

ORIGINAL ARTICLE

“When the surgery was over, I felt like the worst part had passed”: experiences of parents of children with craniosynostosis

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Abstract

Purpose: Parents of children scheduled for surgery often experience emotional distress and anxiety. This study aimed to explore parents' experiences of hospital care after their child's craniosynostosis surgery and their perception of support during the year after discharge.

Design and Methods: A purposive sample of 19 parents of 12 children with nonsyndromic craniosynostosis, who had undergone surgery, was recruited from one of two national centers in Sweden. An interview was conducted ~1 year after the child's surgery, from September 2017 to August 2018. The interviews followed a semistructured interview guide, were recorded, transcribed verbatim, and analyzed using inductive content analysis.

Results: The analysis yielded six categories with subcategories as follows: (1) cared for and confident: the hospital staff was perceived as kind, professional, and reliable. (2) Alone and abandoned: sometimes, parents found it hard to initiate contact with professionals during hospitalization and after discharge. (3) The importance of information: thorough information was perceived as essential and the need for information varied during postsurgery period. (4) Feelings of worry: some parents remained worried about risks during recovery and were concerned about comorbidities and development. (5) Alright after all: parents felt that the worst part had been before surgery. (6) The need for support: parents were generally satisfied with the support offered and they often received support from family and friends, or other parents through social media/online forums.

Practice Implications: Healthcare professionals must be responsive to what support parents need at different stages in the care process and be aware that parents sometimes hesitate to initiate contact and ask for help and support. Support from healthcare professionals to everyone in the follow-up program, as a default, might be more accessible or acceptable for some parents. Providing online support from

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professionals should be considered and caregivers could also facilitate peer support among parents, either face-to-face or online.

KEYWORDS

craniosynostosis, multidisciplinary team care, parent experience, support

WHAT IS CURRENTLY KNOWN?

Being a parent of a child who has to undergo surgery is commonly experienced as challenging. Parents' needs for support often change during the care process.

WHAT DOES THIS ARTICLE ADD?

Further insights into how parents experience the care and support given during and after their child's craniosynostosis surgery. Caregivers must be responsive to what support parents need at different stages in the care process and be aware that some parents hesitate to ask for support, so they can facilitate for them. Support from healthcare professionals as part of routine care might be one solution, support available online should also be considered.

1 | INTRODUCTION

Parents of children scheduled for surgery often experience emotional distress and anxiety (Charana et al., 2018; Hinton et al., 2018; Pomicino et al., 2018). The wait while the child is in surgery can be distressing for parents and concerns about potential complications, surgical outcomes, anesthesia-related side effects, and postoperative care are reported (Hui et al., 2020). Moreover, the inevitable transition between different levels of care, from intensive care to a pediatric ward, can be experienced as being downgraded from a controlled and supportive environment with one-to-one nursing care to a less monitored, and more unsafe ward setting (Suleman et al., 2019). Furthermore, after discharge, some parents are overwhelmed by feelings of uncertainty (Simeone et al., 2018). Parental needs for information and support vary during the period from the day of surgery to the time after discharge (Kirk et al., 2015).

Craniosynostosis is a congenital malformation leading to premature fusion of one or more of the cranial sutures, resulting in abnormal head shape and growth (Di Rocco et al., 2009; Dias et al., 2020; Ursitti et al., 2011). Approximately 1 in 2000 live births is affected by craniosynostosis (Di Rocco et al., 2009; Neusel et al., 2018) and it is usually diagnosed in early infancy. Surgical treatment aiming to normalize the head shape and avoid a raised intracranial pressure is often performed during the child's first year of life. Care can be optimized by being organized around an interdisciplinary team (Mathijssen, 2015). Accessibility to information and support from an expert team has been described as key to mitigating parental stress and anxiety (Myhre et al., 2019).

