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## Unmet Expectations in Healthcare Settings: Experiences of Transgender and Gender Diverse Adults in the Central Great Plains

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**Unmet Expectations in Healthcare Settings:  
Experiences of Transgender and Gender Diverse Adults in the Central Great Plains**

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**Unmet Expectations in Healthcare Settings:  
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**Abstract**

Transgender and gender diverse (TGD) individuals face a long-term, multi-faceted process if they choose to begin a gender affirmation journey. Decisions to go on hormone therapy and/or have a surgical procedure necessitate the TGD individual to set up an appointment with a healthcare provider. However, when TGD patients interact with healthcare practitioners, problems can arise. This article documents and categorizes the types of unmet expectations that are common in the TGD patient-healthcare provider social dynamic in the Central Great Plains of the United States. Utilizing a community-based participatory research model, qualitative in-depth interviews were conducted with 27 TGD individuals about their healthcare experiences. From this, the researchers identified four main themes of unmet expectations: probing, gatekeeping, stigmatizing stance, and misgendering/deadnaming. Steps that can be taken by both the healthcare provider and the TGD individual to have a more successful encounter are discussed.

Individuals who identify as transgender and/or gender diverse (TGD) are people whose gender identity does not fully line up with their biological sex (American Psychological Association, 2014). These individuals face a long-term, multi-faceted process if they choose to begin a gender affirmation journey. Steps in this process can include a shift in preferred pronouns, a legal name change, and altering one's appearance (including clothes, hairstyles, makeup, electrolysis, etc.). Decisions on hormone therapy and surgery are two of the more intensely deliberated steps in this journey because they bring about dramatic changes to the individual's physical body. In order to obtain either of these procedures, the TGD individual must set up an appointment with a healthcare provider (Murjan & T'Sjoen, 2017). However, when TGD individuals interact with healthcare practitioners—including receptionists, nurses, and doctors—problems can arise (Reisner et al., 2018). These problems primarily take place in the form of unmet expectations for the TGD individual. In addition, TGD individuals living in underserved areas (i.e., rural and suburban populations that are not located on the coasts in the U.S.) may be more likely to develop unmet expectations in healthcare settings (Dewey, 2008; Nordmarken & Kelly, 2014; Smalley, Warren, Rickard, & Barefoot, 2018). Therefore, the goal of this study was to document and categorize the types of unmet expectations that are common in the TGD patient-healthcare provider social dynamic in the Central Great Plains of the United States. In-depth interviews were conducted with 27 transgender and gender diverse individuals about their healthcare experiences. From the interviews, the researchers identified four main themes of unmet expectations: probing, gatekeeping, stigmatizing stance, and misgendering/deadnaming.

## **Theoretical Background**

### **Unmet Expectations**

The term “unmet expectations” originates in the organizational behavior literature, and was initially developed to explain employee turnover (Porter & Steers, 1973). It is argued

that unmet expectations generate job dissatisfaction, which in turn produces absenteeism and turnover (Pearson, 1995; Taris, Feij, & Capel, 2006). Today, unmet expectations have been researched in a variety of contexts, including customer satisfaction and consumer behavior (Goles, Rao, Lee, & Warren, 2009), marriage and interpersonal relationships (McMahon, 2015), child adoption and family dynamics (Moyer & Goldberg, 2017), and international diplomatic relations (Seabra, 2014).

Unmet expectations represent a breach of trust between individuals. A common term utilized when unmet expectations occur is “psychological contract violation” (Goles et al., 2009, p. 1). Each individual brings anticipated perceptions to any form of social interaction (Rousseau, 1998). Therefore, unmet expectations occur because the social dynamic did not go as planned for one or both parties. When unmet expectations do occur, the individual usually has some type of emotional response. This can range anywhere from a pleasant surprise to disappointment to significant stress (Moyer & Goldberg, 2017). The individual may also feel a sense of depersonalization (Burke & Greenglass, 1995), since their needs were not met by another.

### **Unmet Expectations in Healthcare Settings**

The variety of social exchanges that occur during a healthcare appointment may also produce unmet expectations for patients and/or practitioners. For example, one common area reported is whether or not the patient perceived that the healthcare provider arrived to the appointment prepared, which was demonstrated by their familiarity with the patient’s health history (Kravitz et al., 1996). Also, the history-taking questions, the physical examination, the administration of diagnostic tests, the prescription of medications, the referral to physician specialists, the delivery of answers to the patient’s symptoms, and the way this information is communicated are all areas where patients experience unmet expectations (Bell, Kravitz, Thom, Krupat, & Azari, 2002; Peck et al., 2004). Finally, once the patient has undergone a

medical procedure or taken a prescription and they still do not feel better, or fully healed from their situation, unmet expectations are sometimes reported (Rivera, Hexem, Womer, Vinelli, & Feudtner, 2013). In the healthcare setting, unmet expectations can create a sense of diminished control for the patient (DeLuca & Lobel, 2014). Research has also shown that unmet expectations in healthcare settings lead to tension in the healthcare provider-patient relationship (Keitz, Stechuchak, Grambow, Koropchak, & Tulsy, 2007) and lower overall patient satisfaction (Jackson & Kroenke, 2001; Bell et al., 2002; Rivera et al., 2013).

Several demographic antecedents may also impact whether or not unmet expectations are more likely to occur during a healthcare appointment. For example, higher rates of unmet expectations are associated with younger patients (Kattari & Hasche, 2016), patients who are an ethnic minority (Haviland, Morales, Dial, & Pincus, 2005), and patients with low socioeconomic status (Thiedke, 2007). In addition, unmet expectations are more likely for patients dealing with a chronic illness, a serious disease, or a new or worsening problem (Kravitz et al., 1996). Patients who suffer from depression and/or anxiety disorders also report higher levels of unmet expectations in healthcare settings (Kroenke, Jackson, & Chamberlin, 1997). The rate of unmet expectations can range anywhere from 8% (Bell et al., 2002) to 60% (Keitz et al., 2007) of patients.

