TRANSGENDER HEALTH

Genitourinary and Sexual Symptoms and Treatments in Transfeminine Individuals: A Qualitative Exploration of Patients' Needs

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ABSTRACT

Introduction: Medical providers may not be familiar with the genitourinary and sexual symptoms of transgender and non-binary (TGNB) individuals. This lack of familiarity may hinder a provider's ability to address these issues as patients may hesitate to report symptoms due to fear of stigma, misgendering, and being treated disrespectfully.

Aim: To describe the array of genitourinary and sexual symptoms in transfeminine individuals.

Methods: Upon institutional review board approval, researchers used semi-structured interviews with 25 transfeminine individuals assigned male at birth to explore urinary and sexual symptoms on a sample of convenience. Participants were recruited and interviews were conducted until saturation was achieved. Two research assistants independently coded all de-identified transcripts and resolved discrepancies.

Outcomes: Thematic codes pertaining to genitourinary and sexual symptoms were defined and assessed in this study.

Results: Some genitourinary symptoms unrelated to hormone therapy or genital gender-affirming surgery (GGAS) included frequency, urgency, nocturia, and incontinence, while those attributed to GGAS included slow stream, spraying, and retention. Sexual symptoms unrelated to hormone therapy or GGAS included sexually transmitted infections, erectile dysfunction, and low libido. Sexual symptoms related to GGAS included delayed ejaculation, penile pain, scar tissue pain, and pain with receptive vaginal penetration.

Clinical Implications: Increased provider awareness of and accountability for the treatment of genital and sexual symptoms of transfeminine individuals.

Strengths and Limitations: Open-ended questions were used to generate a range of responses and perspectives through conversation instead of quantifiable data. Findings are not applicable to all TGNB people since participants were limited to transfeminine adults assigned male at birth only. Recruitment was limited by the sensitive nature of the topic and hard-to-reach populations and relied on convenience through flyers and a chain-referral sampling approach.

Conclusion: Transfeminine individuals experience a wide array of genitourinary and sexual symptoms both similar and different to their cis gender counterparts. **Chung PH, Swaminathan V, Spigner S, et al. Genitourinary and Sexual Symptoms and Treatments in Transfeminine Individuals: A Qualitative Exploration of Patients' Needs. Sex Med 2022;10:100566.**

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INTRODUCTION

Approximately 1 million individuals 18 years of age and older identify themselves as transgender or nonbinary (TGNB) in the United States based on population-based probability samples analyzed in 2016, with this number increasing every year.[1] It is well documented that these individuals have decreased access to care, are often denied care, and commonly suffer from negative

health care experiences.[2-5] Recent studies have shed light on the underlying causes, which include in part a lack of providers' with sufficient TGNB health knowledge.[4] Regardless of a physicians' welcoming nature or sensitivity, survey participants often report that physicians do not know enough about the specific health issues and treatment provisions specific to the TGNB community to provide adequate care.[4,5]

Patients from the TGNB community may have sensitive symptoms (ie, genitourinary and sexual) which may be difficult to discuss with a provider. TGNB individuals may also have increased difficulty discussing such sensitive issues when they relate to their anatomy.[6] Primarily, TGNB adults attempting to access care face significant barriers when there is a scarcity of knowledgeable and well-informed physicians.[7-11] Providers in turn may not be aware or may not feel comfortable inquiring about such symptoms, leaving them unaddressed.[12] Providers need to be able to adequately, appropriately, and respectfully identify these symptoms and create a space wherein these patients feel free to describe the nuances of their conditions.

A lack of provider education in TGNB care may contribute to missed opportunities in addressing issues during patient encounters.[13] Increased provider exposure to TGNB needs may pave the way for improved care.[14] In this study, we aim to describe the array of genitourinary and sexual symptoms in transfeminine (TGNB individuals assigned male at birth) individuals in a qualitative manner. A qualitative approach was utilized to elicit an array of deeper insights into the experiences, behaviors, and attitudes of participants, which may otherwise be difficult to capture with quantitative techniques. Since genitourinary and sexual symptoms of TGNB are not well described, this approach will help to identify the sensitive issues that can then be translated into a quantitative study. Information gathered from this study will also be utilized to guide the development of a questionnaire which assesses relevant genitourinary and sexual symptoms within the TGNB community.

