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The parental experience of participating in surgical decision-making regarding one's child with a congenital heart disease in Taiwan

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ABSTRACT

Purpose: This study explores how parents experienced the surgical decision-making process for their child with a congenital heart disease (CHD).

Design and methods: Purposive sampling was used in this qualitative descriptive study at a medical center in Northern Taiwan. Twelve parents whose children had cardiac corrective surgery participated in one-to-one in-depth interviews. The interview content subsequently was transcribed verbatim and analyzed by content analysis.

Results: Five themes, with 2 to 3 subthemes, were identified: 1) accumulating medical knowledge in a short time, 2) trusting the medical teams but parents needing clear communication, 3) feeling pervasive uncertainty, 4) using self-talk to calm down, and 5) looking for positive energy from various sources.

Conclusions: For the parents of these children with CHD, participating in surgical decision-making can be a difficult and stressful experience. When explaining the disease and treatment procedures, it is important for medical professionals to make sure of the individual parent's information needs, to use plain language and encourage parents to ask questions.

Practice implications: Although the surgery is imperative and inevitable, understanding the parents' worries and providing adequate support can help them reduce feelings of uncertainty during the decision-making and surgical processes.

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Introduction

Congenital heart disease (CHD) is a common congenital illness in children. From the national health insurance database 2000–2010, the overall prevalence of CHD in Taiwan was 12.88%. Atrial septal defect (ASD), ventricular septal defect (VSD), patent ductus arteriosus (PDA), anomalies of the pulmonary valve, and tetralogy of Fallot (TOF) are five common diagnoses (Yeh et al., 2015). Many children with CHD require a partial or total corrective surgery during their early life to prevent pulmonary hypertension and heart failure (Rosenzweig & Krishnan, 2021; Tort et al., 2021). For these children, having the cardiac surgical procedure is often inevitable, but the surgery itself also has potential risks and complications for the child's health (Joshi et al., 2016; Mari et al., 2016). When the parents face the decision for surgery they often have to understand a complex situation and the emergency surgical procedure in a short period of time before signing a consent form for

the surgery (Shinkunas et al., 2020). A previous adult study found that insufficient information from the surgeons about the procedure made the patients feel less involved than they preferred in making a decision. This may lead to decisional conflicts and regrets, which can further cause physical and mental problems (Etnel et al., 2018).

Shared decision-making (SDM) is a current trend which refers to a collaborative process between the clinicians and patients (or surrogates) to exchange information and to reach a medical decision together (Hoang et al., 2020). It exists on a continuum between solely patient-driven to physician-driven decision-making, and different approaches in-between with different levels of patient-physician responsibility for decisions (Kon, 2010). Patient preferences for decision-making approaches vary widely regardless of the type of decision being considered. For example, many parents in acute care settings preferred more autonomy in the final decision, but also there were some parents who preferred the doctors to make the final decision (Madrigal et al., 2012). Recent pediatric practice has encouraged the shift from a physician-centered to a patient-centered approach, which emphasizes the parents' responsibility to make a final decision (Tom et al., 2017). However, in Taiwan, the physician is a member of a highly respected

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and entrusted profession; the families of patients with a surgical complexity tend to follow the authority of the healthcare professional in obtaining good medical care (Lin et al., 2016). Within this cultural and medical environments, the aim of this study was to explore how the parents felt, how they were assisted, and what they expected during their participation in the surgical decision-making process.

Methods

Research design

A qualitative descriptive design was used because it is “the method of choice when straight descriptions of phenomena are desired” (Sandelowski, 2000, p.339) and allows for a rich description framed by the environmental and cultural contexts to clearly reflect the view of the participants. Using a qualitative descriptive design can provide a comprehensive narrative of an event or experience using clear everyday terms, avoiding high-level interpretation (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). The results of a qualitative descriptive study have tremendous potential to translate directly to pressing health care situations and provide clear information about ways to improve clinical practice (Sullivan-Bolyai et al., 2005).

Participants

Twelve participating parents (of ten children) were recruited from the pediatric intensive care unit of a medical center in Northern Taiwan. Purposive sampling was used, based on the following inclusion criteria: 1) parents of a child with CHD having heart surgery, and 2) who had talked with the surgical team regarding the surgery. Data collection was continued until saturation was reached.

Table 1 presents the demographic data of the children. In addition, the age range of the parents was from 33 to 55 years old. Two of the parent's education level was high school, while 8 of them were at college and above. Two parents were Christians; 6 were Buddhists; 1 was Taoist; and 3 were no religion.

