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TRANSITIONING EXPERIENCES: ACCESS AND BARRIERS TO  
TRANSGENDER HEALTHCARE

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TRANSITIONING EXPERIENCES: ACCESS AND BARRIERS TO  
TRANSGENDER HEALTHCARE

A DISSERTATION APPROVED FOR THE  
DEPARTMENT OF SOCIOLOGY

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## TABLE OF CONTENTS

	Pages
Chapter 1: Introduction	1
Chapter 2: Defining Transgender and the Use of Terminology	5
Chapter 3: Theoretical Approaches to the Study of the Body	18
Chapter 4: Previous Research on Transgender Healthcare and Healthcare Inequalities	28
Chapter 5: Data and Methods	43
Chapter 6: Analysis	53
Chapter 7: Social Capital and Transitioning Healthcare Services	57
Chapter 8: Ignorance and Discrimination and Transitioning Healthcare Services	66
Chapter 9: Instrumental Factors and Transitioning Healthcare Services	78
Chapter 10: Agency and Transitioning Healthcare Services	85
Chapter 11: Discussion and Conclusion	96
References	113
Appendix A: Glossary of Terms	119
Appendix B1: Web-based and Email Recruitment Text	124
Appendix B2: Recruitment Flyer	125
Appendix C1: Interview Schedule	126
Appendix C2: Demographic Questionnaire	129

## LIST OF TABLES

	Page
Table 4.1: Healthcare Paradigm Shift (Singer)	31
Table 5.1: Gender Identity of Participants	52
Table 6.1: Major Categories with Sub-Codes	55

## LIST OF FIGURES

	Page
Figure 2.1: Traditional Gender Identity Spectrum	6
Figure 2.2: Traditional Sex Identity Spectrum	6
Figure 2.3: One Directional Spectrums	7
Figure 2.4: Transgender Identity Spectrum	9

## ABSTRACT

Marginalized populations, including racial and ethnic minorities, women, and gays and lesbians, have often been discriminated against in healthcare, and this has been an important focus of health and medical research within sociology. But little attention has been paid by sociologists to the healthcare experiences of transgender individuals undergoing the *transitioning process*, which includes the specific medical and psychological steps taken to transition from either male to female or female to male. In-depth interviews with twenty transgender identified individuals were conducted to investigate access and barriers to transitioning healthcare services. A grounded theory approach was used for analysis. Four major themes related to accessing (or not accessing) transitioning healthcare services emerged from the analysis: social capital, ignorance and discrimination, instrumental factors, and agency. The findings suggest that constrained choice theory and social capital frameworks may be useful for understanding experiences with transitioning healthcare services.

**Key Words:** Transgender, Healthcare, Healthcare Access and Barriers, Social Capital, Agency, Ignorance, and Discrimination



## CHAPTER 1: Introduction

Healthcare among populations that have often been discriminated against, such as racial minorities, ethnic minorities, women, and gays and lesbians, has been an important focus of health and medical research within sociology. This research often addresses issues of access, barriers, specific illnesses and diseases, and doctor-patient relationships for these disadvantaged populations. Yet, within sociology, there is very little research on the healthcare of the transgender population. The limited empirical work that does exist focuses on HIV/AIDS prevention, mental health issues, and access to general healthcare. There is little attention to the healthcare needs of transgender individuals undergoing the *transitioning process*, which includes the specific medical and psychological steps taken to transition from either male to female or female to male<sup>1</sup>. *Transitioning healthcare services* needed during the transitioning process may include, but are not limited to, mental health assessments and therapy, hormone therapy, laboratory services, and gender affirming sex reassignment surgeries (SRS). This study investigates ease of access to these types of services, barriers to these services that may exist, and strategies employed by this segment of the transgender population for overcoming or attempting to overcome any barriers. The study uses a qualitative research design that consists of in-depth interviews of individuals in the transgender community. For the purpose of this study, only those individuals who self-identified as transgender *and* are in any stage of a transitioning

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<sup>1</sup> It is important to point out that not all transgender individuals are transitioning from male to female or female to male. While my study uses significant identity markers, there are individuals who participate in the transitioning process but do not identify as transgender, or conversely, individuals who identify as transgender but do not participate in the transitioning process.

process (or have gone through a transitioning process) are examined. The sample includes individuals from all points within the transitioning process and is evenly divided between female-to-male (FTM)/male identified participants and male-to-female (MTF)/female identified participants. My research questions include the following: What access to transitioning healthcare services do transgender people have? What are the barriers to transitioning healthcare services? And, what factors facilitate access or serve as barriers to transitioning healthcare services?

There are sociological implications to this study beyond simply looking at issues of healthcare access and barriers within the transgender community. This study speaks to broader sociological questions, such as: How do the experiences of the transgender population compare to other marginalized groups? Will the issues of access and barriers be different from or similar to other marginalized groups? Thus, the implications of my study are not simply descriptive.

The dissertation proceeds as follows. In Chapter Two, I define the term transgender and discuss the trends in transgenderism in relation to meaning and terminology, including terminology in the medical field. Terminology referring to gender identity has not been consistent, especially across time and discipline (Ekins and King 2006; Lombardi 2001). Due to this, there tends to be little common understanding of what people mean by transgender (Lombardi 2001). Therefore, this chapter is helpful in gaining a more general understanding of terminology as well as an understanding of the specific terms used throughout the course of this study.

There is a theoretical discussion of the various sociological approaches to studying the body in Chapter Three. The body is critical to discussions of transgender

issues; therefore, it is important to review sociological work on embodiment and the physical body and to consider where transgender bodies ‘fit’ into this work. Included in this theoretical discussion is the emerging field of transgender theory, which draws from work on the body, but also draws on queer theory and feminist theory to provide a new perspective on transgender bodies and transgender identities.

Previous research on transgender healthcare in the social sciences is reviewed in the first half of Chapter Four. Prior research in this area tends to focus on the debate over the use of the disease-based model, which involves pathology and medicalization of gender identity (Billings and Urban 1982; Ekins and King 1997; Green 2006; Shepherdson 2006; Spade 2006; Whittle 2006), and a comprehensive overview of this work is provided. In the second part of this chapter, I discuss more general work on health inequalities within medical sociology, including theories of healthcare inequalities and studies that explore how other marginalized groups, as defined by race-ethnicity and gender, experience inequalities in the healthcare system.

In Chapter Five, I describe how I use a qualitative research design with semi-structured interviews to study transgender individuals’ healthcare experiences during the transitioning process. This chapter also includes the details of my recruitment methods and sample demographics.

Chapter Six gives a comprehensive overview of my analytical technique as well as a broad overview of my findings. I describe my use of a feminist grounded theory approach for analysis. I also provide a complete overview of my coding and use of codes and sub-codes to create the four main themes of my analysis.

In Chapters Seven through Ten, I address the four main themes my analysis revealed: *social capital*, *ignorance and discrimination*, *instrumental resources*, and *agency*, respectively. The theme of social capital is discussed in Chapter Seven. This chapter includes a discussion of the sub-themes that fall under social capital. Additionally, I provide quotes from my interview data that illustrate social capital as identified by each sub-theme.

In Chapter Eight, I discuss the theme of ignorance and discrimination. This discussion centers on my sub-themes, which represent various sources of ignorance and discrimination. I use quotes from my data to illustrate ignorance and discrimination as shown by each sub-theme.

Chapter Nine begins with a discussion of the definition of instrumental factors. As with the previous two chapters, I provide a discussion of the sub-themes that make up the instrumental factors category and illustrate them using quotes from my data.

In Chapter Ten, I discuss the last of my four main themes, agency. After a brief discussion of the concept of agency, I provide an overview of the sub-themes that fall under agency as well as illustrations of agency using quotes from my interview data.

Finally, in Chapter Eleven I provide a discussion of the findings and show the potential usefulness of the constrained choice model and the social capital framework for understanding them. I also discuss the limitations of the study and provide suggestions for future research and advocacy.

## CHAPTER 2: Defining Transgender and the Use of Terminology

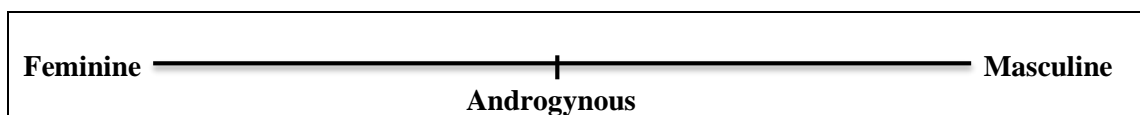
In this study, definitions of terms pertaining to the transgender community are important. Specifically, there needs to be a thorough discussion of what the term 'transgender' will mean throughout this writing and who will be considered transgender in this particular study. A glossary of terms is provided (see Appendix A) that provides exact definitions of the terms being used in this study. Terms and definitions have been evolving and changing over time; I will be using terms that are most comfortable to me, but this is not to say that other terms could not be used as well.

Terminology referring to transgender has not been consistent, especially across time and discipline (Ekins and King 2006; Lombardi 2001), and multiple definitions of transgender exist. Due to this, there tends to be little common understanding of what people mean by transgender (Lombardi 2001). From a positivist point of view, little importance is placed on having different terms describing the 'same' thing (Ekins and King 2006). However, because changing terms and changing meanings are related to the changing social constructions of reality, including social constructions of transgender, we must pay attention to these multiple definitions. Additionally, variation in personal preference regarding terminology also contributes to the plethora of terms and definitions.

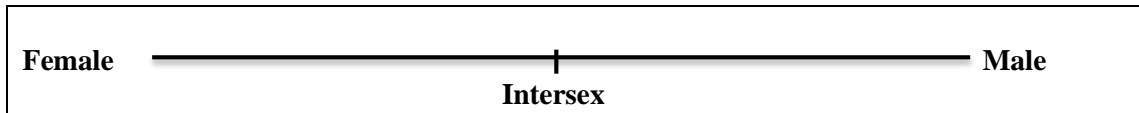
Before discussing definitions of transgender, it is important to discuss gender and sex identity. *Gender identity* refers to a person's internal or perceived sense of

gender and *sex identity* refers to a person's internal or perceived sense of sex. The traditional gender identity spectrum (see Figure 2.1) runs from feminine to masculine, with a midpoint of androgynous. The traditional sex identity spectrum (see Figure 2.2) runs from male to female, with intersex as the midpoint. Traditionally, biological sex runs along the same spectrum as sex identity, but refers to the actual physical sex traits of an individual. While most gender and feminist researchers do identify the more socially constructed spectrum as gender and the biological, or physical, spectrum as sex, not all do. Some (Killerman 2013; Nagoshi and Brzuzy 2010) have re-conceptualized the idea of spectrums to be broader and more inclusive. Specifically, Killerman (2013) promotes the idea of one directional gender spectrums that allow identities to be more specific on both masculine and feminine points. Figure 2.3 illustrates a variety of one directional spectrums that pertain to not only gender identity but also gender expression, biological sex, and attractedness. Each set of one directional spectrums allows for an identity to be plotted on both a man/masculine/male line as well as on the woman/feminine/female line. These spectrums allow individuals to identify specifically their masculinity and femininity regarding both gender identity and gender expression, thereby giving scholars a more specific view of an individual's identity.

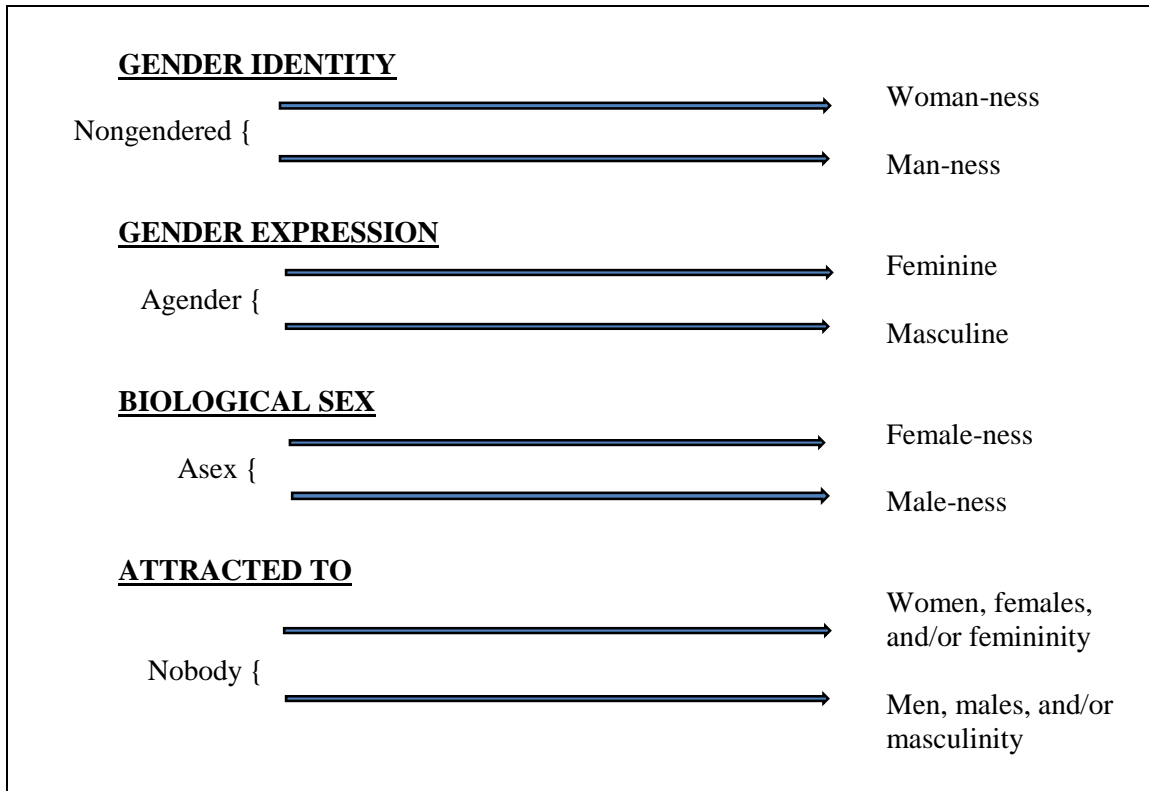
**FIGURE 2.1: Traditional Gender Identity Spectrum**



**FIGURE 2.2: Traditional Sex Identity Spectrum**



**FIGURE 2.3: One Directional Spectrums**



Killerman, Sam. 2013. *The Social Justice Advocate's Handbook: A Guide to Gender*. Austin, TX: Impetus Books.

Using the traditional gender and sex continuums detailed in Figures 2.1 and 2.2 often reinforces the binary between feminine and masculine and female and male, while the newer spectrum models, such as Figure 2.3, try to erase the binary from being emphasized. Some would say that recognizing the boundaries of gender categories could, or should, lead to the deconstruction of them (see Butler 2004; Feinburg 1998; Halberstam 1988) and some (e.g., Lorber 1994; Risman 2004) view gender in multiple ways, as a social structure, social institution, and/or a social

stratification system. Many follow the conceptualization put forward by West and Zimmerman (1987) that sees gender as a dynamic process of social interaction that creates and reproduces inequality. Although West and Zimmerman specifically address gender, this dynamic process can be discussed in terms of both gender identity and sex identity. I will be using the newer, one directional spectrums of gender and sex in this study, which will enable me to gauge both gender identity and sex identity among transgender people as a dynamic process while also recognizing the possibility for deconstruction.

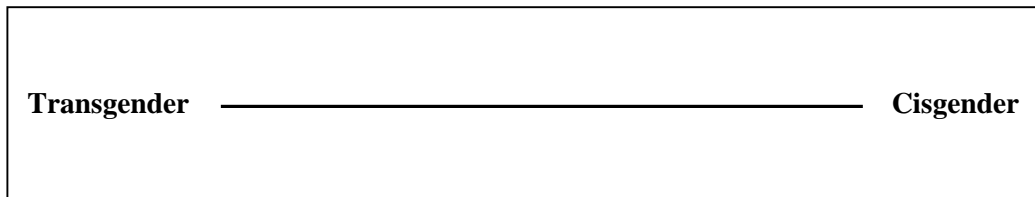
The term 'transgender' is most often seen as an umbrella term, one that can encompass transsexuals, transvestites, cross-dressers, or any self-defined gender variant. According to Ekins and King (1997), the term transgender has come to have a number of connotations that can refer to "...any kind of dress and/or behavior interpreted as 'transgressing' gender roles" (p. 6). The term transgender has been used within the transgender subculture as an umbrella term uniting transvestites, those who dress in clothing of the opposite gender for emotional satisfaction or erotic pleasure, and transsexuals, those living and passing in the role of the opposite sex and who have the conviction that they belong to the opposite sex (as they experience discomfort with the match between their biological sex organs and their gender identity) and are driven to attain the appearance and social status of such. Increasingly, it has been used by members of the transgender community, as well as academics, to refer to those who live full-time in the 'opposite' gender with or without surgery (Ekins and King 1997).

The notion of transgender identities can also be conceptualized on a spectrum in relation to non-transgender identities. If we think of someone who identifies as



transgender as experiencing discomfort with the match between biological sex organs and their preferred gender identity, then one who does not feel discomfort, or is comfortable with the matchup between their biological sex organs and preferred gender identity, would be termed cisgender. Figure 2.4 illustrates this spectrum. Due to cultural conceptions of “normal” gender identity, it appears that someone who fell in the middle of this spectrum would still be seen as transgender (fitting under the transgender umbrella).

**FIGURE 2.4: Transgender Identity Spectrum**



While Ekins and King’s work was done in 1997, it was the first to introduce an umbrella term to conceptualize transgender and is still used today by many scholars. Another definition, from Raj (2002), states that transgender is: *An umbrella term for all transpeople or members of the trans community; in particular, those individuals who identify as transgender (on a gender identity continuum in between transsexual and transvestite)* (p. 3), and will serve as the definition of transgender for this study. A transsexual can be defined as one who behaviorally and physically has adopted the role and physical attributes of the opposite sex. This would include one who has transitioned from one sex to the other by means of hormones, surgery, and legal sex reassignment (Raj 2002). Transvestite, or cross-dresser, refers to one who dresses in clothing of the opposite gender for emotional satisfaction or pleasure without any

desire to permanently change to the other sex, either physically or in any other way (Raj 2002). In order to follow Raj's (2002) definition of transgender, we must recognize that transgender individuals are often placed along a spectrum between transsexual and transvestite. Some fit closer to one end or the other, but others may fall closer to the middle of the spectrum. For example, a transgender identified person who is physically female, dresses as male and socially has adopted a male identity, but has no desire to have surgery to reassigned biological sex, would fall somewhere between the midpoint of the spectrum and the transsexual end.

A variety of other terms require discussion in order to understand their usage in this study. Throughout this study, I will be using the terms male-to-female (MTF) and female-to-male (FTM). These terms indicate the direction of transitioning. While often used in medical and scholarly research, sometimes these terms are adopted by transpeople for identity purposes. For example, someone who is transitioning might say they are a 'pre-op MTF' meaning they are transitioning from male to female and have yet to undergo surgeries. Additionally, the terms transman/transmen (i.e., transitioned to a man) and transwoman/transwomen (i.e., transitioned to a woman) may be used as a point of identification. These terms tend to be less medical or diagnostic than the MTF and FTM identifiers, although this is a personal preference within the trans community. For example, a transperson might identify as a transman if he has successfully adopted an identity and the outward appearance of being male, even after fully transitioning. These identifiers (i.e., transman, transwoman) generally illustrate a firm identity in the transgender community, signifying that the individual has transitioned, yet still identify as transgender. Not all transgender individuals who

transition identify with these terms; some who have transitioned wish to simply identify as male or female and distance themselves from the transgender identity and transgender community after a transition is complete<sup>2</sup>.

To investigate the meanings behind the word transgender, Kessler and McKenna (2000) explore three different meanings of the prefix 'trans'. First, they identify trans as meaning *change*, as in the word 'transform.' To use this meaning is to basically look at changing sex, or more specifically, changing the body to fit the gender one feels, as in the case of male-to-female (MTF) and female-to-male (FTM). Second, an additional meaning of the word trans is identified as *across*, as in the word 'transcontinental'. This meaning implies that a person is able to move across genders, or perhaps even move across an aspect of gender, such as dress or language. This draws on the image of a spectrum and suggests a lack of permanent change or commitment. Similarly, Stryker (2008) defines transgender and as a label for individuals “who move away from the gender[sex] they were assigned at birth, people who *cross over (trans-)* (emphasis added) the boundaries constructed by their culture to define and contain that gender” (p. 1).

