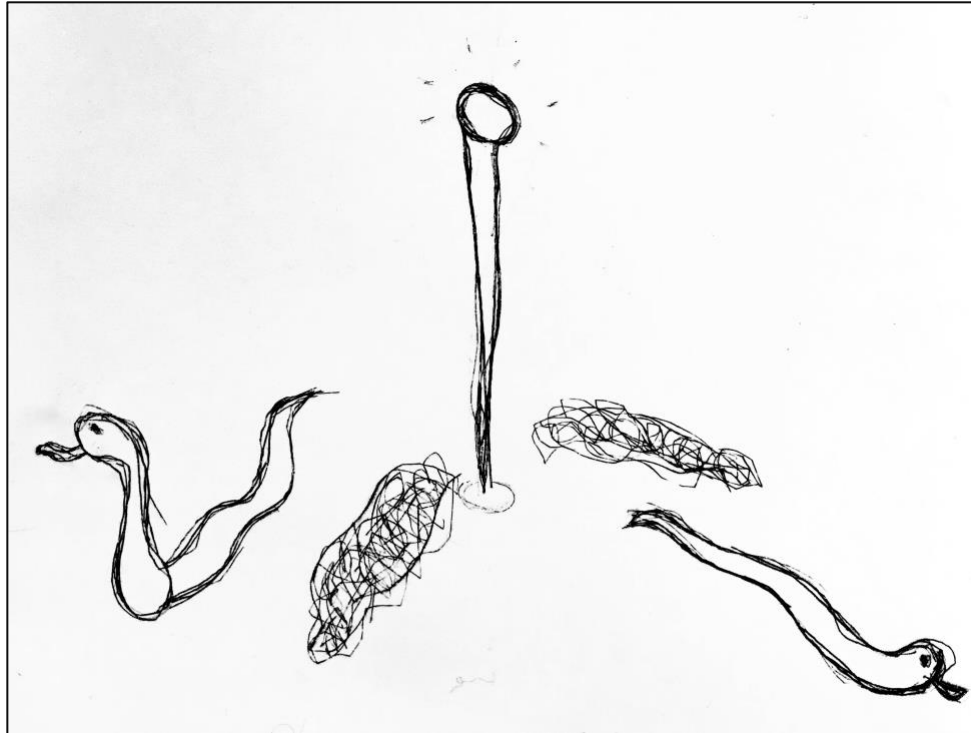


TAKING A QUEER PULSE:
*The Impact of Medical Structure on Healthcare for
Non-Binary Patients in Boston*

An Honors Thesis for the Department of Sociology
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“the structurally unsound caduceus”
a monoprint etching by Neeki Parsa

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in no particular order

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Abstract

Individuals with non-binary gender identities must pass through medical bureaucracy to meet their healthcare needs. The present study sought to understand the associated experiences by employing semi-structured interviews in the Greater Boston Area for seventeen non-binary individuals. Non-binary medical patients are often faced with highly bureaucratized medical systems with intake forms without sufficient opportunity to reflect their gender identity, and insurance companies that have exclusive stipulations for transition care. Furthermore, physicians that are not a part of clinical systems labeled as “queer-friendly” are often not sufficiently educated on non-binary gender identity. The poor cultural competence that precipitates results in non-binary patients’ avoidance of care, and acquisition of transition-related information in online community spaces instead of in healthcare spaces. For participants with disabilities, or who were chronically in pain or chronically ill, it was not uncommon for participants to limit disclosure of associated symptoms or experiences to facilitate “getting in and out” of the doctor’s office. Lastly, participants expressed hesitance to disclose their gender identity because of the expectation that they may have to exert emotional labor for physicians who do not understand gender; This entailed participants expecting to have to manage their own emotions as they explain their gender identity, or as they experience instances of discrimination from physicians. The present study adds to literature on LGBTQ+ health using theories in sociology by elucidating a few social facets of the non-binary medical experience.

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Introduction

At the Intersection of Healthcare and Personhood

The most fundamental human experience is that of body occupation. Narrowed down some, each person has a gendered and sexed body that differently corresponds to their self-perception. For some people assigned female at birth who identify as women, having pronounced sexually dimorphic features may be integral to her gender identity performance. Some men who are assigned male at birth may feel the same way. For example, the former may exaggerate the length of her eyelashes with mascara, and the latter may spend extra time at the gym to augment his musculature. Both may feel uncomfortable if they were rendered unable to execute their own iteration of gender, but perhaps neither feel markedly uncomfortable as a consequence. Such is the variable nature of gender: To some, gender performance is deliberate, painstaking, and central to identity. To others, less so. Certainly, gender is a part of every person's life, be it conscious or not.

When an individual's sex assignment at birth does not correspond with their gender identity, this person can be referred to as *transgender* (trans). Those with gender identities neither woman nor man can be referred to as *gender non-binary*. For trans and non-binary Americans, gender is often rendered a sociopolitical ordeal. Because institutional and historical transphobia is rampant, being openly trans or non-binary in America is often not only socially stigmatized, but tangibly dangerous and potentially lethal. A 2008 survey finds that 32% of non-binary informants report having been physically assaulted as a consequence of their gender, 43% report having attempted suicide, and 25%

report feeling uncomfortable seeking help from police officers.¹ Across class and racial lines, these statistics are subject to change, as black trans and non-binary people are multiply vulnerable to institutional discrimination and police violence. For people who are not cis, the experience of occupying a body is often thick with self-awareness: of themselves and their bodies, and the extent they are rendered vulnerable to others as a consequence of the stigma their gender non-conformity carries.

For every embodied person, trans or cis, routine body maintenance is important. One part of such maintenance is identifying when one is no longer in good health, and seeking the help of a medical professional. For Americans, seeing a medical professional often means entering the practice of a primary care doctor, filling out a form, and meeting with a professional healthcare practitioner who can give informed health insight. For each of these encounters, the process of patient intake can be characterized by a short stack of medical forms, and sitting idly in a room with dusty air and plain walls. Perhaps a fish tank. Such a waiting room is not intimidating on its own; it has no moral character without the administration that self-adorns with requisites for entry and respect. It is the doctor's office as a subjective arbiter of health and illness that can yield stress and moral ambiguity.

The present study operates at the nexus of non-binary gender and the doctor's office. For those who do not identify within the gender binary, moving through administrative hurdles and interacting with physicians is not always straightforward; The confusion not only lies in socially navigating the physician-

patient relationship and the impact of perceived physician knowledgeability and prejudice, but at the structural level, in the paperwork and policy minutia. For non-binary people, the discomfort associated with the institution of medicine is inextricably tied to the stigma that is attached to their identities and bodies, and the experiences associated with medical professionals who historically have not been equipped to field their intake.^{2,3,4} When gender variant people pass through these administrative hurdles, they often must engage with the added burden of navigating which binary sex and/or gender they should mark down on forms requesting such a classification. To have a clear picture of a patient's predisposition to illnesses that may be more common in one sex than another, such a classification can be consequential for care. When a patient's sex is not clear based on their appearance, or when their different secondary sex characteristics are not binary in the same way, the options listed for "sex" often are not exhaustive. An example of this would be an individual who was assigned female at birth, has begun hormone replacement therapy with intravenously administered testosterone, and perhaps has had surgery to remove their breast tissue, but not surgery to alter or remove their ovaries, uterus, or vagina. The person may appear masculine and be presumed a male sex category by their peers, but may have health concerns associated with their reproductive organs that are classified as "female" concerns. Furthermore, they may not use "he" or "she" pronouns or identify with either sex or gender. Before even stepping into the doctor's office, it is evident the lack of administrative space or preparation allotted for this patient's intake. As the patient moves past this hurdle and into the

doctor's office, the disposition and cultural competence of the doctor are critical, as it can determine the willingness of the non-binary patient to seek care for other health concerns.⁵ As an authority on and arbiter of health and illness, the disposition of the doctor, and consequentially the content of doctor-patient relationship, is of the utmost importance. The delivery of adequate healthcare is contingent on mutual trust and comfort. These are major factors that impact healthy disparity; Comfort seeking out medical care impacts the likelihood of going to a physician, and trust for one's physician impacts the likelihood that a patient will comply with the doctor's orders.

Medicine as an institution is relatively new, with the American Medical Association beginning to standardize medical practice and establish standards for medical licensing in the mid-to-late-nineteenth century. Over time, what it means to be a doctor and deliver healthcare has vastly changed, both as a consequence of changing medical technology and a growing patient population. Even in the past decade, health policy and protocol has been rapidly changing to simultaneously improve cultural competence and efficiency. While just a half-century ago, physicians were more often self-employed and locally practicing, today most practicing physicians are employed by and beholden to hospital or managed care systems. Such a shift serves to organize and standardize care, but may function to change the nature of medical practice. As these changes occur, having a pulse on who is impacted, and how severely is of utmost importance. This thesis focuses on a cohort of seventeen gender non-binary Boston residents, and seeks to address how their care fares in the manner modern medicine is organized.

This project has three empirical chapters. The first engages with medical bureaucracy, the second with medical authority, and the last with emotional labor. In the first chapter, I take you through the original intention of trans-exclusive Medical intake forms, and the limitations of expanding gender and sex options on such forms. I then discuss Boston's queer medical landscape at the time of my interviews to preface patient narratives I gathered from my participants. In these narratives, I observe participants' routine assent to being processed as their assigned sex at birth, and queer-friendly physician's inability to ensure that patients are referred to other queer-friendly physicians, both illustrating the ubiquity of binary healthcare, even in what participants describe as America's best city for queer-friendly healthcare. The last part of this chapter looks at the obscure nature of insurance policy and physician's ability to circumvent trans-exclusionary insurance stipulations.

The second chapter has two parts: One of physician competence as it pertains to gender, and another of physician competence as it pertains to chronic illness. The first part outlines a brief history of physician authority, and then narrows into an overview of physician LGBTQ competence in Boston. Following this overview, I examine the impact of poor physician competence for non-binary gender identities and discuss the implications of non-binary and trans people feeling more at ease in online communities discussing health, than with their own physicians. The second part of the first chapter undertakes the high prevalence of chronic illness among trans and non-binary people, and integrates this into the discussion of physician authority. That trans and non-binary people are

disproportionately predisposed to chronic pain, engaging with the experiences of participants pertaining to their chronic conditions was a pertinent aspect of a discussion of queer-tailored healthcare. Since the etiology of chronic pain is often unknown, non-binary patients with chronic pain often opted not to disclose their daily pain, in addition to their gender non-disclosure, obscuring progressively more of their lived realities for convenience's sake.

In the last empirical chapter, I engage with emotional labor of patients, flipping the typical healthcare emotional labor narrative. Patients who must visit healthcare spaces wherein they must regularly manage their emotions are subject to patient burnout as a consequence of these repetitive exertions of emotional labor. This chapter talks about how emotional labor is gradually less of a concern when a physician's practice shows that it will administer affirming care. This can be done through inclusive intake, but was most effectively accomplished when the healthcare practitioner shared one or more of the identities of the patient. This chapter also engages with racial and queer identities in caretakers, and the impact of shared identity on patient trust.

The overarching narrative that strings these three chapters together is one of a tension between the impersonal nature of Medicine, and non-binary patients' unsteady dependence on their authority. If a non-binary participant was not completely dissuaded from the institution of medicine, their time in doctors' offices consisted of a handful of compromises, be it allowing themselves to be misgendered by their physicians, opting not to talk about their chronic pain, or managing their emotions by hiding their discomfort when addressed by their

‘dead name’ (given name) or incorrect pronouns. In these chapters, I seek to answer: *what are the impacts of medical bureaucratic inertia on the people whose existence fundamentally defies its structure?*

Literature Review

Medical Sociological Perspectives: Power and Bureaucracy

As a legitimate and venerated field, the institution of medicine (capital “M” Medicine) has the power to institute socially informed criteria for an “ideally” functioning human body. In America, such an institution was deemed necessary circa 1847, when medical practice was established as the sole authority on healthy human functioning by the American Medical Association (AMA) in an effort to standardize and systematically improve medical care (Conrad, 1992). Since then, the jurisdiction of the field of medicine has only expanded, taking dominion over health matters as particular as social adjustment and sexual preference (Herzberg 2010). For the entire course of the 20th century, doctors illustrated their ability to overtly medicalize and performance of gender and pathologize ambiguous genitalia (Ehrenreich and English 2005; Fausto-Sterling 2000; Litt 2000; Preves 2003). In 1980, sociologists began to observe the field of medicine increasingly as a legitimate judge of morality, pointing to the medicalization of homosexuality as a major example of its unprecedented assertion of authority (Conrad and Schneider). A decade later, sociologist Irving Zola (1992) demonstrated the role of medicalization on social control, purporting that adults will use a narrative of accountability to explain to children how illness comes about. In medical sociological literature of the turn of the century, it is evident that the scope of the profession has expanded in an irreversible way, giving physicians a monopoly on their caliber of health professionalism (Conrad 1992). To the public, the field of medicine has the final say on the location of the

border between illness and health, and of the parameters around medically-sanctioned bodies.

Beyond the scope of its jurisdiction, the population of patients in medicine's purview has also remarkably expanded. To accommodate a large intake volume of patients seeking care, Medicine also had to make its services more efficient; this is done through large-scale systems of "managed care," and by more minor administrative fixtures like intake forms. The term "managed care" broadly refers to any healthcare system that selects healthcare services based on their effectiveness and utility (Mullner 2018). Often, systems of managed care will require that face-to-face physician-patient interactions be constricted by a time cap, rendering the conversations between physician and patient scripted and almost identical (Dugdale, Epstein, and Pantilat 1999). Deborah Stone (1997) engages with the impact of managed care on the doctor-patient relationship, observing that giving financial rewards to physicians who spent fewer resources on patients impacted the relationship in a way that obscured the overarching goal of medical practice: to treat illness. About a decade later, Atul Gawande (2009) reinforces this notion that the way that healthcare is set up doesn't reliably correlate cost with quality of care. He gives the examples of a surgeon scheduling surgeries to solve health problems that a change in diet could mitigate, or physicians feeling pressured to order unnecessary tests for multiple patients a day to avoid a malpractice lawsuit. Besides affecting the kind of care that is being administered, America's modern iteration of Medicine discourages too heavy a time-investment in the physician-patient relationship. John McKinlay

and Lisa Marceau (2002) cite that in certain managed care systems, physicians are only permitted six to eight minutes per patient. This constraint impacts the doctor-patient relationship, as physicians with half their patients enrolled in managed care were found to be twice as likely to be dissatisfied with the length of their patient visits (Dugdale et. al. 1999).

In addition to managed care, uniform patient intake and esoteric insurance policy heavily impact the way healthcare is carried out by professionals. Medical sociologists in the latter half of the twentieth century observed the gradual bureaucratization of Medicine, and theorized its potential ramifications; George Ritzer and David Walczak apply Max Weber's rationalization to medical bureaucratization, stating that with time, the hyper-organization and standardization of medical care will render physicians indistinguishable from "bureaucrats and capitalists" (1988). To substantiate this prediction, in 2002 McKinlay and Marceau observe a potent trend of physicians moving from self-employment to systems of practices with uniform care. They describe the resulting style of healthcare "assembly-line medicine." The extent of such standardized care-management will indubitably affect the physician-patient relationship. The bureaucratization of medicine plays a critical hand in the way patients interact with physicians, as it characterizes the environment in which a patient seeks care.

Physician- and Patient-Exerted Emotional Labor

The kind of labor that healthcare practitioners carry out is often at a vulnerable juncture in a patients' life, usually at a time they are concerned about

their wellness. To navigate this interactional location pre-imbued with emotional potential, healthcare professionals often must manage their emotions, in a process Arlie Russell Hochschild (1983) coins *emotional labor*. Hochschild makes the distinction between *deep-acting*, managing one's emotions to be congruent with the emotional experience, and *surface-acting*, managing one's outward reactions to said experience. As it pertains to emotional labor in healthcare, much of the research concerns healthcare practitioners' emotional labor for patients; Among healthcare practitioners, it is further divided, as female nurses are shouldered with much of the emotion-work exerted for patients (Gray and Smith 2009; Reverby 1987; Riley and Weiss 2016). The literature suggests that physician-exerted surface-acting predisposes practitioners to what is termed "physician-burnout," a syndrome characterized by lethargy and a diminished zeal for doctoring (Ruzycki and Lemaire 2018). However, Larson and Yao (2005) illustrate the benefits for care that emotional labor can yield: Improved physician-patient relationship through facilitated communication, and higher levels of trust. In short, emotional labor can take a long-term toll on physicians and nurses, but improve their relationships with patients.

The current study will also engage with patient-exerted emotional labor, an infrequently studied aspect of emotional management in healthcare relationships. Joan Williams Hoover (1983) looks at "patient burnout" as a cause for medical non-compliance in diabetic patients. Hoover advises taking time away from the source of burnout (often the practitioner themselves) to alleviate its non-compliance ramifications, and to ease the burden of the high-demand job of

chronic illness. Despite its apparent prevalence as a phenomenon, the literature on patient-exerted emotional labor is thin; The present thesis will elaborate on the ramifications of the demand for patients to continually manage their emotions as self-caretakers with stigmatized bodies.

Gender Variance in Medicine

The extent to the American non-binary community and their experiences in healthcare are not extensively documented. For statistics that try to quantify the proportion of Americans who identify outside the binary, methodology can be unreliable due to the private nature of gender for many gender variant people and due to the fact that many survey questions seeking to clarify gender do not have exhaustive options. For trans people in general, discrimination upon identity disclosure is a major issue, with 90% having reported discrimination in their workplace, and 71% having taken measures to hide their gender or transition to avoid discrimination (Deschamps and Singer 2017).

Regarding quality of healthcare, much of the existing literature looks at binary trans patients and their hurdles to adequate care. Surveying the experiences of binary transgender patients illustrates that stigma and mutual trust can hinder the doctor-patient relationship, as many transgender patients will walk into a clinic expecting the disposition of their physician to reflect those of their cisgender peers outside of the medical world, suggesting low expectations for cultural competence (Poteat, German, and Kerrigan 2013). These preconceived notions about how doctors will behave are reinforced by the repetitively cisnormative and heteronormative attitudes employed physicians, that are taught

to them in medical school (Alencar Albuquerque et al. 2016; Bauer et al. 2009; Snelgrove et al. 2012). In the 2008 national Transgender discrimination survey, Harrison and colleagues find that 14% of non-binary patients report being refused medical care due to physician prejudice, and 36% report avoiding seeking medical care at all due to expectations for bias. A 2012 set of physician-focused interviews determined that barriers to care are multifactorial, but are primarily a lack of knowledge of the part of physicians resulting in cultural incompetence, and poor inclusion in medical students' curricula (Snelgrove et al). Meanwhile, Boston University Medical Center determined that simply including a single lecture in a medical school curriculum regarding gender variance significantly improved their comfort and willingness to treat transgender medical patients (Deschamps and Singer 2017).

This mistrust and cultural miscommunication can also manifest in the process of obtaining prescriptions for transition-related hormones, as many transgender patients seeking to transition will often say what they believe the doctor needs to hear to give them gender transition hormones, and for gender non-binary patients, this can involve misreporting their gender as binary (Deutsch 2012; Green 2004). Madeline Deutsch (2012) also finds that that the mandatory screening process to determine whether a person is eligible for gender transition does not have a significant bearing on whether that person will regret their transition. Nevertheless, this convention persists, and is often required to precede prescription of trans patients of hormones or permission to have gender confirmation surgery (Deutsch 2012).

