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Hannah Noël Smith  
Unequal Treatment: Sociocultural  
Identities and Their Effects on  
Eating Disorder Treatment Access  
and Efficacy

## **ABSTRACT**

The purpose of this study is to explore ways in which eating disorder treatment can be made not only more accessible, but more effective for clients who identify as people of color, lower-socioeconomic status (SES), trans and gender nonconforming, and people whose Body Mass Index (BMI) normal or higher at the time of treatment.

Data was collected using a survey, which was completed by 28 participants recruited through Facebook eating disorder recovery groups and Instagram. Participants were asked to describe their racial identity, gender identity, SES, and BMI, then reflect on the experience of seeking eating disorder treatment.

The findings suggest that individuals seeking treatment for eating disorders encounter barriers related to lack of insurance coverage, cost of care, and inability to leave school or work responsibilities. Individuals who perceive their identities to be incongruent with the societal image of eating disorder sufferers are less likely to seek treatment.

# **Unequal Treatment: Sociocultural Identities and Their Effects on Eating Disorder**

## **Treatment Access and Efficacy**

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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2017

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## **CHAPTER I**

### **Introduction**

Eating disorders have entered public conversations regarding mental health relatively recently, most notably after the anorexia-related death of beloved singer Karen Carpenter in 1983. While hers was not the first life claimed by an eating disorder, the event acted as a societal catalyst that resulted in an increase in research and treatment of anorexia nervosa and bulimia nervosa. However, most of the research done on eating disorder patients occurred in private hospitals that employed specialty staff and cutting edge treatments—facilities that were inaccessible to individuals in marginalized communities. As a result, the entire body of early research was focused on young, white, affluent women, and these identifiers became synonymous with the disease itself (Thompson, 1994).

Much of the logic behind the misconception of eating disorders as a syndrome of privilege comes from the perceived association between self-image and Western culture's assertion that thinness is essential to beauty (Hogan & Strasberger, 2008). An incredible amount of blame is directed toward the media for promoting unattainable beauty standards, but often it seems people forget that media does not create value, it reflects values that are already present. In the matter of body perception, the media mirrors the fact that we interpret one's physical appearance based on characteristics we associate with aspects of their presentation. For example, overweight people are perceived to be lazy while thin people are assumed to be in control and hardworking. These ideas of appearance as signifier of personal attributes are not new to America, the country known for seeing skin color as the only differentiation between a slave, a terrorist, or a "normal" (read as: white) person. The assumption that a person's behavior can be predicted by appearance is shaped by structural inequality so insidious and so deeply entrenched that we can scarcely identify the ways it is woven into each moment of our lives.

Medical and mental health professionals are not immune to stereotyping, which is made even more evident by the research that is starting to emerge regarding the prevalence and treatment prognosis of individuals with eating disorders who do not fit neatly into the narrative of white feminine affluence; we are beginning to understand that self-starvation and purging behaviors exist in people of color, communities outside of Judeo-Christian faith, across the gender and sexuality spectrum, in people of larger size, in elders, and in individuals experiencing poverty. The problem is that the medical community does not move swiftly when it comes to paradigm shift, and this results in an inability or unwillingness to consider an eating disorder diagnosis for patients who do not match the clinician's perception of what the disease looks like.

Given that identity factors can cause a help-seeking person to be ignored or misdiagnosed, thus decreasing access and referral to specialized eating disorder treatment. Ignorance in the medical and mental health community merely adds another barrier on top of societal stigma, potentially negative cultural attitudes about mental health, and the stunning lack of affordability of the necessary treatment. Additional considerations include the lack of treatment options local to marginalized areas, insurance companies' perpetual denial of mental health benefits, and children who need to be taken care of during a parent's treatment (Thompson & Park, 2016).

The aforementioned barriers are only the beginning: another struggle occurs once the person goes through the treatment center door. Most treatments are based on studies of the stereotypical eating disorder client with very little consideration as to how sociocultural factors may impact the treatment. The methods employed center whiteness and affluence without directly saying so, which may not only be ineffective but actually harmful to patients who cannot identify with the culture of white wealth. Some recent studies emerging from psychodynamic, feminist, and critical theorists working with the eating disorder population have explored the

diagnosis beyond the buzzwords like “media,” and “thigh gap,” and are identifying the ways in which eating disorders present as illnesses of disconnection from the self as well as the greater community (Tantillo, 2006). What then must it feel like to be othered in a treatment facility? While treatment centers and clinicians from every discipline like to boast that they don’t believe they treat clients differently based on their sociocultural background, the stories told by their clients suggest that perhaps they should.

The purpose of this study is to explore ways in which eating disorder treatment can be made not only more accessible, but more effective for clients who identify as people of color, lower-socioeconomic status, or any number of identities held that conflict with a one-size-fits-all treatment model. In order to explore how these barriers can be overcome, we must first research which barriers are most pervasive and do what most research has not yet done, which is to ask the individuals themselves about what they see as potential solutions. Thus, the research question must be as follows: What barriers exist for marginalized individuals in terms of seeking and receiving timely and appropriate treatment for their eating disorders? What are some methods that can help to sustainably remove these barriers?

My hope is that by both surveying and interviewing marginalized individuals with eating disorders, the barriers will be identified and elaborated upon—at the same time, the study will strive to amplify the voices of clients who have been spoken for, but not listened to. The impact of this could mean a more narrow research gap in the field of eating disorders treatment, increased accessibility and effectiveness of treatment services, and a reduction in socioculturally ignorant methods which may in time lead to decreased racism, sexism, homophobia, transphobia, and classism in the therapeutic space.

## **CHAPTER II**

### **Literature Review**

The following literature review is comprised of six sections: a brief overview of eating disorders, the myth of the white female disease, prevalence, culturally significant aspects of eating behavior and the body, assessment measures for diagnosis, and treatment access and

utilization. It is organized in this fashion to acquaint the reader with background information about the medical risks of eating disorders, provide a historical context for the way this category of disorder is envisioned in our culture, explore the existing knowledge of how these disorders vary culturally, and develop a basic frame of reference for how often individuals seek and access treatment as well as which factors tend to hold people back.

### **Eating Disorders: A Brief Overview**

Eating disorders are often misinterpreted as a benign adolescent phase or a “diet gone too far,” but in reality eating disorders affect millions of individuals across the world and have the highest mortality rate of any psychiatric illness. When adjusted for age, individuals with Anorexia Nervosa (AN) have a risk of premature death 6-12 times that of the general population (Academy for Eating Disorders, 2016) and individuals who engage in purging may deplete their electrolytes to the point of sudden cardiac arrest (Myatt, 2014). While disordered eating behaviors are incredibly complicated and put the client at high risk for health issues, there is some cause for hope: as long as the illness is detected early, it is likely that the individual will fully recover. However, the longer the illness continues untreated the more severe it becomes (Academy for Eating Disorders, 2016). It is for this reason that further research is needed regarding the prevalence, assessment, access to treatment, and quality of treatment for individuals from marginalized groups who have eating disorders.

### **The Myth of the Thin White Female Disease**

While there are many factors affecting clinicians’ lack of understanding when it comes to cross-cultural and other differential types of eating disorder presentations, one factor is the stereotype of the “typical eating disorder patient.” Though outdated and thoroughly debunked by recent research, many providers who assess for eating disorders suspect that disordered eating is a problem of thin white female adolescents and may be less likely to take seriously a client

whose appearance conflicts with this mental image (Mensing, Russon, Shearer, SlaughterAcey, Atte, & Diamond, 2016). This stereotype is the result of an observation made by Hilde Bruch in 1973 after she published *The Golden Cage*, one of the first books written about anorexia nervosa. According to Bruch, the absence of patients of color within hospitals signified a lack of clinically significant symptoms in communities that were not white, suburban, and affluent. Unfortunately since Bruch was among the first to study this set of behaviors, her observations guided much of the research at the time and resulted in a damaging myth that continues to plague society and the treatment field to this day (Brooks, 2016). As a result, diagnostic criteria, assessment measures, and treatment protocols have been developed based on the research available--which is to say the research that was developed with young white affluent women in mind.

## **Prevalence**

Prevalence of eating disorder symptoms tends to be relatively consistent across identity factors although presentation and internal motivation may be incredibly different. The more studies are conducted on presence of eating disorder symptoms, the more we find that it is not a problem that is isolated to one segment of the population. Tallyrand notes in her 2012 paper that it had recently been discovered that approximately 25% of black college women engage in symptoms consistent with a diagnosis of bulimia--a percentage that is very much like the prevalence of those same behaviors in white college women.

Additionally, there are differences between groups that a white researcher may mistakenly lump together: a 2007 quantitative national study of African American and Caribbean Black adults and adolescents found that African American Black individuals are more likely to develop eating disorders than Caribbean Black individuals (Taylor, Caldwell, Baser, Faison, & Jackson). Though this study found that the rates of anorexia nervosa were low, age of onset in African American Black individuals is lower than general US population--this could mean longer

duration of illness since clinicians are unfamiliar with population and presentation to begin with and may assume that they don't need to assess for eating disorders until later, if at all. The rate of bulimia nervosa is much higher in African American Black individuals compared with Caribbean Black individuals and possibly associated with stress, especially acculturation stress. A potential explanation for this is the erosion of culturally positive body image, which is a protective factor within Black American communities. The study again demonstrated that the disorder continues to be underdiagnosed because it is unanticipated. The most common eating disorder in the study of Black African Americans was binge eating disorder, and the age of onset was markedly higher when compared to the onset of anorexia or bulimia—it is hypothesized that this is a result of reduced investment in small body size as women age, and overeating as a condition developed in response to economic deprivation and food scarcity. Another finding of this study is evidence for presence of eating disorders in black boys, which the researchers state is likely associated with weight restrictions for sports participation (Taylor, Caldwell, Baser, Faison, & Jackson, 2007).

### **Culturally Significant Aspects of Eating Behavior and the Body**

Despite research demonstrating similar rates of eating disorders across varying populations, there continues to be a lack of study of culturally unique symptoms. Some trends have been observed in existing literature: for example, black women appear to engage in more bingeing than white women and women of Asian descent report more body dissatisfaction than white women (Tallyrand, 2012). This is hardly surprising, since culturally different women will have different contexts for beauty and is a sign that identifying the individual's motivation as “drive for thinness” is likely a projection of the researcher's cultural bias as opposed to a true understanding of the internal workings of the person with the disorder. Existing literature



attributes eating disorders to multiple factors including acculturation stress, racism, and poverty, but not necessarily a combination of all three--for example, in a study of Latina teenagers it was found that higher socioeconomic status and higher parental levels of education correlated positively with body dissatisfaction, low self-esteem, substance abuse, poor mood, and eating disorders due to the level of acculturation stress that exists for adolescents of color within predominantly white wealthy communities (Tallyrand, 2012). Additionally Tallyrand notes that most studies focused on eating disorders across cultural contexts attempt to compare black American women to white American women, while individuals from Asian, Hispanic, and multiethnic backgrounds are included as an afterthought, if at all (2012).

At the conclusion of her research, Tallyrand identifies ways in which future studies can seek to gather useful and culturally appropriate information. She recommends that researchers dedicate themselves to understanding barriers to care, identifying culture-specific themes, concentrate on the effects of acculturation versus enculturation on food and body perception, and assess the individual's level of internalized oppression (2012).

