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## Improving Transgender Healthcare Experiences Using Photovoice

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IMPROVING TRANSGENDER HEALTHCARE EXPERIENCES USING PHOTOVOICE

By

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A scholarly project submitted in partial fulfillment

Of the requirements for the degree of

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### **Abstract**

The transgender community is one of many marginalized populations. There are a variety of factors that influence the healthcare experiences and quality of care that members of the community receive. Some aspects of the difficulties experienced are widespread and not limited to transgender individuals while others are exclusively experienced by transgender patients related to their unique needs. Transgender patients agree that issues identified by providers, like access to insurance and lack of protocols and provider education, are indeed barriers. However, transgender patients have identified other issues, like stigma and discrimination, to be more significant barriers to their accessing healthcare. Additionally, barriers identified by providers effect transgender patients in a manner that most providers would never normally consider as cis-gender individuals.

This study gathers data sourced directly from members of the transgender community to better understand the healthcare experiences and needs of transgender patients. Findings show barriers to transgender healthcare to be multifaceted and complex. Providers who are cis-gender and have not personally experienced the daily rigors that are typical for members of the transgender community cannot begin to understand the needs of the community without context and education directly informed by transgender individuals.

## Introduction

Most people live their entire lives and never question, disagree with, or feel uncomfortable with the sex that they were assigned at birth. These individuals are referred to as having cis-gender identities. The gender they were assigned at birth matches the way they feel or identify throughout their lives. Transgender individuals do not identify as being the same sex as they were assigned at birth. Transgender is an “umbrella term” that has been used to describe people who do not fall into this norm (Bauer, Hammond, Travers, Kaay, Hohenadel, & Boyce, 2009; Hughto, Reisner, & Pachankis, 2015; Kosenko, Rintamaki, Raney, & Maness, 2013; Shipherd, Mizock, Maguen, & Green, 2012).

In the United States (US), it is standard practice for insurance companies to require a specific diagnosis to consider reimbursement or coverage for gender affirming treatments that could possibly be provided specifically to transgender patients. In the fourth edition (2000) of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) the term “Gender Identity Disorder” (GID) was used and classified as a mental disorder. The American Psychiatric Association (APA) acknowledged that there were negative stigmas attached to the use of the word “disorder” and to having a mental disorder associated with the GID diagnosis. Changing the term GID to “Gender Dysphoria” and moving the diagnosis from the mental disorders chapter to the sexual health chapter of the book was approved by the APA for inclusion in the fifth edition of the DSM (2017). It is important to note that identifying as a transgender person is not a mental illness. By making minor changes to the GID diagnosis, transgender individuals are no longer designated as having a mental health disorder and there is still a diagnosis code available for use as is required by insurance companies. Some individuals who identify as

transgender may seek to physically change their sex or affirm their gender via hormone therapy and/or surgeries while others do not.

There are an increasing number of transgender individuals accessing health care practices as patients across the nation. Gates (2011) surveyed a limited sample size that covered only a few states in the US. He found approximately 0.3% of people, roughly 700,000, identified as transgender. Five years later there was a national survey done, in which nineteen states provided information specific to the transgender population. This survey found 0.6% or about 1.4 million adults in the US identified as transgender at the time (Flores, Herman, Gates, & Brown, 2016). The authors of the 2016 survey suggest that the increase in number may be related to increased visibility and greater social acceptance of transgender people as well as a significantly higher volume of people who were surveyed (Flores et al, 2016). Since 2016, transgender people have continued to become more visible in various forms of media as social attitudes continue to evolve over time. It is likely that the numbers, even from the 2016 study, are underestimated and continue to increase as self-identified transgender individuals become more comfortable with sharing this information.

Transgender patients come from a wide variety of backgrounds and ethnicities and have faced disparities in health care related to their histories and roots as well as their identities as transgender individuals. Many transgender patients experience difficulties accessing care and most have experienced stigma and discrimination when seeking care (Cruz, 2014). Health care providers are often inexperienced and ill-equipped to provide trans-competent care to transgendered patients. Chan, Skocylas, and Safer (2016) surveyed medical students attending Canadian medical schools regarding transgender healthcare issues. They found that 95% of students identified transgender healthcare as being important curriculum that should be included

in the education of healthcare providers. However, less than 10% of students reported they felt educated enough to provide care to transgender patients. The authors recognize that, while including transgender healthcare in education curriculum is of utmost importance in improving transgender care, it is only one piece of a multifactorial puzzle (Chan et al., 2016). Even the most well-intentioned providers can hold unidentified biases toward transgender patients, unintentionally carrying societal norms and expectations into the clinical setting. These biases have the potential to make transgender patients feel discriminated against and marginalized, leading to mistrust, unbalanced power differentials, and other barriers to healthcare and access (Poteat, German, & Kerrigan, 2013).

The Office of Disease Prevention and Health Promotion (ODPHP) (n.d.) lists improving the health, well-being, and safety of lesbian, gay, bisexual, and transgender (LGBT) individuals as one of their Healthy People 2020 goals. Papers have been written and introduced into scholarly conversation where researchers assume knowledge of barriers to care for transgender patients. Recommendations have been made in regard to navigating these barriers but, in these instances, feedback from the transgender population has not been actively sought out (Coleman et al., 2012; McCann & Sharek, 2016; Roberts & Fantz, 2014; Snelgrove et al., 2012). Few studies involve transgender individuals being surveyed to inform researchers what barriers to healthcare exist. Often members of the transgender community are not provided the opportunity to share their thoughts and experiences beyond answering multiple choice questions. In these cases, the questions are created by researchers or government organizations who are not members of the transgender community (Chan et al., 2016; Florez et al., 2016; Gates, 2011). This leads to questions biased by perspectives that do not resemble that of the relevant population.

There have been a limited number of studies that have asked transgender individuals to share their perspectives and experiences in healthcare. Most studies make recommendations for minimizing various barriers to healthcare for the transgender community. Identified barriers differ based on the sources utilized to inform what specific barriers were. In order to effectively improve transgender experiences in healthcare, the barriers that are specifically identified by the affected community need to be considered. Currently, there is a disparity between the barriers identified by providers and the transgender community. Like many people, members of the transgender community deal with common issues that affect access to healthcare, like affordable insurance. What is unique for members of the transgender community are the other situations they endure, such as lack of provider education, stigmatization, and gender discrimination.

There are currently few spaces in health care that are safe enough for transgender patients to comfortably share medically relevant information or to receive complete and competent health care specific to their unique needs. This is discussed further in the literature review.

## **Background and Significance**

### **Literature Review**

Markwick (2016) discusses widely acknowledged barriers to care that many transgender individuals experience. Financial and structural barriers are commonly experienced in this community. Many transgender individuals expressed difficulty in securing employment. This results in not only a lack of access to insurance but also a lack of income or limited income. Social norms and expectations affect the rate of employment thereby influencing the income and access to employer supplemented health insurance. The rate of insurance coverage amongst transgender patients is notably lower than that of gender normative patients. Even transgender patients with health care have issues with coverage of treatments or procedures by their

insurance policies. Hormone treatments and surgeries are often not covered by insurance companies resulting in significant costs transgender patients must pay out of their own pockets. For regular health maintenance care visits, some insurance plans base reimbursement for specific tests, treatments, and even regular health screenings on the sex of the patients receiving care. This often leads to situations where transgender patients have anatomy that does not match the “male” or “female” label on their chart or are receiving hormone therapy that their medically assigned sex does not normally receive. Both situations put transgender patients in situations that leave them with little to no reimbursement or financial assistance from insurance for the purpose of maintaining basic preventative health care (Markwick, 2016).

### ***Provider Education***

The education of many health care providers does not include information on the needs or care of transgender individuals. Providers who treat transgender patients are often undereducated in transgender needs and do not have a basic understanding or access to clear protocols in treating said patients. Transgender care is still relatively new and understudied. Currently there are no set parameters and recommendations for treatment as there are for other conditions like diabetes, asthma, or hypertension. Providers themselves have acknowledged a lack of education, protocols, and processes for the treatment, maintenance, and care specific to transgender patients as primary barriers to access to culturally specific care (Snelgrove, Jasudavicius, Rowe, Head, & Bauer, 2012).

### ***Stigma and Discrimination***

Less commonly acknowledged barriers to care for transgender patients are the influence of stigma and discrimination. Scholarly conversation is increasingly considering this as a root cause of health care disparity for transgender individuals (Bauer et al., 2009; Cruz, 2014; Dutton



et al., 2008; Hughto et al., 2015; Kosenko et al., 2013; ODPHP, n.d.; Poteat, German, & Kerrigan, 2013; Roberts & Fantz, 2014). Transgender individuals report experiencing incidents of stigma and discrimination when attempting to find employment or housing, or even when simply navigating their everyday routines. Transgender patients have reported parallel experiences occurring in their health care interactions as well (Poteat et al., 2013). ODPHP (n.d.) acknowledges the shift in research and scholarly conversation recognizing stigma and discrimination as significant barriers and adds the denial of basic human and civil rights as an issue.

Transgender men, female-to-male, have reported gynecologic care as being an important component of their health care needs but found themselves struggling to disclose their gender identity and the details of their anatomy with health care providers. Elements of their health care experience that might be as simple as being asked to check the male or female box on an intake form as well as the tendency of the staff to use gender specific pronouns were reported to be significant barriers to their care (Dutton, Koenig, & Fennie, 2008). Cruz (2014) found that within the transgender community, those who are known to most other people as being transgender had the highest rate of postponing their care. Those who were known to only select people or groups as being transgender postponed their care more than those who were not yet known to others as being transgender. In the same study, Cruz also acknowledges that “historical stigmatization as well as many negative personal experiences in healthcare settings fosters a reluctance to disclose gender identity” (2014, p.987).

