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A SURVEY OF GENDER CLINICS IN THE UNITED STATES

Elise Lehotsky
Developing a Protocol for the
Treatment of Transitioning
Adolescents: A Survey of
Gender Clinics in
the United States

ABSTRACT

The goal of this descriptive study is to determine what is common practice for endocrine intervention with adolescents diagnosed with GD or seeking treatment related to gender identity. The study surveyed gender clinics in the United States that work with adolescent clients. Gender clinics are defined by this study to be one or more providers who work with adolescents to actualize their gender identity. Twenty gender clinics completed a mixed method survey that asked them to describe basic demographics of their clinic, what recommendations they utilize to influence their treatment protocols, if and how mental health is involved in treatment, what the most important aspects of treatment are according to their clinic, and suggestions for what helps improve treatment. The findings indicate that gender clinics are using similar protocols that are based on harm reduction and providing support to adolescents and their families. Recommendations for the development of a standard protocol for adolescents and future research of gender clinics are discussed.

A SURVEY OF GENDER CLINICS IN THE UNITED STATES

**DEVELOPING A PROTOCOL FOR THE TREATMENT OF TRANSITIONING
ADOLESCENTS:
A SURVEY OF GENDER CLINICS IN THE UNITED STATES**

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

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2015

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CHAPTER I
INTRODUCTION

Across the United States and internationally, mental health professionals and endocrinologists are beginning to determine best practices for treating adolescents who are diagnosed with Gender Dysphoria (GD). There is currently no standard protocol for mental health treatment with dysphoric adolescents recognized by the American Psychological Association or the American Psychiatric Association, though both of these associations have created task forces researching the subject. The Endocrine Society has published treatment recommendations for hormone intervention and for surgical referral and intervention as well. Internationally, gender clinics draw influence from the World Professional Association for Transgender Health (WPATH) Standard of Care 7 (Coleman et al., 2011).

This study aims to explore the current treatment protocols used in gender clinics in the United States when leading up to the decision to begin hormone treatments with or provide a surgical referral for an adolescent client. Gender clinics are defined by this study as a provider or providers that endeavor to treat individuals diagnosed with GD. This exploration will include looking at patterns of protocol and treatment in gender clinics across the United States to better understand what influences facilities' and providers' methods in treating their clients. Understanding what is going on in the United States will be helpful in determining what clinics are doing well and what changes might improve treatment. Once common standards for protocols are available, there will be a greater potential for outcome data collection and much-needed research into the understanding and support of clients experiencing GD.

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Perception of gender identity in clients has had a long and complicated history in clinical therapy and mental health. It has often been conflated with sexual identity, condemned as “a phase” or “unhealthy coping,” and generally misunderstood and misdiagnosed. Historically, the DSM-4 categorized gender identity that does not match natal sex as gender identity disorder (GID). In the DSM-5, an individual’s gender identity that does not match natal sex has been re-categorized as “gender dysphoria,” or GD. The idea behind this change in diagnosis is to emphasize that it is external factors such as society or physical body that cause “dysphoria” within an individual, rather than viewing their identity as a disordered way of thinking or feeling. There has been a relatively recent and overdue escalation in interest and investigation in what model of care is best for adolescents and their families.

Understanding how to support clients’ gender identity is imperative. There are higher rates of attempts and deaths by suicide among individuals who are transgender than among cisgender individuals (Dhejne et al., 2011; Mathy, 2002). Twenty-five percent of transgendered youth attempt suicide in their lifetime (Grossman and D’Augelli, 2007). Transgender youth experience higher rates of depression, generalized anxiety disorder, and substance abuse, conduct disorder, and disordered eating (Mustanski & Liu, 2013, 2012). Hidalgo et al. (2013) described that children who were not free to express their gender without restriction or rejection are later at risk for developing “depressive symptoms, low life satisfaction, self-harm, isolation, homelessness, incarceration, posttraumatic stress, and suicide ideation and attempts” (Hidalgo et al.; 2013, Roberts et al., 2012; Toomey et al., 2010; Travers et al., 2012).

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It has also been found that resilience is correlated with family support and identity pride (Bockting et al., 2007).

When making medical decisions about gender and sex, comprehensive emotional support is needed from the family and community surrounding the identified patient. Co-occurring diagnoses and assessment of social and family systems of the client are an important part of treating any individual. Often a mental health assessment will dictate whether or not a recommendation is made to see a therapist for individual or family therapy. In the Netherlands the focus is taken off the GD itself; instead the focus is on treating concurrent emotional, behavioral, and familial problems if any are present (de Vries & Cohen-Kettenis, 2012).

Clients are diagnosed with GD and receive mental health intervention prior to hormone intervention or surgery. Surrounding supports or a lack thereof, are assessed along with any current mental health disorders that are either related or unrelated to their GD. Clients are made aware of the physical, social, and reproductive consequences of medical intervention. Many clients are also supported through social transitions in their family, school, and work place. Insurance companies require one or two letters of referral by a qualified mental health professional before moving forward with medical treatments, a requirement which is supported by literature studying the mental health of individuals transitioning (Coleman et al., 2012).

Phenomenological studies indicate children may show features indicating GD as early as age two (e.g. dissatisfaction with their physical sex characteristics and functions or preference for gendered-toys and clothing). Some children may express “persistent and severe discomfort with their primary sex” (p. 172) coupled with obvious gender-

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nonconforming behavior, while others may be inclined to internalize their discomfort. It is common for gender dysphoric children to have coexisting disorders such as anxiety and depression. For adolescents the development of secondary sex characteristics with the onset of puberty serves to intensify dysphoria related to dissatisfaction with their sex assigned at birth (Coleman et al., 2012). Until the last decade, little attention and funding have been dedicated to empirical study of the experience of individuals grappling with their gender-identity. There are a growing number of hormone and surgical treatments being made available to clients to help them transition.

Outcome studies of these interventions in the United States would help to determine which strategies are successful in working with and supporting clients in achieving their desired representations of gender identity. Ideally, researchers would get as broad a sample as possible, be able to expand on recommendations, and improve unaddressed areas of treatment. The goal would be to determine which recommendations have garnered positive outcomes and what interventions have been missing from treatment. Providing this information to both mental health professionals and endocrinologists will help them better deliver quality treatment to clients. Even with the recent surge of attention to GD, there is no framework for collecting and assessing outcomes from clinics across the United States. Creating a standard protocol, measuring of quality of life and perceptions of care, and surveying clients for what they feel is missing will create more patient-centered standards of care in the United States. This study asks what treatment protocols are being used with the adolescent population of individuals who have GD or are gender nonconforming.

CHAPTER II

LITERATURE REVIEW

The historical background of gender identity, Gender Dysphoria (GD), and gender nonconforming medical and therapeutic intervention is a complicated story of oppression, stereotyping, and lack of access to treatment. There has been, until recently, little research and literature concerning treatment of GD and gender nonconforming clients. Clinics in the Netherlands and Canada have been at the forefront of expanding and exploring treatments in transgender health. In the United States, the WPATH is working to educate providers and connect consumers with those providers nationwide (Coleman, et al., 2011). There are many protocols that have been agreed upon by these organizations. There is a significant lack of studies regarding the outcomes of treatment or of what consumers perceive as helpful and meaningful to them in treatment.

Gender Dysphoria

The World Health Organization (WHO) defines *gender* as “socially constructed roles, behaviors, activities, and attributes that a given society considers appropriate for men and women.” *Sex* is defined as “the biological and physiological characteristics that define men and women” (World Health Organization, 2014). Through the WHO database it is possible to find articles regarding *transgender* health, though none directly address the definitions or identity complications. The American Psychological Association offers a more detailed explanation in their guidelines for psychological practice with “LGB clients,”

[g]ender refers to the attitudes, feelings, and behaviors that a given culture associates with a person’s biological sex. Behavior that is compatible with

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cultural expectations is referred to as gender-normative; behaviors that are viewed as incompatible with these expectations constitute gender non-conformity.

The American Psychological Association further explains,

[s]ex refers to a person's biological status and is typically categorized as male, female, or intersex (i.e., atypical combinations of features that usually distinguish male from female). There are a number of indicators of biological sex, including sex chromosomes, gonads, internal reproductive organs, and external genitalia.

The American Psychological Association also defines gender identity as "one's sense of self as male, female, or transgender," and explains that gender identity and biological sex are not necessarily congruent. Additionally, gender expression is defined as the "way in which a person acts to communicate gender within a given culture." Importantly, the American Psychological Association distinguishes that "[s]exual orientation refers to the sex of those to whom one is sexually and romantically attracted," differentiating this part of an individual's identity from their gender identity or sex identity. The American Psychological Association's official definitions take into account the multi-dimensional aspects of an individual's identity (Schneider, et al., 2009)

To be diagnosed with GD an adolescent's symptoms are considered through the lens of the DSM-5 criteria (see Table 1 at end of chapter). Gender identity is defined for adolescents and adults as "incongruence between one's experienced/expressed gender and assigned gender ... causing clinically significant distress and impairment in social, school, or other important areas of functioning" (American Psychiatric Association, 2013). Ecklund (2009) wrote,

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During early latency, children usually develop a basic self-identity that is linked to their primary ethnic and gender identities. Because of cognitive developmental status these self-identities tend to be fairly concrete. Malpas and his gender clinic work with children as young as two years old regarding non-traditional gender expression (2011). Hidalgo et al. (2013) wrote “research and our clinical experience suggest that children develop a strong sense of gender identity at a young age.” Gender identity is understood to be firmly established by age 4 (Fraser, 2009; Schor, 1999). It is possible to block the onset of puberty by means of a GnRH analogue. This buys an individual time before more permanent interventions are decided upon, and allows the individual to develop other areas of their identity as they age. There is evidence that young children who want to pursue transition may decide that they identify with their assigned gender (Steensma & Cohen-Kettenis, 2011). However, there is substantial data confirming that GD is not likely to subside with at onset of puberty (Spack et al., 2012). Keeping this in mind, there is research that illustrates that leaving GD unaddressed or unsupported in children and adolescents will most likely have a detrimental impact on their psychological wellbeing (Byne et al.; 2012, Fraser, 2009; Drescher & Byne, 2012; Spack et al., 2012; de Vries & Cohen-Kettenis, 2012).

