

Queer Becomings: The Ethics, Rhetoric, and Materiality of Care in Trans Networks

This project's subject matter is the rhetoric and ethics of transgender medical literacies, particularly in online spaces. While positive cultural representations of transgender (referred throughout as “trans”) people in television shows have increased public awareness of the complexities of trans identities, these fictional representations cannot always capture the challenges of trans experiences. As a case in point, trans individuals in many countries including the United States face considerable barriers in accessing affordable and comfortable healthcare, especially for gender transition care. Even if insurance offers coverage, gender transition care can entail burdensome travel to locate qualified, let alone sympathetic, medical practitioners and lengthy surgery waiting lists.

The global pandemic of COVID-19 has significantly exacerbated healthcare inequalities for LGBT—and specifically trans—people around the world. According to a recent United Nations report, some concerns involve a “de-prioritization of health care services,” including cross-sex hormone therapy for trans people undergoing medical transition (Office of United Nations, 2020, p. 1). They may also face increased “stigmatization, discrimination, hate speech and attacks,” particularly when they are blamed for the pandemic, police orders are used to discriminate, or emergency powers are employed to restrict rights (Office of United Nations, 2020, p. 1). And, because LGBT people already face rampant employment discrimination and economic precarity (e.g., lack of paid leave, insurance coverage, or unemployment benefits), COVID-19 represents a greater risk for loss of income and access to work (Office of United Nations, 2020, p. 1; see Edenfield, 2020). In sum, COVID-19 has intensified already present obstacles to care, especially for trans people.

In response to such obstacles, many trans people have sought methods of administering their own regimen of hormone replacement therapy (HRT), a process increasingly made possible through international pharmaceutical websites. Far from an ad hoc process, trans individuals have employed anonymous online communities and social media to produce and circulate a range of user-generated instruction sets—including user posts, videos, manuals, and wikis, to name a few—that provide directions on obtaining, administering, and monitoring HRT. While these do-it-yourself (DIY) practices proliferated prior to the pandemic, as even previously stable trans people are being affected, more and more turn to these DIY networks to self-manage their care (López, 2020; see Edenfield, 2020).

Any patient who has the ability to see a licensed pharmacist with a prescription is familiar with instructions such as “take 1 pill every 12 hours with food.” However, the following query posted to an online forum (anonymized and redacted here to protect the user and the forums) encapsulates the unique communication and ethical needs of trans individuals:

I'm taking my transition (MtF) into my own hands and have decided to seriously plan out my DIY HRT. I have a [doctor] whom has made a referral, but I've not yet been called for a followup...and reading about the timelines here... I think waiting on [the healthcare system] several years to even begin HRT would be very detrimental to my health. So here I am, trying to work my way around a broken system. One thing I know I need to do is get a baseline blood test to establish not just my hormone levels but also liver function, renal, etc. basic health levels.

This quote makes it clear that for trans people seeking alternative access to health care, the process is a uniquely different challenge. This project seeks to document these challenges as well as look for opportunities to advocate for better access to health care for trans individuals. In this sense, this project is not merely descriptive—that is, describing the practices I observe—but activist in that my aim is to improve health outcomes. In this way, my project is clearly invested in social justice and equity for trans communities.

My previous research and analysis in this area, which includes surveys with trans men and women who operate inside and outside medical institutions, reveals that the above user's experience is common. And it is important to note that “inside” and “outside” here are not stable categories. An earlier project (IRB #8212) found that people sometimes operated in both locations simultaneously or moved back and forth as needed. In fact, medical literacy involves a negotiation between what

institutional practices she, he, or they can access alongside the reality of shifting cultural and legal hurdles. The above post emphasizes that medical literacy for trans individuals is frequently a collaborative one that draws on official and unofficial technical documents and medical rhetorics produced and verified by a collaborative user base. Furthermore, responses to this user and other similar queries confirmed the online community's willingness to help serve as a proxy doctor: "Post your results here and we can interpret them," one user replied to this post within a matter of hours.

Several factors point to the significance of studying the ethics and rhetoric of these texts for members of SIGDOC. Trans communities are underrepresented research populations even among medical researchers and practitioners. In a statement aimed at multiple disciplines, Hughto et al. (2017) tellingly commented in a summary of existing work in this area: "Future research would also benefit from examining the role of health literacy in access to transition-related care for transgender patient populations" (p. 115). Bauer et al. (2014) noted that healthcare for trans persons is remarkable in its institutional and informational erasures, erasures that produce a system where a trans individual is "an anomaly" (p. 348), a disruption. In 2015, MacCarthy et al. called for increased investment and attention to trans health in the United States.

