LGBTQ Young Adults Online Health Information Behavior

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Abstract

The purpose of this paper is to propose a three-month online study that is an open-ended qualitative questionnaire to gather feedback and behavioral patterns about the online health information seeking, use, and needs behaviors of lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) young adults. The participants will be non-heterosexual leaning young adults ages 18 to 35 years old from all races and ethnicities within the United States. The impact of this study will help create an awareness and better understanding of the degrees to which this population is marginalized within the health care institution and will highlight the motivations of these young adults into why they prefer to seek online health information instead of going to their offline healthcare provider. From this study, scholars, health care professionals, governments, and members of the LGBTQ community will gain a better understanding to the motives and reasons behind the LGBTQ young adult’s Internet health‐related uses and learn of the current barriers they face when seeking medical care both offline and online.

* Literature Review
* Research Questions:
  + RQ 1: What online sources do they use to seek health information?
  + RQ 2: What types of health issues do they research online?
  + RQ 3: Do they visit these sites before or after they go to their doctor?
* Proposed Study
* Proposed Impact

*Keywords:* LGBTQ, non-heterosexual, lesbian, gay, bisexual, transgender, queer, questioning, health, health care, online, medical, information behavior, IB

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When author Geoffrey Ream (2019) set up to do a study on the circumstances surrounding teen suicides by sexuality and gender, he was surprised to find that one in four teens were lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) youth and that they were more likely than their heterosexual peers to die from suicide. Ream's study found that the leading factor that attributed to these deaths was the stress of coming out. To understand the LGBTQ young adult population’s health care information-seeking and needs behavior, we first need to address their current state of being within society.

In past studies, researchers have estimated that 3.4% of adults (ages 18 and older in the U.S.) identified as LGBTQ (Gates, 2010). Winter (2012) suggests that with more and more people coming out as LGBTQ, the population has grown and is underserved in many ways throughout the United States. The non-heterosexual community represents all ages, races, ethnicities, and socioeconomic statuses (Ward, Dahlhamer, Galinsky, & Joestl, 2014). However, in the U.S., the health care system is still adversely affecting these individuals by marginalization (Bjorkman & Malterud, 2009). Approximately 30% of LGBTQ individuals do not seek health care services or have a regular medical provider (Winter, 2012).

Unlike their heterosexual peers, LGBTQ young adults have a complicated process when seeking information (Cass, 1979; Troiden, 1988). Parents play a critical role in the development of the sexual health among heterosexual youth and may become silent and unwilling to acknowledge the sexual orientation of their LGBTQ children (Miller, Benson, & Galbraith, 2001). According to Troiden (1988), these individuals face a distinct path, and consciously have to navigate as they inform others about their sexual identity. In his book “Gay and lesbian identity: A sociological analysis” (1988), Troiden defines a set of stages that the non-heterosexual young adult goes through before coming to terms with his or her sexuality, and these stages are the sensitization stage, assumption stage, and the commitment stage. Troiden (1988) observed that during any one of these stages, an LGBTQ young adult is likely to seek out information to learn more about their sexual identity.

One issue that plays a role within the LGBTQ young adult community is the process of acquiring information about their sexual identity, and that is due to the fact that there are not enough positive role models for non-heterosexual young adults to look up to as mentors and therefore their learned experiences and opportunities are limited (Brown, 2002). As an example, Mustanski, Lyons, and Garcia’s (2011) study reported a few participants who suggested that they use gay pornography to serve as a significant role model in their sexual identity development. Fox and Ralston (2016) acknowledge the limitations of traditional media and informational sources and suggest that the Internet is an excellent source for such diverse experiences of an LGBTQ-identified individual due to its accessibility. According to Craig and McInroy (2014), non-heterosexuals do not always have access to information that applies to their sexual identity the way their heterosexual counterparts do, such as information that is available through interpersonal sources or media which may be limited to the non-heterosexual youth (e.g., library books). They believe the amount of data on the web, and the ability to access it anonymously is invaluable for the LGBTQ youth (Craig & McInroy, 2014).

# **Literature Review**

The major concepts and themes that emerge from the current research literature on LGBTQ young adults online information seeking, needs, and behavior highlights how non-heterosexual individuals explore the Internet, health sites, social media, and particularly social networking sites, to serve as informal learning environments during the formative stages of their evolving LGBTQ identity (Fox & Ralston, 2016). This is due to offline youth information behavior literature that does not accurately relate to most LGBTQ youth’s needs (Hawkins, 2017).