GD was formerly categorized as Gender Identity Disorder (GID) in the DSM-4. The name changed from GID to GD because the diagnosis of GID was considered stigmatizing (Drescher, 2010; Zucker, 2013). GD describes the discomfort individuals experience with the gender they were assigned at birth and the associated societally imposed gender roles; identities differing from assigned gender at birth are no longer labeled as “disordered.” The benefits to continuing to utilize the diagnosis GD include

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access to treatment, and insurance reimbursement (Reitman, 2014) and it emphasizes the potential distress, impairment, and increased risk of suffering or disability that may be associated with gender identity not matching assigned gender. Overall, the American Psychiatric Association found that this was received well by gender nonconforming communities (Zucker et al., 2013). GD was also decoupled from the Sexual Dysfunctions and Paraphilias chapter and sexual attraction specifiers were removed, as sexual dysfunction, paraphilias, and sexual attraction are unrelated to gender identity. Diagnosis criteria were also made to be polythetic in form: meaning that one criterion was not made essential to be diagnosed with GD. It also included the inclusion of a subtype pertaining to the presence or absence of disorder of sex development (DSD), and the inclusion of post-transition specifier for adolescents/adults (Zucker et al. 2013, p. 903-906).

Recommendations and standards for sound hormone and surgical interventions with adolescents. Hormone therapy reduces the presentation of the secondary sex characteristics of an individual's natal sex and replaces endogenous sex hormone levels using the methods of hormone replacement treatment for hypogonadal patients. Endocrinologists manage dosage, observe patients for adverse reactions, monitor hormone levels, and look for appropriate signs of virilization or feminization. They are also responsible for discussing the possible adverse outcomes of cross-sex hormones. It is recommended that opposite sex hormones be initiated at approximately 16 years of age. Those under 16 years old have pubertal or hormonal suppression to prevent secondary sex characteristics from developing. It has been recommended that this treatment be initiated when physical changes of puberty start to be observed and are confirmed by levels of estradiol and testosterone (Hembree et al., 2009).

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Surgical interventions are included for female to male and male to female transition. Removal of endogenous gonads and mastectomies can be considered, and are permanent. It is recommended that surgery be deferred until an individual is at least 18 years of age (Hembree et al., 2009).

Recommendations and standards for sound mental health practice with adolescents. In 2012, Coleman et al., on behalf of the WPATH presented *Standards of Care 7 (SOC) for the Health of Transsexual, Transgender, and Gender Nonconforming People*. The SOC's scope includes all ages, all presentations of gender variance, and all treatments to be considered when working with clients. The SOC outlines the assessment and treatment of adolescents with GD, highlighting the differences in phenomenology, developmental course, and treatment approaches from adult clients (p. 172).

Despite the SOC, there is a lack of consensus regarding fundamental issues in treating these age groups (Drescher & Byne, 2012), and there are few articles published in 2013 or 2014 regarding adolescents. In 2012, the DSM IV had not evaluated treatments of gender identity disorder and the Board of Trustees of the American Psychiatric Association therefore formed a task force to do a critical review of literature of treatment of gender identity disorder (Byne, et al., 2012). Gender identity disorder has been since removed from the DSM and the symptoms and demographics once used to diagnose have been gathered under the diagnosis of GD in the DSM V. The American Psychiatric Association task force determined there is a lack of randomized controlled treatment outcome studies of children and adolescents with any presentation of gender variance, meaning recommendations for best treatment are left primarily to expert opinion. Expert opinions vary and are influenced by “theoretical orientation, as well as

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assumptions and beliefs (including religious) regarding origins, meanings, and perceived fixity or malleability of gender identity” (p.763).

Additionally, primary caregivers have ultimate control over decisions made in their child’s treatment including what providers are seen and what treatments are pursued. Legally, guardians must make decisions on their child’s behalf. The task force identified the subsequent suggestions for treatment: (1) to accurately evaluate the gender concerns precipitating the referral; 2) to accurately diagnose any gender identity related disorder to the child according to the criteria of the most current DSM; (3) to accurately diagnose any coexisting psychiatric conditions in the child, as well as problems in the parent-child relationship, and to recommend their appropriate treatment; (4) to provide psychoeducation and counseling to the caregivers about the range of treatment options and their implications; (5) to provide psychoeducation and counseling to the child appropriate to his or her level of cognitive development; (6) when indicated, to engage in psychotherapy with the appropriate persons, such as the child and/or primary caregivers, or to make appropriate referrals for these services; (7) to educate family members and institutions (e.g., day care and preschools, kindergartens, schools, churches) about gender variance; (8) to assess the safety of the family, school, and community environments in terms of bullying and stigmatization related to gender atypicality, and to address suitable protective measures (p. 764).

Two clinics (one in Canada and one in the Netherlands) have gathered data to provide an empirical experience base on treatment of gender variance in adolescents (ages 12-18). Existing literature is still too limited to develop an American Psychiatric Association Practice Guideline for treatment of gender variance in adolescents but the

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task force has identified three major tasks: (1) psychiatric and psychological assessment to both assure that any psychopathology is adequately diagnosed and addressed, and to determine whether the clinicians' approach will be neutral or supportive with respect to the desire to transition in gender; (2) provision of psychotherapy as indicated by the initial assessment and as indicated by changes over time. This includes providing psychological support during the real life experience and suspension of puberty and/or the administration of cross-sex hormones; (3) assessment of eligibility and readiness for each step of treatment (Byne, et al., 2012, p.765). The publication by the American Psychiatric Association task force stresses the critical need for an American Psychiatric Association position statement on the treatment of Gender Identity Disorder, and a concurrent emphasis to be in the field on ameliorating the need for mental-health service providers with expertise in treating gender identity disorder (Byne, et al., 2012).

In early 2015, Tishelman et al. published, "Serving Transgender Youth: Challenges, Dilemmas, and Clinical Examples." Tishelman et al. wrote that the WPATH SOC7 and the American Psychological Association task force guidelines are helpful, but do not focus enough on the issues specific to transgender *youth*. The Tishelman et al. study looks at the Gender Management Services program (GeMS). GeMS utilizes the treatment recommendations for treatment with lesbian, gay, bisexual, and transgender adolescents from the Society for Adolescent Health and Medicine (2013) and practice parameters from the American Academy of Child and Adolescent Psychiatry (2012). With these two protocols, coupled with GeMS' gender affirming model (Hidalgo et al. 2013) as well as the passing of time, the GeMS clinic developed into a flexible, individualized approach to care.

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The Gender Management Services program's protocol, including intake, psychological evaluation, medical intervention, expectations of the child and family, psychosocial considerations, and service gaps, are clearly outlined in "Serving Transgender Youth: Challenges, Dilemmas, and Clinical Examples." GeMS is the first multidisciplinary gender clinic set in a pediatric academic center to serve gender variant youths. The publication focuses on the model of care, focusing on the psychologist's role with the youths and families assisted (p. 37). The GeMS' mental health protocols were developed by supporting their lead psychologist to train with Peggy Cohen-Kettenis, PhD, and her team, who are based in Amsterdam. Cohen-Kettenis and her team were the first to research the assessment and treatment of gender variant youth and their families. With this influence, GeMS began with a focus of working with the youths to manage psychosocial challenges,

such as managing family responses, including anxieties and discord related to atypical gender expressions and/or disclosures of children; managing peer, school, and other social circumstances in contexts that were often less than accepting; and managing mental health issues.

...a social worker joined the team to conduct prescreening telephone intakes, aid families in finding resources, and to help develop written clinic protocols in collaboration with the psychologist (p. 38).

In the past five years, providers who work with adolescents and gender identity have begun publishing about an "affirmative approach" (Byne et al., 2012; Hildago et al., 2013; Malpas, 2011). The idea behind the affirmative approach is that providers work to

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affirm individuals and their families, as well as all aspects of their identities. This approach is informed by:

(a) gender variations are not disorders; (b) gender presentations are diverse and varied across cultures, therefore requiring our cultural sensitivity; (c) to the best of our knowledge at present, gender involves an interweaving of biology, development and socialization, and culture and context, with all three bearing on any individual's gender self; (d) gender may be fluid, and it is not binary, both at a particular time and if and when it changes within an individual across time; (e) if there is pathology, it more often stems from cultural reactions (e.g., transphobia, homophobia, sexism) rather than from within the child (Hidalgo, et al., 2013).

Goals of the model are to listen to the child and family, and together understand the identity of the child. Gender identity is defined on a case-by-case basis as the gender articulated by the child. The model draws from a study by Milton Diamond (2000), "...we understand gender identity, both in its match and mismatch with assigned natal sex, as primarily informed by a child's cognitions and emotions, rather than by genitalia and observable external sex characteristics."

Recommended treatment is one step in the journey toward providing the best treatment. Fraser (2009) describes researching ways to eliminating barriers to sexual health, learn from other cultures, effectively train allied health professionals, challenging discrimination and stigma, and to best improve protection by law and public policies as an effective way to help improve care provided to individuals diagnosed with GD.

Table 1

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DSM-5 Criteria for Gender Dysphoria (in adolescents/adults)

- A. A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration, as manifested by at least two of the following:
- B. The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning

Specify if: With a disorder of sex development (e.g. a congenital adrenogenital disorder such as 255.2 [E25.0] congenital adrenal hyperplasia or 259.50 [E34.50] androgen insensitivity syndrome).

Specify if: Posttransition: The individual has transitioned to full-time living in the desired gender (with or without legalization of gender change) and has undergone (or is preparing to have) at least one cross-sex medical procedure or treatment regimen—namely, regular cross-sex hormone treatment or gender reassignment surgery confirming the desired gender (e.g., penectomy, vaginoplasty in a natal male; mastectomy or phalloplasty in a natal female).

