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Female-To-Male Transgenders Patients' Perceived Disparities in Cancer Screening Adherence: A Phenomenological Study

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Abstract

Members of the transgender community may have a higher risk for cancer due to certain factors like smoking, alcohol and drug use, obesity, and significantly higher rates of HIV. However, transgender persons are less likely to adhere to life-saving cancer screening exams than cisgender individuals. Although quantitative data exist showing the lower percentage of transgender vs. heterosexual cancer screening adherence rates, qualitative research from a transgender person's point of view is needed to understand the barriers to why fewer transgender individuals adhere to cancer screening guidelines. This qualitative, phenomenological study aims to explore female-to-male transgender individuals' perceived experiences with cancer screening exams. A convenience sample of seven female-to-male transgender individuals was recruited from LGBTQ social media support websites. Qualitative data were collected through in-depth Zoom interviews using open-ended questions regarding the participant's level of knowledge of routine cancer screening exams and the barriers preventing them from seeking these exams. Results from data analysis showed that overall, participants were unfamiliar with routine cancer screening recommendations. To determine barriers, thematic analysis of the interview data generated four main themes. These included: social stigma (discrimination), financial/insurance difficulty, emotional stress, and previous traumatic experiences. Understanding why this underserved population does not adhere to cancer screening exams will help identify specific barriers that can be addressed through interventions and education. If improvements can be made in health care so that the percentage of trans-patients who commit to routine cancer screening increases, diagnosis and treatment will improve, and lives will be saved.

Keywords: Transgender, Female-To-Male Transgender, Transgender Health, Stigma, Health Care, Cancer Screening

1. Introduction

According to the American Cancer Society, almost 2 million new cancer cases were diagnosed, and over 600,000 people died from the disease in the United States in 2021 [1]. Cancer screening is an essential tool to discover cancer before symptoms appear and when the chances for successful treatment are at their highest [2]. The American Society of Clinical Oncology and the United States Preventive Services Task Force offers recommendations for screening for different types of cancer which differ depending on a person's age and risk factors. These recommendations include breast, cervical, colorectal, and lung cancer. Mortality rates for cervical, lung, breast, prostate, and colorectal cancer have decreased since the adoption of cancer screenings [3]. However, statistics show that members of the transgender community are less likely to adhere to or undergo routine cancer screenings than the cisgender population [4].

The number of young people who identify as transgender has nearly doubled in recent years. In the United States, over 1.6 million youth and adults (0.6 % of the total population) identify as transgender [5]. Transgender individuals have unique health

care needs. For example, a female-to-male (FTM) transgender man may retain their cervix, which still requires sexual health care. Likewise, some male-to-female transgender women still have a prostate that requires care. Members of the transgender community may have a higher risk for cancer due to certain factors like smoking, alcohol and drug use, obesity, and significantly higher rates of HIV. Hormone therapy can also be a risk factor for an increased incidence of cancer. Therefore, it is imperative that members of this community adhere to recommended routine cancer screening protocols.

2. Background

Transgender patients experience significant disparities in health care, including discrimination in medical facilities, lack of access to knowledgeable providers, lack of education on recommended cancer screening exams, lack of insurance coverage, and lack of acknowledgment in electronic medical records of their specific health care needs. These barriers may discourage transgender people from adhering to recommended cancer screening protocols, leading to a delay in diagnosis and treatment, and resulting in decreased survival rates for transgender

patients. Though transgender people are more likely to develop cancer than cisgender individuals, data show that they are 50-70 % less likely to adhere to routine cancer screening protocols [6].

3. Rationale

Learning more about the experiences of FTM transgenders' adherence or lack thereof to routine cancer screening protocols will help identify gaps in care. Many qualitative data studies describe the lack of knowledgeable providers, lack of insurance, and lack of patient education. Qualitative research from a transgender person's point of view is needed to understand the barriers to seeking cancer screening. Research that engages transgender community members may help address health disparities by empowering patients, increasing trust, and updating medical curricula to increase competence.

4. Significance

Transgender people have described current health care as “terrible, limited, in its infancy, and very limited in terms of places that provide trans-affirming care” [7]. Considerable research has been done on cancer incidence and the barriers regarding adherence to routine cancer screening in the transgender population. Quantitative studies based on data pulled from national databanks have been the primary foundation for research on trans-health needs. Qualitative research has encompassed the transgender patient’s general experiences in health care or with mental health. There is a need for more qualitative research to recognize barriers to non-observance of cancer screening exams and identify themes from the patient's point of view.