In the past five years, there have been a number of smaller scale exploratory studies with a focus on gender non-binary or gender non-conforming medical patients. Radix and colleagues conducted a number of focus groups in New York City which shed light on significant erasure in medical documentation manifesting as a lack of exhaustive survey questions on intake forms regarding sex and gender, and also revealed a few consequences of the patients' expectation to experience stigma, such as delaying their own care for time-sensitive testing for HIV and other illnesses. The researchers note that the results indicating marginalization, low levels of provider competence, and barriers to acquiring care are particularly concerning observations for New York City residents, where significant advancements in policy for trans people have been established already (Radix et al. 2014). There are two existing theses which have conducted exploratory surveys on the experience of non-binary people in healthcare (Mogul-Adlin 2015; Schulz 2012). These studies found that gender affirming behaviors (such as addressing a patient with their correct pronouns and appropriately gendered nicknames), and inclusive intake forms resulted in comfortable experiences and active seeking of care, while a lack of inclusion on intake forms and demonstrated incompetence ultimately resulted in avoidance of care (Mogul-Adlin 2015; Schulz 2012).

In her 2010 dissertation, Tey Meadow analyzes thirty-eight judicial gender determinations to observe how the state "gives gender" to certain individuals and withholds it from others, explicitly upholding the antiquated precedent that the state has authority to determine the legitimacy of someone's gender. Through the

lack of administrative space for gender variance in medical intake, and the lack of organization and education surrounding appropriate healthcare for gender non-binary patients, the medical community can be seen as implicitly allocating gender legitimacy to certain (binary) patients, and withholding it from other (non-binary) patients. By conditioning trans patients to present themselves as binary through denying certain patients hormones, they have the power to “administer gender” in a similar fashion to the state.

Conclusion

Both the medical sociological insight into bureaucratized healthcare structure and the relationship between gender variance and medical authority have long histories, and are rife with implications for current and future care. While existing literature has insight into the extent of the massive, uniformed authority of Medicine and the LGBT patients within the structure of Medicine, it lacks depth at the nexus. While we understand the ornate bureaucratic structure of Medicine and the scope of its power, seeing how different patients interact with this structure is not currently a research area getting attention. This thesis seeks to bring more insight to a discussion of gender non-binary patients at the mercy of medical authority, to hopefully pave the way to more specialized research.

Methods

The semi-structured interview data for present study were collected over the course of Fall and Winter of 2017. Full IRB approval was granted in the Fall of 2017, prior to participant recruitment. Recruitment occurred exclusively on Facebook, on the Facebook groups “Queer Exchange Boston”, and “Queer and Trans POC Exchange: Boston”. Participants were first sought in the latter Facebook group, and then in the former. After the posts were made, upwards of fifty individuals expressed interest in participating, both via Facebook and via email. Only participants who replied to my follow-up message explaining the consent process and expectations for the study were included. Ultimately, seventeen non-binary individuals residing in the Boston area were recruited for participation in this study.

Upon receiving responses from participant outreach, contact was made to the potential participant to electronically send them consent materials, and to schedule a time to meet. Initial contact was made with the participant online through email or social media. Interviews were conducted exclusively in person. The location of the interview varied depending on the ability of the participant to travel, but was exclusive to the Greater Boston Area. The data collection was exclusive to the interview time frame during the scheduled meeting with the participant. The participant were only be asked to answer questions over the duration of the interview. Only the interview was audio recorded, and each audio recording was transcribed and subsequently deleted after being secured on Tufts Box with a coded file name. The interviewee was able to opt out of the study at

any point prior to its completion, and their identity was disguised as early as interview transcription.

Consent was obtained at the outset of my meeting with participants. To document consent, the participant signed a written consent form (see Appendix for consent materials) prior to beginning the interview. In addition to having the participant read the consent form, time was devoted to verbally explain the parameters of the research and their ability to control what parts (if any) are included in the research prior to asking for any signature denoting their consent. A time slot of fifteen minutes was allocated to explaining the research and consent form, and allowing the participant to consider opting in or out of the interview. The use of such time varied on the participants' questions about the process and project timeframe. The participant was then informed of their complete control over their data's inclusion in the research. They were given the ability to contact me at any point after the interview prior to the submission of the thesis, to request that their interview data be excluded.

After consent is obtained, the interview was able to commence. The interview was recorded with a portable recording device. The participant was only be involved in the study over the duration of the initial (and only) interview, which varied in length from thirty minutes to two hours. Participants were provided \$25 of compensation in the form of a Visa gift card. Participants were informed that if they were unable to complete the interview, or if they wish to opt out of the interview at a later date, the compensation would not be taken from them.

After the interview was conducted, uploaded to a Tufts Box, deleted from the portable device and transcribed, it underwent analysis. The application *Dedoose* was used to organize and code the interview transcripts, to locate central and reoccurring themes in the data. Access to the documents on Dedoose was protected by both the account password, and the project password. The weeks following those of data collection consisted of location of themes and conducting supplementary literature reviews to better make sense of potentially unanticipated results.

Methodology

Feminist critiques of qualitative data collection observe many problems inherent to the power dynamic in the researcher-participant relationship, including the objectification of the participant and the salience of race, gender, and class in the relationship.⁶ By dedicating a subsection of my thesis to situating my shared knowledge in my own identity and privilege, I hope to underscore the subjectivity of the narrative I create out of the data I have collected. My interpretation of the research will be informed, and ultimately shaped by my limited perspective.⁷ Over the course of data collection and analysis, my limited vantage point was continually a shortcoming in obtaining a full understanding my participants' experiences.

Snowball sampling is ideal for this research because of the relatively small sample size. Furthermore, by relying on referrals in established social networks, participants feel more at ease if the interviewer is implicitly endorsed by a fellow community member through such a referral.⁸ Because the thesis does not seek to draw generalizable conclusions, having a sample that does not represent the larger gender variant community in Boston does not render this research futile. In-depth, semi-structured interviews were employed to allow the participant to elaborate on their experiences in an open-ended manner. Furthermore, it allowed me as a researcher to follow up with clarifying questions, to ensure that their sentiments will not be miscoded or mischaracterized in the final product; Being in close quarters with the interviewee eliminated the obscurity of reading responses from

an online form. Furthermore, being given the opportunity to foster trust and comfort with the participant facilitated obtaining honest and full answers.

Giving the interviewee \$25 for participating in the study served to compensate for the time they invested in the interview, away from other obligations. Such a compensation pays a degree of respect to the time the individual has devoted to the project.⁹ Twenty-five dollars was deemed as an appropriate alternative to thirty to fifty dollars, as such sums of money may have been coercive to the participant. By ensuring the participant that opting out of the study would not affect their compensation, it should not have posed as a coercive factor in the participants' agreement to participate.

Discussion: Chapter 1

The Role of Medical Bureaucracy in Non-Binary Medical Experiences

“Efficiency is a virtue in health care, but as a religion it can run roughshod over personal needs.”¹⁰

–Elliott A. Kraus

In the United States, being processed through medical bureaucracy is a requisite for many, beginning at birth, punctuated by visits to primary care physicians, and ending in death. The ubiquity of medicine as an institution has been gradually developing over centuries. When the current iteration of the institution of Western medicine was established circa 1847 as the American Medical Association (AMA), its intention was to standardize and systematically improve medical care.¹¹ As a consequence of its recruitment and educational practices, and its historical precedent as the sole authority on medicine, Medicine has unparalleled jurisdiction over the boundaries of health and illness, and the legitimate means of staying well.¹² Medicine’s intricate bureaucracy serves as its means to maintain and organize health data, to ultimately improve knowledge about health populations and facilitate efficient caretaking. Drawing on data from seventeen semi-structured interviews of gender non-binary adults, this chapter illustrates the failure of Medicine to bureaucratically account for and process medical patients who do not identify inside the gender binary. Such a miscalculation came to fruition in a lack of administrative space to establish patients’ gender identity as unique from their assigned sex at birth, an inability for patients to subvert that lack of space, and in the red tape that stands between non-binary patients and the “partial” medical transition they often seek for their bodies.

M or F: Physician Rationality

At times, contingent on a physician's administration of specified healthcare is a classification of their patients as one sex: Male or Female. To have a clear picture of a patient's predisposition to illnesses that may be more common in one sex than another, such a classification can be consequential for care. Max Weber theorized this type of reasoning for social action as *means-ends rationality*; an "action...rationally oriented to a system of discrete individual ends (*zweckrational*) when the end, the means, and the secondary results are all rationally taken into account and weighed."¹³ Classifying assigned sex at birth, or "sex category," because of its salience for healthcare decision-making, facilitates the care provided by the physician by establishing at the outset aspects of a human's anatomy that would be too cumbersome to substantiate through a verbal triage in each patient-physician interaction; The intake forms' indispensability lies in its ability maximize efficiency in the hospital when patient volume can be quite high. Establishing sex classification and any pre-existing conditions allows physicians to make some conclusions prior to face-to-face interaction. However, as Weber notes, "it would be very unusual to find concrete cases of social action, which were oriented *only* in one or another of these ways..."¹⁴ While the pragmatism in such an intake question is incontrovertible, there is also a *traditional* precedent involved in its persistence; Weber describes this type of social action as an "almost automatic reaction to habitual stimuli"¹⁵; As much of gender performance and identity is unconscious for cisgender people,¹⁶ its invisibility in paperwork may habitually follow. Such invisibility may be

reminiscent of George Ritzer and David Walczak's prediction in 1988 that as means-end rationality in medicine expands, it will lead to "lead to greater external control over physicians and to a decline in the ability of the medical profession to distinguish itself from bureaucrats and capitalists."¹⁷ In 2005, Peter Conrad observed that such a change was being realized, in shifting engines of medicalization that in some ways, further bureaucratically organized Medicine.¹⁸ John B. McKinlay and Lisa D. Marceau observe this as the "end of the golden age of doctoring," citing that from 1983 to 1997, "patient-care physicians working as employees" shot upward from 24 to 43%, while privately practicing physicians fell from 40% to 26%, painting an image of a gradually growing medical bureaucracy over this time period.¹⁹ The consequence of such heavy bureaucratization of doctoring is that physicians have less time to sit face-to-face with patients, and, as a result, have less time to foster mutual trust with their patients.^{20,21} Over the course of the twentieth century, The Doctor shifted from being a neighborhood fixture, personally acquainted with an individual's family and personal habits, to an elevated, impersonal professional figure, with two to six minutes to diagnose your problem and see the next patient.

Contemporary trans health researchers have developed a "two-step" gender identity question to accommodate gender-variant populations seeking medical care, because the "sex" question has the potential to erase gender identity that is contrary to an individual's sex assignment at birth. The two-step gender identity question, involving disclosure of *both* assigned sex at birth and gender identity was determined to be a reliable alternative to a single, unqualified

assigned sex at birth question.²² LGBTQ advocates have recently begun to deliberate the inclusion of gender-identity questions on intake forms, weighing the potential harm for systematically required disclosure, and the improved visibility for transgender and non-binary patients.²³ Required disclosure may inadvertently pressure patients who are not ready or unwilling to share their gender identity with physicians to “come out.” Optional disclosure does not fully relieve this pressure, but allows for those who would benefit from disclosure the option to have their gender recorded in their medical forms. Despite the research establishing the benefits to bureaucratic inclusion of gender variance, including unrequired gender identity questions in mainstream medical care is not yet commonplace. As visibility for trans and gender non-conforming Americans becomes more frequent, the landscape for gender identity disclosure in medical settings changes as well.

Intake in Boston: 2017-8

Of the seventeen individuals interviewed for this project, each one had either encountered a required sex classification question, or had expected to. For these individuals, the persistence of bureaucratic invisibility of their gender variance had varying outcomes. Assent to being processed as their assigned sex at birth depended on their medical transition status, their level of trust for physicians, and the circumstances around which they were receiving care.

For patients with primary and secondary sex categories that do not correspond (due to having pursued a “partial” gender transition), this question can be cumbersome. For these individuals, such a categorization is not straight-

forward. While only 40% of the participants who had not undergone any form of medical transition contributed insight into their experiences of “binary care,” 60% of participants who had undergone some medical transition contributed to this portion of the data. An example is Wynn (they/them), a non-binary gender fluid person who has undergone Hormone Replacement Therapy (HRT) with a relatively low-dose of estrogen and spironolactone. They describe themselves as having some of the development associated with taking these hormones, but also having characteristics that are “male.” They express the concern that checking off one box or another would not give the physician the information they need:

Well I don't like the fact that you have to check a gender box on intake forms. More often than not, it's irrelevant. I think a better way to do it would be... Like, 'do you have X body part, yes or no?' Cause like, it's like... Even for something so ubiquitous like cancer screenings... I have breasts and a prostate.

Wynn's concern here is that the sex marker they provided for their intake form would be insufficient for the physician's presumed intentions. Their concern is reflected in the WPATH standards for care; Too many cancer screenings may subject the patient to high levels of radiation, and not enough may result in finding cancer later than healthcare professionals otherwise could.²⁴ Such a conundrum is not easily mitigated, and remains a problem for many individuals who may need more cancer screenings as a result of having transitioned. Wynn goes on to clarify that depending on their mood, the confusion of others regarding their gender is sometimes par for their course, but other times uncomfortable:

When I'm in a really confident mood like, 'Hey! I'm non-binary, suck it world!', I revel in the confusion of others. But, when people make too many uh, assumptions about myself and my gender and my experience, it grates on my nerves after a while.

Wynn's experience, therefore, is twofold: regarding a concern for their health, and their desire to be addressed with an identity that is congruent with their experience. When asked about how they field the 'Sex' question, Wynn described their thought process by telling me that "If there is an 'Other' option I will select it. If there isn't and I'm feeling bold, I might just not bother. Or I might ask, like 'Hey, this is a thing, what do I do about it?'" Thus, for every medical intake form that does not have an 'other' option, Wynn has to deliberate their response. While the 'Sex' question on intake forms was designed to streamline care, for people like Wynn, it adds some confusion and another step to the intake process.

Wynn's latter concern, of not being addressed with an identity congruent with their experience, was more common for those who had not undergone any degree of medical transition. Often, these participants described allowing themselves to be referred to, processed, and treated either as the binary gender they were assigned at birth, or as the binary gender they were not assigned at birth. An example is River (they/he) a twenty-year old, non-binary student, who discusses his lack of experience with intake forms that aren't binary. He says that while he has never had an intake form that was not binary, he hopes this changes in the future. He explains his rationale for recording his assigned sex at birth on these binary forms: "I've found that when I need to fill out those forms, I fill them out by my biology since I don't fully identify as male. But it's always just this adventure of like, 'do I misgender myself now, or do I out myself later?'" River's decision to fill the form out by his "biology" is a very common one, especially for gender-variant folks who have not taken steps to medically transition. The

understanding for many is that the question is a rational, medical question intended to streamline care. However, River later clarifies that he knows he will be mischaracterized as the incorrect binary gender as a direct consequence of this, and even alludes to his avoiding care as a consequence of this worry:

I'm also planning to [see a gynecologist], 'cause I still haven't been to a gynecologist and I feel like I should at this point in my life, but I've been putting it off because I'm one hundred percent going to get misgendered. And it's just... It's been interesting in that way. A lot of my experience since I came out has been... I haven't gone to a whole lot of medical stuff and some of it has been [because] I haven't needed to, and some has been [because]... I don't want to go through the misgendering experience that is definitely going to happen every time.

In this way, River illustrates how disclosure of sex assignment at birth can facilitate physician's placement of patients into a "sex category"; an individual's assumed sex, independent of their assignment at birth and their gender identification.²⁵ Many gender-variant patients go to lengths to conceal their sex category in a conscious effort to avoid the social treatment associated with their assigned sex at birth; The unqualified disclosure of sex category renders physicians ill-equipped to treating their patients as a gender congruent with their identity. Elian, a non-binary Bostonian in their mid-twenties, describes the consequences of being placed into a sex category by a counselor at their women-only alma mater:

Okay so I had this person that I saw, at the [college] counseling center. Oh boy, she was very infantilizing and [would say things] like, 'Oh baby...' and I was like 'Please don't.' She wouldn't use my pronouns all the time. Occasionally she would, and then when I would correct her... she would be like 'Oh I'm sorry, it's just like with how you look!' Like... it's hard. Like maybe don't tell me I look like a girl if I'm not... Also like, you're a therapist, man, come on! That was very frustrating.

In Elian's case, feeling patronized was enough to indicate that they were being treated according to their sex category and warrant frustration; The explicit acknowledgement that followed seemed to add a layer of frustration, making the abstract mischaracterization more concrete. Their attendance at a women-only university, disclosure of their assigned sex at birth, and their outward appearance were being used as social tools for the counselor's administration of culturally relevant healthcare; Contrary to their counselor's assumption, knowledge of their assigned sex at birth did not give sufficient information for administration of patient-centered care. Taylor (they/them) expresses that they will also answer to their anatomy: "I always circle F, because I assume they want to know about like, my anatomy. So, it's like, okay, this is the information they're going to want. It's just like mildly frustrating." Taylor is describing their assent to the bureaucratic rigidity of medical intake forms and sex-specific care by their choosing F on the intake form. Taylor also signals that they can understand the rationality of the assigned sex at birth question, and that doctors should reasonably be able to ask for details about a patient's anatomy. They go on to qualify their reaction to such an expectation: "And I guess it depends on how I feel about gender and society on that particular day. How much I'm already angry about it [chuckles]. It's difficult feeling like you're not seeing a space where you can exist." Taylor goes as far as to characterize the gender exclusivity as "not seeing a space where [they] can exist," implicitly establishing the centrality of their gender to their identity and indicating the importance of their gender disclosure in their interpersonal interaction. To exacerbate the adverse experience of obscuring one's gender

identity, Taylor shares that due to their genital chronic pain, being referred to “Women’s Health” clinics often requires them to be processed as a woman, inextricably tying them to their primary sex anatomy.

Nicky (they/them), a non-binary trans woman, echoes Taylor’s emphasis on the negative impact of bureaucratic invisibility. When asked about the changes they would make to the way healthcare is routinely administered, Nicky started with “the check box,” referring to the sex assignment question on intake forms:

First thing would be that you don't need the check box. You don't need that. I think it feels very similar to my actual ideal expectations for non-medical circumstances, too. It feels like the trick would be to make sure that the language and practices and ideas that are being followed by the doctors in question are like, scrubbed of all the gendered violence things that make assumptions about like, sexual behavior, and about like pronouns and language, in general...

Nicky describes physician’s binary language as “gendered violence things,” and also begins to broach the assumptions associated with such language that have implications for sexual behavior and preferences for being addressed.

Wynn, River, Taylor, Nicky and Elian’s narratives are reflected in other participant’s appraisals of Medicine’s *M or F* question. Both the health and social consequences of being processed as one’s assigned sex at birth were relevant to the discussion of intake forms. Being sure that the patient has given exhaustive information about their health, and being sure that the patient is being clear about their name and pronouns are both related to their opportunities to disclose in medical paperwork. The struggle and deliberation associated with being non-binary and deciding what to record as a sex category is the antithesis to the intention of intake forms. That patients must spend a moment, or ask an employee

about how to respond is evidence that the purpose of the intake form is not being fulfilled, and what is posed as purely means-end rationality, also has some features of traditional rationality. That patients are behaving as rational actors by giving a quality appraisal of the bureaucratic hurdles to accessing care is contrary to Weber's qualification of bureaucracy as a tool to guide the irrational actor.

Non-binary patients are hyper-aware of the reasoning behind such a question, and also aware of the ways it could be improved to streamline their own care acquisition.

