

“EVERY NOW AND THEN I GET FLAGGED FOR A PAP SMEAR”: GENDER TRANSITION, EMBODIMENT, AND “SEX- SPECIFIC” CANCER SCREENINGS

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ABSTRACT

Purpose: We respond to a call for studies of “embodied experiences of stigma in context” by investigating how transgender embodiment shapes perceived needs for access to and experiences of “sex-specific” cancer screenings (SSCS) (e.g., breast and prostate exams, Pap smears) in the North American healthcare system.

Design/Methodology/Approach: We analyze data from semistructured interviews with a diverse sample of 35 transgender-identified adults. Based on thematic narrative analysis, we explore four themes in relation to embodiment: discrimination; discomfort and hyperawareness of genitalia; strategic reframing and active management; and SSCS health care encounters as positive and gender affirming.

Findings: In relation to SSCS, transgender individuals experience discrimination, do emotion work, and actively manage situations to obtain needed health care, and sometimes forego care because barriers are insurmountable. Health care providers’ responses to transgender embodiment can disrupt health care encounters, but they can also facilitate access and create opportunities for affirmation, agency, advocacy, and new forms of interaction.

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Embodiment- and gender-affirming interactions with health care providers, which varied by gender, emerged as key influences on participants' experiences of SSCS.

Research Limitations/Implications: Our sample primarily includes binary gender-identified individuals, and while our interview guide covered many topics, the SSCS question did not explicitly reference testicular exams.

Practical Implications: Cancer prevention and detection require health care professionals who are prepared for differently embodied persons. Preventive cancer screenings are not "sex-specific"; they are relevant to individuals with medically necessary needs regardless of gender identity or embodiment.

Social Implications

Originality/Value: Few medical sociologists have focused on transgender embodiment. Findings enhance our understanding of how transgender embodiment and minority stress processes influence access to needed SSCS.

Keywords: Transgender; embodiment; cancer screening; minority stress; discrimination; health care

Medical sociologists have a long-standing commitment to analyzing the influences of sex and gender on health and health care use (Annandale, 2009; Bird & Rieker, 2008; Nathanson, 1984; Verbrugge & Wingard, 1987). An emergent medical sociological literature that focuses on transgender identity, gender expression, and embodiment extends this commitment in new directions (Dewey, 2008; Johnson, 2019; Lagos, 2018; Pearce, 2018; Sledge, 2019; Taliaferro et al., 2019). The transgender population includes anyone whose gender identity does not match their birth sex assignment (Stryker, 2008). It includes people who identify as gender binary or gender nonbinary, and it is heterogeneous along a range of biological, psychological, and social dimensions.

In relation to transgender experience, the concept of embodiment¹ encompasses a biopsychosocial nexus that includes an individual's experience of their body (e.g., anatomy, physiology, hormones, gender-affirming surgeries), gender identity over the life course (e.g., childhood experiences, names, pronouns), and gender expression and performance. Embodiment "recogniz[es] the social consequentiality of the body's materiality" and its relationship to identities and social structures (Shilling, 2007, p. 11). Thus, we must take embodiment into account in relation to how transgender people, like Julie, whose experience inspired the title of this paper, manage interactions with health care providers in various medical contexts. Julie, is sometimes flagged by electronic medical records systems and health care providers for a cervical screening even though she does not have a cervix. In this regard, Paine (2018) recently introduced the concept of embodied disruption to draw attention to how patient nonconformity to societal gender norms provokes responses from medical personnel that reify normative sex/

gender/sexuality binaries, provoke confusion and distress, and compromise gender nonconforming individuals’ access to health care.

The biopsychosocial nexus that influences transgender individuals’ use of health care in general, and cancer screenings in particular, is what drives this research. Cancer is the second leading cause of death in the United States (Siegel, Miller, & Jemal, 2019), and generally there are substantial social inequalities in cancer mortality, incidence, and survival (Singh & Jemal, 2017; Singh, Williams, Siahpush, & Mulhollen, 2011), as well as access to preventive cancer screenings (Harper, Plegue, Harmes, Jimbo, & SheinfeldGorin, 2020). Transgender individuals have medically necessary needs for cancer screenings that are related to natal organs and tissues, as well as gender transition–related hormone use. However, these screenings do not always align with gender identity or expression. From the perspective of the medical system, which assumes sex/gender and body alignment (Patel, Dolitsky, Bachman, & De Meritens, 2019), cancer screenings related to those anatomical structures – Papanicolaou (Pap) smears, mammograms, prostate exams, testicular exams – are assumed to be sex-specific. However, this can introduce discordance for transgender individuals based on their sex assigned at birth, gender identity, and/or embodiment, which manifests in various ways during health care encounters and contributes to experiences of stigma, discrimination, and conflict. As Paine (2018) notes, discordance occurs at the moment of misrecognition by health care providers, which leads to the experience of embodied disruption. However, the revelation of the discordance between gender identity and expression, which includes the body, also creates opportunity structures in which affirmation, agency, advocacy, and new forms of health care provider-patient interaction can occur (Johnson, 2019).

Little systematic research by medical sociologists has examined how transgender individuals experience cancer screenings or other kinds of cancer care (Wanta & Unger, 2017). One recent sociological study of decision-making related to elective surgeries for cancer prevention included a transgender comparison group and showed that evidence-based medical practices and individuals’ preferences for their own bodies were sometimes subordinated to normative ideas about gender (Sledge, 2019). We build on emergent research that calls for studies that consider “how larger institutional- and organizational-level factors determine interpersonal and embodied experiences of stigma in context” (Paine, 2018, p. 357). Drawing on interviews with 35 transgender people, we investigate how gender identity and embodiment shape perceived needs for, access to, and encounters with what are medically thought of as “sex-specific” cancer screenings (hereafter SSCS) in the context of the contemporary North American healthcare system. Although our sample is primarily limited to binary-identified transgender people, focusing on SSCS is important precisely because of the ways SSCS engage parts of the body that may be discordant with transgender embodiment. Such screenings may pose a challenge to an individual’s sense of self, increase exposure to stigma and discrimination, and require the active management of gender identity and embodiment in order to obtain needed medical care (Patel et al., 2019). Our analyses reveal participants’ approaches to, understandings of, and agency related to accessing SSCS, as well as gender differences in experiences of

SSCS that reflect variability in age, embodiment, management strategies, and responses to health care providers. They also illustrate how transgender people experience discrimination, physical discomfort, and dysphoria during medically necessary SSCS, as well as the critical roles health care providers, staff, and clinical spaces that affirm transgender individuals' gender identity and embodiment can play in enhancing access to and use of SSCS by transgender people.

