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BMJ Open

Patient-centered outcomes on preparing for and undergoing gender-affirming phalloplasty: a qualitative, descriptive study

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To cite: Mmonu N, Radix A, Castle E, *et al*. Patient-centered outcomes on preparing for and undergoing gender-affirming phalloplasty: a qualitative, descriptive study. *BMJ Open* 2025;**15**:e090614. doi:10.1136/bmjopen-2024-090614

► Prepublication history for this paper is available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-090614).

Received 28 June 2024
Accepted 26 February 2025

Check for updates

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ABSTRACT

Objective Despite increasing incidence of genital gender-affirming surgery (GGAS), there is no systematic method of evaluating patient perspectives. The objective of this study is to elucidate transgender and non-binary patient perspectives on gender-affirming phalloplasty/metoidioplasty via structured focus groups and determine convergent themes as the first step towards the development of a GGAS patient-reported outcome measure.

Design We conducted a systematic qualitative study using a thematic content analysis of four focus groups from April 2021 to April 2022 comprising 8 patients undergoing phalloplasty/metoidioplasty and 10 patients post-phalloplasty/metoidioplasty. Focus groups were hosted virtually and recorded and transcribed. Discussions were guided by participant input and focused on goals, experiences, outcomes, satisfaction, and quality of life.

Setting This volunteer but purposive sample of patients was recruited directly in clinic, via email, and via social media at NYU Langone Health (primary site), Callen-Lorde Community Health Center (New York, New York, USA) and the San Francisco Community Health Center.

Participants We conducted focus groups with 18 patients before/after undergoing gender-affirming phalloplasty/metoidioplasty.

Primary and secondary outcome measurements and statistical analysis Transcripts were uploaded into ATLAS.ti, a qualitative data analysis software that facilitates coding for thematic content analysis. We performed deductive and inductive coding to identify the themes that were clustered into overarching domains.

Results The mean duration of focus groups was 81.5 min. Seven themes and 19 subthemes were constructed. The major themes were (1) goals, expectations, and priorities before/after surgery; (2) sexual function; (3) urinary function; (4) peer support; (5) decision-making; (6) mental health and quality of life; and (7) gender dysphoria. Of the major themes, those determined before the study included themes 1–3 and 6–7. Limitations include small sample size and bias in patient selection.

Conclusions We conducted focus groups with 18 patients before/after undergoing gender-affirming phalloplasty/metoidioplasty. Mental health, quality of life, functional, and aesthetic outcomes are all critical to patients. Phalloplasty/metoidioplasty impact numerous aspects of patients' lives. Experiential components of the surgical process, mental health, and quality of life are important metrics to consider in addition to functional and aesthetic outcomes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Focus groups conducted with patients who have undergone gender-affirming phalloplasty/metoidioplasty, strong centering in patient perspective.
- ⇒ Limitation includes geographic limits of New York and San Francisco; despite this, patients who underwent or were planning to undergo gender-affirming phalloplasty/metoidioplasty procedures were from various geographic locations.
- ⇒ Strengths include co-moderation of focus groups with community members.

INTRODUCTION

Transgender and non-binary (TGNB) individuals may pursue genital gender-affirming surgery (GGAS) so that their genitourinary anatomy aligns with their experienced gender.[1] Gender-affirming phalloplasty and metoidioplasty create a penis, which can enable the individual to achieve greater embodiment and improved quality of life.[1] In recent years, increased availability and wider insurance coverage have led more individuals to pursue these procedures.[2–5] Proponents of laws to limit gender-affirming surgery cite the lack of empirical evidence, which has resulted in policies to limit access. There is no systematic way to examine patients' perspectives on their care, and, moreover, there is a lack of information on patient-centered outcomes following gender-affirming phalloplasty and metoidioplasty.[6 7] Provider- and system-level outcomes have predominated, which severely limits the patient voice. Integrating patient perspectives would empower them to

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determine when to have surgery, which surgery to have and potentially whether to have surgery.[8] Not all patients desire the same outcomes, and as access increases, it is important to ensure care is patient-centered and high quality.[9]

Patient-reported outcome measures (PROMs) facilitate an individualised, patient-centered approach. PROMs are patient-centered metrics that not only improve patient outcomes, but can facilitate informed decision-making about medical procedures, including surgery and help patients develop realistic expectations.[10] Despite these known benefits, there are limited PROMs for GGAS.