Bureaucratic Subversion and Patient Ritualism

For participants who felt frustrated with bureaucratic gender exclusion, there were a handful who decided to attempt to override the lack of exhaustive options, by creating their own box, writing a note, or talking to someone who works at their clinic. Attempts at subtle, non-disruptive subversion can be conceptualized through Robert Merton's *strain theory*. Merton's strain theory attempted to outline how societal pressure drives people to behave to attain their (usually financial) goals.²⁶ To apply his theory to non-binary patients going to the doctor, the features of strain theory need to be reframed.¹ At the outset, non-binary medical participants may have used bureaucratic avenues to attempt to subvert their lack of inclusion, using what Merton called *conformity*.²⁷

Participants perceived that if they made a note of their gender variance on forms,

¹ Employment of 'strain theory' for gender non-binary individuals in healthcare bureaucracy somewhat alienates the term from its initial purpose, which was to conceptualize social reactions to poor socioeconomic mobility in America. Such a radically different reapplication is intended.

or mentioned it to someone working at a clinic, they could bureaucratically show their variance through institutional avenues. With time, these participants fell into Merton's *ritualism*, assenting to their being processed as their assigned sex at birth, and passive to the exclusive intake language. In the following excerpt, Nicky elaborates on their discussion of binary intake forms by commenting on the inescapability of "the paperwork":

Like not just with physicians, but any place where someone gives you a form and you have to pick a ... I think it's really funny because sometimes people label it as sex and sometimes people label it as gender. There's no consistency about what the check boxes are labeled at the end of the day. I'm familiar enough with how these things happen that it's just like structurally hilarious and funny and also horrible because you know there's no conversation you could have with these people that could end with them being like 'Oh, yeah you're right we don't actually need to write it this way, let's just take it off.' It feels like the thing ... There's some sense in which I feel like the structures of gender are so deeply embedded in like, the paperwork. Not necessarily the social structures in the people's heads. Like, I believe that people can change their attitudes towards gender over time, but when it's embedded in the paperwork, that feels like something insurmountable somehow.

In this way, Nicky's prognosis for the ability for individuals to change is unique from their perception of Medicine's capacity to create accommodating paperwork. Their claim that binary language being "embedded in the paperwork" proved true for many participants' experiences attempting to overcome their exclusion. Taylor relays a tangible example of the "insurmountable" nature of bureaucracy, in an account of attempting to let their primary care providers know their gender identity:

I don't end up talking about gender very much in most medical settings. I have tried repeatedly with the like, healthcare system that I see... where my primary care is. I tried multiple times to indicate what pronouns I use but they literally don't have a place to indicate

that in your medical records. I could say it as many times as I want but no one's gonna remember cause it's not on their forms. So, I generally think that most of my providers probably don't know or don't remember cause it's not in the forms. So, I generally think that most of my providers probably either don't know or don't remember my pronouns.

Taylor's attempt to enforce the recording and retention of their pronouns and gender, to avoid their being misgendered in the future, was to no avail. They later characterize their push to be recognized as gender variant as "vulnerable":

I think the things that make it hard to talk about gender is the fact that either they don't ask and they just assume, or they do ask and their only options are like, M and F. And I'm like okay, well, this is not going to reflect my complete identity. Or, they either like they ask or like I ask or I find a way to tell them my actual identity and how I want to be referred to and they don't remember. So, it's like, what good was it to be vulnerable and tell them and then like, nothing changes. Those are the things that discourage me, just feeling like there isn't space to talk about it or express it. Even if I make the space, it's not really taken seriously or made note of.

In the process of attempting to override Medicine's administrative oversight, Taylor was given the impression that it wouldn't be made note of no matter how many times they used administrative avenues to make an exception. Over time, Taylor began habitually choosing "F," in accordance with Merton's notion of ritualism. Kai, a non-binary person who has undergone some transition with testosterone, expresses a similar notion; In the following excerpt, they express their ability to be referred to as their assigned sex at birth as one reason the consequences of passivity is palatable to them:

I used to pick the M one but that was just [to be] spiteful. Now I'm like 'Ehh, the F is okay I guess.' Because my gender is like loosely linked to femininity, and I'll use she/her pronouns. I don't mind being seen as a quote unquote girl, and in like a medical setting I'm like, it might lead to less uncomfortable questions than if I check M on there and they're like 'But...' and I'm like 'ha-ha, you see... about

that...' So, I just check F because it leads to less questions that might be uncomfortable, so.

Kai reasons that assenting to the intake's binary isn't impossible for them, because their gender is linked to the gender corresponding to their assigned sex at birth. Negotiating with the binary options by leveraging their indifference to one of the options was central to their ability to move through this administrative step. Having used to choose "M" in a "spiteful" way, and then giving into the option that promised less social resistance seems to be a symptom of the lethargy associated with pushing back on bureaucratic inertia. Their protocol at the outset was reminiscent of Merton's conformity, using institutional means to question the binary precedent, but with time they situated into Merton's ritualism, in their desire to receive care without social friction taking precedence over the non-binary nature of their gender. That patients struggled with subverting the bureaucratic invisibility highlights the importance of bureaucratic inclusion; If non-binary people are expressing a desire to be included in paperwork, then a lack of inclusion and/or accommodation is contrary to the means-end rationality that supposedly comprises Medical paperwork.

Bureaucratic Subversion and Physician Ritualism

For the physicians and healthcare systems who sought to overcome the binarism of medical bureaucracy, a tendency toward ritualism was also a barrier to attaining these goals. In *Power and Illness*, Elliott Kraus observes that "At best, only a segment of bureaucratic workers can be expected to continue with the enthusiasm that they might have originally brought to their job," later explicitly

linking the steady decline of enthusiasm to Merton's ritualism; "Going through the motions while no longer really caring about the goals and purpose of the organization."²⁸ Participants describing the shortcomings of LGBT-centered (clinics *designed for* LGBT clientele) and LGBT-friendly (clinics *welcoming to* LGBT clientele) healthcare providers in Boston seemed to focus on the non-compliance of clinic personnel to the bureaucratic changes that were made, or the ultimate failure of the changes due to referrals to outside healthcare providers without a patient-organizing systems that gave specificity to gender. Nicky describes the student health system at their university, which allowed them to share their new name that did not correspond to their given name:

At [my university] they have this in their filing system... they allow you to enter a pseudonym, basically, an alternative name. I entered a different name and they never actually used it. And like, I don't know if this was just like... I don't know how to interpret or feel about that. I know how I felt about it at the time, like 'fuck you, how dare you?' But like, also it's a system that doesn't respond to people.

In this excerpt, Nicky elucidates the limitations of minor subversive elements of LGBT-friendly bureaucracy. That they were able to give an alternative name was a positive aspect of their intake, but that it was not acknowledged in their actual care was offensive. Kraus' application of Merton's ritualism to bureaucracy is relevant here, because it shows how employees steeped in the ritual of bureaucracy may be subject to its inertia, and not respond to changes subversive to its precedent. Nicky's inability to be addressed with the name congruent with their gender is a consequence of this phenomenon; While it is in the interest of caretakers' intentions to address Nicky the way they prefer, paying attention to

and employing the preferred name recorded in their student file was not a part of their ritual.

Bo, a 22-year-old recent college graduate, describes the limitations of the LGBT-centered clinic they were recommended (given the pseudonym LGBT Health). They share that they had a “really terrible experience there”:

Bo: In a medical office, I have very low expectations. I go to LGBT Health, and I was told by people that it was the best option. But I had a really terrible experience there, and when I told my therapist about it, my therapist has a lot of queer and trans folks of color as their clients, and they said that oftentimes at least with their clientele, like AFAB² non-binary folks don't really get gendered properly or treated properly-- from their clientele list. So, when I went there, I put like, my name, and they were like 'Oh, you can put your gender, your pronouns,' so I did all that, but they'll still give you things with like, F on it. And when you call on the phone they'll like 'ma'am' and 'sir' you. So, it's supposed to be like the premier LGBT healthcare organization in the United States, and I feel like they don't properly train their staff. I feel like maybe the doctors who work only with trans patients are probably better, but, they make a lot of assumptions about you based on what you look like. And when I was having issues with like, my... vagina, STIs, and stuff, they gave me a 'Women's Health doctor.'

Neeki: They referred you?

Bo: Yeah, they referred me to this person... My PCP and [I] don't really talk much about things, they try to be inclusive with like language, like sometimes they'll be like 'oh, do you have sex that could get you pregnant?' as opposed to assuming I have sex with cis men. But sometimes they say like, 'Oh do you have a male-bodied partner or a female-bodied partner?' So, I think medicine has a long way to go with figuring out how to be accurate with terminology but also respectful of the patient's needs. Cause I often, I understand why it's important to talk about my partner's genitalia because of like, STIs and whatever, but it does make me uncomfortable because that's not something that they would want to be shared openly. They're also non-binary.

² Assigned Female at Birth

In the above excerpt, Bo describes the feeling associated with expecting proper treatment at an LGBTQ organization, and being let down. They say, “I’m telling myself like, ‘Okay I can just get the care and go,’ but it’s an alienating experience because I feel like I went there for specifically queer and trans-inclusive healthcare.” They characterize their experience being given the opportunity to share their gender, chosen name, and pronouns, and then still feeling beholden to their sex category in the documents with “F” written on it, as a negative one. The clinic itself, because of the emphasis on assigned sex at birth in caretaking associated with primary and secondary sex characteristics, failed to separate Bo from the sex characterization that caused them discomfort. In the excerpt, Bo implicitly shares that feeling categorized by sex is an untoward byproduct of medical bureaucracy that remains unmitigated by even what Bo describes as the “premier LGBT healthcare organization in the United States.” Furthermore, Bo’s referral to a “Women’s Health” doctor sheds light on another important limitation of LGBT-centered healthcare; Their reliance on outside organizations without the same queer-tailored intake characterizations. Bo’s discomfort with the moniker “Women’s Health” comes from the linguistic tie that is being made from reproductive health to womanhood. For AFAB non-binary patients, going to a “Women’s Health” clinic to address the health needs that pertain to their primary sex characteristics often resulted in some discomfort. Bo’s referral by an LGBT-centered health organization to a clinic that did not accommodate gender variance in their intake or apparent physician competence resulted in their ultimate assent to being processed and referred to as a woman. Bo’s inability to overcome being

processed as a woman was not helped by the steps that were initially taken at LGBT Health to establish their gender-variance. As observed by the literature on the ethics of the two-step gender question, disclosure of a patient's gender identity without the patient's consent has serious ethical implications²⁹; Not only is gender identity at times a private matter, but non-disclosure can confer safety that can be integral to a patient's comfort seeing a physician. However, Bo did not describe any communication asking for their preference for disclosure to the Women's Health clinic they were referred. In this way, there was no fixture in referral protocol being employed to afford Bo informed consent regarding disclosure of their gender identification in the process of being sent to a different healthcare provider.

Nicky and Bo's experiences illustrate how difficult it can be to combat innocuous-seeming demographic questions on intake forms. Even when steps are taken to lessen the social, and at times clinical-grade discomfort associated with being misgendered as a consequence of medical bureaucracy, such a sex categorization often still persists. The persistence lies either in the vulnerability of physicians to ritualism, or in the lack of uniformity in healthcare intake as it pertains to gender inclusivity.

Insurance and Pathologization

*"The gravest error of all is to assume that most definitions or decisions about who is ill or who needs help are unbiased and unmotivated by factors directly related to the broader social context which surrounds the patient and the physician."*³⁰

- Elliot A. Kraus

For participants seeking medical transition resources, there were a number of concerns regarding the way physicians read patients' gender, and how that translated to gender transition accessibility. In the current DSM, "Gender Dysphoric Disorder" is listed as the clinical-grade discomfort associated with the incongruence between assigned gender and gender identification.³¹ The classification of Gender Dysphoria (GD) as a disorder is disputed; Some participants expressed that its classification as an illness legitimizes the discomfort of the associated symptoms, and facilitates access to transition care. Some thought of it as an unwarranted pathologization of gender variance, and a byproduct of institutional transphobia. Many expressed feeling conflicted and uninformed on the topic, and expressed both of these sentiments.

At the moment, some medical insurance companies use the classification of gender dysphoria as an illness in the DSM to offer coverage for transition surgery and Hormone Replacement Therapy (HRT). Some participants expressed discomfort with the notion that they would have to present as or pretend to be a single binary gender to access transition-related care. There are some insurance companies that accommodate non-binary gender variance, and some that do not. Coverage also often varies by state, and by transition procedure.³² Dean Spade engages with the gatekeeping bureaucratic intricacies that were inextricable from medical involvement in medical gender management; In their piece, Spade highlights the problematic nature of relying on medical evaluation for change of legal gender status.³³ Spade describes a byproduct of medical gatekeeping as "...the requirement that trans people exhibit hyper-masculine or hyper-feminine

characteristics...” to access legal gender legitimacy.³⁴ What Spade describes as medical gatekeeping proved to be a concern in a number of the participants of this study. For many non-binary participants, the transition services being sought were not “complete” medical gender transitions. Transition services for non-binary people assigned male at birth include (but are not limited to) facial feminization surgery, oriechtomy, and hormone replacement therapy. Transition services for non-binary people assigned female at birth include double mastectomy, hysterectomy, and hormone replacement therapy. For some binary trans individuals, taking all of these measures is important for alleviating gender dysphoria. For many non-binary individuals, taking some of these measures but not others is just as necessary. As Jack Halberstam notes in their account of ‘Border Wars’ among Butch women and trans men, medical descriptions of the trans experience have been “preoccupied with a discourse of ‘the wrong body’ that describes transsexual embodiment in terms of an error of nature whereby gender identity and biological sex are not only discontinuous but catastrophically at odds.”³⁵ The “wrong body” narrative is one that persists in popular discourse and medical understanding of a transgender experience, despite its poor generalizability. A perception that Medicine may be seeking some form of the “wrong body” narrative to ensure that individuals seeking transition are “really ready” for surgery or hormone transition was not uncommon among participants; This perception is not unsubstantiated, as Blue Cross Blue Shield requires a gender identity to be “present for 12 months” before transition-related care is covered.³⁶ Such a stipulation is congruent with a notion of legitimate gender that

is concrete and unchanging with time, which is not the case for some gender non-binary individuals. Halberstam's insight into the "wrong body" discourse highlights the existentially absurd notion of delineating the "playful masculinity" of people who identify as butch and "real and desperate desires for re-embodiment" of trans men.³⁷ That Medicine (medical insurance companies and the AMA and APA, as well as mental healthcare institutions, transition surgeons, and primary care physicians) is saddled with this delineation may be contrary to what would be the Weberian goal of rational Medical bureaucracy: to allocate medical care in an efficient and accurate way. Trying to use means-end rationality to draw a line between clinical grade gender-variance and "casual" gender-variance, without a scientific basis for "gender" or all-encompassing social definition of "gender," may be difficult. Doing so despite this hurdle may be a feature of Medical bureaucratic rationality that is traditional, because it is based on notions of gender shaped by social precedent. That they are based on social precedent is supported by a few of the narratives of the participants of the present study.

For this project's participants, concerns about ability to access transition-related care stemmed from personal experiences, stories of others' experiences, and perceptions of physician and insurance receptiveness to non-binary gender-variance. The experiences and associated worries of three participants, Emery, Eli, and Bay, illustrate the complicated nature of patient-physician, physician-insurance, and insurance-patient interactions as medical transition care was being sought after.

Emery (they/them) is a non-binary person in their mid-to-late-twenties who has received top surgery and some HRT with testosterone. They describe their experience seeking top surgery and having to provide a letter of approval from a therapist before being eligible to receive the surgery:

Emery: Yeah and the surgeon specifically needed you to go to three months of therapy. So, like, I found a therapist who was willing to write me a letter in one appointment and then had to keep seeing her for three months before the letter counted for the surgeon.

Neeki: Wow. And what frustrated you about that?

Emery: The surgeon's a gatekeeper. She's transphobic. That's all really there is to say about it. [chuckles]. Like that's another thing with surgeons like, because I'm not good at lying and I don't [want to] pretend to be a binary trans dude if I don't have to. I don't think I'd be good at it. Like, when I was looking for surgeons I emailed them and needed to find one that would be okay with an open, non-binary patient. And so, the one I ended up with, like the person who emailed me back from the office said that was fine and I never claimed to be binary. But the surgeon is clearly transphobic and has no idea with trans stuff is about. She just does good surgeries.

Emery goes on to explain the process that took them to the surgeon that ultimately carried out their top surgery. In the following explanation, Emery describes needing a surgeon that would take on a patient that was non-binary and that did not have plans to take testosterone, and that would agree to remove their nipples entirely:

Emery: I should also mention, I don't know if this might be relevant. But I did things, in, not a typical order quote unquote. Like, I wasn't on hormones when I got top surgery and I didn't have plans to at that point. So that's another reason I needed a surgeon who was okay with an openly non-binary patient. Cause I needed one that didn't have a hormone requirement to get the surgery. And being non-binary explains not wanting hormones.

Neeki: Did you have to go through a couple practices?

Emery: I started off by just emailing people's offices, yeah. I think I emailed... I might have only three. [Dr. A] emailed back that they absolutely would not remove nipples unless medically indicated, which is a completely nonsensical phrase, absolutely hysterical. Because I was big enough that I would have needed grafts, they would have had to completely cut them off and then reattach them, so it was apparently medically indicated to reattach them, is what they were saying. Yeah, no. And then I got two surgeons [Dr. B] and [Dr. C] who said they were fine with it, but [Dr. B] was a nicer guy, but also had at least one red flag for me, but [Dr. C] gave me a lot more confidence that she would do the procedure how I wanted it.

Emery struggled to find a surgeon that met all of these criteria.

After finding someone that met these requirements, they were saddled

with the interactional transphobia that came with the surgeon's care.

Emery elaborates on what made features of the surgeon's care

transphobic:

When I showed up at the waiting room, there were pamphlets but only for plastic surgery, but no trans stuff out in the open, just very cis-looking stuff. At least one other trans looking person in the waiting room. All of the office staff surgery called me "he," assuming that was correct... And I was fine with that because it was the first time anyone had assumed anything other than 'she' without being told first. And like, I was like this is fine, this is still affirming in a way even though I came out as non-binary via email to one of you via email at some point. The surgeon used 'she.' The two times I heard her pronoun me she used she/her.

In this way, the transition care that Emery sought out involved being misgendered as the binary gender not associated with their assigned sex *and* the binary gender associated with their assigned sex. In order for Emery to receive top surgery, they needed to find a surgeon that would complete the surgery the way they preferred (complete removal of nipples), and that would not require them to take testosterone. When they did find this surgeon, they were required to receive three months of therapy. There were a number of patients who also had to receive

therapy before accessing transition care as well, with varied opinions; Some participants already had therapists who could write them a letter, and others expressed indifference as long as they were able to ultimately access the care they sought. For Emery, even with their ability to find a therapist receptive to their desire to “partially” transition, they still had to endure the misgendering by the clinic staff and surgeon herself.

For Eli, the perception that they may have to take testosterone to be covered by insurance for a hysterectomy caused them some discomfort. They state that even though it isn’t “ethical or moral,” they would say what they needed to for access to the services that they need, and avoidance of the services that aren’t right for their body:

... I kind of at this point refuse to like, I’m already unhappy with how my body is, like if I can take this one step that’s going to make things presumably a little bit easier for me, I’m going to do whatever it takes and I can’t afford to pay it on my own, so if I have to lie to my health insurance to get this to go through then I’m going to do that because the system is unfair in the current way it is, if it requires me to have to jump through that hoop then I’m going to do it in order to get it. And like, I think I was joking with one of my friends, I was like ‘If they tell me I need to be on T, I’m [going to] be like ‘oh, yeah, yeah, yeah, no, I’m [going to] wait a little bit afterward... I’ll do it in like three months, I just need a little breathing time.’ And then just kind of like drop off the map and move states or something so they can’t find me anymore. But it’s like... I’m like, listen, I’m glad that you cover people who [want to] do binary transition, but also please give me money because I need it.

