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The Lived Experience of Transgender Individuals with Eating Disorders

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The Lived Experience of Transgender Individuals with Eating Disorders

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Abstract

Transgender individuals with eating disorders face severe and potentially fatal health risks, yet there is little known research on the needs of this vulnerable population. Eating disorders affect at least 30 million people in the United States, and have the highest mortality rate of all mental illnesses. Research to date suggests that transgender people may suffer disproportionately from disordered eating, and has shown the attempted suicide rate among transgender individuals to be five-to-ten times higher than the general population. No known study to date has described eating disorders in the transgender population from a qualitative perspective. The purpose of the study was to describe the lived experience of transgender individuals with eating disorders. Semi-structured, open-ended interviews were conducted with transgender participants with eating disorders over age 18. Inductive thematic analysis illuminated the intersection of transgender identity and disordered eating. Three themes were identified: presentation and perception; autonomy and control; and support. The findings suggest transgender individuals may experience eating disorders differently than cisgender individuals. Many improvements to clinical practice for this population were identified, including using patients' preferred gender pronouns, receiving training in cultural and clinical competency in transgender health, and facilitating access to gender-affirming interventions. Supporting individuals in the self-determination of their gender identity in social, community, family, and healthcare systems is fundamental to successful prevention, intervention, and treatment of eating disorders in transgender populations.

Keywords: transgender, trans, eating disorder, disordered eating

Eating Disorders and Transgender Identity

Background

Eating disorders (EDs) affect at least 30 million people in the United States, and have the highest mortality rate of all mental illnesses (Hudson, Hiripi, & Kessler, 2007; LeGrange, Swanson, Crow, & Merikangas, 2012; Arcelus, Mitchell, Wales, & Nielsen, 2011). Research to date suggests that transgender people may suffer disproportionately from body dysmorphia and disordered eating (Jones, Haycraft, Murjan, & Arcelus 2015). Research to date has also shown the attempted suicide rate among trans individuals to be five to ten times higher than the general population (Haas, Rodgers, & Herman, 2014). Therefore, when transgender identity and eating disorders co-occur, the individuals experiencing this intersection face high risks of suicidality, self-harm, and mortality.

Despite the complexity and urgency of this population's care needs, a paucity of research exists exploring the intersection of transgender identity and disordered eating. Moreover, no known research has been published on best practices for management of eating disorders in the trans population. As a historically marginalized and oppressed population, transgender individuals' control of their health and healthcare experiences has been challenged or stripped, limiting or entirely impeding access to appropriate, respectful services. Much of the historical research on transgender communities from a clinical perspective has not valued the lived experience of trans individuals or allocated space for them to voice their own experiences and needs. This research study begins to address these gaps through identification of the lived experience of transgender individuals with eating disorders.

Study Purpose

The purpose of the study was to describe the lived experience of transgender-identified

individuals over age 18 with a self-reported history of disordered eating through in-depth qualitative interviewing.

Clinical Questions

- What are the lived experiences of transgender individuals with eating disorders?
- How does disordered eating behavior correlate with transgender identity for transgender individuals with eating disorders?

Literature Review

A review of the literature was conducted through WorldCat, CINAHL and PubMed databases, yielding one systematic review, eleven case studies, three qualitative studies, and four quantitative studies specific to the research area. Jones, Haycraft, Murjan, and Arcelus (2015) found that “body dissatisfaction is core to the distress of trans people, which may put some people at risk for disordered eating,” and that “trans people engage in disordered eating” (Jones et al., 2015, p. 91), though only one study reviewed explicitly established that (Khoosal, Langham, Palmer, Terry, & Minajagi, 2009), and only one other study explored why trans people do so (Ålgars, Alanko, Sattila, & Sadabba, 2012). Jones et al. (2015) concluded that more research is needed on the subject, especially research of higher methodological quality.

Though case studies were not included in the systematic literature review, between 1997 and 2015, at least eleven in-depth case studies of trans people with eating disorders were published as preliminary investigations of the phenomena (Couturier, Pindiprolu, Findlay, & Johnson, 2015; Ewan, Middleman, & Feldmann, 2013; Fernández-Aranda et al., 2000; Hepp & Milos, 2002; Hepp, Milos, & Braun-Scharm, 2004; Murray, Boon, & Touyz, 2013; Strandjord, Ng, & Rome, 2015; Surgenor & Fear, 1998; Turan, Poyraz, & Duran, 2015; Walters & Whitehead, 1997; Winston, Acharya, Chaudhuri, & Fellowes, 2004). Each case study concluded

with pertinent clinical questions regarding the comorbidity of the two phenomena and how they may interact with and impact each other.

The findings of one qualitative study and one quantitative study were consistent with some of the speculative theories from earlier case studies, e.g. disordered eating for suppression of biological sex characteristics (Khoosal et al., 2008; Ålgars et al., 2012). Only one qualitative study (Duffy, Henkel, & Earnshaw, 2016) asked trans people with eating disorders about their ED treatment experiences, and reported the participants' recommendations for practice improvements.

Three qualitative studies of transgender people with disordered eating have been published. Duffy et al. (2016) conducted a qualitative study of trans individuals' experiences of eating disorder treatment and found "none of the 84 participants in this study reported having had a positive experience in treatment for their ED," possibly due to clinicians' lack of competency in transgender care or "resistance to addressing EDs among patients" (p. 144). In the 2012 qualitative study of Finnish transgender adults, participants frequently described disordered eating as an effort to suppress biological sex characteristics, and the majority of participants reported that gender confirmation surgery alleviated symptoms of disordered eating (Ålgars, et al). In-depth interviews of young trans women recruited from an HIV-risk study revealed intersections of weight and shape control behaviors with gender identity as well as education level, annual income and employment status (Gordon, Austin, Krieger, Hughto, & Reisner, 2016).

All of the four known quantitative studies compared transgender individuals' responses on eating disorder questionnaires to those of cisgender and eating disorder control groups (Bandini et al., 2013; Khoosal et al., 2009; Vocks, Stahn, Loenser, & Legenbauer, 2008;

Witcomb et al. 2015). These studies did not specifically examine eating disorders in the trans community but instead compared body dissatisfaction, drive for thinness, and other markers of disordered eating between transgender people, cisgender people, and people with eating disorders to evaluate if being transgender is associated with comparable, greater or lesser of these markers compared to controls. Khoosal et al. (2009) found that motivations for disordered eating differed between transgender and cisgender participants. Two studies established that trans people may be at an increased risk for disordered eating (Vocks et al. 2008; Witcomb et al. 2015). Two studies recommended the development of an ED questionnaire specific to people with gender dysphoria (Khoosal et al., 2009; Witcomb et al., 2015).