TGD individuals are one group for whom it appears that healthcare providers may not be meeting all of their expectations (Bottorff, Oliffe, & Kelly, 2012; Ross, Scholl, & Bell, 2014). As documented in a large national survey, one-third of TGD individuals reported at least one negative experience with a healthcare provider in the past year (National Center for Transgender Equality, 2015). There were higher rates of unmet expectations for transgender men and TGD people of color. Also, many of TGD individuals reported that these negative experiences lead them to avoid seeking further healthcare services (Hughto, Pachankis, & Reisner, 2018). Issues with healthcare providers and TGD patients are not just localized to

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those seeking gender affirmation health services (Stroumsa, Shires, Richardson, Jaffee, & Woodford, 2019). Evidence of discriminatory treatment has been documented for TGD individuals seeking routine healthcare procedures as well (Peitzmeier et al., 2017).

Of course, not all TGD individuals report negative experiences with healthcare providers. Affirming healthcare providers do exist, and they are accessible to the TGD population (Klein, Narasimhan, & Safer, 2018). However, the reports of negative experiences for TGD patients are numerous (Hughto, Reisner, & Pachankis, 2015). This may be especially true for TGD individuals living in underserved areas (Smalley et al., 2018), where physicians are not as well versed on the subject, and they have not had as much experience in treating TGD patients (Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012). Therefore, the primary purpose of this study was to document and categorize the types of negative experiences that are common in the TGD patient-healthcare provider social dynamic in the Central Great Plains of the United States. These social interactions are described from the patient's perspective, and they are based on prior real-life encounters with healthcare providers.

### **Methodology**

#### **Study Design**

Interview participants for this study were recruited through a community-based participatory research model. Community-based participatory research (CBPR) is focused on improving the lives of a particular community (Mayan & Daum, 2014). Therefore, research utilizing this method is geared towards identifying a problem facing that community, and then searching for knowledge that can be used to address this problem. Approaches to research that fall under the CBPR umbrella include collaborative research, participatory action research, etc. CBPR partnerships are mutually beneficial for the academic researchers and the community members because this research can help shed light on an important issue

for that community, and the researchers are better able to navigate the community since they have the backing of current group members (Kneipp et al., 2013). In particular to community health issues, CBPR can be especially useful because this approach decenters the authority of the academic researcher. To accomplish this, community members are often involved during the initial discussions of the topic at hand, they give input while the interview protocols are being drafted, and they provide feedback on the interpretation of results (Belone et al., 2016).

The researchers in this study first set up partnerships with local TGD community groups whose members live in suburban and rural settings in the Central Great Plains. First, they made contact with the leaders of these community groups. Then, a local advisory board was set up that consisted of these community leaders. Researchers met with the local advisory board on a semi-annual basis. Some pilot interviews were conducted as the local advisory board was forming, and board members made suggestions on the wording of interview questions before full data collection began. The input from the local community board was also present during the IRB approval process and the NIH grant funding application. Then, during the analysis phase, local community board members made suggestions for the names and descriptions of coded labels, which were incorporated into the reporting of study results. In addition, all of the procedures in this study design were approved by the University of Nebraska-Lincoln Institutional Review Board.

### **Sample**

In-depth interviews were conducted with 27 transgender and gender diverse individuals in order to gain an understanding of their healthcare experiences. The eligibility criteria for participation in this study consisted of individuals who were at least 19 years old (age of majority in Nebraska) and identified as transgender or gender diverse. A combination of convenience sampling and snowball sampling methods were implemented in order to recruit participants (Lincoln & Guba, 1985). The local advisory board helped recruit



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participants by handing out flyers which contained information about the study and contact information for the researchers. These flyers were handed out at area TGD community meetings. The information on these flyers were also posted on local TGD community groups' social media profiles.

Interview participants' ages ranged from 22 to 64, with an average age of 36. Participants in this study described their gender identity in several ways (male, female, male-to-female, female-to-male, non-binary, gender queer, agender, etc.). Broadly, 14 (52%) participants identified as transgender women, 10 (37%) participants identified as transgender men, and three (11%) identified as non-binary. Nearly half of the sample (48%) reported living in a rural area. The majority of participants identified as Caucasian (81%), while one participant identified as African American, one participant identified as Native American, and three participants identified as multiracial (two as Native American and Caucasian; one as Native American, African American, and Caucasian). In terms of education, six participants reported some college experience (22%), two reported obtaining an associate's degree (7%), four reported obtaining a bachelor's degree (15%), three reported obtaining a master's degree (11%), and one reported military training in addition to a high school degree (4%). In terms of marital status, one participant reported being single (4%), six reported being married (22%), and five reported being divorced or legally separated (19%). Seven participants (26%) reported having children. Some of the participants declined to answer one or more of the demographic questions. In particular, education level, marital status, and number of children questions were left blank by several participants.

### **Study Protocol**

Each interview occurred in person and in a private setting (conference room or researcher's office). Most interviews were one-on-one, where the single academic researcher was interviewing a single participant. During the first few interviews, another researcher was

present during the interview, but this person's main role was to observe the interviewer, and provide guidance and feedback to this individual about the interview process, which took place after the formal interview with the research participant had concluded.

