

# Patient Experience of Head and Neck Surgery With Free Flap Reconstruction

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**IMPORTANCE** Major head and neck surgery with microvascular free tissue transfer reconstruction is complex, with considerable risk of morbidity. Little is known about patients' experiences, including decision-making prior to, and regret following, free flap surgery.

**OBJECTIVE** To characterize patient experiences and decision regret of patients undergoing head and neck reconstructive free flap surgery.

**DESIGN, SETTING, AND PARTICIPANTS** This mixed-methods cohort study comprising semistructured interviews was conducted June to August 2021 at a single tertiary academic cancer center. Participants underwent head and neck reconstructive surgery with microvascular free tissue transfer (flap) more than 3 months before recruitment (range, 3 months to 4 years). Interview transcripts were qualitatively analyzed for themes. Participants also completed a Decision Regret Scale questionnaire.

**EXPOSURE** Microvascular free flap surgery for head and neck reconstruction.

**MAIN OUTCOMES AND MEASURES** Thematic analysis of interviews, decision regret score.

**RESULTS** Seventeen participants were interviewed. Median (IQR) age was 61 (52-70) years. Overall, 7 participants were women (49%), and 10 of 17 were men (59%). The most common free flap was fibula (8/17, 47%). Three major themes with 9 subthemes were identified: theme 1 was the tremendous effect of preoperative counseling on surgical decision-making and satisfaction, with subthemes including (1) importance of clinical care team counseling on decision to have surgery; (2) emotional context colors preoperative understanding and retention of information; (3) expectation-setting affects satisfaction with preoperative counseling; and (4) desire for diversified delivery of preoperative information. Theme 2 was coexisting and often conflicting priorities, including (1) desire to survive above all else, and (2) desire for quality of life. Theme 3 was perception of surgery as momentous and distressing, including (1) surgery as a traumatic event; (2) centrality of mental health, emotional resolve, and gratitude to enduring surgery and recovery; and (3) sense of accomplishment in recovery. On the Decision Regret Scale, most participants had no regret (n = 8, 47%) or mild regret (n = 5, 29%); 4 had moderate-to-severe regret (24%).

**CONCLUSIONS AND RELEVANCE** In this mixed-methods cohort study, patient experiences surrounding major head and neck reconstructive free flap surgery were described. Opportunities to improve support for this complex and vulnerable population, and to mitigate decision regret, were identified.

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JAMA Otolaryngol Head Neck Surg. doi:10.1001/jamaoto.2023.4750  
Published online February 22, 2024.

Head and neck cancer (HNC) and its treatment can profoundly affect quality of life for patients and caregivers.<sup>1-6</sup> Patients with HNC are often asked to make decisions about proceeding with life-altering treatments with limited understanding of complex treatment and survivorship plans. Nearly half of patients with HNC experience clinically significant decisional conflict during this time.<sup>7</sup> Posttreatment decision regret (DR) is associated with lower quality of life and higher anxiety.<sup>8</sup>

Surgery is frequently a recommended element of HNC treatment. Following resection of more extensive tumors, many patients require reconstructive surgery with microvascular free tissue transfer from distant anatomic sites, or *free flaps*. Free flap surgery, though associated with favorable long-term functional and quality-of-life outcomes in many patients,<sup>9</sup> is highly complex and includes potential morbidity. Multiple studies have demonstrated significant complication rates, postoperative pain, and functional limitations after such surgeries, with concomitant declines in quality of life.<sup>10-12</sup> Patients with HNC often also endure arduous radiation and/or chemotherapy treatments, increasing the risk of surgical complications and long-term toxic effects.<sup>13</sup>

Emerging literature is dedicated to understanding decision-making and DR among patients with HNC.<sup>7,8,14-17</sup> However, preoperative decision-making, patient experiences of surgery and recovery, and DR for the unique population of patients undergoing free flap reconstruction for HNC defects have not been well characterized. Using qualitative and quantitative methods, we sought to elucidate themes associated with the experience of free flap surgery among patients with HNC and to identify opportunities for improving care of this complex and vulnerable population.