Data collection

After the study was approved by the ethics committees at the hospital, parents who met the criteria were approached by the first author before their child's surgery; they were given oral and written information explaining the study. Those who agreed to participate signed a consent form. Subsequently, an interview was arranged at about two weeks after the surgery in a private room near the intensive care unit.

A semi-structured interview guide with 12 open-ended questions was prepared for the parents to share their surgical feelings, perceptions and expectations. Questions such as, how the parents learnt of their child's heart problem and treatment, how they participated in the

surgical decision, and how they felt before and after the surgical process, were included. Probes were used when necessary to elicit deeper expressions. The one-to-one in-depth interview lasted 50 to 70 min, and a second interview was arranged if needed. The interviewer recorded each participant's nonverbal behaviors, which were summarized in field notes for each interview. Demographic data of the parents and children were obtained from the parents themselves and the medical charts.

Data were collected between June and December 2020. Twelve parents (four fathers and eight mothers, and including two couples) of ten children participated. In order to maintain anonymity, each participant's child was identified by a code number, and the letters F or M to represent the child's father or mother to protect each participant's identity.

Data analysis and rigor

All the interviews were undertaken by the first author, who also contacted participants to establish positive relationships and rapport before the surgery. Each digital audio-recorded interview was transcribed verbatim. Data were analyzed using the processes of content analysis (Graneheim & Lundman, 2004). The transcriptions were read line-by-line several times by the authors to obtain a sense of the whole. The text was divided into meaningful units and reduced into codes which described all aspects of these parents' experiences. Through discussions by the research team in order to reach consensus, codes with similar meanings were organized and grouped into themes and subthemes of these parents' surgical decision-making process for their children. Two parents were invited to confirm the findings of their experience.

Findings

Five themes were identified: Accumulating medical knowledge in a short period of time; Trusting the medical teams but parents needing clear communication; Feeling pervasive uncertainty; Using self-talk to calm down; Looking for positive energy from various sources. A summary of the five themes and 13 subthemes is presented in Table 2.

Accumulating medical knowledge in a short time

The parents felt shocked in learning about the abnormal cardiac structures of their young child. Facing the unknown disease and their

Table 2
Main themes and subthemes.

Themes	Sub-themes
Accumulating medical knowledge in a short time	<ul style="list-style-type: none"> Searching for information online Information from family and friends
Trusting the medical teams but parents needing clear communication	<ul style="list-style-type: none"> Expecting clear and detailed surgical explanations Choosing to trust the surgeon Clarifying information through the nurses
Feeling pervasive uncertainty	<ul style="list-style-type: none"> Wondering if the child should have the surgery Wondering if the child could handle the agony of surgery Wondering if the surgery would be successful
Using self-talk to calm down	<ul style="list-style-type: none"> Felt lucky to have a way to fix the defect Perceived as the possibility of a rebirth of the child
Looking for positive energy from various sources	<ul style="list-style-type: none"> Consolation of religion Mutual support of the couple Support from family members

Table 1
Demographic data of the children.

No.	Sex	Age of surgery	Birth order	Admitted from	Diagnosis
1	Boy	4 months	2	Emergency room	VSD
2	Boy	1 day	3	Delivery room	TAPVR
3	Boy	52 days	1	Outside of hospital	VSD, PAPVR
4	Girl	8 months	2	Outpatient clinic	DORV, VSD, ASD
5	Girl	12 years old	2	Outpatient clinic	AS
6	Girl	2 years old	2	Outpatient clinic	TA, VSD, ASD
7	Girl	3 years old	2	Outpatient clinic	ASD
8	Girl	29 days	1	Outside of hospital	CoA, VSD
9	Girl	2 days	2	Delivery room	CoA, VSD
10	Girl	50 days	1	Delivery room	AS, MR, ASD, CoA

Note. VSD = Ventricular Septal Defect; TAPVR = Total Anomalous Pulmonary Venous Return; PAPVR = Partial Anomalous Pulmonary Venous Return; DORV = Double Outlet Right Ventricle; ASD = Atrial Septal Defect; AR = Aortic stenosis; TA = Tricuspid Valve Atresia; CoA = Coarctation of Aorta; MR = Mitral Regurgitation.

child's treatment, they had to learn medical information as soon as possible from any source they could get in order to make the "best" decisions to help their child. Searching for information online and obtaining information from family and friends were common strategies these parents used.