CHAPTER III

Methodology

The goal of this descriptive study is to determine what is common practice for endocrine intervention with adolescents diagnosed with GD or seeking treatment related to gender identity across the United States. A mixed-method exploratory online survey has been created to investigate what gender clinic protocol is for interacting with clients. The survey and its questions are based on Drescher & Byne's work (2012) that outlines ideal outcomes and values for clinical providers to consider when formulating program guidelines for the treatment of children and adolescents.

The survey was reviewed to ensure the language used was suitable and directions and questions were comprehensible. No reliability or validity tests were done for the survey instrument. Before use, the survey was referred to two professionals in the social work field, a psychiatrist who focuses on treatment of gender non-conforming clients, and an endocrinologist who treats adolescents diagnosed with gender dysphoria.

Sample

Participants were "gender clinics," defined by this study as endocrine or multidisciplinary clinics or departments that treat individuals diagnosed with gender dysphoria pursuing hormone treatment. Using non-probability, purposive sampling thirty-two gender clinics were identified using the Resource List: Clinical Care Programs for Gender-Nonconforming Children and Adolescents collected by Hsieh and Leininger, published in the *Pediatric Annals* (2014). Additional clinics were identified in a search for endocrinologists who manage hormones for transgender clients by state, using the Google search engine, transgender health resource websites, and recommendations by

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professional colleagues. This created a total 105 potential gender clinics. One individual from each gender clinic was responsible for filling out the survey. Any program employee that works at the gender clinic may complete the survey. Respondents were asked to report their role at the clinic. The goal was to have as many gender clinics participate as possible, with an attempt to enlist at least one clinic or provider from each state. One hundred clinics were contacted with a hope to yield at least fifty clinics with a broad geographical spread and variation will be included.

Selection criteria for participants required that gender clinics be able to discuss treating adolescents up to and including hormonal intervention and surgical referral. If there is no gender clinic in a state, endocrinologists who specialize in treatment with GD will be contacted. Additionally, clinics and providers were encouraged to recommend other clinics in their area to extend the reach of the survey.

Recruitment

Clinics were initially recruited by email (Appendix A) to invite them to participate in the study. The email contained a brief explanation of what the study entailed, an explanation of informed consent, and a statement that participation was completely voluntary. For gender clinics that did not have an email contact online, a preliminary phone call was made. If contact was made via phone the person at the clinic was asked the following questions: 1) who at their gender clinic is available to best answer a survey as described; 2) if they would like to participate in the survey; 3) for an email address for whomever they select as most able to answer the survey questions. Follow up included a form email with a link to the survey.

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Ethics and Safeguards

The thesis proposal was submitted and approved by the Human Subjects Review Board (HSRB) at Smith School for Social work to ensure acceptable measures were taken in the design of the research study (Appendix C).

Informed consent was included in both the emails and the first page of the survey. Informed consent covered the potential risks and benefits of participation, the ethical standards and measures to protect confidentiality, and the researcher's contact information (Appendix C). Participants were informed that participation in the online survey would serve as their acknowledgement of informed consent and their agreement to participate. Participants were also informed that the survey was in no way mandatory and that they might choose not to participate or might leave the survey at any time, and therefore would not be included in the study.

There were no identified risks from participating in the survey. No judgment was applied to these programs or providers; the survey was intended to be a descriptive study of current practices. However, gender clinics could benefit from participating in this survey because the survey stands to find strengths and gaps in current treatment protocol across the country. By participating, clinics provided information that might further other clinics' abilities to provide optimal care for patients. Ultimately, they would be contributing to the community they are serving already. At the end of the survey, participants had the option to access direct links to the American Psychological Association's and the American Psychiatric Association's recommendations, the WPATH SOC7 recommendations, the Endocrine Society's recommendations, and transgender health support groups across the nation.

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Data was collected only through Survey Monkey and only the researcher saw the collected data. Program or provider names were not published at any point, though the state of practice and additional de-identified demographics were included to describe differences between samples and explain perceived needs of clients specific to each gender clinics. De-identified demographics included establishing whether the clinic was in a rural area, town, or city, describing whether the clinic was part of a larger hospital or a research institution, and if known, how many child and adolescent clients they saw annually.

The data collected from gender clinics contained no sensitive or identifying information. There also were no responses that divulged information about clients served at the gender clinics. Data was stored on the survey monkey website in a private account that is password protected. It is also temporarily stored on a password protected personal desktop computer as a “.pdf” file. All data will be kept secure as password protected files for three years as per federal regulations. Both the online data and the personal computer data will be destroyed at this time.

Data Collection

Data was collected by a mixed-methods Survey Monkey survey. The survey was emailed out to clinics that have been identified as gender clinics. The form email can be found in Appendix A. Small changes in the language were made to the email (see appendix E). If gender clinics were not reachable by email, they were contacted by phone using the script found in Appendix B. All clinics were contacted with a reminder emails after their first email contact (Appendix H). The survey consists of four sections, including multiple choice and open-ended questions (Appendix C).

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The first section of the survey invites the survey taker to participate. The second section of the survey provides informed consent and if the survey taker agreed to participate in the survey, they automatically continued with the survey. If the survey taker declined to take the survey, they were automatically directed out of the survey. The third section of the survey collected demographics of the survey participant, including the survey taker's role at the gender clinic, the gender clinic's relationship to hospitals or research institutions, and if known, how many child and adolescent clients they see annually. This section also asked what disciplines were included on site at the gender clinic. This information may help in understanding what types of programs are associated with what protocol that is addressed in the fourth section. The fifth and final section asked what exceptions and improvements are made in the gender clinic where the survey participant who is taking the survey works. The original survey did not have a question regarding reasons not to continue with treatment, and this was added just prior to sending out the survey (see Appendix F).

I have constructed this survey based on an article by Drescher and Byne (2012), which questions what treatment is recommended for adolescent clients. I wanted questions in the survey to respond to literature that suggests is that there are not specific protocols published regarding treating adolescents with gender dysphoria and gender variance in the United States. I kept some questions short answer because a yes or no can explain what the gender clinic is like or what influences their protocol. I included "Other" on many questions in order to leave room for differences amongst clinics that I may not have accounted for. I included long answer open-ended questions for the same reason, to account for the differences between gender clinics, and also to provide potential depth

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that could be involved in describing how their program protocol is organized. Because this survey is meant to describe, not measure, gender clinics, the survey has not undergone reliability or validity tests.

The research question of this study was developed at the adolescent gender clinic “M” where I work. This clinic was not included in the study. The WPATH SOC7 guidelines and the Endocrine Society Guidelines influence M’s protocol for working with adolescent clients. M has encountered situations where these guidelines do not outline clearly enough what interventions would be most effective for clients and their families in all situations. M’s administrators were curious to see what other clinics did in various situations, what exceptions were made for clients, and what other gender clinics saw as the most important aspects of treatment. Gender clinics contacted to participate in the study are also working with adolescents who are looking to develop their gender identity.

In this study it was not possible to ask follow-up questions to responses, in part because surveys were collected online and because they were anonymous. This was intended to allow clinics to answer without feeling they may be misrepresented, and also to be sensitive to the length of time responding to the survey might take.

Data Analysis

No specific questions were required for surveys to be included in the analysis but it was expected that a majority of the questions would have responses.. Twenty respondents were included in this study, 65% of whom completed the survey, the remaining finished 75% or more of questions. Descriptive statistics were used to characterize the gender clinics that respond to the study and the data collected regarding gender clinic programming was described in the findings and discussion sections.

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Short and long answer open-ended questions were examined using thematic analysis. Possible categories for types of protocol were noted as the researcher read responses. Themes identified include: access to treatment; gender clinic staffing; the diagnosis of gender dysphoria and its role in treatment; the importance personalization of treatment; the involvement of mental health in treatment; and the critical impact of social and family support.

CHAPTER IV

Findings

This study attempts to understand the protocol of gender clinics when they are working with adolescent clients diagnosed with GD or seeking treatment related to gender identity. Gender clinics completed a survey (Appendix C). This chapter will first present the demographics of the sample. It will then discuss themes and differences in program protocols, exceptions to treatment, and suggested improvements as written by the survey takers. The study does not intend to rate gender clinic responses. It strives to describe strategies and protocols that are being used by individual gender clinics across the United States.

One hundred and five gender clinics were identified and sixty-one were contacted by email. Clinics emailed were sent reminder emails. The remaining forty-four clinics were contacted by phone. Twenty phone numbers failed to connect to a provider who worked with adolescents and gender identity. It was found that many clinics had ceased to exist or staff members who had worked with adolescent clients had retired. The remaining twenty-four were left messages on machines or with administrative assistants. None of these potential gender clinics called back. They were recalled one more time (a total of two times). No responses came through this method.

A total of twenty-four survey responses were collected for this study. Four gender clinics consented to participate and failed to complete any questions on the survey, and were thus excluded from the survey. Though twenty gender clinics were included in the survey, only eighteen gender clinics answered a majority of questions, and thirteen of those clinics answered all questions.

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One clinic did not provide hormone or surgical intervention for clients, but provides education to clients regarding treatments, and makes referrals for endocrine and surgical consults. They were included in the findings because they provided meaningful answers regarding working with adolescents and their gender identity.

Demographics

I asked about location of gender clinics to know where in the country responses were coming from, while allowing clinics to maintain anonymity. Five clinics responded from New England (Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut). Four responded from the Middle Atlantic region (New York, New Jersey, Pennsylvania). One responded from the East North Central region (Ohio, Indiana, Illinois, Michigan, Wisconsin). Three responded from the West North Central region (Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, Kansas). One responded from the South Atlantic region (Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida). One clinic responded from the West South Central region (Arkansas, Louisiana, Oklahoma, Texas). One responded from the Mountain region (Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, Nevada). Four clinics responded from the Pacific region (Washington, Oregon, California, Alaska, Hawaii). No clinics responded from the East South Central region (Kentucky, Tennessee, Alabama, Mississippi).

