FACTORS IMPACTING HEALTH SEEKING BEHAVIORS OF ADULT TRANSGENDER PEOPLE

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

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COLLEGE OF NURSING

BY

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DEDICATION

I dedicate this dissertation to LGBTQI+ people everywhere. Our struggles to achieve human rights equity have not gone without modest success, but we must continue onward. Those in power may choose to exercise a temporary oppression, if we let them. Even today in the US, events happening all around us show us that history attempts to repeat itself, if we let it. I am hopeful that the research described here will, in some way, support the brave men, women, non-binary people, and all folx on the gender continuum to stand together in dignity and power to overcome those forces that would seek to oppress. Things can change. We must transform our will to power to make that change happen, for all of us.

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ABSTRACT

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Transgender people, those who do not identify with the sex traits assigned at birth, are a vulnerable population with unique health risks and they face inequities in seeking care. The factors impacting the health seeking behaviors of transgender people are not well studied, and there is a dearth of qualitative studies available to aid researchers, academia, and healthcare professionals' understanding of the population's ability to engage in health seeking behaviors. Using grounded theory as a basis, the study design utilized qualitative semi-structured one-on-one interviews to explore the barriers and supportive structures involved with transgender people's health seeking behaviors. The study sample (n = 30) included adult transgender men and women, and non-binary people, regardless of the stage or type of transition the individual had, or desired in the future.

The overall findings of the study revealed an ongoing state of dynamic tension being experienced by transgender people as they desire or actually attempt to engage in health seeking behaviors in the face of impactful factors acting as barriers or supporting influences. Primary barriers to seeking care included fearing, oppression, and lack of access. In contrast, affirming and trusting support structures served to facilitate health

seeking behaviors. The results are relevant to nursing, and all healthcare as they inform the profession of the needs of transgender people from both the larger social perspective, and from the participants' point of view with the healthcare experience. The participants' rich descriptions of personal experiences and fears relay their challenges in attempting to seek care, that remain hidden to others. Their accounts also help to link encouraging factors present in their lives that tend to be supportive influences that improve their access to care.

TABLE OF CONTENTS

LIST OF TABLES

Table Page

LIST OF FIGURES

Figure Page

CHAPTER I

INTRODUCTION

Focus of Inquiry

As the society in the United States (US) continues to grow and evolve, the population of transgender people has also grown in numbers. Transgender people are more visible in the community and the public eye than ever before. Though visibility is improved, many in the general public do not understand what is meant by the term *transgender*. A current definition supported by the World Professional Association for Transgender Health (WPATH; 2012) refers to the adjective form of the term describing the diverse group of people who transcend established cultural norms of defined categories of gender. The gender identity of transgender persons differs from the sex they were assigned at birth (WPATH, 2012). A complementary definition for the term can be found from the U.S. Centers for Disease Control and Prevention (CDC). The CDC (n.d.) posits the word to be an umbrella term for those whose current gender identity or expression is different from, and does not match, the sex trait they were assigned at birth. One's gender identity is not related to one's sexual orientation. Transgender persons, just as all people, identify as straight, gay, bisexual, asexual, or any other sexual orientation (CDC, n.d.).

It is difficult to ascertain an exact estimate of the number of transgender people existing in the US today as the official U.S. census has not sought to capture gender

identity information of its residents. However, statistical estimates of the population exist that are based on scientifically sound sampling methods of related surveys that do report gender identity information. Using a meta-regression analysis model of population-based probability samples from multiple surveys, Meerwijk and Sevelius (2017) estimated the population size of transgender people in the US to be 390 adults per 100,000, or one in 250 adults. This equates to nearly one million adults nationally, as of 2016, though the authors acknowledge this is likely an underrepresentation of the true size of the population.

As the overall population and visibility of transgender people has increased in the US, so has our understanding of the complexity involved in the transgender person's individual gender transition journey. The process for the transgender person transitioning from their sex trait and associated sex assignment present at birth, to that of the sex that affirms the person's true self, is lengthy and entails extraordinary individual self-discovery with multiple pathways to affirmation. Gender affirmation may be described as an individual's self-discovery of one's true gender. It is interpersonal and interactive by its nature, in which a person eventually receives social recognition and support for their true gender identity and expression (Sevelius, 2013). However, the average healthcare professional has virtually no understanding of the multiplicity of ways persons may choose to undergo gender transition. To illustrate, some transgender people opt to transition socially with changes to their names, pronouns, dress, and cosmetic appearance, while others may transition with the aid of hormones, and some may choose, or need, gender affirming surgery(s). Others may elect to employ some combination of

all of these options at various points in life. Because of the multiple options available, and the personal choice considerations made by the one transitioning, the pathway involved to getting the needed care may be opaque to the patient, and a point of ignorance on the part of the healthcare provider.

Further, healthcare providers can have their own educational inadequacies, pre-formed societal impressions, implicit or personal biases of the population. This may lead to poor interactions while making the effort to seek care, or in the healthcare encounter itself. The healthcare encounter should otherwise be focused on the desired health goal, and be professionally objective. If not, the result can be a distrust of the healthcare community as a whole due to the negative experiences, and can leave lasting emotional wounds within the transgender individual. Sallans (2016) highlighted the extreme nature of the problem in a survey of nearly 6,500 transgender people, in which 19% were reported being denied access or treatment due to their transgender identity in a clinician's office; twenty-eight percent were harassed or disrespected; two percent were physically assaulted in hospital settings; and 50% reported having to teach their clinicians about the care they needed. Though the overall state of care for the transgender person is thought to have improved over recent years, transgender people still contend with inequitable access to healthcare, and can experience professionals who often are not educationally prepared to care for transgender health needs, or may have or personal biases of the population (Austin & Goodman, 2017).

When care is available, it may not be an affirming situation for the individual to pursue. This may in part be due to historically oppressive views held by society and

healthcare towards transgender people. In 2009, Bauer et al. pointed out at the time that the larger U.S. healthcare community tended to view transgender people, regardless of the stage of transition, as societal and medical anomalies and therefore their needs are not seriously studied or known in their institutional practices. When this is experienced, it has a lasting effect of erasing the transgender community as a whole, and results in a dearth of knowledge of the professional healthcare provider about the intricacies of healthcare needs of the transgender individual. Given the complexity of social experiences, individual life paths, and unique potentially unmet care needs, transgender people frequently contend with inequity when attempting to seek healthcare to achieve a desired health goal. The term *health seeking behaviors* is often interchanged with the term *help seeking behaviors*. Health seeking behaviors has been defined as any action undertaken by individuals who perceive having a health need with the intent of accessing an appropriate remedy (Oberoi, Chaudhary, Patnaik, & Singh, 2016). Both terms represent precursor health-related decision-making processes by an individual or group. The process is influenced by individual behavioral or community norms, individual role and societal expectations, and perceived and actual characteristics and behavior of healthcare providers.

Modern American healthcare professionals are not well-equipped or educated to meet the needs of transgender people on a large scale compared to cisgender people (those whose current sense of gender identity and expression matches that same gender and sex trait assigned at birth). Romanelli and Lindsey (2020) explained that transgender people may experience discrimination in healthcare that can eliminate timely health

seeking behaviors and participation in healthcare. Much of the reason for this is that there is often a lack of understanding and empathy on the part of healthcare professionals, coupled with a lack of knowledge of how to provide competent care to transgender people (Romanelli & Lindsey, 2020). The physical health related needs, along with human needs, form the basis of the why and how people are able to engage in seeking care. Further, the influential forces involved in the transgender person's health seeking behavior and decisions are also not known.

Problem of Study/Statement of Purpose

The transgender population is a unique cultural subset of the lesbian, gay, bi-sexual, transgender, queer, intersex, + others (LGBTQI+) community. This population is a vulnerable and marginalized group by society as a whole, as well as occasionally within the LGBTQI+ community itself. Transgender people have unique needs and seek specialized healthcare that is often unavailable to them. According to Healthy People 2020 (U.S. Department of Health and Human Services, 2019), transgender individuals are at increased risk for being victims of violence, a higher incidence of sexually transmitted infections, mental health issues, and suicide. They are also less likely to have health insurance than heterosexual, lesbian, gay, or bisexual individuals, and have less access to care compared to others.

In seeking and obtaining care for their needs, transgender people must 'come out' to their healthcare provider as transgender to have an adequate and open dialogue that is supportive of a beneficial transactional health relationship. Transgender people who are fortunate enough to have health insurance coverage may still face inequity in their ability

to access a healthcare provider due to inadequate or absent coverage for transgender specific healthcare needs (Gorton, 2007). In addition, transgender people may still encounter healthcare providers who are ill prepared to competently manage the transgender person's unique healthcare needs. The provider may be biased towards the LGBTQI+ group as a whole. The American Medical Student Association (2015) highlighted this assertion with their findings that one in five transgender individuals avoided seeking care for fear of discrimination.

Qualitative research is needed on this topic to establish a scientific basis to inform healthcare professionals in academia, nursing, and the larger interprofessional disciplines of further specific quantitative research needed. The aim of this study is to gain conceptualization and understanding of the factors that may impact the health seeking behaviors of the adult transgender person by individually interviewing participants about their health seeking behaviors. The qualitative themes that may emerge from the interview data will inform healthcare professionals and researchers about the transgender person's experience(s) that influence decision making while seeking needed healthcare, yet prior to obtaining it. Further, this qualitative study examined the factors affecting the health seeking behaviors of transgender people; it will serve not only to illuminate care needs, but also those pre-decisional factors that may potentially be modifiable to improve the care experiences and ultimate outcomes for the population.

Study Rationale/Background Justification

Published studies examining the clinical outcomes related to gender transition surgery, hormonal use, and long-term health issues experienced by transgender people

can be readily found. However, little relevant transgender population-based research has been conducted regarding health promotion, access to care, and health seeking behaviors outside of the clinical outcomes. Though more research is thought to be occurring recently, an overall scarcity of population specific research for the transgender community still exists, resulting in a knowledge lag in healthcare (Wanta & Unger, 2017). Gaining clinical outcomes knowledge associated with the longitudinal effects of surgical transition related surgery and the effects of long-term hormonal replacement therapies by transgender people is important knowledge, though it has overshadowed much needed foundational qualitative research.

As with all people, understanding the health seeking behaviors of transgender people will better support the health promotion of the population as a whole. Understanding the factors that impact those health seeking behaviors is a prerequisite to that body of health-related knowledge that is thought to lead to improved outcomes and a better quality of life. One can look back into the historical public health development and knowledge of health promotion to understand the importance of health seeking behaviors upon health promotion and disease prevention. In 1979, the Surgeon General of the U.S. Department of Health, Education, and Welfare, documented the Healthy People initiative, revealing multiple areas and actions that impact people and their health. This tenet of identifying the modifiable actions, or factors, that impact health seeking behaviors apply today to all, including the transgender population. The early Healthy People initiative has continued to evolve its program and targets. In the Healthy People 2020 initiative, health disparities and heightened risk factors of the transgender person are better described than

compared to earlier periods of time in the program (U.S. Department of Health and Human Services, 2019). However, while the general population's health seeking behaviors are fairly well studied, the transgender population's is not.

Gaining a baseline understanding of factors influencing health seeking and decision making of the transgender person is just as important as clinical outcomes knowledge for the healthcare community would never know how to provide competent and respectful care to the transgender community. Whether transgender persons seek or avoid healthcare remains poorly understood even as modern society evolves toward increased acceptance and integration of the transgender population. As this population continues to grow, it is imperative that nursing and healthcare be better suited to competently and respectfully provide care for this unique population.

Scientific Need

The transgender population is a subset of the larger LGBTQI+ community. The collective labels 'LGBTQI+', 'LGBT', and 'GLBT' are synonymous references to the collective sexual orientation and gender identity minority population, and are often used interchangeably with the taxonomy of LGBTQI+ groups. The 'T' in the LGBTQI+ grouping, as is the case with the other representative letters in the chain, identifies transgender people as part of an allied group that is more analogous to a community or a coalition, rather than a homogenously cultural or ethnic group. However, the LGBTQI+ group tends to be researched as a single entity, as if it were a single homogenous population. This drastically limits the potential description and understanding of the

transgender persons' unique experiences and represents a noticeable gap in the scientific literature.

From the worldview of most transgender individuals, the daily societal and healthcare challenges they face are an affront to their individuality and sense of personhood, thus setting a stage for problematic interactions, healthcare avoidance and inequity. The cumulative result of these experiences of transgender people with society and in healthcare may be an influence upon their health seeking behaviors and brings about the research question, "What is the collection of factors affecting the health seeking behaviors of the transgender population?"

Having practiced in a public health environment for many years, I have had the opportunity to observe how the evolution of social attitudes can affect the healthcare of underserved and marginalized groups of people in need of healthcare. Transgender individuals represent one such marginalization in the current state of society, as evident in the literature, as well as in my observation in public health. The lack of access to competent and accepting care is commonplace in many area settings. Even as society becomes more accepting of LGBTQI+ people, transgender people are at the fringe of this movement towards acceptance. They are left without professional healthcare services being readily available.

The premise and rationale of the research question are founded on the notion that the health seeking behaviors of transgender people are impacted by complex and dynamic factors related to their unique needs. The factors are poorly understood and not well studied in the transgender population. Thus, the purpose of the study is to develop a

conceptual understanding of transgender people's health seeking behaviors, as well as to discover the array of factors that may impact them in supportive or obstructive ways.

Importance to Nursing

Nursing has long been at the forefront of advocacy for all people and their needs. There is an essential obligation to improve the understanding of transgender people's healthcare and social needs and nurses are well poised to address this concern. There are also opportunities in academia and practice to improve the competencies of nurses in their understanding, and use of language, and therapeutic care parameters specific to the individual transgender person's gender presentation. Hallman and Duhamel (2016) identified that the barriers (for nurses) to teaching (transgender patients) have more to do with lack of awareness of the transgender person's unique needs, and an unspecified curriculum rather than personal beliefs or biases of the individual nurse.

Being that the transgender population faces multiple barriers to accessing quality medical care in the U.S. healthcare system, the issues that may prevent this marginalized group from obtaining high-quality healthcare services specific to their needs can be improved with even simple efforts such as establishing a welcoming environment for transgender patients in the healthcare environment (Rowe, Ng, & O'Keefe, 2019).

Of universal importance, the nursing profession at all practice levels can serve as a catalyst for transgender people's needs to influence the furthering of their acceptance, just as nurses have done with other marginalized populations throughout history. Fairman and D'Antonio (2013) explained that nurses are frequently looked to by governments as health policy problem solvers and are intermediary driving forces for the implementation

of new or unpopular policy applying for the benefit of traditionally marginalized communities. It is documented as far back as the U.S. civil war that nurses help to integrate acceptance of minority religions and people into the larger U.S. population during and after the war. Later, nurses' further ongoing efforts helped to being about midwifery programs in traditionally Black communities in the southern region of the US (Fairman & D'Antonio, 2013). Similarly, professional nurses have a role in advancing public health policy change that could bring about lasting, improved, and equitable care for the transgender population.

Philosophical Underpinnings

The philosophical orientation forming the foundation of this study is Paulo Freire's theory of the oppressed, also termed *pedagogy of the oppressed*. Freire's theory, which he first articulated in Portuguese in 1968, describes the concept wherein he explores how oppression has been justified historically, as well as what was contemporaneous at the period in time of publication, and how oppression is cyclically repeated via mutual dynamic processes between the oppressor and the oppressed. In his account, the balance of power between the oppressor and the oppressed remains relatively constant, until a disruptive influence occurs that overrides the uneasy status quo that yet also seeks to achieve a new praxis and a steady state of humanity. Freire (2018) concedes that the less powerful members in a given society (the oppressed) can be frightened of a freedom that can be achieved with the knowledge that this freedom state often comes at a very high price. Freire revealed, "Freedom is acquired by conquest, not by gift. Freedom is not an ideal located outside of man; nor is it an idea which becomes

myth. It is rather the indispensable condition for the quest for human completion" (Freire, 2018, p. 42).

As was the case with the social unrest and difficult political discourse occurring in the 1960s when Freire first articulated the Pedagogy of the Oppressed, some today may readily associate Freire's human drive towards freedom with that of modern politics and governments frequently changing hands of power, often under heated public debate. In the United States, a limited representative party system results in a periodic shift from conservative to progressive political dominance, and back again, often with jarring effect. The 2008 and 2018 Democratic political "blue waves" in politics in the US provide one such practical example of this shifting ideological environment that is disagreeable to observe at best, and resulting in loss of civil rights for some, at worst.

This basic notion of human freedom equating to human completion fits well with the experiences of the transgender person in the modern-day United States, who today struggle to achieve basic equality as members of society. Incendiary public rhetoric, baseless "bathroom bills," denial of rights to serve in the military, exclusion from equal protections of housing access and employment, and more, are all earnest efforts underway today by a dominant conservative political party in power, which has acted to deny the basic human rights of others without consideration for equality and fairness of the whole of society. Politicians and extremist leaning media outlets broadcast populist notions that castigate the less powerful individuals in society as something less worthy and less deserving of human rights, equality, and fairness in treatment by the government. The vocal and legal dehumanization by those more powerful are key tactics to maintain a

dominance of power and status quo enjoyed by the more powerful oppressors. For example, in 2018 when the United States Supreme Court declared in its opinion of the Masterpiece Cake Shop vs. Colorado Civil Rights Commission case (Supreme Court of the United States, 2018), that discrimination against LGBTQI+ persons was acceptable via declaration of sincerely held religious belief, whereas a similar discrimination on the basis of race would not be allowed. The Court's opinion provides a modern example of a larger and powerful entity systematically oppressing the equity of those of a lesser powerful group in U.S. society.

Freire (2018) suggested that populist, oppressive discourse is actually a necessity to revolution. The oppressed must reach a place of realization of their state of dehumanization that is often occurring via the large spread populist disparagement that is whirling around them. The oppressed realize at some point that they can no longer contribute to it or tolerate it with acquiescence, with the realization that lest this dehumanizing dialogue is overcome, it will continue to feed and embolden the status quo of their oppression. Today, the effort to equalize the rights of transgender individuals is observed in the vocal efforts made by political actions groups such as Equality Texas, who advocate for transgender people's rights often at the political and legislative level. Equally fierce attempts toward the oppression of those same rights are simultaneously occurring in more extreme versions of U.S. politics.

Freire (2018) further advocates that human freedom is contingent upon the conscious, wide application of education and the realization of the necessity of mutual acceptance of all, for fear that anything less will result in dehumanization of the less

powerful individual. Without widespread education and mutual expansion of the human consciousness, the ongoing stimulation of oppression is sure to occur.

Education takes many forms and occurs in learning environments that vary widely in their application as well. Today, community organizations including the Human Rights Campaign, Parents Friends of Lesbian and Gays, and Equality Texas all focus on the well-being, advocacy, and equal rights of the LGBTQI+ population, with particular affinity to transgender people. These organizational groups also address public education and advocacy regarding LGBTQI+ needs. These credibly represent the modern application of Freire's pedagogy of the oppressed (2018) in a modern day US where transgender individuals are fighting to overcome the oppression of their civil rights, and to realize equity in humanness, including having their healthcare needs met.

Theoretical/Conceptual Framework

Using a semi-structured, one-on-one interview technique, grounded theory was the qualitative research method used to answer the research question. The rationale behind the choice of grounded theory is that grounded theory allows the researcher to find, describe, and explain concepts related to patterns of human behavior within a social context, as well establish relationships among them (Munhall, 2012). Grounded theory also allows the researcher to conduct data analysis concurrently with data collection, and the research focus continues to evolve as the analysis unfolds. Symbolic interactionism is a key element in grounded theory, as it sets out conceptual formation of meaning of individuals and their interactions with others and the environment, within their own contextual understanding (Munhall, 2012). Further, the grounded theory method is an

excellent fit for the study as this population is not well studied and there is little qualitative information about what impacts the transgender population's health seeking behaviors (Munhall, 2012). The study's philosophical underpinnings are rooted in Paulo Freire's theory of the oppressed (2018), while employing the grounded theory approach as a qualitative methodological framework.