Finally, Kessler and McKenna (2000) identify trans as meaning *beyond* or *through*, as in the word 'transcutaneous.' Here, the meaning suggests that one can go through or beyond gender in that no clear gender attribution can be made. This could result in the creation of a third gender option or simply that gender ceases to exist for

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<sup>2</sup> Using the term “complete” for transitioning is complicated. Some feel the transitioning process is fluid and not necessarily ending, therefore having no completion. Others do identify as finished with their transition once they reach the point of passing and living in their preferred gender. In fact, those who feel the process is complete will often shed the transgender identity and identify as solely male or female.

that individual. While all three meanings provide important implications for transgender identity, this research will be focusing mainly on the first, (i.e., meaning “change”) and to an extent, the second of the meanings (i.e., “across”) laid out by Kessler and McKenna. More specifically, I will be looking at those individuals who seek to change their position on the line of the transgender spectrum or move across the spectrum. While understanding how transpeople move beyond or through the spectrum is fascinating, investigating those types of trans identities lays outside the scope of this study.

Perhaps the most current terminology within the transgender community, and one increasingly used in pop culture, is that of trans\*. The asterisk being placed at the end of the word is often seen as an inclusionary step in order to recognize that what defines being transgender for one may differ from another. While there seems to be no one specific definition of the term trans\*, it is clearly an attempt to broaden the umbrella that already exists for the term transgender. Killerman (2013) notes that trans\* can be seen as one word for a variety of identities that are incredibly diverse, but share one simple, common denominator, “a trans\* person is not your traditional cisgender wo/man. Beyond that, there is a lot of variation. Some of identities I’ve seen used under this term include Genderqueer, genderless, third gender, bigender, and two spirit” (p. 49).

It should be pointed out, and emphasized, that gender is attributed to people by themselves and by others, which is a core element in the everyday presentation of self (Goffman 1959). Therefore, if one identifies as transgender, they should be considered transgender. But for the purpose of this study, only those individuals who identify as

transgender *and* are in any stage of the transitioning process (or have gone through the transitioning process) are examined. As mentioned above, a glossary of terms is provided (see Appendix A) that provides exact definitions of the terms being used in this study, including tables and figures within this dissertation and terms that are used in quotations to illustrate my findings.

### *The Transitioning Process*

In addition to defining the terms in relation to transgender, I am providing an overview of the transitioning process, specifically, a description of the “most common paths” for male to female (MTF) transitioning and female to male (FTM) transitioning and associated costs<sup>3</sup>. It was noted in the introduction that healthcare services during the transitioning process may include, but are not limited to, mental health assessments and therapy, hormone therapy, laboratory services, and gender affirming sex reassignment surgeries (SRS). It is crucial to recognize that there is tremendous variation in the transitioning process and not all of the steps that I outline below are taken in a particular order, if they are taken at all.

One step that all individuals seeking to transition “should” begin with is a mental health assessment. While there certainly is variation, most individuals are expected to meet with a therapist or other mental health professional for as much as a year or more. This is because mental health professionals who follow the standard protocol that one should live in the preferred gender (e.g., in terms of dress, gender expression, and other behaviors known to be a part of “passing”) for at least one year before proceeding further (e.g., taking hormones or having surgeries) may require a

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<sup>3</sup> Costs provided are estimates from treatment received in the United States. Estimates were based on reports from my participants and information from the Philadelphia Center for Transgender Surgery.

minimum of one year of treatment before providing the patient with a diagnosis of Gender Dysphoria (formerly Gender Identity Diagnosis) and a referral letter for other transitioning healthcare services. Therapy services, which typically are one session per week, can cost anywhere from \$50.00 to \$100.00 per session.

In female to male (FTM) transitioning, the next step most often is hormone treatment, specifically testosterone. This treatment requires not only obtaining the hormone, but medical consultations, office visits, and laboratory services. Hormone treatment with testosterone is lifelong, and has been estimated to cost between \$100.00 and \$200.00 per month. FTM transitioning then may include top surgery, a gender affirming surgery to remove breast tissue. This surgery alone can cost anywhere from \$1,500.00 to \$4,000.00, which does not include the cost of travel to a facility where the surgery can be performed. FTM transitioning often will include a hysterectomy, a major surgical procedure that is very costly, requiring a hospital stay. The majority of transmen do not undergo bottom surgery, or gender affirming surgery to alter their external genitalia, mainly due to little progress or efficacy in this particular FTM sex reassignment procedure. However, FTM gender affirming surgery (bottom surgery) would cost approximately \$20,000.00.

After therapy, the next step in male to female (MTF) transitioning is often hormone therapy, specifically estrogen. As with testosterone treatment, estrogen treatment requires not only obtaining the hormone, but includes medical consultations, office visits, and laboratory services. Hormone treatment with estrogen is lifelong, and has been estimated to cost between \$100.00 and \$200.00 per month. Following hormone therapy, the path for MTF transitioning may include a variety of elective

surgeries, which do not necessarily follow a particular sequence. These surgeries may include, but are not limited to breast augmentation, vaginoplasty, laser hair removal, and other feminizing surgical procedures such as facial feminization surgeries (i.e., facelift, rhinoplasty, chin augmentation, cheek augmentation, and thyroid cartilage reduction) and other body feminization surgeries (i.e., liposuction, abdominoplasty, buttock augmentation, and orchiectomy [the removal of the testicles]). These procedures are estimated to cost anywhere from \$3,000.00 to \$10,000.00 each.

Some individuals consider themselves transitioned (i.e., they no longer identify as transgender) once they have had therapy, hormone treatment, and gender affirming reassignment surgery; however, some individuals continue to identify as transgender even after completing these steps. Once again, it is important to recognize that not all transpeople complete all the possible steps in the transitioning process or complete the steps in a particular order (e.g., they may stop services after therapy and hormones, they may only participate in therapy, or they may only have one particular surgery instead of multiple possible surgeries). Additionally, there are people who will bypass therapy and obtain hormones illegally. In sum, the transitioning process and the path to transitioning is complex, and this will be discussed further later in the dissertation.

### *Definitions in the Medical Field*

As noted in the previous section, a medical diagnosis, which currently is Gender Dysphoria, is needed to proceed with hormone treatments and gender affirming reassignment surgeries. Until very recently, the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* listed

‘Gender Identity Disorder’ as a diagnosis under the category of sexual disorders (APA 2000). Gender Identity Disorder (GID) was diagnosed using the following four criteria: 1) longstanding and strong identification with another gender, 2) longstanding disquiet about the sex assigned or a sense of incongruity in the gender assigned role of that sex, 3) no physical intersex characteristics, and 4) significant clinical discomfort or impairment at work, social situations, or other important life areas (APA 2000). However, the APA has recently published their fifth edition of the *Diagnostic and Statistical Manual of Mental Disorder (DSM-V)*. Changes were made to replace the GID diagnosis with the diagnosis of Gender Dysphoria, which uses an updated set of diagnostic criteria. The new diagnostic manual states that Gender Dysphoria is a “marked incongruence between one’s experienced/expressed gender and assigned gender, of at least six month duration, as manifested by two or more indicators of gender incongruity” (APA 2013). Some of these indicators include a desire to be rid of one’s primary sex characteristics, a desire for the primary sex characteristics of the other gender, and a strong desire to be treated as the other gender. Additional stipulations have been included in the new manual for exiting the diagnosis, meaning that transgender individuals could no longer fall under the diagnosis once transitioned.

These changes appear to be moving the treatment of transgender people in the right direction according to many transgender healthcare advocates, including the World Professionals Association for Transgender Health (WPATH). First, the name change from GID to Gender Dysphoria is seen as a vast improvement, especially removing ‘disorder’ from the diagnosis, which tends to place a stigma on the transgendered, both inside and outside the transgender community. Second, the



addition of an ‘exit clause,’ so that those who have resolved their incongruence can have the mental disorder label removed, is considered positive. Interestingly, the WPATH workgroup involved in the early stages of proposing the change could not come to an agreement on whether or not the diagnosis should be retained or removed altogether, reflecting the longstanding argument that a ‘condition’ with an entry in the *DSM* creates stigma and pathology (DeCuypere, Knudson, and Bockting 2011).

In summary, terminology has not always been consistent, which has caused difficulty in understanding the term transgender. While the inconsistencies have been especially difficult for me when trying to understand the term transgender through a lens that is both academic and medical, I believe I have defined and conceptualized transgender in ways that are appropriate for this study. It should be noted that a variety of terms for transgender will be used interchangeably in this dissertation (e.g., trans\*, transpeople, transperson). Finally, I have reviewed the steps commonly taken during the transitioning process, although it should be stressed that there is tremendous variation among individuals in the number of steps and order of steps taken.

## CHAPTER 3: Theoretical Approaches to the Study of the Body

This project has little to do with sexuality and much more to do with gender, because transgender is usually an issue of gender and gender identity and not one of sexual orientation<sup>4</sup>. However, examinations of transgender issues do involve the body. In fact, the body is critical to discussions of transgender issues; therefore, it is important to review sociological work on embodiment and the physical body and to consider where transgender bodies ‘fit’ into this work. Attention to the body has often been viewed as an intellectual response to the crisis of modernity, especially within social and cultural theory. While some modern theorists have attempted to produce comprehensive theories of the self that are centered on the mind, bodies have material outcomes. Holliday and Hassard (2010) note, “Early work on the body appeared to reclaim theory from the abstract, shifting it to the local, specific and phenomenological” (p. 2). Initially, this work was undertaken mostly by feminist, black, and queer theorists. The experiences of feminists, blacks, and queer (or LGBT) identified individuals, specifically the experiences of their own bodies, made them the ‘other’ to more traditional discourse on the body. In this chapter I will review earlier work, as well as more recent thinking about the body.

In looking at more traditional discourse on the body I begin with Descartes, who claimed that “the mind, by which I am what I am, is entirely distinct from the body so that even if the body were to cease, it [the mind] would not cease to be all that it is” (Descartes 1968 in Holliday and Hassard 2001:4). Following the position of

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<sup>4</sup> Work by Valentine (2002, 2007) discusses how gender and sexual orientation are often conflated in everyday life and often it is hard to disentangle the two. More recent work by Westbrook and Schilt (2014) explores how determining gender can differ across social spaces, including spaces that include sexual orientation.

Descartes on the distinct nature of the mind and body is the notion that the body has a 'normal' state that can be altered. This seems to be accepted in Western culture in that we see normal and natural as one in the same; however, this normal is a social construction. Ironically, we search for ways to become 'normal' according to society's standards, especially standards pertaining to fashion and physical beauty, which contradict the natural physical body (e.g., shaving legs, having plastic surgeries to change the body). As a result of socially constructed standards, individual minds are made responsible by society for the control and regulation of bodies, the aim being to produce 'normal' bodies. Again, there is a paradox here in that the 'normal' body is often diametrically opposed to the 'natural' body, and feminist writers on the body have been quick to point this out. Specifically, some feminists link the socially constructed definition of the normal body as one that is linked to binary gender reinforcement, including the different (and powerful) meanings associated with men's and women's bodies. Holliday and Hassard (2001) state that:

Many of the feminists who concern themselves with the disciplinary inscription of feminine bodies, thereby neglecting the masculine, thus simply serve to reinforce the binary of man=control/woman=unruly=abnormal. The age-old discourse of embodied women and disembodied men is unwittingly reproduced (p. 6).

This statement captures some of the contested thought surrounding transgender identity in that transitioning from one sex and gender to the other reinforces the binary of masculine/feminine and ignores the possibility of fluidity and duality.

While many contemporary scholars of the body have drawn from the work of classical theorists (e.g., Comte, Descartes, Marx, Engels, and Durkheim), they also have been bringing new theories to the forefront (Shilling 2007). Shilling (2007)

illustrates the contemporary 'rise of the body' in sociological work by looking at the various schools of thought that have evolved over time. First, Shilling identifies an approach drawn from Bourdieu (1978). Bourdieu relies on a more 'topological approach to the body', mapping out the physical body as predictive of appearance and performance. This theoretical approach allows for appearance, body shape, and physical control to be increasingly more central to one's sense of self identity than in the past. A second approach, which is built upon having a 'meaningful bodily experience,' involves a much more heightened concern with one's internal environment. Here we find thinking about the relationship between the body and the mind and ways that individuals can enhance their lived experience with somatic improvements such as diet and yoga and other Zen body awareness practices (Levine 2006; Shusterman 1997).

The third theoretical approach outlined by Shilling is one that came out of the rise of second wave feminism. During that time, scholars began a critical interrogation of the sex/gender divide (Irigary 1986; Mackinnon 1989) that included studies of the female body in law, the construction of compulsory heterosexuality, female sexuality, and female corporeality. It is within this approach that scholars began to understand the concept of the body as fluid, which is illustrated early on through controversies surrounding transgenderism and transexualism (for example, Garfinkel's ethnomethodological study of 'Agnes' [Shilling 2007:8]). While scholars began to view the female body and even bodies in general as fluid, medical providers were and are still largely unable to recognize the body as fluid.

Fourth, Shilling looks toward Foucault to understand the role of ‘government’ in the study of the body:

Foucault’s analysis of how creation of the modern subject was accompanied by a shift in the target, object and scope of governmental disciplinary regimes during which the fleshy body gave way to the mindful body as a focus of concern, preoccupation with matters of death was replaced by an interest in controlling details of life, and the control of anonymous individuals was replaced by attempts to manage differentiated populations (2007:8).

For example, Foucault often illustrates this with discourse on sexuality that specifically includes problems faced by government regulation of the treatment of HIV/AIDS, specifically the way in which the government, and society at large, viewed the physical manifestation of HIV/AIDS as being parallel with the gay male body. As a result, HIV/AIDS was known as a “gay disease,” and research and treatment of HIV/AIDS has faced discrimination institutionally and has been seen as the responsibility of the LGBT community.

The final theoretical approach discussed by Shilling is that of ‘technological advances’ and the way in which they contribute to uncertainty about the ‘reality’ of the body. For example, medical advances such as in vitro fertilization, organ transplants, and the use of stem cells in research and treatments have caused scholars to cast doubt on truly understanding the notion of embodiment (e.g., Haraway’s [1985] notion of ‘humans as cyborgs’).

### *Postmodern Feminism and the Body*

The work of some of the more postmodern feminist scholars also helps us understand the theoretical implications of the body. Judith Butler (1990, 2004) and

other postmodern feminist scholars (e.g., Iriargy, Kristeva, and Wittig) have discussed the theoretical implications of the body and embodiment, specifically looking at the idea of performativity. One of Butler's foundational claims is that the boundaries of the body have been drawn by society in a way that create and solidify certain taboos about limits and even the possibility of exchange. In fact, Butler's claim is that "the body is itself a consequence of taboos that render that body discrete by virtue of its stable boundaries" (1990:133). Additionally, Butler views gender as something that is created through the stylization of the body and therefore must be understood in ways as simple as our bodily gestures, movement, and enactments of various kinds that constitute the illusion of a gendered self. Furthermore, gender identity can be viewed as a performance that is compelled by social sanctions and various taboos. In this vein, Butler proposes the practice of drag (cross-dressing) as a way to destabilize the exteriority/interiority binary, thereby reinstating her claim that gendered bodies are not natural but rather that gender is scripted, rehearsed, and performed. Butler states:

The act that one does, the act that one performs, is in a sense an act that has been going on before one arrived on the scene. Hence, gender is an act which has been rehearsed, much as a script survives the particular actors who make use of it; but which requires individual actors in order to be actualized and reproduced as reality once again (1988:7).

Yet, we must be careful not to confuse the idea of performativity with the idea of gender expression; in fact, the distinction between expression and performance is quite crucial. According to Butler:

...if gender attributes and acts, the various ways in which a body shows or produces its cultural signification, are performative, then there is no preexisting identity by which an act or attribute might be measured; there would be no true or false, real or distorted acts of gender, and the postulation of a true gender identity would be revealed as a regulatory fiction (1998: 12).

Indeed, it seems as though gender is real only to the extent to which it is performed, and yet we must question the role of agency in the performance of gender because social structures place constraints on agency. Individuals are nuanced in the way that they perform gender and there are variations on gender performance; Butler asserts that these variations do not imply agency but rather they show that the performance aligns with certain sanctions and taboos set by society. Therefore, performativity is not done in a fully individual manner. To be clear, Butler is not arguing that we are ‘passively scripted with cultural codes’ but we are utilizing agency to make choices in our performances that are constrained by societal scripts. Of course, these scripts do change over time and place, and the way one ‘does one’s body,’ and more specifically gender, will appear different from both one’s predecessors and successors.

If Butler were to apply her theory of performativity to the transgender issue of transitioning, she might argue that a transperson does more than simply express the difference between sex and gender. A transperson challenges the difference between appearance and reality, the gender reality to which popular culture subscribes. Therefore, performing one’s own gender in an “incorrect” manner “initiates a set of punishments both obvious and indirect, and performing it well provides reassurance that there is an essentialism of gender identity after all” (Butler 2001:24). My research may uncover some of the obvious and indirect ‘punishments’ that Butler is referring to while showing the performative experiences of transpeople who are in the process of transitioning. Barriers to medical care may be a specific ‘punishment’ transpeople experience. For example, medical staff may discriminate if a patient’s performance of gender does not ‘match’ the gender script that ‘corresponds’ to one’s sex.

In summary, two major points can be taken away from this discussion of the body, both of which apply to this study. First, the body matters. In understanding the complexities of sex and gender and the dysphoria potentially surrounding transitioning, it cannot be emphasized enough how the physical body itself will affect the experiences of transpeople in that they assign meaning to the way their bodies feel and look. Second, appearance matters. This differs from the way that the body matters in that society assists greatly in constructing meanings of appearance. Performativity is an act that requires agency on the part of the actor, but it is society that constructs the boundaries that define violation and ‘punishment’. Paying attention to the way appearance matters will aid in understanding the experiences of transpeople.

### *Transgender Theory*

The emerging area of transgender theory (Nagoshi and Brzuzy 2010) may provide additional guidance in understanding the healthcare experiences of transpeople. Transgender theory integrates ideas about physical embodiment, the self, and social construction of identity through lived experiences. Stated differently, understanding the experiences of transpeople is integral to understanding the way in which their identities are constructed both in the body (e.g., its appearance) and the mind (e.g., one’s gender identity). Nagoshi and Brzuzy state that transgender theory is a “gender identity theory that incorporates both a fluid self-embodiment and a self-construction of identity that would dynamically interact with this embodiment in the context of social expectations and lived experiences” (2010:435).



Transgender theory provides a basis for reconciling feminist and queer theory with social work practices and advocacy. While Nagoshi and Brzuzy show how transgender theory can guide social work, it is not a far jump to imagine how transgender healthcare could be guided by transgender theory. For example, one particular protocol that has been used with the World Professional Association of Transgender Health (WPATH) standards of care and by mental health practitioners is the “real life experience.” Transgender patients are often encouraged, if not required, to live in the body of their preferred gender for one year prior to accessing transitioning healthcare services. Evaluating this protocol with the lens of transgender theory might make us question its efficacy: Does this protocol add more constraints to the choices a transgender individual would have in exploring a fluid self-embodiment? Would this protocol require an individual to move to the other side of a gender spectrum or continuum, rather than place themselves where they best fit along the spectrum? I would argue that yes, the WPATH protocol could add more constraints to an individual seeking transitioning healthcare service by interfering with quality of care and by ignoring the fluidity of a transgender identity.

Two applications of transgender theory focus on language and assumptions. Nagoshi and Brzuzy state, “social workers can challenge old terminology and categorical ways of thinking by embracing a more fluid view of gender and addressing individuals by the names they prefer” (2010:439). By adopting a fluid view of gender healthcare practitioners can also be instrumental in promoting the use of proper and non-offensive language, such as proper pronoun use and understanding the complexities of transgender definitions. More specifically, healthcare professionals

should change the names and pronouns they use to refer to transgender patients in accordance with patients wishes if patients' names or preferred pronouns change during the transitioning process. In addition, transgender theory claims that "real ≠ biological." Using language that avoids the assumption that real = biological can assist healthcare practitioners in creating a safe and non-offensive space for providing healthcare. More specifically, healthcare professionals can avoid the use of terminology that implies a lack of realness in treatment (e.g., real breasts, fake breasts, real genitals, fake genitals), which would also affirm the identity of the patient.

Transgender theory also acknowledges the importance of looking at intersectional identities. Collins (1990) explained how gender, race, class, and sexuality are not separate but mutually constructed systems of oppression, organized into a "matrix of domination." More recently, scholarship on intersectionality also has considered how citizenship, age, ability, and other aspects of social location may be mutually constructed in the United States and in other places (Bose 2012; Purkayastha 2012). A study looking at the use of intersectionality in gender scholarship revealed that its use has increased but it still could be used more often (Brune and Beutel 2013). Of particular relevance to this study, Namaste (2009) examines the theoretical approach of Anglo-American feminist theorists on transgender identities and concludes that attention to transgender identities is lacking in intersectional theory. According to Namaste, theoretical frameworks must include indigenous knowledge, that is, knowledge that comes from the intersecting identities of transpeople themselves. Nagoshi and Brzuzy (2010) note that intersectionality needs to be more integral not only to research, but to clinical (e.g., social work) applications. This final

aspect to transgender theory, which builds upon the importance of intersectionality, is a way in which coalition building across diverse groups (e.g., in terms of race, class, gender, and sexuality) can be important when working with the transgender community, both in social work practice and in the healthcare field.

