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Transgender perspectives on accessible primary healthcare : a mixed method study

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Transgender Perspectives on
Accessible Primary Healthcare:
A Mixed Method Study

ABSTRACT

This mixed method study was undertaken to explore and describe the transgender perspective of socially sensitive and medically competent primary healthcare provision. So far the focus of activists and researchers has concerned the barriers to care rather than positive models of the transgender healthcare experience. To gather viewpoints nationally from people of various transgender identities, an internet survey was conducted yielding responses from 116 participants from ages 18 to 72.

Quantitative data was gathered on demographic, gender identities and present healthcare access and quality. Qualitative questions were asked about positive models for accessible healthcare in four areas: office structure, staff behavior, primary healthcare providers' clinical relationship practices, and knowledge of transgender healthcare.

Key findings include importance of all healthcare providers and support staff addressing transgender people respectfully and sensitively by using their preferred pronouns and names; respectful and sensitive treatment is supported healthcare providers and support staff having or acquiring basic awareness and knowledge of transgender identities. Effective quality clinical relationships are built via healthcare providers' willingness to cultivate open and non-judgmental communication and by listening and learning from their transgender patients' specific individual health needs . Additional findings showed that while respondents valued their primary care providers having prior knowledge of transgender specific healthcare, they found their willingness

to learn more about transgender identity and the negative impacts of social and institutional stigma even more important.

TRANSGENDER PERSPECTIVES ON ACCESSIBLE PRIMARY HEALTHCARE:

A MIXED METHOD STUDY

A project based upon independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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Dedicated to the memory of my parents, Frank and Jane Coakley.

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Chapter I

Introduction

The Stonewall Riots of 1969 is popularly seen as the flashpoint that launched the Gay Liberation Movement. By the early 1990's, the movement evolved into the Lesbian, Gay, Bisexual and Transgender (LGBT) civil rights movement. Yet there is a challenging, compelling and cruel irony in the slow inclusion of the "T" with the "LGB" given who the NYC vice squad was targeting that June night at the Stonewall Inn, and who fought back: drag queens, butch dikes and teenage street queens (Rivera, 2002; Carter, 2004). All along, transgender, transsexual and other gender nonconforming people have long been in the frontlines of stigmatization and the vanguard of change. Not necessarily because they want to, but because they often have their backs to the wall, fighting to be recognized and treated as human beings. It was the 1990's when the transgender rights movement began to galvanize and build momentum, working to have rights to protection against violence, discrimination in housing, and jobs, and oppression based on gender identity, as well as access to healthcare.

Healthcare access and affordability has been center stage of public and political discourse in the United States intensely over the past couple of years. Even though this has been a long mounting crisis, healthcare access and affordability has especially been a prominent issue within marginalized and vulnerable populations. Celebrated transgender writer and activist, Leslie Feinberg wrote about the critical problems of access for transgender people, citing the example of her own denial of care, including being turned away in an emergency room when she had a

104 degree fever, specifically because of her transgender presentation (Feinberg, 2001). This concern is represented in a published symposium in the *Journal of Homosexuality* in 2008 that examined health care issues nationwide for lesbian, gay, bisexual, transgender and intersex (LGBTI) populations (Johnson, Mimiaga & Bradford, 2008). Therein it was noted transgender people have the highest rates of being uninsured, 21-25% among studies, with populations of people of color being disproportionally represented (p. 216). While lack of health insurance is a critical block to access to quality care, so is social and medical preparedness of health practitioners, agencies and staff who may serve transgender people. As was reported by Rachlin, Green & Lombardi in their 2008 study, the transgender population that had a high rate (82%) of having health insurance, yet had a lower rate of accessing care. In four studies that looked at different transgender populations, 12% to 30% of the participants reported their transgender identity was implicated as a reason for denial of healthcare services (Rachlin et al., 2008; Kenagy, 2005; Sanchez, Sanchez, & Danoff, 2009). The focus of LGBTQ community activists and researchers so far has been about barriers to care, with identity being central to the issue. Barriers to *good quality healthcare* for transgender people are the next major issues to be addressed. Yet looking at barriers alone does not describe what good accessible health care for transgender people might look like. Since issues of culture and identity are central in care provision being appropriate medically and socially sensitive, it is key that solutions are constructed, using an empowerment approach, from a transgender perspective. So addressing the problem of healthcare access from positive model building approach, what does socially and medically appropriate medical care look like?

This leads to the next question, why is healthcare a concern of clinical social work? Given that standards of care for transgender medical treatment, as set forth by the World

Professional Association for Transgender Health (WPATH), still require the involvement of mental health professionals, including clinical social workers, for medical access to transgender specific medical support, and given the social work profession's commitment to social justice and service to clients (NASW), this matter is a valid concern for clinical social workers. Because of this ethical and professional mandate, the purpose of this research is to identify, especially from a transgender perspective, what socially and medically appropriate care looks like. The next step in the process is to look at how relevant literature frames and informs the focus and method of this research.

A key concept in this research is defining what is meant by transgender. In broad terms, transgender refers to individuals who are assigned one gender at birth, and later determine their gender themselves as other than what was assigned at birth (Lev,2004; Johnson, Mimiaga,& Bradford 2008; Kenagy, 2005; Lambardi, 2001; Rachlin, et al., 2008; Sanchez, et al., 2009). There is no universal term that all people who may fit the above definition identify with, but transgender is the broadest term that comes up in all literature read for this research. It does not necessarily include or exclude a person due to use of hormones, gender related surgeries or shift in socially-lived gender identity (Lev, 2004, pp.87-90). The terms male-to-female and female-to-male were used in the studies examined for this research. Male-to-female (MTF) refers to a person who was assigned a male gender at birth and now lives as female, and female-to-male (FTM) refers to a person who was assigned a female gender at birth and now lives as a male. In many studies the term transsexual is used. Transsexual is most often used for individuals who have made social and physical changes via hormones and/or surgery. Many MTF and FTM individuals would use the term transsexual, though this is not universal. Though transgender is considered to be the most inclusive term possible, concern was expressed in the Philadelphia report (Kenagy, 2008, pp. 24) that some potential participants may have been excluded since they may have been unfamiliar with the term “transgender”. The Philadelphia report presented findings of two community health needs assessments with total of 182 respondents that were conducted by either mail-in surveys or face-to-face interviews. A Boston study on healthcare access, (Sperber et al, 2005), conducted four focus groups with a total of 34 transgendered individuals , worked with the terms “transgender” and “transsexual” and found inconsistent use of these terms, with complex overlapping identifications or abandonment of these terms, or preferred use of other gender terms such as “queer.” A recommendation that comes out this study is a better capture of terms and definitions of existing language to better guide appropriate usage of those involved in providing healthcare for people of all gender variations. A deeper discussion of terms and uses will be offered in future chapters. The closest to a unifying term for referring to individuals in this report is “trans” and will be used in conjunction with other words such as “trans people”, “trans person” or “trans folk”. This will include all people in this report that “transcend” gender in some way.

Studies reviewed for this research have examined the state of health care access for various transgender populations. All have been aimed to represent and describe the unmet needs of transgender people. Lombardi’s article (2001) in the *American Journal of Public Health* is a salient piece of advocacy within public health to improve transgender health care and includes a summary detailing seven strategies (p. 871). It is very comprehensive and worth restating in brief here:

1. Acknowledge the authenticity of transgender individuals and lives in all areas (policy, research and clinical practice).

2. Promote the view that discrimination and denial of services to transgender men and women will not be tolerated.
3. Allow young people some flexibility in questioning their gender.
4. Advocate for increased and better access to health care resources.
5. Advocate for cultural relevancy with research, policy, education, and prevention and direct care contexts.
6. Advocate for more and better promotion of transgender-related research and more innovation within transgender health care practices.
7. Advocate for greater awareness of intersex individuals and against practices of surgically altering children and infants for aesthetic reasons.

While it is important to continue to identify and document the barriers to care, this is the first step. What this does not show is the framework of what good health care for transgender people looks like. The next step is to develop a model of good access. A study on the efficacy of a brief curriculum intervention for second year medical students (Kelley, Calvin, Dibble & Robertson, 2008) to provide introductory cultural and healthcare knowledge for working with LGBT patients, showed a significant improvement in the students' *willingness* to serve these populations. While transgender people do face some similar and shared experiences of discrimination as do lesbians, gays and bisexuals, their experiences of discrimination are more profound and their health needs distinct. Still what is not provided are clear standards and expectations of best practices of engaging transgender people from their own perspective. The study of barriers illustrates what does not work, but it is short of building the solutions of what does work, so health providers can be prepared. This model can be informed by the study of barriers.

Yet the inclusion of what transgender people want or see as needed to open up access in healthcare provider relationships, from an empowerment and efficacy viewpoint appears to be a critical element in addressing the problem of access. This leads to the research question: what do transgender people see as characteristics of socially and medically competent and sensitive healthcare provision?

Chapter II

Literature Review

Coming to Terms with Gender Outlaws

Transgender is a term and a label that has been developed and informed from the confluences of history, culture, medical science, psychology, law and self definition. Over the last one hundred fifty years, within Western discourse, terminology used to label gender variant people keeps on evolving and has been inconsistent in use and meanings, reflecting the mores and bias and the academic or social locations of the users. Lev (2002) compares “the fields of sexology…the study of gender and sexual identity in particular” to “rubble of the Tower of Babel”. Examples of terminology within the early field of sexology are Richard von Krafft-Ebing’s ornately Victorian and pathologizing *Psychopathia Sexualis* or Magnus Hirschfeld’s less pathologizing “transvestites” as described within his theory of “sexual intermediaries”. Hirschfeld is associated with early examples of cross gender surgeries and hormone treatments at his institute in Germany, before fleeing Nazi repression (Stryker & Whittle, 2006). Harry Benjamin, a former protégé of Hirschfeld popularized and edified the term “transsexual”. In his 1966 book, written for a wide readership “The Transsexual Phenomena”, he laid out a continuum of “sex and gender role disorientation and indecision” running from the transvestites to “true transsexual”. Here Benjamin also presented a protocol for the medical treatment of the gender dysphoria of the transsexual via body modifying hormones and surgeries and psychotherapy. This laid out the basis of the professional guide for Standards of Care (SOC) for treatment of gender dysphoria. From this developed the Harry Benjamin International Gender Dysphoria

Association (HBIGD) which is now called World Professional Association for Transgender Health (WPATH). Benjamin, like Hirschfeld before him was an advocate for compassionate treatment of transgender people, but his guidelines lead to another phenomenon of transsexuals learning how to present as “true transsexuals” to receive the body modifications they desired. Thus transsexual has its origins in the medical model of with surgery as a solution to what has been framed as a psychological problem. So "transsexual" was created in the professional and academic realm with a formal meaning, yet over the last 40 years it has been used colloquially with evolving and inconsistent meanings. This reveals the gap between the formal academic discourse and the ordinary, lived experience of the transgender community.

