Online Transgender Health Information Seeking:
Facilitators, Barriers, and Future Directions

by

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Introduction

Trans Health Needs

Transgender (defined as those whose current gender is different from that assigned at birth, including non-binary people, hereafter shortened to "trans") communities disproportionately experience structural and social barriers to accessing healthcare, which contribute to significant health disparities.

There is not enough information surrounding trans health needs. This is produced by a variety of factors including: erasure in data, trans people not accessing health care, inadequate knowledge of healthcare providers working with trans people, and research around health topics are lacking. It is difficult to estimate the number of trans people because trans identities are often erased in health data both un- and intentionally. For example, underestimation of trans people globally are further exacerbated when researchers (such as medical institutions) provide binary male and female gender markers, do not ask about gender and sex separately using the two-step method (Lombardi & Banik, 2016), and lump trans people within cisgender groupings (e.g., characterizing trans feminine people as gay and bisexual men). Moreover, trans people often delay seeking healthcare due to factors such as minority stress, traumatization in medical environments, and structural barriers such as cost and access to insurance. For example, delaying care due to avoiding discrimination contributed to poorer health outcomes among a sample of transgender people (Seelman et al., 2017). Research specific to trans health needs unfortunately are often case studies such as surgical case studies, not community engaged, conflate sexual orientation with gender identity, and/or inadequately provide mechanisms to identify people of trans experience within the sample. Among information needs of trans people, health information has often been listed as a top priority (Drake & Bielefield, 2017). Within this context of pervasive structural and social barriers to accessing health care providers and comprehensive medical information, the Internet provides promise for trans people to access appropriate information.

The purpose of this research project was to explore the experiences of trans people accessing health information online, including the sources they use to access information. Additionally, it aimed to address which aspects of extant online platforms (among social media platforms and user-generated information sites) are facilitators and barriers to searching for health information. To address these questions, I conducted three asynchronous online focus groups with 26 participants from across the United States. The main results substantiate and expand previous literature that discuss platform-specific policies that disproportionately block and exclude trans users (Carrasco & Kerne, 2018; Haimson & Hoffmann, 2016). To my knowledge, this is the first time these barriers are positioned in a trans health context. Lastly, the results posit design suggestions to improve existing and future platforms to better serve trans users. This research is highly relevant for increasing trans people's access to relevant health

information in alternate formats and reducing proliferation of inaccurate trans health information within online spaces.

Related Works

Online Health Information Seeking

Seeking health information online has long been fairly well studied among non-trans specific health information seekers. For example, De Choudhury et al. (2014) found that users reported seeking information online rather than in person because it is convenient, they get many results for each fresh query, and because of the privacy. To a lesser extent, participants sometimes reported using online searching because they were unhappy with information they had received from providers. Twitter was used by participants as a means to also gain and share health information. Reddit has also been demonstrated with a non-trans sample to have provided a source of dermatological (Buntinx-Krieg et al., 2017) and mental health information (Park et al., 2018) for people. Liao (2019) discusses the social media platform affordances orchestrating where people share some information versus others. For example, an anonymized online platform such as Reddit may help with searching for depression help, whereas Facebook was used by the same person to share fitness data. However, there is a dearth of published research exploring online health information seeking within LGBTQ+ communities, especially with trans populations.

Among non-trans specific LGBTQ+ online health information seeking research, the published studies are largely focused on sexual health. Mitchell et al. (2014) found using a large survey that sexual minority youth were more than three times more likely to report using online resources to access sexual health information than heterosexual/straight-identified youth. Magee et al. (2012) utilized qualitative interviews with LGBTQ+ youth to explore if and how they seek sexual health information online. The most prominent topic area of information seeking was HIV/STIs, but also to a lesser extent included interpersonal topics such as relationship advice. There are even fewer studies that specifically have studied the information searching needs of people of trans experience.

Online Trans Health Information Seeking: Using Social Media

For general information seeking, transgender people in qualitative interviews reported utilizing both online and in person support networks in seeking transgender identity specific information (Pohjanen & Kortelainen, 2016). The participants claimed that finding related information about gender identities is crucial to people's identity formation. For health information searching, several researchers have quantitatively found that social media platforms such as Twitter (Karami et al., 2018) and Tumblr (Hawkins & Gieseking, 2017) have provided space for transgender individuals to voice health concerns, questions, needs, and thoughts. Karami et al. (2018) systematically observed thousands of tweets from about 300 users and out of 125 topics, 54 topics were health-related. Hawkins and Gieseking (2017) found that posts associated with the hashtags #ftm (female to male) and #mtf (male to female) commonly also included other hashtags about surgeries, hormones, and even doctors' names amongst the greater than 700,000 posts analyzed. Qualitative works in this research area with a trans sample seem to be sparse. Selkie et al. (2020) recruited trans participants from a midwestern health center and found that the sample often made health decisions with support from trans communities on social media. However, understanding social media platform affordances and motivators similar to

what Liao (2019) outlines has not been studied in the context of trans users and health information.