The existent research shows that little is known about eating disorders in the transgender community. Case studies, the earliest published material on the phenomena, conclude with speculations about several possible reasons trans people might engage in disordered eating behaviors. Overwhelmingly the case studies recommend hormonal and surgical management for gender dysphoria alongside appropriate treatment for eating disorders, as well as further research investigating this rare but complex phenomenon. While case studies were a useful starting point to establish the existence of the phenomena, the one-sided observations are insufficient for understanding the phenomena and addressing the needs of this population and their providers.

From all the qualitative and quantitative studies reviewed, recommendations for future research included: objective measurement of eating disorders and gender dysphoria (e.g. diagnoses versus self-report); more diversity in study samples to compare varying experiences by gender identity within the transgender community (men, women, non-binary, etc.); validating eating disorder and body image questionnaires in trans individuals; and longitudinal studies to better identify how eating behaviors and body dysphoria may change depending on one's point

in their transition (Duffy et al., 2016; Jones et al., 2015; Witcomb et al., 2015). Two studies identified a need for the creation of clinical ED prevention and intervention tools/programs specific to the trans patient population (Gordon et al., 2016; Vocks et al., 2008).

Conceptual Framework

King's Conceptual Systems Framework

King's Conceptual Systems Framework established that an individual is a personal system, which is both total and open (1981). Individuals comprise interpersonal and social systems, all of which mutually interact (King, 1981). Of the six key concepts of personal systems identified by King, self, body image, and growth/development are of primary relevance to this study. King described body image as “an integral component of growth and development, which in turn influences a concept of self” (p. 31), and then went on to say, “It is a universal principle that individuals identify self in relation to their body appearance and others' reaction to them” (p. 32). For transgender individuals, incongruities between their gender identity and their physical appearance can impact their growth and development, as well as their self-concept in relation to how they are perceived by others and in society. Disordered eating can be tied to one's body image (and therefore one's self-concept, growth, and development), either as a precursor to the behavior or as a function of the disorder.

Of the five concepts of interpersonal systems King named, role and stress are of primary relevance to this current study. Multiple definitions from the literature were summarized to define role as “the behavior that is expected of one who occupies a given position” relative to the members of a group, such as a family or an organization (1981, p. 93). Gender role theory has sought to examine how gender roles are developed, maintained, and internalized. Therefore, transgender individuals may identify role transitions or conflicts based on expectations of self

and others throughout their lives.

Stress can result from the incongruities transgender individuals experience as their self-concept and body image develop, and from the role conflicts they may experience through interpersonal and social interactions. Stress is “a dynamic state whereby a human being interacts with the environment to maintain balance for growth, development, and performance” (King, 1981, p. 98). Stress may motivate a trans person to seek gender-affirming healthcare, thus helping to resolve the original disruption; or stress may prevent a trans person from seeking care based on their experience or expectation of rejection by healthcare providers or care teams. Stress is often a mediator in the development of disordered eating.

A social system is “an organized boundary system of social rules, behaviors, and practices developed to maintain values and the mechanisms to regulate the practices and rules” (King, 1981, p. 115). Transgender individuals are often viewed as breaking the societal rules of binary gender presentation and exhibiting “deviance” from their sex-assignment at birth. Trans people may seek to fit into societal expectations by “passing” in society as the binary gender with which they identify. Conversely, transgender people may reject binary gender altogether, and advocate the development of new rules and practices based on non-binary presentation and behaviors. Some individuals engaging in disordered eating behaviors may understand their behavior as in agreement with social values, e.g. idealized feminine presentation and the value of female thinness.

In this study, King’s framework of conceptual systems serves as the guiding principle to better understand the personal, interpersonal, and societal relationships of trans individuals with eating disorders. This conceptual framework suggests that transgender individuals with eating disorders may often be experiencing conflict personally, interpersonally, and socially.

Methods

Design

This study utilized a descriptive, qualitative research design. Through one-on-one semi-structured interviewing (see Appendix C: Interview Guide), the lived experience of transgender-identified individuals over age 18 with a self-reported history of eating disorder(s) was derived. An interview was chosen as the method of collecting data because unlike a questionnaire, asking open-ended questions in person can add dimension and substance to participant responses. The interviewer, by building trust and rapport with participants, was able to evoke detailed, emotional narrative responses to questions, especially when exploring sensitive subject areas, such as gender identity and eating disorders (Sorrell & Redmond, 1995). In such circumstances, the interviewer could also contribute to the participants' processing of challenging feelings and personal information. Interviews allowed for a more flexible conversation which both the participant and interviewer could affect and direct, yielding narrative responses which provided context for participants' experiences, feelings, and decisions (Laverty, 2003).

Participants & Recruitment

Inclusion criteria for study participation included transgender identity, report of disordered eating behaviors or diagnosed eating disorder(s), and age 18 or older. A convenience sample was recruited through flyers posted in LGBTQ mental health and support centers, and two large college campuses in Chicago. Additional recruitment from the initial convenience sample was conducted by snowball sampling technique. In total, 14 individuals participated and completed the interviews.

Recruitment flyers (see Appendix A: Recruitment Flyer) invited interested community members to contact the primary investigator by email or phone for more information on the

research study. Upon contact by potential participants, the primary investigator invited them to schedule a subsequent phone conversation to determine eligibility (see Appendix B: Phone Eligibility Script). If respondents were eligible, the primary investigator attempted to schedule an in-person interview with the individual at the end of the eligibility screening, though some individuals preferred to be contacted at a later date to schedule the interview.

An amendment to the original proposal was added to include long-distance participants by way of phone or online video-streaming interviews, after a particularly effective snowball sample which yielded three interested individuals from out of state. Upon the approval of this amendment, the flyers and informed consent were updated with language pertaining to phone and online interviewing for out-of-state participants, and language was crafted for sharing informed consent documents via email (see Appendix D: Email Script for Long-distance Participants).

Interview Guide

Interview questions were developed based upon the most recent literature review conducted by the principal investigator (PI) and the PI's own empirical clinical experience working with transgender individuals (see: Appendix C).

