

Patient and parent perspectives on the utility of telemedicine for initial surgical gender care consultations: A cross-sectional survey

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Abstract

Introduction: The COVID-19 pandemic has expanded the use of telemedicine to patient populations that were previously constrained to in-person visits. Few studies have investigated the role that telemedicine plays in shaping the care of these patient populations. This project explores the impact of telemedicine for one such population: patients and parents of gender-diverse individuals seeking gender-affirming surgery.

Methods: A 10-question survey using previously validated questions was completed by 34 patients and 9 parents of patients (aged 15–31) who received virtual care at the Center for Gender Surgery at Boston Children’s Hospital between March 2020 and April 2021. The survey was divided into two parts. The first section collected demographic information. The second assessed participant perspectives on remote surgical gender care through a series of Likert-type and open-ended questions.

Results: A total of 100% of the respondents felt that their telemedicine visit was convenient; 60% (18) of the patients and 87% (7) of the parents stated that they look forward to future use of this modality. Free responses highlighted common perspectives on remote surgical gender care, including the increased accessibility of gender-affirming care through telehealth, the limitations of telehealth for addressing physical and relational aspects of gender care, patients’ desire for autonomy and privacy during telehealth visits, and parents’ desire to be involved throughout their children’s gender journey.

Conclusion: These results demonstrate the unique ability of telemedicine, if implemented thoughtfully, to enhance outcomes for patients seeking surgical gender affirmation.

Keywords

Telemedicine, family dynamics, transgender, non-binary, gender-affirming surgery

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Introduction

Telemedicine is defined as the use of electronic information and telecommunications technologies to support and promote long-distance clinical healthcare, patient and professional health-related education, public health, and health administration.^{1,2} While telemedicine has been influential in improving care delivery and equity since its inception, large-scale implementation has traditionally been stifled by various regulatory, reimbursement, technological, and confidentiality hurdles.³ Prior to 2020, healthcare

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providers were not generally trained in the use of telehealth technologies, and provider resistance to the widespread implementation of telemedicine in the United States was common.^{4,5}

The COVID-19 pandemic quickly changed the landscape of telemedicine by magnifying the need for rapid implementation of alternative healthcare delivery modalities. On 17 March 2020, the Office of Civil Rights (OCR) at the Department of Health and Human Services issued guidance regarding enforcement discretion for telemedicine remote communications during the COVID-19 pandemic.⁶ Guidance stated that the OCR would not penalize covered healthcare providers for noncompliance with the usual regulatory requirements under HIPAA if telemedicine was provided in good faith, regardless of the health insurance provider.^{6,7} This is of particular importance to patient populations that have previously been constrained to in-person visits, such as many transgender and gender-diverse (TGD) individuals.

In the United States, there are an estimated 300,000 (1.4%) trans-identifying youth in addition to 1.3 million (0.5%) transgender adults.⁸ Many TGD individuals rely on tailored multidisciplinary support while navigating their gender journey.⁹ Prior studies have highlighted the role of gender-affirming care (GAC) on positive psychosocial outcomes in tandem to improving quality of life, reaffirming the need for both continued and increased access to this type of care.¹⁰ Although failure to receive GAC has proven to be detrimental, many barriers to pursuing care continue to burden the TGD community, including anxiety due to fear of discrimination, lack of insurance coverage, increased out of pocket cost, and proximity to quality care.^{11–14} Increasing the availability of telemedicine is one potential way of addressing these barriers.¹⁵

Like most healthcare in the United States, prior to the COVID-19 pandemic, GAC was provided primarily in-person. However, some initial interventions had already found telehealth to be effective in increasing the general health-seeking behaviors of transgender patients, and some states had begun considering the use of telehealth for GAC due to the shortage of providers offering such services.^{16–19} Shortly after the onset of the COVID-19 pandemic, a study conducted with TGD individuals found that nearly half of the participants were interested in receiving GAC via telemedicine, with especially high interest from those with lower levels of perceived parental support.¹ Additional studies demonstrated the utility of telehealth in increasing the accessibility of care,^{3,15,20–23} although there were concerns that issues of privacy and confidentiality were not always effectively addressed through these models.^{24–26}

