

ORIGINAL ARTICLE

Decision-making process to undergo surgery among adolescent patients with cleft lip and/or palate

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Abstract

Aim: As patients with cleft lip and/or palate grow older, the main decision-making process for treatment is likely to shift from a parent-centered to a patient-centered process. However, many adolescent patients have difficulty in treatment decision-making. This study aimed to clarify the decision-making process regarding undergoing surgery among adolescent patients with cleft lip and/or palate.

Methods: Participants were adolescent patients with cleft lip and/or palate aged 14–18 years who were admitted to a hospital in Japan for surgery. Fourteen patients (six boys, eight girls) and their parents agreed to participate in this study. Data were collected in face-to-face semi-structured interviews. Data were analyzed qualitatively with inductive content analysis.

Results: Fifteen categories were classified into three themes for adolescent patients' decision-making processes regarding undergoing surgery. The three themes were: (a) a doctor's recommendation for surgery, (b) psychological conflict about surgery, and (c) a final decision about surgery.

Conclusion: This study's findings suggest that adolescent patients with cleft lip and/or palate were not adequately involved in the decision-making process before undergoing surgery. Medical staff need to explain other treatment options, the risks and benefits of surgery with materials and methods that adolescent patients can understand as part of "a doctor's recommendation for surgery." Medical staff and parents need to encourage adolescent patients to communicate their preferences and values to reduce patients' "psychological conflict about surgery" and adolescent patients' intentions should be considered in "a final decision about surgery."

KEYWORDS

adolescent, cleft lip, cleft palate, decision-making, surgery

1 | INTRODUCTION

Cleft lip and/or palate is a craniofacial anomaly and common birth defect, with an overall worldwide prevalence of 9.92 per 10,000 live births (International Perinatal

Database of Typical Oral Clefts Working Group, 2011). Cleft lip and/or palate affects speech and language development, dental development, and facial appearance. Patients with cleft lip and/or palate usually undergo a combination of surgical interventions, speech therapy,

and orthodontic treatment from infancy to young adulthood (Edwards & Costello, 2007). These patients grow up in the context of dealing with the fact that their appearance differs from that of others (Chetpakdechit, Hallberg, Hagberg, & Mohlin, 2009; Omiya, Ito, & Yamazaki, 2012). Adolescence is the time when the development of the appearance is almost completed, and most adolescent patients with cleft lip and/or palate undergo surgery for aesthetic reasons.

As patients with cleft lip and/or palate grow older, their decision-making capacity develops. It is likely that the main treatment decision-making process shifts from parents to patients. However, many adolescent patients have difficulty in treatment decision-making. Adolescent patients with cleft lip and/or palate may not properly understand explanations about treatment provided by their doctor (Noor & Musa, 2007). A study involving 45 adolescent patients with cleft lip and/or palate found that 48.9% did not want surgery and 24.4% had surgery because their parents believed that they would benefit from surgery, even though they did not want to have surgery (Ranganathan et al., 2016).

One study found that approximately 60% of adult patients with cleft lip and/or palate were satisfied with treatment results and their appearance after treatment was completed (Stock, Feragen, & Rumsey, 2015). However, some adult patients remained dissatisfied with their nose, teeth, and lips (Chuo et al., 2008) and wished for more surgery to further improve their appearance (Sinko et al., 2005; Stock et al., 2015). The aim of treatment for cleft lip and/or palate is not only to achieve a good appearance, but to support psychological adjustment to the cleft lip and/or palate. Treatment autonomy contributes to a patient's psychological adjustment to cleft lip and/or palate after completion of treatment (Stock, Feragen, & Rumsey, 2016). Therefore, it is important for adolescent patients with cleft lip and/or palate to receive treatment autonomously and participate in treatment decision-making to facilitate their psychological adjustment.

In the last decade, the inclusion of patients and their parents in decision-making has been emphasized in pediatric health care (Aarthun & Akerjordet, 2014). Shared decision-making has been promoted in medical care, including pediatric health care. In shared decision-making, medical staff and patients work together to select treatments based on evidence and the patient's informed preferences (NICE/NHS England, 2016). In shared decision-making, medical staff and patients share information: medical staff members offer options and describe the associated risks and benefits, and patients express their preferences and

values (Barry & Edgman-Levitan, 2012). However, the implementation of shared decision-making in real settings has been incomplete (Aarthun & Akerjordet, 2014).

