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THE LIVED EXPERIENCE OF TRANSGENDER COLLEGE-AGED STUDENTS RECEIVING HEALTHCARE

A Thesis Presented

by

Lisa Lopatofsky Schaffer

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements for the Degree of Master of Science Specializing in Nursing

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Defense Date: October 31, 2014 Thesis Examination Committee:

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Abstract

Background

There is a relative dearth of information regarding transgender patient perceptions of healthcare provider interactions and experiences. Previous studies have examined the experiences of transgender patients across multiple generations.

Purpose

This research focuses on understanding the lived experience of transgender college-aged students receiving healthcare. The goal of this research is to help inform the practices of healthcare providers in order to improve care experiences.

Methods

Hermeneutic phenomenology was utilized to illuminate the lived experiences of three college-aged transgender patients receiving healthcare. Interviews were conducted with research participants. After transcription, interview content was read and re-read for significant statements. Significant statements were then grouped to identify themes.

Results

Theme 1: provider knowledge. Study participants noted that provider knowledge was associated with several behaviors and impacted their feelings regarding the experience and willingness to seek future healthcare. The trans-friendly provider was identified as a provider who uses preferred language, shares decision-making, and is aware of medical treatments.

Theme 2: being defined. Study participants felt defined through a variety of provider interactions. These included experiences wherein providers question timelines of transition and question the patient regarding their identity using static terminology.

Theme 3: loss of power. Participants noted the experience of loss of control when receiving healthcare. Loss of control was felt in a variety of ways including: loss of control over naming, identity, and care decisions.

Conclusions

This research begins to identify emerging themes expressed by transgender college-aged patients. By identifying these themes, future research can be conducted to further clarify patient feelings associated with their experiences in seeking healthcare in order to inform provider behaviors. More research is needed regarding transgender patient experiences receiving healthcare and whether these experiences impact health outcomes.

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Introduction

Individuals who identify as transgender, a gender other than their natal sex, are at an increased risk for alterations in health including; depression, substance abuse, anxiety, risk for suicide, HIV/AIDs and somatization disorders (Bockting, Miner, Swinburne, Romine, Hamilton, & Coleman, 2013; Mayer, Bradford, Makadon, Stall, Goldhammer, & Landers, 2008; Xavier, Honnold, & Bradford, 2007). Healthcare providers may play a critical role in helping to prevent and manage these disease sequelae; however, research indicates that healthcare providers contribute to the perceived mistreatment of transgender patients in a variety of settings. For instance, research has found that social stigma, lack of provider knowledge, and previous patient experiences of mistreatment by healthcare providers represent just some of the barriers to healthcare that transgender patients experience (Kosenko, Rintamaki, Raney, & Maness, 2013).

Previous research in transgender patient perception of medical care in relation to disclosure of gender status has focused on multiple age-groups or generations. Because the laws and knowledge of transgender health issues have evolved over time, more research is needed to assess the current experience of younger generations of transgender patients. Data from 2008 show that 13 states have adopted gender identity inclusion measures (Taylor, Lewis, Jacobsmeier, & DiSarro, 2012). This is a sharp rise from 2002 when only two states had adopted any gender inclusive legislation (Taylor et al., 2012). Previous research and the changing nature of gender rights indicate that more studies are needed to examine the perceptions of medical care in relation to gender disclosure by younger generations of transgender patients.

Philosophical Framework

This qualitative research is philosophically and methodologically grounded in hermeneutic phenomenology as outlined by Max Van Manen (1990). Van Manen states that, "Phenomenology aims at gaining a deeper understanding of the nature or meaning of our experiences" (Van Manen, 1990, p.11). The philosophical underpinnings of hermeneutic phenomenology were first described by Immanuel Kant and further developed by Edmund Husserl and Martin Heidegger (Cohen, Kahn, & Steeves, 2000). Immanuel Kant described the philosophical perspective of phenomenology, as a distinction between the study of objects and the study of our experience of objects or phenomena (Kant, 1964). Husserl (1970) described this philosophy as a way of understanding the lived experience and the structure of the lifeworld, which is the everyday natural world. Heidegger (1962) further distilled hermeneutic phenomenology by describing it as an attempt to understand the natural meaning of a phenomena, which he described as being. In this way, hermeneutic phenomenology has developed from a philosophical framework to a methodology for qualitative research in order to bring to light a particular experience or lifeworld.

