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Decision-Making in Cleft-Related Surgery: A Qualitative Analysis of Patients and Caregivers

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Abstract

Objective: Preference-sensitive surgical decisions merit shared decision-making, as decision engagement can reduce decisional conflict and regret. Elective cleft-related procedures are often preference sensitive, and therefore, we sought to better understand decision-making in this population.

Design: Semistructured interviews were conducted to elicit qualitative data. A hierarchical codebook was developed through an iterative process in preparation for thematic analysis. Thematic analysis was performed to examine differences between patients and caregivers.

Setting: Multidisciplinary cleft clinic at a tertiary care center.

Participants: Patients with cleft lip aged 8 and older (n = 31) and their caregivers (n = 31) were purposively sampled. Inability to converse in English, intellectual disability, or syndromic diagnoses resulted in exclusion.

Main Outcome Measures: Preferences surrounding surgical decision-making identified during thematic analysis.

Results: Mean patient age was 12.7 (standard deviation: 3.1). Most had unilateral cleft lip and palate (43.8%). Three themes emerged: Insufficient Understanding of Facial Difference and Treatment, Diversity of Surgical Indications, and Barriers to Patient Autonomy. Almost half of caregivers believed their children understood their clefts, but most of these children failed to provide information about their cleft. Although many patients and caregivers acknowledged that surgery addressed function and/or appearance, patients and caregivers exhibited differences regarding the necessity of surgery. Furthermore, a large proportion of patients believed their opinions mattered in decisions, but less than half of caregivers agreed.

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Supplemental Material

Supplemental material for this article is available online.

Conclusions: Patients with clefts desire to participate in surgical decisions but have limited understanding of their facial difference and surgical indications. Cleft surgeons must educate patients and facilitate shared decision-making.

Keywords

decision-making[MeSH]; cleft lip[MeSH]; cleft palate[MeSH]

Introduction

Shared decision-making in plastic surgery is a critical element of preference-sensitive health-care decisions in which multiple treatment options are available (Margenthaler and Ollila, 2016). Familiar examples of preference-centered treatment decisions among adults undergoing surgical care include breast conservation therapy versus mastectomy as well as implant-based breast reconstruction versus autologous breast reconstruction (Sherman et al., 2016; Ager et al., 2018). Improving decision quality in these situations offers a more patient-centered perspective and can improve cost-effectiveness by minimizing care utilization in patients who remain uncertain about surgery (Sepucha et al., 2004). Furthermore, most providers adhere to the growing consensus that shared decision-making has supplanted paternalism as the standard for health-care decisions (Barry and Edgman-Levitan, 2012).

Among children undergoing surgical care, shared decision-making is less well described. In pediatric patients, the decision for surgery includes the opportunity for caregivers to “consent” by giving permission for an operation, but surgeons should simultaneously seek the child’s assent (Katz and Webb, 2016). Orofacial clefts, the most common craniofacial anomaly, occur in approximately 7500 children each year with almost all primary reconstructions performed in infancy (Basseri et al., 2011). However, revision-related procedures for orofacial clefts occur later, when children can often participate meaningfully in such decisions (Monson et al., 2014; Ranganathan et al., 2016). Nonetheless, research surrounding shared decision-making in cleft-related revision procedures is noticeably absent from the literature. However, the choice to pursue cleft-related revision procedures is preference-sensitive given that revision procedures are undertaken to improve aesthetic and functional elements that impact quality of life (Monson et al., 2014). Prior decision research highlights caregivers as important stakeholders and focuses on providing resources to reduce decisional conflict and regret among caregivers rather than in the patients (Carr et al., 2016; Hong et al., 2016). However, patients with cleft lip and/or palate (CLCP) frequently disagree with caregivers in terms of appearance-related complaints and procedures (Ranganathan et al., 2016). Therefore, understanding the role of shared decision-making among these patients is a critical opportunity to enhance quality of care.

To gain a better sense of treatment and decision-making preferences among patients with CLCP and their caregivers, we performed semistructured interviews, utilizing a largely inductive, exploratory approach. Questions were designed to elicit knowledge, values, and preferences. Subsequent thematic analysis was completed to identify prominent themes originating from both patients and caregivers. Throughout this investigation, we questioned

if decision-making preferences differed between patients and caregivers, which could impact decision quality and care utilization.