There are previous descriptions of parental stress in connection to an infant's initial diagnosis of craniosynostosis. Parents have described worries about surgery and concerns about the infant's

long-term prognosis (Rosenberg et al., 2011; Zerpe et al., 2020). In a Canadian study, parents reported significant anxiety before their child's surgery, even though they felt well-informed. After surgery, parents described that they felt relieved, but there were also descriptions of further challenges when they left the hospital for home (Kuta et al., 2020). After surgical treatment, parents of children with craniosynostosis mostly report high satisfaction with the interdisciplinary craniofacial care provided (Kluba et al., 2016; Kuta et al., 2020; Wong-Gibbons et al., 2009). It is evident that parents of children scheduled for craniofacial surgery have worries and can experience emotional distress, like any parents with a child who must undergo surgery. To further develop evidence-based care, it is crucial to have more knowledge of parents' perspectives and their experiences of care during the whole process, including the time at home after discharge from the hospital. Qualitative research methods are particularly useful to answer questions about the individual's experiences. Integration of these methods into craniofacial research can ensure that patient and family perspectives are considered when developing practice and policy in craniofacial care (Nelson, 2009). This study aimed to explore parents' experiences of the time at the hospital and the year after discharge, and their perceived support needs after their child's craniosynostosis surgery.

2 | METHOD

2.1 | Design

This is an explorative interview-study with qualitative analysis.

2.2 | Setting

This study was conducted at the Uppsala Craniofacial Center, which is one of two national reference centers for craniosynostosis in Sweden. Patients are typically referred to the multidisciplinary craniosynostosis clinic by local pediatricians upon suspicion of craniosynostosis. During the first appointment, the family will learn about the diagnosis and whether surgery is indicated. Surgery is preferably performed during the first year of life, with the timepoint depending on the type of craniosynostosis and age at referral. During the hospital stay ahead of surgery, the child and parents are enrolled at a pediatric ward. After surgery, the child typically stays in an intensive care unit (ICU) for about 24 h before returning to the pediatric ward for further postoperative care. The total length of stay

ranges between 4 and 7 days, depending on the type of surgical procedure. At discharge, the parents are provided with verbal and written information about aftercare and contact information to the ward and the specialist team. A follow-up visit to the craniofacial nurse is scheduled one month after surgery. The nonsyndromic craniosynostosis protocol includes appointments with the team 12 months after surgery and at 3, 5, and 8 years of age.

2.3 | Participants

A purposive sample was used, and participants were parents of children with nonsyndromic craniosynostosis, who had undergone surgery at the Uppsala Craniofacial Center. From August 2016 to October 2016, seven children had undergone surgery and parents of these children were invited by post to participate in the study. Six mothers and three fathers of the seven children agreed to participate. In addition, we included parents who, at their first meeting with the craniofacial team, were invited to participate in an ongoing follow-up study (Zerpe et al., 2020). From that cohort, parents were contacted consecutively, by phone, 12 months after surgery. The additional inclusion was ended after interviews with five mothers and five fathers of five children due to saturation; no new information was discovered in data analysis. In all, 19 parents, 11 mothers, and 8 fathers, of 12 children, agreed to participate. The parents' age ranged from 26 to 40 years (mean 35, SD 4). Seven participants were first-time parents and 12 had at least 1 child before. Six of the participants lived in bigger cities, seven in small towns, and six lived in the countryside. All participants signed consent forms that the researchers collected before the interviews were conducted. The study was approved by the Regional Ethical Review Board in Uppsala (Dnr 2014/396/1).

2.4 | Data collection

All interviews but two were conducted by phone, ~1 year after the child's surgery, from September 2017 to August 2018. Based on participants' requests, two interviews took place at the 1-year follow-up with the craniofacial team. All parents were interviewed individually by a social worker experienced in conducting interviews and not involved in the treatment of the children. An interview guide with areas of interest was developed by the authors (A.S.Z. & C.Ö.) based on previous research. It consisted of open-ended questions about the parents' experiences and feelings regarding support needs and information, both in the postoperative period at the hospital and after discharge to home. The interview guide started with the phrase "If you think back to the time when it was detected that your child had a skull deformity..." to help the parents bring back memories from the period when their child was diagnosed or had surgery. This was followed by questions: "How do you recall the time in the hospital relating to the surgery? Where there something that you thought was lacking? How has the time at home been, after the surgery? Have you

felt need for support since you came home from the hospital? Have you sought support? If you got support, what sort of support and how was the support you received? Did you miss support missing during the past year?" Sociodemographic information was collected before the research interview through standard questions on the first page of the interview guide. The interviews (6–39 min, mean 15) were recorded digitally and then transcribed verbatim by a professional transcription service. All transcripts were given code numbers to protect anonymity and encourage accurate reporting. Only transcripts with coded data were discussed among the researchers.