BACKGROUND

Barriers to Health Care Among Transgender People

Access to and use of medically necessary health care is a core area of medical sociological inquiry (Andersen, 1995; Pescosolido, 1992; Pescosolido & Boyer, 1999). According to the Institute of Medicine (1993, p. 4), access is defined as "the timely use of personal health services to achieve the best possible health outcomes." Others define access as the ability to receive regular, high-quality medical care in the most appropriate health care setting (Myers & London, 2005). Health care access and use are important for people with existing health problems (ameliorative and curative health care) and risks for new or more-complicated health problems (preventive health care).

An extensive literature has critiqued and refined the Andersen's behavioral model of health service use, yet it remains a dominant sociological model for conceptualizing health care access and use (Andersen, 1995). The behavioral model posits that health care access is influenced by need, enabling, and predisposing factors. Needs are the medical conditions and recommended health screenings that drive help-seeking. Enabling factors include health insurance, a usual source of care, and other resources (e.g., networks) that facilitate health care access, as well as corollary barriers to health care use that impede or block access. Predisposing factors are attitudinal and experiential influences that are anchored in lived experiences and systems of stratification, and shape propensities to use or forgo health care.

Many transgender people in the United States experience significant barriers to health care in part because there are no federal protections related to health care access for transgender people (Lerner & Robles, 2017). Patel et al. (2019, p. 40) noted, for transgender individuals, "access to healthcare is challenging in a system built on a binary model that exacerbates gender dysphoria and on healthcare insurance schemes that do not cover gender affirmation therapy." As of 2018, 12 states had antidiscrimination policies for Medicaid, private insurance, and state employee benefits that could protect transgender people (Bakko & Kattari, 2019). Barriers to health care among transgender individuals vary substantially by geographic region, with care refusal being more common in the South and West (Safer & Chan, 2019).

Beyond the lack of widespread antidiscrimination protection, transgender people commonly experience other barriers to health care. Although some barriers are similar to those experienced by cisgender individuals, the contexts in which they emerge in the lives of transgender individuals are notably different. Many transgender people cannot access needed medical care because they lack health insurance and do not have the resources to pay out of pocket. Lack of health insurance

and economic resources is due to under- and unemployment (Gehi & Arkles, 2007; James et al., 2016). Even with insurance, health care and gender transition-related care are regularly denied (Gorton, 2007). Hostility, refusal of service, and dehumanizing health care interactions are commonly reported by transgender people (Harless, Nanney, Johnson, Polaski, & Beach-Ferrara, 2019; Wanta & Unger, 2017). According to the 2015 Transgender Discrimination Survey, one-third of participants who visited a health care provider in the previous year had at least one negative incident, while transgender people of color and those living with disabilities reported even higher rates (James et al., 2016).

The minority stress framework (Meyer, 2003) explains that stigma, anticipated stigma, and concealment of stigmatized identities are unique stressors experienced by those with minority statuses as they navigate systems and institutions designed for the normative majority. Recent research suggests that anticipated stigma is influential and critically shapes decisions about the future (Thomeer, LeBlanc, Frost, & Bowen, 2018). Although many sexual and gender minority individuals are resilient (Meyer, 2015), minority stress and outright discrimination cause distress and can limit or disrupt access to a usual source of health care – one of the primary indicators of inadequate access (Myers & London, 2005). Few health care providers are adequately prepared to provide competent and affirming care to patients whose embodiment complicates normative sex/gender/sexuality binaries. Thus, intentionally or unintentionally, providers may behave in offensive ways that trigger minority stress processes and further compromise health care access (Agénor et al., 2016; Dickey, 2017; Harb, Pass, De Soriano, Zwick, & Gilbert, 2019). One-quarter of the transgender participants in the Southern LGBTQ Health Survey reported rarely or never feeling comfortable seeking care in their community (Harless et al., 2019). Although designed to increase access to affirming care, LGBTQ community-based health care clinics are not always equipped to meet transgender people’s needs (Paine, 2018; Seay et al., 2017).

Evidence indicates that transgender people face numerous challenges to accessing health care. These include a lack of federal protection, exclusionary insurance policies, lack of transgender-specific training for providers, and discriminatory practices both outside of and within the LGBTQ community. For many transgender individuals, these factors trigger minority stress processes and create barriers to accessing needed health care that compromise their ability to benefit from “continuity of care and positive health outcomes across the life course” (Bakko & Kattari, 2019, p. 1).

SSCS and Transgender People

The American Cancer Society (ACS) (2020) recommends that women obtain a Pap smear for cervical cancer beginning at age 21, with retesting every three years up to age 29 and, with normal results, every five years thereafter. For women, the ACS recommends yearly mammograms for breast cancer from age 45 to 54, and every two years thereafter. Men at normal risk for prostate cancer are recommended to obtain a prostate-specific antigen (PSA) test and/or digital rectal exam at age 50, with retesting every 1–2 years thereafter based on PSA level. Men at

high risk begin screenings at 40. Although the ACS acknowledges that testicular cancer can be detected at young ages, it notes insufficient evidence regarding the effect of regular testicular self-exam on testicular cancer mortality. Therefore, the ACS does not have a policy recommendation about self-exam, but most physicians agree that testicular exams should be a routine part of general physical exams.

Screening guidelines published by the ACS and other organizations aid in the prevention and detection of cancer. Recommendations are based on sex assignment at birth, natal organs (e.g., breasts, cervix, prostate, testicles), age, and previous screening results. They do not have specific recommendations for transgender people. As a result, providers must assess the cancer prevention screening needs of individuals whose gender identity, natal organs, and/or embodiment do not align due to gender transition-related hormones or surgeries. Relying on birth sex assignment or embodiment alone is inadequate to assess medically needed screenings and may result in unmet needs for cancer prevention and detection.