**The Need to Be Anonymous**

There are not many places where a non-heterosexual youth can go in their daily life to learn about their sexual identity or sexual gender. Mehra and Braquet (2006) highlight the role that libraries play in the coming‐out process of LGBTQ young adults. The authors describe libraries as having the potential for being safe spaces with the necessary information for non-heterosexual youth during the coming‐out experience (Mehra & Braquet, 2006). Fox and Ralston (2016) point out that in the United States there is a growing acceptance of the LGBTQ community but suggest that the process of identification and socialization for these individuals can be challenging and filled with uncertainty. Unlike their heterosexual peers, LGBTQ young adults have to deal with negative family stigmas (Parker, Hirsch, Philbin, & Parker, 2018), a homophobic culture that promotes bullying and victimization (Proulx, Coulter, Egan, Matthews, & Mair, 2018), lack of acceptance from their religious institutions (Dahl & Galliher, 2012), and laws and criminal liability that deal with their sexual identity (Dentato, 2018).

In Danah Boyd's book “It's Complicated” (2014), the author discusses how LGBTQ young adults use secondary identities online when seeking information about their sexuality or for when interacting with other individuals in virtual communities. She suggests that this behavior is a result of the negative stigmas that many in the LGBTQ community face due to their sexual orientation and gender (Boyd, 2014). Troiden (1988) observed that for LGBTQ young adults the need to be anonymous in their sexuality forces them to behave differently than heterosexual youths when seeking information about who they are, how they should behave, and how to deal with issues concerning their sexual identity. While many young adults face obstacles to the successful development of sexual health, LGBTQ youth face particular challenges due to lack of support in the settings that traditionally promote positive youth development (Mustanski, Lyons, & Garcia, 2011).

**Seeking Health Care Online**

LGBTQ young adults are more likely than heterosexual youth to report that they looked for health information online because they did not have anyone to ask (Mitchell, Ybarra, Korchmaros, & Kosciw, 2013).

While the Affordable Care Act was introduced in 2010 to ban preexisting conditions and included an option for same-sex partner coverage, LGBTQ young adults still continue to experience difficult barriers to health care access (The White House, 2013). Lesbian, gay, bisexual, transgender, and queer/questioning populations face multiple obstacles that make it challenging to get health care (Greene, France, Kreider, Wolfe-Roubatis, Chen, Wu, & Yehia, 2018). These non-heterosexual young adults may experience interpersonal and structural stigmas within the standard health care environment (Hadland, 2016). DeHaan (2013) believes that using the Internet, as a means to find health care resources is so crucial to non-heterosexual young adults because it provides unprecedented access to information.

The access to sexual health information online is vital for the minority sexual LGBTQ young adults because they are less likely to receive this information offline from standard institutional programs like school-based sexual health education (DeHaan, 2013). In their article “Young sexual minority women’s use of the internet and other digital technologies for sexual health information seeking” (2017), authors Flanders, Pragg, and Logie conducted a study on abused non-heterosexual young minority women's use of the Internet for seeking sexual health information. The purpose of their research was to understand two things: what online and digital technologies were these women using; and why did they use these resources. The results of their findings list the participant’s three central motivations as safety, easy access, and lack of offline resources (Flanders, Pragg, & Logie, 2017).

According to Hawkins and Watson (2017), there are some downsides to LGBTQ young adults going online to seek health information. The authors fear that LGBTQ young adults might use online forums to build social networks where they have un-moderated health discussions on different health topics (e.g., dieting, relationships, and mental or sexual health) and urge that the potential for unsubstantiated, and inaccurate information is a cause for concern, and they fear it may result in unhealthy outcomes (Hawkins & Watson, 2017).

Mustanski, Lyons, and Garcia (2011) created a study intended to show whether the effects of seeking online health information positively or negatively affected the sexual health of the user. Their mixed-method survey reflected both qualitative and quantitative analysis to explore Internet-related behaviors among young men who have sex with other men (MSM). The quantitative results of their research were used to estimate predictors and frequency, and the qualitative results were used to explore meanings and subjective understandings. They focused on three areas of interest HIV/STI knowledge, sexual self-acceptance, and sexual risk behaviors. In referencing their quantitative findings, Mustanski, Lyons, and Garcia (2011) pointed out that the MSM participants who tested HIV negative demonstrated high levels of Internet use and went online several times a week seeking health information. And while the qualitative results mirrored the same high levels of Internet activity, it also provided reasons for the patterns of behavior. The study’s qualitative results suggested that the MSM participants used the Internet to search for facts about HIV, STIs, local testing centers, pricing on affordable care, risk reduction techniques, and information on how to self-diagnose their symptoms (Mustanski, Lyons, & Garcia, 2011).