Data Collection

Participants' eligibility for inclusion in the study was determined through review of their self-reported gender identity and report of disordered eating behaviors and/or diagnosed eating disorder(s). Interviews using a semi-structured interview guide (see Appendix D) were conducted one-on-one in private conference rooms at the DePaul University libraries. Interviews were audio-recorded in their entirety once participants provided their informed consent verbally. Prior to the initiation of interviewing, the interview questions and interview guide were reviewed

by expert members of the community (trans-identified with ED diagnosis) for both cultural competency and sensitivity, and the questions' utility and relevance to the research goals.

The informed consent was reviewed prior to initiation and recording of the interview questions. Interviews lasted approximately thirty minutes to two hours. Participants were encouraged to take breaks as needed or discontinue the interview at will. The interviewer concluded the interview by communicating that all questions had been asked, and inviting the participant to ask questions or add any final comments. Interviews were ended once the participant indicated they were finished, and the audio recording was stopped. The resource pamphlet was provided after the conclusion of the recording, and participants were encouraged to contact the researcher with any additional thoughts, concerns, or questions.

Data Analysis

The study utilized inductive thematic analysis, following Braun and Clarke's six-phase guide (2006). Thematic analysis was chosen for its accessibility, flexibility, and inclusivity for rich, detailed data sets, as well as its favorability for use with qualitative interviews. The first phase for analysis involved verbatim transcription of the audio-recorded interviews by the principal investigator into secure computer documents which were then verified by two trans health experts and spot-checked by the doctoral committee. The first phase of analysis continued through subsequent reading and re-reading with preliminary note-taking on observed patterns and concepts. In the second and third phases, transcripts were reviewed and coded by hand for thematic analysis, while NVivo Pro 11 was used to organize the data for statistical analysis. The primary investigator and co-author built consensus on codes and themes through transcript review and analysis meetings. Inductive analysis was used to derive themes from the data with minimal researcher precognition, and to describe more broadly the themes of the rich data set

(Braun & Clarke, 2006).

The analysis was performed at the latent level, meaning themes were derived not only from the literal language of the interviews but the researcher's interpretation of "underlying ideas, assumptions, and conceptualizations—and ideologies—that are theorized as shaping or informing the semantic content of the data" (Braun & Clarke, 2006). A thematic map was generated to define codes and themes after initial analysis and coding, Braun and Clarke's fourth phase, while the fifth phase entailed additional refinement of each theme, including precise definitions and names (2006). Finally, in the writing of the report, the sixth and final phase of analysis, relevant and representative data extracts were incorporated into the written results and discussions sections of the scholarly report (Braun & Clarke, 2006).

To establish credibility, participants' self-reported medical history was reviewed during the interview; specifically, date of ED diagnosis or initial symptom presentation and any history of treatment for either EDs or gender dysphoria, including hormone management, counseling, surgical procedures, etc. The analysis and conclusions of the study were committee-reviewed for confirmability. For transferability, the interview guide and interview contexts, as well as any potential bias of the researcher, were included in the final study report (Morse, 2015). For authenticity, recruitment efforts were made to capture a wide cross-section of the transgender community, including a variety of gender identities, ethnicities, races, and socio-economic realities (Polit & Beck, 2017).

Protection of Human Subjects

Discussing disordered eating behaviors and transgender identity were potentially emotionally and psychologically vulnerable conversations for participants. When developing the interview guide, it was reviewed with expert community members to anticipate how questions

may have triggered emotional or psychological distress. Based on the resulting feedback, a distress protocol was established and communicated to participants prior to interviews (Dempsey et al., 2016; see Appendix C: Interview Guide, paragraph 1).

Anonymity for participants was achieved through de-identifying interviews in transcriptions/documentation and assigning each participant a random numerical identifier. A waiver of documentation of consent was acquired from the DePaul Institutional Review Board for additional protection of the participants' identities. All Chicago-based participants were given a referral list of local trans-friendly mental health and primary care facilities, as well as eating disorder management facilities (see Appendix E: Chicago Area Resources Pamphlet). The same pamphlet was provided to an out-of-state participant living in Wisconsin, along with an additional referral to a reputable trans healthcare provider in Milwaukee, Wisconsin.

Results

The median age of study participants was 24 years-old. The range was 19 to 65 years, with a minimum of 19 and a maximum of 65. Participants were asked to self-describe race and Latinx identity. The study sample was comprised of 10 individuals who described their race as white (71.4%), two individuals who identified as Asian (14.3%), one individual who identified as "Native American and Black" (7.1%), and one "mixed-Arab" individual (7.1%). None of the participants identified as Latinx.

Gender was measured via self-report at the beginning of each interview. Eight individuals (57.1%) self-identified as nonbinary. Three participants (21.4%) identified as agender. More broadly, six participants (42.9%) identified as on the masculine spectrum, and three (21.4%) identified as on the feminine spectrum. Specifically individuals used an array of identifiers to describe their gender identities, including: "trans dude," "two-spirited transfeminine,"

“nonbinary/agender/genderqueer,” and one individual declined to specifically identify, saying, “I’m not super tied down on that.” Eleven participants reported female sex assignment at birth, and three participants reported male sex assignment at birth. While some participants said they disagreed with continued reference to their binary sex assignment, none reported intersex assignment or other “disorders” of sexual development. The majority of the sample (57.1%) had not received a formal ED diagnosis, compared to 42.9% who had been formally diagnosed by a provider.

The majority (57.1%) of the study participants had not received formal diagnoses of eating disorders but described current or historical behaviors which were consistent with formal diagnosis per the clinical judgment of the interviewer. Two individuals reported disordered eating behaviors that did not constitute a formal diagnosis by existent DSM criteria. These individuals were also the only two individuals to not explicitly relate their eating behaviors to their gender identity. Interview questions focused on participants’ gender identity formation and expression, participants’ experiences of disordered eating, participants’ understanding of the interaction between their gender and their eating behaviors, and participants’ healthcare experiences and needs. Three themes related to the lived experience of transgender identity and disordered eating were derived from the interviews: (1) presentation and perception; (2) autonomy and control; and (3) support. Subordinate themes (or sub-themes) were defined within each broader theme. Illustrative supporting quotes from the interviews are provided in the third column of Table 1, and referred to parenthetically in the following discussion.