Online Trans Information Seeking: Identifying and Navigating Barriers

There are barriers to seeking trans health information online. Although trans people have health-related questions and concerns, accurate and consistent information is not yet available. Pohjanen and Kortelainen (2016) reported that the trans sample stated that the barriers to accessing information online was not just due to external and internalized stigma, but also a lack of information present. Other times, the information is not accessible. For example, Deutsch (2016) searched the web using eight structured search strings and found that many sources were not in a bulleted, informative format (and lacked graphics). This could be a large barrier to engage with health-related materials and also poses accessibility concerns for users that may not be as familiar with medical jargon. Furthermore, information can be inaccurate. Deutsch (2016) found that only 40% of the sites included accurate prescription information for hormones. As misinformation on online platforms has become a common occurrence in mainstream rhetoric, it is lesser understood to what extent trans people mediate these perceived risks to online health information seeking. With regards to general LGBTQ+ online health information seeking, Magee et al. (2012) described that a number of participants noted not using the internet to seek health information due to mistrust of accuracy of information and stigma associated with being discovered seeking out health information online.

Outside of a health context, it has been shown that in aims of identity curation on social media platforms, trans users engage with online platforms in novel, unexpected ways. For example, Hanckel et al. (2019) described that some trans participants utilized the nickname feature in Facebook Messenger to try out different preferred names. The authors noted that the nickname feature was most likely not designed with this use case in mind. They also mentioned that being able to adjust post privacy settings to hide posts from particular audiences was especially important for their trans participants. Social media platforms provide their own suite of barriers specific to trans users. Cumbersome content deletion pathways, "real name" requirements, and one-profile policies have been shown to be inhibitory to trans users (Carrasco & Kerne, 2018; Haimson et al., 2016; Haimson & Hoffmann, 2016). Specific social media platform facilitators and barriers to online trans health information seeking have yet to be studied.

Research Aims and Contributions

Although there is not a lot of research published on transgender health information seeking online, the existing body of literature supports that transgender people often seek health information through online social networks such as through social media platforms. However, platform affordances related to accessing trans health information through social media platforms have been under-studied. Thus, we lack vital knowledge about how social media and online resources may support or hinder trans health information seeking practices via their features, content, privacy affordances, and policies. Therefore, this study takes first steps in filling this research gap to the facilitators and barriers to online trans information seeking using social media. Additionally, it posits implications for design of not only existing systems, but also a dedicated trans health platform. This work is essential to increase trans people's access to health information in the wake of widespread health disparities.

Methods

Unlike utilizing document review methods like Hawkins and Gieseking (2017) and Karami et al. (2018) or semi-structured interviews like Selkie et al. (2020), we used an asynchronous online focus group methodology. Asynchronous focus groups have previously been used for health research with minority populations and discussions of sensitive topics (Reisner et al., 2018). We used an asynchronous online focus group methodology to foster flexibility and intergroup dialogue and minimize disruptions caused by time zone and participant schedule differences, and to enable people to discuss potentially sensitive topics without having their real name or identity attached. Subject recruitment was completed by means of social media posting flyers on Facebook, Twitter, Instagram, and Tumblr (Appendix I). The posts included hashtags that were relevant to trans communities as well as some intersections thereof with racial and ethnic identities (e.g., #transgénero and #qtpoc).

A total of 257 individuals completed a screening survey that was linked from a recruitment flyer posted on social media outlets. The only eligibility criteria for participants was being trans and/or non-binary and 18+ years of age. However, the screening survey offered space for participants to self-identify their name, gender, sexual orientation, race, ethnicity, geographical area, and (dis)ability status. I reached out to potential research participants via email individually to ask whether the participant was still interested and obtained written consent to the online consent form. I remained available to answer questions via email throughout the duration of the study and until it was confirmed that participants received their participant incentive payments.

