Observational Study

Medicine

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Transgender gender-affirming surgery consultation among patients seeking care in the Midwestern United States

Jesse R. Smith, MD, MS[a], Mikhail Pakvasa, BS[b], Leonie A. Oostrom, MD[c], Lawrence J. Gottlieb, MD, FACS[a], Darnell N. Motley, PhD[d,e], Brandon J. Hill, PhD[d,f]

Abstract

Gender-affirming surgery (GAS) is among the most rapidly growing and expanding subfields in plastic surgery due to increased awareness, decreased stigma, rising demand, and improved access for transgender and gender non-conforming individuals (TGNC). In order to address potential barriers and facilitators in GAS education and training, there is a need to explore the experiences of TGNC individuals. The purpose of this study was to qualitatively explore the factors that influence TGNC patient experiences in surgical consultation for GAS. Targeted recruitment was used to recruit and enroll participants who identified as TGNC and who had undergone consultation with a surgeon to discuss GAS. Semi-structured interviews were used to explore patient experiences with GAS. Recorded audio from these interviews was later transcribed verbatim. Open coding of these transcripts was then performed independently by 3 individual members of the research team using the consensual qualitative coding methods. Fifteen interviews were conducted (transmale, n = 7; transfemale, n = 4; gender non-conforming/non-binary, n = 4). Participants frequently expressed worry and frustration over insurance coverage and exorbitant out-of-pocket expense, whether actual or perceived. Logistical barriers were the most frequently cited category of barriers. The majority of participants made at least 1 reference to relying on others during the process of insurance pre-authorization. The majority of participants described their interactions with surgeons as positive, indicating that they felt comfortable during consultation and that their surgeons ensured their understanding. Our findings provide important insight into this often stressful and challenging process. Ensuring a welcoming, safe, and gender-affirming environment and experience for these individuals is essential. These findings may help to guide future education for medical students, trainees, clinic staff, and surgeons, as well as to direct changes necessary to improve the patient experience in clinics and hospitals for TGNC individuals undergoing consultation for GAS.

Abbreviations: GAS = gender-affirming surgery, GNC/NB = gender non-conforming/non-binary, TGNC = transgender and gender non-conforming, USTS = US transgender survey.

1. Introduction

The combination of increased awareness, decreased stigma, rising demand, and fewer barriers (including better coverage) has resulted in gender-affirming surgery (GAS) becoming among the most rapidly expanding and growing subfields in plastic surgery, with an annual increase of 155% in gender-affirming surgical procedures reported by the American Society of Plastic Surgeons in 2017.[1,2] However, it remains unclear whether medical students, trainees, clinic staff, and surgeons are adequately prepared to adapt to the demand for GAS and to provide quality care to a demographic of patients predisposed to discrimination and health disparities.[3–5]

Several authors have recently examined the role of transgender and gender non-conforming (TGNC) cultural competency in the surgical care of these patients, providing surgeons with a framework for evaluating patients with gender dysphoria and advocating for the need of systematic approaches to competency and sensitivity training.[6,7] The importance of surgeon cultural competency is highlighted by a study showing that when TGNC individuals have access to surgeons with an expertise in GAS, it tends to alleviate stress associated with the process of such a life-changing experience as GAS.[8] This finding underscores that, regardless of gender identity, physicians should strive to

Portions of this project were funded by a grant from the University of Chicago Medicine Biological Sciences Division's Office of Diversity & Inclusion.

The authors have no conflicts of interest to disclose.

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Supplemental Digital Content is available for this article.

[a] Section of Plastic and Reconstructive Surgery, Department of Surgery, University of Chicago Medicine & Biological Sciences, Chicago, IL, [b] Pritzker School of Medicine, University of Chicago Biological Sciences Division, Chicago, IL, [c] Department of Emergency Medicine, Beth Israel Deaconess Medical Center, Boston, MA, [d] Center for Interdisciplinary Inquiry and Innovation in Sexual and Reproductive Health, Department of Obstetrics and Gynecology, University of Chicago Medicine & Biological Sciences, Chicago, IL, [e] Section of Family Planning and Contraceptive Research, Department of Obstetrics and Gynecology, University of Chicago Medicine & Biological Sciences, Chicago, IL, [f] Planned Parenthood Great Plains, Overland Park, KS.

**Correspondence: Jesse R. Smith, Section of Plastic Surgery and Reconstructive Surgery, Department of Surgery, University of Chicago Medicine & Biological Sciences, 5841 S. Maryland Ave., Rm. J-641, M/C 6035, Chicago, IL 60637 (e-mail: jesseryansmith@gmail.com).*

How to cite this article: Smith JR, Pakvasa M, Oostrom LA, Gottlieb LJ, Motley DN, Hill BJ. Transgender gender-affirming surgery consultation among patients seeking care in the Midwestern United States. Medicine 2022;101:45(e31319).

Received: 31 March 2021 / Received in final form: 20 September 2022 / Accepted: 21 September 2022

http://dx.doi.org/10.1097/MD.0000000000031319

provide nothing less than the highest quality, patient-centered care to all patients.

Carefully designed studies that allow TGNC individuals to express their experiences in their own words provide important input and direction from this underrepresented and marginalized population. There have been previous qualitative studies examining TGNC experiences in primary care,[9–17] radiology,[18] emergency departments,[19] and sexual and reproductive health.[20–22] In order to address potential deficiencies in education and training of those involved in the surgical care of TGNC individuals, there is a need to better understand the patient experience during consultation for GAS.[23] The purpose of this study was to elucidate factors influencing the overall experience for TGNC individuals undergoing surgical consultation for GAS.