McCann and Sharek (2016) note documented disparities in mental health care and social inclusion of transgender individuals that are cited by governmental agencies in Australia and Scotland as well as the United States. Transgender individuals identified a lack of safe

environments, specifically related to health issues, as contributing to their vulnerability. Additional concerns identified, both in and outside of healthcare settings, include harassment, discrimination, physical violence, and sexual abuse. Further reinforcing the feeling of marginalization are the patterns of avoidance behaviors followed by transgender individuals in response to the aforementioned concerns. Many transgender patients feel the need to avoid what most would consider necessary treatment for the maintenance of health resulting in minimal opportunities for optimal health care (Coleman et al., 2012). Stroumsa (2014) reviewed policies, laws, and medical frameworks for transgender health. The author states that “[the needs of transgender patients] are compounded by prejudices against transgender people within both the medical system and society at large. These prejudices create barriers to accessing timely, culturally competent, medically appropriate, and respectful care” (Stroumsa, 2014, p. e31). These ineffective care practices have serious consequences. For instance, ODPHP (n.d.) noted a correlation between the stigma and discrimination that LGBT individuals experience and higher rates of depression, substance abuse, and suicide. The transgender community experiences a rate of attempted suicide more than twice the general population. Youth who identify as either transgender or questioning report rates of attempted suicide between 28% to 50%, compared to youth who identify as cis-gender, who reported attempted suicide rates between 10% to 18% (Toomey, Syvertsen, & Shramko, 2018).

The Human Rights Campaign (HRC) has released a 2018 LGBTQ Youth Report in which they report increased occurrences of depression and elevated stress levels when members of this youth group do not experience support at home. Behaviors that might seem little or insignificant to parents, like negative remarks about the LGBTQ population in general, are enough to undermine the trust and safety that LGBTQ youth feel at home. More than 70% of

LGBTQ youth reported feeling depressed, worthless, or hopeless within a week of taking their survey. As little as 26% feel safe at school and more than half do not feel safe using restrooms that align with the gender they identify as. McCann and Sharek (2016) note transgender individuals report feelings of shame and unworthiness being commonplace.

The National Institute on Drug Abuse (NIDA) has, in recent years, begun collecting more data on sexual orientation and identification. They have labeled anyone who does not identify as being a cis-gendered heterosexual adult as being a “sexual minority.” NIDA states that individuals who identify as “sexual minority” are more than twice as likely to use illicit drugs than heteronormative adults.

### **How Gaps in the Literature Inform this Project**

A study on LGBT youth found that these patients placed less importance on a providers’ sex or sexual orientation than they did the providers interpersonal skills and experience. (Hoffman, Freeman, & Swann, 2009). Providers need to improve the quality and relevance of healthcare interactions currently experienced by many transgender patients. McCann and Sharek (2016) note the need for providers to be competent and knowledgeable with regards to transgender care and issues, but that patients preferred providers that were able to appreciate their unique experiences and needs with understanding and without judgement.

Providers have cited a lack of education and protocol as the primary barriers to providing better transgender health care, but there is also a gap between the assumption that providers make as to what the barriers to care are for the transgender community and what the transgender community feels their barriers to care are (Snelgrove et al., 2012). While provider education and lack of clear protocols may be legitimate barriers to care, the transgender community has identified barriers beyond these items. Further research with the transgender community is

needed to better inform current health care experiences provided to transgender patients as well as future protocols that might be used to inform their care. Community based participatory research (CBPR) methods like photovoice provide researchers the means to gather qualitative information on the views and experiences of the transgender population that can be used to inform everything in transgender health care, from broad protocols to smaller personal interactions between staff and patient.

Transgender individuals looking for comprehensive quality health care services are interested in protecting their physical, emotional, and mental health. Currently, transgender patients must educate themselves on their options and what to expect before walking into most healthcare settings. In addition to being educated on their own needs, these patients must also be confident enough to advocate for all their physical and mental healthcare needs. The providers that care for transgender patients are directly responsible for their health and ethically obligated to provide for the health and well-being of all their patients, including transgender.

With the overall topic and process of transgender health care still being in its infancy research is needed to set protocols for treatment, gender transition, and even basic health care maintenance and screening. Some providers are better equipped to do the research required to create new protocols for treatment and screening while others are better equipped to move for social change and create an awareness and improvement in the health of the transgender community. Both fronts require continued study and efforts toward improvement of transgender healthcare experiences. Healthcare workers must thoroughly understand community identified barriers in order to address them. This study will utilize the CBPR method of photovoice to increase empowerment within the transgender community and move for social change and

increase awareness and understanding of the healthcare needs of the transgender community for healthcare providers.

### **Purpose of the Project**

The goals of this project are 1) to increase the sense of empowerment and confidence of transgender co-researchers in advocating for their healthcare needs and 2) to collect insightful data on healthcare experiences, perspectives, and needs of transgender patients for healthcare professionals and educators for future use.

There are currently few spaces in health care that are safe enough for transgender patients to comfortably share medically relevant information or to receive complete and competent health care specific to their unique needs. It is important for all patients, including transgender patients, to feel confident in sharing important information that might influence their healthcare needs. Providers need to better understand the perspectives and experiences unique to the transgender population in order to create safer spaces for transgender patients. This study is intended to begin the process of closing the gap between literature and practice by gathering data directly from members of the transgender community. A PowerPoint presentation will be created from data collected during the photovoice process as a means of disseminating findings to medical professionals in the future. The presentation will be created as a voice over PowerPoint recording available on-demand as well as being available for live presentation.

### **Theoretical Framework**

Minority Stress Theory proposes that sexual minority health disparities can be explained in large part by external stressors in the environment induced by a hostile culture which often results in a lifetime of harassment, maltreatment, discrimination, and victimization (Marshall et al., 2008; Meyer, 2003). This stress environment can ultimately impact access to care. The

Minority Stress Model (MSM) (See Appendix A) points out that the characteristics of any given minority identity, the ability to cope, and community and individual social support all play a role in mental health outcomes of the members of a community. As with any general population, members of the transgender community experience typical stressors every day. In addition to common stressors, members of the transgender community are also “subjected to alarmingly high rates of discrimination, violence, and rejection related to their gender identity or expression” (Hendricks & Testa, 2012, p. 462). This model illustrates that the mental health and resilience of members of a minority community can be directly affected by the absence or presence of a support network and coping strategies.

The principle of Allostatic Overload bolsters the MSM by linking the damage that chronic stress can cause directly to biological responses. Juster (2019) recognizes that external environmental stressors, psychological distress, and biological stress responses are all most often studied independently from each other despite their intricate relationship. It is important to consider these elements together in order to provide context and strengthen the significance of any findings and the extent to which effective change can be made. Pairing the minority stress MSM with the principle of Allostatic Overload illustrates that adverse health outcomes for minority communities can include both mental and physical detrimental health changes.

This study couples the MSM and principle of Allostatic Overload with Bandura’s Theory of Self-Efficacy (Bandura, Freeman, & Lightsey, 1999). Bandura outlines four sources of self-efficacy that work together to improve the individual’s sense of self-efficacy and ultimately have a positive effect on their behaviors. Photovoice is used to encourage the project’s co-researchers to advance through Bandura’s four courses of action (See Appendix B): enactive mastery through sharing lived experiences, vicarious experience through photo sharing, verbal persuasion

through story sharing, and physiological arousal by creating emotional reactions within the group that all work together to encourage the development of a sense of self efficacy resulting in increased empowerment for each co-researcher (Bandura et al., 1999). The pre- and post-participation surveys (See Appendix C and D) were designed using a modified Self-Efficacy Scale (SES; Bandura, 2006).

### **Methodology**

Generally, an individual who plays a role in a study is referred to as either a participant or a researcher. Traditionally the researcher is the person who runs the study to collect data and the participant is the person who is subject to the conditions of the study. Due to the nature of the photovoice process, those who would normally be referred to as participants are not subject to study, rather they are subject matter experts and will be referred to throughout this paper as co-researchers. The individual who would customarily be referred to as the researcher will be known as the facilitator as this is more indicative of the role they fulfill throughout the photovoice process. This study included three co-researchers and one facilitator.

### **Setting**

This study was conducted in the greater Seattle area from February 15, 2020 to March 23, 2020. An expedited application for review by Institutional Review Board (IRB) was submitted in December of 2019. This study was reviewed by Seattle University's IRB and on January 20, 2020 this project proposal was endorsed for implementation. Informed consent for participation was obtained from each co-researcher at the first group meeting.

### **Design**

This was a qualitative study using photovoice, a community based participatory research method, primarily to empower transgender individuals to advocate for their own healthcare

needs and secondarily to begin a data collection process where the input originates from members of the affected community and results in a resource that could help providers better respond to the healthcare needs of transgender individuals.

### **Sample**

Using an outward snowball convenience sample method through word of mouth and social media, 3 co-researchers were recruited. Prospective co-researchers were provided with the study facilitators contact information and a brief summary of the study. No personal information of prospective co-researchers was provided to the study facilitator for recruitment purposes except by prospective co-researchers themselves. Each prospective co-researcher shared their names and contact information with the facilitator in order to communicate details regarding the first meeting after co-researchers made the decision to participate or not. After co-researchers consented to participate in the study, contact information was kept for the purpose of coordinating meetings and facilitating the photovoice process. The short study description used for recruitment was:

The study asks trans folks to use photography to share their lived experiences and needs as individuals in healthcare settings as Participant Co-Researchers and Subject Matter Experts.

Inclusion criteria for co-researchers consisted of being 1) self-identified transgender individual, 2) aged 18 years or older, 3) at the time of the study lived near enough to the greater Seattle area to attend group meetings, and 4) due to the nature of the project it was necessary for co-researchers to speak English in order to participate in group conversation.

### **Intervention: The Photovoice Process**

Photovoice provides an opportunity to decolonize the research process by allowing



individuals to speak for themselves and share their own experiences as members of the transgender community. It uses co-researchers photographs and narratives to communicate their story. The photovoice process consists of a series of group meetings, with a facilitator and all co-researchers, and individual meetings, between each co-researcher and the facilitator. This study included a total of twenty individual meetings, four individual meetings with each co-researcher, and five group meetings.

