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Vanessa L. Kitzie

University of South Carolina, kitzie@mailbox.sc.edu

Travis L. Wagner

University of South Carolina - Columbia, wagnertl@email.sc.edu

A. Nick Vera

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University of South Carolina - Columbia, veraan@email.sc.edu



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“When Someone Sees Me, I Am Nothing of the Norm”: Examining the Discursive Role Power Plays in Shaping LGBTQ+ Health Information Practices

Vanessa L. Kitzie,¹ Travis L. Wagner,¹ and A. Nick Vera¹

1. University of South Carolina, School of Information Science

Abstract

This paper examines how discursive power shapes LGBTQ+ community health information practices. Informed by analysis of 10 information world maps drawn by SC LGBTQ+ community leaders, our findings indicate that while community can be a valuable construct to reject mainstream discourses of regulation and correction, it inevitably is fraught and not representative of all LGBTQ+ individuals. Findings can inform strategies for community leaders to facilitate more equitable information flow among members by identifying key structural elements impeding this flow at the community level.

Introduction

While equitable access to health information is a preeminent goal among patients, practitioners, and information professionals, inequity along sociocultural lines remains. Lesbian, gay, bisexual, transgender, and queer (LGBTQ+) populations face aggravated relationships with power that uniquely shape their engagement with health information. This paper presents preliminary qualitative findings informed by situational analysis of 10 information world maps created by LGBTQ+ community leaders in South Carolina (SC) depicting how their communities create, seek, share, and use health information. These findings explore how discursive power within and outside of SC LGBTQ+ communities shapes their health information practices.

Literature Review

Discourses consist of the relationships between people, texts, ideas, and institutions within a particular socio-historical context. Power orders these elements based on their proximity to a desired ideal; the meanings attached to this ordering constitute knowledge (Foucault, 1978). Therefore, we define discursive power as the knowledge and practices considered normal or acceptable within society. For LGBTQ+ people, historical relations to power – whether legal, economic, social, or otherwise – have occurred through intensified surveillance and demarcation as different from the norm. Bodies whose existence challenged Victorian era regimes of reproductive heterosexual familial structures became subject to correction through imprisonment, hospitalization, and death under the guise of medical science (Foucault, 1978). While the coercive power of these corrections has relaxed, the long-term discursive impact of seeing the LGBTQ+ body as an object of curious spectacle remains. Scholarship has addressed how heteronormative (i.e., presuming all persons are heterosexual) and cisnormative (i.e., assuming a person’s gender matches their sex assigned at birth) discourses have stifled the mobility and visibility of LGBTQ+ people in contexts such as law (Spade, 2015), public policy, (Davis, 2017), and librarianship (Adler, 2017). Our work envisions discursive power as operating when LGBTQ+ people create, seek, share, and use health information.

An information practice approach understands people’s information-related activities and skills as socially constructed (Savolainen, 2008). Work describing the information practices of LGBTQ+ people has found that they engage in practices that disavow normative and dominant ideologies, and benefit LGBTQ+ individuals and communities (Floegel & Costello, 2019; Kitzie, Wagner, &

Vera, 2020). Within health narratives specifically, LGBTQ+ individuals remain outside of the scope of normative discursive practices, excluding moments of regulation and correction (Charest, Klien, & Lund, 2016). As our prior work shows (Kitzie, Wagner, & Vera, 2020), such exclusions result in LGBTQ+ individuals and their communities creating and engaging in health information practices that respond to negative discursive encounters. Less is known about how such discursive power might seep into LGBTQ+ community dynamics. This work attends to this gap by addressing the following research question: How does discursive power within and outside of LGBTQ+ communities shape their health information practices?

Methods

We completed 30 semi-structured individual interviews with SC LGBTQ+ community leaders from January – August 2019. We recruited community leaders by contacting visible SC LGBTQ+ communities and affinity groups via email and asking them to nominate leaders to participate. Existing constructs in fields like sociology and geography informed community criteria (Hillary, 1995). Interview topics centered on the community's health questions and concerns and how they addressed them. Following the interview, participants engaged in information world mapping (IWM). IWM is a participatory arts-based elicitation technique (Greyson, O'Brien, Shoveiler, 2017) where participants put their communities on a piece of paper and draw the people, places, and things influencing how their communities create, seek, share, and use health information. We focus on the participants' information world maps for this paper.

Informed by theorizations of information grounds, horizons, ecologies, and worlds, IWM captures participants' conceptual geographies inclusive of elements such as place/space, social context, people, and technologies. IWM empowers socially marginalized participants to define and depict their information worlds and elicits in-depth information about participants' everyday information practices in context (Greyson, O'Brien, & Shoveiler, 2017). While creators of this technique initially viewed it as supplementary to interviews, their recent work demonstrates that situational analysis of maps contributes insights beyond the analysis of interview transcripts alone (Greyson, O'Brien, & Shankar, 2019).

