clinical ethics for two years). During this conference, clinical situations and specialists' points of view were summarized and presented by consultants to the group. The ethical issues were presented based on the principles of biomedical ethics to initiate a discussion among the participants. The objective was not to draw up recommendations to answer the question raised, but to provide health professionals with lines of thought based on this multidisciplinary discussion.

Finally, one of the consultants participated in the second meeting of experts "Taking CPSS to the next level" (n=79 onsite participants and n= 101 online participants) in Geneva, in July 2022.⁵ The aim was to present to experts (physicians, scientists, patient organizations, allied health professionals) some ethical

⁵ <https://www.hug.ch/en/evenement/symposium-taking-congenital-portosystemic-shunt-next-level-2nd-expert-meeting>

lines of thoughts concerning aspects of preemptive closure. This presentation was followed by a discussion with experts.

This article offers a reflection based on these interviews, the multidisciplinary case review and the discussions that took place during the symposium. Everything mentioned below is based on these three steps.

Doctors' perspectives: "Close or not to close, that is the question!"

Professionals are mainly concerned with the risk/benefit balance of the procedure to treat the shunt. They broach different points: the lack of validated scientific knowledge, the medical questions inherent in decision-making, and their discussions with patients and parents.

From the interviews, we found that doctors were facing difficulties in assessing the risk/benefit balance in cases of asymptomatic CPSS. Some of them argued that there was a lack of scientific data: "Can we offer prophylactic treatment when there is no evidence-based medicine for this particular problem?"

Specialists explained that they rely on collegiality and consensus in order to build expertise on the subject. At a local level, decision-making occurs in multidisciplinary meetings. At an international level, videoconferencing discussions among expert teams from different countries are used. It helps to reassure specialists making the medical decision: "I tell the parents I don't decide alone, that there is a multidisciplinary discussion."

Although the experts are organized at the international and local levels, both for clinical and research aspects, there are still many scientifically unresolved questions. It is known that chances of spontaneous closure are maximal before the age of two. The rationale for preventive closure is, based on expert opinion, that spontaneous closure beyond this age is unlikely, and that complications can potentially be severe [1]. Nonetheless, there is a lack of knowledge concerning the incidence of these complications and their systemic repercussions. It should be noted that there is no biological marker to aid in the medical decision-making.

On the one hand, experts emphasize the risk of irreversible complications if shunt closure is postponed. They are also concerned by patients lost to follow-up. One of the hepatologist we interviewed mentioned her concern about a patient presented during an international meeting: "a young Spanish boy wants to go around the world before having surgery. He may never come back". But on the other hand, it is impossible to know if other symptoms would appear after shunt closure. An expert told us about one of her patients: "She exudes health! Twenty years ago she would not have had a morphologic ultrasound. We are going to make her sick before she gets sick."

From an ethical point of view, and considering the beneficence/non-maleficence balance, there may be a loss of opportunity whether we do or do not perform surgery.

In this uncertain context, experts have difficulties determining the right time to perform the procedure. Specialists fear being too proactive and prompt in performing surgery, even as a preventive measure. Also, choosing to perform the procedure can be considered as more transgressive by doctors due to its preventive character. They can express a certain fascination regarding this rare congenital malformation and what CPSS treatment can enable; which could impact medical decision-making and motivate them to perform surgery.

One hepatologist highlighted her personal practice linked to her medical experience: “I tend to push for CPSS closure because of the unexpected neurological improvements”. Nevertheless, some professionals worry that some parents tend to push for closure. As a surgeon related: “a father sent me all the literature so that I could operate on his child before three months”. In those cases, specialists tend, and seem able, to reassure parents.

Overall, professionals are mainly concerned about overtreating patients. The consequence might be that the risk outweighs the benefit. In ethical terms, it can be summarized by the principle “*primum non nocere*”; which mainly guides any medical decision. It is particularly complicated for them to apprehend this principle because of the medical uncertainty; despite an organized and helpful network that enables medical decision-making in collegiality.

Patients’ and parents’ perspectives: A wish for a more peaceful life

Of the six medical histories presented to us, two patients were considered as asymptomatic to date. CPSS had been discovered through prenatal ultrasounds. Neither has closed spontaneously. They were operated on at 7 and 2 years of age, without any procedural complications. Three other patients had presented CPSS complications. A 14-year-old patient had developed unexplained cardiopulmonary failure at 9 months. She was finally operated on at the age of seven after a CPSS diagnosis. Another 2-year-old patient had suffered from cardiomyopathy, portal hypertension, and diabetes before closure. The last family we interviewed had an 18-month-old baby who was born with a severe polymalformative syndrome and CPSS. The operation was planned for two months later. Only one patient we interviewed was an adult and was operated on at the age of 24 because she had presented hepatic nodules and neurocognitive delay.

