

Exploring Decisional Conflict Experienced by Individuals Considering Metoidioplasty and Phalloplasty Gender-affirming Surgery

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Background: Metoidioplasty and phalloplasty gender-affirming surgery (MaPGAS) is increasingly performed and requires patients to make complex decisions that may lead to decisional uncertainty. This study aimed to evaluate decisional conflict in individuals considering MaPGAS.

Methods: We administered a cross-sectional survey to adult participants assigned female sex at birth and considering MaPGAS, recruited via social media platforms and community health centers. We collected data on demographics, medical and surgical history, MaPGAS type considered, and the Decisional Conflict Scale (DCS). DCS scores range from 0 to 100 (>37.5 indicates greater decisional conflict). Demographic characteristics and DCS scores were compared between subgroups, using descriptive and chi-square statistics. Participants commented on MaPGAS uncertainty, and their comments were evaluated and thematically analyzed.

Results: Responses from 264 participants were analyzed: mean age 29 years; 64% (n = 168) trans men, 80% (n = 210) White, 78% (n = 206) nonrural, 45% (n = 120) privately insured, 56% (n = 148) had 4 or more years of college, 23% (n = 84) considering metoidioplasty, 24% (n = 87) considering phalloplasty, and 26% (n = 93) considering metoidioplasty and phalloplasty. DCS total scores were significantly higher (39.8; $P < 0.001$) among those considering both MaPGAS options, as were mean ratings on the Uncertainty subscale [64.1 (SD 25.5; $P < 0.001$)]. Concerns surrounding complications were the top factor contributing to uncertainty and decisional conflict.

Conclusions: In a cross-sectional national sample of individuals seeking MaPGAS, decisional uncertainty was the highest for those considering both MaPGAS options compared with metoidioplasty or phalloplasty alone. This suggests this cohort would benefit from focused decision support. (*Plast Reconstr Surg Glob Open* 2024; 12:e5840; doi: [10.1097/GOX.0000000000005840](https://doi.org/10.1097/GOX.0000000000005840); Published online 30 May 2024.)

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INTRODUCTION AND OBJECTIVES

Metoidioplasty and phalloplasty gender-affirming surgery (MaPGAS) is increasingly performed for transgender and nonbinary individuals assigned female sex at birth (AFAB) to facilitate genital gender identity congruence.^{1,2} Although MaPGAS is associated with improved quality of life³ and gender congruence,² it carries high risk and requires patients to make multiple complex decisions. For example, patients must make decisions about surgical timing, whether to have removal of internal reproductive organs (the cervix, vagina, uterus, uterine tubes, and ovaries), fertility planning, perineal reconstruction (vaginectomy and/or scrotoplasty), and decide between metoidioplasty and phalloplasty. Metoidioplasty is the creation of a penis of limited size using testosterone-induced clitoral hypertrophy and local genital tissue reconstruction. Phalloplasty is the creation of a penis with greater size flexibility using a free or pedicle tissue flap most commonly from the forearm or thigh. Each can be performed

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with or without urethral lengthening to allow standing urination from the tip of the penis and other component procedures. These procedural choices have lasting implications for future fertility, urinary, and sexual function.^{4,5} MaPGAS performed with urethral lengthening is associated with a high risk of urologic complications including up to 50% urethral stricture and fistula rate,⁶ potentially resulting in repeat procedures, prolonged catheterization, genitourinary infection, and lower urinary tract compromise. As is true of many complex reconstructive surgical procedures, there is currently a lack of quality published patient-reported outcome measures (PROMs) to elucidate the extent and impact of MaPGAS genitourinary outcomes and complications.⁷

Given the complexity of MaPGAS decision-making, it follows that many individuals would experience decisional conflict. Numerous prior studies have evaluated decisional conflict in patients considering reconstructive surgery, such as breast reconstruction after oncologic mastectomy,^{8–11} yet few published studies from the United States have used validated measures to evaluate decisional uncertainty or conflict in individuals considering MaPGAS. The 2015 United States Transgender Survey¹² (an anonymous survey that queried 27,715 transgender and nonbinary respondents from all 50 states on a variety of categories, including demographics and health-related subject matter) found that 49% of transgender men reported being unsure if they wanted metoidioplasty, and 43% reported being unsure if they wanted phalloplasty. The level of uncertainty was lower among nonbinary participants AFAB, with 24% being unsure if they wanted metoidioplasty and 19% being unsure if they wanted phalloplasty. Although some degree of decisional conflict is inherent in complex decision-making, studies associated with high levels of decisional conflict found delayed decisions, poor quality decisions, and decision regret.^{11,13,14}