We first analyzed interview transcripts using open qualitative coding (Kitzie, Wagner, & Vera, 2020), granting us a crucial context for understanding the maps. We then performed situational analysis on a random sample of 10 maps, guided by Greyson, O'Brien, and Shankar (2019) and Clarke (2005). For each map, we wrote three memos:

1. *Locating memos* overviewing the *map's context*
2. *Big picture memos* describing the map and our initial impressions
3. *Specification memos* discussing various map elements, such as composition, presence/absence, and work of the image

We then identified keywords and phrases from these memos to create a "messy situational map" (Figure 1). We organized these data into an "ordered situational map" using Clarke's (2005) deductive categories (see Table 1).

[Insert Figure 1 here]

[Insert Table 1 here]

Results

Data analysis of participants' information world maps identified three ways that discursive power shapes the health information practices of LGBTQ+ communities: 1) condensing LGBTQ+ people into monoliths; 2) establishing community's normative role in information practices; 3) applying metronormative discourses to information sources. We illustrate these findings using participant information world maps and their descriptions of them. We refer to all participants using pseudonyms.

Condensing LGBTQ+ people into monoliths

This theme illustrates discourses that conflate the experiences of *some* community members with those of *all* LGBTQ+ individuals. In some cases, participants explicitly reject this conflation onto their maps. On her map, Vada (white, gay, young cisgender woman) symbolizes a group of people accessing information via a laptop using Google (*Figure 2*). The closer the person is to the computer, the more access they experience. One "cis het" (cisgender and heterosexual) person is closer than the other LGBTQ+ people to the computer. However, Vada's map indicates that not all LGBTQ+ people in her community experience access equally. Bodies that are "white cis LGBT" (Vada's self-described identity) have more access than "POC trans" (a transgender person of color), for example.

[Insert Figure 2 here]

Identity-based distinctions such as these speak to Vada's awareness of how one's intersecting experiences of social difference – here gender, sexuality, and race – impact access to information (Crenshaw, 1991). Her map illustrates the need for both a collective LGBTQ+ identity in opposition to cisgender and heterosexual privileges, as well as distinctions to LGBTQ+ identities, such as one's race in informing how they access health information.

Other participants place themselves on the map as implicit stand-ins for their community. In his map (*Figure 3*), Charles (white gay, older cisgender man) depicts a quadrant of Earth displaying two places of significance to him – Alaska, where he lived, and his local LGBTQ+ center. Using arrows, he illustrates how his community gives and receives information "sideways" and "back and forth." A combination of geographical and spatial contexts unique to Charles informs this process. Further, the side profile depicts Charles, literalizing him as the community figurehead. Charles' map does not indicate egoism but instead denotes the difficulty of articulating the collective practices of a community he can only imagine and never truly know (Ross, 2012). The consequences of such community imaginaries become realized as discursive power when SC LGBTQ+ community leadership coalesces around a constellation of privileged, intersecting identities, such as white, cisgender, and male.

[Insert Figure 3 here]

Establishing community's normative role in information practices

This theme denotes instances where what a community collectively defines as normative information practices harm individual members. Tony (middle-aged, black, transman) exemplifies

this finding in the bottom right quadrant of his map (*Figure 4*). The circle labeled “reception of info” symbolizes how Tony’s community engages in information sharing practices like word of mouth to ensure that members receive needed information. Although Tony would like all who need health information centered on transgender identities to be welcome in this circle (signified by the peace sign labeled “all are welcome” with an arrow pointing at the circle), he discusses community gatekeepers (red transgender symbols and line with perpendicular crosses symbolizing a barrier) who keep those deemed “outsiders” at bay. Tony further indicates being at odds with this gatekeeping practice by placing himself separate from the circle, as symbolized by the purple transgender symbol. He sees himself as the “Lone Ranger,” who asks outsiders their intentions (indicated by the purple question mark), letting them into the community if they desire trans-specific health information.

[Insert Figure 4 here]

Charles’ map (*Figure 3*) provides another example of a normative community practice: “getting information sideways,” symbolized by the blue arrow going into this ear (arrow located below the ear). In the interview, Charles elaborates on this practice stating that his community will disclose the personal health information of individual members (e.g., sexual health status) if they feel others should know. To prevent “having all your business on the street,” community members will search for health information on “Google, if [they’re] smart.”

Applying metronormative discourses to information sources

Metronormativity is a theoretical construct describing the binarization of LGBTQ+ experiences into urban/rural and good/bad. Metronormativity assumes that a person cannot live a meaningful life as LGBTQ+ outside of a metropolitan area (Halberstam, 2005). Participants implicitly and explicitly mapped metronormativity discourses onto information sources by privileging those cosmopolitan in scope over those more localized.