Illuminating the lived experiences of individuals can be achieved through a variety of methods, including: written diaries, interviews, film, poetry, etc. (Van Manen, 1990). Hermeneutics, as described by Van Manen (1990), is the theory and practice of interpretation of these experiences utilizing the methods outlined above. Hermeneutics is an important component of developing an understanding of a lived experience when misunderstanding is possible. In this way, hermeneutic phenomenological research both describes and interprets the lived experience by interacting with those whose experience

may not be as widely accessible or as widely understood (Van Manen, 1990).

By utilizing hermeneutic phenomenology the researcher seeks to explore the lived experience and develop a conversation about the meaning of the experience (Van Manen, 1990). This research study is guided by the philosophy and methodology of hermeneutic phenomenology because this philosophical perspective places value on the meaning that people attribute to their experiences as a way to inform what needs an individual has and how their needs can best be met (Cohen, Kahn, & Steeves, 2000). This method was chosen by the principal investigator to help illuminate the lived experience of transgender and gender queer individuals seeking healthcare. The themes that are identified are presented to the reader for further interpretation or understanding regarding transgender patient' experiences.

Literature Review

Perceived Provider Knowledge

Studies that have examined the healthcare needs and perception of healthcare services of transgender patients highlight the dearth of knowledge regarding this community's basic healthcare needs and experiences. Quantitative analysis of surveys completed by transgender patients revealed that while a majority of individuals had a primary care provider (PCP) most were very uncomfortable discussing transgender specific healthcare needs with this provider. Moreover, a large number of transgender patients report having to educate their providers about their healthcare needs (Bradford, Reisner, Honnold, & Xavier, 2013). This perceived lack of knowledge by healthcare providers contributes to a decline in utilization of healthcare services by transgender patients (Bradford et al., 2013). These healthcare services include: consults for transgender-related surgeries, counseling or psychotherapy, gynecological treatment, and hormone replacement therapies (Bradford et al., 2013). In this way, perception of provider knowledge by transgender patients has been linked to transgender patients' access to healthcare services.

Qualitative research that has focused on perceived provider knowledge has found that providers who demonstrate knowledge of trans (transgender) issues, use appropriate language and demonstrate knowledge of insurance coverage issues are associated with positive patient experiences for transgender patients (Rounds, McGrath, & Walsh, 2013). Appropriate language includes the use of patient preferred pronouns and patient preferred names for anatomy (Rounds et al., 2013). Lack of provider knowledge has even been found among healthcare providers specializing in providing care to the LGBTQ (lesbian,

gay, bisexual, transgender, queer) community (Laurie, 2005; Poteat, German, & Kerrigan, 2013). In qualitative analysis of provider interviews, healthcare providers have reported feelings of ambivalence in treating LGBTQ patients, which they attribute to an inadequate knowledge base (Laurie, 2005; Poteat et al., 2013). In turn, interview data from LGBTQ patients revealed that patients feel medical providers use authority over patients when the provider does not possess knowledge of LGBTQ healthcare (Poteat, et al., 2013).

These qualitative and quantitative data highlight how perception of provider knowledge and the provider's understanding of healthcare needs related to sexual and gender identity might impact the patient interaction or patient perception of the experience.

Perceived Discrimination

Research studies that focus on the experiences of transgender individuals interacting within various systems have found discrimination or perceived discrimination to be a consistent theme. Cross-sectional and community-based convenience samples have shown that transgender people report high rates of discrimination throughout many areas of their lives, including their access to, and interactions with, the healthcare system (Bradford, et al., 2013). Quantitative research, using questionnaires, found that more than half of transgender respondents reported experiencing discrimination and violence within their lifetime with one quarter reporting a violent incident (Lombardi, Wilchins, Priesing, & Malouf, 2001). While these violent incidents were not necessarily associated with healthcare, systemic discrimination has implications for transgender patients on the individual level.

In a quantitative study that examined the impact of cognitive behavioral therapy on transgender patients' pre and post-test scores of depression, anxiety, and quality of life indices, researchers found that transgender patients had limited social supports (Maguen, Shipherd, & Harris, 2005). Previous to the intervention of support groups, transgender patients reported few support systems and greater feelings of societal marginalization, which were associated with higher indices scores for depression and anxiety (Maguen et al., 2005). These findings are similar to the results of a large quantitative study in which researchers used hierarchal regression analysis on the mental health surveys of transgender and cisgender patients. In their review, researchers found disproportionately high rates of depression, anxiety, somatization disorders, and overall distress among transgender individuals compared to cisgender men and women (Bockting et al., 2013).