Searching for information online

Parents browsed websites such as the Cardiac Children's Foundation, those of pediatric cardiologists and parental groups to know about CHD and treatments. Through the sharing of information via online social media, many parents learned to face the child's health problems and felt their surgical decision was informed by other's successful experience. Mother 3 thought her child was about to die when she heard the diagnosis: "I was stricken...could not listen to what the doctor said... After I Googled a lot and understood the disease, I became less nervous. If I had not done it, I would hesitate to make a surgical decision." Many parents used online information to rapidly accumulate knowledge so they could discuss and clarify concerns with the medical professionals.

Information from family and friends

Parents would consult their relatives or friends who had experienced heart surgery or whose child had had heart surgery. It helped to shorten the shock and denial periods and "have mental preparation."

Trusting the medical teams, but parents needing clear communication

CHD can be life-threatening and complex. Parents searched for a good surgeon to treat their children. The surgeon would have a meeting with the parents, who expected that the surgical suggestion and plan would be explained clearly. Through a good communication process, parents could gain confidence in surgical decisions. However, they might not obtain clear and detailed surgical explanations from the surgeon. At time they would need the nurses' help to clarify information. Regardless of their understanding, they chose to trust the surgeon.

Expecting clear and detailed surgical explanations

Many parents mentioned that the surgeon drew a diagram or showed a computer tomography scan to explain the defect and explained the necessity of the surgery. However, mother 4 expressed: "He (the surgeon) explained the heart condition in detail, but we did not understand the terminology, so we did not know how to ask questions." Father 2, a car mechanic, hoped that the surgeon could use less terminology. He said: "Just like when I fix cars, I always use simple language to let my customer understand."

Some parents were upset about the surgeon who explained in a hurry, talked fast and answered with short comments. They hoped the surgeon would tell them not only what surgery their child would have, but also what the risks of the surgery were, what they should prepare, how many days the child would be hospitalized, and what kinds of care were involved after surgery. Mother 3 said: "Actually, I really wanted to know what the worst outcomes were if the surgery failed. No one told us this. Especially the surgeon, he did not tell us the risk of surgery, so I think the explanation was not enough. Although this would not affect our decision to have the surgery, I would worry."

On the other hand, three parents felt cared for by the surgeon during the process of decision-making because the surgeon offered time, shared suggestions, listened, and welcomed parents to ask questions. Two children needed to have cardiac valve replacement. The parents appreciated the surgeon helping them to decide. Mother 5 said: "He explained to us why the valve needed to be replaced. He asked if we wanted to use the valve paid by the health insurance or the one paid for at our own expense. He cared about our economic situation and if we could afford it. He gave us choices, explained differences, and allowed us to discuss with our families. He was very helpful."

Choosing to trust the surgeon

Parents made an effort to search for the best medical team for their child, so they tended to accept the surgeon's suggestions and believed in the team's expertise. Mother 10 explained: "The key is trust. Because we did not understand the surgery and did not know what to do, we just let the physician to arrange it and take his suggestions." Parents felt that if the surgeon showed his confidence during explanations and replied to their questions without hesitation, it was a way of showing professionalism and everything was under the surgeon's control. They chose to trust his professional skills. Mother 7 said: "He explained to us how he would do the procedure and said it was not difficult...seemed like routine work he did everyday...very confident. That gave me a sense of security."

Clarifying information through the nurses

Parents would turn to the nurses in the pediatric cardiac unit when they could not understand the physician's explanations. Father 3 said: "The surgeon talked so fast that I only caught some keywords. Our nurses explained again and helped us clarify what we did not know." Mother 4 also shared her experience: "When we had questions after our talk with the surgeon, but he often was not available. We would consult with the nurses, and they were very helpful." Compared to the surgeon's authoritative image, the nurses were warm and patient and gave psychological support.

Feeling pervasive uncertainty

Ever since they knew their child had CHD, the parents mentioned that they had uncertain feelings and thoughts mixed with worry and fear throughout the whole process of the child's diagnosis, surgery and prognosis. They would wonder if they should let their child have the surgery, if their child could handle the agony of surgery, and if the surgery would succeed.

Wondering if the child should have the surgery

After they knew that their child's condition needed heart surgery, they were afraid their child's health condition might change while waiting. Some parents knew their unborn child's heart defect since pregnancy. After birth, they would worry the defect would be different from the antepartum assessment and the child could not be operated on as scheduled. Father 2 expressed, "I was afraid that the surgeon would tell me his condition could not be operated. What should I do?"

After the surgery was scheduled, the parents worried that the child might have a cold or lung infection before surgery. They feared any delay in surgery would increase the chance of sudden death.