The interviews began after the research participant signed an informed consent document. Each interview lasted about one hour, and it was audio recorded with a digital voice recorder. During the interviews, research participants were asked about their experiences in obtaining healthcare, both in relation to their gender affirmation journey, and outside of this process ("Please share with us your own experiences obtaining health care."; "Have these experiences been consistent across your gender journey?"; "If not, what are the differences at different points in your journey?"). These initial questions were meant to capture a range of healthcare experiences, both positive and negative. But then, the challenges TGD individuals faced while trying to obtain healthcare were directly addressed ("What are challenges to accessing health care for you?"; "What are challenges to accessing health care for the transgender and gender non-conforming community?"). Finally, participants filled out a demographic survey, which included open-ended questions on describing their gender identity and their preferred use of pronouns. At the conclusion of the interview, each participant was compensated \$50 for their time.

### **Analysis**

The audio recordings of the interviews were transcribed, and the interview participants were de-identified. The transcripts were then thematically analyzed utilizing Weiss's (1994) four-step method: coding, sorting, local integration, inclusive integration. During the coding stage, Dr. Meyer read through all of the interview transcripts and generated thematic categories. These thematic categories are a level of abstraction, and multiple examples must occur in the data, across participants, for any theme to be recorded by the researchers. Next, during the sorting stage, Dr. Meyer made a copy of the coded

transcripts, and then sorted interview excerpts into the themed categories. It is common for a single interview excerpt to be labeled with multiple codes. Therefore, several copies of that excerpt are generated, and one excerpt is placed into each thematic category. The third stage of analysis is local integration, and this is when the researcher examined each thematic category and looked for consistency and variation. Finally, the last stage is inclusive integration. This is when the researcher looked across themes and interpreted the data in a more holistic manner.

### **Results**

A variety of TGD healthcare experiences were reported in the interviews for this study. They ranged from very negative to neutral to positive. Emergent themes from within the positive healthcare experience included healthcare providers who offered vocal support, validation, and compassion to the TGD individual upon the revelation of their TGD status.

For example:

“I told her I was trans, so she immediately starting referring to me as [preferred name]. She had them put it as [preferred name]...so when I came I could say, ‘Hey, I am [preferred name] and I am here to see her.’ She is also really validating.”

“My most recent counselor that I had, a psychologist in [city] had very little experience with transgendered individuals when I went and saw him. But he just did a lot of research and was like, ‘We are going to figure this out together,’ and has been really, really great and helpful and understanding.”

Other participants noted that signage markers which indicated that the healthcare provider was supportive of LGBT communities made them feel like they were meeting with a social ally.

However, these positive experiences were heavily outweighed by the number of negative healthcare experiences discussed by interview participants in this study. Therefore, the results presented here primarily focus on the negative experiences provided by interview participants. These negative experiences translate into unmet expectations in the TGD patient-healthcare provider social dynamic. Reporting this information may provide insight

for healthcare practitioners on how to create more successful encounters with their TGD patients.

Every participant in this study reported at least one negative experience while trying to obtain some form of healthcare. These experiences included healthcare appointments set up specifically to address TGD-related issues, while others were simply check-ups or appointments to address a health issue unrelated to their TGD identities. The most prominent and vividly described negative scenarios took place in the patient rooms, often while interacting with the doctor directly. Others negative experiences occurred while the TGD individual was interacting with nurses, receptionists, pharmacists, etc. During each negative encounter, the psychological contract between patient and healthcare provider was disrupted, and therefore unmet expectations were generated for the TGD individual. The TGD individual expected the social interaction to occur in one manner, but then was surprised and/or disappointed to experience a dramatically different social exchange. The four main categories of unmet expectations for TGD patients that will be presented here are: 1) probing, 2) gatekeeping, 3) stigmatizing stance, and 4) misgendering and/or deadnaming.

### **Probing**

The first theme of unmet expectations for TGD patients is probing. With this theme, the TGD individual felt like they were not being treated as a person with a health concern, but rather a specimen being investigated by a scientist. It may be the case that they were the first TGD patient for that particular doctor (Snelgrove et al., 2012). Yet, this patient was made acutely aware of the unusualness of their situation by the healthcare provider in a way that made the TGD individual feel deeply uncomfortable. For example:

“The doctor starts asking [me] invasive questions about being transgender...”

“They just don’t know how to ask questions. It’s understandable that they need to ask things and make sure you are healthy...but there is a very fine line of being so blunt that you push away your client.”

“Every time I go into [doctor’s office], when they are trying to check their boxes they always have to say, ‘So you are technically a woman who sleeps with women?’ and I am like, ‘No. I have a vagina if that’s what you mean, so sure.’ It’s a little weird. I don’t identify as a woman. So no, that’s not right at all. I understand that it’s just the way their questionnaire is worded, and they have to go through it for legal reasons, or whatever. It just is a little off-putting.”

Doctors are met with patients with new and different health conditions all of the time.

However, most individuals are not made hyper-aware of this singularity. Therefore, the default expectation is that the TGD patient would be treated like any other patient at a doctor’s office for a health-related issue, and the unmet expectation occurs when this individual does not feel like they are being treated like any other patient. Three sub-codes emerged under the probing theme, and they detail how the TGD patient is made to feel uncomfortable in the social exchange and leave the doctor’s office with unmet expectations. The sub-themes are: 1) asking inappropriate questions, 2) expanding sphere of focus, and 3) requesting to see genitals/touch body parts.