There are a large variety of types of communities served by clinics. Different types of communities can present different barriers to treatment (e.g. rural communities might not have public transportation, urban communities might have more options for mental health providers) so I asked clinics to describe their population. One clinic

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reported serving a rural community, eleven clinics reported serving urban communities, five clinics reported serving a population comprised of urban, suburban, and rural communities, one clinic reported serving a suburban community, one clinic reported serving a population that combined suburban and rural communities, and one clinic reported serving a population that combined urban and suburban communities.

It is hard to measure the exact percentage of adolescents who identify as transgender or gender nonconforming as compared to adolescents who identify as cisgendered or binary gender conforming. Many individuals do not have access to gender clinics until they are adults. In hindsight, it would have been best to ask for an approximate average per year and an approximate total number of clients served. Stating the question this way may have led to more specific answers numerically. Thirteen of these clinics report they work with fewer than 100 individuals per year by providing hormone intervention, five clinics reported work with 100-200 individuals on average per year, and one clinic reported they work with 200-300 individuals. One clinic did not respond. When it came to working with gender identity, fifteen clinics reported that they work with fewer than 100 individuals regarding gender identity in a year, three clinics reported that they work with 200-300 individuals, and two clinics reported they work with 100-200 individuals.

Clinics were asked if they continue working with clients if clients decide not to pursue hormone intervention. Sixteen clinics did continue to work with clients if they chose not to pursue hormone treatments. Four clinics do not continue to work with clients if they decide not to pursue hormone treatments. One of these clinics specified that they refer individuals to psychology. I was also curious if clinics refer out for surgery, which

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for some would be the next step after either hormone intervention. Eighteen clinics responded that they do refer clients for surgical consults, and one clinic responded that they do not. One clinic declined to answer.

Multidisciplinary approaches are written about in the literature, and I was curious to observe what types of providers were involved in gender clinics. Individual responders included seven endocrinologists, one nurse practitioner, one member of the nursing staff, one psychiatrist, one community educator, three adolescent medicine specialists, one clinical supervisor of mental health, one family practice doctor, one OB/Gyn physician, one family physician, and one responder who identified as “owner/operator and main healthcare provider.” As for their entire staffing, twelve clinics reported having registered nurses, eleven clinics reported having endocrinologists, ten clinics reported having psychiatrists, nine clinics reported having clinical social workers, six clinics reported having psychologists (PhD or PsyD), six clinics reported having case management social workers, five clinics reported having nurse practitioners, four clinics reported having community educators, five clinics reported having adolescent medicine specialists, three clinics reported having licensed professional counselors (LPC), one clinic reported having interns in MFT and LPC graduate programs (interns), one clinic reported having internal medicine and family practice doctors, one clinic reported having a physician assistant and one clinic reported having gynecology. Table 1 illustrates the demographics of the gender clinics responding.

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Table 2

Demographic Characteristics of the Responding Gender Clinics

n=20		
Location	New England	5
	Middle Atlantic	4
	East North Central	1
	West North Central	3
	South Atlantic	1
	Mountain	1
	Pacific	4
	East South Central	0
Type of Population Served	Rural	1
	Urban	11
	Suburban	1
	Suburban and Rural	1
	Urban and Suburban	1
	Rural, Suburban, and Urban	5
Rough Estimate of Clients per year regarding hormone intervention*	Fewer than 100	13
	100-200	5
	200-300	1
	Above 300	0
Rough Estimate of Clients served per year regarding gender identity	Fewer than 100	15
	100-200	2
	200-300	3
	Above 300	0
Clinics that continue care if there is no hormone intervention	Yes	16
	No	4**
Surgical Referral	Yes	18
	No	1
	Unanswered	1
Disciplines onsite	Endocrinologists	12
	Nurse Practitioners	5
	Registered Nurses	12

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	Psychiatrists	10
	Clinical Social Workers	9
	Psychologists	6
	Case Management Social Workers	6
	Community Educators	3
	OB/GYN Physicians	1
	Adolescent Specialist Physicians	5
	Family/Internal Doctor	2
	LPC	3
	Interns	1
	Physician Assistant	1
Participant role at clinic	Endocrinologist	7
	Nurse Practitioner	1
	Nursing Staff	1
	Psychiatrist	1
	Community Educator	1
	Adolescent Specialist Physician	3
	Family Practice Doctor	2
	Co-Director/healthcare provider	1
	OB/GYN Physicians	1
Disciplines at the gender clinic	Multidisciplinary	18
	Endocrinologist only	2

* *one clinic did not participate*

** *One clinic specified that they refer clients to psychology.*

Program Protocols

The WPATH SOC7 gives recommendations for providers on how to provide the best treatment for individuals when it comes to actualizing gender identity. I was curious to see what recommendations clinics are using, so I asked if their program utilizes the WPATH SOC7, and gave clinics an option to respond with “other” recommendations that they use. Ten clinics responded that they use the World Professional Association for Transgender Health’s (WPATH) Standards of Care to inform their program protocols. Nine clinics responded that they use a different standard or treatment recommendation to inform their protocol. Of these nine clinics, three clinics responded that they use the

Endocrine Society Guidelines and WPATH guidelines in combination, two clinics responded that they use the Endocrine Society Guidelines alone, two clinics responded they use WPATH and “also use informed consent method,” one clinic responded they use “harm reduction” to inform their protocol, and one clinic responded “WPATH and others.” One clinic declined to answer this question.

The diagnosis of gender dysphoria is a recent edit to the DSM-5, and is still controversial, as many believe gender identity should not be considered a mental health issue. I asked clinics if a diagnosis of gender dysphoria is assessed or required for treatment. Ten clinics responded that a DSM-5 diagnosis of gender dysphoria is always required for treatment before moving forward with hormone treatments (or surgical referral). Seven clinics responded that it is assessed but it is not required for treatment. One clinic responded that GD is neither diagnosed nor required for treatment.

As there are no official recommendations published in the United States regarding requirements for treatment, I was curious to see what clinics required with regard to mental health status assessment before treatment begins. Fourteen clinics responded that they require a psychological assessment from a mental health professional before considering hormone or surgical interventions, five clinics reported that they do not require a psychological assessment before considering hormone or surgical interventions, and one clinic declined to answer. All fourteen of the clinics that require a psychological assessment also require letter or letters from a mental health professional before considering hormone or surgical interventions. The same five clinics that do not require a psychological assessment do not require a letter or letters from mental health professional. The same clinic that declined to answer the previous question also declined

to answer this question. This clinic reported that they are primarily endocrinology and did not complete the remainder of survey.

Table 3

Program protocols

n=19		
Guidelines used for protocol	WPATH	10
	Endocrine Society and WPATH	3
	Endocrine Society	2
	WPATH and Informed Consent Method	2
	Harm Reduction	1
	WPATH “and others”	1
Gender Dysphoria Diagnosis*	Required	10
	Assessed not required	7
	Not required	1
Psychological Assessments*	Required	14
	Not required	5
Letter from mental health professional	Required	14
	Not required	5

**one clinic skipped this question*

Involvement of mental and behavioral health. I asked clinics if mental health professionals are involved in determining whether or not to recommend hormones or surgical consults. Fourteen clinics responded that behavioral or mental health services are always involved in determining whether or not to recommend hormones or surgical consult. Two clinics responded that behavioral and mental health services are not typically involved in determining whether or not to recommend hormones or surgical consult. Three clinics responded “other,” and their answers were as follows:

“Sometimes—case by case,” “They are recommended but not required,” and “for hormones if the provider feels mental health services would be helpful. [F]or surgery,

most surgeons require mental health letters so we link people who need that to services.” The remaining clinic did not respond to any mental health-related questions.

When asked in what capacity behavioral or mental health service is involved for adolescents in their families, sixteen clinics responded. Three clinics did not respond to this question. Two clinics that did not respond were clinics that answered they do not require mental health and one other clinic did not respond to this question. Seven clinics described mental health as having involvement in the initial assessment, diagnosis, ongoing counseling, and letters of support. One of these clinics added “supportive therapy, family therapy, psychological assessment.” One clinic stressed the importance of informed consent: “we provide informed consent information about the procedures, and help individuals/families determine if/when it is the best move forward. We provide MH assessment if the client is pursuing medical care from a provider who requires a letter from a MH professional; we also inform clients about informed consent model providers in the community. We provide comprehensive mental health services, as well as group/community building, advocacy, and education services.” Six clinics responded that clients are referred as needed, or as requested. One of these six clinics specified that “They [mental health services] are not part of the clinic, but I work with outside therapists. They are to support the adolescent/family during transition.” Two clinics stated that they do “require” therapy before starting treatment. One clinic responded “6 months of counseling with a gender therapy specialist is required before starting treatment.” In a similar vein a clinic responded, “I require teens on blockers and hormones to be followed by a therapist. They don’t always do it, however. I still see them if they don’t.” One clinic responded that services are “out [patient] consults.” Another

clinic responded “Therapists refer clients to me for HRT [hormone replacement therapy].”

Information gathered from clients. Careful assessment of each individual client has been noted as important in the literature. Fifteen clinics responded to the open-ended question “What information do treatment providers require about their client’s history to determine if it is appropriate to start hormone treatments.” One clinic responded that they perform a “comprehensive H&P [history & physical] including a full HEADSS¹ Assessment.” (¹ H.E.A.D.S.S. Home & Environment, Education & Employment, Activities, Drugs, Sexuality, Suicide/Depression is a psychosocial interview for adolescents.) Nine other clinics echoed this saying they do clinical evaluations of the adolescent and their family. Two clinics explained that they rely on a letter from a therapist stating the diagnosis and they are in favor of treatment. Two clinics described that they require what is in the WPATH outlines.

Information communicated to clients. It is also important to educate clients about what treatments and support are available. Twelve clinics responded to the question “What information is delivered to clients and their families to fully explain the expectations and implications of sexual reassignment treatment processes?” One of the twelve clinics knew the answer to this question only regarding their adult clinic, not pediatric. They explained that it is likely similar, and the adult clinic “communicates informed consent form with risks and benefits.” The remaining eleven clinics also stated that risks and benefits were communicated to the families. Two of these clinics clarified that they also explain the processes and requirements of treatment. One clinic responded that they discuss alternatives to hormone intervention or surgery.