MATERIALS AND METHODS

Study Design

This Health Insurance Portability and Accountability Act (HIPAA)-compliant study received institutional review board approval (19D.006). We present our article in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).[15] A qualitative approach was selected to allow participants to express themselves and provide first-hand documentation of experiences while providing data on sensitive issues. Semi-structured interviews were conducted using an interview guide of open-ended questions designed to elicit a range of responses rather than quantifiable data about genitourinary and sexual symptoms and relationships with and openness of disclosing symptoms to health care providers (Appendix 1). The interview guide was informed by the literature and Andersen's Model, a framework commonly employed to explore health care utilization among underserved and marginalized persons.[16,17] The team developed and piloted the guide, and minor modifications were made after the first 10 interviews were completed and reviewed. When data collection was completed, the team conducted a content analysis of interview transcripts. The details of our study have been previously described, with use of similar methodologies and sample patient population.[2] Briefly, thematic codes were developed using directed content analysis in 2 ways: a priori (informed by the literature and interview guide) and through line-by-line reading of a subsample of interview transcripts.[18] Each code was given an explicit definition to ensure coding accuracy and improve intercoder reliability.

Data Acquisition

Twenty-five transfeminine participants assigned male at birth ages 18 and older were recruited from May 2019 to July 2019. Flyers detailing our research project were posted at our outpatient urology clinic and community centers frequented by TGNB adults to recruit patients. Some of the participants were patients of the principal investigator (PC) and freely participated in the study because of their desire to help advance LGBTQ+ care. A snowball or chain-referral sampling approach, a technique used when researching hard-to-reach populations or sensitive topics, was also employed within the general community and clinical setting to increase sample size.[19] Participants provided informed verbal consent and participated in audio recorded telephone interviews with SS at a designated research workplace, which lasted approximately 60 minutes. During the study period, SS was a full-time student completing her degree in Master of Public Health who underwent specific qualitative research and interview training and received guidance from a qualitative research expert (RF) with over 20 years of experience. As is common in qualitative research, the interview guide was reviewed and modified following early interviews to improve data collection throughout the study.[20]

Demographic data including patient age, identity, pronouns and whether they had undergone genital gender-affirming surgery (GGAS) were queried. Follow-up interviews were not performed. Participants did not provide feedback on the transcripts or findings of this study. Transcriptions were deidentified and reviewed by the team (SS and VS) to check for accuracy. Participants received a $40 gift card as compensation.

Coding and Statistical Analysis

A constant-comparison approach, commonly used when conducting content analysis, was used to evaluate earlier interviews before conducting later interviews. A total of 25 people were interviewed, which was a sufficient sample size to achieve thematic saturation, meaning that later interviews did not generate new codes.[20,21] A code book (Appendix 2) was developed using directed content analysis as informed by the literature and interview guide and through reading of a subsample of transcripts.[18]

Each code was given a clear definition to improve intercoder reliability and ensure coding accuracy.[21] SS and VS coded all transcripts independently. Coding and analysis were performed with NVivo software (version 12, QSR International, Melbourne, Australia). κ coefficient was calculated to determine intercoder reliability to improve communicability, systematicity and transparency of the coding process.[22,23] Upon completion of coding, reports were reviewed, and findings were organized into thematic categories by team consensus. Participant quotations are presented to illustrate these findings.

RESULTS

Twenty-five transfeminine individuals with a mean age of 36 (range 23−67) years completed an interview. No participants dropped out during or after the study period. Of these, 12 participants reported having undergone GGAS, 16 were on hormone therapy, (eg, estradiol or anti-androgens), and 7 reported both having undergone GGAS and remained on hormone therapy. Intercoder reliability analysis revealed near-perfect agreement between coders (mean κ = 0.99; range κ = 0.71−1.00). This result was supported by percentage of agreement analysis, which yielded a mean of 99.9% (range 95%−100%) agreement of all codes. This indicates that the coding frame allows for communicability across coders. Responses were broadly classified into 3 categories for analysis: genitourinary symptoms, sexual symptoms, and successful relationships with providers. Representative participant responses for each category are exhibited in Table 1.