In summary, examination of any transgender issue involves consideration of the body. Sociological and feminist work on embodiment and the physical body help us to understand where transgender bodies “fit” into scholarship. From the early writings of Descartes to the postmodern writings of Foucault and Judith Butler, we find that, indeed, bodies do matter. The more recent model of transgender theory allows us to move the discussion away from binary gendered bodies to discussions of the relationship between physical embodiment and social constructions of identity. This shift in thinking is important because it can help us better understand the experiences of those with transgender identities, particularly how they are affected by the way healthcare protocols are written and the quality of care that is given to them when they seek transitioning healthcare services.

## CHAPTER 4: Previous Research on Transgender Healthcare and Healthcare Inequalities

This chapter provides a review of previous research on transgender healthcare, which largely has focused on issues outside of the transitioning process, such as HIV/AIDS, mental health outcomes, and access and barriers to routine healthcare services. I also include a discussion of two prominent organizations for transgender health and their protocols and standards for medical care. Finally, I end the chapter with a discussion of healthcare inequalities that draws upon the medical sociology literature, including some general theoretical frameworks for explaining health inequalities used by medical sociologists.

### *Transgender Healthcare*

Much of the existing literature on healthcare within the transgender community has not been guided by a theoretical approach about the body. Prior research on transgender health and healthcare tends to focus on the debate over the use of the disease-based model, including the pathology of gender identity and the medicalization of gender identity (Billings and Urban 1982; Ekins and King 1997; Green 2006; Shepherdson 2006; Spade 2006; Whittle 2006). The disease-based model would view a transperson as having a psychiatric condition, one that needs treatment in order to be remedied. After transition, the diagnosis of GID (now Gender Dysphoria) would be removed and the person would be considered cured. In opposition to this disease-based model, a few select medical and research

organizations have developed their own standards and treatment protocols for transgender healthcare (Fenway; WPATH; Kelley et al. 2008).

Overall, there is a limited amount of research looking at health issues in the transgender community (Bockting et al. 2004; Kenagy and Bostwick 2005). Past studies have focused on services for HIV/AIDS prevention, suicide, violence, and discrimination (Lombardi 2001; Reback et al. 2001; Wilchens et al. 1997; Xavier 2000). For example, Lombardi (2001) discusses how HIV/AIDS is a major health concern for the transgender community, because of unprotected sexual activity and sharing needles from hormone injections (also see Reback et al. 2001). In looking at mental health, results from a Washington D.C. study reveal that 35 percent of transpeople had suicidal ideation and 64 percent attributed this to gender-related issues (Xavier 2000). Violence, both physical and sexual, are recurring issues, with 47 percent of transpeople experiencing physical assault and 14 percent having been the victim of a rape or an attempted rape (Lombardi 2001; Wilchens et al. 1997). These past studies illustrate that access to healthcare is important to transpeople above and beyond the healthcare that everyone needs.

While the literature on medical access and barriers is limited, it does show that transpeople experience difficulty accessing (due to being denied) general healthcare, transgender-related healthcare, and HIV/AIDS related healthcare (Bowen 1995; Reback et al. 2001). One study done in Philadelphia (Kenagy 2005) found that out of 182 transgender participants, 26 percent had been denied medical services and 51.5 percent had difficulty gaining access to one or more of the following services: general medical care, hormones and other prescriptions, gender-related surgery, and

counseling or therapy. More specifically, 21.8 percent were unable to obtain hormones because of prohibitive costs, 39.6 percent were unable to obtain gender-related surgery related to prohibitive costs, and 32.7 percent were unable to obtain counseling and therapy due to prohibitive costs. While prohibitive cost is one of the main reasons for not accessing care, discrimination plays a role as well. In looking at discrimination, Kenagy concluded that approximately 25 percent of his respondents who were denied medical services were denied due to discrimination, because they were transgender. Other barriers that have been identified include providers' lack of knowledge about transgender issues, insensitivity and hostility, and their refusal to provide care based on transgender status (Kenagy 2005; Reback et al. 2001; Xavier 2000). Overall, Lombardi (2001) concludes, as do other scholars, that "individuals who do not conform to traditional conceptions of sex and gender are likely to be at risk for many health-related problems, including, unfortunately, discrimination within the treatment setting" (p. 870).

In order to propose effective socio-cultural responses by healthcare providers to transpeople, Singer (2006) studied transgender healthcare access and barriers from the side of the provider. Singer found that "the effective response of care-providers who are unable to comprehend the complex configurations of transgender bodies and identities often results in poor health care for transgender people" (p. 601). He uses disability rights discourse and queer theories of disability to suggest a large shift in the way transgender identities and bodies are viewed, although this has not happened in a widespread fashion. Table 4.1 illustrates the suggestions Singer makes for a paradigm shift.

**Table 4.1: Healthcare Paradigm Shift (Singer 2006)**

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<b>Pathology (Disease-Based) Model</b>	<b>Trans-Health Model</b>
Normative bodies and genders	Nonstandard bodies and genders
M/F only two types	Spectrum of body types and genders
Institutional regulation	Harm reduction and advocacy
Gate-keeping	Informed consent
Experts and providers in control	Peer expertise and community partnering
Pathologization	Self-determination
Gender Identity Disorder	Non-disordered gender complexity

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As Table 4.1 shows, the disease-based model has a rigid definition of gender and body types whereas the trans-health model is more inclusive, has fluidity, and recognizes multiple definitions of gender and the body. The disease-based model also focuses on having strict regulations created (and enforced) by medical providers that dictate the care and treatment of an individual with a gender dysphoria diagnosis, whereas the trans-health model stresses a less rigid form of treatment that includes peers, community partnerships, and self-determination by the transgender individual. Finally, one of the main differences between the models is that the disease-based model places importance on viewing the experiences of transpeople as a disorder, whereas the trans-health model focuses on the complexity of gender experiences without giving a stigmatizing diagnosis.

A paradigm shift from a pathology model to a trans-health model could impact not only the access and barrier issues that exist, and the higher quality of care that

would likely be given because of reduced stigma, but also could increase the ability and likelihood of transpeople to feel ownership of their own trans-related healthcare. Singer's model may be helpful for teasing out the types of care experienced by my research participants. I can see whether this new trans-health model is being followed and whether it does provide better access and fewer barriers.

Although a trans-health type of model has been used to some degree in the mental health field (but even less so in the medical field, see Raj 2002), negative treatment of transgender individuals by mental professionals has occurred and continues to occur. Raj (2002) identifies a variety of specific forms of transphobia that appear in interactions with clinical psychologists. Additionally, many of the examples of clinical transphobia outlined below speak to some of the differences at the initial stage of transitioning between FTM and MTF, suggesting that there are different experience of healthcare access and barriers for FTM and MTF. Some examples of clinical transphobia according to Raj (2002) include:

- Pathologizing gender dysphoric (GD)/gender variant (GV) clients as having a mental illness, perpetuating myths and enforcing stereotypes.
- Employing ethically questionable psychological assessments of genetically male GD clients to gender identity programs.
- Using reconditioning behavior-modification therapies with GD/GV youth to prevent the adult manifestation of transgenderism.
- The virtual denial of the existence of female transvestites.



- A double standard around granting approval for hormone therapy and sex reassignment surgery to lesbian transwomen while withholding the same from gay transmen.
- Denial of treatment of transpeople who do not work or attend higher education full-time as proof of the ‘real life test’, which requires transgender patients to live in the body of their preferred gender for one year in all aspects of life, including the workplace and school.
- An ‘all or nothing’ treatment approach, meaning one should obtain hormones and surgeries or nothing at all.
- Excessive ‘gatekeeping’ by withholding recommendation letters for desired gender reassignment procedures.

These types of discrimination could possibly be alleviated as part of a widespread paradigm shift. The findings of previous research suggest such a paradigm shift has not happened yet, and transgender healthcare is still mostly operating under a limited understanding of transgender identity. More research is needed to investigate the experiences of transpeople. Specifically, a better understanding of healthcare related to transitioning issues, such as therapy, hormones, sex reassignment and other surgeries, and post transitioning care, is needed.

In looking at transgender patient satisfaction, only a few studies have been conducted to date (Bockting et al. 2004; Kenagy and Bostwick 2005). One study that is relevant to transgender healthcare access and barriers investigated patient satisfaction with transgender healthcare services and found consistently high levels of

patient satisfaction at one specific clinic (Bockting et al. 2004). The clinic in the study by Bockting et al. (2004) provides services specific to transitioning for transgender patients, and the staff are trained in following a trans-centered standard of care. It is important to evaluate the transpositive programs (a comprehensive approach toward advocating for transgender individuals and communities), to the extent that they exist, in order to make sure they are effective and producing patient satisfaction, as they are not mainstream health clinics. Only a few clinics such as the one Bockting et al. (2004) studied exist in the United States; using them is not necessarily the typical experience for most transpeople in the United States seeking services. It still remains unknown what the broader picture of transgender healthcare access looks like. My research will broaden the scope to look at those receiving transitioning services from providers that probably do not work within a dedicated transgender clinic. As noted earlier, while transgender healthcare access has been the subject of limited research, it mainly has focused on *general* healthcare, not specifically healthcare related to gender identity and/or transitioning.

In an effort to understand what the best practices are currently for transitioning-specific healthcare, I turn to two of the more prominent organizations for transgender health, the World Professionals Association of Transgender Health (WPATH) and the Fenway Institute. WPATH and the Fenway Institute provide standards for medical care and protocols to healthcare providers. They also provide guidelines to educate healthcare providers on cultural, social, and diversity issues specific to interacting with transpeople. WPATH originally began as the Harry Benjamin International Gender Dysphoria Association in honor of Harry Benjamin

(1885-1986), one of the first physicians to work with gender dysphoric individuals.

WPATH has established its own Standards of Care (SOC) for the treatment of gender identity disorders, which are internationally recognized. Additionally, the guidelines for clinicians use non-discriminatory language and include an in-depth discussion of the history of transsexual healthcare (WPATH 2001).

The Fenway Institute began in the early 1970s in Boston, Massachusetts. The mission of the institute is to enhance the well-being of the lesbian, gay, bisexual and transgender community through access to the highest quality healthcare, education, research and advocacy (Fenway 2009). The “Guide for Physicians,” a manual provided by the Fenway Institute, includes a variety of topics that speak to the importance of having cultural understanding of the transgender community. These topics include stigma of transgender identities, mental health assessment, and the clinical environment for transgender patients (e.g., offering unisex bathrooms, having educated and trained staff, and providing transgender-inclusive terminology on intake forms) (Fenway 2009). The findings of Kelley et al. (2008) show that organizations such as WPATH and the Fenway Institute provide important and much needed resources for physicians. They conducted a study of second-year medical students about transgender healthcare issues and found that second-year students were not very knowledgeable about these issues. Kelly et al.’s findings suggest that information and education are key; second-year medical students with more education on gender identity and the trans community were more willing to treat people with gender identity issues and had greater awareness that sexual orientation, identity, and gender are relevant to clinical practice.

The findings of studies such as Kelley et al.'s also show that the discourse surrounding the role of gender identity in the field of medicine is important. In fact, many scholars feel that a medical diagnosis of gender dysphoria leads to the pathology of transpeople which has vast negative repercussions (e.g., Billings and Urban 1982; Spade 2006). Gender identity disorder (GID) was only in the *DSM* from 1994 to 2013; prior to that, those experiencing gender dysphoria were diagnosed with transsexualism (WPATH 2012). The point of contention surrounding the medicalization of gender dysphoria has been large in the transgender community and among sex and gender scholars. The dominant position within the medical field is that transsexualism or gender dysphoria is a 'disorder' that has been 'discovered', although some scholars argue it has been invented (Billings and Urban 1982; Spade 2006). Furthermore, much of the medical community sees GID, or what is now called gender dysphoria, as the disease and sex reassignment surgery as the treatment (Spade 2006). Some would argue that gender dysphoria needs to be de-pathologized in order to recognize that identifying at any point in the gender spectrum can be normal, as gender is a social construction. More specifically, if we advocate for 'changing one's sex' as the one and only treatment, then we are considering a treatment successful once the patient has successfully changed sex. This approach seeks to make sure that identity, social status related to gender, and biology match and in fact, end up reinforcing the binary structure of gender (Elkins and King 1997). Indeed, a widespread paradigm shift, as suggested by Singer (2006), would be useful for changing medical professionals' perceptions of the structure of gender (i.e., away from the binary perceptions).

Green (2006) and Shepherdson (2006) also criticize the medicalization of transgender bodies. They argue science presupposes that it is dealing with "the organism rather than the body...they seek an anatomical change rather than a different embodiment" (Shepherdson 2006:95). Whittle (2006) agrees that the medicalization of transgender bodies is a problem for the transgender community because transpeople usually have not been part of the discussion about the transitioning process and sex reassignment surgery. As noted earlier, very limited research has been done to look at patient satisfaction and assessment of transgender health services (Bockting et al. 2004; Kenagy and Bostwick 2005).

To summarize, the existing literature on transgender healthcare shows a large gap in research on access to and barriers for those who are actively seeking or in the process of transitioning. My research will fill this gap in order to advocate for the transgender community and to provide more empirical evidence to help scholars understand the state of transgender healthcare.

### *Healthcare Inequalities in Society: Approaches from Medical Sociology*

My research also will fill gaps in knowledge of transgender healthcare that exist within medical sociology. Because prior research within medical sociology on transgender issues is very limited, I have turned to research within medical sociology on other marginalized groups, namely racial and ethnic minorities and women, to inform my understanding of health inequalities. A large body of medical sociology literature shows variation in illness and disease based on race and ethnicity (e.g., Dubowitz et al. 2010; Takeuchi et al. 2010). For example, compared to whites,

African Americans have a higher incidence, greater prevalence, and longer duration of hypertension, which is a major risk factor for heart disease, kidney disease, and stroke (Takeuchi et al. 2010). Belonging to other racial and ethnic minority groups also is strongly associated with diseases and injuries: Puerto Rican Americans have the highest rate of lifetime asthma prevalence; Mexican American adults are 100 percent more likely than whites to have been diagnosed with diabetes; cancer incidence and death rates are higher for Native Americans and Pacific Islanders than for whites; Native American males have substantially higher death rates for motor vehicle-related injuries; and Asian Americans are 20 percent more likely to have hepatitis B than whites and comprise almost 50 percent of chronic hepatitis B infections (Dubowitz et al. 2010 and Takeuchi et al. 2010).

Negative health outcomes among racial/ethnic minorities may be due, in part, to characteristics of the healthcare they receive. For example, Shavers et al. (2012:960) report that “African Americans and Latinos more frequently report race/ethnicity-based discrimination during their health care encounters compared with Non-Hispanic Whites.” Shavers et al. also report that perceptions of discriminatory treatment during healthcare encounters have been associated with a variety of negative health-related outcomes, including poorer self-reported health, more bodily pain, poorer mental health, and less utilization of healthcare services. Of course, poorer health outcomes and less healthcare utilization among racial and ethnic minorities also are due to factors related to other discrimination (i.e., institutional racism), such as discriminatory treatment by employers (which blocks racial and ethnic minority access to well-paying jobs that provide health insurance) and residential segregation (which

increases the likelihood of racial and ethnic minorities living in unsafe houses and violent neighborhoods) (e.g., Richardson and Norris 2010). Nevertheless, research suggests that specific characteristics of the healthcare received by racial and ethnic minorities (e.g., their healthcare encounters) are important.

Similarly, although broad systems of gender stratification and inequality (and gendered roles) have consequences for women's health (e.g., by limiting their access to well-paying jobs that provide high-quality health insurance or by limiting their ability to engage in healthy behaviors), inequalities specific to healthcare also have consequences for their health. Although women are more likely to utilize healthcare services than men (e.g., Bertakis et al. 2000; Van Wijk, Van Vliet, and Kolk 1996), "(m)ore health care is not always better health care" (Van Wijk et al. 1996:708). For example, women with a low socio-economic status are less likely to be involved in healthcare decision-making and may experience gender bias in treatment, especially the treatment of serious diseases (e.g., women may receive less aggressive treatment than men for the same disease) (Van Wijk et al. 1996).

It is also important to point out that systems of racial and ethnic and gender inequality may intersect to produce health disparities. In discussing the results of his study of self-rated health, Veenstra (2011) points to the importance of using an intersectional approach:

...race, gender class, and sexual orientation all manifested independent relationships with health at the additive stage of my analysis and each of the four axes intersected meaningfully with at least one other axis, suggesting that all four of these intersectionality axes of inequality were operative for better or worse in many of the social situations encountered by survey respondents in their everyday life. In short, the principles of simultaneity and multiplicatively founded upon the

inequality foursome of race, class, gender, and sexual orientation appear to be relevant for disparities in health in Canada (p. 9).

Veenstra's work underscores the importance not only of intersectionality, but also the importance of understanding the healthcare experiences of *many* marginalized groups; the most insightful intersectional analyses of healthcare will examine not only racial and ethnic minorities and women, but other marginalized groups as well, including those with transgender identities.

Three theoretical approaches that are often used in the medical sociology literature lend themselves to discussions of health outcomes and healthcare access and barriers among marginalized groups. These theories include constrained choice theory, fundamental causes theory, and social capital theory. According to the constrained choice model, individuals do make everyday choices that can create health outcomes, but the wider context shapes and constrains opportunity and individual choices (Rieker et al. 2010). Decisions made within social contexts can limit opportunity for access to, and quality of, healthcare (Rieker et al. 2010). Specifically, Rieker et al. (2010) investigate health choices in families and their effect on health. The choices of parents in a dual earner family could result in a mother skipping breakfast in order to get the children off to school on time, or a father bringing home fast food in order to get food on the table quickly, or to save money. These choices may seem inconsequential for health outcomes, but in the context of wider societal contexts, such as social policies, community actions, or work and family – they likely could have cumulative effects on the parents' health, morbidity, or mortality outcomes (Rieker et al. 2010:63).

Link and Phelan (2010) recognize that health inequalities are not just about individual risk factors but they also are about social conditions that are fundamental



causes of health inequalities. For example, Link and Phelan (2010) find that there is an association between mortality and educational attainment, occupation, and income and that this association is persistent across time and place even when traditional risk factors are eliminated (p. 4). The social conditions identified in their study are called “flexible resources” and not only include educational attainment, occupation, and income, but also access to the best doctors, knowing about health procedures, and having friends and family who support health lifestyles. Link and Phelan (2010) outline three major ways in which health inequalities may vary according to fundamental causes theory: if flexible resources change, the health inequalities change; some interventions do not require flexible resources to procure benefits; and attention must be paid to what puts people at risk of risk – SES factors can be diminished if attention is paid to the chain of circumstances (p. 7). These aspects of fundamental causes theory then, recognize that it is more than the actions of medical personnel that determine access and barriers to healthcare services.

Within the fields of population health and medical sociology, social capital theories are popular exports from mainstream sociological theory. Most often following in the steps of James Coleman and a functionalist approach, social capital is seen as having an aspect of social structure which facilitate the actions of individuals within the structure (Coleman 1988). According to Coleman:

Social Capital is defined by its function. It is not a single entity but a variety of different entities, with two elements in common: They all consist of some aspect of social structures, and they facilitate certain actions of actors...within the structure...social capital is productive, making possible the achievements of certain ends that in the absence would not be possible (1988:98).

Some research, such as that conducted by Lovasi et al. (2010), shows the importance of social capital for health. Looking at sexual health, nutrition, and body image, Lovasi et al. find that social support is associated with lower risk of isolation and that social networks are a useful tool for promoting health and healthy behaviors.

In summary, constrained choice, fundamental causes, and social capital are used in the field of medical sociology for understanding healthcare disparities and inequalities, especially among marginalized populations. Due to my grounded theory approach to analysis, I was neither guided by nor tested a specific theory; I discussed these three frameworks in this chapter because, in addition to being important to the field of medical sociology, they helped me to frame my research questions.

## CHAPTER 5: Data and Methods

One main principle guiding my research is to subscribe to the feminist tradition, which emphasizes respect for and an intimate appreciation of the lives of people in a study, in this instance, members of the transgender community. In brief, the characteristics of the feminist approach to research that I follow are: firstly, that it focus on women and/or gender in research conducted by feminists; secondly, that it recognizes the distinction between ‘male’ quantitative methods and feminist qualitative ones; and finally, that it views feminist research as political by promoting women’s active engagement in changing their lives (Stanley and Wise 1990:21). The third characteristic, which can also be defined as a commitment to *praxis*, particularly drives my research. Praxis is a commitment to putting theory into action (Charmaz 2012). For feminists engaging in research, often the goal is not necessarily to prove a hypothesis null, or to find knowledge that is ‘true’ according to a statistical model, but rather to see our analysis as playing a role in progressive change. This study uses a feminist approach to grounded theory and qualitative methods, which will allow me to both further transgender knowledge within sociology and provide new vehicles for social change and social justice.