Gender-diverse persons and patients seeking surgical gender care have been a particularly vulnerable patient population with uncertain outcomes arising during the rapid transition to virtual care during the COVID-19

pandemic.³ Presently, research that focused on patient and parent perspectives regarding the utility of telemedicine is scant in the context of surgical gender care, despite telemedicine having been shown to be beneficial in other facets of healthcare, including plastic surgery.^{23,27} This demonstrates an urgent need to better understand the promise and/or obstacles that telemedicine might pose in shaping the care of these patients, particularly as the increase in anti-transgender legislation has forced some TGD individuals to seek out-of-state care.^{28,29} Using a two-part cross-sectional survey with previously validated questions,³⁰ this project aims to understand the impact of telemedicine for patients and parents of gender-diverse individuals seeking gender-affirming surgery (GAS).

Materials and methods

A 10-question survey using previously validated questions was distributed to all 224 patients who received virtual care at the Center for Gender Surgery at Boston Children's Hospital at least once between March 2020 and April 2021. This study was deemed exempt by the Boston Children's Hospital IRB (IRB-P00039185), and participant consent was considered implied by their response to the questionnaire sent by the research team. The questionnaire was administered via REDCap and distributed via email. If the patient was over the age of 18, the survey was sent directly to the patient for completion. If the patient was under the age of 18, the survey could not be sent to the patient and was instead sent to the patient's parent to complete regarding their perspective on telehealth for their child's gender care. Only one email address was used for each patient, and only one survey could be completed by either the patient or the patient's parent. Nine additional emails were excluded because they could not be connected to a patient or their parent. Reminder emails were sent two weeks after the initial survey invitation to those who had not yet responded.

The survey was divided into two parts. The first portion collected demographic information about the patient, including age, gender identity, race, highest education, health insurance, and home zip code. The parent participants provided demographic information about their children, not themselves. The second portion of the survey posed a series of questions about the participants' experiences with telemedicine, using Likert scale and open-ended responses. Scales were created on a 5-point spectrum of agreement, including strongly disagree, disagree, neutral, agree, and strongly agree. The participant responses to these questions were visualized using tables presenting the percentage of responses per category of agreement. These percentages were used to quantitatively and visually assess patient and parent perspectives on remote surgical gender care as they pertained to a variety of topics, including convenience, privacy, and stigma.

Lastly, open coding was used to identify and refine themes found in the open-ended survey responses.^{31,32} All responses were blind coded by two separate researchers, who then met to resolve any discrepancies in their codes and develop the final codebook. Once coding was complete, the codes were organized into overarching themes. These themes were shared with the full research team for final approval (the full set of patient and parent responses are available as Supplemental Table 4a).

Results

A total of 30 patients and 9 parents participated in the survey, for a total of 39 responses and a total response rate of 17.4% (patient response rate: 16.1%, parent response rate: 23.7%). Four additional patient responses were dropped because they did not complete the survey. Of the nine parents who responded, one submitted an incomplete survey, only completing the demographic information for their child. The partial response by a parent was included for demographic analysis.

Demographics

Of the 39 participants included in this survey, there is an average age of 21 ± 4.8 years with a range of 15–31 years old. There were 32 male/transgender male, two female/transgender female, and five non-binary/genderqueer. Of them, 90% (35) identified as being White, 8% (3) as Black/African-American, and 2% (1) as Asian. In addition, 15% (6) identified as Hispanic/Latin (o/a/x) (Table 1). Zip codes showed that patients sought care from a variety of both neighboring and removed states, including ME, CT, RI, IL, and MN.

Table 1. Patient demographics.

	Total	Male/transgender male (%)	Female/transgender female (%)	Non-binary/genderqueer (%)
Number of patients, <i>N</i> (%)	39	32 (82.1)	2 (5.1)	5 (12.8)
Age, mean \pm SD	21 ± 4.8	22 ± 4.7	18 ± 1.4	21 ± 3.8
Age, <i>N</i> (%)				
10–15	3 (7.7)	3 (7.7)	0.0	0.0
16–20	21 (53.8)	17 (43.6)	2 (5.1)	2 (5.1)
21–35	7 (17.9)	5 (17.9)	0.0	2 (5.1)
26–30	7 (17.9)	6 (15.4)	0.0	1 (2.6)
>30	1 (2.6)	1 (2.6)	0.0	0.0

Likert analysis—patient perspectives

A total of 100% (30) of patients felt that their telemedicine visit was convenient, and 60% (18) stated that they looked forward to future use of this modality—26% (8) had a neutral stance, and only 13% (4) stated they did not look forward to future telemedicine use. A total of 80% (24) of patients were not concerned about privacy during their telehealth visits, whereas 10% (3) felt some privacy concerns and 10% (3) were neutral. The participants were largely neutral regarding how comfortable they felt during a telemedicine visit versus an in-person visit (Table 2).