Genitourinary Symptoms − Participants both with and without a history of hormone therapy or GGAS reported genitourinary symptoms. Common genitourinary issues reported by both groups included urge incontinence, stress incontinence, urinary retention, and recurrent urinary tract and prostate infections. Spraying of urine, dysuria, and varicoceles were also noted. Several patients were frustrated that they had to learn about urinary side effects from hormone therapy (ie, spironolactone) through their own research and experience rather than through education from a provider. Participants who had undergone gender-reaffirming surgical intervention reported urethral strictures and external scar tissue restricting urine outflow, loss of sensation, and chronic pain in the genital region as post-procedure symptoms.

Sexual Symptoms − Participants both with and without a history of hormone therapy or GGAS reported sexual symptoms. Respondents described both their penis or vagina as being important for sexual function. Most participants, regardless of whether treated with hormone therapy, reported symptoms of lowered libido, anorgasmia, and erectile dysfunction. Pain in the genital and perineal region during sexual encounters and delayed ejaculation were common issues encountered by participants who did undergo hormone therapy or GGAS. In addition, several participants reported seeking psychological care due to distress from inadequate sexual performances.

Successful Relationships with Providers − Participants described the characteristics of a productive provider-patient relationship when visiting providers for genitourinary and sexual symptoms. It was detailed how a single provider may not encompass and treat all conditions a patient may experience, and thus additional ancillary care may be needed as a holistic approach to treatment. For example, although one patient described a strong relationship with their urologist with regards to their GGAS and hormone therapy, they described the need for physical therapy to strengthen pelvic floor function. Patients also valued providers who had expertise and additional training specifically in the care of TGNB patients, as they reported lower rates of misgendering and discrimination in these instances. They stated that seeing TGNB knowledgeable physicians encouraged them to speak more about their genitourinary and sexual symptoms. Some participants pointed to a lack of provider knowledge and poor provider-patient communication in their care as a reason for avoidance of care.

DISCUSSION

As the number of TGNB individuals presenting as patients continues to increase, providers will benefit from an improved understanding of the bothersome genitourinary and sexual symptoms that TGNB may present with. Prior investigations have revealed that providers lack sufficient training, specifically with regards to these domains.[3] In this study, transfeminine individuals detailed many genitourinary and sexual symptoms, including sequelae that present after hormone therapy and/or GGAS. These participants also confirmed the conclusions of the literature, stating that poor provider understanding of these urological problems and communicative barriers play a part in some reluctance to seek treatment.

For proper education and subsequent clinical treatment of common genitourinary and sexual symptoms experienced by the TGNB population, medical providers will benefit from listening to members of said population with regards to the issues they most commonly face. Some of these symptoms may be a result of hormone therapy or GGAS, while other issues may persist regardless of treatment status. It is important that urologists recognize that transfeminine individuals do not always present requesting or have even undergone urology-related transition care. Many individuals seek care from urologists for routine urological issues such as, urological cancer screening and interventions, urolithiasis, voiding dysfunction, and erectile dysfunction.

With regards to genitourinary symptoms specifically, various forms of incontinence and retention, along with variations in one's urine stream with regards to force and spray were the main issues faced by respondents regardless of their intervention status. One participant stated, "I will not be able to hold when I need to pee, and then after I pee, I'll sit there for a few minutes. I'll think it's completely done, but inevitably, after I stand up, there's still something that comes out, and it causes some minor problems. I

Table 1. Representative participant responses.