2.5 | Data analysis

The interviews were analyzed using content analysis, a process of identifying, coding, and categorizing the primary pattern in the data (Krippendorff, 2018). Content analysis with an inductive approach was used, following the process described by Elo and Kyngäs (2008). Two of the authors conducted the analysis: A.S.Z., specialist nurse, PhD student, and C.Ö., specialist nurse, PhD, trained in qualitative methods.

The analysis commenced with the authors reading the transcripts several times to become familiar with the data and get an overview of the material. The authors then discussed the contents and their understanding of the text in relation to the aim. Keywords and phrases were identified from the transcripts, and open coding was conducted. The codes were compared to find commonalities and variations, and codes with similar meanings were grouped into categories to capture the parents' experiences (Elo & Kyngäs, 2008). The categories were then divided into subcategories based on dissimilarities within the categories, and the analysis continued until all categories and subcategories were considered clearly defined and distinct from one another. The two authors discussed the categorization until consensus was achieved. Please see Table 1 for examples of the analysis process.

3 | RESULT

The analysis of the interviews yielded 6 categories with 10 subcategories, presented in Table 2. Categories and subcategories are presented below with numbered quotes, selected to strengthen the validity of the analysis.

3.1 | Cared for and confident

3.1.1 | Competent and reliable staff

The hospital staff was perceived as kind, helpful, and understanding, as well as confident and professional. Cooperation with the staff worked well, and the parents felt secure in that the staff

TABLE 1 Example of the steps in the analysis process

Meaning unit	Code	Subcategory	Category
I want all the information there is so that I know, whether it is good or bad [information] it [the care] was very structured, and that felt very relieving	Need for "all" information Structure is comforting	Clarity produces security	The importance of information
most of all, my wife needed some support, so she has received help through that psychologist	The need for support	Perceived support	The need for support
We have a big family and lots of people was there, helping, listening, and supporting us	Got support from family	Getting support	

TABLE 2 The results presented in categories and subcategories

Categories	Subcategories
Cared for and confident	Competent and reliable staff Follow-up contacts
Alone and abandoned	
The importance of information	Clarity produces security Insecurity in not knowing
Feelings of worry	Worrying in advance Suffering with the child What the future holds
Alright after all	
The need for support	Perceived support Getting support Giving support

was competent and reliable. The simplicity of just ringing a bell to get attention was appreciated and created a feeling of security. Parents were offered help even with things they had not realized they needed help with. The staff offered support and advice at all times.

"Very good. Both I and my wife have talked a lot about it and we are extremely satisfied with their conduct and information and we really felt well taken care of and very secure" (10, father).

3.1.2 | Follow-up contacts

After discharge, the possibility to call the nurse in the craniofacial team or the pediatric ward, if needed, was perceived by some parents as comforting. Having easy access to the craniofacial team even after the acute phase made parents feel well taken care of. A phone call to the nurse was often enough to ease worries and to answer questions that had arisen. Overall, the dialogue with the craniofacial team was experienced as good and reliable. However, there were also descriptions that despite having been asked to contact the team if needed, some parents found it difficult to bring themselves to call.

"As I said, I think the dialogue with Uppsala has been good, like that there is a nurse and you can always like call them. As I said, round the clock, so the care afterward has been great, that we got what you ... had the security of calling them ... calling 'Health care information' when you get home or whatever, that would have been really weird" (1, mother).

The follow-up appointments with the craniofacial team members were appreciated, although some parents wished for more frequent visits during the first year after surgery. All kinds of follow-up appointments seemed to be appreciated. Whether it was a follow-up in a research study in which the child participated, with a physiotherapist, or at the childcare center, it gave the parents a sense of security that their child was checked up on.

3.2 | Alone and abandoned

This category includes descriptions of parents' feeling that no one took overall responsibility during the hospital stay. They were left with a feeling of being alone and on their own. Some suggested that they would probably have received more help if they had asked for it, but that it felt hard to ask.