Guided by the principles of the Ottawa Decision Support Framework,¹⁵ the primary purpose of this study was to further explore the decisional uncertainty suggested by the 2015 United States Transgender Survey and to evaluate the degree of decisional conflict among individuals in the United States considering MaPGAS, using the Decisional Conflict Scale (DCS). The DCS was developed in 1995 to measure healthcare consumer uncertainty, factors that contribute to uncertainty, and perceived effectiveness of decision-making. The instrument was validated in an influenza immunization study and a breast cancer screening study and is widely used to objectively measure decisional conflict surrounding medical decision-making.¹⁶ We hypothesize that those considering both metoidioplasty and phalloplasty will have greater decisional conflict than those considering metoidioplasty or phalloplasty alone.

METHODS

A cross-sectional survey was administered via Research Electronic Data Capture (REDCap) to a national convenience sample of adult English-speaking participants AFAB

Takeaways

Question: What is the landscape of decisional uncertainty amongst transgender men and nonbinary individuals assigned female sex at birth, considering metoidioplasty and phalloplasty gender-affirming surgery (MaPGAS)?

Findings: A cross-sectional national sample of individuals considering MaPGAS showed higher decisional conflict amongst those considering both MaPGAS options compared with those considering only one option.

Meaning: Because decisional conflict was highest for individuals considering both MaPGAS options, this population would likely benefit from focused decision support.

interested in MaPGAS. The study was approved by the IRB (STUDY02000222). Participants were recruited by members of the community via social media platforms, network forums, and flyers at one urban clinic. Participants were not offered monetary compensation for completion of the survey. The survey took an average of 30 minutes to complete and included demographic information (medical, emotional, and surgical history), type of gender-affirming surgery considered, and the DCS.

The DCS includes 16 items grouped into five domains, which measure uncertainty (eg, “I am clear about the best choice for me”), perceptions of feeling informed (eg, “I know which options are available to me”), clarity of personal values (eg, “I am clear about which benefits mean the most to me”), perceived support (eg, “I have enough support from others to make a choice”), and perceived effectiveness of prior decisions (eg, “I am satisfied with my decision”). Items are rated on a five-point Likert scale (list scale anchors low to high). Total DCS scores range from 0 to 100. A score less than 25 is associated with low conflict, whereas scores greater than 37.5 indicate greater decisional conflict, “decision delay, or feeling unsure about implementation.”¹⁶ Survey responses were included if all DCS questions were answered. We analyzed demographic and past medical history data using descriptive statistics and chi-square tests to compare surgical subgroups. Further, we used one-factor analysis of variances with Bonferroni adjustments and post hoc Tukey’s tests to compare mean DCS scores between groups. In an open-ended question following the DCS items, participants were also asked to list any reasons for uncertainty about the treatment options they were considering. We used content analysis to identify and group the most common themes emerging in responses.¹⁷

RESULTS

Responses from 264 participants were included in this analysis. Mean age was 29 years (SD 8.18, range 18–64); 57% (n = 151) and 64% (n = 168), respectively, identified as men or transgender men (multiple responses allowed), and 43% (n = 114) identified as gender diverse (nonbinary, gender queer, or gender nonconforming). The sample was 80% (n = 210) White, 78% (n = 206) nonrural, 45% (n = 120) privately insured, and 56% (n = 148) had

completed 4 or more years of college. Evaluating cohorts by MaPGAS options being considered, three groups emerged: considering metoidioplasty only ($n = 84$), considering phalloplasty only ($n = 87$), and considering both metoidioplasty and phalloplasty ($n = 93$; ie, undecided on MaPGAS option). There were no significant differences between the three groups in demographic characteristics (Table 1).