Clinic involvement in social systems. Social and familial support has been found to be vital in healthy transitions for adolescents. I asked clinics what social systems in a client's life the clinic works with, and seventeen clinics responded. All of these clinics work with family members, twelve of the clinics work with schools, six of the clinics work with places of employment, and five of the clinics work with neighborhoods. One clinic noted, "we also advocate at larger systemic levels to increase access to care opportunities." Another clinic noted that they work with "churches." Another clinic responded that they work with "whatever is needed."

Deciding not to move forward with hormone intervention. Fourteen clinics responded to the question asking what reasons their clinic has chosen not to move forward with hormonal or surgical intervention. These reasons could be helpful "red flags" for other clinics encountering something that is new to them, or it could be worth research whether or not these "red flags" are always reasons to delay or stop treatment. One clinic responded "none as of yet. We are working with a patient who has some cognitive limitations and unstable housing and other psychosocial stressors to get them stable and determine appropriate course of treatment." Another clinic noted that it "very rarely happens- usually because of patients' ambivalence or not feeling ready themselves. Other more common reasons are lack of parental consent of patient less than 18." Six other clinics also mentioned that lack of parental consent has slowed or stopped treatment. One of those six clinics specified that danger in the client's community has also stopped treatment from moving forward. Five clinics noted that significant suicidal ideation or unstable mental health concerns (including dissociation, hallucinations, delusions) would prevent them from moving forward. Two clinics noted their only

reasons for not moving forward were “client un-educated about surgical procedures, desired outcomes not realistic for hormonal therapy” and “not wanting to transition to male, just wanting to look less feminine.” A third said that a “client’s lack of understanding” of treatment was a reason to delay or defer intervention. Three clinics discussed the issue of the child or adolescent is still exploring gender fluidity and not sure of semi-permanent changes, as reasons not to continue with hormone therapy or surgical intervention. Three clinics specified that gender dysphoria criteria must be met. One clinic stated clearly that if the client did not follow through with recommendations, it was grounds for not moving forward. One clinic mentioned that a client changing their mind has contributed to not moving forward as well. The same clinic also mentioned that if coercion by a partner or family member appears present, the clinic would decide to stall or defer treatment. One clinic mentioned “in doing my assessment, regardless of what the therapist may have written in their letter, I feel the client is not a candidate or a candidate at that time.”

Exceptions made to treatment. It is common knowledge that when you are working with an individual, their situation will be different from that of other individuals you have worked with, no matter the context. In the mental health and medical world this sometimes means making accommodations tailored to specific needs. Gender clinics were asked if and what exceptions were made to treatment. Seventeen clinics responded that there are exceptions and alterations made to treatment protocols made for individuals. No clinics responded that they do not make exceptions. Twelve clinics specified what exceptions are made. One clinic summed it up as “Too many to enumerate. By definition, they are personal and individual. All circumstances are taken

into account.” Another clinic listed off several reasons for exceptions, “geography, finances, religious, social, professional,” as their answer.

Financial and location exceptions from different clinics included “if insurance lapsed, could alter timing of follow up labs to wait for new insurance”, “Inability to follow up routinely due to circumstances beyond their control (transport, finances, etc...)”, “Financial reasons, unable to get to therapy or follow through,” “People have done Skype therapy, people have had no access to mental health.”

Three gender clinics included finance and location issues and also elaborated on what else they may assess families for in order to make exceptions while still providing what they considered safe and appropriate treatment. One clinic said:

Exceptions are made for many families based on distance, already having time to come for assessment visits based on additional children or work responsibilities, if the child/youth has already been living as their true gender for years and has a good relationship with an outside provider (we’ll get collateral information versus having to see the child for 3 full assessment visits).

Another clinic said:

If transportation is a barrier, we conduct phone therapy or may abbreviate the assessment if the client presents as well informed with high social support. For families in which the client has lived socially in their gender identity and the medical procedure is a natural next step we sometimes abbreviate the assessment.

The third and final clinic said:

We do not have specific requirements for visits, and if mental health is included in a patient's care, the goal is to do so close to home, and through free services if needed. If a parent will not consent for a minor, and the team believes that starting cross gender hormones is in the best interest of that patient, this will be discussed with the ethics board. In general I see patients one month after starting hormones, and every three months thereafter. Prior to starting hormones, visit frequency is dependent on patient needs and circumstances.

Perceived most important aspects of treatment. Gender clinics were asked what is the most important aspect of treatment planning their program recommends. The goal of this question was to highlight what gender clinics found most valuable in their protocol, so that it could be understand what providers believe is effective in treatment. Twelve clinics responded to what they felt is the most important aspect of treatment planning that their program recommends. One clinic specified that “staying ‘healthy and happy’” is the most valuable thing in treatment. Two clinics specifically mentioned routine medical and mental health follow-up, and one of these clinics specified getting prior-authorizations from insurance for expensive treatments as important. Communication and a “mutually collaborative approach” were highlighted by three clinics, specifically regarding “explanations of process” and complications. This is similar to a clinic that mentioned that “coordination of care with [a] therapist” is important. Four clinics mentioned that supportive communities and networks, including parents are important. These clinics also mentioned that “a plan for transition” is

important along with on-going mental healthcare. Another clinic mentioned that “providing psychosocial support to patients with gender questions” is important.

Future Improvements

The providers at these gender clinics get to see on a daily basis what works and does not work with clients, and perhaps, hear first hand from clients what did not work for them at other gender clinics. Second to their clients, gender clinic providers are most in tune about what is working in the current system of health care when working with adolescent clients and their gender identity. Gender clinics were asked what could be done more effectively or differently when working with clients seeking treatment related to gender identity, ten clinics responded. One clinic’s response was not included in discussion because their response stated, “In my office? No. In other offices? No way of knowing. In this country? I don’t have the time to answer that question, and Survey Monkey does not have enough space to accommodate my answer.”

Two clinics mentioned improvements to financing treatment would be helpful, specifically saying if “all our care is free to patients” it would be an improvement and “improvement in insurance coverage of mental health and medical interventions. Very often adolescents are brought in too late for puberty suppression.” This comment related closely to,

The earlier that patients with gender identity issues are [brought] into care, the better the outcomes... both from a mental health perspective and a physical outcome perspective. So I think earlier discussions, or even any discussion, of gender with patients and [parents] would be great.

One clinic that had several providers on site working separately from one another described wanting “a multidisciplinary clinic where providers can easily communicate and patients can see all in one visit.” This was echoed by another clinic that mentioned they would like to “have more staff,” and another clinic noted they wished they had a “nurse coordinator to help me with these patients. I had one before, but lost her due to budget cuts.”

Another clinic pointed out,

The DSM diagnosis of dysphoria does not fit all clients. Some are not dysphoric. Eventually, this is not a mental health concern; gender lives outside of our psychological experience, and should be treated as a primarily medical issue. Informed consent models are likely the best way forward.

In similar, though more administrative veins, a gender clinic said, “electronic medical records need a way to record gender and a non-binary alternative,” and another clinic noted that they wished for “more rigorous and standardized psychological testing.”

With twenty gender clinics that responded and 65% of clinics fully completing the survey, there are many emerging themes relating to gender clinic staffing, exceptions and difficulties to be mindful of, including what the scope of treatment includes, and how to best serve clients. In the next chapter there is a discussion of the findings, the strengths and the limitations of the study, the findings’ potential implications for the study of intervention with clients with a diagnosis of GD or seeking treatment for gender identity, and the potential implications for the field of social work.

CHAPTER V

Discussion

The aim of this mixed methods study was to explore gender clinics' protocols for hormone and surgical intervention with adolescent clients. This discussion reviews the study's findings, including its implications for research, theoretical frameworks regarding gender identity, and the social work field. The chapter will discuss obstacles and limitations in this research project.

Strengths and Limitations

This survey is one of the first of its kind to focus exclusively on adolescent gender clinics. The data and conclusions drawn therefrom could have tremendous influence on how protocol is implemented in the future. This influence is tempered by the small number of respondents. Although the small number of respondents could be indicative of the study design, when data collection began it was found that the prospective sample of adolescent gender clinics was much lower than originally anticipated. There could be limited value to the conclusions that are drawn from such a small sample size.

The survey was written for this study and has not been used in data collection before. Thus, the responses may not have captured all the relevant information. Nonetheless some valuable conclusions can be drawn from the information that was collected.

Access to Treatment

On a regional level, gender treatment for adolescents is generally available, with the exception of the East South Central region (Kentucky, Tennessee, Alabama, Mississippi). The findings of this study are consistent with the limited literature available

on the subject of gender treatment availability for adolescents, which suggests that treatment is most readily available on the Northeast and Northwest coasts, and North Central region of the country (Hsieh & Leninger, 2014). It would be advantageous to study adolescents and adults who have not received treatment for gender dysphoria in regions with low or no responding gender clinics. Additionally, a survey of adult gender dysphoric clients who have received treatment in those regions as compared to regions with more resources for adolescents could indicate how great the need for early intervention is.

On a local scale, the findings paint a more complicated picture. Rural populations are comparatively underserved with only 35% of respondents offering their services in such areas. Suburban populations are similarly underserved, as only 40% of respondents reported having clients from those areas. In contrast, 85% of respondents serve urban populations. This data confirms my experience. Anecdotally, the gender clinic “M” at which I work is located in an urban area and has been working towards providing care for clients who live in rural communities, which has proved very challenging. We have had to accommodate problems such as insurance companies not allowing us to bill for two appointments in the same day, clients being unable to obtain transportation, and having to spend an inordinate amount of time and money to get to our clinic.