There is much irony in the origin and development in the word “transgender.” In 1992, Leslie Feinberg, a Marxist, broadened the meaning and usage of "transgender" in hir[1] pamphlet *Transgender Liberation* as an effort to consolidate a movement against the oppression of people whose gender expression lies outside the “norm”, and it was offered as a term connoting pride. Here Feinberg astutely predicted that usage of terms for and by people of gender variant expression would remain “slippery”. Transgender as a term has so far endured and spread in use, as s/he framed it. It has become the default “umbrella term” for a variety of gender transgressive identities. The irony is in the narrowness of its beginnings. According to Stryker and Whittle (2006) transgender referred originally to preoperative (or non-operative) male to female transsexual. The 1980s coining was attributed to Virginia Price, the founder of the first national organization for cross dressers “Foundation of Personality Expression” (Stryker, 2008). It was in the 1990’s that transgender academic studies across disciplines took off in its usage. While the

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[1] Hir is the gender neutral pronoun, along with "ze" that Fienberg prefers to be addressed by.

term “transsexual” has its origins in the medical model of transformation from one sex to the opposite sex, transgender is associated with traveling across gender, implying that physical embodiment may not necessarily align with gender expression. It creates a space for those who may be transitioning but also for gender identities and expression that exists beyond the dichotomous concepts of woman and man. Yet Wilchins refers to the tension between transsexual and transgender identities, by pointing out that it matters who is "holding up the umbrella"(2002, pp. 59). Transsexuals are understood as transitioning from one gender to another by way of surgical, hormonal and legal interventions. Not all people who want to move from a gender are making these changes. In the mainstream Western culture that is deeply invested in the binary gender structure of men and women, it is the most accessible narrative to understand.

Gender under (de)construction. Dean Spade (2006) writes about his experience in the 1990's of confronting the conforming structures of the “real transsexual” narratives to receive the surgery he wants. This, of course, involved having to receive letters from a therapist, as laid out in the Harry Benjamin International Standard of Care (HBIGSOC), but is refused since his story did not fit. It also, leaves no room for those who do not want to fulfill expectations of transitioning fully and in the prescribed order to receive body modification or legal change of gender status. His therapist refused to cooperate with his transition since he did not want to reveal his transsexual status or his chest surgery to his foster parents as he was concerned it would he alienate them from him. Spade (2006) suggests that transsexuals, as a group, may not be willing “gender defenders”, but some are put in the place of conforming to especially rigid expectations of what a proper transsexual is in order to receive the modifications they want. The emotional, social and financial costs are high and the choices are difficult. There are many ways people experience, perceive and express their gendered selves that push the binary concept of the either/or of men and women, but are not necessarily in opposition with the gender they were given at birth. Some of the choices are informed by what is practical, workable or even financially accessible.

Gender Broken down.

> The reason that “normals” do not walk around questioning the gender attributions they make or wondering whether people see them as they “really” are, is not because gender is a given, but because gender variance is an incorrigible proposition. Rather than violating invariance, people use what might be seen as discrediting information to reflexively support the proposition. “I know that Greta has a penis, but that’s irrelevant because she’s really a woman.” All of us, transsexuals and “normals” alike, are in as little danger of not being able to be seen as what we “really” are. It is our method of applying information which maintains our gender, not some intrinsic quality of our gender, itself. (Kessler & McKenna, 1978, pp 161)

> If gender is a kind of a doing, an incessant activity performed, in part, without one’s knowing and without one’s willing, it is not for that reason automatic or mechanical. On the contrary, it is a practice of improvisation with a scene of constraint. Moreover, one does not “do” gender alone. One is always “doing” with or for another, even if the other is imaginary. (Butler, 2004, pp 1)

Whatever happened to men and women? Benjamin in his introduction to “Transsexual Phenomena" (1966) stated that to “the simple man on the street, there are only two sexes” and goes on to explain that closer examination of this binary assumption reveals more complexity. Much has transpired and evolved in popular discourse on “the sexes” and assumptions about men and women in regards to roles, status, behavior and language in forty years hence. While the popular notion of the woman/man dichotomy does persist as dominant, the attributes of what constitute man or woman are far less rigid then when Kessler and McKenna conducted their research on how gender is attributed. Still those confounding the gender binary, continue to present an “incorrigible proposition"(Kessler& McKenna, 1978), that is still volatile, contested and potentially dangerous for the beheld, such as a perceived male body in a dress.

Taking a step back, the above paragraph slips from the use of “sexes” to “gender” in references to “men and women” interchangeably and problematically, when sex and gender are separate and distinct. Here we encounter Lev’s Babel reference of inconsistent meanings and uses of words. Formally though, sex refers to biological and anatomical features related to reproductive functions. Gender is the appearance and behavior that is associated with, but independent of the biological and anatomical. Gender fulfills a cultural expectation of what is feminine and masculine, which varies greatly over context. Still, commonly the terms sex and gender are used interchangeably (Kessler & Mckenna pp.197). Gender is associated with biological sex. Biological sex is assumed to be dichotomous. The assumption that one is either male or female, with chromosomes of XY or XX, complementary reproductive organs and distinct, dichotomous secondary characteristics such as beards, breasts, higher or lower pitched voices, is disrupted by the reality that intersex bodies can have mixtures of these aspects. Gender is more than biological sex. Additionally, biological sex is not as clearly dichotomous nor are all features regularly included and accounted for on all bodies.

Biological sex is only one of the components of gender. Butler (2004) states that gender is a “doing”. More specifically she calls it a performative act that involves an “other” either present or imagined. In varied literature gender has been parsed out into the additional components of gender identity, social role, presentation, performance, sexual orientation and gender assignment and gender attribution. Gender identity is how one thinks of oneself, as Bornstein puts it “who am I” (1993, pg 24). Social role or gender role is how one functions to fulfill one's societal notion of a particular gender; this is comprised of behavior, social position, sexual orientation, presentation, and how one’s gender is attributed by others as either feminine or masculine. Presentation refers to how ones outward appearance, including physical form and features such as build or even voice, as well as clothing. Performance is how one acts or behaves which encompasses subtleties of gaze or gesture to activities that have gendered associations such as being a soldier in combat or caring for infants. Sexual orientation is whom one is attracted to, with the dominant assumption that one is attracted to the “opposite sex”. Gender assignment is the gender given at birth, determined by a medical provider, based usually on external genitalia. Gender attribution is the interpretation of cues drawn from the various components listed above by another person. In the findings of by Kessler and Mckenna (1978), it took four female attributes to outweigh perceptually one male associated attribute. An example would be person in a frilly dress, a high pitched voice and breasts and beard would be perceived as male.

What It Takes To Go To The Doctor.

Four empirical studies were examined that described the problems in health care access and practice and, embraced much of the seven strategies outlined by Lombardi (2001) in the *American Journal of Public Health*. The studies had different ways of representing the kind of access to services participants had. In the FTM national study (n=122) 82% had health insurance compared to the New York City study (n=101) with 77% having health insurance. The Philadelphia combined study (n=173) reported as not asking this question, yet of the 173 respondents 67.1 % did have a primary care physician. In measuring access barriers, the Philadelphia study 26% of the combined respondents reported denial of care. In the NYC study 25% reported “a paucity of transgender friendly …knowledgeable providers” (p 713). The national FTM study does not statistically describe the denial of services directly, but does briefly discuss the dynamic of the anticipation of prejudice or ignorance in seeking care for their transgender bodies. This same dynamic is qualitatively reflected across the four focus groups in the Boston study (n=37) as a common experience. Also reported qualitatively in the Boston study was how some health insurance policies specifically exclude transgender care such as cross gender hormone use and SRS procedures. This is at the heart of the problem that Feinberg writes about in the *American Journal of Public Health,* which raises questions about what can be done to build new roads to access specifically for transgender people.

The studies had different sample biases that were tied to how and where outreach was conducted. In Kenagy’s (2008) combined report on findings in the greater Philadelphia area, the varied sampling methods yielded a wide socioeconomic demographic as well as a broad spectrum of transgender presentations, as compared to the other studies examined, but likely reflected an urban population. The NYC study demographic had a strong bias to the homeless and lower socioeconomic groups, since two of their three outreach sites were general community programs for mainly homeless or near homeless people. Though the national FTM study did not gather socioeconomic data, a bias was reported by the researchers (Rachlin et al, 2008, pp. 254), as the sample method engaged a more socially advantaged cohort- those who had the resources to travel to a national event and had access to the internet. The Boston study (Sperber et al, 2005, pp. 88) reported that data may have been influenced by the nature of the data collection via group discussion, since many of the participants were known to each other from the transgender community, thus perhaps being less open about some personal information. A possible bias was reported in the NYC study about face-to-face interviews participants giving answers more “socially desirable than their actual experiences (Sanchez et al, 2009, pp. 718). This may also have played a role in the part of Philadelphia study where data was collected by trained interviewers from within the transgender community.

Though transgender is considered to be the most inclusive term possible, concern was expressed in the Philadelphia report (p 24) that some potential participants may have been excluded since they may have been unfamiliar with the term “transgender” or its variations in that paper survey. The Boston study worked with the terms “transgender” and “transsexual” and found inconsistent use of these terms, in the complexity of overlapping identification or abandonment of terms, or use of other gender terms such as “queer.” A recommendation from this study is to gather more precise understanding of community use of identity terms to better guide appropriate usage by health care providers of people of all non conforming gender identities.

All studies reported problems of access or quality of care. Most egregious were the reports of access denied either due to lack of practitioner knowledge of transgender specific health needs or refusal of care due to being transgender. The studies do overlap and share design features, and especially sharing the feature of looking at what bars access, with all indicating that a transgender presentation is implicated as a barrier. A common challenge in all of these studies is a wider outreach to this hard to access population. It is not known what proportion of the

American population may be transgender. Socioeconomics, race, geographic location and population density also are important factors for access to and the quality of health care for all living in the United States. More development of this information is also needed in understanding respondents' experiences and challenges.

The purpose of this research is to contribute to the development of a positive model of what medically and socially sensitive healthcare provider relationships would look like from the perspectives of trans people, with a focus on primary care providers. Research thus far about healthcare access has been framed to look at the barriers to care, which has indicated the problem of socially insensitive and medically unprepared practices of healthcare providers. The next chapter will describe the methods of the study informed by the literature reviewed to research the query of what this positive model of health care provision looks like from a transgender perspective.

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Chapter III

Methodology

Introduction

Transgender people suffer many indignities and dangers socially, emotionally, physically and politically. Research on transgender experiences of healthcare have largely focused on barriers to care. Consistent in the studies about health care access for this population is the focus on barriers to care. Missing in this growing body of research thus far is the affirmative transgender perspective of a receptive and prepared health care model, as the focus has been on barriers and mistreatment. Given that primary care providers are at the frontline of guiding people in their general overall health, they are the health providers that this research project focuses on. The purpose of this research is exploratory and descriptive, underpinned by the stance of empowerment. Thus this study looks to gather the perspectives of transgender people to help develop positive model of care for socially and medically prepared primary health care providers.

Much attention is given to health care needs in gender transitioning. While it is critical to identify and remove barriers to care, and assure care for the transition process, there is a great need for further development of a positive view of welcoming and prepared healthcare overall. Yet trans people need access to primary healthcare providers to for their general healthcare needs, also. To do this effectively, a broad transgender community perspective is key in the development of a positive and effective model of care for trans people. Therefore, the aim of this research is to add to the developing model of effective and sensitive care generated from qualitative input from the transgender community. This research used mixed method in an anonymous Internet survey across the United States that was created for this study. The survey purpose was to elicit input on expectations and needs in care provision by primary health care providers from trans people’s viewpoints via open-ended questions from a broad demographic of people across the United States. The survey has four sections: 1.) general demographics, 2.) health care access and quality, 3.) gender and 4.) key narrative questions. There were four narrative questions each addressing areas of provision of care by primary health care services: setting, support staff, provider practices, and provider knowledge. This chapter describes the research methods used for this study, covering sampling, data collection and data analysis procedures employed.