5. Methods

5.1. Institutional Review Board Approval

IRB approval was needed to conduct the semi-structured inter-

views. The IRB approval process was completed through two accredited universities.

5.2. Sample Characteristics

Participants were recruited from LGBTQ social media support websites. Participants were required to be over the age of 21, English-speaking, identify as a female-to-male transgender, and be able to interview via Zoom. Exclusion criteria included those individuals under the age of 21, non-English-speaking, anyone identifying as a gender other than female-to-male transgender, and anyone unable to interview via Zoom. All participants interested in participating were sent an informed consent via email and asked to sign and return it. Once this was completed, a Zoom interview was then scheduled. A \$25 Amazon gift card was offered and given to all participants who met criteria and completed an interview. All interviews were conducted over 4 weeks.

5.3. Participants

Twelve individuals expressed interest in participating in the study. Of the 12, only seven participants met the inclusion requirements for this study. Of the five participants excluded from interviewing, one had technical difficulties with Zoom and the other four did not speak English. All seven participants who met the inclusion criteria participated in one-on-one interviews via Zoom. All seven of the participants were between the ages of 25 and 33 (mean [M]= 28.86; standard deviation [SD]= 2.67). All participants were from the United States. Among the seven participants, four were African American (57.1 %), and three were Caucasian (42.9 %). All seven participants identified as FTM transgender, assigned female at birth, and currently identified as a male. All seven participants completed the interview survey in full (Table 1).

Characteristic	N	%
Age		
<21	0	(100.0%)
22-30	6	(85.7%)
31-40	1	(14.3%)
>40	0	(100.0%)
Sex Assigned at Birth		
Female	7	(100.0%)
Male	0	(100.0%)
Current Gender Identity		
Male	7	(100.0%)
Female	0	(100.0%)
Country of Residence		
United States	7	(100.0%)
Other	0	(100.0%)
Race		
African American	4	(57.1%)
Caucasian	3	(42.9%)
Mastectomy		

Yes	5	(71.7%)
No	1	(14.3%)
Single	1	(14.3%)
Hysterectomy		
Yes	3	(42.9%)
No	4	(57.1%)

Note: N=7. Participants were on average 28.9 years old (SD=2.7) and participant age did not differ by condition

Table 1: Demographics of Participants

6. Data Collection

Each interview lasted approximately 30–60 minutes in length and each participant agreed to having the interview recorded. All interviews were recorded and transcribed via Zoom, and then analyzed inductively through the qualitative research platform Dedoose. To protect anonymity, the researcher assigned each interviewer a code (e.g., Participant A, January 21, 2023). After each interview, the researcher went back and listened again while taking field notes, including observational, theoretical, methodological, and analytical notes. The next step in data interpretation was examining the data for important information. Notes and transcriptions were recognized, and key text was highlighted. Labels, or codes, were then assigned to highlighted blocks of information.

Next, categories and themes were created by linking and organizing the codes together. Once categories had been created, themes were identified. The themes that emerged from the data were considered the primary findings. Themes were given titles that captured their meaning and reflected the phenomenon under investigation. Two peer-reviewers also examined the data and

identified similar codes and themes to reduce the possibility of bias.

7. Findings and Discussion

7.1. RQ 1: What is the level of familiarity that FTM transgender patients have with recommended cancer screening guidelines?

All participants were asked questions related to their knowledge of the recommended age of three different cancer screening exams (cervical, breast, and colon cancer). Questions were also asked regarding the recommendations of how often these cancer screening exams should be performed. In general, transgender males should adhere to the same screening recommendations as cisgender individuals which include cervical cancer screening beginning at age 21 and repeated annually; breast cancer screening beginning at age 40 and repeated annually; and colorectal cancer screening beginning at age 45 and repeated every 10 years. Five of the seven participants had little to no knowledge of cancer screening recommendations. One participant was somewhat knowledgeable, and one participant was very knowledgeable (see Figure 1).

