"You Never Know What You’re Gonna Get!": the Lived Health Care Experience of Individuals Who Identify as Transgender

Joyce Lyn Cole

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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

“YOU NEVER KNOW WHAT YOU’RE GONNA GET!”: THE LIVED HEALTH CARE EXPERIENCE OF INDIVIDUALS WHO IDENTIFY AS TRANSGENDER

A Dissertation Submitted in Partial Fulfillment Of the Requirements for the Degree of Doctor of Philosophy

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December 2019
This Dissertation by: Joyce Lyn Cole

Entitled: “You Never Know What You’re Gonna Get!”: The Lived Health Care Experience of Individuals Who Identify as Transgender

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in College of Natural and Health Sciences in School of Nursing, Program of Nursing Education

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ABSTRACT


This study used descriptive phenomenological investigation to explore the lived health care experience of individuals who identify as transgender. Results gleaned from the study provide a resource for nurse educators to employ when preparing future nurses to practice in an increasingly diverse environment. Eighteen adult members of the transgender community who had experienced health care completed virtual face-to-face, in-depth interviews. The data provided a rich description of the experiences, and analysis yielded the identification of themes that illuminate the essence of the lived healthcare experience. Findings from the data indicate that the transgender health care experience can be unpredictable and contributes to the population’s recognized health disparities. The nursing education profession should incorporate curricular changes aimed at preparing future nurses to provide compassionate and appropriate care to individuals who identify as transgender.
ACKNOWLEDGEMENTS

Oprah Winfrey once said, “The key to realizing a dream is not to focus on success but significance, and then even the small steps and little victories along your path will take on greater meaning” (Winfrey, 2002, p.37). My doctoral journey has been wrought with numerous little victories - some of which occurred after seemingly enormous defeats. Nevertheless, the significance of this endeavor provided a constant motivation to keep trying, and keep trying, and keep trying some more. Having started my higher education experience classified as a “disadvantaged student”, I wanted to be an example for my own children and for the many others who face obstacles while gaining an education. I wanted to become a nurse educator who grasped the “big picture” of the profession so that I could be a more effective teacher. Most importantly, I wanted to produce something that might make our world just a little bit better by improving the way that people are treated.

The realization of my educational dream occurred only because I received support along the way from many sources. Sometimes the support came from the very direct feedback I received from my committee members that may have seemed less than supportive but was much needed. To my chair, Dr. Faye Hummel, I express my deepest appreciation for sticking with me and encouraging me to stretch farther than I ever imagined possible. Dr. Kathy Sullivan provided excellent guidance regarding scholarly research, and Dr. Katrina Einhellig gave encouragement at pivotal moments. Her
message saying, “You’re so close!”, became my rallying cry during the final push toward completion of this journey. Finally, the expertise of Dr. Joe Ososkie helped me to recognize my own privileged perspective and to tackle the task at hand with greater empathy.

Earning this degree would never have happened without the enduring support of my family and friends. Although I grew up in poverty, my parents always taught me that “As long as I was getting older, I might as well try to get smarter, too.” They taught me to work hard and to do my best at every task. Along the way, people babysat, provided rides, and cheered me on. My siblings encouraged me and made me realize that I was part of a team that is bound by more than genetics. To my children -- Brianne, Chelsea, Evan, Jared, and Joshua -- thank you for eating tons of take-out and heat-and-eat food, for forgiving me when my stress resulted in imperfect behavior, and for believing in me when I was ready to give up. To my eternal companion, Ron, thank you for giving me wings and letting me fly. I would have remained in the nest forever without your “let’s go do it” attitude and the love that I could always depend upon.

I know that many miracles occurred along the way and on a day when I honestly had no idea how to proceed, a tender mercy occurred that truly brought me to my knees in a spirit of gratitude. Summarily, the “small steps and little victories” really do hold deep significance. My deepest desire is that the work that we have all accomplished will somehow lighten others’ burdens, bring comfort to the wounded, and provide hope for those who mourn.
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CHAPTER I

INTRODUCTION

Background

A military commander clothed in shining armor led a group of bedraggled, formerly uninspired troops to battle. The commander had not risen through the ranks in a traditional manner, but instead, approached the French heir apparent with a tale of a divine vision that would allow France to regain control of lands currently held by the English. Following several very successful campaigns, the commander presented the King of France with a crown and asked to be relieved of military duty. Dissatisfied with simply regaining the crown, the French ruler ordered the military leader to initiate another campaign that resulted in the soldier’s betrayal to the enemy. Eventually, this 18-year-old military genius was burned at the stake. The greatest offense committed by the soldier was not disloyalty nor even a violation of the contemporary mores of war; Joan of Arc suffered death because she chose to ignore conventional tradition and live as she believed she should.

Although this event seems barbaric by contemporary standards, modern society continues to sanction people who defy social norms. The Pulse Nightclub shootings in 2016 that targeted same-sex couples, the high rates of sexual assault reported by members of gender and sexual minorities, and the 18 murders of individuals who identify as transgender during 2018 reveal that some members of society still choose to discriminate.
against those who are non-conforming to traditional roles (Jones-Schenk, 2018; Marbury, 2017).

Members of gender and sexual minorities (GSM) experience marginalization, discrimination, and violence at a greater rate than those who make up the majority of society (Jones-Schenk, 2018). While the GSM umbrella term includes individuals who identify as transgender, the health care needs of these individuals present significant and distinct challenges not sufficiently addressed by studies whose focus is the overall GSM population (Wanta & Unger, 2017). Wanta and Unger (2017) found that despite small advances in the clinical reduction of stigmatization, from an academic perspective, a paucity of published data exists related to the health care experience of individuals who identify as transgender.

Individuals who identify as transgender experience a gender identity that differs from the sex assigned at birth. Conversely, individuals who identify as cisgender embrace the sex assigned at birth. This gender identity should not be confused with sexual identity as individuals who identify as transgender may be homosexual, heterosexual, pansexual, or asexual (Understanding Transgender People, 2016). Meerwijk and Sevelius (2017) completed a meta-regression analysis of 12 surveys conducted between 2007 and 2015 that quantifies the growing number of individuals who identify as transgender. Their findings indicate steady increases in the number of people who identify as transgender as well as projected increases in the future. Current estimates suggest that about one million adults in the United states comprise the population of individuals who identify as transgender (Meerwijk & Sevelius, 2017).
Gender transition is an outward expression of gender identity and can include an act as simple as donning a different type of clothing, or as complex as receiving gender confirmation therapy (Understanding Transgender People, 2016). Historical documents reveal that aspects of gender nonconforming behaviors existed in the earliest societies. In the ancient Americas, some Native Americans recognized a third gender that applied to people who were assigned a gender at birth but adopted the traditional roles of the opposite gender (Katz, 1976). In ancient Assyria, a cult comprised of people assigned as male at birth danced and sang while dressed as women and pretended to give birth (Holland, 2004). Likewise, in ancient Greece, some individuals born with male anatomy castrated themselves, donned traditionally female clothing, and referred to themselves as women (Katz, 1976). Historically, young Afghan girls may be reassigned a male gender by their parents—a practice known as “bacha posh”—to escape the restrictions placed upon women in a highly patriarchal society (Menon & Vajayalakshmi, 2018).

Although examples of non-traditional gender expression can be found in most modern societies, the soldier and actress, Christine Jorgensen, is credited with taking the beginning steps to legitimize the transgender identity movement in the United States as her gender confirmation surgery was widely publicized in 1952 (Meyerowitz, 2006; Townsend, 2012; Zimmerman, 2015). More recently, the athlete and television personality, Caitlyn Jenner, garnered national attention and heightened awareness of the transgender movement in the United States (Zimmerman, 2015).

While modes of gender expression differ among times and cultures, the constant issues faced by most individuals seeking to confirm their gender identity include misunderstanding, discrimination, and marginalization. Even among health care workers
who promise to “do no harm,” individuals who identify as transgender report feeling unwelcome as patients. This maltreatment may be as subtle as supporting an atmosphere of binary gender stereotypes or as unconscionable as committing assault during health care encounters. Overall, greater than 70% of transgender individuals surveyed report having experienced discrimination in health care (Poteat, German, & Kerrigan, 2013).

The effects of this discrimination become evident through examination of health statistics that compare transgender and cisgender populations. Individuals who identify as transgender shoulder a greater share of physical maladies than their cisgender counterparts (Mirza & Rooney, 2018). Mental health issues are prevalent in the transgender population and contribute to the greatly magnified rate of suicide attempts within this population (Mirza & Rooney, 2018). Receiving hormonal therapy, undergoing gender confirming surgery, and engaging in practices that promote public acceptance of one’s gender identity place an additional burden on individuals who identify as transgender (Mirza & Rooney, 2018). While many of these health issues occur among other minorities, they may be significantly magnified for patients who identify as transgender (Lerner & Robles, 2017).

Legal protections for individuals who identify as transgender remain in limbo. Although a status of transgender does not represent a disability, the intense emotional stress of gender dysphoria can no longer be excluded as a disability according to the Americans with Disabilities Act (GLBTQ Legal Advocates and Defenders [GLAD], 2017). The American Civil Liberties Union (ACLU) cites advancements including prohibition of denial of care based on pre-existing conditions and passage of specific legislation requiring health care workers to participate in abortions and care of
individuals who identify as transgender (American Civil Liberties Union [ACLU], 2018). More recent legal developments place even these basic protections in jeopardy (Welna & Chappell, 2019).

Social acceptance of individuals who identify as transgender is increasing, but transphobia remains pervasive. Among health care providers, prejudice against individuals who identify as transgender exists and results in reduced access to care and reticence to seek needed health care (Hughto, Reisner, & Pachankis, 2015). Most nurses (over 80%) report discomfort in caring for patients who are transgender, but they cite a lack of knowledge regarding appropriate care practices as the primary reason for their discomfort (Lim, Johnson, & Eliason, 2015).

**Statement of the Problem**

Acknowledged disparities in meeting the health care needs of individuals who identify as transgender may be related to limited recognition and acceptance of transgender worldviews by health care providers. Fear of rejection, harassment, and violence contribute to the delay of treatment reported in the transgender community. Many individuals who identify as transgender acutely experience an absence of acceptance and empowerment during health care encounters that perpetuates a cycle of health care avoidance and continued disparities. Overall, discriminatory practices among health care providers toward individuals who identify as transgender may contribute to delayed or deferred health care thus compounding the health disparities plaguing the transgender community (Christian et al., 2018). Because the health care needs of individuals who identify as transgender are unique and largely ignored, research that
recognizes the community members’ authority as authentic voices for their lived health care experience should be completed.

Barriers to health care exist for individuals who identify as transgender including discrimination, prerequisites for treatment, prohibitive expenses, and a dearth of transgender-inclusive health care providers (Christian et al., 2018). Additionally, individuals who identify as transgender experience significant health disparities including higher rates of mental illness, violence, sexually transmitted infections, comorbidities, and a lower incidence of wellness exams (Christian et al., 2018; Jones-Schenk, 2018).

Individuals who identify as transgender report delaying health treatment more frequently than individuals who identify as cisgender (Lerner & Robles, 2017). Because a previous negative health care experience--or the anticipation of a negative health care experience--results in delayed care, the interactions between health care providers and individuals who identify as transgender stand to greatly influence the overall quality of the encounter.

While a growing body of research addresses the health care experiences and needs of individuals who identify as transgender, the need for inquiry remains. Healthy People 2020 recommends recognizing and addressing the medical necessity of the health needs of individuals who identify as transgender as a continuing issue in Lesbian-Gay-Bisexual-Transgender (LGBT) health (U.S. Department of Health and Human Services, 2019). Additionally, a study sponsored by the National Institutes of Health (NIH) cites the need for research that measures the effects of interventions such as transgender friendly health centers and the level of education received by health care workers (as cited in Feldman et al., 2016). Moreover, the transgender training project of
the New England AIDS education and training center conducted research among health care providers to determine their educational needs. Participants reported that learning from individuals who identify as transgender should be included as an essential element of provider education (as cited in Laurie, 2005).

A very limited amount of research exists that captures the essence of the health care experience of individuals who identify as transgender. While the volume of gender and sexual minority research has increased during the last three decades, the specific and distinct experiences of individuals who identify as transgender remain under-researched (Feldman et al., 2016).

The challenges that face health care providers, health care educators, and health care students who desire to provide safe and compassionate care are multi-factorial. Published literature points to inadequate education in both academia and industry (Carabez, Pellegrini, Mankovitz, Eliason, & Ciano, 2015), limited opportunities to provide care for patients who openly identify as transgender (Cleveland Clinic, 2018), and feelings of discomfort regarding care of individuals who identify as transgender (Laurie, 2005). As health care providers continue to offer suboptimal transgender focused care and as individuals who identify as transgender continue to avoid needed health care, the health disparities within this population persist. The aim of this study was to discover themes that reveal the essence of the lived health care experience for individuals who identify as transgender. It is anticipated that the results will provide nurse educators with access to an expanded knowledge base to guide curricular changes and improve competencies of nurses.
Purpose of the Study

This research aimed to explore and describe the lived health care experience of individuals who identify as transgender. This study sought to gain insight into the real-world phenomenon and to identify themes and the essence of transgender health care experiences. Interviews with individuals who identify as transgender allowed the researcher to gather insights contributing to a rich description of participant health care experiences. The researcher identified themes associated with the health care experience of individuals who identify as transgender and from those identified themes, described the essence of the lived experience.

Significance of the Study

Currently, the specific health needs of individuals who identify as transgender receive little attention in health care education. In nursing education specifically, a nationwide study revealed that educational efforts focused on LGBT issues received an average of 2.12 hours of class time (Carabez et al., 2015). The combining of gender identity issues with sexual orientation issues results in students receiving only cursory—if any—education related to individuals who identify as transgender in most nursing curricula. In fact, among nurses surveyed in the San Francisco Bay area in 2015, 80% reported receiving no education focused on health care needs of individuals who identify as transgender care as either a student or a practicing nurse (Carabez et al., 2015).

The combination of the aforementioned factors—discrimination, marginalization, financial and physical barriers to health care, and limited knowledge of health care providers—results in a continuing cycle that promotes sustained disparities in health care for the transgender population. These disparities stand to increase unless individuals who
identify as transgender feel safe and accepted during health care encounters. Laws and policies that reinforce discrimination and marginalization hinder access to health care and in turn, contribute to increased rates of anxiety, suicide, and substance abuse. The long-term effects of health disparities result in reduced life expectancy for individuals who identify as transgender with recent studies reporting that some segments of the transgender population have a life expectancy that is less than half that of the general population (Baker, K., 2019).

Nurse educators can shape curricular content, thus providing appropriate educational offerings for nursing students. As nurses become more recognized as care coordinators and patient advocates, their role in the health care team evolves and places them as a possible catalyst for changing the health care encounter into a safe, nurturing experience for individuals who identify as transgender. Additionally, as health care moves to a community centered model, nurses must stand prepared to provide an accepting environment replete with appropriate resources for all people—including those who identify as transgender.

**Research Question**

This study was designed to explore and describe the phenomenon of transgender health care. Qualitative inquiry was used to address the following question:

Q1 What is the lived health care experience of individuals who identify as transgender?
Overview of Methodology and Theoretical Framework

Phenomenology

To answer the research question, the appropriate research methodology for this study was a qualitative, phenomenological, descriptive approach. Qualitative research aims to capture a holistic understanding of a phenomenon from the natural setting point of view of the individual(s) participating in a study. As stated by Merriam and Tisdell (2015) “research focused on discovery, insight, and understanding from the perspectives of those being studied offers the greatest promise of making a difference in people’s lives” (p. 1).

As a guiding philosophy for nursing research, phenomenology focuses on illuminating the first-person experiences of a phenomenon with an understanding that reality is best described by utilizing the perspective of those who have real-life experience (Matua, 2015). Three approaches to phenomenology as a philosophy exist: transcendental, hermeneutic, and existential. Transcendental phenomenology as described by Edmund Husserl, attempts to describe the lived experience of a phenomenon. It aims to capture the way something is experienced by a person as well as the person’s interpretation of the reality of the experience (Merriam & Tisdell, 2015). The researcher uses transcendental reduction to describe the essence of the lived experience and seeks only to describe the experience rather than interpret it. Hermeneutic phenomenology comes from Martin Heidegger, a student of Husserl who believed that true reductionism is not possible because of the researcher’s intrinsic awareness (Creswell, 2017). This philosophical approach focuses on the interpretive efforts of the researcher. Existential phenomenology seeks to understand subjective
human experiences and strives to achieve a direct, primitive contact with the world as might be accomplished in a field study (Merriam & Tisdell, 2015).

As a research methodology, phenomenology is divided into the descriptive approach and the interpretive approach. Both methods focus on the lived experiences of individuals and the meanings associated with those experiences. Descriptive phenomenology seeks to emphasize the pure description of subjects’ experiences while interpretative phenomenology considers contextual features as they relate to influences that affect the subjects of the study (Matua & Van Der Wal, 2015). Descriptive phenomenology calls upon the investigator to bracket personal experience and then describe and reveal the meaning of the relationship between the subject and the object—or the person and the experience (Matua & Van Der Wal, 2015).

**Health as Expanding Consciousness Theory**

Margaret Newman’s theory of health as expanding consciousness (HEC) provided the theoretical framework for this study. Although the impetus for Newman’s theory centered on a concern for individuals for whom health without illness or disability was not feasible, the theory has evolved to include each person without regard to the presence or absence of illness or disability (Newman, 1994). Health as expanding consciousness theory recognizes that regardless of the situation, every person is part of the universal process of expanding consciousness. The process of expanding consciousness involves “becoming more of oneself, finding greater meaning in life, and reaching an enhanced connectedness with other people and the world” (Newman, 1994, p. 8).
Newman (1994) cites the paradigms of health, human, nursing, and environment in the HEC theory. This grand theory is abstract, multi-dimensional, and is applicable in any setting. Newman’s representation of health and illness as integrated phenomena representing evolving patterns of unitary human consciousness speak to an expansion of the unitary paradigm of Martha Rogers (Newman, 1994). The framework expands nursing art and practice to a more encompassing perspective of people as unique individuals possessing underlying patterns that reflect their underlying wholeness. Individuals are viewed as dynamic beings existing in a continuous process within a larger environmental field (Newman, 1994).

**Definition of Terms**

In this research, an effort was made to use the most current, inclusive language available from experts in the fields of both phenomenology and GSM studies. The following definitions reflect the frame of reference used by the researcher to describe the lived health care experience of individuals who identify as transgender:

*Health care*: Efforts made to maintain or restore physical, mental, or emotional well-being especially by trained and licensed professionals (*Merriam-Webster Dictionary*, 2019, Entry 1).

*Transgender*: A term used to describe individuals whose gender identity or gender expression conflicts with the sex assigned at birth (Gay and Lesbian Alliance against Defamation [GLAAD], 2019).

*Cisgender*: The antonym for transgender; this term describes people who identify with the sex assigned at birth (GLAAD, 2019).
*Gender identity:* An individual’s internal, deeply recognized sense of their personal gender (GLAAD, 2019).

*Sexual orientation:* An individual’s enduring physical, romantic, and/or emotional attraction to another individual (GLAAD, 2019).

*Lived experience:* Represents the experiences and choices of an individual along with the knowledge gained from those experiences and choices (Creswell, 2017).

*Descriptive phenomenological research:* Research using first-person reports to illuminate aspects of experiences not fully understood (Creswell, 2017).

*Transphobia:* Intense dislike or prejudice against individuals who identify as transgender (GLAAD, 2019).

*LGBT:* Refers to lesbian, gay, bisexual, and individuals who identify as transgender; may be used as an umbrella term for all members of a sexual and/or gender minority (also LGBTQ or LGBTQIA) (GLAAD, 2019).

*Gender dysphoria:* A condition or psychiatric diagnosis that refers to an incongruity between the way an individual interprets their gender identity and the sex assigned at birth; some advocates embrace this term as a diagnosis because medical treatment requires a diagnosis to qualify for health insurance coverage (GLAAD, 2019).

*Gender expression:* External manifestations of gender that include an individual’s name, preferred pronouns, dress and grooming choices, and/or physical characteristics (GLAAD, 2019).

*Gender non-conforming:* Describes an individual whose gender expressions conflict with conventional expectations of male and female roles (GLAAD, 2019).
**Transition:** A continuum of actions that an individual may exhibit when embracing their gender identity; may include name changes, legal document alterations, hormone therapy, and possibly surgery (GLAAD, 2019).

**Sex:** The assignment of a classification of male or female based on external genitalia at birth (GLAAD, 2019).

**Outing:** Revealing personal information to other people before an individual chooses to disclose it (GLAAD, 2019).

**Passing:** The experience of being seen by others as the identified gender (also stealth) (GLAAD, 2019).

**Delimitations and Limitations**

**Delimitations**

Researchers make decisions during the process of project planning that create parameters that limit the scope of the study. Some of these decisions include the chosen type of research, the population of interest, the research methodology, the research question, and the theoretical framework. For this study, a qualitative inquiry fostered the gathering of information from participants about the meaning of the health care experience. According to Merriam and Tisdell (2015), qualitative research focuses on “understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences” (p. 9). Qualitative research seeks to describe commonalities of a shared experience. Because this description matches the aim of this study, a qualitative--rather than quantitative--approach best supported the study.
This study focused on individuals who identify as transgender and thus excluded individuals who do not identify as transgender. Moreover, investigating the health care experience further narrowed the scope of the research. While some consider a transgender status to be a psychological disorder, others prefer to depathologize the condition and identify it as a state of being. Because of this dichotomy, the researcher searched for a theoretical framework that could be implemented from either perspective. After considering many nursing theories, the HEC theory emerged as the most appropriate choice for this study because it defines health as “the expansion of consciousness as a result of choices made within the context of patterns of behavior” (Newman, 1994, p. 13).