Adolescent patients with cleft lip and/or palate feel that with increasing age should come increased involvement in decision-making and that it is important for adolescents to have a voice during decision-making; these patients want to be more involved in making decisions about treatments to improve speech and/or appearance (Wogden, Norman, & Dibben, 2019). However, most adolescent patients with cleft lip and/or palate fail to provide information about their cleft during decision-making prior to cleft-related surgery even though almost half of parents believe their children understand their clefts (Bennett et al., 2020). Decision-making is a process involving a variety of activities, interactions, and emotional responses over time when medical staff, patients, and their parents work together to select treatments. However, little is known about the decision-making process of adolescent patients with cleft lip and/or palate who undergo surgery.

Therefore, this study aimed to clarify the process of decision-making about surgery among adolescent patients with cleft lip and/or palate.

2 | METHODS

2.1 | Participants

Participants were adolescent patients aged 14–18 years with cleft lip and/or palate who were admitted to a Japanese university hospital for surgery from March to August 2017. The study setting was a hospital where comprehensive cleft lip and/or palate treatment was provided from infancy through childhood, with surgery offered to adolescent patients. This study included adolescent patients who could participate in an interview by themselves without their parents being present, could answer questions in the interview, and who volunteered to participate in this study. We continued participant recruitment until no more categories emerged.

In total, 18 sets of adolescent patients with cleft lip and/or palate and their parents received an explanation and invitation to participate in this study. Fourteen adolescent patients (six boys and eight girls) and their parents agreed to participate. The mean age of patients was 16.2 years ($SD = 1.26$, range 14–18). The mean number of previous surgeries was 3.6 ($SD = 1.18$, range 2–6). Seven patients had cleft lip and seven had cleft lip and palate. The mean age of the parents was 46.0 years ($SD = 5.49$, range 37–60).

2.2 | Data collection

Data were collected from March to August 2017. Individual face-to-face semi-structured interviews lasting 15–63 min were conducted with participants 2–9 days after surgery. The interviews were recorded on digital voice recorders and transcribed in full. All interviews were conducted by one researcher to avoid any interviewer-based differences. The interviews were based on an interview guide and conducted in a room in the hospital where privacy could be secured. In the interviews, participants were encouraged to speak freely about the process they used and the feelings they experienced in decision-making about surgery. The main interview questions were as follows.

- 1 Why did you have the surgery for cleft lip and/or palate treatment?
- 2 What did you think when you heard the explanation about the surgery?
- 3 Who decided that you should have the surgery?
- 4 What did you think about the surgery before you had surgery?
- 5 How did you feel about the surgery before you had surgery?

2.3 | Data analysis

Data were processed qualitatively using inductive content analysis. The qualitative analysis focused on participants' perspectives and could comprehensively summarize the natural context of their actual narratives (Sandelowski, 2000). Inductive content analysis is used when there are no previous studies dealing with the phenomenon (Elo & Kyngäs, 2008). Currently, little is known about the decision-making process of adolescent patients with cleft lip and/or palate who undergo surgery. Therefore, we used inductive content analysis to clarify the decision-making process of adolescent patients with cleft lip and/or palate who underwent surgery.

The process of inductive content analysis consisted of: (a) open coding, (b) creating categories, and (c) abstraction (Elo & Kyngäs, 2008). The interviews were audio-recorded and transcribed verbatim. All data were read repeatedly word-by-word to grasp the whole picture of each interview. Open coding was performed using the exact words from the text related to the decision-making process about surgery used by adolescent patients with cleft lip and/or palate. Labels for codes emerged as this process advanced. After this open coding, categories were grouped based on how codes were related and linked. Each category was given a name. When codes and

categories were extracted, we confirmed that they were based on the data. Finally, themes were extracted based on associations among the categories to clarify the surgery decision-making process over time. This approach was used because the process involves a variety of activities, interactions, and emotional responses to the experience of a given situation or problem over time (Corbin & Strauss, 2012). Data abstraction was schematized using categories and themes.

Credibility was established through member checking. Analyses were supervised by an expert in nursing science and psychological qualitative research who had conducted studies involving families of patients with cleft lip and/or palate and two nurses with more than 20 years of experience in a hospital offering treatment for cleft lip and/or palate.

