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CONTEXTUALIZING TRANSGENDER INDIVIDUALS'
DISCOURSES ABOUT HEALTH INSURANCE

By

Jonathan Baker

A THESIS

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CONTEXTUALIZING TRANSGENDER INDIVIDUALS'
DISCOURSES ABOUT HEALTH INSURANCE

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University of Nebraska, 2019

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Transgender individuals face a variety of disparate health outcomes compared to cisgender individuals within the United States. Additionally, 23% to 52% of transgender individuals do not have health insurance, meaning transgender individuals are two to five times more likely than the general population to lack access to health insurance coverage. Extant research typically treats health insurance as a quantitative (yes/no) variable; thus, we do not know what (not) having insurance contextually means for transgender individuals. The current study addresses this gap by privileging the voices of 17 transgender individuals through in-depth, semi-structured interviews. Using the Culture-Centered Approach (CCA), I conducted a constructivist grounded theory analysis to identify three key themes: *Including/Excluding Transgender Health Needs in Health Insurance Structures* (conditions), *Advocating Against and Resisting Structural Insurance Barriers* (actions/interactions), and *Compromised Health Decision Making* (consequences). I then lay out theoretical implications for Health Communication and systematic change, and practical implications for patient-centered advocacy.

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INTRODUCTION

The Affordable Care Act (ACA) was signed by President Obama in 2010 to ensure more accessible health insurance to U.S. citizens. Prior to 2010, 48.3 million Americans were uninsured; by 2015 the number of uninsured citizens dropped to 28.7 million (CDC, 2018), and in 2016, the number of uninsured individuals within the U.S. decreased by an additional one million individuals (Barnett & Berchick, 2017). While the number of uninsured Americans has steadily decreased since the ACA went into effect, access to insurance continues to be a highly contested subject within our current political climate—with democrats predominantly in favor of initiatives like Medicaid expansion and defending the ACA, and republicans typically opposing government expansion of social services prioritizing privatized individual choice of coverage—including the option to not purchase health insurance. For example, with the most recent tax law passed by Congress, financial sanctions for uninsured individuals were eliminated (Rappeport, 2018). Donald Trump claims that these recent actions have essentially eliminated the ACA; however, the tax plan still requires companies with 50 or more full-time employees to offer health insurance plans to full-time workers (Rappeport, 2018). The attacks on the ACA by our current administration and Trump's continued misrepresentation of legal precedent has created a state of political quandary, leaving citizens in a precarious situation in knowing their rights to insurance coverage (e.g. where to access insurance, potential penalties, and whether or not their employer is required to offer insurance).

While insurance is an often-discussed topic within politics and activism, research indicates that pragmatically it is also difficult to understand and navigate (Paez et al, 2014). Individual knowledge about health insurance is linked to health literacy in so far

as understanding one's own general health, health risks, and wellbeing; however, *health insurance literacy* is distinct because it is concerned with an individual's ability to understand payment sharing responsibilities, insurance coverage, and the organizational structures that must be accomplished to utilize coverage for care. Thus, increased attention has been focused on *health insurance literacy* within both health communication and public health research (see Furtado, Kaphingst, Perkins, & Politi, 2016; Paez et al, 2014).

Transgender individuals are less likely to be insured than cisgender individuals, and their health and wellbeing is impacted by the discourses surrounding health insurance, healthcare, and rights to accessing care. The National Women's Law Center (2013) argued that the ACA was a tremendous step toward access to insurance and healthcare for transgender individuals. This increase in coverage and access is connected to the ACA, which prevents insurance companies from denying coverage for preexisting conditions. The current attacks on the ACA will have tangible effects on transgender individuals, specifically their ability to access insurance and healthcare services in order to address their healthcare concerns (Kaiser Family Foundation, 2018). For example, transgender individuals experience rates of pre-existing conditions, lack of access to health insurance coverage, and inadequate care at rates up to twice as much as cisgender heterosexual populations (National Women's Law Center, 2013). Research on health outcomes for the transgender population is limited; however, extant research indicates that key issues include increased violence, mental health issues, suicide, and STIs (Substance Abuse and Mental Health Services Administration, 2012). In terms of health insurance, research indicates that between 23% to 52% of transgender individuals are

uninsured (Clements-Nolle, Marx, Guzman, & Katz, 2001; Sanchez, Sanchez, & Danoff, 2009; Xavier 2000). Therefore, transgender people are two to five times more likely than the general population to lack access to health insurance coverage that allows them to address health concerns (Barnett & Berchick, 2017; Clements-Nolle et al., 2001; Xavier, 2000).

The disparity in coverage for the transgender population reflects the struggle that marginalized groups encounter when addressing their health concerns within dominant political and health structures (Dutta, 2008; Dutta & Krepps 2013). As Harcourt (2006) points out, in health research “we still lack information of LGBT demographics and culture(s)” (p. 3), such as expanded nuances in our understanding of both gender and sexual identities. It is important to study the needs of LGBTQ groups because their health concerns are significantly different than cisgender heterosexual populations. For example, gender pronouns (i.e., he/she) and gender identity are often taken-for-granted by cisgender individuals who identify with the binary gender assigned to them at birth. The gender binary operates in a dichotomous relationship that limits gender identity to female and male; identities that fall outside of the scope of these two normative identities (e.g. transgender, gender queer, gender non-binary) are misunderstood and marginalized. For example, by centralizing the voices of transgender participants Ross and Castle Bell (2017) concluded that transgender patients trust healthcare professionals when providers use a patient’s correct name and pronoun. Therefore, as Dutta (2008) contends, it is imperative to begin understanding the culturally-centered meaning of health and health institutions starting with the voices of transgender individuals who are impacted by medical and academic discourses.

One way to better understand the experiences of these populations is through rich qualitative inquiry centered around the voices and experiences of transgender individuals (Harcourt, 2006; Stroumsa, 2014). Thus, this present study seeks to elucidate the meaning of health insurance and insurance coverage for transgender individuals within the United States starting from a culture-centered perspective (Dutta, 2008). To accomplish this goal, the voices of transgender individuals must be brought to the forefront of larger health insurance discussions. Below I provide a review of extant literature to document two things: (1) the challenges and experiences surrounding health insurance, (2) and patient-provider communication for transgender individuals. I then provide a rationale for a culture-centered approach (CCA) to studying health communication about insurance for transgender individuals (Dutta, 2008; Ross & Castle Bell, 2017).

LITERATURE REVIEW

The Problems with Insurance

Insurance is a complex system and difficult for individuals to understand and navigate (Furtado et al., 2016). Yet consumers must be able to make informed healthcare decisions to make the expanded insurance marketplace effective in addressing health concerns (Paez et al., 2014). Paez et al. (2014) created the Health Insurance Literacy Measure (HILM); the HILM identifies what health insurance information is most confusing for individuals to understand. HILM can be used for health insurance intervention efforts designed to assist individuals in choosing plans that cover their specific health needs. The HILM was developed using a sample that included moderate racial, educational, and socioeconomic status diversity; however, transgender identity categories were not included. The exclusion of transgender individuals is common in

health research because traditional methods of collecting large scale generalizable data sets struggle to gain representative numbers of transgender participants (Harcourt, 2006). Therefore, when addressing insurance knowledge and access for transgender people, purposive/participant-driven sampling and rich qualitative exploration allows researchers to more deeply understand the experiences and needs of these individuals. In turn, these methods allow researchers to advocate for increased access to insurance and healthcare to increase well-being for transgender individuals.

Though critiqued for their lack of attention to gender and sexual minorities, public health researchers have begun to expand their research goals to include specific concerns for transgender individuals (Boehmer, 2002; Ndiaye, Kreiger, Warren, & Hecht, 2011). Research shows that insurance influences an individual's ability to seek healthcare services to address health concerns and increase wellbeing. For transgender individuals, health insurance is also related to their ability to seek hormone replacement therapy, sexual reassignment surgery, mental health services, and general care (Bauer et al., 2009; Bauer et al., 2015; Clements-Nolle, et al. 2001; Khobzi Rotondi et al., 2013; Sanchez et al., 2009; Xavier 2000; Xavier, Honnold, & Bradford, 2007). Sanchez et al. (2009) found that for transgender women, access to insurance and a primary care provider increased the likelihood that individuals lived in their own home, were U.S. born, and were able to cover daily expenses. Conversely, inadequate access to coverage and not having a primary care provider was significantly associated with increased high-risk behaviors such as illegal drug use, smoking, needle sharing, and obtaining needles and prescription drugs from "nontraditional source" (Sanchez et al, 2009). However, their study did not provide an in-depth discussion of *why* some individuals engage in "high-risk" behaviors,

or the variety of reasons individuals seek hormone replacement drugs and needles from their interpersonal networks. Thus, transgender health literature would benefit from understanding what having insurance means for an individual's ability to seek healthcare to address their needs to increase wellbeing and their health concerns when and if they are not insured, or when coverage is limited.