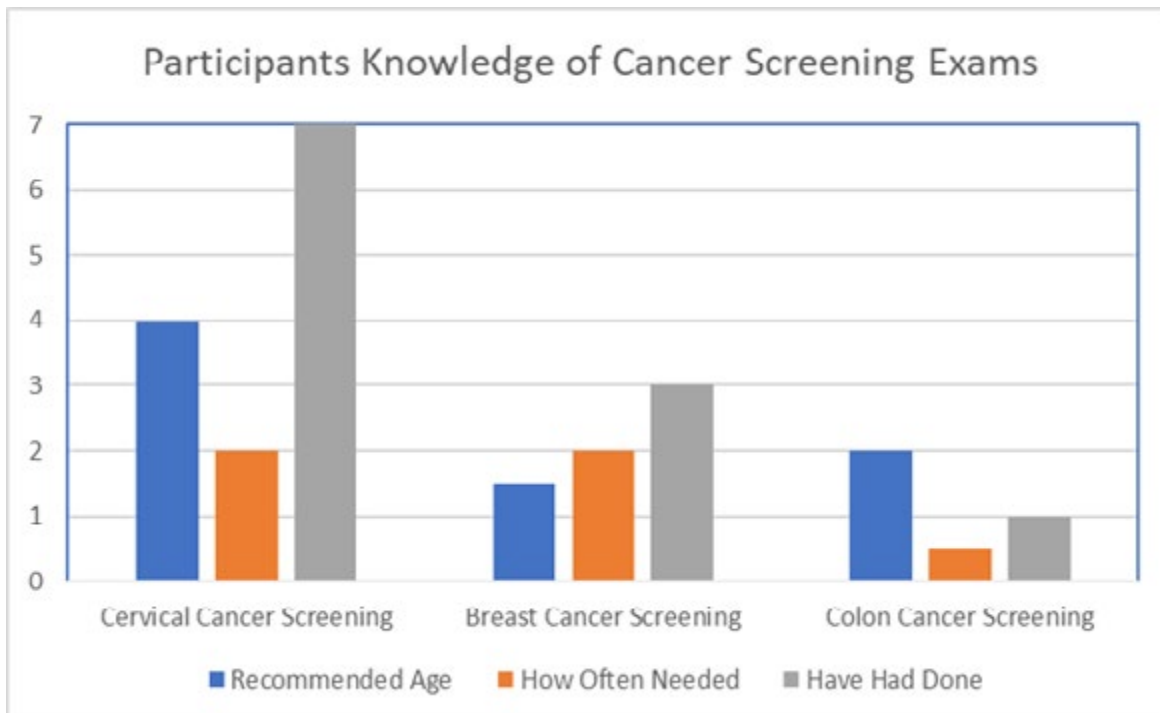


Figure 1: Coded responses for Participant’s knowledge for recommended age and how often should cancer screening be done

Although none of the participants were of the age to require a mammogram (typically at age 40 or older), three out of the seven (42.9 %) had undergone a mammogram prior to top surgery (mastectomy). All participants were eligible for routine cervical cancer screening, and four of the seven participants (57.1 %) had had a pap smear within the past 5 years. Though none of the participants met the age requirement for a colonoscopy (usually at or above age 45), one participant (14.2 %) had undergone the procedure due to a family history of colon cancer.

Results from data analysis showed that overall, participants (N=7) were unfamiliar with cancer screening recommendations for all three cancer screening exams. The transgender and sexual gender minority population (TG/SGM) account for 4.5% of the U.S. population (Lombardo et al. 2022). Unfortunately, the recommended cancer screening guidelines set forth by governing bodies such as the United States Preventive Services Task Force and the National Comprehensive Cancer Network do not consider the unique medical situations of the TG/SGM population (Lombardo et al. 2022). Despite the vital need for improved health care in the TG/SGM community, there are no cancer screening guidelines specific to this population, leading to uncertainty for health care providers and members of the transgender community. Lack of cancer screening guidelines leads to a lack of cancer screening education for TG/SGMs, making it hard for them to know what and when to adhere to routine cancer screening exams. Brown and Tracy (2008) searched databases to determine the amount of literature available on cancer screening recommendations for the TG/SGM population. Most literature was related only to breast and cervical cancer screen-