What's more is that some cultural traditions may mask eating disorders if the individuals assessing the patients are ignorant of the person's background, values, and heritage. This is well demonstrated in a study of Ramadan's impact on eating disorder presentation at a hospital in Turkey. In the study, clinicians at an adolescent medical center found that 25-33% of eating disorder patients diagnosed within the calendar year present during or immediately following Ramadan. The article was a case study of six adolescents who presented to the unit during or after Ramadan and met diagnostic criteria for an eating disorder. Within these six cases, the background of each individual was unique as was their presentation of symptoms. The client in Case One was a fourteen year old female from a low-income family who started dieting a month prior to Ramadan and used culturally normative fasting to disguise her restriction. The individual

in Case Two was a fifteen year old girl who grew up in a high-income very religious family--as they fasted during Ramadan she lost weight, noticed an eventual decrease in her appetite, was pleased with the results and decided to continue restricting after end of Ramadan. In Case Three, a sixteen year old female from a low-income household reported a lifelong struggle with food, which was exacerbated by the traditions of Ramadan. By the time she was presented to the hospital she stated that she “could not eat properly even if she wanted to,” and was noncompliant with diet and treatment. The point was also made that holidays such as Ramadan or any fasting period can disguise eating disorder behaviors other than restriction. This is evident in Case four, in which a sixteen year old girl from a low-income background started dieting seven months prior to Ramadan and reported lack of time to eat during day due to stressful internship; meals permitted during Ramadan prior to and following the daily fasting period resulted in excessive bloating and nausea which she relieved by self-induced vomiting; in Case Five, a fourteen year old female who was from a low-income family and classified as obese, felt “out of control of what she ate” but felt an increase in this during Ramadan due to compensatory eating after break of fast. Thus she reported that she felt immense guilt and began to purge, eventually developed self-harming behaviors and suicidal ideation. Male presentations were also observed in this study, as in Case Six: a seventeen year old male was presented to the unit by his family after losing a significant amount of weight within the brief period of Ramadan. The patient denied follow up, stating that he had always felt overweight but Ramadan “gave him motivation to diet” (Akgul, Derman, & Kanbur, 2014).

Religiosity and self-starvation has been studied in Christianity, and in these instances researchers have claimed that the level of religious adherence is partially responsible for the development of eating disorders. This study differs in its conclusion: researchers observed that in this context, religious fasting does not cause but rather triggers, accelerates, or masks disordered

eating. Adolescents with predisposition to eating disorders and personal characteristics of individuals who develop eating disorders achieve “what was previously thought of as impossible” when fasting because it is seen as a duty, and are encouraged by their ability to successfully accomplish what they had felt unable to sustain in previous periods. Another finding of this study serves as a reminder that even brief struggles with an eating disorder can have lasting effects: the individual described in Case Two had developed osteoporosis despite severe food restriction spanning only two months. Though the researchers caution that the individual’s restriction cannot be proven as the sole cause of her osteoporosis, even the thought of such a severe magnitude of damage within a brief period is chilling (Akgul, Derman, & Kanbur, 2014).

While these are only examples of cultural difference in relation to eating disorder presentation, it begs the question of what else the research has neglected to find because it has neglected to search. Furthermore in a world where bodies are so politicized through racism, sexism, and nationalism, it would make sense that the body then becomes the target of cultural anxieties and internalized oppression.

### **Assessment Measures**

There are several manners in which a treatment provider can assess clients for eating disorders. Some screening tools exist, such as the Eating Attitudes Test (EAT) and the SCOFF questionnaire (named for its five assessment questions: Sick/Vomiting, Control, One stone weight loss, Fat, and Food). Treatment providers can also attempt to assess according to the listed criteria in the DSM-5. However, the literature raises a question of whether categorical assessment is as effective across cultures as dimensional assessment of symptoms and distress. For example, Pike (2013) advocates for dimensional assessment of severity rather than categorical assessment of a particular set of symptoms. The DSM-5 attempts to incorporate dimensional assessment, yet as it stands the dimensional measures have merely been applied to

preexisting criteria. This is problematic, as it does not expand the diagnostic set to encompass culturally variable presentations and as such, cross-cultural samples may have severe disordered eating patterns yet lack other diagnostic criteria that would enable them to be diagnosed appropriately. For example, in Fiji, study participants displayed dieting and bingeing patterns that were significant, but weren't able to be categorized within the existing diagnoses. Additionally, the researcher noted that a significant proportion of psychiatrists in Asia, Latin America, and South Asia, identified that they struggle to appropriately diagnose across cultures using the current criteria and would much prefer a system which allows them to assess clients in terms of distress relative to cultural norms.

Pike also discussed the recent boom in biomedical research in the eating disorder field, and noted that the increased biological focus has caused some professionals to “choose sides,” so to speak. The researcher points out that this is particularly unfortunate as much of the biomedical data supports sociocultural theories and observations—for example, eating disorders surge within cultures that experience rapid social change—yet clinicians' belief in heritability and biological causes takes focus and funding away from cross-cultural research and populations whose eating disorders are profoundly related to sociocultural stressors and struggles of identity.

As for the current tools used to screen for eating disorders, they are based in Western presentations of the illness, and when observed cross-culturally it is difficult to decipher what the core characteristics of eating disorders include (Becker 2007). The author points out that eating disorder screening tools are rarely assessed for reliability and validity in heterogeneous populations, and when they are assessed they often lack both sensitivity and specificity. For example, a group of South African teens scored high values on the EAT assessment; however, when they were interviewed, it became clear that their fixation on food and related symptoms were due to poverty and food insecurity rather than eating disorder pathology. Becker adds that

researchers are more likely to inaccurately count cross-cultural participants as non-cases if they present without “fatphobia,” or disturbances in body perception, which are hallmarks of restrictive eating disorder diagnoses in Western culture. While the author states that research with culturally heterogeneous participants is lacking in breadth, she also notes that the studies conducted often have sample sizes too small for their findings to be statistically significant. What’s more, the author observes that lack of access to treatment most critically affects participants who do not fit the stereotype of the “typical” eating disorder patient. This results in clinicians’ and researchers’ stereotypes become reinforced by sheer absence of presentations outside of the status quo.

It is worth noting that assessment tools and clinicians can miss the signs of an eating disorder even if the presentation is within the aforementioned status quo. This is observed in the recent study attempting to validate the SCOFF questionnaire in an ethnically heterogeneous sample group (Solmi, Hatch, Hotopf, Treasure, Micali, 2015). The SCOFF questionnaire is one of the most frequently used measures within primary care settings to screen for eating disorders, and has been validated repeatedly for homogenous groups of white, female participants. However, when researchers aimed to validate the SCOFF in a multiethnic group of participants, they found that the sensitivity was 53.7% while the specificity was measured at 93.5%. This means that while the SCOFF is useful for measuring the level of pathology of individuals who have eating disorders, it is unreliable in its ability to screen for the presence of an eating disorder. The study found that the SCOFF questionnaire resulted in many false negatives especially among eating disorder sufferers who were not low-weight or who had maintained their weight without a recent significant loss. Further investigation is recommended to assess its use across various populations.

## **Treatment access and utilization**

The struggle to engage in eating disorder treatment is well demonstrated in the 2000 study by Cachelin, Rebeck, Veisel, & Striegel-Moore in which a multiethnic sample of women with eating disorders reported their willingness to seek treatment, their success with attaining treatment, and the barriers that prevented them from treatment engagement. The study found that while 85% of the participants reported a desire for eating disorder treatment, only 57% of the sample had sought treatment. Of the aforementioned individuals who sought treatment, 86% did not receive treatment for their eating disorder. For perspective, this means that only 8% of the original sample received any kind of treatment. What is more troubling is that of those who were prescribed treatment, 65.7% were prescribed treatment for weight control rather than eating disorders. Though there were several limitations to the study including small sample size, a relatively small proportion of participants who identify as Asian, and vastly more individuals with Binge Eating Disorder and Bulimia Nervosa than Anorexia Nervosa or Eating Disorder Not Otherwise Specified, the researchers identified an apparent lack of awareness of eating disorders in marginalized populations among both professionals and clients themselves.

A 2010 study by Becker, Arrindell, Perloe, Fay, & Striegel-Moore was focused on identifying and discussing barriers to seeking eating disorder treatment in multiethnic populations, and included both sociocultural barriers and practical barriers. Interestingly, this study was a secondary analysis of interview transcripts from a previous study of past and potential consumers of eating disorder treatment. The researchers found that 78% of participants identified one or more social barriers to seeking treatment. Social barriers included “culturally based barriers” (i.e. defined social norms and costs associated with ethnic, local, or hybrid identity), and societal barriers related to whether specialty eating disorder treatment was available and affordable. Over half of participants stated that they felt held back from seeking

treatment due to a culturally-based barrier, especially the stereotype of what types of people suffer from eating disorders. Interestingly, racial and ethnic factors were identified as problematic by both participants of color and by white participants. For example, one white participant stated that her referral to a gastroenterologist for treatment of an unrelated illness was delayed because her physician so strongly believed she was causing the symptoms by engaging in disordered eating. In contrast, two participants who identified as African American reported incredibly discouraging encounters with mental health and primary care professionals. The first participant detailed her experience of visiting a psychologist who did not believe that she could have an eating disorder, and that she became even more averse to seeking treatment after that encounter. Another participant expressed that she did not feel seen or understood by her clinician because she was never asked about her familial or cultural relationship to food. “I was very much aware that she knew very little about my culture and she wasn’t asking me, ‘Well, what does food mean to me in my family, what is it like for you, let me understand better your world,’ she never did that.” A further reflection by this participant: “Yeah, because I’m not just a darker version of the prototype, I’ve got some things, you know that might be different than what she’s experiencing going on in my life. So ask me. Find out what my life is like. What this means for me, what’s so difficult for me. [...] but she never did that. I was pretty disgusted with her. I stayed a year, I tried.” The participant added, “I think [my clinician] put me into the generic mold, which happens to be the white mold, and I don’t even know if that same white mold applies to some of the white people I encounter.” Multiple participants who identify as people of color spoke of discouragement from seeking treatment within their social support network, verbalizing loved ones’ comments such as “oh, well you don’t want them to know that about you,” or fears related to violating social norms. One participant in particular stated that it would be overwhelming to have both their health and their cultural identity damaged. Aside from

factors related to race and ethnicity, there were perceived barriers related to age, gender, weight, and class. Participants described encounters in which their symptoms were minimized by the clinical perception that the behaviors were indicators of an age-appropriate phase that would be outgrown with time; several participants stated that they were uncomfortable discussing their experience with a male clinician due to their feeling that the clinician was “condescending,” and that “they are just tolerating you, like you’re lucky to have their time to sit there and for them to listen to you. You know. And then with women, it’s so different.” There was also a concern voiced by a participant that a male clinician would “have no frame of reference” to understand eating and weight struggles. Furthermore, participants said that they were not encouraged to get help because of societal expectations for all eating disorder sufferers to be visibly underweight or overweight. One participant who identifies as white reported that her family’s Italian heritage leads them to be “more tolerant of weight fluctuations,” and that they had difficulty accepting her illness because she appeared healthy. Another participant who identifies as white reported that her family expressed fear that if she sought treatment, she would have a “black mark on her record,” and that it would keep her from being hired for a “good job.”

When researchers studied the barriers related to availability and affordability of treatment, they found that there were several difficulties accessing specialized eating disorder care. One identified barrier was the geographic placement of treatment providers: a participant stated, “I think access to care can be a big problem. Even if it’s not a factor of, ‘I don’t have insurance, I don’t have money,’ finding places at least here where I live that treat eating problems is hard. There are not a lot of places here.” Other participants spoke of the perceived unhelpfulness of covered services being too limited or time-constrained to be effective, or struggles with insurance companies’ policies which made it difficult to switch providers or access geographically feasible providers. The most salient factor throughout the featured



statements was a pattern of insurance companies refusing to cover necessary services, or terminating services before the participant felt that they were stable enough to discontinue treatment.

Throughout the discussion portion of the study, the authors reflect on the fact that “clinical prototypes derived from homogeneous and unrepresentative study populations may be self-perpetuating,” and that differing clinical presentations and help-seeking rates across populations may mean that any data regarding demographic risk is likely unreliable.

Furthermore the authors point out that the eating disorder population could be uniquely vulnerable in their struggle to seek care, since the level of shame and internalized stigma associated with seeking treatment could be affected by the person’s ability to modulate social norms—which is to say that the same internal mechanisms that are associated with eating disorder pathology are also associated with hesitance to seek help.

## **Summary**

The societal and clinical perception of eating disorders has been skewed by the initial research conducted during the 1970s, and has been the basis upon which diagnostic tools, theoretical understandings, and treatment modalities were developed. As a result, individuals who do not present with the social location or physical appearance of how eating disorders have been portrayed historically are not only at risk for misdiagnosis and poor understanding of their struggle, but are likely to encounter stigma from professionals in addition to existing stigma that exists for anyone who lives with an eating disorder. Due to the myth of who gets eating disorders and how those eating disorders appear, treatment is rarely accessible in the first place because part of the false narrative of eating disorders is that they only occur in individuals with class privilege who are able to easily afford healthcare. When there is a structural expectation of

wealth and personal agency, there is little structural preparation for handling the messy business of poverty, racism, gender violence, and other forms of oppression.