The focus groups each occurred over the course of three days in August, November, and December 2019. Each focus group included 7-10 participants (3 focus groups, N = 26 participants) and was formed from the survey responses to include diverse races, ethnicities, geographical areas, ages, and (dis)ability statuses. Summary of participant demographics are included in Tables 1-5. *Note*: Groupings are not mutually exclusive; therefore, percentages may total to greater than 100%. Focus group prompts approached topic areas such as 1) where participants access trans health information outside of providers, 2) what are facilitators and barriers to online trans health information seeking, and 3) what are potential features, layouts, and stakeholders to include for an ideal online trans health platform. Focus group prompts were slightly modified iteratively to increase clarity. Each participant was given the choice to get their participant incentive payment through a virtual Amazon gift card or a physical Prepaid MasterCard gift card. This choice allowed participant choice in several areas. The Amazon gift card provided instant payment and did not require sharing an address, whereas the MasterCard gift card allowed for funds to be used outside of Amazon.com. Participant incentive was increased from $25 to $40 for focus groups 2 and 3 because additional questions may have taken participants more time to answer. I notified the participants of the incentive options and increase prior to acquiring digital consent.

I analyzed the transcripts first using an inductive open coding approach then met with advisors and the thesis committee to confer emergent themes (Charmaz, 2006). All study procedures were reviewed and deemed exempt by the University of Michigan Institutional Review Board (IRB).

Table 1: Participant Age (N = 26)

Mean	30.2
SD	8.4
Range	19 - 50

Table 2: Participant Gender (N = 26)

Transfeminine	30.8%
Transmasculine	34.6%
Nonbinary	34.6%

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Table 3: Participant Race/Ethnicity (N = 26)

Latino/Hispanic	26.9%
White	26.9%
African American/Black	19.2%
Asian/Asian American	19.2%
Mixed/Multiracial	19.2%
Native American/Indigenous	3.8%

Table 4: Participants Identifying Having One or More Disabilities (N = 26)

Yes	57.7%
No	42.3%

Table 5: Participant Geographical Locations in USA (N = 26)

South	30.8%
West	30.8%
East	15.4%
Midwest	15.4%
Central	7.7%

Results

Seeking Health Information Outside of Providers

When asked where they go to find online trans health information, participants listed a wide range of sources of information with online sources, particularly social media websites, occurring at the highest frequency. Other online sources included online communities such as user-generated information sites (e.g., Quora, Reddit, Yelp) and specialized health provider

websites such as Planned Parenthood and the Callen Lorde site (an LGBTQ+ health center in New York City). Additionally, participants mentioned using community-generated online resources such as the FTM guide and Transbucket (a repository for post-surgery photos). Several participants also mentioned utilizing resources not online such as free clinics, local support groups, mental health providers, and LGBTQ+ non-profit organizations.

Overwhelmingly, participants listed one or more social media platforms or user-generated information sites as major sources of health information – from Facebook, Reddit, YouTube, Tumblr, and Instagram, to Discord (a chat platform initially for gamers, but now used in many contexts). Participants noted the benefit of connecting with people who could provide a firsthand account of the information. For example, P20 stated: *"I trust personal experiences by trans people that have already went through what I am currently facing for the first time; even though everyone's experience is different, it helps give a general insight."* Participants used social media for both medical and identity-related support. Many participants noted the profound impact that online trans communities provide for their own identity formation and validation, especially trans people in isolated areas. Participants particularly emphasized receiving support from other trans people (quote frequency = 27) such as through word of mouth was essential. For example, P2 said *"Having a recommendation from another trans person makes me the most comfortable."* Similarly, other participants noted the opportunities social media platforms provide to return the favor to other trans people. For instance, P14 said: *"The most joyful thing for me was connecting people with each other and with resources, and still is today."* Not every participant said that they access health information from online sources.

A subset of participants dissented, claiming that they only trust medical journals or medical providers for health-related information: *"I steer clear of social media as a resource for healthcare advice and stick to relevant articles from respected journals"* (P24). The distribution of responses to questions where and why they access health information online heavily focused along social media platforms and user-generated information platforms. As such, the remaining sections of the results predominantly focus on participants' reactions to the performance of these tools for a health information seeking purpose. Additionally, they outline future design suggestions.

Facilitators and Barriers to Online Health Information Seeking
Facilitators

Aspects of social media platforms that facilitated health information seeking related to a variety of privacy features and discovery mechanisms available within social media groups, and online platform content temporality.