Sample

The sample for this study was a non-probability, convenience snowball technique using the Internet as outreach for this online survey. All participants had to affirm that they were at least 18 years of age and reside in the United States of America. They also had to affirm that they identified as a different gender than was assigned to them at birth. This third qualifying question was framed to include the widest possible variety of transpeople. The word "gender" was selected rather than "sex". The word "sex" in this context connotes whether one's physical presentation, especially genitalia are recognized as typically and female or male. This is basic method of sex assignment at birth. This researcher chose "gender" to include intersex people, whose physical presentation was unclear to medical providers at their birth and thus were assigned a "gender". While intersex is a distinction from transgender by etiology, they are not mutually exclusive. A transgender person can be intersexed and an intersex person can be transgendered, and both face similar oppressive forces of rigid gender expectations the path to authentic representation of their gendered self (Kaldera, 2002).

Data Collection

The survey instrument used was generated by this researcher specifically for this project. It was sent out to colleagues active in various segments of the trans community for critique. Adjustments were made accordingly. The survey, as seen in Appendix C had 28 questions, after the three qualifying questions. Survey Monkey was used to create the survey, and distributed and gather data of the returned anonymous surveys. One of the functions of the Survey Monkey survey software allow for "skipped" questions. This survey design did not allow for "skipped" questions until after the first qualifying questions and consent form was affirmed. After these qualifiers, respondents could skip questions. The first 21 questions were demographic, gender descriptive, or about present health care access, using yes/no, multiple choice and Likert scale formats. The final four questions were open-ended to elicit descriptions of accessible and positive models for engagement in primary health care setting and interactions, from the person's served perspective.

The anonymous survey was distributed on the Internet and hosted through Survey Monkey. Initial efforts were made to send out the recruitment email on list serves that served trans and queer identified communities of which the researcher was a member. The recruitment email was also sent to colleagues who had many contacts in the trans and queer identified communities nationally. This outreach effort was initiated on February 5th and 6th. On February 14th, the survey had met the then set target of 100 respondents that automatically barred new recipients. Emails came in to researching expressing disappointment that the survey was closed. The survey was reopened and reset to close on the date of March 10, 2011. Given this response, no further efforts were made in outreach. In total there were 145 respondents, of which 103 completed the survey and 88 answering all questions on the survey. The speed by which the survey reached 100 respondents came as a surprise, so no further outreach efforts were made. This made for a departure from the proposed recruitment process that also included outreach to organizations for recruitment, with the possibility of participants using Internet access at these sites of the organizations to include those who would not have access otherwise. This was intended to broaden the socioeconomic representation of respondents.

This study had only three intentional limitations to characteristics of participants. First, they must be at least 18 years old; second, be residents of the United States of America; and thirdly, they must identify as having a different gender from the assigned to them at birth. The third qualifier was designed be as open as possible to welcome the widest possible sample of gender identity. Important to this study was to be open and welcoming to a broad continuum of gender identities. Reliance on the Internet for the survey did create unintended exclusions. The Internet is less accessible to those of fewer social and economic resources, as well as, those in rural settings where broadband access can be markedly lacking. Another limitation was that participants needed to be comfortable with reading and writing in English.

Data Analysis

Data was cleaned of surveys that did not answer yes to the first three qualifying questions and agree to the informed consent, or did not answer any questions after these, thus generating the sample 131 participants. Of this group, three did not answer any questions beyond the consent and twelve only answered the demographic questions (comprising a quarter of the total survey questions), so were cleaned from the data set, leaving remaining n=116.

The next 21 questions were demographic and/or descriptive of access and experience in the primary care setting. The data was exported from Survey Monkey and sent to Marjorie Postal for assistance with quantitative analysis, where frequencies for run for descriptive analysis of, including mean, mode and median. The final four narrative questions were analyzed in isolation from any identifying information and reviewed for developing themes. Where necessary, text was edited for quoting in the report for clarity only. The chapter on Findings will provide detailed survey results qualitative data and analysis of the response to research question of the trans person view of positive health care access.

Chapter IV

Findings

Introduction

The purpose of this study is to explore and describe what transgender people see as socially and medically competent and sensitive primary health care providers. To gather viewpoints of trans people across the United States a survey was created that inquired: What elements of a physical office space support you feeling welcome and at ease? What could support staff say and do to support you feeling welcome and respected? What practices of your health care provider provide dignified and respectful treatment and support open communication about your non-gender and gender related needs? What do you expect a provider to know about transgender medical and physical needs in order to treat you or support you getting appropriate, timely treatment from a specialist?

This chapter will present the major findings yielded from this study starting with a report on respondents' demographics. This will be followed by respondents' status of their present health care access and the report on their assessment of the quality of their present healthcare. The final section of this chapter will present the findings of the four narrative questions: 1) accessible and welcoming medical office setting; 2) best practices of office support staff; 3) best practices in clinical relationship and communication of healthcare provider; and 4) expectations of primary healthcare knowledge of transgender medical and physical needs.

Demographics

For this study there were 145 respondents. Of these, 131 met the three qualifications: 1) be at least 18 years old; 2) reside in the U SA; 3) identify as a different gender than was assigned at birth and also accepted the consent agreement. Of this group, three did not answer any questions beyond the consent and twelve only answered the demographic questions (comprising a quarter of the total survey questions), so were cleaned from the data set.

Age, race and ethnicity. This created a data set from 116 qualified participants, as seen on Table 1 on page 23. These participants ranged in age from 18 to 72 years old, with 62 participants (53.5%) between 18 to 31 years, and five (4.3%) 67 years and over. In this sample, 88.7% (110) identified as White when offered nine choices of race: Native American, Afro American, Indian, Latin or Hispanic, Pacific Islander, Asian, Multiracial, Black, and White. The balance of those selections were eight (6.7 %) Multiracial, one each of Native American (0.8%) and Black (0.8%). Given the limited choices of race, this question was followed by an open-ended question on ethnicity to give participants another opportunity to more richly represent their social identity. It is difficult to briefly summarize the findings on ethnicity, given the complexity of possible interpretations and meanings held by respondents. Ethnically, 82 (70.7%) identified as having some variation of European heritage, seven identified as Caucasian, four as White, three as simply "American" and seven as "mutt, mixed or even "???". Looking at the samples choices across racial and ethnic identities, those selecting Black (1), Native American (1), or Multiracial (7), Multiracial offer some rich identities: Chinese American, Caucasian/Filipino, Hawaiian, black/Mexican, Mixed Blood White and Nez Perce, White US and Nez Perce, and Multi-ethnic. It is interesting to note that two participants, who selected

White for race, described their ethnic identity as: Black/White/ Cherokee, White/Native American/Asian, suggesting a complexity of identity, social engagement and lived experience.

Table 1

Age in intervals of 7 years	***Frequency***
18-24	32 (27.6%)
25-31	30 (25.9%)
32-38	12 (10.3%)
39-45	10 (8.6%)
46-52	7 (6%)
53-59	10 (8.6%)
60-66	10 (8.6%)
67-73	5 (4.3%)
Race	
Native American	1 (0.9)
Multiracial	8 (6.7%)
Black	1 (0.9%)
White	106 (89.1%)

Locations. Participants were asked select their state of residence from a dropdown box. Findings on frequency and percent are displayed in Table 2 on page 24. This sample represents 24 states with 33.6% (39) residing in Oregon. The next most well represented states are: Massachusetts 10(8.6 %) Washington 9 (8.4%) and Vermont 7 (6%). Looking at larger patterns the West Coast and then East Coast dominated this internet snowball sample that was initiated in Vermont. The West Coast as comprised of Oregon, Washington and California represented 46.6% (54) of the sample. The East Coast representing 34.5% (40) is comprised of: Connecticut, Florida, Georgia, Massachusetts, Maryland, New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, Vermont, Virginia. The remaining nine states: Alabama, Arizona, Colorado, Illinois, Minnesota, Montana, Tennessee, and Wisconsin covered a broad area of the central states and representing 19% (22) of the sample.

Table 2

States Represented	***Frequency***	
Alabama	1	(0.9%)
Arizona	6	(5.2%)
California	6	(5.2%)
Colorado	3	(2.6%)
Connecticut	2	(1.7%)
Florida	6	(5.2%)
Georgia	1	(0.9%)
Illinois	2	(1.7%)
Maryland	1	(0.9%)
Massachusetts	10	(8.6%)
Minnesota	2	(1.7%)
Montana	1	(0.9%)
New Jersey	1	(0.9%)
New York	3	(2.6%)
North Carolina	1	(0.9%)
Oklahoma	2	(1.7%)
Oregon	39	(33.6%)
Pennsylvania	2	(1.7%)
Rhode Island	3	(2.6%)
Tennessee	1	(0.9%)
Vermont	7	(6 %)
Virginia	6	(5.2%)
Washington	9	(7/8%)
Wisconsin	1	(0.9%)

Further findings on location came from responses to the question about the distance from the nearest city of 100,000 or more? This survey question offered four selections: a) Less than an hour, b) 1-2 hours, c) 3-5 hours, d) more than 5 hours. This purpose here was to determine the likelihood of respondents living in an urban setting (a) or suburb (a or b) or suburb to rural (c or d).The findings to this are in Table 3 on page 25. With the entire sample responding, 76.7% (89) selected that they were less than an hour from for a city and none selecting five or more hours. Only 8 (6.9%) selected 3 to 5 hours, so it is likely few were in a rural setting. Living near or in a population center suggests a much more diverse and rich selection of health care choices. This does not always work as Leslie Fienberg's example of extreme discrimination and denial of services happened in New York City and Jersey City.

Table 3

Distance from city of 100,000		
Less than an hour	89	(76,7%)
1-2 hours	19	(16.4%)
3-5 hours	8	(6.9%)
More than 5 hours	0	

Employment and education. The survey asks "Yes" or "No" for employment and one choice of four on educational level as seen on Table 4 on page 26. This sample has a high rate of unemployment 37.1% (43) even in these difficult economic times. Also it is notable how few respondents 0.9% (1) reported high school completion as highest attainment. Examination of employment in terms of age, four or the five participants over 63 years were no employed, which is a traditional age for possible retirement. Looking to the other end of the age, with so many under the age of 25, this researcher looked at the traditional college age participants for level of employment since "in school" was not a choice in the survey. Of the unemployed, 3 under the age of 23 years and reported "some college". Suggesting an adjustment for retirement or traditional aged student status of 8 participants, there would still remain a 30.2% (35) level of unemployment. At the same time, sample-wide, 33.6% (39) have Bachelor degrees and 20.8% (23) have Post Graduate degrees. Within this sample with Bachelor degrees, the unemployment rate is 28.2 % (11) and for those with Post Graduate degrees the rate is 26.1 % (6). Health insurance is very tied to employment at this time in the US and thus influencing the kind and quality of health care access.

Table 4

Currently Employed?	***Frequency***	
Yes	73	(61.3%)
No	43	(37.8%)
Education Completed		
Post Graduate	23	(20.8%)
Bachelors	39	(33.6%)
Some College	53	(45.7%)
High School	1	(0.9%)

Dimensions of gender: Identity, physicality, and lived experience. This next and final section on demographics will look at the data that dimensionally describes the gender of this sample, since the binary of male or female, or even the inclusion of "transgender" would be insufficient, or invalidating to the complex and diverse identities of participants. How participants experience, view and express their gender is explored in the seven questions about gender.