Additionally, public health research on transgender health has focused on the eradication of HIV/AIDS, which the transgender community experiences at disproportionately higher rates than the heterosexual cisgender population (see Clements-Nolle, et al., 2001; Xavier, 2009). Research has shown that the absence of or lack of comprehensive insurance coverage increases individuals' risk of contracting HIV and the inability to address health related concerns once diagnosed with HIV. While this work on sexual health is important, the overemphasis on sexual health reifies stigma surrounding transgender identities and their sexual bodies—especially when one considers the limited research devoted to other aspects of health such as preventative care and general health concerns (Boehmer, 2002; Dutta 2008; Ndiaye, Kreiger, Warren, & Hecht, 2011). One way to fill this gap would be to centralize the voices of transgender people and provide culture-centered accounts of their experiences in a broader range of health contexts.

Patient-Provider Communication

The relationship between doctors and transgender patients is a tension between care and control. West (2011) notes that prominent doctors in New York City assisted transgender activists in New York City to change state and city laws about how sex and gender are reported on birth certificates. These providers felt that legal documents should affirm an individual's sex, but that healthcare professionals are important stakeholders in

this legal process. Therefore, the policy changes placed doctors in strict control over the legal recognition of an individual's sex (West, 2011). Typically, these policies require transgender individuals to be diagnosed with gender dysphoria, and in some instances undergo various gender affirming surgeries (e.g. double mastectomy, breast augmentation, sexual reassignment surgery) to *prove* their identity, before they can request changes to legal documents (e.g. birth certificate, driver's license, social security card) (Bigner & Wetchler, 2012). This begs the question: why are providers and government agencies given the power to construct definitions of gender and sex, often within binary understandings of both (West, 2011)? Definitions of gender and sex influence the daily lives of transgender individuals, from driver's licenses/photo IDs, to citizenry documents (e.g. birth certificates, social security cards, etc.) that are needed for employment, housing, and healthcare. Despite these legal linkages between doctors and patients, however, healthcare professionals often struggle to adequately provide care for transgender patients (Hudak & Bates, 2018; Ross & Castle Bell, 2017).

Education is a primary barrier between healthcare providers and transgender patients. Healthcare providers receive little to no training on the specific health needs of transgender patients. Obedin-Maliver et al. (2011) investigated the degree to which medical students are exposed to content on gender and sexual minorities. This study surveyed medical schools across the U.S. and Canada. Medical school deans were asked to fill out the survey and consult with other faculty members at their institution in order to gain the most accurate representation of the school's curriculum. To assess exposure to gender and sexual minority health information, they did two things: (1) they asked for the average hours of lecture dedicated to gender and sexual minority specific health

information in both pre and post-practical coursework, and (2) they created a 16-subject non-exhaustive list of topics (e.g. sexual orientation, gender identity, sexual reassignment surgery, transition, barriers to care) that medical schools offer in coursework. U.S. medical students are exposed to a total average of five hours of content lecture on gender and sexual minorities. 97% of medical schools taught students to ask patients if they have sex with: men, women, or both; but only 72% taught students the difference between sexual behavior and sexual identity (e.g. men who have sex with men vs. gay/bisexual men). Roughly 78% of schools teach students about gender identity, but only 35% provide instruction on sexual reassignment surgery and 30% discuss transitioning for transgender patients. Additionally, about 65% of schools discuss barriers to care experienced by gender and sexual minorities (Obedin-Maliver et al., 2011). Therefore, the present study seeks to understand how transgender patients discuss insurance with providers which could lead to implications for patient-provider communication about health insurance. By listening to the stories of transgender individuals, we can elucidate the ways in which doctors can better relay information about health insurance to provide more adequate care, leading to increased wellbeing and health access.

Furthermore, Ross & Castle Bell (2017) found that transgender individuals specifically feel more comfortable with their providers when their gender pronouns are respected during health encounters. Yet, transgender individuals are still frequently misgendered by healthcare workers, and extant research has found negative associations between provider use of gendered language and patients' perceptions of their providers' ability to help them address their health concerns (Bauer et al., 2009; Goins & Pye, 2013; Harbin, Beagan, & Goldberg, 2012; Ross & Castle Bell, 2017; Wagner, Kunkel, Asbury,

& Sotot, 2016). Discussing health concerns and informing patients about their insurance coverage can be difficult for providers in general, but this can be compounded for providers serving transgender patients who are negotiating communicative experiences they are rarely prepared for (Obedin-Maliver et al, 2011). Therefore, it is important to consider the varied levels of structural and interpersonal communication that influences transgender individuals' access to and discourses about health insurance.

The Culture Centered Approach to Health

Health Communication research has a long history of galvanizing dominant discourses of health produced by the biomedical model. A core value of this perspective on health and healthcare is focused on the eradication of disease and curing illness (Dutta, 2008). This requires doctors to be in charge of patient's health, with the patient acting as a passive recipient of care, rather than an active agent in their healthcare journey (Frank, 2013). Additionally, the attention to provider-patient interactions within the biomedical model does not address the social influences that impact health, such as political institutions and personal network relationships like family members, friends, and caregivers (Charon, 2006).

Dutta (2007; 2008) proposed the culture-centered approach (CCA) to theorize health and health disparities beginning with the voices of marginalized groups. Rooted in critical cultural theory and subaltern studies, the CCA interrogates the ways individuals and collectives negotiate structure, power and agency (Dutta, 2010). *Structure* is concerned with the rules, policies, and regulations imposed by larger health structures that marginalize subaltern communities. *Culture* refers to the daily practices of group members and the ways in which they come to understand shared meanings about health

and how it shapes the ways individuals understand and negotiate their health and health concerns. *Agency* is concerned with the ability of cultural groups to choose how to engage with their health, specifically whether or not they are able/want to gain access to certain aspects of healthcare systems. The CCA contends that health must be understood from the ground up to create meaningful change for disenfranchised groups (Dutta & Basu, 2008; Dutta & deSouza, 2008).

The CCA stands in stark contrast to the biomedical model's *objective* and *rational* understandings of health. The dominant biomedical healthcare model positions the medical community as the most, if not the only, group equipped to address and study health (Dutta, 2008); whereas the CCA "argues that the content of [these] knowledge claims are embedded within the practices of powerful actors in social systems that have access to the spaces of knowledge" (Dutta, 2008, p. 9). Thus, it is important to interrogate the knowledge claims made by dominant healthcare actors/institutions, because the discourses of the medical community historically and contemporarily benefit white, heterosexual, and cisgender individuals, which overpower the voices of marginalized groups through policies and procedures that privilege the knowledge of doctors and policy makers. Patients' cultural background is viewed as a barrier to improving health (e.g. religious beliefs, exploitation of people of color, gender or sexual identity as *cause* for mental/physical health issues) (de Souza, 2013, p. 415, as cited in Dutta, 2008). By constructing the medical community as the only rational study of health, providers and policy makers are positioned as gatekeepers of health and wellbeing. Health Communication has long been rooted within the biomedical model of health and dedicated to upholding and maintaining the status quo outlined by the medical

community; Health Communication has contributed to the erasure of marginalized voices from dominant understandings of health and well-being (Dutta et al., 2013; Dutta-Bergman, 2004a, 2004b). Thus, a central component of the CCA is to uplift the voices of marginalized populations, in order to articulate new ways to understand health, well-being, and health institutions.

According to the CCA, researchers must call into question taken-for-granted assumptions of the political, social, and economic order that structure the ways in which individuals communicate about their health (Dutta, 2008; Dutta, 2013). The biomedical model makes places healthcare providers and healthcare institutions in control of monitoring, studying, and addressing patients' health (Dutta, 2008). Thus, scholars must be careful in their research and praxis to not strip individuals of the agency to monitor and care for their own health and health concerns within and around healthcare establishments (Dutta & de Souza, 2008). The CCA is a practice of honoring cultural understandings of health from marginalized group perspectives to clarify the struggles they negotiate with dominant structures. This in turn allows research to denaturalize the existing order of healthcare and health research—producing theories that imagine new ways of understanding health and wellbeing (Dutta, 2008; Dutta 2013). Therefore, it becomes increasingly important to understand the ways marginalized groups come to understand the meaning behind dominant health structures, such as insurance, in order to advocate for systemic changes to increase wellbeing for marginalized communities.