There are few transgender-specific recommendations for breast, cervical, prostate, and testicular cancer screenings and limited data on use of SSCS by transgender individuals (Patel et al., 2019). Fenway Health recommends that transgender women who have used hormones for five years or more and are over age 50 have breast exams annually, and that transgender men who have had a bilateral mastectomy receive chest wall and axillary exams after age 50 (as cited by Susan G. Komen Foundation, 2019). For transgender men without bilateral mastectomy, Fenway Health's recommendation is the same as the ACS's recommendation for women (as cited by Susan G. Komen Foundation, 2019). Emerging research shows that transgender people receive SSCS at different rates than cisgender people. Pap smear rates are lower among transgender individuals assigned female at birth than cisgender women (Gatos, 2018; James et al., 2016; Peitzmeier, Khullar, Reisner, & Potter, 2014; Seay et al., 2017). Transgender people assigned male at birth have lower rates of up-to-date PSA screenings (Dente, Farneth, Purks, & Torelli, 2019).

An under-researched, under-researched concern that intersects with transgender embodiment and cancer risk is long-term hormone replacement therapy (HRT) (Tabaac, Sutter, Wall, & Baker, 2018). We know less about long-term testosterone use and breast cancer risk among transgender men (Dente et al., 2019; Tanini et al., 2019), or breast cancer risk associated with long-term progesterone use among transgender women. One study reported a higher, but not statistically significant, incidence of breast cancer among transgender women than among cisgender men (Dente et al., 2019).

Although some extant research focuses on the nexus of gender identity and cancer care (Sledge, 2019), few medical sociologists have focused on transgender embodiment and cancer prevention. We focus on SSCS among transgender people because of their importance for overall health. Additionally, we concentrate on SSCS because they represent a theoretically important context for investigating the influence of transgender identity and embodiment on health care access and experiences. We contend that many health care barriers that transgender people face can be overcome by policy and practice changes. Our primary research question is: How do people who gender transition manage entrenched

binary sex/gender approaches to SSCS when they themselves are renegotiating the same binary through their own gender identity and embodied transition?

METHOD

The sample includes 39 participants who identified with the term “transgender,” were 18 years or older, and lived or desired to live in a gender different from their birth sex assignment. These individuals had participated in the lead author’s mixed methods dissertation project (Wentling, 2016, 2020) and indicated that they were willing to be recontacted for a follow-up interview. Given that transgender studies have mostly focused on gender transition among white, middle-class transgender people (Bryant & Schilt, 2008; Witten, 2009), our research team purposively sampled on the basis of race/ethnicity, as well as younger and older age, and military service status. Interviews were completed between March 14, 2012 and July 3, 2012, and ranged from 35 minutes to 3 hours and 17 minutes. We conducted interviews by telephone or voice over internet protocols, and, with participants’ consent, we audio recorded. We transcribed audio-recordings verbatim. Our project was collaboratively designed by the authors and approved by Syracuse University’s Institutional Review Board. Our five-member research team is diversely embodied by race, nationality, gender, sexuality, age, and transgender status.

Interview Questions and Analysis

Participants were interviewed conversationally. Our semistructured interview guide included a broad range of topics, with an extensive module of open-ended questions and probes related to health and health care, hormone use, and reproduction. One question asked about SSCS: “One thing that we are interested in learning more about is how people get information about and access to sex-specific screenings. For example, how do trans folks get needed, regular gynecological care and/or breast exams and/or prostate cancer screenings?” Most participants were asked the question directly, but sometimes information about cancer and SSCS emerged in the course of discussing other topics. Since interviews were conversational, we probed for additional details when health care access, cancer, or related topics appeared salient. We focus our analysis on the 35 individuals whose interviews included relevant SSCS information.

Informed by thematic narrative analysis (Riessman, 2008), we read transcripts to obtain a comprehensive understanding of participants’ experiences with health, health care, cancer, and SSCS. In the next stage of open coding, we created codes and later identified themes and analytical connections based on responses to the SSCS question or information volunteered in the interview. Through an iterative process of coding and rereading the transcripts, recurring codes were further refined until we arrived at a consensus concerning the primary themes for this paper. We present the dominant themes that emerged and include longer interview quotes to allow readers to hear participants’ voices (Denzin, 1989) and to better understand the complex, intertwined social processes that influence access to SSCS among transgender people. All names are pseudonyms.

Sample

Nineteen of the 35 participants identified as men, 15 as women, and one identified as genderqueer.² Nineteen identified as white, 10 as multi-racial, four as Asian, one as Black, and one as Hispanic. Twelve participants had military experience, 26 had an Associate's degree or more, and more than half were working. Household income varied considerably; 14 participants reported household incomes below \$30,000, while seven reported \$90,000 or more. Twenty-six participants had some form of health insurance.

Our sample is primarily binary gender-identified and diversely embodied, with participants reporting a broad range of gender transition-related decisions (Table 1). All but two men and all of the women were taking or had taken hormones. There were gender differences in reported transition-related procedures. Most men had undergone chest reconstructive surgery, while few women had received surgical breast augmentation. Two men had completed genital

Table 1. Transition-Related Decisions.

	Total <i>N</i> = 35	Men <i>N</i> = 19	Women <i>N</i> = 15	Genderqueer <i>N</i> = 1
	% (<i>N</i>)	% (<i>N</i>)	% (<i>N</i>)	% (<i>N</i>)
Age at Medical Transition				
18–24 yrs	34.3 (12)	45.0 (9)	16.7 (3)	–
25–34 yrs	20.0 (7)	20.0 (4)	16.7 (3)	–
35–44 yrs	22.9 (8)	10.0 (2)	38.9 (7)	–
45–54 yrs	2.9 (1)	–	16.7 (3)	–
55–64 yrs	8.6 (3)	10.0 (2)	5.6 (1)	–
Not Applicable	11.4 (4)	10.0 (2)	5.6 (1)	100 (1)
Total Years Since Medical Transition				
0–5 years	45.7 (16)	57.9 (11)	33.3 (5)	–
6–10 years	22.9 (8)	21.1 (4)	26.7 (4)	–
11–59 years	14.3 (5)	10.5 (2)	20.0 (3)	–
Not Applicable/Missing	17.1 (6)	10.5 (2)	20.0 (3)	100 (1)
Hormones				
Yes	91.4 (32)	89.5 (17)	100.0 (15)	–
No	8.6 (3)	10.5 (2)	–	100 (1)
Procedures and Surgery				
Breast Augmentation	8.6 (3)	–	20.0 (3)	–
Chest Masculinization	40.0 (14)	73.7 (14)	–	–
Genital Surgery	20.0 (7)	10.5 (2)	33.3 (5)	–
Hysterectomy	14.3 (5)	26.3 (5)	–	–
Health Provider Knows				
None of the Time	8.6 (3)	–	13.3 (2)	100 (1)
Some of the Time	11.4 (4)	21.1 (4)	–	–
Half of the Time	14.3 (5)	10.5 (2)	20.0 (3)	–
Most of the Time	17.1 (6)	21.1 (4)	13.3 (2)	–
All of the Time	48.6 (17)	47.4 (9)	53.3 (8)	–