The transgender population is considered a difficult to reach population in research (IOM, 2011), and snowballing promoted the recruitment of participants because a trusted member of the community participated in the process. In an attempt to recruit a heterogenous sample, the inclusion criteria for the study were broad and general. The criteria for participation included identifying as transgender at any stage of transition, being at least 18 years old, having the capacity for self-determination and decision-making, and having experienced health care.

**Limitations**

Despite careful planning, some aspects of research fall outside the researcher’s control and have unexpected effects on the results. These limitations may be inherent due to the nature of the research. While descriptive phenomenology calls upon the researcher to bracket personal experience to reduce bias, absolute bracketing presents a challenge as the researcher may possess unrecognized biases. Additionally, qualitative
research yields data from the subjective perspective of the participants and often occurs within the participants’ natural settings. These factors can make efforts to replicate the study more complex. Other limitations directly related to study participants appear in the discussion presented in Chapter V.

**Summary**

The phenomenon of interest was the lived health care experience of individuals who identify as transgender. The descriptive phenomenological methodology was ideal for this research because it allowed the researcher to explore transgender persons’ interactions with the health care system and to provide a descriptive account from the participants’ perspective(s) of the reality of the encounter(s) (Lopez & Willis, 2004). This approach allowed the investigator to describe and reveal the meaning of the relationship between the subject and the object--or the person and the experience. Because information provided by individuals who identify as transgender comes from their worldview, a richer description of health care experiences among this population was revealed.
CHAPTER II
LITERATURE REVIEW

Introduction

The objective of providing a scholarly review of existing literature regarding health care experiences of individuals who identify as transgender provides the foundation for this chapter. Organization of the chapter appears as follows: The first section introduces the theoretical framework for the study, Margaret Newman’s health as expanding consciousness. The second section focuses on the health disparities and the inequities faced by the marginalized transgender community. The third section illuminates the current state of health care for individuals who identify as transgender in the United States. Finally, the last section highlights recent research results along with knowledge gaps identified through analysis of the literature.

The researcher performed an extensive literature review using a variety of databases including the Cumulative Index to Nursing and Allied Health (CINAHL), Ovid Technologies, Inc. (OVID), ProQuest Direct, and Elton B. Stephens, Co. (EBSCO). Because of the recently evolving view of the transgender status as an identity rather than a pathology (Reisner et al., 2016), the literature search was limited to the years 2000 through 2018. Search terms used included: health care needs of individuals who identify as transgender, gender minority health, gender queer health, health care disparities of individuals who identify as transgender, gender minority health disparities, gender queer
health disparities, transgender barriers to access, gender minority barriers to access, gender queer barriers to access, qualitative transgender research, gender minority qualitative research, gender queer qualitative research, transgender research, gender minority research, and gender queer research. Frequently cited classic works encountered in the literature were also included. The basis for review inclusion consisted of appraisal of abstracts for significant related content and the absence of serious methodological flaws.

**Health as Expanding Consciousness**

Margaret Newman developed the theory of health as expanding consciousness after becoming acquainted with Martha Roger’s theory of unitary human beings (Newman, 1994). Further theoretical support for HEC comes from the works of Bentov, Bohm, Prigogine, Whitmont, and Young (Newman, 1994). Congruent with the unitary-transformative nursing paradigm, the focus of Newman’s theory lies in a search for patterns of wholeness rather than the prediction or identification of the etiology of disease (Musker & Kagan, 2011). Moreover, rather than fixating on finding a cure, nursing actions include the process of pattern recognition and “to recognize it as information that depicts the whole and relate to it as it unfolds” (Newman, 1994, p. 13). Although the impetus for this theory centered on a concern for individuals for whom health without illness or disability was not feasible, the theory has evolved to include each person without regard to the presence or absence of illness or disability (Newman, 1994). Health as expanding consciousness theory recognizes that regardless of the situation, every person is part of the universal process of expanding consciousness. The process of expanding consciousness involves “becoming more of oneself, finding greater
meaning in life, and reaching an enhanced connectedness with other people and the world” (Newman, 1994, p. 8).

Assumptions of the Theory

Assumptions contain statements accepted by the theorist and the researcher as given truths without proof. The foundations for the application of a theory rest on its assumptions. Explicit assumptions consist of clearly expressed statements of truth (Marchione, 1993). For Newman, the explicit assumptions of HEC theory originate from the proposition that health comprises a synthesis of disease and non-disease (Marchione, 1993). Implicit assumptions are truths that are implied rather than clearly stated, and many of the implicit assumptions of HEC theory evolved from Roger’s theory of unitary human beings (Marchione, 1993). The explicit and implicit assumptions of the theory are contained in Table 1.
Table 1

Explicit and Implicit Assumptions of Health as Expending Consciousness Theory

<table>
<thead>
<tr>
<th>Explicit Assumption</th>
<th>Implicit Assumption</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health includes conditions once viewed from a pathological perspective.</td>
<td>Humans are open energy systems.</td>
</tr>
<tr>
<td>The “pathology can be evidence of the total life pattern.</td>
<td>Humans are in continual interconnectedness with a universe of open systems (the environment).</td>
</tr>
<tr>
<td>Pathology may exist as a manifestation of a pattern that exists prior to the manifestation of physical or structural changes</td>
<td>Humans are continually engaged in evolving their personal pattern of the whole.</td>
</tr>
<tr>
<td>Removal of the pathology does not change the pathology.</td>
<td>Humans are intuitive, cognitive, affective beings.</td>
</tr>
<tr>
<td>“Illness” may be the only way an individual’s pattern can manifest and therefore, represents health for that individual.</td>
<td>Humans can think abstractly and experience sensations.</td>
</tr>
<tr>
<td>Health is an expansion of consciousness.</td>
<td>Humans are more than the sum of their parts.</td>
</tr>
</tbody>
</table>

Concepts of the Theory

Theoretical concepts allow researchers to understand the basic meaning of a theory. Although they are made up of abstract ideas, concepts allow the researcher to focus on thinking about a problem in a particular way (Marchione, 1993). Four basic concepts form the basis for the HEC theory: consciousness, movement, space, and time. Newman opined that these concepts share an inter-relational status (Marchione, 1993). These relationships are illustrated in Figure 1.
Figure 1. Relationships of concepts of health as expanding consciousness.

Newman (1994) defined consciousness as:

The informational capacity of a system to interact with its environment. In the human system, the informational capacity includes all of our present and developing knowledge about the nervous system, the endocrine system, the immune system, the genetic, and so on. (p. 33)

Interactions allow us to see consciousness in action. The complexity, variability, and capacity for response to the environment allow insight into the development of the human system.

While time and space are strongly interrelated, each of the concepts contains identifiable aspects. Examples of aspects of time include subjective time, time perspective, private time, and shared time. Likewise, aspects of space include personal
space, geographical space, maneuverable space, and life space (Marchione, 1993). The complementary nature of time and space can be seen in everyday life. When a person experiences a decrease in space such as physical or social immobility, their time increases. This increased time provides an opportunity for increased attention to inner space and the changing level of consciousness (Marchione, 1993).

Movement is seen as the fundamental unit of analysis in Newman’s HEC theory and represents “a pivotal choice point in the evolution of human consciousness” (Newman, 1986, p. 58). Movement includes self-awareness, a communication mode, and a means of expression in gesture and speech (Marchione, 1993). Newman illustrated case studies of individuals’ movement, time, space and environment interactions and demonstrated the inextricable links among the concepts (Marchione, 1993).

The potential for human insight achieved at the choice point serves as an integral step in the process and results in recognition of the need for change because prior behaviors no longer produce desired results (Marchione, 1993). Newman (1994) presented human expansion beyond the choice point as an indicator of growth. Transformative action occurring through consciousness expansion is accelerated by the recognition of novel growth needs and engagement in the progressive transitions of decision making.

For Newman, health is consciousness. The process of expanding consciousness occurs before a period of relative stability lasting until some event initiates a large disturbance from which the person eventually emerges at a higher level of organization (Newman, 1994). For the individual who identifies as transgender, the trigger event may be the realization that the current body is in conflict with the view of the true self. The
trigger event disrupts an individual’s previous pattern and presents an opportunity for change. For individuals who identify as transgender, the opportunity for movement often necessitates interactions with health care providers. Increased complexity and diversity characterize the emerging order of transition. With growing awareness, the potential for change and repatterning emerge and the individual can experience increasing integration and complexity of interaction with the environment. Expanding consciousness is manifested by choice and movement toward a new order and increasing complexity (Newman, 1994).

Health as expanding consciousness theory was selected as the guiding framework because the gender transition process aligns with the process of expanding consciousness. Following a relatively stable period, the individual develops an awareness that the body and the personal identity are incongruent. This realization is not a choice; rather it represents a desire to “(become) more of oneself, (find) greater meaning in life, and (reach) an enhanced connectedness with other people and the world” (Newman, 1994, p. 8). For most individuals who identify as transgender, transition involves interacting with the health care system--the choice point that precedes movement. Therefore, the health care experience plays a preeminent role in facilitating or impeding the movement toward expansion of consciousness. Based upon Newman’s theory, understanding the lived health care experience of individuals who identify as transgender presents an opportunity for workers in health care to foster expanding consciousness.

Connections between HEC theory assumptions to the lived health care experience of individuals who identify as transgender are shown in Table 2. An illustration of the HEC
conceputal relationships as applied to the lived health care experience of transgender individuals appears in Figure 2.

Table 2

*Relationships between HEC and Transgender Healthcare*

<table>
<thead>
<tr>
<th>HEC Theory Assumption</th>
<th>Transgender Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health includes conditions once viewed from a pathological perspective.</td>
<td>For someone who experiences gender dysphoria, health may include the recognition of the status and its place in the individual’s expanding consciousness.</td>
</tr>
<tr>
<td>The “pathology” can be outward evidence of the total life pattern</td>
<td>Gender dysphoria may be the outward evidence of a transgender life pattern.</td>
</tr>
<tr>
<td>Pathology may exist as a manifestation of a pattern that exists prior to the manifestation of physical or structural changes.</td>
<td>Pathologies frequently associated with gender dysphoria including depression, suicidal ideation, and self-harm may exist even before an individual recognizes gender dysphoria.</td>
</tr>
<tr>
<td>Removal of the pathology does not change the pathology</td>
<td>Addressing gender dysphoria does not change the individual’s state of having been misgendered at birth.</td>
</tr>
<tr>
<td>“Illness” may be the only way an individual’s pattern can manifest, and therefore represents health for that individual.</td>
<td>Accepting a “diagnosis” of gender dysphoria may be the only way that an individual can become more of oneself and find greater meaning in life.</td>
</tr>
<tr>
<td>Health is an expansion of consciousness.</td>
<td>As transition occurs, the individual becomes “more of oneself, finding greater meaning in life, and reaching an enhanced connectedness with other people and the world” (Newman, 1994, p. 8).</td>
</tr>
</tbody>
</table>
Figure 2. Conceptual relationships of HEC and transgender health care.

The health as expanding consciousness theory has been used as a framework in several phenomenological studies. Zanarini, Gunderson, Marino, Schwartz, and Frankenburg (1989) interviewed individuals with borderline personality disorder to discover themes or patterns and concluded that prior abuse contributed to their condition. Kweon and Lee (2009) used HEC theory along with a phenomenological approach to study the health experience of adolescents suffering from depression. Hanks (2008) relied on HEC to produce a phenomenology of the lived experience of nurse advocacy. All of these researchers relied upon Newman’s theory that patterns (or themes) can emerge as the nurse (or nurse researcher) engages in an experience that allows the nurse to gain a better understanding of the person’s experience within a particular phenomenon.

The rationale for using HEC as the guiding framework for this study came from the view that individual uniqueness is valued and reverence for the human experience is
encouraged. An orientation toward discovering and uncovering insights, meanings, and understanding of human responses is central to the theory and provided a foundation for this phenomenological inquiry. The researcher openly received the messages of participants and gained a greater understanding of their lived experience. Overall, the value of using HEC theory in phenomenology was clearly stated by Margaret Pharris (2011):

Newman sees meaning as almost synonymous with pattern. When nurses engage with people in dialogue focused on meaning, they hold no judgment of good or bad, right or wrong. Nurses regard whatever arises in the evolving pattern in the lives of individuals, families, and communities with a nonjudgmental, authentic presence. (p. 194)

**Transgender Health Disparities and Inequities**

Individuals who identify as transgender bear a greater health burden than their cisgender counterparts. These disparities chronicled by recent research demonstrate the great need for increased attention to the health care experiences of this population group. Previously completed research findings can be categorized to include the areas of physical health disparities, mental health disparities, violent victimization, and high-risk health behaviors.

A study completed by Downing and Prsedworski (2018) offered comprehensive evidence that some disease processes occur more commonly among individuals who identify as transgender. The research they conducted included over 500,000 participants from 31 states. Both transgender and cisgender individuals participated and
self-identified their gender identity, and the information retrieved was compared to present a more accurate evaluation of the health care disparities than had ever been presented before (Downing & Przedworski, 2018).

Within the transgender population, health disparities include a higher incidence of sexually transmitted infections, higher rates of disability, and greater odds of suffering from multiple chronic conditions (Downing & Przedworski, 2018). Asthma, arthritis, diabetes, and depressive disorder comprise the multiple chronic conditions included in the study. Respondents were considered to suffer from multiple chronic conditions if they reported the presence of at least three conditions--two of the aforementioned conditions and at least one additional condition including cancer, stroke, chronic obstructive pulmonary disease, and/or kidney disease (Downing & Przedworski, 2018). Coronary heart disease and myocardial infarctions occurred at a higher rate among male-to-female (MTF) as well as female-to-male (FTM) and gender non-conforming (GNC) study participants (Downing & Przedworski, 2018). Female-to-male individuals suffer a greater burden of arthritis and multiple chronic conditions (Downing & Przedworski, 2018). Members of all transgender groups reported higher levels of disability than cisgender individuals (Downing & Przedworski, 2018). These data support reports from Medicare showing that 71% of gender minority beneficiaries meet the criteria for disability benefits (Dragon, Guerino, Ewald, & Laffan, 2017).

Sexually transmitted infections (STIs) present more frequently among members of the transgender community. In 2017, 2.3 million cases of chlamydia, gonorrhea, and syphilis were diagnosed in the total United States population resulting in an incidence rate of 0.69% for the general population. This number is dwarfed by the rates among
individuals who identify as transgender which range from 7.7 to 14.2% testing positive for the same STIs (CDC, 2018).

The prevalence of human immunodeficiency virus (HIV) among individuals who identify as transgender significantly outweighs the presence of HIV in the cisgender population. The incidence of MTF individuals living with HIV ranges from 22 to 28% as compared to a rate of 0.33% of the general United States population making the rates in the MTF transgender population about 75 times greater than the national average (Centers for Disease Control [CDC], 2017). Moreover, an astounding 56% of Black/African American MTF individuals have HIV (CDC, 2018). This finding correlates with other reports stating that racial minorities in the transgender population bear a profoundly increased burden of disease (Clark, Babu, Wiewel, Opoku, & Crepaz, 2017).

Individuals who identify as transgender are also at a greater risk for mental health difficulties. Because western psychiatry continues to perpetuate the idea that gender incongruity is a mental disorder, all individuals who identify as transgender can be tagged as having a mental health disorder (American Counseling Association, 2010). Recent efforts to move gender incongruity from the “mental disorder” heading to a “condition related to sexual health” description received a welcoming approval in the transgender community (Winter et al., 2016). Nevertheless, most health insurers in tandem with the World Professional Association for Transgender Health (WPATH) recommendations still require the presence of a pathologized diagnosis before providing coverage for related treatments.
Beyond the gender incongruity diagnosis, multiple researchers report the mental health disparities borne by the LGBT community as a whole (Jones-Schenk, 2018; Marbury, 2017; Mirza & Rooney, 2018), but recent reports show that individuals who identify as transgender carry an even greater burden. Regarding depression and suicidal ideation, 41% of individuals who identify as transgender have had suicidal ideation compared to 1.6% of the general population with at least 37.7% of individuals who identify as transgender actually attempting suicide (Winter et al., 2016). Some statistical reports suggest the attempted suicide rates among segments of the transgender population to be as high as 51% (Grant et al., 2011). Additionally, substance use including nicotine, alcohol, and drug use rates are double among individuals who identify as transgender when compared to their cisgender counterparts (Grant et al., 2011).

Violence against members of the transgender community presents a significant health risk. Internationally, 2,982 individuals who identify as transgender were murdered between the years of 2008 and 2018 (Transrespect Versus Transphobia Worldwide [TvT], 2019) with approximately one-third of those homicides occurring within the last three years and upward trends reflected each year. More specifically, 28 gender non-conforming people were victims of homicide in the United States during the 2018 reporting year (TvT, 2019). Other forms of violence are much more widespread. School-age gender non-conforming youth reported that 35% experienced physical violence and 12% reported sexual violence once their gender identity was expressed (Grant et al., 2011). The same study showed that 7% of transgender adults experienced physical assault in the workplace and 6% encountered sexual assault in the workplace (Grant et al., 2011). Another risk factor for violence relates to the high number of
individuals who identify as transgender who are employed as sex workers where reports of physical violence and emotional abuse abound (Nadal, Davidoff, & Fujii-Doe, 2014). Additionally, the reports of violence against individuals who identify as transgender extend into the criminal justice system and the health care system in the United States (Nadal, Erazo, Final, Marillo-Parilla, & Han, 2018).

High-risk behaviors present another significant risk for individuals who identify as transgender. As mentioned above, nicotine, alcohol, and drug use occur disproportionately in the transgender community, (Grant et al., 2011) and workplace discrimination makes affiliation in the sex work industry an appealing alternative for some individuals who identify as transgender (Nadal et al., 2014). Health care postponement and deferment present another high-risk health behavior. Results from a survey in Massachusetts reported astounding results:

Public accommodations discrimination in the past 12 months in health care settings was independently associated with a 31% to 81% increased risk of adverse emotional and physical symptoms and a 2-fold to 3-fold increased risk of postponement of needed care when sick or injured and of preventive or routine health care, adjusting for discrimination in other public accommodations settings (which also conferred an additional 20% to 77% risk per discrimination setting endorsed). (Reisner et al., 2015, p. 510)

**Current State of Transgender Health Care**

As established in the introductory section, gender non-conforming behaviors appear in the earliest recorded human history, however, the recognition of the need for specific guidelines and legislation to address the health care disparities and care barriers
of this population remains in its relative infancy. In addition to acute care needs and health screenings, individuals who identify as transgender often desire specific treatments related to transition. The first well-documented case of modernized treatment to address gender incongruity occurred in 1917 when Dr. Albert Hart experienced female-to-male transition surgery (The Proud Trust, 2019). Since that time, the movement to acknowledge and support individuals who identify as gender non-conformists evolved on several fronts including medical considerations, ethical considerations, legal and financial issues, and the psychological and social consequences of these developments.

**Medical Considerations**

Individuals who identify as transgender have acute care needs and benefit from preventive health measures. Unfortunately, members of the transgender population often delay or defer interactions with health care providers. Additionally, many individuals who identify as transgender desire medical treatments that support the transition process. The transition from one gender to another exists on a spectrum from making a very private and unpublicized determination to a more drastic transformation involving hormone therapy and gender confirmation surgery. Currently in the United States, many people who choose to undergo hormone therapy or surgery must first subject themselves to several prerequisite steps including completing a lengthy psychological evaluation, living in the role of the targeted gender for a prescribed period of time, and obtaining two recommendations from medical professionals stating that medical intervention is the most appropriate course of treatment for the individual (WPATH, 2012). While many physicians subscribe to the standards of care disseminated by WPATH, controversy exists surrounding the issue of the appropriate course of treatment if the patient has HIV
or hepatitis (WPATH, 2012). Other considerations that may affect a patient’s eligibility for medical intervention include obesity, smoking cessation, and willingness to endure hormone replacement abstinence before surgery (WPATH, 2012). Sexual satisfaction after gender confirmation surgery must also be considered by the patient and provider. Recent research reports that MTF patients report sexual satisfaction about equal to that of cisgender women, while FTM patients reports a lower sense of sexual satisfaction than cisgender males (Wierckx et al., 2011).

**Ethical Considerations**

A recent ethnography focused on the ethical dilemmas associated with transitional care (Gerritse et al., 2018). The ethical themes identified include the following:

1. assessing eligibility based on age, level of distress related to gender incongruity, understanding of the long-term realities of treatment, the ability to cope with treatment effects, and the level of medical criterion that should represent exclusion criteria;
2. content of the proposed treatment and care based on normative societal expectations and the implications of current evidence and scientific ambiguities; (3) the interconnectedness of different aspects of care and whether a sequential order and provider consensus is necessary; (4) the role of clinical guidelines with regard to flexibility and deviations based on patient individuality; (5) beliefs regarding gender identity such as determination of gender dysphoria diagnosis and determination of dysphoria by parents on behalf of minors, and (6) the decision-making process and whose opinion carries the most weight: the patient, the provider(s), or the family members of the patient. Overall, the end result of this ethnography states:
The main clinical implication of this research is that transgender-affirming medical care requires continuous moral deliberation and sensitivity toward (normative) intuitions, presuppositions, claims and changing contextual factors. Ongoing moral deliberation on what constitutes good care is in itself an element of (re)constructing good care. (Gerritse et al., 2018, p. 2330)

**Legal and Financial Issues**

Recently, legal protections emerged that ban discrimination based on pre-existing conditions thus implying health care coverage of treatment for individuals previously diagnosed with gender dysphoria (ACLU, 2018). Additionally, this policy (Section 1557 of the Patient Protection and Affordable Care Act [ACA]) prohibited the refusal of treatment by health care workers to individuals who identify as transgender (Kodjak, 2018). Unfortunately for the transgender population, many of the anti-discrimination laws speak to sexual orientation and exclude individuals who identify as transgender unless the law specifically states that sexual orientation includes gender identity (ACLU, 2018). Moreover, in 2016, a judge rendered the 2010 ACA provisions as unenforceable (Kodjak, 2018).