### *Researcher Background*

It is important to feminist scholars to explain their interest in, and connection to, that which they are studying (Reinharz 1992). I am a nontrans (cisgender) individual researching transgender issues and the transgender community. My interest in this research topic stems from previous volunteer and paid employment in the service sector that occasionally involved transgender issues, specifically those issues

surrounding transitioning healthcare services. In particular, I once worked with a non-profit healthcare organization in an advocacy capacity that allowed me to assist in development of transitioning healthcare services. I was also involved in the training of healthcare workers, including clinic and non-clinic office staff. These experiences allowed me to engage in discourse with members of the transgender community, which initially piqued my interest in issues of access and barriers to transitioning healthcare services. I was fortunate to form friendships and networking relationships with members of the transgender community in the geographic area where my dissertation research was conducted, and I am proud to be able to use my research experience in a way that further advocates for the transgender community in a way that could increase access and reduce barriers to transitioning healthcare services.

The three broad research questions that are the focus of this study are:

1. What access to transitioning healthcare services do transgender people have?
2. What are the barriers to transitioning healthcare services?
3. What factors facilitate access or serve as barriers to transitioning healthcare services?

While these questions are largely descriptive, they allow me to speak to larger issues about social inequality and the experiences of disadvantaged populations in healthcare.

## DATA AND METHODS

I used a qualitative approach for collecting data, specifically semi-structured interviews. Qualitative research allows for gathering in-depth and rich data. For example, as I expected, I found in my interviews that even use of the word transgender

involved a variety of symbolic elements that are not included in a textbook definition of the word, and this finding could not have been captured through other types of research methods. Additionally, using qualitative methods gave my participants an opportunity to share their voices and their personal experiences as interpreted by them: “...qualitative techniques allow researchers to share in the understandings and perceptions of others...qualitative techniques examine how people learn about and make sense of themselves and others” (Berg 2007: 8-9).

### *Sample Recruitment*

Web-based announcements through email list serves and social networking sites were used for recruitment (see Appendices B1 and B2). Web-based announcements were made on my personal Facebook page and Tumblr accounts. These announcements were then often shared by others (those who viewed them from my personal pages); however, there was no tracking of the frequency of shares. Additional recruitment announcements were made on transgender support and advocacy and LGBT support and advocacy Facebook pages focused on the region in which my sample members lived at the time of the study. The email list serves that I had access to were through various LGBT centers and other trans\* support groups also in the region in which my sample members lived at the time of the study. (The exact names of these Facebook pages and email list serves will not be given here in order to protect participant identities.) In addition, I worked closely with advocates in the transgendered community on recruitment. Finally, participants were also recruited

through a snowball sampling method once my initial recruitment began yielding participants.

Interested participants for this study were eligible if they self-identified as transgender, were in the transitioning process (or had gone through the transitioning process), and were between the ages of 18 and 64. No stipend or incentive to participate was offered. Participants were recruited primarily from the central Oklahoma region, although any eligible person within reasonable driving distance of central Oklahoma was considered for the study, and a number of participants were from eastern and northeastern Oklahoma and northern Texas. My recruitment efforts resulted in a total of twenty individuals who were interviewed. The majority of my interviews were conducted in person; however, in two instances a phone interview proved to be the best option. The majority of the in-person interviews took place at either my office at the University of Oklahoma or my office at the University of Tulsa. The remaining interviews either took place at a participant's home or office. Each participant was interviewed once, and interviews lasted anywhere from 40 minutes to slightly over two hours. Interviews were all audio-recorded with the participants' permission. Additionally, I made summary notes as soon as I was able to following each interview.

As a cisgender researcher who is interested in a transgender topic, I entered the study with the understanding that there may be suspicion or at least concern by possible participants of my intentions, which could limit access to transpersons. This suspicion is not unfounded given the history of harmful and exploitative research that has been conducted on transpeople by nontranspeople (Connell 2010). To help

alleviate this possible access problem, I networked with a number of transgender individuals, transgender support groups, and those in transgender advocacy. I feel confident that through this work I have been able to show my intention to advocate for the transgender community and do no harm.

### *Data Collection*

Most data were collected via semi-structured interview. The semi-structured interview guide (schedule) included open-ended questions and prompts. The guide was fairly extensive in order to gather detailed information from the participants about their transitioning process and their experiences within the healthcare system while transitioning (see Appendix C1). For my interview schedule, I adapted some questions from a Philadelphia area needs-based study of transpeople (Kenagy and Bostwick 2008) and other questions were formulated using resources on creating questions for qualitative research (Berg 2007). A member of the transgender advocacy community reviewed my interview guide with me to insure that my questions were appropriate and not harmful to my participants, and changes were made accordingly. The research design was granted approval through the Institutional Review Board (IRB) at the University of Oklahoma.

I utilized the HyperTRANSCRIBE computer program for transcription of all interviews, which were performed by me as the principal investigator.

HyperTRANSCRIBE is a qualitative methods computer software for transcribing audio files. The program allows for keyboard control to play, pause, and loop audio playback, resulting in an easier transcription process.

A demographic questionnaire was also administered to each participant. The questionnaire included ten items pertaining to age, race, education, income, religion, relationship status, sexual orientation, and biological sex at birth (see Appendix C2).

### *Sample Demographics*

This section describes the demographic make-up of my sample of 20 participants<sup>5</sup>. I was fortunate to have a diverse representation of age in my sample, ranging from 19 years to 64 years. The age distribution of my sample is as follows: five (25 percent) fell into the under 24 year category; six (30 percent) fell into the 25-34 year category; three (15 percent) fell into the 35-44 year category; two (10 percent) fell into the 45-54 year category; and four (20 percent) fell into the 55-64 year category.

The education level of my sample ranged from having a high school diploma to having a graduate or professional degree. Six participants (30 percent) reported having a high school diploma, two (10 percent) reported having skilled or vocational training, one (5 percent) reported some college, two (10 percent) reported having an associate's degree, four (20 percent) had attained a four year college degree, three (15 percent) had some graduate work, and two (10 percent) had attained a graduate or professional degree.

The racial make-up of my sample, while not representative of the racial make-up of the U.S. population, is fairly representative of the racial make-up of the primary

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<sup>5</sup> Although it is common in reporting the results of a qualitative study to include a table that summarizes the demographic characteristics of each participant, I do not include such a table so the identity of each of my participants is protected.



recruitment area, Oklahoma. Twelve participants (60 percent) identified as white or Caucasian, two participants (10 percent) identified as Black or African American, two participants (10 percent) identified as Native American, and four participants (20 percent) identified as bi-racial (three participants have one Black parent and one white parent and one participant has one as Black parent and one parent who is both Native American, and white).

Seventeen of my participants (85 percent) were living in an urban area at the time of their interview whereas only three (15 percent) of my participants were living in a rural area<sup>6</sup> at the time of their interview. For geographical location of the respondents when they initiated transitioning healthcare services, 12 (60 percent) lived in urban areas and eight (40 percent) lived in rural areas. As I discuss later, I found geographical location to be important, specifically the difference between urban and rural locations, when initiating transitioning services.

The vast majority of my participants fell into one of two income categories. Eleven (55 percent), reported their annual income as falling between 0 - \$19,999 and eight (40 percent) reported falling between \$20,000 - \$39,999, while one participant (5 percent) reported an annual income in the \$80,000 or above category. Over half (11 respondents, or 55 percent) of the sample identified their occupation as “student.” Students were currently enrolled, either full-time or part-time, in a vocational training program, an undergraduate degree program, or a graduate degree program. The

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<sup>6</sup> According to the U.S. Census Bureau (2010), “rural encompasses all population, housing, and territory not included in an urban area. Urban areas include two types, urbanized areas (population greater than 50,000) and urban clusters (areas adjacent to urbanized areas with population of 2,500-50,000).”

occupational demographics may be a limitation of the study, especially in evaluating their perceptions of access and barriers.

In reporting current religious affiliation, the majority either reported to be Atheist or to have no religious affiliation, with seven (35 percent) reporting as Atheist and six (30 percent) reporting none. Of the remaining participants, two (10 percent) identified as Unitarian Universalist and five (25 percent) identified as Christian. Among the five that identified as Christian, two identified as Episcopal, two did not give a specific denomination, and one identified as Methodist.

In reporting their relationship status, ten members (50 percent) of the sample reported not being in a relationship currently nor ever having been married, eight (40 percent) reported being in a relationship, and two (10 percent) reported have been separated, divorced, or widowed but not currently in a relationship. It is worth noting that no one in my sample reported being legally married at the time of the interview.

Participants' answers about their sexual orientation were sometimes complex. Six (30 percent) identified as heterosexual, three (15 percent) identified as homosexual, and three (15 percent) identified as bisexual. The remaining eight participants either reported multiple categories or "other." Participants were asked to specify their sexual orientation when reporting "other," and five (25 percent) identified as queer, one (5 percent) as pansexual, one (5 percent) as both bisexual and pansexual, and one (5 percent) as both heterosexual and queer.

Gender identity responses also were complex<sup>7</sup>. Participants were given seven options for gender on the demographic questionnaire (and could choose more than one

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<sup>7</sup> There may seem to be some incongruences between the recruitment requirements (i.e., identifying as transgender) and the actual sample composition because some respondents did not self-identify as

option): male; female; MTF; FTM; Genderqueer; trans\*, and other (those choosing other were asked to specify their gender). A vast majority of the respondents (75 percent) reported two or more gender identity markers while one participant (5 percent) reported identifying as male only and four (20 percent) identified as female only. It is worth noting that the five participants who identified with only one gender marker all identified with the marker that was the binary opposite of their biological sex at birth. Table 5.1 illustrates the breakdown of gender identity for all of the participants in my sample.

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transgender at the time of the study. The complexities of terminology and the transitioning process can account for this. For example, some participants, after receiving such transitioning healthcare services as SRS, may refer to themselves as male or female and not transgender because they feel their experiences with transitioning is complete. These respondents certainly did refer to themselves as transgender while they were transitioning, and while they do still consider themselves as part of the transgender community, they no longer see transgender as their most salient gender identity marker. Conversely, some participants may still label themselves as transgender even if they have undergone SRS and other transitioning healthcare services.

**Table 5.1: Gender Identity of Participants\***

<b>Gender Identity Categories</b>						<b>Number of Participants</b>
<b>Male</b>	<b>Female</b>	<b>MTF</b>	<b>FTM</b>	<b>Genderqueer</b>	<b>Trans*</b>	
X						<b>1 (5%)</b>
	X		X	X	X	<b>1 (5%)</b>
	X				X	<b>1 (5%)</b>
	X	X				<b>1 (5%)</b>
X		X				<b>1 (5%)</b>
			X		X	<b>1 (5%)</b>
X					X	<b>2 (10%)</b>
	X	X			X	<b>3 (15%)</b>
	X					<b>4 (20%)</b>
X			X		X	<b>5 (25%)</b>
<b>Total:</b>						<b>20 (100%)</b>

\*See footnote 7 for details about self-identification.

## CHAPTER 6: Analysis

I analyzed my data using a feminist approach to grounded theory. Grounded theory was initially presented by B. Glaser and A. Strauss (1967). Over the last four decades, grounded theory has been developed more in the social sciences, placing grounded theory firmly into the tool box of qualitative researchers, especially feminist ones (Breckenridge et al. 2012; Bryant and Charmaz 2010; Charmaz 2012). Grounded theory is a systematic method involving the discovery of theory through analysis of data (Charmaz 2012). Strauss continues to be an important reference in grounded theory, and I used an outline from Strauss and Corbin (1998) for grounded theory as a guide for my analysis.

The first step in grounded theory is to extract codes from the text, the text being the transcribed interviews. These codes are then grouped into similar concepts before formal categories are formed, which then leads to either the creation of theory or application and/or modification of an existing theory. This initial coding was done through *substantive* or *open coding*, which aims to code just about everything in order to move on to selective coding. Using an inductive approach, I developed codes as I read the interview data. My open coding produced forty-three codes and from those codes I was able to move on to selective coding. *Selective coding* is done next by revisiting open coding and selecting core and sub-core variables. This allows for operationalizing codes into concepts and categories, paying close attention to themes and patterns that begin to emerge (Charmaz 2012; Strauss and Corbin 1998). My selective coding led to combining the forty-three codes into nine new categories. Further selective coding led to the elimination of six codes from further analysis.

These codes were determined to either have too few data points or an ambiguous meaning that could be adequately rolled into another code. After this portion of the selective coding was completed, I was left with twenty unique codes to analyze.

At the core of my research is the shared experience (or problem, as Strauss [1967] would call it) of my participants, and through my coding I was able to identify the ways in which this shared experience, that of transitioning within the healthcare system (and sometimes independently of the healthcare system), is being resolved or dealt with by my participants. More specifically, I identified and categorized themes and patterns that related to access to healthcare and barriers to healthcare during transitioning. This allowed for the concepts, patterns and themes to move toward the creation of a theory. Therefore, the final aspect of my selective coding was to find the *major categories*, which is the last step in the grounded theory approach, relevant to my remaining twenty codes. After multiple rounds of analysis, four major categories emerged: Social Capital, Ignorance and Discrimination, Instrumental Factors, and Agency. Table 6.1 displays the four major categories along with the sub-codes from which each category emerged. These four categories form the core of my findings on transitioning access and barriers. It is important to note that some codes fit into more than one of the four categories. In the following chapters, I discuss each individual category (theme) as well as the sub-categories (i.e., sub-codes or sub-themes) within each theme. Additionally, I illustrate the connections between sub-codes within each category.

A common critique of grounded theory is its inability to provide validity in research. Strauss and Corbin (1998) stress that rather than validity, grounded theory

should be evaluated by four characteristics: fit, relevance, workability, and modifiability. I paid close attention to these principles in my analysis. Additionally, I received considerable feedback from my dissertation chair during my selective coding process, thereby creating a stronger sense of validity.

**Table 6.1: Major Categories with Sub-Codes**

<b>Categories</b>	<b>Sub-Codes</b>
1. Social Capital	Family and Friends, Workplace, Internet, School, and Other Forms of Support (5 sub-codes).
2. Ignorance and Discrimination	Doctors, Family and Friends, Religion, Clinic Experiences, Therapists, Workplace, and Gender Identity Diagnosis (7 sub-codes).
3. Instrumental Factors	Money and Financial Resources, Insurance Status, Distance, and Location (4 sub-codes).
4. Agency	Research/Self-Educate, Internet, Informed Consent, Gender Identity Diagnosis, Self-Medicare, Hormones, Anxiety, Depression (8 sub-codes).

Once my major categories and sub-codes were identified, I then utilized Spradley’s Universal Semantic Relationships (Miles et al. 2013) to understand the relationship each sub-code had with other sub-codes in the same major category. In contrast, many qualitative researchers attempt to understand their data with an inventory or hierarchical system approach, which simply lists or identifies the domains

they have discovered, for example, counting words and ranking them by frequency. However, Spradley suggests that an important extension of the inventory approach consists of a theme-based analysis. More specifically, his approach consists of “a system of meaning that is integrated into some kind of larger pattern” and defines “a cultural theme as any principle recurrent in a number of domains, tacit or explicit, and serving as a relationship among subsystems of cultural meaning” (Miles et al. 2013:514). Therefore, once I was able to create codes and take inventory of them during my first two rounds of coding, I was then able to place meaning to these codes in relation to the (major) categories (themes) under which they fell in my inventory. For example, as seen in Table 6.1, the sub-code “family and friends” falls into two categories, social capital and ignorance and discrimination. Using Spradley’s approach I was able to explore the role these sub-codes play in relation to both of the larger themes. In the following chapters, I include descriptions of the way I have used Spradley’s approach in my study.



## CHAPTER 7: Social Capital and Transitioning Healthcare Services

One of the four major themes that emerged from my grounded theory analysis was that of social capital. Although social capital is an important concept within sociology in general and medical sociology in particular, I had not considered social capital as a possible theme before beginning my analysis; rather, my coding convinced me that social capital is an appropriate term for a particular grouping of sub-codes.

Social capital is a concept that has been defined in varying ways among sociologists.

Pierre Bourdieu (1986) defined social capital as:

The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition – or in other words, to membership in a group – which provides each of its members with the backing of the collectivity-owned capital, a ‘credential’ which entitles them to credit, in the various senses of the word (p. 250).

James Coleman (1988) sees social capital as a variety of entities with two elements in common. These elements consist of some aspect of social structure and facilitate certain actions by individuals within the structure (Coleman 1988). In other words, social capital is that which facilitates individual or collective action, generated by networks that often involve relationships, reciprocity, trust, or social norms (Coleman 1988). This chapter will illustrate the ways in which five sub-codes relate to social capital and the larger issues of access and barriers to transitioning healthcare. I will use quotes from my interviews to illustrate the ways in which social capital plays an important role in transitioning healthcare.

### *Coding for Social Capital*

My analysis revealed that the category of social capital has five sub-codes, which include: family and friends, workplace, the Internet, school, and other types of support. Using Spradley's Universal Semantic Relationships (Miles et al. 2013), I am able to explain the role each of the five plays in contributing to social capital. Family and friends can serve many roles in one's life, including as a distinct source of social capital. The workplace and school are places where one can either gain or lose social capital. The Internet is also a context where one can gain social capital. Finally, participants also experienced other types of support, such as through support groups and local community centers, and these types of support are also sources of social capital.

### *Family and Friends*

Family and friends are an important source of social capital, in that they serve as a durable network that can facilitate access to resources related to transitioning healthcare services. For example, Dylan<sup>8</sup>, a 39 year-old female<sup>9</sup>, points to friends as a resource when saying, "Looking back, I think I just asked around. I had a few friends...or acquaintances I guess, who were getting services. I found out through them." Thus, having transgender friends or friends who are knowledgeable about transgender services can serve as a source of social capital. Eve, a 22 year-old who identifies as MTF relates, "I was going to do it [transition] with or with support from

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<sup>8</sup> Every name of a study participant given in this dissertation is a pseudonym.

<sup>9</sup> The gender identifiers for participants are the exact terms they used to describe themselves.

my friends and family but it wasn't like I feared...they did support me and that made it easier." Eve continued to talk about her immediate family:

My Mom was great. She was really kinda crazy trying to educate herself. She did all the research for the doctors and stuff. It really made it easier and since my Dad didn't want to talk about it AT ALL...mom was like a buffer. Or like, she uh...told me what dad said or what maybe I shouldn't say to him just yet.

In addition to serving as a source of social capital for her daughter in regards to accessing transitioning services, Eve's mother negotiated communication with Eve's father surrounding the topic of transitioning. In highlighting these narratives, I thus far have pointed to one of the most oft reported source of social capital, friends and family. However, participants also discussed other places where one could gain (or lose) social capital and the impacts these gains (or losses) can have on transitioning.

### *The Workplace*

The workplace can be a complicated context for transitioning, as coworkers are often the people one sees as much as, if not more often than, immediate family. Through discussions of workplace issues, participants revealed how coworkers or the climate of a workplace can play a role in gaining social capital, by providing support and increasing one's network, or as a place to lose social capital, through ignorance or hostile environments. Chase, a 30 year-old who identifies as FTM and male and works as a server, sounds ambivalent about the role of his workplace: "I think it's kind of like, uh...unspoken you know. Like I know they (coworkers) know but we don't have to talk about it. No one brings it up and I'm fine with that cause they are cool...like they don't uh...like treat me strange or anything." The lack of a hostile environment in

his experience really does add to his support but it does not detract from his existing support either. On the other hand, Jamie, a 53 year-old CPA who identifies as both MTF and female, shared the following:

...right now my job is the one thing keeping me from being 100 percent out. I still have to act as a man at work and to my clients because my employer – who I am fairly close to – has known me for so long as a man and would probably not welcome my transition. It certainly feels like an unsupportive environment.

Unlike Chase, Jamie's experience shows how social capital can be lost through an unsupportive workplace, as he could not use his close relationship with his employer as a resource because his employer was not open to the transition. Research suggests that there are a variety of negative life outcomes associated with decreased or lower levels of social capital (e.g., Dunham and Wilson 2007; Lareau 1989; Macinko and Starfield 2001).

### *School*

My interviewees expressed a mix of sentiments when talking about school, just as they did when talking about the workplace. Just as Jamie found a hostile environment at work, Liz, a 21 year-old female, felt herself in a similar situation when she entered a small private college after transitioning. Previously she had attended an urban high school. She said:

It's funny how I feel better being stealth here (at college). I was so open about my trans\* status in high school and my friends were supportive, like they did volunteer stuff at the center with me...like *that* supportive. When I got to college, I just didn't feel that supportive vibe. I was afraid I wouldn't have the same support from my new friends.