*Asking inappropriate questions.* One common experience that TGD participants reported as making them feel singled out is when they were asked questions during their healthcare visit that came across as tactless, inconsiderate, or callous. These are questions that do not normally come up during a healthcare visit. The healthcare provider has gone off script and is just inquiring about the TGD experience when it is unrelated to that particular healthcare appointment. These questions are often asked merely for the healthcare practitioner’s own curiosity, but they may come across as inappropriate when being asked during a healthcare appointment. For example, one non-binary person stated:

“When I was pregnant with my second kid I was carrying a child for myself and my partner, who is female...and she came in with me and the midwife like looked at her and looked at me and was like, ‘Well, this isn’t your baby right?’ to my partner. It was just really awkward, and then I got a lot of questions like that afterwards, about how we got pregnant and how I conceived. I guess your midwife needs to know those questions, but it just felt really degrading and uncomfortable.”

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This individual was already pregnant, and accordingly was not seeking fertility services in order to get pregnant. Therefore, the focus of the healthcare appointment was to check on the status of the baby and the pregnant individual. Yet the healthcare practitioner proceeded to intersperse the conversation with probing questions about the TGD patient's personal life. As stated in the quote, these questions made this person feel very uncomfortable.

The following is another example of an inappropriate question being asked by a healthcare provider to a TGD patient:

“I went for an employee physical once and the nurse was really great, the people at the counter were really nice, and then when the doctor came in. I was only with this doctor for maybe two minutes, and she was misgendering and talking about...I think she said, ‘But you are really a man, aren't you though?’ and I am like, ‘Well, down there yeah.’”

This interview participant is a transgender woman, and during her healthcare appointment the receptionist and the nurse treated her the same as they treated all of their other patients.

However, when the doctor came in and asked this patient her gender, and was told it was female, the doctor tried to correct her and label her as male. This doctor may have been trying to understand her patient's situation, but she was going about it in an inappropriate manner.

In this case, the doctor even implied that the patient was being deceitful. Asking the TGD individual if she was “really a man” put her in a defensive posture because this question implied that she was being untruthful and/or unintelligent about her own health situation.

As research has shown, one set of unmet expectations that are common during the social interaction taking place in healthcare settings is when the patient perceives that the healthcare provider is unfamiliar with their health history (Kravitz et al., 1996; Bell et al., 2002). When a patient meets with a new healthcare provider for the first time, they are often asked numerous questions in order for the healthcare provider to become familiar with that patient's past health issues and their current state of health. However, when the patient returns for follow-up appointments and they still feel like the healthcare provider is arriving

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unprepared by repeatedly asking the same questions over and over again, then this creates unmet expectations for the patient, and ultimately generates tension in the patient-provider social dynamic (Keitz et al., 2007). This next example showcases the frustration one TGD individual felt when she had to explain her TGD identity each time she met with the staff of her healthcare provider:

“I have had to explain in detail to several nurses why I am not having my period because they ask you, ‘When was your last period?’ ‘I don’t have one.’ ‘Why?’ ‘Transgender.’ ‘What’s that mean?’ ‘Can you just check me in?’”

The nurses at this women’s health clinic are at first just asking standard questions. Women are frequently asked to report the first day of their last period during healthcare appointments. However, this patient is a transgender woman, and therefore she does not get periods. But since she is on hormones and has had gender affirmation surgery, she needs to obtain regular healthcare checkups from a gynecologist. Nonetheless, every time she has arrived at this office, she has had to explain her TGD status to the staff, nurses, and physicians.

*Expanding sphere of focus.* In addition to asking inappropriate questions, TGD individuals also provided examples where the healthcare provider started to inquire about areas outside of their expertise. One common occurrence is when a TGD patient went to a healthcare provider in order to obtain hormone therapy to aid in their gender affirmation journey, but was then asked to explain their sexual orientation. For example:

“When I do go to the doctor’s, a lot actually are like, ‘Ok, so you are transitioning from male to female, so you must be interested in boys?’ And when you say you are not, unfortunately with a lot of doctors that are not more specialized, they are like, it blows their mind. They are not sure what to do. Then they will question, ‘Well, why are you transitioning?’ Unfortunately it gets into that awkward conversation of the sexuality, gender identity, and the lot. Some doctors just don’t realize that there is that difference there...it can cause a hiccup which can lead to some not-so-comfortable conversations.”

Research has shown that the disclosing of one’s sexual orientation during healthcare appointments can be beneficial because this information offers a more holistic view of the individual (Willes & Allen, 2014). However, the disclosure of this information should be at

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the TGD individual's discretion, and not prompted by the healthcare provider (Nordmarken & Kelly, 2014).

In another example of a healthcare practitioner expanding the sphere of focus, a transgender woman described the process by which she legally changed her name and subsequently updated her insurance information. This process went smoothly, as was her notification of this change with the staff at her dentist's office. However, she had a different encounter with the dentist herself:

“I am sitting in the chair and she [the dentist] just starts kind of freaking out and was super-excited and curious. It came from a good place, but she was like, ‘So how do you even come up with a new name?’ and asking me these questions super-loud. I felt like I was outed to everybody, and they couldn't even see me at the time. But to avoid embarrassment, it would be nice if all medical professionals would get a small crash course at least.”

When this individual legally changed her name, she notified her healthcare providers of the change. As she stated, the billing office calmly updated this information. But when the dentist arrived, she proceeded to loudly inquire about the TGD individual's gender affirmation journey without respect to her privacy. This social exchange took place in an open space, and therefore other patients and staff members overheard their conversation. As the interview participant noted, this experience left her feeling very exposed and embarrassed. The purpose of her healthcare appointment was a routine teeth cleaning and check-up, but her exchange with the healthcare provider expanded beyond the range of expected communications between dentist and patient.

