

Seeking Ways to Our Transgender Bodies, by Ourselves: Rationalizing Transgender-Specific Health Information Behaviors

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ABSTRACT

Transgender people have typically been pooled in studies on lesbian, gay, bisexual, transgender and queer (LGBTQ) health information behavior. We, however, argue that transgender people have unique health needs and context that differ from LGBQ people. To demonstrate our argument, we are using the transitioning process from male-to-female or female-to-male as a case study. We are using data currently being analyzed from Tumblr to demonstrate how their process of seeking health information differs from LGBQ and highlights why information science needs to better understand this population and their information needs.

KEYWORDS

health information behavior, transgender health, transitioning, social media, sexuality & information behaviors

INTRODUCTION

Scholars in information studies are beginning to conceptualize the ways in which gender and sexuality impact health information-seeking behaviors. These studies address a wide range of issues, including the affordance of safe spaces to interact with health professionals, rates of human immunodeficiency virus (HIV) and sexually transmitted infection (STI), cancer prevention and information sharing, and mental health discrepancies (Scheim et al., 2015). It is clear that gender and sexuality can influence where one will seek or avoid health information (Hawkins, 2017). Do these advancements in health information behavior scholarship on sex and gender properly represent the challenges faced by the transgender population and gender non-conforming (GNC) people? In most of this scholarship, transgender and GNC populations are integrated with lesbian, gay, bisexual and queer people, typically in a homogenous manner. The scholarship from public health (Bauer et al., 2012; Scheim et al., 2015) has demonstrated with population-based data that transgender and GNC people have unique context for health needs. One of the most prevalent topics is identifying trained healthcare professionals who understand health issues for transgender

people during the transitioning period. As the process for transitioning is not a straightforward or monolithic process, there is a need for scholarship to recognize their information needs, health information seeking behaviors, resources and health information best practices.

In this paper, we argue that health information literature needs to improve representation of the transgender and GNC population's information behaviors. We summarize an example of transgender online health information behaviors by transgender youth utilizing the photo blogging and social network site Tumblr. This study highlights some of the information behaviors of transgender youth exploring and needing health information on transitioning from male-to-female (MTF) or female-to-male (FTM). This paper is based on recent empirical health research that called for the development of transgender-specific health interventions designed to meet the unique needs of this marginalized group and questions how that will materialize. Transgender-specific and GNC social determinants of health include racism, transphobia, cultural competence and training support for healthcare professionals, and a lack of safe spaces in healthcare settings (e.g., waiting rooms with other patients) (Hawkins and Watson 2017; Veale et al., 2015). We believe that mirroring this call for lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) and gender-oriented health information behavior, researchers will discover an opportunity to develop new research trends within this health information behavior sub-discipline.

HEALTH INFORMATION-SEEKING BEHAVIORS

Health information-seeking behaviors traditionally lack a homogenous definition as they are used distinctly in multiple disciplines without interdisciplinary concern and hence bear assumed simplicity (Lambert and Loiselle, 2007). Health information seeking is in fact a complex process influenced by many factors, such as motivation and channels of information, and should not be reduced to the simple act of "looking" for information (Lambert and Loiselle, 2007; Johnson and Case, 2012). Much of the literature demonstrates that health information seeking is primarily an active process whereby people search for information based on their medical condition(s) (Case 2012; Greyson and Johnson 2016; Harris and Wathen 2011; Lambert and Loiselle 2007). However, other scholars recognize that health information seeking can be enacted in different forms based on their specific needs, such as exercise, parenting and other less important forms of

information (Johnson and Case 2012). Monitoring health literature for issues like new parenting or transitioning are ongoing and do not stop after one particular issue is resolved (McKenzie, 2006)

Multiple social determinants of health influence the information-seeking process, including the medical condition, level of education, place, internet access, age and sexuality (Harris and Wathen, 2011; Johnson and Case, 2012; Lambert and Loisselle, 2007; Greyson and Johnson, 2016; Veinot et al., 2013). Previous research has demonstrated that youth are critical when locating health information (Greyson, in press). In the case of LGBTQ youth, they are cognizant of their information source and where they can go for different types of information (Hawkins, 2017). LGBTQ youth may have online networks and social support (nurses, parents, friends or others) that they trust to provide information (Hawkins, Morris, Nguyen et al., 2017). This is in contrast to previous literature that describes youth as uncritical and passive in regard to their health information-seeking behaviors (Grey, 2005).

Another contributing factor on health information-seeking is an individual's ability to construct his or her own information channels, which is a complex process. Channels are where one goes to find information when one rarely trusts a single person or information source. For instance, having people share their opinions or experiences on a transgender or GNC health topic may result in a better understanding of the issue (Johnson & Case, 2012). For example, transgender youth may only reach out to friends and non-family adults for information, while middle-age and elderly transgender adults are less likely to seek medical care in an emergency because of the pathologization of their gender in past years (DeHaan et al., 2013; Veinot et al., 2013). If transgender youth seek health information from family, they might ask broader questions since they might not be "out" as transgender to family members (Veale et al., 2015).