2. Methods

This was a carefully designed, qualitative study that recruited participants who: self-identified as transgender or gender non-conforming/non-binary (GNC/NB); were at least 18 years of age or older; and experienced consultation with a surgeon to discuss surgically changing their body in order to better reflect their gender identity (i.e., GAS). A total of 15 participants (n = 15) met inclusion criteria, enrolled, and completed study interviews. Interviews were conducted using open-ended responses in order to gather and organize all possible information about the participants' experience during consultation for GAS. The limited number of participants allowed for in-depth analysis of extensive and comprehensive interviews.

Study recruitment was performed passively by using materials (e.g., flyers, posters) posted in health centers specializing in the care of TGNC patients. These health centers were located in Chicago, Illinois and the surrounding metropolitan area. Consent was obtained from each participant following an explanation of the study, and each participant received $20.00 cash remuneration upon successfully completing the interview.

Interviews were conducted in-person by a single interviewer (JRS) who asked each participant to describe their experience during consultation for GAS at length and in detail. All interviews were conducted between November 2017 and May 2018. Audio from these interviews was recorded so that it could be transcribed verbatim and made available to the entire research team for coding and analysis. Codes and subcodes were created in an inductive fashion (by conventional content analysis)[24] based on themes that emerged from the data. Three members of the research team (JRS, MP, and LAO) then independently performed open coding of these transcripts using the consensual qualitative coding methods.[9] Discrepancies in individual coding of the data were resolved by discussion and consensus. Appendix 1 (Supplemental Digital Content http://links.lww.com/MD/H729) lists the code categories, codes and subcodes used in this study. Of note, each subcode was used in the final independent coding at least once. A definition and representative excerpt for each code and subcode can also be found in Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

Data management and systematic analysis was facilitated by the use of qualitative analysis software (Dedoose Version 8.3.17; SocioCultural Research Consultants, LLC, Los Angeles, CA). Excerpts were edited to de-identify participants who are referenced below by pseudonyms. Clarifications in text are marked with square brackets and excisions are marked with ellipses. This study was approved by the Biological Sciences Division and University of Chicago Medical Center Institutional Review Boards of the University of Chicago (Protocol Number: IRB16-0694).

3. Results

3.1. Participant demographic and clinical characteristics

Fifteen interviews were completed by 1 member of the research team (JRS) using the methods described above. The limited number of participants allowed for in-depth analysis of study data, which included a total of 1563 minutes of audio. Mean interview duration was found to be 104 minutes. Table 1 summarizes patient demographic and clinical characteristics. Most participants were 18 to 34 years of age (n = 9, 60.0%). Participants self-identified as transmale (n = 7, 46.7%), transfemale (n = 4, 26.7%), and GNC/NB (n = 4, 26.7%).

3.2. Details from participants' most recent surgical consultation

Participants reported having undergone consultation with a wide range of surgeon types, including plastic surgeons (n = 8, 53.3%), gynecologists (n = 4, 26.7%), and urologists (n = 3, 20.0%). In total, participants underwent consultation with at least 9 different surgeons. All surgeons abided to the Standards of Care for the health of TGNC individuals established by the World Professional Association for Transgender Health. This important document sets forth criterion for TGNC individuals who seek top and/or bottom surgery and recommends that these individuals provide documentation of persistent gender dysphoria by a qualified mental health professional.[10] Participants reported having undergone consultation for a wide range of surgery types, including: ablative bottom surgery (n = 7, 46.7%), reconstructive bottom surgery (n = 4, 26.7%), top surgery (n = 3, 20.0%), and facial feminization surgery (n = 1, 6.7%). Tables 2 and 3 summarize details from participants' most recent surgical consultation.

3.3. Barriers to consultation for GAS

3.3.1. Support. For reference, a description and an example of each code can be found in Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729). Many participants described lack of social support presenting as a direct barrier to their ability to undergo surgical consultation. Broadly, participants described lack of support from: family; friends; spouse; and community. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729). More participants described an instance of lack of support from family than from community, friends, or spouse.

> "[My wife] already made it clear that if I did transition, she wanted no part of it."—Anne

This was especially true for participants who self-identified as GNC/NB.

> "My dad said he was disgusted. My mom was very much like, 'Oh my god. Are you sure you want to do this?'"—Sam

Lack of support delayed initiating surgical consultation for a variety of reasons. These included fear of disappointing or upsetting someone as well as a sense of embarrassment or shame.

> "Most of my friends… would viciously mock and deride anything they found [outside] of normal."—Grace

In several cases, this manifested as the lack of emotional support sometimes required to schedule a consultation and/or physically experience the consultation. This also included the worry of not having someone available to physically care for them around the time of surgery, such as during the immediate post-operative period or if an unexpected complication should occur.

Table 1

Participant demographic and clinical characteristics.

Demographics and clinical characteristics	n = 15	%
Age, yr		
18–24	4	26.7
25–34	5	33.3
35–44	2	13.3
45–54	2	13.3
≥55	2	13.3
Ethnicity		
Hispanic, Latinx or Spanish?	0	0.0
Non-Hispanic	15	100.0
Race		
White/Caucasian	13	86.7
Asian	1	6.7
Other/unsure	1	6.7
Highest level of education		
Trade, technical or vocational	1	6.7
Some college	6	40.0
Associate degree	1	6.7
Bachelor's degree	6	40.0
Master's degree	1	6.7
Permanent residence		
Urban	10	66.7
Suburban	5	33.3
Rural	0	0.0
Hours worked/wk		
<35	4	26.7
≥35	4	26.7
Not currently working	7	46.7
Household income, USD		
<$10,000	5	33.3
$10,000–$29,000	3	20.0
$75,000–$99,000	2	13.3
>$150,000	1	6.7
Other/unsure	4	26.7
Sex assigned at birth		
Male	5	33.3
Female	10	66.7
Gender identity		
Transmale	7	46.7
Transfemale	4	26.7
GNC/NB	4	26.7

GNC/NB = gender non-conforming/non-binary, USD = United States Dollar.