### ***Photovoice Workshop and Initial Meeting***

The first meeting was a group meeting. This meeting served as an education and training session on the photovoice study format and set up for the remaining meetings and structure of this specific study. The photovoice information sheet and informed consent form was reviewed, expectations for participation were set, and any questions regarding the study were answered. Consent (See Appendix E) was obtained by the facilitator during this initial gathering of co-researchers. Co-researchers were given the opportunity to ask questions before signing the consent form as well as throughout the project as they came up. Pre-participation surveys were distributed, completed by co-researchers, and collected by the facilitator, also at the first group meeting.

The photovoice workshop followed. It explained the photovoice process and ensured that the co-researchers were comfortable with the process and this study. Basic digital cameras were checked out to each co-researcher. The cameras loaned to co-researchers were provided by Seattle University College of Nursing. The purpose of utilizing loaned cameras was to mitigate any issues with access to technology and avoid breaches of confidentiality that may have resulted from the use of the co-researcher's cell phones. There was instruction on the use and care of the loaned cameras and memory cards. The workshop also included exercises to help enhance the

co-researchers' understanding of and level of comfort with the photovoice process. Once the workshop was complete, expectations to maintain a safe group environment were set and goals for the study. Included in discussion of expectations was conversation around protecting the conversations had in during group meetings as well as discussions between individual co-researchers and the facilitator. Guiding topics were decided upon as a group: access including but not limited to healthcare, health insurance, daily experiences or struggles. Model consent forms (See Appendix F) were provided to all co-researchers.

### ***Individual Meetings***

The remaining group meetings were preceded by individual meetings between the facilitator and each co-researcher. The purpose of the individual meetings was to review and collect photographs that had been taken by each co-researcher during each round in response to the chosen theme and prepare for the upcoming group meeting. The photographs selected for sharing were compiled and prepared for the group meeting by the facilitator.

### ***Group Meetings***

The format for group meetings was as follows: as each photograph was shared, the photographer would share their own thoughts and feelings specific to that photograph before opening up the discussion to the group. After all photos were shared and discussed, the group identified themes and discussed similarities and differences between that weeks' photographs. The photographers' titles and narratives for each image, written at the group meeting for each round of photographs, were collected by the facilitator.

The second group meeting took place one week after the first group meeting. After some conversation the co-researchers determined that two weeks between group meetings would provide more time and opportunity for taking photographs for each topic. The remaining group

meetings were all held two weeks apart. Due to the evolving COVID-19 pandemic, the third and fourth group meetings were held virtually for the safety of all group members. The fourth group meeting included discussion of selection of photographs for inclusion in the image use agreements (See Appendix G) and compilation in a PowerPoint presentation for future dissemination.

The facilitator shared the photograph selections accompanied by their titles and narratives by email to each co-researcher for final review and input before their inclusion in a PowerPoint presentation aimed at local area healthcare providers and this paper. Any suggestions or recommendations for change by the co-researchers were made via email and phone call. Adjustments were made according to co-researcher feedback. Post-participation surveys and image use agreements were sent to each co-researcher via email. Co-researchers completed the surveys and signed the image use agreements and returned them to the facilitator by email.

The length of the study was determined by co-researchers. Completion of the photovoice portion of the study took approximately five weeks. Compilation, analysis of the data, and writing up the findings took approximately another five weeks. This study took a total of approximately ten weeks to complete.

### ***Confidentiality and Other Consent Processes***

Co-researchers were made aware of how their images would be used so that they could make an educated decision on whether they would like to have their real names accompany their photographic work. They were free to use pseudonyms or simply be anonymous if they preferred to protect their identities. For those who wished to remain “anonymous” no names or identifiers were recorded or tied to any of their work. When photographic attribution is required, “anonymous” or a chosen pseudonym was used in place of their name.

Since photography is being used in this project, model consent forms were provided to co-researchers for use with photographs of a person who was identifiable in the resulting image. Co-researchers also signed an image use agreement at the end of the photovoice phase dictating the use of their photos with their titles and captions. This form makes it clear that, in order to maintain the integrity of their voice and data, the facilitator will not separate their images from their words. It also makes clear that the images and words can be used for future exhibits, presentations, papers, and other scholarly or educational uses.

### **Instruments**

Pre-participation and post-participation surveys were completed by each co-researcher. The first part of the pre- and post-surveys were identical in order to measure any change in confidence levels of the co-researchers.

First, modified SES questions were used to determine the degree to which the co-researchers felt confident enough to advocate for their needs in the healthcare setting at the time they took their surveys. Some of these items included confidence level in discussing mental health needs, pronouns, gender identity, sexual health, and current anatomy. Co-researchers were asked to rate their confidence levels on a scale from zero to one hundred, with zero representing not confident at all and one hundred being completely confident.

The second portion of the pre-survey asked co-researchers to describe in words their own barriers to health care in a qualitative manner. This information was used as a starting point to spark conversation between co-researchers during the first group meeting. The second part of the post-survey was a reflection exercise, using six open ended questions, to help the facilitator understand the impact that participating in this project had on the co-researchers, if any.

## **Data Analysis**

Two types of data were collected over the course of this study. The first was quantitative and qualitative data in the form of paired pre- and post-participation surveys for the purpose of determining whether co-researchers felt more empowered to advocate for their healthcare needs through participation in this study, using the SES scale and open-ended reflection questions. The second was qualitative data collected in the photographs and their titles and captions that will be used in the future to communicate the healthcare needs of transgender patients to healthcare workers.

For analysis of the quantitative section of pre- and post- participation surveys, answers from the SES items were entered into an excel spreadsheet (See Appendix H). Pre- and post-surveys were matched and answers were compared to evaluate whether there was any change over time in confidence levels of co-researchers to advocate for their own healthcare needs with their providers. A paired T-test (See Appendix I) was used to determine the significance of changes.

The second portion of the post-participation survey consisted of a series of open-ended questions guiding co-researchers through a reflective process and asked them to provide feedback on their individual experiences as they relate to participation in this study. Free text answers for the open-ended reflection questions were reviewed and evaluated for themes and indications of change in levels of confidence or empowerment. All post-participation surveys were collected within two weeks of the last group meeting of the photovoice process.

Analysis of the photographs was done as a group with the co-researchers. Each selected photograph was reviewed and discussed as a group. Each group meeting included some time to identify similarities and differences between the photographs and shared experiences during

discussion. Co-researchers identified common themes throughout this study. With consent of the co-researchers, the facilitator took notes during group discussions to capture discussed themes and record important points that were brought up during the discussion.

## **Results**

### **Survey Findings**

SES ratings showed mixed results in changes to level of confidence in advocating for co-researchers own healthcare needs. The three SES items that showed the most improvement were confidence in 1) disclosing my pronoun, 2) discussing my gender identity, and 3) requesting guidance or support in transitional paperwork. As a group there was minimal increase in overall SES ratings with the group average changing from 89.2 on the pre-participation survey to 89.1 on the post-participation survey.

### ***Co-Researcher A***

Co-researcher A rated themselves as having a net zero change in confidence levels. Three items showed a total of 22 points increase in confidence level, four items showed a total 22 points decrease in confidence level, and four items showed no change in confidence levels. Their average SES rating across all eleven items was 96 on both pre- and post-participation surveys.

### ***Co-Researcher B***

Co-researcher B rated themselves as having a net change of -175 points, approximately 17.6%, decrease in confidence levels. Two items showed a total of 20 points increase in confidence, six items showed a total 195 points decrease in confidence level, and three items showed no change in confidence levels. Their average self-efficacy rating across all eleven items was 90 on the pre-participation survey and 74 on the post-participation survey.

### ***Co-Researcher C***

Co-researcher C rated themselves as having a net 175, approximately 19.5%, increase in confidence levels. Six items showed a total of 180 points increase in confidence levels, one item showed five points decrease in confidence level, and four items showed no change in confidence levels.

### ***Co-Researchers as Group***

Overall SES ratings express varying levels in change in levels of confidence in each co-researchers' abilities to advocate for their own healthcare needs with their respective healthcare providers. Their average self-efficacy rating across all eleven items was 82 on the pre-participation survey and 98 on the post-participation survey.

### **Identified Barriers**

The barriers to healthcare as identified by co-researchers on the pre-participation survey are “[access to insurance covered] gender affirming surgeries,” life event causing ineligibility for maintaining current insurance “and then I won’t have it,” and “...the fact that I am living in a body that does not match a societal/biological assumptive form, I will always experience some level of distress and barriers to navigate.”

### **Reflections**

A qualitative evaluation of the reflection exercise at the end of the post-participation survey reveals results equally as mixed as findings in the SES items. Two out of three co-researchers reported that they felt they had made important contributions to improving the future of transgender healthcare. One co-researcher stated “...it’s important to detail for cis people exactly what trans healthcare looks like right now, because almost none of them really know... since it doesn’t apply to them.” Another stated that “...great humongous strides in healthcare,

practices, procedure and respectful treatment...[is] entirely due to the fact that numerous transgender and [non-binary] participants have over time become informed patients willing to advocate for better, trained, and respectful treatment for all patients.” One co-researcher did not comment on their feelings around having made important contributions to the improvement of transgender healthcare.

When asked about their feelings regarding their experience having participated in this study, all co-researchers expressed feelings of positivity. One co-researcher stated:

“I think this study is important not only as an instructive teaching tool to cisgender, uninitiated, and uninformed study moderators and later readers, but as an empowering tether among weary and often dejected trans-participants. By telling our stories, we were able to share strategies in navigating the healthcare, legal, and insurance industries to our benefit rather than to our detriment.”

When asked what parts of their experience were most impactful on a personal level, all three co-researchers indicated unique elements. One co-researcher reported that over the course of their participation in this study that they came to the realization that they identify specifically as transsexual, a subset of the greater transgender community. Two co-researchers noted the importance of connections made with other co-researchers. One co-researcher specifically described the feeling of empowerment that accompanied particular elements of their participation in this study.

“The joint sharing of experiences within the cohort was very cathartic. I felt empowered by the telling of my experiences, joint acknowledgement, respectful and active listening, and getting to be ‘the authority’/SME [Subject Matter Expert] of my own experience. The validation and expansion I felt through the telling, showing, answering questions, and



sharing strategies was actually a surprising but welcomed opportunity. Somehow the photographic element lent a credibility and substantiating condition to my experience, even if it simply served as an illustrative ‘talking point.’”