## Methods

### Study Population

Eligible participants were adults who underwent head and neck reconstructive free flap surgery at a single tertiary academic cancer center more than 3 months prior to study enrollment. Participants were a convenience sample recruited in-person at regularly scheduled follow-up clinic visit, or via telephone. Telephone recruitment was preceded by mailing of an opt-out letter with an opportunity to decline participation, and patients who did not decline were called sequentially starting with those who had surgery most recently. Verbal informed consent was obtained. The Dana-Farber Cancer Institute (DFCI) institutional review board approved this study. Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines were followed.<sup>18</sup>

### Interviews

The semistructured interview guide was developed by 3 of the authors (C.B.W., E.M.R., and R.W.B.) (eAppendixes 1 and 2 in Supplement 1). The one-time interview included open-ended questions about the decision to undergo surgery, the experience of surgery and recovery, and DR. Interviews were conducted June to August 2021 in-person, over telephone, or

## Key Points

**Question** How do patients experience head and neck surgery with free flap reconstruction, including preoperative decision-making and postoperative decision regret?

**Findings** In this mixed-methods cohort study, patients relied heavily on clinical care team recommendations during preoperative decision-making and wished for more diversified preoperative information delivery; patients weighed competing priorities for survival vs quality of life and described surgery as a momentous and distressing event, with decision regret being reported by half of the patients.

**Meaning** Head and neck free flap reconstruction is complex and life altering; opportunities to better support patients include multiple-modality preoperative counseling and attention to mental health needs.

via Zoom by T.I.R., a female medical student unfamiliar to patients and trained in study procedures, introduced as a DFCI Researcher. Caregivers were invited to participate in interviews as able. Transcripts were not returned to participants.

### Data Analysis

Interviews were audio recorded, transcribed verbatim using NVivo software with manual editing, and coded by 2 to 3 study team members (L.D. [female medical student], E.M.R. [female HNC surgery faculty], and/or T.I.R.; L.W.D. coded all transcripts) using Dedoose online qualitative software package (version 9.0.62; Dedoose). A codebook with code definitions was developed during transcript review and shared. Researchers met after coding the first 7 transcripts to evaluate coding agreement. Disagreements were resolved through discussion, and the remaining transcripts were coded and cross-checked for agreement and to ensure thematic saturation had been reached, meaning coding of additional interviews did not offer new thematic insights, which occurred after 12 interviews.<sup>19</sup> Researchers then met to organize codes into themes and subthemes. Representative quotations were compiled and edited for readability, reported with participant study IDs.

Medical record abstraction was performed to ascertain relevant clinical data. Study data were managed using REDCap electronic data capture tools hosted at Mass General Brigham.<sup>20,21</sup>

Participants completed a validated 5-item Decision Regret Scale (DRS; eAppendix 2 in Supplement 1).<sup>22</sup> Items were scored in a Likert-type scale from 0 (no regret) to 5 (high regret). Total DR scores were obtained by subtracting 1 from the mean of all scores and multiplying by 25, obtaining a score from 0 to 100.<sup>22</sup> Scores were categorized as no (0), mild (1-25), and moderate-to-severe regret (>25).

## Results

### Participants

Twenty-seven patients were invited to participate, and 10 declined. Seventeen participants completed interviews lasting a median (range) of 13:38 (5:56-35:28) minutes. Median

(IQR) time since surgery was 11 (8-19) months. Participant characteristics are presented in **Table 1**. The median (IQR) age of participants was 61 (52-70) years. Participants were predominantly male (n = 10 [59%]) and non-Hispanic White (n = 14 [82%]), consistent with our center's practice and similar populations nationally.<sup>23,24</sup> The most common free flap type was fibular (n = 8 [47%]), a higher proportion than national data due to practice patterns at our center.<sup>23,25</sup>

### Thematic Analysis

Three distinct themes were identified: (1) the tremendous effect of preoperative counseling on surgical decision-making and satisfaction; (2) coexisting and often conflicting priorities regarding survival vs quality of life; and (3) surgery as a momentous and distressing event (**Figure**).

#### Importance of Preoperative Counseling for Surgical Decision-Making and Satisfaction

Participants almost uniformly identified preoperative discussions as central to their decisions to undergo surgery, not only in terms of the informational content of those discussions but also the manner and emotional context in which information was conveyed.

#### Importance of Clinical Care Team Counseling for Decision to Have Surgery

Surgeons played prominent roles in most participants' decisions to undergo surgery. Most participants described their surgeon's recommendation as the most influential factor in their decision, referencing the surgeon's expertise and their own limited knowledge: "it was not my decision. It was [the surgeon's] decision...telling me...here's what our options are. Here's what I think we should do. I said, OK...I wasn't going to second guess them" (participant ID, 02). Trust in the surgeon, care team, and institution weighed heavily in many participants' decisions: "I made that decision that [the cancer center] and the surgeons therein knew what they were doing" (participant ID, 16).