Table 2

Details from each participant's most recent surgical consultation.

Most recent surgical consultation	n = 15	%
Region of consultation		
East North Central (WI, MI, IL, IN, OH)	14	93.3
Pacific (WA, OR, CA, AK, HI)	1	6.7
Type of surgeon		
Plastic surgeon	8	53.3
Urologist	3	20.0
Gynecologist	4	26.7
Type of surgery		
Top surgery	3	20.0
Mastectomy/chest masculinization	3	20.0
Breast augmentation	0	0.0
All bottom surgery	11	73.3
Ablative bottom surgery	7	46.7
Oophorectomy	0	0.0
Hysterectomy	3	20.0
Vaginectomy	1	6.7
Orchiectomy	3	20.0
Reconstructive bottom surgery	4	26.7
Metoidioplasty	1	6.7
Phalloplasty	2	13.3
Vaginoplasty	1	6.7
Facial feminization surgery	1	6.7

> "I'll need to have an assistant to help me do basic tasks for a while, or I need to be in a live-in [hospital]. There's this big, long tail to any major surgery where I need to be in care. If I go for facial feminization surgery, I have months of recovery time where my face will be swollen and bruised, and I'll need extra emotional support. If I go for vaginoplasty, I'll be immobile for a bit… I haven't had a stable support. I haven't had a stable system."—Grace

3.3.2. Knowledge. Lack of knowledge presented as a barrier when it resulted in a delay of consultation with a surgeon for GAS due to: lack of information regarding available techniques and procedures; lack of information regarding whether the participant was a candidate for GAS; lack of information on how the participant could have initiated consultation with a surgeon for GAS; or due to lack of exposure to and/or awareness of GAS. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

3.3.3. Finances. Among the types of barriers to consultation, barriers related to financial issues were among the most frequently reported. When discussing this type of barrier, the following 3 major themes emerged: capital; insurance; and employment. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729). These subcodes were applied when participants expressed that money, cost, insurance coverage, or an employer (or lack thereof) inhibited or delayed their ability to undergo surgical consultation. Of these subcodes, "capital" was the most frequently applied in regard to barriers to consultation.

> "Certainly, the frustration of financial aspects. That would probably have been the biggest barrier. Just going, 'How in the world am I going to pay for all this?' puts enough doubt in your mind that you maybe don't pursue it as quickly"—Anne

Participants earning less than $10,000 United States dollar commonly referenced capital as a barrier to consultation. This was also true for participants who underwent consultation with a plastic surgeon as compared to a gynecologist or urologist. Barriers related to insurance affected participants across all types of employment status, including those who were not working, those working less than 35 hours per week, and those working 35 hours per week or more.

> "… my insurance wasn't covering it at the time. It's like a daunting amount of money… I want to say it was like $60,000 at the time to pay cash out-of-pocket kind of thing. I was like, 'There's no way.' I could save from here until the cows come home, and I would never have that kind of money. It was kind of [put on the backburner] so to speak."—Chad

A number of participants expressed that their insurers did provide adequate coverage, but they were not aware of this information for a period of time. Therefore, it was the perceived out-of-pocket expense, not the actual out-of-pocket expense, that deterred or delayed these individuals from initiating consultation with a surgeon.

> "I didn't realize that my insurance covered surgery until last year, and I was kicking myself when I found out because I was like, 'I could have done this sooner.'"—David

It also became apparent that several participants, who might have otherwise been denied, were able to obtain adequate coverage because their surgeons processed the claims under a different diagnosis code (unrelated to gender dysphoria). This was particularly true for patients who were under the care of a gynecologist or urologist for ablative bottom surgery. For example,

Table 3

Patient demographic and clinical characteristics by individual participant.