Summary

Chapter One provides an overview of the focus of inquiry, the problem of study, and the compelling need for qualitative research into the constellation of factors impacting the health seeking behaviors of transgender people. The transgender population is understudied in many researchable areas, though qualitative research is primarily needed to identify the themes that may later inform potential quantitative research into specific subareas. Without this foundational qualitative research, nursing and all other healthcare disciplines are not adequately prepared to understand the experiential, environmental, and formative factors that help or prevent transgender persons when seeking, accessing, and getting the competent care that they need.

Utilizing Paulo Freire's pedagogy of the oppressed (2018) as the philosophical underpinnings to the study, it will allow the research to continually frame the data from the contextual worldview of the transgender person. Subsequently, grounded theory can be readily applied as the research framework to identify emerging qualitative themes as expressed by the transgender person throughout the course of the research to articulate the research question findings related to the factors impacting the health seeking behaviors of the transgender person.

CHAPTER II

ARTICLE SUBMITTED FOR PUBLICATION

The Health Seeking Behaviors of Adult Transgender People: An Integrated Literature Review

To Be Submitted for Publication in

Nursing Outlook

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Abstract

Background: Transgender people's health seeking behaviors are not well studied, and there is a dearth of qualitative studies available to aid researchers' understanding of the population's ability to engage in health seeking behaviors.

Purpose: The aim of the integrated literature review was to explore the available research and relevant background information related to the factors affecting the health seeking behaviors of transgender people. The review aids in the formation of a deeper conceptual understanding of the complex factors impacting transgender people in society and in health seeking behavior.

Methods: Whittemore and Knafl's (2005) structured integrative literature review process and methodology was used to guide an updated literature review for a qualitative research study. This integrated review built upon existing knowledge and literature reviews investigated by the author.

Findings: 17 studies and articles were found relevant to the topic, revealing five influential themes of stigma, discrimination, avoidance, inequity, and competence affecting health seeking behaviors of transgender people.

Discussion: Given the documented intolerances surrounding transgender people, it is critical that nurse led research be furthered to aid in attaining equitable health behaviors and outcomes.

Highlights

- Transgender people are underrepresented in the health seeking behavior literature.
- Stigma, discrimination, avoidance, inequity, and incompetence influence health seeking behaviors.
- Transgender people are stigmatized and marginalized resulting in care avoidance.
- Variable public policies stifle transgender people's ability to seek care.

Introduction

The deeply intimate nature of seeking care is not a singular or homogenous act, and it greatly depends upon a myriad of factors that are contextual in nature. These factors can vary from person to person, or group to group, and may stem from unique forces, that are situational, cognitive, sociocultural, economic, values-based, and occasionally have legal implications. For transgender people, living life and seeking healthcare can be complicated and frightening endeavors, often subject to political and legislative controls and inequities. For example, a U.S. policy took effect in 2019 banning transgender people from most military service simply for having a gender identity differing than how they were labeled at birth. This ban on personhood is a federal level example of what barriers and inequities transgender people regularly face that are often unknown to the larger world, and may be unstudied in research, including the ability to obtain healthcare.

Given the aforementioned background, it is important to understand what is meant by health seeking behaviors, and to have a common contextual definition of them to guide one in the synthesis of the literature review supporting a qualitative understanding of the phenomenon. The term health seeking behaviors is often interchanged with the term help seeking behaviors. Both terms represent a precursor to health-related decision-making processes by an individual or group that is influenced by individual behavioral or community norms, individual role and societal expectations, as well as perceived and actual characteristics. Health seeking behavior has been defined as any action undertaken by individuals, who perceive having a health need with the intent of accessing an

appropriate remedy (Oberoi et al., 2016). This working definition provides a conceptual basis for the comprehensive search of the topics' relevant literature base.

In qualitative research, any initial literature review is precursory to the qualitative study evolution (Polit & Beck, 2017). During the course of the research, new themes or sub-areas needing literature review may be discovered. Accordingly, an update of the literature review incorporating a new facet of the study may be needed once data analysis is completed. With that premise, an integrated literature on this topic was conducted while applying the process and methodology described by Whittemore and Knafl (2005). This methodology was used to guide the conducting of an updated literature review for a qualitative research study, with an aim of exploring the available research and relevant background information related to the factors affecting the health seeking behaviors of transgender people. Reexamining the literature post study aids in the formation of a deeper understanding of the complex nature of these impactful health seeking factors as they relate to transgender people in society and in healthcare settings.

Methods

Literature Search Methodology

A computer-aided search for relevant literature was conducted using the Texas Woman's University library's online universal search function. This allowed for the simultaneous search of all peer reviewed journals housed in the database of the university library to gain the most possible relevant results. The search terms included the strings "health seeking behavior(s)" AND "transgender," which yielded nearly 12,000 results from various fields of study. The large number of results indicated further refining of the

search method was warranted. Additional filters were then applied for better accuracy of the results. Inclusion and exclusion criteria were refined from that point. The decision to expand the search to include all indexed databases available within the online library was made after a preliminary initial search of the Cumulative Index to Nursing and Allied Health Literature was conducted with negligible relevant results. Additional sources found from a hand-search of citations of articles was also employed.

Inclusion Criteria

The inclusion criteria applied in the literature search consisted of published scientific articles written in English, addressing the health seeking behaviors specifically of adults identifying as transgender people, regardless of the stage of a person's gender transition, published within the last 10 years in peer reviewed journals. Some latitude was allowed in regards to considering a publication that may have fallen outside the 10-year age range, if such a publication was relevant. Secondary general resources from common and popular information sources available on the internet were also included. Only full text articles originally from peer reviewed journals were then included for formal review. Content of the articles needed to focus on elements acting as barriers or supports for the transgender person seeking health in some manner.

Exclusion Criteria

The exclusion criteria applied in the literature search exceeded the inclusion criteria due to the variation in the literature accuracy for the research question and an overall dearth of literature on the topic. These exclusionary criteria consisted of articles and studies that exclusively looked at substance abuse, mental health related to those

considered with an identity disorder or gender dysphoria, rather than those with an affirmed transgender identity, violence intervention, articles that were inclusive of the larger Lesbian, Gay, Bi-sexual, Transgender (LGBT) community but did not include data specific to the transgender population, studies solely examining sexual behavior or risk behaviors related to sexual activity, and those studies that only analyzed transgender people's clinical outcomes post gender affirming surgery without the inclusion of individual transgender health seeking behaviors.

Results

The search of the literature databases yielded 11,932 articles with an additional four articles found from other sources as previously described. As delineated by the PRISMA flow diagram in Figure 1, the literature search results were refined based on systematic identification, screening, and eligibility of the records to come to the final number of records included in the integrative review. Figure 1 also further details the initial identification of records using database screening that resulted in 11,932 articles, plus the four located from outside sources. Duplicate articles were removed leaving 7,998 records. Screening was then conducted by article title, abstract, and keyword content. After additional exclusionary filters were applied via the computer aided database screening function within the library database system, the screening process excluded 7,925 records due to non-relevance of content related to participants' age, classification of the participants as transvestite or crossdresser, gender dysphoria content, or labeling indicative of sex rather than gender identification. An additional 61 articles were then excluded from eligibility as they indicated non-relevant content, participants not being

transgender, the studies solely reviewed sexual risk behaviors, mental health issues related to gender affirmation ambiguity, or intimate partner violence, those focusing on clinical care outcomes but not health seeking behaviors, or the full-text article was not readily available. Due to the limited number of relevant items found using the initial and refined search methods described, a hand search of the reference lists of articles from the initial refined search was also employed.

Additional secondary general resources from common and popular information sources available on the internet were subsequently sought for further background information. These secondary sources included an internet search as well as a targeted online search using the same search terms via Google Scholar. While Google Scholar is generally not the preferred approach for a primary source of literature, it was necessary in this study due to the rapidly changing societal views of transgender people. Any additional relevant items found with this method were cross-checked in academic journals databases.

The process resulted in the final identification of 17 relevant sources, including a systematic review, a public health study, and various articles that were appropriate to include in the integrative review (see Figure 1).

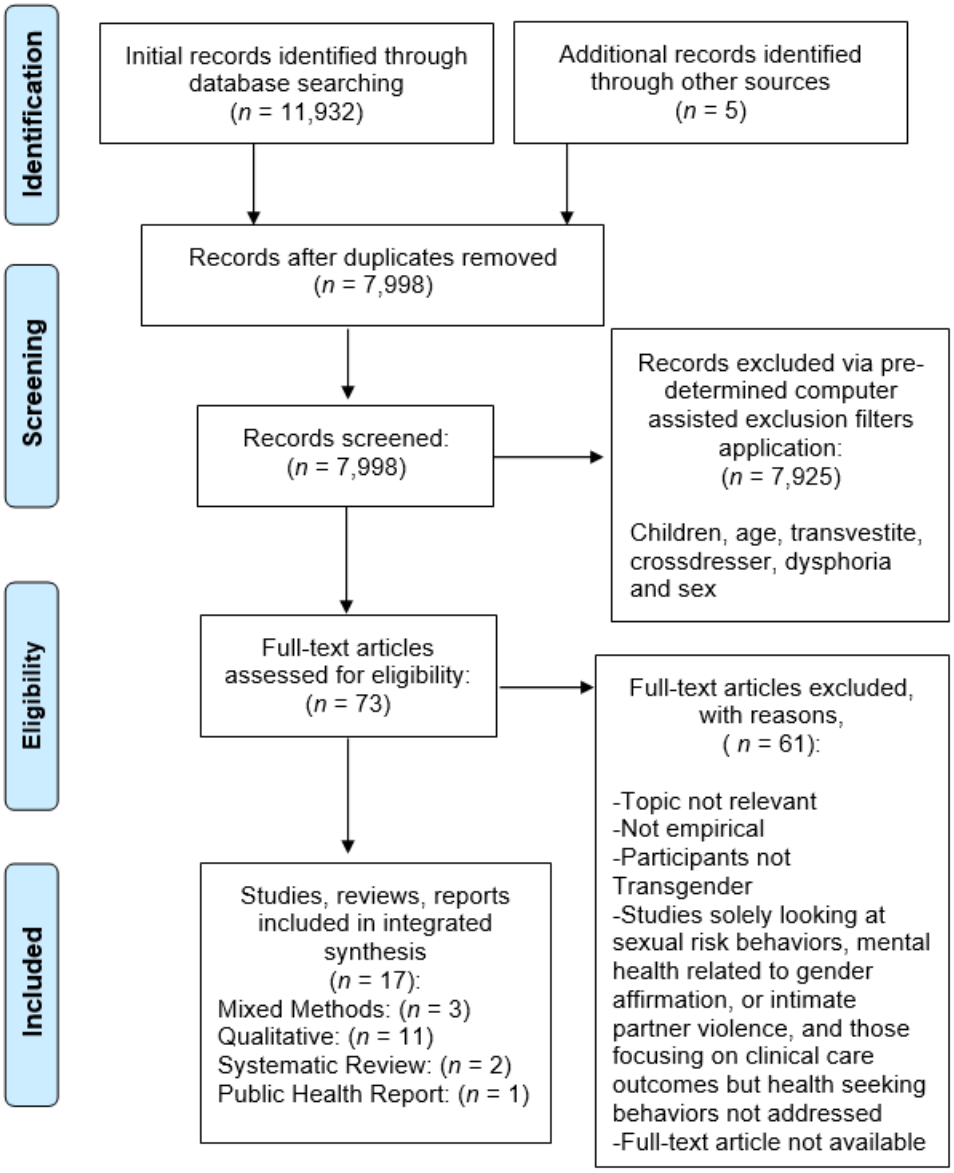

Figure 1. PRISMA flow diagram. This figure depicts the PRISMA process used for record identification in the integrative literature review.

Literature Evaluation

The final sample of available relevant primary source literature was inclusive of empirical reports of qualitative and mixed methods research approaches. No relevant quantitative studies were found to be eligible for inclusion in the review. The qualitative

empirical studies reflected a range of methodologies inclusive of focus groups, case studies, demography, surveys, and grounded theory.

In all, data was evaluated for inclusion based on the tenets of being peer reviewed, studies that were qualitative, quantitative, or mixed methods in methodology, regardless of rigor, and studies being no older than 12 years of age at the time of the search. A 10-year frame for the age of the literature was initially preferred, though one article was selected outside this age range and was included for its direct relevance to the overall review. No studies were initially discarded if they met the established criteria, pending further or ongoing review. No theoretical reports were found in the data search. Additional evaluative considerations were applied using a modified application of the recommendations by Polit and Beck (2017) in their suggested guidelines for data evaluation. The evaluative elements included full text reference accessibility, relevance of the problem of study, and appropriateness of the study methodology (e.g., quantitative, qualitative or mixed methods) to the topic (Polit & Beck, 2017). The rigor of each study was also reviewed, though due to the relative newness of the topic and the limited number of available research studies related to it, none of the final studies were excluded based solely on rigor.

Literature Data Analysis

Subsequent to the data evaluation, data abstraction commenced for further analysis. Being that the relevant literature consisted largely of a qualitative methodology, the goal of the data analysis was determined to discern the thematic patterns described by the collective sample of the available literature. With that goal in mind, an integrative

literature review was conducted, with a subsequent systematic qualitative thematic analysis performed of the relevant literature found. The information from 11 articles and one published state department of health report were reduced into five overarching categorizations of identified themes. The studies were grouped by theme for comparison and then identified using the categories comprised of: stigma, discrimination, generalized health seeking, inequity or disparity, and healthcare professional incompetence. Inequity and disparity were often referenced together in the articles leading to a similar thematic grouping in the review. Some articles indicated multiple themes within the article. In those instances, the article was grouped under the primary theme. Table 1 provides a summary of the studies, articles, and reports informing of the qualitative themes impactful of the health seeking behaviors of transgender people. The literature summary found on Table 1 is grouped by theme, which is reflective of the following elaborative discussion.

Table 1

Studies Informing Themes

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Poteat et al. (2013), USA	S	Seek understanding of how stigma and discrimination manifest and function in healthcare encounters.	Qualitative grounded theory approach (n = 67)	Five categories of themes surrounding transgender people's healthcare encounters identified: feelings about transgender peoples' identities, feelings about transgender peoples' hormone therapy, learning about transgender health, clinical interactions with transgender patients, and interactions with colleagues. Transgender participants demonstrated a dynamic interplay between acceptance and resistance to stigma.
Kosenko et al. (2013), USA	S	Seek insight into transgender patients' perceptions of stigma and sensitivity to mistreatment in healthcare contexts.	Qualitative; survey (n = 152)	Participants' descriptions of mistreatment coalesced around six themes: gender insensitivity, displays of discomfort, denied services, substandard care, verbal abuse, and forced care. These findings provide insight into transgender patients' perceptions of and sensitivity to mistreatment in healthcare contexts.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Bauer et al. (2009), USA	S	Seek deeper understanding of trans stigma and marginalization and vulnerability with focus on healthcare exclusion.	Qualitative; Grounded theory with focus groups, surveys (*n* = 85)	Marginalization and transphobia were identified. Impacts verbalized upon health, income instability, barriers to accessing trans-inclusive healthcare services, lack of relevant and accessible information, systemic social service barriers, self-esteem and mental health issues, challenges to finding help, and relationship and sexual health concerns.
James et al. (2016), USA	D	Extensive nationwide examination of the experiences of transgender focusing on mistreatment and discrimination.	Qualitative/ Correlational descriptive; Survey (*n* = 27,715)	Patterns of mistreatment, discrimination and disparities between transgender people in the survey and the U.S. general population identified related to: finding a job, having a place to live, accessing medical care, and support of family and community. Respondents experienced harassment and violence.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Bradford et al. (2013), USA	D	Examination of relationships of social determinants of health and experiences of transgender participants.	Qualitative; survey (*n* = 387)	41% reported experiences of transgender related discrimination. Findings suggest that transgender Virginians experience widespread discrimination in healthcare, employment, and housing. Multilevel interventions are needed for transgender populations, including legal protections and training for healthcare providers.
Jackson et al. (2008), USA	D	Exploration of the potential impact of fears of discrimination against GLBT people in long-term healthcare settings, this study compared perceptions of GLBT persons and heterosexuals.	Qualitative survey; (*n* = 132 LGBT, 187 Heterosexual)	Attitudes that the GLBT respondents expressed about discrimination in retirement care facilities were consistent with the literature that has established discrimination against GLBT persons in such settings as a real problem.
Samuels, et al. (2018), USA	D	Identify barriers and challenges for trans people needing acute emergency care.	Qualitative Survey and focus groups (*n* = 32)	43.8% avoid ED care due to fear of discrimination, length of wait, and negative previous experiences.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Hagen & Galupo (2014), England	HSA	Highlights the experiences of trans individuals in regard to the use of gendered language by their medical providers.	Qualitative survey (*n* = 20)	Medical providers' gender pathologizing negatively impacts trans experiences and expectations of care, while affirming language supports care received.
Massachusetts Department of Public Health (2009), USA	HSA	Study the impact of IPV upon transgender people related to healthcare utilization.	Report: quantitative/ descriptive online survey (*n* = 1603, transgender person *n* = 65)	MA public health department study found intimate partner violence (IPV) likely affects transgender individuals more commonly than those who are heterosexual, gay, lesbian, or bisexual. The study data points to the impact of when transgender people suffer IPV, the effects of victimization in addition to limited access to providers can have an avoidance effect of the seeking of healthcare.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Mizuno et al. (2015), USA	HSA	Compare demographic, behavioral, and clinical characteristics, and met and unmet needs for supportive services and outcomes of transgender women with non-transgender persons.	Qualitative, retrospective comparative descriptive demography/ transwomen (*n* = 166); Non-trans (*n* = 13,001)	Noted differences in durable viral suppression and unmet needs for basic services of transgender women with HIV compared to non-transgender persons.
Socías et al. (2014), Argentina	HSA	Exploration of individual, social-structural and environmental factors associated with healthcare seeking and avoidance among transgender women in Argentina resulting from stigma and discrimination.	Mixed methods; cross-sectional study (*n* = 452)	40.7% of transgender women in the sample reported avoiding healthcare. Avoiding healthcare was associated with stigma and discrimination in healthcare settings, as well as police violence experiences.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Lerner & Robles (2017), USA	ID	Systematic literature review assessing for barriers and facilitators to utilization of care for transgender people.	Systematic literature review of studies, 2001–2015. Both quantitative (10), qualitative (9), and mixed methods (2) studies included (*n* = 21)	All 21 studies found similar barriers in utilization, with one study indicating a facilitator found in the literature. Four barriers identified: provider lack of knowledge of transgender identity and health issues, transgender patients' previous negative experiences with the healthcare system or anticipation of these experiences, inability to pay for healthcare services, and healthcare provider refusal to provide healthcare services. Integration of health systems was a facilitator.
Gonzales, & Henning-Smith (2017), USA	ID	Systematic review estimating prevalence of having no health insurance, unmet care needs due to cost, no routine checkup, and no usual source of care of transgender and GNC adults.	Systematic records review of 2014-2015 Behavioral Risk Factor Surveillance System (*n* = 315,893)	Transgender and GNC adults more likely to be nonwhite, sexual minority, and socioeconomically disadvantaged as greater barriers to care, compared to cisgender adults.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Tanner, et al. (2014), USA	ID	Examined factors influencing access, perceptions, and use of HIV services in immigrant LGBT Hispanic men living in North Carolina.	Mixed-methods; logistic regression models and GIS mapping (n = 180)	Perceptions of access and actual care behaviors are low and affected by individual and structural factors, including: years living in state, reported poor health, perceptions of discrimination, micro, meso, and macro-level barriers, and residence in a medically underserved area.
Koh, et al. (2014), Australia	ID	Seek understanding of themes related to disparities and experiences of LGBT people attempting to access primary healthcare in Australia.	Qualitative, thematic analysis with open ended questionnaire design (n = 99)	Perceptions of access and actual care behaviors are low and affected by individual and structural factors, including: years living in state, reported poor health, perceptions of discrimination, micro, meso, and macro-level barriers, and residence in a medically underserved area.