Social Media Group Privacy Features

Participants mentioned that privacy features such as private and hidden groups on sites like Facebook were helpful. Additionally, group composition also allowed for a level of privacy. As P19 put it, *"I love joining private groups that are moderated by trans people and all members are trans."* P19's quote mentions both the group composition and the privacy key words 'private groups.' Private groups only permit people in a Facebook group to see the other members in the group. This feature sometimes moderated participants' decisions of whether or not to join trans groups. When group affiliations are publicly listed, it can out people as trans to their entire network. Within groups, fostering favorable group composition with tools such as questioning prompts were highly acclaimed by participants. For example, *"Groups having the ability to vet*

people via a questioning system make for the safest spaces you can find with the most first-hand experience from other trans gnc [gender non-conforming] people" (P21). Privacy features were important not only to moderate the members who join social media groups, but also helped some participants moderate how their identity is visible to others across the platform.

Social Media Group Discovery

Participants appreciated the diverse abundance of community groups and resources continuously available on social media platforms. Additionally, the tools are accessible to broad audiences, including allies. Several noted that search features allowed for them to find unique, affirming groups such as *"trans people with children"* (P14). Being able to locate local trans people, for example, assisted with finding health provider location recommendations.

Platform Content Temporality

Many positive comments about social media helping to find health information seeking was about the synchronous and asynchronous duality of online interactions. Information is available in an archival format, while also allowing for real-time interactions such as through group dialogue and audience participation. One participant described this always-accessible nature as such: *"I like the fact that I can be actively involved or just hop on there if I need to connect with someone or want to be supportive"* (P14). This synchronicity was not exclusive to online groups (e.g., trans support groups on Facebook), but also included features that allow for audience participation such the Question/Answer feature in Instagram stories as a method to gather input. Another participant pointed out their experience of watching YouTube videos as sometimes feeling more genuine. *"In some ways using YouTube 'testimonials' feels like a more genuine representation of how folks are feeling about their bodies in real-time"* (P11). The same participant mentioned that they like to validate the information by watching several videos because people are not straightforward about their privileges and biases.

These same social media platforms often also provide asynchronous support for health information seeking. A participant mentioned that Instagram posts are permanent. Another mentioned how the archive of YouTube videos available helped them realize the abundance of online resources available. *"I think YouTube has also helped with the proliferation of health info: seeing queer YouTubers definitely helped me realize how many resources there are out there"* (P7). Participants also mentioned that they use social media to follow other trans people's experiences such as through photos of hormones effects or surgery results. Another person mentioned that keyword searching within a group's conversation history was a helpful way to find relevant health information for their needs. *"I like that I can search for individual words in Facebook groups"* (P23). The presentation and archiving information were important for participants to both find and share information.

Barriers

Unfortunately, social media platforms also posed a number of barriers to fostering community connections among trans people seeking health information, including platform-initiated censorship and the presence of abundant misinformation and hate speech.

Platform Censorship – Educational Posts and Identity Labels

There was a direct negative response from participants to unproductive censorship on platforms, especially platform-initiated censorship. With regards to over-censorship, many people brought up Tumblr's updated posting policy which banned all "adult" content, which inadvertently included medical and educational trans content (Haimson et al., 2019). As P21 stated, *"Tumblr lost a lot of its credibility from heavy moderating and non-friendly behavior towards trans educational posts."* Censoring identity expression with name and pronouns also fall into a category of platform-initiated censorship.

Participants frequently commented negatively about name and pronoun labeling on social media sites. "Real name" (Haimson & Hoffmann, 2016) policies provided barriers to joining trans health information seeking community spaces on Facebook. P23 stated, *"I think it's important for trans people to not be booted from social media over dead names. That's a first step."* "Referring to a transgender person by their birth name, even after they have specified their chosen name, is known as 'deadnaming'" (Michallon, 2019). Participants commented on bureaucratic name changing policies, remarking that these made it seem as though *"Facebook was some government ID"* (P21). P22 described, *"I used to have a second Facebook account under an alternate name that I used to access transgender health groups, but Facebook deactivated it for suspecting me of having that second account that wasn't under my birth name. Despite my pleas they didn't give it back; … the fact that I can only have one account under my birth name limits the amount of groups I am able to join, and also ensures I'm dead named within the trans groups that I'm in unfortunately."* Additionally, some participants talked about the fact that pronouns stay the same across the platform, which forces them to choose non-representative pronouns to avoid being outed to their entire network.