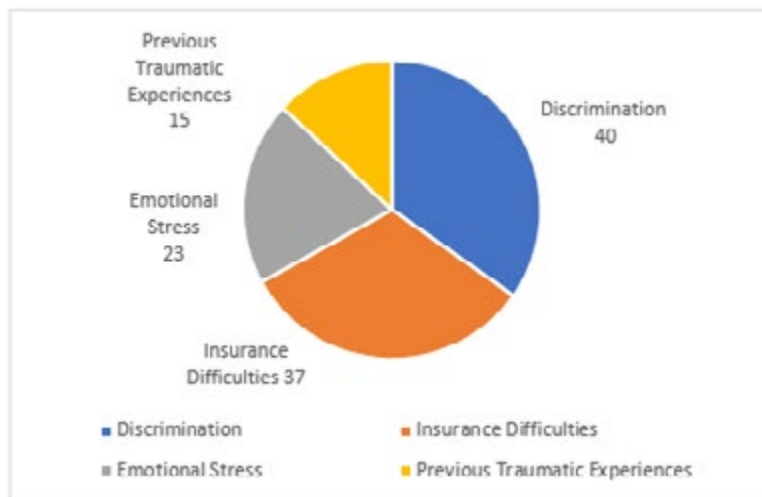
ing. In a quantitative survey, Lombardo et al. (2022) found that a staggering 65 % of transgender participants were unfamiliar with what cancer screening to do for themselves, and 71 % were uncertain what age to begin screening. Lombardo et al. (2022) also found that most transgender participants were less knowledgeable about cancer screening than gay participants. Data analysis from this study concurred with these results, showing that only one participant was knowledgeable on cancer screening recommendations.

7.2. RQ 2: What are the lived experiences of the FTM transgender patients' adherence or non-adherence to recommended cancer screening exams?

Thematic analysis of the interview data generated four main themes. These included: social stigma (discrimination), financial/insurance difficulty, emotional stress, and previous traumatic experiences (see Figure 2). The initial aim of the current research was to determine the lived experience of female-to-male transgender patients in adherence or non-adherence to obtaining cancer screening examinations. All participants shared experiences of general encounters with a range of health care professionals who conduct cancer screening exams. Health care providers included those who specialize in transgender health care as well as those who did not.

8. Social Stigma

Results found that of the four themes identified, social stigma (discrimination) was the most common theme mentioned by the FTM transgender participants (see Figure 2).



Note. Coded responses come from the number of times the seven participants made comments regarding their lived experiences in obtaining cancer screening examinations

Figure 2: Coded responses for common stressors against cancer screening.

Social stigma is the negative association between a person or group of people who share certain characteristics and the discrimination they face due to their differing characteristics (World Health Organization 2020). Transgender patients experience stigma, judgment, and discrimination from health care faculty and physicians. Often this discrimination happens due to a lack of education on trans-health needs [8]. Other times, discrimina-

tion occurs based on health care workers' personal beliefs and biases. Whatever the reasons, transgender patients often do not seek routine health care, including cancer screening exams, because of the fear of discrimination. Perceived stigma based on appearance and sexual identity caused negative encounters in obtaining cancer screening exams for all seven of the participants. Participant 5 related an incident with a proctologist result-

ing in him being unable to receive their colonoscopy from this specific provider:

“I was pretty newly out as trans and wasn't on hormones or anything, and I think my mom had told the nurse that I was trans, and the nurse told the doctor, and the doctor screamed at me... it was very much just like this is wrong...you're a freak and like an abomination and all those types of things.” (Anonymous, personal communication, Jan. 18 2023). A study published by the Center of American Progress showed that 15 % of 1,528 self-identified LGBTQ respondents endorsed postponing or avoiding medical treatment due to fear of discrimination. The transgender population, in particular, suffered even more pervasive discrimination [9]. Trends of poor health care for trans people can be due to the denial of care from physicians [10]. A national report by the National LGBTQ Task Force was recently released with a key finding that nearly one in five (19 %) transexual people reported being refused care because they were transgender or gender non-conforming, 28 % were subjected to harassment, and 50% had to teach their providers about trans-health care (National LGBTQ Task Force 2022). However, some medical institutions, such as Intermountain Healthcare, are working to determine which physicians and hospitals in their organization have trans health training (Intermountain Health Care 2022). A list of these providers and hospitals is being provided via the internet and through local LGBTQ support groups. Findings from multiple studies also suggest a need for trans health education as part of the medical training so that health care providers can become more competent in caring for transgender patients.

Participants also related experiences of the discrimination they experienced from support staff (reception, nurses, etc.) when they were seen for their cancer screening exams. One participant described their experience when checking in at the front desk for a pap smear, stating,

“...the old ladies that were the secretaries were mighty confused” (Anonymous, personal communication, Feb. 13 2023).