Qualitative research employing patient interviews reveal that patients believe that the medical system is also part of the systemic discrimination that they experience. In a three phase, mixed quantitative and qualitative study, researchers used software analysis on interview transcripts to identify several themes associated with discrimination among transgender participants (Bauer, Hammond, Travers, Kaay, Hohenadel, & Boyce, 2009) These areas of discrimination included: income instability, barriers to accessing transinclusive healthcare, the dearth of relevant information, and systemic social service barriers (Bauer et al., 2009)

Patients report that lack of provider knowledge and subsequent lack of access to health services after disclosure of gender identity has been directly correlated with feelings of discrimination leading some researchers to assert that discrimination is directly tied to disclosure of transgender status (Bradford et al., 2013).

Disclosure of Identity

Researchers have examined the factors that contribute and deter patients from revealing their gender identity to healthcare providers (Bradford et al., 2013; Lombardi et al., 2001; Rounds et al., 2013). Results from these studies consistently indicate the complex nature of gender identity. Transgender people often use a wide spectrum of terms to self-identify, "and some gender variant people do not use transgender as either an individual identity or an umbrella term to refer to themselves" (Bradford et al., 2013, p.1824). Quantitative research through questionnaire has found over thirty-five specific gender identity terms and five preferred pronouns, which reflect a more complex understanding of identity (Factor & Rothblum, 2008). Identification of transgender issues is largely based on subjective experience, the individual patient history, and individual patient descriptors; this places some importance on the patient-provider interaction.

In previous qualitative research, transgender patients report that certain provider behaviors lead patients to give purposely- vague responses regarding their identity and sexual history (Rounds et al., 2013). These provider behaviors include: unclear questions, blushing, poor eye contact, looking confused or staring blankly (Rounds et al., 2013). In this way, perception of provider comfort with communication regarding transgender health issues after disclosure plays an important role in the patient's ability to give an accurate history. In a qualitative study of gender disclosure and descriptions of mistreatment, researchers have identified themes of: gender insensitivity, displays of discomfort, denied services, verbal abuse, and forced care (Kosenko et al., 2013).

Furthermore, themes regarding fear have emerged from qualitative interviews of patients who have disclosed their gender identity. In one study, respondents reported that

disclosure of gender identity had led to fear of the reaction of the provider, fear of how their care might be affected, and worry over whether a note would be placed in their chart impacting future provider interactions (Rounds et al., 2013). Other prominent themes that have emerged in quantitative research include individuals identifying the feeling of shame in relation to the need for secrecy regarding their gender identity (Factor & Rothblum, 2008).

In surveys of transgender individuals, feelings of shame and worthlessness have been found to increase in direct relation to whether an individual feels the need for secrecy regarding gender identity (Factor & Rothblum, 2008). While researchers did not specifically examine how gender identity and feelings of shame play out within healthcare interactions, this research provides a general understanding of how previous feelings might effect future interactions (Factor & Rothblum, 2008).

Implications

Analysis of these research studies reveals a few common limitations in study data. The quantitative studies reviewed data obtained largely from questionnaires and surveys administered online. While this contributed to larger sample sizes for data analysis, all the data sets included multiple age groups and generations of patients who might be drawing on historical experiences with healthcare providers. While data were stratified by age, statistically significant themes that emerged in most of the research were pooled from aggregate questionnaire data. Like the quantitative data sets, qualitative data sets include variation in age and most qualitative design did not limit participant responses to a specific time frame. In this way, research regarding the experiences and perceptions of study participants, could include experiences from decades ago and may be more

reflective of older notions of transgender healthcare or provider knowledge.

Moreover many of the qualitative and quantitative research studies included lesbian, gay, and bisexual participants within their participant pools. Only one qualitative study examined the experience of transgender and gender queer individuals using individual interviews (Poteat et al., 2013).

A review of the literature helps to distill several common themes with regard to disclosure of transgender identity to healthcare providers. Healthcare provider's knowledge base and communication abilities play a critical role in patient's comfort with disclosure and future gender identity disclosure. A significant theme from these studies was that transgender patients face a variety of challenges in navigating the multiple systems before and even after disclosure of gender identity. These challenges can lead to feelings of shame, discrimination, and fear of future disclosure of gender identity.

Because previous studies have included such large variation in participant ages, participant identifiers, and little information regarding the timeline of experiences, it is challenging to understand the lived experience of a younger generation of transgender and gender queer individuals specifically in relation to healthcare. This study will seek to explore the lived experience of transgender college-aged students.

Research Question

What is the experience of transgender college-aged students who disclose their transgender identity to healthcare providers?