The majority of respondents, 82% ($n = 216$), were on gender-affirming hormone therapy for more than one year, and 75% ($n = 199$) had previously undergone chest surgery. Among respondents considering MaPGAS, less than half had undergone hysterectomy or oophorectomy.

The mean total DCS scores (Table 2) were significantly higher for those considering both metoidioplasty and phalloplasty (39.8, $P < 0.001$) compared with either MaPGAS option alone. These same respondents who were considering both MaPGAS options also had significantly higher Uncertainty subscale scores 65.4 (25.5, $P < 0.001$) than respondents in the other two groups: considering metoidioplasty only 43.3 (29.7) and considering phalloplasty only 36.7 (30.4). Those considering only phalloplasty had significantly lower scores on Informed, Values Clarity, and Support subscales indicating feeling less conflict and more informed, clear, and supported (Table 2).

A total of 167 (63%) participants provided responses to the open-ended question “Please list any reasons for uncertainty about the gender affirming medical treatment you are considering.” On analysis, we found five main themes as reasons for uncertainty. The five themes centered around fear of, and questions about, complications, concern about outcomes (eg, if they would be able to achieve the outcomes they wanted), lack of information/knowledge, cost/insurance concerns, and difficulty weighing risks versus benefits. Exemplar quotes for top themes related to MaPGAS decision uncertainty can be found in Table 3.

The most common reason for MaPGAS uncertainty was concern about complications, including urinary complications (urethral stricture and fistula), loss of sensation, loss of sexual function, and infection. Many respondents were concerned about long-term complications necessitating additional surgery. These concerns were especially pronounced for those considering phalloplasty or urethral lengthening and those with preexisting medical conditions. Some respondents indicated that they were leaning toward having a surgery that is associated with a lower risk of complications rather than having a surgery that would allow them to achieve their transition goals. Other respondents wondered if there would be better options with fewer complications if they waited to have surgery.

“Phalloplasty has a very high complication rate and the complications that often arise are psychologically and physically traumatic. I don’t have any way to know whether I’ll have those complications or how bad they will be.”

Some participants noted concern about outcomes, such as aesthetics and function, as a reason for uncertainty. They expressed that there are no guaranteed results, and

they had seen varying results from MaPGAS. Others worried that ending up with imperfect results could make their dysphoria worse.

“I’ve almost completely decided MLD [musculocutaneous latissimus dorsi flap] phalloplasty is the best choice for my goals, but it could still result in loss of sensation, and potentially increased dysphoria if I look down and see this part of my body still not being a ‘real’ penis.”

Respondents also cited a lack of knowledge about MaPGAS, including risks, complications, outcomes, and options as a cause of uncertainty, and some emphasized a need for information on surgeons who perform MaPGAS and access to their outcome photographs.

“I would love more peer-reviewed, rigorous studies regarding complication rates and outcomes, especially about the UL [urethral lengthening] w/o vaginectomy combination. Some surgeons say it significantly increases the risk of complications and won’t do it, others say it is somewhat of a risk but not an enormous one, others don’t seem particularly concerned at all. Anecdotal evidence is helpful, but I don’t feel I have complete information about the overall risk profile of UL beyond individual surgeons’ advice and opinions.”

Concerns about cost and insurance contributed to uncertainty in making a decision about what kind of surgery to have. Some respondents were unsure if MaPGAS would be covered by their insurance or how much of the cost would be covered. Some respondents, especially those considering phalloplasty, expressed that they may not be able to afford the surgery they want and would have to compromise. Other respondents indicated they were unable to afford the travel expenses associated with seeing a surgeon who performs the surgery they want, limiting their options.

“Also don’t have a chance in hell of affording to travel to the surgeon doing the procedure I want so I’m likely going to have to compromise.”

Difficulty weighing the risks versus benefits of MaPGAS was another source of uncertainty, and some were additionally uncertain whether resolution of dysphoria or being able to stand to urinate would be worth such an involved surgery, complication risk, and extended time away from work. For these reasons, some participants leaned toward not having any MaPGAS procedures.

“Am I making the wrong choice by holding out for something better that might never exist? Which choice will bring me the most joy and least suffering overall?”