Wondering if the child could handle the agony of surgery

The parents worried about the pain from the surgery. Some would imagine the surgical knife cutting the child's chest and wonder if the little body could handle such major surgery. Mother 6 compared this type of pain to her own experience of cesarean section and thought her child must have more pain. The uncertain feelings made them more anxious as the date of the surgery approached. Mother 4 said: "The surgery made me feel like the end of the world and I wanted to take him and run away. He is too little... I felt bad for him. I could not sleep, I just looked at him and wondered what I should do."

After the surgery parents saw the child lying on the bed with invasive tubing left in the small body and being restrained in the intensive care unit. They were wondering if their child could recover well.

Wondering if the surgery would be successful

Some wondered if any threatening condition would occur during the surgery, or if the defect could not be corrected by the surgery, which caused serious fears for the parents. Father 3 expressed his fear: "I was afraid they would call my name when I waited outside the surgery room. It was open-heart surgery. Even if the doctor had great skills,

my son was too little. You never knew if his physical condition could tolerate it.” Father 8 expressed that he was not a pessimistic person, but he could not help to have negative thoughts and wondered if his daughter might die during the surgery. During our data collection period, a young celebrity died during her heart surgery and the news exerted pressure on several parents. They felt they were the ones who had sent their child to surgery and they would feel guilty if the surgery failed.

Using self-talk to calm down

Parents knew they had to remain calm in order to seek the best way to help their child. If any negative thoughts evolved, they tried to adjust their mindset and reassure themselves of the decision. They told themselves they were lucky to have a way to fix the child's defect and perceived the surgery as a rebirth of the child because their child was no longer to suffer from the symptoms of the defect.

Felt lucky to have a way to fix the defect

When the parents saw the child suffering, they told themselves that the child needed the surgery; if they delayed the surgery, the child's health condition would deteriorate. Mother 7 stated: “The surgeon said if it's not treated, her lungs' hypertension would get worse and be irreversible. We had better to do it (the surgery) now. At least her condition would be on the positive side.” Mother 10 explained her daughter's urgent condition: “She could not live without immediate surgery, so we had to accept it. There is no right or wrong decision.”

In the hospital, parents compared their child to the situation of others. When parents found that another child's condition was more severe than their own child, they told themselves that at least their child had a defect that could be treated by the surgery. Mother 1 said: “If one can be ‘cured’ by surgery, then the diagnosis is not a ‘disease’. We saw many sicker kids in the hospital. Like cancer, it may not be cured by surgery. I told my husband we should accept the need for surgery.”

Perceived as the possibility of a rebirth of the child

Parents expected the surgery could solve the child's uncomfortable symptoms and their child could live well. Mother 4 said: “Surgery is a trial, a chance. She would get better after the surgery. Her body function would improve and grow better. She could live a different life.” For older children with CHD, parents would restrain their activities before the surgery. After the surgery they hoped their child could live like a ‘normal’ person.

Looking for positive energy from various sources

When the parents thought that their child had to go through the tough situations as a result of the CHD and its treatment, negative feelings affected their daily living and mentality. They realized they needed sources from outside to build strength and face the challenges. The sources were from the religion, mutual support between the couple, and support from family members.

Consolation of religion

Parents sought religious support when they felt worried. Mother 2 said: “I often worried at night, and I would pray. I just let God to lead. We Christians believe God will not give an ordeal one cannot bear, so we tried not to complain ‘why us!’ Just pray. When my child had the surgery, I stayed outside the operation room and prayed to God to intervene in the surgery.” Mother 4 recited the Medicine Buddha Sutra outside the operation room to bless her daughter and the medical team during the surgical period.

Many parents, including a mother who had no religion, went to temples to worship and draw lots. Mother 7 said: “Any method is good, and any God can be trusted as long as we pray. Religious strength more or less comforts me.”

Although parents trusted the surgeon's expertise, they still feared that any incident could happen. Father 8 said: “We feared any minute the possibility of failure, so we traveled to a temple and sought spiritual trust and prayed. We did everything to get a sense of peace. If anything happens, we won't regret it.” Mother 5 worried that she and her husband might make a wrong surgical decision, so they sought a folk religion, Jitong (in which God can attach to one's body so the people can ask questions) for assurance. “Before the surgery, we were afraid she (their daughter) would die during the surgery, but Jitong told us to trust the doctor. She would be cured by the surgery. That helped us.”

Mutual support of the couple

Mothers tended to blame themselves and worried they would be blamed by the family members having a child born with CHD. Thus, they appreciated the support from their spouse. Mother 3 said: “I was very worried about my in-laws' reactions, but my husband just said ‘let's face it together!’...”