# **Research Questions**

In previous studies, research questions asked LGBTQ participants how they found the health care information and what was the quality of the information (Hawkins, 2017). Little is known about the non-heterosexual young adult’s health information-seeking behavior on the web such as how did they found out about the resource (e.g., did they learn about it from a friend, social media, or a social networking site), and which websites were their trusted favorites (Mehar & Braquet, 2006). According to Siegel and Raveis (1997), most scholars have done targeted studies that focused on adult gay men, bisexuals, and men who have sex with men (MSM) to learn more about sexually transmitted diseases or HIV literacy.

**Partially Answered Questions**

* What are their favorite health sites to visit?
* Why do they perceive these sites to be credible or valuable?

Past research that applies to answer either of these two questions has had to do with the participants being non-heterosexual adults for the most part or a specific subset of the LGBTQ population and usually focused on a particular condition of health (Siegel & Raveis, 1997).

In researching for their study, Mustanski, Lyons, and Garcia (2011) emphasized that prior health information research focused exclusively on whether meeting sexual partners online was linked to HIV/STI risk. They point out that while young MSM experience sexual health disparities due to a lack of support from traditionally settings that would normally promote a positive environment for youth development and suggest that the Internet may help in filling this void, but they reported that there little is known about its use for sexual health purposes.

**LGBTQ Young Adult’s Unanswered Questions**

**R1:** What online sources do LGBTQ young adults use to seek health information?

* What are their favorite health sites to visit?
* Why do they perceive these sites to be credible or valuable?
* How did they become aware of these online resources?
* What is the frequency to which they utilize these websites?

**R2:** What kinds of health issues do LGBTQ young adults research online?

* What types of health care information do they seek?
* Are their searches based on basic health care needs or more advanced illnesses?
* Are these illnesses specific to LGBTQ related conditions?

**R3:** Do they visit these sites before or after they go to their doctor or both?

* Does the information they learn affect how they seek medical care offline?

# **Proposed Study**

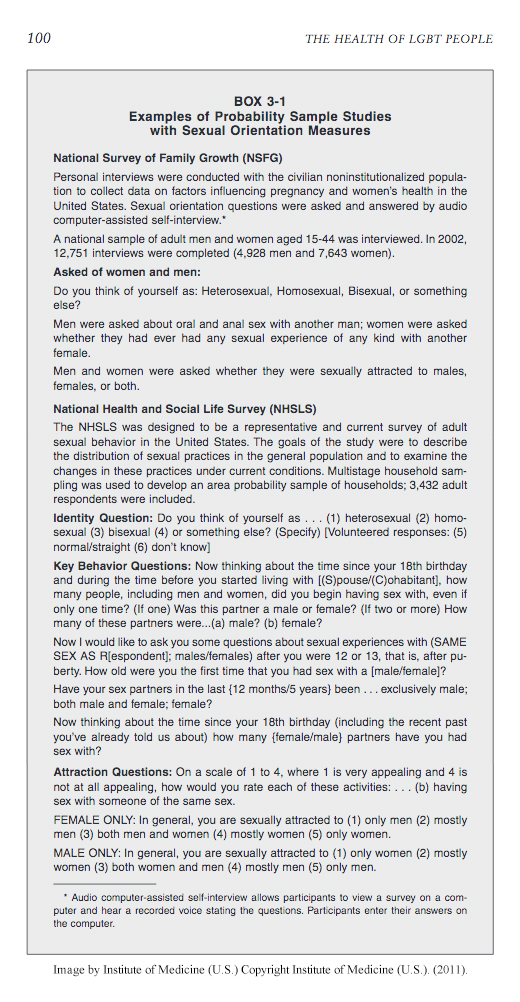
**Methodology**

To maximize the data collection response rate of the LGBTQ young adult’s online health-seeking information behavior, a web-based survey of ten questions will be structured based on the concepts formulated in the report “The Health Of Lesbian, Gay, Bisexual, and Transgender People: Building A Foundation for Better Understanding” by the Institute of Medicine (2011). The questions will be constructed to allow the participants to critically consider how they seek health information and the characteristics of the places they visit. This will be a three-month study of open-ended qualitative questions regarding the LGBTQ young adult's use of online Internet-based searches regarding everyday health topics that deal with their personal health and medical concerns. Once they complete the study, they will be given the option to answer additional questions that deal with their overall offline experiences with health care providers and facilities, affordability of care, recent experiences related to hospitalization, and a section on the website to provide comments on areas in need of improvement.