Some insurance companies require that policy holders disclose their gender and then only cover procedures and treatments that are deemed “gender congruent” (ACLU, 2018). Medicare covers gender confirmation surgery, but the actual procedures covered remain unclear and many physicians refuse to provide this service due to the low reimbursement rates associated with Medicare (ACLU, 2018). At this time, only six states provide coverage for gender confirmation surgery through Medicaid (ACLU, 2018). Private insurance companies who sell policies to people in the nine states that ban
gender identity discrimination must cover transition-related treatments (ACLU, 2018). Finally, many states require the completion of gender confirmation surgery as a prerequisite to changing one’s gender expression on legal documents (ACLU, 2018).

**Barriers to Health Care for Individuals Who Identify as Transgender**

A 2016 literature review that focused on barriers to health care for individuals who identify as transgender highlighted problems that exist in multiple arenas (Safer et al., 2016). The most common barriers to health care reported include lack of access to knowledgeable providers, financial barriers, and discrimination (Safer et al., 2016). The report notes that most of these identified barriers come from self-reports by individuals who identify as transgender rather than from direct methods (Safer et al., 2016). Because the self-reported database comprises the available knowledge at this time, the barriers discussed below come from the perspectives of the transgender community.

**Dearth of providers.** The health care needs of individuals who identify as transgender include usual acute care issues, population-specific mental health needs, and medical interventions such as hormone therapy and/or surgery. The most commonly reported barrier to health care for individuals who identify as transgender centers on the paucity of providers adequately prepared to care for transgender patients (Safer et al., 2016; Sanchez, Sanchez, & Danoff, 2009). A recent survey of individuals who identify as transgender in Massachusetts indicated that a full 100% of participants believed that health care professionals lack basic knowledge about even routine care including annual physicals and gynecological care for patients who identify as transgender (Harvard
Pilgrim Health Care Foundation [HPHCF], 2016). This finding correlates with reports that inadequate provider training specifically addressing health care of individuals who identify as transgender continues among medical students, nursing students, and practicing health care providers (Korpaisarn & Safer, 2018; Laurie, 2005; McNeil & Elertson, 2018).

In the United States, approximately 620 surgeons currently offer some form of gender confirming surgery including facial feminization and masculinization surgery, body sculpting, breast augmentation and reduction, reconstructive urology, genital reconstruction, tracheal shaving, and hair grafting (Trans Health Care, 2019). Each surgeon offers different services and only a small percentage of these professionals offer “bottom surgery”—procedures performed to align the physiologic genitalia with the patient’s gender identity (Trans Health Care, 2019). The need for an individual who identifies as transgender to seek specific services from several providers results in a cafeteria style approach to care needs. Further complicating this issue is the lack of mental health providers who are trained to address gender identity issues—a frequent prerequisite for gender affirming treatments (ACLU, 2018; HPHCF, 2016). The low number of pediatric endocrinologists who can prescribe puberty suppressing agents to children who desire this intervention also presents a formidable barrier (HPHCF, 2016).

**Financial barriers.** The transgender community carries a greater load of socioeconomic disadvantage than their cisgender counterparts (Gonzales & Henning-Smith, 2017). About one-third of individuals who identify as transgender surveyed reported deferring a needed doctor visit because of cost. People who identify as transgender are more likely to be without health insurance (Gonzales & Henning-Smith,
Female-to-male individuals are more likely to have no usual source of care and most gender nonconforming adults suffer a greater burden of unmet medical care needs related to cost (Gonzales & Henning-Smith, 2017).

The cost of surgery to transition presents a significant barrier to individuals who identify as transgender. Estimates for the cost of transition surgeries range from $100,000 to $150,000 (Gonzales & Henning-Smith, 2017). While all states do require insurance providers to sell policies to individuals who identify as transgender, the anti-discrimination laws are still unclear. Furthermore, the wait to see a provider in the states with laws friendly to individuals who identify as transgender results in another barrier (ACLU, 2018). Provisions in the ACA afforded relief from the pre-existing conditions clause that many insurance providers used as a basis to deny coverage for treatment of gender identity disorder, but many insurers set conditions and do not automatically approve payment (ACLU, 2018). A nationwide survey conducted by the National Center for Transgender Equality (NCTE) (2015) indicates that among survey respondents, 55% were denied coverage for transition-related surgeries, 42% could not get complete coverage for needed treatments, 25% were denied coverage for hormone therapy, and 13% were denied coverage for care that was deemed gender-specific. Even for those individuals who have health insurance, the out-of-pocket costs for ongoing hormone treatments, hair electrolysis, and illnesses associated with complications of gender affirming care may be prohibitive (Dragon et al., 2017). Additionally, 21% of individuals who identify as transgender surveyed reported that although transition surgeries were covered by their insurance carriers, there were no available in-network providers.
Discrimination. Many factors related to discrimination in health care affect individuals who identify as transgender. Geographic location, being recognized as transgender, religiosity, and social determinants may contribute to this mistreatment (Rodriguez, Agardh, & Asamoah, 2018). More than one-third of individuals who identify as transgender report having experienced some form of discrimination in a health care setting (Rodriguez et al., 2018). Key findings of the National Transgender Discrimination Survey (NCTE, 2015) include reports of refusal of care, discrimination, and harassment. Among those who responded to the survey, 19% reported being refused care because of their transgender or gender non-conforming status, 28% reported postponing needed care related to previous experiences of discrimination and/or disrespect, and 28% reported experiencing harassment in a health care setting (NCTE, 2015). Negative experiences in health care included being asked unnecessary or invasive questions not related to the purpose of the visit, providers refusing to provide transition-related care, staff members and providers using harsh or abusive language, and experiencing outright violence such as physical roughness, physical attacks, and/or sexual assault (NCTE, 2015).

Current State of the Science

Advances in Transgender Health Care

The news about health care for the transgender community is not all negative. Leading the charge in advancements is Fenway Health in Massachusetts. Fenway Health states that their mission is to “enhance the well-being of the lesbian, gay, bisexual, and transgender community and all people in our neighborhoods and beyond through access to the highest quality care, research, education, and advocacy” (Fenway Health, 2019,
Mission Statement 1). Some of the advances heralded by this institution include the founding of the Fenway Community Health Center in 1971, the advent of anonymous STD testing in 1976, initiation of investigation into viral immune disorders and initiation of community mental health services in 1980, diagnosis of AIDS in 1981, anonymous HIV testing in 1984, continuing research related to HIV treatment and prevention, the forming of a same-sex pre-marital counseling center, the launch of the Transgender Health Center in 2004, and a patient load of over 100,000 individuals in 2016 (Fenway Health, 2019).

Health Care Research

While the body of knowledge addressing health care of individuals who identify as transgender continues to expand, the experiences of this population remain the subject of a paucity of focused research. Both clinical experience and research suggest that both acute medical care and transition-related procedures can be an integral component to achieving well-being for individuals who identify as transgender (Feldman et al., 2016). Most literature focusing on health care in the transgender population centers on several cross-sectional studies, a series of retrospective studies with large numbers of participants, and many case reports (Feldman et al., 2016). Brown and Jones (2016) conducted a survey of 5,135 transgender veterans that led to the publication of findings focused on racial health disparities, mental health disparities, and the incidence of breast cancer. In 2015, 27,715 individuals who identify as transgender provided survey responses to the National Center for Transgender Equality’s study about discrimination experienced by members of the transgender population (NCTE, 2015). Additionally, the Colorado Health Transgender Health Survey included over 400 transgender respondents
who answered survey questions related to health found in the Behavioral Risk Factor Surveillance Survey (One Colorado Education Fund, 2017). These studies represent the largest surveys to date that address health care experiences of individuals who identify as transgender.

Some medical research completed focuses on hormone therapy and its physiologic effects, the long-term effects of hormones and surgery on psychosocial outcomes, and the incidence of cancer and diabetes among individuals who identify as transgender receiving cross-sex hormone therapy. Because HIV infection plays a prominent role in health care needs of individuals who identify as transgender, researchers have sought to identify risk factors, barriers to care, and interventions to combat HIV within the transgender population (Marbury, 2017). Another area of research focus centers on the mental health difficulties experienced by many individuals who identify as transgender; these studies consist mostly of surveys and case studies (Marbury, 2017).

Dr. Tamar Reisman recently published the results of a successful intervention to induce lactation in a MTF individual (as cited in Milks, 2018). Dr. Reisman expresses optimism about the future of health care for the transgender population stating, “There’s a huge paucity in the literature regarding trans medicine, and people are eagerly trying to fill in those holes. Everything you can think of is being studied” (as cited in Milks, 2018, p. 6).

Qualitative studies involving individuals who identify as transgender often occur in conjunction with studies involving lesbian, gay, and bisexual populations. Because gender identity represents a different issue than sexual orientation, these studies fail to
capture the experiences that are unique to individuals who identify as transgender. Recent qualitative research involving only individuals who identify as transgender centers on relationship partners, adolescent experiences in primary care and their perceptions of treatment, identity concealment, nurses’ knowledge of health care needs of individuals who identify as transgender needs, and lived experiences of population subsets including prisoners, veterans, and transgender women seeking gynecologic care (Mirza & Rooney, 2018).

Because of this researcher’s interest in the lived health care experiences of individuals who identify as transgender, four studies that centered on the transgender health care experience received focused consideration: (1) Samuels, Tape, Garber, Bowman, and Choo’s (2018) study of emergency department visits; (2) Guss et al.’s (2018) interviews about positive health care experiences; (3) Fowler et al.’s (2018) adolescent focus group interviews; and (4) Roller, Sedlak, and Drauker’s (2015) analysis of interviews with 25 individuals who identify as transgender.

Samuels et al. (2018) surveyed and completed focus group interviews with 32 individuals who identify as transgender following emergency department visits. Major findings associated with this study include complaints of discrimination, long wait times, and planned avoidance of the emergency department based on negative experiences. Recommendations from the researchers include staff training and accurate descriptions of sex, gender, and sexual orientation in data gathering. While the sample size of the participants allowed for significant data collection, the fact that all participants discussed emergency department visits limits the scope of the results and their applicability in other settings.
The research conducted by Guss et al. (2018) included seven semi-structured interviews with adolescents who identify as FTM transgender. The researchers focused on the positive aspects of the health care experience and identified thematic elements including use of preferred pronouns, protection of privacy, comfortable physical spaces, appropriate conversation, adequate provider knowledge, and identified medical staff roles. The data gathered related to positive experiences provides basic information that can be used to improve the experience, however the small sample size and its limitation to adolescent males reduces its generalizability.

Four focus groups made up of 31 adolescents comprised the sample for a study conducted by Fowler et al. (2018). Two of the focus groups were reported as having autism. The main findings of this study include the fact that participants prefer to be called “transgender” and that most of the participants had endured negative health experiences. Themes identified include respect for identity and boundaries, proper pronoun use, creation of inclusive record keeping strategies, and recommendations for patient-centered measures to validate identity. The makeup of the sample limits the ability to validate this information with repeated research.

Roller et al. (2015) conducted individual interviews with 25 participants who identify as transgender. The overall essence extracted from the interviews through identification of the themes was “navigating the system,” “needing to move forward,” “doing due diligence,” “finding loopholes,” and “making it work.” The focus of this study centered on overcoming barriers to health care.


Identified Gaps

In 2011, the Institute of Medicine published a research agenda recommendation to promote the efforts of those seeking advancements in LGBT health (IOM, 2011). One of the recommendations of the committee includes the desegregation of individuals who identify as transgender from the LGBT umbrella because the combining of populations “obscures differences among them” (IOM, 2011, Chapter 7). Much of the research completed continues to clump individuals who identify as transgender with sexual minority groups. Consequently, little research exists that focuses on individuals who identify as transgender and the committee issued recommendations to increase this body of knowledge (IOM, 2011). Other recommendations from this report include gaining a better understanding of the demographics of the transgender population, examining the role of social support in the transgender experience, and developing an evidence base that informs decisions about transgender-specific health needs (IOM, 2011). Deemed as “particularly helpful” is the recommendation of “studies aimed at developing innovative ways to conduct research with small and difficult-to-reach populations” (IOM, 2011, Recommendation 5).

Summary

A recent article written by Edmiston (2018) acknowledges that although the body of transgender research is growing, the research remains in its infancy. Edmiston states, “More individuals who identify as transgender are coming out to their providers, but the literature has not caught up with our needs” (Edmiston, 2018, p. 1513). While Edmiston and others opine about the dearth of interventional and longitudinal studies (MacCarthy, Reisner, Nunn, Perez-Brumer, & Operario, 2015), attention is also called to the idea that
cisgender researchers have tended to view individuals who identify as transgender as “unusual or strange” and this issue reduces the quality of the published research (Edmiston, 2018, p. 1513). Research performed within the assumptions of the health as expanding consciousness theory may alleviate some of this bias as the researcher describes the health care experiences of the research participants. While the research performed in this study did not meet all of the 2011 IOM recommendations, it does speak to several identified gaps including segregation of the transgender population from the LGBT umbrella, using innovative techniques to recruit a difficult-to-reach population, and viewing participants through a lens of acceptance with a goal of creating mutual understanding. Therefore, this qualitative research capturing the essence of the health care experience of individuals who identify as transgender stands to broaden the knowledge base available to nurse educators who can recommend and implement curricular changes.
CHAPTER III

METHODOLOGY

Introduction

The number of people identifying as transgender is increasing and the desire among individuals who identify as transgender to acquire gender affirming treatments is also increasing (HPHCF, 2016; Meerwijk & Sevelius, 2017). The majority of individuals who identify as transgender surveyed report dissatisfaction with the care they receive from members of the health care team including physicians, nurses, care technicians, and ancillary staff members (Mirza & Rooney, 2018). Numerous factors affect the care received by individuals who identify as transgender including multiple discriminatory practices (Mirza & Rooney, 2018), a lack of knowledgeable providers (Carabez et al., 2015; Guss et al., 2018; Korpaisarn & Safer, 2018), financial barriers (Gonzales & Henning-Smith, 2017), difficulties in navigating the United States health care system (Roller et al., 2015), and issues related to stigma and marginalization (Wanta & Unger, 2017). Researchers bear a responsibility to increase the body of knowledge that specifically addresses the health needs of the transgender community. Describing the essence of the health care experiences of individuals who identify as transgender based upon data collected from study participants provides insight into the unique health care experience and lays a beginning foundation for the development of strategies to improve
educational efforts in nursing schools and consequently, improve the health care experience of individuals who identify as transgender.

The purpose of this chapter is to discuss the approach used for the study, the inquiry method employed, and the data analysis methods use to answer the research question. The chapter begins with a short review of the study’s purpose and the research question. Next, a discussion of the chosen methodology—descriptive phenomenology—and its philosophical underpinnings occurs. The specific parameters for the study including participant selection, the research setting, the methods of data collection, and the process used for data analysis will follow. This chapter then presents the methodological strategies intended to protect human subjects and to enhance trustworthiness and credibility. Finally, a short summary concludes the chapter.

**Study Purpose and Research Question**

This study sought to gain insight into the lived health care experience of individuals who identify as transgender by describing their reports of the experience and the attached meaning. Clark Moustakas’ approach to transcendental phenomenology was used to address the central research question:

Q1 What is the lived health care experience of individuals who identify as transgender?

The goal of this study centered on presenting a rich, composite description of the experience that is important to understanding the meaning of health care for individuals who identify as transgender through examination of the shared experiences of participants recalling health care encounters.
Research Methodology

The selected methodology for the study is a qualitative phenomenological approach. Phenomenological studies aim to describe the meaning of a phenomenon for several individuals by focusing on commonalities experienced by the participants (Creswell, 2017). The overall purpose of phenomenology is to “reduce individual experiences with a phenomenon to a description of the universal essence” (Creswell, 2017, p. 58). The procedure for this qualitative research was to identify a phenomenon—health care experiences of individuals who identify as transgender—and then collect experiential data from appropriate study participants. Following data collection, the researcher composed a composite description of the essence of the experience for all of the study participants (Creswell, 2017). Rather than dwelling upon the researcher’s point of view (etic), the participant’s story and their intention to convey meaning (emic) provide the focus of qualitative research (de Chesnay, 2015).

Philosophical Framework

The qualitative researcher holds beliefs and philosophical assumptions that accompany the choice of theory used to guide the research (Creswell, 2017). Recommendations from Creswell (2017) suggest that the researcher understand the assumptions and beliefs that inform qualitative research and that a discussion of these philosophical aspects should be included in written research. Based upon this recommendation, a discussion of transcendental phenomenology follows.

Moustakas states that transcendental phenomenology, originally developed by Husserl, seeks to understand human experience through qualitative research methodology using a philosophical approach (Moustakas, 1994). Setting aside all preconceived ideas
and viewing the phenomenon with an unencumbered point of view allows the phenomenon’s true meaning to naturally emerge with a unique identity (Moustakas, 1994). These prerequisites for the researcher promote phenomenology as an appropriate tool for investigating and describing the shared experiences of a phenomenon. Blum (2012) describes phenomenology as “seek[ing] to describe and interpret the perspective of the subject or the . . . experience that the subject regards as real” (Blum, 2012, p. 1030). Padgett (2008) more succinctly states that phenomenology involves “explor[ing] the lived experience of a phenomenon” (Padgett, 2008, p. 35). Moustakas relies on the Greek origins of the word “phenomenology” to further explain its purpose. Phenomenon comes from the Greek word “phaenesthai” that means to “flare up” or “appear” along with its construct, “phaino,” that means “to bring to light” (Moustakas, 1994, p. 26).

**Epoche**

“Bringing light” (Moustakas, 1994, p. 26) allows an authentic viewing of the phenomenon because of the provision of clarity, but this unencumbered vision requires epoche on the part of the researcher (Sheehan, 2014). The Greek word “epoche” means “to stay away from or abstain” (Moustakas, 1994, p. 85) and was used by Husserl to introduce the concept of segregating one’s thoughts, beliefs, and judgments which may influence the researcher. Moustakas clarifies that epoche involves the researcher’s conscious process of identifying and quarantining patterns of thought that may occur unconsciously. Because epoche is a process, the need to “suspend everything that interferes with fresh vision” (Moustakas, 1994, p. 86) must occur continuously during the research process (Moustakas, 1994). Epoche occurs only through acknowledgement of the researcher’s previous thought processes and the intentional act of repeatedly setting
them aside (Moustakas, 1994). The advantage of epoche lies in the ability of the researcher to “perceive and receive that which is communicated without tainting its purity with preconceived beliefs, thoughts, or judgments” (Sheehan, 2014, p. 11).

Moustakas recommends bracketing, or the setting aside of the researcher’s own experiences as much as possible, when conducting phenomenological research. While Moustakas states that true epoche is difficult to achieve, the act on the part of the researcher of describing personal experiences and bracketing out their own views allows the researcher to “perceive freshly” “as if for the first time” (Moustakas, 1994, p. 34).

**Noesis and Noema**

Preconceived ideas emerge from experiences that result in individual meanings. The appearance of objects involved in the experiences constitute the noema which Moustakas defined as “not the real object but the phenomenon,” “not the tree but the appearance of the tree” (Moustakas, 1994, p. 29). The noema, or appearance of an object, is derived from factors unique to the experience of each individual. Considering the example of the tree, the noema may be influenced by the observer’s angle of sight, the observer’s visual acuity, and the observer’s past experiences (Moustakas, 1994). Noema ascribes meaning to an object or a feeling while respecting that each individual’s meaning derives from their own experience. Noesis, which is inseparable from noema, refers to internal structuring that informs the interpretation of the noema. Moustakas (1994) describes noesis as the “act of perceiving, feeling, thinking, remembering, or judging” (p. 69). The noema (social phenomenon) depends upon the noesis (a framework for experiencing). For research to be legitimate, noesis must be set aside when observing the noema and through this repeated exercise, epoche is achieved.
Rationale for Study Design

Transcendental phenomenology served as an appropriate vehicle for conducting this research based on the desire of the researcher to set aside personal experience that might influence data interpretation. The researcher considered the health care experience as if seeing it for the first time through the reports from individuals who identify as transgender, whose voices may have been silenced. The researcher extracted the essence of the participants’ experiences based upon their textural descriptions. The structural description of the essence was developed through the synthesis of the participant experiences supported by their verbatim statements.

Because of the continuous evolution of phenomenology, nurse researchers may choose from several phenomenological methods. The different options align with historical phenomenologists such as Heidegger and Husserl, but they have distinctive features regarding procedures and techniques (Creswell, 2017). Moustakas provides a synthesis of the works of past phenomenological researchers to prescribe a method for conducting research and gathering data (Creswell, 2017). Creswell (2017) outlines the major procedural steps that should occur during this process. First, the researcher must determine whether or not the phenomenological approach provides an appropriate fit for the research question. Problems best suited for this type of research are those in which understanding of several individuals’ commonalities related to an experience can be used to develop deeper descriptive meanings that can form the basis for development of practices or policies. Next, the phenomenon of interest must be identified and articulated by the researcher. Following this identification, the researcher should recognize and discuss broad philosophical assumptions related to phenomenology and bracket out their
own experiences to the furthest possible extent. The next step occurs as the researcher collects data from people experiencing the phenomenon. This task can be performed through in-depth or repeated interviews with several individuals. Finally, the researcher should ask broad general questions regarding the participants’ experience in terms of the phenomenon and the situations that may have affected those experiences.