Health insurance is a complex socio-legal institution, and it is often employed as a variable within social scientific research. In quantitative health research, the use of health insurance as a dichotomous (yes/no) variable allows researchers to understand the ways

insurance is statistically associated with various health outcomes. However, the present study contributes to extent literature by using the CCA to: (1) situate U.S. based health insurance as a unique healthcare context for transgender individuals; (2) focus on how transgender individuals articulate physical and mental needs (not) being met through insurance coverage; and (3) use rich qualitative data to understand what (lack of) insurance coverage means for transgender individuals health decision making. Therefore, I proposed the following research question:

RQ: How do transgender individuals use communication to navigate (not) accessing transition-related healthcare through the structure of health insurance?

METHOD

The CCA positions the researcher in conversation with cultural members, in order to allow individuals to articulate meanings of health from their subjective vantage point (Dutta, 2008). This dialogic process allows theoretical understandings about health and healthcare to emerge from the data in a co-constructive process between participants and the researcher and privileges the voices of marginalized communities. Thus, the current study sought to explore *how* insurance, as a structural context, enabled and constrained participants' ability to access gender-affirming care, rather than using insurance as a quantitative variable associated with (not) receiving care.

Participants

Following approval from UNL's institutional review board, individuals were recruited through purposive and participant-driven sampling (Tracy, 2013). To gain a broad understanding of individual's experiences, I recruited individuals who were at least 19 years of age and identified as transgender, genderqueer, or gender non-binary.

Interested individuals contacted me via email and were sent a link to a Qualtrics survey where they electronically gave consent to participate in the study and then filled out a brief demographics survey (See Appendix A). I posted the recruitment script in 17 Subreddit online communities ($n = 14$), contacted people within my social networks ($n = 2$), and shared my research call with LGBTQ support groups ($n = 1$). In total, 17 individuals who identified as transgender participated in the current study. Three individuals were uninsured at the time of the interview (see table 1 for participant demographics).

Procedures

Interviews were scheduled and conducted in a space and at a time that was most convenient and comfortable for participants (e.g. coffee shop, campus office, community center, etc.). For individuals who did not live within a commutable distance, phone or video chat interviews were conducted. In total, interviews were conducted via: face-to-face ($n = 2$), video chat ($n = 5$), phone ($n = 9$), and video chat started but completed via phone due to network connection issues ($n = 1$). No differences between face-to-face interviews and distance interviews were apparent during analysis. The interviews ranged from 35 minutes to 3 hours and 10 minutes and averaged around 68 minutes.

Consistent with other health communication studies exploring the experiences of transgender individuals, semi-structured, in-depth interviews were used (Kosenko, 2010; Ross & Castle Bell, 2017). The interview guide included five sections (See Appendix B). The first section was an icebreaker where I asked participants to share an image with me that represented their experiences with health insurance and healthcare and explained the meaning behind their chosen image. The second section focused on access to healthcare

and health insurance. In this section, individuals were asked about how their coverage or lack of coverage impacts their decision making, what being insured means/would mean, and how they perceived their needs being discussed within larger political discussions about healthcare. The third section asked participants to reflect on patient-provider communication. Specially, they were asked about how provider(s) talk to them about their health and healthcare needs as well as how their provider(s) explain their coverage/lack of coverage to them, and the resulting options they have in decision making. In the fourth section participants were asked to discuss how they talk about health and health insurance with people in their social circles. In particular I asked who they talk to about these topics, how much information they share, and their satisfaction with this communication. The final section asked participants to reflect on why they participated in the current project, and to give advice to other transgender individuals about healthcare and health insurance. This portion was concluded by asking if I should be aware of anything that I did not ask them about during the interview. After the first five interviews I reviewed and reflected on this portion of our conversations and determined that my interview guide was adequate in addressing the scope of this current study (Charmaz, 2014).

Data Analysis

Interviews were audio recorded, transcribed verbatim, and checked for accuracy. I used Temi, an online computer-generated transcription service to transcribe these interviews. Following transcription, I read through each interview transcript to familiarize myself with the data. All transcripts were uploaded and coded using NVivo 12 software. To capture the critical cultural theorization of the CCA, I used constructivist grounded

theory for analysis (Charmaz, 2014). As outlined by Charmaz (2017) constructivist grounded theory is apt for critical inquiry and interrogating discourses of power, while also following the steps of the grounded theory method. To ensure the accuracy of my analysis, I have kept journal entries before and during the research process to track methodological choices I made (Bute, 2009). Additionally, during the initial and focused coding stages, I wrote theoretical memos to begin making sense of the interconnected relationship between themes in my data (Charmaz, 2014).

I began my analysis by initial coding the entirety of the first five interviews. During this phase I remained open to all possible emergent themes (i.e. prominent and recurrent patterns regarding health and health insurance generally) within my data by using in vivo codes (Saldaña, 2013). I then reviewed these codes and created a focused codebook that specifically addressed process codes to capture actions related to health insurance (Saldaña, 2013) (See Appendix C). I then went back and coded all transcripts using the focused code book. Finally, during axial coding I met with a researcher who has experience in grounded theory and qualitative research methods to discuss how the focused themes in my data relate and interact with one another to achieve a more complete picture of seemingly unrelated themes within my data set (Charmaz, 2014). Charmaz (2014) suggests that axial codes should focus on three things: (1) the *conditions* that arise within one's data; (2) the *actions/interactions* that individuals take in response to these conditions; and (3) the *consequences*, or what results from these responses (Basynat, 2017; Charmaz, 2014). Finally, I created an axial codebook that focused on: (1) *including/excluding transgender health needs in health insurance structures* (conditions); (2) *advocating against and resisting structural insurance barriers* (actions/interactions);

and (3) *compromised health decision making* (consequences). I then recoded my entire data set using the axial codebook. All participants have been assigned pseudonyms to ensure our conversations remain confidential.

RESULTS

Individuals discussed that the insurance system within the United States is overly difficult to navigate for accessing general health concerns; however, as transgender individuals they noted that they faced unique barriers to accessing and paying for gender affirming care. The following sections map out the terrain of these difficulties and how these particular individuals have communicatively navigated the structures of insurance (see figure 1).

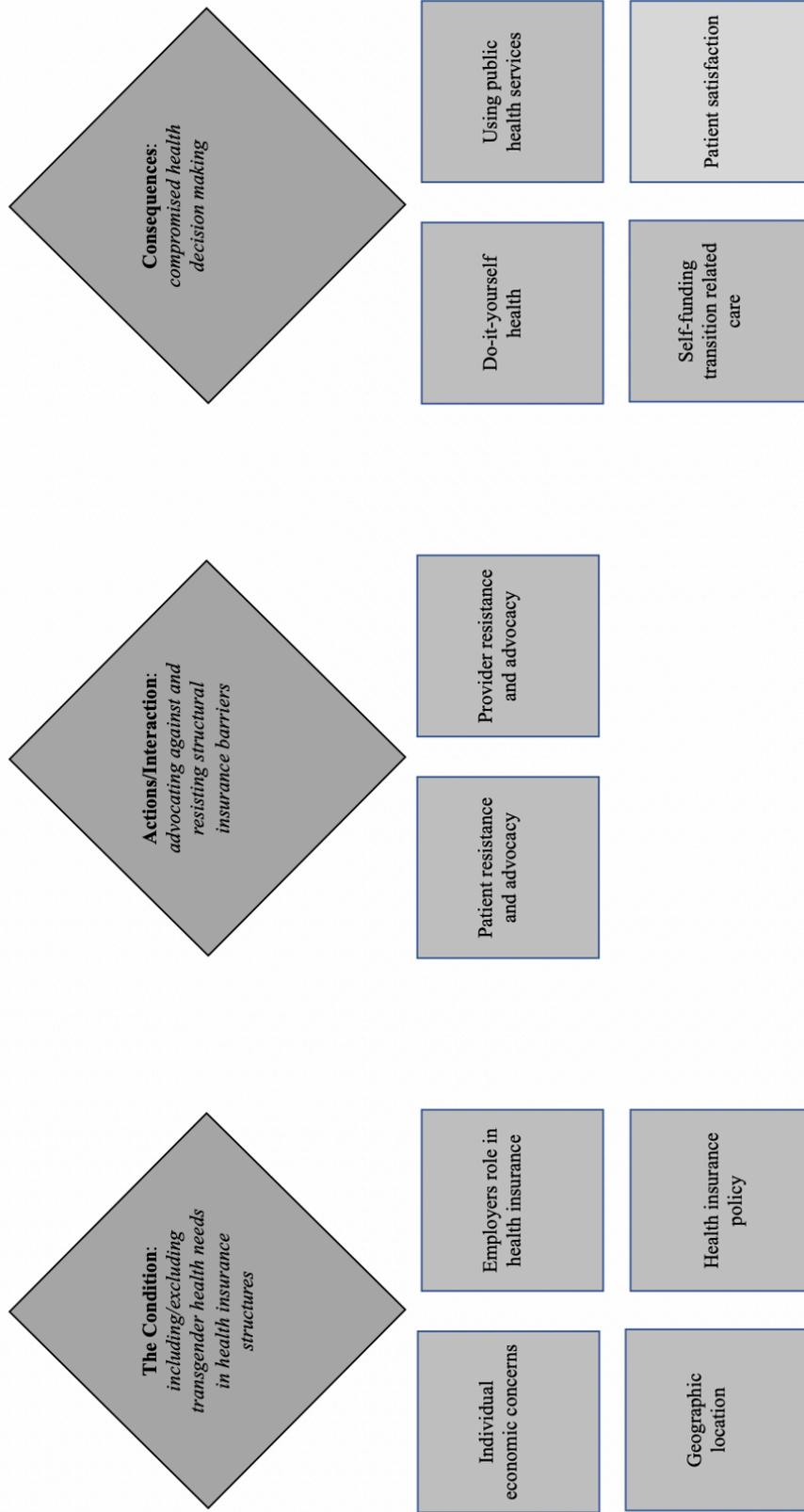


Fig. 1. Conceptual Model of (Not) Accessing Transition Related Healthcare Through Insurance