## **CHAPTER III**

### **Methodology**

This study aims to explore whether there are specific barriers to treatment access for individuals from diverse populations, and the extent to which these participants felt that any treatment they received was helpful. In order to gather the data necessary to understand participants' experiences, the study design is a quantitative survey with several opportunities to participants to elaborate on their answers in open-ended fields. While the study predominantly focuses on quantitative measures, the open fields were included to provide participants a space to voice their individual experiences and specific examples of the barriers they may have faced. In this way, participants are able to inform the researcher of factors which may not have been included in the construction of the survey tool and provide narrative data to accompany the quantitative measures.

### **Sample**

The first step in sampling the population was to narrow the frame of the study and construct an operational definition of both "marginalized," and "eating disorder." For the purposes of this study, "marginalized" includes individuals who self-identify with one or more of the following criteria: belonging to any gender identity aside from cisgender; racially or ethnically non-Caucasian; ranging in weight from "normal" to "obese" based on BMI; and

annual earnings equal to no more than 125% Federal Poverty Level. Multiple categories of marginalization were included to allow data comparison across identity as well as offer insight into the effects of intersecting marginalized identities on participants. When deciding how to operationalize the terms “eating disorder,” and “disordered eating,” it was decided that participants would need to have used behaviors specified in the diagnostic criteria rather than meet full criteria. This decision was made in order to include individuals whose presentations and cognitive symptoms vary according to identity factors, as this more dimensional approach includes individuals whose lower-frequency behaviors would render them ineligible for inclusion based on a traditional categorical approach (Pike, 2013). To collect the sample population, the researcher used snowball sampling which began by purposively selecting groups and individuals who are likely to meet most aspects of the inclusion criteria. For example, since the study seeks to understand the experiences of individuals who are marginalized in the context of eating disorder research and treatment, the study was advertised in internet communities including Trans Folx Fighting Eating Disorders, and a Facebook group entitled “I Am Not White and I have an Eating Disorder.” The post was also shared on several social media platforms including Twitter, Facebook, and Instagram since these communication tools are widely accessible to large numbers of potential participants. The posts were shared to others’ social media pages across several geographic locations and communities.

### **Ethics and Safeguards**

To uphold participant confidentiality, the researcher implemented settings within the survey software to ensure that none of a respondent’s identifying information is collected, including ISP address. Risks to the participant were outlined in the informed consent prior to the start of the survey, and the informed consent also specified that participants could discontinue the survey at any time. The identified risk to respondents was the potential to become emotionally

uncomfortable as a result of sharing the difficulties of their experience. To counter this risk, the researcher included several referral sources that participants may access in order to find support. Since a main component of this study is the differential treatment of marginalized individuals, the referral list included resources which specifically serve marginalized groups and maintain a list of culturally sensitive clinicians. Additionally, the researcher included referral information at the end of the study as well as within the informed consent to safeguard participants who may not have chosen to print their informed consent information, and to encourage individuals who have completed the survey to explore the resources which could be beneficial in the future.

### **Data Collection**

The data for the study was collected using a survey which is predominantly quantitative, yet also includes an optional field for comments and participant narrative following each question. The researcher used a self-developed measure rather than a published instrument due to literature findings which demonstrate the lack of reliability of most published measures across ethnically diverse samples (Solmi, Hatch, Hotopf, Treasure, & Micali, 2015). While developing the survey, the researcher utilized the literature to compile a list of factors which influence eating behaviors across cultures such as religious practices involving food, geographic availability of foods most commonly offered in treatment centers, and stereotypes which may result in an eating disorder continuing for an extended period without detection. Questions about these factors were included alongside more traditional assessment questions, which inquire about specific disordered eating behaviors used by the respondent. The inclusion of open narrative fields was significant to the survey because the researcher recognizes the potential for a participant's experience to differ from those included in the survey design. Thus, the inclusion of narrative fields encourages a more comprehensive and accurate understanding of respondents' experiences. An example of this is a question in the survey which asks participants to rate the

likelihood of their seeking support from a number of listed sources; immediately following the list of providers and supports is an open-ended question about where else they would be likely to seek support. By including this open-ended question, a participant would be able to inform the researcher of relevant support entities which the researcher overlooked.

### **Data Analysis**

Data analysis was initiated with the construction of a codebook, which assigned quantitative values to each of the themes identified in the qualitative survey responses. This data was entered into a spreadsheet where coded responses could be viewed in relationship to the participants' identifying factors. The data was assessed for patterns with attention to variance between each marginalized group as well as participants who self-identify as marginalized in more than one category. The quantitative data analysis was based primarily on frequencies, with use of cross tabulations to assess response content across key subgroups in the data.

### **Discussion**

The study results are fully presented in the Findings Chapter, and discussed in the Discussion Chapter.

## CHAPTER IV

### Findings

This was an exploratory study that used a quantitative survey with the opportunity to add additional narrative to each response. The sampling method was a purposive snowball design, and the goal was to understand the ways in which sociocultural identities impact the ability for individuals with eating disorders to access treatment and to explore whether they felt any treatment received was effective. This chapter contains a summary of findings, demographic information, and participant voice interwoven with quantitative data. The small sample size indicates that these results cannot be generalized across demographic subsets of individuals with eating disorders. While the inability to generalize is less than ideal in the quantitative sphere of research, the qualitative input from the participants speaks to the complications that have arisen as a result of hasty generalization in the field of eating disorder treatment.

### Demographic Data

The survey was accessed by forty-six participants initially, however many of the surveys were never completed once started. Thirty-four participants met the screening criteria, and thirty-two of those individuals agreed to the informed consent. The participants were asked to identify their race, ethnicity, assigned sex at birth, any religious or spiritual affiliations, disability information, gender identity, and socioeconomic background. In addition the participants were asked for information from the period at which they sought treatment including their age and Body Mass Index (BMI).

Table 1: Demographics of Survey Participants			
N=28		Frequency	Percentage
Race			

	Caucasian	21	75
	African American	1	3.5
	Biracial	3	11
	Asian	1	3.5
	Latinx	1	3.5
	Did not respond	1	3.5
		1	3.5
Assigned Sex at Birth	Female	28	100
	Male	0	0
Religious/Spiritually Affiliated	Yes	13	46
	No	15	54
Disabled	Yes	7	25
	No	21	75

Gender Identity	Cisgender	15	54
	Gender Nonconforming	13	46
Socioeconomic Background	Under 125% of the Federal Poverty Guideline	10	36
	Working Class	12	43
	Middle Class	6	21
	Upper Class	0	0
BMI When Seeking Treatment	Below 19	9	32
	19-24.9	7	25
	25-29.9	6	21
	30-39.9	6	21
	40 or Above	6	21
		0	0



Age When Seeking Treatment			
	0-17	13	46
	18-29	23	82
	30-39		
	40-49	2	7
	50-59		4
	60+	1	0
		0	0
		0	

In addition, the survey collected information about the types of eating disorder behavior in which the participants engaged.

Table 2: Use of Disordered Eating Behaviors			
Disordered Eating Behavior N=28	Frequency	Percentage of sample	
Restricting Food Intake	25	89	
Using Laxatives	15	54	
Exercising Excessively	14	50	
Abusing Diet Pills or Supplements	11	39	
Using Diuretics	5	18	

Eating Non-Food Items (i.e. clay, toothpaste, etc.)	0	0
Restricting Amount of Insulin Required to Absorb Nutrients (For individuals with Diabetes Mellitus)	0	0
Self-Induced Vomiting	16	57
Chewing Food and Spitting it Out	10	36
Bingeing	18	64

The breakdown of the sample's demographic information makes it apparent that the sample is not only small, but that most of the respondents were Caucasian. This further limits the study due to the lack of African American, Latinx, Asian, and multiracial representation.

### Access to Treatment

To address the issue of treatment access, participants were asked a series of questions:

1. If they sought professional help for their eating behaviors
2. If they were referred for treatment
3. If they completed any treatment that was recommended
4. Which obstacles they encountered when seeking the recommended treatment.

Table 3: Number of Individuals Referred to Treatment vs. Individuals Who Completed Treatment		
N = 28	Number of People Referred to Treatment	Number of People Who Completed Treatment

Entire Group	13	6
By Race		
Caucasian	11	5
African	1	0
American	1	1
	0	0
Multiracial	0	0
Asian		
Latinx		
By BMI		
Below 19	4	2
19-24.9	2	1
25-29.9	4	1
30-39.9	3	2
By Gender Identity		
Cisgender	6	5
	7	1
Trans and Gender		
Nonconforming		
By Socioeconomic Status		
Under 125% of the Federal Poverty Guideline	5	2
	4	3
	4	1
Working Class		
Middle Class		

Although the research cannot be generalized, there is a noticeable disparity between the proportion of cisgender individuals who were able to complete treatment and the amount of trans and gender nonconforming participants who completed treatment.

Table 4: Barriers to Accessing Treatment After Referral									
Barrier	Transport	Insurance	Social	Time	Work	Caretaking	Gender	Geo	Cost
Freq.	7	12	6	7	11	3	1	6	13

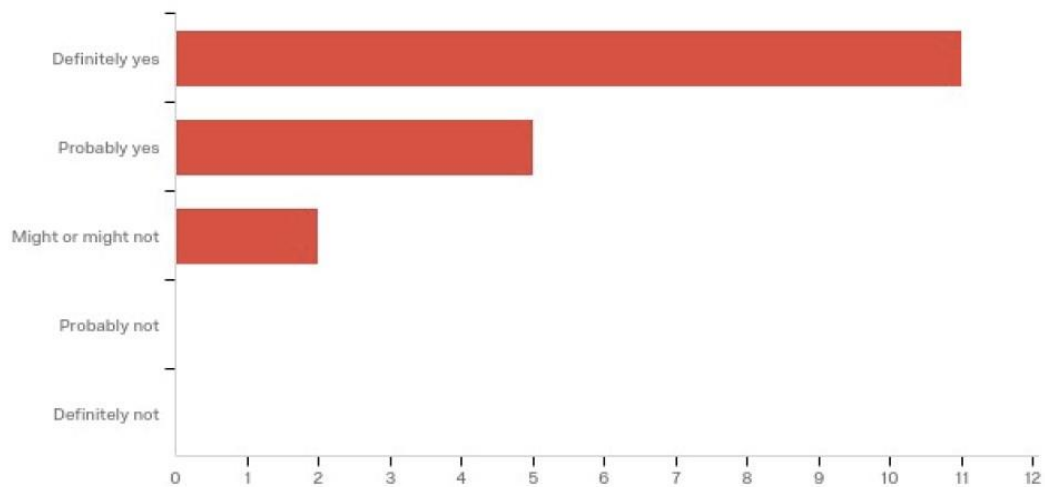
In the table above, nine categories of barriers are represented. They include issues of Transportation, Insurance Coverage, Social Support, Time Commitment, Work/Academic Responsibilities, Parenting or Other Caretaking Responsibilities, Gender Specificity of Treatment Environments, Geographic Location, and Cost. The most frequent barrier was cost, followed by insurance coverage and inability to take leave from work or school.

### **Stereotypes and Seeking Help**

To assess for issues of shame and stigma based on the intersection of participants' identities and the stereotype of individuals with eating disorders, the survey included a question about whether the individual thought others would be surprised to find out that they struggled with disordered eating based on their physical appearance.