Methodology

Setting

This research study was conducted at a land-grant university. As is typical for most universities, students can access healthcare services at a student healthcare center located on its campus but students also have the option to seek care in several other locations including the university hospital, local urgent care centers off-campus, and primary care offices off-campus. The university- based healthcare clinic provides students with primary care services, women's health services, nutritional counseling, allergic clinical care, and specialized health services that includes: ADHD management, limited mobility issues, and assistance with house modifications (University of Vermont, 2013). Additionally the university provides support and community to transgender students through the LGBTQA (Lesbian, Gay, Bisexual, Transgender, Queer, Ally) center located on its campus. Students can also seek support at off-campus organizations that encourage outreach, provide education and programs specifically geared towards the LBGTQA community (Outright Vermont, 2014). The study was reviewed and approved by the Institutional Review Board.

Sampling

The Institutional Review Board, which approved the study sampling techniques, determined that because participants might not want to disclose their transgender or gender-queer identity by accessing a flyer (Appendix A) in public spaces, listservs and electronic techniques should also be utilized for sampling. The target sample was transgender college students at the university. Students were recruited through flyers posted around campus, the LGBTQA center, off-campus buildings, and advertised on the

LGBTQA center listserv. Students had to self-identify for inclusion in the study. The inclusion criteria for participation in this study included: full-time college student, self-reported disclosure of transgender status to healthcare providers, and the ability to speak and read English. Exclusion criteria include: non-disclosed transgender status to healthcare provider, and not currently enrolled in the University.

Procedure

Study participants contacted the researcher through contact information on the flyer. A mutually agreed upon time and location was arranged via email. Prior to the interview, the study participant received a consent form (Appendix B) that discussed the design of the study and the confidentiality measures employed by the principal investigator. Informed consent was reviewed with all participants prior to data collection. Study participants were given a copy of their completed consent form, which contained the contact information of the principal investigator and faculty advisor. The consent form outlined that the principal investigator and the study participant could to terminate participation in the study at any time. The principal investigator used a private password-protected computer for all communication and data storage. Signed consent forms and any notes taken during the interviews were kept in a locked filing cabinet, which was only accessible to the principal investigator.

Design

This study used research methods rooted in hermeneutic phenomenology to explore the lived experience of students seeking healthcare after disclosure of female-to-male (FtM), male-to-female (MtF), or non-specified transgender status (gender queer) to

a healthcare provider. Data were collected through audio-recorded interviews utilizing semi-structured, open-ended questions approved by the Institutional Review Board (Appendix C). Interview questions moved from the general to the specific with a focus on the student's experience with healthcare providers receiving care. Topic questions included: a disclosure of transgender status to the healthcare provider, feelings about disclosure, description of access to transgender-specific care, and thoughts regarding seeking care in the future. Follow-up questions were asked of study participants for clarity or explication. Data from interviews were transcribed verbatim and secured through encrypted files on the principal investigator's computer.

Data Analysis

The transcribed interview data was read and reread to identify themes within and between individual interviews, consistent with qualitative research methods. Significant statements were identified within study participant's answers. Data analysis began with each line of the transcribed interview was labeled and reviewed for significant statements without preconceived themes in mind. The significant statements were then grouped into categories and collapsed into more focused themes. Through the reading and rereading of responses to interview questions across all participants, themes emerged that help to describe the individual experience, and a shared experience, of study participants' healthcare experiences (Bazeley, 2009; Polit & Beck, 2012). It is important to note that themes are not intended to capture the entirety of the lived experience, but serve to shed light on an aspect of the lived experience (Van Manen, 1990).

Hermeneutic Reduction: Positioning the Researcher

Because the method of reduction is interpretative in nature, it is important to position the researcher to monitor for bias and perspective throughout the research process. This is particularly important during the interviews and thematic analysis, when the researcher must be able to place emphasis on how the participants understand and define their experiences. In order to better understand bias and thought process throughout the study, the principal investigator wrote periodic memos of their thoughts to monitor for bias and perspective (Van Manen, 1990).

The principle investigator used self-reflection to monitor interpretations and personal beliefs throughout the research process. Through writing journals and memos the researcher is able to overcome or identify subjective feelings, preferences, expectations or one-sided understandings of an experience. Journaling helps to support the researcher have a better understanding of the phenomenon (Cohen, Kahn, & Steeves, 2000). The researcher kept a journal of thoughts, questions, and possible interpretations throughout the interview process. These practices were utilized throughout interviews to assure the principal investigator was present and open to participant demeanor and interpretations of behavior.

Results

A variety of perspectives and experiences were shared during study participant interviews. Three college-aged individuals participated in individual interview sessions. Each individual and the principle investigator met for a one-hour interview. Using the procedures described in the methods section, three themes emerged from the transcribed interviews of the study participants: Perceived Provider Trans-Health Knowledge, Being Defined, Loss of Power. In keeping with the chosen method of phenomenology, themes represent common elements of the participant experiences; individual excerpts are included to explicate the themes. Participant names or any pseudonyms are purposefully left out to protect the confidentiality and anonymity of the study participants.