Involving patients in PROM development improves the effectiveness and utility of the PROM as they capture what is important to and defined by patients themselves. The first step in the development of effective, patient-centered GGAS-related PROMs is ensuring effective and meaningful engagement of the TGNB community throughout the measure development process.

In this systematic qualitative study, we describe this first critical step to the development of PROMs. We conducted focus groups with patients who will undergo or have undergone phalloplasty and metoidioplasty to gain a deep and detailed understanding of goals, outcome experiences, quality of life, expectations and aspirations to generate rich, valid data which will inform further study and practice. Our findings provide insights into the impact of phalloplasty and metoidioplasty on patients and, moreover, establish a foundation for high-quality evidence obtained through rigorous methodology. The format of this article follows the 32-item Consolidated Criteria for Reporting Qualitative Research.[11]

METHODS

Research team and reflexivity

This study was conducted at NYU Langone Health (NYULH) in partnership with the Callen-Lorde Community Health Center (CLCHC) in New York City and San Francisco Community Health Center (SFCHC), which are LGBTQ community health centres. Partner community members were highly engaged in every stage of the study, including study conception, protocol development, focus group guide development, assistance with recruitment, moderation of focus groups, data analysis and interpretation of preliminary findings. A relationship was established prior to study commencement.

The study team includes urologists (NM, LZ), gender-affirming surgeons (LZ, RB-L), a plastic surgeon (RB-L), research coordinator (EC), psychometrician and statistician (DH), internist (AR, AMF), qualitative research experts (CAB) and gender-affirming community healthcare providers (AR, CO-N). The research team also includes health services researchers who have specialised training in qualitative and quantitative research methods. All researchers are interested in patient care, centering the patient voice and patient-reported outcomes.

Patient and public involvement

Patients were involved in the conduct of this research. Patients participated in focus groups. Discussions in focus groups will guide the development of a PROM for GGAS.

Study design

We conducted a qualitative descriptive study using a thematic content analysis of four focus groups with patients who have undergone or will undergo gender-affirming phalloplasty or metoidioplasty.[12] These focus groups sought to elucidate patient-centered outcomes for gender-affirming phalloplasty through an interactional discussion on goals, experiences, outcomes, expectations, perspectives, satisfaction and quality of life before or after GGAS. Patients were separated into groups based on preoperative or postoperative status. Discussions were guided by participant input and progressively focused on impacts of GGAS on sexual functioning (ie, orgasm and sensation), intimacy, relationships, urinary function, mental health, gender dysphoria/incongruence, quality of life and self-perception. Focus groups were conducted on WebEx, a virtual and secure platform to facilitate participation during the COVID-19 pandemic. Verbal and written informed consent was done through REDCap, an electronic secure data capture tool hosted at NYULH.[13] Focus groups were recorded and transcribed verbatim, with de-identification of participant information.

Recruitment and data collection

A purposive sample of TGNB persons were recruited via social media, direct contact in clinic or email, or through partnering LGBTQ community health centres in New York (CLCHC) and San Francisco (SFCHC). Patients who were 18 years or older and had undergone or were preparing to undergo phalloplasty and/or metoidioplasty within 18 months were eligible to participate. Patients were compensated with a gift card for their time and participation.

Recruitment from NYULH

1. DataCore and EPIC: DataCore, a database of patients seen at NYULH, identified patients who had consultations for GGAS. EPIC, the electronic health record system at NYULH, was used to verify age and if patients were scheduled for or had undergone surgery. Patients were emailed and invited to participate, and interested participants were then directed to REDCap for the completion of enrolment forms and eligibility screener.
2. Recruitment in the clinic: Flyers posted in the waiting area and exam rooms directed interested individuals to contact NYULH study staff for enrolment. Patients were also recruited during office visits. These individuals were then directed to complete the REDCap study enrolment form to determine eligibility. Once participants were deemed eligible, they received a REDCap link for electronic consent.

