Discrimination in Healthcare and LGBTQ+ Information and Care-seeking Behaviors

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ABSTRACT

Members of the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, plus (LGBTQ+) community may face discrimination in healthcare, which can subsequently impact information and care-seeking patterns. A tendency to avoid or delay health care is particularly concerning for LGBTQ+ people who face both physical and mental health disparities. This paper presents a literature review of literature on healthcare discrimination, LGBTQ+ care-seeking, and associated information behaviors in order to generate a preliminary model of LGBTQ+ decision-making around care and well-being, called the *Model of the Pathways to LGBTQ+ Well-Being*. This model can be used to investigate links between information behavior and relevant health behaviors and outcomes in a marginalized population.

INTRODUCTION

Members of the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, plus (LGBTQ+) community may face discrimination in their daily lives, and specifically during their interactions with healthcare and healthcare professionals. Discriminatory interactions in healthcare can have negative impacts on LGBTQ+ people, including fear of discrimination and delays in, or avoidance of, care; this can lead to disparate health outcomes. This impact is particularly concerning given that LGBTQ+ individuals already face a variety of health and healthcare disparities. Therefore, it is important to develop greater understanding of the ways in which experienced or feared discrimination may impact information seeking around health and healthcare, and healthcare-seeking decisions. The following presents a literature review of multidisciplinary literature, and proposes a preliminary model, adapted from an existing general model from the field of medical sociology, as a theoretical framework for future research.

Health services and medical sociology research shows that care-seeking involves consciously deciding to seek care, and the means through which an individual moves from that decision to actualization by actually accessing care. Information acquisition (both conscious information seeking and incidental exposure to information; Williamson, 1998) and use can play critical roles in this decision-making process, such as deciding that one has a symptom of concern one would like to pursue in healthcare based on recommendations from one's personal network (lay referral, Sulz & Goodkin, 1994). Information can also be used in the actualization of care-seeking decisions, such as when selecting a suitable provider and scheduling an appointment. Various fields describe similar processes and concepts, such as help-seeking in psychology which describes the process of seeking assistance such as for mental health or other disabilities. However, these fields do not focus on information seeking in the same way that information science does, and the role of information is often left implicit in existing work (e.g. Cardol, et al., 2006; Schomerus & Angermeyer, 2008). Therefore, this paper synthesizes literature from these fields to propose a model which explores care-seeking, but with an explicit inclusion of the roles that information may play in this process, particularly for LGBTQ+ individuals who may have experienced and/or fear discrimination in healthcare.

Discrimination and its Consequences

Discrimination involves negative behavior towards a group or its members; this includes both judgements/decisions about group members and actions toward group members (Al Ramiah, Hewstone, Dovidio, & Penner, 2010). LGBTQ+ individuals are more likely to report experiencing discrimination in healthcare settings than their heterosexual and cisgender counterparts (Lambda Legal, 2010). This discrimination is experienced through a variety of means such as refusals to provide care due to a person's LGBTQ+ identity and making assumptions about patients (either based on negative stereotypes about LGBTQ+ communities or assumptions of cisgender/heterosexual identities) (Lambda Legal, 2010). Discrimination against LGBTQ+ individuals can also be less overt, such as providers being ill-trained to provide care relevant to the specific concerns and needs of LGBTQ+ patients, or unable to provide the most accurate, relevant information to them (Lambda Legal, 2010).

Given potential experiences and fears of discrimination, LGBTQ+ individuals may be less inclined to seek healthcare immediately upon recognizing a health need in order to avoid exposure to discrimination in healthcare settings (Turan, Rogers, Rice, Atkins, Cohen, Wilson, Adimora, et al., 2017; Jacobs, Rathouz, Karavolos, Everson-Rose, Jannsen, Kravitz, et al., 2014; Hatzenbuehler, et al., 2013). These delays in care-seeking can lead to negative health outcomes as lack of: regular preventative care (Pace & Keating, 2014), prompt "sick care" (Ho, Eisenberg, Litwin, Schaffer, & Salkeld, 1998), and routine care for chronic illnesses like HIV (Montaner, Lima, Harrigan, et al., 2014) and depression (Greden, 1993) can lead to escalation of health concerns.

This prevalence of healthcare discrimination, combined with decreased willingness to seek care is particularly concerning given the health and healthcare disparities to which LGBTQ+ individuals are already exposed. Health disparities occur when population subgroups have worse health outcomes along certain metrics as compared to the general population (Veinot, Mitchell, & Ancker, 2018). LGBTQ+ individuals face a series of health disparities as compared to their heterosexual and cisgender counterparts, including physical disparities such as increased HIV transmission, increased exposure to violence, and obesity (Struble, Lindley, Montgomer, Hardin, & Burcin, 2010).