	Demographic and clinical characteristics										
	Age	Gender	Sex	Race	LOE	Loc	Hours worked	Income, USD	Area	Type	Surgery
Sean	18–24 (26.7)	TM (46.7)	F (66.7)	W/C (86.7)	SC (40.0)	Urb (66.6)	<35 (26.7)	O/U (26.7)	ENC (93.3)	PRS (53.3)	Phallo (13.3)
David	18–24 (26.7)	TM (46.7)	F (66.7)	Asian (6.7)	SC (40.0)	Urb (66.6)	NCW (46.7)	O/U (26.7)	ENC (93.3)	GYN (26.7)	Hyst (20.0)
Hunter	25–34 (33.3)	TM (46.7)	F (66.7)	O/U (6.7)	SC (40.0)	Urb (66.6)	NCW (46.7)	O/U (26.7)	ENC (93.3)	GYN (26.7)	Hyst (20.0)
Peter	25–34 (33.3)	TM (46.7)	F (66.7)	W/C (86.7)	AD (6.7)	Urb 66.6)	≥35 (26.7)	$75,000–$99,999 (13.3)	ENC (93.3)	PRS (53.3)	Meta (6.7)
John	35–44 (13.3)	TM (46.7)	F (66.7)	W/C (86.7)	SC (40.0)	Urb (66.6)	NCW (46.7)	<$10,000 (33.3)	ENC (93.3)	GYN (26.7)	Vaginect (6.7)
Chad	35–44 (13.3)	TM (46.7)	F (66.7)	W/C (86.7)	BD (40.0)	Sub (33.3)	≥35 (26.7)	$75,000–$99,999 (13.3)	ENC (93.3)	PRS (53.3)	Phallo (13.3)
Richard	45–54 (13.3)	TM (46.7)	F (66.7)	W/C (86.7)	BD (40.0)	Urb (66.6)	NCW (46.7)	<$10,000 (33.3)	ENC (93.3)	PRS (53.3)	M/CM (20.0)
Grace	25–34 (33.3)	TF (26.7)	M (33.3)	W/C (86.7)	SC (40.0)	Urb (66.6)	NCW (46.7)	<$10,000 (33.3)	ENC (93.3)	URO (20.0)	Orchi (20.0)
Anne	45–54 (13.3)	TF (26.7)	M (33.3)	W/C (86.7)	BD (40.0)	Sub (33.3)	≥35 (26.7)	>$150,000 (6.7)	ENC (93.3)	PRS (53.3)	Vaginop (6.7)
Tina	55–64 (6.7)	TF (26.7)	M (33.3)	W/C (86.7)	TTV (6.7)	Sub (33.3)	<35 (26.7)	<$10,000 (33.3)	ENC (93.3)	URO (20.0)	Orchi (20.0)
Judith	>64 (6.7)	TF (26.7)	M (33.3)	W/C (86.7)	MD (6.7)	Urb (66.6)	NCW (46.7)	$10,000–$29,999 (20.0)	ENC (93.3)	PRS (53.3)	FFS (6.7)
Gabriel	18–24 (26.7)	G/N (26.7)	F (66.7)	W/C (86.7)	BD (40.0)	Urb (66.6)	≥35 (26.7)	$10,000–$29,999 (20.0)	ENC (93.3)	PRS (53.3)	M/CM (20.0)
Sam	18–24 (26.7)	G/N (26.7)	M (33.3)	W/C (86.7)	BD (40.0)	Urb (66.6)	NCW (46.7)	O/U (26.7)	ENC (93.3)	URO (20.0)	Orchi (20.0)
Kerry	25–34 (33.3)	G/N (26.7)	F (66.7)	W/C (86.7)	BD (40.0)	Sub (33.3)	<35 (26.7)	$10,000–$29,999 (20.0)	ENC (93.3)	GYN (26.7)	Hyst (20.0)
Jamey	25–34 (33.3)	G/N (26.7)	F (66.7)	W/C (86.7)	SC (40.0)	Sub (33.3)	<35 (26.7)	<$10,000 (33.3)	P (6.7)	PRS (53.3)	M/CM (20.0)

AD = associate degree, BD = Bachelor's degree, ENC = East North Central (WI, MI, IL, IN, OH), FFS = facial feminization surgery, G/N = gender non-conforming/non-binary, GYN = gynecologist, hyst = hysterectomy, loc = location, LOE = level of education, M/CM = mastectomy/chest masculinization, MD = Master's degree, meta = metoidioplasty, NCW = not currently working, O/U = other/unsure, orchi = orchioplasty, P = Pacific (WA, OR, CA, AK, HI), phallo = phalloplasty, PRS = plastic surgeon, SC = some college, sub = suburban, TF = transfemale, TM = transmale, TTV = trade, technical or vocational, urb = urban, URO = urologist, USD = United States Dollar, vaginect = vaginectomy, vaginop = vaginoplasty, W/C = white/Caucasian.

a hysterectomy may be coded under the diagnosis of "chronic pelvic pain" rather than the diagnosis of gender dysphoria to improve the likelihood that it would be covered.

> "… I had the impression that insurance would barely cover it, but there were ways you could work around… codes you could use that could probably work if you had a doctor who was fluent in the language of how to file it."—Grace

3.3.4. Logistics. The group of "logistics" subcodes was the most frequently applied of those relating to barriers to consultation, with at least 1 of these subcodes appearing in nearly all fifteen transcripts. Participants' discussion about logistical barriers followed the themes: finding a surgeon; mental health; wait time; patient readiness; and referrals. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729). These subcodes were generally applied to excerpts describing barriers to consultation related to scheduling and to initiating surgical consultations. Of the barriers related to logistics, difficulty with finding a surgeon and circumstances surrounding patient readiness were identified in the greatest number of transcripts.

> "When I lived [in a small town], there was nothing for three, four hundred miles… the insurance doesn't matter because there's no options."—Grace
>
> "I was researching everything to do with surgical processes and procedures, and so on and so forth. … [but then] we accidentally ended up pregnant together. I put everything on hold for that… I waited several years after that to become invested [again]."—John

Notably, difficulty with finding a surgeon was a barrier reported by participants living in urban locations as well as those living in suburban locations. The frequency at which the "patient readiness" subcode was applied did not vary significantly between the transcripts of younger participants as compared to those from older participants. "Wait time" and "mental health" were also among the frequently applied subcodes. Participants who underwent consultation with a plastic surgeon frequently referenced "wait time" as a barrier.

> "… I had to schedule 18 months in advance because these surgeons are good surgeons. There aren't a lot of good surgeons doing these procedures, so there's want. There's an 18-month wait… [it is unfair] that more surgeons aren't trained to do these procedures well."—Jamey

It was also noted that participants with lower levels of education and those earning less income were likely to make at least 1 reference to the subcode, "mental health," when discussing barriers to consultation.

> "Sometimes I feel like I can't be out in public [because of my mental health], but if I have an appointment, I really don't want to miss it. Sometimes I will. … the dysphoria does make that hard sometimes. Also, the anxiety makes that hard, and the depression. They all work together…"—Sam

This subcode was also applied to situations in which participants described difficulty with obtaining required mental health referrals.

> "The thing that drove me the craziest was, to get bottom surgery, even a hysterectomy, I needed a letter from two different psychologists or mental health providers, one of whom had to have a doctoral level of training, which was hard for me because my therapist was only a [licensed clinical social worker]."—Peter

3.3.5. Interaction with clinic staff and clinic environment. The majority of participants referred to at least 1 positive or neutral interaction with the clinic staff. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

> "The staff [were] accepting and weren't uncomfortable by me being trans."—Peter

However, all individuals who self-identified as GNC/NB referred to at least 1 negative interaction and less frequently referred to at least 1 positive or neutral interaction.