Theme 1: Perceived Provider Trans- Health Knowledge

Participants in the study shared experiences while receiving healthcare, where provider knowledge or lack of knowledge of trans health issues became apparent to the study participant. All study participants shared, without prompting, at least one negative and positive interaction with a healthcare provider. Participants equated positive interactions with more knowledge of trans healthcare and more years of experience. Negative interactions were attributed to less education or comfort of the provider in providing trans healthcare.

Trans-friendly provider. Participants described their experiences with providers who were knowledgeable with medical care, referrals, procedures, cost, and timing of trans- related healthcare. Participants used terms to describes these providers as "transfriendly", "*the person* who sees trans folks", "in the know" about trans issues and non-judgmental. Several behaviors were consistently identified in knowledgeable providers,

these include: normalizing questions, using preferred names for body parts, working with the patient on their timeline for care, conveying sensitivity, being aware of the difference between a patient's legal name and preferred pronoun. When describing interactions with a knowledgeable trans health provider, participants smiled and spoke passionately often using their hands to describe the importance of this provider in their life.

One participant became tearful with describing the trans-friendly provider interaction, stating,

I already felt comfortable discussing this with her [the provider] and I knew it was going to be ok because of her background. So that was a very good experience. The edge was off because I knew there would be some commonality there and she had an interest and I anticipated some compassion there. That was a very good experience and she sort of congratulated me on my discovery and it was the ideal. She said, "This is amazing that you have figured this out and I'm excited to be a part of this adventure with you". So that was pretty amazing and it ended with a hug, it was that sort of energy.

The trans-friendly provider interactions and behaviors that study participants experienced were always explained in relation to a negative interaction with another healthcare provider. One participant noted that the good interactions with healthcare providers help to heal the less favorable interactions with other healthcare providers:

from so many directions when you come out, it is met with resistance, but to have this healthcare experience that is like a coming of age or like a big marker in your life and "I [the provider] am really excited that I am a part of it", like that kind of energy is powerful and it can get you through some of the harder stuff.

When describing this important interaction, this participant placed their fisted hand over their heart, and open and closed their fist to express their point.

Lack of trans-health knowledge. Perceived lack of knowledge of trans health needs were universally associated with negative experiences by study participants. Each participant discussed the experience of being the first trans patient of a healthcare provider. Provider behaviors in these interactions were described using terms: awkward and tip-toeing around words and definitions. When asked about how these interactions made the study participant feel, participants described feeling unsure about what was going to happen during the visit, feeling frustrated, and anger with not having someone to lead them through a process. One participant described getting blood levels following hormone therapy, stating,

you know you think it would be simple. You know my blood work comes back and it is this number it should be between these numbers, what do we do now to balance it out? My primary doctor would be like "I don't know, I'm going to go ask" and then we would both get reassured by another provider. My immediate thoughts are like I'm going to die, my levels are off, and I'm dead [stated loudly with open hands in the air]. Then they other provider would be like "you're fine, don't worry about it". So having a doctor that didn't know was not reassuring or calming to me. Because I was already super anxious about the process.

Study participants discussed how these interactions might shape future care decisions. Participants described that they would rather wait to see a provider who they knew was trans-friendly than risk seeing someone who was not experienced with trans healthcare. In thinking about seeking healthcare from an unknown provider, it evoked feelings of

fear and hesitancy. One participant shook their finger back and forth while describing how they would not like to see another.

Theme 2: Being Defined

In discussing interactions with healthcare providers and seeking treatments, all participants discussed a time when a healthcare provider asked them questions regarding a timeline of their transition, a point when they decided to transition, or when they no longer identified as their natal sex. One participant noted that:

They [the provider] is not really coming at it from a perspective like: "this may be a natural process for you to explore and discover this" and more like: "how long have you been living as a man?" and "when do you anticipate having surgery?" and kind of like these rigid sort of questions that might work for somebody who hasn't experienced it but when you are sort of in the middle of it having definitions around anything can be intimidating.

Participants discussed that this felt particularly unnatural or bothersome to be forced into categories of gender or sexual identity. Another participant noted that providers often ask questions regarding gender and sexual identity with an emphasis placed on timing, stating,

I am not sure whether they [the provider] needs to complete a form with a year on it, but it seems odd for me to give a time and day of when I identified as a man. I want to say [shouting]: I've been a man for twenty years and I'm just waiting for everyone to catch up!