A total of 60% (18) of patients preferred that their parents not accompany them on their telehealth visits, 36% (11) of whom felt strongly about this; 56% (17) of patients shared a similar preference for visits related to gender affirmation more generally, and 70.5% (12) of whom felt strongly that they did not want their parents to accompany them. An additional 26% (8) were neutral on parent accompaniment during their telehealth visits, and 40% (12) were neutral on parent involvement for GAC more generally.

Likert analysis—parent perspectives

Parents demonstrated similar opinions on the convenience and privacy of telehealth, with 100% (8) of the parents agreeing that the telehealth visit was convenient and maintained privacy. A total of 100% (8) also felt that their children got the care that they needed (Table 3). Even more so than patients, parents overwhelmingly looked forward to future telemedicine visits 87% (7), with only one parent taking a neutral stance on the matter. Also, 100% of the parents wanted to accompany their child on the visit. One parent stated that they felt as though their child did not

Table 2. Patient perspectives on telehealth use for initial gender-affirming surgery consultation.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The telehealth visit was convenient	0	0	0	9 (30%)	21 (70%)
I was concerned about privacy	10 (33.3%)	14 (46.7%)	3 (10%)	3 (10%)	0
I felt more comfortable in this telehealth visit than I did for an in-person gender affirmation consult	2 (6.7%)	6 (20%)	16 (53.5%)	4 (13.3%)	2 (6.7%)
I look forward to using telehealth in the future	2 (6.7%)	2 (6.7%)	8 (26.7%)	11 (36.7%)	7 (23.3%)
I wanted my parents to accompany on this visit	11 (36.7%)	7 (23.3%)	8 (26.7%)	3 (10%)	1 (3.3%)
I prefer that my parents accompany me on visits related to gender affirmation	12 (40%)	5 (16.7%)	12 (40%)	1 (3.3%)	0

Table 3. Parent perspectives on telehealth use for initial gender-affirming surgery consultation.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The telehealth visit was convenient for my child	0	0	0	2 (25%)	6 (75%)
I was concerned about my child's privacy	3 (37.5%)	5 (62.5%)	0	0	0
I felt my child got the care they needed	0	0	0	2 (25%)	6 (75%)
I look forward to using telehealth for my child in the future	0	1 (12.5%)	0	2 (25%)	5 (62.5%)
My child wanted me to accompany on this visit	1 (12.5%)	1 (12.5%)	0	1 (12.5%)	5 (62.5%)
I wanted to accompany my child on this visit	0	0	0	1 (12.5%)	7 (87.5%)

want them to accompany them on the visit, one took a neutral stance, and 75% (6) felt that their child wanted them to accompany them on their visit.

Free response

A total of 25 patients and 7 parents responded to the free response portion of the survey. Four key themes emerged from the data, pertaining to the following: the increased accessibility of telehealth for GAC, the inability of telehealth to address the physical and relational aspects of GAC, patients' desire for autonomy and privacy during telehealth visits, and parents' desire to be involved throughout their child's gender journey. Representative responses for each theme are included in Table 4, and all quotes can be found in Supplemental Table 4a.

Theme One: "I can have a full on appointment from the comfort of my bedroom"—Telehealth as increasing the accessibility of gender-affirming care

Nearly all the participants described telehealth as reducing the burdens associated with in-person GAC in some way. Over half of the patients and parents responded that the lack of travel required for telemedicine visits made accessing GAC much easier, especially for patients who lived outside of Boston. In addition to the increased convenience of telehealth, nearly a third of the patients and parents reported feeling more comfortable doing visits from their own home, with patients citing decreased anxiety when in their own space, as well as feeling less gender dysphoria and facing less stigma from other people than when attending appointments in public.