Fathers also expressed that couples should mutually understand, share each other's thoughts and make decisions together. Father 9 said: “I often needed to console my wife because she worried too much about the risks of the surgery.”

Support from family members

Family members often offered great support mentally and instrumentally. Mother 6 said: “My parents and in-laws knew she (her daughter) had heart surgery, so they provided us some financial support. My sister and my husband's brother also wanted to help us to care for her.” Some fathers did not want to add more stress to their spouse, so they expressed their worries to their parents and siblings and got warm support from them.

Discussion

This qualitative study explored how the parents of children with CHD experienced the surgical decision-making for their child. [Thomi et al. \(2019\)](#) indicated that when facing a child's critical disease, parents needed to reorganize themselves, try to understand the disease, and find the best treatment for their child's health. With the increasing popularity of information networks and smart phones, parents of children with a disease use such technology as their sources of health information to understand their child's health conditions and to make treatment decisions, especially among parents with high education levels ([Kubb & Foran, 2020](#)). However, parents often were not sure about the accuracy of the online information ([Yardi et al., 2018](#)). If the parents received inaccurate information or had an incorrect understanding, this could result in increased anxiety ([Hand et al., 2013](#)). Ten of our 12 parents had a high education level of college or above and everyone used online information to prepare themselves to ask the surgeon questions and to supplement what they did not understand after the surgeon's explanation. They would search professional websites to compare and cross-check the information's accuracy. They also learned from similar experiences shared by others. Through knowing many successful cases, they gained courage and confidence. Our finding is consistent with a previous study ([Thoren et al., 2013](#)).

There is often no other alternative to cardiac surgery, which is usually an urgent treatment for the child. Parents can only passively accept the arrangement of surgery. However, regardless of the complexity and severity of the disease, parents still expect to be fully informed by the professional so they can make final decisions ([Gutman et al., 2018](#)). In this study, the surgeons explained the examination's imaging to help parents understand their child's abnormal cardiac structure and the necessity of the surgery; nevertheless, most of the time parents felt the surgeon was too busy for them to ask questions, overly used medical terms, or explained issues insufficiently. Previous research indicates that if the physicians speak too fast and do not provide parents the opportunity to ask questions, it may lead to ambiguity of the content

(Gutman et al., 2018). Lack of information, unclear information and an unpredictable disease are also further causes for the parents of hospitalized children to feel uncertainty (Krick et al., 2020; Stewart & Mishel, 2000). Using simple language to explain information and respecting the parents' preferences will help parents make important decisions, especially regarding highly complex cardiac surgery (Allen, 2014; Etnel et al., 2018). Providing the appropriate amount of guidance from the surgeon can enhance a parent's satisfaction with the clinical encounter and trust in the surgeon (Carlisle et al., 2021). This is in line with our study in that the parents of two children with a valve replacement felt satisfied because the surgeon explained the choices and respected their preferences. However, although our parents had trust in the surgical team, they still hoped to have sufficient and clear information, including the worst outcomes, risks and complications of the surgery, to ensure the best decision for their child before the surgery.

Previous research found that it is particularly difficult for parents to live through the day of the operation, and feelings of uncertainty are most obvious while waiting outside the operating room because they are not sure of the outcome of the surgery (McMahon & Chang, 2020; Wei et al., 2016). In our study, the news related to a celebrity's unexpected death during heart surgery further exacerbated the parents' uncertain feeling about the success of heart surgery.

Nurses can play an important role during the surgical decision-making process. They often are considered as a dependable resource to the parents because of their medical background, working with the medical teams and spending time with the parents (Tariman & Szubski, 2015). They can share experiences, answer questions and clarify the doctors' information (Bos-van den Hoek et al., 2021). Their informal conversation before the parents' discussion with the doctors or after the doctor's explanation can help the parents face the heart surgery (de Man et al., 2020) and make a decision (Strachan et al., 2018). It is suggested that nurses continue to assess the parents' needs and provide support to reduce their anxiety and feelings of uncertainty before and after a child's surgery.

When the child has a life-threatening disease, parents will go through a process of self-adjustment to manage adversity and psychological trauma (Bally et al., 2018). They find positive meanings through the process of surgical decision-making (McMahon & Chang, 2020). After comparing the diseases and treatments of other children, they learn to see their situation from a different perspective and increase their hope (Smith et al., 2018). These adjustments are in line with our finding. Because our parents faced the child's critical condition, they knew their child needed surgery to survive, despite of lot of worry and concerns. Parents gained confidence when they learned other children had recovered from a serious heart condition or when they realized that at least their child could be treated.