The Condition: Including/Excluding Transgender Health Needs in Health Insurance

The first overarching theme demonstrated how transgender health needs are included and excluded within the structure of health insurance. Four subthemes emerged to construct the *condition*: (1) individual economic concerns, (2) employers' role in health insurance, (3) geographic location, and (4) health insurance policy.

Individual economic concerns. Individual economic concerns about healthcare and health insurance costs emerged as a salient concern for the inclusion/exclusion of transgender individuals from the insurance structure. All participants emphasized the importance of insurance coverage to avoid “catastrophic healthcare debt.” However, the cost of insurance was a barrier to access. For example, Jackson, 27, lives in a midsized metropolitan city in Nebraska, and he received insurance through his ex-spouse's job, but after their divorce he was left uninsured:

I'm a student, and I can't afford it and I'm over the age of 26, which means I can no longer be on my parent's insurance... I just can't afford to pay the premiums when you have to do like solo insurance.

Living in New Jersey, Veronica, 27, was unemployed and uninsured but said she had insurance in the past when she “had to because of school requiring coverage.” Yet, even when insured, her economic concerns influenced how she communicated with providers. She would, “withhold information or lie [about her gender dysphoria]” to therapists, because “therapy was so expensive...I didn't want to waste my time talking about that kind of stuff because I don't know how much of a big deal it was.” She believed that if she had been honest with her therapists, she would have begun her transition much earlier. Veronica also had thoughts of suicide and self-harm, but when

talking to providers, “those are always off the table...because once they hear that red flag, they don’t really let you go, and I’ve been shipped off to emergency care hospitals.” She had received astronomical bills that were, “far too expensive;” therefore, she would exert her agency and, “never talk about [suicide and self-harm].”

Karen, 45, who lives in a major metropolitan city in Florida and works in IT, explained that in the past she had chosen to forgo purchasing transition and non-transition related prescriptions because it wasn’t in her family’s budget. She was preparing to undergo a major gender affirming surgery, and the cost of this procedure would meet both her deductible and out-of-pocket maximum; therefore, “I am in a weird position [this year] where I can now make decisions based upon “Do I need this?” instead of “Do I need it and can I afford it?”” She already had plans for appointments and procedures to address non-life-threatening concerns she had before the year was up. Thus, economic concerns must be taken into account to understand how transgender people are included and excluded in the insurance system.

Employers’ role in health insurance. Employers included/excluded transgender individuals from insurance by providing/not providing health insurance, and by including/not including transition health benefits in their coverage plans. Employment, however, does not ensure access to health insurance. As Arlise, 27, who worked part-time as a librarian in a rural community, put it: “Well, where I work it's not a full-time position, so they don't offer me insurance.” Because she lacks access to insurance, Arlise addresses her health concerns outside of healthcare structures.

Additionally, Nick, 22, lives in in a large metropolitan city in Texas, and works as a software developer. He described his job search: “I didn’t want to work for a small

startup tech company with the more volatile insurance situation because insurance companies are not as friendly to small companies. They can't get you as good a deal." Courtney, 28, living in a midsized metropolitan city in Nebraska, works as a teacher in a large public-school district. She echoed Nick's sentiment about work, and noted political concerns about employer-based plans:

You just hear like with like Hobby Lobby and the birth control coverage, you just see like ...companies are deciding...what their values are, because they're now trying to see themselves as entities even though they're corporations. And then they're subjecting [their employees] at top's will down...If a company doesn't want to support trans people, well they can send the message by just not insuring them and therefore if I can't be insured with them, I can't work for them.

Gainful employment with health benefits can help people access healthcare and address health concerns, but transgender individuals' access to gender affirming healthcare depends on how and to what extent employers include or exclude transition specific healthcare in their plans.

Geographic location. Many participants discussed moving within and across insurance structures because of significant relocations within and outside of the United States. For example, growing up Timothy, 26, was covered by an insurance plan his father received through his employer. When he was 17, Timothy:

lived kind of all over the world/halftime in Idaho and [my fathers' insurance] covered me pretty effectively... When I was 17, I came out and I moved to North Carolina, and North Carolina does not have great health services for Trans Folk."

Around the age of 21 he moved to Scotland, which has nationalized healthcare and, “Insurance-wise was great, although actual services-wise wasn't great because you'd just get bounced to whatever doctor was available at the time.” Shortly after, he relocated to the state of Washington, and because he was 23 at the time was once again covered by his father’s insurance; however, with that plan, “you had to pay for everything out of pocket initially. And then three months later you would get reimbursed and I was making no money, so it wasn't actually an option.” At that time Washington was an early adopter of Medicaid expansion (Kaiser Family Foundation, 2019), so he removed himself from his father’s plan and enrolled with Washington State’s Medicaid plan, AppleHealth, which had better coverage for transition related care.

Diane, 35, lives in a large metropolitan city in California, and works as a software developer for a small startup company that does not offer health insurance benefits. She is a veteran and is covered by the VA; she noted, however, that this access to care is limited by what providers her VA hires. She stated:

There are some VAs that will cover some services that others don't. Um, so for instance, there's a VA that's 300 miles from me that will take care of hair removal, so, laser and electrolysis. And that's just because they happen to employ someone that specializes in that. So, they offer it only to the people that are in care at that facility.

Arlise lives in rural Georgia, and she would qualify for Medicaid benefits, but Georgia has not expanded Medicaid benefits to low-income adults (Kaiser Family Foundation, 2019). She has tried to work around these barriers to care by accessing health public resources, but she does not have access to reliable transportation. She explained:

I can only find Planned Parenthood; they're one of the ones that go off of your income, [but] for me, I think it's 180 miles away... I'm in, like it's farm country so everything's you know a distance away. And those places that have those resources, I mean I understand they're in a larger city, and there's more people who have access, but there's not a lot of those places out in smaller towns.

Health insurance policy. In addition to geographic location, insurance policies influence transgender individuals' inclusion/exclusion within the structure of insurance. Health insurance policies dictate what insurance will cover. Participants' access to various therapies (i.e. voice therapy, gender identity counseling, general counseling services), medications for hormone replacement therapy, and gender affirming surgeries (i.e. sexual reassignment surgery, breast augmentation, double mastectomy, facial feminization surgery) emerged as salient concerns. Coverage for these transition specific health concerns vary across insurance policies vastly. Sif, 23, lives in a major metropolitan city in Minnesota, and currently works in construction for a national nonprofit organization. She explained: "Things like voice therapy I think is one of the biggest battles with insurance I've had." The policy on her insurance plan excluded coverage for this therapy that she considered important for her transition journey.

In terms of hormones, towards the beginning of his transition, Jackson would communicate directly with his insurance company. He explained that these conversations were:

Friendly and it's like, "Oh yeah, I have this question" and "Let me ask you this question." And they're like, "Uh, let me look through your policy. No, that's not covered." And I was like, "Okay, well, is there, is, is there a workaround? Is there

anything we can do? Like do you have options for things like this?" And ... it's like talking to a mom who was at her wits end and you're like, "Can I do this?" And she's like, "No." And you say, "But why?" And she's like, "Because I said so." It just gets really short.

Despite being covered by an insurance plan, specific policies excluded Jackson from receiving transition care through insurance early on during his transition.