Once a phenomenon is identified, a question is formed, and participants are interviewed, data analysis occurs. Creswell (2017) also recommends a stepwise approach to the data analysis. First, the researcher employs horizontalization using the data obtained from the broad, general questions. The researcher carefully studies the transcriptions from interviews looking for significant statements that contribute to the understanding of how the participants experienced the phenomenon. The significant statements then suggest clusters of meaning that can be organized into themes. Next, textual description occurs next as the researcher uses the significant statements and themes to write a description of the experiences as reported by the participants. Structural description also comes from the significant statements and themes and reveals the influencing context or settings associated with the participants’ experience. The third step requires the researcher to compose a written description of their own experiences that require bracketing. Creswell suggests that this step can be included in a research methods discussion regarding the researcher’s role. Finally, from the structural and textual descriptions, the researcher extracts the essence of the phenomenon which is based on the common experiences of the participants. This essence shows that all of the experiences possess an underlying structure that will allow those who read the
phenomenology to feel that they better understand what the experience is like for the participants (Creswell, 2017).

Researchers conducting phenomenological studies demonstrate an interest in the life experiences of the research participants in relation to a particular phenomenon (Creswell, 2017). As the researcher brackets biases and preconceived notions, the feelings, perceptions, and perspectives of the participants are more accurately described by the researcher. Phenomenology was appropriate for this study because it afforded the researcher the opportunity to explore the lived health care experiences of individuals who identify as transgender in order to create a deeper understanding of the meaning of this experience.

Assumptions of the Research Design

The researcher used qualitative phenomenology to address the purpose of this study and acknowledged four assumptions. First, health care experience includes all activities associated with seeking, obtaining, and paying for services intended to maintain and/or enhance the participants’ wellbeing. Second, participants tell the truth and accurately recall their experiences. Third, use of the qualitative method will produce comprehensive findings to address gaps in the existing body of knowledge. Fourth, all individuals who identify as transgender have needs that comprise their health and well-being.
Study Parameters

Setting

The setting for this study was the natural environment of the participants. As suggested by the Institute of Medicine recommendation in 2011, this researcher utilized novel approaches to make contact with and interview the participants who may have otherwise been difficult to recruit (IOM, 2011). Once participants agreed to engage in the research study, they chose a setting where they felt comfortable to complete an in-depth interview. Some participants were in their homes while some went just outside their home to promote privacy and to reduce distractions. Two participants used a computer in a library to complete the interview. These two participants used headphones and temporarily suspended the interview when other library users entered the area. For the researcher, the interviews were conducted from either the home office or the professional office to allow for privacy and protection of the participants. ZOOM Cloud Meetings technology and other virtual presence technologies including FaceTime and Hang Outs were used for the interviews so that the researcher and participants could fully engage in a virtual face-to-face experience. The participants were able to download the ZOOM application free-of-charge to any handheld electronic device or personal computer. The use of FaceTime and Hang Outs occurred at the request of some of the participants who did not want to download Zoom technology. The researcher visualized the participants during the interview so that body language and facial expressions would help convey the meaning(s) attached to their experiences. The interview sessions were recorded and stored on the researcher’s computer that is kept in a locked room. The researcher destroyed these recordings following transcription of the conversations.
Sampling Strategy

Prior to participant recruitment, the researcher sought and secured appropriate Institutional Review Board (IRB) approval (Appendix A). One important aspect of sampling for a qualitative study involves reaching participants who have all experienced a phenomenon and can articulate their experience (Polit & Beck, 2014). A snowball sampling strategy depends upon early participants to recruit other participants who qualify for a study. This strategy is useful when potential participants may be hard to find (Polit & Beck, 2014). One of the criticisms of previously conducted research in the transgender community centers on the recruitment of study participants from clinical databases (Marbury, 2017). This purposive sampling may result in a very homogenized population sample such as MTF HIV patients or FTM hormone therapy recipients. By using snowballing, a variant of convenience sampling (Polit & Beck, 2014), the researcher hoped to reach a more heterogenous sample of the transgender population.

Participants recruited were required to meet the following inclusion criteria: self-identification as a transgender person at any stage of the transition process; over 18 years of age; previous experience with accessing or attempting to access health care services; and self-identification as being of sound reasoning ability and self-determination.

After contacting a member of a local online transgender support group through Facebook Messenger, the researcher provided this contact person with an electronic copy of the recruitment document (Appendix B) containing the researcher’s contact information. Additionally, the researcher made contact with the administrator of a second Facebook transgender support group and received approval to post a picture of the
recruitment flyer on the group’s site. Interested parties were encouraged to contact the researcher by telephone or email to schedule the interview. The recruitment flyer post on Facebook included the purpose of the study, its design, and the contact information of the researcher. Interested individuals were encouraged to respond by replying to the post or sending a private message through Facebook Messenger. Early participants were encouraged to invite other members of the transgender community to participate. Two people responded to this invitation and scheduled interviews. Disappointed with these results, the researcher reconnected with the local support group leader and asked that other possible candidates be invited to participate in the research. That person posted a “tweet” on Twitter, and within three hours, 40 potential participants contacted the researcher either through a text or a phone call. Because the original research proposal specified that a maximum of 25 interviews would be conducted, some potential participants were turned away. Among the 25 people who scheduled interviews, 18 completed the interview process. Seven individuals who were scheduled for an interview did not respond when the researcher called and did not respond to a follow-up text message to set another appointment.

Qualitative research does not rely on a set sample size, but theoretical saturation represents the highest standard by which sample sizes may be determined when conducting health-science research (Creswell, 2017). Data saturation and its variations continue to evolve, and the current understanding of data saturation focuses on continuing to sample until no new data is generated (Creswell, 2017). Moustakas states that a sample size of 5 to 25 qualified individuals usually allows for data saturation to occur (as cited in Creswell, 2017). Conversely, some researchers argue that saturation
may not be the best indicator of quality research and that instead, the researcher should focus on obtaining richness of information (O’Reilly & Parker, 2012). Predetermining the needed sample size presented challenges based on the ambiguity of research regarding qualitative sampling sizes. The researcher planned to interview no more than 25 participants based upon recommendations from the IRB. Implementation of a flexible approach guided by insight from peer reviewers allowed the researcher to determine the appropriateness and adequacy of the sample size. While data saturation seemed evident to the researcher after 14 interviews, the researcher felt morally obligated to complete all scheduled interviews and to provide the promised honorarium to the 18 participants who completed the interview.

**Data Collection**

The researcher functioned as the primary instrument of data collection in this qualitative study. Virtual face-to-face interviews were used to capture the descriptions of the health care experience of individuals who identify as transgender. An inclusion questionnaire (Appendix D) was used at the beginning of the interview to ensure that participants met the inclusion requirements. Next, participants were asked to choose a pseudonym. During the interviews, other demographic information emerged that heightened the description of the experience and this information was recorded as part of the data collection process. Participants talked about their jobs, the areas where they live, their age, and other demographic information. The researcher recorded field notes and kept a journal that contains observations, impressions, and memos obtained during the research process. The field notes were especially useful because both recording devices
failed during one of the interviews. While no direct quotes were available for this interview, the information provided by the individual did become part of the data set.

The interviews were arranged and conducted in neutral settings as determined by the participants with the researcher working from a private office. Study participants also directed the timing of the interviews to maximize the depth of the interview. The interviews occurred during a 60- to 90-minute time block reserved specifically for the research purpose. While the researcher planned to use ZOOM meeting technology to conduct the interviews, other virtual interview arrangements were made at the participants’ requests. Before the interviews began, the researcher reviewed the qualifying criteria for study inclusion and discussed the meaning of consent to participate. Additionally, the researcher provided information regarding the overall aim of the study.

The researcher used an interview guide (Appendix E) to provide the focus for the interaction and asked probing follow-up questions to elicit the meaning of the participants’ experiences. A semi-structured interview represents a vehicle for the researcher to be more flexible in the interview process and use open-ended and less structured questions (Creswell, 2017). The participants were asked to share their health care experiences with the open-ended prompt, “Please tell me anything that you would like to share about your health care experiences.” A few participants asked for a more detailed question, and the researcher clarified the question by saying, “You can talk about any experience you have had with health care.” The researcher interrupted only when follow-up questions would allow for detail clarification or foster the sharing of more information. The researcher manually recorded field notes, and, per the consent, video
recordings of the interviews were obtained. At the conclusion of each interview, the participants were asked if they would like to add to or clarify anything that was presented during the interview. Participation was voluntary, and no coercion was involved. During one interview, a participant cried, and the researcher asked whether or not the interview should continue. This individual clearly stated a willingness to complete the interview. The participants were thanked for their time and participation by receiving a $45 honorarium in the form of a gift card or an electronic fund transfer through PayPal or Venmo. The National Institutes of Health recognize that the inclusion of an honorarium facilitates recruitment and demonstrates the researcher’s respect for the time of the participant (Grady, 2005). All participants received the honorarium and this fact was verified through text messaging or e-mail with each participant.

**Study Data and Analysis**

Interviews with 18 individuals who identify as transgender and volunteered as research participants contributed to the data set for the study. The researcher’s field notes and journal entries added to the achievement of epoche and thus, became part of the data as well. Due to the failure of both recording devices during one interview, the researcher used hand-written notes recorded during the interview to document that participant’s comments. The interview transcripts, notes from one interview, field notes, and the researcher’s journal entries comprised the study data. Details about the interviews and the participants appear in the following sections.

**Interviews**

Each study participant chose the setting for their interview and the researcher conducted the interviews from a private office. Most participants remained in their
homes for the interview, but two individuals stepped outside to promote privacy and two other individuals used public computers and headphones to complete the process. All of the participants appeared eager to talk about their health care experiences, and using virtual face-to-face technology allowed the researcher to include emotional and non-verbal responses. One participant cried during the interview and was offered the opportunity to withdraw or take a break. This participant chose to continue the interview and seemed to recover within moments of the episode. Several of the participants avoided eye contact when speaking about health care, but they became more engaged when discussing demographic information and making arrangements for payment of the honorarium. Additionally, some participants exhibited discomfort when speaking about health care experiences as evidenced by halting speech patterns and taking time to choose words carefully. Conversations not related to health care experiences seemed to flow easily and provided for a relaxed exchange. One interview lasted only 14 minutes, and a different interview lasted for about 50 minutes. The average length of the interviews was 28 minutes.

The researcher used the interview guide (Appendix E) approved by the IRB to elicit participant responses. Before talking about health care experiences, the researcher reiterated the rights of research participants to each individual and ensured the receipt of signed informed consent documents (Appendix C). As part of this process, every participant chose a pseudonym for themselves that was used in all data transcription. Participants also received information about available psychological support services (Appendix F).
Once these tasks were completed, the researcher asked the participants to talk about whatever information they wanted to share. Although the study purpose had been included in the consent form, many participants initially asked what they should include in their interview. The researcher explained the duty to avoid influencing the conversation and skewing data results, then encouraged participants to share whatever information they deemed important. The researcher did ask some follow-up questions for clarification and richer description such as, “What do you mean by feeling safe?” or “Did obtaining the medication require you to use a compounding pharmacy?” One other question asked of each participant was, “If there were one concept that I could teach nursing students about providing health care to individuals who identify as transgender, what should that be?” This question allowed the researcher to glean valuable insight from the participants about the most important aspects of their health care experience.

**Participants**

The individuals who participated in the study include 18 people who self-identify as transgender. Each participant contacted the researcher through a phone call or text message to indicate interest in being included in the research, and the researcher responded with an offer to schedule an interview date and time. Altogether, 25 people scheduled interviews, but 7 people did not respond to the researcher when contacted at the agreed upon time. Eighteen people completed the interviews and did not indicate in any way that their interview should be excluded from the data. All of the participants were between the ages of 18 and 40. Three participants had recognized their transgender status but had not yet received any transgender-related services. One of these 3 individuals remained closeted about their transgender identity. Fifteen participants
reported using hormone therapy and of those 15, two individuals had received transgender-related surgical interventions. Seventeen participants reside in the United States, and 1 person contacted the researcher from Europe. Most participants spoke about being employed, and 3 were full-time students at the time of the interview. Seventy-two percent of participants identified as male-to-female, and 28% identified as female to male. Fifteen participants reported having health insurance. The demographic data obtained are summarized in Table 3.
Table 3

Participant Demographic Information

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender Identity</th>
<th>Geographic Area</th>
<th>Employment Status</th>
<th>Insurance Status</th>
<th>Stage of Transition</th>
<th>Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chloe</td>
<td>MtF</td>
<td>Western US</td>
<td>Employed</td>
<td>Insured</td>
<td>Closeted; Seeking transgender related health care</td>
<td>26-40</td>
</tr>
<tr>
<td>Alexander</td>
<td>FtM</td>
<td>Eastern US</td>
<td>Student</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Lee</td>
<td>MtF</td>
<td>Northeast US</td>
<td>Student</td>
<td>Insured</td>
<td>Out; Seeking hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Riley</td>
<td>MtF</td>
<td>Northwest US</td>
<td>Employed</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Samuel</td>
<td>FtM</td>
<td>Unspecified US</td>
<td>Employed</td>
<td>Undeclared</td>
<td>Receiving hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Honor</td>
<td>MtF</td>
<td>Southern US</td>
<td>Employed</td>
<td>Uninsured</td>
<td>Receiving hormone therapy</td>
<td>26-40</td>
</tr>
<tr>
<td>Nova</td>
<td>MtF</td>
<td>Unspecified US</td>
<td>Employed</td>
<td>Insured</td>
<td>Receiving hormone therapy; preparing for surgery</td>
<td>25-40</td>
</tr>
<tr>
<td>Raven</td>
<td>MtF</td>
<td>Western US</td>
<td>Employed</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>26-40</td>
</tr>
<tr>
<td>Morgan</td>
<td>MtF</td>
<td>Western US</td>
<td>Employed</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Maria</td>
<td>MtF</td>
<td>Southern US</td>
<td>Undeclared</td>
<td>Insured</td>
<td>Receiving hormone therapy; top surgery</td>
<td>26-40</td>
</tr>
<tr>
<td>Lara</td>
<td>MtF</td>
<td>Europe</td>
<td>Employed</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>26-40</td>
</tr>
<tr>
<td>Kevin</td>
<td>FtM</td>
<td>Western US</td>
<td>Student</td>
<td>Insured</td>
<td>Receiving hormone therapy</td>
<td>18-25</td>
</tr>
<tr>
<td>Kara</td>
<td>MtF</td>
<td>Western US</td>
<td>Undeclared</td>
<td>Insured</td>
<td>Receiving hormone therapy and surgery</td>
<td>26-40</td>
</tr>
</tbody>
</table>
The demographic data revealed that the participants were either classified as young adult (18-25) or middle adult (26-40) and individual interviews allowed the researcher to obtain a richness of detail about each person. In an effort to remain true to the nature of descriptive phenomenology, some details and contextual factors appear in the following participant descriptions. No information is included that could reveal the identity of any participant.

**Chloe.** Chloe hails from the west coast and works at a hospital. The hospital provides health insurance, but Chloe shared that she feels uncomfortable coming out to the insurance company due to feelings of distrust regarding information sharing between the insurer and the employer. Because of this factor, Chloe obtains transgender-related testing and health information from a community clinic. Chloe lives in a progressive area and worries that her transition is stagnant as she tries to resolve the privacy concerns. Respecting confidentiality stands as the most important factor in health care for Chloe.
**Alexander.** Alexander is a full-time student at a university in the northeast United States and feels supported in his transition now that he is living away from home and is surrounded by people who are more accepting of his identity. Alexander reports that his mental health improved dramatically once he gained access to transition hormones. Alexander regularly works with other peoples’ confidential information and stresses the importance of never making assumptions and asking individuals how they want to be identified to prevent unintentional outing in certain situations.

**Lee.** Lee is a recent college graduate now living in the northeastern United States. Lee has made the decision to seek hormone therapy once he starts a new job and is settled in his new residence. Recommendations from members of the LGBT community helped Lee connect with transgender-friendly providers. Lee values health care providers who show awareness of and familiarity with the nature of health care visits for individuals who identify as transgender.

**Riley.** Riley lives in the northwestern United States and reports having a relatively positive experience with health care. She expressed concern about the requirements for individuals who identify as transgender to receive a mental health diagnosis from cisgender providers. She feels a sense of mistrust toward a governmental agency having lists of people who identify as transgender. Riley wants health care workers to recognize that anatomical parts should not be used to categorize people and that individual needs should drive the care provided.

**Samuel.** Samuel works as an online personality and recognizes the need for advocacy and education regarding transgender health care. He spoke of the emotional toll borne by members of the transgender community when interacting with health care
providers. He would like for each individual to determine their own journey and be able to live safely and without labels.

**Honor.** Honor referred to her home environment as the “gayborhood” of a conservative area in the southern United States. She states that decisions about employment and choice of residence are influenced by her ability to continue with hormone therapy. She recognizes that individuals who identify as transgender feel “unheard” and need the validation that comes from health care workers listening and withholding judgement. She also wants transgender health care to be more available and easier to navigate.

**Nova.** Nova shared that persistence helped her in her transitional journey. She expresses an awareness of the discrimination—both intentional and unrecognized—that plagues the transgender community. She also recognizes the stepwise approach that is required to transition and how that process can lead to unintentional outing and danger. Nova says that health care workers can make simple gestures that recognize and validate individuals who identify as transgender.

**Raven.** Raven lives in the western United States and advocates for the transgender community through social media. She uses hormonal therapy and is receiving adjunctive therapies to aid in her transition. She feels fortunate to be able to afford the expenses of transitional health care. Raven spoke about the uncertainty that accompanies interactions with strangers and how simple courtesy, kindness, and validation make health care experiences more bearable. She says that even brief encounters that validate the individual’s existence and transgender status are helpful.
**Morgan.** Morgan is a young adult who lives in a conservative area of the United States. She states that recognizing her transgender status and discontinuing patterns of self-repression contributed greatly to her self-esteem. Morgan discussed the financial responsibility of setting aside funds to ensure that her hormone therapy can continue. She feels that conservative areas do not have the infrastructure in place to respond appropriately to the needs of members of the transgender community.

**Maria.** Maria advocates for the transgender community by facilitating online support groups. She sets aside time regularly to be a sounding board, to offer practical advice, and to exhibit sympathy for individuals who face struggles during their transition. She takes hormones and has received surgical interventions as part of her transition journey. Although Maria speaks positively of her personal experience, she recognizes the discrimination, danger, and stigma often faced by individuals who identify as transgender.

**Lara.** Lara called from Europe to discuss her experiences with health care. She describes herself as an “influencer” in her region. She works a full-time job and enjoys taking care of her cat. Lara stressed the urgency related to transition and that long waits contribute to dysphoria and could even result in suicide. She would like for health care workers to recognize how painful the health care experience can be when misgendering, deadnaming, and invalidation occur.

**Kevin.** Kevin is a college student who receives his health care through the school’s health center and the school insurance plan. He talked about the trauma of being battered during a health care encounter and stressed the importance of health care workers recognizing that health care visits can be inherently traumatizing. He spoke of
the ignorance in the health care system regarding gender dysphoria, stating that recognition of one’s transgender status is not an event, but it is an identity that surfaces over an extended time.

**Kara.** Kara seemed very prepared for her interview. She has been taking hormones and has completed several surgical procedures to aid in her transition. She described the long process that she endured to reach her current stage of transition and the frustration she feels about meeting gatekeeping requirements to receive needed procedures. Kara echoed the sentiments of other study participants stating that health care workers need to listen to patients and avoid an attitude of knowing what is best for the patient.

**Haley.** Haley works two jobs and must stay at one of those jobs to receive health insurance that covers transition related procedures. She is currently receiving hormone therapy and is preparing for surgical procedures. She spoke of the self-education that she has completed and how that knowledge informs many of her decisions. Haley feels that health care workers need to convey a sense of acceptance along with a recognition of the validity of a patient’s identity.

**Dakota.** Dakota lives in the southern United States and receives his transition-related care through a Planned Parenthood clinic. Dakota worries about the long-term effects of hormone therapy because of the lack of research completed on the subject. Dakota is uninsured and must pay for all of his medications. He states that he must choose between receiving health screenings and paying for his prescriptions. He is actually young enough to qualify for coverage under his parents’ insurance, but his parents are also uninsured.
**Fern.** Fern is a veteran who receives her care through the Veterans Administration. She lives in the southern United States. Her greatest concern is a requirement to live in the identified gender role for a period of time before receiving any transition-related care. She shared that those transitioning from male-to-female who have prominently male features face great danger when living in the female gender role in a very conservative area.

**Mason.** Mason lives in the Eastern United States and is receiving hormone therapy. He works a job and has health insurance. Mason spoke confidently about his transition experience, but he recognized the lack of validation received by individuals who identify as transgender from health care workers.

**Amy.** Amy is a young adult from the western United States who is receiving hormone therapy. She is employed and is insured under her parents’ health care plan. Amy spoke of the urgency of accomplishing her transition goals before she turns 26 and will no longer covered by her parents’ insurance policy. She recognizes that the necessity of having health insurance will play a part in her career decisions.

**Data Analysis**

In a private office, the researcher listened to the recordings and transcribed the conversations verbatim using a word processing program. The researcher stopped the recordings after short phrases, typed what was heard, and moved to the next phrase. This activity allowed the researcher to become more familiar with the data and to capture subtle nuances of the interviews such as thoughtful pauses and participant self-corrections. After an interview was transcribed, the researcher played the recorded interview again, checked the transcription for errors, and made any needed corrections.
Each transcript contained the participant’s pseudonym, and the lines of the transcript were numbered to promote more efficient data analysis. Additionally, the date and time of each interview were included in the transcript. The researcher used this information during data analysis to properly determine saturation. The narratives and impressions gleaned from recordings of the participants served as the vehicle for describing the healthcare experiences of individuals who identify as transgender.

Using the steps outlined by Moustakas described earlier, the analysis process allowed themes and meanings about the participant experiences to emerge (Creswell, 2017). Moustakas popularized the Modified Van Kaam approach to data analysis (Moustakas, 1994). The process includes the following steps, each of which was completed.