2.4 | Ethics approval

The study protocol was approved by the ethics committees of the first author's institution (Approval number: 16–020) and of the university hospital in which the study was conducted (Approval number: H28–E29). A researcher provided an explanation about this study to participants and their parents because participants in this study were minors. The researcher provided both verbal and written information about this study and obtained written informed consent from both participants and their parents.

3 | RESULTS

Fifteen categories were extracted from 248 codes using inductive content analysis. Exploration of associations among the 15 categories resulted in three themes that reflected the time progress in the decision-making regarding surgery of adolescent patients with cleft lip and/or palate. When the adolescent patients made decisions relating to surgery, they passed through a three-stage process:

- First stage: a doctor's recommendation for surgery
- Second stage: psychological conflict about surgery
- Third stage: a final decision about surgery.

3.1 | First stage: A doctor's recommendation for surgery

Two categories were extracted: "Surgery planned as part of a treatment plan" and "Advice from a doctor."

3.1.1 | Surgery planned as part of a treatment plan

Participants perceived that the surgery during this hospitalization had been planned as part of the treatment plan from their childhood. They perceived that they would receive the surgery someday.

I've been going to this hospital since I was young, so it just seemed like part of the flow. There was an expectation that ultimately I would have the treatment. (Boy, 18)

3.1.2 | Advice from a doctor

Participants considered whether they should have the surgery after receiving advice from a doctor.

It wasn't like the doctor told me I had to have the surgery, and the surgery wasn't forced upon me, but the doctor did say something like, "I think you should have the surgery." (Girl, 18)

3.2 | Second stage: Psychological conflict about surgery

The second stage comprised nine categories. Participants felt they had to have surgery for reasons such as: "I feel discomfort with my appearance," "I wanted to improve my appearance," "I have experienced surgeries ever since I can remember," "it is natural to be treated," and "cleft lip and/or palate is cured by appropriate treatment." Reasons participants did not want to have a surgery included: "I feel a quality of myself in my appearance," "I was worried about evaluation from others after surgery," "surgery limits everyday life," and "I feel burdened by treatment."

3.2.1 | I feel discomfort with my appearance

Participants expressed an inferiority complex regarding parts of their face, such as lips, nose, or mandibular overlap. They felt different from people without cleft lip and/or palate and wanted to cover their face. Therefore, many participants wished that they had received surgery earlier.

I felt it was enough that people could only see my eyes, so I would wear a face mask.

My parents told me I didn't need to wear a face mask, that I was OK without one, but I am the one who feels the most self-conscious about my lips. (Girl, 15)

3.2.2 | I wanted to improve my appearance for my future

Participants wanted to improve their noses, correct tooth alignment or mandibular overlap, and become "beautiful" through surgery. After surgery, they expected to be able to be photographed without being conscious of their appearance. They indicated that they were being treated for their future.

I hate treatment even if I become a high school student. However, I am undergoing treatment for the future. Though it is tough now, I wonder if it will be more comfortable in the future. (Girl, 16)

3.2.3 | I have experienced surgeries ever since I can remember

Because many participants had experienced surgeries throughout their life, they were not worried about surgery.

I had surgery 2 years ago and spent a week in hospital, so I'm not that worried. I've had surgery before, so I feel that this surgery will be OK. (Girl, 18)

3.2.4 | It is natural to be treated

Participants felt that it was natural to be treated because they had visited a hospital for treatment ever since they could remember. They had heard about treatment from their parents and were aware of the need to have surgery for their cleft lip and/or palate.

I didn't really understand the severity of my condition or how bad my symptoms were until I was told. I also didn't understand the impact this illness would have on my future until I was told. So, I think hearing about cleft lip and palate from my parents at age 9 had a pretty big influence on my decision to have surgeries later. (Boy, 17)

3.2.5 | Cleft lip and/or palate is cured by appropriate treatment

Participants chose to have surgery because they regarded their cleft lip and/or palate as a disease to be cured by appropriate treatment. They thought that surgery would make them attractive and acknowledged the effect of the treatments that they had received so far.