Other reasons for uncertainty, cited by fewer than 10% of respondents, included the desire for better options, surgeon availability, preexisting conditions, lengthy recovery time, and mistrust toward surgeons.

DISCUSSION

In our cross-sectional sample of transgender and nonbinary individuals AFAB considering MaPGAS, we found higher levels of decisional uncertainty in

Table 1. Demographic Characteristics of DCS Respondents (n = 264)

	All Respondents (N = 264)	Considering Metoidioplasty (n = 84)	Considering Phalloplasty (n = 87)	Considering Both (n = 93)
Gender Identity*				
Male	151 (57%)	40 (48%)	55 (65%)	56 (60%)
Trans man/male	168 (64%)	48 (57%)	53 (61%)	67 (72%)
Nonbinary	64 (24%)	26 (31%)	17 (19%)	21 (23%)
Gender queer/nonconforming	50 (19%)	20 (24%)	12 (14%)	18 (19%)
Female	0 (0%)	—	—	—
Other	10 (4%)	5 (6%)	3 (3%)	2 (2%)
Missing	31 (12%)	12 (14%)	11 (13%)	8 (9%)
Race*				
White	210 (80%)	63 (70%)	68 (78%)	79 (85%)
Hispanic	20 (8%)	5 (6%)	10 (11%)	5 (5%)
African American	17 (6%)	5 (6%)	7 (8%)	5 (4%)
Asian	7 (3%)	2 (2%)	1 (1%)	4 (4%)
AIAN	4 (1.5%)	—	2 (2%)	2 (2%)
Middle Eastern	5 (1%)	2 (2%)	—	3 (3%)
Other	4 (1.5%)	1 (1%)	—	3 (3%)
Missing	31 (12%)	12 (14%)	11 (13%)	8 (9%)
Geography				
Urban	121 (46%)	37 (44%)	39 (45%)	45 (48%)
Suburban	85 (32%)	26 (31%)	28 (42%)	31 (33%)
Rural	27 (10%)	9 (11%)	9 (10%)	9 (10%)
Missing	31 (12%)	12 (14%)	11 (13%)	8 (9%)
Education				
Less than HS	3 (1%)	1 (1%)	1 (1%)	1 (1%)
HS diploma	30 (11%)	10 (12%)	9 (10%)	11 (12%)
Some college or 2-year degree	51 (19%)	14 (17%)	21 (24%)	16 (17%)
Four-year college degree	89 (34%)	27 (32%)	30 (34%)	32 (34%)
Graduate degree	59 (22%)	19 (23%)	15 (17%)	25 (27%)
Missing	32 (12%)	13 (15%)	11 (13%)	8 (9%)
Income				
Less than \$20,000	53 (20%)	19 (23%)	18 (21%)	16 (17%)
\$20,000–\$40,000	52 (20%)	17 (20%)	14 (16%)	21 (23%)
\$41,000–\$60,000	43 (16%)	13 (16%)	14 (16%)	16 (17%)
\$61,000–\$80,000	25 (9%)	8 (9%)	6 (7%)	11 (12%)
\$81,000–\$100,000	17 (6%)	4 (5%)	9 (10%)	4 (4%)
>\$100,000	38 (14%)	9 (11%)	14 (16%)	15 (16%)
Missing	36 (14%)	14 (17%)	12 (14%)	10 (11%)
Health Insurance				
Employer plan	120 (45%)	38 (45%)	39 (45%)	43 (46%)
Medicare	5 (1%)	—	4 (5%)	1 (1%)
Medicaid	30 (11%)	12 (14%)	12 (14%)	12 (13%)
State exchange	16 (6%)	5 (6%)	4 (5%)	7 (7%)
Tri-care/VA health plan†	7 (3%)	2 (2%)	1 (1%)	4 (4%)
Other	32 (12%)	9 (11%)	14 (15%)	9 (10%)
Not sure	5 (1%)	1 (1%)	3 (3%)	1 (1%)
No insurance	12 (4%)	5 (6%)	—	7 (7%)
Missing	32 (12%)	12 (14%)	11 (13%)	9 (10%)
Relationship Status				
Single	150 (57%)	45 (54%)	54 (62%)	51 (55%)
Single	37 (14%)	17 (20%)	7 (8%)	13 (14%)
Married/civil union	38 (14%)	10 (11%)	13 (15%)	15 (16%)
Domestic partner	7 (3%)	—	2 (2%)	5 (5%)
Divorced	1 (0.4%)	—	—	1 (1%)
Widowed	31 (12%)	12 (14%)	11 (13%)	8 (9%)
Missing	150 (57%)	45 (54%)	54 (62%)	51 (55%)
Mental Health History				
Anxiety	191 (72%)	57 (81%)	67 (89%)	67 (79%)
Depression	180 (68%)	51 (73%)	62 (83%)	67 (79%)