Tony Solano (young, white, gay, cisgender, man) implicitly engages with these discourses in his map (*Figure 5*). It depicts a list of information resources organized by scope – ranging from national to interpersonal. To the left of the list are two blue squiggly lines depicting a river, which symbolizes information flowing “mostly downstream” from national health institutions to Tony Solano’s organization (blurred to protect his privacy) to his community members and, finally, to interpersonal interactions between individual community members and medical professionals. Tony Solano expresses concern with community members who engage in health information practices that do not include their organization’s input, which sources its information from national health institutions. An example can illustrate this concern regarding how community members might address a health question about the effectiveness of PrEP (pre-exposure prophylaxis) versus how Tony Solano’s organization would address it:

PrEP. Is it effective? [The community wants] to hear from people who were actually on the medication. Are they using it? Have they had side effects? How is it affecting them and their day-to-day life? Is that something that I want to openly put out to all my group members and followers or is it something that we want to say, “Hey, let’s give a little bit more time to see what’s going to happen with this.”

[Insert Figure 5 here]

Tony Solano's map can be contrasted with Pat's, an Afro-Caribbean, queer, transgender woman (*Figure 6*). In her map, Pat draws a dollar sign signifying how her community's health data are "profitable." For Pat, larger companies and organizations "exploit" her community by offering "free clinical trials" to access these data. When compared to Tony Solano's map and description, the very clinical trials that exploit Pat's community members are those likely to influence what information Tony Solano and his organization disseminate to their community (e.g., results of clinical trials by national pharmaceutical industries about the effects of health interventions like PrEP). Participants like Pat view national health institutions with increased wariness compared to those like Tony Solano, who see them as benevolent. The variance of experience and perspective likely corresponds with the privileged identity intersections of people like Tony Solano and his community leadership, centered on white, cis male identities. Paralleling the arguments made by Vada in her map (*Figure 2*), such individuals are subject to discrimination and other hardships not experienced by non-LGBTQ+ people. However, this discrimination varies based on intersecting experiences of social differences in ways that render national-level information sources most relevant and safe for those with privilege.

[Insert Figure 6 here]

Discussion

Findings from this paper nuance identify some of the instabilities and shortcomings of communities for specific individuals. We found that influential members, such as leaders and gatekeepers, adopted the imagined construct of an LGBTQ+ community and normative expectations therein. Such expectations shape community criteria for belonging in an information world, acceptable health information practices, and valuable information sources. Our analysis does not intend to critique the participants or their maps. Instead, we wanted to identify how discursive power shapes LGBTQ+ health information practices at the community level. We do not question that participants' information world maps work for some if not many, of their community members.

It is important to conclude by noting how participant maps resist identified normative discourses. Jordan (black, gay, cisgender male, in college at a Historically Black College/University) created a map that illustrates this resistance (*Figure 7*). In the interview, Jordan discusses his frustrations with his HBCU openly denying the existence of LGBTQ+ students. Jordan's map depicts a bird's eye view re-creation of his college campus, which is visibly inclusive of LGBTQ+ students. His drawing includes "dorms for students who have been kicked out of their homes for being out," a library and archive staffed with people promoting LGBTQ+ history and culture, and a rainbow archway marking his campus as a site of visible LGBTQ+ pride. Jordan's map exists in an imagined future as a way to resist a current reality where he and his LGBTQ+ community are denied acknowledgment.

[Insert Figure 7 here]

Conclusion

Based on our findings, a vital way that leaders can provide more equitable information flow in their communities is to critically consider existing arrangements of people, knowledge, practices, and sources. What meanings do these arrangements produce? Who functions as authorities within these arrangements? By understanding how discursive power functions within their communities, leaders can design paths for collective resistance that incorporate alternate subjectivities and ways of being, extending their information worlds to members who have historically been pushed to the margins. IWM can function as a pedagogical tool used by information service providers like librarians in their engagements with LGBTQ+ community leaders to elicit this information, which in turn can inform services, spaces, and collections for local LGBTQ+ communities.

Limitations of this work relate to what and how LGBTQ+ communities are represented in data collection and analysis. While generalizability is not a goal of qualitative research, there are essential community experiences and perspectives we missed from hidden communities like sex workers or those distrusting of researchers. Further, our methods implicitly assume that leaders can map their communities' health information practices. In reality, we understand that leaders are not spokespeople for their communities and that any representation of these practices would be limited. Our positionalities and their attendant privileges, namely our whiteness and elite status as academics, produced blindspots within our data analysis. Ways that we will address these limitations in future work is by conducting focus groups with SC LGBTQ+ community members and critically analyzing how our positionalities shaped our data collection and analysis through reflexive journals.

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