The first two questions are about gender identity. For these two questions there were two purposes: to develop a profile of the complexity of gender identity of the participants, and to gather terms and perspectives on usage of terms, since both are evolving rapidly with varied meanings and use. In both these questions it was possible to make multiple selections, recognizing that participants may find more than one choice positive and appropriate. The first question asked: "What pronouns to you prefer to be addressed by?", with four selections of pairs of pronouns and an open "Fill in" response, as seen in Table 5 on page 27. All participants selected at least one pronoun set. Sixteen chose more than one set of pronouns and up to five sets. The most chosen pronoun set was "He or him"(49.6%), and always chosen along with at least one other set of pronouns. A close second was "She or Her", (45.9%) selected four times along with "He or Him". Sixteen chose more than one pronoun set (13.4%) Three participants responded in the open-ended write-in with:"Not sure", "prefer when people switch" and "ze or zyr". The second question asked of participants was "Choose all terms that respectfully and positively name or identify your gender". (See Table 6 on page 28.) The survey offered a

Table 5

Pronoun Sets	***Frequency***	
She or Her	54	(45.4%)
He or Him	59	(49.6%)
They or Their	19	(16%)
Ze or Hir	10	(8.4%)
Total Write-in Responses	3	(2.5%)
Total Selections Pronoun sets	145	
Participants more than one set	16	(13.4%)

selection of 19 terms and a space for write-ins. There was no missing data for this question. There was much overlap in the selections, with 110 respondents choosing more than one term out of a sample of 116. The total sum of terms selected across all respondents is 576 selections. The mean for terms chosen for entire sample is 4.8 terms per respondent. The most frequently chosen term was "transgender", with 78 selections representing 65.5% of the total sample. The next three most chosen terms "trans person"(59 at 49.6 %), "queer"(47 at 41.61%), and "transsexual" (49 at 43.4%) are all gender neutral. Fifth and six terms, "woman" and "man" were choose by 40.3% (48) and 36.7% (46) of the sample, are notably close at less than 4% apart. At the same time, in the breakdown of the six respondents (5.2%) who only made one term selection, three selected "woman", two selected "man" and one "gender nonconforming". Looking more deeply into the data to find those whose identity is beyond the binary of

Table 6

Gender Identity Terms	***Frequency***	
Transgender	78	(65.5%)
Trans person	59	(49.6%)
Queer	47	(41.6%)
Transsexual	49	(43.4%)
Woman	48	(40.3%)
Man	46	(36.7%)
Transman	46	(36.7%)
Transwoman	38	(31.9%)
Gender nonconforming	33	(27.7%)
Gender variant	33	(27.7%)
Genderqueer	30	(25.2%)
Gender Fluid	15	(12.6%)
Boi	10	(8.6%)
Grrl	5	(4.3%)
Drag King	3	(2.6%)
Transgenderist	1	(0.9%)
Cross Dresser or Transvestite	0	(0%)
*Write-in Responses(multiples)*singles below table*		
Trans	2	(1.7%)
Transmasculine	2	(1.7%)
Details of term selections		
Respondents choosing more than one term	110	(94.8%)
Sum total of term selections including write-ins and mean for total sample	576	
Respondents Who:		
Chose only one term	6	(5.2%)
Chose only "Woman"	3	(2.6%)
Chose only "Man"	2	(1.7%)
Chose only "Gender nonconforming"	1	(0.9%)
Did not chose "Woman" or "Man"	22	(18.5%)
Within this group chose only gender neutral terms	16	(13.4%)

*Single Responses To Write-in Terms: A Lady, boy, guy, co-gendered, Fairy, Female, FTM, Genderfuck, none of the above, Trans masculine genderqueer, agendered, Transguy, Tgirl, me, Human, Person/Individual.

"woman or man", 21(17.6%) respondents did not choose either of these two terms. Within this data set, sixteen of these respondents (13.4%) selected exclusively gender neutral terms: transgender, trans person, queer, gender nonconforming, gender variant, genderqueer, gender fluid. It is notable that there is only one selection each of "trangenderist" and "drag queen" and no selections for "cross dresser" or "transvestite", strongly suggesting these as not "positive" or "respectful".

The findings for the next five questions on gender are represented in the next two Tables 7 and 8 found on pages 30 and 31 respectively. The purpose of these questions was to portray the lived social experience and the physical presentation of the respondents in each table respectively. The social experience offers a sense of the global interactions the world, where gender is often tacitly negotiated yet matters profoundly, especially when gender expectations are not met. The questions on physicality are important in this study, since one may not have deal with these matters socially, but it is a tender matter in the doctor's office. It is central in the upcoming findings of the narrative question. Also this data rounds out a sense the gender demographic of the participants. Table 7 shows the results to the multiple single choice question: "How much time do you spend socially in a gender other than the one you were assigned at birth?" with 72.3% (86) selecting "All of the time" and 10.1% (12) "Most of the time". Combined 83.4% of participants largely are living socially in a gender that better reflects their gender identity. In the next question, a "Yes" or "No" choice to "Have you legally changes your name?", 59.7% affirmed they had.

Table 7

Social gender lived	***Frequency***
All the time	86 (72.3%)
Most of the time	12 (10.1%)
Sometimes	12 (10.1%)
Very little of the time	8 (6.7%)
Never	0
No Response	1 (0.8%)
Legal Name Change?	
Yes	71 (59.7%)
No	45 (37.8%)
No Response	3 (2.5%)

Table 8 (page 31) displays the amount of physical change that participants have taken on to live their gender identity in a more satisfying manner. The first question in Table 8 was a single selection of a multiple choice to answer "Some people transition physically from the gender given at birth to a different gender. Choose what best describes your experience:" Findings are 47.9 % (57) of respondents are in transition and 30.3% (36) have completed transition, combined represents 78. 2%. This supports the finding for socially lived gender from Table 7 of 83.4% for this sample, as socially lived experience is often begins before any physical changes. Additionally not everyone one is interested in making physical changes as in the 4.4% (4) represented here or can be due to unavailability of services or the cost of services. The answers to the next two and final questions on gender "Yes" or "No" question fit this portrayal. For hormone use 75.6% of the participants (90) affirmed this, with only two not responding. Answering "Yes" to having had "Gender Related Surgery" were 42% of respondents (50). This also confirms this profile that is developing for this sample. In the transitions query, 36 had completed physical transition, which often includes surgery, but not always. Additionally 57 were in transition which would be the period when people maybe having or between various surgeries. While some are not interested in changing physical features, surgery also can be inaccessible due to the lack of affordable, effective, and good quality surgery. This is repeated theme in the qualitative findings.

Table 8

Physical Transitions	***Frequency***	
Not interested	4	(4.4%)
Thinking about it	12	(10.1%)
Planning for it	10	(8.4%)
In transition	57	(47.9%)
Transition complete more than a year ago	36	(30.3%)
No response	0	
Hormone Use		
Yes	90	(75.6%)
No	27	(22.7%)
No response	2	(1.7%)
Gender Related Surgery		
Yes	50	(42%)
No	68	(57%)
No response	1	(0.8%)

Healthcare profile of access and quality. Before presenting participants with the key questions of what they see as socially and medically competent and sensitive primary health care providers, they were asked provide about their present access and quality of experience in health care. Of these next two sections, Access and Quality has 3 questions, first with a Yes/No question and two are multiple choice that allowed for more than one selection. The next set of three on Quality are all Likert scale. Both sets of questions are to contextualize the responses in the final and upcoming section and to put this study in the context of other studies that have explored health care access of Trans people. This research did not see any studies that asked about kinds of primary care access and quality of experience in particular. Nor has this researcher seen a study that offers any kind of description of the kind of health insurance that participants have. See corresponding Table 9 on page 33.

Healthcare assess. The first question in this section asks: "Do you have health insurance?" with a "no or yes" answer. With all participants answering, 74.8% (89) affirmed they had health insurance. The remainder, 25.2% (30) reported not having insurance. The national average of uninsured people according to the Kaiser Family Foundation in 2009 was 15.1 %, which suggests a 10.1 % gap. The next question asked participants to choose "Source[s] of health insurance, check all that applies", with six general categories of health insurance presented. Ten respondents (8.4%) selected two sources; all others chose one source of insurance. Health insurance is frequently an employment benefit. Yet only 40% had their source of health insurance clearly through employers, in these cases 34 via a private employer (28.6%) and 14 (11.8%) via Government employment (Federal, State or Local). Two forms of insurance, Government (Medicaid, Medicare and Tricare) and "Through a family member" are not linked to present employment, were chosen by 47 (39.5%) of the respondents. The remaining form of insurance "Private Insurance" was chosen by 13 of the respondents (10.9 %), which is accessed independent of employment. All respondents with private insurance are employed, and four of these also selected an additional source of insurance. Of the 30 that reported not having any insurance, 7 (5.9%) went on to select an insurance source in the survey. It is not clear to this researcher whether to interpret this as an error by the respondent or a problem with insurance (i.e. paying for services). A different set of seven respondents (6%) reported not being employed and not having health insurance.

The third question was "What medical care provider do you use for your primary medical care? Select all that apply." Out of the sample, 70 (58.8%) selected more than one choice, with 7 selecting none (6.9%) Five of the selections were some form of Primary Care Physician: Primary Care Physician, General Physician, Family Practitioner, Naturopath and Internists. In total, these were selected as a group 134 times across the sample. Two other selections were Physician's Assistant and Nurse Practitioner, with total of 26 selections. Other two were Endocrinologist and Gender Specialist, with total selections of 39.

Table 9

Health Insurance Status	***Frequency***	
Yes	89	(74.8%)
No	30	(25.2%)
Source of Health Insurance		
Private Employer	34	(28.6%)
Private Individual Insurance	13	(10.9%)
Through a Family Member	23	(19.3%)
Gov't Employment (Federal, State, Local)	14	(11.8%)
Gov't (Medicaid, Medicare, Tricare)	24	(20.2%)
Selected Two Sources	9	(7.6%)
Selected None	26	(21..8%)
Health care Provider Type		
Primary Care Physician	75	(63%)
General Practitioner	22	(18.5%)
Family Practitioner	14	(11.8%)
Internist	8	(6.7%)
Physician's Assistant	8	(6.7%)
Nurse Practitioner	18	(15.1%)
Naturopath	15	(12.6%)
Endocrinologist	20	(16.8%)
Gender Specialist	19	(16%)
Selected more than one	70	(58.8%)
Not select traditional PCP*	3	(2.5%)
No Response	5	(4.2%)

*only selected Endocrinologist or Gender Specialist as Primary Care Physician

Healthcare quality. The last three questions in this section focus on recent experiences related to quality. The format for these questions was a five point Likert scale, with lowest quality at 1 and the highest as 5. To the first question" How would you rate the level of respect and appropriate behavior by your primary care provider?" 114 responded with a mean value of 3.9, not factoring the two non responses. To the next question "How would you rate the overall quality of the social interaction with your primary care provider's support staff (may include receptionist, office staff, medical assistants and nurses)?", again 114 responded with a mean value of 4.1, not factoring the two non responses. To the final question in this section "How would you rate the preparedness and appropriate medical knowledge of your primary medical care provider?" 113 responded with a mean value of 3.9, not factoring in the three non responses. Summing up the group means on quality of 3.9 (Physician interaction), 4.1 (Staff interaction), 3.9 (Provider preparedness/knowledge) portrays this sample as mostly satisfactory experiences with their health care services. Findings are in Table 10 below.

Table 10

Respect/appropriate behavior by Provider		***Frequency***	
1	Lowest	2	(1.7%)
2		8	(6.7%)
3		17	(14.3%)
4		31	(26.1%)
5	Highest	56	(47.1%)
No Response		2	(1.7%)
Interaction with Support Staff			
1	Lowest	1	(0.9%)
2		7	(5.9%)
3		16	(13.4%)
4		41	(34.5%)
5	Highest	49	(41.2%)
No Response		2	(1.7%)

Preparedness/Medical Knowledge of Provider	
1 Lowest	2 (1.7%)
2	11 (9.2%)
3	25 (21%)
4	37 (31.1%)
5 Highest	38 (31.9%)
No Response	3 (2.7%)

Narrative Findings.