Continued

Table 1 Continued

Author/Year/ Country	Theme	Aim/Purpose/Question	Method (sample size)	Findings
Goldberg et al. (2019), USA	IC	Aim to understand factors related to misgendering and less affirming treatment by providers participants' mental health and healthcare experiences.	Mixed-methods; survey and multivariate modeling (*n* = 506)	Mental and medical health experiences of invalidation and invisibility that binary and nonbinary trans people frequently face in society are amplified in mental health and healthcare settings. Providers do not have baseline competency with transgender needs.
Parameshwaran et al. (2016), UK	IC	Seek understanding of medical personnel perceptions of preparedness to manage LGBT needs. LGBT people frequently report negative healthcare encounters due to medical professionals' inadequate training.	Qualitative survey of medical students' efficacy in LGBTQ-health situations (*n* = 166)	Most participants had not received LGBTQ healthcare–specific medical education. The knowledge deficits included a lack of confidence clarifying unfamiliar sexual and gender terms, deciding in which ward to nurse transgender patients, discussing domestic abuse, and finding LGBTQ healthcare resources.

Note. The table of literature describes the literature available at the time of the review as relevant to the factors affecting the health seeking behaviors of transgender people. S = stigma. D = discrimination. HSA = health seeking avoidance. ID = inequity/disparity. IC = incompetence.

Findings: Literature Themes, Relationships, Patterns

Stigma

The literature identified the theme of stigma, showing itself to be a significant issue for the transgender population with overlap noted in multiple thematic categories. Three of the 17 articles described findings of stigma being present in healthcare encounters to the degree that it was perceived as a barrier to the healthcare encounter and a conduit to discrimination. Poteat, German, and Kerrigan (2013) described how stigma and discrimination manifested and functioned in healthcare encounters. Similarly, Kosenko, Rintamaki, Raney, and Maness (2013) found descriptions of stigma that provided insight into transgender patients' perceptions of and sensitivity to mistreatment in healthcare contexts. Bauer et al. (2009) identified experiences of stigma and marginalization resulting in an erasure effect in society and in healthcare. Bauer et al. (2009) described the negative impacts upon health, income instability, and resulting barriers to accessing transgender inclusive healthcare.

Discrimination

The theme of discrimination was also experienced by the transgender population was found in four of the 17 studies. James et al. (2016) revealed overlapping patterns of discrimination, mistreatment, and disparities between transgender people in their extensive nationwide survey of transgender people in the U.S. general population regarding the basic elements of life including seeking healthcare, socialization, and denial of equal rights. The report was beneficial to include as it reflected the findings as a credible expert agency based on a large quantitative survey, had an enormous sample

size, with highly relevant detailed descriptive findings. Bradford, Reisner, Honnold, and Xavier (2013) reported experiences of transgender related discrimination experiences suggesting that transgender Virginians experience widespread discrimination in healthcare, employment, and housing. Jackson, Johnson, and Roberts (2008) reported on the attitudes of LGBT residents in retirement facilities, including transgender respondents, who expressed discrimination while living in the retirement care facilities. This study is unique as it considers elderly LGBT experiences. Its inclusion provides support from the literature consistent with findings of established discrimination against LGBT persons across varies settings and age groups. Samuels, Tape, Garber, Bowman, and Choo (2018) studied barriers and challenges for trans people needing acute emergency care. Samuels et al. (2018) found that 43.8% of study participants avoided seeking emergency care when it was needed due to fear of discrimination, length of wait, and previous negative experiences with healthcare providers.

Health Seeking/Avoidance

Three of the articles found transgender people encountering difficulty as they sought out satisfactory healthcare unique to their needs. Hagen and Galupo (2014) qualitatively examined trans individuals' experiences with healthcare providers' use of gendered based language within the context of healthcare services. The authors documented that having positive and affirming experiences with medical providers can improve the lives of trans-identified individuals by improving the healthcare they receive. Notably, the study participants expressed a distrust of medical providers that reveals a pathologizing effect upon their future experiences and their expectations of care from

providers. However, when healthcare providers and their offices are actively working to be inclusive, affirming, and respectful of trans identities, the perception and delivery of care is improved.

In their study of HIV disease treatment differences encountered in transgender and non-transgender women, Mizuno, Frazier, Huang, and Skarbinski (2015) found that transgender women were more marginalized, had higher unmet basic social needs, and overall poorer disease control compared to others in the same setting. Mizuno et al.'s (2015) study intimated a need to further study the link of social barriers from the meeting of basic needs contributing to their health outcomes. Socías et al. (2014) found that transgender women in Argentina, in their sample, reported avoiding healthcare as a result of their experiences with stigma and discrimination related to being transgender females. The articles point to the negative effects of social and healthcare related experiences encountered, driving the seeking and avoidance of their health seeking behaviors.

A public health department study by the Massachusetts Department of Health found that intimate partner violence (IPV) likely affects transgender individuals more commonly than those who are heterosexual, gay, lesbian, or bisexual (Massachusetts Department of Health, 2009). The Massachusetts Department of Health (2009) study data points to the impact of when transgender people suffer IPV, the effects of victimization, in addition to limited access to providers, can have an avoidance effect on the seeking of healthcare.

Inequity/Disparity

Four of the articles dealt with the results of inequity, or disparity, in the experiences and outcomes of LGBT people, specifically including transgender people, as they sought access to healthcare. Discrimination was a real or perceived barrier to accessing healthcare in Australia and led to inequitable access (Koh, Kang, & Usherwood, 2014). In the Hombres Ofreciendo Liderazgo y Apoyo intervention study, Tanner et al. (2014) illustrated the perception that access to care was limited for LGBT people, including transgender persons, resulting in care seeking behaviors being affected by individual and structural factors, notably by perceptions of discrimination, micro, meso, and macro-level barriers. The study also indicated the influencing factors of healthcare access and perceptions of social network support for immigrant Latino sexual minority men and transgender individuals resulted in inhibiting their care. Similarly, in their systematic review of data from the 2014–2015 Behavioral Risk Factor Surveillance System, Gonzales and Henning-Smith (2017) uncovered barriers to care among transgender and gender nonconforming adults. Using logistic regression models, Gonzales and Henning-Smith (2017) found that transgender and gender non-conforming adults were more likely to be nonwhite, a sexual minority, and be socioeconomically disadvantaged compared to cisgender adults.

Lerner and Robles (2017) conducted a systematic literature review of 21 studies focusing more so on the utilization of care, and related disparities for the transgender person, rather than the larger health seeking behaviors. The literature cited by the authors spanned a time range of the year of publication of 2001 to 2015. All 21 studies found

similar barriers to utilization, though just one study cited indicated a facilitator being documented in the literature. The barriers they found throughout the studies included provider lack of knowledge concerning transgender identity and health issues, transgender patients' previous negative experiences with the healthcare system or anticipation of these experiences, patients' inability to pay for healthcare services, and healthcare provider refusal to provide services to transgender people. The single facilitator documented in the review was that of the positive effect of the integration of health systems.

Healthcare Provider Incompetence

Two of the articles highlighted the theme of incompetence encountered with various healthcare professionals. This theme enveloped the medical treatment knowledge base, as well as social inclusion and trans sensitivity aspects. Goldberg, Kuvalanka, Budge, Benz, and Smith (2019) considered the healthcare experiences of transgender binary and nonbinary university students. The authors found the participants who were seeing mental health providers perceived misgendering and trans-insensitive treatment by therapists and other health providers. It was determined that the experiences of invalidation and invisibility binary and non-binary trans people often face in society may be amplified in both mental health and general healthcare settings. This speaks to a baseline level of incompetence surrounding trans sensitive cultural inclusiveness of healthcare providers that interfered with healthcare delivery.

Parameshwaran, Cockbain, Hillyard, and Price (2016) provided an interesting indication in the self-awareness of healthcare providers lack of competence in being

properly prepared to treat transgender people. An absence of specific education on the LGBT population, particularly for transgender people, led to knowledge deficits and a lack of confidence in the acceptable use of gender terms, deciding how to place transgender patients in hospital beds, discussing domestic abuse, and finding LGBT healthcare resources (Parameshwaran et al., 2016). This finding highlights the experiences of LGBT people having negative healthcare encounters due to medical professionals' inadequate education and training.

Integrated Summation

The five themes identified in the integrative review demonstrated a pattern of interconnectedness and what appears to be a link to the impact upon the health seeking behaviors of transgender people. Multiple studies implicated societal factors and barriers to the acceptance of the transgender individual as an equal member of society while healthcare professionals lack clinical and cultural competence regarding healthcare for transgender people. The results of the review suggested that transgender people are stigmatized and marginalized to such an extent that their health seeking behaviors are affected, leadings to avoidance of healthcare, inequity or disparity in access, and causes variations in the outcomes of their care.

Discussions and Recommendations

The review of the available literature surrounding the health seeking behaviors of adult transgender people was purposefully not focused on clinical outcomes. It was instead focused on the factors and themes that influence the behaviors leading up to and including the healthcare encounter, or its avoidance. The framework, population, and

results of the review indicate further nursing research topics, including sub-segments of the transgender population. For example, it is postulated that the experiences and influencing factors of a transgender man (e.g., one who transitioned from female to male) are different than the experiences and influencing factors of a transgender woman (e.g., one who transitioned from male to female).

Gaps in Science

As mentioned, the transgender population is a subset of the larger LGBTQ+ community, a minority group based on gender identity, not sexual orientation. While the available literature occasionally describes an opportunity for conducting more research specifically about the health seeking behaviors of transgender persons, it also demonstrates the related gap in scientific knowledge related to the population's constituent sub-groups, the unique cultures, as well as the factors impacting engagement in health seeking behaviors. The tendency of clustering the larger LGBTQ+ population in the research makes it difficult to discern what, if any, data is related to transgender people. Combining the LGBTQ+ population into one group for research calls into doubt the accuracy of our understanding of all of the findings. This could possibly result in an over generalization of the LGBTQ+ studies' findings. It further begs the question of if there really exists a reliable, valid, scientific, and culturally sound knowing of the unique phenomena of transgender people's experiences with their health seeking behaviors. Additionally, the themes found in the existing literature point to the effects of barriers to care but do not specifically assess all factors impacting health seeking behaviors of the population, whether they be negative or supportive in nature.

Limitations

While five overarching themes were identified in this integrative literature review, there are likely more themes experienced by transgender people that are not necessarily represented in the available literature. It was apparent there are a multitude of complex and overlapping patterns of experiences leading transgender individuals to seek or avoid healthcare. Additionally, there are likely more thematic experiences of transgender people that are not necessarily represented in the available literature. There was little nursing research reflecting the complexity of patterns, and there was a low number of comparative studies, and no quantitative interventional studies available for review. The dearth of published research on the health seeking behaviors of adult transgender people was a notable limitation and it was not possible to determine effective interventions for the problem at hand. This highlights the need for further research and societal progress towards social justice for transgender people. Nursing researchers are well poised to further both qualitative and quantitative research around transgender people's needs, not only to answer important questions such as "What are the factors impacting the health seeking behaviors of the adult transgender person?", but many others that we have yet begun to explore.

Conclusions

This integrative literature review has demonstrated several important themes impacting the ability to seek healthcare by transgender adults in the United States, not all of which are controllable by an individual transgender person. At the time of authoring this article, the human rights journey of all marginalized people in the United States

continues to be mapped. For transgender people, as is with members of the larger LGBT community, this is an especially poignant moment in history as the fight continues for equality at the Federal level with some states enacting non-discrimination laws and others removing them. The right of access to culturally competent healthcare is viewed by many as fundamental and should not be subject to political machinations. However, the literature highlights that this is not necessarily the case for transgender people today. Some progress has been made, but the journey to the realization of equitable acceptance and care is not yet complete, giving hope for even more meaningful progress. While transgender people are clearly underrepresented in the research literature, this review will contribute to the body of knowledge for nursing and healthcare. More importantly, it will play a part in improving the lives of transgender people as they seek to live a healthy, equitable life.

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CHAPTER III

METHODOLGY AND PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

Introduction

The integrated literature review demonstrated a gap in the scientific knowledge about the transgender population outside of the larger LGBTQI+ community. The literature further provided a solid reference point for the initiation of research into the subject area. The purpose of this chapter is to present the grounded research methodology used in this qualitative study that explored the barriers and supportive influences experienced by transgender people to engage in health seeking behaviors. Using the grounded theory method for the research methodology provided the opportunity to gain in depth data directly from the study participants, and to develop a theory from the data that encapsulates the transgender person's experiences in seeking healthcare.

This chapter also discusses the suitability applying the grounded theory method using an inductive approach. The research plan, including the setting, methodology, study participants, protection of human subjects, data collection procedures, recruitment, analysis, and study rigor are the principal elements of this chapter.

Research Question

This study aimed to build a theory to answer the following research question: What is the collection of factors impacting the health seeking behaviors of the transgender population?

Research Plan

Setting and Method

The research plan included a pilot study to evaluate the feasibility of exploring the research question as well as the interview guide that was developed. The pilot study followed the same research plan as the full study and proved to be a successful construct with two participants who were recruited and interviewed. Based on the initial pilot study's success, the full study ensued using the research plan that was approved by the Institutional Review Board (IRB) and the research proposal approved by the dissertation committee.

The general setting for the study is in the United States, with focus in the local transgender population residing in or near Harris County, Texas. However, the study was open to any adult transgender person in the US. The local setting for individual participant data collection was planned to vary with the procedure for the study utilizing semi-structured one on one interviews, preferably conducted in person, in any number of environments as mutually agreed upon by the participant and the interviewer. Examples of planned settings included the participant's home, a mutually agreed upon and arranged meeting location, an office, or at a local community center, such as the United Way or the Montrose Center, as well as LGBTQI+ specific community center(s). An additional setting included the use of a secure online video conferencing application (e.g., Zoom or Skype) for those participants who did not live in the immediate area, or who did not want to meet in person. The researcher's preference was for the interview to occur in a venue that offered a reasonable degree of privacy, confidentiality, and safety for all parties.

Being able to view the participant during the interview, whether it be in person or via an online video conferencing app, was anticipated to be an important aspect for data collection as it allows one to gauge body language and emotion that may come through during the dialogue.

Participants

The target population for participants in the study were those adults identifying as transgender, non-binary, or gender fluid. The stage, type, or number of gender transition steps taken by the participant were not criteria for participation in the study. Charmaz (2014) relayed that that there is no minimum or maximum number of subjects specifically required in qualitative grounded theory research studies that utilize an individual interview method. The goal of the number of interviews conducted should be centered on achieving the data that answers the research question. The depth and significance of the interviews are more relevant than a specific number of interviews conducted (Charmaz, 2014). Artinian, Giske, and Cone (2009) additionally explained that the sample size in grounded theory research is not readily determined prior to the study and data collection continues until thematic saturation occurs. Thus, the sample needed for the study was initially broadly estimated to be 20 to 30 participants, or until thematic data saturation was achieved. This estimate was based on what was observed in the available relevant qualitative literature, and in the integrative literature review completed on the same topic also found in this dissertation. The sampling procedure employed purposive and snowball sampling techniques, in which participant eligibility was based on the unique characteristics of the adult transgender person identified and their consent

to participate in the study. The initial participants assisted with recruitment from among peers in their network, largely by word of mouth. The principal investigator (PI) partnered with local LGBTQI+ community agencies and leaders, and a statewide LGBTQI+ advocacy agency, Equality Texas, committed its support for recruitment in the study and granted access to the organizational membership contact lists for the purpose of recruitment.

Recruitment

Using the previously discussed purposive and snowball sampling as a framework for recruitment, a multitude of recruitment techniques were applied to recruit participants into the study. The IRB approved recruitment flyer (see Appendix A) was sent to community centers, clinics, support groups, and to trusted social media contacts. A developed network within the transgender community aided in flyer distribution. Students from TWU were eligible to participate. Additionally, professional relationships formed by the researcher with contacts in the healthcare institutions and schools bolstered recruitment opportunities with support and word of mouth.

Protection of Human Subjects

An IRB approval was obtained that encompassed both the pilot and the full study (see Appendix B). The study was approved by the Texas Woman's University (TWU) IRB on August 18, 2018, and extended on August 8, 2019. Compliance with the current federal rules and regulations and those of the TWU IRB were observed throughout the study. An informed consent (see Appendix C) was obtained for all participants prior to the beginning of individual research interviews. For in-person interviews, the informed

consent was reviewed and signed at the interview session prior to the initiation of the interview questions. For those interviews that took place via an electronic web-based video conferencing app, the informed consent document was provided electronically to the participant prior to the interview. The signed consent was returned electronically to the researcher prior to the start of the interview. Electronic signatures of the participants were allowable on consents for interviews that were conducted exclusively via web-based video conferencing applications. All subjects' rights were respected and protected, with potential risks explained during the informed consent process. The researcher and research assistants participating in the study all successfully completed the required collaborative institutional training initiative course.

Supplemental human protection considerations were readied for study's participants to aid them should emotional distress have occurred during or as a result of the interview. Participants were able to discontinue participation at any time for any reason. A counseling referral resource was available to a preferred LGBTQI+ counseling center (i.e., Montrose Counseling Center) for participants in case of any emotional distress encountered. Referrals were not needed however.

Data Collection Procedures

Following participant recruitment and obtaining informed consent, individual one-on-one interview sessions were conducted. The interviewer used a semi-structured, open-ended questioning interview technique with participants, with all interviews occurring at a pre-arranged and at a mutually agreed upon locale. An interview guide and protocol (see Appendix D) was developed to guide the researcher's procedure and

dialogue when interviewing the study participants. The researcher recorded the individual interviews with two digital audio recording devices, as well as taking brief field notes during the interviews to aid with subsequent transcription and data analysis. The digital recordings of the interviews' were kept secure with electronic PIN numbers, and kept confidential at all times. The audio recordings of the interviews were transcribed as soon as feasibly possible following the interview personally by the researcher, or by a professional transcriptionist. Once transcribed, the electronic version of the transcription document has been kept securely in the researchers password protected and secured computer. Printed versions of the interview transcriptions documents were kept securely in the researcher's office in a locked cabinet. Privacy procedures were reviewed with the participant prior to the start of the interview.

Grounded theory was applied to the interview transcripts allowing the researcher to find, describe and explain concepts, themes, and related patterns of human behavior within a transgender person's context. Grounded theory also allowed the interviewer to establish relationships and patterns found among the data in the transcripts, relative to the interviewees' health seeking behaviors. A significant beneficial tenet of grounded theory is the ability to conduct data analysis concurrently with data collection allowing the research focus to continue to evolve as the data analysis unfolds. Integral in this analysis is the constant comparison data collection technique, in which the researcher analyzes data gleaned from each interview, comparing it to the data from the initial interview and all subsequent interviews, perpetually evolving the theory based on the emerging themes identified. In addition to the audio recordings made of the interviews, the researcher

developed a field notes document to capture notable observations of the environment, the participants' body language, as well as any important concepts and themes that emerged during the interview (see Appendix E). When possible, the researcher completed the field notes within the same day to more thoroughly and accurately capture the information as soon as possible. Some interviews occurred in later evening hours, with field notes completion occurring the following day.

A limitation of the interview procedure was related to the participants possibly not feeling comfortable in fully describing their experiences related to their health seeking behaviors. This was thought to potentially limit an understanding of the decision-making process and the full spectrum of factors impacting their health seeking behaviors may subsequently not be fully revealed and understood. This potential limitation was not generally experienced as nearly all of the participants being forthcoming and highly conversant with the interviewer.