**Figure 1. Perception of Appearance Related to Stereotype of Eating Disorders**

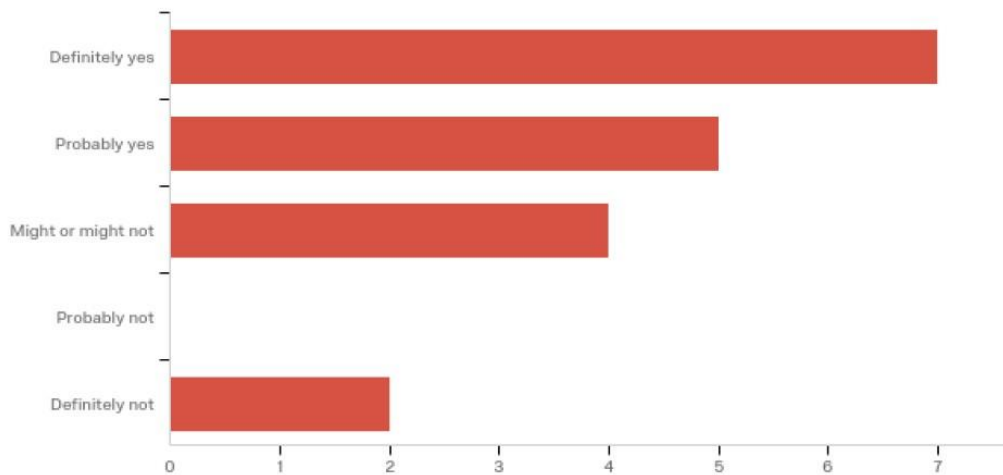
Q66 - Do you feel like someone would be surprised that you struggle with food issues based on your physical appearance?



Of the participants who answered the question, eighty-nine percent felt that people would be probably or definitely surprised while eleven percent of individuals were uncertain. The following question asked if it had impacted their decision to seek treatment, reflected in the chart below:

**Figure 2. Impact of Self-Perception on Decision to Seek Treatment**

**Q67 - Did this impact your decision whether to seek treatment?**



Eleven percent indicated that their treatment seeking was not affected by physical appearance, twenty-two percent reflected that it might or might not have affected their treatmentseeking choices, and sixty-one percent of respondents to the question indicated that their physical appearance probably or definitely contributed to their decision whether to seek treatment. When taking into account that the eleven percent whose physical appearance did not affect their decision to seek treatment were the same respondents who thought others might or might not be surprised that they had difficulties with food, it appears that seventy-five percent of participants who did not think they would meet the physical description of a person with disordered eating believed that this probably or definitely affected their choice whether to seek treatment.

The two questions described above also included space for qualitative input, and some of the feedback included statements such as, *“if I look fine I must be fine,” “only white people throw up their food,”* and several individuals commented on the effects of body weight on their choice whether or not to seek treatment. One participant said, *“I’m fat so I constantly feel like folks are judging me for my body: ‘she’s fat, she can’t have issues with an eating disorder.’”* One participant described the complexity of holding multiple marginalized identities by stating, *“Being queer and an ethnic minority as well as disabled, there is a lot of stigma and judgment in both the community and from the outside world. It makes it very hard to speak up.”*

### **Qualitative Responses**

Participants identified additional barriers and shared helpful insights through qualitative portions of the survey, ranging from reflections on the physical treatment environment to reflections on how they feel eating disorder treatment could be improved. One participant noted that they use a wheelchair and that the environment for treatment was physically inaccessible and difficult to enter, which created an additional barrier to treatment based on her disability. The same participant stated,

*“I could tell that my visible physical disability was a curveball for my providers. I felt paranoid that they were pitying me and my situation. We didn’t talk about my disability often. I would have liked to do that when I was in treatment.”* Many other participants gave voice to the feelings of shame they felt when addressing their eating behaviors, and more often the ways in which the response of doctors and mental health professionals dissuaded them from seeking further treatment. When asked if treatment had helped participants to improve their opinion of themselves, one respondent stated, *“Yes, I now know that I am smarter than the average therapist.”* While the participant also reflected that it might be related to their geographic location’s limited amount of resources, there were many separate reports of

encounters with mental health providers and primary care doctors that were harmful to clients. For example, the following statements about treatment professionals were made by participants throughout the survey:

“I was only 13 when I began seeking treatment for depression and self harm. No one took me seriously. I was so young, even mental health professionals wrote it off as a phase.”

“My last psychiatrist was extremely rude. He said, ‘The world would keep turning if you died.’”

“A therapist told me I couldn't have an eating disorder and called me a liar because I wasn't losing enough weight, when I actually wasn't losing weight because my body was malfunctioning which prevented weight loss.”

“Doctors that told me that I had ‘a body to die for,’ and that's why I didn't need any help. They also told me to just eat what I like and just eat what I wanted. None of them cared when I said I couldn't eat a single thing, not even an apple or a grape. They just prescribed strong medicine and sent me away.”

“I didn't fit in to the category for anorexia/bulimia so my former treatment center decided they couldn't treat me because I ‘only had EDNOS.’”

“My primary doctor told me eating disorders are a teenage problem, and I'm not a kid. So I should just stop.”

“When I became bulimic. I went to two family therapists (all that is available in my area). The first told me that my problem was that I had been a bad, disobedient Christian wife. The second therapist began to spend our entire sessions talking about her personal issues, if she had anything to say about me it would always be focused on how clear minded I am and no further than that. Both of these therapists are fully licensed and the second had a doctorate.”

The preceding statements are disappointing at best, and clearly demonstrate a lack of the most rudimentary knowledge of how to assess, identify, and treat disordered eating. When one considers the effects of stigma and stereotyping, issues of insurance and finance, and the indefensible lack of both ethics and knowledge in many professionals, it is no wonder that eating disorders are the most lethal category of psychiatric disorder. Lack of accurate representation makes it difficult to ask for help, the insurance market and for-profit medical system make it



difficult to access and complete treatment, and poorly educated doctors and mental health staff can cause any treatment the individual is able to access to be ineffective if not outright harmful.

## **CHAPTER V**

### **Discussion**

This exploratory study sought to investigate whether an individual's sociocultural identity impacts their ability to access eating disorder treatment that is effective. The study looked at who was referred for treatment, barriers to accessing and completing that treatment, and whether participants found that treatment to be helpful. Though the number of participants is too small to generalize to the larger population, the insights of the respondents support the notion that there is an increased difficulty in accessing effective eating disorder treatment for people of color, trans and gender nonconforming individuals, those who are socioeconomically disadvantaged, and people who are not seen as "thin." While some respondents spoke to stigma within population groups, the frequency and content of inappropriate remarks made by doctors and mental health professionals was a dominant indicator of whether an individual would be properly diagnosed, referred, and treated. As expected and as demonstrated in both quantitative and qualitative responses, financial and insurance-related barriers were a near-universal issue for the participants. A review of literature and qualitative data insists on the consideration of sociocultural identities when assessing, diagnosing, and treating individuals with eating disorders. In order to avoid the harm inflicted by the academic tendency to rely only on peerreviewed publications, numeric data, and medicalized interpretations of lived experience, this discussion is interwoven with contributions from people who hold marginalized identities, individuals who experience eating disorders, and some more accessible sources of dialogue

regarding the topic of eating disorder diagnosis and treatment. The discussion also includes topics for further study and potential changes that could be made to reform the eating disorder field into one that demonstrates humility and respect for all individuals who struggle with eating issues: one of those suggestions is to come to the conversation as a compassionate listener rather than asserting one's perceived expertise on the experiences of the marginalized body and spirit. The inclusion of sources that may be read by the academe as "atypical" is merely an attempt to start the change work in the present moment, asserting a position of activism without waiting for institutional change.

### **The Mythological Standard Presentation--Implications for Media**

As previously discussed, the cultural stereotype of the standard eating disorder patient was developed upon a foundation of scientific error: studying those who presented to treatment tells us more about who can access treatment than who is affected by a particular condition. While Hilde Bruch's contributions to the field of eating disorder research were necessary to draw attention to the illness, it is telling that *The Golden Cage* is dedicated to "the skinny kids who helped me write this book," and has a chapter entitled "The Perfect Childhood" in which she describes in detail how every eating disorder case begins with a happy family, a well-behaved and brilliant child, and a pattern of achievement and success (Bruch, 1973). Of course we now know that eating disorders are correlated with adverse childhood experiences, genetic predisposition, inconsistent social supports, and many other factors—which an individual can possess regardless of weight, heritage, gender identity, or socioeconomic status. However, when one considers how eating disorders are portrayed in the media, it would seem that our society is still caught in the eating disorder mythology of the last century. In her 2015 article "Seven Ways the Media's Depiction of Eating Disorders Failed Me as a Woman of Color," Raquel Reichard says:

“The media is not to blame for my eating disorder. But it never showed images of girls who looked like me or suffered with disordered eating the way that I did, which absolutely contributed to preventing me and my family from recognizing that I was sick sooner. If the media wants to be accurate and responsible, the scope of disordered eating representations must be broadened to reflect the diversity of those suffering.”

The difficulty of demolishing the barriers to eating disorder treatment is the way in which many separate issues are entangled. For example, we know that eating disorder treatment is expensive (Thompson & Park, 2016). We also know that private insurance often cuts treatment short, if it is covered at all (Crow, 2014). Doctors might mishandle clients with eating disorders due to their limited awareness of the varying symptom presentations, their own attitudes, and a lack of training (Striegel-Weissman & Rosselli, 2016; Thompson & Park, 2016; Bulman, 2017). Something as simple as media depictions of eating disorders that accurately represent the breadth of affected people and the highly individualized development and course of the illness could drastically change society. When doctors cannot recognize an eating disorder in a person of average BMI, or a person of color, when the sufferers themselves don't see someone who looks like them going to the doctor or seeking therapy and therefore second guesses their condition, it makes sense that policymakers and insurance executives wouldn't make eating disorder treatment a priority. They don't know the extent of the suffering, the numbers of the affected people, because even the people who have the illness second guess their diagnosis (Striegel-Moore & Rosselli, 2016). When we frame “legitimate suffering” as an emaciated, tube fed white adolescent girl, it is harder for anyone outside of the frame to accept the truth of their own experience. As people who consume media, we must ask ourselves why we continue to support a narrow focus on narratives of anorexia nervosa when the diagnosis is far less prevalent than other eating disorders. This is not to say that there isn't space for narratives of anorexia, but why haven't we seen a depiction in which the focus is on internal suffering, both physical and

emotional? Low body weight is something that only a fraction of individuals with anorexia experience, which is what makes the association between eating disorders and emaciation dangerous given the sometimes competitive nature of an illness that compels sufferers to earn their worth by being exceptional at something, even if that thing is their own demise. In Amelia Tait's article *When You're Both Overweight and Anorexic*, a male identified by the pseudonym "Luke," said, "Being sick enough to be admitted to hospital was one of many goals. My desire to be sick enough for hospitalization came from wanting to be the 'best' anorexic possible," (2015). The concept of the "best anorexic" or the most deserving, disciplined patient is not recent—in one of the most well-known eating disorder memoirs, *Wasted: A Memoir of Anorexia and Bulimia*, Marya Hornbacher says the following:

"When I got to treatment the first time, I was not one of the emaciated ones. I was definitely slim, far thinner than is normal or attractive, but because I was not visibly sick, the very picture of sick, because I did not warrant the coveted title of Anorectic, I was embarrassed. Ignore the fact that my diastolic pressure had a habit of falling through the floor every time I stood up, putting me on watch for sudden cardiac arrest, or the fact that my heart puttered along, slow and uneven as an old man taking a solitary walk through the park. Ignore the fact that I had a perforated esophagus and a nasty little habit of coughing blood all over my shirt. In treatment, as in the rest of the world, bulimia is seen as a step down from anorexia, both in terms of medical seriousness and in terms of admirability. Bulimia, of course, gives in to the temptations of the flesh, while anorexia is anointed, is a complete removal of the bearer from the material realm. Bulimia hearkens back to the hedonistic Roman days of pleasure and feast, anorexia to the medieval age of bodily mortification and voluntary famine. In truth, bulimics do not usually bear the hallowed stigmata of a skeletal body. Their self-torture is private, far more secret and guilty than is the visible statement of anoretics, whose whittled bodies are admired as the epitome of feminine beauty. There is nothing feminine, delicate, acclaimed, about sticking your fingers down your throat and spewing puke. Denial of the flesh, however, is not only the obvious culmination of centuries of bizarre ideas about the dainty nature of women but also an active realization of religious and cultural ideals," (1999).

In reproducing the images of old, the media continues the perception of eating problems as a sickness of thigh, stomach, and bone rather than an emotional response that affects the body.

It tells people that to be taken seriously, to be 'the best anorexic possible,' one must be as thin as possible without dying—although it has also been said that 'the best anorexic is a dead one.'