All participants noted a feeling of anger or frustration when being defined by providers within binary systems of identity or when trying to determine an exact time

when they no longer prescribed to their natal sex. One participant explained how these defining questions lead to unsettling feelings, saying,

I wonder what does that mean to them does those that include my whole trajectory of how I got to the point I am at or does that mean the part at which I start wearing certain clothes or changed my name or told my family. What does that mean? It is very confusing to me so I think I find that there have been two providers along those veins readily needing to hone in on factual components of my transition and that being an unsettling process for me.

Theme 3: Loss of Power

When discussing the provider and patient interactions in both primary care and specialty care, study participants described times when their identity and care would be under another individual's control. One participant described it in terms of being called the correct name, saying,

There is no preferred name system for the doctor's office, so whenever I go none of it is taken care of. I could change my name legally but I don't want to until all my financial aid for school is done. So going to the doctor and showing up with my legal name and sex, and then showing up, like I have to shave so they don't see my beard. Like what clothes am I going to wear? I've had people not believe who I say I am. Being called the wrong name in the waiting room full of people thinking, "who is this guy standing up with that name, weird." So something as simple as even if you are not going to put the right name in your system, just make a note in the chart and please call it in the waiting room.

Participants acknowledged that the loss of control and power was felt in several

areas of their care experience including; being called the preferred name, in physical exams by new providers or surgical consults, and in the loss of control regarding who is aware of their transition both before and after transition. Another study participant tearfully described this loss of control in relation to being asked questions during a surgical consultation, where pictures were taken,

They've [the surgeons] asked some fairly triggering questions and then they do their physical exam where they are touching you in places where you dislike or where you don't want much attention, which they need to do understandable, they need to assess what kind of surgery they need to do. And then after that you've made if through all of that, then you take your clothes off. So it is kind of like, I left and I felt like awful for probably a week or two, and I had to work through it in my mind. I have to imagine that there could probably be a way where a person could leave those appointments and not feel really awful.

Loss of power and control were also described in the experience of: waiting for appointments, waiting in exam rooms, waiting for medications and clearances for surgeries by psychiatry. Power was also discussed in relation to obtaining clearance for surgery by psychiatrists. All participants noted that being questioned by someone whom they have never met in order to be approved or cleared for surgical aspects of their transition was odd or uncomfortable.

Discussion

The study presented some thematic congruence with previous research in the field of transgender perceptions of providers and transgender experiences of healthcare. Lack of knowledge, was described by study participants as: inexperience with treatment guidelines or monitoring and improper use of language. The provider behaviors associated with lack of knowledge supports previous research that also identified such behaviors (Round et al., 2013). This study presents some new information regarding the patient feelings associated with perceived lack of provider knowledge: anxiety and general uneasiness. Feeling anxious and uneasy was surprising to patients who all described previous experiences seeking healthcare for health conditions, like sickness or immunizations, where the provider was described as knowledgeable and competent.

In previous research studies and this study, experiences with a provider who was perceived as lacking knowledge regarding trans healthcare, made individuals less likely to seek care from providers who they did not know as trans-friendly. Study participants described the importance of going to a trans-friendly provider, who was known within the community. Trans-friendly providers were associated with values like trust and knowledge. This notion of the trans-friendly provider who is well known within the community was identified by participants as an important part of the patient care experience and an important way that trans patients were able to seek care from a provider. Even when study participants did not know the provider personally, they were comfortable seeking care from a provider who was known within the community.

This research study also supports previous research findings regarding provider behaviors that trans patients found to be positive. These behaviors included: using appropriate pronouns and conferring with the patient regarding their preferred names for body parts (Round et al., 2013). This study also identified that a trans-friendly provider works with the patient regarding a timeline for their care, which was not discussed in previous research in this population.

Previous research in transgender healthcare experiences has found that discrimination and feelings of shame were tied to seeking care as a trans patient (Bradford, et al, 2013). This study identified similar feelings of trans patients being asked questions regarding the timeline of their transition. Questions were described as "static" and "defining" and often placed a large emphasis on the exact time a patient no longer identified as cisgender. Study participants reported feelings of frustration and anger in relation to these types of defining provider questions.

This study also found that transgender patients have experienced a loss of power in relation to working with providers. Loss of power was associated with provider actions like being called the wrong name, not being given options with regard to physical exam, and a loss of control over who is aware of their transition. This is supported by previous interview research, which found that patients report that medical providers use authority over when they lack LGBTQ care knowledge (Poteat et al, 2013). Loss of power was associated with participants feeling awful, uncomfortable, or frustrated.