Nick graduated with a job lined up at a large software development firm, and he wanted to have his top surgery (i.e. a gender affirming double mastectomy for transgender men) and recover from it before he started working. At the time he was covered by his parent's insurance plan. When he tried to get his insurance to cover the cost of his surgery, he explained:

I had problems...because they wanted to prove it was medically necessary. They wanted two different psychiatrists to give letters, saying it was necessary. And I, and each of those, like how that works is that you'd have to go in for three sessions so they can give you a good profile. And then at the end they write you a letter. So that means to pay for six sessions, and then, uh, and then submit the letter and then afterwards they'd approve. And then after all of that I could actually have the surgery. So that was, that was a lot of hoops to jump through. And I didn't have time because I had a time window where, the only time I could really get the surgery where it wasn't a huge problem with work was the time between, I graduated college and I started working.

Even though Nick's insurance would cover his surgery, he needed to have the surgery and another two weeks to recover before he could go to work. Therefore, time constraints

created barriers to care that excluded him from getting transgender-related care with his insurance.

Action/Interaction: Advocating Against and Resisting Structural Insurance Barriers

The second overarching theme that emerged showed how transgender patients and providers used communication to navigate barriers in accessing gender affirming care.

Both patients and providers advocated against and resisted structural insurance barriers to transition related healthcare needs.

Patient resistance and advocacy. When faced with conditions of being excluded from health insurance structures, many participants directly advocated against the source of their exclusion. For example, Courtney was previously insured by BlueCross BlueShield (BCBS) when she was in graduate school, and she knew that BCBS covered sexual reassignment surgery (SRS). Her current employer also offered BCBS, and she assumed that the procedure would be covered. When she realized that her employer did not include SRS in their policy, she:

Contacted my union rep and I said, "Can this be covered?" And they said, "We'll look into it." And because we're part of a larger educational system who deals [with] our insurance for multiple school districts, they just contacted their rep and then they contacted BlueCross BlueShield and then they got it covered. It was so easy. Shockingly easy. And then I was like, then I was like, "Oh, I don't really want to get SRS anyways". But now anyone who wants it can have it. So that's cool.

She ultimately decided against the procedure, but her efforts to resist transgender-exclusionary policies created space for future transgender employees to access SRS with her employer's insurance plan.

While Courtney's experience was met with little pushback, others described having to go to great lengths to fight against insurance for transition-specific care. Robyn, 37, lives in a large metropolitan city in California, and works as a software engineer. She needed facial feminization surgery (FFS) (i.e. a gender affirming combination of procedures that feminizes facial features), but her insurance network did not have enough specialists who could perform the necessary procedures in a timely manner. California has a 'timely access to care' statute that mandates insurance companies provide access to appointments with a specialist within at least 15 days (Timely Access to Non-Emergency Health Care Services Act, 2002). She wrote a grievance to Kaiser, her insurance coverage at the time, to prove that their network was not adequate; her goal was to force Kaiser to expand or approve out-of-network providers. She accomplished this goal by going to "an out-of-network surgeon for a consult, [to] get a date from them [so that] like hypothetically, if they were doing my surgery, they would be able to do on this date." Kaiser, however, did not allow her to go out-of-network; instead they gave her:

A new date [with Kaiser's in-network surgeon] and buried the grievance.

Normally when you file a grievance, you got a formal response afterward with all the things that are required to do for a grievance. Kaiser never sent that. They just buried it.

Citing mental health concerns, she did not follow up with Kaiser after they buried her grievance, and instead made her grievances letter into a template for other

transgender individuals to use when appealing their insurance companies. Robyn has coped with a depersonalization disorder, and reflecting on her labor to reduce insurance barriers for transgender health needs, she said:

Yeah, if you wanted like a takeaway, one sentence, like a statement to center this on for me, like it would be this, I've interacted with health insurance frequently enough and negatively enough that it accelerated the pathogenesis of like a psych disorder for me. So that's fun. Yeah, no. Health insurance is not fun.

Additionally, Timothy had just been hired for a position that offered health benefits and was in the process of transferring to their plan from AppleHealth. At the time of our interview, he had just signed up for his new plan. When he enrolled, he was only given the option to select male or female for his identity category. Frustrated by this limitation, he emailed the head of the insurance company to voice his complaint. He told them:

This question is not effective...If you want to know exactly what kind of coverage I need based on this demographic information that you're asking me, you're not getting my full information by just asking my gender because I'm saying male and that's totally genuine, but I'm also trans and I have different needs than what you think of when you think of male. And also, you're missing out on all the non-binary people as well as any intersex people. And this is just a badly formed question.

The head of insurance responded to his complaint stating, "Well, that's just the, like, that's just the system we have. We totally cover trans people. Don't worry about it. Like, it's fine." To which Timothy replied by explaining, "It's not about whether or not you cover

me, I know that you cover me; I researched this beforehand. But that from the get-go, you're not actually being inclusive to the community that you say you cover." The insurance company acknowledged that the binary system is limiting, but that they were not going to fix it to address his concerns. Not wanting to back down he sent a final response telling them that if they are "stuck with the binary system," then they should control what they can control, which is the form that they use. He suggested they:

Include something says, 'We have a binary system. We acknowledge that people have identities beyond the binary. Please email us with your gender identity and just pick whatever is the best fit. If you were intersex or nonbinary or transgender, we want to ensure that we provide you with the best possible care.'

The company told him that that his solution was a good idea, and that they would look into it. Reflecting on his experience he told me:

It seemed like an actually successful conclusion. We'll see whether it does change or not ... I'm obviously not the first person who's had this complaint. But I guess I'm the first person that offered them a solution that they might be able to do, which is a small step.

Thus, through individual efforts, transgender people were able to fight against exclusionary policies and practices of insurance. The results of these efforts, however, vary widely. On one end of the spectrum, transgender individuals were easily able to overcome insurance barriers and create space for gender affirming care. Yet, on the other end of this spectrum, legitimate healthcare access concerns were: (1) individually addressed, (2) not solved, and (3) large scale change was stalled by burying complaints altogether.

Provider resistance and advocacy. In addition to patients' advocating against insurance structures, healthcare providers played a pivotal role in resisting insurance policy: Providers would "write letters," on behalf of patients, "keep them in the loop," and "advocate" on their behalf to ensure that insurance covered a variety of gender affirming physical and mental health services. A consistent concern for participants was getting insurance coverage for hormone medications. When Nick began taking testosterone in college, he was covered by his parent's insurance that was, "a very standard insurance. There was nothing like overtly anti-LGBT or a pro, you know, so middle of the road." However, he and his doctor knew that for his hormone replacement therapy if they "categorized it under like adult gender identity disorder or something like that, then [the insurance company] would deny it." Therefore, he and his provider "categorized the insurance claim as "endocrinal disorder not otherwise specified" because they basically approve all of those because it's your "other" category." As a result of this strategic coding choice, Nick's prescription cost was \$10 for a six-month supply, far less than the \$230 he found when researching the out-of-pocket cost for the prescriptions where he is located. Though he said he does not frequently talk with providers about insurance specifically, when it does come up "the conversations are always about how to help me save money and be more covered," which he appreciates.

Stephanie, 27, lives in major metropolitan city in California, and had a similar situation when prescribed hormones. She said healthcare providers, "knew how to navigate the system...they would code it differently...they understood what needed to happen and did what was necessary to achieve that. So, it was certainly providing a lot of confidence, and a lot of security."

Nevertheless, providers' voices do not ensure that insurance companies will cover gender affirming healthcare. Jackson had a therapist's letter stating his hysterectomy was medically necessary; thus, theoretically his insurance should have covered the cost of the surgery. However, his doctor had some reservations about the procedure being covered by health insurance because, "sometimes [coverage] comes down to coding," meaning that the letter from his therapist wouldn't guarantee insurance coverage. But then:

When [my doctor] was doing my exam, she actually found out that I had really bad polycystic ovarian syndrome, so like, the hysterectomy could be put as medically necessary as an actual, like this, it needs to happen anyway, whether I was transgender or not. So, for me, like I say that I got lucky, but that's not the case for everybody.

Thus, when providers' voices alone are able to ensure that insurance will cover transition care, this care is covertly coded so that it is covered as a non-transition related medical necessity.

Yet, sometimes persistent and consistent advocacy from providers successfully resulted in care being covered. Sif talked to me about how her voice was a trigger for her dysphoria, and that voice therapy is medically necessary for her wellbeing. Initially, her insurance refused to cover voice therapy, because the company did not recognize voice therapy as medically necessary. She explained:

So then, my speech and language pathologist was amazing, and really liked her, and she kept badgering the insurance company and wrote them letters about how it was medically necessary and everything, and uh, eventually they decided they

would cover it and then they covered all, all appointments up through a certain date, and from when I started.

Consequence: Compromised health decision making

Advocating and resisting structural insurance barriers resulted in various outcomes that compromised the health decision making capabilities of transgender people, which is the final overarching theme: (1) do-it-yourself (DIY) health, (2) using public services, (3) self-funding transition related care, and (4) patient satisfaction.