Patients and their close relatives related the medical information process, shared decision-making, and their difficulties living with CPSS.

What emerged from parents' and patients' interviews is that trust is the strongest root of therapeutic alliance. Thus, medical information is expected to be given properly to patients and especially parents. A mother of a 3-year-old girl emphasized: "I need to understand everything. I needed to be sure to make the right decision ... This balance was important to do. For us, it was important to know exactly what was going to happen to her". Her father added: "the second point that pushed me [to agree to the intervention] was to say that when you follow the doctor, you are making the right choice. I didn't feel like going against him. I remain humble. (...) If I have a doctor who tells me he doesn't know what to do, I change doctor! We have to be sure of what the doctor says. He must be able to argue."

They consider this process as an exercise in shared decision-making while recognizing the crucial role of medicine as a scientific specialty. None of the interviewees chose a wait-and-see approach. One of the interviewed fathers insisted on each stakeholder's role in the decision-making process: "the doctor has an expert job. We have the responsibility of parents. We made our decision after examining his arguments ... It's very reassuring when a doctor is ready to collaborate, discuss". His wife pointed out that they didn't necessarily want full decision autonomy: "It is true that it is preventive but we trusted the team. We weren't the ones who decided to do something preventive, but we worked with the doctors." According to these parents, doctors have a medical expertise role and parents are responsible for their child's lifelong well-being.

During the interviews, parents emphasized the benefits of shunt closure beyond the risks associated with CPSS. Parents cling to the possibility of a future without treatment and burdensome follow-ups. They are often relieved to have acted and want to be considered "good parents". The father of the 3-year-old asymptomatic child explained his approach: "we said to ourselves that if we did nothing, we had to follow up and hope that everything went well. But if one day she turns 12 and something happens, we can't say we didn't know. That's what prompted me to have her operated on early."

The 24-year-old patient who was operated on during adulthood also highlighted the benefits of the intervention despite knowledge of operational risks: "I know that every operation has risks. I didn't really have a choice, I preferred to seek treatment (...) I couldn't write and read, it's too complex for me. Since the operation, I remember better, and I can remember the value of money too."

Parents highlighted the fact that it is sometimes difficult to live with the disease. It is hard for them to comprehend its future risks, especially when their child seems in good health. The parents of the 3-year-old girl related that they had waited until she was two to see if the shunt would close spontaneously. They explained that after discussing with the surgeons they understood that it was necessary to close it because it was safer. "It avoided the sword of Damocles in the years to come". The mother of a 2-year-old patient shared how her daugh-

ter's night tube feeding was psychologically stressful and energy consuming. She also explained the impact the disease had had on her professional activity in terms of organization: "it was in Paris ... I have a farm. We had planned 4 days. In fact, there were 15. I had planned everything for 4 days, even the food ... It's a good ward. Nothing compared to here. They explain everything. We had a mother-child room. I was able to do a PCR test to go buy food. I felt like the team understood my distress". She added: "it was difficult with the farm. At first, when she came back we were milking at 2 o'clock in the morning. We were tired. We thought it best to take care of her. We are shutting down the business. We had already stopped the milk. We're going to move somewhere else. We will return to being employees."

Ultimately, patients and their relatives are more concerned about the impact of the disease and the medicalization it implies, whether the shunt is symptomatic or not, than about the benefits and risks directly related to the procedure. As one mother pointed out about her daughter's shunt follow-up: "it was not an easy experience when she was little. She had blood tests and ultrasounds. It was complicated every time. We didn't want her to be a subject of experimentation." Appropriate information is crucial in order to maintain a therapeutic alliance. Even though they are unable to decide medically, they seek to be convinced that the doctor's decision is the right one. The main risk for them is that the intervention isn't done or is not done early enough. Whatever the severity of the medical situation, they want to be relieved of the sword of Damocles and ask that the CPSS be treated.

Discussion

Asymptomatic shunt or "silent shunt"?

Initially, Cec was solicited to help discuss the ethics of prophylactic treatment of asymptomatic CPSS. This is understandable from an ethical point of view since taking the risk of treating "unnecessarily" is all the more transgressive with regard to the "*primum non nocere*" in this case. Nevertheless, over the course of the interviews, it was notable that physical or biological symptoms often seem present or suspected in patients. First, CPSS were more often discovered in the context of a severe health problem such as cardiopulmonary failure, seizure with hypothermia and hypoglycemia, or hepatic nodules. CPSS could also be asymptomatic in the setting of polymalformative syndromes. Secondly, even when the shunt was considered as asymptomatic, some symptoms were suspected by doctors such as neurological or endocrine ones, often underestimated. In one case, we learned from the parents that hyperammonemia was detected when treatment for an asymptomatic CPSS was discussed. We can wonder if "truly asymp-

omatic shunts” exist. Therefore, the use of the expression “silent shunt” seems more appropriate.