Eli elaborates on this perception that they may have to be on testosterone to access hysterectomy services. In the following excerpt, they clarify that they are unsure as to whether this would be a requirement for their access to the surgery

they need, but that they don't have trust for the "shadowy" people that even LGBT-centered caretakers are accountable to:

Yeah. Cause like, LGBT Health tries their best and stuff like that, but I'm sure like, the shadowy people running the... I don't know how the healthcare system works in its entirety because I'm not part of it but... You know there are doctors who mean well and maybe know about non-binary and agender trans people all that stuff, but they're still held back by limitations put on them. It is that thing where like, okay, maybe I talk to someone at my insurance who knows what a non-binary person is and totally gets it. But, according to their policy, I would have to be a trans male in order to get what I need. And they individually understand but they can't fudge the system. So, I'd have to play by the rules for lack of a better term. It's kind of like, people may be morally aligned, or well-intentioned but the system is put in there, and can be archaic and it won't change, and it doesn't care what new things come up, or what new expressions have evolved and given words to. It's just [going to] do the thing it's always done and just kind of limit people.

Depending on Eli's insurance, it is possible that they would be able to access a hysterectomy without testosterone services; Eli expresses firmly that they are unsure about the reality of this requirement. Eli does make it clear that it is their perception that because of the nature of the insurance-physician relationship and their mutual accountability to bureaucracy, that they may have to pretend to identify as binary in order to access care. Eli's perception is that in order for them to be able to access care as a non-binary person, is if the language in their insurance policy, the policy of the physician's office, the insurance worker, and the physician were all on the same page about non-binary access to "partial" transition services. Whether or not this is the case for Eli's insurance, Eli makes it clear that it has affected their comfort with navigating care. They state that they are often worried they will something that would preclude them from care without knowing.

Bay, a non-binary Bostonian in their mid-forties, describes their comfort with the potential hormone requirement. In the following excerpt, they describe their interest in a hysterectomy, and the ways that they perceive identity impacts access to this procedure:

I don't know if what you have to clinically talk [about] with your doctor is different from what they fill out. I don't see what they actually fill out on their paperwork, I do know that they have an interest in conjunction with this, on starting low-dose testosterone. I have no intention of removing the breasts I do have. They don't really get in my way... I suspect if you have certain check boxes it passes a certain kind of test in a way. Like, okay, she wants her uterus removed but she's straight and cis. Can't do it. This person, they're non-binary they want their uterus removed. Okay, we'll think about it. Oh, they [want to] do testosterone too? Okay that's more likely to get approved. It seems like the more check boxes... It's an impression, I have no way of knowing how accurate my impression is. I seem to get this impression that the more check boxes you have that'll put you under a category of transgender it seems more likely you... the insurance will deal with that as yes. [Because] I do also want T,³ and it seemed like that might make it easier.

Similarly to Eli, Bay states that they don't know whether their impression of the system is accurate, but that they perceive that the more binary a patient presents, the more likely they are to be approved by their insurance for coverage. Because Bay does not mind the idea of undergoing hormone replacement therapy, this potential stipulation did not cause them discomfort. However, consistent with the other participants engaging with their perceptions about requirements to access transition care, Bay, Eli, and Emery express their perception that physicians, and medicine in general, see binary transness as more medically legitimate than non-binary transness.

³ Testosterone

The foggy perceptions of the relationships that impact non-binary access to care, the reality of some gatekeeping insurance and physician practice policy, and the at times linguistically inaccessible nature of insurance policy, all contribute to the reality of seeking care as a non-binary medical patient seeking “partial” medical transition. In Peter Conrad (2005) argues that the engines of medicalization are shifting; That physicians are losing their sole monopoly on the power to diagnose and delineate health and illness. He claims that with advancing biotechnology, patients as consumers, and the development of managed care, the forces of medicalization are shifting from physicians. The participants who struggle with insurance, practices, and individual physicians are illustrative of Conrad’s third prediction; That the advent of managed care would further bureaucratize Medicine and take power from the individual physician. As a consequence of the progressive rationalization of Medicine, its mechanisms will be more deeply bureaucratized in the name of efficiency. Bay and Eli expressed concern for this very notion: that even if their physician were on board with their preferences, that they are beholden to larger structures and health-system protocol.

Conclusion

Historical precedent situates physicians as friends of community members, having to garner trust not from their legal-rational authority on health and illness, but on their relationship to the community members.³⁸ As Medicine grew, and scientific understanding of the human body improved, the population that relied on medical care gradually grew as well.³⁹ To accommodate such a rise in demand

for healthcare, improving efficiency became a necessity. Imbuing healthcare with bureaucratic organizational structure became a logical solution.⁴⁰

Demographically dividing humans into sex and racial groups to facilitate diagnosis was initially an attempt by physicians to employ means-end rationality to catalyze the time length of patient visits and gather health demographic data for different groups (more often than not, such categorizations were leveraged to perpetuate sexist and racist, particularly anti-black, assumptions, and by proxy uphold white supremacy and male dominance). As illustrated by the narratives of non-binary patients, clashes with gender-exclusive intake forms, intake forms that are incongruent across practices, and subjective policy and disease delineation, the policies and forms in place have long-slipped into the realm of traditional rationality; Rationality that is employed based on historical precedent.⁴¹ This is made clear based on the struggle of non-binary patients to be processed with their gender identity, and the red tape they must navigate (or think they must navigate) in order to receive transitional care. Clinics that have updated their intake forms are still subject to misgendering their patients or referring patients to a clinic that may misgender them. Patients who are willing to be open and disclose their gender to clinics that don't provide gender variant visibility in their intake forms are likely to wane in their insistence on being processed as their non-conforming gender. The bureaucratic inertia that permeates Medicine has power that transcends the defiant non-binary patient, the progressive caretakers, and inclusive insurance policy.

Discussion: Chapter 2

Implications for Cultural Incompetence: A Legal-Rational and Traditional Authority

Part I: Gender Care

As an institution possessing legal-rational authority sits with unquestioned legitimacy, it follows that after a few centuries, parts of the rational basis to its authority may ossify to traditionality. This is because as humanity advances, the knowledge that fuels rational decision-making changes. If the structure of legal-rational authority has not changed to accommodate new knowledge but the legitimacy of its authority remains, it may be that parts of its legitimacy is coming from its precedent as an authority. An authority based on precedent is traditional; Weber defines traditional authority as one that obtains its legitimacy from custom.⁴² A lack of informed, LGBTQ-competent healthcare in 2018 can be framed as a byproduct of the features of Medicine that leverage traditional authority. If physicians are not taught how to administer culturally competent care to queer patients, nor are they educated on in-depth health protocol for gender-transitioning individuals, but they are still given almost total authority in the administration of their healthcare, then that aspect of their authority is traditional.

A Brief History of Physician Authority

The AMA (est. 1847) made a concerted effort in its inception two centuries ago to standardize medical practice and enforce licensing laws on those who sought to become medical professionals, making anyone without a license

unable to practice medicine.⁴³ It was this practice of standardization that afforded medical professionals Weberian legal-rational authority within the field of medicine. This intentional establishment of a system of abstract rules is consistent with Weber's characterization of what guarantees the effectiveness of legal-rational authority.⁴⁴ Furthermore, the bureaucratic nature of medical licensure and practice, as enforced by the AMA, coincides with his characterization of the "purest" iteration of this type of authority as carried out by a bureaucratic administrative staff.⁴⁵ Since the 1980s, medical sociologists have been observing the bureaucratic expansion of medicine, speculating that over time, the medical profession will become more bureaucratized due to rationalization. In 2005, Peter Conrad argued that such a trend toward rationalization was indeed occurring due to the advancement of biotechnology, patients becoming consumers, and managed care.⁴⁶

Adhering to Weber's stipulation that legal-rational authority often necessitates training to obtain competence,⁴⁷ Medicine requires that prior to obtaining a medical degree that individuals complete four years of post-graduate training after having obtained a four-year undergraduate degree with experience in the field of medicine. Physicians today thus wield legal-rational authority over patients because they have devoted years to understanding patterns of biochemical phenomena in the human body that have been established by empirical studies and repetitively verified by practice in the field. The United States endows physicians with this authority by legally requiring physicians to have an MD or DO degree administered by a state's medical board, all accountable to the

Federation of State Medical Boards (FSMB).⁴⁸ The state medical boards sets “minimum qualifications” for medical practice, and has the power to issue and revoke a physician’s medical license.⁴⁹ This state board is universally accountable to state legislatures and executive branches. In 1889, *Dent v. West Virginia* established the precedent that the state has an integral role in the determination of what a viable medical license is. The Supreme Court allowed the state of West Virginia to revoke Dr. Frank Dent’s ability to practice medicine due to his lack of license from a “reputable medical school,” stating that the only “authority competent to judge” aspiring physicians was the state medical boards.⁵⁰ The presumption is that if a physician has a degree from medical school, that physician can be reliably elevated to an authority that affords them jurisdiction over managing the health of medical patients who enter their practice. John McKinlay and Lisa Marceau implicate the state in the professionalization of medicine over the course of the 19th and 20th centuries as well, stating plainly that “the rise of the medical profession during the 20th century was powerfully reinforced by government action.”⁵¹ The modern precedent of medical authority was set in the mid-19th century, and established that physicians who acquired license to practice medicine through a state medical board after their education in medical school were valid arbiters of health and illness, and legal-rationally so. Until LGBTQ-competent care is a fixture in Medical education and a baseline expectation for any kind of physician, physicians rely on their traditional authority as professionals to carry out gender-inclusive care for their gender-variant patients.

LGBTQ+ Research and Cultural Competence in Boston

To facilitate the treatment of any patient, the ability of a physician to carry out culturally competent care is critical. To be culturally competent, providers must be acquainted with the features of a patient's preferences for care as it pertains to their sociocultural ethos. Such knowledge of how to administer culturally competent care is obtained by physicians in lectures over the course of their medical training. In their 2008 book on cultural competence in healthcare, Wen-Shing Tseng and Jon Streltzer describe this as requiring a "culturally sensitive attitude, appropriate cultural knowledge, and flexible enough skills to provide culturally relevant and effective care for the patients of diverse backgrounds."⁵² For gender non-binary medical patients, the World Professional Association for Transgender Health created a comprehensive document establishing standards for care for transgender, transsexual, and gender non-conforming patients, including physical, mental and transition-related and unrelated care.⁵³ There is ample research engaging with ideals for care for trans and gender non-conforming people, and the research is expanding rapidly. As medical institutions and training catch up to the research clarifying the needs for more diverse people, quality of care will gradually improve as well. In 2012, Snelgrove and colleagues determined that the most evident barrier to delivering competent healthcare to gender non-binary patients is physicians' lack of knowledge, which results in poor cultural competence⁵⁴; The ensuing lack of knowledge leaves physicians ill-equipped to care for transgender and non-binary patients with the correct names, pronouns, and use of medical language. In a study

by Boston University Medical Center, it was established that one single lecture on gender variance significantly improved physicians' comfort and willingness to care for transgender patients.⁵⁵

In Boston currently, Fenway Health's three clinics (the Ansin, Fenway, and Borum centers) are a major health resource for LGBT patients, as the city's only major queer-centered healthcare providers. Notably, Fenway's mission statement promises competent care for LGBT patients (as opposed to LGBTQ+), excluding a large portion of gender non-binary individuals who identify more closely with the term "queer" than "trans". The clinic was established in the 1970s during America's HIV crisis, and eventually boasts the first diagnosis of AIDS in New England, in 1981.⁵⁶ Since then, it has expanded to three locations and provides access to both general and transition-related care to many trans and non-binary patients in Boston. Among the participants of this study, a few either knew non-binary people who received culturally incompetent care by the Fenway community, or did themselves. Such experiences, while not nearly as severe as cultural incompetence experienced at other healthcare locales, were often made worse by high expectations held for Fenway. 82.3% of participants received affirming care from a queer-friendly health provider at some point in Boston. Additionally, 82.3% of participants either had themselves, or heard of negative experiences coming from queer-friendly clinics. However, as visibility improves and initiatives for improving care are expanding, physician competence improves. As of 2018, there are physician re-education campaigns and longitudinal studies being done to improve care for LGBTQ+ medical patients. To help patients find

competent care, there are phone applications and advertising campaigns being implemented across Boston and elsewhere. However, as community memory persists, the development of long-term trust is still in process; Many cite community anecdotes to express apprehensions about the medical community and LGBTQ+ cultural competence.

This chapter will engage with the factors that impact physician competence, and the consequences of poor competence. This will be done by offering social context for non-binary cultural incompetence, and outline community-wide expectations for Medicine. Because “non-binary” identity in its current linguistic iteration is a recent development, practices are catching up to research that is currently being implemented. As a consequence, many physicians lack basic knowledge about gender and the non-binary transition process; The negative experiences that non-binary individuals have are shared by word-of-mouth and in online spaces, and community trust in Medicine is affected. The aspect of physician authority that renders individuals most vulnerable in a doctor’s office are the practices and norms which haven’t been updated to respond to a relatively new development for the social reality of many non-cis people.

A Linguistic Development

If collecting qualitative data over the course of two months is akin to taking a snapshot, the data for this study yielded an image of a landscape in motion: There were experiences that were crisp, with a clearly positive narrative associated with queer-inclusive care, some with unambiguously negative features, and many with contradicting experiences and ensuing confusion. There were a

few participants who expressed this notion: that things are changing and while they anticipate more accessible and affirming care, they are uneasy in the interim. This is captured well in Elian's (they/them) lament about the difficulty of answering about the state of medicine because "...everything is sort of in motion right now, which is like weird." Nicky echoes this perception that things are changing very rapidly in their observation of how things were a generation ago:

But it feels like there is a competency in talking about the issues of gender that we have that a generation ago they didn't have, and it was just because we've had more time to figure out what does and doesn't work. Like, part of it feels like accommodations aren't being made is just because there aren't people to give those lectures who are out of undergrad yet, or out of their ... Who are in a position where they have the authority to give that. Um... Which makes me honestly really excited when I saw that you were doing this study, because I was like 'that's really great, that people with positions of authority and who are going to be given authority in some context are having this conversation and talking about it. Because it's so important and it's happening outside of the medical community all the time anyway. And the institutions, as much as my little anarchist heart wants to tear it all down, I like... The institution of medical care needs to persist, and it needs to be able to respond to these circumstances.

In these parts of their interviews, Nicky and Elian give a very insightful observation that the way medicine is changing makes it difficult to see the direction and scale of the re-orientation of queer-friendly healthcare. Jay mentions this as well, stating that "...this previously ignored demographic is sort of like being catered—or not catered to, but being understood, and their health is finally coming to the forefront." Moving into the analysis of participants' variable experiences in healthcare, it is important to situate the healthcare landscape as one that is responding fast to recent sociocultural changes. Because the terms "non-binary" and "gender non-conforming" are recent linguistic developments, many

gender variant individuals are coming into their identities only as they find language for it—A finding reflected in Sarah Schulz’s dissertation on trans-masculine and genderqueer health as well.⁵⁷ While the notion of not being a man or a woman is not new and social androgyny in America has existed for decades, names for non-binary gender identities are a relatively new development. One participant in their mid-forties, Bay, describes coming into their identity only in the last half-decade: “So teenager years in the 80s we had 'new wave' and 'androgyny'. We didn't have terms like 'non-binary.' This isn't something that was really talked about. Anything but transgender was usually something you'd see in a movie as the butt of a joke.” The idea that many are starting to consider self-labeling with non-binary identities after decades of identifying as cis, implies a growing population with sociocultural demands. These demands are being met with new research that is being sparsely implemented in Boston; Of seventeen participants, seven mention that they think living in Boston affords them the privilege of queer-centered healthcare. Since Boston is seen as a leader in LGBTQ+ healthcare, much of these changes are happening here, albeit differentially among providers. Keeping in mind that experiences will differ among individual’s own appraisals of “positive” and “negative” experiences, as well as the time of their experiences and their personal physicians, emergency care locales, and clinics, a critical discussion of physician competence can commence.

Apprehensions about the Field of Medicine

An important aspect of physician-patient trust that plays a part before a patient even steps into a physician's office is perceptions about the medical community. The qualms discussed in this section will be distinct from much of the other excerpts in this chapter, because they engage with perceptions that healthcare providers may be overtly prejudicial or cause harm greater than the routine discomfort of being misgendered. Many participants qualified the good experiences they shared with their understanding that many in their queer community have had starkly contrasting "horror stories". Nicky shares that they have not had a physician relationship in a long time, because they do not have faith in the system:

So, it's been a long time now since I had a physician relationship ... Yeah, so earlier in the summer I did a name-change thing, I haven't had a physician relationship since then...my attitude always going into other things was like, unless I was seeing a therapist or [the visit] was very [relevant to] gender issues... I normally would just deadname myself and go through it... Because... It feels like I can't trust that it will just go right.

In our interview, Nicky describes having avoided healthcare for a great deal of time because of this perception that it might not "go right". Their discomfort with Medicine comes from both stories they hear, and their frustration with their past experiences. They state that "The closest things that felt like, not explicitly negative, come with this sense of patronizing things with it. Like it feels like if they're respecting it they're respecting it as like a contrivance. That's better than it just being fucking ignored, but it still leaves me with a really sour feeling in the end," elucidating their perception that if a medical professional is nice to them,

their kindness is a façade being obviously fabricated in a patronizing way. While Nicky did not have any serious health issues that demanded a doctor visit, they did share that they had a metamour (a partner of a partner's) who was able to build a positive relationship with their physician and obtain an orchiectomy (a surgical transition service); Hearing about their metamour's success at a doctor's office inspired in them what they described as "jealousy," indicating that Nicky feels as though their discomfort with physicians precludes them from access to medical transition services that they may want for themselves. In this way, their apprehensions about the medical system is explicitly impacting their ability to transition. Echoing Nicky, Emery (they/them) shares that they think "...a lot of the trans medical experience is like navigating things that are impossible to navigate with people who are often uninformed and/or unsympathetic." Emery's perception was reinforced by their own experience with a surgeon that provided them a double mastectomy procedure (top surgery); Emery shared that they had heard about the surgeon's circumstantial transphobia, and that the stories they heard about this surgeon were reinforced by their uncomfortable interactions before and after their surgery took place. Emery's disposition about Medicine is that it does not care about trans people and that it serves as an arbiter of comfort and safety to trans people, and as a mechanism to gatekeep services based on arbitrary parameters. They get this perception from their own experiences, and those of their online trans community. Emery and Nicky both have poor perceptions of Medicine's ability to socially accommodate gender variance in a way that will afford non-binary patients healthcare conditions conducive to

mutual trust, and these perceptions came from what they heard from other people, and having those apprehensions reinforced by their own negative experiences.