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Recruitment from partner LGBTQ community health centres

1. Direct recruitment: LGBTQ partner community centres directly contacted GGAS preoperative and postoperative patients to invite them to participate in this study by secure email with the prepared and IRB-approved recruitment email-based script. The script then directed patients to REDCap for completion of the study enrolment form to confirm eligibility. If eligible, electronic consent and enrolment into the study proceeded.
2. Recruitment in community centre clinics: LGBTQ community centres conducted direct and indirect recruitment. Flyers in the waiting areas and exam rooms directed interested persons to contact NYULH study staff for determination of eligibility and enrolment. Clinic staff also discussed the study with eligible patients.
3. Social media: A QR code and link with accompanying text was posted on the social media platforms (eg, Twitter) of our LGBTQ community health centres. The QR code/link directed patients to complete the REDCap enrolment form, which was automatically routed to the study team, and if eligible, patients were enrolled.

Focus groups

Informed consent was obtained from all focus group participants. Participants were informed of the background of researchers as well as reasons for the research, which are to establish and develop PROMs for GGAS. Informed consent was obtained using the RedCap platform, and written consent was obtained through RedCap. Focus groups occurred from April 2021 to April 2022. Preoperative and postoperative phalloplasty and metoidioplasty focus groups were held separately in order to maintain homogeneity during focus group discussions. A focus group guide was developed with input from GGAS surgeons and TGNB persons who had undergone GGAS. When there was thematic saturation, the focus group guide was revised to capture emerging themes from prior focus group discussions. We recorded the focus groups via WebEx to facilitate transcription by GMR Transcription Services, a secure transcription service. The first and third authors, respectively, moderated and co-moderated all focus groups, with co-moderation with research staff from the primary study site as well as partner community health centres. None of the study team members involved in moderation of the focus groups were involved in direct patient care for the participants. The first and third authors also conducted the focus group coding with input and insights from the entire study team.

Coding and qualitative analysis

De-identified, uncoded transcripts were uploaded into ATLAS.ti, V.4.15.2, a computer-assisted qualitative data analysis software that facilitates coding for thematic content analysis.[14] The first and third authors read through all the transcripts and then conducted inductive and deductive coding. Deductive concept-driven coding from the focus group guide ensured that no themes were neglected and inductive coding facilitated the derivation of new codes from the focus group data.[15] A codebook was developed consisting of inductive and deductive codes, definitions and examples of the codes. Codes were compared iteratively across transcripts to identify convergent and divergent themes, experiences and goals. Relationships and inter-relatedness between variables, statements, codes and differences between subgroups were noted, and themes that were conceptually related were generated and clustered into categories. From there, they were grouped into comprehensive overarching themes and domains. An audit trail documented decisions made during analysis. Focus group data were concurrently analysed to first develop a conceptual framework augmented by literature review.

RESULTS

Participant characteristics

Participants consisted of TGNB persons who were undergoing (preoperative) (n=8 participants, two focus groups) or had undergone (postoperative) (n=10 participants, two focus groups) phalloplasty and metoidioplasty. Mean age was 34.1 (SD=4.4) and 34.2 (SD=8.6) years for preoperative and postoperative phalloplasty, respectively, and 37.5 (SD=19.0) and 31.9 (SD=3.5) years for preoperative and postoperative metoidioplasty, respectively. Table 1 shows a summary of participant characteristics. The mean duration of focus groups was 81.5 min (range 63–108 min). No participant dropped out or refused to participate.

Themes

Seven themes and 19 subthemes were constructed from the data. The major themes included (1) surgery goals and expectations; (2) sexual function; (3) urinary function; (4) knowledge gathering and support systems; (5) decision-making; (6) mental health and quality of life; and (7) gender dysphoria/incongruence. Of the major themes, those determined before the study included themes 1–3 and 6–7. Themes 2–5 were determined during the course of the study. All subthemes were informed during the course of the study. All themes were identified in every focus group, providing evidence of thematic saturation.

Theme 1: surgery goals and expectations

Subthemes: defining goals before surgery, evolving expectations and shifted priorities after surgery

Defining goals and making decisions

Most goals related to preparing for surgery concerned aesthetics, function and the desire to improve gender dysphoria/incongruence. Gender dysphoria/incongruence was, in fact, a driver of surgery, and some participants did not initially consider bottom surgery when they began transition, for example, *"So I think that bottom surgery was, for a long time, something that I thought I had no interest in."*

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Table 1 Demographic characteristics of focus group participants

	Phalloplasty/metoidioplasty	
	Pre	Post
Total (n)	8	10
Race/ethnicity		
Asian	0	0
Black	1	1
Hispanic	1	0
White	5	8
More than one	0	1
Other	0	0
Not reported	1	0
Income		
<20 000	1	1
20 000–34 999	0	2
35 000–49 999	1	0
50 000–74 999	1	1
80 000 or more	2	5
Not reported	3	1
Sexual activity		
Currently sexually active, n (%)	6 (75)	5 (50)
Patient-reported gender		
Transgender man	3	4
Transmasculine	2	0
Man	3	5
Non-binary		1

Participants discussed their decision in terms of gender dysphoria, stating,

> I think my biggest goal was really dysphoria reduction, going back to that point of feeling comfortable in your body.