*Multiple answers allowed.

†Veterans affairs.

AIAN: American Indian and Alaska Native; HS: High school.

Table 2. Mean Scale Scores (SD) for Decisional Conflict Scale by Domain and Status of Considering MaPGAS

Decisional Conflict Subscales	All Respondents (n = 264)	Considering Metoidioplasty Only (n = 84)	Considering Phalloplasty Only (n = 87)	Considering Both Metoidioplasty and Phalloplasty (n = 93)
DCS total score	31.8 (20.2)	31.0 (19.3)	24.1 (20.1)	39.8 (18.1)*
Uncertainty (three items)	48.5 (30.8)	43.5 (29.7)	36.7 (30.4)	64.1 (25.5)*
Informed (three items)	26.7 (23.5)	28.2 (23.6)	20.4 (21.3)†	31.3 (24.5)
Values clarity (three items)	24.6 (22.0)	22.8 (18.3)	20.1 (21.6)†	30.3 (24.8)
Support (three items)	29.9 (21.5)	31.9 (22.7)	23.4 (20.0)†	34.0 (20.5)
Effective decision (four items)	30.2 (22.0)	29.2 (20.5)	21.0 (21.7)	39.6 (19.7)

*P ≤ 0.001.

†P ≤ 0.01.

Note: Scores range from 0 to 100; a higher score indicates a more negative outcome (greater decisional conflict, feeling more uncertain and less informed). Typically, a score <25 indicates no conflict and >37.5 associated with decisional conflict/delayed decisions.

Table 3. Themes Related to Uncertainty and Decisional Conflict in Open-ended Survey Responses Listed from Most to Least Frequently Cited