> "I was like really kind of wanting to be made to feel welcome. [It] definitely seemed like they were trying to make me feel welcome, but it didn't work. I just got weird, off-putting vibes, and they definitely misgendered me a few times."—Sam

Several GNC/NB participants expressed doubt related to the clinic staff's experience with and knowledge of diverse gender identities.

> "I'm not sure if [GNC/NB] is a [term] that a lot of people understand. The phrasing that I used was that I wasn't interested in transitioning fully, by which I meant that it wouldn't be a full transition from binary female to binary male. It would be a full transition for me, for what my identity is. I don't know if this is the case or not, but I assumed that someone who had experience

with trans patients… would probably mostly have experience with binary trans patients."—Kerry

When participants reported a negative interaction with the clinic staff, this was more commonly related to difficulty with scheduling surgery, as these 2 subcodes commonly occurred together. When discussing their experiences with the clinic environment, the majority of participants referred to at least 1 comfortable or neutral interaction.

"It was a fine waiting room. There [were] a few materials on trans stuff, but it wasn't explicitly trans-related at all. It was good though."—Peter

Most commonly, participants who referred to at least 1 uncomfortable interaction with the clinic environment was the result of undergoing consultation at a "gender-centric" clinic or health center, which manifested as a source of dysphoria for participants.

"[It was] awkward because there [were] a lot of pregnant ladies, and I was trying to do the opposite."—David
"… but we definitely stood out like sore thumbs… it felt like I was a boy walking down the Barbie aisle. 'Okay, this isn't for me.'"—Grace
"It was definitely a very woman-focused center. When the receptionists would come out to call and have me go back into the exam room and stuff like that, they would address me as, 'Miss [my last name],' because they addressed everyone that way. It didn't really seem to occur to anyone that I could be there for any reason…"—Kerry

3.3.6. Experience with scheduling surgery. About the same number of participants made at least 1 reference to having no difficulty with scheduling surgery as having some difficulty. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

"Something really great about it [was that] I was able to get everything booked within two weeks."—John

GNC/NB individuals more commonly described having difficulty with this process.

"It's not really acceptable. I'm accepting it because I have to accept it. We had to wait, and it's going to be more expensive now because I aged out of my mother's insurance because we couldn't have it done fast enough for me to have it done while I was still insured. It's not fair. It's not fair."—Jamey

3.3.7. Experience with insurance pre-authorization The majority of participants made at least 1 reference to relying on others during the process of insurance pre-authorization. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

"I would like to say that I can sit down and be able to read the manual and get everything about the surgery. I kind of can, but if I don't have their staff, which means their medical coders and billers, then I'm completely lost."—John

Fewer of the participants made at least 1 reference to relying on themselves.

"I try to keep myself informed. I ask questions first… if people don't know the answers, then I educate myself. Just specifically with insurance, because I assume that medical providers would know about that and stuff, but I often know considerably more than them about that for my specific plan or whatever."—Sam

GNC/NB individuals reported unique concerns regarding difficulty with scheduling surgery and the process of insurance pre-authorization, such as having felt worried about whether insurers would cover procedures that did not result in a "full transition" (i.e., fully masculine or fully feminine).

"[There's this idea that] you have a specific arc of surgeries that you're going through, and I think that's a bad concept. … They have this one directional coverage. If you get surgeries that are labeled as, '[female-to-male],' then you cannot get coverage for surgeries that are labeled, '[male-to-female].' The coverage only goes in one direction."—Sam

3.4. Interaction with surgeon

During the participants' accounts of their interactions with the surgeons, the following subcodes were most commonly applied at least once per transcript: "encounter was adequate and/or positive;" "surgeon ensured patient's understanding;" "patient felt comfortable;" and "physical exam was adequate and/or appropriate." See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729).

"Pretty much [everything went well] after I was in the consultation office. It was a very informed and very open conversation. I was informed of my options. I was informed of the downsides. The doctor was knowledgeable."—Grace
"I really liked her. I thought she was really wonderful. She was above and beyond what I would expect from a healthcare provider. She was just very sweet and maternal, but not in a creepy way. She just seemed to really care about her patients. She answered a lot of questions, because I ask a lot of technical questions. She was very patient with that."—Hunter
"More than 90 percent of what I was concerned about had been addressed, and the other 10 percent she actually said she didn't know, which I found refreshing… I was confident in my decision, and I was confident in her abilities."—Grace
"I would say it's pretty much like every other physical exam of that kind that I've had."—Richard

The subcodes that were applied to the fewest number of transcripts included: "surgeon seemed uncomfortable" and "patient felt uncomfortable due to surgeon."

"… [he was] a little brisk during the examination. I was fine with it, but it seemed like, maybe towards the tail end of things, he was a little bit uncomfortable. I wasn't sure as to why."—John
"They did misgender me. They called me 'her' several times… but some people are nonbinary… I forget what it [was that the doctor said] that felt very dysphoric. She said, 'You are a girl.'"—Sam

The subcode, "patient felt uncomfortable due to self," was frequently applied to transcripts from GNC/NB individuals.

"I wasn't in the place to talk about it. I don't know. I don't want to say that [the surgeon] didn't offer to talk to me, [but] I don't remember being or feeling open to discussing complicated emotions. Because I also felt like she holds the power until it's done. If you say something, you're afraid of it being misconstrued as, 'I don't actually want this' or 'I'm second guessing this.' … It wasn't uncomfortable at all even though I might have felt uncomfortable… I probably would have asked more vulnerable, emotional questions or been more honest."—Gabriel

It was also found that more GNC/NB individuals commonly described the feeling of needing more information.