Grounded Theory Methodology

Using a semi-structured, one-on-one interview technique, the grounded theory method adapted from the approaches used by Glaser (2008), Charmaz (2014), and Urquhart (2013) was used to interview participants in order to answer the research question. Grounded theory has evolved since first introduced by Glaser in 1967, and there is an overlap in the approaches that have since developed. Whereas Glaser (2008) traditionally applied grounded theory research with the researcher being as a blank slate of new knowledge discovery in which the researcher is a disinterested observer without opinion, Charmaz (2014) and Urquhart (2013) are more pragmatic in their grounded

theory philosophy. They indicate that the researcher can be interactive with the data and the process results in cocreation of emergent knowledge and theory. All are inductive in nature. Though the researcher may influence the direction of the data collection and its interpretation, objective separation occurs in throughout the research process so that any preconceived notions of researcher are neutralized.

As further detailed in this chapter, grounded theory allows the researcher to concurrently discover, describe, and explain concepts related to patterns of human behavior within a social context, as well as establish relationships among them (Munhall, 2012). Given that grounded theory was used in this study the researcher conducted data analysis concurrently with data collection, and the research focus continued to evolve as the analysis unfolded. Integral in this analysis is the constant comparison data collection technique, in which the researcher analyzes data gleaned from each interview, comparing it to the data from the initial interview and all subsequent interviews, perpetually evolving the theory based on the emerging themes identified (Munhall, 2012).

The study's philosophical underpinnings are rooted in Paulo Freire's (2018) theory of the pedagogy of the oppressed, while employing the grounded theory approach as a qualitative methodological research framework. Embedded within the grounded theory study methodology, symbolic interactionism was a key component. Charon (2007) describes symbolic interactionism as human interaction and communication being enabled by words, gestures, and other environmental symbols that have attained conventional meanings that are contextually relevant to a particular culture. This is important in the study as the transgender community is a minority population that is not

well understood. Members of the group have unique needs and experiences that are not well described in research literature. It is one of the aims of the study that the unique cultural characteristics of transgender people are highlighted in the study with the symbolic interactionism incorporated into the findings.

Data Analysis

In keeping with the grounded theory method, data was analyzed concurrently with the completion of new interview data. The constant comparative qualitative analysis method is designed to support generating, or redesigning, a theory consistent with the data already gleaned from the research, when the data is plausibly related to the new information presented. In this study, the data revealed in each interview was compared to other participants' interviews, as well as to that of the available relevant literature on the topic (Glaser, 2008). Using the constant comparison analytic technique, theoretical sensitivity was applied from the outset of the data collection. This drove the theory's evolution throughout the study, as did systematizing the inspection of data gleaned from the interviews. Charmaz's more direct and linear style of coding was blended with Glaser's classical approach to coding and data analysis to better accommodate for the uniqueness of the codes and categories that emerged. Comparison of initial and open code elements to identify the significant categories that the elements belong to, along with creating conceptual memos to analyze emerging themes, were applied. These data analyses methods assisted the guidance of the ongoing theory generation (Polit & Beck, 2017).

Data were coded by significant statements made and the resulting prominent categories identified. The coded data and established categories were compared and analyzed against each other for consistency or variance, as well as repetition, and any identifiable relationships among them. Field notes, conceptual memos, interview voice recordings and their transcripts, and journaling were all also used as devices for data collection, data management, and subsequent analysis. Analysis of the codes and categorical data was done in a constant comparison manner. This provided a framework for the establishment of emerging themes and theories. To further aid the trustworthiness, and accuracy, of the review and analysis of the interviews, a thematic data analysis form adapted from a pilot study (see Appendix F) aided the researcher in detecting emerging qualitative data codes, categories, and themes from the interviews. Interview transcripts were analyzed using the thematic data analysis form, along with the interview field notes made during and immediately following the interviews. This thematic data analysis form supported the overall qualitative research construct in the spirit of grounded theory data analysis, with the aim of thematic revelation and theory development.

Applied with the Glaserian based constant comparison technique, this analytic approach allowed the researcher some latitude in the generation of a theory based on the data analysis and subsequent emergence of themes unique to the participants in the study. This theory development approach in grounded theory is inductive in nature and is well suited for the research question and population of study.

Rigor/Trustworthiness

Trustworthiness

The analytic induction method is used with grounded theory to analyze qualitative data that was part of the discovery of knowledge in the study. The process hinges upon the articulation of the study's aim and research question, followed by the collection and analysis of data, and the subsequent evaluation of results supporting theory generation accounting for patterns of human behavior relevant to the topic of study (Munhall, 2012). The study follows Glaser's criteria of data fit and modifiability to provide trustworthiness to the research as they are specifically modelled in grounded theory (Munhall, 2012). To aid in the trustworthiness of the data collection and analysis, several procedures were incorporated in the collection and subsequent analysis process. Trustworthiness and rigor in this qualitative study were centered around a modified application of Lincoln and Guba's (1985) methods for qualitative research rigor and trustworthiness. Credibility, integrity (credibility), dependability, and potential transferability of the findings (Polit & Beck, 2017) were structured for reassessment post study conclusion. The data collection methods previously described supported the credibility of the information gleaned from the interviews. Procedurally, this included adherence to prompt transcription and analysis of interviews, completion of field notes, and constant comparison of the data set from each interview. The data were anticipated to demonstrate evidential applicability for the transferability of the findings to the larger transgender population.

Credibility

The study's credibility, or confidence in the truth of the findings, is reinforced with the researcher's confidence in the research process involving the deep dialogue during the interviews. The participants described their experiences directly to the interviewer as opposed to a detached survey. This is believed to have significantly added to the credibility of the study. The in-person discussions with participants provided a conduit for thorough communication of detailed and rich information. Subsequently, all interview transcripts were individually hand-reviewed and analyzed. Additionally, the researcher developed a network of relationships throughout the research process with transgender residents, community advocates, and healthcare professionals considered experts in the field. The network offered deep access to the local transgender population, providing an opportunity to have contextual balance to the findings. This networked relationship building and access was crucial to obtaining a meaningfully diverse and broad sample size for the study. It also provided the opportunity to perform persistent observation and limited member checking needed for credibility.

Transferability

Transferability is defined as demonstrating that the qualitative findings are applicable in other settings (Lincoln & Guba, 1985). This study's transferability can be seen in the culminating thick description of the experiences of the participants throughout the data analysis and the dissertation. Thick description, as noted by Lincoln and Guba (1985), is a measure of external validity. In this case, it refers to the detailed field recording and transcription of the participants' experiences. Detailed description of a

phenomenon allows the researcher to evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people. The study methodology provided intimate access to the study population, and lengthy personal dialogue that explored factors impacting their health seeking behaviors.

Dependability and Confirmability

An adaptation of Lincoln and Guba's (1985) methods of dependability and confirmability was achieved via limited member-checking of the summative findings, conclusions, and the emerging theory by two participants in the study. Without revealing any individual study participant information to the two individuals, they provided a gauge the accuracy of the interpretation of the aggregate blinded findings, and helped the researcher to assess the need for better articulation of the theory and findings from the worldview of a member of the population being studied. The member checking was carried out in a controlled manner to assure privacy of the participants, and was done on a limited basis after research data collection was complete and theory emergence was documented as to not influence its development.

Limited theoretical triangulation was also applied to the study data and its findings to further support its dependability and confirmability. As defined by Lincoln and Guba (1985), triangulation involves the use of multiple data sources in an inquiry to produce understanding. Triangulation was engaged for confirmability to assist with the different perspectives presented by Paulo Freire's theory of the oppressed, Charon's symbolic interactionism, and the themes seen with the literature cited throughout the dissertation. As the theory presented with this novel research represents an emerging

grounded theory, there is not another existing theory well suited to apply to the examination of the factors of the health seeking behaviors of adult transgender people.

Support

Facilities/Resources

The facilities needed for the study included the potential use of local community centers such as the United Way, the Montrose Center, as well as other LGBTQI+ friendly community center(s). These were not as widely utilized as anticipated, however, as most participants were amiable to meeting in mutually convenient public establishments, such as local coffee shops or cafes. An additional and highly accessible study setting included the use of an online video conference applications, including Zoom, Facebook Messenger, and Skype, for those participants who did not live in the immediate area, or who otherwise elected to not meet in person, but still desired to participate in the study.

Collaborative Arrangements

Aside from TWU, no other academic institution collaborated in the study.

Consultative Support

Consultative support was anticipated with academic experts in the field of qualitative research accessible at TWU, as well as other nursing scholars whose expertise lie within the realm of LGBTQI+ issues, and LGBTQI+ community leaders with expertise in the transgender population. In particular, Mr. Lou Weaver, the transgender programs coordinator for the Equality Texas organization at the time of the study, a transgender community leader, and subject matter expert and consultant, agreed to be

available for consultative support in addition to providing contacts for the research process and potential participants in the study.

CHAPTER IV

ARTICLE SUBMITTED FOR PUBLICATION

The Factors Impacting the Health Seeking Behaviors of Adult Transgender People

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Title Page

The Factors Impacting the Health Seeking Behaviors of Adult Transgender People

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Abstract

Transgender people, those who do not identify with the sex assigned at birth, are a vulnerable population with unique health risks and they face inequities in seeking care. The factors impacting the health seeking behaviors of transgender people are not well studied, and there is a dearth of qualitative studies available to aid researchers, academia, and healthcare professionals' understanding of the population's ability to engage in health seeking behaviors. Using grounded theory method, the study design utilized qualitative semi-structured one-on-one interviews to explore the barriers and supportive structures involved with transgender people's health seeking behaviors. The study sample (n = 30) included adult transgender men and women and non-binary people, regardless of the stage or type of transition the individual had, or desired in the future. The findings of the study reveal an ongoing state of dynamic tension being experienced by transgender people as they desire or actually attempt to engage in health seeking in the face of impactful factors acting as barriers or supporting influences. Themes of fearing, remembering, oppressing and accessing act as primary barriers to seeking care, while affirming and trusting support structures served to facilitate health seeking behaviors. The results are relevant to nursing, and all healthcare as they inform the profession of the needs of transgender people from both the larger social perspective and from participants point of view with the healthcare experience. Their experiences serve to inform healthcare of the challenges and encouragements that can be addressed to improve the access to care for this unique population**.**

Keywords: transgender, health seeking behaviors, grounded theory

Introduction and Background

As U.S. society continues to grow and evolve, the population of transgender people has also continued to grow. Flores, Herman, Gates, and Brown (2016) of the University of California Williams Institute estimate that the number of U.S. adults identifying as transgender has grown from 0.3% of the population, to 0.6% over the prior decade. With this growth, transgender people are more visible in the community and the public than ever before. For example, when public celebrity Bruce Jenner publicly transitioned to Caitlin Jenner in 2015, it was greatly publicized and generally accepted. This general public view was not generally seen prior to this. Despite this growth, transgender people face an ongoing struggle to achieve equitable civil rights. For example, it was only until recently that LGBTQI+ people, including transgender people, could be fired from their place of employment for no other reason than being gay or transgender. In the case of Bostock v. Clayton County Georgia, Aimee Stephens brought a suit to the US Supreme Court for being fired from her job once she came out as being a transgender woman to her employer (Supreme Court of the United States, 2020). Ms. Stephens sued under the 1967 Civil Rights Act with a claim of sex discrimination in the workplace. In June 2020, the Supreme Court decided the case and ordered that a person's gender identity and sexual orientation related to employment was protected, and therefore people cannot be fired for being transgender or gay. However, no other protections were argued in the case, such as housing or public accommodation. The Equality Act proposed by the House of Representatives, which would ensure all LGBTQI+ persons are equally protected in all of these areas, has not passed as of this writing.

As the overall population and visibility of transgender people has increased in the US, so has our understanding of the complexity involved in the transgender person's individual gender transition journey. The process for the transgender person transitioning from the associated gender trait present at birth, to that of the gender that affirms the person's true self, can be lengthy and entail extraordinary individual self-discovery with multiple pathways to affirmation unique to the individual making the transition (WPATH, 2012). Gender affirmation may be described as an individual's self-discovery of one's true gender. It is interpersonal and interactive by its nature, in which a person eventually receives social recognition and support for their true gender identity and expression (Sevelius, 2013). Though basic medical knowledge base appears to be improving, the average healthcare provider receives little transgender specific care educational preparation, and may have inadequate understanding of the multiplicity of ways persons may choose to undergo gender transition (Austin & Goodman, 2017). To illustrate, some transgender people opt to transition socially with changes to their outward dress and appearance, others may transition with the aid of prescription hormones, some may choose multiple transition related surgeries, while others may desire a legal transition with the change of name and gender identifiers on legal documents. Some may elect to employ a combination of these options at various points in life. Because of the multiple options available, and the personal choice considerations that may be made by the individual, the pathway to getting the needed care may be opaque to the transgender person, and a point of ignorance on the part of the healthcare provider. This may lead to a conundrum whereby the individual's need for primary care,

as well as care related to gender transition, tends to be unavailable to the transgender person, and fully unknown to the practitioner. This is likely partially due to a history of pathologizing the transgender person as having a mental illness (Austin & Goodman, 2017).

It was not until 2013 that the American Psychiatric Association declassified being transgender as a mental disorder. The slow pace of change in the classification may stem from the more historical perspective held by some in healthcare community that tended to view transgender people, regardless of the stage of transition, as societal and medical anomalies and therefore their needs are not seriously studied or known in their institutional practices (Bauer et al., 2009). Though some may argue much has changed for the better over the past decade, these remnant oppressive views of transgender people and their care needs have an effect of erasing the transgender community as a whole. One end effect can be seen by the lack of knowledge of the professional healthcare provider about the gamut of healthcare needs of the transgender individual.

Given this complexity of social experiences, individual life path trajectories, and unique healthcare needs that appear to be at risk for being unmet, transgender people contend with inequitable access to healthcare, and experience professionals who often have their own educational inadequacies, pre-formed societal impressions, or personal biases of the population (Austin & Goodman, 2017). This can lead to situations of poor interactions in healthcare encounters that should be ostensibly problem and patient focused, and professionally objective. It can result in distrust of the healthcare

community as a whole from the negative experiences, and can leave lasting emotional wounds with the transgender person.

Modern healthcare is not well equipped or educated enough to meet the needs of transgender people on a large scale compared to cisgender people (those whose sense of gender identity and expression matches that same gender and sex trait assigned at birth). Much of the reason for this is a general lack of understanding and empathy on the part of healthcare professionals and the larger healthcare system of the influential forces involved in the transgender person's health seeking decisions and behaviors. This qualitative research informs nursing, and the larger interprofessional discipline of healthcare, of further specific quantitative research needed. Further, this study will serve not only to illuminate their care needs, but also those pre-decisional factors that may potentially be modifiable to improve the care experiences and ultimate outcomes of the unique population.

Little relevant research has been conducted related to the health seeking behaviors of transgender people, other than clinical outcomes related to gender affirmation surgeries and long-term care issues. Gaining clinical outcomes knowledge related to the longitudinal effects of transition surgery and the effects of long-term hormonal replacement therapies taken by transgender people is important. Gaining a baseline understanding of the realm of factors influencing the health seeking and decision making of the transgender individual is equally important to clinical outcomes knowledge. Otherwise, the healthcare community would never know how to provide completely competent and respectful care to the transgender community in the first place. Whether

the community seeks, or avoids, healthcare remains poorly understood even as modern society evolves toward increased acceptance and integration of the transgender population. As this community continues to grow and be more visible, nursing and healthcare are ill-prepared for the adequate provision of care needed for this unique population.

Scientific Need

The transgender population is a subset of the larger vulnerable LGBTQI+ community. LGBTQI+ people encounter impediments to equitable social and human rights due to a disadvantaged social status (Social Protection and Human Rights Organization, n.d.). The collective labels LGBTQI+, LGBT, and GLBT are synonymous references to the collective population, and are often used interchangeably with the taxonomy of LGBTQI+ groups. The 'T' in the LGBTQI+ grouping, as is the case with the other representative letters in the chain, identifies transgender people as part of an allied group that is more analogous to a community or a coalition, rather than a homogenously cultural or ethnic group. However, the LGBTQI+ group tends to be researched as a single entity, as if it were a single homogenous population. This drastically limits the potential description and understanding of the transgender individuals' unique experiences and represents a noticeable gap in the scientific literature.

From the worldview perspective of the transgender individual, the daily societal and healthcare challenges they face are an affront to their individuality and sense of personhood; thus setting a stage for problematic interactions, healthcare avoidance, and

inequity. This reality brings about the research question of "What are the collection of factors affecting the health seeking behaviors of the transgender population?"

Having practiced in a public health environment for many years, the researcher has had the opportunity to observe how the evolution of social attitudes can affect the healthcare of underserved and marginalized groups of people in need of healthcare. Transgender individuals represent one such marginalized group in the current state of society, as evident in the literature, as well as in my observation in public health nursing practice. The lack of access to culturally competent and accepting care is commonplace in many areas and settings. Even as society becomes more accepting of LGBTQI+ people, transgender people are at the frayed edges of this movement towards acceptance, and thus are left without professional healthcare being readily available.

The premise and rationale of the research question remains that the health seeking behaviors of transgender people are impacted by complex and dynamic factors related to their unique needs, but the factors are poorly understood and not well studied within the community. Thus, the purpose of the study was to develop a conceptual understanding of the array of factors that may impact health seeking behavior, either in supportive or obstructive ways.

Importance to Nursing

With this foundational research, the implications for nursing practice and nursing research are numerous. Nursing has long been at the forefront of advocacy for all people and their needs. With the transgender population, there is an essential obligation to improve the understanding of transgender people's healthcare and social needs that

nursing is poised to address well. There are also academic and practice opportunities to improve the various competencies of nurses in their understanding, use of language, and care parameters specific to the individual transgender individual's gender expression. Hallman and Duhamel (2016) identified that the barriers (for nurses) to teaching (transgender patients) have more to do with lack of awareness of the transgender person's unique needs, and a non-specific curriculum in nursing school, rather than the personal beliefs of the individual nurse.

Being that the transgender population faces multiple barriers to accessing quality medical care in the U.S. healthcare system, the issues that may prevent this marginalized group from obtaining high-quality healthcare services specific to their needs can be improved with even simple efforts such as establishing a welcoming environment for transgender patients in the healthcare environment (Rowe et al., 2019).

Perhaps as equally importantly to furthering equitable access to high quality care unique to individual needs, the nursing profession at all practice levels can serve as a catalyst in its advocacy for the advancement of transgender people towards broader recognition of their health and human needs. Facilitating acceptance and the social justice needed to meaningfully inform and affect public policy change would bring about better care and equity to the transgender population as a whole.

Methods

The study design was built on individual qualitative interviews using grounded theory method. The setting for study was the US, with local focus in the transgender population residing in Harris County, Texas. However, the study was open to

participation by any adult transgender person in the US. The local setting for individual participant data collection varied as the study is qualitative in nature. The methodology for the study utilized semi-structured one on one interviews that naturally occurred in any number of environments as mutually agreed upon by the participant and the interviewer. Examples of the planned settings included the participant's home, a mutually agreed upon and arranged meeting location, an office, or at a local community center, such as the United Way or the Montrose Center, as well as LGBTQI+ specific community center(s). An additional setting included the use of an online video conferencing application, such as Zoom or Skype, for those participants who did not live in the immediate area, or who otherwise did not want to meet in person. The date, time, location, and mode of the interview setting was mutually agreed upon by the interview and the participant in advance of the interview.