Liz had experienced social capital in the form of support during high school, but believed she would not have any support, specifically with transitioning, in college. This risk caused her to go *stealth*, or hide her transgender identity when entering college. Interestingly, Andi, a 28 year-old MTF, felt differently when she moved to a new college for her graduate degree. She talked about the experience of finding support for her transgender identity on campus and said, “The LGBTQ group on campus. Like I didn’t go much after my first few times, but I got on their listserve and got hooked up with some great people through Campus Ally<sup>10</sup>.” This group, which trains faculty, staff, and students about the complexities of LGBT life in college, allowed Andi to continue having support with her transgender identity in a new school environment, thus adding to her social capital. Eve, who had the support of her family, also talked about her school environment: “In fact, looking back, everyone around me seemed to be supportive really. Like, I had one professor at [community college] that I talked to about it and even some of my classmates that semester.”

### *The Internet*

The Internet, which has been a factor in the experiences of many, but not all, of my participants, served as another place for gaining social capital. Some of my participants were constrained by historical time and geographic place which did not allow the Internet to be a resource for them while they were transitioning, while others just could not fathom transitioning without the Internet. Rylan, a 20 year-old FTM who was one of the youngest participants in my study, falls into the latter category:

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<sup>10</sup> All organizations related to participants’ experiences have been assigned pseudonyms.

I don't get how anyone transitioned before the Internet! Like really! (laughing) Like how did you find other people or resources or stuff? Even though I'm not like in a big urban area, I was still able to talk to people online and stuff. Otherwise, I would probably be in some loony bin heh, heh.

Rylan's quote shows how instrumental the Internet was for him in gaining social capital that led to accessing transitioning healthcare and to other transgender people's support and experiences. Unlike Rylan, Jamie was constrained by the time period in which she transitioned; thus, experiences with the Internet may reflect cohort or historical period effects. When asked about the role of the Internet in her experience, Jamie said, "Ha-ha, there wasn't Internet then! Can you imagine? If someone could have just told me no you're not gay...you're just in the wrong body and there is a word for it. Kids and the younger kids have no idea how easy they have it."

Interviewees repeatedly talked about the way in which social media on the Internet, such as Facebook and Tumblr, aided in increasing both knowledge about transitioning and networks of support. When I asked about the role of social media, Chase, a 30 year-old male described his experience: "I joined a few Facebook groups for trans folk, and while they weren't specific to my area people asked questions and posted about their experiences so it gave me an idea of what to look for, what to expect." Similarly, Alex, a 22 year-old MTF identified student said, "Just from asking one friend on Facebook I got invited to join a [Facebook] group for trans resources in the [local city] area and those guys had an answer for everything [laughing] like support group numbers, therapists, docs, everything."

As Alex's comment suggests, the type of information about transitioning obtained from social media sites was often varied, but quite comprehensive in

covering all aspects of transitioning. For example, information was obtained about treatment costs, treatment information, medical protocols, where to obtain transitioning healthcare services, treatment expectations, ways to deal with problems with family and friends, experiences with discrimination, and transgender issues not related to healthcare, such as clothing, passing, and social interactions with others in the workplace, educational settings, and among family and friends . My interviews also revealed that transgender individuals were also able to develop support systems from their interactions online. The Facebook and Tumblr communities often became support systems where “followers” of particular groups and pages were able to provide support to one another regarding not only navigating everyday life as a trans person, but also in navigating the transitioning process.

#### *Other Types of Support*

Not all of the interviewees described networking as happening online; some described the use of community centers – physical locations that offered free resources to either LGBT or transgender specific populations. Many community centers also facilitated support groups as well. Jamie began transitioning when the Internet was in its early days and therefore could not rely on the Internet for a source of networking. Explaining her experience, she said, “The people at the center were really great even though I didn’t go to the support group. They gave me information about GID...although I already knew that stuff, but they gave me contacts for a therapist and doctors and that helped a lot.”

Similarly, Carter, a 27 year-old male spoke about the role of his support group: “Because I was going to the support group, I was able to find out who everyone else was using (as a therapist). Otherwise, I don’t know where I would have started to look.” His experience illustrates how having this type of support allowed him to initiate transitioning services.

### *Variation by Age*

While participants were not asked specific questions regarding their age in relation to social capital, an analysis of responses to questions about social capital crossed with participants’ age (18-24, 25-34, 35-44, 45-54, and 55-64 year-old categories) did reveal some interesting results. The following two patterns emerged: (1) participants in the 18-24, 25-34, and 35-44 year-old age categories generally had higher levels of social capital than those in the 45 plus age categories, specifically in relation to Internet access and use, family and friends, and other types of support, and (2) those in the 45-54 and 55-64 categories generally had lower levels of social capital compared to all participants who were 44 and younger. This pattern may speak to a cohort shift in accessing social capital, especially online.

### *Conclusion*

In this chapter, I described the ways in which social capital, in terms of family and friends, workplace, school, the Internet, and other types of support, impact the experiences of those seeking transitioning healthcare services. My data reveal that more, or a higher level of, social capital tends to lead to better access to transitioning



healthcare services, whereas less, or a lower level of, social capital tends to lead to less access and more potential barriers to transitioning healthcare services. Therefore, having a durable network and strong support systems are key to making positive decisions and taking positive actions related to one's own transitioning healthcare, just as Pierre Bourdieu's (1986) and James Coleman's (1988) conceptualizations of social capital would suggest.

## CHAPTER 8: Ignorance and Discrimination and Transitioning Healthcare Services

The second of the four major themes that emerged from my data was a barrier to transitioning healthcare, ignorance and discrimination. This theme encompasses ignorance and discrimination from a variety of people and social locations. It is important to note that ignorance can take two main forms, one of malicious inability to believe facts and truth concerning transgenderism and transgender healthcare needs and one of a non-malicious lack of education about the facts and truth concerning these transgender issues. Oftentimes the former turns into an act of discrimination and there are even times when non-malicious ignorance can result in discrimination as well. This chapter will illustrate the way that seven of my twenty codes together represent ignorance and discrimination that can negatively impact transitioning healthcare. Furthermore, I will use quotes from my interviews to illustrate the ways in which ignorance and discrimination play an important role in the transitioning healthcare process.

### *Coding for Ignorance and Discrimination*

The category of ignorance and discrimination was compiled using seven sub-codes: doctors, therapists, clinic experience, gender identity diagnosis (GID), family and friends, workplace, and religion. Once again, using Spradley's Universal Semantic Relationships (Miles et al. 2013), I am able to explain the relation of each sub-code to a theme, in this case, ignorance and discrimination. During round two of coding, I was able to combine many co-occurring codes and found that some coalesced into their own category representing sources of ignorance or discrimination. Therefore, my

discussion in this chapter will focus on these sources: doctors, therapists, clinic experiences, GID, family and friends, workplace, and religion.

Treatment by doctors can serve as a source of ignorance and discrimination, and a way to experience the two as well. Therapists were also reported as both a source of ignorance and discrimination as well as a way to experience ignorance and discrimination. Similarly, clinic experiences, which encompasses experiences with healthcare staff are also a source of, and a way to experience, ignorance and discrimination. These experiences are separate from interactions with the doctor and include interactions with such staff as nurses, clinic assistants, and receptionists. A Gender Identity Diagnosis (GID) plays an important role in transitioning healthcare and my data suggest that physicians use GID as a way to discriminate and also can be ignorant of the complexities of GID. I gave GID its own sub-code (apart from doctors or therapists) because of the special role it plays in the transitioning process. My final three sub-codes, family and friends, workplace, and religion, also serve as sources from which to experience ignorance and discrimination. All seven sub-codes will be explored further in the following sections, with narratives from my interviews illustrating the ways ignorance and discrimination serve as barriers to transitioning healthcare.

#### *Doctors, Therapists, Clinic Experiences, and Gender Identity Diagnosis*

While most individuals see their physician as an expert on healthcare as well as on their own specific healthcare needs, this is not always the case for those seeking transitioning healthcare. Whether intentional or not, the ignorance and discrimination

of doctors, therapists, and healthcare clinic workers were very commonly experienced by my study participants. When I asked participants whether they had experienced acts of discrimination or ignorance by their doctors, many spoke right up. Trey, a 43 year-old male who had been on testosterone for over five years, had some blood work come back with abnormal results and he said, "...the doctor immediately stopped prescribing hormones until it got 'figured out'. I was outraged that the doc wouldn't weigh the consequences of stopping T (testosterone) over some non-emergency blood test result." When asked how this was resolved, he said, "Oh, I'm still getting T – just not from a doctor." Similarly, Carter, a 27 year-old FTM, experienced ignorance and discrimination when getting routine blood tests for hormone treatment, "...the one and only time I got my blood drawn at my PCP's (primary care provider's) office he lectured me about transition in a negative way. Like I said, one and only time there – never even went back for regular stuff." The experiences of Trey and Carter show that even while receiving transitioning healthcare services, discrimination and ignorance still occur and can put up barriers for continuing care.

Others experienced ignorance in initiating services. Skyler, a 19 year-old who identifies as FTM and is a college student, related the following:

I knew that the student health center didn't do trans stuff, but I had the student health coverage so I figured I would start there because uh, someone told me I would need a referral to go to another doctor. But uh...the guy, I think he was a PA [physician assistant], um just didn't seem to know, uh basically had no clue and didn't care to look into it to help me and was really abrupt about it.

Many of the participants had learned from their networks that this type of health provider ignorance is common. In fact, Chase, a 30 year-old male, anticipated this

from his doctor on their first meeting: “I pretty much knew going in that I was gonna know more than the doctor. Lots of people told me I would, so I came prepared.”

Unfortunately, not everyone is as knowledgeable as Chase, and this kind of situation presents barriers to individuals who are relying on their doctors to provide them with transitioning healthcare information.

Ignorance and discrimination did not stop with doctors; therapists and other clinic staff were just as likely to display ignorance and discrimination. According to Rylan, a 20 year-old FTM and male, his first therapist provided incorrect information and a hostile environment:

The first therapist, I didn't really like her, she didn't help me or uh, even take me seriously. She told me apparently, that uh apparently it's really hard to get hormones, and because I was 18 that they did not believe that I'm really trans\*, like maybe they would when I was older, so um, like I shouldn't get my hopes up.

Similarly, Finn, a 25 year-old who identifies as female, trans\* and FTM, responded to my question about therapist discrimination by saying:

It took three therapists before I found one I clicked with. The first two at least were just honest and told me they didn't have enough, uh, experience I guess. But, uh the third. WOOWEE! That crazy lady tried to diagnose me with bi-polar and depression and something else on day one. She wanted to see if my gender stuff went away in treating those. Crazy lady, seemed pretty anti-trans to me.

The experiences of Rylan and Finn illustrate more than just ignorance or discrimination from a particular therapist, but also call into question the ability of health professionals to adequately diagnose GID or Gender Dysphoria, creating a very powerful barrier for accessing transitioning healthcare services because the diagnosis is needed to proceed further with transitioning healthcare services. Interestingly, Andi, a 28 year-old MTF, anticipated facing ignorance surrounding her diagnosis and she

had this to say about her preparations for initiating transitioning services with a therapist, specifically obtaining a letter from a mental health provider indicating her diagnosis and that she was a good candidate for transitioning healthcare services: “I knew from researching online what all went into the GID diagnosis. I was prepared to...well, to make sure I “fit” all the criteria at the doctor’s, well for the therapist ya know, in case she didn’t know what to look for.” Other patients may not have the forethought, preparedness, and social capital that Andi did, creating another barrier to accessing healthcare from both therapists and physicians.

In revisiting the clinic experiences of those who had already initiated services, interviewees repeatedly talked about discrimination and ignorance among clinic staff, such as nurses, receptionists, and clinic assistants. Chase was particularly vocal about his experience of discrimination:

She [clinic assistant] made a snide remark. I’ve been on T for like two years now...but I still can’t give myself injections. She said something like, uh...like “well sweetie”, real condescending like, “well sweetie seems like you’ll need to get used to it” Or something like that, it just rubbed me really wrong.

When asked if the rest of the staff acted in a similar manner, Chase responded:

It was the worst feeling ever the way that the clinic staff looked at me, like a fucking oddity, like they were gonna “catch it” and it made me feel like shit. I didn’t think it would, but I guess I expected them to be more professional – at least cover up and pretend to be nice.

Ironically, Chase pointed out to me that this behavior came exclusively from the clinic support staff and not the doctor, and the clinic he used was in fact a clinic that advertised providing transitioning healthcare services. These findings lead me to argue that even when a healthcare professional is educated on transgender healthcare, the

clinic staff might not be and may need to be educated in order for a clinic to provide discrimination-free services.

Other examples of discrimination from clinic staff included the use of incorrect pronouns and incorrect names. Dillon, a 26 year-old identified as FTM and male, described his experience with a clinic receptionist who “called me (previous name) in the waiting room. When I reminded them that I go by (current name), the lady said that due to insurance they had to use (previous name). That was bullshit. Maybe on paper but there is no reason they can’t use my preferred name.” A similar experience was related during Trey’s interview in which he said, “Although I had been in there twice, the clinic person still used my former name to call me back. I had already said something last time and this time she was like “Oh, that’s what’s on your chart.” I was like, ‘change it’, and she just stared at me.” This could be an example of ignorance, the employee simply following a discriminatory policy, or one of discrimination on her part; without more context and information, it is hard to tell the exact motives of her actions.

### *Family and Friends, Workplace, and Religion*

While the above narratives suggest a plethora of negative experiences in the healthcare field itself, other people and social contexts also prove to be rife with ignorance and discrimination. Ignorance of transgender healthcare issues among family and friends, at the workplace, and within one’s own religious community can lead to either teachable moments, where displays of ignorance are used to educate others so that their ignorance does not lead to discrimination, or to acts of

discrimination. Many of the participants discussed their experiences of ignorance and discrimination with family and friends and Finn, a 25 year-old FTM who also still identifies as female, specifically discussed hir<sup>11</sup> father's ignorance in saying:

My Dad didn't want me to take T 'cause he thought it would make me violent. No matter how many times I tell him no, that isn't true...he just doesn't listen. We still fight about it...like he's waiting for me to turn into some violent psychopath. I'm like really? Really Dad? It's so frustrating...

While Finn's father does not fully understand the effects of testosterone, there is a chance that he will come to understand the facts as Finn continues to inject testosterone without turning into a "violent psychopath", to use Finn's own words. However, not all relationships are amenable to greater understanding at a later time. Dillon saw a relationship dissolve when he became more vocal about transitioning: "My girlfriend was against it...like at the time, my girlfriend at the time she was very against me coming out or transitioning." When pressed for more details about this specific relationship, Dillon noted that:

She was fine with it at first. Like I could talk to her about how I felt, how I felt I wasn't a girl or wasn't even a lesbian. She really did help me work through some of the initial feelings. But when I wanted to tell others, or go see about T, she was against it. I was even binding<sup>12</sup> and she was cool with that. It's like it was okay as our little secret, but she got downright mean at the thought of me coming out.

Over time, Dillon's girlfriend appeared to take issue with his transition, and her unkind requests for him to stay closeted and not further his transition with hormones

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<sup>11</sup> Finn's preferred pronoun is hir.

<sup>12</sup> Binding is the process of flattening breast tissue in order to create a male-appearing chest. Types of material used to bind vary; however, the most popular is a binder made from nylon and spandex.



made him feel as though she was discriminating against him. Ann, a 64 year-old female shared a similar experience with her long time roommate:

...it was really hard and when I told her (roommate) that I'm so old to be realizing this, she suggested I was right. And that I uh, uh like just stop, like just continue living in this body wrong. I guess because I had been doing it for so long, but that was it – she didn't want to talk about it past that because, well uh...um, I think she just didn't approve.

As with Finn, Ann informed me that prior to initiating a physical transition, her roommate had shown signs of support and had been a good listener when she needed to talk. But afterward, her roommate's suggestion that she not transition left Ann feeling quite sad and discriminated against. In sum, my data suggest that even family and friends are not immune from displaying ignorance and discrimination toward their transitioning loved ones and could pose barriers to transitioning healthcare because of emotional distress or financial distress if one is still financially dependent upon parents.

Interestingly, very few interviewees discussed experiences of ignorance and discrimination at the workplace. Some, like Jamie, a 53 year-old MTF and female, mentioned not being out as transgender at their place of employment for fear of discrimination, while many others were students in college and therefore had little to no workplace experience. However, the limited data do suggest that fear of being out in the workplace due to discrimination is real. Transgender individuals do feel as though they would be discriminated against verbally or physically, or would lose their jobs if their employers and coworkers were aware of their transgender identity and transitioning process.

There was nothing subtle about the discrimination expressed by participants' religious communities, and many participants had these experiences. The narratives given by Andi and Jamie illustrate the two common ways discrimination by a religious community played a role in their transitioning experiences. Andi, looking back at when she first began to identify as transgender, shared the following:

“When I was 17, I told my parents and they were like all understanding and said they would send me to therapy. I thought for a letter but it was some Christian therapist and I shoulda known, my parents wanted me fixed, but heh, heh, heh...like Christian fixed.”

Andi retells this story with some humor, yet at the time it was traumatic and served as a barrier to transitioning healthcare services. Others had also experienced Christian therapists who were more interested in “fixing” the gender problems in a way that did not involve transitioning, but rather prayer and religious healing.

Andi was confined by her parent's religious beliefs, but Jamie came to struggle with confinement stemming from her own religious beliefs:

I'll admit I went to my pastor. My wife (at the time) suggested it. It's like in the back of my head I knew it wouldn't help. I think my marriage only lasted those last few years because I kept meeting with him and my wife had hope. It's sad because deep down inside I knew this wasn't something religion could fix...and uh, and it didn't.

Religion could not “fix” Jamie's issues with gender identity because her pastor and her religion had negative views on GID, including the view that being transgender was not a legitimate identity in God's eyes. Having grown up in the church and having been a practicing Christian all of her adult life, Jamie struggled with reconciling her gender identity with her religion. At the time of our interview, Jamie had kept her spirituality but had exited her specific religious community. As Andi's and Jamie's words

underscore, discrimination can be found in many religious communities in a way that denies the existence of a transgender identity<sup>13</sup>. This incongruence will always pose as a barrier to moving forward in the transitioning process unless the religious belief is shed and the religious community is left.

### *Variation by Age and Location*

To investigate whether age and location are associated with experiences of ignorance and discrimination, participants' transitioning experiences were cross-referenced with their respective age categories (18-24, 25-34, 35-44, 45-54, and 55-64 year-old categories). In looking at ignorance and discrimination (based on experiences with doctors, therapists, and healthcare staff; gender identity diagnosis; family and friends; the workplace; and religion), I found similar frequencies of and sources of ignorance and discrimination across all age groups, meaning that not one particular age category stood out as having more or fewer experiences with ignorance and discrimination during transitioning. Similarly, I found fairly similar frequencies and types of ignorance and discrimination by place of residence during transitioning (rural versus urban location). My initial surprise at the findings for location was tempered as I began to take into account the politically and religiously conservative area in which my interviews were conducted. The two major urban areas represented in my sample are Tulsa and Oklahoma City. While these are certainly urban areas, they are also much smaller and more conservative than San Francisco and Washington D.C, where

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<sup>13</sup> It is important to note that not all religious faiths deny the existence of a transgender identity. However, many of the mainline Christian churches (e.g., Baptist, Evangelical, Catholic) do not condone transitioning and will often lead people who are questioning their gender identity toward reparative therapy.

two of my respondents transitioned. An important question, then, is whether these findings would be significantly different if conducted with a geographically representative sample from a variety of rural and urban areas across the entire United States. For example, would transitioning individuals who reside in urban areas such as Los Angeles or New York have similar experiences with ignorance and discrimination as those who reside in small towns in Oklahoma and Texas? Further analysis of age and location may lead to some interesting insights and should be considered in future research.

### *Conclusion*

In this chapter, I described how ignorance and discrimination impact the experiences of those seeking transitioning healthcare services. Overall, my findings suggest that higher levels of ignorance and discrimination are barriers to accessing transitioning healthcare. More specifically, healthcare providers who convey ignorance or discrimination are not able to offer the best, or even accurate, transitioning services. This is illustrated by doctors and therapists who could not fully understand the complexities of a GID or even accept it as a legitimate medical diagnosis. Additionally, the quality of care is negatively affected when patients face ignorance and discrimination from others within their clinics besides the doctor. While possibly less severe than ignorance and discrimination in the healthcare field, my data reveal that other people and social contexts can convey messages of ignorance and discrimination, such as family and friends, the workplace, and the religious

community. These sources also have the potential to be barriers to accessing transitioning healthcare services.