“Gender 101”

Less severe than a sweeping lack of trust for Medicine’s ability to afford safety to non-binary patients, but still a significant aspect of obtaining care, many participants shared experiences their physicians lacked “Gender 101.” Participants described “Gender 101” as basic knowledge of either how to medically treat a non-binary patient who has transitioned, or how to socially refer to people in a gender-inclusive manner. Given that different provider institutions, insurance programs, and individual providers are often in different places regarding queer-competent care, the likelihood that patients would come into contact with queer-incompetent care is compounded. Participants would describe situations in which they felt their doctors knew next to nothing about gender variance, how that impacted quality of care, and how they reacted to this experience. In a frustrated tone, Rae (they/them), a non-binary person in their late-twenties, describes their sentiment at a physician’s office when they perceive cultural incompetence on the part of their doctors: “I’m not gonna be a person in this professional interaction to give you Gender 101. I don’t want to risk... I will give it to my step-mother, I will give it to all these other people, [but] I don’t want to... have this long conversation with you.” Rae’s frustration lies in the expectation that physicians, with such a comprehensive education in cultural competence and sensitive care, shouldn’t have to be informed by a patient basic gender matters; While they would happily educate people in their personal life, the medical sphere is a

different matter. Em echoes and expands upon this sentiment by speculating that physicians would not likely take their advice seriously: "...and a lot of the time they don't really know the nuances of gender and sex... and I'm like, okay, number one I don't have the time or patience to educate you, plus you're not gonna listen to me." Em's perception here is that often their physicians do not understand the distinction between sex and gender, illustrating well the extent they perceive physicians do not understand gender variance. Em's ability to disclose an identity they think their doctor would never have encountered is understandably poor, as explanation would likely have to acquaint disclosure. A quote by Ari ties Em and Rae's sentiments in with the vulnerability associated with the doctor's office:

Yeah, because it's that vulnerable piece of being one-on-one, and having to like, advocate for myself, and not knowing whether they already know. Like if I knew that she already knew about these things, I'd be like 'Oh yeah, by the way!' It's just 'cause I don't know.

Here, Ari observes the vulnerability associated with self-advocacy. In this way, Ari expresses that perceived cultural competence is central to disclosure, and establishes their minimum competence level as knowing what gender variance is at all. When asked about their worst-case scenario, Ari states, "if the actual worst-case scenario were to happen, they'd be like 'That's not real,' you know? Or just like, a repetitive, 'I don't understand.' That's actually probably worse." Ari clarifies that they are assuming the "best of intentions" with their physician, and that refusal of care and outward and intentional prejudice would not occur. Even with the potential for malice off the table, the idea that their physician might not know anything about their identity and express confusion was enough to result in

gender non-disclosure. At the time of the interview, Ari had not disclosed to a single doctor their gender as a consequence of this worst-case scenario. Ari's concern sheds a great deal of light on the impact of micro-aggressions and social misunderstanding on comfort-level at a doctor's office. Ari, Em, and Rae's experiences teach us about how a lack of "Gender 101" can influence a non-binary patient's comfort in a medical environment.

Beyond micro-aggressions and social missteps, a lack of "Gender 101" knowledge at times seeped into the ability of physicians to carry out their duties as authorities on health and illness. Kai (they/them) discusses a time their primary care provider (PCP) claimed that the measures they had taken to transition on testosterone helped cause their diabetes. Upon objecting to this claim, stating "that's now how it works!" their provider replied, "Oh no, it is, trust me." The PCP then tried to refer them to an endocrinologist, claiming that their queer-centered medical clinic might not know how to "handle" such a situation. They describe feeling extremely uncomfortable and not being sure how to proceed. While intravenous testosterone can impact likelihood of contracting type two diabetes provided other risk factors are already present,⁵⁸ making an unqualified claim and a referral to an outside healthcare provider was understandably upsetting to Kai. Furthermore, aside from the consequences of distancing Kai from a queer-friendly clinic, referring patients to separate specialists may be a financial burden to low-income patients. In an experience with transition-related care, Emery describes when they had to explain to their surgeon that their method of birth control did not have estrogen in it. Emery was on a regularly administered

birth control shot lasting three months. Such a period-prevention method is useful for patients who experience dysphoria due to their periods and do not want to use a birth control method with estrogen. Emery describes having to explain this to their surgeon, despite the fact that the surgeon was carrying out a transition-related procedure. They describe feeling concerned that a physician might not have basic knowledge of the intervention measures AFAB non-binary patients take to prevent their periods, especially because the surgeon's specialty was the double mastectomy procedure. Emery shared with me their experience trying to get onto a birth control method like theirs in the first place as well:

The fact that I had to go through like three different gynecologists who all told me slightly different things about how to best prevent my period with birth control. Like, I was on multiple low-dose methods before someone told me that you can't use low-dose for extended cycle and that's why I was getting so much break-through bleeding. Like, they just don't know. They don't know anything outside what they're programmed to handle. Like, they know how to use birth control to prevent a period, but you ask a doctor, who's not like a real trans-specialist, how to like, stop a period completely, and they just don't know what to do... They haven't learned what to do, or some of them are just baseline resistant to doing something that they haven't learned as a medical thing.

Emery's experience looking for a birth control method, and ultimately having to explain to their surgeon what their particular birth control method entailed, was described by Emery as not only frustrating, but as an example of poor queer-competence by their surgeon.

The use of a term like "Gender 101," illustrates how basic patients perceive their physician's lack of knowledge to be regarding gender. To not understand what an individual's identity is, but still be expected to treat these

patients as whole people and with respect is an example of the dissonance between education and responsibility of physicians as it pertains to gender-variance. Physicians have not been educated about gender-variance, but still must deliver culturally competent care. Such a dissonance can be traced back to the FSMB, the federal organization that sets the minimum curricula for physicians' board certification, and also ratifies the authority of professional medicine. To reiterate, the extensive physician training and state-endorsement of Medicine is reminiscent of Weber's legal-rational authority, but its pairing with circumstantial cultural incompetence due to inexhaustive training may be indicative of a (traditional) authority based on precedent.

Cultural competence and physician empathy would facilitate a physician's ability to engage with a gender-variant patient's disclosure of gender and preferences for care. It has been empirically established that cultural competence and physician empathy help the physician-patient relationship and improve a patient's honest appraisal of symptoms and medical compliance.^{59,60} Consistent with these studies, non-binary participants expressed that if physicians had a friendly disposition and understood basic ideas about gender, that they would feel more comfortable and be more likely to mention their gender in passing.

Information Acquisition: Centrality of the Internet and Community

As a consequence of poor collective trust, participants shared that they most often obtained transition-related information from their community in Boston, and their online trans communities. While some participants stated that

they would not have an issue asking a queer-friendly physician about transition-related issues, research still began in the community and on the internet. Kristen Barker, in a study of internet communities of patients with fibromyalgia, observed that because many physicians did not give credence to “fibromyalgia” as a legitimate illness, groups of (mostly women) congregated online to talk to one another about their experiences and solutions to common symptoms.⁶¹ In her observation of these forums, Barker notes a “skeptical dependency on medical expertise”; Because physicians variably accept fibromyalgia as an illness, patients rely on one another to validate the reality of their experiences.⁶² Since physicians did not exhibit socially sensitive care to these patients, nor did many physicians offer tangible advice, patients turned to the internet. Barker cites Peter Conrad’s observation that there are shifting engines of medicalization; with the advent of the internet, patients can self-diagnose and rally for the medicalization of their symptom clusters as well, as in the case of fibromyalgia.⁶³ Gender variance itself is not an illness, but gender variant patients share a commonality with patients of fibromyalgia: their fear of being told that their experiences are not “real,” and of being delivered insensitive or incompetent care relating to an inexact social reality incompatible with the rigid structure of medicine. Consistent with other findings for non-binary people seeking healthcare in America, participants of this study turned to the internet to learn about expectations for transitioning from other trans people.⁶⁴ Of the participants of this study, 70.6% stated that they rely on the community for health information pertaining to their transitions or potential

transitions. Rae describes how their online resources and greater queer community has helped them with their decision not to transition:

Honestly, [I got my information] exclusively from the community... I think the first friend I had, who was not [non-binary], who was a trans dude, who like I watched go through that. I knew what he was experiencing in the sense that I knew what was happening... but like, post-college and in the community in Philly, not all my friends, like most of my friends were very femme queer women like there were like a few very femme people who were my good friends, and my other good friends were non binary [masculine]-of-center [assigned female at birth] people who at this point like, all of them have gone on [testosterone] and I can literally watch them transitioning, and like hearing them talk about it and like, also just like reading online, I'm not researching transitioning so much as like a lot of the media that I consume is like queer media. And also like, from women's college, the number of people who have come out as trans from there, who have documented their transition on social media spaces where it's like, I'm not close to these people, but I am close enough to have connected with them on social media, and I'm watching their very public transition. Um, and so there's like a lot of directions where I'm getting this information about what it means to be transitioning in that way. And I don't want that body. I don't want that for myself. I also want my body to do other things that it's also not doing, but that I feel I can control on a personal level, and it's hard and annoying and I don't like it. And I don't like that I can't just be okay. But it is at least within the realm of control. It's a different shitty time, but it's not that narrative.

By watching so many public transitions and learning about what it means to transition with testosterone, Rae learned that they did not want to transition in that way. For Rae, the most exhaustive information they could acquire about transitions and the associated implications for their body was from the internet, watching other transgender men or trans-masculine people go through the process. Bee describes a very similar process: "I started online and just like looked at what the process looks like, and it seemed a little bit daunting. So, I talked to some of my trans guy friends who either have had surgery or thought

through it, and like... I don't know, like. Their experience works for them, but I didn't feel like it would be the best choice for me after talking to them.”

Facilitating such a decision by providing examples of transitions and queer media for patients to consume would be contrary to the means-end rationality that is so important to Medical efficiency. Because they cannot be given adequate information, and also because of perceived cultural incompetence and lack of trust, non-binary patients will turn to the internet and their queer communities for this information. Bay illustrates the perceived cultural incompetence that steered them to the internet and their community and initially away from Medicine. Bay explains that they would want to be on low-dose testosterone to achieve an androgynous outer appearance and that they “feel weird explaining that to people outside of the community.” Because genderqueer and non-binary medical patients seeking care are not adequately educated or do not have adequate trust in Medicine to seek out information from physicians, they carved out a rich space online and in queer-community spaces like BAGLY (Boston Alliance for Gay Lesbian Bisexual Youth) where information can be shared interpersonally. Such a shift from reliance on physicians for information to reliance on one’s community and the internet for information is illustrative of a community filling a need where Medicine failed to do so.

Conclusion

As illustrated by the participants of this study, despite groundbreaking research being carried out and important changes being made in health policy and

protocol, there remain a great deal of clinics, hospital systems and individual physicians who need to improve gender-inclusivity in their practices. The circumstantial lack of knowledge surrounding culturally competent care and biomedical protocol for patients undergoing transition, paired with the continued authority of physicians over non-binary patients, plainly highlights the small features of physician authority which are traditional. The legal-rationality of physician authority is predicated on the extensive training they receive, and the endorsement of their authority by the state. Their state-endorsed authority remains intact for medical matters not included in their medical school curricula. Thus, when they lack “Gender 101,” and their cultural incompetence hurts their physician-patient relationships and encourages non-binary people to seek their information elsewhere, it is the precedent of their authority that allows its persistence.

Discussion: Chapter 2

Implications for Cultural Incompetence: A Legal-Rational and Traditional Authority

Part II: Chronic Illness, Parceled Personhood

Introduction

Part I of this chapter discusses physician authority and cultural competence; When physicians are not educated on LGBTQ+ competence, the care they deliver can be insensitive or inadvertently harmful. Cultural incompetence results in avoidance of care and/or acquisition of care in online trans and non-binary communities. Part II adds another facet to this discussion of physician authority, by incorporating an experience that often *accompanies* gender variance, and also requires specialized physician cultural and biomedical competence: chronic illness and disability. Participants who parcel parts of their lived experiences to facilitate passage through Medicine progressively obscure more of their personhood. This parceling may function to impede physicians' ability to care for whole patients. For chronically ill, chronically in pain, or disabled patients, the incompatibility of the medical model of illness with disability justice can be problematic for acquisition of care; Among the five participants who have a chronic illness or disability, Kai, Emery and Taylor shared in-depth their relationship to Medicine as people with chronic somatic syndromes relating to pain. All three of these participants describe an initial trust for physicians, and gradually feeling unheard or not taken seriously. At the time of their interviews, none of the three participants regularly disclose their pain-related symptoms to physicians. As a consequence, participants treat their

symptoms on their own terms, self-label based on their experiences, and turn to other individuals with chronic pain to locate coping mechanisms.

A Note on Terminology

Kai uses the word “disability” to describe their pain, and Emery and Taylor use “chronic illness” and “chronic pain” for their symptoms. Because “disability” is a fluid social identity, its usage among individuals with chronic illness is variable. I will mirror the language participants use for themselves, and preface with literature on both disability and chronic illness and pain. Lastly, that chronic pain has a high prevalence in trans populations is significant for the circumstances around which they seek care, but does not render the identities the same; To be gender variant alone is not a pathology, but the discrimination and consequential stress that habitually accompanies gender variance may increase an individual’s likelihood for experiencing psychosomatic pain. This is to say that a discussion of chronic pain is relevant to a discussion of gender because some people who are non-binary are also chronically in pain as a consequence of exposure to gender-related discrimination. This being said, the cause of my participants’ pain may not be discrimination-related, but their experiences are important because of how common chronic illness is among non-binary and trans people.

The Medical Model and Disability

As it pertains to conceptualizing and improving quality of life, contemporary disability studies is often at odds with the biomedical model of

medicine. In 2008, Tobin Siebers points out that “Disability studies does not treat disease or disability, hoping to cure or avoid them; it studies the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression, attacking the widespread belief that having an able body and mind determines whether one is a quality human being.”⁶⁵ Siebers goes on to emphasize that having a disability is not a “physical or mental defect but a cultural and minority identity,” and that such a distinction makes room for conceptualizing disability as a fluid social category “both subject to social control and capable of effecting social change.”⁶⁶ Siebers thus demonstrates a critical juncture where the medical model of illness diverge from disability justice; Where Medicine may establish able-bodied-ness as an ideal, and create structure and intervention to achieve that goal, disability studies advocates for environmental justice and structural accessibility.⁶⁷ In a 2005 publication, Martin Sullivan employs Foucault to discuss power disparity in a spinal rehabilitation unit. In his piece, Sullivan portrays how, in being processed through a hospital’s Spinal Unit, patients lose autonomy of their bodies; That physicians and health caretakers were able to get away with poor communication and, at times, malpractice, was a product of the physician-patient power dynamic compounded by the institutional ableism of Medicine.⁶⁸

Eli Clare, a genderqueer writer and activist with a disability, writes about living at this intersection. In his 1999 book, Clare details a history of classifying people with disability as “freaks” and parading them among the circus, and the particular vulnerability of black disabled people to this phenomenon. He describes

how then, the medical model of disability did not exist, and how now, Medicine can serve as a mechanism for controlling disabled peoples' lives.⁶⁹ Clare quotes Michael Oliver, author of *The Politics of Disablement* (1990), in saying “...doctors are also involved in assessing driving ability, prescribing wheelchairs, determining the allocation of financial benefits, selecting educational provision and measuring work capabilities and potential; in none of these cases it is immediately obvious that medical training and qualifications make doctors the most appropriate persons to be involved.”⁷⁰ Clare's invocation of this quote makes an important point: That many physicians treating disability are able-bodied, and that their perspective on disability is limited as a consequence. This observation falls in line with Siebers' discussion of the limitations of the medical model for disability. Thinking of disability as a bodily malfunction is contrary to disability justice initiatives which prioritize improving built environments that can facilitate living with disabilities. The rift in thinking between medicine and disability studies may foreshadow a point of friction between the experiences of disabled patients and their treatment in Medicine.

A discussion of disability is relevant to a discussion of gender non-binary identity for many reasons, but foremost because many non-binary people also have disabilities and/or are chronically ill or chronically in pain. In fact, gender non-conforming people are disproportionately susceptible to chronic pain and illness. Literature on psychosomatic pain find that having experienced trauma or severe stress or anxiety increases an individual's risk for chronic pain. In 2014, Afari and colleagues conducted a meta-analysis on studies looking at the

association of psychological trauma and PTSD to an array of illnesses including fibromyalgia, temporomandibular disorder, chronic pain, chronic fatigue syndrome, and irritable bowel syndrome. It was found that trauma exposure renders individuals 2.7 times more likely to have one of these syndromes.⁷¹ Because trans and non-binary populations are disproportionately vulnerable to violence, they are also vulnerable to the psychosomatic aftermath of such violence. Beyond likelihood attributable to trauma exposure and marginalized identity, studies in the past half-decade have continued to find an explicit relationship between transgender identity and chronic pain and illness.^{72,73} Thus, discussing a healthcare interaction disproportionately likely to occur in gender-variant populations is relevant to a discussion of gender-variant quality of healthcare.

Kai needs a cane to help them walk due to chronic pain in their legs, and identifies this as a disability. Kai stated that they obtained their cane on their own volition, after their doctors couldn't find a medical explanation for their chronic leg pain, and the care that was suggested to them did not help. In the following excerpt, they describe how being unseen as a disabled person seeking care is similar to being non-binary and unseen seeking medical care:

I feel like people have... People who aren't disabled have ideas about what being disabled is. I use a cane but I might not need it all the time. Some days I don't need my cane to walk for most of the day. Maybe I'll just need it at the end of one day. Fluid mobility is a hard thing to explain to people unless you've experienced it. People have ideas. 'Oh, being disabled is being para- or quadriplegic needing a chair to move around.' You can use a walker or a chair or a cane and not necessarily be 'severely disabled.' There are so many things that people who aren't disabled don't know about being disabled. And because the disability is seen as like something like that you

shouldn't be proud of or something that you need to fix or cure. It makes it harder to have conversations that are educational in nature. And as a result, people who aren't educated about disability and how it works remain uneducated, and stigma only gets worse. Having to explain I use a cane because on some days it hurts too much to walk without it but other days, or explaining why I need to use a cane or explaining how my pain is or how my disability is... is like complicated. [It is similar] to why I don't like to explain to people in depth about my gender, same reason with my disability. My disability is very fluid. Some days my pain will be so bad I can't get out of bed or I can't even think of standing up on my own without my cane. There are other days where I'll have my cane with me but I won't need it at all. It's a spectrum and spectrums are hard for people to understand unless they're on that spectrum. I don't know or feel like I have the... I don't think I'm the best person to explain it to people. Sometimes I don't explain it at all.

The comparison Kai makes from disability to gender is important, because it illustrates a perceived lack of competence as it pertains to disability as an identity, consistent with the critiques of the medical model Siebers discusses in *Disability Theory*. Both disability and non-binary gender are social identities with structures that are frequently incompatible with their existence; For disability, this is often tangible, built structures, but also institutions like Medicine. Kai elaborates on their link between gender and disability, and how both are unseen by physicians:

Yeah, [because] I feel like for my gender as well, it's like, people who don't know about the idea of gender being on a spectrum, rather than two set things, or even people who understand the concept of being a binary trans person but don't necessarily a non-binary trans person or what being non-binary is. My parents understand being a binary trans person but they don't get anything beyond that. So, they understood me being trans in the beginning, but other than that they don't get it. So, like, because people don't necessarily have that understanding, it makes conversations about my gender hard. Because they just don't have any idea what the heck I'm talking about. They can't wrap their head around it because they don't understand gender as a concept in the same way. And sometimes they don't even understand gender as a concept. They still [think] gender equals sex. So, like explaining it can be really hard when you know they don't think of gender in the same way that you do. So

oftentimes I don't go to the trouble of explaining it, other than like, 'oh yeah, I'm trans' or 'I'm non-binary' if they know what that means.

Kai explains that they no longer see a physician for their leg pain, they simply deal with the pain on a day-to-day basis, and hope that their physician doesn't ask them about it:

I want to go to a pain clinic for it, but I don't know how to initiate it, but I don't feel comfortable asking my PCP about it... I'm glad she didn't ask me more about [my cane] because I didn't know what to expect. I was worried that she would try to tell me I shouldn't be using it.