surgery, while one-third of the women had done so. One-quarter of the men had obtained a complete hysterectomy. This aspect of embodiment (i.e., hormone use and gender-affirming surgeries) informs needs for specific kinds of exams and thus shapes narratives about SSCS-related encounters. For example, a man who had a complete hysterectomy would no longer need a Pap smear, while a woman who had genital surgery would not need a testicular exam, but would need vaginal and prostate exams.

Participants ranged in age from 19 to 70, with 20 of the participants between 25 and 44. Overall, the men in our sample were substantially younger than the women. Almost half of the men reported that they tell their providers about their transgender status all the time, while a little more than half of the women reported the same. Concealment of transgender identity and anticipated stigma related to health care encounters can produce significant distress and may represent barriers to needed health care.

NARRATIVES

SSCS and Embodiment

Embodiment shapes SSCS experiences. For transgender people, SSCS can be difficult if they give rise to or intensify body dysphoria. Transgender persons are socialized in a cancer-aware culture, which is suffused with admonitions about cancer prevention, direct-to-consumer advertising of cancer treatments, and tributes to cancer charities by famous people. Therefore, they are likely to recognize cancer risk and the importance of screenings. Yet, screenings involve personal histories and identification requirements that highlight transgender status. As a result, SSCS can increase personal discomfort and vulnerability to discrimination by health care professionals, which in turn can activate minority stress processes. Moreover, SSCS are body focused and concentrated on areas that often do not feel good to transgender people. Thus, embodiment is central to these processes. As [Paine \(2018, p. 353\)](#) notes, gender nonconformity – “one’s performed or embodied relationship to dominant biomedical definitions of binary sex/gender/sexuality, which assume gender identity, sex assigned at birth, sexual identity, and performance of gender to normatively align” – can disrupt medical encounters. In such circumstances, patients’ bodies and embodied gender performances become foci of gender nonconforming individuals’ medical encounters and management strategies.

Demonstrating the salience of cancer in the lives of transgender people, 21 participants discussed cancer in some detail. Some participants spoke about how cancer affected family members, and a few shared their experiences as caretakers. Participants also talked about their own strategic use of cancer-related insurance codes as a means to get access to gender transition–related care, personal fears about getting cancer, and experiences with cancer, including surgeries. These experiences provided the context for discussions of SSCS and cancer-related encounters with health care providers.

Participants discussed strategies to make SSCS more positive experiences. In some cases, they identified gender-affirming aspects of these events. Our findings resonate with those reported by Dewey (2008), who found that transgender individuals experienced anticipatory stigma-related stress and invested a lot of energy in preparing for medical encounters. They also resonate with and extend Paine's (2018) findings related to embodied disruption in medical encounters. With attention to gender differences, age, and embodiment, we elaborate on four themes that emerged in participants' SSCS discussions: discrimination; discomfort and hyperawareness of genitalia; strategic reframing and active management; and SSCS health care encounters as positive and gender affirming.

Experiences of Discrimination

Participants described researching extensively to find transgender-friendly and transgender-competent providers, reflecting agency and resourcefulness. They found these providers through referrals from transgender friends, by querying local community networks, and through internet research. Still, several individuals reported experiencing discrimination when accessing SSCS. Many of these experiences resonate with gender nonconforming patients' experiences of embodied disruption in health care encounters (Paine, 2018).

Nova, a white woman in her late 40's, is a veteran who received all her health care through the Veterans Administration (VA). Revealing the complexities of embodiment in context, she described negative experiences with VA staff when accessing care.

[The VA is] extremely prejudicial. They refused to use proper pronouns and they would do things like, you know your presentation is female, you look female, none of the other veterans are looking at you funny and you're sitting in the waiting room waiting for your appointment, waiting with your fellow veterans. And the VA staffer, VA doctors come out to the waiting room with the clipboard and loudly announces, "Mr. Jones? Mr. Jones? Is there a Mr. Nova Jones?" So, you stand up and walk across the lobby and everybody's just staring at you with their mouths open. And you go into the examining room and tell the person, "What the hell is that all about?" And you explain to them, and sometimes they just stare at you and don't apologize, and sometimes they do. It depends on the person....It was like trying to move mountains to get them to comply with their own directives to use proper citations, proper gender, when they talk to you, and in their correspondence, and in their records. They're supposed to change that. They have federal directives that are mandatory. To this day, some of the clinics won't comply with their duty to do that, and depending on the clinic you go to, it still happens.

Specifically discussing SSCS, she told us, "I haven't even had any yet. According to their new directive, [the VA is] supposed to provide all that. Before that directive, I was told there would be no, for example, mammograms. Now, at least they're talking about giving mammograms and any kind of gynecological exams too." Although Nova reported positive experiences with her primary care physician at the VA, accessing care required her to interact with staff who refused to use correct gender designations, essentially outing her to fellow veterans. Her encounter reveals the salience of embodiment and both the importance and

limitations of federal directives; federal mandates can change discriminatory healthcare policy, but staff attitudes and behaviors are more difficult to change.

Alix, a 35-year-old Native American man, shared how his negative experiences with cancer care have predisposed him against seeking future medical care. His story makes explicit that transgender embodiment can disrupt medical encounters when providers assume alignment of all of the components of embodiment, and that the scars from medical procedures are not always only physical. Doctors found an enlarged lymph node in his groin, requiring multiple gynecological exams and its ultimate removal.