"[The surgeon] answered some of the specific questions that I had. Beyond that, she didn't really give me any pamphlets or anything. Some of the questions that I needed [answered] were medical [and] anatomical… I think, for me, it's less clear. There's less of a template. If you are born a female and you want a transition to being a man, you know what a cisgender man looks like. Even if maybe you personally don't want all of the procedures done on yourself, there is a Platonic ideal of what a man looks like. For me, as a non-binary person, that's not really the case. I think that was something that was as much figuring out my identity as it was related to surgical consults. I do think that contributed a little to feeling overwhelmed and confused during [the] consult."—Kerry

When participants reported that the encounter was adequate and/or positive, this was more commonly associated with the participants' sense of comfort and sense of understanding, as these combinations of subcodes commonly occurred together.

The opposite was also true. When participants reported that the encounter was inadequate and/or negative, this was more commonly associated with the participants needing more information.

Many participants reported feeling "uncomfortable due to self" during consultation with a gynecologist and urologist. Participants aged 34 years or younger reported feeling this way as well. Furthermore, participants with a Bachelor's or Master's degree frequently described needing more information, and fewer of these participants made at least 1 reference to the surgeon having ensured their understanding.

3.5. Areas for improvement

Participants discussed many other aspects integral to the experience of surgical consultation for TGNC individuals aside from those related to the surgeon. The themes that emerged centered around the following: barriers to access; the clinic staff and clinic environment; and the TGNC community. See Appendix 1 (Supplemental Digital Content, http://links.lww.com/MD/H729). The majority of participants made at least 1 reference to both "address barriers" as well as "clinic staff and clinic environment." In this setting, the subcode, "address barriers," applied to the need for individuals, organizations and/or society to address the barriers to GAS that exist for TGNC individuals.

> "If a surgeon's office would maybe just have a monthly kind of presentation where anybody interested could come… As soon as people start seeing that there [are] others and they're all going to be going through the same thing together… that would just make all the difference in the world, to help go through this decision even more informed. Maybe even have a former patient there to describe their experiences. I would have been there. I would have been there, and it would have been such a huge help."—Anne
> "I don't know if this exists, but I would like to see a hotline or something set up for transgender people who are going through surgeries who need support, because any trans hotline you call now, they're just people to talk to. They don't really know a lot about the actual specifics."—Tina

Regarding clinic staff and clinic environment, several participants suggested that seemingly small and simple interventions have the potential to make a big difference for TGNC individuals undergoing the process.

> "I think that it probably can't be too hard to put a note on the chart when the nurse is taking me back. Something to say, 'Hey, these are the pronouns this person uses.'"—Richard
> "Places that receive a lot of transgender and nonbinary patients [can] get informed with maybe having a speaker coming to talk to staff…"—David

Notably, the subcode, "clinic staff and clinic environment," was commonly applied to transcripts from GNC/NB individuals. We identified many fewer transcripts with a reference to the TGNC community as an important area for improvement. These references focused on the need for more TGNC group meetings and other opportunities for TGNC individuals to share experiences with and to learn from 1 another, especially for older TGNC individuals.

4. Discussion

Multiple studies have shown that TGNC individuals experience a lack of social support and have revealed the ways in which this negatively affects individuals.[11,12] For example, longitudinal surveys have uncovered that TGNC youth who reported low social and family support experienced higher levels of distress, lower self-esteem and higher rates of homelessness.[13,14] Our data shows that lack of support can also manifest as a barrier to TGNC individuals receiving gender-affirming care, such as GAS. This was especially true for our GNC/NB participants, which is consistent with other studies.[15] Therefore, our findings add to the current body of literature identifying GNC/NB individuals as a population vulnerable to this important barrier to undergoing surgical consultation.

Lack of information about and awareness of GAS can present as an additional barrier. Survey data shows that over 60% of respondents report "access to information" as a barrier to receiving GAS.[16] Our participants suggest that this barrier is secondary to lack of available information, lack of accessible information, lack of exposure to information, or a combination of the 3. We also found that most participants were searching online for information, which is consistent with findings from other authors.[16] It has been shown that online resources providing information about GAS are written, on average, at an eleventh-grade reading level, which is higher than the American Medical Association-recommended sixth-grade reading level for patient education materials.[17,18] These important findings highlight the need for increased outreach within the TGNC community. This includes efforts to increase the volume of available, accessible resources for those wishing to learn about gender-affirming care, such as GAS.

Of all the different types of barriers described by participants in our study, a large majority were financial in nature. Healthcare is expensive in the United States, and gender-affirming care can be particularly expensive. Therefore, most TGNC individuals rely on insurers to bear the burden of this otherwise prohibitive expense. The 2015 US Transgender Survey (USTS) is the largest survey ever devoted to the lives and experiences of TGNC individuals, with 27,715 respondents across the US. The results showed that 55% of respondents who sought GAS coverage were denied. The results also showed that respondents who were living in poverty, those with low incomes, and those who were uninsured were less likely to have GAS.[19] These data are somewhat outdated, as we know that coverage has improved over recent years, but financial barriers still have a very significant impact on TGNC individuals seeking GAS. When describing barriers to surgical consultation, the overwhelming majority of our participants experienced at least 1 barrier related to capital, insurance and/or employment. This is consistent with survey data examining barriers to care by other authors.[16,20,25]

In managing out-of-pocket expenses, our data suggests that individuals seeking consultation with a plastic surgeon may be especially vulnerable. Many of these participants described "capital" as being a barrier to surgical consultation. It is likely that procedures performed by gynecologists and urologists are primarily ablative in nature (e.g., hysterectomy, orchiectomy) and are, therefore, less prone to lapses in insurance coverage.