DIY health. Access to insurance offsets the ever-increasing costs of healthcare, but when participants did not have coverage, they found ways to address health concerns. Jackson explained how he tries to mitigate the effects of being uninsured after his divorce:

I don't involve myself in any reckless behavior. [Laughs] Um, I don't jump any fences. For the medicines. I mean I don't know; I take medicine for ADHD and for that I just kinda like use caffeine as a substitute, try to mitigate the best you can with some proven methods. But, outside of that, like, I mean there's, there's no way to mitigate the damage from like not having my hormones or anything. Like there's no substitute for actually making them. I can't just like rub some grass on my elbow and be like, yeah, testosterone.

Jackson was able to find alternative ways of addressing some of his health concerns but did not have an alternative for accessing hormone medications; however, other people have found ways to work around the healthcare system for their transition related care.

Arlise similarly mitigated general health concerns through a DIY route. Because Arlise has not had insurance coverage since she was a child and has not visited a doctor

in a number of years, during college she began self-administering HRT medications she purchased without a prescription. She explained, “I just looked up what people said would be a good recommendation, a good type of dose to try, and I've been going on that.” Transgender people can face many barriers to accessing transition care including long wait times, gatekeeping providers, and required letters from providers. For people like Arlise, rurality creates geographic barriers to accessing healthcare services. She elaborated:

I mean, I'm glad that I could do that because it's been three years now. I mean, that would have been three years I would have had to wait. I know a lot of people say it's not good to do [DIY] ... but I would have rather have the opportunity to seen a doctor.

For participants, taking a DIY approach to health was not to spite the healthcare system; instead people did what they deemed necessary for their survival and well-being.

Using public health services. When insurance structures failed to adequately create space for transgender people, participants sought healthcare services elsewhere. Timothy began his transition at the age of 17, but faced difficulties finding a provider who would take his insurance in North Carolina, so he went to a community health clinic that served uninsured patients. To do this he explained:

Under direction of my therapist as well as other people that were using [the clinic], they're like, “You just have to lie and say that you don't have health insurance in order to use those because otherwise you'd have to drive three hours to maybe get into this other health clinic that will use insurance”. So, it was this weird, ethically fraught choice to then just say, “I don't have health insurance.”

And then just pay out of pocket at this community health clinic for the next three years because there was no other place that was, that had any services that I could use in our area.

When Diane began her transition, the VA told her she would need a formal diagnosis of gender dysphoria to speak with an endocrinologist about hormone replacement therapy. However, the VA she goes to did not have a therapist that would help her access the care she needed, therefore:

They referred me to a gender center that is nearby that is based on income...at the time I was a student. So you know, I didn't pay anything for that, which was just nice. And so, you know, it took about a month and a half for me to get a therapist there to get a letter to say, "Hey, this person's actually trans, maybe you should treat them as such."

Self-funding health care. For transgender people who were financially able, self-funding transition-related care was an option when health insurance would not cover the costs of transition care. Lydia, 28, lives in a major metropolitan city in California, and works as a software engineer. Her insurance policy excluded facial hair removal, but it would “in theory pay for hair removal in preparation for vaginoplasty.” But in practice, “finding someone that actually will do it and take insurance is almost impossible with my insurance and they don't help... They're like, ‘Go find someone that does it and then we'll pay them.’ Then you go look and there's no one.” Because her insurance company did not help her find a provider, she's, “paid out-of-pocket thousands of dollars...and just kind of written it off as I'm never going to get this covered so I'm just going to do it because I need to... It's a burden that I have to deal with.”

Whereas Lydia’s difficulty was finding a provider who would accept her insurance, Nick’s insurance would cover the cost of his top surgery with the provider he wanted; however, his insurance required several letters from mental health practitioners. He described these letters as “barriers to care,” because each letter would require him to schedule several visits with several mental health practitioners before they would sign letters approving him for surgery. But he was on a strict time schedule, and he needed to have the surgery between graduation starting his new job. Therefore he:

Ended up not doing insurance for my top surgery because of that. And I had to pay out of pocket, which took my entire starting bonus for my salary, and left me with a lot of problems later on because I had no more starting bonus. Um, but that was the only time window I had, cause like when am I going to get, you know, a couple of weeks off work? Never. Yeah. Yeah. So that sucked, jumping through a lot of hoops.

Insurance companies decide what they will and will not cover, and for Sif this created difficulties when making family planning decision with her partner. Sif’s partner is a cisgender woman, therefore before Sif began taking hormones, Sif, “chose to freeze sperm...because in talking with my partner, we decided that in the future it would be nice to have children that are biologically both of ours, which is several thousands of dollars.” And because her insurance does not consider fertility treatment medically necessary, she, “had to pay that out of pocket. As a senior in college.”

Patient Satisfaction. When providers advocated on behalf of patients’ needs and openly communicated about this process, participants reported being more satisfied with their providers. Providers openly centering the needs of transgender patients when

resisting structural barriers was important for the patient-provider relationship. For example, when Stephanie was getting a prescription for hormones the nurse practitioner, she met with explained, “Okay, you know, so this is what we need. You need hormones, or you'd like hormones.” Stephanie confirmed that she wanted to begin hormones, and her nurse practitioner told her that insurance would not cover transgender care but that:

they will accept a hormone disorder. So, she's like, "We code it this way, so it actually gets covered." So, she's like, "It's very standard practice." She really kind of kept me in the loop about it. So, I felt very, very comfortable with her.

Additionally, persistent patient-centered advocacy led to provider satisfaction.

When Sif's insurance refused to cover voice therapy, her voice therapist created a plan to fit as many therapy exercises into as few sessions as possible to help offset the financial burden of paying for therapy out-of-pocket. Sif explained that her therapist, “cared about me as an individual, cared about my treatment and...that I was going to get the treatment and everything that I needed in a way that was going to work out well for me.” But her therapist did not stop there, and persistently “badgered” Sif's insurance company.

Ultimately her voice therapy was covered. Sif spoke about her voice therapist saying:

That was kind of this big moment of, there is somebody. That even though there's like one system that was... pretending that it was helping me, but it was also being really detrimental. There's also this other person who I describe in this as my Athena [Speech Pathologist] who was really trying to like, pull me up and help me along, both in the treatment that she was giving me, but also in making sure that I didn't have to pay for it. Yeah. So that was, that was exciting.

In sum, the currently fragmented insurance system within the U.S. enables and constrains health decision making for transgender individuals because it continues to be a complex system that can be extremely difficult to navigate. (Not) having insurance enables and constrains transgender individuals' ability to address general health concerns, and access necessary transition care that is necessary for their well-being. Thus, as shown through the stories of transgender individuals above, working within and around the U.S. insurance system: creates (1) conditions of inclusion/exclusion of transgender health concerns within health insurance structures; (2) making it necessary for both transgender individuals and their providers to respond by advocating for, and resisting barriers to, transgender health care, and ultimately (3) results in compromised health decision making, but also sheds light on the potential for increased patient satisfaction.

DISCUSSION

The purpose of this study was to explain how transgender individuals use communication to navigate accessing or not accessing healthcare using health insurance. This project contributes to extant literature by using the CCA to (1) situate health insurance as a unique healthcare context for transgender individuals; (2) pay close attention to how transgender individuals articulate their physical and mental health needs, and how those needs are (not) being met through insurance coverage; and (3) use rich qualitative data to understand what (lack of) insurance coverage does for transgender individuals health decision making, to build a theoretical understanding that starts with the voices of transgender patients. Below I outline the theoretical and practical implications of this project for health communication research and providers.

Health Communication and Theorizing Systematic Change

These results contribute to extent health communication literature concerned with health insurance. Past research has focused on how to increase patient knowledge about how to use health insurance effectively, and what type of health insurance plan will best address their health needs (Furtado et al, 2016; Huhman, Quick, & Payne, 2016; Paez et al, 2014). Participants in this study were particularly attuned to how insurance enabled and constrained their ability to seek both general and transition related healthcare. Consistent with other culture-centered work in other contexts (for example, Basnyat, 2017), when transition care was excluded from insurance coverage, participants found ways to work within (i.e. advocate for coverage), around (i.e. access community resources), and outside (i.e. use DIY health) of the healthcare system. Being excluded from the structure of health insurance did not indicate that participants lacked knowledge about how insurance works; in fact the fear of not being adequately covered lead many participants to learn more about health insurance policy by: (1) reading their policies, (2) staying up to date on policy changes, and (3) finding ways to advocate for transition care to be recognized as medically necessary.