Major Themes from Participants’ Interviews

Presentation & Perception

In describing the relationship between their disordered eating and their gender identity,

participants identified the difficulty they had separating their feelings of dysphoria from their feelings of dysmorphia to discern which could be ascribed to gender and which to their eating disorder (ED) [Q1, Q7-9]. For some individuals, specific things were quite clear, such as the desire for surgery to alleviate gender dysphoria as distinct from their eating disorder: “I think it will make recovery easier just because my body will look more like I want it to.” Others had less clarity about where their desire for surgery was coming from and what needs it would satisfy—healthy gender affirmation or their mental illness: “I don’t want to get into this whole of being like too focused on my body again.”

Participants communicated the pressure and necessity to be recognized socially and societally by their gender identity as determined by their gender presentation. While nonbinary individuals did not express a desire to pass—“you can’t pass as nonbinary” [Q6]—they did indicate that body shape changes helped to differentiate their presentation from their sex assignment at birth [Q10-12]. Several nonbinary individuals also indicated that revelation and expression of their nonbinary identity reduced their ED symptoms because of the self-determined and category-less nature of that identity: “I am that way without changing my body—that just freed me up to worry about it a lot less.” Many participants viewed their weight and shape as key to how they were gendered by society [Q2-5]. Some described perceived positive social responses to masculine or feminine presentation when they were thinner or had lost weight.

Autonomy & Control

As is true for many individuals with eating disorders of all genders, participants identified “control” as a key feature of their ED, in some cases especially as it related to their gender identity: “...I think [control] was like the main function of my eating disorder period.” Control of their gender presentation [Q14], control of their body shape and size [Q15-17], control of their

life circumstances [Q20], control of their treatment and care plans [Q18-19, Q21-22]—participants placed a high value on having control over how they look, how they feel, and how they are treated. One participant described control as the pivotal axis for both their gender identity and their eating disorder: “...getting more control over my life and my identity definitely was connected to all the same reasons that I picked up my eating disorder.”

Relatedly, participants expressed a desire for agency or autonomy, often in reference to healthcare, access to hormones, and specialized eating disorder treatment. The experience or expectation of transphobia in healthcare spaces was commonly expressed in tandem with the desire to have more autonomy in those spaces—either to avoid them, to leave them, or to be more actively included in their treatment goals and plan: “I wish they’d been able to listen to me when I was like, ‘This is not right for me.’” Some participants viewed in-patient treatment for their EDs as antithetical to how their own recovery and healing needed to happen [Q18, Q21]. Autonomy also came up as counter-posed to gatekeeping—the withholding of hormone therapy until a provider feels that an individual has adequately proven their gender identity: “...they want to make sure that I’m ‘real’ transgender, which I think I only know.”

Support

Support from their community of partners and friends, their biological families, and their healthcare teams were all identified as central to the experience of both their gender identity and their disordered eating. For many, coming out to their community provided positive reinforcement for their gender presentation, and that gender affirmation reduced their urge to engage in disorder eating [Q23]. Actively including their partners and families in both their recovery and their gender transitions meant improvement of ED symptoms and more comfort with the transition process [Q24-25]. Unfortunately, when most participants discussed their

families, specifically their parents, they described a conspicuous and significant lack of support. These participants would then conversely describe how, without the support of their parents and families, they could not fully transition, which impeded some aspects of their recovery [Q26-28].

Participants described many negative interactions with healthcare providers illustrating the ways they had not been or were not currently supported by their care teams in regards to their gender and/or their eating disorder: “There was nobody that had both the eating disorder and the HRT knowledge to help me.” All participants were asked to describe helpful, supportive experiences they’d had with healthcare providers, or to identify what they would need to feel safe and supported by healthcare providers. Multiple participants quickly named asking for gender pronouns and the correct use of their pronouns as indicative of safe, respectful healthcare spaces, from intensive outpatient programs to primary care provider’s offices [Q29-31]. Some participants referred to institution-wide policies of transgender support and acceptance [Q34].

Building a relationship and rapport with a provider prior to disclosure of either gender identity or disordered eating was identified as requisite for trust and safety [Q32]. Participants desired providers, organizations, and facilities serving trans patients or clientele to educate their staff and providers on respectful care of trans individuals, some expressing that they did not want to “be a teacher” themselves, while others reported openness to educating providers as long as they were listened to, and met with understanding and respect [Q29, Q31, 35]. Providers’ bedside manner and approach to care were cited as important aspects of feeling comfortable working with them, specifically providing reassurance and affirmation, and being “nonjudgmental” in their care [Q33, Q36].

Discussion

This was the first known research study of its type to examine these co-occurring phenomena. The lived experience of transgender individuals with eating disorders is a complex series of interactions between internal systems of the body and self, and external systems of society, community, family, and healthcare. King's Conceptual Systems Theory offers a useful framework for understanding these dialectical relationships, specifically how one's body image and self are reflected, defined, and managed through social rules and regulations of gender roles and presentation.

Gender identity and disordered eating development are not always straightforward or "textbook" experiences for individuals, and often significantly interact with each other. This interaction may be especially pronounced during adolescence when secondary sex characteristics appear and individuals feel less control over their gender presentation and their changing bodies. Social and societal experiences can profoundly impact individuals' gender presentation and eating behaviors, both negatively and positively. Family, friends, and healthcare teams play an essential role in supporting transgender individuals as they navigate their transitions, recover from disordered eating, and establish healthy relationships with their bodies.

An individual's gender presentation is in dialectical relationship to how they perceive themselves and how they are perceived by society. For transgender individuals, recognition of their gender in relation to their body and self-concept can be warped by transphobia, binary gender expectations, and cultural pressures around conventionally attractive presentation. Living as one's true gender may be synonymous with food or calorie restriction, a supposedly feminine trait; or those same behaviors may support a more masculine presentation to suppress body "curves" associated with femininity. Realization of nonbinary gender identity may be relieving

and thus reduce ED behaviors. Whether an individual's gender is affirmed or dismissed by society can signal to them that their eating disorder is either necessary or unnecessary to maintain their presentation.

Transgender individuals may seek to control their gender presentation and experience through disordered eating behaviors. For trans individuals with EDs, their relationship to and experience of their bodies can be complicated by both gender dysphoria and body dysmorphia, which may be difficult to distinguish from one another. Body dysmorphia is symptomatic of both eating disorders and gender dysphoria, and therefore may originate from and give rise to both, similar to the dialectics of presentation and perception. Enabling transgender individuals to manage their dysphoria through gender affirmation (medical transition with hormones, surgical transitions, socially transitioning, etc.) can reduce dysmorphia and ED behaviors.