## CHAPTER 9: Instrumental Factors and Transitioning Healthcare Services

My analysis revealed a group of sub-codes falling under what I have labeled instrumental factors. The common theme characterizing these sub-codes is resources that are instrumental to accessing transitioning healthcare services. The lack of these instrumental factors often serves as a barrier to accessing transitioning healthcare services. I found four factors play a powerful role in an individual's experience with transitioning: money and financial resources, insurance status, geographic distance, and geographic location. Some of these factors may fall under what is traditionally thought of as socio-economic resources. My interview data show that factors besides socio-economic ones also can be instrumental for accessing transitioning healthcare services.

### *Coding of Instrumental Factors*

Using Spradley's Universal Semantic Relationships (Miles et al. 2013), I am able to explain the role each sub-code plays in contributing to the category of instrumental factors. For example, having money and financial resources and health insurance coverage are instrumental for accessing transitioning healthcare services (i.e., paying for them). Geographic distance from transitioning services and residential location (i.e., its urbanicity) are also instrumental to the transitioning process. Below, I will discuss more specifically the ways in which participants' experiences with instrumental factors shaped their access to transitioning healthcare.

### *Money and Financial Resources and Insurance Status*

As with any healthcare service, having money and financial resources to pay for the service or treatment is important for accessing it, and this was certainly the case for my participants. Closely related to this is insurance status. While the majority of my respondents did not have health insurance coverage, even those who did found there to be many personal costs because of co-payments and services not covered through their health insurance plans. Emma, a 63 year-old who identifies as MTF and female, shared her concerns about saving money for facial feminization surgery. She is able to pay for her hormones regularly, but saving up for a surgery, one that is not covered by insurance plans, is difficult for her: “Something else always comes up. I’m a student and trying to work and I have a crappy car and even when I can get some saved away – something stupid comes up...like that damn ticket (for speeding) I got. So frustrating!” The inability of Emma to save money, sometimes due to reasons outside of her personal control (e.g., her car breaking down), creates not only frustration, but barriers to desired transitioning healthcare services. Alex, a 22 year-old who identifies as male, also shared his experience in trying to raise money for top surgery, the FTM gender-affirming surgery to remove breast tissue. As someone who is uninsured, Alex was trying to raise close to \$3,000 for this particular surgery and related costs. Alex said, “I’ve tried raising money online – like [gofundme.com](https://www.gofundme.com)<sup>14</sup>. It just sucks because I know my friends mean well but they are poor too! So as you can tell...that didn’t work (pointing to chest).” With Alex, his fundraising goal was not

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<sup>14</sup> Gofundme.com is a fundraising website that allows users to share their story about what they are trying to raise money for and then solicit others to give money online through the site. Kiskstarter.com is another popular website in which to raise money. Users must set a fundraising goal and money that is donated is only processed if the fundraising goal is met.

met during the timeframe allowed by gofundme.com, and money pledged by family, friends, and other supporters was not processed.

While unsuccessful, Alex was creative in his attempt to raise money. He was not the only participant who attempted to raise funds over the Internet or in other innovative ways. Andi, a 28 year-old graduate student who identifies as MTF and female, utilized her resources as a student: “I used student loans. Saved up for a few semesters until I had enough.” Andi took out the upper limit in federal student loan money that was offered to her. She was able to save money to travel overseas for gender-affirming sex reassignment surgery. While she shared her experience in a very matter of fact way, she also seemed a little uncomfortable, as if she was afraid of being judged. She was silent for a few moments after describing this particular experience, but she followed up by saying, “It’s not something that is covered by my student insurance and as a grad student, where else was I going to get that sort of money? It was the most efficient way to raise the ten grand.”

Others shared their experiences of having transitioning services paid for by insurance providers. Skyler, a 19 year-old student who identifies as FTM and male, did not know the complexities of his insurance coverage, but he did express the importance of it by saying, “Yeah, I was still on my parents’ insurance, so that was cool. Wouldn’t have been able to afford it. And I don’t know how much the insurance covered and all that, but my folks paid the rest I guess.” The treatment Skyler received included therapy, doctor consultations, hormones, and top surgery. There appeared to be no barriers to transitioning healthcare services in Skyler’s experience, because he possessed instrumental factors, insurance coverage and his parents’ financial



resources. However Dylan, a 39 year-old who identifies as MTF and female, shared a very different experience:

Because of my disability I just get Medicare and not real insurance so it's not gonna cover surgeries and all the cosmetic. Like, I get my hormones, but that's it. And since I can't work I'm just not sure I'll ever get the money for things I want.

Although Dylan may not see Medicare as real insurance, it is her primary way to access hormones; however, it does not provide coverage for any other transitioning-related healthcare services. Skyler's and Dylan's experiences show that type of insurance can create access or can create barriers to transitioning healthcare services. Additionally, it is important not to forget how money and financial resources intersect with insurance status. As Dylan's experience shows, even having a health insurance plan does not guarantee complete access to comprehensive transitioning healthcare services. Skyler's story illustrates how his parents' financial resources were needed to pay for the part of services not covered by their health insurance plan.

### *Distance and Location*

Geographic distance and location serve as two other instrumental factors in seeking and obtaining transitioning healthcare services. The majority of my interviewees commented on the fact that most transitioning healthcare was provided in larger urban areas, even larger than the main urban areas in which most of my sample currently lived (Oklahoma City and Tulsa). For example, participants who lived in the Oklahoma City and Tulsa areas and were seeking top surgery all mentioned having to go to Dallas for this procedure. Parker, a 40 year-old who identifies as FTM and male,

shared his experiences with distance and obtaining hormones. He was driving long distances to get a month's worth of testosterone at a time because he did not have insurance coverage and could not afford to get it at the local pharmacy in the rural area where he now lived. He shared the following:

I was getting T from [clinic name] and they were doing the injections every week. It was easy because I lived right near there. But when I moved to [rural town], that was like over an hour away, I couldn't just drive up every week. I had to learn to inject [myself] and had to drive up once a month and get a month of T at a time.

When asked why he was unable to pick up his hormones at a local pharmacy, Parker explained that he did not have insurance or prescription coverage and the clinic he received hormones from worked with him by giving him hormone services on a sliding scale based on his income. This also shows how it is difficult to separate the factors of distance, insurance status, and financial resources.

Some participants faced distance issues that would certainly be barriers if other instrumental factors were not in place. Andi, who had raised money for gender-affirming surgery using student loan money, discussed location and distance: "I knew that I had to go overseas...go to Thailand. It was like my only option. So I did what I had to do ya know, travel across the world." Andi believed that she had to go to Thailand after researching her options for gender affirming surgery, and found the options in the United States to be lacking and inadequate, in her opinion. Fortunately, Andi's financial situation, because she was able to take out student loans, allowed her to access the services in

Thailand. However, many other interviewees often viewed the same surgery as an unattainable goal due to long distances and a lack of financial resources.

Some of my participants who were seeking surgery in the United States still found location to be a source of frustration if not a barrier. Dillon, a 26 year-old who identified as FTM and male, received top surgery in Dallas. He shared his experience:

Like the drive there wasn't too bad – like three hours, but I couldn't just drive home or even have someone drive me home (post-surgery) so we had to get a hotel, which just added more cost to it all. God, how I wish I could have been in my own bed that first night.

While Dillon was able to access services for top surgery, the distance that he had to drive to obtain the surgery seemed to negatively impact his experience and recovery. Overall, these narratives support my argument that those living in urban locations have somewhat greater access to transitioning healthcare services whereas those in rural locations have somewhat less access to transitioning healthcare services. Additionally, the distance to services creates a barrier that can be lessened through higher levels of financial resources.

### *Age*

To see whether age plays a role in possession of instrumental factors, participants' experiences were cross-referenced with their respective age categories (18-24, 25-34, 35-44, 45-54, and 55-64 year-old categories). The main pattern that emerged is that those aged 18-24 were more likely to have health insurance coverage, either through their parents or through college student health insurance, compared to

all other age groups. This stark finding reflects the make-up of my sample. As noted earlier, over half of my sample reported “student” as their occupation. Thus, over half of my sample was in a category that often is not gainfully employed and without their own health insurance coverage; therefore, they utilize their parents’ insurance or a student health plan. However, student health plans tend not to have the most comprehensive healthcare coverage; coverage is often limited to a campus health center for both routine physical and mental healthcare needs.

### *Conclusion*

Overall, this chapter has illustrated how having more money and financial resources, as well as having health insurance, tends to increase access to transitioning healthcare services. Conversely, lesser access to money and financial resources and health insurance tends to create, or lead to, barriers to accessing transitioning healthcare services. Geographic distance plays a role in healthcare access by creating barriers when needed services are located in a different state or even a different country. Having access to money and financial resources appears to lessen the barriers for individuals who live far away from transitioning healthcare services. The residential location of an individual can create barriers to care; those in urban locations have somewhat greater access to transitioning healthcare services while those in rural locations have somewhat greater barriers to accessing transitioning healthcare services. Finally, in examining age and the impact it has on instrumental factors, I found that those who are 18-24 years old are more likely to have health insurance coverage, usually through a parent or campus program.

## CHAPTER 10: Agency and Transitioning Healthcare Services

The last of the four themes that emerged as a major category in my analysis was agency. Agency, as generally defined in sociology and other social sciences, is the capacity of a person to act independently and to make his or her own free choices. However, the conceptualization and analysis of agency is fraught with complexities and ambiguities (Emirbayer and Mische 1989). A long list of terms can be associated with agency (e.g., self-hood, motivation, will, intentionality, choice, and freedom) (Emirbayer and Mische 1989). Anthony Giddens holds one of the dominant perspectives on agency within contemporary American sociology (Emirbayer and Mische 1989). Giddens (1991) argues that structure and agency are a duality that cannot be conceived of apart from one another. He gives selective attention to the role of habitus and routinized practices and sees human agency as habitual, repetitive, and taken for granted (Giddens 1991). I suggest that agency may not be as habitual, repetitive and taken for granted as Giddens suggests, yet I agree that agency should not stand alone in my analysis as it is constrained by social structures and social context. Supporting my stance, Emirbayer and Mische (1989) parse out the differences between the routine and purposeful conceptions of agency, recognizing that not all agency is repetitive and taken for granted. Additionally, Emirbayer and Mische (1989) believe we need to be attuned to the interplay between routine and purposeful conceptions of agency and various structural contexts. They state:

How are social actors, we ask, capable (at least in principle) of critically evaluating and reconstructing the conditions of their own lives? If structural contexts are analytically separable from (and stand over against) capacities for human agency, how is it possible for actors ever to mediate or to transform their own relationships to these contexts? (p. 964).

Williams (2003) specifically theorizes about the role of agency in the determinants of health. His work suggests the interplay between agency and social structures is important, and he states that researchers in the health field can examine that interplay by “looking at the recursive relationships, to use the jargon, between people’s knowledge and the places or locales in which they live” (p. 146). I believe that recognizing the relationship between social structure and agency is integral to understanding the larger picture of access and barriers to transitioning healthcare, and this chapter helps to illustrate not only how the theme of agency is an important finding of mine, but also how the social structure-agency relationship impacts access and barriers to transitioning healthcare services.

### *Coding of Agency*

My analysis suggests that the category of agency is made up of eight sub-codes. They are: research/self-education, the Internet, knowledge about informed consent, knowledge about Gender Identity Diagnosis (GID), self-medication, knowledge about hormones, anxiety, and depression. Using Spradley’s Universal Semantic Relationships (Miles et al. 2013), I am able to explain the relation of each sub-code to agency. Research/self-education is a way to exercise agency. Using the Internet also is a way to exercise agency in that the Internet provides individuals with

access to an abundance of information. The Internet also serves as a device for conducting research and self-education. Knowledge about informed consent can be the result of exercising agency; one who is self-educated on transitioning will have knowledge about informed consent that healthcare professionals might not have (see the discussion in Chapter Eight). Similarly, knowledge about GID and hormones can be the result of exercising agency. Self-medicating can be a way to exercise agency and is closely related to one's knowledge about hormones. Finally, anxiety and depression often occur as a consequence of having limited agency, and being anxious and/or depressed also creates barriers to exercising the agency one does have. While the majority of the sub-themes point to having and exercising agency, it would be remiss to ignore the impact that limited agency can have on the ability to access transitioning healthcare services.

#### *Research/Self-Education and the Internet*

As stated earlier, most often we rely on our doctors to be the experts on information concerning our health. However, as discussed in Chapter Eight, there are healthcare providers who are ignorant, if not discriminatory, about GID and transitioning healthcare services. Due to this, many of my participants felt it was important to research GID and transitioning healthcare protocols on their own, and interviewees repeatedly talked about their experiences in doing so. Miles, a 53 year-old who identifies as FTM and male, had to rely on the research and self-education he had done when he faced doctor ignorance. Miles said, "I've been on T (testosterone) for seven years so when I moved to OKC I basically had to tell the clinic doc what

regular uh, labs...like what tests to run to make sure my numbers were okay.” He elaborated that he also needed to inform his doctor what results are considered to be in the normal range.

The Internet has been discussed in relation to social capital (in Chapter Seven), and it fits into the major category of agency as well. The most common place to research transitioning healthcare was on the Internet; it served as a key way to research and self-educate on transitioning issues. Parker, a 40 year-old who identifies as both FTM and male, said, “I would print out information from websites and take it with me to the doctor because I knew that I was more knowledgeable about my own health needs than he was.” Not only did Parker feel the need to self-educate on the matter of his own transitioning healthcare, he took the initiative to educate his doctor as well when he assumed the doctor would be ignorant.

The Internet allows an individual to exercise agency, but individuals who do not have access to the Internet or who do not have proper online research skills cannot exercise agency in this way. Carter, a 27 year-old male, felt fortunate to have had the Internet and assistance from friends and said, “I was lucky I had help in figuring out where to look. I had a few links that were really helpful and because of who gave me them, I knew they were good. Cause like you can imagine there are bad links out there too.” Indeed, those who are given specific websites as resources are more likely to find the transitioning-related information they need than those who simply google the term “transgender” or “transitioning.” Thus, Carter’s narrative illustrates the connections between social capital and agency.



### *Knowledge about Informed Consent and Gender Identity Diagnosis (GID)*

As shown above, the ability to conduct research and to self-educate gives my participants a greater sense of empowerment and is a way to exercise agency as well. But it is important to understand what exactly they are educating themselves about. One specific item very commonly mentioned by my participants was that of informed consent. Informed consent is a process that requires a detailed discussion by a doctor with the patient regarding risks and benefits of transitioning-related treatment. Once informed of all the issues surrounding medical treatment (i.e., estrogen therapy or testosterone therapy, and surgical sex reassignment), the patient signs an informed consent document and can then access that treatment without a referral letter from a mental health provider.<sup>15</sup> Being able to bypass the mental health provider demonstrates that individuals have the agency to make choices about their own bodies without a mental health diagnosis and costly therapy. Carter, who had utilized the Internet for research, intended to use informed consent but was unable to do so:

I wanted to transition using informed consent for a T script as I'm not into therapy, so I was like please don't suggest therapy, heh heh...but I couldn't find a doctor who would see me without a therapy note, they didn't even know what informed consent was.

Carter's experience also illustrates how the informed consent sub-code overlaps with the doctors sub-code. Similarly, Parker stated, "I was very much looking forward to

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<sup>15</sup> The organization ICATH (Informed Consent for Access to Trans Health) was recently formed to advocate for an informed consent model as an alternative to the WPATH (World Physicians Association of Transgender Health) Standards of Care discussed in Chapter Four. There are very few clinics in the U.S. that have adopted the informed consent model, although support for informed consent is growing.

being able to do informed consent, but no clinic or doctors in the area would, it wasn't in their policies [they followed the WPATH Standards of Care].”

In addition to educating themselves about informed consent, participants almost always mentioned educating themselves about the GID diagnosis. The WPATH Standards of Care require a referral letter of a GID diagnosis from a mental health practitioner; acquiring the letter is often the first interaction with healthcare professionals as part of initiating transitioning healthcare services. Participants researched GID in an effort to access appropriate care. For example, Ashlee, a 32-year-old female, shared the following:

I knew from researching online what all went into the GID diagnosis. I was prepared to...well, to make sure I “fit” all the criteria at the doctors, well for the therapist ya know, in case she didn't know what to look for. It just felt like formalities though, kinda like jumping through hoops – the formal hoops – to get on estrogen and to get it all started.

This quote does not necessarily illustrate that Ashlee is trying to dupe the system, but rather she is being as efficient as possible getting through the first step of the transitioning process (i.e., receiving a GID diagnosis) in order to be prescribed estrogen. Here, we see another relationship to physician or therapist ignorance and find respondents exercising agency as a way to overcome practitioner ignorance.

Other participants had experiences at this stage that were different from those described so far. Emma, a 63 year-old female, had this to say: “I knew my diagnosis, but the therapist wanted to concentrate on my depression – like that was the real issue, but the real issue was I needed estrogen, I needed to be in the right body.” While Ashlee and Emma may not have had the same experience, both narratives support the idea that knowledge about one's diagnosis is a way of exercising agency in order to

obtain transitioning healthcare services. However, when informed consent was not available or people experienced ignorance from healthcare professionals regarding GID, some of my participants took matters into their own hands through self-medication and hormone use.

### *Self-Medication and Knowledge about Hormones*

The term “self-medicate” is used often in the transgender community to denote that an individual is obtaining and using hormones (testosterone or estrogen) illegally, meaning the hormones are not prescribed for the individual’s use by a physician or other medical practitioner. While the topic of self-medication in the transgender community may be controversial, data from my interviews show it is happening and often is a way of exercising agency. Sometimes it was done in an educated and healthful way, and other times it was done in a risky and unhealthful way. Miles, a 53 year-old male who had been on testosterone for almost 15 years, had a lapse in his healthcare during a move. Knowing the harm that would be done to his body if he did not take testosterone regularly, he stated, “I self-medicated...meaning I bought it from my friend while I couldn’t get a prescription. Like I’m pretty sure she got it from a friend or somewhere – but I trust her. I couldn’t just stop taking it, ya know?” Miles’ experience using the hormones for a long period of time made him feel safe in his decision. Ashlee also felt that self-medicating could be an option depending on whether or not she could obtain a letter from a therapist allowing her to initiate hormone services:

...there were online forums. I used to get info about hormone dosages and stuff. I wanted to know what to start on in case my therapist wouldn't write the letter, so I could know what to get on my own...and the online forums helped with that too.

Many participants were surprised at how easy it was to self-medicate.

Shannon, a 57 year-old female without health insurance said, "It wasn't hard to find online. I just ordered it, the estrogen. Some Internet searching and boom, I had it delivered right to my house." When I asked whether she was confident in self-medicating she responded, "Well, I didn't really have any clue what I was doing," meaning she was not confident in the initial dosage to take and when to increase her dosage. Shannon's experience illustrates how risky the consequences of exercising agency can be. However, with the ability to research self-medication and hormones, risk can be lessened.

### *Anxiety and Depression*

Shannon and Miles, both quoted above, may have had the agency to research and find hormones online, but not everyone had this ability. Another important aspect to agency is understanding the consequences of having limited agency, especially in relation to obtaining transitioning healthcare services. Parker, who was successful in educating himself about informed consent and GID, had less success when it came to self-medication. Parker described his situation:

It was really easy for me to get on T, ya know in the beginning. But once I lost my job I started having panic attacks thinking about where I would get my next dose if I couldn't afford the script. I knew people got it...illegally I guess you would say, but I didn't know how to do that.

Without information about self-medicating and accessing hormones illegally, Parker was faced with increasing anxiety at the thought of not being able to afford and obtain testosterone. Others who had limited agency also faced anxiety in the overwhelming process of accessing transition healthcare services. Not having the ability to conduct research and self-educate (due to generational differences in Internet use and lack of Internet services), Jamie reported that, “The anxiety was so bad for a long time. I’m sure it was coming from everywhere – the really bad body days, my wife, my church – but also because I just didn’t know where to start. It just seemed like too much.” It is possible that there is a feedback loop taking place in some instances, such as Jamie’s, where her limited agency (due to her inability to conduct research and self-educate) created anxiety which further limited her agency.

Anxiety surrounding the inability to access services, as illustrated above, was often coupled with depression. Emma, who admitted to experiencing depression, felt as though initiating the transition would help alleviate her depression. However, her experience with her therapist suggested otherwise when she said:

I knew my diagnosis, but the therapist wanted to concentrate on my depression – like that was the real issue, but the real issue was I needed estrogen, I needed to be in the right body. ... That went on for almost a year. I guess I could have changed therapists but I didn’t know who else to go to and so it probably took a year before we concentrated on transitioning instead of depression.

Although Emma had an understanding of her GID diagnosis, she was ill-equipped to search for a more effective therapist, most likely due to her depression, suggesting

another feedback loop where limited agency might lead to depression which might then lead to even more limited agency.