Methods

Study Participants

Prior to data collection, approval from the institutional review board was obtained for the study. Any patient with a cleft lip who was at least 8 years of age and able to read and converse in English, along with their caregivers, was eligible for inclusion. All patients were receiving care from 1 of 4 cleft surgeons and attending annual appointments at our multidisciplinary cleft clinic, accredited by the American Cleft Palate-Craniofacial Association. Patients were excluded if they could not converse and read in English, had intellectual disability, or had a syndromic diagnosis. Eligible patients were identified using the electronic medical record, and recruitment occurred prior to scheduled clinic appointments via telephone. Caregivers and patients were both offered a gift card incentive for participating in an in-person interview. Purposive sampling of patients with CLCP was utilized to ensure the collection of data relevant to decision-making surrounding appearance concerns. As such, patients with isolated cleft palates were excluded. Interviews with caregivers and patients lasted approximately 60 minutes, with 30 minutes allocated to each participant. Consent was obtained from all caregivers, with patients older than 9 providing written assent. Patients aged 8 and 9 provided verbal assent.

Interview Procedures

After consent was obtained, caregivers underwent semistructured interviews without the patient present. Interviews were conducted with 4 of the authors (K.G.B., A.K.P., K.S., and M.H.), none of who were part of the cleft team. The facilitator recorded the entire encounter, which was later transferred onto an encrypted hospital computer. All questions were open ended, and questions centered around reasons for surgery, decision-making, and appearance. The facilitator led with an open-ended question, asking caregivers what they understood about their child's cleft. Relevant topics mentioned by the caregiver were explored further, but the interview guide was followed consistently to target the predetermined areas of inquiry Supplemental Digital Content 1 (SCD1). After completion of the caregiver interview, the patient was given the choice to interview alone or in the presence of their caregiver. Age-appropriate modifications to the interview guide were made to facilitate interviews with patients. Additionally, all interview questions were adapted iteratively throughout the process in order to facilitate rich responses. Once both interviews were complete, caregivers and patients received gift cards. Demographic data were obtained both from the medical record and previously administered surveys.

Data Coding and Thematic Analysis

Recorded interviews were transcribed verbatim by 3 research assistants (MHH, KAS, and AKP). Two authors (K.G.B. and A.K.P.) further familiarized themselves with the data by reading the interview transcripts. These same 2 authors then performed semantic coding of the first 2 transcripts using NVivo 11 software. Coding was participant driven and conducted in a largely inductive and exploratory fashion. Coding between the 2 authors in the first

2 transcripts was highly reliable (interrater reliability 84.3%), thus allowing the remaining transcripts to be coded independently. In the infrequent cases where agreement could not be reached, the first author provided reconciliation. Prior codes were altered to assimilate new data as coding continued. The 2 authors then developed a hierarchical codebook through an iterative process in preparation for thematic analysis.

The codebook was subsequently developed by transferring the codes from NVivo to Microsoft Excel and was then used to establish emerging themes regarding surgical decision-making. Codes were reviewed for recurring topics and patterns across both patients and caregivers. As codes were reviewed and consolidated, themes were developed to reflect the entirety of the participants' decision-making experiences. Established themes were then reviewed to ensure an accurate reflection of the transcripts and codes. Themes related to our research question were thus further defined and exhibited minimal overlap (Braun and Clarke, 2006).

Results

Sample Characteristics

A total of 62 interviews were completed—31 patients and 31 caregivers. Demographic data for the patients are presented in Table 1. The mean age was 12.7 (standard deviation: 3.2), and most patients were male (59.4%) and white (65.6%). Just over half of the cohort were covered by Medicaid (53.1%), and unilateral cleft lip and palate was the most common cleft type (43.8%).

Qualitative Themes

Three major themes emerged from the analysis: Insufficient Understanding of Facial Difference and Treatment, Diversity of Surgical Indications, and Barriers to Patient Autonomy. These 3 themes were present in both patients and caregivers. Definitions and representative quotes summarize the themes in Table 2, and a thematic map is provided in Figure 1.