The hospitalization was an intense experience and the feeling of insecurity and abandonment was sometimes increased by practical issues, such as being obliged to change rooms in the pediatric ward. Others found that the time at the ICU was the hardest. The child woke up and cried after surgery, making the parents feel alone and insecure. They would have wanted someone to be there, to help them with the medical equipment that sometimes made it difficult to hold and care for the child.

"I guess I have a memory that I can think back to quite often, it wasn't that great, it was, I guess, when she woke up after the operation and she was so upset, and I felt like there was no one there, really, who could help me with all the tubes and everything" (12, mother).

After discharge, some parents felt they were left on their own. There were sometimes difficulties in finding the right help at the local

hospital and they felt like they had to fight for their child's care themselves; no one else took responsibility.

3.3 | The importance of information

3.3.1 | Clarity produces security

Many parents expressed satisfaction with the information they received at the hospital. Some wished to be given all the available information, whether good or bad, to make informed decisions. It was valued when the doctors answered the parents' questions adequately, directly, and honestly. Some parents appreciated being present during change of dressing, so they knew what to expect. The plan for the care of the child was perceived as clear, and the families experienced that information fell into place piece by piece. Clarity and a well-established structure were considered reassuring and beneficial for both children and parents.

"You could tell we were not the first ones with a child who had undergone that surgery because it just went so smoothly, and there was a common thread in what was going to happen and which days it was and so on. Yeah, it went well" (2, father).

The discharge was a positive experience and both verbal and written information were valuable and satisfying. Some parents stated that they were pleased that they got information about the post-discharge aftercare already before the surgery.

3.3.2 | Insecurity in not knowing

It could be challenging not knowing precisely how long the surgery would take. Insecurity increased when directions to the ICU ward were not given correctly, delaying a parent's reunion with their child. Others described the uncertainty during the ICU stay as the hardest part, as they did not know, so soon after the surgery, how the child would recover. Some parents wanted more information about the risk for an imperfectly shaped head after surgery.

Uncertainty about when to expect the physician and if scheduled appointments would take place at the agreed time made the parents uncertain about when they could leave the room without the risk of missing important information. They said that it was difficult for them to plan their time and that they would have appreciated more forward planning.

At discharge, parents often experienced a lack of information and felt that staff was not fully informed about the discharge plan, delaying the journey home. Some parents would have wanted more detailed information about the child's expected physical and psychological development, and other diagnoses connected to craniosynostosis.

3.4 | Feelings of worry

3.4.1 | Worrying in advance

Some parents said that they worried more in advance and felt almost calm during the hospital stay. Expecting the worse made the problems during hospitalization seem small. Others said they took turns with their partner in being worried; when one parent felt worried, the other took on the calming role and vice versa. Some parents stated that they did not feel worried at all before the surgery.

"Because when we got to the hospital and the operation ... It was like ... I had taken it all out in advance, so once I was in the hospital then I just felt relieved, everything went so well, it was like ... But then, on the other hand, my boyfriend had a really hard time, so it was good that we had [laugh] ... that we took turns, so they had at least one parent who was ... conscious, I almost said" (8, mother).

3.4.2 | Suffering with the child

Parents described that the worst experience during the hospitalization was seeing their child sad, afraid, and in pain. They were in a situation they had never experienced before and wanted to switch places with their child. It was a challenging time and an intense experience. Some parents found it hard to manage; they felt like they were supposed to be stronger than they were actually capable of.

"Yeah, well it was an emotional rollercoaster. It was ... it was despair and happiness and at the same time and then it was sadness, what she had been through and what we are going through and so on, but I always felt that I was safe" (7, mother).

Coming home was a relief for most parents; some said that their child got better immediately when they got home. For some families, the first few weeks were a struggle; problems with the sleeping position, nights with many awakenings, and a baby with extra proximity needs were considered challenging. Some parents perceived that their child was in pain during those first few weeks, whereas others did not. The scar on the head also made some parents feel concerned. The child's recovery was described as very quick in most cases, although it took a little longer for some to get back to normal.

3.4.3 | What the future holds

There was relief after the surgery had been performed, although new worries appeared. Worries about complications sometimes made the

parents overprotective, trying to prevent their child from falling or hitting their head. Other worries were connected to the child's development and long-term consequences of the surgery and the diagnosis. Parents stated that they would probably be more observant of head shape if they were to have another child.