### *Age and Location*

To see whether agency varies by age, participants' experiences were cross-referenced with their respective age categories (18-24, 25-34, 35-44, 45-54, and 55-64 year-old categories). The patterns that emerged indicate that those aged 25-45 had higher levels of agency, or more often exercised agency, than those in the 18-24 and 45-54 age groups. This may be explained by the fact that younger participants, those in the 18-24 age category, probably have fewer financial resources, which constrains agency. The 55-64 age category showed lower levels of agency than any other age category in regards to research, self-education, and healthy self-medicating. These findings may point to cohort or period differences in that older participants may have transitioned at a time when the Internet was smaller in scope than it is today, giving them fewer opportunities to exercise agency.

The findings of my analysis of location (rural versus urban) cross-referenced with agency, suggest that those living in urban areas have higher levels of agency, or more often exercised agency, than those who resided in rural areas. This finding may be explained by the networks and resources, other than the Internet, available to individuals living in urban areas. For example, while some participants self-medicated with hormones bought online, other used their social capital to illegally obtain hormones from people in the city where they lived. One interesting finding to note is that the differences between the rural and urban groups were sometimes mitigated by

access to the Internet or Internet usage. That is, those in rural areas who used the Internet exercised higher levels of agency than their counterparts who did not utilize the Internet as much.

### *Conclusion*

In this chapter, I described the ways in which agency impacts the experiences of those seeking transitioning healthcare services. Overall, my findings suggest that a greater ability to exercise agency can lead to greater success in accessing transitioning healthcare. Additionally, individuals could face barriers to healthcare if their agency was constrained, sometimes resulting in negative outcomes such as unhealthy self-medicating, anxiety, and depression. As discussed in the introduction to the chapter, and as suggested by Emirbayer and Mische (1989), we must be attuned to the interplay between routine and purposeful agency and the various structural context. The narratives from my interviews illustrate this by looking at the interplay between research and self-educating and the larger context of ignorance among doctors and therapists. Carter's experience was an example of this: he tried to find a clinic that would provide informed consent, which he has researched, but he was ultimately unable to use informed consent because of doctor ignorance (i.e., he could not find a doctor who know about it). Finally, I discussed the ways in which age and geographic location intersect with agency, and how access to the Internet might be a mitigating factor allowing rural individuals to have increased agency.

## CHAPTER 11: Discussion and Conclusion

As discussed in Chapter Four, very little research has looked at the healthcare experiences of transpeople, especially their experiences with transitioning healthcare services. The goal of my study was to add to the literature on healthcare services for transpeople, while specifically addressing the gap in knowledge on transitioning experiences. I conducted twenty semi-structured interviews with transgender identified individuals who were going through (or had gone through) the transitioning process. My use of grounded theory allowed themes (major categories) and sub-themes (sub-codes) to emerge from my data. Consequently, I am able to consider my findings in relation to existing theoretical models. I do the following in this chapter: first, I provide a summary of my results; second, I discuss the theoretical implications of my research as well as my study's implications for future research; third, I discuss transitioning healthcare issues suggested by my study; fourth, I discuss implications of my study for transgender healthcare advocacy; and finally, I discuss the strengths and limitations of my research.

### *Summary of Results*

My investigation of access and barriers to transitioning healthcare services revealed four important themes: social capital, ignorance and discrimination, instrumental resources, and agency. First, my analysis revealed the ways in which social capital, in terms of five sub-themes (family and friends, workplace, school, the Internet, and other types of support), impact the experiences of those seeking transitioning healthcare services. My interview data reveal that more, or a higher level



of, social capital tends to lead to better access to transitioning healthcare services, whereas less, or a lower level of, social capital tends to lead to less access and more potential barriers to transitioning healthcare services. Therefore, having a durable network and strong support systems are key to making positive decisions and taking positive actions related to one's own transitioning healthcare.

Second, I identified the theme of ignorance and discrimination as having an impact on transitioning healthcare services with seven sub-themes (doctors, therapists, clinic experiences, gender identity diagnosis, family and friends, workplace, and religion). Overall, my findings suggest that, the higher the levels of ignorance and discrimination, the greater the barriers to accessing transitioning healthcare. More specifically, healthcare providers who convey ignorance or discrimination do not offer the best, or even accurate, transitioning services. This is the case with doctors and therapists who do not fully understand the complexities of GID or even accept it as a legitimate medical diagnosis. Additionally, the quality of transitioning care is negatively affected when patients face ignorance and discrimination from individuals within clinics besides doctors, such as nurses and receptionists.

Third, I found the theme of instrumental factors in terms of four sub-themes (money and financial resources, insurance status, distance, and location) to be important. The findings indicate that having more money and financial resources, as well as having health insurance, tends to increase access to transitioning healthcare services. Conversely, having lesser amounts of money and financial resources and little or no health insurance tends to create, or lead to, barriers to accessing transitioning healthcare services. Geographic distance plays a role in transitioning

healthcare by creating barriers when needed services are located in a different state or even a different country. Having access to money and financial resources appears to lessen the barriers for individuals who live far away from transitioning healthcare services. The residential location of an individual also can create barriers to transitioning care; those in urban locations have somewhat greater access to transitioning healthcare services while those in rural locations have somewhat greater barriers to utilizing transitioning healthcare services.

Finally, I found agency impacts the experiences of those seeking transitioning healthcare services. Eight sub-themes (research/self-educate, the Internet, knowledge about informed consent, knowledge about GID, self-medication, knowledge about hormones, anxiety, and depression) fall under this theme. Overall, my findings suggest that a greater ability to exercise agency can lead to greater success in accessing proper transitioning healthcare. Additionally, individuals could face barriers to transitioning healthcare if their agency is constrained, sometimes resulting in such negative outcomes as unhealthy self-medicating, anxiety, and depression.

My findings suggest patterns of social capital, instrumental factors, and agency, but not ignorance and discrimination, vary by age. Participants who fell in age categories under 44 generally had higher levels of social capital than those in the 45 plus age categories, who generally had lower levels of social capital compared to all participants who were 44 and younger. This pattern may speak to a cohort or period shift in accessing social capital online. I found similar frequencies of and sources of ignorance and discrimination across all age groups, meaning that not one particular age category of participants stood out as having more or fewer experiences with

ignorance and discrimination. The main pattern that emerged in looking at age and instrumental factors was that those aged 18-24 were more likely to have health insurance coverage. This may be related to the fact that over half of my sample reported “student” as their occupation and were receiving healthcare from their parents or from a student health plan. Finally, the findings from looking at age and agency indicate that those aged 25-45 had higher levels of agency and exercised agency more often than any other age categories, with the category of 55-64 having the lowest levels of agency. This finding may point to cohort or period differences in that older participants may have been transitioning at a time when the Internet was more limited in scope than today, giving them fewer opportunities to exercise agency.

It also should be noted that my findings suggest possible age patterns and cohort differences regarding when the transitioning process was initiated. A few older participants reported that they waited until they were at a later stage in life, often after their children from a heterosexual marriage were raised, before initiating and undertaking the transitioning process. These experiences further illustrate that examining age patterns and cohort differences in the transitioning process is worthy of future investigation.

Overall, these findings based on age suggest future research could use a life course perspective to investigate possible age, cohort, and/or period effects in access and barriers to transitioning healthcare, specifically in relation to Internet availability and use.

*Connections to Past Theoretical and Empirical Work.*

In Chapter Three, I provided a discussion of the body in terms of the way the body matters and the way appearance matters (e.g., Butler 1990; Holliday and Hassard 2001; Shilling 2007). I emphasized how the physical body itself will affect the experiences of transpeople in that they assign meaning to the way their bodies feel and look. This was certainly apparent in my interviews. For example, I found that many participants experienced anxiety and depression when they were unable to receive transitioning healthcare services, services that alter the body. Anxiety and depression may be consequences of continuing body dysphoria, brought about by barriers or limited access to transitioning services. These results show the importance of appearance in that society constructs meanings related to appearance; what it means to be masculine and what it means to be feminine in a society will impact the specific services that transpeople seek for altering their bodies. Paying attention to the way both the body and appearance matter helped me to understand the experiences of individuals who had transitioned or were in the process of transitioning. In fact, my stance was consistent with that of transgender theory (Nagoshi and Brzuzy 2010) in that, as a researcher, I looked to integrate physical embodiment of my participants with the self and the socially constructed aspects of their identity in order to understand their lived experiences. In summary, I utilized ideas from theoretical work on the body, not to test a theoretical framework, but to increase my effectiveness as a researcher and to guide my grounded theory approach.

Although the findings from my research are not generalizable, my participants' experiences suggest that Singer's (2006) new trans-health model, which was discussed

in Chapter Four, is generally not being followed. It would seem that the pathology, or diseased-based, model is still the standard approach to care. Although the complete trans-health model generally seems to be missing from the experiences of my participants, aspects of it were not, however. Informed consent, that is, the ability for patients to access care without a mental health diagnosis and referral letter with their consent of treatment protocols, is advanced by Singer as a new approach to replace gate-keeping by medical professionals. Informed consent did come up in the narratives from my participants. As a result of utilizing social capital and exercising agency, transpeople are learning about informed consent and are presenting information about it to therapists and physicians. Interest in this approach among transpeople may be an indication that the paradigm shift from a disease-based model to a trans-health model is beginning. Of particular importance is that transpeople are educating themselves and healthcare workers on informed consent. This seems to indicate that transgender individuals are trying to make the paradigm shift occur more than the healthcare workers are.

My findings generally are consistent with research on transgender issues in social interactions (Schilt and Connell 2007) and in the workplace (Schilt and Westbrook 2009), and research on navigating cisnormativity (i.e., the belief that those assigned male at birth always grow up to be men and those assigned female at birth always grow up to be women) in healthcare settings (Bauer et.al 2009). Schilt and Connell (2007) find that cisgender (nontrans) individuals, when interacting with transpeople, tend to reinforce the sex/gender/sexuality systems that are often biological in nature and signal only two, distinctly opposite sexes and genders. Their

findings generally parallel my finding of discriminatory, or negative, face-to-face interactions while obtaining transitioning healthcare services. Schilt and Westbrook (2009) report findings similar to Schilt and Connell (2007), but in the workplace specifically: social interactions with coworkers and employers tend to reinforce the binary sex and gender system.

Looking at transpeople in the healthcare system, Bauer et al. (2009) find that cisnormativity leads to erasure of transpeople in healthcare settings, that is, they are treated as non-entities. Their findings parallel some of the experiences of my participants, particularly in relation to ignorance and discrimination by doctors, therapists, and healthcare staff. In particular, they found that transpeople “have difficulty finding health care providers who can provide trans-competent care, both in terms of providing a trans-friendly environment and having specific knowledge of trans health issues” (Bauer et. al 2009:356).

Finally, my findings suggest similarities between the transgender community and other marginalized communities in experiencing inequalities in healthcare (Veenstra 2011; Richardson and Norris 2010; Shaver et al. 2012; Van Wijk et al. 1996). As discussed in Chapter Four, healthcare experiences and health outcomes vary by race, ethnicity, and gender, with minority members of each of these groups being at a disadvantage. As a marginalized population, transgender patients also face ignorance and discrimination in healthcare. Additionally, many of the transgender patients I interviewed lacked socio-economic resources and insurance coverage, which also has been the case for other socially disadvantaged patients.

### *Theoretical Implications*

Consistent with a grounded theory approach, I analyzed my data with no specific theoretical framework in mind to test. My grounded theory analysis suggested that two specific theories/models that are important in the fields of population health and medical sociology may be useful for understanding my findings. One is constrained choice theory, which may help to show how social factors influence individuals' access and barriers to transitioning healthcare services. Second, social capital theory may show how the social capital one possesses can facilitate the actions of transgender individuals within structural contexts.

The constrained choice model demonstrates how decisions made within social contexts can limit access to, and quality of, healthcare (Rieker et al. 2010). Rieker et al. (2010) recognize that while individuals do make everyday choices that can influence health outcomes, the wider social context shapes and constrains individual choices. Illustrations of the model place broader social factors (e.g., social policy) at the top of an inverted triangle that narrows to more specific contexts (e.g., the workplace). Together, these social factors influence the everyday choices of individuals, which have cumulative effects on health.

The constrained choice model was developed to understand gender and health outcomes, but I believe it can be used to understand the transitioning healthcare process, although the constrained choice model in its current form might not be a perfect fit to my findings. My results suggest that broadly-held cultural ideas about what it means to be transgender (e.g., negative views toward gender variance) and cultural conceptions of the body (e.g., as not "normal" if it does not appear a certain

way) influence what happens in specific social contexts, such as family and friends, educational settings, the workplace, and religious settings. These contexts (i.e., interactions occurring within them) then shape the individual factors that impact access to transitioning healthcare services, such as possession of social capital, certain instrumental factors (e.g., financial resources, health insurance), and agency. Thus, the constrained choice model may help us understand the interplay between social factors and the individual factors that lead to having access or facing barriers to transitioning healthcare services. Future empirical work on transitioning healthcare could explicitly test the theory of constrained choice. Additionally, future research might lead to modifications and/or improvements of the constrained choice model.

Social capital emerged as one of my four main themes in my study. As noted in Chapter Seven, Pierre Bourdieu (1986) defined social capital as:

The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition – or in other words, to membership in a group – which provides each of its members with the backing of the collectivity-owned capital, a ‘credential’ which entitles them to credit, in the various senses of the word (p. 250).

Also noted in Chapter Seven is that James Coleman (1988) sees social capital as that which facilitates individual or collective action and is generated by networks that often involve relationships, reciprocity, trust, or social norms (Coleman 1988). The example below uses Coleman’s (1988) framework to illustrate how social capital can facilitate actions by patients who are seeking transitioning healthcare services.

Looking at the social structure of healthcare and transgender patients as actors in their own healthcare, my findings show how the Internet, which was one of my



social capital sub-themes, can play an integral role in transitioning. Consider two scenarios. In the first scenario, Patient A sought transitioning services through the healthcare system and went to his primary care physician to gain information. His physician seemed baffled and informed patient A that this was not his area of specialty. He sent patient A on his way with no referral or further information regarding transitioning healthcare services. Patient A is frustrated and unsure where to go next, as he had used this particular physician his entire life. In contrast, Patient B is also seeking transitioning healthcare services but he took to the Internet before setting up a doctor's appointment. After much Internet research, patient B was armed with knowledge about GID as well as the steps he would need to take to initiate transitioning services. Additionally, patient B used the Internet to connect with others who were transitioning. They gave patient B contact information for a physician who provides transitioning services and is well known in the transgender community as being an advocate and ally for transpeople. Patient B was able to make an appointment with this physician. The major differences between the two scenarios are the use of the Internet and the outcome. Patient A did not have the Internet as a source of social capital and therefore was not able to perform actions necessary for obtain transitioning services. Patient B did have the Internet as a source of social capital and used it to his advantage for taking actions that would lead to proper transitioning services.

To summarize, I believe more understanding of social capital and access and barriers to transitioning healthcare services is needed. For example, future research could be done that explicitly applies Coleman's (1988) framework to investigate how

social capital can facilitate actions by patients who are seeking transitioning healthcare services.

### *Transitioning Healthcare Issues*

My study suggests at least three issues related transitioning healthcare services: legal liabilities and ethical considerations; the “cultural geography” of transitioning healthcare services; and tension surrounding a *DSM* diagnosis for gender dysphoria. First, it is important to note the tensions physicians face between liability issues and providing transgender healthcare. For example, recall the experience of Trey (reported in Chapter Eight) whose physician, unable to ignore Trey’s atypical blood test results while taking testosterone, stopped prescribing testosterone. While this scenario was portrayed in Chapter Eight as an example of physician ignorance, it is important to understand and acknowledge the potential legal liability the physician may have felt he faced if he had not stopped prescribing testosterone. While Trey viewed continuing testosterone treatment as the number one priority, his physician may have viewed following standard medical protocol and possible liability issues if such protocol is not followed as the number one priority. This sort of tension will most likely continue until clearer protocols are in place that take into account the social and legal considerations of both doctor and patient.

It is important to note that clinic staff (e.g., receptionists and clinic assistants) are not bound by professional codes of ethics the way physicians and mental health professionals are, so their actions are most likely not scrutinized as much or held to the same level of accountability. As a result, trans patients are susceptible to the kinds of

negative interactions with clinic staff (discussed in Chapter Eight) that some of my participants experienced. This set of findings particularly underscores the need for education and awareness training of clinic staff, especially those who are not bound by codes of medical ethics.

Second, the “cultural geography” of healthcare needs to be considered. My sample was confined to participants living in a particular geographic area (Oklahoma and northern Texas), and the physicians and mental health practitioners within that area were most likely educated within that geographic location. Thus, the cultural norms of the area most likely shaped the interactions of physicians and mental health professionals with their transgender patients. For example, information concerning the issue of informed consent was not readily available or even present among most physicians and their clinics within the region, according to my findings. Metropolitan areas in different locations, such as Baltimore or San Francisco, may provide greater access to physicians and clinics who have more information regarding informed consent and other transitioning healthcare services because the cultural geography of those highly urban locations differs from the cultural geography of the area where my study was conducted.

Finally, there is still considerable tension surrounding the gender dysphoria diagnosis. As discussed in Chapter Four, changes in the *DSM* (from gender identity diagnosis to gender dysphoria in the fifth edition) were made to alleviate the stigma surrounding a medical diagnosis for transgender identity. The debate over the ramifications of a medical diagnosis continues. Some advocates and transpeople claim that a diagnosis causes stigma and should not even be included in the *DSM*, which is

similar to the debates in the 1970s over including homosexuality in the *DSM*. Other advocates and transpeople argue that the existence of a *DSM* diagnosis is helpful, if not very important, for accessing much needed transitioning healthcare services. This viewpoint is seen when transgender advocates fight for trans-related health coverage from insurance companies. Both views contain good points, but their current co-existence creates tension, especially over the steps that should be taken to access transitioning services (i.e., whether a psychiatric diagnosis should be necessary).

### *Advocacy Implications*

Because I utilized a feminist research approach, I find it important to point out some of the implications of my research that can lead to praxis. In particular I believe the transgender community and its supporters can utilize Kawachi's (2010) conception of social capital theory in a way that can create collective action. According to Kawachi, "more cohesive groups are better equipped to undertake collective action" (p. 19), which describes the concept of "collective efficacy." One of the sub-themes that appeared repeatedly in my findings was that of the Internet. I believe that the Internet can be a mechanism for creating a more cohesive group of transgender individuals and their supporters that has collective efficacy for fighting the prevalent ignorance and discrimination toward transitioning found in healthcare settings.

Kawachi's conception of social capital also includes the notion of diffusion of innovations via information channels that exist within network structures. I think this ties into the experiences many of my participants had with informed consent. Although use of informed consent during the transitioning process is infrequent,

someday it may be used routinely for accessing transitioning healthcare services. The narratives in my research indicate that individuals learned about informed consent from other transpeople, often over the Internet. The Internet is serving as an information channel in the transgender community, where transpeople are able to access information about informed consent and other innovations in transgender healthcare services. Additionally, the Internet is likely to be important in spreading knowledge about advocacy work.

Based on the experiences of my study participants, I have two specific advocacy recommendations pertaining to medical staff and providers. First, more education and awareness training needs to be provided to healthcare professionals and healthcare staff. While a particular doctor may be well-educated on transgender healthcare issues, the physician and his or her staff might not be educated on other transgender issues. These issues include ones of social interaction, such as appropriate pronoun use and learning to avoid terms that may be viewed as derogatory or discriminatory. Both healthcare providers and their staff would benefit from increased education not only on transitioning healthcare services but also on transgender terminology and definitions. Second, health clinics should have inclusive forms. Having correct and inclusive options for gender identity (i.e. an “other” category or a transgender category) on forms could ease anxiety for transgender patients as well as serve as a sign of inclusivity and acceptance on the part of the clinic. In short, for a clinic that is providing any transitioning healthcare services, I recommend creating an environment that is welcoming and positive in all aspects of clinic contact and

healthcare, as a transperson's experience within a clinic is much more than just receiving medical treatment.

In sum, my findings related to the use of the Internet suggest that it can be very important when creating plans for advocacy in the transgender community, especially when advocating for access to transitioning healthcare services. In addition to the use of the Internet, education and awareness training of healthcare professionals and their staff will serve as an important way to change experiences with transitioning healthcare services.

### *Study Limitations*

While my research had a number of strengths, such as helping to fill a gap in the transgender literature (i.e., expanding knowledge on transgender healthcare experiences specific to transitioning), there were also limitations to my study. A major limitation is that over half of my sample reported "student" as their occupation. One of the areas from which I recruited was a college town, and the use of snowball sampling led to more participants from the college town, resulting in many participants who were either undergraduates or graduate students. Students' experiences, especially with social capital and instrumental factors, may differ from those who hold other occupations (i.e. paying ones); therefore, I suggest future research utilize more diverse samples. Related to this limitation is that few of my participants actually had health insurance or health insurance that covers a wide range of services, which may be due to their student status and/or their socio-economic status. It should be noted that the

Affordable Care Act<sup>16</sup> went into effect after my data collection occurred. Transitioning experiences may be different in the future, as a result of individuals being required to obtain health insurance coverage. Looking at the experiences of a sample that has greater health insurance coverage may reveal findings that differ from those of my study.