Reducing health disparities and advancing transgender-related health equity requires greater investment in research that addresses current gaps to more comprehensively respond to the diverse health needs of transgender people. (p. 287)

To date, there is little to no research that studies the informal or hybrid rhetorical practices of trans persons. Such research would be a clear subject matter of interest for a specific set of researchers: namely, those who are interested in technical rhetorics, public health, transgender medicine, and gender studies. For example, in recent years, technical communication researchers have called for their field to study "social justice," which involves connecting technical documents that institutions create to the social and political contexts that produce them, as well as the privileged or marginalized communities that they fail to represent or serve (see, for example, Agboka, 2013; Haas, 2012; Jones, Moore, & Walton, 2016; Leydens, 2012; Walton & Jones, 2013). As several scholars have noted (Jones, 2016; Cox & Faris, 2015; Cox, 2018), technical communicators have been slow to engage queer and especially trans technical communication texts.

Yet, remedying this oversight is not merely additive, that is, merely grafting trans people as an object of inquiry into existing technical and medical rhetoric paradigms. Rather, this project argues that studying these hybrid texts requires more fundamentally reckoning with some of the foundational concepts and methodologies that produced these sorts of exclusions in the first place.

This project is invested in intersectional research. Any account of trans experiences must also carefully consider those who live with multiple and compounding vectors of discrimination (e.g., race, class, ability, or citizen status). For example, "trans" often implies *white* trans people, a construction that erases the unique vulnerabilities and struggles of non-white trans experiences. Therefore, in this project, I will use an intersectional feminist lens in my analysis. I have successfully employed this lens in a co-authored academic article recently accepted (blind refereed) into a special issue on the rhetoric of health and medicine and social justice (*Unruly Bodies, Intersectionality, and Marginalization in Health and Medical Discourse*). Our article examines the specific DIY experience of Black trans users and was well received by reviewers.

Methodology and Work Plan

The award money will be used to write a comprehensive literature review in support the larger project. It will also be used to create and pilot a survey (spring 2021).

This survey will ask people to reflect on the role of documentation within their transition experiences—within and without institutional contexts—including how many of those surveyed use some form of DIY methods. For those who DIY, I will ask them to identify the reasons they first began the practice, the role a medical institution plays in their gender transition (if any), the documents (technical or otherwise) they use(d) to gain knowledge about gender transition, the documents (technical or otherwise) they create(d) to share knowledge and experience with others, how those documents are

circulated and remixed through various networks, and their perspective on their experience with DIY methods. For those who do not DIY, I will inquire as to their perceptions of DIY care and on their experiences within medical institutions.

The goal of the survey is to ascertain attitudes, beliefs, and behaviors within DIY and official medical contexts. I will also ask for contact information for any individuals willing to be interviewed (interviews will take place in the fall of 2021). According to the Williams Institute, there are 1.4 million transgender adults in the US (Flores, Herman, Gates, & Brown, 2016). Given that many who DIY may be not self-reporting and may not seek medical care for gender transition or keep it from their doctors, there are no data on how many trans people DIY. A previous survey (IRB #8212) received 82 responses over one summer. I believe a target sample size of 100 people will garner significant insight.

Work Plan

In spring 2021, I will circulate a small pilot survey, revise according to feedback, finalize surveys, receive IRB approval, and begin collecting resources toward a comprehensive literature review. In June 2021, I will begin circulating the survey and writing the literature review. I will complete the project in July 2021 by analyzing the collected survey data and creating a report. I will also complete the literature review, which will result in an annotated bibliography. The survey data report will inform questions for the individuals who agreed to be interviewed. Interviews will be conducted in fall (2021) and spring (2022). Complete data analysis will be conducted over the summer of 2022. The book manuscript will be completed over fall 2022 through spring 2023.

Competencies, Skills, and Access

I have been a part of a research team studying trans technical rhetorics since 2017. I have six blind refereed academic articles either published or accepted in the area of trans medical rhetorics and two more under review.

I have contact with physicians who treat trans patients and I have a good relationship with several communities of trans populations including local communities such as the Utah Pride Center, the University of Utah Transgender Health Program, Utah State University's Inclusion Center, and Utah State University's Center of Intersectional Gender Studies and Research. I am also a participant in several online research communities who can help disseminate the surveys and identify participants, including SIGDOC, the Association for Rhetoric of Science, Technology, and Medicine (ARSTM), Rhetoric Society of America (RSA), Queer Ph.D. Network, FemTechNet, and Flux: A Space of Rhetoricians of Health and Medicine. I also participate in several related listservs (e.g., National Communication Association, ARSTM, Association for Teachers of Technical Writing).

Final Product and Dissemination

The final product for this book is a book manuscript intended for scholars in rhetoric and writing studies, particularly those interested in technical, queer, medical, and digital rhetorics. My academic articles specifically investigating DIY methods of gender transition will inform the book project. I have completed a book proposal and have submitted it to review to the Ohio State University Press. While they were not interested at this time, I am using their feedback to revise the proposal to submit to another press soon.

Projected Budget

The award money will be used to purchase materials for the literature review (\$500), pay participants for their feedback on the pilot study (\$200), and pay salary (\$500) to help with the pilot and literature review.