Care Seeking and its Determinants
Even for those willing to seek care, decisions around seeking care are influenced by a variety of factors, including: perceived severity/risk of illness, illness-related stigma (Schomerus & Angermeyer, 2008; Druss & Rosenheck, 1998; Britt et al., 2008), cost, access and availability of care. All of these factors may apply to many groups and individuals, including those that are LGBTQ+ identified. However, LGBTQ+ individuals may be more likely to run into these logistical barriers given increased rates of poverty and unemployment as compared to cisgender and heterosexual counterparts (DeFilippis, 2016) and increased likelihood of experiencing stigmatized illnesses like HIV (Golub & Gamarel, 2013) and mental illness (Clement, Schauman, Graham, Maggioni, Evans-Lacko, Bezborodovs, Morgan, et al., 2014).

Information Behavior, Discrimination and Care Seeking
Information behavior is likely integral to both LGBTQ+ peoples' perceptions of the likelihood of discrimination in a given healthcare setting, and to judgements made about illness severity, stigmatization, and the availability and accessibility of care. Although information behavior research with LGBTQ people has shown resilient, community-based health information practices (Kitzie, 2021), mistrust in healthcare providers' abilities to provide relevant healthcare information (Hawkins, 2017), and possible differences in information behaviors and needs among various subgroups of the LGBTQ+ population (Hawkins & Gieseking, 2017), little work has focused on the links between information seeking, discrimination and care-seeking. Therefore, we know little about the role of information behavior in the development of these perceptions and judgments, and ultimately decisions to seek, delay or forego healthcare. Therefore, as a platform for future research, this paper synthesizes multiple literatures to propose a preliminary conceptual model of the role of information behaviors in the context of care-seeking. Given the prevalence of discrimination, and the existence of the aforementioned disparities, LGBTQ+ people provide an important population in which to examine these issues.

Proposed Model and Associated Literature
Below we propose the *Model of the Pathways to LGBTQ+ Well-being (Figure 1)*. Though many models and mechanisms of health information behavior exist, including lay information mediary behavior (i.e. Abrahamson, Fisher, Turner, Durrance, & Turner, 2008) and peer-based information exchange (i.e. Veinot, 2010; Hartzler & Pratt, 2011), these center information behavior rather than decision-making as a process, even if decision-making is ultimately connected to these information behaviors. By contrast, the proposed model places information seeking in its context so as to clarify relationships between information behavior, decision-making and healthcare and health outcomes. For the purposes of this proposed model, care-seeking (*Figure 1: 4b)* is limited to seeking care within the traditional, western biomedical system of healthcare. Alternative activities (*Figure 1: 2d-2e)*, therefore, can involve any activities undertaken related to the identified concern or health risk as an alternative to this biomedical care-seeking. This may include seeking alternative medicine or therapy, such as holistic medicine, but it may also include less defined activities such as self-evaluation and -treatment, or even simply ignoring the concern altogether.

This proposed model is built upon the Model of the Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emory, 2012) from the field of medical sociology. Scott and colleagues' general model elaborates on how an individual moves from perceiving a possible need for care (i.e., a bodily change) to actually initiating treatment (i.e, the "pathway"). Features of Scott and colleagues' model which were kept in the proposed model of LGBTQ+ well-being (*Figure 1)* include the overall layout of the model as well as any non-bolded text. The components of the model that we have added based on additional literature include row 1 (information behaviors) as well as 2c-2e (provider selection and alternative activities), 2g (persisting with care), 3b (searching for providers), and 5c (Concern factors). Scott and colleagues' model is not without limitations, such as its dependence on bodily/somatic changes as a starting point, limiting applicability to preventative and well-being related care (e.g., HIV prevention or

gender-affirming care),Despite these limitations, the pathways to treatment model has some key strengths which may make it a useful tool for exploring care-seeking decisions, though with some modifications to tailor it to the specific needs and experiences of LGBTQ+ individuals and to emphasize the role of information behavior in the decision-making process as outlined above.
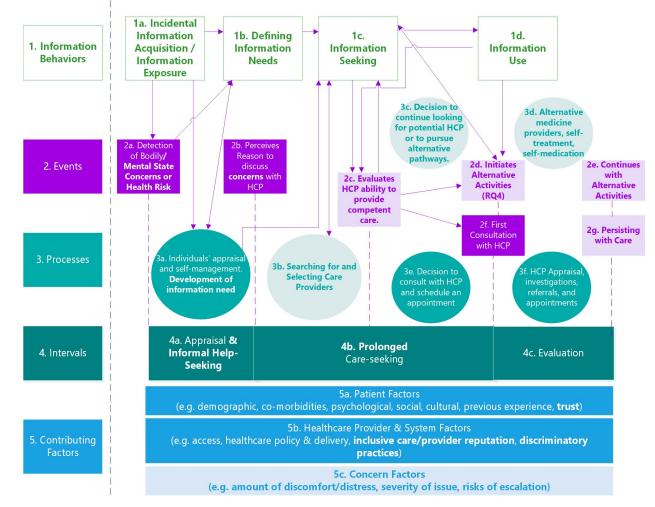