Insufficient Understanding of Facial Difference and Treatment

Insufficient understanding of clefts and associated treatment was much more common in patients than caregivers. The majority of patients had significant difficulty explaining their clefts and associated treatment, whereas only a few caregivers had difficulty articulating their child's facial difference. For example, when asked what a child knew about a cleft, their responses included (Table 2):

There was a hole I guess.

I know that my lip was like connected to my nose or something.

I know that I've done a lot of surgeries because of it. Other than that I don't really know.

This reflects a very simplistic understanding at best and even leans toward considerable inaccuracy. However, roughly half of caregivers felt confident that their child understood

their cleft and the associated treatment. Within caregiver–patient dyads, many caregivers thought their child understood their clefts and associated treatment, whereas patients reported a lack of understanding. For example, when asked if their children understood, some parents stated:

I think he understands it and we've told him ... I think he gets it.

We haven't really needed to explain them to her. She's a smart kid ...

Mmm hmmm, we want him to be his own advocate ...

These quotes portray an assumption, on the part of the caregivers that the patients are processing and understanding the information that they and the cleft team provide. However, when children were asked if they understood the procedures they had, they replied:

Um, some of them yes, but some of them, they don't make sense.

Like I'm not really sure what a lot of the early ones were for ...

Well, first I had to have the surgery to—well, when I was one, I had like, I don't know how to explain anything.

In addition to an incomplete and sometimes inaccurate understanding of their clefts, children similarly did not comprehend the purpose of various surgical interventions.

Diversity of Surgical Indications

Reasons for proceeding with surgical intervention varied among both patients and caregivers. Several patients believed surgery was performed to address appearance (Table 2).

So I could basically look like everyone else.

Well, it's made me look a little more normal.

To improve what I look like in the future.

Like, I like the way I look now, but I'm excited to get surgery and I'm going to be getting a surgery where they are going to move my top jaw because I have underbite.

These quotes thus demonstrate the belief that surgery improves and normalizes patient appearance. Similarly, many caregivers identified cosmesis as the reason for surgical intervention.

Well the lip repair was probably cosmetic.

Mainly just because for her mainly appearance and that.

Just to make her have a more normal appearance.

However, some patients referenced functional issues as the primary reason for surgery:

I know it's slowly trying to fix my body.

So I can eat normally and everything.

Then I had a fat graft where they take fat from somewhere and put it in the back of your neck. That's supposed to help you speak better.

Some patients thus believed that prior procedures allowed them to perform basic but critical tasks, such as eating and speaking. A similar proportion of caregivers felt that restoring function was the primary driver for surgery:

The palate was eating and speaking and so was the pharyngoplasty.

Functionality has been far more important than aesthetics.

Speech and teeth coming together so she can bite properly.

Similar to patients, eating and speech were frequently mentioned by caregivers as the primary drivers for surgery. A few patients also expressed that surgery had been performed out of necessity:

I have to have surgeries to fix it.

I just know that I needed them.

These explanations reflect a perception that none of the previous procedures were optional. Although this was articulated by only a few patients, the majority of caregivers articulated that prior surgical interventions had been performed simply because they were necessary:

Well she basically needed them is why.

I mean like any surgeries that we've had have been necessary for speech or for just basic—they were necessary. Like I don't feel as if we've had any elective surgeries.

If it's not necessary, don't do it. As long as it's necessary, by all means.

Regardless of specific indications for past procedures, some caregivers tended to see surgical interventions as always necessary. This may point to an incomplete understanding of indications for surgery, or even a desire to justify elective, appearance-related procedures.

Regarding specific caregiver–patient dyads, only a small number of dyads agreed on the purpose for surgery. Just a few caregiver–patient dyads both articulated that surgery addressed appearance, a slightly higher proportion agreed that surgery restored function, and some dyads concordantly expressed that surgery had been necessary. Only a small number of dyads agreed that changing the child's appearance might be beneficial. This reflects only minimal agreement and mutual understanding between the caregiver and the patient, which could render surgical decision-making considerably more difficult.

Barriers to Patient Autonomy

Preferences for surgical decision-making varied between patients and caregivers. Although only some caregivers expressed that the child's opinion mattered, the majority of patients believed that their opinions mattered when making surgical decisions (Table 2):

When it comes to surgery and whose opinion matters most, I'd say that the opinion that matters most is mostly mine and then my parents'.