I knew that I was different from other people beginning when I was in primary school, so I thought I could be cured if I went to this hospital. I thought that my cleft lip and palate could definitely be fixed, so I felt reassured that it would all be OK if I had treatment. (Boy, 17)

3.2.6 | I feel a quality of myself in my appearance

Some participants did not feel any discomfort about their appearance before surgery and hated that their appearance was changed by surgery; these participants indicated that they had not intended to have surgery.

Originally, I didn't have any intention to have surgery. Before surgery I wasn't concerned about the cleft lip and palate at all. (Boy, 17)

3.2.7 | I am worried about evaluation from others after surgery

Other participants were hesitant about surgery and were worried about the change of their appearance after surgery being noticed by others, including others' reactions to the change in their appearance. They thought about how they would cope with comments from other people after surgery and did not tell their friends about the surgery because they were concerned about rumors.

I hated my nose because it was different from everyone else's, but if my nose was made more prominent with this surgery, I might be bullied again. I'm really worried that if my nose is made more prominent with surgery, my friends might say something like, "You've had plastic surgery, haven't you!" And I was also worried that my close friends might abandon me, so I always hated the thought of having surgery. (Girl, 16)

3.2.8 | Surgery limits everyday life

Some participants were hesitant about having surgery because of limitations in their everyday life. For example, they would not be able to participate in school events and club activities, their study would be delayed, and they would not be able to play with their friends. It was also necessary to decide about the operation timing in consideration of aspects such as examinations and entrance to a higher school grade.

I feel quite frustrated about having to take time out of my vacation to have surgery. After graduation my friends are going to parties, but I can't go because I'm stuck in hospital. It makes me want to cry. I find the surgeries quite vexing. Because of being hospitalized, I have to take time off school. (Girl, 15)

3.2.9 | I feel burdened by treatment

Many participants felt burdened by treatment. For example, it was hard for them to have surgery, they were lonely during hospitalization, postoperative self-care was hard, and they had to cope with pain resulting from treatment.

I think the surgery is a bit hard. After surgery it's difficult to eat and I can't have a bath. When I remembered previous surgeries before this surgery, I did sometimes think that surgery was hard. (Boy, 15)

3.3 | Third stage: A final decision about surgery

Four categories were involved in participants' decisions to undergo surgery: "my intention," "I cannot avoid being treated," "intention of family," and "I left it to a doctor."

3.3.1 | My intention

Participants felt that it was important for them to make the decision to undergo surgery with conviction. Many participants reported that their mothers and doctors respected their intention when decision-making. Participants hoped others would respect their final decision to undergo surgery.

When I asked my mother, “Which do you think is better: to undergo surgery or not?” she said, “You can do as you like. If you don’t want to have surgery, then you don’t have to. If you want to have surgery, you can.” So, I decided myself, thinking I would have it if I can. (Girl, 18)

3.3.2 | I cannot avoid being treated

Some participants decided to have surgery because surgery was perceived as unavoidable. For example, they felt they had no option but to have surgery because they had always believed they would receive surgery someday, or they had surgery because the situation required that they have surgery.

I’d heard that it has something to do with insurance coverage, like it would be possible at a lower price, so I thought I should have surgery. At first, I didn’t understand why the option of surgery was recommended so strongly. Then as I thought about it, I was in a situation where I could have surgery, and I had a chance, so I felt like it would be better to have surgery than not to have surgery. (Boy, 17)

3.3.3 | Intention of family

Some participants indicated that the decision about surgery reflected the intention of their family. For example, they thought that their parents wanted them to be beautiful, or their family suggested they have surgery.

I think it was probably my parents who made the decision that I have surgery. I’m pretty sure my parents said something like, “We’re not telling you to have surgery, but we think it would be better if you did.” (Girl, 15)

3.3.4 | I left the decision about surgery to my doctor

Other participants reported that they left the decision about surgery to their doctor, because it was all right to entrust a doctor with the decision or they trusted the doctor’s intention.