This anecdotal experience combined with the findings here suggest that in the future more attention should be given to finding creative solutions to serving rural and suburban communities. A variety of options towards this aim should be given consideration. Communities and providers should examine whether building new clinics, adding shuttle transportation, changing how insurance companies bill for treatment, or

creating mobile clinics could effectively increase accessibility to treatment for rural and suburban populations. Indeed, 30% of respondents noted that distance was a major factor in treatment, and that they attempt to accommodate families who find distance or transportation a barrier to accessing treatment. Other options involve working with other healthcare providers that do not consider themselves part of a gender clinic, through training and education. This study provides information that would apply in crafting protocols for hospitals and primary care physicians when working with gender. If competency around gender identity development were expected of all medical and mental health providers, more clients would have support and access to interventions, and at earlier stages in their development.

It is not important which option makes care more accessible, but access to early intervention must be improved. The literature demonstrates that early intervention can be vital to mental health of gender dysphoric clients (Byne, et al., 2012; Cousino, Davis, Ng, & Stancin, 2014; Schneider et al., 2009; Tishelman et al., 2015). Additionally, from a medical perspective, early intervention improves patient outcomes; intervening early on in puberty prevents clients from experiencing secondary sex characteristics of their natal sex (Coleman et al., 2012; Hembree et al., 2009).

None of the clinics served more than 300 clients per year. This is important because according to the DSM-5 the prevalence of gender dysphoria is .005-.014% for adult natal males and .002-.003% for adult natal females. This suggests that in the United States there are somewhere between 15,000-40,000 people who are diagnosed with gender dysphoria in adulthood. Literature suggests that at least some of these people could have benefited from early intervention. The low numbers served by the respondents

suggest that some cases are still not identified and treated during adolescence. In the future, gender clinics should strive to increase outreach to potential adolescent clients, which may reduce the number of adults who receive no treatment.

Usefulness of the Gender Dysphoria Diagnosis

Nearly all gender clinics use a protocol that requires a diagnosis of gender dysphoria (GD) for developing a treatment plan for adolescents seeking gender treatment. A majority of clinics go so far as to require a substantiated history and a diagnosis of GD for treatment to continue; a minority of clinics (39%) have a protocol that assesses for GD but does not require a diagnosis for treatment to begin. Only one clinic uses a protocol that does not require them to look for a diagnosis of GD. This shows that gender dysphoria is pervasively used by gender clinics as a pre-requisite for treatment. Any protocol relying a diagnosis of gender dysphoria is implicitly relying on the diagnosis in the DSM-5.

One gender clinic that assesses but does not require GD diagnoses stated that the “diagnosis does not fit all clients,” emphasizing that “gender lives outside of our psychological experience, and should be treated as a primary medical issue.” This is similar to the aforementioned ideas in the literature of creating an affirming, non-pathologizing assessment of gender identity when working with clients. The definition of GD in the DSM-V began to shift the focus from psychological disorder of the individual to the biological and social stressors that cause psychological distress regarding gender identity, an approach which is considered vital to treatment in the Netherlands (de Vries & Cohen-Kettenis, 2012) and is becoming prevalent in the United States (Malpas, 2011; Schneider et al., 2009; Tishelman et al., 2015).

Further study of the appropriateness of the diagnosis of gender dysphoria and its usefulness in application is necessary. Post-diagnosis patient outcomes should be analyzed and compared to those who remain undiagnosed, to determine whether the diagnosis is an appropriate screening tool. Moreover, it is important to understand if providers find it helpful to utilize the diagnosis as a component of the treatment protocol or whether they prefer a more individualized approach.

Requirements for Mental Health Intervention

Overall, gender clinic protocol requirements related to mental health intervention are consistent with recommendations from the literature and demonstrate recognition of the mental health needs of the adolescent population. All respondents reported having a protocol that involved mental health intervention. These results comported with currently accepted best practices, which include providing an initial assessment of all clients, and therapeutic support as needed (Byne, et al., 2012; Coleman et al., 2012; Drescher & Byne, 2012). Clinics went on to describe informed consent and clear explanation of the potential consequences as part of protocol for moving forward in treatment, which is congruent with the literature as well (Byne et al. 2012; Coleman, et al.; 2012, Malpas, 2011; Schneider, et al., 2009). The gender clinics also appear to focus not only on the adolescent individual and their gender identity, but also on family therapy and intervention with social supports as something that is an important part of treatment (Byne et al., 2012; Coleman et al., 2012; Drescher & Byne, 2012, Dhejne et al., 2011; Malpas, 2011). The respondents show a commitment to creating a protocol that enables them to adequately care for adolescents and their community.

Multi-disciplinary Staffing

Gender treatment spans a variety of disciplines. Gender clinics are by and large multidisciplinary institutions; 90% of responding facilities reported having staff from both the medical and mental health fields. Unfortunately, a small minority (10% in this study) are staffed exclusively by medical professionals, relying on other institutions for mental health support. Integrating medical and mental health treatment provides a more efficient and effective method of care delivery. Providers are more able to communicate with one another regarding patient-specific situations. Indeed, one of the clinics surveyed reported “a multidisciplinary clinic” would be an improvement, making it possible for clients to see all providers related to their gender identity work in one visit.

The few clinics that are unable to offer multidisciplinary care fail to do so because of budgetary constraints on staffing. One respondent, indicative of a typical multidisciplinary gender clinic, reported employing endocrinologists, RNs, psychiatrists, and LPCs. Even with this sizeable and diverse team, the clinic indicated that “more staff” would improve their ability to provide treatment. Increasing staffing could mean that clients who travel far for treatment or need to take off school to attend appointments could more easily afford and coordinate care in the same location. The literature frequently reinforces the importance of multi-disciplinary teams when approaching gender identity with adolescence (Byne et al., 2012; Cousino, M.K., Davis A.; Ng, H, & Stancin, T., 2014; Eckland, K., 2012; Fraser, L., 2009; Möller, Schreier, Li, & Romer, 2009; Tishelman et al., 2015). Hildago et al. included multidisciplinary networks as well in 2013 saying,

We also encourage the development of informal, multidisciplinary networks, such as our own, comprised of providers who abide by a gender-affirming model of care, are curious about finding answers to the questions about the gender-nonconforming children and youth we serve, and are eminently guided by the oath of our professions: to “do no harm.”

Integration of Family and Social Supports Into the Protocol

Parents or guardians are always involved because adolescents under the age of 18 require parental consent. This is true even in the absence of any mention of them in the protocol. Nonetheless, gender clinics generally utilize a protocol that requires a degree of family therapy and social outreach; 100% of responding clinics reported doing so. The responses demonstrated that protocols integrate family and social supports into treatment in a variety of ways. The report that clinics are working with families is encouraging, as the literature has recognized social supports as influential to mental health for gender non-conforming individuals (Birkett, Newcomb, & Mustanski, 2015; Bockting, Coleman, & Brenner, 2007; Byne et al, 2012; Dhejne et al., 2011, Fraser, 2009; Grossman & D'Augelli, 2007; Hidalgo et al., 2013; Mustanski & Liu, 2013; Toomey et al., 2010; Travers et al., 2012). Hidalgo et al. (2013), Malpas (2011), and Tishelman et al., (2015) all report that they have or have observed collaboration with families throughout the process of treatment, and work with families to help support and affirm gender identity of their child. The WPATH SOC7 (Fraser, 2009) and APA (Byne, 2012) guidelines all suggest that engagement with social networks can benefit mental health development. Future research could study the most effective type of intervention with families and support networks of adolescents seeking gender treatment.

Exceptions to Protocol

As expected, gender clinics recognize that there must be exceptions to protocols; all respondents reported making exceptions to their protocols. While it is admirable that gender clinics recognize that each individual has unique treatment needs, designing

protocols that broadly address the needs of individuals is still preferable to individualized treatment plans. The results of this study provide insight into how protocols might be expanded in the future to be more inclusive. Future protocols might take into account such factors as location, finances, religion, social supports, professional supports, insurance, transportation, level of mental health crisis due to gender dysphoria, and access to mental health supports.

Moving Towards a Uniform Protocol

From the above analysis of the responses from gender clinics that are using different protocols, one can begin to craft a uniform protocol for working with adolescents. First and foremost, the protocol should be accessible to a provider who is not fluent in gender treatment. For example, the protocol could direct providers on how to ask about preferred pronouns of adolescents. The protocol could also include the DSM-5 characteristics for GD, the diagnosis of which is a key component of protocol.

The GD diagnosis is the currently accepted method of determining whether or not treatment is recommended. While there is some dispute as to its necessity, the benefit of implementing it uniformly in protocol outweighs the potential drawbacks and presents an opportunity to better test its efficacy.

In order to accurately assess GD, the involvement of mental health support is essential. Thus, any uniform protocol must include a mental health assessment to be completed by a mental health professional either within or without an organization. Gender clinics with the available resources should strive to meet this protocol requirement by using their own mental health providers. The mental health assessment part of the protocol should include different pathways for different types of mental health

concerns. For example, if someone is living as their preferred gender and has ample positive social support, and no co-occurring mental health diagnoses, the assessment (and protocol) should indicate that they do not need to continue with individual mental health treatment unless they request it.

Family and social support involvement should be incorporated into the protocol by providing options for as many different family status scenarios as possible. For example, if a couple is divorced, the protocol should remind providers that both parents must consent if parents share custody. Another example would be if parents refuse, after a designated number of attempts, to consent to treatment and the adolescent's health is determined at risk, the provider would be directed by the protocol to consult an ethics board associated with their organization.

With each step of the protocol, designated alternative pathways should be based on specific circumstances acknowledging barriers to treatment observed in this study (e.g., location, finances, religion, lack of support). For example, in the part of the protocol that deals with required mental health visits, the provider would be directed to approve treatment with mental health visits of varying frequency and duration (i.e., patients could attend individual therapy less frequently for longer durations, or more frequently for shorter durations).

According to this study, these are the significant components of accepted gender clinic protocol. Future research is necessary to determine the efficacy of the specific parameters of these components. That research would benefit greatly from uniform adoption of them.