**Horizontilization.** During this step, all data were treated equally with no quote or excerpt holding more importance than another. Altogether, 196 pages of transcribed interviews were included in this process. The transcripts were analyzed by the researcher according to the date and time of the interviews. Analysis of the earliest transcript was completed before moving on to the next transcript, and this process continued during data analysis. The researcher began to perform preliminary coding by using a green highlighter to mark every statement on the transcript that was relevant to the research question. Of the 3,920 lines of transcribed conversation, 2,667 lines contained text deemed pertinent to the study. This accounted for about 68% of the conversations. The remaining 32% included introductions, discussion of informed consent, follow-up questions from the researcher, and personal information related to providing the honorarium payments to each participant.
**Reduction and elimination.** The researcher asked two questions during this stage: (1) Is this statement important to the person’s lived experience? and (2) Can this statement be reduced to its latent meaning? If the answer to either of these questions was “no,” the statement was eliminated to foster the separation of invariant constituents from redundant or ancillary data. This task was accomplished by using a pink highlighter on the transcripts to indicate the less-relevant portions of the text. Almost all (98%) of the data deemed as relevant through horizontalization passed the two-question qualifier for inclusion as being important to the lived experience and having the capacity to be reduced to latent meaning. Examples of excluded comments include, “Sorry, the cat got on my keyboard” and “Hold on, my hair keeps getting in my face.”

**Thematize the invariant constituents.** Using the data not eliminated in the previous steps, the researcher began to explore latent meanings and then grouped the excerpts. These groupings form the themes that express the participants’ experiences. The researcher used index cards and labeled each one with information shared such as “fear,” “excitement,” and “frustration.” These categories were elicited from the line-by-line analysis of each interview. When information pertinent to a category was discovered, the researcher recorded the participant pseudonym and the number of the line of type in the transcript on the appropriate card. Altogether, 52 index cards were compiled that exhibited facets of the participants’ experiences. Because the transcripts were analyzed in the same order as the interviews were conducted, the researcher recognized saturation when no new data were recorded on a new index card. Saturation occurred at the 14th interview, but analysis included all 18 interviews to foster a richness of the data.
Check the themes against the data. Once the themes were generated, the researcher returned to the data set to ensure that the themes actually represent the participants’ experiences and tell the stories accurately. Performing this step allowed the researcher to become aware that the original thematization failed to yield accurate results. The researcher had attended to the transition process rather than the health care experience. After acknowledging this error, the researcher returned to the data and repeated the process described in the “thematize the invariant constituents” step. The new thematic elements were checked against the data and the researcher determined that the themes do represent the participant experiences accurately.

Create individual textural descriptions. The researcher created individual textural descriptions derived from verbatim quotes and excerpts from the interview. Using the coded index cards, the researcher was able to return to the data and extract specific quotes from the transcripts that represent the thematic elements.

Create individual structural descriptions. The researcher wrote descriptions that explore the emotional and social connections between the participants’ responses. This task presented a challenge to the researcher because the researcher tried to remain true to the chosen method and only describe what the participants reported. Once the researcher recognized the need to use inferences related to the data, this task became much easier. Inference differs from interpretation in that inference comes as a result of inductive reasoning, while interpretation considers the inference from a particular point of view. For example, when a participant stated that they were “pleasantly surprised” by a health care experience, the researcher was able to infer that the individual had expected a less pleasant experience.
**Create composite textural descriptions.** During this phase, the researcher outlined the themes from each participant to identify reoccurring and prominent themes across the participant group. The researcher accomplished this task by grouping index cards together that were closely related. For example, the cards for “afraid,” “scary,” and “terrifying” were grouped together as “fear,” and the cards for “being stuck,” “stagnant,” and “holding pattern” formed another group called “inability to move forward.”

**Create composite structural descriptions.** The researcher explored the emotional and social connections of the experiences across all participants and described common elements of the experiences. For this step, the researcher broadened the focus to find the outstanding common elements of the experience. For the groups of cards that contained subthemes of “inability to move forward,” “lack of self-determination,” and “difficulty navigating requirements,” the theme of related to barriers to care evolved.

**Create composite structural-textural descriptions.** The researcher synthesized the textural and structural descriptions to gain a comprehensive essence of the phenomenon. For this step, the researcher considered the themes of the experience to gain the essence of the lived health care experience of individuals who identify as transgender.

Analysis of the data included a prolonged, intensive experience with the interview data. The verbatim transcripts received multiple viewings and the researcher analyzed them in their entirety. The transcripts were reviewed exhaustively in order to gain understanding of the participants’ experiences as related to the specific research question. The researcher used manual coding to discover significant statements that seemed to reveal the meaning of the experience.
Following identification of transcript themes, the researcher collaborated with participants to interpret the significance of the themes and ask the participant, “Is this what the experience is really like?” A second interview was offered to each participant to allow collaboration and validation of the preliminary themes. While the participants did not request a second interview, all who responded to the question through electronic media indicated their agreement with the findings. This exercise was actually completed twice because of the researcher’s initial focus on the transition experience, rather than the health care experience.

**Ethical Considerations**

Full disclosure calls upon the researcher to completely describe the nature and the purpose of the study along with the right to refuse participation, the likely risks and benefits, and the individual’s right to withdraw from participation at any point during the study. This task was addressed repeatedly during recruitment and data collection as the researcher included this information on the recruitment flier, the consent form, and a verbal exchange at the beginning of each interview.

The principle of beneficence demands that the researcher minimize harm and maximize participant benefits including freedom from harm and freedom from exploitation. While the participants may have benefited from reflection about their health care experiences, an improved health care experience was neither expressed nor implied. The risks to the participants were deemed as minimal with emotional discomfort named as the only possible risk. At the request of a member of the IRB, information regarding counseling hotlines was added to the recruitment fliers (Appendix F). This intervention aimed to address the potential risk of emotional discomfort.
Because phenomenology innately requires exploration of one’s personal experiences, the researcher must attend to the principle of justice including the right to fair treatment in all stages of the study. These steps promote ethical research and contribute to the researcher’s understanding of the ethical responsibility of human subject research. To meet this requirement the researcher handled data with great care. The researcher’s computer is password protected and kept in a locked facility. The printed copies of the transcripts were placed in a binder and kept with the computer in the locked facility. Additionally, the researcher payed an honorarium to each participant to exhibit respect for their time and experience.

The researcher implemented safeguards to protect the rights of research participants. The study occurred only following IRB approval from the University of Northern Colorado (Appendix A). A written consent form (Appendix D) was provided to each participant that explains the procedures, assures a commitment to confidentiality, protection from harm, and the right to withdraw from the study at any time. The consent form includes a description of the qualitative procedures used, permission to record the interview, and an explanation of the researcher’s plan to maintain confidentiality and privacy. The consent form was provided to the participants at least 24 hours before the scheduled interviews through e-mail or text message and the participants received an opportunity to ask the researcher any questions about the study. The signed original consent forms are stored in a password-encrypted file on the researcher’s computer and at the University of Northern Colorado.

The researcher initiated the contact for the interview with each participant and learned after just one interview that participants were likely to share their own name if a
standard introduction was used. After this experience, the researcher approached the beginning of subsequent interviews by using self-identification followed by an expression of appreciation for the individual’s participation. Following this introduction, the researcher immediately informed the individual that using pseudonyms would promote the maintenance of privacy. A few participants stated they would prefer to use their own name in the research. The researcher explained the need to promote an atmosphere of privacy for all participants and again requested a pseudonym. All of the participants provided a pseudonym and the data is devoid of any identifiable features of the participants. The recordings were destroyed after the transcription process was completed. All transcribed data will remain securely stored in a locked office for a maximum of three years and will then be destroyed by shredding.

The participants encountered minimal risks through their study participation. Self-reflection and the sharing of experiences may have resulted in the participants experiencing some psychological distress. When the researcher became aware of such distress during interviews, participants were reminded of their right to withdraw and asked if participation should continue. Participants may have benefited from having an opportunity to reflect on their health care experiences; however, the study was not designed to facilitate health care experiences.

Qualitative researchers bear the responsibility of engendering a level of trust with participants by practicing transparency before, during, and after the study. The avoidance of coercion and exploitation promotes this goal and confidentiality of those participating stands as a foundational requirement. Rigor in qualitative research relies on trustworthiness and is measured by the concepts of credibility, transferability,
confirmability, and dependability (Creswell, 2017). Member checks and peer review were used during the data analysis process to foster the reporting of sound and credible findings. The researcher wished to make every effort to ensure that the participants’ actual experiences are reflected in the study results. Credibility refers to the confidence of the researcher in the truth of the responses to a particular inquiry (de Chesnay, 2015). Through member checking, the researcher hoped to establish greater credibility. This process involved going back to the participant and gaining feedback from them about the themes and their description. It was important for the researcher to focus on the description of the lived experience to avoid placing the participant in the role of evaluator, rather than describer (de Chesnay, 2015).

A second external check used by the researcher was peer review. Frequent interaction with experienced, doctorally prepared researchers and educators occurred throughout the study process. These experts assisted the researcher by highlighting deficits in the study design as well as the study analysis. They also provided recommendations for style and editing requirements.

Creswell (2017) recommends maintaining an audit trail to document the research process. The audit trail included the research process, research activities, interview transcripts, coding, categories, themes, and how decisions were made regarding the analysis. The researcher kept an online journal that is password protected to document each step of the research process. Additionally, a file was created for each research participant that contained a checklist of tasks performed to ensure ethical treatment. The task-list included responding to the participant’s indication of interest in participation, sending the informed consent document, receiving a signed copy of the consent
document, reasserting the participants’ rights at the beginning of each interview, transcribing the interview, destroying the recording, paying the honorarium, and providing the opportunity for member-checking. Furthermore, another online document contains field notes, self-reflections, analysis, and a log of interactions with research advisors.

Moustakas (1994) recognized that researchers must bracket their own experiences to avoid bringing assumptions and biases to the study that could affect data collection and analysis. This researcher recognizes that past experience with the health care system as both a care provider and a patient must be segregated from the experiences reported by the study participants. As a person coping with a rare condition, the researcher was tempted to compare personal experiences with those of the participants. The production of good research strongly depended on the repeated bracketing of this experience. An excerpt from the researcher’s journal illustrates the attempt to bracket personal experience:

The research participants keep talking about how stressful it is to take hormones when there is very little research that shows it is safe. I totally get how they feel. Every time that I take my Natpara injection, I see the big label on the box that warns users of the risk that long-term use of this medication may result in osteosarcoma. Nobody got cancer during the human trials, but with the drug having been on the market only three years, I still get a little feeling of discomfort whenever I see that warning. So, I need to think about how my experience is different from those in the study. First of all, my medication greatly enhances my comfort and functional ability, but it is not associated with my ability to feel
whole and complete. Also, I do not need it to confirm characteristics of my most basic identity. The study participants are willing to assume the risk of unknown outcomes because they cannot be true to themselves without the medication. That perspective is much different from my own that centers on comfort.

Another researcher characteristic that required bracketing centers on my experiences identifying with a gender binary. My life experience with individuals who identify as transgender has been very limited. This quality may have been a strength to the study because the experiences reported by participants were novel and incomparable to those of the researcher. The researcher did not identify other biases during the course of the study but did develop an awareness of personal ignorance about individuals who identify as transgender that was previously unrecognized. A journal entry recorded after a particularly poignant interview illustrates this issue:

I totally was unprofessional during today’s interview. As she talked about just wanting to be noticed and acknowledged rather than ignored, I found that tears were flowing down my face. She only asks for basic human courtesy! I cannot imagine living each and every day feeling and fearing persecution at every turn. Gender dysphoria may or may not be an illness, but mistreating people for any reason is wrong. What matters is that there are human beings among us who carry the weight of rejection and stigma everywhere and at all times. My heart hurts for Raven. I think I would want to be her friend. She is intelligent and funny and genuine. Her greatest desire is to be seen as normal. In her words, “I just want to be treated like any other girl with a penis.” Don’t all of us have things about us that defy the norm? Why can’t we all just be nice to each other?
During the process of data collection and analysis, the researcher consciously acknowledged the awareness of personal lived experiences and made efforts to reduce—and hopefully eliminate—their impact on the study. Following each interview, the researcher engaged in self-reflection through journaling to explore biases and their possible effect on the study.

**Summary**

This chapter provides a review of the purpose of the study, the research question, and a discussion of the chosen methodology along with its philosophical underpinnings. Moustakas’ methodology served as an appropriate vehicle for investigating the research question:

Q1 What is the lived health care experience of individuals who identify as transgender?

Using Moustakas’ method allowed the researcher to explore the meaning of health care for individuals who identify as transgender through the use of shared descriptions from the participants. Methods of data collection and analysis and strategies to promote trustworthiness and credibility received in-depth description. Because human participant requires awareness of ethical issues, these issues were outlined along with the safeguards implemented to protect the participants.
CHAPTER IV

DATA ANALYSIS RESULTS

Results and Findings

The central question addressed by this research was:

Q1 What is the lived health care experience of individuals who identify as transgender?

Descriptive phenomenological research rests on the foundational belief that human consciousness originates in shared experiences and that every phenomenon contains elements that are shared by all of the individuals living within the examined phenomenon. Therefore, the aim of the phenomenological researcher is to analyze the subjective experiences of the study participants to reveal common thematic elements that comprise the essence of the phenomenon. From analysis of the data collected for this study, four themes emerged including (a) Theme 1, “Flip a coin for every new person that you talk to.”; (b) Theme 2, “Oh, my God! If I wasn’t trans, this wouldn’t have happened!”; (c) Theme 3, “I’m in a race against time, and there’s no good answers.”; and (d) Theme 4, “I’m stuck here, and no one is doing anything.”

From the initial 52 aspects of the health care experience extracted from analysis of the data, the researcher categorized the findings into 12 subthemes. The 12 subthemes were then regrouped and resulted in the recognition of four themes. Table 4 provides an overview of the organization of the themes and subthemes.
Table 4

*Themes and Subthemes that Emerged from This Study*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Flip a coin for every new person that you talk to.”</td>
<td>Fortunate, Surprised, Guarded</td>
</tr>
<tr>
<td>“Oh, my God! If I wasn’t trans, this wouldn’t have happened.”</td>
<td>Fear, Vulnerability, Trauma</td>
</tr>
<tr>
<td>“I’m in a race against time and there’s no good answers.”</td>
<td>Financial challenges, Gatekeeping, Dearth of qualified providers</td>
</tr>
<tr>
<td>“I’m stuck here, and no one is doing anything.”</td>
<td>Networking, Being assertive, Becoming informed</td>
</tr>
</tbody>
</table>

**Presentation of Themes**

**Theme 1: “Flip a Coin for Every New Person that You Talk To.”**  
Fortunate, Surprised, and Guarded

The first theme that emerged from analysis of the participant interviews centered on an uncertainty of acceptance. Most of the participants seemed surprised by positive health care experiences either because of a previous negative experience or anecdotal evidence of negative experiences from members of the transgender community. Therefore, even though the participants received good care in some places, they were doubtful that their experiences were applicable to every situation for themselves or other transgender individuals.
Fifteen of the participants used words that indicate unexpectedly good encounters when describing their health care experiences. Some of the descriptors used by participants included “lucky,” “surprised,” “privileged,” “surprisingly pleasant,” “blessed,” “fortunate,” “thankfully,” “surprising,” “relieved,” “easy,” and “pretty positive.” One can infer from the use of these words that a negative experience was the expectation and that those interviewed experienced care whose quality exceeded their expectations.

Alexander talked about two experiences that illustrate his surprise at having a good experience. He said:

I’ve been hospitalized twice this year and both of those emergency room visits have gone more smoothly than I was expecting them to. Um, I feel pretty lucky as far as most of the other people I’ve met that go through similar experiences. I have a lot of friends who have not had as positive an experience um with like medical things that I have.

Alexander also compared two experiences related to gaining access to hormone therapy. He stated:

I was talking to my primary care doctor at the time back in my hometown just about the idea of like getting on testosterone. And he didn’t even . . . he didn’t get the concept at all. He just totally didn’t understand what I was even talking about so just through that lack of understanding, I wasn’t able to make any progress there until I moved out and into college. Um, where I’m in just a totally separate city now. Um, and I was able to, through other friends of mine who are transgender, find a health clinic here that specializes in LGBT care in general.
So, thankfully, through them, I was able to um get on testosterone very easily um just because that’s what they specialize in.

Honor reported feeling “very fortunate” to live in the “gayborhood” of a large city in a conservative area. She feels that her doctor is well-educated, very responsive, and is very committed to expanding access to care for members of the LGBTQ community. She describes her situation as atypical and demonstrated her lack of confidence in receiving good care in other settings. She recalled visits to an urgent care clinic and said:

The only time that it really came up was when they asked me when my last period was, and I explained that that’s not a thing that I have, and they were both surprised. I’m lucky in that I tend to be fairly passable and have passing privilege. So, for me, it’s not really been an issue and even when I said that I don’t have periods because . . . they just both kind of looked at me and shrugged and said, “Oh, I couldn’t tell,” and that was the extent of it. Um, I haven’t had any prescriptions or anything for that, so overall, my experience has been positive. But that’s because my experience has really been limited to my hormone doctor. So, you know.

Like Honor, Raven sees a health care provider who specializes in LGBTQ care and describes him as “outstanding”. She feels very comfortable in this health care setting but indicated that going to a new facility or even seeing a new provider can be unnerving. She said:

You know, sometimes people can like--especially some health care providers can maybe seem a little tense or uncomfortable--not because they have something against transgender people--but they might not have just had a lot of experience
with trans people or they’re afraid they’re going to say the wrong things or ask the wrong questions, so there is that just little bit of kind of like a trepidation . . . and generally speaking--yeah, I guess for a clinical outcome thing--always preferred to work with the same kind of provider repeatedly, because any new kind of place is kind of like, “Oh! We’ll book you for whenever we have the next opening and whoever is available at that time will work with you or work on you.” Um, generally speaking, I had the same one pretty repeatedly. But whenever it was a new person, I was kind of like, “Oh, my God!” You’ve gotta get a read on that person. You’re kind of like stereotyping. What if--is this person going to be transphobic or say a bunch of dumb shit?

Nova echoed Raven’s reports about inconsistencies among care providers as she said:

So, I’ve been lucky with my doctor, with like my primary care so far. I have a primary care who also prescribes hormones as well, so, does both. So that’s very helpful and useful for me. My biggest issue has been with the psychological part of it--with therapists. Um, when I was first like coming out and figuring out who I was, one of the therapists was super transphobic. So, that didn’t go over very well, and I left that therapist really, really quickly. Then I had another therapist who knew I was trans and was okay with it but wouldn’t refer to me by my preferred name and pronouns ever. Right now, I have one who respects both.

Morgan also described her experience as being much better than she had expected and expressed relief when she was “treated as a person” and was able to gain access to hormone therapy in a conservative area of the country. She said:
I can give some idea to at least how it is in my area, which I would not consider to be on the more progressive front, but we still do have a surprising amount of progress here. When I went, we had kind of a family medical clinic area and they operated on informed consent. And that was really relieving that I didn’t have to go jump through hoops.

When asked if her experience was comparable to that of other individuals who identify as transgender, Morgan replied:

I feel that I was maybe fortunate because at least in my state, there’s not very many informed consent clinics and especially, just in general, I don’t think there’d be as many clinics that will even take in LGBT. Although that is changing as we get, you know, more and more visibility. It’s more like the conservative areas . . . they just don’t have really the infrastructure set up yet to support people like us.

Kevin expressed gratitude for receiving hormone therapy and not having to “go through that many loops” and considered himself fortunate to access a therapist that other people drive hours to see. Conversely, he also shared his doubts about the treatment he will receive from health care workers when he said:

Luckily for me, I haven’t had any invasive questions like some of my friends have had but, that’s yeah, so I think like there’s like three kinds of experiences. There’s like the really bad emergency room, the really good with my like regular, trans-affirming doctor, and then the vast majority of experiences which are just like not terribly pleasant and really make me not enjoy going to see a doctor.

Haley talked about having a “pretty positive” experience when receiving care from an LGBT clinic, but she feels that the positivity does not extend to other health care
situations. She said, “I generally try to keep healthy because I am worried about what to expect at the doctor’s offices. Sometimes, prevention is better than actually going in to get medical service.”

Lee is still in the early stages of transition and expressed surprise that staff members at a clinic used trans-affirming procedures when scheduling appointments. Lee said:

One thing that stood out to me when I made the initial appointment with the clinic was, they asked for my name and I gave it. And then they asked for my legal name. I didn’t understand initially what was going on--that you could make your appointment under your like pseudo name, or the name you go by, which is not your legal name. Which doesn’t apply to me, but I thought that was very helpful and thoughtful of them.

When Riley talked about her transition experience, she originally used the word “lucky” as a descriptor then said “well, not luckily, really.” She shared, “Um, luckily, well not luckily really, but I only started transitioning about a year ago. My experience has been very pleasant. I am very privileged to live in a state where there are protections for trans people.”

Samuel praised the health care staff members who are trans-affirming, but expressed deep uncertainty about the quality of providers who offer transgender-specific procedures when he said: “A lot of the people who are trained in trans everything are really nice and they’re totally respectful about it but I’ve heard some like top surgeon absolute horror stories. Like they did this, that, and the other. They didn’t care.”
Raven gave voice to a reason for the uncertainty that was expressed by most of the participants when she said:

When you’re transgender, it can feel kind of like you’ve got a target on your back or at least it’s kind of like, you know, flip a coin for every new person that you talk to for more than two minutes; that person could like kind of hate you on some kind of level and just kind of I think that everyone--everyone that has privilege--that courtesy is expected and invisible and not even thought of and not a need for acknowledgement. But trans people, we keep our guards up so much that it’s kind of like, that courtesy needs to be stated so that we know that like that courtesy will be present. Because sometimes it’s just really not.

Raven’s words, “Flip a coin for every new person you talk to,” summarize the uncertainty and inconsistency that accompany healthcare encounters for individuals who identify as transgender. The expectation of a negative experience surfaced in almost every interview. Several participants did mention that things are “getting better” or “there is some progress,” but the perspective that positive health care experiences are attributed to luck and good fortune implies that low expectations prevail. Therefore, even in the face of advancements, the unpredictability of health care interactions among individuals who identify as transgender plays a role in the lived experience.