I think that, if possible, having tooth alignment surgery earlier is better. But I really don’t know. I think it is up to the doctor to make the decision. Simply worrying about cleft lip and palate won’t fix it, so I think it’s better to leave it up to the doctor. (Girl, 18)

4 | DISCUSSION

4.1 | First stage: A doctor’s recommendation for surgery

This study’s findings suggest that adolescent patients with cleft lip and/or palate were not adequately involved in the decision-making process before undergoing surgery. In shared decision-making, medical staff and patients share information; medical staff members offer options and describe the associated risks and benefits (Barry & Edgman-Levitan, 2012). Our findings suggest that “a doctor’s recommendation for surgery” played a role in the decision-making process before surgery. However, explanations of other options and of the risks and benefits of surgery were not provided from the viewpoint of adolescent patients in this study. In actual clinical practice, doctors may describe other options and explain the risks and benefits of surgery to adolescent patients when recommending surgery. However, this information may be not provided in a format that adolescent patients can understand. In fact, most adolescent patients fail to provide information about their cleft during decision-making prior to cleft-related surgery (Bennett et al., 2020). Medical staff need to explain other treatment options, the risks and benefits of surgery with information and methods that adolescent patients can understand as part of “a doctor’s recommendation for surgery.”

Decision aids were developed in Europe and America in the 1990s to promote more effective decision-making of patients and families. Decision aids enable patients and families to obtain more knowledge and information about treatment options and associated risks and benefits, allowing them to clarify their values and to play a more active role in decision-making (Stacey et al., 2017). Further studies should develop a decision aid regarding surgery for adolescent patients with cleft lip and/or palate.

4.2 | Second stage: Psychological conflict about surgery

This study revealed that adolescent patients with cleft lip and/or palate have psychological conflict about surgery

during the decision-making process. Adolescent patients with cleft lip and/or palate were aware that they were different from others and wanted to become like others after surgery (e.g., “I feel discomfort with my appearance” or “I wanted to improve my appearance for my future”). This finding suggests adolescent patients with cleft lip and/or palate chose to have surgery because they expected that surgery would change their appearance. However, some adolescent patients were not able to clearly express their wishes (Hall, Gibson, James, & Rodd, 2012). Even adults may have difficulty adjusting to their postoperative appearance after surgery (Cadogan & Bennun, 2011). Therefore, it is necessary that medical staff understand adolescents' views before surgery (e.g., “I feel discomfort with my appearance” or “I wanted to improve my appearance for my future”), clearly explain surgery and postoperative appearance, and try to ensure that the patient's expectations and hopes match the results of surgery.

Our findings showed that treatment experiences from childhood had a positive influence on adolescent patients' decisions about surgery. Almost half of adolescent patients with cleft lip and/or palate who had undergone surgery in their earlier school years wanted to have surgery for reasons such as, “I have experienced some surgeries ever since I can remember” and “it is natural to be treated.” These adolescent patients could imagine changes and progress after surgery because they had extensive previous experience of surgeries. Therefore, they decided to have additional surgery.

There may be a risk that treatment experience from childhood may result in some patients repeatedly receiving further surgeries because they had high expectations of the change in their appearance. A previous study reported that most adult patients with cleft lip and/or palate were satisfied with the results of surgery and adjusted to their new appearance; however, 36.5% of adult patients underwent additional surgery because they believed that surgical techniques had improved since they were originally treated (Stock et al., 2015). How one values one's appearance is influenced by subjective evaluation rather than a clinician's objective evaluation of severity (Brown, Moss, McGrouther, & Bayat, 2010). It is therefore essential for medical staff to understand how patients with cleft lip and/or palate experience and recognize their condition and childhood treatments so they can support their psychological adjustment.

Some adolescent patients with cleft lip and/or palate in our study did not want to have surgery because “I feel a quality of myself in my appearance,” “I am worried about the evaluation of others after surgery,” “surgery limits everyday life,” and “I feel burdened by treatment.” Adolescent patients tend to be relatively satisfied with

their appearance (Van Lierde et al., 2012). However, the disagreement between their evaluations of their appearance and others' evaluations produced psychological conflict about surgery. It is important for medical staff to understand that these feelings represent some of the psychological conflicts that adolescent patients experience about surgery.

Our results showed that some adolescent patients with cleft lip and/or palate did not want to have surgery because they were worried about evaluations from others after surgery. A previous study reported that around 69% of adolescents with cleft lip and/or palate suffered from bullying in school, with bullying related to having a cleft lip and/or palate in 84% of these cases (Lorot-Marchand et al., 2015). Social attitudes toward people with visible differences, such as cleft lip and/or palate, have changed over time; however, these changes are not necessarily for the better (Hamlet & Harcourt, 2015). When others compared faces of patients with and without cleft lip and/or palate, faces without cleft lip and/or palate were evaluated higher than those with cleft lip and/or palate (Eichenberger, Staudt, Pandis, Gnoinski, & Eliades, 2014). Adolescent patients with cleft lip and/or palate recognize they are different from others and grow up dealing with this difference (Chetpakdeechit et al., 2009; Omiya et al., 2012). Social recognition of patients with cleft lip and/or palate and patients' recognition of their differences from others may lead to worry about evaluations from others after surgery.