Theme 2: "Gender-affirming care is so embodied"—Telehealth as unable to address the physical and relational aspects of gender-affirming care

The patients and parents alike recognized that telemedicine visits alone were insufficient for the kinds of consults required for GAC. Over half of the patients and nearly all

Table 4. Key patient and parent quotes on the use of telehealth for GAC.

Theme	Key quotes
Telehealth as reducing the burdens associated with in-person gender-affirming care	<ul style="list-style-type: none"> -“I was able to meet with all of the necessary surgery team members without having to go all the way to Boston. I do not live in MA, so this saves me a lot of time.” - “It was convenient to be able to attend the appointment at home. In relation to gender, before top surgery I wore a binder whenever I was outside the house, and I liked that I didn’t have to worry as much about hiding my chest to travel to the appointment.” - “The patient gets to stay in the comfort of their home while discussing treatment for the first time with someone. No fear of staff, office, other patients. Once the patient makes a bond with the doctor they get to make the choice to go see them in person.” - “Lack of commute time, especially for a short consult, is a HUGE plus. I have a chronic pain disorder, which was worse before I had top surgery, and the 45-60 minute one-way commute to Longwood was incredibly physically taxing. It can also be very reassuring to sit in my own room rather than in a more detached clinical setting.” - “I think it is good for the patient to be in a comfortable environment when discussing their gender care issues to put them more at ease. It also allows for people from multiple locations to participate and give input.”
Telehealth as unable to address the physical and relational aspects of gender-affirming care	<ul style="list-style-type: none"> - “It is impossible to have any sort of physical exam over telehealth, and [provider name] will only share photos in person. These are both extremely important for most appointments related to gender surgery.” - “Harder to schedule a follow-up appointment, not really possible to discuss exactly what type of surgery, didn’t seem like a ‘real’ doctor’s appointment” - “I feel like in person you feel more secure and not too pressured cause it’s a timed call it was very awkward for me and I didn’t feel like it was taken very seriously” - “I missed the personal connection. Because gender-affirming care is so embodied, I kept wanting to show how my body looked/moved and how I wanted it to look/move. That was hard to do over telehealth.” - “It felt odd to meet a doctor for the first time over zoom, especially because I didn’t know whether he would need to see my chest at the consultation and the idea of that examination over zoom just felt unnerving-I wished I at least knew in advance if it would be a thing or not.”
Patients’ desire for autonomy and privacy during telehealth visits	<ul style="list-style-type: none"> - “I may have very private questions about bottom surgery that I do not wish to ask in front of my parents. I prefer to decide which information is important for them to know.” - “I’m 31 year old adult and do not need my parents to hold any control over my medical care for these visits. One parent is not supportive of my transition, so having them there would not be helpful” - “I prefer my privacy and the ability to be open with my doctor without fear of family knowledge” - “While my parents are very supportive, it’s not an area of my life I’ve shown to them. They might derail the visit with their own concerns.” - “My mom can have her unsupportive moments, and I’m adult and can/will make my own decisions and speak for myself. My parents tend to speak over me.”
Parents’ desire to be involved throughout the gender care process	<ul style="list-style-type: none"> - “My son can be a little shy, and it helps for me to be there at times when he may be less talkative. Plus I think he appreciates the support even when I sit there and don’t say anything.”

(continued)

Table 4. Continued.

Theme	Key quotes
	<ul style="list-style-type: none"> - "I tend to ask more questions than he does as he tends to have some social anxiety so he appreciates having me help him remember what he wants to ask. Additionally, I understand the information better than he does." - "I prefer to be informed and that happens when I am involved in the process." - "I simply like to understand what is going on and to know if there is anything I can do to help, and to be available if there is any information I can give that can be helpful to the doctor." - "I want to be part of this journey with my child and make sure he is receiving the care that he needs."

Note: Key quotes used from patient and parent free responses on telehealth survey.

the parents described feeling less connected to their health-care providers during telehealth visits, due both to technological issues (e.g. unstable internet connection) and the structure of the visits (e.g. less social interaction, greater time constraints). Some of the patients connected these issues to greater discomfort asking questions and a lower likelihood of having their concerns addressed. Moreover, nearly half of the patients recognized that physical assessments—examining the areas of the body targeted by surgery, taking pre-surgical photos, assessing surgical outcomes—could not be done or were more awkward over telemedicine.