Even though Marya Hornbacher's memoir added a much-needed complexity to the narratives of eating disorders at that time, it cannot be ignored that she was still a white, classprivileged, cisgender, weight-suppressed young woman when she received treatment. This begs the question of whose stories get told, and whose stories get buried? Despite the less frivolous and shallow examination of the eating disorder experience offered in *Wasted*, Becky Thompson observes in *A Hunger So Wide and So Deep*,

“The portrayal of bulimia and anorexia as appearance-based disorders is rooted in a notion of femininity in which white middle- and upper-class women are presented as frivolous, obsessed with their bodies, and accepting of narrow gender roles. This representation, like the reputation of AIDS and some cancers, fuels people’s shame and guilt about them,” (1994).

This is echoed by participants' statements, "Only white people throw up their food," "Black girls don't cry," and "[Treatment centers] don't care about me, I'm just a poor overweight girl and I'm not made of money."

Further, the standard portrayal of eating disorders as a disease of whiteness, weight status, wealth, and womanhood worsens outcomes for everyone who does not fit the description. According to an article by May Bullman, most doctors receive no training in eating disorders throughout their schooling. Of those who do, the training ranges in length from two to six hours, total (2017). This means that, like the rest of us, doctors are getting their information on eating disorders from what they see in the media and are thus unlikely to see anything that calls upon them to reevaluate their assumptions regarding who gets eating disorders and what those presentations might look like. The thin white body tells a story that is so familiar that doctors, insurance companies, and those who develop diagnostic criteria know it by heart.

There has been some reflection in recent work addressing the body's unwilling participation in the politics of narrative. For example, in *Hunger: A Memoir of My Body*,

Roxane Gay makes the astute observation:

“When you’re overweight, your body becomes a matter of public record in many respects. Your body is constantly and prominently on display. People project assumed narratives onto your body and are not at all interested in the truth of your body, whatever that truth might be,” (2017).

As reflected in the qualitative data from the study's participants, as well as any venture into the comments section of internet content generated or shared by individuals (especially women) of larger size, people will cling to their projections onto the body no matter how much information they receive that speaks to the contrary. What's particularly depressing is the willing participation of medical and "helping" professionals in this dynamic.

Not only is this evident in regard to size, but to race as well. As Becky Thompson observed, “The association of eating problems with whiteness has made some women of color unwilling to seek help.” Rosalee, one of the participants in her narrative collection elaborated on this, stating: "admitting to sickness means admitting just one more thing wrong with this black person," and, as Thompson points out, is even worse when the people labeling the black body and mind as pathological are white (1994). This is an example of a white supremacist tradition, white control over the black female experience, a history that began in this country with slavery but lives on through the pathologizing of black women in policy, in media, and by America's unwillingness to protect them from police brutality and sexual assault. When eating disorders are dismissed and ignored even in women with white skin and class privilege, it is no wonder why people of color and in particular black women would want to avoid exposing an area of vulnerability to a system that has never been anything but predatory. Audre Lorde echoes in her poem, *Song for a Thin Sister* (2000), the expectation that eating problems and thinness are a

symptom of white culture and the bewilderment of its existence in not only the black community, but a loved one:

**Song for a thin Sister**

Either heard or taught  
as girls we thought  
that skinny was  
funny  
or a little bit silly  
and feeling a  
pull  
toward the large and the colorful  
I would joke you  
when you grew  
too thin.

But your new kind of hunger  
makes me chilly like danger  
for I see you forever retreating  
shrinking into a stranger in  
flight— and growing up black  
and fat I was so sure that  
skinny was funny or silly but  
always white.

Media taunts the sufferer who has experienced violence and alienation in many cases based on outside interpretations of the body, and now alienates them from ownership of their own suffering. Additionally the media's insistence on reusing buzzwords such as control, selfesteem, etc. ignores the words that are harder to say, such as "rape," "racism," slurs based on gender identity; it places the main character in a story that revolves around the fear of being fat, but doesn't dare hold up a mirror to a society that treats fat people as subhuman. It doesn't theorize what fatness, or thinness, or space, or disappearance might represent. And because the story is so simplified and shallow, the answers come easily. The main character "loves her body," (which is always still culturally normative after weight restoration despite the reality that

some sufferers, even those recovering from anorexia, recover into a healthy body that is categorized as overweight or obese) (Tait, 2015). She (and it's always a she) falls in love, is rescued, goes to therapy and treatment where everyone looks like her, understands her, respects her. As therapists we should all know that this is not how most stories of mental health struggles play out. It is time that we demand portrayals of eating disorders that include trans youth suppressing secondary sex characteristics through starvation (Levine, 2016); black women who aren't permitted to cry but can express pain through food (Covington Armstrong, 2009); people with anorexia who, despite the same behaviors, distress, and physical consequences as their thin peers, do not get treatment because they started at a higher weight, (Tait, 2015). These stories need to be seen, valued, believed, and discussed if we are to truly "spread awareness." We will never come up with new solutions if we continue to privilege the same voices who have led us astray.

### **Intersecting Identities, Intersectional Traumas**

The oversimplified depiction of eating disorders that has been given to us through the media and a legacy of flawed research means that what we know of eating disorders cumulatively is only applicable to wealthy, white, cisgender, thin women in Western society, under the current systems of medicine and mental health, and with healthcare access as it stands now. Even then, much of what has been written about eating disorders aside from memoirs are the interpretations of the (largely male) medical professionals who have projected theories onto the (predominantly female) experience. When one considers this, it seems that we know almost nothing at all about eating disorders, how they function, and how to help individuals recover. Unfortunately, it is true—our understanding of eating disorders at this point in history will likely be regarded by mental health professionals of the future as similar to the era in which women were diagnosed with hysteria.



To understand an eating disorder is to understand how a particular body exists in the world, and how that body's existence impacts the self. It is not up for debate whether women, people of color, trans and gender nonconforming people, individuals who live in poverty, and individuals who live in what we consider larger bodies are oppressed. It is common knowledge that sexual violence is rampant and most often perpetrated against women (National Sexual Violence Resource Center, 2015). The life expectancy of a trans woman of color is thirty-five years of age because of the likelihood of violence (Richards, 2015; Murphy, 2012). People in larger bodies are now casualties of "The War on Obesity," a declaration that our society has taken to heart if only for the reason that it legitimizes the idea that fat people are lazy, undisciplined, and unable to make their own decisions regarding their health, which is actually to the detriment of their health: a recent study found that the number one medical complication of binge eating disorder is poor general medical and surgical care arising from weight stigma (Olguin, Fuentes, Gabler, Guerdjikova, Keck, & McElroy, 2017). People who live in poverty are often unable to afford medical care, or unable to access that care (Office of Health Promotion and Disease Prevention, 2016). All of these factors speak to how one's body is impacted by the judgments put upon it by those in positions of privilege. Is it no wonder that the trauma is taken out on the body, or an attempt to flee it? The eating disorder is a desperate attempt by the disembodied self—escaping a body that is seen as probable cause, traded as property, violated sexually, forced violently into a binary or punished for the perceived inability to do so. This is all to say that the functions of an eating disorder are as varied as the individuals who have them, and that needs to be taken into consideration.

The understanding of racism, sexism, transphobia, heteronormativity, classism, and weight bias as trauma helps to understand some of the hesitance of individuals from marginalized groups to present to the medical community, even if healthcare is available. For example, as

Becky Thompson points out, "the historical association of lesbian sexuality with mental illness and deviance undercuts many lesbians' willingness to identify themselves with any stigmatizing illness (1994)." Thompson goes on to describe pressures for thinness even in groups that do not typically value thinness, as the thin ideal in American culture has come to represent belonging and not only attainment, but literal embodiment of white American values.

"Underlying an attempt to make a girl thin is an often unspoken assumption that while the family might not be financially stable, or it cannot fully shield her from racism, or it does not speak English without an accent, her small size may make her life and theirs somewhat easier," (Thompson, 1994).

Even without direct external pressures to become thin by friends or family, food becomes the method of expressing pain for many people of color as a result of historical trauma. Gloria Lucas runs Nalonga Positivity Pride, an organization operated by and specifically serving people of color who struggle with disordered eating. In her writings about the relationship between oppression and eating disorders, she states:

"Due to colonialism we experience contemporary oppression. We feel that we have no control or visibility and we use food as a coping mechanism to disappear, feel power over our numb bodies, escape, vent, release, inflict pain, and more. Eating disorders are our scream for help. We have embodied the pain from our ancestors and we have had little to no help healing, (2016)."

The fact that there has been no help in healing is reminiscent of a comment from one participant in the study who left an additional comment at the end, "I feel like it's kinda too late for me—I'm exhausted from everything, but thank you for doing this. I hardly ever get helped."

Childhood sexual trauma is often associated with development of eating disorders in particular (National Eating Disorders Association, 2012). This may be explained in part by the fact that children, while craving a way to block out the feelings associated with the abuse, have more access to food than other numbing agents such as drugs or alcohol (Thompson, 1994). Further, sexual abuse of children is typically committed by someone known to the child, often a

family member—Thompson reflects on the particular detriment when this occurs in the lives of individuals who are oppressed on the basis of their race or ethnicity:

"Whether a child is a toddler or a teenager, victimized for six months or six years, sexual violation shakes up what "home" means —what it feels like to be comfortable and safe with those who are charged with keeping children out of harm's way. Since racial and cultural identity is primarily taught in the home, this socialization process is inevitably disrupted when the home is no longer a refuge, but rather a place of stress and fear," (1994).

Thompson's statement that sexual trauma "shakes up what 'home' means" is doubly impactful when one considers that the body is the home of the self, and the sense of 'home' has been forever changed in that regard as well. She speaks to this in the following passage:

"Sexual victimization can cause body-image disturbances, mistrust of one's experiences, confusion about bodily sensations, negative self-esteem, and difficulties in identifying or knowing one's feelings. Dieting, bingeing, and purging are all ways women respond to these disturbances. Dieting can help a woman regain control of her body, which is lost during sexual abuse. Women may try to 'get rid of' their bodies—which they see as bad as a consequence of abuse—by purging. Bulimia anesthetizes painful feelings and helps dissipate anger, but also justifies feelings of unworthiness and self-hatred," (1994). It is heartbreaking when one considers all that is lost in childhood sexual abuse in specific reference to the relationship between the body and the self—to have a natural exploration of one's sexuality or a celebration of the body's capacity to sense pleasure forever altered by the fact that the first sexual experience is one of terror, shame, and loss that cannot be grieved in public.

The purpose of explicitly defining the traumatic experience of oppression is to name that which is often insidious, and to demonstrate the association between oppression and eating disorders—especially when the system meant to treat the eating disorder exists as an institutional perpetrator of these violations. There is power to be gained by speaking aloud of the continual injuries of oppression—Roxane Gay says in her recent memoir,

"This is what most girls are taught—that we should be slender and small. We should not take up space. We should be seen and not heard, and if we are seen, we should be pleasing to men, acceptable to society. And most women know this,

that we are supposed to disappear, but it's something that needs to be said, loudly, over and over again, so that we can resist surrendering to what is expected of us," (2017).

## **Treatment Implications**

To begin, treatment centers need to address the issues around accessibility. This means that treatment centers need to contract with public health insurance options such as Medicare and Medicaid, and offer additional options for financing such as payment plans or scholarships. The latter of these could be achieved by fundraising efforts and campaigns that not only focus on awareness of eating disorders as a serious illness, but also centers the lack of access to treatment. Furthermore, treatment centers need to personalize their approaches to treatment, because the eating disorder is always deeply personal. Suggestions include having continuing education opportunities based on cultural humility and historical trauma, as well as the ways in which eating disorders differ in presentation across the world. Other practical ways to address issues in treatment might be making sure that there are people on staff who are bilingual and educational materials in several different languages. An assessment of food offerings should be conducted to ensure that clients are eating food in treatment that they can afford to prepare at home, and food that is similar to what they might be eating in their communities after treatment has ended. It may also be beneficial to incorporate family and other community members to the extent that the client feels helpful in an effort to increase dialogue about eating disorders and offer a space of learning for the clinician and the family.