The last section in the survey contained four open-ended questions. At this point 13 of the participants left this part blank. Impact on the demographic of these 13 was on race: 13 white, 13 30 years or less, 9 from the West Coast, and 9 with some college. Two others did not answer two questions each. This narrative data represents findings from 101 who responded to all four questions and 2 answering either question 25 and 26 or 27 and 28. Even with the absence of these respondents in this key section, the voices reflected in is these findings are still biased to those of more privilege: by being mostly white, having more education and living in or close to more urban settings, thus closer to richer medical and social resources. It is noted here that these respondents, in their evaluation of their present health care provision gave it an overall high rating of 4 on a 5 point scale. Respondents' answers drew from their successful experiences with providers and their clinical staff, and welcoming surroundings that were to be expected given the level of satisfaction, which tracks roughly with the Likert scale data. Respondents also drew from sometimes deep dissatisfaction that they managed and coped with or that have kept them from services altogether. Lack of affordable care, fear of humiliation, experiences of discrimination may have colored what accessible care could be like. Many themes and concerns overlapped or were repeated across the four narrative queries. Often respondents would address an area that would be addressed in the next question. For this narrative section findings area presented in four sections: 1) Accessible and welcoming medical office setting; 2) Office and Support Staff Interactions; 3) Medical provider's exam room manner; and 4) Medical provider's knowledge of transgender care. Questions to these four sections can be seen in Appendix B on pages 71 and 72.

Accessible and welcoming medical office setting. The major themes found for this first open-ended question will be presented here in the order of the frequency discussed by participants. Minor themes will be brought in as they provide useful caveats and nuance to the findings. The most frequently repeated item that made for a welcoming medical space was restrooms, specifically either gender neutral or single stall restrooms. This was distinctly named and described by 15 respondents. This item was not suggested in the original question.

The next most frequent item under this heading was forms for intake and medical history, which were suggested in the prompting question. Forms had six different aspects that were discussed. As a group of items they comprised 53 responses, yet with many respondents touching on two to four of these aspects. Two aspects of forms most discussed were the inclusion of space that allowed for more gender representation besides "male" or "female", allowing for other bodies and identities, and to provide space to record preferred pronouns and names. These key points were tied to many other issues and concerns at the office, extending to interactions with staff and medical providers, as well as, concerns with communication and coverage/payment issues with medical insurance. In line with gender and forms, next was a place to write in what body parts they did have and how the person wanted them referred to. Female bodied, masculine persons had the most to say about this. For example, it is most difficult and awkward for a trans man have his bound chest referred to as breasts. Other recommendations were for a space to write in transgender status, so specific descriptions of social and physical aspects of a person could be presented, including non-binary or androgynous presentations being presented as stable and intentional. A number of respondents asked for a space within a form to make clear the distinction of their representation of gender in the medical clinic and gender representation for insurance companies, as to be consistent with the insurance carrier records. This distinction was to address the risk of a person not having coverage for various procedures or care. An example of this could be coverage for a pap smear for a trans man. This is the tip of larger issue that will be brought up later with more depth in the discussion chapter. Several recommended it would be better to create write-in space dedicated to gender.

The next most addressed group of responses was about literature available and on display at the clinical setting involving 24 responses. The need for literature addressing trans identity and/or health needs was specifically endorsed by eleven respondents. Specific literature requests were for "Proper tuck and bind procedures" or "information about gender identity and children". Closely related to this were explicit requests for health brochures that did not talk about "men's or women's" health (such as heart health) but use language such as "female bodies" or "male bodied".

The prompt for this category was listed "posters" and was addressed in 22 responses. Fourteen respondents stated that the presence of posters or pictures either including or representing Trans or LGBTQ identities or lives would be increase a sense of welcome. Two requested images of trans people. Additionally, four named "rainbow" images or stickers would be a welcoming sight and two named "safe space" stickers in the same way. Two would like a clear statement of "Trans Policy" posted in the waiting room. One suggested posting in the waiting room of a general statement of "safe space" for all people.

It has been noted that the overall rating on quality of health care by respondents was notably high, perhaps reflecting the level of socioeconomic and racial privilege of the sample. So it is not a surprise that 17 respondents expressed satisfaction with the status quo of the office space. Ten said they just needed a clean, comfortable (as in seating), professional office setting. On this most concrete matter of room structure, three mentioned they preferred an open reception desk/area with no one "hidden" beyond a small window. Two preferred "gender neutral office", such as not having pink and frilly décor in what sounded like the gynecologist's office. One asked for the absence of religious imagery or iconography specifically, which is related to "professional" space. Two used this question to state the need for better ways to access and identify medical practices that are welcoming to low income trans people.

Office and support staff interactions. This question focuses on the how receptionists, office workers, nurses and other medical assistants could provide respectful and welcoming interactions. The most frequent themes in response to the query about interactions with staff were the use of preferred pronouns (34) and names (22). This was followed by a cluster of responses stating the importance of staff interaction being respectful and friendly (17), professional (10) and sensitive or discreet (7). Related to staff deportment and professionalism, four respondents specifically addressed the need for staff to keep their questions appropriate to the needs of care and only "on a need to know" basis. Additionally, there were requests to be "treated like everyone else" came up 13 times. This fits into 15 direct references and 8 implied references for the need for staff training or "Trans 101". One would hope that people working directly with patients have skills to interact in a professional, respectful, discrete and sensitive way. Yet this can break down when people do not know or understand and when they have little cultural knowledge, in this case on transgender identities. One respondent statement illustrates the social breakdown due to lack of knowledge and understanding and perhaps the way forward:

> I would much prefer that they ask, rather than guess - just a simple, "what pronouns do you prefer?" would be fine, or "how would you like to be addressed?" If they make a mistake, apologize, correct, and move on - don't dwell on it. Just take me in stride, as if I'm normal. Don't act like anything's a big deal. It's not. Receptionists have no business asking about surgery and stuff - nurses do (depending on the situation), and they should just ask in the most straightforward way possible.

Gender rules are deeply embedded and tacit in our mainstream American culture. When people do not appear to fit the assumptions of sex and gender being one and the same, it can generate social awkwardness from the benign to more intense painful experience. Trans people contend with this daily. Yet in a professional setting, the onus is on the service provider to be socially skillful. This is supported with some basic education on what transgender means and what is necessary to know medically and socially in a medical setting. Another example from a transgender person's point of view of importance of basic knowledge trans people:

> It would be nice if support staff actually had any idea what the word "transgender" even meant… when giving my medical history I acknowledge being transgender or that I've had gender reassignment surgery, and inevitably I get a dull, vacant stare until I dumb it down and say "I had a sex change" as if I was on Jerry Springer. It's definitely embarrassing and frustrating to have to confront that level of ignorance, especially when you're sick.

Support staff having basic knowledge and awareness both socially and culturally of what transgender means, as well as, understanding that transgender medical needs may cross the dominant assumptions about gender of bodies (example: some women have prostates and some men have cervixes), will help support staff respond in appropriate, professional and sensitive ways. Using appropriate pronouns and names seems obvious enough, a pervasive concern of many respondents. An example is addressing patients by using the correct gender titles such as Miss, Ms. or Mr. (3 respondents) or not using them at all (2). A more intense or personal matter is in referring to body parts, especially private ones (5). This theme comes up again with medical providers, too. This touches on one the most challenging and potentially painful aspects of going to the doctor when dealing with assumptions about bodies and gender come to the fore. Trans men are much more likely to "pass" as their presenting social gender, leading to surprised or invalidating reactions, such as when scheduling a pap smear or asking for a "female" form for a medical history. But some of the examples provided by respondents illustrated the need to have their body parts referred to properly. This from a trans man with "bass voice" and "shaves every day":

> [The] nurse handed me a robe and told me to remove everything including my bra and panties...she was clueless. Then she hooked me up for a cardio with those little stickers all over the place. Afterwards she told me to get them off the parts and listed them: "2 under each breast". Then the doctor came in, knew better than to examine my chest as he would for a woman. He sent in a different nurse to give me my vaccinations. I guess...comfort with the situation is key. I am okay if folks get confused, but I find it offensive if they don't even try. "Panties, bra, and breasts" will echo in my brain for a few weeks after that physical. Good thing I have a sense of humor.

Another respondent asked "not be laughed at when I schedule a pelvic examine." This leads into the next major area of interest addressed by respondents: the use and management of filed information. In answers to the first narrative question on office and other concrete matters, recommendations were offered to make personal and medical history forms work as a place to lay out their social identity, their physical and medical history and their insurance coverage. In this query, respondents (10) wanted this information used and known, to support better interaction with staff and managed so privacy was also protected. They wanted staff use that filed information in the gendered interactions: filing insurance claims with the name and gender tags that the patient's insurer knew them by, to know what name and pronouns to use in office, and to know, as fitting to medical appointment the body parts they did and did not have, and terms for parts that fit their social gender.

Medical provider's exam room manner. The third narrative question encompasses the practices both in the clinical encounter and the supportive and administrative practices that inform it. The responses are outlined here in five larger themes of 1) Transgender knowledge; 2) Respectful engagement; 3) Listening/communication; 4) Nonjudgmental engagement and 5) Administration. There is much overlap in these themes and in their content. In fact, what comes from these narrative responses is a developing picture that respectful treatment is supported by provider knowledge and awareness of transgender health and social experience, and expressed in communication featuring nonjudgmental and assumption free listening and questions.

Transgender knowledge is for the findings of this prompt parsed into two categories: 1) social/cultural knowledge and awareness of transgender identities; and 2) medical and physical health knowledge. Social and cultural knowledge was often referred to directly often as "Trans 101", by 15 respondents. The second category of medical and physical health was directly referred to by 14 respondents to this question, and will be covered in the responses to the fourth and final narrative response from the survey, since this is the heart of the that final question. Much of the awareness and knowledge called for by respondents was for providers to know that transgender is not equated with surgeries, nor are transgender people mentally ill or freaks. That said, nine respondents said, even if a provider had little knowledge of transgender matters socially or medically, it would help the clinical relationship if the provider could be open and honest about their limitations. A specific kind of knowledge that five respondents wanted was the provider to know about transgender specific medical care, therapists and social resources. The most frequent item (18) for this question is that any gender related questions should be relevant to the purpose of the medical visit. This is where knowledge and awareness overlaps into respect.

Under the theme of respect, most frequent and persistent was the plea to be addressed in one's preferred pronouns (16) and preferred name (13). Two asked the titles (Mr., Miss and so forth) not be used. Throughout the narrative survey, respondents recommended these prompts when addressing when people and gender was not clear to the staff, such as: "How do you preferred to be addressed?" or "What pronouns do you prefer?" This is followed by the direction to "Treat me like and other patient" and to "take in stride working with me" (13). One respondent put it magnanimously:

> Dignified and respectful treatment can be very simple in the sense of "treat me as you would any patient" in terms of treating me like a person with sensitive feelings, possible physical and emotional trauma, etc., but the fact remains that in medical settings, transpeople are not "just like any patient"... however, most patients are not 'just like any patient"!

This fits into the advocacy by 13 respondents for being treated respectfully as a human being and in their presenting gender. In a similar vein, it was stated by seven respondents "to meet me where I am" in part referring to their gender identity. Respect is represented in the matters of sensitivity and understanding patient autonomy. The statement made in various ways by at least five respondents was for medical providers to accept refusal or delays of some procedures and tests due intense emotional discomfort trans people have with some parts of their bodies. This was especially brought up by people with masculine identities and female bodies. This issue deeply involves the next major theme: communication.