During this difficult time parents would seek external support such as from religion and social networks to reduce their emotional distress (de Man et al., 2020). With religious diversity in Taiwan, Zimmer et al. (2018) found that the reasons for participation in religious activities among Taiwanese was that of mostly praying for peace and health. Believing in a supernatural Will of a deity they believed in and worshipped, and knowing that there were things beyond their control, could reduce their tension (Lee & Lin, 2013). Parents relied on religious rituals such as prayer, the Bible, and cultural relics to connect with a higher-powered God for guidance, comfort and support (Uveges et al., 2019). They believed that religious rituals would affect the survival and health of their children after surgery (Ladak et al., 2020) and a deity would guide them to make a right decision (Superdock et al., 2018). These attitudes may explain why most of our parents, including atheists, sought religious help when facing the surgical decision.

Mutual support from the spouse is also very important when facing the child's life-threatening disease and surgery. Their child's disease makes them act together and take care of each other (Rempel et al., 2012). Besides, the instrumental and emotional support from other family members could share the parents' concerns. Through sharing

and talking with their close relatives and friends, parents would have courage to face the crisis and make a surgical decision (de Man et al., 2020).

Practice implications

Although an urgent corrective surgery is inevitable for many children with CHD, when explaining the treatment procedures, the surgeon still needs to make sure of the individual parent's information needs, use plain language, and encourage parents to ask questions. Nurses can play an important role in providing adequate preparation and support to reduce the parents' worries and feelings of uncertainty during the decision-making and surgical processes. Our findings are contributory to the global body of literature and practice to broaden understanding of the needs of parents of children with CHD.

Limitations

The limitation of this study was due to the Coronavirus pandemic and the strict visiting policy in the research hospital; thus, the parents' willingness to participate was affected. In addition, because the interview was arranged two weeks after the surgery, these parents' thoughts and feelings might be influenced by the outcomes of the surgery.

Conclusion

Overall, within Taiwanese cultural and medical environments, informational, instrumental and emotional support needs are essential for parents during their participation in the surgical decision-making process. The findings of this study can serve as a reference for health professionals.

Credit author statement

Mei-Hua Wu: Conceptualization, Methodology, Investigation, Formal analysis, Writing- Original draft.

Tzu-Ying Lee: Conceptualization, Methodology, Formal analysis, Writing- Original draft, Writing - review & editing.

Mei-Hsiang Lin: Supervision, Validation, Writing- reviewing & Editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

- Allen, K. A. (2014). Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*, 51(9), 1289–1304. <https://doi.org/10.1016/j.ijnurstu.2014.02.003>.
- Bally, J. M. G., Smith, N. R., Holtslander, L., Duncan, V., Hodgson-Viden, H., Mpofu, C., & Zimmer, M. (2018). A metasynthesis: Uncovering what is known about the experiences of families with children who have life-limiting and life-threatening illnesses. *Journal of Pediatric Nursing*, 38, 88–98. <https://doi.org/10.1016/j.pedn.2017.11.004>.
- Bos-van den Hoek, D. W., Thodé, M., Jongerden, I. P., Van Laarhoven, H. W. M., Smets, E. M. A., Tange, D., ... Pasman, H. R. (2021). The role of hospital nurses in shared decision-making about life-prolonging treatment: A qualitative interview study. *Journal of Advanced Nursing*, 77(1), 296–307. <https://doi.org/10.1111/jan.14549>.
- Carlisle, E. M., Klipowicz, C. J., Shinkunas, L. A., Scherer, A. M., & Kaldjian, L. C. (2021). Discrepancies in decision making preferences between parents and surgeons in pediatric surgery. *BMC Medical Informatics and Decision Making*, 21(1), 42. <https://doi.org/10.1186/s12911-021-01414-z>.