An even more helpful approach might be to leave the office or treatment center and go into communities: talk with clergy, community centers, librarians, and teachers. Rather than venturing out to educate them from a place of expertise, the clinician should understand that they are the one in need of education if entering a community to which they do not belong. In these

cases there should also be awareness of the potential for emotional labor to be contributed by anyone who holds a marginalized identity, so take the initiative to self-educate rather than placing the burden on anyone who holds a marginalized identity. Rather than expecting to receive information merely because it has the potential to help the community, treatment providers should apply the same logic to these interactions that they would with business interactions: for example, if the treatment provider or facility would compensate an outside consultant for business or marketing insight, the people giving insight on behalf of their social location should be compensated as well. In addition to consultation, the clinical entity could invite community leaders and affected individuals to take part in the decision making for an organization by creating an advisory board (Okun & Jones, 2001).

There has been some success with early intervention efforts which focus on participatory action and consciousness raising in peer environments: when a peer community is given a forum in which to discuss issues of body image and body-based oppression, it both builds awareness of messages that individuals receive about their bodies and dispels the sense that the individual may be the only one experiencing issues with food or the body. It has also appeared to be beneficial to involve role models in modeling body acceptance, emotional vulnerability, and discussion of topics that have been traditionally viewed as shameful (mental health, sexuality, or abuse) (Levine & Piran, 2002).

It is also important to take a critical perspective when considering professional standards. The therapeutic professions often include an expectation of objectivity; "objectivity" is usually congruent with the experience of individuals with dominant identities. The expectation that professionals are objective is to ignore the ways in which oppression operates in ways that are undetectable to people who are doing the oppressing. What's more, professional spaces need to engage in dialogue about social justice and encourage advocacy. As the legacy of trauma

demonstrates, there are legitimate reasons for the body to not feel safe based on identity, and so treatment providers cannot hope to heal clients unless we dedicate ourselves to healing our society through activism and advocacy. To declare a stance of objectivity and neutrality desirable is similar to declaring oneself "colorblind" and ignoring race rather than seeing the complexity of human experience.

The most helpful approach in many cases is what Patricia Hill Collins calls "an ethic of care," which she defines as understanding that "personal expressiveness, emotions and empathy are central to the knowledge validation process," (Thompson, 1994).

Finally, treatment should utilize a variety of methods in order to promote healing. Becky Thompson again addresses this in *A Hunger So Wide and So Deep*:

"Effectively combating eating problems across the lines of class, race, religion, and ethnicity hinges on understanding that there are many possible approaches: going to Egypt, getting financial aid to attend college, working for a rape crisis hotline, becoming an athlete, seeking counseling, becoming an activist, joining a self-help group. Long-term healing is often born of counseling coupled with involvement in community, political, educational, and religious organizations. A therapist's ability to support a multifaceted approach to healing often depends on willingness to build multiracial, multicultural bridges, both personally and professionally. Such a commitment may determine whether women of color and working-class women seek and benefit from treatment—and can change the epidemiological portrait that hinders a comprehensive understanding of the causes of eating problems and the methods of healing from them," (1994).

### **Research Implications:**

Many of the responses in the qualitative portions of the study have indications for further study: one in particular might be additional study on the attitudes and clinical understanding of eating disorders by primary care physicians. In addition to studying knowledge of the particular category of illness, it begs study into the ways in which treatment professionals communicate with their clients and whether they understand the implications of the harmful comments.

In addition to conducting future studies, treating clients justly means that professionals must take a critical stance when interpreting research and "evidence," especially in this age of "evidence-based practice." This means asking questions when presented with research, and asking questions about what is missing from research. Some of the questions identified by Cool, LaMarre, and Kinavy (2017) include:

- What counts as evidence? What doesn't?
  - Are researchers including lived experience as evidence?
  - Why does the construct of "evidence-based" originate from research that then is meant to apply to everyone?
  - Who funds that research?
  - Why is there so little participatory action research?
  - How does this research involve other ways of knowing that aren't top-down or mechanistic?
  - Who owns knowledge? Who owns researchers? Who owns science?
  - What might be the financial impacts that motivate this particular research?
  - What treatments, modalities insurance will pay for and for how long?
- When research is critically reviewed with attention to power dynamics and philosophical

understandings of science, logic, and scientism as potential agents of white supremacy and colonialism, it is possible that "evidence-based practice" might take on a new meaning for the field.

## **Conclusion**

The field of eating disorder treatment has been inaccessible and ineffective when it comes to meeting the needs of individuals from marginalized populations who present with issues related to food and the body. The only way to correct this is to collectively aim for social justice.

To quote LaMarre, "Social justice means thinking at a systems level – meaning political, economic, social and other systems like government, corporations, institutions, and more – to consider how we might better support equitable access to needed services and supports of all kinds for diverse people," (2016).

One way in which the mental health field could progress is by reevaluating standards that uphold white supremacy, classism, transphobia, and weight bias. The institutions that are responsible for training mental health professionals and the professional organizations which develop ethical codes should ask themselves whether their standards are liberatory or repeat dynamics of oppression. While there has been much fanfare for the so-called "gatekeeping responsibility" of the professions (Miehls, 2016), it is crucial that professional organizations and places of learning pay attention to who is standing outside the gate, and whether that is a reflection of the person or a historically controlling institution. Clients deserve to see themselves reflected in those who are involved in their healing process, and if the body is already interpreted as the site of pain and otherness it is detrimental to enter a healing environment where one's body is, yet again, the site of alienation. There needs to be evaluation on behalf of the professions about who it is that we are serving in a system that replicates historical trauma and remains inaccessible to those who desperately need it. If there are no clinicians with identities similar to the clients, that needs to be interrogated and if an entire category of diagnosis has a "standard clinical presentation," based on race, gender identity, weight, or wealth, there needs to be inquiry regarding the formulation of that stereotype.

Furthermore, it is beyond time for the helping professions to return to activities that are helpful; it is imperative that social activism be included in this. To quote Dr. Linda Bacon, "No amount of self-love can change how people perceive marginalized bodies," (2017).

Selfcompassion needs systemic and societal change to flourish just like a plant needs sunlight



and water. When a person is not valued by systems and broader society, it is unrealistic to ask that person to love themselves.

Again, Becky Thompson perfectly states what needs to occur:

"Prevention of eating problems depends on changing the social conditions that support violence and injustice. Making it possible for women to have healthy relationships with their bodies and their food is a comprehensive task: we need to ensure that children grow up free of racism and sexual abuse, that parents have adequate resources to raise their children, and that young lesbians have a chance to see their reflection in their teachers and community leaders. We must confront the myth of a monolingual society and support multilingual education; change a welfare system in which a household that is eligible for the maximum amount of assistance receives an average of forty cents worth of food stamps per meal; dismantle the alliance of the medical, insurance, reducing, and advertising industries that capitalizes on reducing women's bodies to childlike sizes; refuse to blame women who are anorexic or bulimic; and dispel the notion that large women automatically eat too much. Women must learn to feed themselves along with—not after—others. Ultimately, the prevention of eating problems depends on economic, cultural, racial, political, and sexual justice," (1994).

While these expectations may seem radical, to quote Angela Davis, "radical simply means grasping something at the root." For too long, the institutions that treat eating disorders and the individuals working within those environments have colluded with the causes of the eating disorder itself. We have deemed people's suffering as illegitimate by judging on basis of appearance rather than severity of distress, we have turned people away from treatment in order to make a profit, and we have perpetuated white supremacy by accepting norms and values without ever stopping to question whose norms and values they actually are. If we are to ever call ourselves helpers, or give ourselves the even more sacred designation of "healer," we need to take responsibility for the injuries we've inflicted in the past. By meeting clients with humility and a willingness to hear their stories, we are creating an inch of safe space for a person who has not been given that luxury. Individuals with eating disorders have experienced trauma and oppression that has shattered the core of what it means to have a home inside the body, just the

way that no one wants to live in a house that is the scene of a crime or the site of immense grief. While the violations cannot be undone and the pain unfelt, they can be validated and the pain can be witnessed. There was no way to protect the individual from violence in the past, but in working toward social justice and naming the trauma we join our clients in an attempt to shift blame away from the body and onto the true causes of distress. When trauma has caused the self to flee from the body, it will almost certainly take a considerable amount of time and effort on the part of the clinician and the client to make the body feel safe again. By naming the crimes that caused sufferers to run away from their own bodies in order to survive, we are unlocking the door and putting a candle in the window, sending a message: no matter what, you can always come home.

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## Appendix A: Human Subjects Review Application

s2016-2017

Smith College School for Social Work

Human Subjects Review Application

**Project title:** Unequal Treatment: Sociocultural Identities and Their Effects on Eating Disorder Treatment Access and Efficacy

**Is this a joint project**(more than one researcher working on this study)?  X  No   Yes

**Name of researcher(s):** Hannah Noel Smith

**Check one:**  X  MSW   PhD

**Phone** (include contact researcher for joint projects): 9373059216

**Email** (include email for contact researcher for joint projects): hnsmith@smith.edu

**Research advisor:** Elaine Kersten

The signature below testifies that I, as the researcher, pledge to conform to the following: As one engaged in research utilizing human subjects, I acknowledge the rights and welfare of the participants involved. I acknowledge my responsibility as a researcher to secure the informed consent of the participants by explaining the procedures and by describing the risks and benefits of the study. I assure the Committee that all procedures performed under the study will be conducted in accordance with those federal regulations and Smith School

for Social Work policies that govern research involving human subjects.

Any deviation from the study (e.g.: change in researcher, research methodology, participant recruitment procedures, data collection procedures, etc.) will be submitted to the Committee by submitting a Protocol Change Form for which you MUST receive approval *prior* to implementation. I agree to report all deviations to the study protocol or adverse events IMMEDIATELY to the Committee.

Researcher: Hannah Smith

\_\_\_\_\_ 10/15/16 \_\_\_\_\_

Name(s)

(Date)

Research Advisor/Committee

Chair \_\_\_\_\_

(Date)

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**IN THE SECTIONS BELOW WHERE DESCRIPTIONS ARE REQUESTED, BE SURE TO PROVIDE SUFFICIENT DETAIL TO ENABLE THE COMMITTEE TO EVALUATE YOUR PROCEDURES AND RESPONSES.**

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**1. DESCRIPTION OF RESEARCH PROJECT INVOLVING HUMAN PARTICIPANTS**



Briefly summarize the purpose of the study, the over-arching research question, the specific research design you will use and why you have chosen it for this study, and the planned use of human participants, and a brief synopsis of relevant literature that points to need for further study (NO MORE THAN A HANDFUL OF ARTICLES) with sufficient detail and in clear, concise language (space will expand in all sections as you enter your information):

While much research has been conducted in the field of eating disorder treatment, many authors have noted limitations in lack of subject diversity, as noted by Wood & Petrie as well as Henrickson & Crowther (2010). In their conclusions, both authors have called for further study in eating disordered behaviors that include subject pools which reflect minority and oppressed subjects, as well as more heterogeneous subjects within these populations. My study seeks to address this issue by asking individuals who identify as a member of at least one marginalized group about their experience seeking treatment for their disordered eating behaviors. To address this gap in research including participants who differ within subgroups, and to understand the impact of intersectionality, this study aims to answer the following questions: are there barriers to treatment access for individuals from diverse populations and do participants in these groups who obtain services feel that the treatment is helpful? For the purpose of this study, I use “eating disorder” and “disordered eating” interchangeably to include individuals who have engaged in behaviors consistent with eating disorder diagnoses but may have never received a diagnosis. Eating behaviors that qualify an individual to participate in the study are any behaviors included in DSM-5 criteria for Anorexia Nervosa, Bulimia Nervosa, Other Specified Feeding and Eating Disorder, Binge Eating Disorder, Rumination Disorder, Avoidant/Restrictive Food Intake Disorder or Pica. One of the issues identified by previous authors has to do with access to treatment, and the authors have additionally noted some question regarding the effectiveness of treatment in reducing or eliminating eating disorders of their clients. Because of the issues of diversity, access and efficacy noted by previous authors, the proposed study seeks to identify issues regarding access to and efficacy of eating disorder treatment with a focus on minority populations. Within the context of this study, “marginalized populations” include individuals that do not identify as white, cisgender, heterosexual, affluent, or thin. Clients will only need to identify with one area of marginalization to participate, but may hold many marginalized identities. The study design will be a quantitative study design method-based on a survey, and will include several open-ended questions, allowing participants to identify specific issues they wish to note that are not reflected in the survey. The only planned use of human subjects will be through an online survey.