At the heart of any relationship is communication. In line with the last item, is the instruction by nine respondents to discuss gender related procedures, treatment and tests prior to conducting them so there is clarity about their utility, timeliness, and necessity. This will also provide time to hear the patient's comfort level and concerns. An example of positive and effective communication is offered by a respondent:

> She [the PCP] was very concerned about the lump as well as my disgust for my breasts and she expressed it by stating "I know you try very hard to keep your breasts out of 'mind' and out of 'sight' but with a lump in your lymph node region I have to order an ultrasound and mammogram to determine what it is. Will you be comfortable enough to have these procedures done?" With cancer being present in my family history I knew that my disgust for my breasts didn't outweigh the necessity of having these procedures being done. I told my PCP that I wouldn't be happy getting the procedure done, but knew the importance of getting it done.

This can also happen in a brief clinical encounter by thoughtful and compassionate engagement by the provider, and brave disclosure on part of a trans person as seen in this quote:

> They changed my gender and name in the system and simply made a small footnote stating that I was in transition. The urgent care physician only mentioned gendered issues when they were specifically relevant, ex. when I had a urinary tract infection. She said: "I do not mean any disrespect, but as you still have the genitalia of your birth gender, I'm supplying you with those care directions." I felt that this was very respectful and tactfully addressed both my health care needs and my right to be respected as anyone else.

Related to procedures and communication, nine respondents talked about the value of communicating specifically about patients' comfort level with their body and touch. In contrast, one complained how touch seemed to be avoided by medical providers. This respondent wondered if this reflected the providers discomfort with their transgender body. This is also ties in with a sensitive awareness of trans body issues and gender dysphoria (4) and communication on how a patient would rather have their genitalia referred as and other gender-associated body parts (8). In talking about body parts, six respondents expressed the importance of not making assumptions, based on social presentation, about what parts are and are not present, assumptions about future transitions(3), and providing space and awareness for gender variance such as androgynous and genderqueer identities (4) . This may appear daunting, but respondents endorse the effectiveness of unassuming and open-end questions.

The next section is about non-judgmental interactions, which starts with asking questions in non-assuming and non-judgmental ways and is addressed directly by seven respondents and indirectly by many more. The five quotes below offer examples of how to discuss in open and nonjudgmental ways, key sensitive points.

> "Can you tell me a bit about your approach to your present gender, if it's relevant to your medical needs today" might be a good beginning with a new caregiver."

> "I don't really know much about this topic, but I am willing to learn to help me be a better healthcare provider for you. Can you recommend some resources that you think would help?" or "I am trying, but not very experienced dealing with trans patients. Please let me know how I can be more sensitive to your needs or expectations so we can discuss it right away."

> Remembering that medical appointments can be, and probably have been, extremely traumatic for trans people, and recognizing that, verbally, with the patient. Maybe even asking "how have your experiences been with past doctors around your gender related health needs?"

> I'd like a doctor to understand that sometimes talking about my body is difficult for me, and to be able, for example, to honestly say something like "I know this is difficult. But it's okay; talking about your period doesn't make you any less of a man."

> Ask me- EVERY VISIT- "Do you have any concerns about hormone levels or physical changes that might be related to hormone use/past surgery?" This leaves the field open for discussion or for me to say, "Nope. But thank you for asking."

The commonalities in these approaches are that they open what could be difficult topics in the patient/provider encounter while engaging a trans person in ways that honor their identity, knowledge and self-efficacy in non-stigmatizing manner, and opening the way for more candor, trust and effective care. This approach also creates a way to fulfill the recommendation brought up directly at least seven times of delivering information and medical advice in a nonjudgmental manner. Another sensitive point brought out clearly by four respondents was not making assumptions about future transition plans or the desire to make other changes. This touches on the point made by at least four about the "cisgendered[2] assumptions", on advice and care around sexual health, or hetero-normative judgments about intimate partner or sexual practices. This goes back to the need for paperwork that allows for people to describe their sexuality, practices and actual sexual organs.

This leads into the final theme for this survey question: administration. Respondents referred to file management, intake forms, including medical history, prescribing and health insurance in this question and the two previous questions. In the clinical encounter, respondents wanted to providers to have had read their chart and to be familiar with their medical, physical and social information. They saw doctors as responsible for how charts were managed and organized to so their transgender identities were apparent when necessary and only then. Respondents all held doctors responsible for the quality of treatment by support staff and their level of transgender awareness. Also on the matter of files and information management was getting one's preferred name and identity used in the clinic and managed so the insurance company received billing requests in the name and identity of the patient that matched the insurer's records. Another respondent was grateful to their PCP for coding a procedure so it would be covered by insurance and two others addressed this directly. One respondent, who was

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[2] Cisgender is a term that has come in recent use. It refers to people who are not transgender.

unemployed, used this question to report how they were denied general health insurance specifically because they were transgender.

Medical provider's knowledge of transgender care. This final narrative question in the survey asked what they expected primary care providers to know about transgender medical and physical needs or supporting timely treatment from a specialist. Responses to this question have been grouped into four categories: 1) transition basics; 2) Trans 101; 3) development of medical transcare knowledge; and 4) administrative knowledge and responsibilities. The responses addressed not only what they expected primary care providers to know, but also how and when they were expected to know. Again there is overlap and repeated themes from the other narrative questions.

The naming of this theme "basics of transition", was drawn from respondents and directly referred to by as many 22 and the most frequently cited response. Within or associated with this are topics of "HRT" (hormone replacement therapy) basics and trans (gender) bodies. To clarify the use of "HRT", in medical literature for this thesis, hormone treatment was frequently referred to as contra hormone or cross gender hormone treatment, but all references by respondents used "HRT". Though hormones profoundly transform and impact bodies, it was the knowledge of medical protocols and management of hormone use that was most frequently and directly cited (22). This included hormone monitoring, management and various approaches to dose and delivery. They also wanted their providers to be aware of the expected positive impacts on their bodies as in this quote:

> The nurse practitioner has done very well except that she was unaware that trans women on a hormone regime not only increase breast mass, but also develop mammary glands.

> This was a shock to her, and while she recovered quickly she had to alter some of her treatments, and showed a distinct lack of knowledge on her part.

There was almost as much concern by 19 respondents for providers to be know about the side effects and treatment interactions with the use of hormones, whether they were the prescriber or not, as this respondent states here, "I'd like them to understand the medication combinations, our risks (e.g. high risk for thrombosis from estrogen use) and any specific needs out of the ordinary" Hormone therapy has impact on the liver, cardiovascular system and could be a factor in cancer given the medical history of the patient and their family or given their biological sex and specific hormone treatment. A few wanted their providers to be aware of alternatives to support and deal with hormones and consequences.

Staying within the physical realm, respondents wanted providers to know about transgender bodies in general ways (8), as to the possible kinds of surgeries, the optional nature of protocols, and the barriers (cost and social) and downsides to surgeries. Some respondents (6) wanted providers to be aware of trans fluid bodies that were not interested in surgeries and/ or starting or continuing hormone treatments for reasons ranging from quality of function, not feeling it necessary, to not being interested in a body that conformed to the "gender binary."

> I need providers to not just be familiar with the "standard trans narrative," but also to be familiar with a non-binary model of gender, and to accept my status as neither male- or female-gender as something that's not pathological. I need them to be prepared to deal with someone who does not relate to their body in a male OR female way, who may not want their hormonal imbalance corrected, who may not want to take female hormones,

> who may want to seek male hormones but not transition to male. I need them to trust that I know what I need to be comfortable in my body.

Five respondents stated that providers need to know or ask patients about language that is sensitive in reference to their trans bodies, such as a chest for a trans man, or gender neutral terms such as genitalia. Along with this they wanted to them to understand the sensitivities of trans people and their bodies such as being touched or a trans man needing to keep his chest bound, because the presence of his breasts can be very difficult for him. This touches on the point made by at least seven respondents for providers to know the facts of individual patients' bodies and not assume what they do or do not have. A few mentioned that they wanted providers to know about long-term care for transitioned bodies. Two others brought up the prevalence of PCOS (Poly Cystic Ovarian Syndrome), as is quoted here: "I expect a provider to be familiar with PCOS including its treatment and all of the things it can affect since this is so prevalent within the ftm community even among those who never undergo medical transition."

The next major emerging theme is "Trans 101" as referred to by 17 respondents. Trans 101 refers to an awareness or familiarity with the foundations of social, emotional and cultural aspects of transgender life. Within this theme, 11 respondents included knowledge of language and concepts of those identities that do not fit in the binary, including the intersex, who can also be transgender. Additionally, seven respondents wanted providers to have a basic understanding of the social and emotional experiences of what it means to be a trans person in our present society and on a personal level. Three wanted to include the understanding that transgender is not a mental illness but a physiological and cultural problem and that trans people are individuals who are unique in their bodies and lives.

Another theme is how PCP's can develop their knowledge of medical transgender care. While three respondents expected their providers "to know everything", nine expressed understanding that PCP's may know little if anything about their transgender specific needs, but respondents expected them to learn. On the topic of lacking knowledge, seven stated that they appreciated or expected their providers to be honest about the limits of their knowledge. Six reported they valued their providers learning from their patient's knowledge on these matters, since they had had done their own research along the way about the needs of their transgender bodies. Eight wanted to learn about their care with their provider along the way. An expectation clearly laid out by another eight respondents was for providers to know when to call a specialist on consults as needed. Overall, this suggests a theme of the desire for a collaborative and respectful relationship, which echoes the calls for respect in the clinical relationship in the previous question. The following quote encapsulates many of the perspectives expressed on a frank and respectful clinical relationship:

> If providers are unfamiliar with transgender issues I would hope they'd be able to simply admit their lack of knowledge and do a little research on their own, perhaps being open to learning from the patient they're treating, also. There's nothing wrong with being unfamiliar with a new medical situation, just don't be an ass about it, you know? The first doctor who prescribed me hormones didn't know anything about trans issues, but because I came to him and asked him he agreed to help me. He said upfront that it was all new to him, he had never helped anyone transition before, but if I really wanted he would research the subject. Looking back on it now I find I don't necessarily agree with how he went about certain things but he was upfront and honest with me the entire time. I believe he did the best he could, and I appreciate that still.

A caveat to this is three respondents resented having to teach their providers about their care and identities.

The final theme is about administrative knowledge and responsibilities, generally about understanding matters that are supportive and collateral to care. The most frequent of these was about making referrals to other medical professionals for transgender care, or knowledge of transgender friendly care networks including therapists (4) and transgender community resources (2). Another two wanted them to have knowledge or awareness of the legal issues for transpeople, but this was not elaborated on. Three wanted their providers to know about the health insurance discrimination that trans people face. One of these said "They should also be familiar with, and hopefully agree with, the AMA's resolution [Resolution 122, June 2008] that discrimination against trans people in health insurance should be ended." Another throughout the narrative section, talked about being denied health insurance for being transgender. Another talked about providers being aware of denial of coverage and the potential of being dropped by a carrier for this same reason and the importance of managing files and information.

The next chapter will discuss these findings, comparing them to studies used to frame and inform this research. From that discussion recommendations for guidelines for practice for improved access to primary care provision and future studies will be presented.

Chapter V

Discussion

Introduction

The purpose of this study has been to explore and describe the transgender perspective of socially sensitive and medically competent primary healthcare provision. Via a nationally-conducted online survey the viewpoints of trans people were gathered to identify welcoming, sensitive practices and structures in areas of: office space, staff behavior and attitudes, medical providers' interpersonal practices, and trans healthcare knowledge and application. This discussion chapter includes a summary of findings, a discussion and comparison to studies in the literature review, and finally, recommendations.