Participants discussed the aesthetic appearance of their genitalia and sexuality as drivers for undergoing phalloplasty/metoidioplasty. Regarding sexuality, one participant stated:

> The biggest aspect of pursuing surgery is centered around sexuality and sexual expression of being able to truly enjoy sex and feel present in my body.

With another stating:

> I deserve to have access to something that I know that would bring me so much more affirmation and joy. And a lot of that is around just my own self-image, a lot of it is around sexuality and both personal sexuality and in relationship to other people.
>
> I think that my biggest goals probably … I think actually my doctor asked me what was most important to me, and I remember saying that penetrative sex was the most important outcome for me.

Regarding aesthetics, which was a major goal for many participants, a participant stated:

> The number one goal is really aesthetic for me. I'm pursuing metoidioplasty, and I'm just really looking for a package that really fits my body. I'm a really small person and the aesthetic more just external genitalia look is my number one goal.

Postoperative participants had varying experiences with their aesthetic outcomes. Some expressed pleasure, for example, *"I'm super happy with the aesthetics,"* while others expressed displeasure, for example, *"Aesthetically it was also a complete failure and since I did get the hysterectomy and vaginectomy as well, I'm kind of left with basically now having no genitalia because what I have does not look like a penis."*

An opportunity where PROMs can help inform patient education and expectation-setting for aesthetics was expressed by one participant, who stated, *"And I wasn't totally sure what aesthetics mattered to me."*

Standing to void was also a major goal for participants as one participant stated that *"My primary goal was really, really being able to stand to pee."*

Complications and shifting expectations

In discussion of goals for patients who underwent phalloplasty and metoidioplasty, some discussed complications and how that shifted their expectations. For example, one participant stated:

> But are there little things that I may have done a little bit differently? Sure. I got a glansplasty about a year or so postop that pretty quickly flattened and I know that happens to a lot of people, but I guess … I don't know that I care one way … I wouldn't say it's a regret or something because it's not a negative so much as a pointless surgery that I had.

Some participants expected to have complications based on knowledge from peers:

> I feel like I went into having surgery basically sure that I was gonna have complications. I feel like I had been told by almost everyone that everybody has complications and, you're gonna have a complication.

Peer input and support helped participants cope with complications when they arose, for example, *"And because I did have complications, it's probably good that I went in with that mindset,"* and *"I know that a lot of problems can arise."*

Theme 2: sexual function—impact of surgery on orgasm, pleasure and sensation

Orgasm and pleasure

Orgasm was an important domain of sexual function for many participants. Preoperative participants discussed the importance of phalloplasty in sexuality and postoperative participants discussed the impact of surgery on orgasm. A preoperative participant stated:

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> And also, I'm leaning more towards phalloplasty, because it's important to me to be able to penetrate my partner. And also, I really love sex in general, but I've never been great at solo play. And I feel like not having a phallus has been part of that. So, yeah. Just sexuality all around for myself and for play with partners.

Postoperative participants discussed the impact of surgery on orgasm:

> I think my ability to orgasm hasn't changed at all. I'd say it doesn't take me as long postop. It's shorter. It's easier for me now. And they're also stronger than they were before. I feel like I've heard that from a lot of people, too, and that's the case for me. So, it's easier, quicker, stronger, better pretty much in every way.

Another participant stated that they were able to orgasm in the same manner they did preoperatively:

> Because I don't really have sensation in my penis, I have an orgasm by touching the same place that I did before I had surgery, where my clitoris is buried. And so, it feels pretty much the same. I think it took about two months for me to be able to. I think probably just with regaining sensation through healing, but it honestly feels very similar.

Another participant stated:

> I guess postop it takes me longer to orgasm than it did before, even being several years postop.