Although there is a growing body of literature concerning LGBTQ population's health information seeking, there are severe limitations to the construction and framing of this work (Hawkins, 2017). The majority of the current studies are only relatable to gay, bisexual and men who have sex with men sexual health information-seeking behaviors. Despite its importance, the majority of the literature on LGBTQ health information is related to a specific health topic within a sub-population that does not properly include transgender and GNC populations. For example, transgender populations in different geographical regions negotiate specific transphobic laws and local assumptions from healthcare providers and other medical professionals that share or regulate access to health information (Doan, 2007).

THE CASE OF TRANSGENDER YOUTH ON TUMBLR

In the author's research on transgender youth use of Tumblr, Hawkins found patterns in medical knowledge exchange which indicate that informal and pseudo-anonymous online

networks are a key source of health information. Tumblr is a photo-blogging site where users follow one another and like or re-blog another's images and comments on their own curated pages. Tumblr is particularly popular with transgender youth who find the site useful to not only develop their own identities, but exchange knowledge and develop community (Fink and Miller, 2014). Using a Python script, the authors examined over two years of posts that utilized the #ftm and #mtf hashtags on Tumblr. As of this writing, the Python script examined over 700,000 discussions. As Tumblr users are usually anonymous, the photos shared usually reveal them to be teen youths. Earlier social network analysis of this data suggests that young transgender populations primarily use the site as a channel to gather and share knowledge and experiences about their transition. In a subset of six months of #ftm data, a significant key trend in their posts is to note temporal elements such as "days," "years" or "months" until or since transitioning, whether that be self-identifying as transgender populations or GNC, taking hormone therapy or surgery to complete their gender transition. A visual analysis of photos shared also highlights pre- and post-surgery or hormone experiences, such as images after surgery or congratulatory photos that mark one, two, three or six months or a year on testosterone.

Health information behaviors shape transgender experience on Tumblr as health-sharing information is a focus of the group's experience. The hashtags #testosterone ranks 8th and #topurgery ranks 16th in the number of hashtags used by FTM youth on Tumblr to mark their #ftm posts. Young transgender populations are eager to offer thoughts and feedback on their doctors, and the doctors themselves become hashtags (ex. #drgarramone, #drccrane, etc.) so that young people can critique the work of and find doctors for their own surgeries. These knowledge exchanges become a networked history of visual and textual reflections leading up to and following these gender transition surgeries. Similarly, communications studies scholar Laura Horak (2014) found that young populations use YouTube in a similar fashion in sharing and seeking health information. The LGBTQ health information behaviors discipline is only beginning to map the various and vast wealth of medical information within or across platforms. The project of querying online spaces such as social media platforms, operating systems and data itself is on-going (Keeling, 2014).

TRANSGENDER HEALTH: WHAT CAN WE LEARN FROM WHERE WE ARE

Health information behavior literature on LGBTQ people, within the last 10-15 years, has substantial growth in scholarship and topic areas for discussion. However, many of the studies that include transgender and GNC populations are combined with other sexual minority populations. These studies do not reflect the important experiences of trans-specific information needs and are primarily based in North America. This body of scholarly research could benefit from transgender population projects focused on youth or adults pre- and post-transition, differences between races and FTM

and MTF transitions (Scheim et al., 2016). As we reflect on the state of transgender and GNC populations seeking and sharing health information on Tumblr or other social media platforms, we see that these channels have a helpful role in their everyday life. These social networks provide a safe space to share and learn from others during the pre- and post-operative periods of FTM and MTF transition. At the same time, transgender health information is found at random and by word-of-mouth (or hashtag), rather than from a trusted source.

The current published literature from information studies could build on public health, media studies and other health disciplines to create a variety of opportunities for future scholarship and projects on transgender information behaviors on health or other topics. Within this community, there are high rates of enacted and anticipated stigma that significantly deter their ability to feel safe. The issue of feeling safe provides an opportunity to explore the social costs (i.e., the potential risk either enacted or anticipated) of finding information (Hawkins, 2017; Veinot et al., 2013). Additional research into the social determinants of health can be explored in the discipline like finding information (person-to-person, social networks and/or social workers) about housing, food insecurity or accessing trans-friendly health organizations (Bauer et al., 2012). An additional topic includes the cultural competencies of libraries and staff in the development of safe spaces for transgender people.

Much remains to be done to shape and support the lives of transgender individuals and their health information behaviors. Transgender populations face a variety of social determinants that can be connected to their information seeking behaviors and/or needs due to their identity. The Tumblr project is an example that demonstrates this need for focused scholarship. Producing research specific to the needs of transgender populations distinct from but related to lesbian, gay, and bisexual populations affords insights beyond social media is an important next step.

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