“...People will, you know, judge me. I don't know that I would feel comfortable having like a pap smear done in like a clinic that wasn't where they would let me do it myself” (Anonymous, personal communication, Jan. 18 2023).

“...You feel very bad, people watching you, people laughing at you” (Anonymous, personal communication, Jan. 10 2023).

“...I took my wife with me...we kind of just made it look like it was for her, and I was just going with her” (Anonymous, personal communication, Feb. 13 2023).

During the study, participants were asked to share their thoughts on how to overcome the discrimination barrier that prevents many individuals from accessing cancer screening exams. The overwhelming consensus among all seven participants was that education and diversity training for health care providers could significantly help alleviate this issue. In particular, the participants emphasized the importance of educating health care staff

on issues related to gender identity and transgender health care needs. They suggested that this could involve training on using correct pronouns, showing compassion towards individuals from diverse backgrounds, and gaining a better understanding of the unique health care needs of transgender patients.

9. Financial/Insurance Difficulty

The second most common theme identified in this study was financial/insurance difficulties. All seven participants (100 %) claimed to have health insurance, and all seven participants (100 %) reported having experienced difficulties obtaining insurance to cover their cancer screening exams. Transgender populations are affected by poverty, unemployment, and lack of insurance at higher rates than the general population [11]. Transgender individuals, whose anatomy may not match their gender identity and expression, may find that they are excluded from existing health screening protocols. For example, a person assigned female at birth but transitioned to male may still have a cervix, ovaries, and uterus. In these cases, coverage could be denied for routine preventive services that are appropriate to the individual's anatomy, such as screenings for breast, ovarian, cervical, or prostate cancer [12]. According to Noonan et al. (2017), 25 % of transgender patients interviewed experienced a problem with their insurance, and over half were denied coverage for gender-changing surgery.

One participant related his frustrations with his insurance company and medical chart, stating:

“...I was kind of forced to go by the old name and sex” (Anonymous, personal communication, Feb. 13 2023).

Participants described their experiences when trying to get insurance approval for a pap smear, stating:

“I had to jump through like 50 hoops. I had to get like 2 different counselors to sign a piece of paper, saying that I knew emotionally that that's what I needed and then I had to have a doctor sign it saying that I needed it, and there were other things. There were 2 or 3 different documents I had to get signed, and it's hard to get one counselor, let alone 2 different ones.” (Anonymous, personal communication, Feb. 13 2023).

“...I am designated as female but it's isolated as diagnosis on my problem list” (Anonymous, personal communication, Jan. 13 2023).

Insurance policies and procedures need to be able to capture information that accurately reflects transgender identity to simplify and standardize trans-health care. Special efforts must be taken to optimize how gender health care information is collected, stored, and accessed in an EMR. Software programs currently exist that improve equality for trans-health care needs [13]. However, a will to undertake the infrastructure and training measures is needed to realize these best practices and ensure success.

10. Emotional Stress

In addition to feelings of discrimination, many of the study's

participants feared the pain and psychological discomfort associated with receiving certain exams, specifically pap smears. The participants discussed the emotional stress they experience when they are required to have exams specific for those anatomical parts that relate to their assigned sex but that they no longer identify with. This phenomenon is known as gender dissonance. Additionally, hormone therapy can cause anatomical atrophy in FTM transgender individuals. Therefore, participants discussed how pap smears can often be painful for them. All seven participants stated emotional and mental stress in relation to obtaining cancer screening exams.

“...a lot of the anatomy had just like atrophied. So they were like, yeah, it's gonna hurt like this is not gonna be a fun thing for you to do and I was like, yeah, let's not do it” (Anonymous, personal communication, Jan. 18 2023).

Several participants stated that there was emotional stress related to having to examine those anatomical parts that relate to their assigned sex.

“...there's a trauma of being looked at in that area when you try to avoid it as much as possible” (Anonymous, personal communication, Jan. 13 2023).

“...it's kind of like being a rape victim...you have trauma from the anatomy itself because it's not concurrent with the way you feel. Those screenings are sensitive topics and sensitive events” (Anonymous, personal communication, Jan. 13 2023).

Pap smears bring about notions of masculinity and femininity and can trigger gender dysphoria. Because pap smears are traditionally perceived as feminine, this exam is incongruous with their masculine identity [14]. Peitzmeier et al. (2017) stated that FTM transgender patients who were unable to reconcile their masculine identity with the feminized concept of the Pap test felt coerced and experienced threats to their privacy and destabilization of their identity and personal integrity. Health care providers who are trained in transgender health can help alleviate these feelings of emotional stress by providing gender-inclusive and sensitive care to transgender patients.