**Theme 2: “Oh My God! If I Wasn’t Trans, This Wouldn’t Have Happened!”: Fear, Vulnerability, And Trauma**

A second theme that emerged from the data analysis revolved around issues specific to the transgender status that occur during health care encounters.
As discussed previously, individuals who identify as transgender may be leery about health encounters, and those feelings are validated by research reporting that the majority of members of the transgender community have endured a bad experience with the health care system. As the researcher examined each transcript line by line, 149 references to the subthemes of fear, vulnerability, and/or trauma were recorded. Some individuals discussed their fears of intentional or unintentional outing, fear of discrimination, and fear about the long-term effects of transgender hormone therapy. Vulnerability centered on the intimate nature of body parts associated with transitioning, the repeated sharing of very personal and deep feelings with strangers, and the risk for violence during transition for a person who is not passing. Many of the participants reported the need to confront the past and/or anticipated trauma associated with transgender health care interactions including physical battery, discrimination, and emotional pain. Data from previous research as presented in Chapter II fully validates these concerns and highlights the adversity faced by members of the transgender community as they initiate health care experiences.

**Fear.** A major facet of receiving health care for individuals who identify as transgender involves acknowledging fears and proceeding despite them. Fear involves the feelings associated with perceived dangers or threats. During interviews, study participants freely discussed feelings of fear. Even the most influential activists who participated in the study related that fear plays a prominent role in the transgender health care experience. The most commonly discussed topics included fear of outing, fear of discrimination, and fear of the unknown risks of gender affirming procedures.
Fear of outing. Disclosing a person’s gender or sexual identity without their consent is known as “outing.” For individuals who identify as transgender, outing potentially places the person in dangerous or threatening situations. Twelve of the 18 research participants talked about the fear of outing during health care experiences. One participant, Chloe, remains “100% closeted” because she fears that using health care services covered by her insurance could result in her being outed to her employer and she worries about the ramifications of that scenario.

Outing can occur in numerous ways. Being publicly called by one’s birth name (referred to by participants as “dead naming”) may result in outing, particularly if the individual has progressed far enough in their transition that the gender-specific dead name conflicts with the outward appearance. Calling patients’ names in waiting rooms represents an insensitivity and lack of awareness of the potential consequences of outing for someone who identifies as transgender.

Alexander says that he specifically asks staff members not to use his dead name at all, especially in common areas. He stated:

When I go in, I’ll always make sure that I’m like, “This is what I prefer to go by” um, “I’d appreciate it if you didn’t say like my birth name in the waiting room. I’d prefer you didn’t refer to me that way at all,” but--especially when they call my name. That’s the worst. Um, its--if it’s like one-on-one with the nurse and they say my birth name, that’s one thing, but when they say it out loud in a room full of people, that’s like extremely uncomfortable and it’s definitely happened a couple of times.
Alexander also discussed the need to avoid assumptions and to ask thoughtful questions of every individual in every situation when he said:

I work in an office where we have a lot of close contact with a lot of people coming in. And that’s one of the things that I’ve like tried to stress to my coworkers that don’t--we deal with like a lot of personal data of people. So, when we like go to call those people or like talk to them, or if they come into our office--just not to assume anything about them. But also, to be--like if parents are there--to be a little careful about it just because you don’t want to accidentally out somebody to their parents either. So, it’s a little bit of like a catch 22 where you want of be like supportive, but you don’t want to make them like feel threatened. So, for me it’s just like--what I try to do is just ask. Cuz the person will know--if their parents aren’t supportive, they’re going to lie and say they identify as whatever their parents think they identify as. That’s just what you should go by. Outing can also occur when paperwork related to health care reflects a strict gender binary frame of reference. Several participants mentioned that changes to intake forms would make them feel safer. Samuel spoke from the perspective of someone who has had negative experiences related to health care paperwork. He said:

I’m just trying to think of like how--what changes to the experiences I’ve had would make it better for me in the future when I go back or for other people who are going to the hospital and don’t want to deal with that. Like a little checkbox like “sex” and then it’s like there should be a check box for like “sex,” “what were you born as” “male,” “female,” “Intersex,” and then like a little gender checkbox where it’s like “male,” “female,” and then like “trans: male to female,”
“trans: female to male,” and then like “other.” And then if you like--if you’re on hormones or not--because whatever. All of those things are important in like the medical thing.

Nova stressed the importance of using proper names and pronouns and having gender inclusive paperwork. She stated:

So, example . . . Like, if you are a woman, are you pregnant or able to become pregnant? If you have this part, are you able to be pregnant? It’s that very slight language change that’s also super helpful. That makes it so that patients don’t have to be like outing themselves or be misgendering themselves on the paperwork.

Fear of outing causes avoidance of health care facilities. Kevin said:

And I kind of put off going to see a doctor sometimes if I’m, like, pretty sick because I’m, like, “Oh my God. What’s if it’s gonna be all awkward? What if they’re going to say my dead name in the lobby?” It’s going to be weird.

Even being outed to the staff members takes a toll and presents a source of anxiety. Samuel summed up this feeling when he said, “Whenever you go into a hospital, even if you’re stealth, they’re going to see it on your chart.”

Facing fears of outing because of health care encounters appears to be a common emotional task faced by individuals who identify as transgender. All of the research participants discussed this issue either from a personal perspective or as a problem frequently faced by members of the transgender community. Thus, fear of outing stands as a major factor of the lived health care experience.
Fear of discrimination. Review of the literature reveals the prevalence of discrimination in health care for the transgender population. This discrimination may be blatant, subtle, or even unrecognized by the offender. Nevertheless, the discrimination that occurs contributes to the health care experience. Study participants discussed common discriminatory practices including refusal of care, disrespect, and passive actions that foster an awkward environment.

Maria expressed gratitude that she receives health care from a provider who is very supportive, but she also discussed the reticence of many providers to engage in gender transition encounters. She said:

[My doctor] was able to start me on hormones and get me going down the road. And he has been a very, very big support for me from a medical standpoint. Because I know there’s a lot of doctors out there who are not willing to even go down that road. So, they would rather just—instead of learning something—they would rather just go ahead and refer their patients on to someone else.

Maria went on to discuss the discrimination related to refusal of care based on moral conflicts on the part of the provider. She shared:

With a lot of the political stuff that’s going on right now, it makes it very difficult for transgender people, because they’re scared to transition and go further with living their truth and just being happy with themselves just because, well, some of the bills that are being introduced will essentially allow medical professionals to deny medical support to these individuals. So, it’s like, oh you can have medical support, but it has to be just for normal, everyday stuff that a cisgender person would go through. But as far as providing estrogen to a transgender female or
providing testosterone to a transgender male, if, well--it conflicts with my religious beliefs, so I’m going to deny you. And so, you know, that definitely has an impact on it and can make a lot of transgender individuals very scared to proceed with it. . . . They are scared that they are going to run into a lot of doctors that are very devout in their religion and are going to turn them away. And they’re just going to keep running into that and not be able to find a doctor that will help them.

Haley employs strategies to determine whether or not she will be refused care from a provider by sending an email to introduce herself and her medical needs. She shared that sometimes providers may blatantly say that they refuse to provide care, but other health care workers may be more passive. She said:

When I first started, one of the first things I did was seek vocal training because that’s a common indicator that you are trans--or that you are trans passing is that your voice will give you away. And there were three or four speech pathologists that were local to me that were listed as being able to perform services for trans individuals. And one didn’t respond, one was just too far away for it to be really useful. They had moved offices that were about 45 to 50 minutes away--which I can’t really afford to take the time to do that. And then the next one expressed shock that there were transgender individuals in my area and informed me that they would charge $600 per visit--which I took to be indicative that they had no desire to see trans patients.

Raven also described a passive refusal of care and said:
There was a previous specialist that I’d been seeing. It was for some digestive issues um so, I was kind of referred, but I like stopped seeing him. I reached out to his office a couple of times and like he just never got back to me and I was just kind of like, “Oh, screw this.”

Enduring disrespect during health care stands as one of the most commonly occurring discriminatory practices faced among individuals who identify as transgender. Every participant discussed the importance of using a preferred name and pronouns as a sign of basic respect. In fact, of the 18 participants interviewed, over half stated that the most important nursing intervention that should be taught to students is the proper use of preferred names and pronouns when working with individuals who identify as transgender.

Raven discussed an incident where she was referred to a provider by a cisgender individual. She stated, “They’re like, ‘Oh! I’ve heard they’re great . . . She misgendered people a couple of times, but she’s a fast learner,’ when actually that is like a really low standard of care comparatively.”

Lara also talked about feeling a lack of respect by being misgendered and deadnamed when she said:

I think there is still a bit of misgendering going around. At least some deadnaming because uh I see too much of nurses relying on paperwork to know how to call you. And even if you take the time to alert them, and even if they go with the paperwork, they will still call out your old name and that takes, uh . . . that is quite harmful.
Kevin recognizes that the use of the non-preferred names and pronouns can be confusing, but he expressed doubt that the problem has been resolved even though he has had a legal name and gender change. He stated:

One thing that happens a lot is they’ll dead name me because that’s what it says in the system and they won’t look at the line where it says the preferred name. And, uh, then they’ll like--you know they’ll make a huge fuss about it once they realize they made a mistake. Um, which like my name is legally changed now, so hopefully that’ll be fine now. But it says in my file--you know it’s like--it says female to male, you know. That’s like permanently on my like “problems” [using air quotes]. So, you know, like I’ve had a legal name and gender change and once that’s updated in the system, I still like feel like it’s gonna be an issue.

Dakota also discussed discrimination through showing a lack of respect and called this factor the greatest indicator of the level of care that would be received. He said:

It is absolutely right all day to use your patient’s name and yes, that’s like a baseline level of respect for trans people. Like the first thing that I look to you to know that I’m actually going to get personalized care if they’re aware that my body chemistry is different--you know, the sex that’s listed on my driver’s license--and they treat me like a man--that’s how I know I’m gonna get good service.

Many study participants talked about subtle--even unintentional--practices that result in discrimination. Samuel discussed this issue when he said:

I feel like doctors need to listen more to marginalized groups in general. Because a lot of the time, they don’t get listened to and it just gets brushed off. And then
people die. And it’s like, “I came to you so that you could help me. You didn’t want to help me, and you just brushed me off.”

Honor further explained the need to be seen and heard when she stated:

I guess probably the number one thing is to listen. I mean in my experience, just having someone who will listen to you and believe you is one of the most important things. One thing that I noticed was that I was having gastrointestinal issues and would get really emotional periodically throughout the year. I just figured that it was a random side effect, whatever. Um, and I finally approached it with a friend of mine who is an OBGYN and I described it as the symptoms that I would have--I don’t know---every four to five weeks. And he just started laughing. Uh, because he said you know, “You realize that you’re having symptoms--period-like symptoms--every month. Right?” And I just--I hadn’t even realized it at that point. Um, but because he was listening and because he actually cared about my symptoms, I mean, he pointed that out as something that I can adjust for now and plan for. And he didn’t mock me or suggest that just because of my genitals that I can’t have a period. I mean, they’re hormonally controlled, so . . . and I have had people laugh when I say that to explain to them. So really just listening, not judging, and being as open and receptive as possible to any concerns, suggestions, anything like that, I think would be great.

Nova pointed out the unintentional discrimination that can occur due to the use of strict gender binary record-keeping practices. She discussed a situation where the office staff did not possess the necessary tools to provide an inclusive experience. She stated:
I have a physical disability, so I went to an appointment to get a prosthetic made for myself and I gave them my preferred name. They had a whole thing on the chart that was trying to figure out what name to put down. It was a whole 30- or 40-minute process to figure out what to do. Those are my really biggest issues with the health care system so far. There’s probably now a few more actually. That’s my main big concern is there’s not really space to put preferred name and pronouns on anything. It’s always biological sex and it’s always whatever is on the legal ID versus what you prefer which helps make my mental health better in every manner everywhere.

Discrimination plays a prominent role in the transgender health care experience. Whether a patient is refused care, does not have their concerns addressed seriously, or is a victim of a system that has not yet embraced inclusivity, the overall feeling of the encounter often includes discrimination. After describing a particularly bad experience, Kevin summed up the feeling of discrimination when he stated, “Oh, my God! If I wasn’t trans, this would not have happened!”

**Fear of unknown risks.** As demonstrated in the literature review in Chapter II, few longitudinal studies have been conducted that address the effects of gender transition interventions. Individuals who identify as transgender inherently encounter some risks because of the lack of an established evidence base to guide care. Because each individual’s history and body makeup vary, providers may place greater emphasis on some risks.

Lara, whose mother died from a blood clot, explained that she had to lose 40 pounds before starting hormone therapy because of the risk of blood clots. Furthermore,
at the recommendation of her health care provider, she is using hormone patches instead of injectables until she loses another 40 pounds. While Lara acknowledged the necessity of these precautions, she also described feelings of sadness:

I’ve been on HRT for three months now. I tried getting it about two years ago, but I got rejected because I was too fat. The doctor told me that I have to lose some weight because the hormones might have some effect on my cardiac system. And they made me lose some weight and they made me wait a lot of time. That was kind of painful because—I don’t know—I didn’t really think I was that fat.

Transmasculine individuals also face risks associated with hormone therapy. The introduction of testosterone changes the overall health risk profile to that of a man, thus reducing life expectancy. These risks are associated with higher hematocrit levels, higher cholesterol levels, and an increased risk of diabetes (Deutsch, 2019).

Most of the study participants stated that they eventually want to have gender confirming surgeries. Samuel talked about the injuries caused by binding his chest but acknowledged the risks of surgery. He said:

I feel like it’s weird that the surgeons who are like changing bodies—a lot of them are cis and I feel like that’s really, really, really weird. . . . I mean, whoever’s best fit for the job should be doing the job, but . . . and who does that because I don’t want—Like, I’ve seen the botched surgeries. I’ve heard the horror stories on top surgery, bottom surgery. Like facial feminization surgery—any of those things. I’ve heard the horror stories about it like, Wow! That’s scary, but let’s go do that shit, right? Um [crying].
The greatest risks may come from the unknown long-term effects of hormone therapy. A paucity of scientific research exists focused on the changes in the level of risk associated with gender specific cancers (Deutsch, 2019). Dakota talked about venturing into the unknown territory of hormone therapy. He said:

One of my major concerns from the trans man perspective is there's not a lot of research that's been done on the effects of testosterone on fertility. Like if, especially if I want to take a pregnancy test um everything on the pregnancy test is based on you know how--how recent your period was or how long it's been since you missed a period, and I haven't had a period in six months, so I don't really know what to do. Uh--birth control there's a lot of options available but you know most fertility stuff is still phrased for a cisgender woman who isn't taking any medications that do anything to their uterus and really the only thing that my clinicians at Planned Parenthood can tell me is, “We don't really know and uh we’ll do our best.”

Mason opined that the literature used as the current evidence base “is based on research completed on post-menopausal women” that cannot “possibly be considered valid for a trans-man.”

Lara acknowledged the serious nature of the risks but revealed that the benefits outweigh the risks and stated:

I know it’s a risk. And you know that is something that most people know. This is a risk for my body. This is a risk for my health. I could die of something related to the hormones maybe in the future like blood clots or liver failure. But if
I didn’t start taking them, I would have killed myself earlier, so I’m not gonna go there.

Fear of outing, fear of discrimination, and fear of unknown risks all accompany the health care experiences of individuals who identify as transgender. Those who face these fears may or may not find them confirmed in the health care setting. Nevertheless, fear remains a common part of the lived health care experience in the transgender community.

**Vulnerability.** Vulnerability occurs when one becomes exposed to the risk of either physical or emotional harm. Every study participant discussed some aspect of vulnerability, and Raven described transgender health care as “an inherently vulnerable experience.” The most common points of vulnerability that the participants talked about related to sharing deeply personal feelings, participating in procedures involving private body parts, and potential violence related to living in a gender role while not passing.

For many individuals who identify as transgender, the first foray into transgender-related health care involves a consultation with a mental health professional. The mental health evaluation may require the patient to share some very deeply held feelings. Kara discussed this factor immediately when she began to share her experience. She said:

The first thing I’d say is that getting the right therapist to start the medical process was just pretty difficult. Um, mainly because most therapists either were coming from a cisgender point of view rather than a queer point of view and we like--so it was kind of hard to--you know--pour out your heart basically and plus like, not only that, they’re not quite understanding the um issues of what you need to get
done to be able to get the letters for whatever your next step is whether that be hormones or surgery or whatever.

Kara further elaborated on this type of vulnerability as she stated:

I’d had this big relationship with the person who I had seen for like years and years. And like, they know, and they’ve been with me since the beginning of the journey and they knew everything. Why do I have to pour out everything to some complete stranger again when I could have this person who’s been with me since the beginning of my transition?

Maria spoke positively of her health care provider, but she shared that even though talking to the doctor was “easy,” the conversation occurred only after she “got over [her] own nerves and stopped being so fearful about going to him.” Raven praised the staff that worked with her to start hormone therapy and acknowledged how emotionally vulnerable the experience can be describing it as “an enormous deal for the patient.”

Because much of the dysphoria related to gender centers on intimate body parts, vulnerability again emerges as a facet of the transgender health care experience. Samuel was emphatic about his feelings when he said:

Well—starters--gyno appointments are absolute nightmares so that’s yeah, no. Those, first off for like any not ciswoman assigned female at birth person, those are not fun. Like they’re not prepared for anybody who isn’t like, “Yes. I am a woman. I identify as a woman.” And this, that, and the other. Just like they don’t--it’s really, really just like an uncomfortable experience. And so, a lot of the time it’s just like, “Oh! A vagina. So, I’m not even going to bother with
anything.” “Oh, she, her, this that and the other. . . . You ok miss? You ok up there?”

Raven talked about the experience of having laser body hair removal and described it as “an extremely vulnerable health care experience.” She further elaborated on this vulnerability saying that it occurred when she was “talking kind of very plainly and without any discomforts about body parts and stuff like that and kind of like having to move my own body during the laser treatments.” Overall, Raven described the vulnerability of the experience by saying, “You never know what you’re gonna get!” She stated:

It’s certainly not like something I want to do with like a doctor that I’m just gonna not trust with anything vulnerable--which is to say--all of my health care needs because it’s inherently like a very vulnerable experience. So, yeah, just kind of like not necessarily oh is this person gonna be too busy to give me adequate care? Or are they gonna be--maybe they know their stuff, but they’re an asshole? Or maybe they’re like nice, but I don’t really get why they don’t understand stuff.

Vulnerability to violence exists as part of the transgender health care experience for many individuals. Living in targeted gender role without the ability to pass can be a very dangerous experience. Some laws and/or policies require living in the role for a specified time before any gender affirming treatments can occur. Fern is a veteran and receives medical care from the Veterans Administration. She lives in a very conservative part of the country and has very masculine features. She wants to progress in her transition, but she continues to live in the male gender role due to fear of hate crimes.
Chloe spoke very frankly about the danger faced by individuals who identify as transgender. She stated:

You know, I’m working two jobs to survive in one of the most expensive cities in America, and frankly, if you’re not in one of the most expensive cities in America, on the coasts, it’s probably not safe to be visibly trans. It’s a hell of a paradox. I mean, we’re kind of backed into a corner. Most of my fellow transgender people living here in the . . . area, they struggle with the same thing.

Riley talked about the vulnerability to physical and emotional violence while living in the northwest region of the United States—an area considered to be more progressive. She said:

I mean like me going to work--like people aren’t like pulling off the side of the road to like threaten to like beat me up, but people still. . . . I’ve had two cases I think since I came out, I’ve had two cases where I have been walking down the street and someone has yelled out the window, the T-slur and there are known neo-Nazis in my town so, [laughing] . . . but . . . but . . . my co-workers call me she.

Maria talked about being vulnerable to violence as a factor in the timing of her transition. She stated:

But, in all honesty, I don’t know why I had such a hard time coming out to any of these people--my doctor or my husband. I think it maybe had to do with just something--maybe how my family raised me and obviously somewhat to do with society and how they view transgender people. And all of the--especially in recent years--all of the horrible things that have happened to transgender people.
That’s the only thing that I could nail down that maybe may have had some impact on my struggles with coming out.

Haley also talked about physical vulnerability playing a role in the transition process. She said:

I didn’t know that trans people existed for most of my life and when I finally found out I was like--this resonates with me. And then after several years, I was like, OK. I really do want to transition. And one of the things that slowed that down was the fact that--what I learned is that it’s incredibly dangerous to have--I think in the U.S., the average income of $10,000 and a 41% suicide rate because of a lack of acceptance and just homelessness, abuse, violence, etcetera so it doesn’t become safe by any stretch of the imagination. I’m fortunate in that I have found ways to build what I hope to allow me to transition less painfully. My family is aware, and my friends are aware. At the same time, I work two jobs to pay for everything and my second job is through an employer that has very strong trans-related health care including several um--the only surgery in my state that is insured is gender confirmation surgery. The only surgeries that would make me feel safer, I had to get employment through this employer because they will cover them. Facial feminization and body contouring are things that I can now pursue and hope to pursue within the next year--probably two years realistically--which will make it much safer when I have to present full time as myself.

Lara summarized the vulnerability experienced by individuals who identify as transgender when she described the meaning of a safe place for health care:
A safe place means somewhere I can go without feeling a fear of rejection, fear of violence—and not just physical violence. It’s about mental and verbal violence as well. It’s about the place where you can be yourself safely.

Feeling vulnerable is the opposite of feeling safe. The “inherently vulnerable” nature of gender-related health care forces those who want to transition to embrace the mental, physical, and social aspects of being vulnerable. Thus, vulnerability carries significant weight in the lived health care experience of individuals who identify as transgender.