Genitourinary Symptoms	• "When I take [spironolactone], I know that I need to pee a lot more and my like retention is like not as good and you're getting up in the middle of the night to go to the restroom." • "I was saying about the. . .urine being stuck in the urethra and no matter how much you pee or how much you drink water, it's never going to go away. So you always have the feeling to pee and just forcing you know or drinking more water, it just makes the urge really more irritating." • "I will not be able to hold when I need to pee, and then after I pee, I'll sit there for a few minutes. I'll think it's completely done, but inevitably, after I stand up, there's still something that comes out, and it causes some minor problems. I haven't really spoken to anybody about it."
Sexual Symptoms	• "My erection has been softer since I've been on hormones and since the orchiectomy I've noticed a lot of pain at the shaft, the base of the shaft. . .I feel like the scar tissue pain." • "Since transitioning I have been pretty sexually inactive. Because estrogen has killed my libido." • "I've had a history of dealing with hemorrhoids and if I have an anal fissure that's come and go, but since the surgery, it's been quite consistent that after sex I'll have. . .terrible, terrible hemorrhoids and fissures flare up afterwards." • "I feel really. . .inadequate. . .we used to have sex a lot. . .in the beginning stages of my transitioning and it just kind of has fizzled, and I think that's just been a little disappointing, for me especially because. . .I don't know what to do." • "Since I had my gender confirmation surgery, I guess it's because of the healing process that it's not over yet. I've had some pain when muscles tense and when I'm aroused. So, it has been, I have to say that it has been uncomfortable."
Successful Relationships with Providers	• "The care provider sort of admitted that. . .they weren't an expert on this and that they weren't totally sure that what they were saying was true. . .it was nice that they admitted that, but was you know just not very like encouraging." • "Most people don't know the least bit how to treat us. They seem to think that because I'm trans a sinus infection is different in me than it is in somebody else. If I wind up talking to them at all about what the surgeries I've had most of them just have no clue about anything to do with any of it." • "It's probably been a decade since I've seen a gynecologist because I don't know any gynecologists with expertise in dealing with trans women. The last time I went to a gynecologist he went down with a speculum, took a look at me, and said everything looked normal, and took a swab to send off for a pap smear. I had to tell him that I was postop trans sexual, and that I don't have a cervix." • "Even at places that specialize in trans care, they simply don't know what's going to happen and they're still learning. I feel like I've been asked a lot and it's great that again, they trust me, in terms of how to handle my HRT therapy, but they don't really have answers in terms of what's going to work."

haven't really spoken to anybody about it." Prior studies have detailed how speaking about these issues may be a sensitive topic, and that providers must be gentle when initiating a conversation.[24] Furthermore, a subset of these urinary symptoms may be explained by obstacles faced by patients in a social setting. Published literature has found that avoidance of gendered public restrooms due to feelings of discrimination may cause subjective reports of "weak bladders."[21]

Genital pain and urethral scarring were also commonly reported urological issues encountered by transfeminine individuals who pursued GGAS. With surgical interventions such as phalloplasty and vaginoplasty carrying complication rates up to 51% and 20%−70%, respectively, surgeons will benefit from surgery study to lower the rates of complications.[25,26] Rather than allowing patients to dismiss these symptoms as a risk of GGAS, further studies into the mechanics and techniques for such procedures will better serve the population. This can only happen when patients feel free to openly discuss their symptoms. The Transgender and Non-Binary − Allied Research Collective (TRANS-ARC), led by advocates, trans community members, researchers, and clinicians, is leading an initiative to learn directly from stakeholders on how to improve surgical care and outcomes.[27]

When analyzing sexual symptoms experienced by respondents, lowered libido and pain during sexual intercourse were the most common symptoms experienced. Although published literature exists to support the incidence of lowered levels of sexual desire among individuals that identify as transfeminine, many of the interviewee's phrased their realization of this symptom as something not clearly detailed to them.[28-30] Members of the transfeminine population may perceive deterioration in sexual function as an eventuality rather than a treatable condition.[6] Providers also need to recognize that patients may remain interested in engaging in sexual activity with their natal anatomy despite identifying as transfeminine. One participant stated, "My erection has been softer since I've been on hormones" while another reported "Since transitioning I have been pretty sexually inactive. Because estrogen has killed my libido." Other symptoms like dyspareunia experienced by respondents are consistent with documented literature and require further clinical work-up by the provider to develop a personalized treatment plan.[31,32]

A strong patient-provider relationship was often quoted to be of great importance when addressing the genitourinary and sexual symptoms experienced by respondents. This is consistent with prior literature, which details how experiences of misgendering, the need to educate physicians on patient experiences, and the degree of compassion expressed by a urologist were all factors that contributed to the success of seeking care by transfeminine patients.[33] While compassion is imperative, knowledge is equally important. One participant stated, "the care provider sort of admitted that. . .they weren't an expert on this and that they weren't totally sure that what they were saying was true. . .it was nice that they admitted that, but was you know just not very like encouraging." Additionally, the claim by some respondents stating that more individuals would seek care for their genitourinary and sexual symptoms given access to more culturally competent physicians is supported by studies showing the same.[34] This supports the possibility that rather than solely educating future clinicians about the clinical signs and symptoms important to this population, the medical community should embrace further teachings regarding proper communication skills towards the transfeminine in particular as well in an effort to increase trust in health care.[35]