Implications for the Field of Social Work

Furthering the creation and implementation of a comprehensive treatment protocol for gender clinics and providers working with clients to realize their gender identity could allow for a clearer understanding of what goals of treatment might be for individuals, and what the best pathways to accomplish them are. In particular, clinical social work intervention and case management services could be more effectively delivered to clients, families, and communities across gender clinics. Per this study and the literature, there is a clear role for clinical social workers in working directly with clients and their families, identifying needs and wants of clients and families, participating on multidisciplinary teams, executing further research of outcomes of treatment related to gender dysphoria, and educating clients, families, and social networks American Psychiatric Association, 2013; Bockting et al., 2007; Byne et al., 2012; Coleman et al., 2012; Schneider et al., 2009; Tishelman et al., 2015).

References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C.: American Psychiatric Association.
- Birkett, M., Newcomb, M.E., & Mustanski, B. (2015). Does it get better? A longitudinal analysis of psychological distress and victimization in lesbian, gay, bisexual, transgender, and questioning youth. *Journal of Adolescent Health, 56*(3), 280-285.
- Bockting, W. O., Coleman, E., & Brenner, A. (2007, September). *Stigma, mental health, and resilience in an online sample of the U.S. transgender population*. Paper from the proceedings of the 20th biennial symposium of WPATH, Chicago, Illinois.
- Byne, W., Bradley, S. J., Coleman, E., Eyler, A., Green, R., Menvielle, E. J., & ... Tompkins, D. (2012). Report of the American Psychiatric Association task force on treatment of gender identity disorder. *Archives of Sexual Behavior, 41*(4), 759-796.
- Coleman, E. E., Bockting, W. W., Botzer, M. M., Cohen-Kettenis, P. P., DeCuypere, G. G., Feldman, J. J., ... Zucker, K. (2012). Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *International Journal of Transgenderism, 13*(4), 165-232.

- Cousino, M.K., Davis, A., Ng, H., & Stancin, T. (2014). An emerging opportunity for pediatric psychologists: our role in a multidisciplinary clinic for youth with gender dysphoria. *Clinical Practice in Pediatric Psychology, 2*(4), 400-411.
- Dhejne, C., Lichtenstein, P., Bowman, M., Johansson, A. V., Långströmm, N., & Landén, M. (2011). Long-term follow-up of transsexual persons undergoing sex reassignment surgery: Cohort study in Sweden. *Plos ONE, 6*(2).
- Diamond, M. (2000). Sex and gender: Same or different? *Feminism & Psychology, 10*, 46-54.
- Drescher, J., & Byne, W. (2012). Introduction to the special issue on “The treatment of gender dysphoric/gender variant children and adolescents”. *Journal of Homosexuality, 59*(3), 295-300.
- Eckland, K. (2012). Intersectionality of identity in children: a case study. *Professional Psychology: Research and Practice 43*(3), 256-264.
- Fraser, L. (2009). Psychotherapy in the World Professional Association for Transgender Health's Standards of Care: Background and recommendations. *International Journal of Transgenderism, 11*(2), 110-126.
- Grossman, A. H., & D’Augelli, A. R. (2007). Transgender youth and life-threatening

- behaviors. *Suicide And Life-Threatening Behavior*, 37(5), 527-537.
- Hembree, W.C., Cohen-Kettenis, P., Delemarre-van de Waal, H.A., Gooren, L.J., Meyer III, W.J., Spack, N.P., Tangpricha, V., & Montori, V.M. (2009). Endocrine treatment of transsexual persons: Endocrine Society Clinical Practice Guideline. *The Journal of Clinical Endocrinology & Metabolism*, 94(9): 3132-3154.
- Hidalgo, M. A., Ehrensaft, D., Tishelman, A.C., Clark, L. Garafalo, R., Rosenthal, S.M., ... Olson, J. (2013). The gender affirmative model: what we know and what we aim to learn. *Human Development*, 56, 285-290.
- Liu, R.T., & Mustanski, B. (2012). Suicidal ideation and self-harm in lesbian, gay, bisexual, and transgender youth. *American Journal of Preventive Medicine*, 42(3), 221-228.
- Malpas, J. (2011). Between pink and blue: A multi-dimensional family approach to gender nonconforming children and their families. *Family Process*, 50(4), 453-470.
- Möller, B., Schreier, H., Li, A., & Romer, G. (2009). Gender identity disorders in childhood and adolescence. *Zeitschrift Für Sexualforschung*, 22(3):227-254.
- Mustanski, B., & Liu, R. T. (2013). A longitudinal study of predictors of suicide attempts

- among lesbian, gay, bisexual, and transgender youth. *Archives of Sexual Behavior*, 42(3), 437-448.
- Reitman, D.S. (2014) Treating Lesbian, Gay, Bisexual, and Transgender Youth. The Carlat Report. September and October, 2014.
- Roberts, A.L., Rosario, M., Corliss, H.L., Koenen, K.C., & Bryn Austin, S. (2012). Childhood gender nonconformity: A risk indicator for childhood abuse and posttraumatic stress in youth. *Pediatrics*, 129,410–417.
- Schneider, M., Bockting, W., Ehrbar, R., Lawrence, A., Rachlin, K., & Zucker, K. (2009). Report of the American Psychological Association Task Force on Gender Identity & Gender Variance. Retrieved October 13, 2014, from <http://www.apa.org/pubs/info/reports/gender-identity.aspx#>
- Schor, E. L. (1999). Caring for your school aged child: Ages 5-12. *Report from the American Academy of Pediatrics*. New York: Bantam Books.
- Spack, N. P., Edwards-Leeper, L., Feldman, H. A., Leibowitz, S., Mandel, F., Diamond, D. A., & Vance, S. R. (2012). Children and adolescents with gender identity disorder referred to a pediatric medical center. *Pediatrics*, 129(3), 418-425.
- Steensma, T. D., & Cohen-Kettenis, P. T. (2011). Gender transitioning before puberty.

Archives of Sexual Behavior, 40(4), 649-650.

Tishelman, A.C., Kaufman, R., Edwards-Leeper, L., Mandel, F.H., Shumer, D.E., & Spack, N.P. (2015). Serving transgender youth; Challenges, dilemmas, and clinical examples. *Professional Psychology: Research And Practice*, 46(1), 37-45.

Toomey, R.B., Ryan, C., Díaz, R.M., Card, N.A., & Russell, S.T. (2010). Gender-nonconforming lesbian, gay, bisexual, and transgender youth: School victimization and young adult psychosocial adjustment. *Developmental Psychology*, 46, 1580–1589.

Travers, R., Bauer, G., Pyne, J., Bradley, K., Gale, L., & Papadimitriou, M. (2012, October). *Impacts of strong parental support for trans youth: A report prepared for Children's Aid Society of Toronto and Delisle Youth Services*.
<http://transpulseproject.ca/wp-content/uploads/2012/10/Impacts-of-Strong-Parental-Support-for-Trans-Youth-vFINAL.pdf>.

de Vries A, Cohen-Kettenis P. (2012). Clinical management of GD in children and adolescents: The Dutch approach. *Journal Of Homosexuality* 59(3): 301-320.

Zucker, K.J., Cohen-Kettenis, P.T., Drescher, J., Mayer-Bahlburg, H.F.L., Pfäfflin, F., Womach, W.H. (2013). Memo Outlining Evidence for Change for Gender Identity Disorder in the DSM-5. *Archives Of Sexual Behavior*, 42(5), 901-914.

Appendix A

Survey Recruitment Email

Bcc: peoplewhoareanonymous@wheretheywork.com

Subject: Elise Lehotsky's MSW Thesis: Gender-related Endocrine and Surgical Interventions.

Hello there,

My name is Elise Lehotsky, and I am a MSW candidate at the Smith School of Social Work. Your clinic has been selected to participate in a study of treatment protocol that is being conducted in the course of completing the requirements for my MSW. The goal of my thesis is to determine what protocol is followed by gender clinics that initiate hormone treatments and refer for surgical interventions. I am also interested in identifying if and when therapeutic interventions are utilized leading up to hormone or surgical interventions. As a clinical provider who works with adolescents and gender identity, I have a particular interest in the results and would be grateful if you would participate in this survey.

Your answers will help further the understanding of trends in treatment for adolescents diagnosed with gender dysphoria. If you and your program are connected with other agencies or individuals you believe would be able to participate, please do not hesitate to forward this email along to your colleagues.

The survey should take approximately 10-15 minutes to complete. Please click on the link below complete the survey as soon as you get this email. Data collection closes March 1st, 2015. The data collected from this study will be used to complete my Master's degree. The results of the study may also be used in publications and presentations. I have completed the Collaborative Institutional Training Initiative (CITI) on line training course prior to HSR approval. The certificate of completion is on file at the Smith School of Social Work.

Best wishes whether you choose to complete the survey or not, please feel free to contact me if you have any questions.

https://www.surveymonkey.com/create/survey/preview?sm=mQcl9oF549_2F0GUvUIWjOSuTb4zrIQlzDMY3Qqj3iBPQpvWoiqMu68u_2BG02qVMB4

Elise Lehotsky
Second Year Student at Smith School of Social Work
elehotsky@smith.edu
(XXX) XXX-XXXX

Appendix B

Survey Recruitment Phone Script

“Hello _____, my name is Elise Lehotsky and I am a master’s student at the Smith School of Social Work. Is this a good time?”

If yes:

“Excellent. I’m doing research for my thesis. My thesis looks at what protocol is being followed by gender clinics that initiate hormone treatments and refer for surgical interventions. I am also interested in identifying if and when therapeutic interventions are utilized leading up to hormone or surgical interventions. As a clinical provider for children and adolescents, I would appreciate if you participated in my survey.

- 1) Would your program be able to participate in my study?
- 2) Who at your program would be most able to answer the survey? It will contain questions describing your programs overall operations, including how many individuals you work with and what kinds of treatment you offer.
- 3) May I have their email address? I will email a copy of the survey to that address.
- 4) Remember, you can always decline to participate at any time!

Thank you for your time, I appreciate it.”