Although several participants mentioned outside research as important to their decision-making, including websites and discussions with people who had undergone similar surgeries, it was unusual for participants to cite resources outside of the clinical care team as playing a significant role. Discussions with family members and friends were typically referenced in a secondary supporting capacity. A minority of participants felt they made the decision entirely on their own: "it was mostly my own decision as far as I'm concerned. I made it by myself" (participant ID, 08).

#### Emotional Context Colors Preoperative Understanding and Retention

Many participants felt that the emotion and sense of urgency inherent to a life-threatening diagnosis precluded them from adequately processing or remembering information and from asking pertinent questions.

One participant shared, "in the chair, they told me all this information. And when you know you have cancer, I think the main thing is if you can get it out, get it out. I am not sure I paid enough attention or was able to really ponder what I was going to go through. I didn't have the capacity to do that in that

**Table 1. Characteristics of Study Population**

Characteristic	No. (%)
Total	17
Age, median (IQR), y	61 (52-70)
Time since surgery, median (IQR), y	1.0 (0.6-1.6)
Sex	
Female	7 (41)
Male	10 (59)
Race and ethnicity	
Black or African American	3 (18)
Non-Hispanic White	14 (82)
Education	
High school diploma	2 (12)
Some college	5 (29)
College degree	7 (41)
Graduate degree	3 (18)
Employment status	
Employed	7 (41)
Unemployed	10 (59)
Residence	
Own home or apartment	15 (88)
Home or apartment of family member	1 (6)
Other	1 (6)
Previous treatment	
Surgery	3 (18)
Radiation with or without chemotherapy	7 (41)
Surgery and radiation with or without chemotherapy	5 (29)
None	2 (12)
Indication for surgery	
Cancer	16 (94)
Osteoradionecrosis <sup>a</sup>	1 (6)
Free flap donor site <sup>b</sup>	
Fibula	8 (42)
Radial forearm	4 (21)
Scapula and/or latissimus	3 (16)
Anterolateral thigh	3 (16)
Latissimus	1 (5)
30-d Readmission	
No	14 (82)
Yes	3 (18)
Postoperative complications <sup>c</sup>	
No complication	5 (29)
Complication(s)	12 (71)

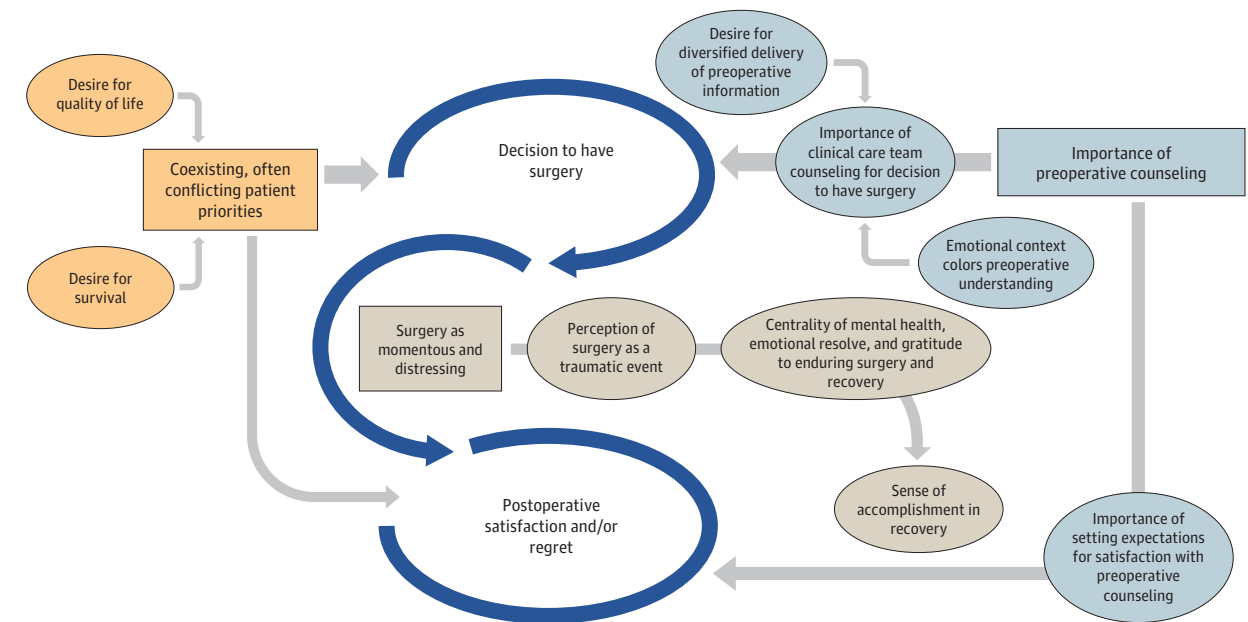
<sup>a</sup> Osteoradionecrosis secondary to prior chemoradiation therapy for tonsil cancer.