"Our biggest concern has not been about his head shape or anything like that but about development and his ... how he ... well, you know ... you've seen that there is some comorbidity in some diagnoses and he was rather late in his development. He went through a lot so maybe there was a reason that he was late, but I guess that's the concern that we've had, but it has successively gotten better, the more he has gained his strength. That worry has been greater than the actual physical, or whatever I should call it" (13, father).

3.5 | Alright after all

Most parents felt that the time after the surgery was alright, there was a feeling that the worst part had passed. The overall feeling was positive and after the acute phase there were no problems. There was a sense of security and comfort in realizing that their child was not the first who had been through this. Parents did not recall that they missed anything and the hospital stay was considered quite good or great overall.

"So, that was good. I can't imagine that I could have better... Okay, it could be better if he maybe had not had this [short laugh], but this whole situation, so yeah, it was good" (6, mother).

The hospital facilities were good, according to most of the parents. The experience was also satisfying thanks to the staff focusing on the next-of-kin as well, which was considered unusual.

After discharge, everything went back to normal and the parents felt relieved seeing that everything was going in the right direction for their child. Several parents described that the child developed more rapidly after the surgery than before.

3.6 | The need for support

3.6.1 | Perceived support

Support was often given by friends and family, usually the other parent or grandparents. Families that could stay together at the hospital often felt that their own family was the best source of support.

The craniofacial team and the hospital staff offered support during the hospital stay, which was often appreciated. Support from

the team was sometimes experienced as being given at the wrong time. Some stated that the support would have been of greater help if it had been given before the surgery, rather than after. Some parents declined support from the team, as they felt they did not need it.

The possibility to have continuous support from the team psychologist after discharge was considered valuable by some. It was suggested that psychological support should not be optional, because parents might not understand that the support would be beneficial in stressful situations. For others, the possibility to call the team nurse if needed was considered enough; although most of them never felt the need to call, the fact that the possibility was given made them feel safe.

"Yeah, so they were so clearer, they were as clear as they could be, they said that we can help you get good help at home. What one might consider, the other thing, is that you should maybe almost force it, that it isn't just an offer, but that you have ... yeah, made contact with someone who calls you or something, because I think there are many who think no, I don't need that, I'm okay" (7, mother).

3.6.2 | Getting support

Some parents stated that they did not need or ask for any support, although they did say that they felt comforted by talking to friends and family.

"I have sought support from my loved ones, so both with my partner, because you talk about it because it's so real for both of us, like been able to hear, what was hard for you, what ... You know, like, what parts ... and then also with friends, I have talked a lot, and then my brother" (3, mother).

Peer support and support from social media was of great importance to some parents. Seeking advice from others in the same situation or with similar experiences was sometimes the most valuable support.

3.6.3 | Giving support

Some parents continued to support other parents in social media and "parenting forums" on the internet long after their own child's surgery. They wanted to offer others the support they had valued so highly themselves.

"Yeah, this kind of group ... There is some Facebook group that I'm still involved in ... and that has been fantastic, that is something that I'm doing for other

parents in similar situations. Because I got to see a mother with a two-year-old boy, and it was so comforting to just ... like ... one worries a lot unnecessarily" (8, mother).

4 | DISCUSSION

Most parents experienced the hospital stay as quite good or great. One of the worst experiences during the hospitalization was seeing their child sad, afraid, and in pain and not being able to do anything as a parent. When the surgery was over, parents felt that the worst part had passed and were relieved. However, there were also descriptions of being left alone during hospital care, in a room with unknown equipment, and feeling abandoned. Coming home was a relief for most parents. Still, the possibility to easily get in contact with the craniofacial team or the pediatric ward after discharge was perceived as comforting and made parents feel well taken care of. Some parents described worries about the long-term consequences on the child's development of the surgery and the diagnosis. Parents were generally satisfied with the support offered, although some found it hard to initiate contact with the professionals. A lot of support was gained through talking to friends and family. For some parents, social media was of great importance.