**Trauma.** Trauma describes an experience that feels deeply distressing or disturbing. Individuals who identify as transgender regularly face trauma and health care encounters can directly cause trauma or foster the resurfacing of previous events. While some traumatic events involve direct mistreatment by health care workers, feelings of trauma can be triggered by unintentionally damaging statements or actions. Kevin noted the importance of recognizing this aspect of the health care experience when he stated:

> I think one thing is that a lot of trans people have been traumatized in medical settings and I just would like it if care providers were sensitive to that. I think also having that context of knowing that the doctor’s office is often like a very traumatic place for trans people; I feel like knowing that will make health care providers more sensitive and more personal and provide better healthcare because it’s like a really important context.

To further illustrate this point, Kevin shared an especially traumatic experience when he sought health care at a hospital emergency department.

> I kept saying that I think it’s a UTI, but I’m like literally in so much pain that I literally can’t urinate. And they were like, “Well, you probably have like pelvic
inflammatory disorder—probably gonorrhea or syphilis.” And I was like, “Well, no . . . that’s not possible.” But they were like basically, “Well, we think that’s what it is.” So, they put like a speculum in me and I was like in so much pain. I was like . . . I was like screaming. I had like never been in that kind of pain and they were like, “It’s not supposed to hurt. You just need to like relax.”

Kevin left the hospital after several hours and remained ill for two more days until he went to a Planned Parenthood clinic and immediately received a diagnosis and appropriate medication. According to Kevin, when he later visited a trans-sensitive gynecologist for a follow-up appointment, the provider told him “This was so unacceptable, and they should know better especially if someone is on testosterone. You can’t just stick stuff in there . . . I am going to file a formal complaint. This is not--like that really shouldn’t have happened to you.” Kevin had been so focused on his illness that he had not acknowledged his feelings until talking to the gynecologist and then referred to the event as “super traumatizing.”

Kara shared that questions that seem benign to health care workers can provoke distress for an individual who identifies as transgender. She stated:

And so, now that I have female written um every time I go to get an x-ray, I’m asked the question of if I’m pregnant. Um, and one, that gets annoying, but also, too, it kind of like lets down, too. Cuz then there’s kind of like the issue of--well a lot of trans women wish they could get pregnant and have kids of their own and . . . I’ve heard that a lot within the community that pretty much no matter what um provider does your health care, that if you’re a trans woman, that then you have the question of if you’re pregnant every time you go for an x-ray. And then
they’re like really depressed afterward and really sad afterwards, cuz they’re like, “Oh. Great.”

Other study participants shared that inappropriate questions can cause past trauma to resurface. Raven spoke about the questions health care workers ask referring to some inquiries as “Grade A dumb questions.” She also shared that asking unnecessary questions can be hurtful. She said:

Also, folks asking some questions that kind of like aren’t necessary--perhaps a little bit more touchy for different and complex reasons. Like someone asking, “Oh, how has your family responded?” or kind of like, “What did your parents say?” that sort of thing like where I actually separated from my parents after I came out and that--especially in the early stages of that--was such an enormously touchy subject that it was like, “If I start talking about this, I’m going to cry.” If I have to even say like, “Oh, I don’t want to talk about this,” I’m going to cry. I’m going to start crying once I hit the “don’t want to talk”--you know what I mean?

Raven further elaborated that trauma from prying questions results in avoidance of care when she said:

But like if it’s like, “Hi, I’m Cheryl. I’ll be like laserin...” Anyway, so what are you doing for like Thanksgiving? Are you like spending it with your family? Do they still like accept you?” instead of being like, “Cheryl, I’m not gonna see you after this--like ever--and I need you to just stop.” Yeah.

Morgan made a distinction between appropriate questions and inappropriate questions that might be traumatizing. She stated:
Depending on the question--um, if it is coming from a purely scientific or medical standpoint and it’s not just like they’re trying to be trolling or just trying to basically pick on or bully people, then it is discomforting because that topic has always had quite a bit of stigma behind it.

While two participants said that misgendering and deadnaming are sometimes understandable, others elaborated on the emotional trauma that accompanies these mistakes. Samuel talked about the importance of having policies in place that reduce deadnaming. He explained his reasoning when he said:

Because I put off my shit for so long just because I knew that would happen and I got used to not being deadnamed and I don’t like it when I am. And that’s just like a harsh reminder. Hey! Guess what! You have to fix a lot of things and spend a ton of money just to be any ounce of what you should have been born as. Ha! In your face! And it’s not fun at all.

Raven also shared the emotional impact of misgendering when she had an unpleasant experience at a medical facility. She explained:

While she was addressing me while talking to the nurse who was assisting, she referred to me with male pronouns pretty repeatedly and she had addressed me with female pronouns previously, I kind of like just picked up and understood that um something that was unintentional on her part that she just kind of wasn’t being consciously aware of. And so actually she did this repeatedly like eight or nine times. Um, just speaking rather quickly of course, but still having that heavier emotional impact. And I corrected her just kind of saying, “Oh ‘she’ or ‘her,’” but her response seemed to be--while she didn’t necessarily stop and consciously
thinking, “Oh, oops!” she was more like, “Oh, sorry,” and carrying on. Um, so I felt really shitty about that. I like had work later on that day and just felt like crying for like the next three hours.

Raven compared this traumatic experience with her regular encounters at her trans-affirming doctor’s office and said, “He just kind of treats me like anybody else. He treats me differently than anyone else would, which is to say, he treats me normally.”

The many examples provided by the study participants where they faced events involving fear, vulnerability, and trauma illustrate that these factors stand as prominent facets of the transgender health care experience. Moreover, these recollections all came from people who felt that they had overall been “lucky,” “fortunate,” and “blessed” in their health care encounters. This dichotomy suggests that many other individuals who identify as transgender may face even greater adversity during health care events.

Theme 3: “I’m in This Race Against Time and There’s No Good Answers”: Finances, Gatekeeping, and Dearth of Providers

All of the study participants described aspects of the health care experience that impede their progress in relieving gender dysphoria. Most of these issues were associated with the financial burden of transgender health care, the gatekeeping requirements encountered, and the inadequate education of providers and staff members. Analysis of the participant interviews clearly indicates that to some extent, frustration partially characterizes their lived healthcare experience.

As discussed earlier in the literature review, the financial aspect of transgender health care places a burden on this marginalized group. Insurance coverage--or the lack
of it—greatly influences the availability of health care. Additionally, even for the individuals who are insured, the ambiguity of coverage guidelines results in increased expenses for the transgender population. Combining these factors with the high unemployment rates within the transgender population creates a considerable barrier to care.

Alexander shared that although he has basic health care coverage as a college student, the more costly aspects of transition-related healthcare including mental health services and surgical interventions remain out of reach. He said:

Other parts of transitioning—definitely, I’d definitely like to have top surgery someday. It’s definitely not financially viable for me anytime soon just because I’m a college student and I’m just working on that. I financially support myself. Um for like 95% of everything that I do. So, like my rent and everything. Between that and just like feeding myself, I don’t really have a lot of extra income to start setting aside for anything like that. Um, but it would be nice sometime in the next like 10 years or if my insurance magically covers it someday that would be great. . . . I can’t afford therapy. That would be nice, but that’s the next step probably but, um someday.

Nova also discussed the expense involved with her medical care and how the financial burden renders many people incapable of accessing services. She shared:

They (insurance providers) don’t cover hormones either so it’s entirely out-of-pocket. It’s very expensive to be trans. . . . Like, my medication is about $40 a month for the hormones—that’s with a coupon. The surgery ended up costing me about $6,000 out-of-pocket, and I won’t be reimbursed for that in any
way, shape, or form. And that’s really very hard, especially since there’s a lot of unemployment especially among trans people because of discrimination and all that stuff. So, making the cost significantly higher to be trans is not helpful at all. It makes it so people typically cannot afford to transition.

Maria talked about the unseen cost of health care related to the travel required to access services. She said:

There’s only a small handful of places that do plastic surgery on the bottom that are close by. And the same goes for around the country, there’s only so many places that do it. So, a lot of times, transgender patients end up having to do a lot of traveling and end up spending a lot more money anyways just to get the bottom surgery done. From a medical standpoint, that’s very difficult. You know, there’s a lot of transgender people that are struggling financially as it is without insurance and medical groups making it even harder on them by doing that to them.

Because Honor is self-employed, she no longer has health insurance and appreciates that she can receive service from a flat-fee clinic and can arrange payment plans. She recognizes, though, that the cost of medical care leaves many individuals who identify as transgender in a frustrating position. She said:

My doctor does run a free clinic every month to where people can go to get HIV tests or get blood tests done to start hormones. So, I would love to see more doctors volunteering for that and more of those programs being set up.

Even when patients are able to meet the financial demands of transgender-related healthcare, the requirements for treatment can result in added frustration. Most insurance
companies and many health care providers ascribe to the WPATH recommendations that suggest mental health evaluations and living in the targeted role as prerequisites for gender affirming treatments. While some participants acknowledged an understanding of the need for these requirements, others consider the guidelines as gatekeeping on the part of the health care system. Many study participants used the words “jumping through hoops” to describe their efforts to meet all of the requirements for treatment.

Chloe shared that working with her health insurer causes her to feel very frustrated. She said:

Honestly, I just feel like my life and my transition is just in this weird holding pattern. I’m trying to figure that out. And it sucks. I’m 33, and the older you are when you start hormone therapy, the worse it works, and I just kinda feel like I’m in this race against time, and there’s no good answers.

Raven feels extremely fortunate to work with a provider who allows some level of self-determination. She said, “That’s kind of, unfortunately, the way the medical system works. Like, the doctor is in control of your transition in many ways. . . . Self-determination is, like, so rare among doctors, not just doctors for transgender people.”

Maria also talked about gatekeeping practices. She said:

When it comes to starting hormones, most times, in many states they do require you to go see a therapist for a period of time, and that period of time really is dependent on the therapist and how long they feel you need to be seeing them before they will release you to actually obtain hormones from a doctor.
Kara spoke very directly about the lack of control over the timing of transitional steps. She said:

When you see a therapist before you’ve even done hormones, they kind of go with you to set a timeline so you have an expectation of when things should happen. So, you know, it’s around the time it should be happening, you’re starting the thing, and then there’s all these little, like, rules and regulations that has to be done. I didn’t end up getting to have my surgery until the following Fall. So, it was like a year later. So, I guess the stuck feeling is just like, “Okay. I’m stuck here. I want to get to the next step, so I can get closer, and feel less dysphoric.” But we’re not getting anywhere, and I am nicely and politely giving a little nudge, “Let’s get the next step done so we can get closer.” And no one’s doing anything. And it’s like, how long is this gonna be?

Every participant commented on the lack of qualified providers in transgender healthcare and shared frustrating experiences related to this factor. Alexander talked about how his general practitioner “just totally didn’t understand what I was even talking about” and needing to move to a highly populated area to receive transgender related care. Lee also shared that the general practitioner providing his care was “definitely unfamiliar with, like, transgender medical issues.” Raven expressed concern about whether or not providers truly have the knowledge base needed to provide appropriate care. She said:

Or maybe they’re, like, nice but I don’t really get why they don’t understand stuff where they’re kind of like, “Oh, yeah, like some of the peers that I work with at a different hospital said that like you’re spironolactone dose should be something
like this”--because anyway, my God! I don’t want my healthcare to be taken care of like secondhand!

Maria expressed concern for patients who might receive incorrect information. She stated:

I think sometimes, some medical professionals give out information and some people may very well be very naïve and will believe anything and everything that they’re told. They get stuck on that. So, it’s important to provide correct information and the doctor needs to give all of the information to patients so that they can have a really good base for whatever decision that they make.

Lara also commented on this scarcity of qualified providers. She said “Most nurses and most doctors aren’t trained in this, because, for example, there is supposed to be a protocol to deal with transgender people and I know most of them don’t even know about it and aren’t trained in it.”

Hayley shared that even “LGBT-friendly” providers may be found lacking. She said:

I’ve found that just because a therapist or a doctor’s office says they are LGBT friendly, that doesn’t always mean that they are knowledgeable about trans-issues. I had one where a few years ago their entire dope was that about five or six years ago they had treated one trans patient. They felt that they could say they were trans-friendly, but they were not very knowledgeable. It was the only time I went.

Several study participants expressed disappointment in not being able to work with a well-qualified provider because of long wait times. A waiting list of two to three months was considered a normal occurrence for an intake appointment. For specialty
providers, waiting times varied and Kara said that the provider she wanted to perform her surgery had a wait list of four and a half years.

The combination of these factors—financial requirements, gatekeeping practices, and the dearth of qualified providers—results in an overall state of frustration among members of the transgender community during health care encounters. Although the study participants related that they had experienced positive encounters, all of them expressed a sense of frustration with some aspect of the health care experience. For this reason, the barriers imposed by healthcare system on individuals who identify as transgender stands as a revealed theme in the study that contributes to the essence of the experience.

**Theme 4: I’m Stuck Here, and No One is Doing Anything: Networking, Assertiveness, and Becoming Informed**

Conversations with study participants highlighted the time and energy committed to addressing both acute and transition-related health care needs. Every participant discussed strategies employed to reach their desired level of health. Through networking, being assertive, and becoming informed, the study participants engaged in activities of self-advocacy as part of the health care experience.

Networking serves several purposes in the transgender community. Referrals to care providers, sharing of anecdotal experiences related to transition, and providing emotional support helps individuals who identify as transgender to address their health care needs. Because of the sampling strategy employed for this study, every participant was engaged in networking.
As mentioned earlier, Alexander could not receive any transition support from his doctor in his hometown, but when he moved to a college town with a larger transgender community, he was able to talk to transgender friends and “find a health care clinic . . . that specializes in LGBT care” and “was able to get on testosterone very easily.” Likewise, Honor credits “other transwomen in (her) area” with informing her about the “golden ticket” required from a therapist to access hormone therapy. Raven also credits reading online discussion forums to interact with “actual trans people talking about how to transition in the state (where I live).”

Networking allows members of the transgender community to share anecdotal evidence and to find support. Maria talked about her role in an online support group. She said:

A friend of mine who is also transgender and I do a weekly live feed on Facebook. Just basically to give them a place for them to come to watch and talk and get advice and tips that they can use in their transition. Or they can just come in to vent about some bad experience that they’ve had recently surrounding their transition. And pretty much they can come in and talk about anything and everything transgender related.

Samuel also provides support and education online and says he is “trying to help when I can the best that I can.” Haley also discussed the use of networking to disseminate information about transgender-related health care. She stated:

From everyone else I’ve spoken with--and I’m part of several support groups and a couple more online support groups--there is a push among trans people to make sure that we are all aware of the roadblocks and issues that can come, and striving
to know what everyone needs to know to stay healthy is a must because there is very little valid documentation. My understanding is that there are very few longitudinal studies. A lot of it is anecdotal evidence which isn’t perfect, but sometimes it’s all you have so you try to communicate what knowledge you have to other trans people to make sure that any pitfalls you experience, they will not experience. Or, similarly, if they have experienced something, you become aware of it in the future.

Haley provided a very clear example of this anecdotal evidence when she shared:

There is a somewhat humorous, somewhat grim joke about how you can’t eat potatoes or bananas anymore because the common U.S. anti-androgen we take—spironolactone will—it’s a potassium sparing diuretic which means that you have to be mindful of your potassium levels and if you experience symptoms, you’ll need to get checked out. That means that a lot of transwomen will avoid consuming things that have a high potassium content. It’s unlikely that you will cause yourself injury but it’s something to be aware of.

Dakota has also benefitted from networking and now tries to assist others who are transitioning by providing helpful information. He said:

I am particularly lucky in that I have a close friend who is in the center that works to help and they were quick to give me a number and they told me that there would be a waitlist and that it would probably take about two months for them to get to me on that waitlist. So, I had a friend who is able to give me those resources, and I do my best when I meet people who are considering transitioning also give them links to those resources. The community itself is probably the best
but if you don't already have friends then I'm not sure how you would go about doing that.

Alexander talked about how networking helped his mental health. He shared:

Just being around supportive people and now being able to have the agency to find my own resources for like actual physical support. Um, and mental support and just stuff like that has been progressively like helping like just my general mental state. And the way that I feel about myself has just drastically--like my self-confidence in general feels a lot higher than it used to be. And just like looking at other trans people--the way the community works--I feel like I’m a lot more positive than I was. I used to be like I would shut a lot of people out and a lot of concepts out because I was like this sucks and I hate myself and everybody else that’s experiencing this should like feel like--I couldn’t process that people could like--like themselves--who were experiencing the same things that I was experiencing. And like being able to like learn that I could and like just kind of like that kind of stuff, it’s been a huge change for me.

These comments from study participants illustrate that networking aids in finding supportive health care resources, sharing information about transition-related challenges, and providing emotional support during difficult periods.

Several participants talked about the need to be proactive and assertive to achieve their transitional goals. Alexander credits some of his positive health care experiences to his proactive attitude. He said:

I have a lot of friends that have not had as positive an experience um with like medical things as I have. I think part of--um I tend to be a little more assertive
than some of my friends, so, I end up um--I’m more confident at correcting people um and like making sure that like when I go in--I’ll always make sure that I’m like, “This is what I prefer to go by” um, “I’d appreciate it if you didn’t say like my birth name in the waiting room.”

Kara also discussed the need to be proactive in order to reach her health goals as she talked about “politely nudging” health care workers to follow through with tasks that required completion before moving forward with the treatment goals. Samuel also talked about the need to have frank and open discussions with healthcare workers. He said that he has learned particular phrases that can be helpful in receiving good health care and he shares that information with other individuals who identify as transgender. Because all of the participants interviewed were at least transitioning in their personal space, they expressed recognition of the need to be proactive in reaching transition health care goals.

Becoming informed intersects with being proactive and networking. All of the participants discussed engaging in formal or informal research to assist them in their transition. Haley started from a position of “not know[ing] that trans people existed for most of [her] life”. She described doing research and learning more about what it means to be transgender and stated, “this really resonates with me.” Conversely, Riley described being well informed about transgender health and the urgency of her research efforts. She said:

Well, luckily, I’m still young enough that I am still on my mother’s health insurance so I’m trying to search for information about doing surgery stuff—the stuff that I am interested in. I want to do it while I’m still on a private insurance
and not having to go through the state or my own stuff, because I don’t have a job that would give me nice insurance.

Kara talked extensively about needing to gain information because while she identified as female, she was not familiar with the care routines associated with being a woman. She stated:

I’ve also noticed too that um there isn’t quite uh--I guess it depends on where you go--that um, I noticed after I had had surgery that there were a lot of different things about using my vagina that I didn’t know about. So, for example, after peeing--I didn’t know that you were supposed to wipe after peeing for like a month and a half before someone was like, “Oh, yeah, yeah, you’re supposed to do that.” And I was like, “Oh, really.” And I think it would be helpful if like while you’re in the hospital in the week or so that you’re recovering that they go over these kind of things that--so you can retrain yourself, um, and get you ready for womanhood I guess you could say for lack of a better term.

The importance of self-advocacy through networking, being assertive, and becoming informed significantly contributes to the lived health care experience of individuals who identify as transgender. Because of public stigma, transgender issues may not be openly discussed and gaining and sharing information is a vital part of the experience.

**Essence of the Experience**

An analysis of all of the interview transcripts yielded themes focused on unpredictable experiences, trepidation related to emotional and physical safety, navigating barriers to care, and self-advocacy. Raven’s comment, “You never know
what you’re gonna get!” was actually made in reference to the unpredictability of the quality of care received from different health care workers. That unpredictability and uncertainty is a common thread running through all of the interviews and leads to questions such as, “Will I be lucky and fortunate during this health care encounter?”; “Am I going to be outing and possibly victimized because of someone’s insensitivity?”; “Am I ever going to be able to reach my transition goals?”; and “What can I do to become the person that I know that I am?”. In the current social, political, and medical climate, all of these concerns remain valid and contribute to the essence of the lived health care experience of individuals who identify as transgender. Thus, the essence of the health care experience centers on the unpredictability of being able to “become more of oneself, find greater meaning in life, and reach an enhanced connectedness with other people and the world” (Newman, 2010, p.8).

**Summary**

The contents of this chapter summarize the findings that occurred following exhaustive analysis of the transcripts of the 18 interviews completed. The sub-themes and themes were described and supported by the words of the participants, themselves. Finally, the commonalities present among the sub-themes and themes revealed the essence of the lived healthcare experience of individuals who identify as transgender.
CHAPTER V

DISCUSSION AND RECOMMENDATIONS

Introduction

The purpose of this qualitative phenomenological study was to explore and describe the lived health care experience of individuals who identify as transgender. Transcripts of in-depth interviews with 18 members of the transgender community contributed to the study data. Analysis of the data revealed the themes related to unpredictability, trans-specific concerns, navigating barriers, and self-advocacy. This chapter includes a discussion of the major findings and their relationship to the existing literature focused on the state of transgender health care. Next, a linking of the findings to Margaret Newman’s health as expanding consciousness theory appears. A discussion of the contributions of the study to nursing science and nursing education comprises the next section and a discussion of study limitations follows. Finally, the chapter includes recommendations for future research and culminates in a brief summary.

Discussion of Findings

This chapter contains discussion related to the research question:

Q1 What is the lived health care experience of individuals who identify as transgender?

As described in Chapter IV, analysis of the data allowed the researcher to discover four themes and 12 sub-themes. The findings of the study reveal the essence of
“what the health care experience is like” for an individual who identifies as transgender. The themes point to an experience that involves more than just receiving treatment and medications. Rather, the experience has the potential to either validate or invalidate the very nature of the person’s identity. As the individual who identifies as transgender navigates the health care experience, events that might seem innocuous to a cisgender patient stand to affect the transgender patient’s feelings of acceptance, safety, and the capacity to be true to oneself.