Our participants frequently expressed worry and frustration over insurance coverage and exorbitant out-of-pocket expense, whether actual or perceived. For example, a number of participants explained that their insurers did provide adequate coverage, but they were not aware of this information for a period of time. Therefore, it was the perceived out-of-pocket expense, not the actual out-of-pocket expense, that deterred or delayed these individuals from initiating consultation with a surgeon. It also became apparent that several participants, who might have otherwise been denied, were able to obtain adequate coverage because their surgeons processed the claims under a different diagnosis code (unrelated to gender dysphoria). This was particularly true for patients who were under the care of a gynecologist or urologist for ablative bottom surgery. These challenges highlight the need for improved coverage by insurers or even a publicly funded pathway to GAS, which has proved to be successful in certain regions of the world.[21]

Several other barriers have been well-documented. In one of the most well-cited studies, Sanchez et al[22] reported that 32% of survey respondents indicated that access to a healthcare provider who was "knowledgeable about transgender health issues" was the main barrier to care. Sineath et al[20] published similar findings from survey data in 2016. We found a similar trend with nearly all of our participants describing "logistics"

as a barrier to consultation for GAS. Specifically "finding a surgeon" was among the most frequently applied subcodes.

Data is lacking on the surgeons' perspectives of their own comfort and competency in the care of TGNC individuals and should be investigated. A 2005 study reported that fewer than 50% of endocrinologists surveyed felt comfortable providing medical hormone therapy for TGNC patients.[26] Other specialists, such as surgeons who perform GAS, may have similar concerns. It is hoped that the progress being made in the realm of education and clinical training for future surgeons will soon improve our current situation of too few well-trained, competent surgeons performing these important procedures.[27] This barrier is also reflected in our data on wait times for scheduling consultation, particularly with plastic surgeons. We found that the majority of our participants reported "wait time" as a barrier to consultation with a plastic surgeon for GAS. Similarly, El-Hadi et al[16] looked at survey data from across Canada and the US and found that wait times ranged from 6 months to 7 years, with 65% of respondents reporting "finding a physician" as a barrier to receiving GAS.

While mental health was found to be a barrier to many fewer of our participants, our results highlight some important points. Firstly, the subcode, "mental health," was commonly applied to transcripts from participants with low levels of education and low income, which may represent a subgroup of patients at greater risk for disparity. Therefore, these individuals may require special attention, including additional time and resources from surgeons. Secondly, several of our participants specifically referenced the "gatekeeping phenomenon" associated with mental health providers as a barrier to consultation for GAS. In brief, insurers frequently require at least 1 letter from a mental health professional carefully documenting persistent gender dysphoria prior to processing preauthorization requests for GAS. This is generally in alignment with the Standards of Care for the health of TGNC individuals established by the World Professional Association for Transgender Health, which sets forth a criterion that TGNC individuals who seek top and/or bottom surgery provide documentation of persistent gender dysphoria by a qualified mental health professional.[10] Often, 2 letters are required. Our findings are consistent with the current literature. Many researchers have highlighted problems associated with this gatekeeping model (both logistical as well as ethical), including the double standard and unnecessary barrier that it creates for TGNC individuals.[25,28–30]

It became clear from these interviews that a number of different elements of the surgical consultation influence the overall patient experience. Interactions with clinic staff and the clinic environment, whether the patient encounters difficulty with scheduling surgery, navigating the process of insurance pre-authorization, and, of course, the actual interaction between the patient and the surgeon are all important.

Notably, GNC/NB individuals commonly referenced a negative interaction with clinic staff and difficulty with scheduling surgery. This may be related to the unique challenges these patients face during the process of insurance pre-authorization due to concerns that insurers may only cover procedures that result in a "full transition" (i.e., fully masculine or fully feminine). On the other hand, this may relate to clinic staff who are unhelpful or inexperienced in handling the scheduling of surgery and/or the process of insurance pre-authorization. Studies show that many GNC/NB individuals have experienced a lack of cultural competence specifically among providers who care for them and that they often cannot locate providers with knowledge of these unique identities.[31] In some situations, and for a multitude of reasons, GNC/NB individuals may adopt the "trans" or "transgender" label in order to access the healthcare they need with fewer negative interactions.[31] This can cause GNC/NB individuals to withhold information or feel hesitant to share information due to fear of being misunderstood and having their sense of certainty and "readiness" doubted by their surgeons. Therefore, surgeons must acknowledge these issues in order to protect this vulnerable population of patients with unique needs and interests. A heightened sense of awareness and careful surveillance is required in order to identify situations during which patients may be withholding information that is essential to the surgeon's ability to provide these individuals with the highest quality patient-centered care. This will require surgeons to reach beyond the transgender binary and to consciously avoid reframing the needs of their GNC/NB patients in terms of a binary narrative.[31]

Participants tended to describe the clinic environment as comfortable or neutral. However, this was less true for patients who underwent consultation with either a gynecologist or a urologist. This was related to the fact that many gynecologists and urologists practice at gender-centric clinics and health centers. For example, a transmale individual who needs a hysterectomy may feel dysphoric while undergoing consultation with a gynecologist practicing at a "women's health clinic." Other researches have demonstrated that positive healthcare experiences for TGNC individuals were characterized by the provision of an inclusive environment.[32] It was also noted that participants who were undergoing consultation with either a gynecologist or urologist had a tendency to feel "uncomfortable due to oneself," meaning that they expressed a feeling of dysphoria or discomfort about themselves. This likely relates to the perceived level of invasiveness and intrusiveness anticipated during these encounters, such as the physical examination of anatomy that may trigger dysphoria for these individuals.