It should be noted that it does not matter that the dentist was excited and seemed to be accepting of this TGD individual. The questions she asked put her TGD patient in an awkward position. As research has shown, unmet expectations can occur for any patient if they feel like they are not being asked the right questions (Kravitz et al., 1996; Bell et al., 2002). For TGD patients, questions from healthcare providers that focus on elements of the



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TGD experience outside of the healthcare realm can be perceived as psychological trust violations, and they are likely to generate unmet expectations.

*Requesting to see genitals/touch body parts.* The last probing sub-theme is arguably the most distressing to the TGD patient. In these situations, a healthcare provider requests to see and/or touch parts of the TGD individual's body. Similar to the other two probing sub-themes, these inquiries are not seen as being directly related to the purpose of the healthcare appointment. In one instance provided by a transgender man, he set up an appointment with an endocrinologist, but was inadvertently scheduled with an urologist. When this mistake was realized by the healthcare providers, the TGD patient should have been directed to a scheduler in order to set up a meeting with the right specialist. Instead, the urologist requested access to observe the TGD individual's genitalia:

“She was really into my genitalia in a weird way, not inappropriate, not sexual at all...she was like, ‘Sorry you are in the wrong department, but while we are here...’ and asked me a bunch of questions. I said that I had lower surgery, and she basically tapped her hands on her knees like, ‘Let’s see it.’ I was thrown off because she was a doctor. She made it out like she was just checking because I had said I had revisions. They were revisions, they weren’t fixing anything. They were just, that’s the way they do the surgery. She said she just wanted to make sure when they did the revisions that there was no scarring. There are a ton of scars. I have got scars everywhere...I felt slightly violated. It was really weird. I was like, ‘What the hell is this about? I wasn't supposed to be there in the first place, and now you want to see my junk?’ Had she said, ‘I have never seen a phalloplasty,’ which is probably the case, I would have happily showed her. I have shown a lot of people and a lot of trans guys, just because they need to know these things, realize there are options. But it was just so bizarre...”

The unmet expectations for the TGD individual in this situation were substantial. Not only was he sent to the wrong specialist, but that healthcare practitioner proceeded to ask inappropriate questions, expand her sphere of focus, and then requested to see his genitals. These actions were clearly separate from the purpose of this patient's visit, which was to discuss hormone treatment. Instead, he was subjected to a physical examination based primarily on the healthcare practitioner's own curiosity.

Other examples included transgender women who reported healthcare providers physically examining their augmented breasts, with the explanation given that the healthcare provider wanted to compare them to cisgender women's breasts. As research has shown, the physical examination during a healthcare appointment is a common area for unmet expectations to form (Kravitz et al., 1996; Bell et al., 2002). This is often because the patient is in a very vulnerable position. Someone is looking at and/or touching their body, and sometimes the healthcare practitioner is looking at and touching very private parts of the body that the individual would not normally expose in public settings. Because of the assumed authority and clear power stance that exists in the doctor-patient relationship, these psychological contract violations can cause significant stress for TGD individual. The diminished control the TGD patient feels over their body during a physical examination at a healthcare office can be anxiety-inducing, and may even prevent that person from seeking other medical services in the future (DeLuca & Lobel, 2014). Many of the interview participants in this study reported feeling that the physical examinations they underwent were not essential to the purpose of their healthcare visit. Therefore, they felt a breach of trust, even if those instances came about due to the healthcare practitioner's interest instead of malice.

### **Gatekeeping**

Another major theme of unmet expectations for TGD patients is experiencing gatekeeping, where the healthcare practitioner imposes barriers to treatment. These barriers can include time, documentation, referral letters, or merely implementing an artificial layer of incrementalism. Regardless of the barrier, the patient walks away from these healthcare experiences feeling that their health issue was not addressed, and therefore that they are still in a state of deficiency. For example:

“I went an endocrinologist at the medical place in [city], and I didn't have a great experience there. They are very, very cautious to the point where I was 28 years old, I

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knew what I wanted, ‘I am smart, I am capable, I can do what I want with my body so let me do it.’ They made me wait for months and had me go through multiple blood tests. Then they started me on a quarter of the normal dose, and said they were going to keep me there for six months. I just couldn’t do it anymore because I was so miserable. So I switched doctors to a primary care here in [another city] and he was like, ‘Yeah, that dose, I give that dose to housewives that want to have sex with their husbands more. That’s not a dose that is going to do anything.’ So he upped me quickly, and I felt a lot better. I don’t have much tolerance for medical care that doesn’t work for me anymore. I have had a good experience with my primary care doctor. He has taken good care of me.”

This transgender man was delayed in his request to begin testosterone hormone therapy with time requirements and blood tests. Then, once he was administered the hormone, it was at such a low dose that he still felt that his request wasn’t fulfilled, and he therefore experienced unmet expectations. However, by switching healthcare providers, this individual was able to get his needs met. In this particular case, incrementalism due to excessive caution led to a negative experience.

Other transgender women described similar incrementalism from healthcare providers. In one instance, the healthcare provider told a TGD patient, “I think we should wait another two months or so before we start this, just to make sure.” At the end of the two month waiting period, the doctor added another layer to the treatment protocol, starting the TGD individual on testosterone blockers, but holding off on administering estrogen. The interview participant reported that the healthcare provider stated that he felt “comfortable starting you on that, at least today.” After another two months, the healthcare provider conducted blood work, and he started the TGD patient on a low dose of estrogen. Again, the doctor stated that he now felt “comfortable” with that step. At each stage of the process, this individual felt that the healthcare provider moved on to the next stage when he felt comfortable, instead of when the TGD patient felt comfortable, transposing the positionality in the relationship. The interview participant also stated that the healthcare provider did not provide any evidence that this incrementalism was medically necessary. Incrementalism is a gatekeeping mechanism that removes the power of the TGD patient in a seemingly innocuous

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way. The healthcare provider disregards the patient's needs and comfort, and sets the pace to deliver health services without the input of the patient.