In the above excerpts, Kai describes the inability of their doctor to understand what they are going through as a barrier to their disclosure. Kai makes an explicit comparison to their inability to disclose their gender identity; If a physician is not gender-variant or disabled themselves, Kai has low expectations for their ability to empathize or understand the nature of their identity or medical concerns. Even further, Kai shares that they worry that their physician might make a comment about their use of a cane: "...[because] I feel like she would try to figure out why I'm using it or try to say that I shouldn't be using one." This also sheds light on Kai's perception that physicians are not taught about the nuanced nature of disability or gender as fluid social identities in their time in medical school. This is consistent with Siebers' discussion of the incompatibility with the biomedical model of illness and disability studies. Physicians are not taught about disabilities in the same way that disabled people think about their own disabilities. Such a disconnect resulted in Kai's disinclination to disclose both their disability and their gender in the doctor's office.

In 1996, Warren J. Bilkey writes in a about perspectives on the medical sociology of chronic pain, emphasizing the importance of sociology in addition to biomedicine to understand the experience of being a chronically-in-pain patient.”⁷⁴ His piece focuses on patients’ coping strategies when physicians do not have adequate treatment plans for chronic pain conditions. Bilkey observes patients’ characterization of this approach as “the do-nothing approach of physicians.”⁷⁵ He pinpoints three features of the search for chronic pain care: physician and patient confusion, patient fear, and clinical chauvinism. Bilkey establishes that the etiology of chronic pain is often murky and difficult to pinpoint, and that such lack of knowledge may precipitate discomfort in the patient. Lastly, he observes the tendency for clinical chauvinism, wherein physicians tell patients that the pain is “in their heads.”⁷⁶ As discussed, chronic pain is more common in trans and non-binary populations than in the general population; understanding how the medical experience of chronic pain is carried out is important to understand much of the gender-variant medical experience. Kai is one of five participants in this study with either chronic pain or a disability, and uses a cane for their pain-related disability. When Kai was seeking care for their ankle and knee pain, the response of their specialist fell in line with Bilkey’s third observation, of clinical chauvinism:

Neeki: So, [you are saying] that people have ideas about what disability is, and that's part of the reason why there's a disconnect between the way your reality is and the way people see [your reality]. And that applies to your doctors too?

Kai: Yeah, especially when I was trying to talk to my doctor about how my knees hurt a lot. Or how my ankles hurt a lot. I’ve always known I have weak ankles from when I’m a kid. My knees feel like

after walking for a while I can't support my own weight, and it's just a lot. I try explaining that and my doctor didn't really listen to me. She was like 'oh we'll send you to a specialist' and the specialist said I was fine...She's like 'Oh, you're fine,' and I'm like 'Okay.'

Neeki: Okay, so you're not fine, [and] your doctor says you are fine.

Kai: Yes.

Neeki: How do you make sense of that?

Kai: I was just like really frustrated, and I was like 'whatever, I don't care about this. I'm gonna do what I think is right for me whether you think it's right or not.

Kai's response to this interaction was to get a cane on their own volition, indicating that they had to take treating their ankle and knee pain into their own hands. Since their physician was not providing them support for the symptoms for which they sought care, Kai had to administer care using their own discretion. They share that they would prefer to be open with their physician about their gender and pain-related disability, but that they "know that the conversation would be really difficult because there's that disconnect, and [they] don't really know how to go about it." Emery, a participant with chronic stomach pain, echoes this sentiment that doctors are not very helpful when they came forward with stomach pain, particularly in the context of worrying about disordered eating as a consequence. They share that to them, "a negative healthcare experience is when the doctor says anything that feels like they're not listening to me and it just goes downhill from there." Emery then elaborates, giving an example of a time they went to their primary care physician for severe chronic stomach pain:

The worst one I had was a few winters ago I had like really bad digestive problems and digestive pain that caused me to feel like no food was okay to eat because I didn't want something to upset my

stomach that badly... so I was eating less. So, I was going to the doctor, then my primary care doctor...to ask her about my stomach pain to see if I could fix that and she told me a list of things not to eat when I was already having trouble eating enough, and I said I was worried it was starting to seem easier not to eat, which I thought was a clear enough cry for help and she just completely blew past it and she just kept telling me what not to eat.

Emery's experience with their primary care physician exists at the intersection of Bilkey's "clinical chauvinism," and McKinlay and Marceau's "end of the golden age of doctoring"; Emery's physician perhaps had a per-patient time limit (be it a formally imposed limit or otherwise) and was thus not able to engage with all of Emery's concerns, and as a consequence did not realize they were missing a big part of Emery's concern for themselves. The scripted patient-education process and ill-preparedness for chronic pain management rendered Emery without Medical support for chronic pain self-care. When I asked Emery how they learned about the nature of their own chronic pain, they replied, "based on years of experience... the couple years I was in New York were like extremely stressful in like every way possible and all my symptoms were very bad since that time, and they've diminished since I've moved in with my parents and stopped working." Thus, Emery has since both mapped their own chronic pain to social stress, and managed their eating concerns. Notably, this is after they went to a physician for care and did not acquire the help they sought. Emery shares that when they go to their physician, they will not report chronic pain to their physician despite its persistence as a symptom:

Emery: I mean like half the time when I go for a regular doctor appointment and they say, "do you have any pain today, I just say 'no' because I have stomach pain like, every day that I get up and

leave the house in the morning. So, it's not always worth bringing up.

Neeki: And is that because you just don't want to have a repetitive—

Emery: Yeah, I have like chronic pain, there's no clear source, I've worked through some of it with my PCP looking for reasons it might be happening but for the most part it's not something that doctors are going to be able to address for me and I'd rather they just not worry about it if it's not directly related to what I'm there for.

Emery thus reinforces the notion that they have developed very low expectations for physicians' ability to troubleshoot their chronic pain in a way that will not cause harm (by perhaps exacerbating their eating concerns) and may actively help by minimizing their symptoms. The unknown etiology of many patients' chronic pain thus has created a problem not only for their physician's ability to help Emery's pain, but also Emery's perception about their physician's ability to help.

In Taylor's experience with chronic genital pain, a similar series of events transpired; Taylor saw a handful of physicians who could not pinpoint their pain's etiology, did not intervene in helpful ways, and as a consequence changed Taylor's perception of physician authority. Taylor shares that they stopped seeing doctors for their chronic pain conditions because "...it just hadn't been useful and it was taking a lot of time." At times, Taylor shares that physicians would suggest surgical interventions with markedly low success rates, inspiring distrust in Taylor for their physicians:

Because I was like, 'you don't even understand like exactly why I'm having this problem, and I've read studies about how low the success rates for surgical approaches are. So, like I'm not interested in that. And like at that point when I was telling them that all of the things they had suggested hadn't worked or had made things worse, and that I wasn't optimistic about surgery, it seemed like they were like 'we've tried everything we know how to try,' so yeah. It feels

discouraging to seek medical treatment for issues that are like that because doctors seem to have particular ideas of how to make it better and if it doesn't work they just don't know what to do. And that's why it's sometimes useful to talk to people who are used to handling chronic pain, and ideally trying to alleviate it, but also just helping you cope with the fact that you're gonna have chronic pain for a while.

Thus, similar to how non-binary patients reacted to culturally-incompetent physicians, or physicians without sympathy for their lived experiences, Taylor turned to chronic pain communities to find coping mechanisms. As discussed in Chapter 2, Kristen Barker documents well the utility of online communities for fibromyalgia, a somatic disorder that is not universally given validity as an illness among medical professionals due to its lack of etiology. Taylor sought medical help for their chronic pain, illustrating what Barker describes as a “skeptical dependence” on physician authority. They share that with time, they have gradually lost trust in the medical establishment: “I think I used to have a really high level in the medical system...and like in most systems and institutions in general...I still am in certain ways, but because I’ve spent so much time going to doctors and trying to treat problems that they haven’t been able to help me very much with, and I’ve had the experience of not feeling very listened to, I have lost a lot of trust in the medical establishment.” In line with Kai and Emery’s experience feeling ignored by physicians, Taylor ties their symptoms not being cared for by physicians to a tapering trust for physicians.

Importantly, Taylor ties the lack of research being done for their genital chronic pain to its characteristic prevalence in female patients. Taylor describes learning how to self-advocate as they move through Medicine with a chronic

illness sans a detailed etiology. They share that they learned to “do a lot of research” for their symptoms, and to “push [their] providers to give a lot of information, and...bring them information that [they] had done research in medical studies outside of [their] appointment.” Taylor made a point to mention that physicians made an effort to give as exhaustive an informational summary as they could regarding what is known about their diagnosis, but that there was not a large body of research on the illness. Taylor expresses that such a lack of research may be connected to sexism. To be seen for genital chronic pain as someone who is assigned female at birth, Taylor had to navigate being assigned a female sex category as they sought care for a syndrome that may not be well-researched because of its prevalence in females:

I feel like it's definitely sexism because it's a chronic pain condition that affects people with vulvas, and so I feel like if there was a similar chronic pain condition that affected people with penises I bet it would be better researched. I think it's probably a lot of things. I think the stigma of people not feeling like they can talk about genitals and sex and pain... And so, I think a lot more people probably have similar pain conditions that never talk to their doctor about them. I think that a lot of people unfortunately talk to their doctor and are given advice that is not valid...that [the patients] are making [their pain] up, or just like other advice that's not very substantive. And I think doctors in general don't listen to people very well, and I think doctors specifically don't listen to women very well... I think if people, because of stigma and because of people not listening very well, may not bring it up, or if they bring it up and get advice that doesn't help, they may stop bringing it up and just give up on it...I think there are a lot of barriers to treatment. And like, I... can see how someone who is like less open and less proactive than me may have gotten a lot less treatment. I think it's just really discouraging when there's not a lot of useful advice, and it's already like a stigmatized topic. And I think especially like, the trope of like, that it's normal for sex to hurt women, is very damaging, because then people either think it's normal and they're just supposed to deal with it, or something. Yeah so, I feel like that's a huge issue.

As someone who is non-binary, seeking care with their assigned sex at birth could have easily compounded the burden of seeking care. If genital dysphoria were a problem for Taylor, as it sometimes was for non-binary participants, it may have been hard to seek care focusing on primary sex characteristics without a physician who understands non-binary gender identity. As discussed in chapter 1, Taylor had tried to tell their primary care providers that they did not identify as a woman, but the clinic did not have room for such a gender characterization in their intake forms. For the chronic pain-related care at this clinic, Taylor was being processed as female. Furthermore, Taylor describes the process of being treated for genital chronic pain as very invasive, physically painful, and “traumatic.” They shared that they were “forcing [them]self through the process of being like, put in pain and sort of traumatized to get care and then the care wasn't helpful,” and gave up on seeking treatment as a consequence. After seeing *eight* providers for this pain, Taylor stopped seeing physicians for the problem, without having arrived at a resolution to the symptoms. At the time of the interview, despite feeling as though they should be medically addressing their chronic pain, Taylor had not seen a physician for their chronic pain for “two or three years,” partially for financial reasons, but also because they felt as though they had exhausted their options. As sociological work on social movements in health illustrate, with a lack of support from medical expertise, patients increasingly rely on lay expertise⁷⁷; Taylor seeking help among other people who must endure similar quotidian pain is an example of a meaningful shift in attention from Medicine to lay experts with the same syndromes.

Conclusion

Connecting disabled and chronically ill patient experiences back to physician authority, the pattern of waning trust and subsequent symptom non-disclosure matches those of participants who struggled to see physicians who did not understand the nuances of gender. Taylor, Emery, and Kai are among almost one-third of participants who were chronically ill or disabled. Such a large proportion of the participant pool can likely be attributed to the selection bias of the recruitment protocol (participants who are chronically ill may have more experience dealing with medicine and may be more willing to participate in a study such as this one), but also may be related to the disproportionate rate of chronic pain and illness among LGBTQ+ individuals relating to susceptibility to trauma, and exposure to discrimination. Receiving sensitive and patient-centered care for chronic illness, therefore, is a part of ensuring adequate healthcare for non-binary individuals. Because of the limitations of knowledge on chronic pain and the implicit bias in Medical care for (cis) women, the theoretical conclusions drawn in Part I of this chapter hold for this part as well: Physicians are both medically and socially ill-equipped to care for chronic pain—Medically because the etiology of illness is often unknown, and socially because the highly bureaucratized, “efficient” structure of physician-patient encounters do not lend themselves to doctors’ appointments that equip physicians with the caliber of information required to administer adequate care. Taylor shares that they found better support in chronic pain communities, tying together the tendency for patients turning elsewhere for pain-related coping mechanisms. The importance of

the incompatibility of the medical model to disability studies and chronic pain treatment is therefore important to a discussion of both authority and bureaucracy. Non-binary patients do not have faith in their physicians' ability to care for them as their gender, and for a portion of the symptoms they experience on a daily basis. Such a lack of trust precipitates from the poor experiences and community consensus on the limited ability for physicians to care for non-binary people, and people in chronic pain.

Discussion: Chapter 3

Flipped Emotional Labor and Patient Burnout

An integral part to managing one's own health is often emotion maintenance. For many participants who need regular care, employing a cost-benefit analysis was described as an integral part of the selective-disclosure of their gender identities. Participants weighed whether the care was affirming, looked for markers of queer-friendly care, and assessed whether they thought their physician would need to be educated on gender matters. Participant assessment of whether they thought their physicians would be competent on queer-friendly matters, as described in Chapter 2, depended on their own experiences, and the experiences of others in their community. For those who expected incompetent care, a “cost” to disclosing was the emotional energy expenditure that they expected would acquaint having to “explain” their identity and remain unbothered. Participants described this as “emotional labor.” While much of the literature on emotional labor in the field of medicine pertains to the emotional labor that is a part of a physician's job and its association with “doctor burnout,” patients must also exert emotional labor for physicians who need to be educated on “Gender 101.” This chapter will first touch on factors that impact a patient's perception that they may need to exert emotional labor for their physician; the purpose of this is to highlight the circumstances participants would use to rationalize their perception that they may have to exert emotional labor, and how “worth it” it would be to invest the emotional labor in that particular physician-patient relationship. The factors involved in this rationalization process are queer-

friendliness of the physician or clinic, the social identities of the healthcare providers (their race, gender, and apparent sexuality), and the duration of their interaction. After this, the chapter will delve into the circumstances surrounding, and consequences of disproportionately-patient-exerted emotional labor.

Cost-Benefit Analysis: Affirming Care

Notably, participants often stated that while it is not a strict requisite for care that their gender be incorporated in their physician-patient relationship, that the receipt of affirming care improved their willingness to disclose their gender identity. Of the seventeen participants, 76.4% expressed that queer-friendly care was either a good addition to healthcare, or a baseline requisite for care. The existing literature on non-binary healthcare acquisition establishes gender-affirming care (compliance with the WPATH standards) as a common requisite for disclosure of gender identity. The findings in Mogul-Adlin's 2015 qualitative dissertation on non-binary medical experiences observed this trend; She finds that non-binary patients would continue seeking care and be honest with their providers in a response to receiving affirming care, and avoid care after negative experiences.⁷⁸ In this piece, Mogul-Adlin diagrams a feedback mechanism, illustrating how patients will respond to provider's intake forms, institutional structure, and physician competence.⁷⁹ This was consistent with the findings in this study. The implicit notion that comes with such a trend is that disclosure is desired, and markers of queer-friendliness facilitates trust and subsequent disclosure. Rae, a participant who had only ever come out to one (queer-friendly)

provider prior, citing apprehensions about physician competence, shared that they would be willing to disclose to any physician with a queer-friendly intake, even if gender was not a part of the care they were seeking: “Oh for sure, if they had [options] in their intake, I would 100% make use of it, ‘cause I am so ready for that.” As established in the first chapter, the notion that it may not be efficient or relevant to include gender in intake forms also did not account for how non-binary people search for intake inclusivity as markers for queer-friendliness.⁸⁰ River (they/he) recalls an instance that they were in a great deal of stomach pain and was asked for their pronouns at their school’s health clinic, stating that “on one hand I was physically dying inside, but on the other hand, I’m being asked my pronouns! That’s wild! ... It really did [set a good tone].” Thus, even in a high-pressure situation in which River anxiously awaited care for their acute pain did they receive the request for their pronouns in a positive way. Their receipt of queer-inclusive care set a good tone for the rest of the visit, and established trust between River and their school’s healthcare administration. For Cam (no pronouns), a genderqueer person working in Boston, a characteristically positive experience was one at a queer-centered clinic. Cam walks me through the positive parts of this experience:

A physician who asks a lot of questions to get an understanding of who I am as a person before treating me, potentially as someone associated with a certain gender. Asking how I refer to things, which was like, that’s never happened before... Letting me know everything before they do it, giving me the option to partake in things, recognizing that partaking in certain things could make me feel like, I’m being gendered. Just being respectful of that. And then... Doing just like a check-in at the end and making sure that I’m okay, and just like, respecting me as a whole person instead of just like an X, Y patient.

Cam describes this experience as the most positive experience that Cam has ever had in healthcare. Cam's detailed account of the good aspects of this experience highlights the centrality of gender in Cam's appraisal of healthcare quality. Cam was not alone in focusing on gender-inclusivity as a part of a positive healthcare experience. Bee (they/them) also centered gender in their description of a positive healthcare experience: "while I was there, doctors had it on record that I'm non-binary, I use they/them pronouns, right from the start, without me having to explain it." Bee's experience adds to Cam's detailed description of a positive healthcare experience by adding that because of their clinic's competence, they would not have to give any additional explanation. With the bureaucratic inclusion of Bee's gender and pronouns, they did not expect to have to talk any more about their gender, re-establishing that the goal of gender-variant patients is not to discuss their gender, but to get care *as* their gender.

Kai shares that an understanding of non-cis gender was not only important for the immediate implications for their care, but also for the ease of conversation with their provider:

I expect my doctor has at least a basic understanding of what being trans is. I'm on HRT right now and have been for some time. So, having a doctor that has a basic understanding of like, what it is... [that's] a requirement. It would be nice to have [a healthcare professional] who understands the way that my gender is set up. Cause like, for like, it's really hard to think about gender in terms of a... vague context. Or that it's not just [a binary]. So, like it's... hard to talk to [a doctor] -- especially when it comes to like mental health stuff.

In this way, Kai illustrates that a lack of "Gender 101," as Chapter 2 established, is hard to traverse in a patient-physician relationship. Kai shares that when they

did go to a queer-friendly provider, and were given an opportunity to share their pronouns, that it “[felt] really good.” They elaborate by saying “it felt nice to know the people that were working there weren't gonna judge ... it felt nice because they didn't know nothing at all....” In this way, Kai shares that they came in with a fear of being judged, and that competence and provider disposition and warmth improved their trust. In their use of the word “hard” to appraise a conversation with their doctor, they signal the associated emotional hurdles of proving the validity of one’s own gender to a resistant professional. Meanwhile, they actively avoid seeking care for their primary sex characteristics, because they dread being associated with the gender associated with their assigned sex at birth;

I don't, that's part of the reason why I don't have [an OB/GYN] ... As a requirement, I would need one who is understanding of non-binary identities and I have yet to really find one who has met those requirements, so I just haven't found one yet. I would not want to get an OB/GYN who started talking to me as if I were a cis woman and have that not be the case. Plus, I just have a lot of trauma stuff. From what I understand about OB/GYNs I don't know if I'd want to have those conversations yet.

This avoidance of care for an entire subspecialty of health was also present for other participants assigned female at birth. Bee shares a characteristically positive experience when they could access gynecological care without having to be labeled as a woman: “Cause I get really dysphoric around my menstrual cycle. And while I was there, doctors had it on record that I'm non-binary, I use they/them pronouns, right from the start, without me having to explain it they were just like, super conscientious about that...It didn't make me feel like a cis girl going in there. So that was rad.” Bee and Kai have opposing experiences here, and both use emotional language to describe their experiences. Here, Kai

illustrates that a lack of emotional labor precludes them from care in their fear of being judged, and Bee illustrates how a positive disposition and simply not needing to “explain” themselves characterized their experience as positive.