I would like to have some say in it.

Whose opinion matters most? “Mine.”

These quotes reflect a general consensus among the patients that their thoughts and perspectives matter when surgical decisions are made, even though some of them are quite young. However, a large number of patients said they had not been involved in decisions or that their parents routinely decided.

Who made those decisions? “My mom and dad.”

I don't think I really made any decision really. I mean, it's not that I didn't want it—I did want it, but I didn't really have a say. I did, but I didn't. I don't know. I was little, so.

Who helps you make decisions about surgery? “Well, I'm kind of forced to do it. Well, I'm not forced to but I have to, because if I don't like- and we already had this all planned out a long time ago.”

As evidenced in the quotes, lack of involvement was related to age or was simply resulted from more powerful stakeholders taking charge, functioning as a significant barrier to these patients growing in autonomous decision-making.

More than half of caregivers also said that the patients were not involved in decisions at all, or that they (the caregivers) made the final decision for surgery.

Does your child play any kind of role in those decisions? “You know, not really. I mean we talk to him about it.”

We spin it in a way where- my husband and I talk about things first and then we decide how to spin it so she's just geeked for it.”

Not only do these quotes indicate that patients are often uninvolved in decisions but also that parents use their influence to sway children's opinions in an effort to obtain assent.

Regardless of past decision experiences, many patients expressed a desire to at least participate in decisions, with some desiring to make the final decision:

What types of surgeries would you like to make the final decision about, do you think? “Maybe making myself look more normal.”

Yeah, I just don't want to be in the corner with them bossing me around. I like to pick what I want to do.

Thus, patients want their opinions considered, especially regarding appearance-related procedures. However, not all children desired such a critical role in decision-making:

And how much do you want to help when choosing to do surgery or not?

Not a lot.

I don't really feel like I'm ready yet to make these tough decisions.

This reflects the considerable variety among children regarding the decision process, with some preferring caregivers or providers to make the final call.

Discussion

In this cohort, decision-making preferences, retained information, and indications for surgery varied considerably between patients and caregivers. Patients were much less likely to express understanding of their clefts and related operations, and patients and caregivers often failed to articulate concordant reasons for pursuing surgery. Finally, while the majority of patients were interested in participating in decisions, many had not participated previously, and caregivers sometimes had opposite opinions on the child's role in these decisions.

Decision-making in pediatrics is complex, given the various stakeholders involved and the dynamic ability of patients to participate as they develop cognitively (Lipstein et al., 2015). Although often assumed that younger children lack the ability to substantially participate in health-care decisions, prior work indicates that children as young as 9 years old can express treatment preferences, and 14-year-olds are able to make decisions in a manner comparable to adults (Weithorn and Campbell, 1982). However, children at the same chronological age possess varying levels of maturity, and development of the brain's control center continues past adolescence, rendering the ongoing need for adult support in health-care decisions (Grootens-Wiegers et al., 2017).

Although the legal guardian ultimately provides informed consent, child assent should be incorporated in all treatment decisions, out of respect for patient dignity and ever-increasing levels of autonomy (Grootens-Wiegers et al., 2017). Fully informed assent requires that children understand their condition, recommended treatment, risks, benefits, and alternatives. This takes considerable effort and age-appropriate language and can be difficult to achieve as evidenced by our results. Even in adult populations, patients usually recall only 50% of an informed consent discussion (Fink et al., 2010). The difficulty of involving children in decisions is reinforced by the dearth of literature targeting pediatric patients as critical stakeholders in decision-making, with most investigations reporting only on parent or caregiver decisional conflict, regret, and satisfaction (Hong et al., 2017; Crosby et al., 2018; Manning et al., 2018). A systematic review by Wyatt et al. (2015) demonstrated that 63% of decision interventions targeted parents alone, while only 4% targeted patients alone, and only 11% targeted both the parents and patients.