Gatekeeping can happen to TGD patients across the spectrum of services available for gender affirmation journeys. One transgender man detailed his experience with artificial regulations while trying to obtain top surgery:

“When I finally approached the right surgeon, I didn't go meet with him. I actually called the office and said, ‘Look, I know I came in about a breast reduction, but that is not what I want. What I really want is top surgery because I am trans,’ and the nurse was like, ‘No problem, we got you.’ She was awesome. But she talked to the doctor, and the doctor said, ‘We want to wait a year.’ My heart sank...I even directly asked him, ‘Why do I have to wait a year?’ and he really didn't give me a clear answer. He was like, ‘Part of it was we want to be sure that you're sure.’ ‘Well I am pretty damn sure.’”

This TGD individual eventually negotiated with his surgeon to schedule the surgery after a six-month waiting period (instead of a year), but not without much strife and persistence. The individual stated that he was able to wrangle support for an earlier surgery date by getting his endocrinologist and his mental healthcare provider to lobby on his behalf to the surgeon. While this speaks volumes about this particular individual's acumen in dealing with the healthcare system, it is certainly not a replicable strategy for every TGD patient seeking surgery services. This individual also summarized the dangers of this type of gatekeeping thusly: “I think that those requirements, I think in some cases it can be detrimental to the mental health of the person.” In other words, when healthcare providers create false steps in the healthcare process, they may actually be causing harm to the TGD patient.

As the literature shows, other groups of healthcare patients experience unmet expectations when it comes to gatekeeping. These groups often include young individuals (Kattari & Hasche, 2016), those with low socioeconomic status, those who are an ethnic minority (Haviland et al., 2005), etc. Sometimes the gatekeeping activities of the healthcare provider may be perceived as discrimination by patients because they do not feel like they are

being treated the same way as other patients. As reported here, this may be especially true for TGD patients when it comes to obtaining hormone therapy and surgery services.

### **Stigmatizing Stance**

The third major theme of unmet expectations for TGD patients in healthcare settings is a stigmatizing stance from the healthcare practitioner. In these scenarios, interview participants reported feeling unwelcome, like a strange person, or just a general sense of otherness from their interaction with a healthcare provider. For example, one transgender man shared that he went to the hospital for a broken arm. While waiting for the results of his x-rays, he overheard the doctor and nurse discuss his TGD status, which he surmised was known due to the x-rays being labeled under his birth name. This is how he described the exchange between the two providers:

“He was like, ‘Are you serious?’ and the nurse was like, ‘Yeah she’s, I mean he’s...,’ and they were laughing about it. I felt like, ‘I can hear you. You left the door open, and you are ten feet away from me.’ That is not only horrible to me, but unprofessional. It just shouldn’t happen. When they came back in the room, they didn’t say anything but I knew by the look in their eyes, especially his. It was like, ‘What am I dealing with?’ I was thinking, ‘You are dealing with a person, and what I need is a doctor.’ I need somebody to just be like, ‘You’ve got a problem, and I am going to fix it.’”

These two healthcare providers are signaling to this TGD individual that he is not welcome at their establishment. The TGD patient was able to receive his care in a timely manner, but the process made him uncomfortable and uneasy, especially when he heard them laughing about him in the hallway. These providers probably did not intend for this conversation to be overheard, but one could argue that this conversation should never have happened. Overheard or unheard, this type of behavior violates the Hippocratic Oath of doing no harm. Plus, by engaging in this type of demeaning conversation with his staff, the doctor signaled to his staff that this type of discrimination is acceptable.

In another example, one transgender woman reported a doctor asking her: “Are you one of them sex change things?” Clearly, this comment is stigmatizing, as it reduces the TGD

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patient to a “thing.” This participant further explained that during the physical examination, “It was like he was dissecting an alien fetus or something.” This individual was seeking care for a staph infection, and she could not disengage from the hostile situation due to the serious nature of her health condition. While it is fairly obvious that these types of comments are stigmatizing, they still happen to TGD individuals, and they do create barriers to future care (Nadal, Skolnik, & Wong, 2012; Reisner, White, Bradford, & Mimiaga, 2014; Hughto, et al., 2015). In fact, research has shown that stigma-related stress can produce future negative health issues and/or exacerbate existing physical and mental health conditions (Strongin, Silva, & Smiley, 2014).

Other TGD participants noted more subtle issues with stigmatization, including instances where healthcare practitioners talked to them about figures in popular culture (such as Caitlyn Jenner). While these comments are not interpreted as injurious, they still changed the valence of the social exchange from welcoming to uneasiness. Being constantly reminded of one’s TGD status signals to TGD patients that they are different from others (Nordmarken & Kelly, 2014). It is a form of social negation, and comments like these may still generate unmet expectations for the TGD individual.

### **Misgendering and Deadnaming**

Finally, the last major theme of unmet expectations for TGD patients is the process of misgendering and/or deadnaming. Misgendering is when the healthcare provider consistently uses the sociological identifier “him” or “her” that is attached to the patient’s sex assigned at birth after this individual has requested that the healthcare practitioner use the pronouns associated with their gender identity. For example:

“I was in a car accident a couple of years ago. My daughter was with me. My driver’s license said ‘male’ and I was on testosterone at the time but they [the paramedics] kept saying ‘she.’ My daughter was sitting in the back of the ambulance and yelled, ‘He is a boy!’ and then they said, “Oh, ok.”