**2. PARTICIPANTS:** if you are only observing public behavior, skip to question d in this section.

a). How many participants will be involved in the study?

b). List specific eligibility requirements for participants (or describe screening procedures), including exclusionary and inclusionary criteria. For example, if including only male participants, say so, and *explain why*. If using data from a secondary de-identified source, skip to question    in this section.

- Finally, the participant must be able to access online surveys and be able to read English.

The recruitment process will begin by my posting about the study in the open social media groups belonging to The Icarus Project, Nalunga Positivity Pride, The Body is Not an Apology, and Trans Folx Fighting Eating Disorders (T-Fed). Permission to post is guaranteed because of

the open status of the group. I will post the information along with permission for members of these groups to share the information in their social/support circles. (See Attachment A: Social Media Post)

d). Is there any relationship between you as the researcher and the participants (e.g. teacher/student, superintendent/principal/teacher; supervisor/clinician; clinician/client, etc.) that might lead to the appearance of coercion? If so, what steps will you take to avoid this situation. For example: "I will not interview individuals who have been direct clients."

As an anonymous survey I will not have a direct relationship with any respondents

e). Are the study *target subjects* members of any of the following federally defined vulnerable populations? (ONLY check if the study focus area is SPECIFICALLY based on any of the listed groups. For instance, if your study is about how persons who are economically disadvantaged access services, you DO check 'Economically disadvantaged' category below. DO NOT CHECK IF SOME OF THESE FOLKS MAY BY CHANCE BE IN A MIXED SAMPLE – EXCEPT IF THERE ARE CHILDREN/UNDER 18 YEAR OLDS. Thus: if you are asking about how individuals who live in inner city locations get to services, you DO NOT check any of the categories below, because there is a range of types of people who live in these environments who may wish to participate, and you do not define the population as 'economically disadvantaged'). Be aware that checking 'yes' **automatically requires the HSR**

**Full Review.**

_____	Yes	<input checked="" type="checkbox"/>	No
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If 'Yes', check the group(s) all that apply in your study:

_____	minors (under 18 years of age) Please indicate the approximate age range of minors to be involved. Participants under age 18 require participant assent AND written consent from the parent/legal guardian. Please use related forms.
_____	prisoners
_____	pregnant women
_____	persons with physical disabilities

\_\_\_ persons with diagnosed  
mental disabilities

\_\_\_ economically disadvantaged

\_\_\_ educationally disadvantaged

### **3. RESEARCH METHODS:**

(Check which applies)

\_\_\_ Interview, focus group, non-anonymous questionnaire

☒ Anonymous questionnaire/survey

\_\_\_ Observation of public behavior

\_\_\_ Analysis of de-identified data collected elsewhere ('secondary data')

( ) Where did these data come from originally?

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Did this original research get IRB  
approval? \_\_\_ Yes \_\_\_ No

(Skip to BENEFITS section)

\_\_\_ Other

(describe):

Describe the nature of the interaction between you and the participants. Additionally, if applicable, include a description of the ways in which different subjects or groups of participants will receive different treatment (e.g., control group vs comparison group, etc.).

I will have no direct interaction with any participants as this is an anonymous survey.

a). Please describe, with sufficient detail, the procedure/plan/research methodology to be followed in your research (e.g. this is a quantitative, survey based study; tell us what participants will do; etc).

In the recruitment materials, the study will be introduced and study participants will be invited to click on a link, which will first bring them to a page which contains an introduction to the study (Attachment B: Introduction), followed by the prescreening page (Attachment C: screening page), and if they check that they meet the inclusion criteria, they will then have to option to continue to the informed consent page (Attachment D: Informed Consent Page), at the end of which they will reach the agreement to participate page which will give them the choice to either exit or proceed. If they check that they wish to continue with the survey, the participant will then be brought to the page with the survey/ questionnaire which will contain both survey and openended questions pertaining to demographics, eating behaviors, access to treatment, efficacy of treatment, and optional open ended questions that ask them to share treatment improvements they feel would have added to their experience.

b). How many times will you meet/interact with participants? *(If you are only observing public behavior, SKIP to question d\_\_\_\_\_in this section.)*

Study participants will be invited to take a survey, which will be the only interaction; there will be a field at the end of the survey which will allow for comments. c). How much total time will be required of each participant?

Each participant will need approximately 15-30 minutes to complete the survey, though it may take longer depending on the length of the participant's open ended answers. d). Where will the data collection occur (pleaseprovide sufficient detail)?

The survey collection will take place online through Qualtrics survey software.

e). If you are conducting surveys, attach a copy of the survey instrument to this application. If you are conducting individual interviews or focus groups, including ethnographies or oral histories, attach a list of the interview questions as an "Attachment". Label attachments alphabetically, with descriptive titles. (See Attachment E: Survey Questions).

**4. INFORMED CONSENT:** *(If you are only observing public behavior, SKIP to next section)*

a). What categories of consent documentation will you be obtaining from your participants?

(Check all that apply)

☒ writtenparticipant consent

\_\_\_\_ writtenparent/guardian consent

\_\_\_ Child assent 14-17

\_\_\_ Child assent, assent 6-13

\_\_\_ Adult with guardian  
consent

b). Attach original consent documents. \*note: be advised that, electronic signatures and faxed, signed consents ARE allowed. Please describe how you will gain consent.

Consent will be collected electronically via the Qualtrics software program at the start of the survey.

#### 5. COLLECTION /RETENTION OF INFORMATION:

a). With sufficient detail, describe the method(s) of recording participant responses (e.g., audiotape, videotape, written notes, surveys, etc.)

Participant responses will be recorded anonymously through the Qualtrics program.

b). Include the following statement to describe where and for how long will these materials will be stored and the precautions being taken to ensure the security and safety of the materials.

All electronically stored data will be password protected during the storage period. I will be utilizing the approved software, Qualtrics, which I will set up to remove email address to maintain anonymity of the subjects.

c). Will the recordings of participant responses be coded for subsequent analysis? ***If you are only observing public behavior, SKIP to next section.***

☒ Yes

\_\_\_ No

#### 6. CONFIDENTIALITY:

a). What assurances about maintaining privacy will be given to participants about the information collected?

☒ 1. Anonymity is assured (data cannot be linked to participant identities)

\_\_\_\_ 2. Confidentiality is assured (names and identifying information are protected, i.e., stored separately from data).

\_\_\_\_ 3. Neither anonymity nor confidentiality is assured

b). If you checked (2) above, describe methods to protect confidentiality with sufficient detail. Describe how you will maintain privacy of the participant as well as the data

c). If you checked (3) above, explain, with sufficient detail, why confidentiality is not assured.

d). If you checked (3) above, provide sufficient detail that describes measures you will take to assure participants understand how their information will be used. Describe and attach any permissions/releases that will be requested from participants.

## **7. RISKS:**

a). Could participation in this study cause participants to feel uncomfortable or distressed?

☒ Yes

\_\_\_\_ No

If yes, provide a detailed description of *what steps* you will take to protect them.

Subjects may feel uncomfortable answering questions about the behaviors in which they used to engage. To protect study participants, they will be given the option to exit the survey at any point by clicking on the 'Escape' button, should they feel uncomfortable or distressed by any of the survey questions. Additionally, resources such as treatment referral agencies, hotlines, and identity-supportive eating disorder agencies will be available as part of the study. (See Attachment F: Referral Sources for Survey Takers)

b). Are there any other risks associated with participation (e.g. financial, social, legal, etc.)? \_\_\_\_ Yes ☒ No

If yes, provide a detailed description of the measures you will take to mitigate these additional risks.

**8. COMPENSATION: (If you are only observing public behavior, SKIP to the next section)**

Describe any cash or 'gifts' (e.g.: coffee shop gift card) that participants will receive for participating in this research (see guidance about payment/gift compensation in the Smith School for Social Work Human Subjects Review Guideline, at the HSR site in the SSW website).

No compensation will be provided to study participants.

**9. BENEFITS:**

a). Describe the potential benefits for you, the researcher, in conducting this study.

The benefit to myself as the researcher is the attainment of my Master of Social Work degree following the completion of the study and ultimately my thesis.

b). Describe the potential benefits for individuals who participate as subjects, EXCLUDING payment/gift compensations.

The potential benefit to the study participants is to have a chance to share their personal experiences.

c). Describe the potential benefits to the field of clinical social work from this research?

The field of clinical social work stands to benefit greatly from this research for several reasons: first, there is a significant gap in research regarding the experiences of individuals from diverse populations and the differences in their ability to access and benefit from treatment. This study aims to inform the profession about how to best demonstrate our ethical standards of cultural competency and our commitment to engage in research-informed practice. Results of this study may provide options or ideas overlooked thus far in the field of eating disorder treatment, and could highlight the importance of intersectionality in how we as clinicians conceptualize our clients' lived experience.

**10. FINAL APPLICATION ELEMENTS:**

a. Include the following statement to describe the intended uses of the data:



The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

b. If there are Co- Researchers, cooperating departments, and/or cooperating institutions, follow the following instructions:

If you are working with/conducting your research with a researcher working at another institution or organization, include a letter of approval from that institution's IRB or agency administrator. If there are multiple researchers, indicate only one person on the Documentation of Review and Approval as the researcher; others should be designated as "CoResearcher(s)" here.

c. TRAINING: Include the following statement to describe training:

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 and was completed within the past four years.

Friends and colleagues,

I'm a student seeking participants for a study as part of my Smith College School for Social Work master's thesis about barriers to treatment access for individuals from diverse backgrounds, and whether participants in these groups who obtain services feel that the treatment is helpful. Participants will take an anonymous survey that can be completed in less than 15- 30 minutes. If you are eligible, please consider taking the time to participate.

Participants must meet the following criteria:

- At least 18 years of age at the time that they take the survey
- History of engaging in disordered eating behaviors such as: bingeing, purging, consuming nonfood items, restricting intake, abusing laxatives, chewing & spitting, exercising excessively, etc.
- Identify as an individual from at least one of the following populations:
  - o Any race or ethnicity aside from white/Caucasian
  - o Any gender

identity aside from cisgender

- o Individuals who have a Body Mass Index (BMI) of 19 or above;
- o Individuals whose income is below the Federal Poverty Level
- o Must be able to access online surveys and be able to read English

No compensation is available for study participants.

Survey can be accessed through this link: [Qualtrics Survey Link](#)

For questions or to learn more, contact Hannah Smith at [hnsmith@smith.edu](mailto:hnsmith@smith.edu) or xxx-xxx-xxxx.

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC).

My name is Hannah Smith and I am a second year Master of Social Work student at Smith College School for Social Work. The purpose of this survey is to learn about barriers to treatment access for individuals from diverse populations, and learn from individuals in these groups who obtain services if they feel that the treatment was helpful.

Note: While this survey asks for participant Body Mass Index (BMI), it is only to assess whether body weight affected decision to seek treatment or professionals' diagnosis/referral process. I do not endorse BMI as an appropriate indicator of health.

All responses to this survey are anonymous, and you may exit the survey at any time should you no longer wish to continue.

If you do not qualify to participate in the survey but would like to learn more about the presentation of eating disorders in diverse populations, feel free to explore the following resources:

National Eating Disorders Association's Marginalized Voices Project

<https://www.nationaleatingdisorders.org/marginalized-voices>

National Eating Disorders Association's Diversity Information Page:

<https://www.nationaleatingdisorders.org/diversity> Nalonga Positivity

Pride

<http://www.nalgonapositivitypride.com/> [npppride@gmail.com](mailto:npppride@gmail.com)

<https://www.facebook.com/nalgonapositivepride/>

<https://twitter.com/nalgonapride> Trans Folx

Fighting Eating Disorders

<http://www.transfolxfightingeds.org/untitled>

<http://www.transfolxfightingeds.org/>

[transfolxfightingeds@gmail.com](mailto:transfolxfightingeds@gmail.com)

[www.facebook.com/transfolxfightingeds](http://www.facebook.com/transfolxfightingeds)

<https://twitter.com/tffed>

Islam and Eating Disorders

<https://www.facebook.com/IslamEatingDisorders/>

<http://waragainsteatingdisorder.com/>

Health at Every Size, Size Diversity, and BMI:

<https://healthateverysizeblog.org/2011/10/24/the-haes-files-is-the-body-mass-index-a-goodmeasure-of-health/>

<https://sizediversityandhealth.org/content.asp?id=34&articleID=177>

<http://www.nationaleatingdisorders.org/size-diversity> <http://haescommunity.com/>

Attachment D: Screening Page

Eating Disorder Treatment Access and Efficacy – PROPER FORMATTING WILL BE IMPLEMENTED IN SOFTWARE SYSTEM

In order to participate in this survey, you must meet the following criteria:

- At least 18 years of age at the time that they take the survey
- History of engaging in disordered eating behaviors such as: bingeing, purging, consuming non-food items, restricting intake, abusing laxatives, chewing & spitting, exercising excessively, etc.
- Identify as an individual from at least one of the following populations:
  - Any race or ethnicity aside from white/Caucasian
  - Any gender identity aside from cisgender
  - Individuals who have a Body Mass Index (BMI) of 19 or above
  - Individuals whose income level is below the Federal Poverty Level
  - Must be able to access online surveys and be able to read English

If you meet any of the above inclusion criteria and wish to learn more about this study, please click 'I meet inclusion criteria' below and you will be taken to the Informed Consent. If you do not meet the above, you are not eligible to participate in this study, but I thank you for your interest.