Sensation

Postoperative participants discussed variable changes to sensation with surgery:

> As far as sensation, it took six months to a year to really, I guess, both developing sensation back and then also learning to adjust to having a new body and how to find pleasure with my new body, but I've been very satisfied.
>
> My goals preop with sensation haven't really been met, and it's about two years after.
>
> The physical sensation, I guess, is pretty similar. It's just as strong and pleasurable, but more, I don't know, emotional good feelings with it.

Another discussed surgical options and the impact on sensation:

> And then I think with my current level of sensation … I know other people don't end up burying their natal parts. I maybe would've thought about that, but it's hard to be told like, 'Well, you could not bury it and not attach the nerves and then maybe you definitely won't have any sensation, or you could, and you might have a really good sensation.'
>
> Because of my lack of sensation, there are things that I don't really enjoy doing just because they kinda remind me that I don't have that sensation

Theme 3: urinary function

Standing to void

Another important theme that arose was urinary function, with standing to void as the major topic of discussion. Preoperative participants anticipated potential complications with urethral lengthening, which led to their decision to forego this. Other participants expressed discomfort with public restrooms as well and how standing to void was very important to them personally and socially. Still others discussed how standing to void was more practical for their lifestyles.

> And also, I'm outside a lot. And the convenience factor of it is also a good thing.

Participants discussed meeting their expectations and the feelings that standing to void provided:

> Now I'm in a place where it's absolutely met my expectation of being able to stand to pee.
>
> Urinating has been super affirming, especially for me, because I did go through some struggles. It was touch and go there when I wasn't sure if I could overcome the stricture.

Common complications such as fistula and stricture were another frequent topic of discussion as participants discussed how these complications impacted them:

> I had a fistula from the beginning, but that only took six weeks to close, so that was okay. Then I had a stricture repair and a fistula pop open after the repair. And then two months later, I had my stricture come back. And then I was hoping I would last long enough until my repair date, but I didn't. I just had to go get dilation … which I really needed.
>
> I think for a long time I had to push really hard to pee, and that doesn't really happen anymore.

Participants expressed that despite urethral strictures and other urologic complications, they would still choose to have surgery and urethral lengthening:

> Definitely 100% would do it again, even with … I could have a million more strictures and I would still do urethral lengthening.

Others discussed that though they can stand to void, there is some anxiety:

> I am able to stand to pee, but I'm not brave enough yet to try it without completely dropping my pants.

Other participants offered advice for those undergoing urethral lengthening in the future, stating:

> At this point, if I was to advise anybody, I would say, "A: make sure there's a really good urologist on if you're doing urethral lengthening as part of the surgery. In some ways the urologist is even more important than the plastic surgeon if you're dealing with aspect of it. And I know not everyone gets urethral lengthening with it. But if you are, definitely make sure that the

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> urologist is up to the task. But, yeah, I think all I have to say."

Theme 4: knowledge gathering and support systems—peer support helps preparation and recovery

Peer support

Participants discussed postoperative experiences and how a peer support system is helpful for the surgical process, for example, "*What I think is really important here … is connecting us to each other*." One participant stated:

> But there were points in time where I felt like my surgeon just wasn't listening to me. I wish that I had been able to access some kind of in-person patient advocate or peer advocate or something, both to help with self-advocacy in those situations and also to help with things on the administrative end when they felt stuck, which happened a lot there.

Another stated:

> I also found the online community with other postop people to be really useful. That was just tremendous for me being able to talk and commiserate with people who kind of were going through the same experience as me.

Participants discussed the importance of having support during the recovery period:

> But I know the next surgery is a very different process than the one I got before because it will be a minimum of three stages, assuming there aren't complications, it will be three stages, four if I get the pump. And I'm going to need the care. I'm going need someone around. So, I guess it will force me to be a little more vulnerable in terms of asking help.

Evolving expectations and changing goals

Participants discussed the impact of surgery on their expectations and goals; after surgery, patients' feelings on their goals and desires adjusted based on their outcomes. A participant stated:

> The ideas that I had about size and stuff before surgery were much more specific than the way I've found myself to feel after.

And another stated:

> The longer I'm postop, the more I care about standing to pee … because I've had complications where I can't.
>
> I used to care more about sensation, but now being postop I care less about it.
>
> What I liked about being postop is different than what I expected to like about being postop.
>
> I think that what I want now and what I'm happy about having now has changed a lot in postop.