- Etnel, J. R. G., Helbing, W. A., Roos-Hesselink, J. W., The, R., Bogers, A., & Takkenberg, J. J. M. (2018). Patient and physician view on patient information and decision-making in congenital aortic and pulmonary valve surgery. *Open Heart*, 5(2), Article e000872. <https://doi.org/10.1136/openhrt-2018-000872>.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10>.
- Gutman, T., Hanson, C. S., Bernays, S., Craig, J. C., Sinha, A., Dart, A., ... Tong, A. (2018). Child and parental perspectives on communication and decision making in pediatric CKD: A focus group study. *American Journal of Kidney Diseases*, 72(4), 547–559. <https://doi.org/10.1053/j.ajkd.2018.05.005>.
- Hand, F., McDowell, D. T., Glynn, R. W., Rowley, H., & Mortell, A. (2013). Patterns of internet use by parents of children attending a pediatric surgical service. *Pediatric Surgery International*, 29(7), 729–733. <https://doi.org/10.1007/s00383-013-3317-5>.
- Hoang, K., Halpern-Felsher, B., Brooks, M., & Blankenburg, R. (2020). Shared decision-making with parents of hospitalized children: A qualitative analysis of parents' and providers' perspectives. *Hospital Pediatrics*, 10(11), 977–985. <https://doi.org/10.1542/hpeds.2020-0075>.
- Joshi, R., Kalra, R., Kumar, N., Aggarwal, N., Joshi, R. K., Aggarwal, M., & Pandey, R. (2016). Critical decision of operability in congenital heart disease patient with severe pulmonary hypertension. *Annals of Cardiac Anaesthesia*, 19(4), 744–746. <https://doi.org/10.4103/0971-9784.191561>.
- Kon, A. A. (2010). The shared decision-making continuum. *JAMA*, 304(8), 903–904. <https://doi.org/10.1001/jama.2010.1208>.
- Krick, J. A., Hogue, J. S., Reese, T. R., & Studer, M. A. (2020). Uncertainty: An uncomfortable companion to decision-making for infants. *Pediatrics*, 146(Suppl. 1), S13–s17. <https://doi.org/10.1542/peds.2020-0818E>.
- Kubb, C., & Foran, H. M. (2020). Online health information seeking by parents for their children: Systematic review and agenda for further research. *Journal of Medical Internet Research*, 22(8), Article e19985. <https://doi.org/10.2196/19985>.
- Ladak, L. A., Gallagher, R., Hasan, B. S., Awais, K., Abdullah, A., & Gullick, J. (2020). Exploring the influence of socio-cultural factors and environmental resources on the health related quality of life of children and adolescents after congenital heart disease surgery: parental perspectives from a low middle income country. *Journal of Patient-Reported Outcomes*, 4, Article 72. <https://doi.org/10.1186/s41687-020-00239-0>.
- Lee, T. Y., & Lin, F. Y. (2013). Taiwanese parents' perceptions of their very low-birth-weight infant with developmental disabilities. *The Journal of Perinatal and Neonatal Nursing*, 27(4), 345–352. <https://doi.org/10.1097/JPN.0b013e3182a98408>.
- Lin, M. L., Huang, C. T., & Chen, C. H. (2016). Reasons for family involvement in elective surgical decision-making in Taiwan: A qualitative study. *Journal of Clinical Nursing*, 26(13–14), 1969–1977. <https://doi.org/10.1111/jocn.13600>.
- Madrugal, V. N., Carroll, K. W., Hexem, K. R., Faerber, J. A., Morrison, W. E., & Feudtner, C. (2012). Parental decision-making preferences in the pediatric intensive care unit. *Critical Care Medicine*, 40(10), 2876–2882. <https://doi.org/10.1097/CCM.0b013e31825b9151>.
- de Man, M. A. C. P., Segers, E. W., Schappin, R., van der Leeden, K., Wösten-van Asperen, R. M., Breur, H., ... van den Hoogen, A. (2020). Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review. *Acta Paediatrica*, 1–11. <https://doi.org/10.1111/apa.15694>.
- Mari, M. A., Cascudo, M. M., & Alchieri, J. C. (2016). Congenital heart disease and impacts on child development. *Brazilian Journal of Cardiovascular Surgery*, 31, 31–37. <https://doi.org/10.5935/1678-9741.20160001>.
- McMahon, E., & Chang, Y. S. (2020). From surviving to thriving - parental experiences of hospitalised infants with congenital heart disease undergoing cardiac surgery: A qualitative synthesis. *Journal of Pediatric Nursing*, 51, 32–41. <https://doi.org/10.1016/j.pedn.2019.12.010>.
- Rempel, G. R., Blythe, C., Rogers, L. G., & Ravindran, V. (2012). The process of family management when a baby is diagnosed with a lethal congenital condition. *Journal of Family Nursing*, 18(1), 35–64. <https://doi.org/10.1177/1074840711427143>.