Additionally, multiple issues prevented me from conducting an in-depth intersectional analysis. It is well known that race and ethnicity impact health and healthcare outcomes, and being able to look at intersections based on race and ethnicity and other factors (e.g., religious affiliation) among transgender individuals, could tease out some patterns that were not clearly apparent in my study. My sample was small in size. In spite of this, there was racial variation in my sample; however, many of the participants who reported their race as non-white were Native American and presented as white. Additionally, my interview schedule did not specifically ask questions related to race and ethnicity, therefore the majority of my respondents did not discuss race or ethnicity as a factor in their transitioning experiences.

Finally, my sample was also limited by geographic location and place of residence. I only recruited participants from Oklahoma and Texas, two southern, conservative states located in the “Bible Belt.” And, although I used the United States Census Bureau’s definition of rural and urban, the urban areas in my study (Tulsa and

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<sup>16</sup> On March 23, 2010, President Obama signed the Affordable Care Act (ACA). The law put in place comprehensive health insurance reforms that would roll out over a four year period and beyond. The main goal of the ACA is for all Americans to have access to affordable health insurance options. The reforms mean that millions of people who were previously uninsured will gain health insurance coverage (U.S. Department of Health and Human Services 2014).

Oklahoma City) likely differ from larger urban areas (e.g., New York, San Francisco). My findings show that for transitioning, living in an urban area like New York or San Francisco, is very different from living in an urban area like Tulsa or Oklahoma City. Having a more geographically diverse sample would likely result in richer findings regarding the relationships between geographic distance and residential location and experiences with transitioning healthcare services.

### *Conclusion*

In conclusion, my study provides insight into issues surrounding access and barriers to transitioning healthcare services. Through my analysis of the experiences of twenty individuals, I have uncovered the importance of social capital, ignorance and discrimination, instrumental factors, and agency to accessing, or not accessing, these services. My findings suggest new directions for future research that will assist in improving transitioning experiences within the transgender community. As with other disadvantaged groups, the transgender community deserves to be studied and supported so that inequalities can be understood and a fairer and more accessible system of healthcare services can be created.



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## APPENDIX A: Glossary of Terms

*Ally:* (1) A straight person who supports LGBT people and their communities. (2) A cisgender person (of any sexuality) who supports transpeople and their communities.

*Androgynous:* A gender expression that has elements of both masculinity and femininity.

*Asex/Asexual:* A person who generally does not experience sexual attraction (or very little) to any specific group of people (e.g., gay men, lesbians, heterosexual men, heterosexual women).

*Bigender:* (1) A person who fluctuates between traditionally “woman” and “man” gender-based behavior and identities. (2) Identifying with both genders.

*Bottom Surgery:* Gender affirming surgery to alter external genitalia.

*Sex:* A biological term referring to genetics and anatomy (e.g., male, female, intersex).

*Cisgender:* A description for a person whose gender identity, gender expression, and biological sex all align (e.g., man, masculine, and male).

*Cisnormativity:* The expectation that all people are cisgender, and that those assigned male at birth always grow up to be men and those assigned female at birth always grow up to be women (Bauer et. al 2009).

*Facial Feminization Surgery:* A set of reconstructive surgical procedures that alter typically male facial features to bring them closer in shape and size to typical female facial features and can include various bony and soft tissue procedures such as brow lift, rhinoplasty, cheek implantation, and lip augmentation.

*FTM:* Female to male, indicating the direction of transitioning.

*Gender Dysphoria:* (1) Strong feelings of discontent experienced by persons who feel their bodies are at odds with the gender they identify as their own (Fenway 2009). (2) A marked incongruence between one’s experienced/expressed gender and assigned gender, of at least six month duration, as manifested by two or more indicators of gender incongruency. (Added to the *DSM V* as a diagnosis to replace Gender Identity Disorder [APA 2013]).

*Gender Expression:* The external display of gender, through a combination of dress, demeanor, social behavior, and other factors, generally measured on a scale ranging from masculinity to femininity.

*Gender Identity*: refers to a person's internal or perceived sense of their gender (e.g., feminine, masculine).

*Gender Identity Disorder (GID)*: Listed in the *DSM IV* as a diagnosis under the category of sexual disorders. Until recently, was used to diagnose patients seeking transitioning healthcare services; the diagnosis was changed to Gender Dysphoria in the *DSM V* (see Gender Dysphoria).

*Genderless*: A person who does not identify with any gender.

*Genderqueer*: (1) Anyone who challenges societal gender norms and those who live in a way that questions gender assumptions. Individuals have the choice to self-identify as Genderqueer (Raj 2002); (2) A blanket term used to describe people whose gender falls outside of the gender binary (Killerman 2013); (3) A person who identifies as both a man and a woman, or as neither a man nor a woman; often used interchangeably with “transgender” (Killerman 2013).

*Hir*: A gender neutral possessive pronoun used by people with alternative gender identities.

*Informed Consent*: A process that requires a detailed discussion by a doctor with a patient regarding risks and benefits of transitioning-related treatment. Once informed of all the issues surrounding medical treatment (i.e., estrogen therapy or testosterone therapy, and surgical sex reassignment), the patient signs an informed consent document and can then access that treatment without a referral letter from a mental health provider.

*Intersex*: A person with a set of sexual anatomy that does not fit within the labels of female or male (e.g., 47, XXY phenotype, uterus, and penis).

*LGBT*: Lesbian, Gay, Bisexual, Transgender. This acronym has become mainstream as a self-designation of sexuality and has been adopted by the majority of LGBT community members, activists, and organizations, as well as the media in the United States and some other English-speaking countries.

*MTF*: Male to female, indicating the direction of transitioning.

*Misgender*: To call someone a gender other than what they are presenting. It can be done deliberately and meant in a disrespectful manner or done unintentionally due to ignorance.

*Non-gender*: A person who generally does not identify with any gender.

*Pansexual*: A person who experiences sexual, romantic, physical, and/or spiritual attraction for members of all gender identities/expressions.



*Queer*: (1) Historically, a derogatory slang term used to identify LGBT people. (2) A term that has been embraced and reclaimed by the LGBT community as a symbol of pride, representing all individuals who fall out of the gender and sexuality “norms” (Killerman 2013).

*Reparative Therapy*: (1) Psychotherapy aimed at changing a person's sexual orientation, based on the view that homosexuality is a mental disorder. (2) Psychotherapy aimed at changing a person’s gender identity, based on the view that being transgender is a mental disorder. (Also known as conversion therapy).

*Self-Medicating*: A term used in the transgender community to denote that an individual is obtaining and using hormones (testosterone or estrogen) illegally, meaning the hormones are not prescribed for the individual’s use by a physician or other medical practitioner.

*Sex Identity*: Refers to a person’s internal or perceived sense of sex (e.g., female, male).

*Sex Reassignment Surgery (SRS)*: (Also known as gender reassignment surgery (GRS), gender affirming surgery, or gender confirmation surgery) is a term for the surgical procedures by which a person's physical appearance and function of their existing sexual characteristics are altered to resemble that of the other sex.

*Stealth*: A term used by individuals who have transitioned and want to hide their transgender identity, most likely identifying as either male or female.

*Third Gender*: (1) A person who does not identify with the traditional genders of “man” or “woman,” but identifies with another gender. (2) A gender category available in societies that recognize three or more genders.

*Top Surgery*: The female-to-male gender-affirming surgery to remove breast tissue.

*Trans\**: Another variation on transgender identity labels. This is perhaps the most current terminology within the transgender community, and one increasingly used in pop culture. The asterisk placed at the end of the word is seen as an inclusionary step in order to recognize that what defines being transgender for one may differ from another (Killerman 2013).

*Transgender*: An umbrella term that can encompass transsexuals, transvestites, cross-dressers, or any other self-defined gender variant. Often used interchangeably with transsexual.

*Transgender Identity*: Refers to a self-defined gender identity which falls under the umbrella term transgender. There is much variation in the labels used for transgender identity (e.g., transman, transwoman, MTF, FTM, Genderqueer).

*Transitioning:* A term used to describe the process of moving from one sex/gender to another, which is done by using hormones or surgical treatments.

*Transitioning Healthcare Services:* Medical services that involve treatment for the diagnosis of Gender Dysphoria. Services may include, but are not limited to, mental health assessments and therapy, hormone therapy, laboratory services, and gender affirming sex reassignment surgeries (SRS).

*Transitioning Process:* Includes the specific medical and psychological steps taken to transition from either male to female or female to male.

*Transman:* A variation of transgender identity, indicating that one has transitioned from female to male.

*Transwoman:* A variation of transgender identity, indicating that one has transitioned from male to female.

*Transpeople:* An umbrella term for individuals who identify as transgender, transsexual, transvestite, or gender variant. The term is commonly used in the trans community and is seen as more humanizing than referring to a group as transsexuals or transvestite, or any other medical terminology (e.g., Gender Identity Disorder) (Raj 2002).

*Transphobia:* (1) Skepticism about the existence of transpeople or a dislike or hatred of, and occasionally, hostility toward them. (2) A fear and hatred of changing sexual characteristics. Clinical transphobia refers to this concept being practiced in a clinical setting (e.g., by a physician or therapist) (Raj 2002).

*Transpositivity:* Respect for and acceptance of people who identify as transgender. A continuum of diversity and acceptance, truly transpositive people go beyond mere acceptance to appreciation and understanding. Clinical transpositivity refers to this concept being practiced in a clinical setting (e.g., by a physician or therapist) (Raj 2002).

*Transsexual:* Behaviorally, the act of living and passing in the role of the opposite sex, before or after having attained hormonal, surgical, and legal sex reassignment. Psychically, the condition of people who have the conviction that they belong to the opposite sex and are driven by the appearance, and social status of the opposite sex (Raj 2002).

*Transvestite:* An individual who dresses in clothing of the opposite gender for emotional satisfaction or erotic pleasure, or both. Transvestites do not wish to permanently alter their biological sex and express no or little desire for hormones or sex reassignment surgery (Raj 2002).

*WPATH*: An acronym for World Physicians Association of Transgender Health, a leading international organization on transgender health care that provides standards of care for transitioning healthcare services.

## APPENDIX B1: Web-based and Email Recruitment Text

### **Recruitment of Volunteer for Participation in Research Study**

#### **Transgender Experiences with Healthcare**

**Adrienne Brune**

**IRB#3345**

I am conducting research that explores how transgender identified individuals navigate the healthcare system and am looking for volunteers to participate in an interview that will last approximately an hour. I am interested in the experiences of healthcare within the transgender community, especially experiences while transitioning and including issues such as healthcare access and barriers.

All interviews will be confidential and no identifying information will be recorded during the interviews or used in analysis or reporting of research findings. Participation in this research study is completely voluntary and participants may choose to not respond to any questions or to end the interview at any time.

In order to qualify for participation you must 1) be between the ages of 18 and 64 and 2) identify as transgender.

If this sounds like something you would like to volunteer for, you can sign up by emailing me at [abrune@ou.edu](mailto:abrune@ou.edu). If this opportunity does not apply to you, feel free to share this information with others you know who might be interested and eligible.

Thank you for your consideration. Please feel free to contact me if you have any questions.

Adrienne Brune  
PhD Candidate  
Department of Sociology  
989-400-9143  
[abrune@ou.edu](mailto:abrune@ou.edu)

**The OU IRB has approved the content of this message but not the method of distribution. The OU IRB has no authority to approve distribution by mass email. OU IRB#3345.**

*The University of Oklahoma is an equal opportunity institution.*

Do you identify as Transgender?

Are 18 or older?

If you answer yes to these questions you meet the qualifications to participate in a research opportunity!

I am conducting research that explores how transgender identified individuals navigate the healthcare system and am looking for volunteers to participate in an interview that will last approximately an hour. I am interested in the experiences of health care in the transgender community, including issues such as healthcare access and barriers.

All interviews will be confidential and no identifying information will be recorded during the interviews, or used in analysis of reporting research findings. Participation in this research study is completely voluntary.

To sign up or for more information, contact [abrune@ou.edu](mailto:abrune@ou.edu). Feel free to share this information with others you know who might be interested.

**The OU IRB has approved the content of this message but not the method of distribution. The OU IRB has no authority to approve distribution by mass email. OU IRB#####.**

*The University of Oklahoma is an equal opportunity institution.*

## APPENDIX C1: Interview Schedule

Introduction to interview:

- Researcher introduction, overview and expectations
  - Consent form
  - Demographic questionnaire
  - Consent to record (also get verbal consent on tape)
  - Any questions for me before we begin?
- 

Okay, so we are going to start out going over some of the demographic questions you just answered.

1. You indicate in the questionnaire that your occupation is \_\_\_\_\_. Do you enjoy your job? How long have you worked there? Is the environment friendly and welcoming? (Probe as needed.)
2. You mention that you have \_\_\_\_\_ diploma/degree. Where did you go to school? When? Tell me more about this. (Probe as needed - where you out, how did you identify, etc.).
3. Tell me about your life growing up (probe for where, what family type, socio-economic status, siblings, and other probes as needed).
4. You mention that your current relationship status is \_\_\_\_\_. Tell me more about that (e.g., length of relationship)? When was your last relationship (if you have had one)? (Other probes as needed.)

TRANSITION: Okay, now we are going to shift gears a little and talk about gender identification.

5. You state that you identify as \_\_\_\_\_( MTF, FTM, M, F, other), tell me more about this? Tell me about your experience as transgender, when did you first identify as transgender? (Probe as needed.)

TRANSITION: Okay, now we are going to move on and talk about health insurance for a bit.

6. Do you have health insurance currently? Who is your carrier? Is it through employment? Is it through school? (Probe as needed, including: whether person is covered under someone else's insurance, what role current health care/insurance plan plays in transitioning?)
7. Do you currently have a family doctor or Primary Care Physician (PCP)?

8. Tell me about your attitudes toward and experiences with healthcare while growing up. As far as you know, did you have health insurance growing up? (Probe as needed.)

TRANSITION: Okay, now we are going to talk about your experience with transitioning and your experiences with the healthcare system.

9. Tell me about your experience with transitioning, specifically, what does transitioning/the transitioning process mean for you? (Use probes as needed, including ones from the following list when appropriate).
  - a. How did you learn about the services? Where was the service provided?
  - b. How was the interaction with the Health Care Providers (HCPs) (e.g., physicians, psychiatrist, surgeon). (For example: were they respectful? Friendly? Open to discussion with you? Did you trust them? Did you lie about any of your personal information?)
  - c. How was the interaction with HCP staff (i.e., everyone but the HCP)?
  - d. Did your HCP or staff ever not respect or acknowledge your identity (i.e. using wrong pronouns)?
  - e. Did your HCP seem knowledgeable about your transitioning process?
  - f. Did you experience any problems or unforeseen events?
  - g. What was/will be the cost? (Prompt for each individual service e.g., hormones, surgery, tests, office visits.)
  - h. Did/will your health insurance cover any of the costs?
10. Tell me about your experience with taking hormones, if any (e.g., for how long, any difficult side effects, how satisfied you have been with them, etc.). Do you intend to take hormones for your entire life, making this a lifetime cost? Have you been “thinking ahead” as to the impact of this (e.g., financially, socially)? How might this impact your future employment or other future plans? (e.g., what job you want to have, what and where you decide to work)? (Use probes from question 9, if needed.)
11. Tell me about your experience, if any, with Gender Reassignment Surgery (GRS) or other gender affirming surgeries (e.g., what type of surgery you had, whether you were anxious about it, what the recovery was like; use probes from question 9, if needed).
  - a. **MTF** (including mastectomy, masculine chest reconstruction, genital reconstruction (phalloplasty, metoidioplasty).
  - b. **FTM** (including facial feminizing surgery, voice-pitch elevating surgery, other feminizing surgery/laser therapy, breast augmentation, vaginoplasty (several procedures).
12. Are there any health services related to your transition that you wanted that you have not received? Which services and why?

13. Tell me about your experience with the continued healthcare involved in transitioning. (This may include things such as hormones, pap/pelvic exams and prostate, among others, depending on transition experience). (E.g., how are you treated by Health Care Providers and their staff when you have such procedures, insurance coverage, costs.)
14. Were you ever denied healthcare in relation to transitioning? (Probe if needed for what happened.) Why do you think that is? (Probe if needed.)
15. What do you think about Gender Identity Disorder (GID) or Gender Dysphoria being a psychiatric diagnosis? (Probe as needed for why they are for or against it, and use other probes as needed.)
16. Do you consider yourself "transitioned?" What does this (i.e., transitioned) mean to you? What are your future plans regarding transitioning? Where do you see yourself in 5, 10, 15 years? (Probe as needed.)

TRANSITION: Okay, now we are going to move on and talk about your support network and experiences in society, more in general.

17. Tell me about your social and support network (friends, family, work, religious, intimate partner). Has your support network changed over time? (Probe for whether people have left or entered the support network and why, especially during the time period around the transitioning process; use other probes as needed.)
18. Are you "out" as transgender (e.g., to coworkers, to family, to peers and acquaintances)? (Probe as needed.)
19. What experiences have you had with public perceptions of your gender? (Probe if needed.)
20. Would you be interested in sharing your thoughts and attitudes about how society categorizes and/or treats gender, just in general?
21. It seems as though we have covered all the questions I have for you. Do you have any questions for me? Did I miss anything you think is important?



## APPENDIX C2: Demographic Questionnaire

**Instructions:** Please complete the following questions by either writing in the correct information or circling the answer that best describes you.

1. What is your current age? \_\_\_\_\_

2. What is your date of birth? \_\_\_\_\_

3. In what city or town do you live? \_\_\_\_\_

4. How long have you lived in the above city or town? \_\_\_\_\_

5. What is your current occupation? \_\_\_\_\_

6. Do you live alone or with others? \_\_\_\_\_

I live alone

I live with others. Please indicate all of the people with whom you live (e.g., parents, siblings, roommates, partner):

\_\_\_\_\_

7. What is the highest education level **you** have completed? (*please circle the answer that best describes you*)

Less than high school

High School or GED

Skilled trade, vocational program

Some college (no degree)

Associate's degree

College degree (4 year)

Some graduate school or professional school (but no graduate or professional degree)

Graduate or professional degree

8. What is the highest education level **your mother** completed? (*please circle the best answer*)

- Less than high school
- High School or GED
- Skilled trade, vocational program
- Some college (no degree)
- Associate's degree
- College degree (4 year)
- Some graduate school or professional school (but no graduate or professional degree)
- Graduate or professional degree

9. What is the highest education level **your father** completed?

- Less than high school
- High School or GED
- Skilled trade, vocational program
- Some college (no degree)
- Associate's degree
- College degree (4 year)
- Some graduate school or professional school (but no graduate or professional degree)
- Graduate or professional degree

10. Which of the following racial or ethnic categories do you consider yourself to belong to?

(Circle all that apply)

- American Indian, Native American, or Alaska Native
- Asian or Asian American
- Black or African American
- Caucasian or White
- Hispanic or Latino/Latina
- Middle Eastern
- Native Hawaiian or other Pacific Islander
- Other (please specify): \_\_\_\_\_

11. What is your current religious affiliation? \_\_\_\_\_

12. What was your religious affiliation growing up? \_\_\_\_\_

13. What is **your** approximate annual income? (Only include income you have earned. Do not include income earned by anyone else in your household.)

0 - \$19,999

\$20,000 - \$39,999

\$40,000 - \$59,999

\$60,000 - \$79,999

\$80,000 or above

14. What is your approximate annual **household** income (combined income of you and your spouse or cohabiting partner), if different from above?

0 - \$19,999

\$20,000 - \$39,999

\$40,000 - \$59,999

\$60,000 - \$79,999

\$80,000 or above

15. Have you ever been legally married?

Yes, I was in the past but I am not legally married now.

Yes, I am legally married now.

No, I have never been legally married.

16. Have you ever been divorced?

Yes, I have been divorced.

No, I have never been divorced.

17. What is your current relationship status?

Not legally married and **not** in a relationship.

Not legally married but in a relationship.

Legally married.

Separated, divorced, or widowed and **not** in a relationship.

Separated, divorced, or widowed and in a relationship.

18. Which of the following terms best describes your sexual orientation?

Heterosexual

Homosexual

Bisexual

Asexual

Other (please specify): \_\_\_\_\_

19. What was your biological sex at birth?

Male

Female

Intersex

20. Which of the following gender categories do you consider yourself to belong to?

Male

Female

Male to Female MTF

Female to Male FTM

Genderqueer

Trans\*

Other (please specify): \_\_\_\_\_