Among children with CLCP, little is known regarding the decision-making process for revision procedures. However, Kapp-Simon et al. (2015) recently demonstrated that patient participation in decisions explained a significant amount of the variance in patients' satisfaction with outcomes. Furthermore, in a study to identify factors affecting psychological adjustment to their clefts, adult patients with CLCP recalled traumatic experiences as children, wherein their opinions about additional surgery were not considered (Stock et al., 2016). Prior work has also shown that correlation between patients' and caregivers' desire for revision surgeries, such as lip revision or rhinoplasty, is low, which we similarly found from our analysis (Ranganathan et al., 2016). Our qualitative data serve to explain these preferences and provide greater depth of insight surrounding these decisions, as children may maintain different opinions due to poor treatment understanding, dissimilar values, or simply a desire for autonomy. Our results, in addition to the current

body of evidence, emphasize the need to consider patients' preferences and values when the decision-making process begins.

However, before taking an active role in decisions, patients must have an appropriate understanding of their cleft, surgical options, risks, benefits, and alternatives. Our findings demonstrated that patients often cannot explain their clefts, much less the reasons for the procedures they have undergone. Furthermore, they differed from caregivers in their understanding of the purpose of surgery, often referencing functional issues but not understanding that such procedures are considered necessary. It is likely that more of our patients would have desired an active role in decisions if they had better understanding, as prior work has demonstrated that pediatric patients feel more confident in decisions when equipped with more information (Shay et al., 2017). Developing and providing decision aids in the adult population has also been shown to reduce decisional conflict and improve satisfaction with information and could be similarly used in the cleft population to enhance understanding of their facial differences and associated treatment (Parkinson et al., 2018).

Facilitating increased participation in decisions is incumbent upon craniofacial surgeons not only as an ethical obligation but also as a duty to promote patient-centered care, improve outcomes, and increase health-care efficiency. This is especially critical when considering revision procedures in cleft surgery. These procedures are elective and performed to improve the appearance of a child's lip or nose (Monson et al., 2014), and concern exists that repeated revision operations will result in excessive scarring (Trotman et al., 2010). Additionally, in an era when patient-reported outcomes are increasingly important for measuring quality, improved outcomes associated with increased decision participation should render a change in practice (Kapp-Simon et al., 2015). Also, negative childhood experiences wherein patients are excluded from surgical decisions could significantly impact how those patients interface with the healthcare system in the future (Stock et al., 2016). Finally, involving patients in the decisions for elective cleft-related operations allows surgeons to target and intervene on patients who are invested in both the operation and recovery, and simultaneously avoid operating on patients who are currently satisfied with their appearance and lack interest in surgery. This approach could also help to avoid the formation of excessive scar tissue in patients who remain uninterested in a younger age, but later express interest in surgery as adolescents, rendering the achievement of an excellent outcome more likely. Finally, involving patients in these decisions could significantly diminish the massive expenditure of health-care dollars on cleft treatment by only pursuing elective, appearance-related surgery when the patient actually wants it (Allareddy et al., 2012).

Our study was limited by its single-center design, as patients from other institutions and other regions of the country may have different levels of understanding of their clefts and varied decision-making preferences. Our study also required that patients and caregivers arrive early or stay late to complete interviews, which may render our results less generalizable to families who live far away, or families who lack the resources that would enable them to spend additional time at the hospital. Thus, our findings merit further investigation.

Conclusion

When questioned about their facial differences and decision-making preferences, patients and caregivers articulated variable understanding of clefts and surgeries, with more patients being incapable of explaining their clefts and related procedures. Patients and caregivers also differed in their understanding of the purpose of surgery, and their preferences for decision-making frequently did not align, creating barriers to patient autonomy. As such, it remains critical for the cleft team to properly educate children so that they may contribute meaningfully to surgical decisions, thus increasing satisfaction with surgery and rendering cleft care more cost-effective.