It was really hard, emotionally really hard. And, you know, [it's] the little things that start happening. They sent off the Pap smear information, and when it came back, it all was terrifying. The numbers were terrifying and the doctor freaked out. And then I freaked out. Then, I realized that she had been coding me as a woman instead of coding it as somebody whose body has had testosterone. We had to do another exam to send it off again. Those are the little things that, even though they are not overt, and they are unintentional, they have absolutely become these micro-abrasions and micro-aggressions of 'I don't want to do this.'...[P]re-surgery [my surgeon] was really great. Male pronouns and everything was fine. Post-surgery, because she had seen my body naked, um, referred to me in the female pronoun. It was two and a half, three years into transition, post-chest surgery. I very much look like I do right now. So, that was her process of like, "Oh, I can't navigate the physicality of this person's body outside of who they are." That was an interesting thing, but again, it's that thing that you put in your pocket and say this is the reason why I don't access medical care.

Alix's encounter was complicated by medical testing that was conducted based on birth sex rather than his embodied testosterone levels. It was made more challenging by his physician, who was unable to reconcile her use of pronouns with her interpretation of Alix's body.

Brenton, a white Hispanic 45-year-old man, described going to a women's clinic for his pelvic exams and experiencing discrimination.

They routed me through the women's clinic because I was pre-surgery, and I still needed my annual checks. They said the only way I'd be able to get them was if I went, if I was a patient of the women's clinic. I said, well, whatever, I don't really care. Those are important, you know, tests to have done. But, then the doctor and the nurse practitioner and the resident, all female, were horrible to me. It was not a good experience, and after about three times of being treated really poorly, I just left. I mean, I lodged a complaint. I did all that I could and then I got them to do in-service training. So, hopefully it's better for people now, but it was a pretty bad experience.

Brenton approached pre-surgical SSCS as a necessity and accepted that it had to take place at a "women's" clinic, justified by his birth sex assignment. He emphasized that the health professionals with whom he interacted at that clinic were women and expressed frustration that implied an unmet expectation: *because of their gender* and where he received care, he should have been treated better. Demonstrating agency and resilience in response to the discrimination, he filed a complaint and pushed for in-service training for staff hoping to improve future care for other transgender people. Ultimately, after having surgery, Brenton no longer needed the SSCS that necessitated his visit to the women's clinic in the first place.

Robert, a 63-year-old white man, began his transition in the 1970s while serving in the U.S. military. Soon thereafter, he received an honorable discharge because of his gender identity. He took testosterone on and off and underwent what he called “a botched double mastectomy.” At age 38, he “wound up getting ovarian cancer and had a hysterectomy.”

I'd been changed for, you know, living as a man for about almost 15 years by then. So, that was a little awkward. I was in the Boston area and I started going to, when I started having problems, I couldn't figure it out. You know, I tried a few times to go for just general medicine, and as soon as the doctor would learn I was transgender or transsexual or gender dysphoric or whatever terms they were using back then, they just freaked out and backed off and wouldn't deal with me. I was totally freaked about approaching anybody medical. I found out about a gay clinic in Boston and so I went there. There it was of course primarily male, but I did find a very sympathetic doctor and he worked with me. He wasn't able to exactly diagnose at first. It was a while before they figured out what was going on. He sent me to a gynecologist in Boston....She wasn't entirely supportive of the transgender thing, but the main concern was the fact that it was cancerous.

Participants' narratives exemplify some of the ways that discrimination related to health care professionals' reactions to their embodiment keeps transgender people from accessing care. Nova had to navigate discriminatory policies at the VA, as well as discrimination from VA employees. Alix, dealing with a physician who struggled to reconcile his gender with his body, described his negative Pap smear event as “that thing that you put in your pocket and say this is the reason why I don't access medical care.” Brenton experienced negative treatment from multiple medical professionals over several visits to the women's clinic, ultimately deciding that he would not return. Robert had difficulty finding a doctor willing to treat him and when he did, “she wasn't entirely supportive of the transgender thing.”

Micro-abrasions, a term Alix introduced, is an apt metaphor for understanding the effect of such embodiment-related discrimination. Regardless of the type, discrimination in health care encounters often wears down self-acceptance and empowerment, and disenables access to medically needed health care. Anticipated stigma resulting from prior discrimination can also predispose transgender individuals to avoid seeking future care. Sometimes discrimination stimulates resistance and advocacy for change, as in the narratives of Nova and Brenton.

Discomfort and Hyperawareness of Genitalia

Participants described how aspects of their embodiment – birth sex assignment, age, and medical transition – led them down different paths with respect to SSCS. Many – mostly male – participants described varying degrees of discomfort rooted in SSCS. For example, Ethan, a 35-year-old Hispanic man, lost his mother to breast cancer when he was nine. His maternal aunts also had breast cancer and his mother's twin sister died from it shortly before the interview. In Ethan's narrative, cancer intersected with his sense of self, embodiment, and health care use in complex ways.

My family is a breast cancer gene carrier....Throughout my life I've had to have mammograms much earlier than most women and often. Tons of testing in an area of my body I did not feel good about....I ended up getting tested for the gene and I didn't have, I don't have the gene.

But, had I had, if I would have had the gene, they told me I was going to have a bi-lateral mastectomy and hysterectomy. I was actually hoping that that was going to be the case. And, you know, that didn't work out. That's one of the things where I look back, which is before I even knew I was transgender....I didn't know why I was excited for that and now looking back, now I understand.

Ethan's genetic history of breast cancer required early and frequent mammograms; while many individuals experience discomfort during SSCS, the individuals we interviewed shared experiences of discomfort that were unique to their embodiment as transgender people. SSCS can call attention to areas of the body that cause dysphoria, that conflict with gender presentation, and/or that they just “[do] not feel good about.” While Ethan chose medicalized language (mammograms, bilateral mastectomy, hysterectomy) to reference things that might happen to his body, he used abstract language when he described his body to distance himself from female-gendered characteristics. Yet, he also indicated that the “BREast CANcer gene” (BRCA) could have been valuable to him. A bilateral mastectomy related to BRCA would be performed as medically necessary preventive care and covered by insurance, while the same procedure as part of his gender transition may not have been. Transgender people navigate discrimination when accessing SSCS, but, as Ethan shows, they also must navigate how SSCS can highlight areas of their bodies that make them uncomfortable.

Sandy, a 40-year-old white/Native American woman, referenced body-focused discomfort when talking about both breast and prostate exams. Not having had genital surgery, she told us about receiving a mammogram and manual prostate exam in the past year: “I thought getting a mammogram was pretty weird cause I don't have that much breast tissue. I guess I had to do that because the guidelines say women over age 40 have to start getting a mammogram every couple of years. The prostate exam kinda freaked me out a little because I don't like people going into my private parts like that.” Sandy followed her doctor's recommendation, although she expressed discomfort with the physicality of the breast and prostate exams.