Recruitment of Participants

The target population for participants in the study were those adults identifying as transgender, non-binary, or gender fluid. The stage, type, or number of gender transition steps taken by the participant was not a criterion for participation in the study. Assumptions related to the adequacy of the sample sized needed in this qualitative inquiry was centered on the researcher accessing an adequate sample sufficient to gain a deep understanding of the forces in transgender people's lives that may impact their health seeking behaviors. Norman Blaikie (2018) supports that a range of an estimated sample size based on available comparable research is what is required in logic base qualitative inquiry. Being that there is no absolute minimum or maximum number of

subjects required in a qualitative grounded theory research studies that utilize an individual interview method, the sample size was not expected to exceed 20 to 30 participants to achieve thematic data saturation was achieved. Additionally, the estimated sample range was determined with consideration of what was observed in the available relevant literature at the time of the study.

The sampling procedure engaged purposive and snowball sampling techniques, in which participant eligibility was based on the unique characteristics of the adult transgender person identified and consenting to participate in the study. Initial participants assisted with recruitment from among peers in their network, largely by word of mouth. The PI partnered with local LGBTQI+ community agencies and leaders and a state-wide LGBTQI+ advocacy agency, who committed their support to the recruitment of participants for the study and granted access to the organizational membership contact lists. The IRB approved recruitment flyers were sent to community centers, clinics, support groups, and to trusted social media contacts. Prior network contacts development from within the transgender community aided in flyer distribution. Additionally, professional colleagues of the researcher bolstered recruitment opportunities via word of mouth. Incorporating the setting of an online video conferencing applications for those participants who did not live in the immediate area, or who otherwise did not want to meet in person, was a significant contributing aspect to the success of the recruitment of participants. Multiple participants did not have transportation, and others lived farther than they cared to travel, but they still wanted to participate in the study.

The final sample size (N = 30) was achieved as was hoped in the research plan. Theoretical saturation occurred at the 23rd interview. Sound qualitative research methodology calls for two additional interviews to be completed at the point of theoretical saturation. However, given the excellent response to the recruitment efforts, and the researcher committed to all 30 participants that each person would be interviewed and have their individual voices added to the body of the study, the five remaining interviews were conducted. It was meaningful to have such a strong response to the study with so many participants eager to contribute to the research.

Protection of Human Subjects

The study was approved by the TWU IRB on August 18, 2018, and extended on August 8, 2019. Compliance with the current rules and regulations of the IRB were strictly observed throughout the study. The PI, all members of the dissertation committee, and research assistants participating in the study all successfully completed the required collaborative institutional training initiative course. An informed consent was obtained for all participants prior to the beginning of individual research interviews. For in-person interviews, the informed consent was reviewed and signed at the interview session prior to the initiation of the interview questions. For interviews that took place via an electronic web-based video conferencing app, the informed consent document was provided electronically to the participant prior to the interview. The signed consent was returned electronically to the researcher prior to the start of the interview. Participants' electronic signatures were allowable on consents for interviews that were conducted via web-based video conferencing app. All subjects' rights were respected and protected,

with any risks thoroughly provided and explained during the informed consent process. Heightened human protection considerations were applied for study's participants, to aid them should emotional distress have occurred during or as a result of the interview. Participants were able to discontinue participation at any time they choose for any reason. For emotional distress encountered during the study, a referral resource to a preferred LGBTQI+ counseling center was readily available, if needed.

Data Collection Procedures

Following participant recruitment and obtaining informed consent, individual one-on-one interview sessions were conducted, with a preference for the interview to be in-person. Alternatively, a secure web based video-conferencing (e.g., Zoom, Skype) was employed if an in-person interview proved to not be possible. The interviewer used a semi-structured interview technique with eligible participants, with all interviews occurring at a pre-arranged and at a mutually agreed upon locale.

An interview guide provided instructions for the researcher's procedure for interviews. The researcher recorded the individual interviews with two digital audio recording devices, as well as taking brief field notes during the interviews to aid with subsequent transcription and data analysis. Following the transcription of the interviews, grounded theory methods were applied to allow the researcher to find, describe, and explain concepts, themes, and related to patterns of human behavior within a transgender person's context, as well to attempt to establish relationships and patterns among them, relative to transgender persons' health seeking behaviors. The digital recording of the interviews was accomplished on audio recording devices with secured electronic PIN

numbers, and kept confidential at all times. The audio recordings of the interviews were transcribed as soon as feasibly possible following the interview. Transcription was accomplished personally by the researcher, or by a professional transcriptionist. Once transcribed, the electronic version of the transcription document was stored securely in the researcher's password protected computer. Any printed versions of the interview transcriptions documents were kept securely in the researcher's office in a locked cabinet.

In addition to the audio recordings made of the interviews, the researcher developed a field notes document to capture notable observations of the environment, the participants' body language, as well as any important concepts and themes that emerged during the interview. Within the same day of the interview, the researcher completed the field notes to more thoroughly and accurately capture the information as soon as possible.

With the semi-structured, one-on-one interview technique, grounded theory method was used as the qualitative research method to interview participants to help answer the research question. Grounded theory allows the researcher to concurrently discover, describe, and explain concepts related to patterns of human behavior within a social context, as well establish relationships among them (Munhall, 2012). A significant beneficial tenet of grounded theory for this study is that it allows the researcher to conduct data analysis concurrently with data collection, and the research focus continues to evolve as the analysis unfolds. Integral in this analysis is the constant comparison data collection technique, in which the researcher analyzes data gleaned from each interview, comparing it to the data from the initial interview and all subsequent interviews, constantly evolving the theory based on the emerging themes identified (Munhall, 2012).

The study's philosophical underpinnings are rooted in Paulo Freire's theory of the pedagogy of the oppressed (Freire, 2018), while employing the grounded theory approach as a qualitative methodological research framework. Embedded within the grounded theory study methodology, symbolic interactionism remains a key component. Charon (2007) described symbolic interactionism as human interaction and communication being enabled by words, gestures, and other environmental symbols that have attained conventional meanings that are contextually relevant to a particular culture. This is important in the study as the transgender community is a sub-culture whose experiences and needs are not well understood. It was an aim of the study that the unique cultural characteristics of transgender people would be demonstrated and the symbolic interactionism present seen.

The limitation of the interview procedure was related to the participants possibly not feeling comfortable in fully describing their experiences related to their health seeking behaviors. This had the potential of affecting the understanding of the decision-making process of the group and the full spectrum of factors impacting their health seeking behaviors may subsequently not be fully understood. This potential issue was not largely experienced. Though some participants were more talkative than others, they all largely freely shared their experiences throughout the interview dialogue.

Results

Data Analysis

The study participants' (N = 30) were largely forthcoming and open with sharing their experiences, thoughts, and perceptions during the interview dialogue. This

openness afforded the PI an insight into the participants experiences, demographics, and characteristics not often seen in research. Immediately prior to the interview questions initiation, the participants answered demographic and characteristic questions that provided context to the transgender individual's experience. The study participants represented a range of ages, gender presentations and ethnicities. The age range of the participants was 20 to 58 years, with a median age of 30.5. The participants' gender and racial characteristics are detailed on Table 2. The participants' education, employment, insurance, legal gender marker change, hormone therapy use, and gender affirming surgery history were also solicited (see Figure 2). Figure 3 demonstrates specific gender affirming surgeries underwent by participants who reported having a gender affirming surgery. This spectrum of background characteristic data provided by the participants contributes to the contextual attributes of the study sample.

Theoretical Sampling

In grounded theory-based research, data collection and data analysis are frequently overlapping processes, and not always discrete from one another. As data and concepts arose from individual interviews, subsequent interviews were guided by the previous interviews' emerging concepts and themes, as a form of theoretical sampling (Urquhart, 2013). Future participants were not necessarily interviewed exclusively based on the emerging themes, more so new themes were incorporated to the interview dialogue and ensuing conversation, if the topic was relevant to the experiences of the particular subject being interviewed. This variant of theoretical sampling contributed to the rich nature of the dialogue, while remaining anchored to the established interview guide.

Table 2

Participant Gender and Racial Characteristics

Participants (N = 30)			
Race/Ethnicity	Transman (n = 19)	Transwoman (n = 8)	Nonbinary (n = 3)
Caucasian	13	3	2
Black/African-American	3	4	0
Hispanic/Latinx	1	1	1
Asian	1	0	0
Indo-European	1	0	0

Note. This table represents gender and race/ethnicity characteristics as described by the participants.

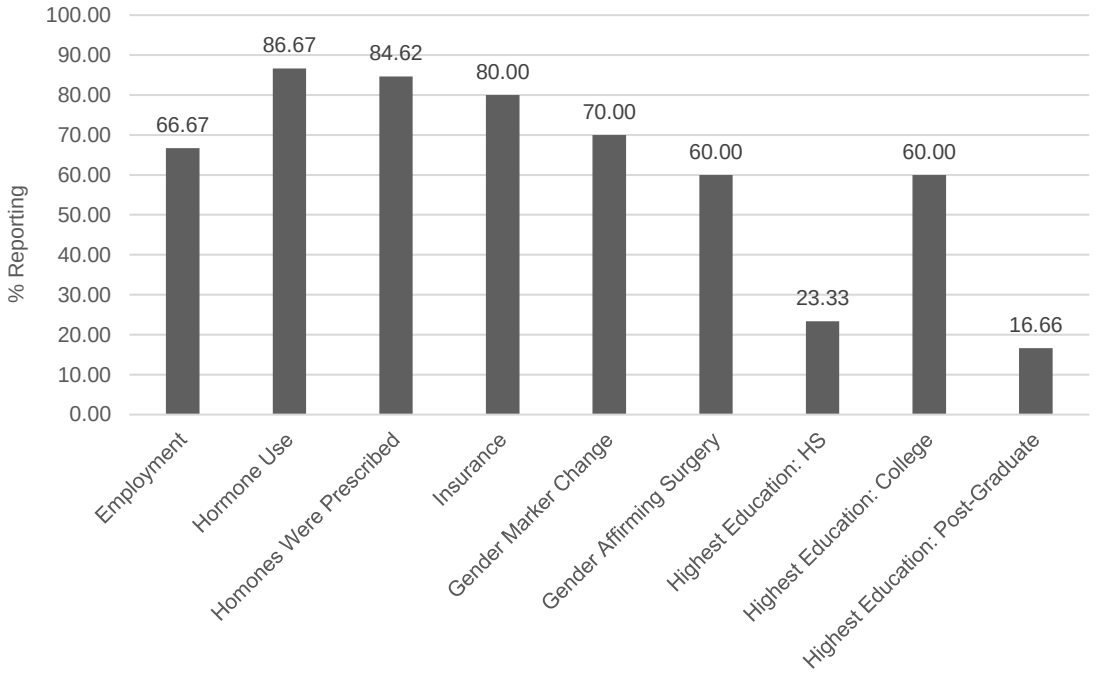

Figure 2. Participant demographic characteristics. This figure depicts the percentages of affirmative responses of demographic information items and characteristics disclosed by the participants.

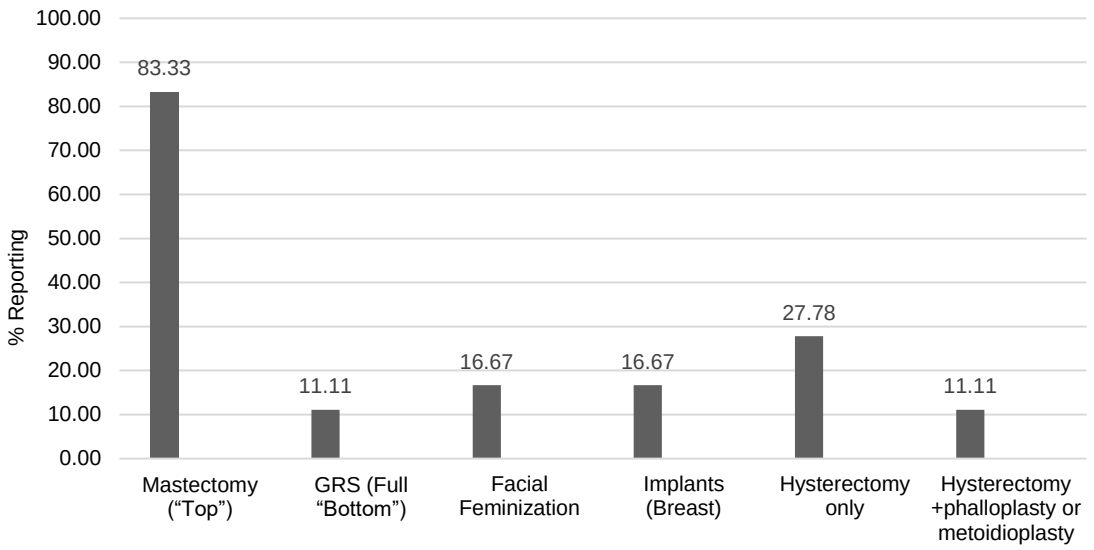

Figure 3. Gender affirmation surgery characteristics. This figure depicts the percentages of gender affirmation surgeries reported by participants who indicated having had a gender affirmation surgery. GRS denotes gender reassignment surgery.

Coding and Constant Comparison

The data coding process is an integral component in grounded theory inquiry that utilizes interviews as the data source. Coding is the critical linkage of data collection to the development of new theory relevant to the data obtained in the inquiry (Charmaz, 2014). Participants' key words, meaningful statements, and overarching themes that emerge from the interviews all require several levels of coding and thematic categorization for analysis. Though Glaser's constant comparison method was utilized to compare data from one interview to the next, and in subsequent comparison to the whole body of interviews as they progressed throughout the study, the coding system methodology developed in this study was adapted and blended from Charmaz's (2014) and Glaser's (2008) methods. Some variation was applied to support this foundational nature of the study and unique population studied. A bottom-up approach as described by

Urquhart (2013) was introduced into the coding scheme. The initial data was derived from the interview notes, interview transcripts, line by line analysis of the transcripts with notes made in the margins of each transcript, field notes, and conceptual memos completed. In order to remain open to new themes and potential new theory emergence, the existing literature was not initially considered in the data collection process and its subsequent coding. Each participant's experiences and expressed themes were considered independently for initial open coding and categorization, and then compared with each other for thematic expression. Each interview transcript was analyzed at the word and sentence level for determination of codes suggested by the data.

As demonstrated in Figure 4, coding followed the bottom-up coding approach. The codes and their trends were then examined with a higher-level analysis aimed at thematic coding of the data, and sorting of the emerging themes.

Chain of Evidence

The strength of the study is bolstered by its depth of data gleaned from the interviews. Demonstrating a chain of evidence in grounded theory studies is an important part of establishing the rigor of the study and resulting theory. The chain of evidence presented in this study is compiled and presented in a constructivist spirit that is meant to convey the rich nature of the participants' dialogue with the researcher. Table 3 details the chain of evidence of the occurrence of the selective codes as grouped by theme and thematic category.

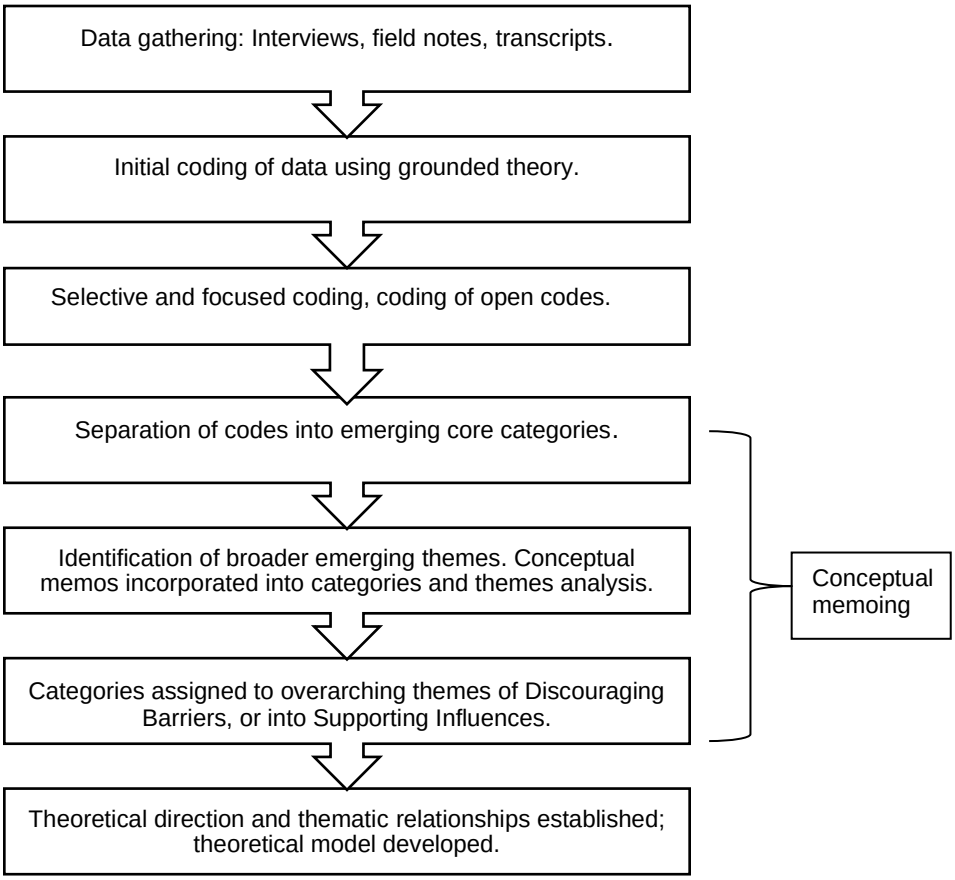

Figure 4. Coding and theory development process. This figure depicts the bottom up approach of coding of data elements that emerged from interviews. Coding and recoding procedures were done to sort codes into emerging categories and themes, until a grounded theory was established.

Table 3

Chain of Evidence

Codes	Theme	Cases occurring	Category	% Cases
Provider Incompetence	DB	1–30	A	100.00
Decision Complexity	DB	1–8, 10–30	A	96.67
Low availability of trans affirming/trans competent providers (general care)	DB	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 15, 16, 17, 19, 20, 21, 22, 23, 24, 25, 26, 27	A	80.00
Low availability of trans affirming/trans competent providers (mental healthcare)	DB	6, 7, 8, 9, 10, 11, 1, 14, 17, 18, 19, 23, 26, 27, 28	A	50.00
Low availability of trans competent providers (trans care specific)	DB	1, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 18 19, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30	A	83.33
Insurance, Cost	DB	1, 2, 3, 4, 5, 7, 8, 10, 11, 12, 13, 15, 16, 17, 18 19, 21, 22, 23, 24, 26, 27, 28, 29, 30	A	83.33
Denial of Care	DB	2, 3, 4, 10, 11, 12, 13, 15, 16, 18, 23, 27, 28	O	43.33
Transphobia	DB	1–8, 10–30	O	96.67
Legal, religious or policy-based discrimination	DB	2, 3, 4, 5, 11, 13, 14, 15, 16, 18, 20, 25, 28, 29, 30	O	50.00

Continued

Table 3 Continued

Codes	Theme	Cases occurring	Category	% Cases
Marginalization, erasure	DB	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 15, 16, 17, 18, 20, 21, 22, 24, 25, 27, 28, 30	O	76.67
Past negative encounters	DB	2, 4, 6, 7, 10, 11, 12, 13, 15, 16, 17, 18 19, 20, 21, 22, 23, 24, 25, 27, 28, 29, 30	FR	76.67
Misgendering	DB	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 15, 16, 17, 18, 20, 22, 24, 25, 27	FR	66.67
Safety not assured: physical, psychological	DB	1, 2, 3, 4, 8, 10, 11, 12, 13, 24, 29	FR	36.67
Having to repeat my story	DB	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13, 15, 16, 18 19, 22, 23, 29	FR	63.33
Avoiding, missing care	DB	1, 2, 3, 4, 5, 6, 10, 11, 12, 13, 15, 16, 17, 18 19, 20, 21, 22, 23, 24, 25, 27, 28, 29	FR	80.00
Fairness, kindness	SI	1, 3, 4, 5, 6, 7, 8, 10, 11, 13, 15, 16, 17, 18 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 30	R	83.33
Pronoun usage (affirming)	SI	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 15, 16, 17, 18 19, 21, 22, 24, 25, 27, 28, 29, 30	R	83.33
Good health provider, gentle exams	SI	7, 10, 12, 15, 16, 17, 19, 21, 23, 25	R	33.33

Continued

Table 3 Continued

Codes	Theme	Cases occurring	Category	% Cases
Available Network of trusted people (support systems), choice providers	SI	1, 2, 4, 5, 6, 7, 10, 11, 12, 13, 14, 15, 16, 18 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30	ATPP	86.67
Understanding, caring, listening	SI	1, 3, 4, 5, 6, 7, 8, 10, 11, 13, 15, 16, 17, 18 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 30	ATPP	83.33
Support, acceptance	SI	12, 13, 15, 17, 18, 19, 20, 24, 26, 27, 28	ATPP	36.67
Autonomy, personhood (respect for)	SI	1, 3, 4, 5, 6, 7, 8, 10, 11, 13, 15, 16, 17, 18 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 30	R, ATPP	83.33

Note: The chain of evidence for codes references the thematic categories identified as accessing (A), oppressing (O), fearing and remembering the past and future (FR), respecting of care needs and individual personhood (R), and affirming/trusting people and providers (ATPP). DB = discouraging barrier theme. SI = supporting influences theme.