Misinformation and Hate Speech

Concurrently in environments of inappropriate platform-initiated censorship, participants mentioned alarming levels of misinformation and hate speech. For example, P24 drew attention to the *"abundance of false information or opinions of transphobic people that can sometimes drown out the important and truthful info."* Participants reported receiving inaccurate information along topics of hormones, mental health, binding, surgery, and coexisting conditions. For example, one participant was accosted online and told that their trans identity was a result of a mental illness. *"I was told – rather incorrectly – that my gender struggle (rather, my difficulty to understand what was feelings of dysphoria) was a dissociative symptom and meant I was bipolar and a danger to myself, but not non-binary. Due to my decaying mental health, I believed this, felt instant guilt, all of which ultimately led to me delaying seeking aid for what is actually a dissociative disorder wholly unconnected from my gender"* (P7). Others reported being provided other inaccurate medical advice such as about binding and hormones. *"I remember before I had access to good binders there was all sorts of bad information about how to bind using ace bandages and duct tape and such. It was bad. I even ended up using an ace bandage at one point because I didn't realize how harmful it could be"* (P16). Another person was told that should not initiate hormones while being treated for anxiety medication. *"I read that my anxiety would be exacerbated by HRT and that my anxiety medications wouldn't be as effective. This scared the shit out of me and contributed to my decision to stop medically transitioning"* (P4). There was also a lot of hate speech that occurred on platforms.

Trans shaming can include many alternate ways of attempting to invalidate someone's trans identity or othering someone. For example, P20 ran across *"a trans shaming video"* about

de-transitioning. Social media also gives transmedicalists (i.e. transmeds) a platform to spread hate speech and misinformation. Transmedicalists believe that trans people who do not have surgeries or go on hormones are not trans. Someone gave the example of a trans person with many social media followers who is a transmed and said: *"[He] disvalues the experiences of people who either can't afford to transition to his level, who just don't pass, or who don't want to transition past a certain point or medically at all"* (P21). P18 mentioned seeing a presence of false information about gatekeeping, bottom surgeries, and puberty blockers. *"I wish the people I heard this from were just being trolls but they were parents that bought into the scare-tactic stories out there. Related to this are people getting puberty blockers and Hormone Replacement Therapy mixed up and that puberty blockers always create irreversible changes and infertility"* (P18). Misinformation and hate speech such as the points mentioned above can become widely shared on platforms and cause a lot of harm.

Lack of Tools to Flag Toxic Users and Content

Participants also raised issues with a lack of member screening and content moderation that leads to high frequencies of transphobic hate speech and misinformation. Participants often reported that necessary censorship became a responsibility of other community members to intervene. For example, one participant mentioned that they had seen other members within trans groups intervene and correct false information. *"[I] have asked questions on Facebook groups and Reddit and received uninformed information from people - but it was essentially corrected by other people so there was no harm"* (P3). Another said that a situation like that had just happened the same day as our focus group, *"This happened today. Someone was talking in a general LGBT group about how the effects of hormone therapy (for trans men) is reversible, and I had to jump in and say that's not the case and that communication between provider and patient is extremely important, as are realistic goals"* (P23). Participants expressed desire to have agency in flagging information as bad such as with "*a fact check score*" (P18). The lack of methods to fact check or determine which information is credible harms trust in platforms and hinders attempts to find actionable trans health information online.

Ideal Online Trans Health Information Seeking Platform

While there is not yet a dedicated social media site for accessing trans health information, we asked participants how a trans health information seeking platform should ideally be created. We asked about the general look and feel, any essential features, and which stakeholders to integrate in planning and sustaining a platform in the future.

Look and Feel of Ideal Trans Health Info Seeking Platform

When participants referenced what they thought that an ideal platform would look like, often they referred to existing platforms in their mental schema. For example, P7 refers to this ideal system as a blend of Tumblr, Twitter, and YouTube but with greater inclusivity for trans users. *"I'd really something that blends Tumblr, Twitter, and YouTube, run by queer folks of all walks of life with a clear statement of inclusivity and actual, active moderation of hate speech, which a lot of platforms are actively... not doing"* (P7). Just one participant mentioned to structure the site as a medical journal. Other themes were more abstract in nature and did not reference extant information sources. For example, participants often mentioned design choices

that promote inclusivity and accessibility. Participants mentioned many times that the site should be cleanly designed, easy to navigate, and designed to not 'out' people. *"I think it should be very user friendly, to be inclusive for everyone including older individuals, or people that have disabilities. Make it easy to use, and an outlay that's not too flashy, more professional. Subtle enough that it's not going to out someone that hasn't maybe came out yet, like a few others have commented"* (P20). Additionally, inclusivity extended to include being trauma-informed. *"The information provided would be culturally informed, trauma-informed and accessible, both in an ability way and in an SES way"* (P6). Participants referenced existing platforms and themes such as inclusivity as inspiration for designing trans health information seeking platforms.