Findings on the demographics for this sample are presented here in categories of socioeconomic, gender profile and current healthcare access. The socioeconomic profile of this sample (n=119) is white (88.7%), young (median age 30), educated (52.1% bachelor degrees or higher), and respondents living in either coastal states (81.5%), within one hour of a city (77.3%), with a high unemployment rate (37.8%) and 25.2% did not have health insurance. This profile is not reflective of the general population, as it is likely a result of the inequalities of access to the online survey instrument. The profile of gender representation is complex and shows a range of identity, expression and experience. Respondents were asked to choose from a list of gender identity terms ranging from masculine, feminine to androgynous or non-binary identities that described them positively. While the average selections of gender identity terms was 4.8, these terms were often a mixture of non-binary and binary, with 40.3% selecting feminine identities, 36.7% selecting masculine and 13.4% choosing only non-binary terms. Additionally, 88.4% reported living in a gender other than assigned at birth, most or all of the time, and 78.2% reported either being in physical transition or having had transitioned; while 4.4% reported not being interested in any hormonal or surgical changes. Finally, in the category of healthcare access and quality, 74.8% had health insurance, 62% had a PCP and 4.2% had no healthcare provider. Overall, this sample rated their current healthcare quality as a "4" on the Likert scale, with 5 as highest.

Findings from key questions in this study suggest:

1) The central importance of respectful and sensitive interpersonal treatment by all staff as well as medical providers in acknowledging all patients' gender identity by use of preferred pronouns and names and supported by staff awareness of transgender identities and basic etiquette.

2) The need for primary care physicians (PCPs) to have the awareness and knowledge to support sensitive and appropriate interaction and treatment transgender peoples' general healthcare needs.

3) The importance that PCPs have a basic knowledge of transgender health issues and/or access to resources, or other transgender-friendly professionals that do.

4) The willingness of PCPs to cultivate open and nonjudgmental communication with transgender patients including listening, thus learning from their patients about their particular needs.

5) Creating a welcoming medical office environment that includes gender neutral restrooms, intake forms which allow patients to describe their identity and physical/medical history more accurately and file management that assures accuracy and discretion.

6) Awareness of social and institutional stigma that create fear and barriers to healthcare for transgender individuals.

In the studies researched on transgender health needs, most looked into barriers to trans healthcare access and found that lack of "trans-friendly" or sensitive providers were a major component (Sanchez, Sanchez,& Danoff; Rachlin, Green& Lombardi; Kenagy; Speber, Landers& Lawrence). The findings in this study did not contradict any of the previous research on transgender healthcare access, but elicited a deeper perspective of the primary care setting and relationship. While the purpose of this research was to collect transgender people's perspectives on accessible healthcare it also aimed to create a guide to sensitive and respectful clinical interactions, based on these perspectives. The most persistent and frequent finding by respondents in this survey was the desire to be addressed by their preferred pronouns and names as a baseline of respectful and sensitive treatment, a basic etiquette that cisgendered people take for granted. This was often stated explicitly, but also implicit in statements such as "take me as I am" or "as I present [my gender socially]". A solution provided by respondents was for staff or providers to ask the open-ended question "how do you wish to be addressed?" which would allow for accuracy and respectful treatment towards all people at any clinic. Respondents frequently stated the need for staff and providers to have "Trans 101" training or education to support professional and appropriate decorum, giving all staff and providers a basic awareness and rudimentary understanding of transgender identities. This was also a strong theme in the Boston study (Speber, Landers & Lawrence) that focused on specifics of healthcare provision.

The next most discussed concern by respondents was for Primary Care Providers' (PCP) knowledge of transgender people's general care needs to support sensitive and appropriate interaction and treatment. This consists of assessing a person's healthcare needs by understanding the specific facts of their patients' bodies, as to what is or is not present (breasts, reproductive organs, etc) and possible hormone use, as well as awareness of the individual's attitudes and sensitive approaches to their own bodies. These findings fit with concerns expressed in the national Female to Male (FTM) study (Rachlin, Green and Lombardi) and the Boston study (Sperber et al, 2005). While this study heard these concerns from various transgender identities, this was most often heard from trans men and other female-bodied masculine people. Additionally, this general knowledge includes routine transgender care, such as the multiple effects and impacts of hormone use. Knowing the patient can support appropriate interaction, such as when transgender issues are actually related to the clinical visit. Additionally, as in the Boston study, findings revealed respondents valued their primary care providers having knowledge of other transgender friendly professionals, such as endocrinologists, gynecologists and mental health professionals, as well as social and community resources. In the FTM study, 60% said they would go to a transgender clinic for more general care if it was available to them (pp.25), indicating a similar value of comprehensive trans-friendly care.

Another key finding was the willingness of PCPs to cultivate open, nonjudgmental communication with transgender patients by use of open-ended questions, listening and thus learning about their unique needs and insights into care as an example of a transgender friendly approach. Again, this was also was reflected in the Boston study. The NYC MTF study (Sanchez, Sanchez, & Danoff, 2009) reported that 30% of participants found a lack of access to transgender friendly providers. This question was not reflected in the national FTM study, yet it is noted that only 36% of these disclosed their transgender status to their PCP, which is associated with trust and communication.

Other salient findings from the survey regarded welcoming office practices, ranging from gender neutral restrooms, intake forms to file management. Gender neutral restrooms send a clear signal of welcome to transgender people. Intake forms that offer the opportunity to accurately record information about name, gender and physical/ medical history and needs are rudimentary for ethical, informed care and instrumental in building respectful treatment relationships. These structures in place communicate preparedness for individuals who do not fit in the confines of either/or gender assumptions. Having a protocol to manage information sensitive to the needs and identity of transgender people was a running theme throughout the four survey questions: managing information to support appropriate social and medical engagement by all staff, sparing individuals either having to bear mistreatment silently or having to "out" their transgender identities, a source of concern and suffering for many respondents. These findings were not seen in other studies, but this was not a question asked in the other studies.

Finally, respondents reported that accessible healthcare providers need to be aware of the social and institutional stigma and discrimination they experience, that unaddressed leads to negative impacts to full care. While many respondents did report satisfaction with their present care, a number of respondents alluded to not being "out" to their providers. While some were concerned about their presenting gender being respectfully engaged, many had concerns about their current healthcare policy provider discovering their transgender identity and denying benefits or dropping them as policy holders. One participant used this survey as a vehicle to document their lack of access to care because they were denied health insurance coverage entirely because of their transgender identity. The Boston findings stated that federally funded Social Security Disability Insurance (SSDI) and Medicaid did not cover hormone therapy or Sex

Reassignment Surgery (SRS). This is certainly a barrier to care, yet the Boston study reported that some individuals were denied health insurance coverage based on their transgender identity. Both in this study and the Boston study participants discussed their doctors representing hormonal treatment to insurers not as transgender care, but as hormone replacement. This is an ethical double bind for providers, since not addressing hormone use may lead to patients procuring hormones off the street, and not disclosing use to the provider. The conundrum for providers is having their patients at risk for their non-disclosure of illicit hormone use and the numerous health risks, from misdiagnosis, treatment interactions, lack of proper monitoring for risks and complications, or the risk that health insurance providers may deny care if patients' identities are discovered. Thus this double bind impinges on the integrity of the treatment relationship.

Social Work Implications

Social work's perspective is that intolerance, poor and inadequate treatment of transgender people in general and especially in the healthcare setting must be addressed. Given the social work value of dignity and empowerment to communities and people who are marginalized and stigmatized, this study is grounded in transgender perspectives to advocate for better healthcare services. In practicing social work on the individual level, a basic assessment of any person, must include healthcare. In this study, respondents wanted their PCPs to know of trans-friendly and prepared mental health providers, various medical specialists and supportive social and community resources. No less is expected of social workers.

Recommendations

This exploratory study of transgender peoples' perspective of accessible and welcoming primary healthcare either corroborated findings from studies focused on barriers to healthcare access and/or enriched the understanding of dignified and welcoming provision of care. These recommendations generated from findings of this study can be easily translated for healthcare professionals, including the social work profession:

All staff and healthcare providers:

- Address all people with their preferred pronouns and names. Not clear? Simply ask "How do you preferred to be addressed?" Make a mistake? Apologize and continue with the conversation.
- Have basic knowledge of transgender identities or "Trans 101" to support a policy of sensitive, respectful engagement with all patients.
- Awareness of the harm via social and institutional stigma and discrimination that creates fear and barriers to healthcare for transgender people

Especially those providing healthcare:

- Provision of healthcare of transgender people's general health care needs based on the patient's reported physical facts (not provider's assumptions) to support sensitive, appropriate interaction.
- Cultivate trust by open and non judgmental communication with transgender patients that includes listening, thus learning about their particular needs.
- Listen and follow patient leads on care and body terminology
    - Include dialoging with patients about gender specific care and hearing and respecting patient limitations and concerns.

- Do not make assumptions about sexual practices or orientation.
- Have some basic knowledge of transgender health care issues and/or have access to transgender friendly and knowledgeable professionals that do.
- Create a welcoming office environment and structure
    - Access to gender neutral restrooms
    - Intake/Medical history forms that:
        - Allow for more than Man or Woman
        - Ask for preferred pronouns
        - Allow for both name and preferred name
        - Allow all patients to describe their physical and medically history accurately
    - Create file management that supports use of preferred name and pronouns

Further recommendations are based on the limitations of this study. The ability to generalize of these findings is limited by the bias of this nonprobability sample that represents a notably white and educated group that had more choices for medical resources by living near or in cities. Additional bias is generated by design limitations, led to the absence of people who do not have easy access to the internet, are not comfortable reading and writing, and non-English speakers. Additionally, the demographic findings reveal a lack representation of the perspectives of transgender people of color and other marginalized racial identities, and those living in rural settings distant from population centers. Recommended are studies designed to gather the perspectives of these missing groups to create a more accurate model of accessible, welcoming care.

Additional recommendations for study are explorations of the impacts on medical care and health outcomes due to health insurance policies that limit or deny healthcare services based on transgender care or identity. A particular area would be the impact of policies and practices of health insurance providers, both public and private, on the access to general healthcare for transgender and other gender non-conforming people, and the impact this has on the relationships and practices of healthcare providers not directly involved gender transition. As was seen in this study, there was a regular undercurrent of concern about having one's transgender status revealed to health insurance providers. As one respondent stated in the Boston study "First you find a physician, then you find health insurance." It would be revealing to approach this study from the perspective of primary care providers who serve or wish to serve transgender people.

This researcher developed an interest in the area of transgender healthcare advocacy after being witness to an unfolding conversation in my rural New England region between trans folks concerned with finding both suitable and trans friendly primary care practice. This was not easy to find. The most important criterion in that conversation, as this study bears out, was the quality of the healthcare relationship. The running themes in my findings were the practices of listening, asking open questions and offering a collaborative relationship. The respondents in this study want and need to be heard as knowledgeable agents in their healthcare, and seen as human beings worthy of basic respect.