Relatedly, receiving support from partners, friends, and family can mean the difference between gender affirmation and ED recovery; or persistent dysphoria, self-harm, and suicidality. Support may be material (financial, insurance coverage, meals), verbal (encouragement, reassurance, kindness), or emotional (being present, maintaining relationships, acceptance). Communication of approval or acceptance from individuals' parents was frequently identified as key to their comfort and safety in true gender expression, and their ability to seek and access necessary gender-related and ED-specific care. In the absence of parental acceptance, individuals' disordered eating behaviors may dangerously persist.

Healthcare is a challenging and historically fraught aspect of the lived experiences of trans individuals with eating disorders. Trust and reliance on healthcare for gender affirmation and ED recovery is inconsistent, and depends upon access to care, to what degree individuals are out to their families and providers, and their understanding of the utility of healthcare

involvement in their transition and/or recovery. Some do not seek care because they have no medical or surgical needs for their transition, while others feel unseen or unsupported by healthcare providers. Many individuals have had transphobic healthcare experiences in primary care, mental health, and ED facilities resulting in their avoidance of subsequent care, despite the acuity or severity of their needs.

Others expect transphobia from healthcare staff and providers as an inevitability, causing them to not seek care at all or to withhold their gender identity and/or ED behaviors from care providers. This may be one factor to consider in determining why the majority of study participants never received a formal diagnosis. Whether based on prior experience or realistic expectation, two common fears were expressed: gatekeeping as a barrier to trans-specific healthcare, and transphobia when seeking ED-specific treatment. Fear regarding the loss of autonomy and agency in healthcare settings was also expressed as a reason for not seeking ED treatment or disclosing ED behaviors. Positive, supportive healthcare experiences facilitated both transition and recovery, if and when individuals felt they could access care, come out as trans, or disclose their eating disorder.

Clinical Implications

To adequately support transgender individuals with eating disorders, healthcare providers can communicate a trans-friendly setting in a myriad of ways: asking for gender pronouns in intake paperwork, adding them to patient charts, and using individuals' preferred pronouns exclusively; transgender affirmation in publicity and advertising materials; training in transgender cultural competencies for all staff, and additional clinical training for providers; organization-wide policies supporting, respecting, and protecting transgender individuals as patients and workers; and hiring transgender individuals as staff members, clinicians, and

administrators.

Utilizing an informed consent model for hormone provision is not only supported by evidence as a safe and effective way of initiating treatment, but also conveys trust and respect for the autonomy of an individual and the self-determination of their gender identity. In the context of specialized eating disorder management and treatment, providing and facilitating access to gender-affirming care—including hormone therapy, surgery, and social transition—is medically indicated for transgender individuals with eating disorders most especially in the context of weight restoration which may severely trigger gender-related body dysmorphia.

Study Limitations & Future Directions

The study sample was predominantly young adults with nonbinary identities who had never received formal diagnosis. Future research could focus on different trans binary identities and/or people under age 18 or over age 30. Researching why many trans individuals go undiagnosed or exclusively focusing on trans individuals with or without diagnoses may yield interesting results. More research on transfeminine identities and disordered eating is indicated as 78.6% of this study sample was assigned female at birth, and the three transfeminine individuals expressed some potentially different motivations for engaging in disordered eating compared to nonbinary and masculine-spectrum individuals.

The sample was self-selected through identification with the recruitment flyer, another limitation in terms of sample composition. Some individuals may not see themselves represented in the language of “eating disorders” even if they engage in disordered eating behaviors, thus future research should factor into study design how to capture a wider cross-section of the community to assess prevalence and frequency of eating disorder behaviors beyond self-selection. While it exceeded data saturation for this study, the sample size of 14 limits

generalizability, and future studies would benefit from more data from a larger sample. The majority (71.4%) of study participants identified as white, another limitation to generalizability. More research into how race, transgender identity, and eating disorders intersect is necessary as racism was identified by both white participants and participants of color as a factor in accessing care.

Participants were not compensated for their travel or time due to funding limitations. The data collection period (September 2017 – January 2018) was shortened by the timeline of the primary investigator's doctoral program despite continued interest from the community. Recruitment was geographically limited to the city of Chicago, and publicity of the flyers was limited to certain locations as the primary investigator was not given access to flyer at ED facilities or LGBTQ health centers due to the facilities' own research interests. The principal investigator identifies as transgender but does not have an eating disorder. While this supported rapport-building during interviews, it may have resulted in researcher bias during questioning and analysis.

Extensive future research is necessary to reduce eating disorders in the transgender community through prevention, intervention, and treatment. The need for two specific clinical tools became clear over the course of the research study: validation of ED screening tools in trans populations, and gender-affirming clinical guidelines for management of eating disorders in transgender individuals. Once screening tools are created/available, future research could study cross-screening for gender dysphoria and eating disorders, especially in adolescent populations, to explore the efficacy of early interventions for gender dysphoria in reducing ED morbidity.

Finally, this researcher would be remiss not to include the specific requests from study participants for future trans health-related research: the effect of exogenous testosterone on

autism, comparing frequency of ED symptomatology in adolescence/at puberty for transgender individuals to cisgender individuals, and transgender individuals' experiences of sexual assault.

Conclusion

The lived experience of transgender individuals with eating disorders can be confusing, difficult, and greatly improved by non-judgmental, trans-competent external support. Transgender individuals with eating disorders deserve to be respected as the experts of their own experience. They want to retain the agency to make their own decisions regarding their lives, bodies, health, and healthcare. While the experience of gender dysphoria can be hugely distressing, transgender identity is not itself an illness. The co-occurrence of transgender identity and disordered eating is not pathological but is a material response to transphobia—from strangers to parents to care providers. Supporting individuals in the self-determination of their gender identity in social, community, family, and healthcare systems is fundamental to successful prevention, intervention, and treatment of eating disorders in trans populations. For healthcare providers, there are many ways of making clinical practices and institutions trans-friendly to reduce barriers to care for this extremely vulnerable population.

Table 1. Themes and Codes from Thematic Analysis of Interviews with Transgender Individuals with Eating Disorders.