Reasons for Uncertainty	Exemplar Quotes
Fear of/concern about complications	<i>I'm worried that if I experience complications secondary to genital surgery that I may become more dependent on the medical established to function.</i> <i>Phalloplasty with UL with vaginal retention virtually guarantees complications and I'm not 100% convinced of my surgeon's urogynecology expertise, but I suspect this is still the best option. I just wish there were better options.</i> <i>Complications. I don't know anyone LITERALLY who hasn't had complications after phallo.</i> <i>I only get one body, and I'm concerned about possible complications from surgery. I wonder if I hold out longer, will the options get better.</i>
Concern about outcomes	<i>I am worried about complications because I tend to have complications with other things and I'm worried it's not going to improve my dysphoria. I don't want to feel like I'm wasting my money and time and feelings and everything.</i> <i>Imperfection, no results are specifically guaranteed, the need for revision surgery and how that would affect my relationship and career, inability to be physically active for a long stretch of time (major outlet for me).</i> <i>Even knowing the options, I don't feel 100% confident that I will know what my genitals will look like after surgery and that feels scarier in some ways than my current situation. I don't want to have surgery to "fix" a situation, only to wind up in "worse" situation.</i> <i>There's always some uncertainty that it won't turn out how I want it to. Or that I could have major complications which prevent me from achieving my goals.</i> <i>Have seen widely varying results and I feel like I would never "get over" spending so much for an undesirable outcome (if that happened).</i>
Cost/insurance concerns	<i>My only uncertainty is if I will actually be able to get bottom surgery. It's expensive, and I cannot afford it, nor will I be able to afford in the future. The healing time for surgery is lengthy and I am a very physical person. I can't even imagine being out of commission for more than a few days, let alone months. I don't know if I could mentally handle that.</i> <i>I'm uncertain whether I can afford the cost of the procedure and the amount of time I would need to take off work. There is only one type of procedure I am interested in (simple meta without UL or vaginectomy) but the surgeons in my area who perform it are not particularly nonbinary friendly and I am ambivalent about trusting them to give me the results I want. I could travel out of state but I don't know how I would afford the expense.</i> <i>I do not foresee myself being able to get phalloplasty without insurance covering it due to the high cost and therefore have to choose between being able to pee or keep my vagina.</i>
Lack of information/knowledge	<i>I'm still uneducated about a number of the surgeries and risks of the surgeries and unsure the medical field is advanced enough in ftm bottom surgeries.</i> <i>I don't feel I have enough information to be comfortable pursuing surgery.</i> <i>Even though I see doctors at a transgender specific clinic, they don't have information available about bottom surgery other than sterilization.</i> <i>I'm having trouble finding options/information to get the results I want and finding pictures showing surgery results and healed results for what I'm looking for</i>
Difficulty weighing risks versus benefits	<i>I'm uncertain that the risks outweigh the benefits, but I also don't know if I have an accurate perspective on the risks.</i> <i>Uncertain that I will be satisfied with the outcome enough that it will be worth it to go through the process.</i> <i>I wonder if my dysphoria is strong enough to justify going through surgery and recovery (even though I know it is). I wonder if it is worth the inconvenience of having to travel, plan around other responsibilities like work and school, or inconvenience my caretaker. I would basically be interrupting my life for weeks to months to have surgery, but it's better than spending the rest of my life with dysphoria.</i> <i>Still doing a cost benefit analysis, leaning towards not pursuing more surgery because of concerns about cost, complications and being told by a potential surgeon that I'm a higher risk patient.</i> <i>Basically, it's weighing the types of scarring, potential for complications, number of surgical stages, and measuring that up with potential benefits. Being able to STP would be great, but not if it's just fistula after fistula after fistula.</i>

those considering both MaPGAS options as opposed to metoidioplasty or phalloplasty alone. Open-ended feedback from participants revealed that the most common reasons for uncertainty included fear of complications, concern about outcomes, cost, lack of knowledge and

information about MaPGAS, and difficulty weighing risks versus benefits.

A study by Chen et al examined factors surrounding decision-making in transgender adolescents considering fertility preservation before the initiation of

gender-affirming hormone therapy. Although not evaluating MaPGAS decision-making, Chen et al similarly found financial considerations and lack of “adequate and accurate information”¹⁸ were associated with reported decisional difficulty.

Based on our review, this is one of the few studies, and the only U.S. study, to evaluate decisional conflict among individuals considering different MaPGAS options using a validated measure. Interestingly, although we found clinically significant DCS total scores for those who were considering both metoidioplasty and phalloplasty (39.8), the DCS total scores of other subgroups considering one option did not reach clinically significant conflict. This may be due to lower complexity of weighing a single option when compared with multiple options¹⁹ or may relate to the stage of decision-making (early versus later in the process).^{16,20} Although not significant, the total DCS scores for those considering phalloplasty alone were lower than for those considering metoidioplasty alone.

Mokken et al evaluated the association of a MaPGAS decision aid and DCS scores in the Netherlands.²¹ The mean decisional conflict score of the two cohorts demonstrated less decisional conflict than in our sample, with total DCS scores of 34.9 for the decision aid intervention group and 30.9 for usual care group before decision aid administration. The lower baseline DCS scores in the Mokken et al study may be due to their cohort having already elected to pursue MaPGAS and being scheduled for a surgical consult as compared with our cross-sectional study, including participants who may have been in earlier stages of considering MaPGAS options. Additionally, while Mokken et al focused exclusively on transgender men, over a third of our respondents identified as gender diverse or nonbinary. Although prior studies have shown nonbinary AFAB individuals may have less interest in MaPGAS, there is limited published data comparing rates of decisional uncertainty between transgender men and nonbinary AFAB individuals.²² Further, their thematic analysis of qualitative interviews from the Netherlands sample revealed different themes associated with decisional conflict, including participant history, mental health, and social support. Although the qualitative analysis of the Netherlands sample revealed some overlap in themes associated with decisional conflict, including concerns related to participant health history, mental health (eg, gender dysphoria), and social support, factors that were more prominent in our findings, such as cost, insurance coverage, and lack of knowledge and information, likely reflect differences in culture and access to gender-affirming care between the United States and the Netherlands, which make our data more generalizable to a US population.