Toby, a 27-year-old Black man, described relatively positive experiences accessing gynecological care at women's clinics. He thought the providers were prepared and interacted with him in supportive ways. Yet, his narrative is infused with moments of social and body-focused discomfort related to being a man in a woman's clinic and receiving a needed SSCS.

It's kinda funny, just to be an unaccompanied man in the gynecologist waiting room....Actually, I've had two Pap smears in two different settings. Both of them were fine. Both of the providers were definitely up to speed and on board. I mean, they made me as comfortable as possible. They were like, “Okay, here comes the speculum. Okay, here's this sensation you might feel,” like all these things, so they were very specific and tried to make me as comfortable as possible. Just the main thing for me is that penetration is not comfortable for me – and it's not psychological, just physically, it's not comfortable. That's a lot of my hesitancy, and also just having to be super aware of my genitals at that moment. It's like AHHHH, on top of the physical discomfort. It's a pretty intense moment, but again the providers that I've had have been great. They are fine with my pronouns, so they make it as comfortable as they can for me.

Toby's positive experience resulted in part from having knowledgeable and affirming providers who attempted to reduce his anxiety by narrating what was happening. Yet, like other men we interviewed, he still described physical discomfort and hyperawareness of his genitalia. Such discomfort – connected to his embodiment as a transgender man – makes him hesitant about accessing needed SSCS.

Brian, a 35-year-old white man, spoke very positively about his primary physician, but his tenor changed in relation to pelvic exams.

Every time I see my doctor, it feels like, oh no, she's gonna want me to have one of those things done. You know? And, to her credit, she does them quickly, efficiently, and asks first if I'm comfortable. Prior to that, I had not had a gynecological exam since I was 17. That was one of the things that we talked about initially. Not only do I hate them, but it's, it's so uncomfortable, even if it's only for 5 minutes. It really is something that I've really had to fight with for myself. I understand health-wise it's important, but mental health-wise, it's, it almost becomes an obsession. It's all I can think about. This is coming up, it's 10 days away, it's 9 days away, and it's tomorrow....This sounds horrible, but I would rather [pauses] without the comfort level there, I would rather even get sick than have someone kind of invade that. I don't even know how else to put it, but, it never, the fear of being sick or having cancer or any of those things was never enough to get me to go have it checked out.

Brian spoke of stress, avoidance, fear, the physical discomfort of the exam, and how the procedure impacted his mental health. While he appreciated his physician's efforts to minimize discomfort, acknowledged the need for the exam, and had health insurance coverage, pelvic exams were still an invasion. The anticipation of the appointment created an obsessive stress that impacted his mental health well before the actual appointment.

Many of the individuals with whom we spoke were uncomfortable with SSCS, sometimes because of where they received them, but more often because of the ways SSCS drew attention to areas of their bodies that made them uncomfortable. Having knowledgeable and supportive providers helped. Some, like Toby and Brian, spoke about physical and psychological distress that went beyond discomfort. Brian went so far as to admit that he might “rather even get sick than have someone kind of invade that.”

Strategic Reframing and Active Management

SSCS are stressful for transgender individuals. From the waiting area to the examination room, there are many opportunities for tension and conflict to materialize. SSCS can inspire a person to be hyperaware of the discordance between their embodiment and how others might perceive and interact with them. Such hyperawareness is exacerbated by the type of screening, the physical space, and who conducts it. Consistent with Dewey (2008) and extending Paine's (2018) analysis of how gender nonconforming individuals manage embodied disruption, participants navigated SSCS by strategically reframing the situation, and by exercising agentic engagement and active management strategies. For example, Vinny, a 38-year-old Black man, talked about getting a mammogram at a prestigious university hospital. He described his family history of breast cancer,

his experience of the space, how his embodiment shaped encounters, and the emotion work he did in order to access needed SSCS.

They call my government name. They look at me, and I greet them with a smile. I’m extra nice to make them feel comfortable. In my mind, I tell myself, men get breast cancer too. This is why it’s okay for me to sit in here and be comfortable. That’s what I have to tell myself. Secondly, I know they’re a little larger than men’s breasts. *[laughs]* In my mind, I create a scenario to help me get through it. In my scenario, in my mind, I have a condition that makes mine extra fatty, which helps me get through. Once I go in there to get the mammogram, I let the woman know I’m on T [testosterone], this is who I am. The lady was really open. She was like, “Oh my God! I never met one. I mean, met a real transgender person in-person.” This took extra-long only because she wanted to know all about it. She was good with it, but it is uncomfortable. But, you have to understand, men do get breast cancer. This is a necessary health care treatment for me. My mother had breast cancer and my aunt. It runs in my family. I need to go get this done no matter what, so let’s get it done....In other words, man up. *[laughs]*

From the initial call of his *dead name* (name given at birth) in the waiting room, Vinny strategically managed the interaction with the health care worker. He is uncomfortable in the space, outs himself as transgender, and endures being treated as a spectacle. His family history contextualizes how he constructs meaning and manages his emotions. Knowing he needs the mammogram, he just has to “man up.” Vinny reminds himself throughout the encounter that “men get breast cancer too,” actively helping himself to feel more confident as a man who requires a mammogram.

Jeff, a 67-year-old white man, shared his encounter at a women’s clinic, where, based on his embodiment, he was initially told he was in the wrong place. Despite this, he describes actively managing the situation to get the needed Pap smear.

Sixty years of being in a female body...you kind of learn to put up with the parts of it that you hate and find the parts in it that are good....a while back *[insurance provider]* sent me to the women’s clinic, which was pretty hilarious because when I got there, the clerk at the Pap smear clinic office told me that I was on the wrong floor and that this was the women’s clinic. Then, I had to explain to her that I was a trans man and I still had a “mangina”....I told my PCP about that. They don’t send me to the women’s clinic anymore.

Naming his “mangina,” Jeff creates a portmanteau that reflects his embodiment and the presence of natal organs, which, under the prevailing institutional arrangements, routed him to a women’s clinic to receive needed SSCS. His retelling is positive and described as humorous, which may be because Jeff, like others who described positive SSCS encounters, experienced it as gender affirming. In initially turning him away from the women’s clinic, the clerk reaffirmed his masculinity; he was so obviously male that she believed he was on the wrong floor. Ultimately, he strategically managed an otherwise trans-incompetent situation to access needed care.