- Rosenzweig, E. B., & Krishnan, U. (2021). Congenital heart disease-associated pulmonary hypertension. *Clinics in Chest Medicine*, 42(1), 9–18. <https://doi.org/10.1016/j.ccm.2020.11.005>.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Shinkunas, L. A., Klipowicz, C. J., & Carlisle, E. M. (2020). Shared decision making in surgery: A scoping review of patient and surgeon preferences. *BMC Medical Informatics and Decision Making*, 20(1), 190. <https://doi.org/10.1186/s12911-020-01211>.
- Smith, N. R., Bally, J. M. G., Holtslander, L., Peacock, S., Spurr, S., Hodgson-Viden, H., ... Zimmer, M. (2018). Supporting parental caregivers of children living with life-threatening or life-limiting illnesses: A delphi study. *Journal of Specialists in Pediatric Nursing*, 23(4), Article e12226. <https://doi.org/10.1111/jspn.12226>.
- Stewart, J. L., & Mishel, M. H. (2000). Uncertainty in childhood illness: a synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice*, 14(4), 299–326.
- Strachan, P. H., Kryworuchko, J., Nouvet, E., Downar, J., & You, J. J. (2018). Canadian hospital nurses' roles in communication and decision-making about goals of care: An interpretive description of critical incidents. *Applied Nursing Research*, 40, 26–33. <https://doi.org/10.1016/j.apnr.2017.12.014>.
- Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nursing Outlook*, 53(3), 127–133. <https://doi.org/10.1016/j.outlook.2005.03.005>.
- Superdock, A. K., Barfield, R. C., Brandon, D. H., & Docherty, S. L. (2018). Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: A qualitative study. *BMC Palliative Care*, 17(1), 107. <https://doi.org/10.1186/s12904-018-0360-y>.
- Tariman, J. D., & Szubski, K. L. (2015). The evolving role of the nurse during the cancer treatment decision-making process: A literature review. *Clinical Journal of Oncology Nursing*, 19(5), 548–556. <https://doi.org/10.1188/15.Cjon.548-556>.
- Thomi, M., Pfammatter, J. P., & Spichiger, E. (2019). Parental emotional and hands-on work-experiences of parents with a newborn undergoing congenital heart surgery: A qualitative study. *Journal for Specialists in Pediatric Nursing*, 24(4), Article e12269. <https://doi.org/10.1111/jspn.12269>.
- Thoren, E. M., Metzke, B., Bühner, C., & Garten, L. (2013). Online support for parents of pre-term infants: A qualitative and content analysis of facebook 'preemie' groups. *Archives of Disease in Childhood - Fetal and Neonatal Edition*, 98(6), F534. <https://doi.org/10.1136/archdischild-2012-303572>.
- Tom, D. M., Aquino, C., Arredondo, A. R., & Foster, B. A. (2017). Parent preferences for shared decision-making in acute versus chronic illness. *Hospital Pediatrics*, 7(10), 602–609. <https://doi.org/10.1542/hpeds.2017-0049>.
- Tort, M., Ceviz, M., Sevil, F., & Becit, N. (2021). Surgical treatment for Patent Ductus Arteriosus: Our experience of 12 years. *Cureus*, 13(4), Article e14731. <https://doi.org/10.7759/cureus.14731>.
- Uveges, M. K., Hamilton, J. B., DePriest, K., Boss, R., Hinds, P. S., & Nolan, M. T. (2019). The Influence of parents' religiosity or spirituality on decision making for their critically ill child: An integrative review. *Journal of Palliative Medicine*, 22(11), 1455–1467. <https://doi.org/10.1089/jpm.2019.0154>.
- Wei, H., Roscigno, C. I., Swanson, K. M., Black, B. P., Hudson-Barr, D., & Hanson, C. C. (2016). Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing. *Heart and Lung*, 45(2), 154–160. <https://doi.org/10.1016/j.hrtlng.2015.12.007>.
- Yardi, S., Caldwell, P. H., Barnes, E. H., & Scott, K. M. (2018). Determining parents' patterns of behaviour when searching for online information on their child's health. *Journal of Paediatrics and Child Health*, 54(11), 1246–1254. <https://doi.org/10.1111/jpc.14068>.
- Yeh, S. J., Chen, H. C., Lu, C. W., Wang, J. K., Huang, L. M., Huang, S. C., ... Wu, M. H. (2015). National database study of survival of pediatric congenital heart disease patients in Taiwan. *Journal of the Formosan Medical Association*, 114(2), 159–163. <https://doi.org/10.1016/j.jfma.2012.10.006>.
- Zimmer, Z., Rojo, F., Ofstedal, M. B., Chiu, C. T., Saito, Y., & Jagger, C. (2018). Religiosity and health: A global comparative study. *SSM Population Health*, 7, 006–6. <https://doi.org/10.1016/j.ssmph.2018.11.006>.