Thus, it is important to consider how academic research can problematically reify the validity of dominant healthcare structures (Dutta, 2008). The current study allowed participants to articulate narrative accounts of accessing/not accessing healthcare through insurance, rather than using insurance as a yes/no variable. Additionally, it provided a space for participants to discuss their needs and how those needs were (not) met using health insurance, which frequently included questions of why our system is the way that it is. Past efforts have been made to nuance quantitative knowledge of insurance for

example the HILM (Paez et al., 2016); however, to date health communication research that specially centers insurance has focused on helping *consumers* pick the most effective plan for their health needs, without considering how insurance structurally struggles to help marginalized groups access the care they need. Certainly, concepts such as health literacy and health insurance literacy allow us to predict the “needs” and “capabilities” of individuals to address their health needs through insurance. However, this research may (un)intentionally reify problematic systems of power, particularly through appeals of pragmatism that fail to break down the system(s) of power that enable and constrain health decision making. Research efforts that accept our current health insurance system as natural and inevitable (un)intentionally contribute to disparate health outcomes, because this work does not strive for better more equitable healthcare systems. Instead this work attempts to push individuals into a system that struggles to serve their needs. Future research is needed to interrogate the systems of power within US healthcare system, particularly insurance, to denaturalize these institutions and theorize solutions for healthcare payment.

Certainly, we cannot quickly change the landscape of the U.S. political system. As Heath, 34, who lives in large suburb in New York, said about current health insurance plans: “Get it, even if it doesn't offer you all the transgender care you want, because you can't be happy with your gender if you can't breathe...I think we should all advocate for great transgender healthcare, but in the meantime don't refuse to get it.” Heath points to a powerful distinction that can be made in Health Communication and public health research that revolves around systematic and structural issues: systematic social change and living under current structural constraints is not an “either/or” situation. Instead, this

duality is a “yes, and” context. So *yes*, we currently operate under a healthcare system that requires health insurance to tangibly afford healthcare, *and* we can simultaneously imagine new systems of healthcare, and advocate for necessary changes to increase equitable access to healthcare for marginalized groups. Thus, future health communication research is needed to explore the ways that, as scholars, we can both acknowledge the need for pragmatic short terms solutions, while also envisioning equitable systematic reforms to increase health and wellbeing for marginalized group.

Patient-Centered Advocacy

In the realm of health insurance, factors like location and health insurance policies largely influence the condition in which transgender individuals find themselves. Because of these conditions, transgender individuals found ways to resist being excluded from insurance structures; however, providers also played a pivotal role as advocates in the process of navigating insurance systems to have transition care covered for patients. Certainly, many participants spoke of negative patient-provider interactions that were consistent with past research (Ross and Castle Bell, 2017), but when talking about insurance in particular, participants overwhelmingly spoke positively about the role their providers played in helping them receive health insurance coverage to mitigate healthcare costs. As Timothy said, “With my current doctor, it has been really inspiring in the ways that they're willing to work with me and work with the insurance that I have.” These findings have clear implications for the patient-provider relationship, as many participants expressed immense feelings of gratitude when providers centered patient needs when appealing to insurance. While providers are part of the healthcare system writ large, they are also enabled and constrained in *their* abilities to provide affordable care to

patients by larger systems of healthcare policy. *Patient-centered advocacy* is a term referring to the unique ways that occupational therapists must advocate on behalf of their patients to prove “medical necessity” to insurance companies (Stover, 2016). Because medical necessity of transition treatment was frequently discussed in the current findings, future work is necessary to explore the nuances of patient centered advocacy, particularly from provider perspectives and its influence on the patient-provider relationship, both inside and outside of the context of transgender individuals’ health.

Additionally, providers might also play an important role in larger political conversations about transgender healthcare rights. For example, in terms of political conversations, Jackson said he wants to see the phrase, “Nothing about us without us; don't make decisions about my transgender healthcare unless you know what transgender healthcare is.” Providers, particularly those who work with transgender patients, are in a unique position to advocate on behalf of transgender health rights. Provider advocacy is particularly necessary to inform current health care policy in light of the recent policy debates surrounding transgender rights and recognition within healthcare policy: the transgender military ban, or the Department of Health and Human Services (DHHS) proposal to narrowly define sex and gender on the basis of biology. Transgender activists responded to the DHHS proposal online and on the ground through the “We Will Not Be Erased” campaign, aimed at increasing transgender visibility (Mervosh & Hauser, 2018). Providers can and should do all they can to play a role in opposing these reductive policies.

Health care provider advocacy can be particularly powerful in terms of influencing insurance companies, but as West (2011) cautions, we should also be wary of

non-transgender stakeholders who attempt to define terms such as sex and gender, which have material consequences for transgender individuals. Therefore, as the CCA (Dutta, 2008) calls for, providers can begin to practice reflexivity in their advocacy on behalf of the patients they serve. This requires providers to consider and account for the lived experiences of their patients as well as the transgender community broadly, as we move forward to push for healthcare policies regarding insurance reform. By using reflexive methods in advocacy, providers can work alongside the transgender community to create meaningful space for transgender bodies in health insurance policy.

Limitations

The current study, nevertheless, comes with some important limitations. First, I used purposive and participant driven sampling (Tracey, 2013), and the voices represented above are individuals who volunteered to share their stories. While I recruited participants from a variety of geographic locations, these findings cannot be read as a comprehensive narrative of transgender individuals' experiences with health insurance. A project that specifically localized experiences with health insurance to a contained geographic location would likely yield important similarities and differences from my findings. Additionally, the results and implications discussed above, while built from participant narratives, come from my perspective as an academic researcher with my own (un)acknowledged biases (Dutta & Basu, 2013). In addition to this influence, I also believe that healthcare is a fundamental human right. My value beliefs about healthcare are important to consider as they effect and reflect my theoretical approaches to researching and advocating for better solutions to healthcare problems. Thus, in line with the CCA's theorizing, I acknowledge the tensions present in this manuscript

between representing the stories of participants and the emancipatory potential of articulating alternative narratives of experiences with health institutions. It is my hope that this project is one step toward increasing healthcare access for transgender individuals.

CONCLUSION

In conclusion, my findings suggest: (1) that transgender individuals are included/excluded in health insurance structures; (2) transgender individuals and their providers respond to exclusion by advocating for, and resisting barriers to transgender health care; and ultimately (3) transgender individuals experience compromised health decision-making due to these barriers to care, but that patient satisfaction increases when providers engage in patient-centered advocacy. This analysis calls for further research to explore both pragmatic solutions and systematic change to insurance structures to increase wellbeing for transgender individuals and reduce health disparities experienced by this marginalized community. Furthermore, more work is necessary to understand and train practitioners working with transgender patients in patient-centered advocacy. Continued attention to the unique experiences of transgender people experience can enable individuals to address their healthcare concerns, and ultimately increase wellbeing.

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TABLE ONE

Participant Statistics

Characteristic	Number (%) <i>N</i> = 17
Age	<i>M</i> = 30.76 (<i>SD</i> = 8.67)
Gender Identity*	-
Ethnicity**	
White/Caucasian/Scandinavian American	15 (88.24)
Mexican	1 (5.88)
Asian	1 (5.88)
Highest Level of Education	
Some college/vocational	4 (23.53)
Bachelor of arts or science	10 (58.82)
Graduate or professional degree	3 (17.65)
Relationship Status	
Single	4 (23.53)
Dating	5 (29.41)
Partnered	4 (23.53)
Married	2 (11.76)
Divorced	2 (11.76)
Currently Employed	
Yes	16 (94.12)
No	1 (5.88)
Annual Household Income	

\$10,000 – \$29,999	5 (29.41)
\$30,000 – \$49,999	1 (5.88)
\$50,000 – \$69,999	6 (35.29)
\$70,000 – \$89,999	1 (5.88)
\$90,000 – \$109,999	1 (5.88)
\$110,000 – \$129,999	-
\$130,000 – \$149,999	1 (5.88)
\$150,000 +	2 (11.76)

Insurance Coverage Type (Last 12 months)***

Health insurance through your or someone else's job or union	12 (70.59)
Health insurance bought directly by you or your family member	3 (17.65)
Medicaid	2 (11.76)
VA (Veteran's Affairs)	1 (5.88)
None	1 (5.88)

During the last 12 months, was there a time when you did not have health insurance coverage?

Yes	3 (17.65)
No	14 (82.35)

During the last 12 months, was there any time when you needed health care but did not get it because you could not afford it?

Yes	6 (35.29)
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No	11 (64.71)
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If you get sick or have an accident, how worried are you that you will be able to pay your medical bills?

Very worried	4 (23.53)
Somewhat worried	10 (58.82)
Not at all worried	3 (17.65)

*Participants were asked to fill in a textbox for their gender identity to avoid any exclusion of gender identities (Clayton & Tannenbaum, 2017; Goins & Pye, 2013; Streed & Makadon, 2017). Self-reported gender identities varied significantly across this sample; therefore I have not reported them here.