While findings from pre- and post-participation survey data had mixed results overall, two out of the three co-researchers described via other data collection elements feeling more empowered to advocate for their own healthcare needs as well as having made a contribution to the advancement of improving the healthcare experiences of the transgender community as a whole.

### **Photovoice Findings**

Four themes associated with barriers to accessing healthcare were identified throughout the photovoice process as co-researchers shared their experiences and stories through photo sharing. Each of these themes can be evaluated and considered as stand-alone issues, however it is important to consider them together as they are all delicately intertwined with each other and provide context to one another. Adding context serves to “enhance the value, validity, and transportability of research” (Tomoaia-Cotisel, Scammon, Waitzman, Cronholm, Halladay, Driscoll, ... & Shih, 2013, p. S122). This section will review each identified theme individually. The images and accompanying titles and captions used to illustrate each theme were not the entirety of the co-researchers work (See Appendix J). The relationships and context of identified themes will be reviewed in the discussion section.

### ***Insurance***

Co-researchers identified several issues dealing with insurance companies or coverage. All co-researchers expressed difficulty in finding a hospital or provider that accepted their insurance or that their insurance company would cover, difficulties with reimbursement or

provisions for basic medical supplies like glucometers, and unreasonable delays in medications or medical supplies when moving from one insurance company to another. For transgender individuals, lapses in medication for any reason results in unpleasant physical consequences that often mimic different phases of menopause depending on which hormone and what dose is being missed.



*Image 1*

*M.C. Hunter. March 2020*

Blood sugar/privilege

Privilege to afford equipment to monitor health as requested by doctor. Issue: When switching insurance, only carries one type of monitor so required to switch equipment - - took 6 mos to get everything figured out between insurance co, pharmacy, and doctors office.



*Image 2*

*Levi Briar B. March 2020*

Mother

I am currently on my mother's healthcare plan, until I turn 26 this year. Then I'm on my own. I haven't found a new plan yet, which scares me because I take pills each day for my anxiety and depression, and administer testosterone to myself once a week.

Sometimes, regardless of gender identity, providers who are covered by insurance are located at a great distance to where patients reside. This increases costs, stress, and

inconvenience by extending travel distances, frustration associated with commuting and traffic, and increasing time away from home and work.



*Image 3*

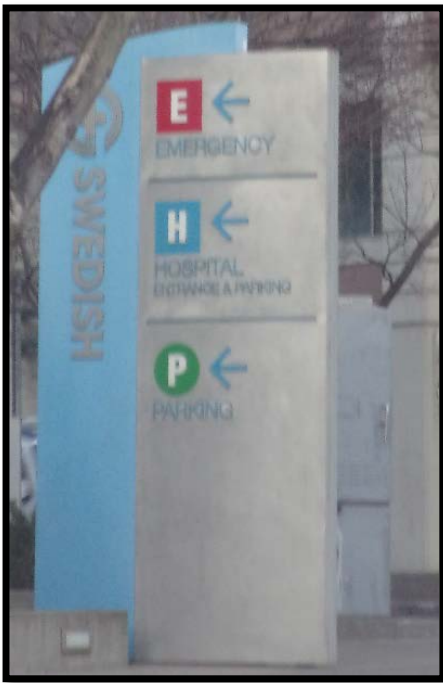
*Dyas D. Alure. March 2020*

Rainier in the VA morning

The VA requires most visits at one of their main campuses. Commute in during rush hour can be frustrating. To counter this, I drive early. This means that I frequently see the sunrise. A disadvantage is I spend more time at the VA.

In addition to common struggles when navigating health insurance, more specific concerns surfaced. All co-researchers note that it was difficult to find affordable insurance coverage that would meet their particular needs as transgender patients was difficult. Many insurance companies do not cover or assist with the cost of gender affirming hormone care (GAHC) or gender affirming surgeries that many transgender patients identify as basic necessities for both physical and mental health management. Due to the “Male/Female” markers in patient charts, standard health screenings are often not covered by insurance because the screening does not always match the designated sex. For example, if a patient chart is identified with the male marker in their chart but the patient’s current anatomy still includes internal organs such as a cervix, the cost for a standard pap smear screening test would not be covered by the insurance company as a direct result of the mismatched sex marker. This is only one way out of pocket costs for transgender patients occurs. Additionally, there are still several hospitals and clinics where basic services considered general practice are offered to gender normative patients,

but the same services are not provided to transgender patients. For example, a transgender patient visits a primary care provider for a standard annual visit. For most patients, this visit includes a physical exam and orders for health screenings or labs to check things like cholesterol or blood sugar levels and liver and kidney functions among others. Sometimes, rather than provide general health checks, providers choose to refer transgender patients to specialists, like an endocrinologist, even for basic health needs because the patient is taking hormones associated with their GAHC. In addition to regular health maintenance, prescribing and monitoring GAHC is within the scope of a primary provider. However, many providers are uncomfortable enough with GAHC that they choose not to provide even basic care themselves. This is another way out of pocket expenses for transgender patients are unnecessarily increased.



*Image 4*

*M.C. Hunter. March 2020*

Hospitals, Healthcare Institutions, Medical - Self advocacy

level of knowing a system. Figuring out whether an institution accepts your form of insurance.

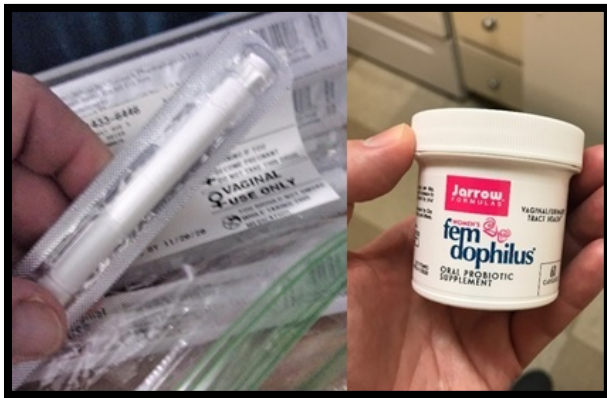
-does this provider accept state funded insurance? (applecare = state funded brand of Medicaid)

-having insurance is a privilege, but more likely since HCA [Health Care Act] [Organizations] work hard to get everyone registered.

Co-researchers shared the sense that their healthcare was provided and decided on by people and organizations that are not educated on or sensitive to their mental or physical needs as transgender individuals.

### *Health Literacy and Provider Education*

Co-researchers shared experiences related to their providers either not being educated on various aspects of gender affirming care or starting GAHC but failing to properly educate the patients on what to expect with starting or continuing this treatment. Group discussions included mention of transgender patients educating themselves enough to be able to educate their providers around their healthcare needs and appropriate treatments. One co-researcher shared a common experience that they and other transgender males faced. Their providers did not address the eventuality of vaginal atrophy as a normal physiological occurrence with aging or in relation to GAHC. The transgender males relied on their own research and each other to educate themselves as to what they were experiencing and how to discuss it with their provider to seek appropriate treatment. It was mentioned that this was a common occurrence among transgender men as well as aging cis-gendered women. Providers in general tend not to discuss sexual health with their patients, regardless of their orientation (Fuzzell, Fedesco, Alexander, Fortenberry, & Shields, 2016).



*Image 5*

*M.C. Hunter. March 2020*

#### Cross Hormones

When an estrogen-based body system is subjected to testosterone (full-dose) for longer than a year, it throws the body into menopause. Conditions within the transman's vagina are that of a post-menopausal woman... The conditions of a post-menopausal vagina in a transman and the neo vagina of a transgender woman are similar in that consistent and continuous dilation or stretching is required for good sexual health...

Another co-researcher shared their experience when starting their GAHC. Their provider was educated enough to prescribe the treatment but did not consider the need that the patient had regarding proper self-administration of the prescribed treatment. The co-researcher struggled through a period of trial and error and eventually turned to social media for guidance.

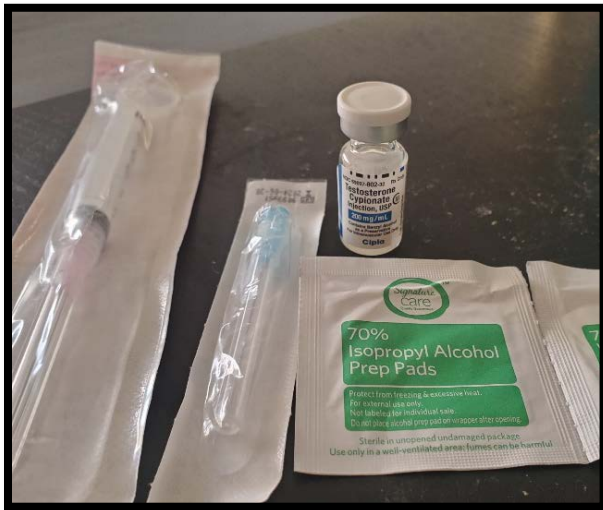


Image 6

Levi Briar B. March 2020

Weekly Injection Supplies

The wider needle is for drawing up the Testosterone, as it is somewhat thick and difficult to draw through smaller needles. Additionally, using a new needle to inject ensures that the needle will be it’s sharpest. This is all information I have learned through trial and error, because no one who prescribed it to me knew enough to warn me not to use the same size of needles. I spent months struggling to draw it up until I googled it and found information in reddit threads from other trans men posing their own experiences.

One co-researcher was fortunate enough to have found a provider who was educated and comfortable enough to not only start GAHC but also to set clear expectations on what they should expect to experience with starting their treatment.