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Deadnaming is when the healthcare practitioner uses the legal name the patient was given at birth, rather than the name that this person has chosen and requested to be used in the future.

As an example:

“I’ve had some trouble with my name in healthcare situations. Even after I changed my name, my gender on my driver’s license, and I told him [an endocrinologist] that my name had changed. The receptionist called to remind me about an appointment, asking for [birth name], and I said, ‘Yeah, it’s [preferred name] now, though,’ and it wasn’t really a big deal to her. But then when I got there for the appointment, the nurse was deadnaming me. The nurse called out from the waiting room, and there were a couple of people in there who hopefully weren’t paying attention.”

Numerous examples of misgendering and deadnaming appeared in the interviews for this study. Participants noted that this type of micro-aggression made them uncomfortable in the healthcare setting, and made them feel unwelcome in general. The healthcare providers engaging in these activities included receptionists, nurses, doctors, pharmacists, and insurance providers. Often, the TGD individual only requested for their first name to be changed. Plus, the legal status of someone’s name did not seem to impact the misgendering and deadnaming activities by healthcare providers. In other words, even after the TGD individual legally changed their name, they still experienced misgendering and deadnaming from others.

### **Discussion**

TGD individuals face numerous challenges while attempting to obtain healthcare. In particular, the interview participants in this study reported unmet expectations in terms of probing questions, requests to see genitals, incremental gatekeeping, overt stigmatization, and intentional misgendering, and/or deadnaming. When these situations occurred, the TGD individual often reported feeling caught off guard, embarrassed, and/or harassed. This is especially true when the TGD individual did not encounter these types of negative social interactions with healthcare providers during appointments that took place before they began their gender affirmation journey. These unmet expectations can be minimized, and steps can

be taken by both the healthcare provider and the TGD individual to have a more successful encounter.

One recommendation for healthcare providers is that they communicate to TGD patients that they are familiar with their TGD status. In other words, they should not make the TGD patient have to explain their situation over and over again. One simple way to do this is to make a permanent note in that patient's files that they are TGD. Protocols also need to be set up in healthcare offices that demonstrate how to adjust intake forms and queries for TGD patients. As an example discussed in the results demonstrated, if a patient is a transgender woman, she may need to visit a women's clinic. But, the women's clinic staff shouldn't ask a transgender woman the first day of her last period at each appointment. When healthcare providers signal their awareness of the TGD patient's status, this lifts the burden for the TGD individual to feel like they have to explain their situation every time they go to the doctor's office. Also, healthcare providers should be sure that everyone in the office (nurses, receptionists, etc.) is aware of a patient's TGD status. That way, whenever this patient calls to set up an appointment (Sikveland & Stokoe, 2017), they are assured that the healthcare provider is mindful about their gender identity.

Another suggestion for healthcare providers is to keep their conversations with TGD patients focused on the purpose of the current healthcare appointment. In particular, they should limit their curiosity about the TGD individual's transition process (name change, surgery, sexual orientation, etc.). These topics are sensitive areas, and many of the TGD individuals in this study reported that they would have preferred to keep this information to themselves. Because of the power imbalance, the TGD individual felt obligated to answer these probing questions because they were coming from a healthcare provider. But if that information is not necessary, then healthcare practitioners should not inquire about these topics during appointed meetings with TGD patients. There are some areas of the gender



affirmation process that the TGD individual should be allowed to keep to themselves and only divulge when they deem it appropriate.

In addition, healthcare providers should not examine the TGD patient to feed their curiosity. This is especially true when it comes to any type of physical examination. Several interview respondents in this study reported having to undergo a physical examination of their genitals or breasts, even when the purpose of their healthcare appointment had nothing to do with these areas of the body. Therefore, it is critical for a healthcare provider to explain the reason why a physical examination is necessary before it is performed on a TGD patient.

In efforts to reduce gatekeeping, healthcare providers need to create documents that summarize the chronological procedures for complex health services. As seen in the interview responses presented here, hormone therapy and surgical procedures are two areas where TGD patients felt like they were being unduly burdened with incremental barriers to care. Therefore, any requirements (such as waiting times) need to be expressly discussed with the TGD patient before they begin treatment. If there are sequential steps that need to be completed (such as obtaining a referral letter from a mental healthcare provider), all of these steps should be summarized and explained to the TGD patient in one setting. That way the TGD individual knows what tasks need to be accomplished, and has a reasonable timeframe in mind on how long it will take to complete all of these steps. Failing to do so will frustrate and confuse the TGD patient, because they will feel like these obstacles are unnecessary and are therefore superfluous. One could even argue that the prerequisite of obtaining a referral letter from a mental health professional before the administration of hormones and/or surgery is pathologizing (Nordmarken & Kelly, 2014). This demand is an obstruction to care for the TGD individual, and further discussions on the merits of this requirement are needed. Many other healthcare patients are able to request hormones (for birth control, menopause, erectile dysfunction, etc.) or surgical procedures (rhinoplasty, liposuction, breast augmentation)

without having to obtain consent letters from mental health providers. The insistence on this requirement for TGD patients signals them out, and may even be interpreted as discriminatory.

Recommendations to health providers to reduce perceptions of stigmatization by TGD patients include shaking the patient's hands at the beginning and end of an appointment, leaning forward and making eye contact during discussions, and showing the steps you are taking to ensure the patient's privacy about their health situation. In addition, healthcare providers who smile, call patients by their first name, and those who leave a patient feeling like they were treated with compassion and dignity are all shown to close the gap of unmet expectations (Thiedke, 2007). Even the intake forms patients fill out to summarize one's sex and gender identity may be seen by some as stigmatizing. This is especially true if the TGD patient faces a limitation of response options. Therefore, allowing TGD individuals to describe their sense of self with more open-ended responses can foster a more affirming healthcare environment.