Features Available on an Ideal Trans Health Info Seeking Platform
Question and Answer

A very frequent suggestion was that there need to be avenues available for discussion on the ideal platform. Namely, it was important for users to be able to ask their health questions relevant to their situations and hear responses from people of trans experience and healthcare experts. As P18 put it, *"An 'Ask me anything' section where people with lived experience and various professionals can answer questions (without trying to replace individualized medical care)"* (P18). A few participants said to borrow ideas from other platforms – Discord, YouTube, and the Kotex website. When one participant referenced the Kotex website as a good platform to model the Q&A features, they suggested making it more gender inclusive and socially aware. P6 said, *"Weirdly enough, I think I would model it after the U by Kotex website, where people can ask questions and they provide an answer from a gyno [gynecologist], a mom and a peer. Ofc [of course] it would be different for a trans health website, maybe from GP/NP [General Practitioner/Nurse Practitioner] who is educated on serving trans folks, perhaps a social worker or something, and a trans person."* Both scientific credibility and individual experiences were important for information trust and validation. P9 said, *"Also verify information with current accepted medical practices and current/new reputable studies. Also offer current news relating to trans medical treatment and offer a forum for discussion. Others experiences are still valuable."* Participants saw strengths in presenting information with scientific input as well as the input from people with lived experiences relevant to the subject material.

Appropriate Identity Labels

Participants posited platform suggestions that remedy the identity label deficits on other platforms. Some people mentioned that there should be more gender, name, and pronoun options. For example, P21 said *"More pronoun options for people who use neopronouns! Some people don't like using just the binary he/she, and having those locked to the most common sex for those pronouns isn't inclusive […] Some people who are gnc [gender non-conforming], don't like binary pronouns or they/them, and would want an option available for it/its, xe/xim, and other neopronouns."* People emphasized again the importance of preferred names over dead names. *"I also think it's important to allow people to use the correct name rather than their dead name"* (P24). One person suggested that names and pronouns should be able to change throughout the site. *"The ability to set a preferred name/pronouns inside of individual groups or visible to individual people of your choosing"* (P22). These suggestions address some topics that came up in the barriers to accessing trans health information online section.

Privacy and Security: Accounts Types

Privacy and security were salient topics in people's suggestions for an ideal platform. To address user account types, people brought up verification processes for users of the sites. *"I think as for access, possibly make an account and go through registration period first (possibly with monthly active registration windows) before any posts can be viewed? This is mostly a precaution because of the internet, and trolls/harassers could potentially make people unsafe on the site"* (P8). One person went on to say that the platform should be invite only. *"I would say a private invite to it in order to screen out potentially dangerous/toxic individuals"* (P20). Some participants mentioned that there should be multiple types of accounts for different users, and that there should explicitly be an authentication process for healthcare providers on the platform. *"I think there would be specific accounts for transgender people and clinicians. And there would be a verification process for the clinicians"* (P24). Along user accounts, several people addressed that it is important for users to have a level of optional anonymity on the platform to conceal people's identifying information. They suggested protecting people's identities with the *"ability to be confidential as not everyone has come out yet"* (P9). Participants did not agree on any single process of administering account types on health information seeking platforms.

Privacy and Security: Moderating and Flagging Content

Participants additionally talked about content moderation on the ideal platform *"to not only squash hate speech but also promote healthy discussion"* (P8). For several participants, presence of human moderators was important to filter out toxic individuals that are abusing the platform. P18 said, *"Forums and chats with human moderators that can keep 'chasers' away who treat us as a fetish."* Often, people mentioned the importance of signaling good and bad sources of information. *"I feel that verification of content truthfulness should be at the forefront"* (P24). Participants suggested implementing trustworthiness signals through platform features such as giving stars, scores, or badges. For example, *"It would be great if social media platforms had easily accessible names of groups and recommendations of those groups by stars so that people could vet them a bit before bothering to join especially since some of them are very toxic environment and that's the last thing we need when we have health needs, especially mental health needs"* (P14). Methods to moderate content such as flagging posts were viewed as means to counter misinformation and hate speech on platforms.