Participants also discussed the possibility of not reaching their expectations. A participant stated:

> I feel like I've talked to people who are preop who think that they're gonna get to give a doctor the length and width that they want and wake up with that. So, I think that maybe I would tell myself that maybe my size wouldn't be exactly what I expected.
>
> Penetrative sex isn't something that I've chosen to make happen for me, which is different than I would've planned.

Theme 5: decision-making and relationships—decision between surgery type, decision-making and relationships with surgeons

Phalloplasty vs. metoidioplasty

Discussions around decision-making focused on choosing between phalloplasty and metoidioplasty. Discussion and explanation of choice were around complications, sensation and size expected with phalloplasty. Some participants discussed the expectation of fewer complications with metoidioplasty was one reason they opted for metoidioplasty. For example, regarding complications, one participant stated:

> I think I'm also, like I said, pretty nervous about surgery in general. Pretty nervous about complications. And while metoidioplasty is certainly a very serious surgery and has many complications, it's also generally less staged out, so I'm usually looking at less surgeries.

Another driving factor for choice between phalloplasty and metoidioplasty was phallus length. Sitting to void was associated with some dysphoria that participants anticipated would be improved with phalloplasty and urethral lengthening. One participant stated:

> It does feel super important to be able to stand to pee. So, that's one of my goals.

Another stated, regarding size:

> Size is certainly an important question to me and it's something that I think that in my ideal world, I'd be able to get something in between.

In addition, for some it was associated with toileting and safety around gendered bathrooms and utilisation. For others, standing to void was necessary for their occupation.

Childbearing was another key point of discussion as participants considered hysterectomy and vaginectomy. One participant stated:

> So, even if I'm also pretty sure that I will also not have a natural, or a vaginal birth, that I will probably be having a cesarian, that I still need that part of my body in order to go through the process of having a child.

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Decision-making and relationships with surgeons

There were divergent experiences wjth regards to decision-making with participants' surgeons. Some participants expressed adequate knowledge from providers and surgeons, for example, "*I feel like I couldn't have known more going into it than I did,"* while others expressed the lack of information from their surgeons and not meeting their goals, for example, "*My goals weren't met."* Participants stated:

> I do not feel I was informed enough by my surgeon on the risks.

Other participants discussed reservations around having conversations related to their goals for surgery with their surgeons, such as

> I would've been very uncomfortable asking my doctors or telling my doctors that I didn't want a vaginectomy.

Another stated that written details would have helped caretakers:

> I know there's some hospital systems … they do a whole video beforehand and stuff like that. And I wish I had more of that specifically in writing so my caretakers and stuff can also see it and have something to refer to.

Others discussed that in the decision-making process there were opportunities to discuss priorities, but there was a lack of clarity around how priorities factored into their surgical plan:

> But I definitely remember telling my doctors that the most important thing to me was being able to have penetrative sex and that I wanted to be able to stand to pee, but I remember feeling like that was … maybe I had to pick between the two if something went wrong, and so I remember saying that penetrative sex was more important.

Some participants discussed the challenges they encountered when navigating complications and feeling dismissed by their surgical team. A participant stated:

> And a lot of it, I think, some of it certainly could have been avoided had I been taken seriously when I was saying, hey, something's wrong here.

Another stated:

> A lot of neglect and a lot of dismissiveness because I kept saying, look, something's wrong here.
>
> I definitely would have done more research into individual surgeons than I did, perhaps.

Some participants discussed their choice of surgical teams, and postoperative participants voiced thoughts on their choice of surgeon in hindsight. Here, some participants expressed regret over their surgeon:

> I would go with the same surgical team. I truly believe they're the only ones that got me through my – I can stand to pee because of them, and I'll be forever grateful for that.
>
> I would have surgery. I would have chosen a different surgical team, but I would definitely – I don't regret transitioning, certainly.
>
> My only regret that I chose the team I chose, but I'm looking forward to doing it again with different people and, hopefully, less complications.

Some participants discussed that though they experienced complications, their physician was key in helping them navigate,

> And I just remember this one encounter I had with the doctor after I was literally sobbing because I so in pain and so scared. He was, like, hey, could you look at me for a second? And I looked. And he was, like, I know that that was really hard, and you're doing really well, and just hang in there. And that one conversation, basically, kept me together until I could go home. So, I really am very grateful for that.