In shared decision-making, patients express their preferences and values (Barry & Edgman-Levitan, 2012). However, adolescent patients did not communicate their preferences and values with medical staff to reduce “psychological conflict about surgery” in this study. Medical staff should communicate more with adolescent patients to understand their preferences and values. In shared decision-making, medical staff need to examine patients' understanding and expectations of treatment and need to talk with patients about treatment options to reach agreement (Kriston et al., 2010). Medical staff need to understand how adolescent patients experience and recognize any psychological conflicts, their cleft lip and/or palate, and their treatments. Medical staff and parents need to encourage adolescent patients to communicate their preferences and values to reduce their “psychological conflict about surgery.”

4.3 | Third stage: A final decision about surgery

Reasons adolescent patients with cleft lip and/or palate in our study finally decided to undergo surgery included “my intention,” “I cannot avoid being

treated,” “intention of family,” and “I left the decision about surgery to my doctor.” Some adolescent patients made decisions with support from their parents and doctors. However, others underwent surgery against their own will. These results were similar to previous studies that found some adolescent patients with cleft lip and/or palate had surgery because their parents believed they would benefit from surgery, even though they did not want to have surgery (Ranganathan et al., 2016). This result may occur for the following reasons. Some adolescent patients are not able to express their wishes clearly and their parents guide their decision (Hall et al., 2012). Japanese parents tend to be overprotective of adolescent patients with cleft lip and/or palate because of strong family cohesiveness (Hirose, 1999). Even though adolescent Japanese patients can understand a doctor's explanations as well as adults, these patients depend on their parents when listening to the doctor's explanations (Hosono & Kataoka, 2014). The surgery that adolescent patients with cleft lip and/or palate undergo is often regarded as a final surgery in the long-term treatment that began in infancy. Treatment autonomy contributes to a patient's psychological adjustment to cleft lip and/or palate after completion of treatment (Stock et al., 2016). Medical staff and parents need to encourage adolescent patients to consider their own intentions when making “a final decision about surgery.”

4.4 | Limitations

There were several limitations in this study. First, this study did not include adolescent patients with cleft lip and/or palate who decided not to have surgery. Not all adolescent patients with cleft lip and/or palate receive surgery, despite surgery being recommended by a doctor (Ranganathan et al., 2016). It will be necessary for future studies to examine the decision-making process of adolescent patients with cleft lip and/or palate who reached the conclusion that they did not want to have surgery. This will help to build clinical support to help adolescent patients make decisions about surgery based on their own intention.

Second, the results of this study were derived from interviews with 14 patients in a single hospital in Japan. The decision-making process may be affected by the medical standards in individual countries, the treatment policies of individual medical institutions, and different cultural backgrounds relating to appearance. The unique Japanese tendency is not to directly address congenital facial anomalies and Japanese parents tend to be overprotective of adolescent patients

with cleft lip and/or palate because of strong family cohesiveness (Hirose, 1999). Even though adolescent Japanese patients can understand a doctor's explanations as well as adults, these patients depend on their parents when listening to the doctor's explanations (Hosono & Kataoka, 2014). In addition, female patients with cleft lip and/or palate have more psychological problems than male patients (Feragen, Stock, & Kvaalem, 2015). Further studies with larger samples and with analyses according to country and gender are necessary to clarify the possibility of generalizing the present findings.

Third, we were not able to show that treatment experience from childhood had a negative impact on adolescent patients' decisions about surgery; in fact our findings showed that treatment experience from childhood influenced adolescent patients' decisions about surgery in a positive way. Treatment experience from childhood is likely to have an impact on adolescent patients' decisions about surgery because these patients usually undergo several surgeries from infancy to young adulthood. Further research is needed to confirm how treatment experience from childhood affects adolescent patients' decisions about surgery.