11. Previous Traumatic Experiences

FTM transgender patients may avoid cancer screening exams because of previous experiences that resulted in traumatization both physically, emotionally, and/or financially. As previously stated, exams such as pap smears may be physically painful due to hormone-related anatomical atrophy. Participants all expressed trouble in getting insurance approval for specific exams that did not coincide with their recorded sex. Having to prove the need for the exam to insurance companies causes emotional stress and embarrassment. Most participants also experienced discrimination and mistreatment from health care providers and support staff, creating a fear of having exams in the future. Participants discussed the traumatic experiences of having to wait in health care facility waiting areas with a room full of women, and about being looked at strangely by other patrons and health care personnel.

Several participants also spoke about a phenomenon called transgender broken arm syndrome. This phenomenon refers to the care received by transgender patients' focusing on the fact that they are transgender, and not the issue at hand (such as a broken arm).

“...you know, if like I have strep and I just don't feel good and I just need a swab and like some azithromycin and sent home, I don't want to talk to you about being trans. ...It's an interesting balance of if it's relevant. But if it's not...yeah, it's not a good day for me.” (Anonymous, personal communication, Jan. 18 2023).

“...now that I'm transitioned, people only want to talk about me being trans. They don't want to talk about my other health issues, and to recognize that being transgender isn't the primary concern for all trans patients” (Anonymous, personal communication, Jan. 13 2023).

“...I'd like to be treated as a person, not as a transgender individual” (Anonymous, personal communication, Jan. 13 2023).

Many of the participants also felt uncomfortable being seen in health care facilities where their gender and/or name was recorded on their electronic medical record as that other than what they identify. Data from The Center for American Progress found that 66 % of transgender patients reported having difficulty obtaining proper documentation of their legal name and gender identity on their medical records [15]. However, several health care organizations, such as Intermountain Healthcare, have updated their electronic medical records to include subset data such as what pronoun and name the patient identifies as [16].

Despite the improvements being made, results showed an overwhelming feeling of emotional stress experienced by all participants. Transgender individuals are often forced to navigate a health care system that is resistant at best and at times openly hostile toward transgender people's need [17]. Negative experiences in health care impact transgender people's desire and ability to access appropriate care. To counteract these barriers, education and inclusivity training is needed to affirm transgender health and competently serve this population.

12. Limitations

This study has several limitations that should be considered. First, it may be possible that transgender participants feared that their participation in this study could have a direct or indirect impact on the subsequent care they received from their health care professionals. To avoid this from happening, the researcher clarified that the confidentiality of the data was ensured throughout the research process and that all personal data would be guaranteed anonymity. Due to the small sample size and the type of sampling used, data may not reflect all transgender realities. Even so, the researcher attempted to diversify the inclusion of participants to reduce this limitation. Finally, the data obtained cannot be generalized, but can be transferred to similar sociocultural contexts, which is the main characteristic of the methodology used.

Future research is needed to understand what health care personnel and systems are doing to improve equality for transgender patients, such as inclusivity training or updating their EMRs. Research on how insurance companies have improved their processes to accommodate the unique needs of transgender patients would also be beneficial. Because the participants in this study were all from the United States, future studies on an international level might be useful to compare trans health experiences in other countries.

13. Conclusion

Considerable research has been done on cancer incidence and the barriers regarding adherence to routine cancer screening in the transgender population. Quantitative studies based on data pulled from national databanks have been the primary foundation for research on trans-health needs. Qualitative research has encompassed the transgender's experience in health care in general, but very little is known about their experiences specific to obtaining cancer screening exams. This study provides evidence of the FTM transgender individual's unfamiliarity of recommended cancer screening guidelines. Additionally, several key themes were identified as to why this underserved population fails to adhere to cancer screening recommendations. Despite its limitations, this study attempted to give a voice to a group of individuals who have been historically marginalized and silenced. Understanding why FTM transgender patients do not adhere to cancer screenings will help identify specific barriers that can be addressed through interventions and education. Future research would benefit from understanding what interventions and education are currently being implemented and what their effect has been. If improvements can be made in health care so that the percentage of trans-patients who commit to routine cancer screenings increases, diagnosis and treatment will improve, and lives will be saved [18-21].

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