Information Accessibility and Information Architecture

Consistently a value among participants was that the solution was made available in multiple formats such as being *"mobile and desktop friendly"* (P21) and as *"a website and an app to have easy access"* (P26). One extended these suggestions to say that phone support should be available. *"People would be able to access this info via the internet and also live phone support for mental health issues"* (P17). Another mentioned to include video content for those that learn that way. *"I like to get information via video content as opposed to reading, so maybe a little like YouTube but with a forum option"* (P22). One person suggested that in addition to being an online resource that some of the resources could potentially be available offline with *"maybe a booklet of some kind, too*" (P5). Format and information architecture features could provide opportunities to promote inclusion on health seeking platforms.

Suggestions to increase accessibility of information and its architecture also included features to assist trans users with disabilities because *"inclusion is imperative"* (P24). P11 said *"It would be accessible for folks with screen readers. It would have a search bar that allows*

people to look up specific tags like (transition, HRT [hormone replacement therapy], gay, asexual, etc...). " Similarly keyword searching and tagging came up frequently again. *"Tags lots of tags, afab [assigned female at birth], amab [assigned male at birth], non-binary, hrt [hormone replacement therapy], surgery, etc. where you can narrow down what you are looking for"* (P2). Once this feature was referenced in terms of intersectionality, P4 said *"It would be able to allow patients to search by intersectionality, so we can search by class, ethnic identity and identity."* Intersectionality as a guiding framework, however, came up numerous times. *"I also think it's important for us to be more intersectional in that one thing may work for someone whose only 'medical issue' is being trans but it could be ineffective or dangerous say for a transgender person with heart problems"* (P24). Intersectionality also was a consideration among the participants for choosing which groups of professionals to integrate into health information seeking platforms.

Constituents for an Online Trans Health Information Seeking Platform

Participants listed off several key participants in the planning and execution of a trans health seeking platform, marking the venture as interdisciplinary. *"A wide network of specialists banding together as a network"* (P4). Most frequently participants mentioned trans people and health care providers. Other people to integrate included family members, mental health professionals, and allies. People mentioned that the platform would be openly accessible to trans people and include different levels of verification for non-trans members. This included ideas such as verification processes for providers and only being welcoming to accepting allies and family members. For example as P21 said, *"[Include] trans/gnc people of all demographics, trans-friendly allies who have made active efforts to improve the trans community/to learn for the betterment of their trans family or partners, and vetted in doctors with experience on trans healthcare." "[Include] anyone that's trans or non-binary, and have a section based for people that are questioning their gender. Maybe have a section for partners, friends and family too, but only if they're accepting."* (P20). People also mentioned integrating professionals working in social work. For example, *"[Integrate] mental health professionals such as social workers [and] medical professionals, including mental health"* (P3). *"Trans friendly health providers, mental health providers and legal assistance would be a part of this site"* (P17). Lastly, one participant suggested to also include both beauty experts and trans activists into the platform *"Doctors, health experts, beauty experts, legal experts, and activists to talk about health systems and rights globally"* (P26). Participants did not limit other participants in a health platform to just medical professionals, but also included professionals integral to multiple layers or healthcare such as legal professionals.

Discussion

The results of this qualitative study substantiate (Hawkins & Gieseking, 2017; Karami et al., 2018; Selkie et al., 2020) and expand extant literature by highlighting facilitators and barriers to trans health information seeking online, primarily in the context of social media platforms. Participants chose to find health information online especially due to the community aspect for seeking and returning advice to others. This differs from (De Choudhury et al., 2014) where social support was the least frequent motivator (among the sample's self-reported motivators) to access health information using a social media platform such as Twitter. Seeking information

using Twitter for convenience reasons was the sample's greatest motivator. In the present study, facilitators to online health information seeking included social media groups and content temporality. Groups helped participants access health information because the groups were identity-specific and some utilized privacy mechanisms such as screening questionnaires. Additionally, the abundant access to information, archived posts, and social networks at any time of day was also very beneficial. Unfortunately, multiple aspects of social media platforms were prohibitive to trans health information seeking. For example, unnecessary platform-initiated censorship of trans educational posts concurrently exist in environments where there are no clear indicators of which information is reliable.

This study, to my knowledge, takes first steps in positioning these platform barriers in a trans health context. Additionally, it posits suggestions for how an ideal online trans health information seeking platform should be designed. Participants suggested that the guiding principle is intersectionality. Namely, the platform must be inclusive to diverse experiences and identities. The platform should not ascribe to any singular narrative of trans experience. Instead, it should be aware of the array of health needs that trans people have such as mental health needs, accessibility needs, and the presence of preexisting conditions. The platform should integrate many groups in addition to trans people such as health providers, social workers, activists, legal advisors, and allies. However, the participants often provided a caveat that non-trans participants such as allies and health providers should be screened in order to participate in community discourse. Participants provided concrete suggestions for design; some remedy the deficits present on other platforms they use to access health information. For example, participants suggested omitting "real name" policies (Haimson & Hoffmann, 2016) and extending content moderation pathways such as by implementing platform specific tools to flag misinformation. Participants reported often needing to create their own online communities within social media platforms and moderate content after it has already been published.