**Participants were asked to fill in a textbox for their ethnic identity, I have collapsed identities that are commonly considered *white* into a single category, because of the small number of words used by participants I have included all of them above.

***Participants were directed to select all insurance types they had been covered by in the past 12 months, therefore these percentages total over 100%.

14. During the last 12 months, was there a time when you did not have health insurance coverage?
- 1 Yes No
15. During the last 12 months, was there any time when you needed healthcare but did not get it because you could not afford it?
- 1 Yes No
16. [During the past 12 months, were you told by a doctor's office or clinic that they would not accept you as a new patient?]
- 1 [Yes]
- 2 [No]
- 3 [Don't know/refused to answer]
17. [If you get sick or have an accident, how worried are you that you will be able to pay your medical bills?]
- 1 [Very worried]
- 2 [Somewhat worried]
- 3 [Not at all worried]
- 4 [Don't know/refused to answer]
18. [About how long has it been since you last saw a dentist? Include all types of dentists, such as orthodontists, oral surgeons, and all other dental specialists, as well as dental hygienists.]
- 1 [6 months or less]
- 2 [More than 6 months, but not more than 1 year ago]
- 3 [More than 1 year, but not more than 2 years ago]
- 4 [More than 2 years, but not more than 5 years ago]
- 5 [More than 5 years ago]
- 6 [Never seen a dentist]
- 7 [Don't know/refused to answer]

For the interview portion of this study, please find and bring to our meeting a visual representation of your experiences with health insurance/health care. Thank you, and I look forward to talking with you and getting to learn more about your experiences.

APPENDIX B

Interview Guide

Interview Guide

Pre-interview ethics statement

Hello. My name is Jonathan Baker. I'm a graduate student at the University of Nebraska-Lincoln. I am doing a study to understand the experiences of transgender, genderqueer, and gender non-binary individuals when discussing health insurance coverage.

Before we begin, there are a few things I would like to go over:

- First, are you at least 19 years old?
- Do you identify as transgender, genderqueer, or gender non-binary?
- What are your gender pronouns?
- Second, in order for me to accurately retain all of the responses you provide in the interview, I will be audio recording this interview. Your name and identity will not be linked in any way to any of the information you provide in your interviews. Even though this interview will be transcribed, your name will not be indicated throughout the transcription of this interview. However, I would like you to know that you are free to ask me to turn off the tape recorder at any time during the interview. You may also refuse to answer any questions during the interview.
- Is there a specific pseudonym you would like me to use in future papers and presentations?
- There are no direct benefits to you as a result of participating in this study except potentially gaining greater insight into your experiences. However, talking about your experiences may make you uncomfortable. Yet, any responses, oral or written will be regarded with the utmost confidentiality.

Do you have any questions for me before we begin?

Ice Breaker

1. So I asked you to share an image with me that represents your experiences with health insurance and health care. Could you talk with me about what this image means to you?
2. I'm interested in a variety of factors that relate to your thoughts about health and wellbeing, so what does health mean to you as a [their stated gender identity, eg. transgender, genderqueer, gender non-binary, etc.] individual?
 - a. What are some of the most important parts of your life as they relate to health?

Access

1. Thinking about insurance in particular, can you describe to me what your access to insurance has been like?
2. So I know on your demographic survey you said that you (do/do not) have health insurance coverage. Is that still correct?
 - a. If yes.

- i. How satisfied are you with your current coverage?
- ii. Does your coverage meet your health needs?
- iii. How often would you say you utilize your insurance?
- iv. How helpful is your insurance?
- v. What, if any, additional coverage would assist you in caring for your own wellbeing?
- vi. Have you ever gone without insurance for any period of time?
 1. What were the reasons you were uninsured at that time?
 2. What concerns, if any, did you have during that time?
- b. If no.
 - i. What are some of the reasons you do not currently have health insurance?
 - ii. What coverage would be most important for you currently or looking to the future?
 - iii. What, if any, concerns do you have about not being insured at this time?
 - iv. Have you been insured in the past?
 1. If yes: Where did you receive insurance?
 2. If yes: How satisfied were at the time with that coverage?
 3. If yes: Did your coverage meet your needs?
 4. If yes: How helpful was that coverage?
 5. If yes: How often did would you say you utilized that coverage?
 - v. How, if at all, do you address your health concerns now?
- c. Both.
 - i. What (does/would) being insured mean for you?
3. Thinking about larger political discussions surrounding health care and health insurance reform, how, if at all, do you see your specific health concerns reflected in these discussions about health insurance?
4. What, if anything, would you like to see represented in these conversations that would address your specific health concerns?

Healthcare Provider Communication

1. Where all do you currently seek out physical and/or mental health services?
 - a) Are these your primary providers?
2. How often do you seek medical attention from healthcare providers?
 - a) What would you say are the primary reasons for healthcare visits?
3. How satisfied are you with the way healthcare professionals talk to you about your health?
4. What conversations have you had with healthcare providers, such as doctors, nurses, or other individuals who work within the medical field about insurance?
5. How have you discussed your insurance coverage with healthcare providers?
 - a) How did your provider explain your coverage to you?

- b) How helpful did you find the information they provided?
 - c) How did you handle this conversation?
 - d) How did you feel in the moment that these conversations occurred?
6. What, if anything could your provider have done to help you better understand your coverage?
 7. If they have or have had Insurance: Have you ever been denied coverage for a treatment from a provider because your insurance would not cover it?
 - a) If yes
 - i) How did your doctor explain the situation to you?
 - ii) How did this conversation make you feel?

Health Insurance and the Social Circles

1. What kinds of conversations have you had with friends, family members, romantic partners, or people in your social circle about health insurance coverage?
2. Who, if anyone, within your social circle do you most often discuss your health insurance with?
 - a) Who do you consider this person to be in relation to you?
3. Can you provide me an example of a conversation you've had with X?
4. How often do you and X talk about your healthcare to each other?
 - a) Does that help?
5. How satisfied are you with the amount of information you and X share with one another?
6. How important would you say talking about health insurance coverage is for you?
 - a) Why?
7. What, if anything, do you wish was a more open topic of discussion with individuals in your social network about coverage?

Wrap up

1. Why did you want to participate in this study?
2. What advice would you give to other [their stated gender identity, eg. transgender, genderqueer, gender non-binary, etc.] individuals about healthcare/health insurance?
3. Is there anything else you think I should know about Transgender, Genderqueer, and Gender Non-Binary health that I didn't ask you today?

APPENDIX C

Codebook for Reliable Themes: Communication for Transgender individuals trying to address health concerns within the US-based healthcare system

- 1) ***Main point:*** *Health insurance, though a hotly contested political topic, is considered to be an essential component of payment for healthcare services in the US based healthcare system. Research on health insurance within the US generally falls within two categories. First, it mostly viewed as a quantitative variable that can be used to find associations between insurance coverage (Has, does not have, Inadequate Coverage) and various health outcomes. This is important but does not account for the lived experience of gaining access to insurance, and the ability to adequately use insurance. The second, and more recent development is to understand health insurance in the context of health literacy. The goal of this research area is to understand the ways individuals can better understand their coverage and use it to effectively address their health concerns. Though an important extension of health insurance research, it doesn't ask "why is the system of healthcare payment good?" Thus, the present study seeks to expand our understanding of health insurance through the experiences of transgender individuals, who's bodies are not well integrated into medical knowledge. It current literature by using rich visual and oral data to start theorizing about health insurance from the ground up. Additionally it seeks to move away from taking insurance for granted (i.e. showing that insurance is not a "natural" construct). Ultimately posing the question:*

RQ: How does one fit within a structure or system that was never built for them or with their needs in mind?

- a. **(Not)Accessing healthcare because of insurance**
 - i. Instances when insurance covered general healthcare/trans care health needs
 - ii. Instances when insurance covered general healthcare needs, but not trans care needs
 - iii. Transition care – medication
 - iv. Transition care – surgeries
- b. **Advocating Against and Resisting Insurance Barriers**
 - i. Individual advocates/resists System for self
 - ii. Provider advocates/resists system for patients
- c. **Addressing health outside of insurance structure**
 - i. Instances when individuals do not/did not have insurance and what they did to address their health
 - ii. Instances when individuals do/did have insurance, but addressed/are addressing health concerns without using insurance coverage
- d. **Transferring across insurance structure**

- i.* Locates where individuals are/have been within the structure of insurance.
 - i.* Instances when individuals change insurance providers
 - ii.* Instances when individuals gain access to insurance coverage
 - iii.* Instances when individuals lost access to insurance coverage

General Coding Rules:

- a. Only code when the phrase, sentence, paragraphs, etc. directly relate to insurance.**
 - ii. i.e. The interview guide included various parts, and some did not directly relate to insurance.**