I meet inclusion criteria  
Attachment E: Informed Consent

I do not meet inclusion criteria



**2016-2017**

**Consent to Participate in a Research Study**  
**Smith College School for Social Work • Northampton, MA**

.....

**Title of Study:** Unequal Treatment: Sociocultural Identities and Their Effects on Eating Disorder Treatment Access and Efficacy

**Investigator(s):** Smith, Hannah : hnsmith@smith.edu

.....

## Introduction

- You are being asked to participate in a research study about the effects of factors such as heritage, class, weight, and gender identity on a person's ability to access appropriate eating disorder treatment.
- You were selected as a possible participant because you are over 18 years of age, have had symptoms of an eating disorder, and self-identify as a member of one or more of the following populations:
  - Any race or ethnicity aside from white/Caucasian
  - Anygender identity aside from cisgender
  - Individuals who have a Body Mass Index (BMI) of 19 or above
  - Individuals whose income is below the Federal Poverty Level
  - Must be able to access online surveys and be able to read English
- I ask that you read this form to fully understand the process of participating in this study.

## Purpose of Study

- The purpose of this survey is to learn about barriers to treatment access for individuals from diverse backgrounds, and learn from individuals in these groups who obtain services if they feel that the treatment was helpful.

- This study is being conducted as a research requirement for my Masters of Social Work degree at Smith College School for Social Work.
- Ultimately, this research may be published or presented at professional conferences.

### **Description of the Study Procedures**

- If you agree to be in this study, you will be asked to do the following things: Participate in an anonymous online survey, which can be completed in an average of 15-30 minutes.

### **Risks/Discomforts of Being in this Study**

- The study has the risk of causing you to feel uncomfortable due to some of the questions asked about your experience with disordered eating.
- If you do feel uncomfortable, you may exit the survey at any time.
- You may also wish to contact any of the supports listed in the referrals at the end of this consent.

### **Benefits of Being in the Study**

- The benefits of participation include the potential to gain insight, a chance to share your personal experience, and an increased understanding of eating disorders.
- The benefits to social work/society is to provide knowledge about treatment for eating disorders for specific diverse populations

### **Confidentiality**

- This study is anonymous. I will not be collecting or retaining any information about your identity because I have set up the survey so that your email address is not accessible to me.

### **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 answer any question or withdraw from the study *at any time* 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. As an anonymous survey, simply exit at any point by clicking on 'escape' at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in my study.

### **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, Hannah Smith at hnsmith@smith.edu or by telephone at (937) 305-9216.  
If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.



## Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep. You will also be given a list of referrals and access information if you experience emotional issues related to your participation in this study.

.....

Name of Participant (print):

\_\_\_\_\_

Signature

of Participant:

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

Signature

of Researcher(s):

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

.....

### Resources for Participants

- **Mental Health Crisis Text Line**

Text “Start” to 741-741

- **National Eating Disorders Association’s Helpline, Crisis, and Support Information** <https://www.nationaleatingdisorders.org/find-help-support>

- **National Eating Disorders Association’s Treatment Finding Tool** <http://www.nationaleatingdisorders.org/find-treatment>

- **ED Referral:** A site dedicated to finding treatment in your area <https://www.edreferral.com/finding-a-therapist>
- **Alliance for Eating Disorders' Treatment Guide**  
<http://www.allianceforeatingdisorders.com/portal/treatment-centers>

#### Attachment F: Survey Questions

Questions to be formatted properly within survey software:

#### **Section One—Demographic Information**

Are you currently at least 18 years of age?

- ☐ Yes
- ☐ No

Q1

Please indicate which, if any, of these disordered eating behaviors you have used.

- Restricting your food intake
- Using laxatives to lose weight
- Exercising excessively
- Abusing diet pills or supplements
- Using diuretics to lose weight
- Eating non-food items (i.e. clay, toothpaste, etc.)

- Restricting amount of insulin your body requires to absorb nutrients (For individuals with Diabetes Mellitus)
- Making yourself vomit after eating
- Eating abnormally large quantities of food in a short period of time
- Chewing food and spitting it out instead of swallowing
- Excluding entire groups of food (i.e. carbohydrates, foods containing fat, etc.) Other (please describe)

How would you define your race?

[text box]

How do you define your ethnicity?

[text box]

What sex were you assigned at birth?

☐ Male

☐ Female

Are you religious or spiritual?

☐ Yes

☐ No

**Display This Question:**

If Are you religious or spiritual? If Yes Is Selected:

Describe your spirituality:

Do you identify as disabled?

☐ Yes

☐ No

Q7

Are you cisgender? (*A person whose gender identity is aligned to what they were designated at birth, based on their physical sex*)

☐ Yes

☐ No

Q8

How would you describe your gender?

Q9

Which of these best describes your socioeconomic class?

☐ Lower socioeconomic status

- ☐ Working class
- ☐ Middle class
- ☐ Upper class

In which range did your Body Mass Index (BMI) fall at the time that you considered seeking treatment? (see [https://www.nhlbi.nih.gov/health/educational/lose\\_wt/BMI/bmi\\_tbl.pdf](https://www.nhlbi.nih.gov/health/educational/lose_wt/BMI/bmi_tbl.pdf) to find your BMI)

- ☐ Below 19
- ☐ 19-24.9
- ☐ 25-29.9
- ☐ 30-39.9
- ☐ 40+

Q11

At what age did you seek, or consider seeking treatment for your eating disorder? (If treatment was considered or sought more than once, check all age ranges that apply):

- ☐ 0-17
- ☐ 18-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60-69
- ☐ 70+

## **Section Two: Seeking Treatment**

How likely are you to seek support or treatment in the following environments? (rated from 1 [unlikely] – 5 [very likely])

- Primary Care Doctor
- Community Clinic
- Therapist
- School
- Friend group
- Internet
- Eating disorder center
- Family
- Spiritual Community
- OBGYN
- Job
- Benefits/Services caseworker
- Hotline

- Crisis text line
- Other

Where else do you think it would be helpful to get information on how to receive treatment?

Did you seek professional help? (Y/N)

Did you seek informal support? (Y/N)

Do you perceive there to be stigma (negative judgment) within your community regarding mental illness? (Y/N) Explain:

Do you perceive there to be stigma within your community for seeking mental health services? (Y/N)

Explain:

Do you perceive there to be stigma within your community for eating disorders specifically? (Y/N)

Explain:

Did you feel like you personally experienced any discrimination while seeking treatment? (Y/N)

Explain:

Did you feel like you personally experienced any discrimination during treatment? (Y/N)

Explain:

Have you had prior experiences of discrimination from health professionals? (Y/N)

Explain:

Was a formal set of questions, or an assessment used? (Y/N)

Did any questions feel like they applied to your experience of having an eating disorder? (Y/N)

Did you receive a formal diagnosis? (Y/N) If

yes, what diagnosis were you given? Do you

believe this diagnosis is correct? (Y/N)

Explain:

How concerned would you say that the person assessing you appeared?

(scale 1-5)

How seriously did you feel that the person took your experience?

(scale 1-5)

Were you referred for further treatment? (Y/N) What level of care was recommended?

- Individual Outpatient
- Group Outpatient
- Intensive Outpatient
- Partial Hospitalization/Day Treatment
- Residential
- Inpatient
- Other [Explain]

Do you think this was appropriate given the severity of your concerns? (Y/N) Explain:

Was eating disorder specific treatment made available to you? (Y/N) Explain:

What were the barriers to accessing that treatment? (Check all that apply)

- Transportation
- Insurance issues
- Lack of family support
- Time commitment
- Gender-specific treatment centers
- Location
- Job Responsibilities
- Parenting or other caregiving responsibilities - Other [please list all]
- Additional comments:

Did you complete the recommended course of treatment? (Y/N) Explain:

Did your identity affect your decision whether to seek treatment? (Y/N) Explain:

When in treatment, did you interact with treatment professionals who shared your identity? (Y/N)

Comments:

Did you feel like the clinical understanding/interpretation of your diagnosis was accurate? (Y/N/Partially)

Did you experience any microaggressions from professionals while in treatment? (Y/N) Explain:

Did you experience any microaggressions from other clients while in treatment? (Y/N) Explain:

Were you required to eat meals during your treatment sessions? (Y/N)

Was the food provided by the center? (Y/N/Sometimes) Explain:

If yes or sometimes: How often did the center provide the type of food that you grew up with, or the type of food you would eat at home?

[scale of “never” to “always”]

How often did the treatment setting provide foods that are affordable to buy in your community?

[scale of “never” to “always”]

How often did the treatment setting serve foods that are available in your community?

[scale of “never” to “always”]

How often were you required to bring your own food to treatment?

[scale of “never” to “always”]

Did anyone make comments about the type of food you brought for meals?

[scale of “never” to “always”]

Did anyone ask you about your access to food or refrigeration?

[scale of “never” to “always”] Additional

comments:

Do you participate in any food rituals or dietary guidelines related to your identity? (Y/N)

Explain:

If yes, were they integrated into your treatment plan? (Y/N/Somewhat) Explain:

Does your family speak English as a first language? (Y/N) If

no--Was a translator available for family? (Y/N/Sometimes)

Explain:

Did your treatment include learning coping skills? (Y/N)

Do you feel that the coping skills you learned are useful in times of distress? (Y/N/Sometimes)

Explain:

Are the coping activities that were recommended costly to engage in? (Y/N/Some) Explain:

Are the coping activities available in your community? (Y/N/Some) Explain:

Did you feel that any of the coping activities were culturally appropriate? (Y/N) Explain:

Was your identity discussed during your treatment? (Y/N) Explain:

Are you satisfied with this? (Y/N) Explain:

If you could recommend changes to the current eating disorder treatment system, what would you suggest?

Do you feel like someone would be surprised that you struggle with food issues based on your physical appearance? (Y/N)

Explain:

Did this impact your decision whether to seek treatment? (Y/N) Explain:

On a scale of 1-5 [with 1 being “not at all helpful” and 5 being “extremely helpful”], how would you rate your treatment provider?

Did treatment result in a reduction of disordered eating behaviors? (Y/N) Explain:

Did treatment make an impact on the way you feel about yourself as a person? (Y/N) Explain:

Did treatment change your outlook on your body? (Y/N) Explain:



- **Mental Health Crisis Text Line**  
Text “Start” to 741-741
- **National Eating Disorders Association’s Helpline, Crisis, and Support Information** <https://www.nationaleatingdisorders.org/find-help-support>
- **National Eating Disorders Association’s Treatment Finding Tool**  
<http://www.nationaleatingdisorders.org/find-treatment>
- **ED Referral: A site dedicated to finding treatment in your area** <https://www.edreferral.com/finding-a-therapist> • **Alliance for Eating Disorders’ Treatment Guide**  
<http://www.allianceforeatingdisorders.com/portal/treatment-centers>

Attachment H: HSR Approval Letter



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**School for Social Work**  
Smith College  
Northampton, Massachusetts 01063

March 8, 2017

Hannah Smith

Dear Hannah,

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,

Michael Murphy  
Human Subjects Review Committee

CC: Elaine Kersten, Research Advisor