There are difficulties related to comparing experiences of hospital care and need for support for parents of children with different diagnoses. For most children with single suture craniosynostosis, one surgery during their first year of life is the only treatment needed. Hospitalization is relatively short in contrast to children with chronic diseases leading to additional treatments and hospitalizations. Nevertheless, the parents' experiences are influenced by the whole treatment process and worries before the surgery and connected to long-term consequences of the surgery and the diagnosis are evident. The aim should be that the experience as a whole is perceived as good. The care around these patients has gradually developed and a team-based approach of working is strongly recommended for children with craniosynostosis and their families (Mathijssen, 2015).

Most parents stated that the hospital staff was perceived as professional. A structure that was well-established and obviously familiar to the staff gave a sense of security and confidence. Parents appreciated being provided with information about changes well in advance. Anxiety arose if there was unclarity about the expected length of surgery; parents could misinterpret a prolonged surgery as a sign that it had gone wrong. Kuta et al. (2020) also found that even, although parents felt it was hard to hand over their child for craniofacial surgery, they were comforted by getting regular updates throughout the procedure. When parents were left alone without being informed, they felt insecure and abandoned. A similar description was seen in a study from pediatric care, where parents described that they received too little kindness, attention, and time with the staff during their hospital stay. They wished for the staff to

support them more by listening and being more available and present (Sarajarvi et al., 2006). Giving continuous information is of great importance, as it comforts parents (Kuta et al., 2020). Nevertheless, there is a risk that information can be rendered ineffective if given at the wrong time or in excessive amounts (Hinton et al., 2018). Therefore, timing is essential. Parents' needs for information and support are not fixed; they change over time and should be evaluated repeatedly, which previous research has identified (Kirk et al., 2015).

Parents stated that they would probably have received more help at the pediatric ward if they had asked for it, but some found it hard to ask. One can only speculate why some parents felt resistance to asking for help during the hospital stay. Previously, it has been shown that parents dissatisfied with pain management those cared for by nurses with less time to communicate with the family (Simons, 2002). It is important to identify and address individual needs during a child's hospitalization. Supporting parents may increase their participation in care, while also decreasing psychological distress (Jones et al., 2017).

Most parents were satisfied with the information offered at discharge, in accordance with results from previous studies of craniosynostosis (Kluba et al., 2016; Wong-Gibbons et al., 2009). On the other hand, parents stated that they would have wished for more information about long-term consequences and risks. Perhaps there is no perfect time to broach the topic of risks, such as the increased risk for developmental delays. Nevertheless, based on the parents' descriptions, these questions should be discussed early in the care process. Some parents requested more information about the risk for abnormal head shape, even after surgery. It seemed that parents were not fully aware of the limitations of surgery and to avoid disappointment it is essential that surgeons clearly explain the goals and limitations of surgical treatment (Kluba et al., 2016).

Most parents found it comforting to receive contact information to the nurse in the craniofacial team or the pediatric ward, so they could get in contact after discharge, if needed. The importance of having access to support from health care after discharge from the hospital and caring for the child during the postoperative time period are highlighted in interviews with parents (Hinton et al., 2018). This is also in line with previous research in craniofacial surgery, showing that easy access to someone in the team, who can handle issues of a medical, psychosocial, or emotional nature, and who can coordinate care, is of great importance (Burokas, 2013; Kuta et al., 2020; Mathijssen, 2015). In addition, the finding from a review, which many parents had difficulty managing the instructions they received when their child was discharged from hospital, underscores the value of clear communication and discharge plans as well as the possibility of getting support after coming home (Glick et al., 2017).

For most parents, worries were replaced by relief immediately after their child's surgery. Nevertheless, new concerns emerged for some, and other worries that had been present from the start remained. Concerns related to protecting the child from getting hurt during recovery made some parents overprotective. Worries about the child's development and potential comorbid disorders linked to craniosynostosis were reported, which was also seen in an earlier

study about parental experiences of the time for identification of craniosynostosis (Zerpe et al., 2020). These results contradict those of another study where parents, after surgery, no longer worried about neurological deficits or their child not meeting developmental milestones (Kuta et al., 2020). This difference may be explained by the time-point for the interview. Parents in the study by Kuta et al. (2020) were interviewed 3 months after surgery, while parents in our study were contacted after a year. It may be that thoughts and worries about the child's development over time become more evident as the child grows.