Implications of the Study for Practice

In keeping with hermeneutic phenomenology, this research study presents several themes offered for the reader to understand the experience of transgender patients. The implications and derivation of meaning associated with these findings are ultimately left to the reader. This study offers several areas for the healthcare provider to consider

further. Notably, it presents a variety of behaviors that providers could employ that were found to be associated with positive patient experiences among college-aged transgender individuals. In the first theme regarding provider knowledge, the trans-friendly provider is an especially important discussion point. This type of healthcare provider utilizes several behaviors that helped to share power and put the patient at ease. Health care providers may utilize these behaviors, which included: using preferred pronouns, calling the patient by their preferred name, discussing body parts with the patient using their preferred terminology, and performing assessments and tests within the time frame that is most comfortable to the patient.

In the second and third themes, commonality was found in the patient experiences with regard to being defined by providers and loss of power in provider/patient interactions. Study participants described questions that felt uncomfortable to them or felt incongruent with their experience. Going forward, healthcare providers may be aware of how questions that impose a concrete timeline or definition might be uncomfortable or difficult to answer. These types of questions may also cause frustration and anger among trans patients. If questions need to be asked with regard to a timeline, the provider may want to provide a reason or rational to the patient that helps to explain the purpose of the question. With regard to power and control, providers could incorporate the preferred names of patients and the patient should dictate to whom they tell their story.

Furthermore, providers could work with the patients to complete physical exams in a way that is comfortable to them and share some control in order to create more equanimity within the provider-patient dynamic.

Conclusions

This study was limited to college-aged transgender patients and presents themes based on their healthcare experiences. While there is some thematic congruence between this study and previous work, this research illuminates some perceived provider behaviors and associated transgender patient feelings within college-aged transgender patients. The findings are aligned with previous broad based studies of transgender and gender queer individuals.

It is the aim of this research that the three themes identified may ultimately contribute to the knowledge base by allowing healthcare providers to draw their own conclusions with regard to the impact of the research. Several behaviors and feelings were illuminated with regard to experience of transgender patients receiving healthcare.

Nurse practitioner core competencies. The Nurse Practitioner Core

Competencies identified by the National Organization of Nurse Practitioner Faculties,
outline several essential behaviors for Nurse Practitioners (NONPF, 2012). In particular
the core competencies outline how Nurse Practitioners improve the quality of health care
delivered through addressing the needs of culturally diverse populations and other
stakeholders (2012). This research study and previous literature within the field of
transgender healthcare illuminate several ways that health care providers have
contributed to positive and negative patient experiences receiving healthcare. While more
research is needed in this field of study, the aim of this research; to understand the lived
experience of transgender patients is consistent with the core competencies. Although
data saturation was not reached, the practice of performing the research study within a
vulnerable population reflects the Nurse Practitioner commitment to the core competency

of practice inquiry, patient centered care improvement, and partnerships with others.

Limitations

This study has several limitations that may limit the understanding of the phenomena. First, only three individuals contacted the principal investigator, met the study criteria, and were interviewed. Therefore, some themes that emerged within individual interviews had to be excluded because the themes were not found within other interviewee's transcribed data. Further, the small sample size of this study did not allow the opportunity to assure saturation in all themes. In this way, it cannot be determined whether the themes were found among other individual experiences not interviewed for this study. Recruiting participants was challenged by the fact that there could be a real of perceived risk of identity disclosure to the community if seen looking at a flyer or contacting the PI. While the principle investigator tried to mitigate this risk of disclosure through sampling techniques as described in the methods section, the perceived risk may have prevented some individuals from participating.

Recommendation for Future Research

Future research could examine larger participant pools to determine whether the themes are identified within an expanded data set. Furthermore it might be valuable to compare perceptions of care received by FTM, MTF, or gender queer individuals.

Beyond the research question investigated in this thesis, future research could examine the relationship between perceived provider knowledge and health outcomes. The individual themes might also present several opportunities for understanding how definitions within healthcare effect the individual patient or how power dynamics impact

individual patients. Overall, transgender healthcare represents a growing body of knowledge and many opportunities to understand how to improve transgender care through research.

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Appendix A

Are you interested in sharing your experience receiving health care?

&

Do you identify as transgender?

Hello! I am a graduate student at the UVM College of Nursing and Health Sciences, I am conducting an interview-based research study to develop a better understanding, of trans persons experience receiving health care.

By trans people I mean, in the broadest sense, people whose gender differs than what was assigned at birth.

- Participants for this study must be over 18 years old,
- Able to converse in English
- · Are a student at UVM
- Identify their gender as different from their natal gender
- Receive health care wherein they disclosed being transgender

Participating in this study will involve a one-time interview (less than 90 minutes in length).

Interview data will be kept confidential.

Questions or Interested in participating?