Notes, Quotes, and Memos

The data coding process accounted for the interviews transcript data, the field notes taken during the interviews, subsequent line-by-line margin notes made in reflection of the interview while reading the transcripts, reflective participant statements and quotes, and conceptual memos written to capture poignant categories identified as contributing to the themes. A conceptual memo was written relative to the categories of fearing and remembering, accessing, and oppression (with respect to the ability to seek care), contributing to the theme discouraging (barriers to seeking care). An additional

conceptual memo was made on the categories of affirming people and providers and respecting leading to the theme of supporting of care.

Discouraging Barriers

The codes and categories documented in the study that contribute to the larger theme of discouraging barriers reflect an often overwhelming situation for the transgender person whereby seeking care becomes a non-viable option. Out of the 14 codes contributing to the three categories of accessing, fearing and remembering, and oppressing, all add up to a large obstructive force negatively impacting health seeking behaviors in the lives of transgender people. One participant noted "…I usually don't even try to look for care when I know I'll be treated badly." Another participant relayed "…unless it is a real emergency, there is no point in looking for care when there are no competent healthcare providers where I live."

Similar feelings regarding the various codes making up the discouraging barriers category were iterated by the majority of the study participants. The meaning behind these statements cannot be underestimated: care is discouraged before it is even pondered.

Supporting Influences

In contrast to the discouraging barriers category, data found in the supporting influences category also revealed deep meaning, though disproportionately less compared to discouraging barriers, to the participants. Seven data codes led to the two categories of respecting, and affirming/trusting people and providers. These categories contributed to the supporting influences theme centered around the presence of social support, respect

received from people and providers, and the presence of affirmation in their lives. One participant noted "…I would not go to anyone else other than to Dr. X. She embraced and respected us [transgender people] when no one else would. Now she is a leader in competent transgender care." It is important to note that this participant drives over two hours each way to Houston to see this provider. Another study participant notes the people in his life that affirmed him, supported him, and provided a network to rely on. "I can't imagine what would have happened to me unless I had Ms. X in my life. I think I probably would be dead. She has guided me, and told me who is safe to go to for care, and what I need to do. I call her my mama bear." The trust gained from affirming people and providers in the lives of transgender people forms a network upon which is constantly relied.

Perhaps one of most significant findings from the study data is the data showing transgender people have a need to be seen and respected for who they are, not necessarily as who they were thought to be at birth. With a majority of participants relaying that they will tolerate a certain amount of erroneous name and pronoun usage from otherwise well-meaning, though unenlightened individuals, if it means healthcare or social needs can be met. It is analogous to accepting a baseline level of disdain, disrespect, or a sense of being non-existent from others in the world about you, so long as you are still able to live. This sense of not having their gender identity recognized or respected occurred in life routinely, but also carried into healthcare encounters. The phenomenon was articulated in various ways by different participants, and was likened to not being visible as a person to those around them. Many participants consistently described the context in

the same way, but not necessarily using the same terms. Some participants used the term erasure, others used the term marginalization, and many spoke of autonomy and respect. The result of their experiencing these occurrences acts to reduce the person to invisibility in the world. This debasing force was relayed as being more powerful than one's own personhood to the transgender person. This knowledge of generalized unacceptance of personhood that is endured by much of the transgender community, is a powerful force that acts to cast doubt in one's own identity, and is a poignant data point reflective of deep meaning.

Memo 1: Remembering + Fearing + Accessing + Oppression = Discouraging (Barriers to seeking care)

The transgender and non-binary participants interviewed throughout the study routinely described a varied number of bad experiences, resource limitations, memories of past bad encounters or with hostile and derogatory people, and extremely limited access to competent providers. These, coupled with a general fear of how they will be treated in life, based on negative experiences of how they have already been treated poorly. Occurrences of poor treatment inclusive of blatant discrimination and physical assault, were described in both social experiences and healthcare encounters. Many of these things described were largely out of their control, and still occurred regularly in their lives, all resulted in a hesitancy to seek care due to fear and emotional labor needed to traverse the fear. Some people had many of these discouraging barriers present in their life, though some had just a few. All of the participants voiced having more than one barrier in their lives that impacted the ability to seek care at one time or another. It had

the impact of discouraging the act of seeking care all together. For those that faced multiple discouraging barriers, they felt as if the world had organized against them in a systematic way. All participants had personal knowledge of at least one negative experience that impacted their future decision making for healthcare. Some experienced negative encounters directly, or knew of someone who had a negative experience that they learned from. Even indirect knowledge of another's bad experience led to changes in participants seeking future care. Because of this, many spoke of a heavy reliance on their network of people and providers that were known and trusted to the community, as well as trusted non-healthcare related advisors, who are regularly advised on where to get what they may need. Along with the previous memories, fears, and negative experiences, networking was a significant factor in how the participants went about accessing care.

The totality of the set of circumstances experienced by transgender people seemed to shape a worldview of fear, and some distrust to a certain extent, acting as a constant discouragement to objectively seek out care when it was desired or acutely needed.

Memo 2: Affirming + Trusting + Respecting = Supporting (Supporting influences to seeking care).

In speaking in-depth with participants, it was clear that there was a true sense of yearning, even a need among many, to have the multiple negative forces in their lives balanced in some way. The transgender and non-binary participants interviewed throughout the study explained how affirming, trusting, and respecting elements in their lives served as a framework of supporting influences, enabling the seeking of care when it was needed or wanted. A sense of being respected as an autonomous person, having

access to affirming spaces, a more available choice of affirming professional healthcare providers, and the presence of a network of people in their lives who were accepting and supportive, all played a big part in contributing an overall supportive force for seeking care. The participants frequently revealed that the blend of supportive influences seemed to show a willingness to accept the negative forces in their lives, if it meant it could be balanced and resulted in the ability to seek care when wanted or needed. However, it was not an ever-present ability for acceptance. Some described an 'emotional bandwidth' was needed in order to prepare to deal with a future healthcare encounter. It was described as being intense. When there was a good balance, there was less internal tension involved to go and get the care needed, and perhaps a desired outcome was achieved.

Emerging Grounded Theory Development

Glaser (2008) reminded researchers that grounded theories become known and remembered by the conceptual ideas rendered through the researcher's written conveyance of their observations and induction. A developed grounded theory is not noted nor remembered because of a particular form or format, and there is no pre-prescribed structure on how it is to be written (Charmaz, 2014). This free-form style of formal qualitative research documentation is both liberating and vexing. It leaves the researcher with immense latitude in the preparation of dissertations and manuscripts related to a grounded theory-based research study. It also presents the researcher with the unenviable reality that the large amount of rich data generated from a grounded theory study can be unwieldy to manage and difficult to reduce to a succinct message. With this

difficulty, several key tenets are in place to describe the grounded theory established in this study.

In addition to coding of the data and establishing themes and categories, the study's grounded theory methodology incorporated symbolic interactionism in consideration of theory emergence and refinement (Charon, 2007). Though not used an explanatory theory per se (Charmaz, 2014), symbolic interactionism was key to understanding the context of daily life from the view of the social reality for the transgender person. The study participants demonstrated that their perceived reality was indeed their own lived truth. The great number of discouraging barriers, not well offset by the supporting influences in their lives, create a situation in which the transgender person wants, or needs, to seek care, but their behaviors are discouraged for multiple categorical reasons. These reasons are outlined in the categories of accessing, fearing and remembering, and strategic oppression. Their unique needs still remain, however. Those needs may become urgent at some point, thus forcing a mental decision to get care despite discouraging barriers that may be present.

This situation sets up a constant backdrop of tension in their lives where there is an internal debate occurring related to the need for health seeking, when it arises. Simplistically put, the person internally debates: "I need care, but there are so many discouraging barriers. Should or shouldn't I seek it out? Are my supporting influences enough to help me get help and healthcare that I need?" This ongoing self-talk debate is forged by their experiences, which then often guides future decisions relative to unknown events that may or may not lead to choosing a healthcare related interaction. This is

reflective of symbolic interactionism whereby transgender people view their lived social and healthcare realities and make decisions on whether or not to engage in health seeking from that perspective. The findings result in the emergence of the grounded theory of transgender heath seeking dynamic tension, as it relates to the transgender or non-binary person. The model depicts the reality of the transgender person's internal and externa struggles for seeking care. There is an ongoing push and pull of wanting, or needing, to seek care for trans specific and general health needs, up against the many discouraging barriers that exist to achieving the health goal. The discouraging barriers are somewhat inadequately balanced by the supporting influences in the person's life. The dynamic push and pull is set within the continuous presence of systemic social and political oppression, and the individual emotional bandwidth available to the person to push back against barriers to seek care. Additionally, there are interactional relationships occurring among the categories of codes on both sides of the model. It is surmised that these clusters of themes occur in varying degrees at different times and are influential upon the ability to seek care.

Figure 5 visually depicts the transgender health seeking dynamic tension theory as a model. The visual aid represents the various factors impacting the transgender individual's health seeking behaviors. There is a constant, dynamic tension occurring within the transgender individual, between discouraging (barriers), and the supporting (supportive influences), to engaging in health seeking. The dynamic is further pressed upon the individual by the ever-presence of systematic social oppression and the individual emotional bandwidth available experienced when transgender people decide

whether or not to seek needed care. Participants described emotional bandwidth as having sufficient emotional and mental energy to engage in health seeking, with the knowledge that it may be a frustrating or perhaps unsatisfactory experience.

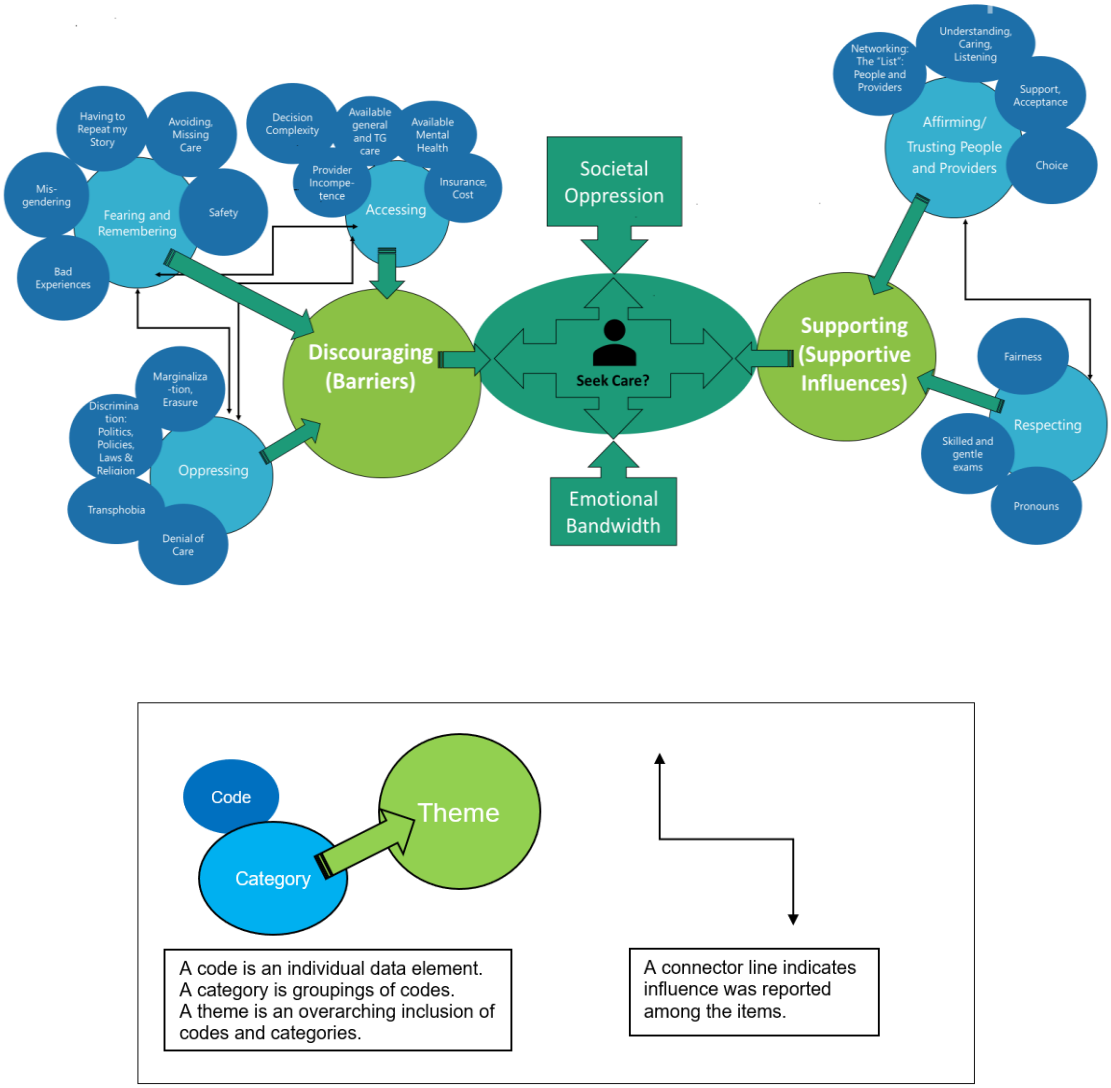

Figure 5. Transgender health seeking dynamic tension model. This figure is a visual depiction of the transgender health seeking dynamic tension theory. The visual model depicts the dynamic tension between the discouraging barriers and supporting influences experienced when transgender persons decide whether or not to engage in health seeking. The presence of an environment of oppression, relative to the individual emotional bandwidth available to seek out care, act as additional impactful factors or tension points that the individual must overcome for the individual to engage in health seeking.

Discussion

This foundational qualitative research study of the factors impacting the health seeking behaviors of transgender people was unique. It resulted in a novel description of the influences upon health seeking in situations endured by transgender and non-binary individuals, and the related grounded theory generation. The article details how the study was formed and evolved using grounded theory, with a philosophical underpinning of Paulo Freire's theory of the oppressed serving as a backdrop providing context to the transgender individual's life experiences contributing to the various factors impacting their health seeking behaviors. The study entailed data collection and analysis from personal interviews with adult transgender and nonbinary people about the barriers in their lives that impact seeking healthcare. Thus, the research question posed at the outset was answered, and a new and foundational grounded theory emerged.

The following assurances highlight the strength and quality of the study while keeping with the philosophy of qualitative grounded theory research:

- Data collection methodology was thorough and rich,
- Deep access to the population afforded a good sample size relative to a qualitative study,
- Transgender community member and advocate served as consultant, and
- Member checking helped to validate findings and emerged theory.

The scholarly quality of this study is further supported with an extensive chain of evidence presented in written form. Additionally, Lincoln and Guba's (1985) evaluative

criteria for the trustworthiness of a qualitative research inquiry supports the study's strength further. The four elements of evaluative criteria, including credibility, transferability, dependability and confirmability, were achieved.

Limitations of the Study

The study examined the perspectives and influences upon health seeking of transgender and non-binary adults in rich detail. The limitations of the study may include:

1. Some of the unique experiences described may not apply universally to the transgender population as a whole in the US. Though common themes emerged in the study, an individual's experiences in seeking healthcare are unique to the person involved. Similarly, the factors and variables influencing health seeking may differ.
2. This study did not delve into gender transition related clinical outcomes. Gender transition is unique to the person as needs of individual people vary widely. Health seeking behaviors will also be unique.
3. Cultures, laws, and resource availability vary throughout the different regions in the US. Such variations in life impact transgender populations throughout the US, and thus a different set of experiences can occur for the transgender population living in other geographically and culturally distinct locales.

Recommendations for Social Change, Practice, and Research

Completing this research has afforded the PI a first-hand look at the lives and needs of 30 transgender people, from within the social context of the barriers and support

systems impacting their ability to seek healthcare. From this arose recommendations for social change, nursing and healthcare disciplines education and practice, and research.

Social Change

- Advocate for policy and legislative driven changes to better protect the transgender population from discrimination in society and the workplace, including respect for transgender people's autonomy and personhood.
- Improve health related businesses culture of affirmation through education and legal protections.
- Update work spaces and outward messaging and signs to be convey safe and affirming spaces in all aspects for transgender people, including public venues, schools, hospitals, and places of business.
- Eliminate strategic and systematic oppression from society driving inequity,
- Instill societal equitability for the transgender community by respecting the transgender individual's journey.
- Model the knowledge that transgender and non-binary people need to be seen and accepted for who they are.
- Be an advocate for and an ally with the transgender community.

Nursing and Healthcare Education and Practice

Multiple recommendations for professional practice and education come forth from the study, for nursing and all health professionals:

1. Improve education of all professional healthcare academic programs and continuing education for practicing professionals to provide competent, inclusive,

and affirming care for transgender and non-binary people. This includes respectful language usage, and avoiding misgendering in healthcare encounters.

2. Improve access to transgender competent and affirming medical providers.
3. Avail case management services to help transgender people obtain the resources they need to afford and seek care, reduce decision complexity.
4. Improve access to transgender competent and affirming mental health providers to address emotional labor of seeking care.

Research

Multiple subtopics arose in the interviews beyond the scope of this study, that warrant future research. Primarily, the impact of access to mental health services for the transgender population is important to investigate. There were multiple study participants who disclosed fragile mental health due to a lack of access to LGBTQI+ mental health professionals. Additionally, the potential effect of removing (or bolstering) one of the initial open codes documented in the chain of evidence upon the effects of the relationships among the categories and themes that were identified in the study is a candidate for further investigation. For example, if a control or intervention is applied to the act of misgendering in the health professional environment, would that improve the accessing of care by the transgender individual, or result in a difference in the individual's ability to conduct health seeking?

Closing

Through the stories and experiences shared, much was learned about factors impacting the health seeking behaviors of transgender people. The findings reveal a wide

range of struggles endured by the transgender community, often on a daily basis. The many discouraging barriers to care are represented by their real daily struggles. While there is some counterbalancing of the discouragements with positive supporting influences, the barriers are not completely equaled out to a steady functional state. The findings discovered in this research can inform nursing practice and research to ultimately achieve an improved state of health seeking behavior for transgender people.

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CHAPTER V

SUMMARY OF THE STUDY JOURNEY

Introduction

When I embarked on the journey to research the factors impacting the health seeking behaviors of transgender and non-binary persons, it was with a limited understanding of their experiences. Having practiced in a public health setting for many years, the outcome of their health seeking was often observable in the acute and chronic setting, and it was often at a crisis level. It occurred to me that there must be influences unknown to health professionals occurring in the lives of transgender people that prevented transgender and non-binary persons from seeking high quality care before it became a crisis. However, life elements occurring prior to arriving at a health encounter may largely go unseen by the academic and healthcare communities, and healthcare was (and still is) generally unprepared to adequately handle the unique needs presented by the population. These predisposing factors were thought to be principally influential upon care seeking behaviors. This study set out to better understand influential factors that tended to impact and drive decision making for related health seeking behaviors. The research question posed in the study was formulated as "What is the collection of factors affecting the health seeking behaviors of the transgender population?"