In Nicky’s shared experience seeking mental healthcare out, they frame queerness as “tangential” to their healthcare;

I told him what I was going through and what I was experiencing, and he just sort of didn't question it anymore. It was just sort of like 'here's the thing, okay, cool, we'll roll with it.' Especially since the things that I was like, seeking care for were like about gender but ultimately sort of, tangential to. The fact of the matter is, the way that I identify doesn't need to bear a critical role in all these other complex things that I'm experiencing. Like was seeking help for depression and anxiety and I just... I obviously part of the reason I was experiencing it was because of the treatment I received from people due to my identity but it's not like a confusion about my identity was the thing that was at the core.

In the above excerpt, Nicky illustrates that they were not seeking healthcare out for reasons related to their gender; The fact that queer-friendliness was a requisite for a healthcare provider was not because specialized expertise was required to administer their mental healthcare, but because they wanted to access care without having to exert emotional labor for their physician to explain the nature of their identity and remain on neutral terms. In a similar way, Emery states that they don’t talk about their gender with their psychiatrist very often, because at their practice all the nurses and providers were affirming and helpful to their acquisition of gender-specific care. Knowing that their psychiatrist was important, but talking about their gender thereafter was not important. River expresses the same sentiment; “It would be a lot easier to just be like, 'I'm non-binary, these are my pronouns,' and I feel like I would feel comfortable expecting that to be the end

of it.” In this way, participants sought emotionally-neutral experiences characterized by a lack of in-depth explanation.

The receipt of actively gender-affirming care for most was a rare, pleasant surprise. For participants seeing healthcare providers outside of queer-centered institutions, it was even more rare and often a very happy occasion. Bay shares their experience bursting into tears in a doctor’s office after a single conversation with a nurse. They began to broach the option of obtaining a hysterectomy with their physician and was referred to a nurse whose interest was LGBTQ+ positive care;

...having her just be like, 'Let's talk about this! This is information I have, now what's your experience?' Having that there was great! It was really great and a relief. Um, I actually burst out crying ten minutes into talking to her because I'd never had this conversation in this context ever, and I was terrified before going in. And then, I was like getting an engaged conversation with her, and I realized, how, just, it came spilling out, and I literally started crying. It was overwhelming because I didn't expect it to be like, 'I'm just gonna dump this all on the table.' I was just gonna keep it to myself.

Bay’s experience is important because they had not planned on sharing their reason for seeking out a hysterectomy. Having a healthcare provider with an open disposition facilitated Bay’s trust of their provider, and this trust facilitated honesty with their provider. This is consistent with the research that surface-level emotional labor exerted by healthcare providers improved relationships with patients and facilitated communication.⁸¹

One way that participants found queer-competent care outside of clinics labeled as “queer-friendly” was by finding providers who were queer themselves. Knowing that a healthcare provider was queer themselves often conferred high

levels of trust. Rae shares an experience at a clinic where the person at the desk was a femme queer person; “She was also like this amazing femme queer who clearly like, 'got' it and like, is part of that community, and definitely had exposure to that outside of her office. But like, I talked to the nurse practitioner and like I don't know nearly about her life as the other person I talked to for a whole long time...” Rae thus makes a direct comparison from the person at the desk to the nurse who took care of them; the visible queerness of the first person Rae interacted with markedly helped their gender-related conversation. Rae overall described this healthcare experience as very positive, because of that initial interaction that facilitated their comfort in the space.

To echo this notion, Cam, Kai, and Jay all describe having queer or non-binary providers they see regularly, because, in Jay's words, “it pulls down a hurdle.” One of Cam's former PCP's was a transgender woman, and Cam shares that “that was comfortable because like... [laughs] I didn't have to explain it! I felt like I didn't have to explain anything, it was just like, great!” Jay's use of the word “hurdle,” relates well to Cam's relief at not having to “explain anything,” because they both signal that they did not expect to have to expend emotional labor, and that this was a positive attribute of healthcare acquisition. Kai says explicitly about their non-binary provider, “And also, I feel more comfortable talking to them about those things sometimes, [because]...when you're in a space with someone who shares the same identity with you, you just feel more comfortable with them...” Kai's feeling of comfort derived from the fact that their provider shared their gender identity with them. Kai ties this comfort with their

ability to speak candidly about their interest in starting HRT. Thus, for Kai, Cam, and Jay, the comfort associated with having a queer healthcare provider improved their comfort, and increased their likelihood of disclosing their own gender.

Affirming, and/or queer-competent care was described as having administrative gender-inclusion, baseline knowledge of gender-variance, reflection of personal language, and friendly disposition. When implemented, such measures for inclusion had such a profound impact on willingness to disclose gender, and as a consequence, had a profound impact on trust, honesty and comfort in a healthcare atmosphere. When providers themselves were queer or non-binary, the physician-patient interaction yielded similarly positive outcomes.

Race and Trust: Seeking Matching Identities

Because demographic information was not systematically collected in the interview guide for this study, only participants who named their race over the course of the interview in the context of their experiences in Medicine are being included in this discussion. Of seventeen participants, seven mentioned their non-white race as a salient aspect of their healthcare experience. Of these seven, one labeled themselves as black, three as a person of color, one as Indian, one as Native American, and one described themselves as having Chinese heritage. Of the other ten participants, one participant discussed their whiteness as a source of privilege in their experiences. Other than this participant, only participants of color opted to discuss race.

In a 2010 literature review on race and trust, Sandra Susan Smith cites a widely-used definition of trust as an expectation that the word or promise of another individual is reliable.⁸² This definition is important for healthcare, because as is the nature of legal-rational authority, administration of healthcare is contingent on the trust of the patient for the expertise of the physician. Smith identifies race as one of the most significant social factors impacting trust, and that generalized trust is highest among white people, and lowest among black and latinx people.⁸³ Smith cites numerous studies linking this in large part to historical and contemporary instances of racial, particularly anti-black, discrimination.⁸⁴ As it pertains to healthcare, there is ample literature suggesting low trust for physicians among black and latinx patients; Stepanikova and colleagues completed a literature review in 2006 relating patients' race, ethnicity, language, and trust for their physicians, ultimately finding that trust for physicians depended on the measure that researchers use to operationalize trust.⁸⁵ However, in a 2002 study on race concordance in physician-patient relationships, Thomas LaVeist and Tamyra Carroll find that African American patients have higher levels of satisfaction when their physician's race matched theirs.⁸⁶ Consistent with this notion and that of trust being heavily influenced by historical and contemporary discrimination, Al, a black genderfluid participant in their late 20s, shares their poor trust for providers being related to the historical medical mistreatment of black Americans:

...I would say there were times where I completely shut down from receiving psychological care because I didn't feel like I could trust [the providers]...There's so little trust, even when you're thinking about the history of how people like me have been treated within the

American healthcare and clinical system, I have no reason to trust you at all... Yeah, I have no reason to trust you at all, because also... the idea that I have a higher pain tolerance, or I don't have the capacity to feel certain emotions or like anything like that. Which, people are afraid of naming but it's just kind of like, this is very true. And it's true in the way that you engage with me and the kind of questions that you ask, and the fact that you're not even trying to like... I've had psychologists and counselors who I've seen who are not ready to delve deeper with me because it's going to places that are really scary. And like, most of them being, period just not black, but definitely even POC providers or white providers...

In the above excerpt, Al shares that they have poor trust for their providers, and implicitly that this is related to the systematic, historical mistreatment of black people in America by Medicine, and explicitly exacerbated by the fact that most of their providers are not black. Furthermore, Al's above excerpt touches on the skewed and often ill-informed perspective of non-black physicians in their caretaking of black patients. Al's statement, "the idea that I have a higher pain tolerance, or I don't have the capacity to feel certain emotions..." hones in on a specific concern that the research that fuels contemporary medical decision-making is racially biased and anti-black. That perhaps white physicians will have to use racially biased research, and that they are subject to their own racism, are both factors that will contribute to their incompetence caring for patients of color. In 2002, LaVeist and Carroll found that 22% of African Americans had race concordant physicians; In a study of the same year, LaVeist and Nuru-Jeter find that given the choice, African American patients will opt for race concordance.⁸⁷ Al later shares that a positive experience, for them, would be to be "treated like a person," because, "looking at this in layers, I get to be black, queer, and non-binary and genderfluid in the doctor's

office, so I get to be dehumanized on three levels.” To avoid this three-fold dehumanization, Al seeks healthcare out among healers; Al’s healer is both black and non-binary, and is described as an “active listener,” as opposed to the inactively listening physicians who “just [sit] there.” Al’s healer uses their pronouns correctly, and identifies them by their chosen name (as opposed to their “dead name,” or birth name), sharing that “It’s not a whole discussion like ‘oh what does that mean blah blah blah,’ or any of that kind of thing I would have to do in a doctor’s office. They are also non-binary. They also understand. They’re like ‘Ok. I respect that, let’s move on to the next thing because we only have an hour.’” In this way, Al does not have to expend labor to explain their identity to an otherwise gender-incompetent physician, and can more easily trust their provider because they share similar experiences as black non-binary people in America.

Bo describes themselves as having Chinese heritage, and discusses with me their frustration with the racialized assumptions they have to deal with in a healthcare setting, particularly when they are stripped of their queer markers, in a hospital gown: “I try to always also think about race, and like queerness and gender intersect, and I’m generally read as queer. But I think, when I’m in like a hospital gown and a lot of my markers of clothing and queer markers are not as visible. I will often be read as straight. And then I think a lot about that cause I’m like, I know it’s racialized.” Bo describes being seen in a particular way as a consequence of their race, that leads to assumptions being made about their gender and sexuality. To mitigate the assumptions they know will be made of

them, Bo found a queer, latinx healthcare provider for their mental healthcare; “They're the one of the only trans or non-binary therapists of color in Boston... I know like 15 people who see them [for that reason].” Bo shares that this experience is “amazing,” and that they were very happy to have found this provider for their mental health. When I asked Bo what drew them to this provider, they provided an in-depth explanation:

So, I was looking for someone who could speak to race and queerness. It just so happened that they were non-binary and at the time I was poly-amorous and they were also versed in that because they were that themselves. So, at the time I was like, this is perfect! But I'm monogamous now. It's still relevant though because they have understanding of like fluidity and different frameworks like that. But it's very helpful because they'll help me brainstorm ways to talk to people about my gender... Yesterday I had a session, we were talking about how to talk to my boss about how they can support me more with when I get misgendered at work, and they were giving me some strategies... And when I had a break-up with an ex-partner like a year or two ago, who was trans, we talked a lot about how our traumas had been interacting in negative ways that led to our break-up. Which is things I don't necessarily feel I would be super comfortable with other therapists who didn't have like, experience, personal experience. And they're also from an immigrant family so it's really helpful to have that context. Cause I talk a lot about my parents and the struggle with them since I came out.

Similar to Al, Bo found comfort in going to a provider who shared some aspects of their different social identities. Bo shares that the fact that they shared so many identity-related experiences, and the fact that different people in their queer community recommended this provider, meant that they felt they could trust their provider “almost immediately.” Thus, Bo not only explicitly links the sharing of their identities to trust, but elaborates on this relationship by giving examples in which having a

shared identity helped the administration of their mental healthcare. Thus, being on the same gender wavelength significantly helped Bo's level of trust for their physician.

Lastly, Ari is Native American and variably identifies as non-binary or Two Spirit. They share that they also must decide to what extent their mental healthcare provider will reflect their identities. They say that when they did have a therapist, that their relationship was very positive and that this was partially because the therapist was queer as well. Regarding their therapists' whiteness, they say, "yeah, I actually ended up sacrificing race over it that one time, [because] I was like, 'this is what I need.'" Ari's use of the word "sacrifice" indicates that ideally, their therapist's identities would match more of their own identities. They say that while they did not go to therapy for gender-related issues, just having a mutual understanding about gender was important. Such a mutual understanding would be improved with other shared experiences as well.

For Al, Bo, and Ari, their ideal healthcare provider would have a general sense of their life experiences. This could be accomplished by seeing a caretaker with similar social identities, such as race, gender, and sexuality. For Ari and Bo, this meant seeing providers whose identities were similar but not the same, but for Al, this meant completely exiting the realm of state-sanctioned MD or DO caretaking. Such compromises were rendered necessary because of the disproportionately white and male

physician population, the historical mistreatment of trans patients of color in America, and the impersonal nature of Medicine.

Cost-Benefit Analysis: Duration of Interaction

Participants also took into account the duration of the interaction when determining whether they would disclose their gender to a physician, making them less likely to disclose to specialists or doctors they did not expect to see often. In this sense, participants were attempting to gauge the extent to the “costs” of coming out to a physician. If they were only going to see the particular physician once and would have to explain their identity to avoid being misgendered over the duration of that single interaction, it would not make sense to disclose their gender identity. If the physician were their primary care, some reasoned, the repetitive misgendering would be costlier and may warrant explanation.

Length of interaction and perception of queer-competence were employed as a trade-off and weighed against one another; At times, if the healthcare system seemed receptive to gender-variance, disclosure was low-risk and high-reward. Patients would be able to avoid being misgendered and not have to justify any aspect of their identity. An example of this is Elia's anticipation of moving from their hometown back to Boston. Elia (they/them), a genderqueer person in their late 20s, stated that they felt they would be able to endure not disclosing their gender to physicians they perceived would be queer-incompetent due to horror stories from people in their community:

...Having heard a lot of horror stories from people that I know. Not about those specific providers but like, because a lot of those providers I didn't have a point of reference for like how they were, I was just sort of like, 'Well, I'm just not gonna deal with it.' I knew I was gonna come back to Boston for grad school, so I was just sort of like if I'm not gonna have a super long-term relationship with this provider, like, I don't wanna deal with it...

Without characterizing the factors that went into their decision not to disclose as costs and benefits, Elian illustrates their own cost-benefit analysis in the above excerpt. An important piece in this is that they would not have to endure the repercussions of not being clear about their pronouns and gender. Most participants described a cost-benefit analysis, and almost all of these participants explicitly cited duration of relationship as a piece to this decision. Ari, Emery, Bo, Taylor, Cam, Bee and Bay all explicitly discuss their expectations for length of interaction as an important tool for assessing their own willingness to disclose, illustrating the centrality of the cost-benefit analysis at the outset of so many doctor's visits.

Cost-Benefit Analysis: Emotional Labor

Participant apprehensions surrounding having to “explain themselves” was eventually explicitly conceptualized as contempt for exerting “emotional labor” for physicians. The concept of emotional labor was introduced in the 1980s by Arlie Russell Hochschild in her book *The Managed Heart*. She conceptualizes this as the emotional management workers in particular fields must do to maintain the outward appearance of socially appropriate emotions, and facilitate comfort in the people around them. She notably establishes that emotional labor is more often demanded of women than men. As it pertains to the medical field, much of

the literature looks at the emotional labor healthcare professionals must exert for patients.

Larson and Yao (2005) purport that much of the work physicians must do for patients is emotional labor, in the part of their job that necessitates feeling empathy and acting sincere.⁸⁸ In their 2005 journal article, they note that this kind of labor is integral to the adequate administration of care, citing literature that linked physician empathy to patient openness and self-efficacy.⁸⁹ Because emotional labor is a fixture in the healthcare profession, Larson and Yao suggest that training should be provided in medical school to help prospective doctors manage the emotions associated with their jobs; There is ample literature on the impact of high demand for emotional labor of physicians and “physician burnout,” a term describing a work-related syndrome associated with “emotional exhaustion, depersonalization, or feelings of detachment and cynicism toward people and work.”⁹⁰ As highly interactive work that engages with people’s health, physicians are subject to burnout. In their piece on emotional labor among healthcare professionals, Bagdasarov and Connelly point out the culpability of what Hochschild conceptualized as surface acting for burnout, along with “psychological strain, physical complaints, emotional exhaustion...and emotional dissonance.”⁹¹ Meanwhile, deep-acting, while also yielding a potential for adverse health outcomes, was associated with more positive consequences.⁹² This 2013 study also points out that the literature on emotional labor in healthcare finds nurses engage in substantial emotion work as a part of their job, and that emotional labor could be positively correlated with levels of stress.⁹³ Ruth Riley

and Marjorie C. Weiss find in 2015 that much of the existing literature on emotional labor focuses on nurses, because of how nursing is seen as a caring profession.⁹⁴ Gray and Smith point out the gendered nature of emotion work in healthcare, stating that “female nurses were ‘invisible carers’ (taken for granted with emotions represented as a ‘natural’ activity) while male nurses were ‘forgotten carers.’”⁹⁵ Within the profession, Gray and Smith find that there is some gendered division of labor to further parcel nursing: “controlling” dangerous behavior for male nurses, and emotion-management for female nurses.⁹⁶ In her qualitative study on nurses working in the neonatal intensive care unit, Roberta Cricco-Lizza pulls together the consequences of placing much of the emotional labor onus on nurses by noting “staff retention, job satisfaction, and delivery of care” as implicated.

A seldom-observed addendum to the concept of healthcare-worker burnout is “patient burnout,” which describes patients who experience repeated, unrelieved stress and avoid care and/or are non-compliant as a consequence.⁹⁷ For patients who must go to physicians and experience a repetitive point of social friction, avoiding the source of stress (often the healthcare provider or the subject matter) was a recommended self-care measure.⁹⁸ For gender non-binary participants of the present study, it was common that interactions involving discussions of gender were described as exhausting and labeled as “emotional labor” when the physician was not adequately educated on gender variant etiquette. Participants of this study described situations they had to both *surface-act* and *deep-act*, and consistent with Bagdasarov and Connelly’s linkage of

surface-acting to burnout, participants described moments they had to surface-act as highly taxing.

Patient-Exerted Emotional Labor

In a rift from much of the sociological precedent engaging with emotional labor as a part of an individual's employment, participants of this study described emotional labor as a part of their patient experience, and many avoided disclosing their gender identity due to the expectation that they may have to expend emotional labor as a consequence. In my conversation with them, Bay offers the term 'emotional labor' as it pertains to gender disclosure:

Depending on how the person reacts, like if they need a lot of explaining, like 'I don't understand, why would you think of that'. I don't even wanna continue the conversation and I am gonna regret bringing it up. Sometimes you project that might happen, and you don't bring it up just because you project it might happen, whether or not it might actually happen. Sometimes people a simple matter of, 'Oh hey I prefer they,' 'Oh cool.' And that's it, and that's fine and that's how I wish all of them were. It's tiring when you have a hundred questions. It detracts from whatever your initial interaction was about. It's emotional labor.

In their naming 'emotional labor,' Bay specifically hones in on the "hundred questions" aspect of the conversation. When prompted to define what 'emotional labor' means to them, Bay elaborates on the part of the hundred questions is cumbersome:

It takes a toll on you, it makes you tired. I don't mind people asking questions, but I'm not here to be an encyclopedia either. And I'm generally pretty open about things, and I don't mind answering questions. But if it goes from curiosity to 100 questions, when I was really here just to show you how to use a sewing machine, for instance, and we can't seem to go back to the task at hand without it repeatedly going back to the same subject and it gets tiring. I would

say that's emotional labor. Putting in an effort to answer questions, not lose my patience, that maybe takes away from the task at hand.

Bay makes a very important distinction in their explanation of emotional labor—that there is an expectation that they will not lose their patience when answering questions as it pertains to gender. When participants describe fatigue from having to explain their gender in an emotionally-neutral manner, they also touch on their resulting apprehension to expend energy for people when “Google is free”; self-education is a matter of having a desire to be inclusive, not access to information. As Cam says, “The internet exists. [laughs]. I want that quote in your thesis. The internet exists!... Ask the questions there, and not put that burden on someone like me, who's just like 'I'm just trying to live my life, and to be respected while doing so!' [laughs].”