Reversible Effects	Expected Onset	Expected Maximum Effect	Reversibility
Changes in libido (sex drive)	1-3 months	1-2 years	Reversible
Decreased spontaneous erections	1-3 months	3-6 months	Reversible
Cessation of male pattern baldness	No regrowth, loss stops	1-2 years	Reversible
Body Fat Redistribution to Feminine Pattern	3-6 months	2-5 years	Reversible
Decreased muscle mass/ strength & strength	3-6 months	1-2 years*	Reversible
Softening of skin/decreased oiliness	3-6 months	Unknown	Reversible
Thinning and slowed growth of body and facial hair	6-12 months	> 3 years*	Reversible
Less firm erections	Variable	Variable	Reversible
Permanent Effects	Expected Onset	Expected Maximum Effect	Reversibility
Breast growth	3-6 months	2-3 years	Permanent
Decreased testicular volume (by 25-50%)	3-6 months	2-3 years	Likely Permanent
Decreased sperm production	Variable	Variable	Possibly Permanent
Reduced Fertility			

Image 7

Dyas D. Alure. March 2020

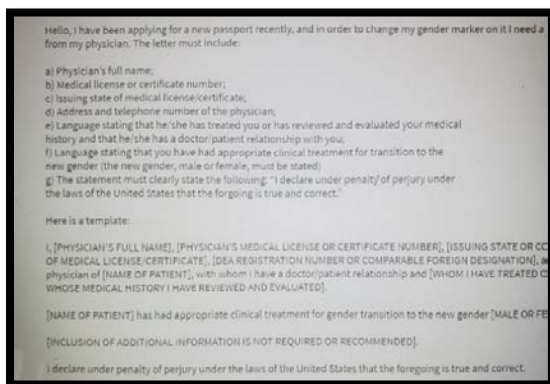
What to look forward to

I had a good experience with Planned Parenthood. I got the start of my HRT [Hormone Replacement Therapy] from there. I got decent information from here. The whole experience was better than expected.

Group discussion highlighted the importance for providers to understand the value and necessity of educating the patients on not only immediate and long-term effects of the treatment but on proper medication administration techniques.

### ***Legal Recognition***

Navigating the intricate processes associated with completing and submitting any government paperwork can be intimidating and complex for most anyone. The complexity is compounded when the item being corrected not simply a person's name but also their sex. The process of making legal changes to sex and name is arduous and not clearly laid out. There are several steps and several levels at which those steps must be made to make corrections to legal sex and legal name on state and federal documents like birth certificates, drivers licenses, and passports. Compounding this already complex process is the particular order in which documents must be submitted for correction. Among co-researcher, a significant amount of time was spent discussing this process during group meetings. Several photographs were chosen for and included in group sessions which related to various steps in this process. Each of these steps must be taken in order and most steps require very specific forms or specifically worded letters to complete the process.



*Image 8*

*Levi Briar B. March 2020*

### Word for word

This is a message I sent to my doctor requesting a letter certifying that I am Trans so I can get my gender marker changed on my passport. I provided him all the details I could and a template because if it's not exactly correct they will deny it.

For transgender individuals, gaining the legal recognition of their correct name and sex is an arduous process. Co-researchers note how the process is often frustrating and emotionally taxing and is always time consuming and expensive. There are many court and processing fees associated with this process. Resources for assistance throughout this process are limited so most transgender individuals are left to rely on their community to offer advice based on experience. Those individuals who do not have as many ties to the greater transgender community are less likely to look to the community for help. For many reasons, not the least of which is the difficulty and expense of this process, some transgender individuals choose not to make these changes.

### ***Stigma and Discrimination***

Transgender individuals experience discrimination on many levels from various sources in all aspects of life. Despite qualifications, many non-binary people often experience direct discrimination when attempting to gain new employment or secure a promotion in their job regardless of whether there is legislation in place to protect from discrimination in the workplace.



*Image 9*

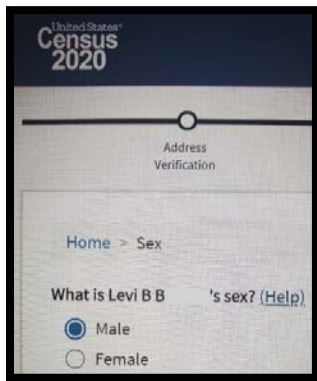
*M. C. Hunter. March 2020*

### **Discrimination in the workplace**

Education programs or vocational training can often give a person a “head start” in trying to establish a steady paycheck and self-esteem. Many continuing education courses at the 2-yr colleges can move someone ahead in a meaningful career. Most trans/nb [non-binary] and LGBTQ folxs [gender neutral collective noun used to address a group of people] have college education however because of other forms of employment discrimination are often not hired on the basis of their gender identity.



There are currently 25 states and three territories in the US where it is still legal to discriminate based on gender identity (Movement Advancement Project, n.d.). This is indirect discrimination. Policies like this affect entire groups and are felt on a larger scale. One co-researcher commented on the frustration experienced when completing their online census form. It asked for “biological sex” and only offered two options as a response, male or female.



*Image 10*

*Levi Briar B. March 2020*

Biological sex

Taking the 2020 census, it asks for biological sex, and then gives examples that would not apply to me as a biological “female” because I am legally and functionally male. They should be asking for gender. Additionally, there are only 2 options for response.

Discrimination was a common experience among co-researchers. One co-researcher often brought up the simple act of being referred to as male or female according to their appearance rather than their preference felt very discriminatory. The same co-researcher recalled a specific hospital stay where meals were refused unless she would refer to herself as a male.

Several experiences of social stigma were shared between co-researchers. There were experiences of public judgement, aggression, and shaming that made simply being in public a stressful situation that could not be easily avoided. Instances of being pointed or laughed at or having had comments made directly at them as they walked past induced stress and feelings of fear or frustration.



*Image 11*

*Dyas D. Alure. March 2020*

Solitude before appointment

With multiple appointments at the VA, I spend more time there. I frequently find places of solitude to reflect. As a transgender I can walk anywhere patients can. I can choose to be in populated areas, but find I worry what others think of me. Any laugh, I can assume is directed at me, true or not. I contribute [sic] this fear to my transgenerness.

Another issue that many transgender individuals experience is discrimination associated with the choice they make when walking into a mens' or womens' public restroom. In recent years some restrooms have been designated as gender neutral, but a majority of restrooms are still gendered. Because these restrooms are public spaces, people generally base judgement on the appropriateness of an individual's choice between male and female on their appearance of masculine or feminine presentation as defined by social expectations rather than internal individual identity. Complicating matters are facilities that require patrons to ask for keys or codes for entry to a restroom, and facilities where designation for male, female, family, or gender-neutral status are not clearly marked.



*Image 12*

*M.C. Hunter. March 2020*

### Bathrooms

... signage is important. Though the homeless population has affected the public accommodation rules around bathrooms and the single-use or “family” bathrooms are often locked. This can be a problem for many who have to or choose to use these rooms... school-age youth and transwomen of all ages often don’t feel comfortable using the restroom in public and arrange their lives around not having to eliminate until they are in the safety of their own homes. This leads to complications such as increased UTIs and other potentially life-threatening conditions.

Included in discussion with the experience of social stigma was the acknowledgement for increased need for use of coping tools where other non-stigmatized people had no need.

Conversations around maintaining stability in their mental health, which carries its own stigma in US-American society, becomes more important and contributes to the disparity in quality of life between people who fit into societal norms versus people who do not.



*Image 13*

*Dyas D. Alure. March 2020*

### Self compassion

As a mental patient I have learned many ways to cope with my mental challenges. I like to “hue sort” puzzles and not start on the edge. Clumps just form as the puzzle forms.

### **Discussion and Implications**

The primary aim of this project was to increase the sense of empowerment and confidence of transgender co-researchers to advocate for better care for themselves and clearly communicate their healthcare needs to their providers whether or not they offer trans-competent care. While the quantitative data showed no great difference at a group level, it did indicate a noticeable change in confidence for two out of the three co-researchers. The qualitative data collected reinforces the individual findings of the quantitative data set.

The secondary aim of this project was to gather data to start work on an educational tool for providers. Considering the impact that the global COVID-19 pandemic has had on work environments and the ability for groups to congregate, the author decided the most effective manner for dissemination of a provider education tool would be to create a voice over PowerPoint recording that could be accessed by individual providers at their convenience with the option for virtual presentation of the photovoice PowerPoint to groups upon request. This flexibility will allow for wider availability of the provider education PowerPoint as well as the capability of expanding the content of the PowerPoint should there be future additional studies or additional information become available.

#### **Co-Researcher Confidence in Self-Advocacy**

Co-researcher A showed no significant change in their self-efficacy ratings between their pre-participation and post-participation surveys, however the qualitative data collected in the reflection section of their post-participation survey indicates a significantly increased sense of empowerment not only to advocate for their own needs, but to continue to work to advocate for the healthcare needs of the transgender community. This co-researcher identified their participation in this study as being significant and that, as the study progressed, they realized

they had entered the study unsure if their experiences were singular and found, through the photovoice process, that all members of the group shared common views and experiences. They expressed feeling validated and having experienced feelings of comfort in realizing there were commonalities in their experiences as members of the transgender community.

Co-researcher B showed a considerable decrease in self-efficacy ratings from their pre-participation survey to their post-participation survey. The qualitative data collected from the reflection section of their post-participation survey supports that finding. The qualitative data also brings to attention some context that was not widely discussed during group meetings. During the course of this study there was a public health crisis that resulted in a “stay home, stay healthy” order limiting social connection and close personal contact. This co-researcher mentions having experienced some mental health issues associated with the isolation that came with social distancing as was indicated by their responses in the reflection portion of their post-participation survey. It is possible that with an interruption of their regular mental health routines and increased isolation there was a negative effect on their self-efficacy ratings associated with their self-identified decrease in sense of belonging in their community and self-identified decrease in their overall confidence regarding wider social interaction.

Co-researcher C showed a significant improvement in self-efficacy ratings from their pre-participation survey to their post-participation survey which was supported by the qualitative data collected from the reflection portion of their post-participation survey. There they noted the importance of trans-competent healthcare and sharing the experiences of transgender people with members of cis-gendered communities including healthcare providers. They reported positive feelings being associated with their participation and felt that they had played a part in raising awareness of transgender needs in healthcare.