Our findings suggest the necessity for additional tools that can be used to address decisional conflict in this population. We also believe it is important to consider the role of PROMs in the creation and implementation of a decision support tool. The use of PROMs in clinical encounters provides the opportunity to collect high-quality patient-centered data²³ and can empower individuals by involving them directly in the decision-making process, which may help enhance shared decision-making and decrease

decisional conflict.²⁴ Currently, PROMs that assess the outcomes of genital gender-affirming procedures such as MaPGAS are not validated in the transgender population, making clear the need for MaPGAS-specific PROMs developed in partnership with transgender patient stakeholders.^{25,26} The lack of PROMs developed with transgender patient stakeholders who have lived experiences relevant to the outcomes measured limits the ability of these measures to accurately reflect the unique concerns, experiences, and outcomes pertinent to transgender individuals.^{7,27} Additionally, the creation of PROMs with patient stakeholders can aid evaluating the accessibility of the PROM and reducing the burden placed on patients completing the measure(s).²⁸ An example of a PROM that could meet these needs is the GENDER-Q, which is currently being developed and may have utility in enhancing decision support.²⁹ Similarly, the GenderCOS aims to develop two clinician-observed core outcome sets for genital gender-affirming surgery, which may improve the quality and consistency of MaPGAS data collected and reported, which can improve the information available for patient education.³⁰

The decisional uncertainty and conflict found in our cohort of individuals considering MaPGAS may also be addressed through a MaPGAS decision support tool. Top reasons for decisional uncertainty (Table 3) in this study mirrored the Ottawa Decision Support Framework domains for criteria needed to make a quality decision including fear of complications, concern about outcomes, cost associated with surgery, lack of knowledge and information about MaPGAS, and difficulty weighing risks and benefits. Several of these factors may be modifiable with improved access to decision support tools that can increase patients' knowledge about MaPGAS procedures, expected outcomes, and known risks and benefits, and help them choose a surgical option that best aligns with their personal goals and priorities. To address this need, there is currently a multicenter project focused on creating a web-based comprehensive decision aid for AFAB individuals considering MaPGAS procedures.

Additional options to explore may include group medical appointments^{31–34} or shared education classes³⁵ tailored to individuals considering MaPGAS, which would offer a moderated forum for discussing concerns, sharing experiences, and addressing questions in a supportive environment. Increased discussion of complications and the provision of photographs of surgical outcomes during consultations can further aid in setting realistic expectations and provide further decision support.³⁶

LIMITATIONS

Cross-sectional survey-based studies have inherent limitations. They capture a single point in time, depend on self-report, and are susceptible to recall bias. Given the high variability in ratings on DCS subscale items, our sample size may have limited power to approach significant differences in subgroup comparisons, although the open-ended responses validate the survey ratings, confirming that uncertainty and lack of feeling informed were major factors in

explaining DCS scores. Additionally, a large proportion of participants were White, could read and understand English, were highly educated and insured, and had access to a computer or smartphone with internet, which may impact the generalizability of the results. However, we used multiple modalities to sample the community, and future phases of this work will prioritize seeking more diverse input.

CONCLUSIONS

This US cross-sectional study of 264 transgender men and nonbinary participants AFAB demonstrates a high level of decisional conflict and uncertainty amongst individuals considering MaPGAS, particularly in those who are undecided between phalloplasty and metoidioplasty. Thematic analysis of open-ended comments revealed that the most common reasons for MaPGAS-related decisional uncertainty included fear of complications, concern about outcomes and associated unresolved gender dysphoria, cost, lack of knowledge and information, and difficulties weighing risks versus benefits. These findings suggest this cohort may benefit from focused decision support that provides information about MaPGAS procedure options, risks, expected outcomes, and goals clarification exercises.

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DISCLOSURES

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