**The Institute of Medicine**

In 2010, the National Institute of Health (NIH) convened a committee to assess the state of knowledge about the health of LGBTQ population in the United States and asked the Institute of Medicine (IOM) to formulate a research agenda (Institute of Medicine, 2011). IOM compiled and organized all of NIH’s collected data on non-heterosexual individuals into a comprehensive report that detailed every aspect of the LGBTQ population and created an awareness about the health of these individuals and highlighted the challenges inherent in conducting research on the health needs and risks of the LGBTQ community. When formulating the report, IOM took into consideration all of the groups and subgroups within the LGBTQ population, because each subpopulation has its own unique health needs (Institute of Medicine, 2011).

The benefit of using the Institute of Medicine’s (2011) report to guide the study is its suggested research method questionnaire procedures. IOM divides the LGBTQ population into three categories childhood, middle adulthood, and adulthood and in each of these stages they list issues concerning sexual orientations, sexual habits, history, mental health issues, illnesses, health care needs, perspectives, barriers, as well as other areas of concern regarding the LGBTQ community (Institute of Medicine, 2011). The IOM points out the sensitivity to which members of the LGBTQ population fear when answering or participating in these surveys (Institute of Medicine, 2011). Diagram BOX 3-1 is an example of how IOM formulates research questions:

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**Participants**

The proposed study will invite non-heterosexual leaning young adult participants from various schools, colleges, LGBTQ young adult groups and organizations, LGBTQ young adult social media pages, and LGBTQ young adult social networking sites across the United States that are from ages 18 to 35 years old to participate. All genders, races, and ethnicity types will be included in the study. Participants will be asked to fill out the online questionnaire and to describe in full detail the steps they take when searching online for health care information.

**Proposed Study Questions:**

1. Do you think of yourself as?
   1. Heterosexual
   2. Lesbian
   3. Gay
   4. Bisexual
   5. Queer/questioning
   6. Don’t know
2. How do you seek health information online?
3. What health care websites do you visit?
4. How did you learn of these websites?
5. Why do you perceive these sites to be trustworthy or credible?
6. What types of health issues do you search for online (e.g., treatment, medication, surgery, mental or sexual health)?
7. How often do you utilize these health websites?
8. Do you seek health information on basic or advanced conditions or both?
9. Do you visit these sites before or after you go to the doctor or both?
10. Does this information affect how you seek offline care?

**Proposed Analysis**

Glaser and Strauss's (1967) grounded theory will be implemented to promote an openness to the actual data analysis allowing the participant's responses to guide the study's results. The qualitative responses from the open-ended survey will be reviewed by coders, hand-coded, and re-grouped into specific categories based on the content of the original questions. The questionnaire results will then be fed into qualitative analysis software, and codes will be generated, analyzed, refined, and augmented using the constant comparison method (Taylor & Bogdan, 1998). Once that is completed, content analysis software will highlight emerging themes and patterns that trend from participants who reported similar answers.

**Ethics**

The study will adhere to the use of professionally accepted best practices that ensure scientific rigor in the design, conduct, and analysis of the sample surveys, and will utilize the guidelines of the American Association for Public Opinion Research (2019), an association of survey methodologists, statisticians, and social science researchers that has identified best practices for its members to follow. The study’s methods will follow the general rules of ethical guidelines to do no harm to the participant, do not deceive the participant, all collected data will be confidential, and to promise to protect the participant’s online privacy.

# **Proposed Impact**

The impact of this proposed study will highlight areas of understandings, needs, and processes that the LGBTQ young adults go through and will establish insight as to how we can provide an avenue where these non-heterosexual individuals feel safe and open in their health care information-seeking journey as they transition into well-adjusted adults. The collected data will show trends in what types of searches that are being performed (e.g., illnesses, medications, surgical procedures, mental illnesses, suicide prevention, clinical care, and other health topics) and areas where health care institutions and providers can improve upon.

The Institute of Medicine (2011) highlighted the importance of doing these research studies because as LGBTQ young adults become a more visible population, health information studies will contribute to the understanding of how, what, and why they find information relevant and useful, which will determine how as a society we facilitate their needs. More importantly, this study can benefit local communities as well as the government by providing important health care information and data on how best to serve these young individuals. Having access to LGBTQ young adult’s health information behavior knowledge is extremely important for both practical and contextual reasons, as their lived experiences differ significantly from that of the heterosexual youth (Institute of Medicine, 2011).

**Conclusion**

And while more and more Americans are using their phones, tablets, and computers to learn about all aspects of their life, evidence-based medicine, health care apps, and health care database sites are popping up all over the web bringing quality health and mental care to patients 24/7, seven days a week, no matter what their sexual orientation is. In concluding this proposed study, the negative stigmas, bullying, and other troublesome elements that exist in the LGBTQ young adults offline experiences also take place online, however the role of the Internet presents an optimistic venue for the development of LGBTQ young adults as they learn about who they are, seek out health information, and facilitate their sexual identity development.

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