This is important to consider because it may affect ethical reasoning in the context of a decision to operate or not. If we assume that shunts that are completely asymptomatic for life and almost do not exist, the argument for not taking the risk of not treating them disappears. In this case, it is not so much the preventive nature that raises ethical questions as the medical uncertainty inherent in the procedure itself, whether the patient is symptomatic or not.

The weight of medical uncertainty

Experts face a lack of scientific data on the benefits of closure. They cannot be certain that their patients will not develop multisystemic complications if they choose a wait-and-see approach. Also, they cannot prevent all repercussions of closure such as portal hypertension if they perform the intervention. As one participant of the multidisciplinary case conference said: “it is a hazardous bet”. In order to improve the evidence-based approach and reduce medical uncertainty, we could again question the feasibility of double-blind research in order to supply scientific data. Anyway, the degree of uncertainty further downplays the usual medical power. Ethically, it is more difficult to inform and decide without having tangible proof of one’s position.

Practicing decision-making without evidence is not unique to CPSS. As an example, the weight of uncertainty is also taken into consideration in preventive management of other pediatric diseases such as congenital pulmonary airway malformations. In this instance, patients can be asymptomatic but are at risk of developing intrathoracic tumor. The exact incidence is unknown. In regard to CPSS closure, doctors have to estimate the benefit/risk balance concerning surgical resection, knowing that an increasing rate of infections over time renders the surgery more difficult after months or years of evolution. They make the decision to perform shunt closure without knowing with certainty if the patient would have developed malignancy [7]. What is at stake in the final decision on managing these complex cases is the specialists’ professional responsibility. Resorting to support from their expert network is a way to minimize this uncertainty. Specialists can share their own medical experience and be reassured or not in their decision.

In addition to medical uncertainty, parents and patients also have to deal with personal and family uncertainty. During the interviews, parents and patients reported searching for information on different management options, their risks and benefits in order to manage medical uncertainty. As some experts said, seeking information can facilitate the decision-making process for some parents but can also be overwhelming, rendering them more anxious and proac-

tive. According to Brashers et al.'s uncertainty management theory, parents who experience uncertainty seek or avoid information to manage their uncertainty in the desired direction. When individuals appraise uncertainty as a danger, they may reduce it by seeking information that helps them distinguish options [8], whereas individuals who positively appraise uncertainty often avoid information to maintain or to increase feelings of hope [9]. Experts help themselves with what Brashers et al. call "parents information balancing act" to manage uncertainty dilemmas [10].

Beyond uncertainty and information, it is trust between parents or patients and the doctors which enables decision-making. Parents assume that autonomy is respected as they exercise parental responsibility. What matters to them is to be able to tell their child or themselves they have done the "right" thing. Here, the concept of autonomy is conceived in the broad sense. By approving shunt closure, parents take into consideration their child's open future and tend to preserve their autonomy as a future adult. Also, they rely on experts' experience and do not claim to interfere in medical choice. Care providers should adapt to parents' dynamic preferences, goals and emotional responses during the decision-making process [11].

Decision-making on a case-by-case basis

We highlighted the fact that doctors and patients/parents have opposing concerns about CPSS intervention. Specialists fear performing interventions excessively or too early whereas parents and patients fear shunts not being closed or not soon enough.

On the physician's side, the beneficence/non-maleficence balance is centered on a benefit/risk analysis regardless of the degree of medical uncertainty. They focus mainly on the medical aspects of the procedure during the decision-making process. Experts' decisions are reinforced by consultation with their international network. The principle of respect for autonomy consists in obtaining free and informed consent.

On the parents' and patients' side, post-operative perspectives lead the decision. They hope that doctors will help them make life more peaceful. The beneficence/non-maleficence balance is linked to the disease's impact and its complications or implications for future life. Thus, it seems particularly important to decide by considering psycho-social-familial factors. Indeed, CPSS and their medical complications can have an influence on the patient's environment. As revealed by patients' parents, the disease may have a real impact on family dynamics. In contrast, shunt closure seems to improve certain psycho-social factors and help patients gain autonomy. The context in which the CPSS was diagnosed is also an element to be considered as it can influence experts' but also

parents' willingness to intervene. The reasoning will be different if the discovery is made prenatally or following a life-threatening complication.