Figure 1. Proposed Model of the Pathways to LGBTQ+ Well-Being

As depicted in 1a-1d, individuals are likely to be exposed to, to seek, and to use information on the pathway to treatment. In the appraisal phase, for instance, the detection and appraisal of a bodily change (Scott, et al., 2014) can be understood as the development of an information need (i.e., "a recognition that your knowledge is inadequate to satisfy a goal that you have"; Case & Given, 2016) (*Figure 1: 1a-1b)*. This may be developed by the individual alone or through information exposure and/or seeking through social networks, such as via lay referral networks (i.e., networks of personal influences such as friends, neighbors, and relatives; Suls & Goodkin, 1994) or peer networks (networks with whom an individual shares a common identity, activity, or interest). Peer-based information exchanges (e.g. Veinot, 2010) may be particularly valuable to LGBTQ+ individuals as other people who share this identity are more likely to understand the health care needs and concerns of fellow LGBTQ+ individuals (such as fears of discrimination) as compared to general networks (Civan, McDonald, Unruh, & Pratt, 2009), and hold given experiential knowledge about care-seeking (a combination of practical strategies and personal stories based on lived experience; Veinot, 2010). Additionally, socialization with peers, even before an individual recognizes a health concern or need, can expose LGBTQ+ individuals to incidentally acquired information (i.e., information discovered by accident, without intent; Williamson, 1998) about the health needs and concerns of the group at large, information which they can then appraise for its relevance to their own personal situation via social comparison (Ziebland & Wyke, 2012). Other ways in which an individual may become exposed to incidental information (*Figure 1: 1a)* about potential, non-symptom related health concerns could be through public health campaigns or marketing efforts by community organizations, such as LGBTQ+ specific non-profits or HIV service organizations.

Later phases of the process, such as after a need for care or treatment is identified (*Figure 1: 2b)*, can also include informational behaviors such as active information seeking (i.e., seeking information with conscious intent; Case & Given, 2014) (*Figure 1: 1c)*. This seeking can again be done individually, such as by searching online, or collectively through peer and/or lay referral networks, and in connection with local service organizations. Lay information mediaries, lay people who seek information on behalf of other individuals, given some understanding of those individuals information needs (Abrahamson & Fischer, 2007) may also be sources of lay referral. This may be especially true in the later stages of the process, after an individual has already developed an informational need through other mechanisms (*Figure 1: 1b, 3a)*, especially considering that lay information mediaries must actively seek information prior to sharing (e.g. Abrahamson & Fischer, 2007). For instance, if an LGBTQ+ individual has decided that they may be at risk for HIV, they may have conversations with a person in their network who decides to seek further information about HIV prevention. After this information seeking process, the lay information mediary would return to the individual with the information need in order to share the information that was found. This information can then be used in order to decide whether or not to move forward with care-seeking in this area.

As stated, peer networks may be particularly valuable for LGBTQ+ individuals in the process of information acquisition (*Figure 1: 1a-1c)*. However, such peer networks may not be easily accessed for all LGBTQ+ individuals given the relatively small population of LGBTQ+ individuals overall (Gallup, 2018) and even smaller numbers for each particular subgroup. Rural areas, for instance, with their smaller, more geographically dispersed populations will not always have easily accessible local peer groups, especially those areas which are particularly conservative and stigmatizing of LGBTQ+ identities. Online peer groups can bridge some gaps for those who may be less able to find local peer groups, particularly around types of care, therapy, and treatment that have worked well for others in one's peer groups, but these online peer groups are limited in their ability to provide specific practical information for care-seeking in a particular locality such as providing suggestions of inclusive providers (*Figure 1: 2c, 3b)*. Local community organizations can meet many of these needs, such as helping individuals to connect to local peers through social events and providing lists of inclusive healthcare providers (e.g., Affirmations, 2020) as well as assistance with navigating care in a specific geographic area (e.g., Unified, 2020) (*Figure 1: 2c, 3b)*. Again, however, these organizations may not be available in all geographic areas.

CONCLUSION AND NEXT STEPS

This paper presents a literature review of literature looking at the possible care-seeking practices of LGBTQ+ individuals given their increased exposure to discrimination in healthcare settings. In addition, this paper includes a preliminary model for LGBTQ+ well-being, incorporating perspectives and concepts primarily from research in the areas of medical sociology, health services, psychology, and information science. This proposed model utilizes these existing empirical and theoretical works to elaborate on care-seeking as a decision-making process, influenced heavily by information behaviors as well as other psychosocial factors, in order to better understand how members of this population make complex decisions around care-seeking in light of potential discrimination. This model, however, is preliminary, and requires empirical validation. We will conduct future mixed methods research, including initial surveys and interviews of diverse LGBTQ+ individuals regarding their discrimination concerns, and information and care-seeking behaviors in order to test and improve this model.

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