<sup>b</sup> Two patients underwent 2 free flaps, 1 for flap failure requiring revision and 1 for second primary cancer. The first surgery date was used to calculate time since surgery.

<sup>c</sup> Postoperative complications included wound infection (n = 5), pharyngeal fistula (n = 3), flap failure requiring revision free flap (n = 1), hematoma (n = 1), seroma (n = 1), pneumomediastinum (n = 1), and tracheostomy false passage requiring urgent replacement (n = 1).

situation" (participant ID, 14) Another participant stated, "it all happened so fast. I just went with what they told me" (participant ID, 12).

Figure. Conceptual Framework for the Patient Experience Surrounding Free Flap Surgery



Themes are enclosed in rectangles, with subthemes denoted by ovals.

Dissatisfaction was expressed when the care team did not accommodate participants' emotional barriers to processing preoperative information. Participants acknowledged that they sometimes did not clearly remember details, but felt it was incumbent on the clinical care team to anticipate this eventuality: "I asked the doctors, why didn't you tell me about this? Why didn't you tell me about that? They said that they did. So, I thought about that. And...I said 'you know you throw all of this stuff at us, saying you told us stuff that we don't remember.' ...I think patients in the future should have a follow-up visit to go over everything they think they heard you say, or you didn't say, to be able to make a more informed decision because it is very emotional" (participant ID, 06).

#### Expectation-Setting and Satisfaction With Preoperative Counseling |

Participants offered differing opinions on the adequacy and appropriateness of the preoperative information they received. Many participants expressed satisfaction with the information they received preoperatively. Among these, several pointed to surgeons' frankness, including "they told me many times this is a major thing" (participant ID, 13) and "[the surgeon] did not sugar coat...[they] admitted this is a big surgery. It's going to take months to recover, not weeks" (participant ID, 16). One respondent particularly appreciated the surgeon's enumeration of difficult aspects of recovery: "[my surgeon] told me everything, what to expect. And it was just as stated, you know, I wouldn't be able to talk for a while. I was going to be very swollen for a while. I was going to hurt for a while and those things were to be expected" (participant ID, 10).

One caregiver who expressed satisfaction with preoperative conversations also appreciated the surgeon's attention to the emotional effect surgery might have: "I was amazed that they took into consideration [the patient's] emotions. They...really care about you and how this would affect us. They offered all kinds of resources to help emotionally" (participant ID, 01).

Other participants wished for more preoperative information, or wished it were communicated more effectively. Dissatisfaction was typically tied to a sense of inadequate preparation leading to inaccurate expectations for the surgery and its long-term sequelae, eroding trust in the clinical care team. A notable example is that of an unexpected long-term feeding tube; several participants mentioned this situation in reference to diminishing trust in their surgeon and causing DR.

#### Desire for Diversified Delivery of Preoperative Information |

Participant suggestions for improving preoperative counseling can be broadly summarized as diversifying the delivery of preoperative information. Multiple participants expressed a desire to speak with other patients who had undergone similar surgeries. Some wished for written documentation or recordings that they could reference outside the emotionally charged clinic room: "you can record what the physician says and you can take it home, then listen to it when you're right...and that's what I suggest for most patients who are getting surgery because you can't comprehend what the doctor is telling you...because you're just too nervous" (participant ID, 03). Finally, several participants desired additional opportunities for follow-up conversations with the

clinical care team, not necessarily the surgeon, to process the decision and ask additional questions.

### Coexisting and Conflicting Priorities

Desire for survival and desire for quality of life emerged as clear themes that were sometimes at odds with each other. A subset of participants viewed surgery as their only alternative to death: “I don’t think we [had] a choice. It was either [surgery] or die, and we were not ready for [death]” (participant ID, 04). These participants felt the decision to undergo surgery was made for them, given how strongly they desired to live: “I don’t think there were options. The other option would be to do nothing and take my chances. And I didn’t want to do that. I respect life too much to want to do that” (participant ID, 14).