### **Development of Educational Materials for Providers**

The secondary aim of this study was to collect input directly from members of the transgender community identifying what they perceive to be their greatest barriers to accessing healthcare are. This data is for future use in providing healthcare professionals and medical educators with insight into healthcare experiences, perspectives, and needs of transgender patients with the intended overall purpose of improving transgender healthcare experiences. A PowerPoint presentation was started to serve as a living document that has flexibility for updating as additional data is collected through future iterations of this study. This PowerPoint will be used to create a short voice over PowerPoint. This will be made available to providers on-demand for review at their individual convenience. The same PowerPoint will also be available for use in a remote presentation setting for groups of providers upon request. Community partners who are already connected to networks of providers and are motivated to improve healthcare interactions for the transgender community will be utilized to aid the process of dissemination.

A review of the literature addressing the current state of transgender healthcare and the healthcare needs of the transgender community highlighted two main points. First, a disparity between the barriers to healthcare access identified by healthcare providers and those identified by members of the transgender community. Second, a lack of trans-competent healthcare providers resulting in a lack of safe spaces in healthcare for transgender patients. The next sections of this paper will discuss study findings in relation to these two main points.

### ***Co-Researcher Defined Barriers***

Four primary themes were identified by co-researchers during group sharing and discussion as barriers to healthcare: insurance, health literacy and provider education, legal

recognition, stigma and discrimination. As it was discovered in review of the literature, providers acknowledge access to insurance and their own lack of education regarding transgender healthcare as barriers that transgender individuals experience to healthcare (Chan et al., 2016; Hughto et al., 2015; Roberts & Fantz, 2014). Though co-researchers agree that insurance and provider education are indeed key issues, their experience is that barriers extend beyond these encounters. Even for transgender patients who have insurance, their claims are reviewed and processed by employees who lack training both in the physical and mental health needs of transgender patients. This is where reimbursement for screenings, treatments, and surgeries are often reflexively denied and typically difficult to appeal. Providing education to insurance employees who process healthcare claims as well as to healthcare providers is vital and necessary. Treatment of transgender patients does not end with writing a prescription for hormones. Providers with transgender patients should be mindful of their insurance barriers and helpful with filing insurance claims for these patients.

Trans-competent providers must understand more than simply being familiar with treatment algorithms. It is essential to understand the complexities of transitioning from one sex to the other and the importance of health literacy of transgender patients regarding what to do and what to expect once treatment has been prescribed. Trans-competent providers will be educated themselves as well as ensuring that their patients are also health literate to encourage transgender patients to take an active role in maintaining their own health in the safest ways possible. When providers supply medications without instructions it sets the stage for the spread of misinformation, which has the potential to put patients' health at risk. Trans-competent providers can also recognize that most general health care concerns can be monitored and addressed without a referral to a specialist, just as they are within the cis-gendered population.

In addition, co-researchers identified legal recognition, stigma, and discrimination as issues. These issues also directly affect health outcomes. The Minority Stress Model illustrates that stigma and discrimination are external environmental stressors that contribute to the minority stress process setting the expectation for rejection and internalized negativity that, without a strong support system in place, can have a negative impact on mental health (Hendricks & Testa, 2012). Mental health was also an issue that repeatedly occurred as an underlying issue or irritant acting to magnify issues within each of the four themes, as was revealed in verbal and photographic responses of co-researchers. Over the course of group discussions, the facilitator noticed a difference in responses, experiences, and general outlook expressed by co-researchers who had strong sources of social support versus co-researchers who had fewer or no source of social support at all. Co-researchers with stronger and more extensive support networks were more likely to express positive experiences and more hopeful outlook in general. Research has suggested that stronger social support structures for transgender individuals can have a positive effect on their mental health outcomes (Budge, Adelson, & Howard, 2013; McConnell, Birkett, & Mustanski, 2016; Pflum, Testa, Balsam, Goldblum, & Bongar, 2015)

### *Complexities of Intersectionality and Context*

While reviewing these themes, organizing photographs with their titles and captions, and revisiting notes from group discussions the author had trouble separating individual themes and assigning photographs with their titles and captions to a single theme. Most photographs, accompanied by their respective titles and captions, fell under multiple themes. Each of the four themes had a relationship with the others which affected healthcare outcomes for transgender patients. In order to analyze this data, it is imperative to consider the complex interactions



between each of these themes and the contexts in which they relate. These contextual factors require attention and discussion and are a vital part of interpreting findings and contributing to scholarly discussion and implementing change (Tomoaia-Cotisel et al, 2013).

People from all walks of life experience stressors associated with insurance, health literacy and provider education, and governmental paperwork to some extent at some point over the course of their lifespan. Many people have recognized and felt the effects of some form of discrimination and social stigma in one way or another, however members of the transgender community face additional layers to those barriers that cis-gendered individuals are privileged not to encounter. These additional layers affect both the physical and mental health of transgender patients and often result in increased costs and further hardship. Cis-gendered individuals are not required to run the gauntlet of governmental red tape and incur additional costs in order for appropriate sex on their various forms of identification to be reflected, nor do they experience the same issues associated with stigma and discrimination based on their gender both in and out of the healthcare setting. Most healthcare providers, being cis-gendered, are unaware of biases they may carry because they do not personally have the experience of navigating the complexities of being a transgender person in a cis-gendered society.

### **Practice Recommendations**

The healthcare needs of transgender patients go beyond access to insurance and education of healthcare providers. More research needs to be done to gather input directly from members of the transgender community who can better identify the issues that affect the access to and quality of their healthcare experiences. Continued use of the photovoice process is worth considering as a tool for gathering of valuable firsthand data and mobilizing the transgender community as a whole in order to more effectively drive change that ultimately results in better understanding

and widely available trans-competent healthcare. The use of data collected from this study, and future series of the photovoice process, can be used to spread awareness and understanding among healthcare teams through photovoice presentations and galleries. Short voice over PowerPoint presentations will be recorded and made available as an on-demand teaching tool for providers, initially through community partners and their networks of providers. The same PowerPoint presentation will be available for remote presentations to groups when requested. Continued cycles of photovoice would serve to enrich and diversify information collected throughout this study and eventually more accurately represent the demographics of the transgender population. The PowerPoint file would serve as a living document easily updated with additional data collected through continued photovoice cycles and feedback directly sourced from members of the transgender population.

### **Project Limitations**

There are limitations of this project that should be recognized. First, this study included a group consisting of three co-researchers. The significance of both the qualitative and quantitative results of this study are highly limited related to number of co-researchers who participated. Second, in addition to small number of co-researchers, the members of the group were not proportionately representative of the transgender community. The co-researchers in this study consisted of one female transgender individual, male to female, and two male transgender individuals, female to male. This sample does not reflect the ratio or diversity of transgender males and females in the community. As with any small samples, the input is limited and not as diverse as it would be with a larger group.

Lastly, this study was facilitated by and findings were analyzed by a single individual. The lack of additional people for implementation of the study and analysis of collected data

limits the interrater reliability. While the group of co-researchers did identify the four themes addressed in the findings, they were not present for analysis of any quantitative data or post-photovoice interpretation of conversations for the purpose of evaluation. This author attempted to limit the influence of any personal biases that might be present and unacknowledged by encouraging the group of co-researchers to participate in a manner such that they contributed the bulk of the content guided minimally by the framework provided by the facilitator.

### **Dissemination of Findings**

The approach to dissemination of findings from this study was developed in response to the COVID-19 pandemic and the uncertainty associated with the ability to carry out in-person education sessions. Currently, future dissemination of findings involves sharing short voice over PowerPoint presentations available to providers on-demand and remote photovoice PowerPoint presentations with healthcare teams including providers. Photovoice PowerPoints and presentations can all be used to spread awareness and understanding of transgender experiences in healthcare settings and increase the number of trans-competent healthcare providers resulting in an increased occurrence of safe spaces in healthcare for transgender patients.

There are a number of trans-care provider and trans-advocate groups who are already motivated to increase provider education and improve transgender healthcare experiences. Locally, the Northwest LGBT Senior Care Network, a group of providers, and the Ingersoll Gender Center, a trans-advocate group, are community partners that are likely to be interested in assisting with dissemination of findings through their networks. With the evolution of the dissemination of the findings from this project, from live and in-person to on-demand and remote, it is also possible to include dissemination to groups nationally for providers and advocates alike.

### **Conclusion**

Barriers to transgender healthcare are multifaceted and complex. Providers who are cis-gender and have not personally experienced the daily rigors that are typical for members of the transgender community cannot begin to understand the needs of the community without context or education directly informed by transgender individuals. Issues that, on the surface, may seem obvious and uncomplicated are not as simple as they appear. Making healthcare spaces safer for the transgender community involves more than educating providers and finding transgender patients access to health insurance. Further studies need to be done to expand understanding of transgender experiences in healthcare from the perspectives of transgender individuals themselves and to increase the safety for and confidence of members of the transgender community within healthcare settings.