SSCS as Positive and Affirming

For participants who described SSCS in positive or gender-affirming terms, the setting, provider competence, and their embodiment were critical factors. Men who reported positive experiences often described them as mitigating their

general discomfort with SSCS because of where they were able to access them and who provided the care. For example, Avinash, a 35-year-old South Asian man, described traumatic psychological discomfort with SSCS. He was also concerned that his embodiment could disrupt the medical encounter and that provider distress could add to his own distress. Yet, despite his anxiety, he reported relatively positive gynecological exams at a LGBT health clinic staffed by trans-knowledgeable providers.

I was always frightened about getting gynecological, like those kinds of exams. That was always something that felt traumatizing for me and freaked me out. And, I think that there is this added layer of freaked out. So, then, I'm freaked out and now you are going to be freaked out. At [clinic name] for the most part, I don't feel that, because I just trust that everyone is on the same page. So, I just have my general freaked out-ness.

For Avinash, getting care at a LGBT health clinic provided a context in which he felt he could be expected as a transgender man and “trust that everyone is on the same page.” Lincoln, a 25-year-old white/Asian man, accessed gynecological care at a student health center, which he described as contributing to his comfort because it masked potentially discordant aspects of his embodiment from public scrutiny.

I went into student health and got my first gynecological exam. It wasn't that bad. Again, the woman was super...I mean, it would have been a lot different going into an office that was basically, for women...sitting in the waiting room with a bunch of women and being called in. That would have been really awkward. But, the fact that you are sitting in student health, no one really knows where you are going. You know, people are just like catted into the waiting room and you have no idea where anyone is going. So, it is a lot more anonymous. And that was good.

Like Toby, Avinash and Lincoln experienced discomfort when accessing gynecological care that was mitigated by their providers and care settings. Avinash can be less “freaked out” knowing that he will not have to explain transgender health to his providers, and Lincoln's gender is not undermined by having to access care in a women's clinic.

In contrast to men, women who reported positive experiences with SSCS often described them in the context of gender-affirming interactions. Anna, a 27-year-old white woman, referenced a breast cancer scare.

They [doctors] felt like I had breast cancer for a while, when I started transitioning. And it came back negative. I had gone a couple times for breast examinations and, like, the doctor, surgeon who I had seen treated me like a woman. They made sure that a female nurse came in with me and was there while they examined me. They were treating me like my gender...On the one hand, it was, it was scary, because I was like, “Oh my gosh, do I have breast cancer?” But, at the same time, it was cool. It was awesome. I felt like a woman. You know it was like this mixture of fear and excitement.

In describing her experience, Anna highlights how the doctor made sure there was a female nurse present during the exam as would be the case for any woman. Despite being scary, the cancer scare was also “awesome” because it affirmed her embodiment, making her feel like a woman.

Marie, a 68-year-old white woman, shared her ongoing, medical need for prostate screening. She referenced the ways that incongruence between anatomy and gender expression complicated access.

Oh, I want to tell you something funny. And this has to do with the healthcare system. I have a prostate gland. They didn't take that out. So, when I have my blood test, my doctor knows my whole history. She has them do PSA tests, which is generally for guys only. The nurse looks at this and she goes, "What? The doctor made a mistake. You don't have one of these things." I say, "Just run the test." She looked at me like what happened, like why? I said, "Just run the test. The doctor knows what she's doing." [laughs] So, they do it, but they look at me really funny. [laughs]

This appointment required Marie to advocate for the screening she needed. The nurse did not imagine that Marie could have a prostate; she looked at her and assumed that "the doctor made a mistake." Rather than being upset at having to correct the nurse and guide her own care, this interaction may have seemed "funny" to Marie because it affirmed her embodiment as a woman.

Similar themes are evident in Julie's narrative. She identifies the setting and having a usual source of care as factors that facilitate having a good experience. Julie is a 30-year-old white veteran with a 30% service-connected disability that entitles her to receive health care from the VA, which she described as the "best healthcare system in the world."

You know what's really funny? Is that every now and then I get flagged for a pap smear. I've taken to answering that question, "You know, if you can find something to smear, go right ahead." [laughs] You know, it's kind of a standing joke with my primary care nurse practitioner. [laughs] Because my records are...listed in the feminine, they do, those screenings do pop up. And so, the first time that came up, you know, my primary care nurse was like, "how the hell do we code this?!" [laughs] And, so, ultimately what we came up with was: "not-applicable, no uterus."

Caroline, a 46-year-old white woman, spoke about receiving manual prostate exams after genital surgery, which she described as positive in part because they are done vaginally rather than anally. Caroline explained that these are part of her gynecological care and described her provider as "cool," someone who self-educated to offer embodiment-affirming, trans-appropriate care.

Women who described positive encounters with SSCS often expressed how these affirmed something about their embodiment and gender. Breast cancer testing made Anna "feel like a woman." Marie's nurse was baffled that she required a PSA test and assumed the doctor had made a mistake. The VA's electronic health record repeatedly flagged Julie for a Pap smear. Caroline's prostate exams were performed by a provider who specializes in the female reproductive system, and, unlike Sandy's experience noted earlier, the completed exam was gender- and body-congruent.

Gender-affirming encounters among women called attention to participants' embodiment and status as women. These encounters were typically noninvasive experiences and did not cause physical or psychological discomfort. The SSCS for women tended to be less invasive (i.e., most prostate exams were PSA tests rather than manual exams) or accentuated gender-congruent areas of their bodies (e.g., breast exams). By contrast, for men, they were invasive or emphasized gender-incongruent areas of their bodies. This contrast is clear in the discussion of

mammograms, a SSCS recommended for transgender men who have not undergone mastectomies and transgender women with breast tissue. Attention to a woman's breasts may make her feel like a woman (see Anna's story), while a man who receives the same attention may experience dysphoria, not affirmation. This dysphoria necessitates cognitive reframing and emotion work to actively manage health care encounters (see Vinny's story).