With another stating:

> And, again, the surgeon was a big part of that. I just was able to trust him so much. They kind of a support team there. I just had so much trust and care from them that made me believe that even when things were getting a little bit harder, we were going to get – we were going to fix this and get to a good place. Yeah, they absolutely nailed it in terms that I could not have.

Others offered advice for what would have improved their experience:

> So, seeing other photos and having more of a discussion of that would have been really helpful.

Theme 6: mental health and quality of life

Some participants stated that surgery improved their lives, for example, "…… *I definitely feel like surgery has improved my life."*

Others discussed worsening mental health after surgery, which may be a potential area of improvement. A participant stated:

> My mental health was kind of on the floor right after surgery. I would probably compare it to postpartum depression. I felt like I didn't understand why I felt so sad, and then I realized it was because my physical capabilities were 100% removed. I was just bound to a bed, bound to a couch. I couldn't bike, which was the one thing that I loved to do every single day is just get on the bike and feel free. I couldn't do that.

Another stated:

> I feel like my mental health is in a better place as a result of the surgery. I feel better about myself and just

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> more at ease. But I also think I dealt with a lot of mental health issues just as a result of complications. It's not an easy process to go through. I think, ultimately, it forced me to look at my mental health a little more seriously and take action to better that. It's also, I feel like, just part of the course of going through life is dealing with that.

Some participants discussed the relationship between mental health and regret:

> I think mental health always has to be a factor in any procedure that you get, and regardless of whether or not it came out looking perfect and there are no functional issues, some people experience regret.
>
> After surgery, I think it was a lot better. It improved my mental health. It didn't fluctuate as much. It was much more stable. I still went to me therapist before and after. I've been going to the same therapist. And I feel like surgery has actually helped. It's been a year now, year and half, that I haven't seen my therapist, and I've been good. I've been very stable. I'm not as emotional, and I've been okay.

A participant discussed the importance of patient-centred outcomes for gender-affirming phalloplasty and metoidioplasty, and surgical outcomes and mental health outcomes should both be prioritised:

> I think that if, despite everything coming out great, your mental health is not where it should be, and you're just feeling that feeling of regret or just unhappiness, that to me overall in the big picture, grand scheme of things is not a good outcome or a desired outcome.

Theme 7: gender dysphoria/incongruence

Gender dysphoria/incongruence was a driving factor for many participants pursuing gender-affirming phalloplasty/metoidioplasty. Though gender dysphoria/incongruence did improve, it was still present for some participants. One participant stated:

> And I wouldn't say that I don't have dysphoria anymore ever, but it's definitely much less of a regular experience in my life, and so it doesn't affect my current relationship.

Another stated:

> And postop, my dysphoria around going to the bathroom has decreased even though I'm still going the same way and don't have urethral lengthening. But I don't know, it bothers me less than it did before.
>
> I feel a lot more like me and my body are on the same team instead of my body being something that I'm fighting against in my day-to-day life, which I think has changed a lot about how I treat myself and how I act in the world.

DISCUSSION

This study provides important insights into patient-centered outcomes and considerations for patients, providers, and policymakers regarding gender-affirming phalloplasty and metoidioplasty. Historically, outcomes for GGAS have focused on clinical metrics with no patient input such as complications after phalloplasty and metoidioplasty.[16] There has been an increase in access to GGAS, but no concurrent quality metric or methodology to measure outcomes that are important to patients and ascertain whether patients are achieving their desired outcomes.[7 17] This study is the first step to the development of PROMs developed by the target community (ie, focus groups) for the target community. Standardised PROMs also measure provider performance and accountability and can serve as a quality metric. In this study, we describe divergence between actual and expected outcomes within the same patient and divergent outcomes between patients; standardised PROMs would address this concern.