Theme 3: "I prefer to decide which information is important for them to know"—Patients' desire for autonomy and privacy during telehealth visits

The patients in this study overwhelmingly preferred to attend their telehealth visits without their parents present. Over a quarter of patients stated that their parents were unsupportive or had their own agenda that would detract from their care goals. An additional quarter of patients described their choices regarding GAC (e.g. whether to pursue bottom surgery) as private decisions for which they did not want their parents' opinions. Even among patients who felt their parents were supportive, a majority said that they would prefer to maintain control over which information to share with their parents and which information to keep private.

Theme 4: "I think he appreciates the support even when I sit there and don't say anything"—Parents' desire to be involved throughout the gender care process

Among the parent participants, there was a universal desire to be involved in their child's gender care. Most parents felt as though their child wanted them to attend appointments with them, both to provide emotional

support and to serve as an advocate by asking questions and gathering relevant information. Similarly, parents all framed their own motivation to accompany their children in terms of two desires: to be informed about the care their child was receiving and/or to show support for their child's gender journey.

Discussion

This study aims to understand the perspectives of TGD individuals and their parents who used telemedicine for their initial medical consultation for GAS at Boston Children's Hospital. Analysis of our results demonstrated an overwhelmingly positive response from the patients and parents alike. While some of the findings of this study reaffirm the known benefits and pitfalls of telehealth broadly (e.g. increased convenience, internet connectivity issues),^{33,34} a number of themes arose that are specific to the needs and experiences of TGD individuals (e.g. the reduction of gender dysphoria and stigma, the elevated need for privacy and autonomy). Overall, our findings suggest that when implemented thoughtfully, telemedicine is a viable alternative to in-person visits for initial GAS consults and can serve as an effective tool to meet the specific needs of some TGD individuals and their families.³⁵

Consistent with prior studies, 60% of our patients stated that they look forward to using telemedicine for future gender care.^{1,36,37} The vast majority of parents and patients reported finding telemedicine to be more convenient than in-person care, and our results specifically suggest that telemedicine can alleviate the burden of excessive travel for appointments that can be effectively completed remotely.^{3,22,23} Many transgender patients live several hours away from gender surgery centers, and without the option for telehealth are forced to travel for every GAS consultation.³⁸ In their free responses, over half of the patients in this study expressed appreciation for the option to complete some GAC appointments remotely, thereby saving on

both financial and time costs associated with commuting and improving the accessibility of care.^{20,21,39} Moreover, as the recent increase in anti-transgender legislation has made it more challenging for many TGD individuals to access care locally, remote GAC may become an increasingly popular option. While the legality of providing telehealth across state lines remains complex, particularly as many COVID-era policies allowing for more flexibility have ended, providing patients with the option for virtual GAC is one concrete way of increasing the accessibility of this critical care.^{40,41}

Adopting telemedicine as an alternative for some in-person gender care visits may also facilitate the clinician–patient relationship by minimizing the potential for patient stress caused by anxiety and stigmatization during in-person visits.^{42,43} The patients in this study described feeling more comfortable in a telemedicine setting where they could avoid harmful office interactions, a finding that is in line with existing literature on the stigma that TGD patients face in medical settings and that leads many to delay medical visits or avoid them entirely.^{44,45} Increased availability of telemedicine for GAC could allow TGD patients to have more autonomy over their care, empowering them to be more comfortable and engaged in subsequent visits.⁴⁶

Importantly, current models of telehealth do not sufficiently address all aspects of gender care. As many patients explained in their free responses, GAC is an embodied process, requiring physical consultations and the opportunity to ask both general and individualized questions about the care process. The patients and parents in this study described feeling less connected to their providers and less able to have their concerns addressed through telehealth.⁴⁷ While the physical components of gender care can only be addressed in person, providers should ensure that they foster a comfortable environment for those appointments that can be completed via telehealth.³⁵ Providers should ensure patient privacy during telehealth appointments (e.g. only allow the necessary providers in the room during video calls), make intentional space for social connection and patient questions that are integral to the consultation process, and avoid time constraints that they would not impose on in-person visits.⁴⁸ Where possible, they should also address whether or not a physical exam will be required ahead of the visit, so that patients can emotionally prepare.