DISCUSSION

In a society where cancer is prevalent and recommendations about cancer prevention circulate widely, it comes as no surprise that most of the participants in this study discussed cancer even when not specifically asked about experiences with SSCS. Cancer talk focused on family loss, care work, participants' own cancer scares, anxieties about getting cancer, and treatment. Such cancer talk served as the context for more detailed discussions about SSCS. Participants had a lot to say because SSCS stimulated hyperawareness of embodiment, and alertness to the health care setting and provider competence. While participants recognized SSCS as medically necessary, body dysphoria, concerns about competent health care, and prior discrimination shaped perceived access to needed screenings, health care experiences, and predispositions to seek future care.

Participants' narratives show how navigating the sex/gender binary built into the health care system and managing SSCS are rooted in a complex web of social processes and bio-logics, providers, electronic medical record systems, and physical spaces (e.g., women's clinics). The healthcare system and providers expect cisgender men and women whose identities, bodies, and medical needs align. Misalignment creates problems that are disproportionately borne by transgender persons. As our data indicate, transgender individuals encounter discrimination during SSCS, do emotion work and actively manage medical situations to obtain necessary care, and sometimes forego care altogether because personal and institutional barriers to access are insurmountable.

Consistent with [Paine \(2018\)](#), participants in our research reported experiences of embodied disruption due to mis/recognition in SSCS-related health care encounters. Embodiment and gender-affirming interactions with healthcare providers emerged as key influences in participants' access to and experience of SSCS. Narratives reveal gender differences in participants' experiences, behaviors, and access to health care. Many men described body dysphoria in anticipatory ways, during pelvic exams, and based on specific provider interactions. They often reported actively avoiding preventive health care, despite acknowledging its value. The women were more likely to share their experiences with pelvic and PSA exams as entertaining and gender-affirming. Because PSA tests are blood tests, and thus less intrusive, women who described prostate screening may have had less dysphoria. Manual prostate exams, completed vaginally instead of anally, may relieve some transgender women's discomfort associated with body incongruence or dysphoria.

Participants' narratives illustrated diverse interactions with healthcare providers in various settings. Some spaces seemed to facilitate access to transgender-competent

care, while others set the stage for discriminatory interactions with staff and health care providers. Some providers were more nurturing and acted proactively as advocates, while others were less willing to provide gender-affirming care. In some cases, providers were affirming while simultaneously treating patients as spectacles. Various factors influence providers' willingness to treat transgender patients. Recent research shows that willingness to provide routine care to transgender patients decreased as primary physicians' ages increased, and that, of all physicians, family physicians (as compared to internists) and providers who had previous interactions with a transgender person were the most willing to provide Pap smears (Shires, Stroumsa, Jaffee, & Woodford, 2018).

In addition to improving overall understanding of how transgender embodiment and minority stress processes influence access to needed cancer care – through nondisclosure of identity, discrimination, and anticipatory stigma – our findings may stimulate future research related to a number of core areas of medical sociological inquiry. These include but are not limited to studies of the politics of medical encounters, agency in managing health care provider interactions, the socialization of health care professionals, and the consequences of incompetent care.

Our study has a number of limitations, which also suggest directions for future research. First, SSCS questions were a minor aspect of a lengthy interview. As such, we minimally probed before moving on to the next topic. Narrower, more in-depth investigations that examine SSCS experiences across the life course, pre- and post-transition, and/or at specific ages or within specific cohorts would add considerably to the literature. Second, our question about SSCS did not include explicit reference to testicular exams, which may partially account for participants' silence about their related experiences. Future studies should prioritize transgender women's experiences with testicular exams. Third, the relatively young age distribution of our participants likely influenced the narratives that we obtained given participants' sense of need as some SSCS exams are recommended only at older ages. Studies that focus on older adults might yield different insights. Fourth, although individuals in our sample were differently embodied in a variety of ways, most participants were binary gender identified. Research with comparably embodied persons, as well as research that focuses on nonbinary-identified transgender persons, is necessary to generate insights about how providers treat transgender persons across a broad range of potential embodiments and identities. Finally, we did not ask participants about their understandings of the long-term impacts of hormone use, in general, or in relation to cancer risk. Future studies should attend to transgender individuals' understandings of the cancer risk associated with long-term hormone use, and how that influences their perceived need for, access to, and use of SSCS. Research on all of these topics can inform policy changes and improve practices.

CONCLUSION

Cancer prevention and detection requires health care professionals to expect diversely embodied people and to have processes in place that enable access to medically necessary care. Our research identifies how gender-affirming care can

enhance access and improve SSCS experiences among transgender individuals. The provision of transgender-competent SSCS is an attainable policy objective. It requires explicit training for office staff, medical providers, specialists, and insurance agents alike. In practice, providers should not make assumptions about medical care needs based on sound of voice or embodied appearance alone. Honoring chosen names, not using dead names, asking for chosen pronouns and respecting them, providing inclusive intake forms, and taking comprehensive patient histories (e.g., preexisting conditions, surgeries, embodiment) are all within the purview and control of health care providers. Providers can mitigate some SSCS-related discomfort by reframing how they talk about the body and screening recommendations. For instance, mammograms are not just for women; they are important for all people considered to be at high risk. Clinics that primarily offer gynecological services can normalize the idea that they are not solely attending to women's issues. Additionally, clinicians should be attentive to how their electronic medical records manage transgender patients. Many healthcare management systems do not distinguish between chosen and legal names. Relatedly, electronic medical records that recommend SSCS rarely account for the varying physical embodiments of transgender patients. By attending to embodiment in thoughtful and affirming ways, providers can decrease discrimination and discomfort and create more gender-affirming health care experiences for transgender patients. Taking these steps will improve interactions between medical providers and transgender patients. Enhancing these practices can reduce anticipatory stigma and improve access to and experiences of health care among transgender people.

Transgender-competent care improves access and health outcomes generally and may be particularly important with respect to SSCS. Reducing barriers and stressors that transgender individuals experience before, during, and after health care encounters, especially SSCS, may have positive spillover effects that impact a range of other physical and mental health processes and outcomes. Thus, we call on all professional bodies that develop and disseminate guidelines for SSCS to explicitly address the specific needs of transgender individuals and to develop training materials to support transgender-inclusive SSCS. A step in that direction is to increase awareness that preventive cancer screenings are not "sex-specific." They are relevant to individuals with medically necessary needs regardless of gender identity or embodiment.

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NOTES

1. We use embodiment and embodied interchangeably in this paper.
2. Genderqueer includes persons whose identities do not fit the binary gender categories of man or woman.

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