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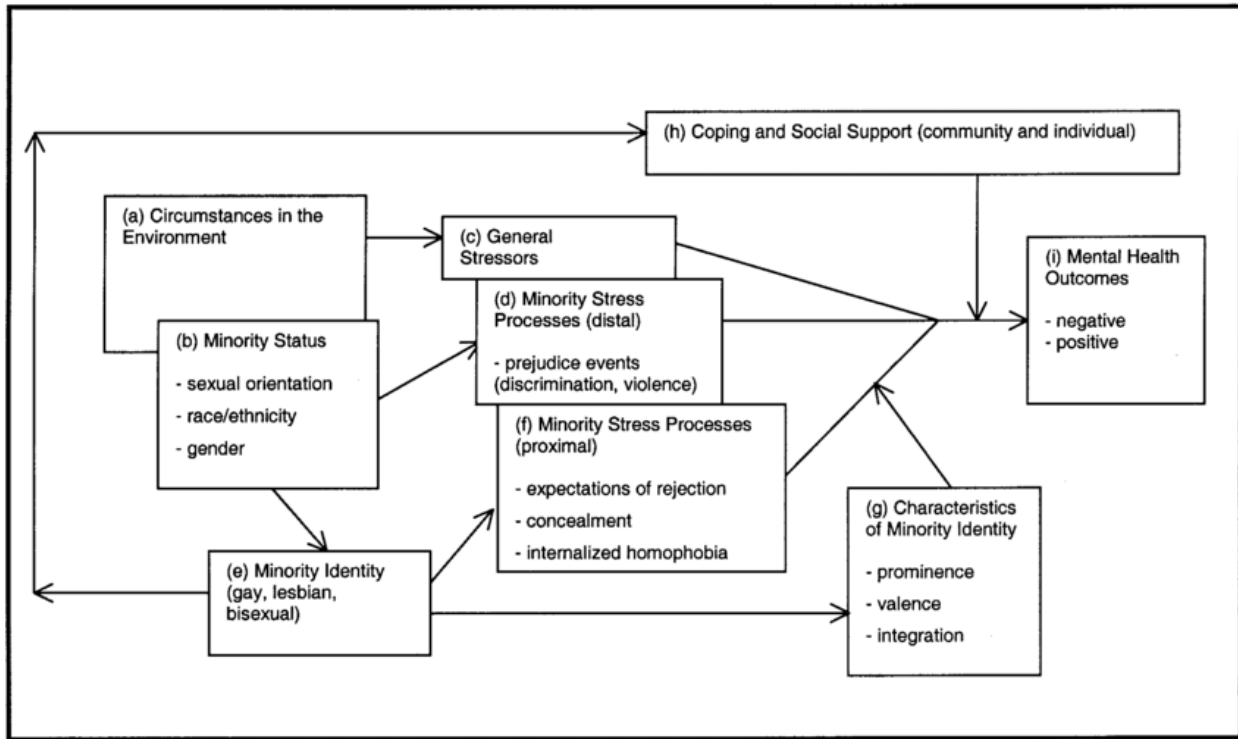
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Appendix A

Minority Stress Model

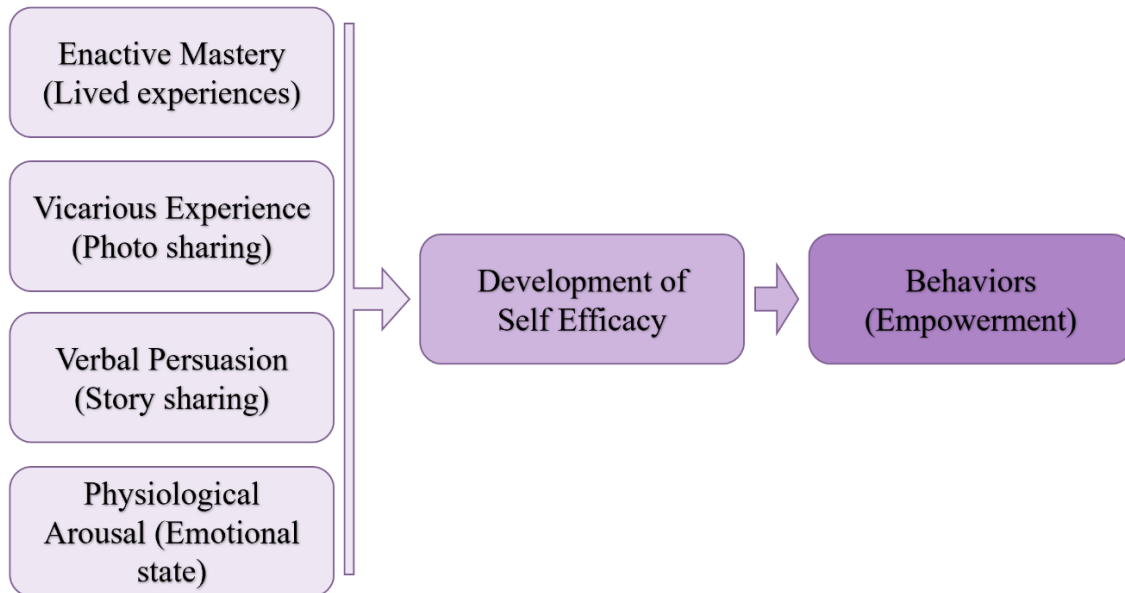


This model illustrates that the mental health and resilience of members of a minority community can be directly affected by the absence or presence of a support network and coping strategies.

(Meyer, 2003, P. 35)

## Appendix B

### Banduras Theory of Self-Efficacy



Bandura outlines four sources of self-efficacy that work together to improve the individual's sense of self-efficacy and ultimately have a positive effect on their behaviors. Photovoice is used to encourage the project's co-researchers to advance through Bandura's four courses of action: enactive mastery through sharing lived experiences, vicarious experience through photo sharing, verbal persuasion through story sharing, and physiological arousal by creating emotional reactions within the group that all work together to encourage the development of a sense of self efficacy resulting in increased empowerment for each co-researcher (Bandura et al., 1999).

**Appendix C**

**PRE-PARTICIPATION SURVEY**

Below is a list of different things that are related to your health care. In the *Confidence* column please rate how confident you are that you can discuss them with your provider *as of right now*. Rate your degree of confidence by recording a number from 0 to 100 using the scale provided below:

0	10	20	30	40	50	60	70	80	90	100
I do not feel confident at all that I could do this				I feel somewhat confident that I could do this					I feel highly confident that I could do this	

Care related Actions

Confidence

- Discuss my mental health needs \_\_\_\_\_
- Disclose my pronoun \_\_\_\_\_
- Discuss my gender identity \_\_\_\_\_
- Express interest in current or future gender affirming hormone care (GAHC) \_\_\_\_\_
- Express interest in current or future gender affirming surgeries \_\_\_\_\_
- Discuss past GAHC \_\_\_\_\_
- Discuss past gender affirming surgeries \_\_\_\_\_
- Discuss my sexual health \_\_\_\_\_
- Discuss my present anatomy \_\_\_\_\_
- Request guidance or support in transitional paperwork \_\_\_\_\_
- Discuss non-surgical gender affirming options (padding, tucking, binding, etc) \_\_\_\_\_

Please answer the following question:

Do you experience any barriers to your own access to healthcare? YES NO

If yes, please explain below (feel free to use the back of the page):

**Appendix D**

**POST-PARTICIPATION SURVEY**

Below is a list of different things that are related to your health care. In the *Confidence* column please rate how confident you are that you can discuss them with your provider *as of right now*. Rate your degree of confidence by recording a number from 0 to 100 using the scale provided below:

0	10	20	30	40	50	60	70	80	90	100
I do not feel confident at all that I could do this			I feel somewhat confident that I could do this				I feel highly confident that I could do this			

<u>Care related Actions</u>	<u>Confidence</u>
Discuss my mental health needs	_____
Disclose my pronoun	_____
Discuss my gender identity	_____
Express interest in current or future gender affirming hormone care (GAHC)	_____
Express interest in current or future gender affirming surgeries	_____
Discuss past GAHC	_____
Discuss past gender affirming surgeries	_____
Discuss my sexual health	_____
Discuss my present anatomy	_____
Request guidance or support in transitional paperwork	_____
Discuss non-surgical gender affirming options (padding, tucking, binding, etc.)	_____

Please answer the following questions:

- 1) Do you feel that your voice has been accurately represented in this study?  
 YES NO Please explain:
- 2) Did you feel safe and free to share your views and experiences openly throughout the study process? YES NO Please explain:
- 3) Do you feel that you were able to contribute information that will be important to transgender healthcare in the future?  
 YES NO Please explain:

Please answer the following questions as thoroughly or briefly as you prefer:

- 4) Now that this project is complete, what are your thoughts/feelings on your experience having participated in this study?
- 5) What do you feel was most impactful for you throughout your participation in this study and why?
- 6) What would you have done differently?

SES scale adapted from Banduras' Guide for constructing self-efficacy scales (2006)

## Appendix E



# CONSENT TO PARTICIPATE IN RESEARCH

## PHOTOVOICE INFORMATION SHEET AND CONSENT

### Improving Transgender Healthcare Experiences Through Photovoice

You have been invited to participate as an expert in a study of transgender experiences in healthcare so that the facilitator can understand more about the needs of transgender individuals in healthcare settings and the barriers transgender individuals face in getting care. The goal of this study is to inform practice recommendations in hopes of improving the experiences of transgender individuals in health care. You were selected as a possible participant because you identify as a transgender person who is over the age of 18, English speaking, and lives in or around the greater Seattle area. Please review this information sheet and ask any questions that you have before agreeing to participate in this project.

This project is being facilitated by Amy Nelson from Seattle University, Seattle, Washington, who is working toward her Doctor of Nursing Practice degree in the College of Nursing. Amy's faculty advisor is Dr. Jennifer Fricas.

#### **Procedures:**

If you agree to participate in this project, you will be asked to do the following:

The project will begin with a training workshop which will take place at a central location. The workshop will consist of training about the photovoice process, a short pre-participation survey, and instructions regarding operation of the camera that will be loaned to you for the purpose of the study.

At the end of the training we will discuss our goals and approach to photographing themes related to the first question or topic.

You will be asked to take a camera for approximately one week in order to take photos, as a part of your daily life, which you believe represent your responses to the first question or topic ender study.

At the end of the first photographic period, you will have a brief meeting with Amy to review your photographs. The location for this meeting is flexible and will be arranged between you and the facilitator. During this meeting you will be asked to select 3-5 photographs from your week to present in a group meeting where photographs from all participants will be discussed.

After the individual meetings have concluded, all participants will attend a group meeting together. This meeting will take place at a central location. At this meeting, participants will be given time to title and caption or narrate their selected photos, with guidance from the facilitator and other participants if you would like. Once the photos have been titled and captioned, you will be asked to share your selections with a brief account of why you took the photograph and how it represents the theme. After you have shared, the other participants may comment. During group meetings you will be asked to comment on photographs of others in the group, so that similarities and differences between all shared photographs can be discussed. Group discussions

will be facilitated by Amy. At the conclusion of this meeting, the group will decide on our approach to photographing our next theme related to a second question.