Some research has suggested that healthcare providers may be able to reduce perceptions of stigma from TGD patients by signaling that their TGD status is not problematic. This "communication of indifference" (Ross et al., 2014, p. 74) may lower anxiety levels in the TGD individual, and therefore reduce tensions in the TGD patient-healthcare provider social dynamic. As discussed above, some TGD patients received hostility and unfriendliness from healthcare providers upon the revelation of their TGD status. Other interview participants reported receiving overwhelmingly positive exclamations from healthcare providers (e.g., the dentist who was super-excited and kind of freaking out). Both of these reactions (very positive and very negative) can cause the TGD individual to tense up and inhibit future disclosures. Therefore, a healthcare provider who indicates an attitude of nonchalance about the topic may help to put the TGD patient at ease.

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In relation to misgendering and deadnaming, healthcare providers can improve the likelihood of having a successful encounter with a TGD patient by asking them about a preferred name and pronoun. This one modification can go a long way towards creating an atmosphere of affirming care. In fact, this may be one of the key barriers for TGD patients. When TGD individuals are misgendered and/or deadnamed, they often reported receiving confused and/or bewildered looks from others. The updating of files and the intentional use of preferred names and pronouns by healthcare providers should not be an insurmountable task. Many cisgender women legally change their last name after they get married, and the transition for them at healthcare offices is often smooth and hassle free. The same should be true for TGD individuals.

Other recommendations for healthcare providers on how to improve their experiences with TGD patients comes from the literature. On a structural level, the activities of healthcare administrators and insurance companies can greatly help or hurt a TGD individual's access to healthcare (Housel & Harvey, 2014). In the United States, the passing of the Affordable Care Act legislation in 2010 did enable more individuals to obtain health insurance through Medicaid expansion and federal subsidies for private insurance premiums. But, some insurance plans do not cover gender affirmation surgeries or hormonal therapy, and a TGD individual without health insurance definitely has limited access to healthcare services (Kattari & Hasche, 2016). In addition, many states in the U.S. have not adopted any type of non-discrimination policies for LGBT citizens in general and TGD individuals in particular. Therefore, the employment status (and as a result, insurance status) for TGD individuals is often constantly in peril.

Another obstacle for TGD patients to receive quality care is when the healthcare institution has some type of formal religious affiliation. About 20% of U.S. hospitals are listed as Catholic, Methodist or Jewish establishments (Stulberg, Lawrence, Shattuck, &

Curlin, 2010). Since these religions often interpret the TGD individual as having some type of moral failing, certain medical procedures that are commonly practiced in the healthcare industry may be off limits in an institution that allows for conscientious objection from healthcare practitioners (Hafner, 2018). Therefore, the TGD patient in a religious-themed healthcare setting may face stigmatization from numerous sources if administrators do not have policies in place preventing this discrimination. In rural areas, access to non-religious healthcare facilities may not even be available.

It is important to note that the occurrence of unmet expectations is subjective. They are built up through the perceptions of patient on the healthcare provider's words and actions. Research has shown that individuals who face unmet expectations in healthcare settings can implement a form of "cognitive flexibility" (Moyer & Goldberg, 2017, p. 12) where they adjust their perceptions to a situation. This shift in perception can reduce stress in the individual and diminish the likelihood of forming future unmet expectations. Individuals exercising this technique are able to reframe the situation that occurred in order to emphasize the positive aspects of the encounter and focus on the overall positive results from that social interaction (Neufeld & Harrison, 2003). Other techniques that TGD individuals can implement may be described as acts of resilience. These include possessing a determination to overcome obstacles, gaining a sense of self-knowledge that will enable a better conversations health providers, having a recognition that adversity exists so as not to be continually surprised when a negative encounter occurs, feeling a sense of gratitude when a positive encounter does occur, and maintaining a continual desire for positive change (Shankar, Gogosis, Palepu, Gadermann, & Hwang, 2018).

Finally, having strong social support is an important asset for any individual (Fisher, 1985). Social support lowers stress levels in the individual, enables more positive perceptions of social encounters, and can overall reduce the chances of unmet expectations occurring

(Thompson-Lastad, 2018). This may be an especially useful tool for TGD individuals during healthcare appointments. In fact, several interviewees in this study provided examples where they went to a healthcare appointment with a support person. This person provided advice, assurance, and even camouflage for the TGD individual, and helped to ameliorate a potentially stressful situation. Unfortunately, many TGD persons do not have the support network needed to overcome these obstacles. More research is needed in this area, and this is especially true for TGD patients.

Overall, the healthcare appointment is a social interaction between patient and provider. Like all social contact, it is a negotiation taking place through communication. Future studies could also focus on conversation analysis where naturalistic audio recordings of TGD patients and healthcare practitioners are deconstructed (Albert et al., 2018), and the spontaneous flow of communication is critiqued from both sides. This type of research would provide both parties with much needed insight on how to approach this situation in a more effective manner.

Unmet expectations are seen across the healthcare system, but are particularly problematic for TGD individuals, especially those living in underserved areas. Utilizing a community-based participatory research method, this study highlighted needs for TGD patients that are still not being met. The goal for any healthcare provider should be to create positive experiences and reduce barriers to care for all of their patients. In the U.S. (and the Central Great Plains), many healthcare providers are being proactive in their efforts to reduce instances of unmet expectations for their TGD patients. They will be catalysts for change as they facilitate healthcare experiences that are increasingly affirming for TGD individuals.

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