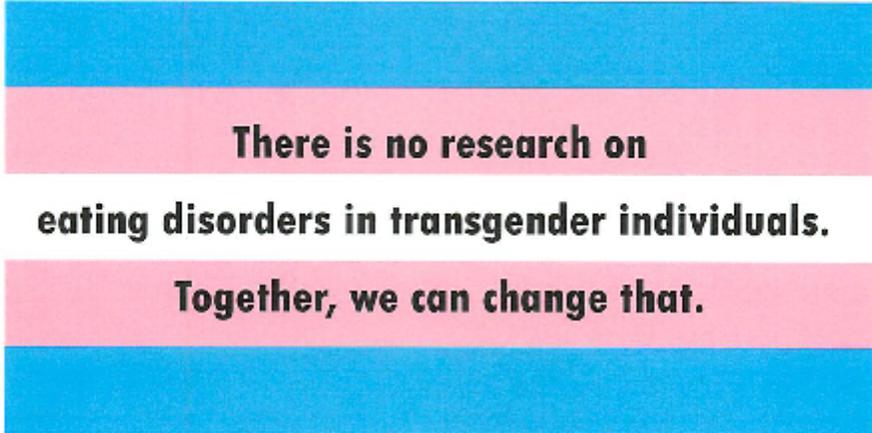
THEME	CODE	SUPPORTING QUOTES
<p>PRESENTATION & PERCEPTION</p>	<p>Social & societal</p>	<p>[Q1] “Saying that I’m trans to people was like saying that it’s not actually super clear, that there’s like this thing that’s actually super complicated that’s sort of in the way of me feeling stoked about myself, and is not really about my weight or like any of that stuff.” [Q2] “...I started passing more consistently when I went outside and so I think it was also this fear of like, well, if I keep gaining weight, is that gonna be taken away from me?” [Q3] “I think if you let yourself fall into the trap of trying to fit into like society’s acceptable definition of trans femininity, I think that it’s almost certain that you will develop an eating disorder” [Q4] “well, you know, women are supposed to be thin, right? [...] we obviously live in a world where we’re not supposed to be overweight.” [Q5] “...presenting more masculine is a way of getting control and respect from the world.” [Q6] “...I think about all the time if I were heavier, like if I gained a lot of weight, how well I’d be able to pass. Um, I haven’t thought about passing until I started identifying as transmasculine because like...you can’t pass as nonbinary.”</p>
	<p>Self</p>	<p>[Q7] “...part of it was deferring my discomfort about my gender to being more discomfort about my body than it really was [...] like deferring my feelings about gender to just [...] hating my body period versus like acknowledging that a lot of that was to do just with not being authentic and acknowledging what was actually going on” [Q8] “I don’t know how much is eating disorder and how much is dysphoria and that’s really challenging, cause I don’t want to just like feed into it and change a bunch of things and have it not be enough. But I also don’t want to just continue living in being upset about it constantly.” [Q9] “I’m still trying to unpack how much of my uncomfortableness with my body starting around like puberty and high school was related to my weight and how much of it was related to like repressed feelings of being trans.” [Q10] “...I was just kind of thinking well I guess I’m nonbinary but you know it doesn’t matter that’s just something I know just for me [...] then eventually becoming more and more like oh yeah no I can like tell people that I’m [nonbinary] and maybe it’s good for me if I do, and if I, you know, express myself in ways that feel more like authentic on gender lines and things like that.” [Q11] “...I just try to make myself look less feminine I guess, because I don’t want to have a feminine body.” [Q12] “...[an eating disorder] seems like the easiest way to like not look like a girl, and when I would gain weight [...] it would accentuate feminine features like hips and thighs, and like the chest, and I wonder if, like if I had a different body shape if I</p>

<p>AUTONOMY & CONTROL</p>	<p>would feel differently [...] that's something that like I don't know if I'll ever be able to figure out, just because I... I don't know, I feel like they're so intertwined.”</p> <p>[Q13] “...I've always just had a weird relationship with my body where I don't like the things it does and I wish [...] there were less of it [...] from a young age, I didn't like the shape of my body and wanted it to be different, and that included gender stuff but that also included weight stuff.”</p> <p>[Q14] “The only thing I can control to be accepted as male right now is weight [...] I just can't get that thought away from me. I'm so terrified of being overweight.”</p> <p>[Q15] On body changes with testosterone: “Oh yeah, that's terrifying. [...] it changes your weight distribution which is obviously very potentially triggering as someone with an eating disorder and also just like the loss of like sense of control of your body [...] there's always that little bit of feeling of betrayal or whatever.”</p> <p>[Q16] “I never wanted an eating disorder because it seemed like the best option. It was always just the easiest, most accessible option.”</p> <p>[Q17] “...a lot of the time I'm like ‘My body seems to maybe want things but I can't figure out what that is, and so I'm just gonna...punish it maybe?’ and I feel like that's been going on since a young age [...] I did not like it or have any way of fixing it, and so I was like angry at my body a lot of the time, which is pretty related to trans-ness I think.”</p>
	<p>Care</p> <p>[Q18] “I don't like the idea of voluntarily locking myself some place for an undetermined amount of time around people that aren't going to like respect me and treat me like I am”</p> <p>[Q19] “I'm afraid that they wouldn't like give me autonomy, that they wouldn't trust me to take T or something like that if they thought I was like unwell or whatever [...] so unless it was someone that I really had a good rapport with, and I knew they weren't going to hold that against me in terms of my decision-making and autonomy, then I wouldn't probably mention [my eating disorder].”</p> <p>[Q20] “...just to get diagnosis is a privilege. There are a lot more POC trans that you know, our main part of life would be just the survival of the day, without getting hurt, without getting beat up, so any other health issues that's not life or death we kind of tend to put it off.”</p> <p>[Q21] “I don't need to be put in a place where I have no control to address my control issues.”</p> <p>[Q22] “...knowing that I still have that agency I think is a big motivator for me to be able to talk about it because like ultimately I know that [the provider] won't force me into anything.”</p>
<p>SUPPORT</p>	<p>Community</p> <p>[Q23] “I was like out online and things like that first [...] but then I came out to my partner and my family and friends and things like that, and um that's definitely helped with body image stuff, it doesn't make it go away but [...] just less self-conscious about a lot of things, I would say.”</p>