This study extends our understanding of outcomes through the collection and analysis of patient and community member perspectives. Patients prefer a patient-centered approach,[17] and in this study, participants highlighted outcomes which are important to them that cannot be directly measured from medical records. We lack a micro-level view of patient-level determinants of satisfaction beyond general satisfaction. These focus groups identified patient-centered outcomes related to sexuality such as orgasm and pleasure. Using a GGAS-specific PROM may also facilitate discussions with providers as patients prepare for surgery and engage with their sexuality after phalloplasty and metoidioplasty. For example, while some patients discussed that they are unable to achieve orgasm years after surgery, to others this is not important, and others are able to achieve orgasm. PROMs would help patients develop realistic expectations as they prepare for GGAS and understand how they may achieve orgasm, and they may help providers have informed discussions as key decisions are made. Importantly, many participants discussed unexpected outcomes, which made coping difficult and subsequently impacted their mental health.

Many participants discussed the impact of surgery on their mental health, with one comparing it to postpartum depression. This is an important point given that gender-affirming phalloplasty and metoidioplasty are procedures purportedly done to improve mental health.[18 19] Worsening mental health after the procedure due to complications or other reasons is something to consider and prepare patients for as they consider, prepare for, and undergo these procedures. Patients also expressed increased mental energy for other aspects of their lives after surgery. One participant stated that despite having the surgery, they still have issues that they need to explore within themselves, which highlights the importance of continued access to mental health resources in the postoperative period. It also highlights that there is no

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one-size-fits-all for patients and the critical importance of an individualised approach, which again emphasises the importance of developing and using PROMs.

Participants also had divergent experiences with respect to decision-making, some stating that they would potentially choose another surgical team and other participants who expressed discomfort with discussing their desires with their surgeons. Patient-centred outcomes, elucidated from these focus groups, may facilitate greater knowledge sharing and comprehensive discussions as patients prepare for surgery. Interestingly, without prompting, many participants mentioned regret. While overall surgical regret is rare,[7] it is important to explore how patients experience their own surgical outcomes and parse out the nuance of regret. Patients may be deterred from seeking surgery due to the pervasive idea of surgical regret. With patient-centred outcomes and the patient perspective, patients can better understand what to expect.

Limitations of this study include its potential limited generalisability given its New York City-based setting. However, 31% of patients were from out of state as a result of recruitment in San Francisco and via online social media forums, and 26% of participants had had surgery out of state; the virtual WebEx platform also facilitated widespread participation. Additional limitations of focus group-based research include reliance on facilitated discussion, which is dependent on the skill of the moderator, as well as potential bias in the participant selection process, as individuals voluntarily elected to participate in the study.[20 21] We also were limited to participants who spoke English as their primary language.

These limitations notwithstanding, this study has implications for patients, providers and policymakers. There is a need for increased patient-centred care and for outcomes to be determined by patient-surgeon collaboration. PROMs have many benefits beyond collecting the patient perspective; they can encourage shared patient-provider decision-making and improve both workflows and patient satisfaction. Patients prefer a patient-centered approach, and thus it is important to collect PROMs data to allow providers to understand patient expectations. PROMs are developed through an iterative process of data collection, tool creation and refinement to ensure the tool is valid in measuring what it is intended to measure in the intended population. While there are existing PROM tools which measure quality of life, physical and mental health, and plastic surgery outcomes, there is no specific GGAS PROM. With this qualitative data collection, we intend to develop a GGAS PROM tool.

CONCLUSIONS

Phalloplasty and metoidioplasty affect numerous aspects of the lives of those undergoing these procedures. Surgical satisfaction, decision-making and quality of life pre- and postoperatively must be measured, including how gender incongruence and embodiment are affected, as well as how individuals feel about their aesthetic and functional outcomes.[39] We have elucidated the impact of surgery on these domains, and this study highlights the importance of specific PROMs for GGAS. With these focus group data, we will develop a GGAS-specific PROM tool through a community-engagement model, ensuring accuracy of the tool and leading to improved patient-centred care in GGAS.

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Acknowledgements We acknowledge Gaines Blasdel and Ali Harris, MPH, CPH, for their contributions to the development of the focus group guides and co-moderation of focus groups.

Contributors All members contributed to the reading and editing of the manuscript. NM, AR, LZ, RB-L and CAB conceived of the presented idea. NM, DH and CAB verified the analytical methods. NM, AR, EC and CAB developed the focus group guides. NM, EC and TRZ drafted the initial manuscript. NM, CO-N, AMF and CAB interpreted the data. All authors edited and contributed to the second and final drafts of the manuscript. NM is the guarantor.

Funding The project described was supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number KL2TR001446. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by NYU Langone Health Institutional Review Board: i20-01509. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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