Moreover, with regard to privacy and parental involvement in gender care, the responses to this survey illuminate important tensions between patient and parent perspectives. While none of the parents in this study reported privacy concerns regarding telehealth, 20% of patients did say privacy was a potential issue. A total of 60% of the patient respondents preferred not to have their parents accompany them to gender care appointments, and their open-ended responses revealed an overall desire to maintain

privacy and autonomy over their medical decision-making.^{47,48} Conversely, the parent respondents wanted to be informed and involved in their children's gender journeys, potentially conflicting with their children's desires. Given the low parent response rate, however, it is likely that this sample was skewed toward parents who are particularly supportive of their children.

These data are somewhat complicated by the nature of the sampling frame. All patients under the age of 18 require parental consent to attend a visit—therefore, any parent receiving a survey was by necessity at least supportive enough to agree that their child should have a consultation for GAS. In contrast, those individuals over the age of 18 at the time of their visit do not need a supportive parent in order to access care and would be expected, inherently, to experience a wider range of support among their family members. We were not able to examine the preferences and experiences of parents of adult patients or of adolescents seeking care, which somewhat limits the interpretability of the differences between the two populations. Additional research including a wider range of parent perspectives, as well as youth perspectives, would provide greater insight into the nuances of why and in what circumstances TGD patients require privacy from their parents. At minimum, providers should consider offering an opportunity for patients to speak privately with them, by asking parents to leave the room or allowing the youth to take part of the visit in a different space.^{47,48} Providers should also be aware that, due to the constraints of telehealth, it is not always possible to ensure privacy for youth, as the provider cannot see the entirety of the space where the visit is taking place or who might be off-camera.⁴⁸

Parental support has been shown to have several benefits for TGD individuals, including improvements in quality of life and lessened depression.^{49,50} Parental involvement in telehealth also has some potential positives. As one parent suggested, telemedicine can make it easier for families to support their TGD children by allowing them to attend visits from multiple locations or without missing a full day of work. Parents may also have an increased ability to engage with, and remember, more complex medical information, either in the form of patient history or information disseminated during the consult.⁴⁸ This could improve the pre- and post-operative experiences of patients both through reducing risk and increasing alignment between expectations and reality. However, parents may also have their own biases and goals around surgery that are not always in agreement with those of the patient. Providers offering telehealth for gender care should be aware of the multifaceted dynamics between patients and their families, ensure that they consistently check in with their patients about who is present during any given telehealth consult, and make certain that the patient's needs, goals, and desires are at the forefront of any decision-making processes.

This study is limited by its single recruitment source and low response rate. Due to the COVID-19 pandemic, recruitment for this study was only possible via email, using email addresses drawn from patients' electronic health records. There were a number of issues with bounced emails, suggesting that not all emails were up-to-date, something that may be more common with transgender patients given that they often update their emails to match their used names rather than their legal names. This likely contributed to the low response rate, and future research should include a more extensive and diverse sample, leading to more generalizable results. Moreover, due to recruitment restrictions, this study does not include TGD youth perspectives. Given how strongly adult patients expressed a need for privacy and autonomy over their gender care, it is likely that patients under the age of 18 would also desire these things.^{4,48,51} However, as minors, their access to care is more likely to be constrained by their families—in our clinic, parental consent is required to schedule a consult, and caregivers are expected to be present for all visits. Future research exploring youth perspectives, and how their perspectives may differ from or conflict with the perspectives of their parents, is critical in order for providers to develop telehealth practices that meet the needs of all TGD patients.

Finally, future research should specifically compare the viability of telehealth for different types of gender care visits. The patients in this study recognized the limitations of telehealth for visits that normally require physical exams but still appreciated the ease of the medium for other consults. A more thorough exploration of which types of gender care visits can be appropriately conducted virtually would help inform how providers approach pre- and post-surgical follow-ups, which is especially important as more and more patients may be seeking out-of-state gender care.

Conclusion

Our findings suggest that telemedicine is a viable alternative to in-person visits during the early phases of consultation for surgical gender care and may even be preferable for some individuals. Our research also suggests that telemedicine may be able to mitigate some of the stigma and macroaggressions TGD individuals are known to face when navigating in-person medical appointments. Seeking GAC can be daunting for many, given the various systemic barriers to care. Healthcare providers have a responsibility to consider how technologies such as telemedicine can facilitate improved access to GAC.

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