	<p>[Q24] “I just have much better support. The people support me. I mean you’re supposed to not want to disappoint yourself but I also don’t want to disappoint them [...] it helps to know that I’ve got [my partner] and all my friends who support me and love me and help me feel better.”</p> <p>[Q25] “...I was like ‘I need to like actually be eating. I need to like not put my body down in these ways. Um, and I need to like talk to my friends about it.’ So my friends were a large support for me. Having friends that I could be myself with in college was really nice”</p>
Family	<p>[Q26] “...the gender <i>non</i>-binary isn’t totally like a concept that like my parents grasp.”</p> <p>[Q27] “...my parents are very against the LGBT community, and so my entire life I’ve kind of, have lived with this like really deep shame of who I am, and so um I just kinda figured that like if my family can’t accept me, why would anybody else?”</p> <p>[Q28] “...I feel like I would have to either lie and tell [my parents] that I am [binary trans male] so I can get the surgery, or like lie to the doctor or whatever because I don’t know if insurance would cover it if I’m, if I don’t identify as like a binary man [...] I think it just depends on like my parents and money.”</p>
Healthcare	<p>[Q29] “...normalizing asking pronouns, educating staff members as to like pronouns, trans-affirmative stuff, the fact that I am not obligated to educate you”</p> <p>[Q30] “I was amazed how doctor would respect my pronouns. They wouldn’t call me with my dead names.”</p> <p>[Q31] “...that was also an office where they asked pronouns too on the intake form [...] just small little things like that and knowing that they must have educated people who work there did make me feel [...] comfortable enough to actually disclose.”</p> <p>[Q32] “I’m usually slow to open up about stuff but especially in an environment where there’s gonna be potential judgement or consequences like that, um, it might take a couple of visits before I tell something that I think could potentially be taken in a way that would make my experience harder”</p> <p>[Q33] “...I really trusted my provider, and she really just like understood and cared and wanted what was best for me. And like she was really nonjudgmental about it.”</p> <p>[Q34] “I guess I’m lucky [...] they’re all very supportive. [My] hospital has a policy of being [...] supportive to transgender people.”</p> <p>[Q35] “...I mostly need people to listen and understand what I’m saying [...] I have no problem correcting people, introducing people to these things, as long as they’re respectful and they listen.”</p> <p>[Q36] “...she adds an air of levity to it [...] if I’m being too serious, she’ll get me to laugh, or she’ll be like, ‘Listen, you’re doing a really good job, you’re already doing so much more than you were doing a year ago or two years ago.’”</p>

Appendix A: Recruitment Flyer

LOOKING FOR TRANS INDIVIDUALS FOR AN IMPORTANT RESEARCH STUDY



We are talking to people about what it's like to be transgender and have an eating disorder.

Participants will be interviewed one-on-one by a nurse researcher for about 60 minutes on their personal experiences and opinions about gender & eating behaviors in a private, confidential space at one of the DePaul University campus libraries. For participants outside of Chicago, interviews will be conducted remotely by phone or video in a private, confidential space.

*This study is a doctoral research project
through the School of Nursing at DePaul University.*

If you...

- ◇ **identify as trans &/or gender non-binary**
- ◇ **are 18 or older**
- ◇ **have or may have an eating disorder**

DePaul University
IRB Approved
Protocol #: MB@21717NUR-82
Start Date: November 8, 2017
Expiration Date: August 30, 2018

**contact Mary Bowman at
transwithEDstudy@gmail.com
or (708) 762-3243 for more information.**

Appendix B: Eligibility Phone Script

Eligibility Phone Screening Script

Introduction: Hello, my name is Mary. I'm calling because you contacted me about a research study about gender and eating disorders. Are you still interested in being this research study? I have 4 questions to ask you to decide if you're a good candidate for this study. The questions should take no more than 5 minutes. Is now a good time to ask you these questions?

Yes: Okay, great. Let's get started.

No: Is there a better time when I can call back? Should I use this same number or is there a different number you'd like me to call?

Modified Verbal Consent: First, I want to tell you a little bit more about the research. The goal of the research study is to learn how trans individuals experience eating disorders. If you're eligible for the research study, then we'll schedule a time to set up an in-person one-on-one interview.

You may not be eligible for the research study. The following 4 questions will help me to determine if you're eligible for the study. The questions regard your age, gender identity, and whether or not you have an eating disorder. Do you agree to completing this screening process?

Yes: *proceed to questions*

No: Okay, I understand. Thanks for your time.

1. Are you 18 years old or older?

-yes

-no

2. Do you identify as transgender and/or gender non-binary?

-yes

-no

3. Have you been diagnosed with an eating disorder, such as anorexia, bulimia, or binge-eating disorder?

-yes

-no

4. Do you think you have an eating disorder but have not received a diagnosis?

-yes

-no

Eligible: X, based on your answers, you are eligible to be interviewed for the study.

For participants in Chicago: The interviews take place in-person at one of the DePaul University libraries, either downtown or in Lincoln Park. I will be interviewing you for about 60 minutes in a private conference room. Would you prefer to meet in Lincoln Park or downtown?

For long-distance participants: For people outside of Chicago, there are 2 options for interviews: online via Google Hangouts on a video stream chat, or over the phone. Do you have a preference

between an online video chat or a phone interview? The interview will last for about 60 minutes. Do you have any questions about the study or the interview process for me? I'd like to schedule our interview with you as soon as possible. Do you know your schedule coming up? Are there good days or times for you generally?

John T. Richardson Library (DePaul University)
2350 N. Kenmore
Chicago, IL 60614

Loop Library (DePaul University)
1 E. Jackson, 10th floor
Chicago IL, 60604

Google Hangouts: transwithEDstudy@gmail.com will invite you to a video call.

Phone: You will receive a phone call from (708) 762-3243

Not eligible: X, based on your answers, you are not eligible to be interviewed for this study.

Thank you for your interest and time. Have a good day.

Appendix C: Interview Guide

Introduction: Thank you for participating in this research study. What I'm interested in learning about is the unique experience of being transgender and having an eating disorder. I'll be asking you a few questions about your personal experience and your opinions. These things can sometimes be difficult for people to talk about. If there are any questions you don't want to answer, just let me know and we'll move on. If at any point during the interview you need a break for any reason or you would like to end the interview, just let me know and we can take a break, check in, or stop all together. Do you have any questions for me before we begin?

First, I'm going to have you complete this short questionnaire on basic information about yourself. (*provide Demographics Sheet for them to complete by hand*).