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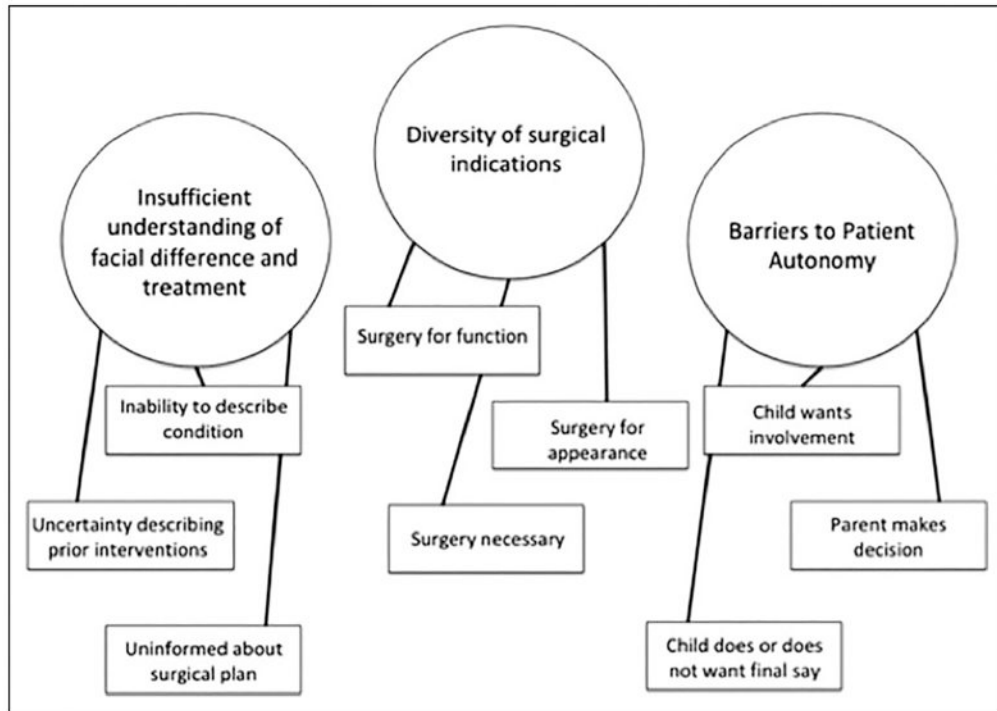


Figure 1.
Thematic map.

Table 1.

Patient Characteristics.

Variable	Mean (SD) or Frequency (%)
Age	12.7 (3.2)
Sex	
Female	13 (40.6%)
Male	19 (59.4%)
Race	
White	21 (65.6%)
Asian	8 (25.0%)
Hispanic	2 (6.3%)
Black	1 (3.1%)
Payer	
Private	15 (46.9%)
Medicaid	17 (53.1%)
Cleft type	
UCL	4 (12.5%)
BCL	1 (3.1%)
UCLP	14 (43.8%)
BCLP	13 (40.6%)

Abbreviations: BCL, bilateral cleft lip; BCLP, bilateral cleft lip and palate; SD, standard deviation; UCL, unilateral cleft lip; UCLP, unilateral cleft lip and palate.

Table 2.

Major Themes.

Theme	Definition	Exemplary Quotes
Insufficient Understanding of Facial Difference and Treatment	Inability to explain a cleft in layman's terms or articulate the procedures and treatment required for clefts	<i>Do you know why you've had the surgeries you've had?</i> Child: "I don't know. I know that I was born without a lip. Yeah. I don't know." Quotes from caregiver-patient dyad: Caregiver: "She understands a lot and she educates people a lot." Child: "It could've been a lot worse and it was really minor. That's it. I don't know."
Diversity of Surgical Indications	Surgical procedures were done to improve function, appearance, or both, and were often regarded as necessary rather than elective	<i>How have surgeries helped you?</i> Child: "Well, it's made me look a little more normal I'm going to assume because my lip is closed now and same with the roof of my mouth. So I can eat normally and everything." <i>Why did you proceed with surgery?</i> Caregiver: "...the best way to fix the problems he would have...Speech for sure I would say. Eating. Drinking out of a straw. Things like that." <i>Why did you decide to proceed with surgery in the past?</i> Caregiver: "Because she needed it."
Barriers to Patient Autonomy	Propensity toward involvement in decision-making varied between caregivers and patients, frequently creating obstacles to patient participation in decisions; desire for involvement also varied between patients	<i>And do you like having the final say?</i> Caregiver: "I mean obviously we have the final say. X has his opinion, but it's not an option." <i>Do you ever want to make the final decision about surgery or do you always want people to help?</i> Patient: "I sort of want to make my own decision when it comes to the final one."