Ensuring a welcoming, safe, and gender-affirming environment and experience for these individuals is essential. The 2015 USTS revealed that 33% of respondents who had seen a healthcare provider in the past year encountered at least 1 negative experience related to being TGNC, such as verbal harassment, refusal of treatment, or having to teach the healthcare provider about TGNC people in order to receive appropriate care. Therefore, it may not be surprising that 23% of respondents did not see a healthcare provider when they needed to because of fear of being mistreated as a TGNC person.[19]

Prior to an encounter, the surgeon should consider that TGNC individuals are more likely to have encountered negative experiences with their healthcare, including discrimination as well as physical or emotional abuse.[19,33,34] This will allow the surgeon to approach the encounter with greater empathy and sensitivity. It was reassuring to find that, overall, participants had a stronger tendency to report positive or neutral interactions with their surgeons than negative interactions. The elements of this interaction that appeared to have the greatest influence included: the surgeon ensuring the patient's understanding, the patient's own perceived sense of comfort, and a physical exam that was either positive or neutral in nature (e.g., straightforward, normal, unremarkable, brief but adequate, focused and to the point).

However, the literature still appears to suggest that healthcare providers lack training, medical knowledge and access to information. The 2015 USTS showed that 24% of respondents who had seen a healthcare provider in the past year had to teach their healthcare provider about TGNC health issues in order to receive appropriate care.[19] Perhaps the differences in our findings suggest that surgeons are getting better. Recent survey data showed that training programs for plastic surgeons are increasing the amount of time dedicated to GAS. Aggregate responses from a substantial number of training programs had previously shown minimal education and training around this topic that has since grown to approximately 3.5 hours (an increase of about 1 hour per year from 2015 to 2018).[5,27]

Very infrequently did participants describe feeling uncomfortable due to the surgeon or express that the surgeon seemed uncomfortable. Similar to other findings in this study, GNC/NB individuals appeared to be the most vulnerable to a negative experience. As noted earlier, our findings are congruent with qualitative data demonstrating that GNC/NB individuals

regularly felt disrespected and frustrated as they sought and accessed healthcare, even at centers specializing in gender-affirming care.[31] In our study, GNC/NB individuals also had a greater tendency to report needing more information than what was delivered at the time of surgical consultation. Participants provided specific examples of how the process of GAS is more challenging for GNC/NB individuals as compared to binary transgender individuals.

By observing subcodes that commonly occurred together, it was identified that the perceived sense of having enough or too little information greatly influenced whether the participant had a positive or negative interaction with the surgeon, regardless of gender identity. This has been found to be true in other healthcare settings as well.[35] Many participants who reported that they needed more information had a high level of education and income. It is unclear why those participants with an assumed higher level of health literacy reported needing more information following the surgical consultation. It may be that "higher-order thinking" generates additional questions with greater complexity and, perhaps, fewer answers with more uncertainty.

4.1. Limitations

Limitations of this study include its small number of participants and the limited ethnic and racial diversity among its participants. Therefore, the participants in this study are not necessarily representative of all TGNC people. Limited diversity may be related to the fact that fewer ethnic and racial minorities undergo surgical consultation for GAS or additional racial ethnic disparities impede access to GAS (e.g., socioeconomics, health care coverage). Also, suburban and rural populations are underrepresented in this study. This is likely due to the fact that the health centers used to recruit participants where located within the Chicago city limits.

Almost all participants in this study underwent consultation in the East North Central region of the United States. While these participants did report undergoing consultation with at least 9 different surgeons, the patient experiences presented here lack regional diversity. Since many barriers to care are specific to individual regions, states, and countries, our study cannot be generalized to the larger TGNC population. Furthermore, this is small, qualitative study and is, therefore, subject to biases limiting the conclusions that can be drawn from the data collected. However, our data highlights the experience of a small group of individuals, allowing for in-depth data collection and rigorous analysis through extensive and comprehensive interviews, and serves as a gateway for further investigation.

5. Conclusions

To our knowledge, this is one of the first qualitative studies to explore how TGNC individuals experience consultation with a surgeon for GAS. Our results provide important insight into this often stressful and challenging process. Ensuring a welcoming, safe, and gender-affirming environment and experience for these individuals is essential. These findings may help to guide future education for medical students, trainees, clinic staff, and surgeons as well as to direct changes necessary to improve the patient experience for TGNC individuals undergoing consultation for GAS.

Author contributions

Conceptualization: Jesse R. Smith, Darnell N. Motley, Brandon J. Hill.
Data curation: Jesse R. Smith, Mikhail Pakvasa, Leonie A. Oostrom.
Formal analysis: Jesse R. Smith, Mikhail Pakvasa, Leonie A. Oostrom, Brandon J. Hill.
Funding acquisition: Jesse R. Smith.
Investigation: Jesse R. Smith, Lawrence J. Gottlieb.
Methodology: Jesse R. Smith, Darnell N. Motley, Brandon J. Hill.
Project administration: Jesse R. Smith, Darnell N. Motley, Brandon J. Hill.
Resources: Jesse R. Smith, Brandon J. Hill.
Software: Jesse R. Smith.
Supervision: Jesse R. Smith, Lawrence J. Gottlieb, Darnell N. Motley, Brandon J. Hill.
Validation: Jesse R. Smith, Darnell N. Motley, Brandon J. Hill.
Writing – original draft: Jesse R. Smith, Mikhail Pakvasa, Leonie A. Oostrom, Brandon J. Hill.
Writing – review & editing: Jesse R. Smith, Mikhail Pakvasa, Leonie A. Oostrom, Lawrence J. Gottlieb, Darnell N. Motley, Brandon J. Hill.

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