Using the grounded theory method, a qualitative semi-structured interview guide employing open-ended questions was developed to guide the researcher in the dialogue with study participants. Transgender and non-binary adults were interviewed on a one-

on-one basis to explore their experiences and to directly gather qualitative data about the elements of life that impact their health seeking behaviors. Since a health seeking behavior can be any act or decision leading to seeking or avoiding care, the study offered an opportunity to gather rich and meaningful data.

Literature Review Philosophy in Grounded Theory

In traditional Glaserian grounded theory method, the researcher does not conduct a literature review related to the problem of study prior to the initiation of the research itself. This Glaserian instruction is designed to prevent the researcher from introducing any bias or preconceived notions into the study. This would influence the emergence and accuracy of themes and theory that should be grounded in the data collected (Artinian et al., 2009). Charmaz (2014) acknowledges that a literature review is a requirement in doctoral level research and dissertations, but allows for it in grounded theory so long as it does not influence the data analysis or theory development.

In relation to examining the existing literature for this study, an adapted and blended approach to these scholarly pillars of grounded theory was incorporated with major elements from Glaser and Charmaz, and with guidance from published nursing researchers familiar with grounded theory research methods. In this case, an integrated literature review was performed prior to the initiation of the research, though it was focused solely on the known knowledge of health seeking behaviors of transgender people. The gap noted in the literature was the absence of the various factors that impact the health seeking behaviors of the transgender and non-binary person. These impactful factors are the key to the research study and formed the basis of the research question.

Artinian et al. (2009) noted that this approach to literature consideration is acceptable for grounded theory if the literature review seeks to understand gaps in the literature as it relates to the research questions, as well as to meet doctoral nursing research and dissertation requirements.

The themes found in the integrated literature review centered around the barriers to care being experienced by transgender people. In re-reviewing the literature at the conclusion of the research, coding, and theory development in this study, the factors impacting the health seeking behaviors were still not readily apparent. Safer et al. (2016) supported this with their findings of multiple barriers to care that are experienced by transgender patients noted in the available literature of the time of writing. The authors also noted that not much research had been done to establish the reasons why those barriers may exist, and data documented in the literature was based on self-report from transgender individuals, rather than the direct research procedures undertaken in this study. Thus, the integrated literature review remains relevant to the study, but it did not interfere with the methodology or the grounded theory development throughout the study. Lastly, the available literature reviewed here was found to be largely limited to self-report data from large scale surveys. Most did not include individual stories and experiences captured in depth directly from individuals of the transgender community, as presented in this study. Thus, demonstrating the research to be foundational in nature.

Summary

This foundational qualitative study examined the experiences and views of transgender and non-binary adults, within the context of the factors impacting their health

seeking behaviors. The study deeply explored the participants' experiences and their views of the forces in their lives relative to these impactful factors. Participants were individually interviewed about their overall experiences, the barriers they encountered, as well as the supporting influences present or desired in their lives that have bearing upon their health seeking behaviors. The study is unique in its examination of the factors impacting health seeking behaviors, rather than merely the identification of those health seeking behaviors.

Thirty transgender adults, including non-binary adults, were individually interviewed for this study. Both an in-person setting, as well as internet-based video chat apps were used to conduct the interviews. With extensive data analysis of the interview transcripts, field notes, and conceptual memos, the data was open and selectively coded into 21 codes, with five categories subsequently identified. The codes and categories were ultimately organized into the two overarching themes of discouraging barriers and supporting influences. Using the grounded theory method, the codes, categories and themes were analyzed for meaning and relationships with a theory and theoretical model emerging. The interplay of the discouraging barriers and supporting influences was seen to be a dynamic and constant ebb and flow within the transgender individual, depending upon the urgency of the care need. This dynamic tension occurs within the context of the person's available emotional bandwidth or tolerance for the stress of the situation, affecting the will to seek the care. Layered on that dynamic tension, is the expressed presence of a continuously residing environment of oppression upon the transgender person's existence.

Discussion of the Findings

Throughout the course of the study, it was noted that barriers to care faced by transgender persons are also found in some of the available literature while less has been reported on supportive influences. However, much of the literature cites self-reported data as opposed to direct research data acquisition from participants, as was done in this study. Safer et al. (2016) found in their review that the most significant barriers to healthcare cited is a lack of access to trans knowledgeable healthcare providers. The authors reported other references to barriers that include financial limitations, discrimination, lack of inclusive cultural competence, healthy system inadequacies to meet care needs, and general socioeconomic barriers. These barriers all lead to disparity in the care available for the transgender community. Respondents in this qualitative study directly revealed these exact barriers, among others, that impact their ability to seek out care. It is important to know that the barriers are being consistently seen from self-reported and direct research studies as it reaffirms the validity of the ongoing pattern of the problem, and the need for intervention. The findings not only support the existing literature, but bolster them with directly obtained data.

To illustrate, the data analysis and resulting findings that emerged from this study were rich with personal experiential accounts and viewpoints from the worldview of the transgender adult. The dynamic tension model discovered in the study reflects and potentially extends Freire's (2018) theory of the pedagogy of the oppressed, which served as the philosophical underpinning for the study. As relayed in earlier chapters, Freire's theory describes the concept of how historical and modern oppression has been justified

by oppressors, and how oppression is cyclically repeated via mutual dynamic processes between the oppressor and the oppressed. Freire shows that the balance of power between the oppressor and the oppressed remains relatively constant, until a disruptive influence occurs that overrides the uneasy status quo that yet also seeks to achieve a new praxis and a steady state of humanity.

Relating Freire's philosophical framework to transgender people's ability to conduct health seeking is a natural product. This can be seen with the multiple legal attempts throughout the US to remove the civil and healthcare rights of transgender people, as well as their rights in many other social aspects. Having one's individual rights denied is a clear indicator of the oppression that is felt by the transgender person. The dynamic of pushing against that oppression to secure one's healthcare becomes apparent in the model as a sign of the oppressed rising up against the oppressor.

Extrapolated Meanings

There are deep meanings residing behind the study's findings and the emerged grounded theory. The findings demonstrated by the theoretical model show an overall state of oppression exists, with varying degrees of emotional bandwidth available to address the discouraging barriers to seek care. The model signals that the supporting influences are outnumbered by negative forces. The themes highlight an overarching oppression that communicates to the transgender person that their desire to seek care is up against formidable counter forces, and care may not necessarily be achievable. This has an effect of clouding the transgender person's perspective on an ongoing basis, and

provides that constant tension of whether or not seeking care is possible when a need may arise.

These meanings further convey that transgender people have a daily existence of feeling they are "less than" compared to cisgender (non-transgender) people. The discouraging barriers to their care outweigh any supporting influences they may have available to them by a factor of 2:1. To exemplify the meanings held, one of the major findings in the study was the participants' frequent reporting of incompetent healthcare providers at all levels of practice. Part of the reason for this observation is that academia in the healthcare disciplines have not universally adopted curricula that teaches healthcare professionals how to treat transgender people, both in terms of their physical needs, as well as how to interact with them as respectful and affirming people (Safer et al., 2016).

Relating to the more academic policy side of the issue, Case, Kanenberg, Erich, and Tittsworth (2012) proposed that higher educational inclusion policy changes are broadly needed to challenge gender conformity norms that tend to shape pedagogy at the university level. This begins with non-discrimination statements for students and faculty, and culminates in inclusive and competent curricula encompassing the needs of the transgender population. This is an important and influential concept to note. The ultimate product of higher education policy is the health field graduate who then goes out into the healthcare world and cares for people in a manner in which they were taught. Starting off a career in healthcare without a professional education that is wholly inclusive and competent in its design and content, it becomes difficult after graduation to build this

competence, affirmational, and knowledge base in practice as continuing nursing education in the subject area is not readily available. Transgender people keenly feel this non-affirmational approach and are acutely aware of the incompetence of healthcare providers.

The data codes and categories documented in the study that contributed to the larger themes of discouraging barriers and supporting influences reflect an often-overwhelming situation for the transgender person. Though care may be needed, seeking it tends to become a non-viable option and becomes a reinforcing state of being. The meaning behind the data and the participants statements is evidence that seeking care is discouraged before it is even pondered.

Assumptions Challenged

One of the products of conducting and analyzing this research is that some existing assumptions in the literature, and the study itself, were refuted, while others were validated. An assumption was made by both the available literature, and by the premise of the study, that problems were likely being experienced by the transgender community in accessing culturally competent care. Both the literature and the study findings affirm that assumption. All of the respondents reported accessing being an impactful force that in one way or another, prevents seeking healthcare. There was some evidence in the literature around lack of access being caused by discrimination, reinforcing an assumption that discrimination was a universal barrier. However, in the study only 50% of participants reported a discriminatory experience in healthcare. Though impactful, this was less than anticipated and refutes discrimination being a primary impact factor for

seeking healthcare. Several people found exactly what they needed in terms of their ability to conduct health seeking behaviors without difficulty. It is noteworthy that the study participants lived largely in the Harris County, Texas region with access to the sizeable Texas Medical Center. This geographic proximity to health professionals and services may account for the rate of discrimination reported being less than assumed.

This study fills in the gaps seen in the literature regrading what unique factors may be impactful in discouraging or supporting ways for transgender people's health seeking behaviors. The study illuminated a myriad of experiences, and themes, that can occur and influence the behaviors of transgender people, highlighted the meanings of the findings that are poignant to transgender people, as well as point a way forward for further study on the transgender population.

Conclusions and Implications

One concludes from these findings that the number of discouraging factors of health seeking behaviors impacting the transgender community greatly exceeds the support structures that may otherwise encourage seeking care. The study suggests that transgender and non-binary people have to live in a world where it is an acceptable status quo to have negative forces impact the likelihood of successfully seeking care. To a certain extent, transgender people have adapted to these discouraging factors but they still do not have equitable access. This is a self-reinforcing dynamic of the factors, many of which are out of the control of the transgender individual.

Conclusions drawn also indicate that transgender people find healthcare providers' educational preparation inadequate when it comes to treating their community

in a competent and affirming way. A likely implication is that various interprofessional healthcare disciplines' academic programs must bolster and embed transgender care within their curricular and practical studies to fill this knowledge gap. Though adding transgender care to healthcare professionals educational curricula naturally should help to improve access to culturally competent and affirming care, caution should be applied to the assumption that this is a desired addition in academic and healthcare circles.

A hidden element in this conclusion is that transphobia and bias (conscious or unconscious) among educators may play a bigger role in limiting access to care than the availability of more competent and affirming educational curricula. In their survey of primary care providers regarding their exposure and knowledge of transgender care needs, Stroumsa, Shires, Richardson, Jaffee, and Woodford (2019) found that only 57.3% of the participants indicated they had received education in this area. Regression analysis of the results showed that the lack of uptake in transgender related care education was more likely due to the respondents' incidence of transphobia, rather than hours of formal or informal education.

Policies in institutions of higher learning also play a foundational role in shaping the bias development of enrolled students towards transgender people. Though some level of bias is likely to be present from the time students first walk in the doors of the university campus, university policies can help shape and even eliminate bias of transgender people within the student body and its faculty. In a case study conducted of their own university, Case et al. (2012) determined that university policy, inclusionary language, and faculty use of gender inclusive terminology was key to creating a non-

discriminatory campus environment and educational programs. The authors also incorporated Freire's pedagogy of the oppressed to examine the cultural change needed to provide a non-discriminatory environment, with focus on the transgender student. One concludes from the educational findings in the study and literature, that oppressive language and discriminatory practices tend to reinforce themselves with powerful effects upon the oppressed. This can occur for the transgender student in the university setting. Providing inclusive policies and practices are key to attracting and keeping a diverse student body, who look for a non-discriminatory environment when applying for admission. If transgender students believe themselves to be free from the oppressive effects of bias from faculty and the student body, the student body as a whole will encapsulate inclusive mentality and behaviors that each will take with them into the world.

A final conclusion can be made relative to the inequitable legal and sociopolitical forces that vary from locale to locale. Different cities and states have different protections in place for transgender people. For instance, the City of Austin has legislated a non-discrimination ordinance inclusive of LGBTQI+ people, whereas the City of Houston has not. Despite the recent U.S. Supreme Court ruling (Supreme Court of the United States, 2020) for protections in the workplace, the variability of legal protections likely impact the ability of transgender people to have equitable access to jobs, housing, and healthcare. Without full legal protections in place, the systemic legal oppression that occurs in the transgender person's reality happens at a baseline in many different aspects, ranging from attempts to discriminate against their personhood, difficulty in gaining insurance,

especially health insurance that covers their care, resources that meets their needs, and obtaining an education free from discrimination and harassment. Thus, if equitable legal protections are instituted, a likely conclusion can be made that the current disproportionate number of discouraging barriers to seeking care could be largely counter-balanced by supporting influences. The legal barrier would be removed, and then transformed to be a support structure to health seeking behaviors.

Evaluative Strength of the Study

As this qualitative study was novel and foundational in nature, it was important to establish trustworthiness of its methods and results from the start of the research process. At the outset of the research plan, the use of Lincoln and Guba's (1985) evaluative criteria for the trustworthiness of a qualitative research inquiry was proposed to support the strength of this study at the conclusion of the data collecting and analysis phases. These evaluative criteria included credibility, transferability, dependability, and confirmability. Post study, the evaluative criteria and strategies to support trustworthiness proved to reinforce the study methodology, procedures, data analysis, and findings. With these, the trustworthiness of the study was accomplished and findings strengthened.

Recommendations for Further Studies

Throughout the data collection and analysis conducted in this research, many topics were revealed directly by the participants or by the data that were of notable interest, but not always directly part of the subject matter of the study itself. These topics warrant further scholarly exploration in their own right. Potential future studies that stem logically from this study include the following subjects.

Nursing Practice

Research subject: the experiences of transgender people with mental health providers and in inpatient settings.

Rationale: multiple participants in the study referred to concerns about seeking mental healthcare due to perceived, or actual safety concerns, particularly in the inpatient psychiatric setting. The safety related experiences of inpatient mental healthcare patients is an important topic for research consideration.

Nursing Research

Research subject: quantitative study of the differences in selected outcomes of interest, to determine the potential effect of mediating variables that could be identified from the codes in the study, particularly accessing to, and presence of, affirming people and providers in the life of the transgender person.

Rationale: While the participants in this study identified the presence of affirming people and providers as a supporting influence for health seeking behaviors, the study did not attempt to quantify the differences in outcomes related to them. Further exploration of this topic may provide evidence of effective social interventions.

Nursing Education

Research subject: the differences in the physical and psychological outcomes of transgender persons for those who were treated by healthcare professionals whose educational background incorporated transgender competent and affirming curricula, compared to those who were treated by healthcare professionals whose educational programs lacked transgender competent and affirming curricula.

Rationale: There was clear evidence presented by the participants that there is a dearth of competent healthcare providers available to them. As such, transgender people may seek out care from less informed providers who may not treat them adequately, or simply go without need care completely.

Closing

This foundational qualitative research study examined the factors impacting the health seeking behaviors of transgender and non-binary adults documented many discouraging elements in life preventing care. Though supporting influences to engage in health seeking behaviors were also found in the study, these positive aspects are overwhelmed by the discouraging barriers present in the life of transgender people. The transgender health seeking dynamic tension theory developed from the study highlights the constant tension of the push and pull of the forces endured by transgender people in daily life, just to consider if care seeking should be attempted. It is hoped that future researchers may be informed by the study findings to explore additional finite subjects to test interventions beyond the recommendations made here.

This study documented various factors that form supporting influences and barriers to equitable access to care for transgender people. For the transgender person, these factors impact their daily ability to engage in health seeking, and are often seemingly insurmountable to achieving a desired health goal. For the health professional and educator, resolving the larger issues that prevent transgender person from receiving equitable and competent care may seem equally insurmountable. It was a goal of the study that the information revealed here will inform academia, interprofessional

healthcare professions, and individual health professionals alike, of the issue that stands before them today. The tangible actions identified in this study can be taken now to make positive changes that benefit transgender persons, educators, and the health professionals. With Paulo Freire's philosophy in mind, the oppressed overcoming the oppressor is a desired state shared by all people. Change can happen for the transgender person today, provided a shared will to make that change is also there.

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APPENDIX A

Recruitment Flyer

Transgender, Non-binary, Gender Fluid

Health Care Experiences Study

Be part of an important research study of transgender, non-binary, and gender fluid people's health care experiences

- *Are you18 years of age or older?*
- *Do you identify as transgender, non-binary, or gender fluid?*
- *Do you want to share your experiences related to seeking health care?*

If you answered YES to these questions, you may be eligible to participate in a research study.

The purpose of this research study is to understand the barriers and supportive influences that transgender, non-binary, gender fluid people encounter seeking health care. Participation involves being interviewed by a researcher.

Your participation in the study contributes to the improvement in the body of knowledge related to the health care needs of transgender, non-binary, gender fluid people. Participants will receive an incentive payment of $25 at the completion of the study interview.

Transgender men, transgender women, non-binary, gender fluid (age 18 and older) are eligible to participate.

Please share your unique experiences!

This study is being conducted at Texas Woman's University, Houston, TX, 77030.

Please call or email Matthew Schlueter at (713) 823-6670/mschlueter@twu.edu for more information.

APPENDIX B

Letters from the Texas Woman's University IRB

TWU
TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: August 28, 2018

TO: Mr. Matthew Schlueter
Nursing - Houston

FROM: Institutional Review Board (IRB) - Houston

Re: Approval for Health Seeking Behaviors of Adult transgender People (Protocol #: 20197)

The above referenced study has been reviewed and approved by the Houston IRB (operating under FWA00000178) on 8/27/2018 using an expedited review procedure. This approval is valid for one year and expires on 8/27/2019. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston
Dr. Sandra Cesario, Nursing - Houston
Graduate School

Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: August 8, 2019

TO: Mr. Matthew Schlueter
Nursing - Houston

FROM: Institutional Review Board (IRB) - Houston

Re: Extension for Health Seeking Behaviors of Adult transgender People (Protocol #: 20197)

The request for an extension of the IRB approval for the above referenced study has been reviewed by the TWU IRB (operating under FWA00000178). This study was originally approved on August 27, 2018 and has been renewed. Approval for this study expires on August 26, 2020.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Ainslie Nibert, Nursing - Houston
Dr. Sandra Cesario, Nursing - Houston

Institutional Review Board
Office of Research
6700 Fannin, Houston, TX 77030
713-794-2480
irb-houston@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: October 30, 2019

TO: Mr. Matthew Schlueter
Nursing - Houston

FROM: Institutional Review Board - Houston

Re: Notification of Approval for Modification for Health Seeking Behaviors of Adult transgender People (Protocol #: 20197)

The following modification(s) have been approved by the IRB:

1. Adding Lou Weaver as research team member.
2. Addition of demographics questions to the existing interview guide demographic page, and rearrangement of the location of questions on the demographics page in order to make them fit on a single page. The addition of the questions will help to gather demographic characteristics unique to the population being studied. Changes in demographics questions include: change of participant 'Name' to just their initials, and change of "Date of Birth' to just their age (in years). Additional demographic questions added include: ethnicity or race, highest level of education, employment status, income, insured status, gender affirming surgey status, legal gender marker change status, homones taken status and if hormones were prescribed. The requested changes are highlighted in yellow on the attached example demographic form document.
3. Grammatical correction on recruitment flyer has been made, and clarification of the language of the description of population being sought for recruitment is made. I received feedback from some potential participants that the way the recruitment flyer was worded was inadvertantly discouraging or excluding some members of the transgender population from particiapting in the study. The gender identifier "transgender' refers to a specturm of people tranistioning their gender, though people may do this any any number of ways. The phrasing on the existing flyer implies to some participants that a completed full gender and sex-trait surgical transition was a requirement in order to be eligible to participate in the survey. The intent was actually to capture any partipant who is transitioning their gender at any stage of their chosen transition process to any other gender on the gender spectrum, regardless of the extent or types of transition methods chosen. The transgender population's gender spetrum is better phrased as "transgender, non-binary, gender fluid". The flyer inadvertantly implied a fully transitioned state to a single other gender was an inclusion criteria to the study, when it was not. These changes to the recruitment flyer will help to attract more of the intended participants to the study. The changes are highlighted in yellow on the attached recruitment flyer document.