Consequently, given the complexity of these cases and the difficulties linked to medical arguments, it seems essential in weighing up the decision to also consider the principles of biomedical ethics and not only a risk benefit analysis; and to take into account non-medical arguments such as the context of discovery, family dynamics, but also psycho-social factors.

Limits

No definite conclusion can be drawn following this exploratory work; it was not the goal. The elements outlined are provided as lines of thought and are not intended to be scientific results linked to empirical work in the strict sense of the term. Our investigation has several limitations. First, the number of interviews is limited and we can consider the description of the cases as too partial. The few elements we had on each case were insufficient to fully explore them. Secondly, we can point out the recruitment bias. All the interviews conducted with parents and patients were made after the closure decision-making. The fact that we could not recruit parents and patients before closure was decided meant that the availability of countervailing arguments was limited. Indeed, we can suspect the ethical reasoning to be different before medical decision-making. None of the patients we were interested in faced any complications after intervention; which can explain the absence of "ethical alert" during interviews. Thirdly, this investigation took place mainly in a pediatric context which focuses the discussion on certain points and leads to the emergence of different arguments. Only one of the patients we interviewed had the procedure performed as an adult. For other cases, parents' place and reasoning in the decision-making process have to be taken into account. Thus, a more in-depth study is needed on the subject if ethical conclusions are necessary.

Conclusion

Cec was approached by experts to discuss the ethical arguments concerning prophylactic treatment of CPSS. By comparing the different stakeholders' perspectives we identified that healthcare providers' and patients' or parents' concerns were divergent. While experts are concerned about overtreating CPSS, patients and mainly parents fear the shunt will not be cured soon enough. In view of these divergent concerns, it seems important to distinguish two levels of discussion in the decision-making process: the scientific one and the ethical one. At the scientific level, international collaboration, discussion and networking seem to reduce uncertainty and improve patient-care decisions. As we have now

shown that this is not enough for the families, our position is that the medical decision for the patient should be taken by the team who knows them best and is aware of the local context and resources. This means that nonscientific arguments can also be considered, such as the diagnostic context, the psycho-socio-familial factors highlighted by patients and parents, and the cultural background; and thus respect the specificity of each case. In this perspective, the use of clinical ethics consultations could facilitate the reflection process.

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Résumé

Le Centre d'éthique clinique a été sollicité afin de discuter des questionnements éthiques concernant le traitement prophylactique des shunts porto-systémiques. Afin de répondre à cette demande, des entretiens semi-structurés ont été conduits avec des médecins, des patients et des parents dans une approche multidisciplinaire et en incluant des non-soignants. Il semble que les perspectives des docteurs et des patients ou des parents soient opposées. Confrontés à l'incertitude médicale, les experts se demandent s'ils opèrent leurs patients de manière excessive ou trop tôt. Les patients et particulièrement les parents ont confiance en leurs médecins mais souhaitent comprendre la situation pour prendre la meilleure décision. Ils préfèrent que l'intervention soit pratiquée afin d'être libéré du poids de l'épée de Damoclès. Si la collégialité internationale peut aider les praticiens à discuter des alternatives thérapeutiques, la réflexion éthique doit avoir lieu davantage localement. En pratique, l'éthique en tant que tiers peut aider à penser ces situations particulières, en prenant en compte des facteurs psycho-sociaux et familiaux.

Mots-clés: shunt, éthique, incertitude, collégialité.

Zusammenfassung

Das Zentrum für klinische Ethik wurde gebeten, ethische Fragen im Zusammenhang mit der prophylaktischen Behandlung von portosystemischen Shunts zu erörtern. Um dieser

Bitte nachzukommen, wurden halbstrukturierte Interviews mit Ärzten, Patienten und Eltern in einem multidisziplinären Ansatz und unter Einbeziehung von Nicht-Pflegekräften geführt. Es scheint, dass die Perspektiven von Ärzten und Patienten oder Eltern gegensätzlich sind. Mit medizinischer Unsicherheit konfrontiert, fragen sich die Experten, ob sie ihre Patienten übermäßig oder zu früh operieren. Patienten und insbesondere Eltern vertrauen ihren Ärzten, möchten aber die Situation verstehen, um die beste Entscheidung treffen zu können. Sie ziehen es vor, dass der Eingriff vorgenommen wird, um von der Last des Damoklesschwertes befreit zu sein. Während die internationale Kollegialität den Praktikern bei der Diskussion über Behandlungsalternativen helfen kann, muss die ethische Reflexion mehr auf lokaler Ebene stattfinden. In der Praxis kann die Ethik als Dritte helfen, diese besonderen Situationen zu durchdenken; unter Berücksichtigung psychosozialer und familiärer Faktoren.

Schlagworte: shunt, Ethik, Unsicherheit, Kollegialität.

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