Our study should be interpreted in the context of several limitations. TGNB stakeholders were not involved in the study design or interview guide development. Therefore, important questions and issues relevant to the community may have been overlooked. However, a qualitative approach and open-ended questions were utilized to generate a range of responses and perspectives through conversation to capture the experiences of the participants instead of quantifiable data. We have developed a questionnaire based on these inputs from stakeholders which we will utilize to quantify symptoms in a future study. Findings are not applicable to all TGNB people since participants were limited to transfeminine adults only. Recruitment was limited by the sensitive nature of the topic and hard-to-reach populations and relied on convenience through flyers and a chain-referral sampling approach from the general community and clinic setting. Despite these limitations, we have achieved the intent of the study, to shed light on the experiences of this demographic and open the door for quantifiable and generalizable studies in the future.

CONCLUSION

Transfeminine individuals experience a wide array of genitourinary and sexual symptoms both similar and different to their cis gender counterparts. Shedding light on a representation of common symptoms may foster awareness among providers and better care for this patient population. We hope that this study can provide an education and understanding of the spectrum of symptoms that transfeminine individuals may experience, regardless of medical or surgical therapy.

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STATEMENT OF AUTHORSHIP

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APPENDIX 1: INTERVIEW GUIDE

A Qualitative Study of the Transgender Patient Experience in the Urology Setting

My name is Sabina Spigner and I am a research assistant working at Thomas Jefferson University with Dr. Paul Chung who is a urologist who deals with the urinary system. We are speaking to you today because we are trying to identify barriers to care for transgender women. We are interested in gaining a better understanding of your experiences and thoughts about health care, in particular with respects to urology.

There are no right or wrong answers because everyone has different ideas and experiences. We are interested in the full range of experiences, so please share your honest point of view. We are here to learn. Is this still a good time to talk? This is going to take between 30 and 50 minutes - do you have that time?

Your participation in this study is voluntary and you can stop our conversation at any time. Your name will not be connected to anything we discuss today. With your permission I will record our conversation, the recording will be transcribed and after that the recording will be deleted. No one knows that you volunteered to talk to me today and I'm not going to reveal your name. Do you have any questions?

Are you ready to begin? Do I have your permission to turn on the recorder?

Ask demographics: Age, identity, pronouns, surgery

(i) Take a minute to think about your past health care visits.
   a) When thinking about these visits, what are some things that went well?
   b) What are somethings that were challenging?
   c) What is important to you in a health care visit and in a medical provider?
   d) What makes a good health care visit and provider to you?
   e) How often have these expectations been met?

(ii) Some people report they may have urinary issues. For example: going too frequently, weak stream, and urinary tract infection are just a few. Have you had any bothersome urinary issues?
   a) Are you satisfied with your urinary abilities as they are now?
   b) Have you ever spoken to a doctor about these issues?
      (i) No → Did you want to? What prevented you from reaching out?
      (ii) Yes → Can we talk about what that experience was like?

(iii) May I ask you some questions about your sexual experiences with others or by yourself? What is important for you sexually?
   a) Some people report having sexual problems. For example: erectile or vaginal function issues, pain with sexual activity, or STIs. Have you had any issues with your sexual ability?
      (i) Pain with sexual activity → Have you met with anyone to help with the pain like a pelvic floor therapist?
      (ii) Are you satisfied with your sexual ability/function?
   b) Have you ever spoken to a doctor about this?
      (i) No → Did you want to? What prevented you from reaching out?
      (ii) Yes → Can we talk about what that experience was like?
      (iii) Is there anything else regarding your health care experiences/urological care that you would like to share before we move on?

(iv) Are there any other things that we might have missed that would be important to include about your health care experiences? Are there any other questions or comments?

Thank you for your time, this concludes our interview. I am now going to turn off the recorder.