This cycle of individual and group meetings will repeat 1-2 more times depending on the number of themes the group members create. After the last group meeting and discussion has taken place, the facilitator will take some time to compile a set of photographs with accompanying titles and captions for a booklet. A final meeting will be held so that participants have the opportunity to review the booklet and provide feedback on the final compilation and their experience in participating in this project. During this meeting there will be a short final survey. If a participant is unable to make it to the final meeting, other arrangements can be made to provide the opportunity for feedback on the final compilation, take the survey, and share anything regarding their experience in participating in this project if they would like.

Additional information:

1. Basic digital cameras will be loaned to participants during the study. During the workshop you will receive information regarding use and care of the camera and ethics of photography.
2. Notes will be taken at all meetings for further analysis by the facilitator. These notes will be kept confidential and will be used only for the purpose of enhancing the facilitators understanding and enriching the write up of this project.
3. You will retain the rights to all of the images. At the conclusion of the project, you will meet with the facilitator to discuss which images you agree to have included in the final compilation as well as for other presentations or community uses. A copy of this consent form is available for your review.
4. You may choose to be involved in exhibitions, presentations, and/or other activities resulting from the data related to this project, in which your photographs and their titles and captions may be used, with your permission. Exhibitions, presentations, and/or other activities may take place after the conclusion of the official project period and with or without the involvement of the facilitator.

### **Risks:**

If you are not already out as a transgender person in your work or social groups there is the possibility, should you choose to use your known name, that others might be able to identify you as transgender. In the instance that you have even the slightest concern about people knowing or not knowing that you identify as transgender, the following measures will be taken to protect your identity. Names or other identifiers associated with dissemination will only be used with your expressed consent. In the case that you are concerned about using your own name, you have the choice of using a pseudonym or simply having your work labeled as anonymous. Names or other identifiers associated with data storage will remain consistent with your choice of identification. Names or other identifiers will not be used without your consent.

### **Confidentiality:**

All records involved in this project will be kept private. In any report that might be published, no information will be included that will make it possible to identify a participant without their expressed consent. All records will be stored securely in password protected files on a password protected external hard drive that will remain in a locked cabinet when not in use. Any paper documents will be entered into an excel spreadsheet and stored on the same password protected hard drive. Once they have been recorded electronically any hard copies will be destroyed. Only the facilitator and the faculty advisor will have access to the records. There is the possibility that

the faculty member responsible for overseeing this project may be provided access to the records should the facilitator need their assistance or if academically required.

**Voluntary Nature of the Project:**

Participation in this project is entirely voluntary. Your decision to participate or not will not affect your current or future relations with the facilitator or with Seattle University. Should you decide to participate, you are free to not answer any question or to withdraw participation at any time without affecting those relationships.

**Contacts and Questions:**

The facilitator conducting this study is Amy Nelson. You may ask any questions you have at any time. If you have questions later, please contact Amy at 206-419-0402 or at [nelson30@seattleu.edu](mailto:nelson30@seattleu.edu). Amy's academic advisor is Dr. Jennifer Fricas. She can be reached at 206-296-2342 or [fricasj@seattleu.edu](mailto:fricasj@seattleu.edu).

If you have questions or concerns regarding this project and would like to speak with someone other than the facilitator or their academic advisor, you are encouraged to contact Dr. Michelle DuBois, chair of Seattle University's Institutional Review Board by phone at 206-296-2585, or by email at [irb@seattleu.edu](mailto:irb@seattleu.edu).

*You will be provided with copies of all consents for your records*

Name of Participant (please print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date of Signature: \_\_\_\_\_



**Appendix F**  
**‘MODEL’ CONSENT FORM**

This consent form is part of a process developed for a project by Amy Nelson, Doctor of Nursing Practice student, from Seattle University College of Nursing and the voluntary participants in this project. The participants are taking photographs to help bring understanding to the healthcare experiences of transgender individuals in the greater Seattle area. As a part of this process, the photographer must ask for your consent to appear in a photograph they took. A person who appears in an identifiable way in a photograph is referred to in this form as a model.

**CONSENT**

I allow [name of the ‘Photographer’] \_\_\_\_\_, to use photos of me [name of the ‘Model’ or person appearing in the photo] \_\_\_\_\_, taken on [date] \_\_\_\_\_, at [location] \_\_\_\_\_ for any purpose, in any media, throughout the world and without time limit. I understand that the Photographer may use the images for any purpose they choose and that this may include:

- Use on websites, available to anyone with internet access worldwide
- In printed materials, including scholarly articles, reports, books, pamphlets, and posters
- In public exhibitions, as agreed to by the project partners

I understand that I will not be paid for any such use.

I agree that I have no right to the images including to inspect or approve the Participant or Facilitators use of the images, and that the rights to the images belong to the Photographer.

I agree that the images may be combined with other images, text, and graphics, and could be cropped or modified.

I agree that the Photographer may assign this permission to another person, such as the Facilitator.

**Contact Information and Signature**

Model’s Full Name (printed): \_\_\_\_\_

Model’s Address: \_\_\_\_\_

Model’s Telephone: \_\_\_\_\_

Model’s Email: \_\_\_\_\_

Model’s Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of parent or guardian if model is under the age of 18:

\_\_\_\_\_

Witness Signature: \_\_\_\_\_

Witness Name (printed): \_\_\_\_\_

## Appendix G

### IMAGE USE AGREEMENT

I, \_\_\_\_\_, creator and copyright owner of the images taken by me during my participation in the study entitled Improving Transgender Healthcare Experiences Through Photovoice, hereby give my permission for the study, to use these images in print and/or electronic form according to the terms detailed below.

#### **Terms and Conditions**

Primary use of these images will be for an original Doctor of Nursing Practice (DNP) project by the facilitator. This may include presentation, publication of scholarly articles, books, pamphlets, or online material relating to the project.

Images may also be used by the facilitator to increase awareness of and support for improved transgender healthcare experiences.

Images may be used in the following ways: at public exhibition or presentation, electronically through websites; in local, national, or international press accompanying a news or feature article; in printed publications or promotional materials produced by the facilitator.

I understand that by signing this agreement, I forfeit the right to withdraw any images to which this form refers from public usage. Whenever possible, the facilitator will withdraw images from public access at the request of the photographer, however where images have already been distributed, they may be copied or saved and used in to the future for purposes which may or may not align with the original aim of the project.

Whenever an image is used it will be accompanied by the following credit:

*{Participant Name or Pseudonym} | {Date} | A. Nelson | Improving Transgender Healthcare Experiences Using Photovoice*

#### **Participant-Photographer Signature and Contract Details**

Name (print): \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

#### **Researcher Signature and Contract Details**

Name (print): \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date:

\_\_\_\_\_

**Listing of Images (with thumbnails) to Which This Agreement Applies**

*[INSERT THUMBNAILS HERE]*

## Appendix H

### Self-Efficacy Scale Items and Answers

Confidence level items	Co-researcher <b>A</b>		Co-researcher <b>B</b>		Co-Researcher <b>C</b>	
	Pre	Post	Pre	Post	Pre	Post
	Discuss my mental health needs	100	95	90	50	80
Disclose my pronoun	100	100	90	100	80	100
Discuss my gender identity	100	100	90	100	80	95
Express interest in current or future gender affirming hormone care (GAHC)	100	100	90	90	100	100
Express interest in current or future gender affirming surgeries	90	97	90	80	0	100
Discuss past GAHC	100	98	90	90	100	100
Discuss past gender affirming surgeries	100	95	90	70	100	100
Discuss my sexual health	85	90	90	90	100	100
Discuss my present anatomy	98	98	90	25	90	100
Request guidance or support in transitional paperwork	80	90	90	50	70	90
Discuss non-surgical gender affirming options (padding, tucking, binding, etc)	100	90	90	70	100	95

### Appendix I

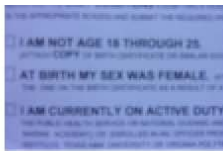
#### Paired Samples Statistics

		Mean	N	Std. Deviation	Std. Error Mean
Co-Researcher A	Pre	95.73	11	7.268	2.191
	Post	95.73	11	4.077	1.229
Co-Researcher B	Pre	90	11	0	0
	Post	74.09	11	23.96	7.224
Co-Researcher C	Pre	81.82	11	29.264	8.823
	Post	97.73	11	3.438	1.037

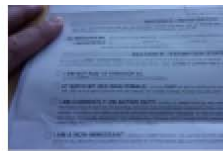
Paired samples statistics generated using Statistical Package for the Social Sciences (SPSS) software.

Appendix J

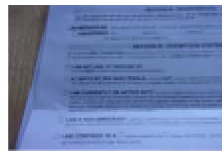
Complete Collection of Photographs Collected During Photovoice Process



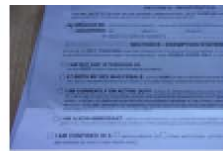
Draft Registration (2)



Draft Registration (3)



Draft Registration (4)



Draft Registration (5)



entering light euro toilet



Euro toilet door



Euro Toilet sign



Expanding VA



Food Bank (1)



Food Bank (2)



Food Bank (3)



Glucometer (1)



Glucometer (2)



Health Classes (1)



Health Classes (2)



Home Sharps



Homework grid



Letter for passport2



light euro toilet sign



Medication Regimen



Medications



Mom



musical health tech 2



musical health tech



Name Change



Opening Public restroom



OTC Treatments



Pattern



PP What to Expect



Public art 1



Puzzle



restroom numlock



Self administering T



skin



Social (1)



Social (3)



Social (4)



Social (5)



Statistics



Stuff (1)



Sunrise Solitude 1



Sunrise Solitude 2



Sunrise solitude 3



Sunrise Solitude 4



Swedish



T supplies



Testosterone supplies



Things to do sign



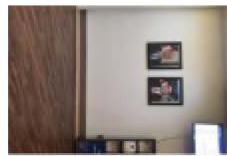
UV Treatment



VA Hospital



VA resources



VA Waiting Room



VM



water taxi



Whole Birth Certificate



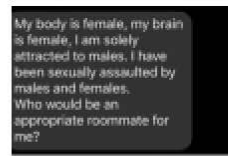
101\_0052



Bathroom Key



Birth Certificate Closer



body is female text



Breakfast



Bus



Census Sex Choices



Census sex definition



Cross Hormones 2



Draft Registration (1)