5 | CONCLUSION

We interviewed 14 patients with cleft lip and/or palate aged 14–18 years to clarify the decision-making process regarding undergoing surgery from their perspective. After receiving a doctor's recommendation for surgery, participants experienced psychological conflict about surgery before reaching a final decision about surgery. This study's findings suggest that adolescent patients with cleft lip and/or palate were not adequately involved in the decision-making process before undergoing surgery. Medical staff need to explain other treatment options and of the risks and benefits of surgery in a manner that adolescent patients can understand as part of “a doctor's recommendation for surgery.” Medical staff and parents need to encourage adolescent patients to communicate their preferences and values to reduce their “psychological conflict about surgery” and patients' intentions need to be considered in “a final decision about surgery.”

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CONFLICT OF INTERESTS

We declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

AUTHORS' CONTRIBUTIONS

E.M. designed this study, conducted interviews, analyzed the data, interpreted the data, and wrote the manuscript. Y.K. and M.I. supervised the study, collected the data, analyzed the data, and interpreted the data. S.T. and M.K. set up the research environment. All the authors read and approved the final manuscript.

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REFERENCES

- Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: An integrative review. *Journal of Nursing Management*, 22(2), 177–191. <https://doi.org/10.1111/j.1365-2834.2012.01457.x>
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making - The pinnacle of patient-centered care. *The New England Journal of Medicine*, 366(9), 780–781.
- Bennett, K. G., Patterson, A. K., Schafer, K., Haase, M., Ranganathan, K., Carlozzi, N., ... Waljee, J. F. (2020). Decision-making in cleft-related surgery: A qualitative analysis of patients and caregivers. *The Cleft Palate-Craniofacial Journal*, 57(2), 161–168. <https://doi.org/10.1177/1055665619866552>
- Brown, B. C., Moss, T. P., McGrouther, D. A., & Bayat, A. (2010). Skin scar preconceptions must be challenged: Importance of self-perception in skin scarring. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 63(6), 1022–1029. <https://doi.org/10.1016/j.bjps.2009.03.019>
- Cadogan, J., & Bennun, I. (2011). Face value: An exploration of the psychological impact of orthognathic surgery. *British Journal of Oral and Maxillofacial Surgery*, 49(5), 376–380. <https://doi.org/10.1016/j.bjoms.2010.07.006>
- Chetpakdeechit, W., Hallberg, U., Hagberg, C., & Mohlin, B. (2009). Social life aspects of young adults with cleft lip and palate: Grounded theory approach. *Acta Odontologica Scandinavica*, 67(2), 122–128. <https://doi.org/10.1080/00016350902720888>
- Chuo, C. B., Searle, Y., Jeremy, A., Richard, B. M., Sharp, I., & Slator, R. (2008). The continuing multidisciplinary needs of adult patients with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 45(6), 633–638. <https://doi.org/10.1597/07-048.1>
- Corbin, J. M., & Strauss, A. L. (2012). In H. Misao & T. Morioka (Eds.), *Trans. Shitsuteki kenkyu no kiso: grounded theory kaihatsu no gihou to tejun* [Basics of qualitative research: techniques and procedures for developing grounded theory] (3rd ed., pp. 134–144). Tokyo, Japan: IgakuShoin (in Japanese).
- Edwards, S. P., & Costello, B. J. (2007). Primary cleft lip. In D. M. Laskin & A. O. Abubaker (Eds.), *Decision making in oral and maxillofacial surgery* (pp. 136–138). Chicago, IL: Quintessence.
- Eichenberger, M., Staudt, C. B., Pandis, N., Gnoinski, W., & Eliades, T. (2014). Facial attractiveness of patients with unilateral cleft lip and palate and of controls assessed by laypersons and professionals. *European Journal of Orthodontics*, 36(3), 284–289. <https://doi.org/10.1093/ejo/cjt047>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Feragen, K. B., Stock, N. M., & Kvaem, I. L. (2015). Risk and protective factors at age 16: Psychological adjustment in children with a cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 52(5), 555–573. <https://doi.org/10.1597/14-063>
- Hall, M., Gibson, B., James, A., & Rodd, H. D. (2012). Children's experiences of participation in the cleft lip and palate care pathway. *International Journal of Paediatric Dentistry*, 22(6), 442–450. <https://doi.org/10.1111/j.1365-263X.2011.01214.x>
- Hamlet, C., & Harcourt, D. (2015). Older adults' experiences of living with cleft lip and palate: A qualitative study exploring aging and appearance. *The Cleft Palate-Craniofacial Journal*, 52(2), e32–e40. <https://doi.org/10.1597/13-308>
- Hirose, T. (1999). A literature review of psychosocial problems of children with cleft lip and cleft palate. *Journal of Japanese Cleft Palate Association*, 24(3), 348–357 (in Japanese).
- Hosono, K., & Kataoka, E. (2014). A study on the responses of adolescents to explanations provided by the medical staff at pediatric outpatients. *The Journal of Faculty of Health and Welfare Science, Asahikawa University*, 6, 1–7 (in Japanese).
- International Perinatal Database of Typical Oral Clefts Working Group. (2011). Prevalence at birth of cleft lip with or without cleft palate: Data from the international perinatal database of typical Oral clefts (IPDTC). *The Cleft Palate-Craniofacial Journal*, 48(1), 66–81.
- Kriston, L., Scholl, I., Hölzel, L., Simon, D., Loh, A., & Härter, M. (2010). The 9-item shared decision making questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Education and Counseling*, 80(1), 94–99. <https://doi.org/10.1016/j.pec.2009.09.034>
- Lorot-Marchand, A., Guerreschi, P., Pellerin, P., Martinot, V., Gbaguidi, C. C., Neiva, C., ... Francois-Fiquet, C. (2015). Frequency and socio-psychological impact of taunting in school-age patients with cleft lip-palate surgical repair. *International Journal of Pediatric Otorhinolaryngology*, 79(7), 1041–1048. <https://doi.org/10.1016/j.ijporl.2015.04.024>
- NICE/NHS England. (2016). *Shared decision making: A consensus statement*. Retrieved from <https://www.nice.org.uk/Media/Default/About/what-we-do/SDM-consensus-statement.pdf>
- Noor, S. N., & Musa, S. (2007). Assessment of patients' level of satisfaction with cleft treatment using the cleft evaluation profile. *The Cleft Palate-Craniofacial Journal*, 44(3), 292–303. <https://doi.org/10.1597/05-151>
- Omiya, T., Ito, M., & Yamazaki, Y. (2012). The process leading to affirmation of life with cleft lip and cleft palate: The importance of acquiring coherence. *Japan Journal of Nursing Science*, 9(2), 127–135. <https://doi.org/10.1111/j.1742-7924.2011.00193.x>
- Ranganathan, K., Shapiro, D., Aliu, O., Vercler, C. J., Baker, M., Kasten, S. J., ... Waljee, J. F. (2016). Health-related quality of life and the desire for revision surgery among children with cleft lip and palate. *Journal of Craniofacial Surgery*, 27(7), 1689–1693.

- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Sinko, K., Jagsch, R., Prechtel, V., Watzinger, F., Hollmann, K., & Baumann, A. (2005). Evaluation of esthetic, functional, and quality-of-life outcome in adult cleft lip and palate patients. *The Cleft Palate-Craniofacial Journal*, 42(4), 355–361. <https://doi.org/10.1597/03-142.1>
- Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., ... Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 4, CD001431 <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001431.pub5/epdf/full>
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2015). "it Doesn't all just stop at 18": Psychological adjustment and support needs of adults born with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 52(5), 543–554. <https://doi.org/10.1597/14-178>
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2016). Adults' narratives of growing up with a cleft lip and/or palate: Factors associated with psychological adjustment. *The Cleft Palate-Craniofacial Journal*, 53(2), 222–239. <https://doi.org/10.1597/14-269>
- Van Lierde, K. M., Dhaeseleer, E., Luyten, A., Van De Woestijne, K., Vermeersch, H., & Roche, N. (2012). Parent and child ratings of satisfaction with speech and facial appearance in Flemish pre-pubescent boys and girls with unilateral cleft lip and palate. *International Journal of Oral and Maxillofacial Surgery*, 41(2), 192–199. <https://doi.org/10.1016/j.ijom.2011.10.030>
- Wogden, F., Norman, A., & Dibben, L. (2019). Treatment choice in adolescents with cleft lip and/or palate: The importance of shared decision-making. *The Cleft Palate-Craniofacial Journal*, 56(9), 1220–1229.

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