It was important for participants that a new platform retain opportunities for community dialogue, presenting information in parallel with firsthand accounts of experiences. This suggestion aligns with trans communities' increased caution towards medical establishments. Participants most often suggested a Question and Answer aspect to any new health information tool. Participants suggested that both healthcare providers and trans people can weigh in and contribute their expertise. Similar to what users liked about some existing platforms was the synchronous and asynchronous duality of information. Participants highly suggested allowing for archival searching and cataloguing of information by means of tags and drop downs. Some also mentioned providing multiple formats to increase accessibility of information to be more accessible in video, graphical, and even offline formats. This corresponds to Deutsch (2016), which reported that much of the available trans health information about hormone therapy for example posed accessibility issues.

Strengths and Limitations

This research presented both strengths and limitations. The sample was diverse across many identities, and many participants held multiple marginalized identities. The sampling technique was a strength because the responses included people from all over the United States and across multiple generations. Additionally, the online focus group research design was highly beneficial in bringing a diverse group together living in different time zones and with variable schedules. However, these data represent a selection bias for trans users who are already adopters of social media platforms and are not generalizable to all trans people. Additionally, participants

that self-reported as Indigenous and/or Native American were disproportionately underrepresented among other racial/ethnic identities in the sample. The recruitment flyer mentioned both health information and online information which likely oversampled people who already search for health information online. The focus group tool allowed for participants to make their posts viewable to the entire group or to only the moderator. Despite this feature, there may have still been a social desirability bias in the focus groups for members to answer in a manner that would be viewed positively by others. Moreover, it was sometimes unspecified as to whether participants were talking about interactions on social media with people in their social networks in the physical world or with strangers. More provisions should be made in the future to minimize this ambiguity.

Conclusion

The results of this research project suggest that social media platforms are serving an unconventional purpose to provide important health information for trans audiences, albeit each platform is abundant with tradeoffs. It is essential that online platforms become more inclusive to the experiences and needs of trans users. For example, reducing unnecessary barriers such as legal name policies and increasing users' ability to moderate problematic content are necessary to ensure that these online trans health communities can thrive. As linguistic norms and needs evolve rapidly among trans communities, ongoing community-engagement is essential for designers of social media platforms.

Further research may explore design and adoptability of a dedicated trans health information seeking platform by integrating some of these findings. For example, researchers can explore experiences using a prototype online health platform with communities. In absence of such prototypes, future research can also provide platform-specific recommendations to extant social media platforms. As Hanckel et al. (2019) points out, platform affordances may be used by trans users especially to foster community connection and navigate boundaries. Therefore, when significant barriers to information seeking surface, designers must adapt. Social media platforms are commonly used for spreading news articles, sales of items, and many other features that were not available in early iterations. Aspects such as the proliferation of trans health misinformation and inhibitory platform policies are negatively affecting the health seeking process of trans users. Therefore, small changes to platforms such as the elimination of negative policies may have a large impact contributing to better health outcomes. However, for the long term, the relationship between trans communities and the medical field should be further remedied by engaging with communities to create a dedicated online platform that blends real person testimonials in parallel with provider advice. Over time, this platform can help dispel misinformation online and facilitate the process for finding accurate and relevant health information. As participants pointed out, it is essential that this work is not completed through a singular perspective. This work should be cooperative and work at reducing structural and interpersonal barriers to accessing appropriate information and care.

Although transgender people have health-related questions and concerns, accurate and consistent information is not abundant online. Pohjanen and Kortelainen (2015) reported that the trans sample stated that the barriers to accessing information online was not just due to external and internalized stigma, but also a lack of information present. For some questions, the correct information is not yet available online. Therefore, it is also essential that researchers are exploring needs specific to trans communities and publishing results in accessible formats.

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Appendix I:

Recruitment flyer with a transgender pride flag color scheme

TEXT Are you 18+ and identify as trans, nonbinary, genderqueer, or another not cis identity? Please share your experiences about searching for health information and get twenty-five dollars. tinyurl.com/transhealthsurvey Please share.