APPENDIX C

Participant Consent Forms 2018 and 2019

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Health Seeking Behaviors of Adult Transgender People

Investigator: Matthew Schlueter ..... mschlueter@twu.edu 713/823-6670
Advisor: Sandra Cesario, PhD.....SCesario@twu.edu 713/794-2110

Explanation and Purpose of the Research

You are being asked to participate in a research study for Mr. Schlueter's dissertation at Texas Woman's University. The purpose of this research is to develop a better understanding of the various reasons affecting transgender people seeking and getting health care. These reasons that may help or prevent transgender people in getting needed health care and living a healthy life are known as 'health seeking behaviors'.

Description of Procedures

As a participant in this study you will be asked to spend one hour of your time in a face-to-face interview with the researcher. The researcher will ask you questions about your desires, experiences, and choices related to seeking healthcare as a transgender person. You and the researcher will decide together on a private location where and when the interview will happen. Your researcher will assign a code to be used during the interview for confidentiality. The interview will be audio recorded and then written down so that the researcher can be accurate when studying what you have said. In order to be a participant in this study, you must be at least 18 years of age or older and identify as a transgender person.

Potential Risks

The researcher will ask you questions about your experiences related to seeking healthcare as a transgender person. The researcher will also ask you questions related to how your personal experiences as a transgender person has affected your ability to get health care and the impact of those experiences in your life. A possible risk in this study is discomfort with these questions that you are asked. If you become tired or upset you may take breaks as needed. You may also stop answering questions at any time and end the interview. If you feel you need to talk to a professional about your discomfort, the researcher has provided you with a list of resources.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location that you and the researcher have agreed upon. A code name, not your real name, will be used during the interview. No one but the researcher will know your real name. The audio recordings and the written interview notes will be stored in a locked cabinet in the researcher's office. Only the researcher, his advisor, and the person who writes down the interview will hear the recordings or read the written interview notes and transcripts. The recordings and the written interview information will be erased and destroyed within 5 years after the study is finished. The results of the study will be reported in scientific magazines or journals, but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and internet transactions.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for any injuries that might happen because you are taking part in this research.

Initials

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study you will receive a $25 gift card for your participation. If you would like to know the results of this study, we will send them to you.*

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2480 or via e-mail at IRB@twu.edu.

_____ _____

Signature of Participant Date

*If you would like to know the results of this study, tell us the email address where you want them to be sent:

Email: _____

Approved by the
Texas Woman's University
Institutional Review Board
Approved: August 27, 2018

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Health Seeking Behaviors of Adult Transgender People

Investigator: Matthew Schlueter ..... mschlueter@twu.edu 713/823-6670
Advisor: Sandra Cesario, PhD .....SCesario@twu.edu 713/794-2110

Summary and Key Information about the Study

You are being asked to participate in a research study conducted by Mr. Matthew Schlueter, a PhD student at Texas Woman's University, as a part of his dissertation. The purpose of this research is to develop a better understanding of the various reasons that affect transgender people seeking and getting health care. These reasons that may help or prevent transgender people in getting needed health care and living a healthy life are known as 'health seeking behaviors'. You have been invited to participate in this study because you are a transgender person. As a participant you will be asked to take part in a face-to-face interview regarding your experiences with seeking health care. This interview will be audio recorded, and we will use a code name to protect your confidentiality. The total time commitment for this study will be about one hour. Following the completion of the study you will receive a $25 gift card for your participation. The greatest risks of this study include potential loss of confidentiality and emotional discomfort. We will discuss these risks and the rest of the study procedures in greater detail below.

Your participation in this study is completely voluntary. If you are interested in learning more about this study, please review this consent form carefully and take your time deciding whether or not you want to participate. Please feel free to ask the researcher any questions you have about the study at any time.

Description of Procedures

As a participant in this study you will be asked to spend one hour of your time in a face-to-face interview with the researcher. The researcher will ask you questions about your desires, experiences, and choices related to seeking healthcare as a transgender person. You and the researcher will decide together on a private location where and when the interview will happen. Your researcher will assign a code to be used during the interview for confidentiality. The interview will be audio recorded and then written down so that the researcher can be accurate when studying what you have said. In order to be a participant in this study, you must be at least 18 years of age or older and identify as a transgender person.

Potential Risks

The researcher will ask you questions about your experiences related to seeking healthcare as a transgender person. The researcher will also ask you questions related to how your personal experiences as a transgender person has affected your ability to get health care and the impact of those experiences in your life. A possible risk in this study is discomfort with these questions that you are asked. If you become tired or upset you may take breaks as needed. You may also stop answering questions at any time and end the interview. If you feel you need to talk to a professional about your discomfort, the researcher will provide you with a list of resources.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location that you and the researcher have both

Initials

agreed. A code name, not your real name, will be used during the interview. No one but the researcher will know your real name. The audio recordings and the written interview notes will be stored in a locked cabinet in the researcher's office. Only the researcher, his advisor, and the person who writes down the interview will hear the recordings or read the written interview notes and transcripts. The recordings and the written interview information will be erased and destroyed within 5 years after the study is finished. The signed consent form will be stored separately from all collected information and will be destroyed no more than 5 years after the study is closed. The results of the study may be reported in scientific magazines or journals, but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and internet transactions.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for any injuries that might happen because you are taking part in this research.

The researchers will remove all of your personal or identifiable information (e.g. your name, date of birth, contact information) from the audio recordings and/or any study information. After all identifiable information is removed, your audio recordings and/or any personal information collected for this study may be used for future research or be given to another researcher for future research without additional informed consent.

If you would like to participate in the current study but not allow your de-identified data to be used for future research, please initial here _____.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study you will receive a $25 gift card for your participation. If you would like to know the results of this study, we will send them to you.*

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2480 or via e-mail at IRB@twu.edu.

_____ _____

Signature of Participant Date

*If you would like to know the results of this study, tell us the email address where you want them to be sent:

Email: _____

Approved by the
Texas Woman's University
Institutional Review Board
Approved: August 27, 2019

APPENDIX D

Interview Guide and Schedule

Interview Guide and Demographic Page for the Study
"Health Seeking Behaviors of Adult Transgender People"

Interview Method: Individual 1:1 interview sessions, in-person or via web based video-conferencing (e.g., Skype), using semi-structured interviews.

Length of interview: 1 hour (approximately).

Date and Time: To be mutually agreed upon and determined by the researcher and the participant.

[Date mm/dd/yyyy]: _____ [Time mm:hh]: _____

Setting/Place: To be mutually agreed upon and determined by the researcher and the participant. Researcher will have knowledge of safe, neutral locations.

Interviewer: [Name of the interviewer]: _____

Unique De-identifying Code Assigned for Interviewee: [α-numeric digit]: _____

Interviewee Demographics: The demographics of the interviewee should be gathered prior to the interview (only gather participant's demographics listed on this page). The audio recording of the interview should only identify the participant using the assigned de-identifying code, not their name.

[Participant's initials (not full name)]: _____ [Race or Ethnicity]: _____

[Age of Participant]: _____ [Highest Level of Education]: _____

[Employment Status]: (FT, PT, No): _____ [Insured]: (Yes/No): _____

[Self-identifying Gender presentation]: _____

Have you legally changed you gender marker?] (Yes/No): _____

Have you begun hormone therapy? (Yes/No): _____	Have you had any gender affirming surgeries?: (Yes/No): _____
If 'yes', were they prescribed by a licensed healthcare professional? (Yes/No): _____	If Yes, when and what type of surgery did you have? _____

Interview Schedule:

I. Welcome and thank the participant for participation.

II. Explain study and obtain consent including: voluntary nature of participation, what is required of the participant, risks, audio recording usage, compensation, exit strategy, timeline, and determine whether participant would like applicable post-study information or follow-up.

III. Interview Questions for Study (Conversation starters)

- Tell me about how you make decisions regarding your healthcare.
    - <probe> Describe the factors that affect your decision making
    - <probe> How do you decide where to seek your healthcare?
- What has your experience been with healthcare?
- Tell me about a time when your felt good about a healthcare experience.
    - <probe> Tell me more about that, what happened?
- Have you ever felt your healthcare experience was lacking in some way?
    - <probe> Tell me more about that, what happened?
    - <probe> Has there ever been a time when you felt unsafe in seeking healthcare?
- Tell me about a time that you felt comfortable in seeking the healthcare you needed.
    - <probe> Tell me more about that, what happened?

- Tell me about a time when you felt that you did not get the healthcare you needed.
    - <probe> Tell me more about that, what happened?
    - <probe> What are your barriers to healthcare?
- Is there anything else that I should know to better understand your experiences in seeking healthcare?
    - <<clarifying question>>What am I not asking that I need to know about your experiences in seeking healthcare?

IV. Summary, closing statements, thank the participant, and ask if there are any other final questions.

- Provide $25 gift card.
- Exit

APPENDIX E

Field Notes Form

Interview Field Notes	
Participant Code	
Date of Interview	
Time of Interview	
Location	
Environmental/Setting Observations	
Jottings	
Themes	
Narrative	
Reflections	

APPENDIX F

Thematic Data Analysis Grid

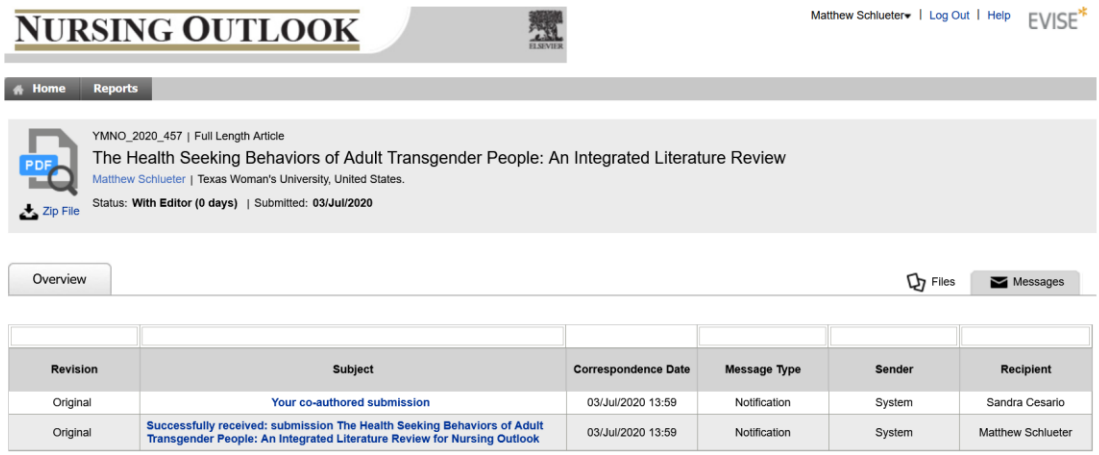
*Thematic Data Analysis Grid	*Participant Response	
Participant (unique code)	1	2
Demographics		
Age at time of interview	30	41
Gender Presentation (1=Transman, 2=Transwoman)	1	2
Employed? (1=FT, 2=PT, 3=No)	1	1
Insured? (1=Yes, 2=No)	1	2
Has had gender affirming surgery? (1=Yes, 2=No)	1	1
If yes, when and what type of surgery?		
Legally changed your gender marker? (1=Yes, 2=No)	2	1
Emerged Theme/>Sub Theme		
Provider Incompetence	x	x
>Lack of **formal** provider education	x	
>Lack of Healthcare Institution education/policy	x	
>Patient having to educate provider on trans health needs	x	x
>Educating providers on trans affirming language		x
>Positive experience when providers ask how to address needs, which pronouns to use	x	x
Access:	x	x
>Trans Affirming Insurance (none or inadequate coverage)	x	x
>Number of willing/available providers	x	
>Healthcare needs unrelated to Transgender care	x	x
>Trusted network utilization		x
Safety:	x	x
>Physical	x	
>Psychological	x	x
Fear	x	x
Marginalization	x	
Pronouns usage (positive or negative experience)	x	x
Erasure	x	
"Missed" episodes of healthcare	x	x
Discrimination		x
Pre-adult perceptions of healthcare importance		x
Cumulative psychological effects of negative encounters		x
Legal problems		x

*For illustrative purposes only, not actual data.

Note: Highlighted rows indicate themes found among at least 2 or more participants.

APPENDIX G

Integrative Literature Review Manuscript Submission to Nursing Outlook



NURSING OUTLOOK

Matthew Schlueter | Log Out | Help EVISE

Home Reports

YMNO_2020_457 | Full Length Article

The Health Seeking Behaviors of Adult Transgender People: An Integrated Literature Review

Matthew Schlueter | Texas Woman's University, United States.

Status: **With Editor (0 days)** | Submitted: **03/Jul/2020**

Zip File

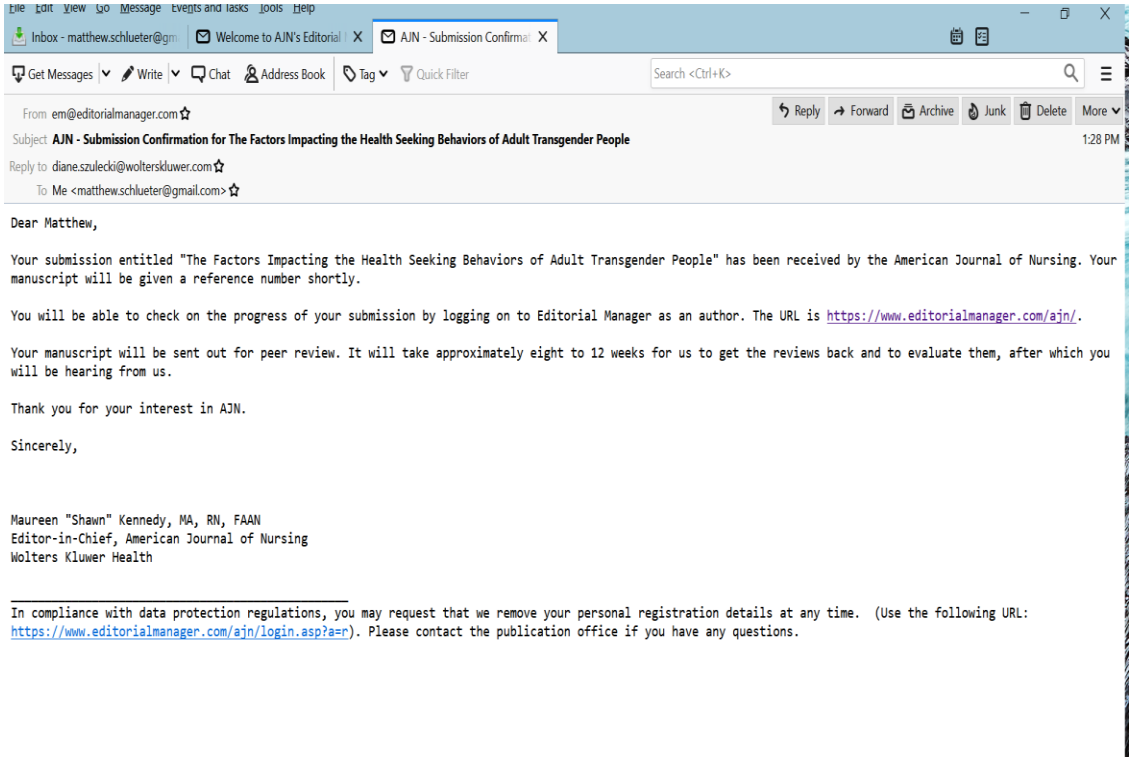
Overview

Files Messages

Revision	Subject	Correspondence Date	Message Type	Sender	Recipient
Original	Your co-authored submission	03/Jul/2020 13:59	Notification	System	Sandra Cesario
Original	Successfully received: submission The Health Seeking Behaviors of Adult Transgender People: An Integrated Literature Review for Nursing Outlook	03/Jul/2020 13:59	Notification	System	Matthew Schlueter

APPENDIX H

Findings Manuscript Submission to the American Journal of Nursing



File Edit View Go Message Events and Tasks Tools Help

Inbox - matthew.schlueter@gm | Welcome to AJN's Editorial | AJN - Submission Confirma

Get Messages | Write | Chat | Address Book | Tag | Quick Filter | Search <Ctrl+K>

Reply | Forward | Archive | Junk | Delete | More

From em@editorialmanager.com

Subject **AJN - Submission Confirmation for The Factors Impacting the Health Seeking Behaviors of Adult Transgender People** 1:28 PM

Reply to diane.szulecki@wolterskluwer.com

To Me <matthew.schlueter@gmail.com>

Dear Matthew,

Your submission entitled "The Factors Impacting the Health Seeking Behaviors of Adult Transgender People" has been received by the American Journal of Nursing. Your manuscript will be given a reference number shortly.

You will be able to check on the progress of your submission by logging on to Editorial Manager as an author. The URL is https://www.editorialmanager.com/ajn/.

Your manuscript will be sent out for peer review. It will take approximately eight to 12 weeks for us to get the reviews back and to evaluate them, after which you will be hearing from us.

Thank you for your interest in AJN.

Sincerely,

Maureen "Shawn" Kennedy, MA, RN, FAAN
Editor-in-Chief, American Journal of Nursing
Wolters Kluwer Health

In compliance with data protection regulations, you may request that we remove your personal registration details at any time. (Use the following URL: https://www.editorialmanager.com/ajn/login.asp?a=r). Please contact the publication office if you have any questions.

APPENDIX I

Dissertation Signature Page

TEXAS WOMAN'S UNIVERSITY

Certificate of Completion for Thesis/Dissertation

Date of final defense: June 29, 2020

Student: Matthew Schlueter

Student ID#: 0095009

We, the undersigned, affirm that according to departmental records, and upon successful completion of the current enrollment term, this student will have successfully completed all coursework and met all requirements for the degree listed below.

We are submitting herewith this student's ☐ Thesis ☑ Dissertation, entitled:

FACTORS IMPACTING HEALTH SEEKING BEHAVIORS OF ADULT TRANSGENDER PEOPLE

written by the aforementioned student. We affirm that we have examined this document for grammar, form, and content and recommend that it be accepted in partial fulfillment of the requirements for the following degree:

PhD in Nursing Science.

with a minor in: NA.

Sandra K. Cesario — Digitally signed by Sandra K. Cesario Date: 2020.06.29 15:04:06 -05'00'
Major Professor/Committee Chair

Committee Member

Nina M. Fredland — Digitally signed by Nina M. Fredland Date: 2020.06.29 16:19:47 -05'00'
Committee Member

Ann Malecha — Digitally signed by Ann Malecha Date: 2020.06.29 17:42:02 -05'00'
Committee Member

Committee Member

Committee Member

Committee Member

Ainslie Nibert — Digitally signed by Ainslie Nibert Date: 2020.06.29 15:49:44 -05'00'
Academic Component Administrator

Once this form has been signed by all members, please return the form to the student to upload through Vireo. The Graduate School will access the document through Vireo and review for approval.

Graduate School Approval

In accordance with Leg. HB 1922, an individual is entitled to: request to be informed about the information collected about them; receive and review their information; and correct any incorrect information.

The Graduate School

P.O. Box 425649 | Denton, TX 76204 | 940 898 3415 | gradschool@twu.edu