Raven’s statement, “Flip a new coin for every person you meet,” acknowledges that members of the transgender community regularly experience marginalization and misunderstanding. Because of past personal experience or anecdotal evidence, the individual enters the health care arena with a guarded attitude and low expectations of receiving acceptance, validation, and healing. This attitude rests on the belief that the transgender status—the person’s deeply held identity—stands as a contributory factor in the quality of care provided. In contrast, while cisgender individuals may feel some skepticism about the competence of providers, they can feel a sense of confidence that their identity will not come into question.

Kevin’s statement, “Oh my God! This wouldn’t have happened if I wasn’t trans,” speaks to the trans-specific difficulties faced in health care encounters and is validated by the body of evidence chronicling the maltreatment of individuals who identify as transgender. Fear of outing, fear of discrimination, and fear of unknown outcomes are inherently embedded in the health care experience for an individual who identifies as transgender. Conversely, cisgender patients rarely—if ever—encounter these challenges. Vulnerability occurs as the patient reveals the most intimate aspects of their identity
without knowing how these revelations will be received. In contrast, cisgender patients enjoy the privilege of knowing that they make up the majority of society and that their identity will seldom be questioned or ridiculed. While all patients may experience trauma related to a health care experience, trauma may be magnified for individuals who identify as transgender when painful reminders of their unique situation initiate or amplify feelings of sadness and distress.

Individuals who identify as transgender often encounter a lack of self-determination regarding health care. Chloe’s statement, “I’m in this race against time and there’s no good answers,” highlights the urgency to access care in the face of multiple barriers. A paternalistic health care system may result in the transgender patient being presented with prerequisites that must be met before needed procedures can be performed. Those prerequisites may involve waiting periods, financial preparation, or judgement from an outsider that the desired interventions are appropriate. While a sense of paternalism is inherent in a patient seeking care from a person who professes unique knowledge, cisgender people seldom find themselves in a position where a moral judgement from an outsider will determine their access to care.

Individuals who identify as transgender face the task of self-advocacy regarding health care. Kara spoke of “being stuck” and “no one is doing anything” as she described her efforts to achieve her health goals and to learn about her new anatomy. Networking with other members of the transgender community, being assertive when collaborating with providers about health needs, and becoming informed stand as necessary elements of the health care experience. While cisgender individuals may also need to advocate for themselves at times, members of the transgender population are more vulnerable to
emotional pain, physical pain, and the risk of violence if self-advocacy is not an integral part of the health care experience.

Overall, the health care experience of individuals who identify as transgender encompasses unique features and differs significantly from the cisgender experience. These differences contribute to the documented health disparities occurring in the transgender population. The staggering rate of suicide, the intentional and unintentional barriers to care, the dangers related to casual attitudes toward privacy, and the ignorance of health care workers deserve more than a cursory completion of a requirement to discuss “cultural sensitivity.” Samuel’s statement, “[We] get brushed off . . . and then people die,” stands as a sobering reprimand to all health care workers and health educators who bear the responsibility of responding to the evolving nature of the patient profile. Awareness and recognition of the unique transgender health care experience provides health care workers with the opportunity--and the solemn responsibility--to be accepting and inclusive and to advocate for the appropriate treatment of individuals who identify as transgender.

**Study Findings in Relation to Existing Literature**

The findings of this study confirm and enhance the existing body of knowledge related to transgender health care. None of the study participants discussed findings that had not been documented before, but the in-depth interviews allowed the researcher to access a more intimate view of the lived health care experience. The results clearly indicate the complexity of this issue and reaffirm that current education practices fail to adequately prepare health care workers to support the health care needs of individuals
who identify as transgender. All previous research findings referred to in this discussion are included in Chapter II.

Participants repeatedly discussed feeling “lucky” or “fortunate” when positive health care experiences occurred. This finding indicates an expectation of a bad experience. This finding may indicate that those who chose to share their experiences recognize that their “luck” and “good fortune” does not apply to all members of the community. It supports research reporting that most individuals who identify as transgender have experienced a negative health care encounter and often delay or defer care based on a previous bad experience.

This study revealed that individuals who identify as transgender face unique and magnified emotional tasks during health care encounters. The subthemes of fear, discrimination, and trauma speak to the repeated desire of the participants to feel “safe” in health care settings. This finding supports research showing that experiences with members of the health care staff significantly affect the likelihood that a person will continue to interact with health care providers. Previous research documents that most individuals who identify as transgender either endured discrimination or found that the health care workers possessed a lack of awareness of the importance of embracing trans-supportive policies and practices.

Study participants clearly highlighted the documented barriers to care found in the existing research. Insufficient financial resources, low numbers of qualified providers, and an incomplete knowledge base to inform appropriate care appear repeatedly in the literature. This study, however, reinforces the impact of these issues by presenting the
extreme emotional and physical burden carried by members of the transgender community.

Self-advocacy as a part of the transgender health care experience is muted in the literature. Nevertheless, the barriers to care documented by past studies support the validity of this finding. Overcoming the barriers to care requires a commitment to find ways to navigate the health care system and to ensure that individuals who identify as transgender are able to receive needed health care.

While the results of this study failed to expose new information about transgender healthcare, the urgency to initiate changes was given voice through the participants’ richly detailed accounts. Current literature was verified during the course of the study, and the first-hand accounts of the health care experience shared by study participants document the far-reaching effects of the previously reported problems. The results of this study not only support the current knowledge base, but also enrich its capacity to serve as a mandate for changes in nursing education.

**Study Findings and the Theoretical Framework**

Margaret Newman’s health as expanding consciousness served as the theoretical framework for this study. The role of the nurse researcher as an interested participant in the sharing of study participants’ experiences facilitated an open dialogue and allowed the researcher to gain greater insight into the phenomenon. Additionally, the fact that Newman views health not as the opposite of illness, but as an expansion of consciousness provided a lens for the researcher to embrace a non-pathologic view of the transgender status. This perspective allowed the researcher to abandon preconceived notions about
the transgender health care experience and fostered a sense of curiosity and wonder related to the unique features of the phenomenon.

Newman’s conceptual relationships showing the complementary nature of time and space gained credence as study participants discussed the frustration experienced by the effect of waiting for health care interventions that would provide a safe space. Being in a safe space is contingent upon the ability to access transition-related treatments in a timely manner so that the individual who identifies as transgender can live as their true selves in a safe space. Time as a function of movement speaks to the commitment of the individual who identifies as transgender to invest time in the health care experience. The theme of self-advocacy identified in the study correlates with this conceptual component. Movement as a function of consciousness is supported by the theme of facing adversity. Although fear, vulnerability, and trauma accompanied the movement, the ability to move forward with health care reflected the consciousness that change is necessary to become more of oneself and that past patterns no longer suffice. Time as a measurement of consciousness correlates with the finding that skepticism may limit the consciousness and decrease the time spent reaching an enhanced connectedness in the world.

Newman opined that health as an expansion of consciousness is based on five assumptions. A short discussion of each assumption and its relationship to the health care of individuals who identify as transgender follows.

1. Health encompasses conditions previously viewed as pathology. For individuals who identify as transgender, health involves embracing the identified gender and moving toward it. The dissonance caused by the sex assigned at birth in opposition
to the fundamental identity may manifest itself as gender dysphoria. To expand one’s health, both physically and mentally, the dysphoria must be recognized and addressed.

2. “Pathology” may manifest itself as part of the total pattern. The diagnosis of gender dysphoria is based on feelings of incongruity that may result in depression, anxiety, and seclusion. These assessment findings contribute to the recognition of one’s status as an individual who identifies as transgender.

3. Pathology may exist as a manifestation of a pattern that exists prior to the manifestation of physical or structural changes. Individuals who identify as transgender clearly report that identifying as transgender cannot be traced to a single incident. Rather, the identity existed before the dysphoria became evident and the individual adopted their gender identity role.

4. Removal of the pathology does not change the pathology. As the transgender community becomes more visible, the “diagnosis” of gender dysphoria may fall from favor and be replaced by a functional pattern of wellness. Despite this change, the feelings of incongruity and/or dysphoria remain and motivate the individual to engage in transition-related activities.

5. “Illness” may be the only way an individual’s pattern can manifest, and as such that is health for that individual. Recognition of dysphoria may provide the only opportunity for individuals who identify as transgender to improve their self-perception and adopting this viewpoint actually translates to improved health for the individual.

Contributions to Nursing Science and Nursing Education

The results of this study provide a more meaningful description of the transgender health care experience. While one can read about individuals who identify as transgender
facing a higher risk of violence, the first-person descriptions of “having a target on your back” and “not knowing if I can ever safely live as my true self” present a more personalized view of the lived experience. Nurse educators can use the study findings to shape curriculum and help students become more accepting and compassionate toward members of the transgender population.

This study also highlights the difficulties faced by marginalized populations during health care encounters. Unrecognized biases such as a strict gender binary view affect the patient experience. The importance of recognizing the distinct needs of marginalized populations and considering all aspects of the health care experience from the perspective of the marginalized individual can result in improved outcomes and reduced disparities.

Validation of the value of performing research using health as expanding consciousness theory contributes to the theoretical foundations of nursing science. The study results demonstrate that interactions between a nurse who suspends judgement and a person who feels uncomfortable in their current space can lead to greater understanding and promote the ability of both parties to move toward an expansion of consciousness. Newman’s theory focuses on the search for patterns of wholeness and the study findings reveal that individuals can recognize and adopt the movements that engender a sense of wholeness. Even if the nurse feels ambiguous about whether pathology is present, approaching patients with the goal of helping them to feel whole promotes a patient-centered focus that reduces stigma and judgement.
Study Limitations

Because the researcher relied on social media to recruit participants, only people who had access to the internet participated. This factor may have excluded a large segment of the transgender population whose financial situation did not support the sampling strategy. Furthermore, the need to rely on technology to complete the interviews compounded this issue. Individuals who could not access a telephone or computer were excluded. Therefore, the study participants represent a rather homogenous sub-group within the transgender population. To address this issue, further research should be conducted that explores ways to engage difficult to reach populations.

Another limitation identified includes the fact that all but one respondent reported feeling “blessed,” “lucky,” or “fortunate.” This finding possibly indicates that those who have only had negative experiences or faced insurmountable barriers did not participate. Therefore, the most marginalized members of the population may not have been included in the participant pool.

The geographic location of study participants may have skewed the results. The laws that govern transgender health care vary from state-to-state and had a direct effect on how participants described their experience. Some participants live in states with legal protections for individuals who identify as transgender, and others live in areas where they did not feel that their safety is a priority.

While the consent forms describing the study were provided 24 hours in advance of every interview, most participants seemed uncomfortable with the unstructured format of the interview. Several individuals asked what the researcher wanted to know, and the lack of structure in the interviews may have resulted in some superficial responses. The
study design necessitated the interview format, but the researcher missed the opportunity to ask specific questions that could have revealed an even richer description of the experience.

**Implications for Nursing Education**

The four themes identified by the researcher provided the basis for the implications for practice and research recommendations section. The researcher evaluated each theme and identified underlying deficiencies in nursing education. By addressing the deficiencies in nursing education, nurses entering the workforce can be better prepared to provide safe, appropriate, and compassionate care to individuals who identify as transgender. While the researcher acknowledges the existing burden of content overload in nursing education, this issue can no longer excuse inattention to the plight of individuals who identify as transgender.

In order for educational interventions to result in a robust curricular adjustment, nurse educators must be made aware of the enormity of the challenges faced by members of the transgender community. Furthermore, awareness must be accompanied by a willingness to recognize personal biases and cease to ignore the “invisible population.” While some may argue that the rarity of encountering transgender patients negates the need for change, the researcher would challenge these individuals to consider the lethality of ongoing apathy. Nurse educators must become knowledgeable about transgender health needs, invite individuals who identify as transgender out of the margins of society, and teach the importance of advocacy for all human beings. This researcher makes the following recommendations for nursing education practice.
Recommendation 1: Transgender health issues should be interwoven into existing curricular offerings. Simple changes such as modeling gender sensitive patient identification, asking about preferred names and pronouns, and promoting a welcoming environment could address many of the difficulties described by participants in this study. Individuals who identify as transgender may doubt the accessibility or quality of health care. The expectation of a negative experience contributes to avoidance of health care and increasing disparities. Educating nurses in a way that fosters inclusivity may change the way that health care encounters are viewed.

Recommendation 2: Initiate educational interventions that introduce nursing students to the transgender community. This task could be accomplished by inviting guest speakers who represent the transgender community. The simulation laboratory could also be used as a space where students can safely practice interactions in scenarios that include individuals who identify as transgender thus contributing to more positive interactions. Furthermore, students should be taught that the nursing assessment should include a respectful discussion of gender identity. Fear, vulnerability, and trauma contribute to the adversity that individuals who identify as transgender must face to access health care.

Recommendation 3: Nurse educators should provide curricular offerings that highlight facets of the transgender health care encounter that contribute to feelings of fear, vulnerability, and trauma. In conjunction with recognizing these problems, students should be given opportunities to practice strategies that promote feelings of safety. Objectives focused on maintaining privacy and confidentiality should specifically address the unique nature of the transgender health care experience. Advocacy for protection of
private information through aborting the current practice of calling patients’ names in medical settings could provide opportunities for students to experience the powerful role of the nurse as a change agent. The barriers to health care experienced by individuals who identify as transgender result in the delayed attainment of health goals. These delays directly contribute to gender dysphoria and stand to affect the high rates of suicide within this population. Moreover, barriers to care for acute illnesses contribute to a decreased level of health for all of society.

Recommendation 4: The curriculum that addresses health disparities should include information about the transgender population. Students should be given opportunities to consider strategies to reduce disparities and be given tools to accomplish this objective. Service learning could provide opportunities for students to address barriers that contribute to disparities. Because of the paucity of research related to transgender health issues, individuals who identify as transgender must engage in networking, being assertive, and becoming informed. As members of the most trusted profession in America, nurses possess the potential to become resources for correct and current information related to transgender health care. Research participants who reported positive health care experiences credited sharing of information with their access to care. While most respondents reported using the internet as their primary information source, nurses can promote access to care by providing referrals and recommendations that enhance the transition process.

Recommendation 5: Nurse educators should ensure that curricular offerings include information related to recognition of the specific transgender health needs. Topics such as the effects of hormone therapy across genders should be included.
Moreover, suicide prevention education should highlight the extreme prevalence of self-harm among individuals who identify as transgender. Nursing education should include activities that allow students to discover, access, and disseminate accurate information to individuals who identify as transgender.

**Recommendations for Future Research**

1. Because nurse educators drive curricular change in accredited programs, research should be completed that broadens the knowledge base of nursing responsibilities in relation to transgender health. The results of these studies could be disseminated and discussed by nurse educators to provide a complete and inclusive curriculum.

2. Little evidence exists that provides nurse educators with tools that specifically address transgender health needs. Research that explores and evaluates the effectiveness of educational interventions should be completed. These studies could include pre-test/post-test designs that evaluate the effectiveness of educational offerings.

3. Because the transgender population represents a difficult to reach group in research, explorations of the effectiveness of using online interactions with individuals who identify as transgender to enhance the knowledge, skills, and attitudes of nursing students should be completed.

4. Because simulation provides a safe place for nursing students to practice new skills, research should be conducted that reveals the best practices for simulation activities that focus on transgender health encounters.
Summary

This qualitative phenomenological study aimed to describe the lived experience of individuals who identify as transgender and to reveal the essence of the experience. Using snowballing through social media as a sampling strategy, the researcher was able to schedule 25 virtual face-to-face interviews and complete 18 interviews. The research was conducted using the health as expanding consciousness theory as a framework. Participants spoke openly and shared their experiences in such a way that the researcher could recognize thematic elements that contribute to the lived health care experience of individuals who identify as transgender. The theme descriptions portrayed the essence—or what it’s like—to experience health care as an individual who identifies as transgender. The researcher used information and direct quotes from the participants to illuminate the urgency to acknowledge deficits and initiate actions related to transgender health. Further analysis prompted the researcher to make recommendations for nursing education practice and to suggest future research activities that address the health care needs of individuals who identify as transgender.
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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL
DATE: April 8, 2019
TO: Joyce Cole, MS
FROM: University of Northern Colorado (UNCO) IRB
PROJECT TITLE: [1401432-2] The Lived Health Care Experiences of Individuals Who Identify as Transgender
SUBMISSION TYPE: Revision
ACTION: APPROVED
APPROVAL DATE: April 8, 2019
EXPIRATION DATE: *see note in bold below*
REVIEW TYPE: Expedited Review

Thank you for your submission of Revision materials for this project. The University of Northern Colorado (UNCO) IRB has APPROVED your submission. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Under the recently revised Common Rule, this project will not require annual continuing review by the committee. Your project has been assigned a "Next Report Due" date of April 8, 2022. Just prior to that date, the IRB will check in with you to get a current status of your project. This will help us determine if your project needs to be extended or if your study is ready to be closed. If you have completed your project prior to that date, please contact the Office of Research & Sponsored Programs to complete a closing report.

Please note that all research records must be retained for a minimum of three years after the completion of the project.
If you have any questions, please contact Nicole Morse at 970-351-1910 or nicole.morse@unco.edu. Please include your project title and reference number in all correspondence with this committee. Just a reminder that the research advisor also keeps a copy of the consent forms on campus for three years.

Best,

Maria

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Northern Colorado (UNCO) IRB’s records.
APPENDIX B

RECRUITMENT MATERIALS
Tell your story.
Contribute to the knowledge base.
Advance the competency of health care providers.

You are invited to participate in an interview for a research study whose focus is the lived health care experiences of individuals who are transgender. Nursing students currently receive very little if any education about providing appropriate, competent care to members of the transgender community. This study aims to glean the essence of the transgender health care experience so that changes in nursing education curriculum can be initiated to respond to the identified needs.

Interested?
Contact Joy Cole, PhD(c), RN
Doctoral Candidate
University of Northern Colorado
joycoleok@gmail.com
801-615-1329 (Call or Text)

Every effort will be made to preserve confidentiality. Study participants will receive a copy of the completed research and a $40 gift card.

Participants recruited must meet the following inclusion criteria:
1. Self-identification as a transgender person at any stage of the transition process
2. Over 18 years of age
3. Previous experience with accessing or attempting to access any type of health care services
4. Self-identification as being of sound reasoning ability and self-determination
APPENDIX C

CONSENT FORM
CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH
UNIVERSITY OF NORTHERN COLORADO

Project Title: The Lived Health Care Experiences of Individuals Who Identify as Transgender
Researcher: Joy Cole, Graduate Student, Nursing Education
Phone: 801-615-1329  E-mail: cole6219@bears.unco.edu
Research Advisor: Professor Faye Hummel, RN, Ph.D., CTN-A, ANEF
Phone: 970-351-1697  E-mail: faye.hummel@unco.edu

The purpose of this study is to better understand the lived health care experience of individuals who identify as transgender. In order to accomplish this goal, I am conducting individual interviews to better understand your experiences and perspectives during health care encounters. In order to incorporate a variety of unique impressions regarding transgender health care, I am asking several adults who identify as transgender (at any stage of transition) to participate in the study. I am asking for your informed consent to participate in a one-hour, recorded online interview.

By agreeing to participate in this study you are agreeing to participate in one sixty (60) minute interview. You may also exercise an option to participate in a second interaction with the researcher to clarify and confirm the data collected. During the interview, you will be asked a series of questions related to your experience with seeking health care. In an effort to keep the identities of the participants confidential, pseudonyms will be used throughout the manuscript to ensure anonymity.

The only foreseen risk for participants includes the possibility of experiencing emotional distress during the interview. Should this issue occur, you will have the opportunity to take a break and resume the interview or to withdraw from the study. The interview questions will deal with your experience only and no feedback about your participation in this study will be provided to any entities other than the research institution, the University of Northern Colorado. This study is not designed to improve your personal health care experience, but to provide information to groups and institutions in an effort to learn more about the topic of this research.

Interviews will be digitally recorded to ensure accuracy. Be assured that I intend to keep the contents of these recordings confidential, but absolute confidentiality cannot be guaranteed. After the interviews have been transcribed, all recordings will be destroyed. To further help maintain confidentiality, participant names will be replaced by pseudonyms during the data analysis and in the final manuscript. Participant names will not appear in any professional report of this research.

Participant’s Initials: ________
Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact Nicole Morse, IRB Administrator, Office of Research, Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

Participant’s Signature  Date

Researcher’s Signature  Date
APPENDIX D

DEMOGRAPHIC/INCLUSION QUESTIONNAIRE
Demographic/Inclusion Questionnaire

1. Do you self-identify as a transgender person at any stage of the transition process?

2. Are you over 18 years of age?

3. Do you have previous experience with accessing or attempting to access health care services?

4. Are you of sound reasoning ability and self-determination?
APPENDIX E

INTERVIEW GUIDE
Interview Guide

Introduction:

My professional and educational history
Purpose of the study
Review of consent form

Opening query:

I would like to know more about your health care experiences. I am interested in learning more about how you have experienced interactions with all people involved in securing health care including ancillary staff, insurance representatives, and care providers. Can you tell me about your health care experiences?

Follow-up questions:

Can you tell me more about that?
How did that make you feel?
How does that experience influence you today?
May I clarify what you just said?
What does that mean to you?
APPENDIX F

COUNSELING SERVICES REFERRAL
## Counseling Services

**IF THIS IS AN EMERGENCY**
Call 911 or go to your local emergency room

Toll-free, 24-hour hotline of the National Suicide Prevention Lifeline
1-800-273-TALK (1800-273-8255)

### Online Resources for Research Participants

<table>
<thead>
<tr>
<th>GoodTherapy.org</th>
<th><a href="https://www.goodtherapy.org/blog/best-transgender-websites-2015-1230155">https://www.goodtherapy.org/blog/best-transgender-websites-2015-1230155</a></th>
<th>Available at all times</th>
</tr>
</thead>
</table>

### National Resources

Mental Health Services Locator: [http://store.samhsa.gov/mhlocator](http://store.samhsa.gov/mhlocator)