Some parents suggested that support from healthcare professionals, offered by the craniofacial team should be offered on a routine basis, not merely upon request. This because parents in this stressful situation might not be able to identify their own support needs. Earlier research from pediatric intensive care has shown that targeted support should be provided to mitigate the negative emotional and psychological effects that parents can experience (Suleman et al., 2019). It might have been easier for some parents to accept support from healthcare professionals if it was integrated into the program and not optional.

On the other hand, support from healthcare professionals may not be the best option for everyone. In this study, many participants stated that they got support from family and friends, which in past research has been found to be associated with less negative family impact and lower psychological stress (Baker et al., 2009). Some considered the support of peers to be the most valuable, and it was often received through social media and internet forums for parents of children with craniosynostosis. Being able to talk to people with similar experiences was considered soothing. This is in line with past results, where parents described support from other parents with similar experiences as crucial for them to understand and cope with their own baby's diagnosis (Hinton et al., 2018). Parents find information, practical and emotional support, and enjoy interacting with each other via internet forums (Jacobs et al., 2016; Niela-Vilén et al., 2014). Internet-based peer support is described as a unique form of support for parents, not replacing but supplementing support from healthcare professionals (Niela-Vilén et al., 2014).

Some parents continued to be active in these social media groups and forums even long after their child's surgery. They described it as a way of paying forward the valuable support they received themselves. Possibly, it was also a way for them to continue to process their own experience. Kuta et al. (2020) found that while parents acted as advocates for their own children in the preoperative period, they advocated for the craniosynostosis community at large in the postoperative period. A study from 2016 investigating peer support in groups and online forums found that most respondents would appreciate the active participation of health care practitioners in their group or forum. The health care practitioners that most respondents wanted to interact with online were specialist nurses (Jacobs et al., 2016). This was not mentioned in this study but could be of great interest to investigate in further research.

4.1 | Strengths and limitations

This study has limitations that should be addressed. The interviews were conducted one year after surgery. To minimize the risk of recall bias, the interviews were opened with a phrase to help the parents bring back memories from the specific period. Still, memories could have faded or been altered. Some of the interviews were shorter than one would wish for in a qualitative interview study. Still, these interviews contained important and valuable information that contributed in the data collection. Strengths include the number of informants, which was rather large for a qualitative study, and the inclusion of both fathers and mothers, which enabled a broader understanding of parental perspectives. The parents' willingness to participate may in some way be related to their perception of the importance of the research topic.

To establish methodological rigor the concepts of trustworthiness from Lincoln and Guba (1985) were applied: credibility, dependability, confirmability, and transferability. To strengthen credibility the sampling was purposeful with participation of both fathers and mothers with experiences of their child's surgery. The parents were interviewed at approximately the same time after the surgery. To further ensure credibility, researcher triangulation was used, in the sense that two authors conducted the analysis together. The interviewer used an interview guide, was experienced in conducting interviews, and was not involved in the treatment of the children, this to provide dependability. To provide confirmability, the analysis was in constant discussion between the two authors performing the analysis. After categorization, all authors, having different expertise and knowledge as physicians and nurses in plastic surgery, child and adolescent psychiatry and pediatric care, discuss the result in light of the interviews. To enable transferability, we sought to ensure transparency by clearly describing the context, participants, data collection, and analysis.

5 | CONCLUSION

Implementing regular updates to parents during surgery could hopefully decrease parental anxiety and improve the information given. Parents' worries and anxieties related to risks for long-term consequences, such as developmental issues, indicate that improved information is needed. Some parents of children with craniosynostosis found it hard to ask for help during the hospital stay and to initiate contact with the craniofacial team after discharge. Mandatory follow-ups might therefore help those parents get support. Research focusing on online peer support could evaluate the benefits of health care practitioners taking part.

6 | HOW MIGHT THIS INFORMATION AFFECT NURSING PRACTICE?

A specialist nurse coordinates the care in a multidisciplinary team and—beyond providing professional nursing care—also serve as the contact point between parents of affected children and the team.

In meetings with mothers and fathers with a child who must undergo surgery, nurses should be aware that it is sometimes hard for parents to initiate contact or ask for help. The specialist nurse should identify and evaluate the needs for support during the care process and tailor the support offered to each family. The specialist nurse could facilitate for parents by helping them find parents with similar experiences or peer support online.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data available on request from the authors

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