For many, the desire to survive outweighed the morbidity of surgery, both in foresight: “If they take my eye, I will just have to adjust” (participant ID, 01) and in hindsight: “It’s life altering. It changed my life and changed my diet...and it changed the way I talk. I had to battle back to gain the...ability to speak properly and enunciate properly with what they took from inside. But I had to do that... and I have no regrets about it whatsoever. I’m here because I went through it” (participant ID, 02).

For others, survival did not justify the effects of surgery on speaking, eating, travel, and even intimacy: “never would [I] have made the decision if I knew it would affect my swallowing and speech” (participant ID, 03). Indeed, many participants who expressed DR secondary to poor quality of life also voiced a lack of preparedness for the sequelae they experienced: “the information wasn’t given to me, the recovery was awful. The end results—so what if I’m cancer free. I’m not enjoying life...and, if I had to...die from the cancer, then so be it. As opposed to doing this” (participant ID, 06).

### Surgery as a Momentous and Distressing Event

Surgery was frequently referenced as a momentous event, rife with challenges but also triumphs, and engendered in some a sense of accomplishment for having endured it. The perception of surgery as a physically and emotionally traumatic event emerged as a consistent theme. As one participant reflected, “it was a brutal experience. It was a tough recovery, and I’m very optimistic and happy to be alive, but I could see how it could be devastating emotionally and send some people into depression...the mental aspects can be worse than the physical aspects” (participant ID, 05). Some participants described their recoveries as “awful,” “brutal,” and “pretty traumatic.” They described feeling “helpless” at times, unable to meet or communicate their own needs.

Caregivers noted a toll of feeling that they had to be on “high alert” while their loved ones coped with recovery: “I wasn’t prepared for the volume of phone calls I was going to get when he was released...I all of a sudden had to become his voice. For everything” (participant ID, 08).

In response to these grueling challenges posed by surgery, some participants emphasized the centrality of mental health, emotional resolve, and gratitude to successful recovery. One participant viewed psychological preparation for surgery as key to recovery: “[you should] get yourself in the best

mental state you can get yourself into so that you are not worried or anxious or depressed. I think a huge part of this type of surgery is the attitude that runs before and after this. The attitude of gratitude that I had the best medical treatment I could possibly get” (participant ID, 14). Survivors also emphasized the importance of “mindfulness,” accepting the decision to undergo surgery, maintaining “a positive mindset and stay[ing] in the present” (participant ID, 05) and “[taking] it day by day” (participant ID, 11).

Several participants described a feeling of accomplishment born of enduring and overcoming the challenges of surgery. One participant shared that “...it can be pretty horrible, or you can come out on the other side and feel way more confident about your life” (participant ID, 07). Another commented, “I knew we had a long road to recovery...but that was such a relief...it’s almost like how could you have such a wonderful experience from...having cancer? It’s the weirdest thing” (participant ID, 01).

### Decision Regret Scale

All 17 participants completed the DRS. Eight participants (47%) had either no DR or mild DR ( $n = 5$  [29%]), with 4 participants (24%) experiencing moderate-to-severe DR. Participants who experienced any DR were older than participants who did not experience any DR (median age, 74 vs 56 years). Prevalence of DR by participant characteristics is reported in **Table 2**. Statistical testing was not performed due to small sample size.

## Discussion

Patients with HNC undergoing reconstructive free flap surgery uniquely endure physically and emotionally demanding procedures that can profoundly affect quality of life. In this study, we made an early foray into characterizing the patient experience of such a complex and life-altering surgery. Through qualitative analysis, we identified several themes representative of participants’ reflections, including the tremendous importance of preoperative counseling, the competing desires for survival vs quality of life, and the perception of surgery as both momentous and distressing.