Next, I'm going to ask some of the same questions I asked you over the phone. Answer with as much detail as you'd like to provide.

1. Do you identify as transgender?
2. How do you identify specifically? (e.g. non-binary, gender non-conforming, trans woman, trans man, woman, man, etc.)
3. What was your sex assignment at birth? (e.g. female, male, intersex)
4. Have you been diagnosed with an eating disorder? (e.g. anorexia, bulimia, binge-eating)
 - a. When were you diagnosed? (year/age)
 - b. What were you diagnosed with?
 - c. Do you agree with that diagnosis?
5. Do you think you have an eating disorder but have not received a diagnosis?
6. What has been your experience as a transgender person with an eating disorder?
 - a. How do you see gender and eating behaviors as connected?
7. What has been your experience with healthcare for your gender, your eating disorder or both?
 - a. Was anything helpful? If so, what?
 - b. Was anything harmful? If so, what?
 - c. Looking back on those experiences, what do you think *would have* been helpful?

Conclusion: Thanks again for contributing your experiences and opinions to this study. We expect to be finished with the study in May 2018. At that time, you may return to the website where you originally entered your contact information to read a summary of the research findings. The website address is on this handout, along with some supportive resources you can utilize if you want to talk about the feelings that today's interview brought up for you. Do you have any other questions for me?

Appendix D: Email Script for Long-distance Participants

DePaul IRB Approved Protocol #MB071717NUR-R2 November 8, 2017 Through August 30, 2018

Email Script for Long-distance Participants

Hello! I am writing to follow up after our phone conversation regarding the research study of transgender identity and eating disorders. I have attached the informed consent document for you to review prior to our phone/online interview. Please read the attached document thoroughly, and let me know if you have any questions or concerns. I'll check in with you about the consent document at the time of our interview before we get started. The consent document also contains my contact information and information about where to review a summary of the study findings next Spring, so please keep a copy for your records should you be interested in contacting me in the future or reviewing the findings.

Thank you for your participation and I look forward to speaking with you soon,

Mary Bowman

Appendix E: Chicago Area Resources Pamphlet

If you're interested in reading a brief summary of the research findings, visit this website (the same site where you originally gave your contact information) in May 2018:

<https://tinyurl.com/y9e6joup>

Support Services & Resources

Hotlines

Trans Lifeline

Crisis hotline by & for the transgender community

(877) 565-8860

<https://www.translifeline.org/>

LGBT National Hotline

Provides telephone, online private one-to-one chat & email peer-support for queer & trans folks

(888) 843-4564

help@LGBThotline.org

National Eating Disorders Association Information & Referral Helpline

Free confidential helpline for information, support & treatment options

(800) 931-2237

Crisis text line: text "NEDA" to 741741

<https://www.nationaleatingdisorders.org/help-support/contact-helpline>

National Association of Anorexia Nervosa and Associated Disorders

Helpline for people with eating disorders who need support or help

(630) 577-1330

Online support group: <https://campfirecare.typeform.com/to/UhMbIy>

Eating Disorder Services & Support

The Awakening Center

Mental health private practice specializing in eating disorders with drop-in support groups

3523 N. Lincoln Ave.

Chicago, IL 60657

(773) 929-6262

<http://www.awakeningcenter.net/drop-in-and-therapy-groups.html>

Insight Behavioral Health Services

Eating disorder treatment facilities with many types of available treatment

<https://www.eatingrecoverycenter.com/recovery-centers/chicago>

For appointments at any location, call (312) 702-1482.

200 E. Ohio St, 4th floor

Chicago, IL 60611

150 E. Huron St.
Chicago, IL 60611

333 N. Michigan Ave, Ste. 1900
Chicago, IL 60601

Lakeview Center for Psychotherapy

Comprehensive mental health services specializing in eating disorders with some LGBTQ programming

3322 N. Ashland Ave.
Chicago, IL 60657
(773) 525-3322

<http://www.lakeviewtherapy.com/schedule.html>

Trans-friendly Counseling & Support Groups

Center on Halsted

LGBTQ+ community center offering behavioral health and social services, including support groups

3656 N. Halsted
Chicago, IL 60613
(773) 472-6469

<http://www.centeronhalsted.org/behavioralhealth.html>

IntraSpectrum Counseling Services

LGBTQI counseling services and support groups offered
For appointments at either location, call (773) 750-3505

180 N. Michigan Ave.
Suite 1830
Chicago, IL 60601

5340 N. Clark St.
Suite 212
Chicago, IL 60640
<http://intraspectrum-chicago.com/get-support/>

Live Oak

Queer and trans-friendly behavioral health services, including support groups & individual counseling

For appointments at any location, call (773) 880-1310.
1300 W. Belmont, Ste. 400
Chicago, IL 60657

30 N. Michigan Ave., Ste. 508
Chicago, IL 60602

4753 N. Broadway, Ste. 1034
Chicago, IL 60640

1740 N. Ridge, Ste. 218
Evanston, IL 60201
<http://www.liveoakchicago.com/index.php/psychotherapy/groups>

Affinity Community Services

Service organization offering volunteer peer-led support groups for Black LGBTQ & trans individuals

2850 S. Wabash, Suite 108
Chicago, IL 60616
(773) 324-0377
<http://affinity95.org/acscontent/the-affinity-calendar/>

Trans-friendly Health & Wellness Centers

Chicago Women's Health Center

Feminist health collective offering gynecology, primary care, hormone management & counseling services to women & trans-identified people. No one is turned away based on their ability to pay.

1025 W. Sunnyside, Ste. 201
Chicago, IL 60640
(773) 935-6126
<http://www.chicagowomenshealthcenter.org/>

Howard Brown Health

Queer & trans-friendly community health centers offering primary care, counseling, & hormone management services. Accept Medicaid & has a self-pay sliding scale.

<http://howardbrown.org/wp/health-centers/>
For appointments at any location, call (773) 388-1600.

6500 N. Clark St.
Chicago, IL 60626

4025 N. Sheridan Rd.
Chicago, IL 60613

1525 E. 55th St.
Chicago, IL 60637

641 W. 63rd St.
Chicago, IL 60621

3245 N. Halsted St.
Chicago, IL 60657

Broadway Youth Center

Queer and trans-friendly health center serving all young people ages 12-24, regardless of ability to pay.

4009 N. Broadway
Chicago, IL 60613

(773) 935-3151

<http://howardbrown.org/wp/byc/>

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