Bo offers that the labor of managing their emotions when they are misgendered and do not want to bother the person that misgendered them or call attention to themselves is debilitating for them: “And although it's not labor expended to correct them ‘cause I'm not correcting them, I feel like my body like churns, and it's a lot of energy because I can't focus on whatever I'm supposed to be doing for that time. Or that meeting. Just makes me really doubt myself.” Bo explains that a consequence of being misgendered is discomfort bordering on psychosomatic physical pain. In order to continue the interaction without making it evident that they were made uncomfortable, Bo and many other participants have to both surface act and deep act; Make it seem as though they feel alright, and also manage their actual emotions to facilitate being misgendered as a regular part of interaction.

The emotions non-binary people describe having to manage at the doctor's office when they are misgendered range from sadness and anger to detachment. Ari describes needing to be in a good mood to educate someone on gender variance: "Yes, absolutely needs energy. I already have to be in like a good mood. If I'm not in a good head space or not feeling good about myself... it's not a good time to do it." Meanwhile, Al describes it as a "fight," when they describe having to ask themselves if they "want to have this fight today," implicitly characterizing the interaction as frustrating and inspiring anger. Elian describes it as tiresome, especially in the context of having to be at the doctor because they are already ill: "...it's just like exhausting. I don't always wanna have to be like 'oh okay, I have to now explain to you all of these things,' that is like time and energy and I really just wanna get my stuff dealt with and leave. Like I'm probably there cause I'm sick." Almost all of the participants of this study described the emotional consequences of being misgendered as draining in some capacity. Furthermore, almost every participant had an experience being misgendered by a healthcare professional. Notably, there were a few participants who described having been much more sensitive to being misgendered by physicians, but who have managed their emotions and are no longer bothered by it, in their success at deep acting. Emery is an example of one of these individuals, explicitly using the term "burnt out" for the consequences of feeling so deeply when they were misgendered repeatedly: "For the most part like, since I still read as a cis girl the people who don't look for those tells... that used to bother me a lot more than it does. I've kind of burnt out on kind of being bothered by that at this point." Emery thus verbally

ties their repetitive deep acting to feeling “burnt out.” Thus, non-binary people must exert emotional labor when they get misgendered and need to act natural, when they have to explain gender matters in an emotionally-neutral manner, and when they manage their emotions to be conducive to being misgendered on a regular basis.

Cost Consequences: Non-Disclosure, Poor Trust

As an explicitly stated consequence of expected cultural incompetence, many participants described poor trust and subsequent non-disclosure. After being met with unfriendly disposition and uncompromising physicians, patients’ trust for their healthcare providers diminished. This is consistent with the research encouraging improved physician empathy. For three of the participants, non-disclosure and poor trust stemmed from impatience with cultural competence, and repeated micro-aggressions. Emery, the aforementioned participant who describes themselves as “burnt out,” describes the aftermath of having to justify and clarify their gender identity as “disappointing but also like crushing, like an onslaught of micro-aggressions... [that] brings up all the past stuff.” In a later part of our conversation, Emery reveals that they usually hear she/her pronouns in reference to themselves in a doctor’s office, because they “don’t bother correcting people.” Emery is exhibiting what Hoover describes as “patient burnout” (coined initially for non-compliant diabetic patients), resulting in poor trust, and as a consequence, poor medical compliance. Consistent with Emery’s appraisal of the energy requirement associated with disclosure, Al explicitly links the perceived cultural incompetence to their hesitation to disclosure. They state, “I never really bring up

my gender that much because it just makes the situation stickier and it's just like... with any person visiting the doctor's office often you just wanna go in, get whatever prescription you need and leave.” With this statement, Al implies that bringing up their gender would hamper their attempt at “getting in and out” of the doctor’s office, and that somehow bringing up their gender would complicate the visit. They state this explicitly: “And I don't really feel like teaching a doctor every single time that I visit that it's just kind of like 'hey actually I use these pronouns and actually could you just refer to me as a person with a vagina and not like, this woman on the table'. I don't feel like it [laughs].” Had Al perceived that disclosure of their pronouns and preferences for care would not have precipitated a long-winded conversation, they express that they would certainly have a lower threshold for disclosure and higher level of trust. Jay, mentions that they won’t disclose their gender to physicians perceived cultural incompetence: “It's so much, and it's not really worth it when I'm not there to discuss my pronouns I'm more there to get like, services... I don't know, if I need someone to like fix a broken finger, and not like worry about my pronouns.” Jay’s description of pronoun disclosure as “worry[ing] about” their pronouns ties a conversation about pronoun preference to low expectations and discomfort. Jay, Al, and Emery illustrate the frustration associated with exerting emotional labor, and how easily this frustration can translate to avoidance of care or non-disclosure.

Conclusion

From the literature on emotional labor that sheds light on physician burnout, it is evident that physicians and nurses are subject to feeling alienated

from their line of work over time, and that even within the healthcare profession, that emotional labor is disproportionately allocated to subspecialties with predominantly women (such as nursing), and carried out by mostly women among healthcare professionals.⁹⁹ Furthermore, physicians and nurses have historically been ill-equipped to handle the emotional toll that their work may take, but also that the work associated with this toll improves patient outcomes and trust. To make this knowledge relevant to non-binary patients, it was established in Chapter 2 that physicians are not educated on how to administer emotional care that includes gender identity and in this chapter that such lack of knowledge results in social friction between the healthcare worker and patient. Thus, the conclusions being made in this chapter call not for an increase in exerted “emotional labor” by healthcare providers (treating a patient as their identity should not call for emotional labor), but to remove the friction in the non-binary patient-physician interaction with structural accommodation. Participants of the present study illustrate that patients with lived experiences incompatible with the biomedical model being employed by Medicine today must endure repeated friction between their non-binary gender and the binary language and intake of Medicine. As this chapter conveys, pushing back against these administrative fixtures renders non-binary patients vulnerable and emotionally tired. Such pushback can be conceptualized as “emotional labor.” Participants of this study described circumstances in which they had to pretend they were feeling fine when they were misgendered (surface-acting), and also manage the way they reacted to gender-related micro-aggressions (deep-acting). Responses further indicate that such

friction renders them vulnerable to patient-burnout, or losing faith in the doctor's ability to adapt to a particular patient's identity. This results in non-binary patients opting to rarely disclose their identity, if at all. The rift between physician- and patient-exerted emotional labor for non-binary participants of this study impacted trust, comfort, and honesty, consistent with findings linking physician emotional labor to patient honesty.

As established in Chapter 1, healthcare is becoming increasingly bureaucratized, and the physician-patient relationship is suffering as a consequence. As trust in a physician improves, as does treatment compliance and patient honesty.¹⁰⁰ This chapter illustrates that as the physician's role in the patient's life becomes more frequent and more consequential, gender disclosure becomes more important. For healthcare providers whose care is administered through socially relating to the patient, such as for Ari and Bo, finding providers with matching social identities mitigated the difficulty of disclosure. The distinction is made by Bay, that as the physician's specialty gets more biomedically technical, the preference for matching identities is rendered progressively less relevant. This is consistent with the fact that when participants discussed finding providers with matching identities, it usually concerned either mental health, or primary care providers. Furthermore, it is consistent with participants' integration of the length of interaction in their cost-benefit analyses for gender-disclosure. The consequences of these cost-benefit analyses and emotionally-strained healthcare interactions can be mitigated through both

structural inclusion of non-binary identity in medical education, and trans-inclusion in patient intake.

Conclusion

A Temporal and Social Location

The research I conducted is informed by my temporal and social positionality. As I write in this moment, it is 2018 and I am a young, non-binary student in Boston with the intention of studying medicine. I started this project only two years after coming into my identity, and only three years after hearing the term “non-binary” for the first time. The term “non-binary,” as I touch on in Chapter 2, is relatively new. With time, the term will indubitably grow antiquated; the term itself indicates a “lack,” and is positioned in relation to binary gender. To be “non-binary” should not be characterized by what it is not, but by the rich multitude of identities it inherently holds. I came into this research as individuals were learning about “non-binariness” on their own bodies, and creating meaning in the term on their own time and in terms of their own comfort. With the passage of time, the identity will grow to mean something new, and this research will take on new meanings.

Aside from the limitations of my temporal location, I mention in my methods that I have limited perspective due to my own social reality. A nationwide transgender study found that in 2011, those with non-binary gender are 1.74 times more likely to have attended college than the general population.¹⁰¹ Attending Tufts, I have had the privilege of exploring my gender identity in a safe and notably queer-friendly institution, and using the resources available to me to acquire a deeper understanding about what gender *can* mean to me. Along with many of my participants, one of the biggest hurdles to self-labeling as non-binary

is not realizing that existing outside of the gender binary was an option available to me. While many have the internet and local queer communities as locations to define and reform their identities, many do not. As a consequence, many individuals who may otherwise have found comfort in a non-binary gender identity may not have shifted their self-understanding until much later in their lives. I owe my self-understanding in its current iteration to my queer community at Tufts and to the authors and theorists who have meticulously outlined gender's various incarnations.

Not only am I privileged for my attendance at Tufts, but for the body I occupy. When Tufts was built, it was built with my body in mind; One that can climb stairs, travel from class to class with fifteen minute gaps, take exams in one-to-two-hour time slots, and have the physical and emotional stamina to attend four to five classes in a semester. While one day I may not have this privilege, thus far I have moved through my life unbothered by my built environment. Such privileges are not afforded to many with disabilities. Having to hear narratives involving limited mobility, and to apply those to theories I was engaging with for the first time (for lack of personal experience) was indubitably a limited methodology. I was lucky to have found the work of Eli Clare, whose eloquent account of the intersection of queerness and disability gave me a jumping point for an existence that occupies both. With time, as more people with disabilities are given *physical and institutional* space to write qualitatively about their own experiences, a more in-depth understanding can come about regarding the fluidity and plurality the experiences of living with disability as a queer person yield.

Furthermore, I come from a family of color, but move through the world as a person being repetitively categorized as white. I therefore benefit from white privilege. My personal understanding of how queerness relates to race is limited to my Iranian-American household, and completely characterized by the experiences growing up with parents who grew up in Iran, and never conceived of “non-binary” as an identity; When my participants talked about being a second-generation immigrant and not having language in their parents’ tongues for their queerness, I shared such pain. However, as it diverges from these niche experiences, I can only speculate about the relationship between each person’s own iterations of queerness and race. For my black genderqueer participants, their experiences were characterized by a multiple marginalization I cannot relate to. Using my participants’ words and linking it to health data on race concordance helped me find patterns in my data, and facilitated my location of an important narrative of physician-patient trust being improved by shared identity, and hurt by a history of institutional racism in Medicine. However, the fact remains that more specialized research on black and brown trans and non-binary people, carried out by people from those communities, is the best way to ascertain a fuller picture of the interactions between race and gender variance in Medicine. To scratch the surface of alleviating the consequences of such institutional violence would be to give black queer researchers and researchers of color both institutional space and funding to carry out their projects.

It is easy to pinpoint these obvious differences in social location, as they are readily visible and identifiable. However, I occupy a body distinct from those

of all my participants. To share a gender identity is not enough to fully understand what their gender means for their experiences in healthcare—Until I am them, I will never know what it feels to be them and sit in a physician’s exam room. Such is the nature of qualitative sociological research. I did my best to listen, ask for clarification, and understand, but after I parted ways with them, their narratives were mine to interpret: A skewed relationship. To the extent that all research is subjective and speculative, my research is as well. The only way to mitigate such limitations is more self-situated research, in which researchers imbue their account of organized data with their socially informed perspective. Donna Haraway reminds us that research does not endow us “objectivity”, and that to build a composite image of collective reality, we must continually ask ourselves: “With whose blood were my eyes crafted?”¹⁰²

Non-Binary Healthcare

Zooming out from the cross-hairs of interpersonal experiences in healthcare and their implications for the livelihood of non-binary people, a few stories emerge: one of a massive bureaucracy standing between physician and patient, one of a lagging physician authority, and one of an emotionally self-managed patient. The narratives that come forward in these chapters illustrate a tension between trans and non-binary patients’ willingness to compromise their personhood to acquire healthcare, and a physician’s attempt (and frequent failure) to meet them in the middle. The transphobic structure of Medicine resides not

only deep in the history of the medical discipline, but permeates the patient protocol and physician education:

“...and it lives and breathes in the flesh and blood of our families, even in the name of love.”¹⁰³

Here, I conclude with Cherríe Moraga’s above lament to evoke the contradictory nature of Medicine’s structure: The values that are institutionally espoused and the passion that drives healthcare practitioners to devote their lives to other people’s wellness could be called love. Despite its intentions, these locales constructed precisely for healing is where many feel the most estranged. Unpending the transphobia at the foundation of Medicine by critically re-appraising its “efficient” structure is the first step to queer-inclusive healthcare.

Afterword

After collecting almost seventeen hours' worth of audio data, and personally transcribing and coding the audio, I only wish I had more time to do participants' narratives justice. The conversations I held with participants ranged so much farther than their experiences in medical care; I heard about families, friends, relationships, conflicting personal identities, and decades' worth of their personal growth. Had this not been an undergraduate thesis, I would have relished in disentangling the other parts of my participants' lives, to give a fuller picture of their individuality and perseverance. Lastly, as an aspiring physician and a gender non-binary student of sociology, this project has been very personal to me.

Through my data collection, I sat down with seventeen non-binary residents of Boston, and heard about their experiences in the hands of medical care. Although we shared parts of our identity, there were many instances I did not see myself in my participants. As a researcher, I had to work to empathize with how they may have felt, and this yielded a range of emotions: heart-break, frustration, and anger, but also admiration, inspiration, and gratitude. My heart is so full for the liberating parts of being queer that my participants will get to enjoy, for as long as they feel safe doing so. Despite the sheer magnitude of changes that need to be made to Medicine to accommodate queer people, I look forward to being a doctor and working on those changes.

Appendix A: Interview Guide

Conceptual Framework and Interview Guide

- What is the gender identity of the participant?
 - What is your name?
 - What is your gender?
 - What are your pronouns?
- What does their gender identity mean to the participant?
- How has your gender identification and presentation changed over the years?
- What has this change meant to you?
- What are the basic expectations of your family and friends concerning your gender identity?
- To what extent do you consider disclosure of your gender identification/label important in your personal relationships?
To what extent do you consider disclosure of your gender identification/label important in your professional relationships?
- What role does gender identification play when the participant seeks out medical care for concerns related or unrelated to gender transition?
 - Of your primary care doctors what are some positive experiences that stick out to you? What are some negative experiences that stick out to you?
 - Do you perceive that your negative experiences are typically characterized by your gender variance?
 - Have you ever changed practices due to a particular experience with a physician?
 - Do you consider it important that your doctor be aware of your gender identity?
 - Does this depend on the subspecialty and primary concern of the doctor, or do you hold the same expectations for all of your doctors?
 - Are you routinely asked for your pronouns when seeking medical care for concerns unrelated to transition? Related to transition?
 - As your physician-patient relationships stand today, do you feel comfortable with the way they refer to you?
 - If you have disclosed your gender identity to your physician, how has your relationship with any of your doctors changed after disclosure?
 - Has this change affected your perception of the quality of care you were receiving? If you have not disclosed your gender identity to your physician, what stops you from doing so?

- What characterizes a positive healthcare experience to the participant? A negative one?
 - To which doctors have you decided not to disclose your gender?
 - Is the participant consistently able to trust their healthcare providers and feel safe in their practice?
 - Describe your relationship with your primary care physician.
 - Has there ever been any instant in which you felt you may not be able entrust a healthcare provider with your health? Describe the circumstances.
 - Do you feel as though procedures pertaining to your transition are explained clearly and fully?
 - What kind of information do you feel is withheld from you as a patient? To what do you ascribe this lack of information (lack of available information/poor communication of existing information etc.)?
 - Is there any information pertaining to your health you feel inclined to withhold from your doctor? What and why?
- Could there be changes to the way medical care is structured that would benefit them? What existing structure works well for them?
 - Are there any interventions or questions routinely carried out by physicians that you consider unnecessary?
 - How relevant do you consider disclosure of your assigned sex to doctors whose subspecialties do not pertain to your secondary sex characteristics?
 - How do you feel about medical emphases on assigned sex? Do you perceive that it is usually important to accomplish what you're asking of the practice?
 - What about the way medical care is carried out do you think works well, particularly pertaining to your gender identity?
 - If you are asked for your pronouns, your gender, your preferred name? If you are *not* asked for your pronouns, gender, or name?

Appendix B: Consent Form

CONSENT: Standard Written

LOCATION: Greater Boston, Cambridge, Medford

PARTICIPANTS: Gender Non-Binary Adults

COMPENSATION: \$25 Visa Gift Card

CONTACT

Tel: [\(203\)-570-0898](tel:(203)570-0898)

Email: neeki.parsa@tufts.edu

Study Title

Gender Non-Binary American Healthcare

Purpose and Duration

This study will look at the medical experiences of people who don't identify within the gender binary using semi-structured interviews. It should not take more than one hour of your time.

Interview Protocol

I will walk you through this consent form. Should you agree to be interviewed, we will begin a one-hour interview. With your consent, I will be audio-recording the interview. At any point during the interview, you are allowed to opt out of the study and ask that your interview not be included in the data. The audio-recording will be stopped, and the file will be destroyed.

Once the interview is completed, I will give you the compensation associated with this study. The audio-file from this interview will be uploaded on a secure server, and deleted from my portable recording device. When the interview is transcribed for analysis, and discussed in the final product of research, a pseudonym will be employed to protect your identity.

If at any point after the interview, you decide that you no longer want to be a participant in the study, the audio-file will be destroyed, along with any transcription of the interview and data analysis. Your participation in this study is completely voluntary. If you later decide that you do not want to participate in the study, your compensation will not be revoked. You will not be asked to return the money you received for completing the interview.

Risks and Discomfort

Over the duration of this interview, I will ask you about experiences of a positive and negative nature in the American healthcare system. Some questions may touch on difficult experiences that may be hard to share. Some discomfort may be associated with sharing such experiences. You are not required to answer every or any question in this interview. If you opt out of questions that are too difficult to answer but still complete the interview, you will still be compensated for this interview.

Benefits

There are no direct benefits to you for participation in this study, although the interview will contribute to a body of knowledge that seeks to improve healthcare for gender-variant populations.

Confidentiality

The audio file associated with this interview will be stored securely, and will be made available to no one besides myself, and my advisor. My advisor will not have the key that links the audio files to the names of the participants. This research will be submitted as my senior thesis and may be made available online on a database. In any discussion of this interview,

your name and any identifiers will be disguised.

Compensation

You will receive a \$25 Visa gift card for participating in this study. You will receive this after completion of the interview. After you receive the gift card it is yours whether or not you later decide to opt out of the study.

Request for more information

You may contact me at any time regarding questions about this study at my personal phone number: [\(203\)-570-0898](tel:203-570-0898). Additionally, you can email me at neeki.parsa@tufts.edu.

Voluntary Participation and Withdrawal

Your participation in this study is completely voluntary. If at any point you no longer wish to participate, you can withdraw your consent and discontinue your participation in this study. This is true during the interview, and at any point before I submit my thesis in May of 2018. There is no penalty for choosing to withdraw from this study, or opting out of participation.

Signature

I confirm that I understand the purpose of the research and the procedure of the study. I understand that I am able to ask questions at any time, and am able to withdraw from this study at any time. I have read this consent form, and my signature below indicates my consent to participate in this study.

Participant Signature
Date

Printed Name of Participant

Researcher Signature
Date

Printed Name of Researcher

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