The importance of physicians’ recommendations emerged as a major theme in this study, consistent with prior studies of decision-making among patients with HNC.<sup>16,17</sup> A previous study by Davies et al<sup>16</sup> of decision-making by patients with HNC found that those with HNC frequently deferred to their physicians’ decisions, citing trust and confidence in the physician. Similar themes emerged in our study, with participants largely deferring to surgeon recommendations. Davies et al concluded that the decision-making process by patients with HNC does not conform to conventional shared decision-making models, where there are several options and uncertainty about which is the best treatment. Forner et al<sup>26</sup> describe an alternative model more germane to patients with HNC, called *value-option congruence*. In this model, there is a serious illness with a clear best option from a disease treatment standpoint, yet decision-making regarding whether to proceed with that recommended treatment is still influenced by patient values

**Table 2. Demographic and Treatment-Related Variables Compared With Decision Regret as Assessed by the Decision Regret Scale**

Characteristic	Participants reporting any decision regret, No./total (%)
Total	17 (100)
Sex	
Female	3/7 (43)
Male	6/10 (60)
Education	
Less than college degree	2/7 (29)
College degree or above	7/10 (70)
Race	
Black or African American	0/3
Non-Hispanic White	9/14 (64)
Smoking status	
Never	2/5 (40)
Ever (former or current)	7/12 (58)
Diet at discharge	
Using feeding tube	7/12 (58)
Completely oral	2/5 (40)
Diet at last follow-up	
Using feeding tube	5/6 (83)
Completely oral	4/11 (36)
Postoperative complications	
No	1/5 (20)
Yes	8/14 (67)
Adjuvant treatment after surgery	
No	6/8 (75)
Yes	3/9 (33)

and preferences.<sup>26</sup> From a practical standpoint, physicians caring for patients with HNC should be cognizant of the unique decision-making considerations for this population, recognize the tremendous weight of their recommendations, and create space for patient preferences to influence decision-making even with a clear best treatment path forward.

Participant dissatisfaction was often tied to a sense of inadequate preoperative preparation leading to inaccurate expectations. Citing intense emotional reactions to their cancer diagnosis and need for surgery as a frequent impairment to information processing during clinic visits, participants strongly desired additional modalities of preoperative information (access to patients who previously underwent surgery, written or recorded materials to reference, and follow-up discussions with care teams). Thus, we suggest that future implementa-

tion research should engage patients<sup>27</sup> to develop comprehensive, diversified preoperative information-sharing strategies that refine expectations, ensure alignment of patient and clinician goals, and minimize DR.

Many participants in this study cited the psychological challenges and tolls of free flap surgery, underscoring the critical importance of mental health care in this population. Patients with HNC suffer disproportionately from depression and anxiety,<sup>28,29</sup> with higher rates of suicide than other patients with cancer.<sup>30-32</sup> Understanding that patients experience this surgery as a traumatic event represents an opportunity for improving mental health awareness and support, such as anxiety and depression screening and referral to mental health services.

The 53% prevalence of DR we observed was similar to the previously reported 48% prevalence of decisional conflict (which correlates with DR) among patients with HNC.<sup>7</sup> Older age had higher prevalence of DR, a link also observed in a previous study of preferences and DR among patients with HNC<sup>14</sup> wherein the relative importance of survival decreased with increasing age. Authors postulated that quality of life gains importance in the context of a shorter remaining natural lifespan.<sup>14</sup> Similarly, competing priorities of quality of life vs survival was a common theme among patients receiving free flap reconstruction.

### Limitations

The generalizability of this study was limited because only post-surgical patients were enrolled, excluding the perspective of patients who declined surgery. The cohort also lacked racial and ethnic diversity and was from a single center. Small cohort size precluded quantitative analysis of factors associated with DR. Finally, interviews were relatively short, potentially due to communication impairment inherent to the HNC population, which should be accounted for in future studies.

### Conclusions

Patients with HNC facing major surgery with free flap reconstruction place tremendous trust in their clinical care teams. This mixed-methods study identifies critical opportunities to better support this vulnerable population, most prominently the optimization and diversification of preoperative information-sharing. Future research to further elucidate these themes is warranted.

#### ARTICLE INFORMATION

**Accepted for Publication:** December 22, 2023.

**Published Online:** February 22, 2024.

doi:10.1001/jamaoto.2023.4750

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**Author Contributions:** Dr Rettig had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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*Acquisition, analysis, or interpretation of data:* Dattilo, Russell, Warinner, Starmer, Annino, Goguen, Windon, Bergmark, Rettig.

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**Conflict of Interest Disclosures:** Dr Bergmark reported unrelated faculty grant funding as the Nesson Fellow at Brigham and Women's Hospital to investigate access to surgical care; unrelated clinical trial grant funding from I-Mab Biopharma; and unrelated research consulting with Analysis Group. Dr Rettig reported nonfinancial support from Naveris (in-kind research essay support) outside the submitted work. No other disclosures were reported.

**Data Sharing Statement:** See Supplement 2.

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