Please e-mail me, Lisa Schaffer:

llopatof@uvm.edu

llopatof@uvm.edu

llopatof@uvm.edu

llopatof@uvm.edu

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Appendix B

Study Consent Form

Title: Transgender College-Aged Students Gender Disclosure to Health Care Providers and Perception of Medical Treatment

Principal Investigator (PI): Lisa Lopatofsky Schaffer, M.Ed., RN

Faculty Sponsor: Jean Coffey, PhD, CPNP

Sponsor: Department of Nursing, University of Vermont.

You are being invited to take part in a research study because you identify as a transgender college student who has received healthcare wherein you disclosed your gender identity and you would like to discuss your experience. This study is being conducted by a Master degree nursing student in the Department of Nursing and the University of Vermont (UVM) and Jean Coffey, PhD, CPNP is a co-investigator and is supervising this study.

Why is this Research Study Being Conducted?

To understand the experience of transgender college-aged students who disclose their gender status to a health care provider.

How Many People Will Take Part in The Study?

About 6-8 participants will be interviewed about their experience.

What is Involved in The Study?

You will be asked to take part in a face-to-face interview that will be audio recorded for transcription purposes only. You will be asked about your health care experience without discussing personal medical information. You will be asked questions such as, "Can you tell me about your experience receiving health care as a transgender patient? How did you feel about the experience? "All interview sessions will take place in a private location. You can choose to skip a question or stop participation at any time. The aim is to understand your experience during your visit with your healthcare provider when you disclosed your gender status. The interview session may take approximately 1.5hrs.

What Are The Risks and Discomforts? We will do our best to protect the information we collect from you. Information that identifies you will be kept secure and restricted. However, there is a potential risk for an accidental breach of confidentiality. You may have thoughts and feelings that make you uncomfortable as you reflect upon your healthcare experience and wellbeing. If you become distressed at any time during this process, you are free to raise your hand to speak and/or stop your participation. Should you desire to process any thoughts or feelings that may have come up for you during your participation, counselors are available at the University Counseling Center (802) 656-3340.

What Are The Benefits of Participating in The Study? There may be no direct benefit to you for your participation in this study. However, others in the community may gain valuable insight from the results of this study.

Is There any Costs or Compensation? The only cost to you for participation is your time. There is no compensation offered for your participation in this study.

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Can You Withdraw or Be Withdrawn from This Study? You may stop your participation at any time. PI reserves the right to discontinue participation if it is in your best interest to do so. All previously recorded or transcribed data will be destroyed if a participant is withdrawn or withdraws.

What About Confidentiality? The research information will be collected through audio recording and note taking with your permission. This information will be coded and kept secure in a locked filing cabinet that only the PI will access. Following the interviews the recordings will be transcribed and analyzed by the PI. The recordings will remain in a locked filing cabinet during analysis and then will be destroyed. Upon request representatives of the Institutional Review Board and regulatory authorities will be granted direct access to your research records for verification of procedures and/or data.

Contact Information: You may contact Lisa Lopatofsky Schaffer, the Investigator in charge of this study at lisa.lopatofsky@uvm.edu or (570) 650-2590 for more information about this study. If you have any questions about your rights as a participant in a research project or for more information on how to proceed should you believe that you have been injured as a results of your participation in this study you should contact Nancy Stalnaker, the Director of the Research Protections Office at the University of Vermont (802) 656-5040.

Statement of Consent: You have been given and have read a summary of this research study. You agree to participate in this study and you understand that you will receive a signed copy of this form.

Signature of Subject	Date	
Name of Subject Printed		
This form is valid only if the Committees on shown below.	Human Research's current stamp of approval is	
Signature of Principal Investigator Name of Principal Investigator Printed	Date	
Principal Investigator Contact: Lisa Lopatofsky Schaffer, M.Ed., RN (570) 650-2590 llopatof@uvm.edu	Faculty Advisor Contact: Jean Coffey, PhD, CPNP 203 Rowell; Department of Nursing University of Vermont 802-656-9032 Jean.Coffey@uvm.edu	

Committee on Human Research Approved Through: <u>05-21-201</u>5 CHRBS # <u>1 4-49</u>

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Appendix C

Interview Guide

- 1. Can you tell me about your experience receiving healthcare as a transgender patient?
- 2. How did you feel about the experience?
 - a. Did you have any apprehension about disclosing gender?
- 3. How did you feel about the providers care?
 - a. How did these behaviors make you feel (comfortable, uncomfortable, etc)?
- 4. Did you feel that your healthcare needs were met?
- 5. Do you feel that your care was/is impacted by this disclosure?
- 6. What feelings do you have about seeking healthcare in the future?