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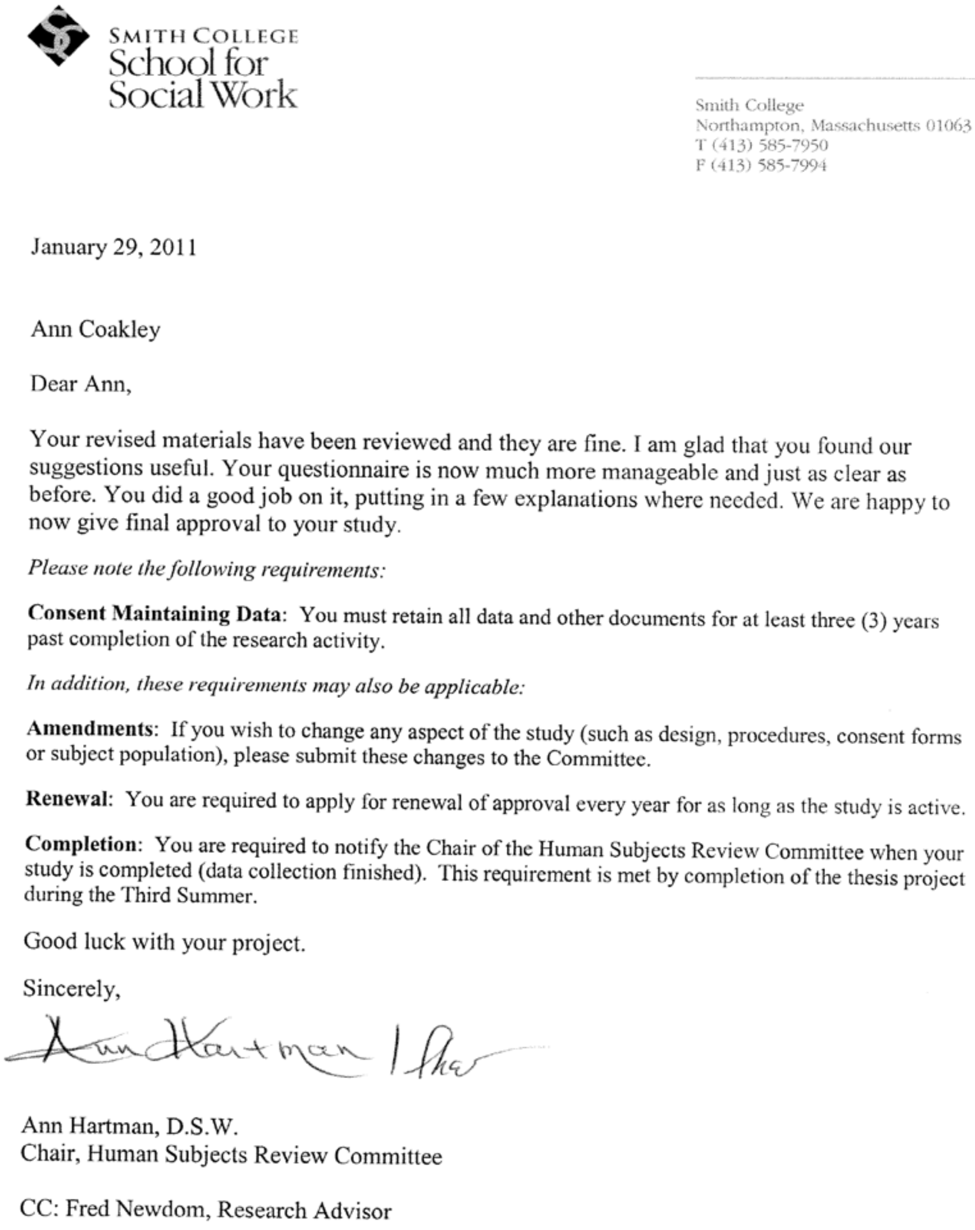
Appendix A



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January 29, 2011

Ann Coakley

Dear Ann,

Your revised materials have been reviewed and they are fine. I am glad that you found our suggestions useful. Your questionnaire is now much more manageable and just as clear as before. You did a good job on it, putting in a few explanations where needed. We are happy to now give final approval to your study.

Please note the following requirements:

Consent Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Fred Newdom, Research Advisor

Appendix B

SURVEY MONKEY

Do the following statements describe you?
The gender I was given at birth does not fit the gender that I identify with today. Yes or No
I am at least eighteen years old. Yes or No
I live in the USA. Yes or No

If you answered “No” to any of these statements-you are not eligible to take part in this study. Thank you for your time and attention.

If you answered “Yes” to all 3 statements- go on to page 2

Dear Potential Participant,

My name is Ann Coakley. I am a graduate student at the Smith College School for Social Work. For my thesis, I am conducting a study to develop a better understanding of what good care and treatment by a primary care healthcare providers looks like from a trans person's viewpoint. By trans people I mean, in the broadest sense, people whose present gender differs than the one that was given to them as a baby. If this matches well enough how you identify yourself, please consider adding your voice and viewpoint to this study. This study will be used for Masters in Social Work Thesis and potentially presented and/or published.

If you choose to participate in this study, you must be over 18 years old, able to read and write English. Participating in this study will involve filling out an online survey taking about 20 or 30 minutes to complete. The survey will have four parts. The first will be general questions about you. The second part will be questions about the kind of healthcare you use and your views on the quality of that care. The third part will be questions related to your gender, since different genders have different medical and social needs in healthcare. The fourth and final part will be questions about what you see as respectful, high quality healthcare by primary healthcare providers and their support staff.

It is possible that filling out this survey could bring up strong feelings related to your healthcare experiences and expectations. If you find you need support for dealing with these feelings, I have listed some mental health resources at the end of this consent form and again at the end of the survey.

You may experience some personal benefit from speaking up and sharing your knowledge and views to help create respectful healthcare fitting to your needs and the needs of other trans people. There is no cash or coupon given to you or other participants in this study.

This survey is anonymous to protect your privacy. All information from age, or residing state or gender will be presented only as grouped information. Any quotes used will be carefully disguised. All materials from this study will be securely stored for three years in accordance with Federal guidelines and destroyed after that time when no longer needed.

All participation in this study is completely voluntary. You may refuse to answer any question. You may withdraw from participating at any time with no penalty. Because the survey is anonymous, you cannot withdraw after submitting, as individual survey cannot be identified. If you have any questions about the study you can reach me at acoakley@smith.edu or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413)585-7974.

CHECKING THE "I AGREE" BOX BELOW INDICATES THAT YOU HAVE READ AND UNDERSTAND AND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

- ○ **I AGREE**

Confidental and Anonymous Resources

for Support, Information and Referrals:

Gay and Lesbian National Hotline
http:www.glbtnationalhelpcenter.org/index2.html
Toll-free 888-THE-GLNH (888-843-4564)
Hours:
Monday thru Friday- 4pm to midnight east time
Saturday-noon to 5pm eastern time
Monday thru Friday-1 pm to 9 pm pacific time
Saturday- 9 am to 2 pm pacific time

Fenway Community Health Gay, Lesbian, Bisexual and Transgender Help Line

617-267-9001 or Toll-free 888-340-4528

Or Peer Listening Line

617-267-2535 or Toll-free 800-399-PEER

GENERAL QUESTIONS

1. Age: ___

2. Race:

   Native American___ Afro American___ Indian ___
   Latin or Hispanic ___ Pacific Islander____ Asian____
   Multiracial___ Black___ White____

3. What best describes your ethnicity? ____________________________________

4. State (select from drop box list)

5. How far away is the nearest city of 100,000 or more? :

   a. Less than an hour; b. 1-2 hours; c. 3-5 hours; d. more than five hours

6. Are you currently employed? –Yes or No,

7. Education-Highest Level completed

   Post Graduate degree ___
   Bachelor’s Degree ___
   Some college ___
   High School ___
   None of the above ___

HEALTHCARE ACCESS

8. Do you have Health Insurance? No or Yes,

9. Source of health insurance ,check all that apply

   a. Private Employer b. Private Individual insurance c. Through a family member
   d. Government Employer, Federal, State, or Local; e. Government-Medicaid, Medicare, Tricare

10. What medical care providers do you use for your primary medical care? Select all that apply:

    a. Primary Care Physician (PCP), b. General Practitioner (GP), c. Family Practitioner (FP), d. Internist, e. Physician's Assistant, f. Nurse Practitioner, g. Endocrinologist, h. Gender Specialist, i. Naturopaths

HEALTHCARE QUALITY

On a scale of 1 to 5, where 1 is Unsatisfactory and 5 is Most satisfactory, rate the quality social interaction and quality of care.

11. How would you rate the level of respect and appropriate behavior by your primary care provider?

    1 2 3 4 5

12. How would you rate the overall quality of the social interaction with your primary care provider's support staff (may include receptionist, office staff, medical assistants and nurses)?

    1 2 3 4 5

13. How would you rate the preparedness and appropriate medical knowledge of your primary medical care provider?

    1 2 3 4 5

GENDER

People have many ways of naming, describing and expressing their gender. Please answer as many as you can.

What pronouns do you prefer to be addressed by?

. She or her___ He or him___ They or their___ Ze or hir___

Fill in____________

16. Please choose all terms that respectfully and positively name or identify your gender. This list certainly does not cover all the way people might name their gender. Include what best describes you in a positive way in the space provided.

Woman____
Man____
Transgender____
Transsexual____
Transgenderist___
Drag King___
Gender Fluid___

Trans man____
Trans person____
Gender queer____
Gender nonconforming___
Grrl___
Transvestite___
Other____

Trans woman____
Queer____
Gender Variant____
Boi___
Drag Queen____
Cross dresser____

17. How much time do you spend socially in a gender other than the one you were assigned at birth?

a. All of the time b. Most of the time c. Sometimes d. Very little time e. Never.

18. Some people transition physically from the gender given at birth to a different gender. Choose what best describes your experience:

a. Not interested. b. Thinking about it. c. Planning and preparing for it. d. In transition. e. Transition complete more than a year ago. .

19. Have you legally changed your name on any documents to better represent your gender?

Yes / No

20. Do you use any gender related hormones? Yes or No

21. Have you ever had any gender related surgery? Yes or No

YOUR VIEWS ON HIGH QUALITY AND ACCESSIBILE HEALTHCARE
Please respond with your views of Quality and Accessibility of your Healthcare

There is no right or wrong response. It is your perspective that is most valued in this survey. Please describe what has or would make for the best welcoming setting and provider care for you.

22. The first question is about the office setting of a primary care provider. Office setting includes the rooms from reception, to treatment, to every space in between. You can include things such as forms, posters, and literature (brochures, magazines, etc), as well as, where these things are found in an office. What has or could help you feel welcome and at ease?

23. The next question is about the office and support staff who works with the primary care provider. These include receptionists, office workers, nurses and other medical assistants. What could support staff say and do to help you feel welcomed and respected?

24. This next question is about the relationship and interactions with a primary healthcare provider, as they provide care and treatment for you. A sprained ankle or strep throat does not involve a discussion about gender, but the periodic physical check-up does. What practices (words, actions and/or policies) provide dignified and respectful treatment and support open communication about your non-gender and gender related needs?

25. This final question is about primary care provider knowledge and readiness for your medical needs. What do you expect a provider to know about transgender medical and physical needs in order to treat you or support you getting appropriate and timely treatment from a specialist?

SURVEY COMPLETE

Thank you for your time, attention and views.
Below are the confidential resources for Support, Information and Referrals:

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http:www.glbtnationalhelpcenter.org/index2.html
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Appendix C

Dear ____________

As a graduate student at Smith College for Social Work I am conducting a study to develop a better understanding, from **a trans person's viewpoint, what good care and treatment by a primary care healthcare provider looks like**. This recruitment letter has the purpose to collect perspectives from a diverse sample of self-identified trans people. By trans people I mean, in the broadest sense, people whose gender differs than what was assigned to them as a baby.

- Participants for this must be over 18 years old,
- able to read and write English,
- reside in the United States and
- identify their gender as different from the gender assigned to them to as baby.

Participating in this study will involve filling out an anonymous online survey taking about 20 to 30 minutes to complete. This confidential survey can be accessed at https://www.surveymonkey.com/s/V78G8F8

I am also asking for help with recruiting other trans people for this study to collect adiverse sample of viewpoints. There are three to ways to help with outreach. One is to forward this email with or without the attached flyer to other people involved in the trans community. Second is print out this letter and or flyer and hand to a potentially interested participants. The third is to post the flyer in places highly trafficked by potential participants. If you work for an organization or agency, make sure you are acting within the policies there.

Thank you for your attention and help in recruiting for my study. If you are interested in the findings of this study please contact me at acoakley@smith.edu.

Sincerely,

Ann Coakley