If it is not a good time, I will quickly explain the reason for calling is to ask them to participate in a study regarding gender-related hormone and surgical interventions. I will then ask if there is a better time for me to call, or if there is an email contact if that is preferred.

Appendix C

Survey

Page one of the surveys:

Title: Welcome to the Gender Related Endocrine and Surgical Intervention Survey.

Thank you for looking at my survey, should you choose to participate, your answers will contribute to the rapidly growing body of literature surrounding gender identity in the areas of mental health and medical interventions.

Page two of the survey:

Title: Informed Consent

Investigator(s):

Elise Lehotsky

MSW Candidate at the Smith School of Social Work

MSW Intern at Maine Medical Center Outpatient Child and Adolescent Psychiatry

elehotsky@smith.edu

(XXX) XXX-XXXX

.....

Introduction

- You are being asked to participate in a research study of gender related endocrine and surgical intervention with adolescents.
- You were selected as a possible participant because you are affiliated with a program that has been identified as a “gender clinic.” Gender clinics were defined by the study as any clinic that provides hormone intervention. Clinics may also provide behavioral and mental health interventions, or surgical referrals, though it is not required to participate in the survey. Please only submit one survey per clinic.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to provide a description of gender related endocrine and surgical intervention with adolescents in the United States. It also aims to expand understanding of how to best serve clients seeking support, specifically regarding their gender identity.
- This study is being conducted as a research requirement for my master’s in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

Information gathered may also be used to help other gender clinics improve their treatments.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:
- Read the Informed Consent and agree to participate by clicking "Yes." at the bottom of this page.
- Fill out this survey, which may take 15-20 minutes of your time.
- Contact the researcher IF you have any questions or comments.

- I have completed the Collaborative Institutional Training Initiative (CITI) on line training course prior to HSR approval. The certificate of completion is on file at the SSW.

Risks/Discomforts of Being in this Study

- There are no reasonable foreseeable (or expected) risks.

Benefits of Being in the Study

- The benefits to social work/society are: your answers will contribute to the rapidly growing body of literature surrounding gender identity in the areas of mental health and medical health, and an understanding of current practices in the United States.

Confidentiality

- This study is anonymous. We will not be collecting or retaining any information that will reveal your identity. Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time (up until March 15th, 2015)

without affecting your relationship with the researchers of this study or Smith College.

Your decision to refuse will not result in any loss of benefits

(including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw

completely up to the point noted below. If you choose to withdraw, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by March 15th, 2015. After that date, your information will be part of the thesis, dissertation or final report.

- You may withdraw from the survey at anytime by clicking the "Exit this survey" button at the top right of the screen.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Elise Lehotsky at elehotsky@smith.edu or by telephone at (207) 2003919.

If you would like a summary of the study results, one will be sent to you once the study is completed.

1. Have you read the informed consent and you agree to participate in this study?

(Answer choices: "Yes, I agree to participate" or "No, please take me out of the survey." If the participant answers "No" they will be automatically exited from the survey).

Page three of the survey:

Title: Demographics

1. Do you or your program treat adolescent clients with hormone interventions targeting gender identity?

(Answer choices: "Yes" or "No." If the participant answers "No" they will be automatically exited from the survey).

2. What disciplines are on-site at your program?

(Answer choices: Endocrinologists, Nurse Practitioners, RNs, Psychiatrists, Clinical Social Workers, Psychologists (PhD or PsyD), Case Management Social Workers, Community Educators, and Other (please specify). Participants may select as many choices as necessary).

3. What is your role at your clinic?

(Answer choices: Endocrinologists, Nurse Practitioners, RNs, Psychiatrists, Clinical Social Workers, Psychologists (PhD or PsyD), Case Management Social Workers, Community Educators, and Other (please specify). Participants may select as many choices as necessary).

4. Do you work with clients regarding their gender identity if they decided not to pursue hormone treatments?

(Answer choices: “Yes” or “No”).

5. In which region of the United States is your practice?

(Answer choices: New England, Middle Atlantic, East North Central, West North Central, South Atlantic, East South Central, West South Central, Mountain, Pacific. On the survey, each region defines specifically which states are included in it).

6. Please pick the option(s) that best describe the community your program serves.

(Answer choices: Urban, suburban, rural. Participants may select more than one option).

7. Approximately how many adolescent clients do you work with by providing hormone interventions per year?

(Answer choices: <100 Individuals, 100-200 Individuals, 200-300 Individuals, or 300+ Individuals, or Other (please specify)).

8. Approximately how many adolescent clients total do you work with per year regarding gender-identity?

(Answer choices: <100 Individuals, 100-200 Individuals, 200-300 Individuals, or 300+ Individuals, or Other (please specify)).

Page four of the survey:

Title: Program Protocols

1. Does your program require a DSM-5 diagnosis of Gender Dysphoria before moving forward with hormone treatments (or surgical referral)?

(Answer choices: “Yes, it is always required for treatment,” “No, it is assessed but not required for treatment,” or “No, it is not diagnosed and it is not required for treatment.”)

2. Does your program refer clients for surgical consults?

(Answer choices: “Yes,” or “No”).

3. Does your program utilize the World Professional Association for Transgender Health’s Standards of Care?

(Answer choices: “Yes” or “No,” or “We use a different standard or treatment recommendation to inform our own protocol (please specify if possible)”).

4. Is a psychological assessment required from a mental health professional before considering hormone or surgical interventions?

(Answer choices: “Yes” or “No”).

5. Is a letter or are letters required from mental health professionals before considering hormone or surgical interventions?

(Answer choices: “Yes” or “No”).

6. Are behavioral or mental health services involved in determining whether or not to recommend hormones or surgical consult?

(Answer choices: “Yes” or “No,” or “Other (please specify)”).

7. In what capacity are behavioral or mental health services involved with adolescents and their families?

Narrative answer box.

8. What information do treatment providers require about their client’s history to determine if it is appropriate to start hormone treatments?

Narrative answer box.

9. What information is delivered to clients and their families to fully explain the expectations and implications of sexual reassignment treatment processes?

Narrative Answer Box.

10. Do you work with client’s social support systems?

(Answer choices: School, Family members, Neighborhoods, Place of employment, or Other (please specify). Participants may select multiple answers).

Page five of the survey:

Title: Exceptions and Improvements

1. Are their exceptions or alterations made to treatment protocols for individuals? For example, if someone lives too far away to attend weekly therapy sessions, are they given an alternate plan?

(Answer choices: “Yes” or “No”).

2. Under what circumstances are exceptions made? Please list possible or past circumstances encountered, and how you accommodated this.

Narrative Answer Box.

3. What is the most important aspect of treatment planning your program recommends?

Narrative Answer Box.

4. IS there something you think could be done more effectively or differently when working with clients seeking treatment related to gender identity?

Narrative Answer Box.

Page six of the survey:

Title: Thank you!

Thank you so much for participating in my survey!

Please contact me if you need anything:

Elise Lehotsky

elehotsky@smith.edu

(~~XXX~~) XXX-XXXX

Additional resources available to you or your program (if you have not already accessed them):

World Professional Organization for Transgender Health Standards of Care (7)
Report of the American Psychiatric Association Task Force on Gender Identity & Gender
Variance

"12 Tips For Nurses And Doctors Treating Transgender Patients."

From WBUR's CommonHealth Reform and Reality

Appendix D

HSR Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-
7994

January 9, 2015

Elise Lehotsky

Dear Elise,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

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.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Claudia Bepko, Research Advisor

Appendix E

HSR Protocol Change Request Form



RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following approved research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

«Project Name»
Elise Lehotsky
Claudia Bepko

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) Change survey recruitment email (Appendix A, first paragraph) phrasing from, "Your answers will help further the understanding of trends in working with teens diagnosed with gender dysphoria."

I would prefer to have it read, "Your answers will help further the understanding of trends in working with teens to actualize their gender identity. "

EL I understand that these proposed changes in protocol will be reviewed by the Committee.
EL I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
EL I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: EL

Name of Researcher (PLEASE PRINT): Elise Lehotsky Date: 1/19/15

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

***Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.

Appendix F

HSR Protocol Change Approval Form



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

January 20, 2015

Elise Lehotsky

Dear Elise,

I have reviewed your amendment and it looks fine. This amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Claudia Bepko, Research Advisor

Appendix G

HSR Protocol Change Request Form



RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following approved research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

«Project_Name»
Elise Lehotsky
Claudia Bepko

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) Add the question to survey: What are reasons your clinic has chosen NOT to move forward with hormonal or surgical interventions with a given client? The answer box will be open ended, short answer.

EL I understand that these proposed changes in protocol will be reviewed by the Committee.
EL I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
EL I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: EL
Name of Researcher (PLEASE PRINT): Elise Lehotsky Date: 1/23/15

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

***Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.

Appendix H

HSR Protocol Change Approval Form



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 3, 2015

Elise Lehotsky

Dear Elise,

I have reviewed your amendment and it looks fine. This amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Claudia Bepko, Research Advisor

Appendix I

HSR Protocol Change Request Form



RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following approved research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

«Project Name»
Elise Lehotsky
Claudia Bepko

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

- 1) I will be sending a second email out as a reminder for people to participate in the survey. It will be an identical email to the original survey, except it will start with the following:

“Hello again! If you have already completed this survey, thank you very much for your participation. You may disregard this email as it is a reminder for those who may still want to participate. In order to protect anonymity of participating gender clinics, it is not possible for me to identify who has already taken the survey. My hope is this email will serve as a reminder that you may still voluntarily participate.”

I plan to send this reminder email at the beginning of March (3/2) in order to hopefully raise the number of participants.

- EL I understand that these proposed changes in protocol will be reviewed by the Committee.
EL I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.
EL I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: EL

Name of Researcher (PLEASE PRINT): Elise Lehotsky Date: 2/17/15

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

***Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.

Appendix J

HSR Protocol Change Approval Form



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 25, 2015

Elise Lehotsky

Dear Elise,

I have reviewed your amendment and it looks fine. This amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Claudia Bepko, Research Advisor