APPENDIX 2: CODE BOOK

A Qualitative Study of the Transgender Patient Experience in the Urology Setting

No.	Code	Definition
1	Positive Experience with Provider	Use this code when respondent describes a positive experience with a health provider.
2	Negative Experience with Provider	Use this code when respondent describes a negative experience with a health provider.
3	Provider attitude	Use this code when respondent comments about a provider's positive or negative attitude towards them during a medical encounter.
4	Patient provider communication	Use this code when respondent describes positive or negative experiences communicating with providers or the health clinic office. Includes conversations re: identity disclosure. Excludes provider attitude.
5	Patient provider trust	Use this code when the respondent describes their trust in their provider, in a positive or negative way.
6	Provider medical knowledge	Use this code when the respondent discusses provider's medical knowledge related to trans-health. Include both negative and positive reports.
7	Provider cultural competency	Use this code when the respondent discusses provider's competency in the social and cultural aspects of the respondent's identity. Include both negative and positive reports.
8	Patient Confidence in Provider	Use this code when the respondent describes either positive or negative confidence in a provider's ability to care for them.
9	Overall clinic experience	Use this code when respondent describes experience engaging with health care staff not including the provider (physicians, NPs, PAs) Include: phone conversations to health care office, staff nurses, etc. Also include any references to the space or resources on site. Excludes experiences of misgendering.
10	Barriers to Care	Use this code when the respondent discusses any barriers access to care. Including, finances, difficulties with insurance, geographical or transportation issues, patient wellness, and any reason given by the respondent delaying or not seeking care. Excludes anxiety and prior negative experiences.
11	Patient provider priorities	Use this code when the respondent reports a mismatch when it comes to what the patient wants as the outcome of health management versus what the physician wants. Includes medication, surgery, and advice.
12	Patient medical knowledge	Use this code when the respondent discusses or refers to their medical knowledge or information obtained from physicians, including unexpected side effects or outcomes. Includes situations where patients were confused about medication use or purpose.
13	Conflicts between treatments/priorities and their side effects	Use this code when the respondent expresses discordance between treatment or course of action and desires of the respondent. Includes medication and side effects.
14	Finding a "safe" provider and space	Use this code when respondent describes how they find a provider and/or health care space wherein they feel "safe". Excludes mention of medical knowledge level of provider.
15	Finding "knowledgeable" provider	Use this code when respondent discusses finding a provider with the knowledge and/or training related to a specific medical issue. Includes gender affirmation surgeries and therapies.
16	Educating the Medical Office	Use this code when the participant reports feeling as if they had to educate the medical office (PCP, nurse, front desk, etc) on the medical and social context related to their gender identity (this would include justifying treatment to provider). Code can be used when the respondent reports not feeling like they have to educate the medical office as well.
17	Misgendered in health care	Use this code when the respondent reports being misgendered by any member of the health care staff at a hospital / clinic, or with the insurance company. Excludes instances that the patient may feel misgendered in social settings. Includes situations where the respondent's sexual partner is misgendered as well, either in person or in conversation.
18	Prior traumatic health care experience	Use this code with the respondent reports a traumatic health care experience. Excludes experiences that are not in a health care setting.
19	Prior traumatic experience general	Use this code when the respondent reports trauma related to their identity (ie, rape, family issues). Excludes experiences of trauma in a health care setting.
20	Health care anxiety	Use this code when respondent reports feelings of anxiety or stress when seeing a health care provider. Includes patient -provider experience.
21	Care seeking	Use this code when respondent discusses symptoms or conditions as they relate to when and why they seek or do not seek care. Including not feeling the need to seek care generally. Excludes mentions of logistical barriers.
22	Urinary symptoms treatment	Use this code when the respondent reports urinary symptoms directly related to medical and surgical treatment.
23	Urinary symptoms other	Use this code when the respondent reports other urinary symptoms not directly related to medical and surgical treatment.
24	Sexual symptoms treatment	Use this code when the respondent reports symptoms with sexual function they believe are related to medical and surgical treatment. Include incidence of STI.
25	Sexual symptoms other	Use this code when the respondent reports other sexual symptoms they believe are not related to medical and surgical treatment. Include incidence of STI.
26	Physical exam	Use this code when the respondent provides positive or negative comments about physical exams.
27	Desired provider and health care visit attributes	Use this code when the respondent discusses what is important to them in a health care provider and visit experience.