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REPRESENTATION MATTERS: AN EXAMINATION IN TO HOW THE PATIENT EXPERIENCE IS IMPACTED BY THE INCLUSION OF SEXUAL ORIENTATION AND GENDER IDENTITY QUESTIONS ON A HEALTH HISTORY INTAKE FORM

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AN EXAMINATION IN TO HOW THE PATIENT EXPERIENCE IS IMPACTED BY
THE INCLUSION OF SEXUAL ORIENTATION AND GENDER IDENTITY
QUESTIONS ON A HEALTH HISTORY INTAKE FORM

By

Meghan Nicole Digneit

DNP PROJECT

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REPRESENTATION MATTERS:

AN EXAMINATION IN TO HOW THE PATIENT EXPERIENCE IS IMPACTED BY
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QUESTIONS ON A HEALTH HISTORY INTAKE FORM

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ABSTRACT

REPRESENTATION MATTERS:

AN EXAMINATION INTO HOW THE PATIENT EXPERIENCE IS IMPACTED BY THE INCLUSION OF SEXUAL ORIENTATION AND GENDER IDENTITY QUESTIONS ON A HEALTH HISTORY INTAKE FORM

By

Meghan Nicole Digneit

The disclosure of one's sexual orientation and gender identity (SOGI) status is an extremely personal decision subject to a variety of internal and external factors. The disclosure of this status in the healthcare setting is an important topic that continues to be subject to discussion, research, education, and mutual understanding between the patient and provider. The purpose of this DNP project is to explore how answering SOGI questions on a general intake form impacts patient attitudes regarding the impending visit. This was a mixed-methods research study that included demographic questions, nominal data in the form of yes/no questions, and two questions that allowed for qualitative answers. Data was collected with the Qualtrics survey system. Over 60% of participants indicated favorable experiences of answering these types of questions before their healthcare visit, 50% of individuals surveyed typically disclosed their SOGI status during visits, and over 70% of participants preferred an intake form as the method of disclosure. This DNP project aims to contribute to the conversation regarding inclusive language in the health care setting and serves as a stepping off point for practitioners and patients to begin to normalize these delicate and sensitive conversations.

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MEGHAN NICOLE DIGNEIT

January 2022

DEDICATION

This DNP project is dedicated to my husband, William Digneit, my two sons Hawkins and Houston, and my parents Mike and Laurie Hawkins.

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Chapter 1

Introduction

For those struggling with sexual orientation or gender identity, the choice to disclose or not to disclose their status can be fraught with a mixture of very strong emotions. The choice to either keep private or to disclose one's lesbian, gay, bisexual, transgender, queer, questioning, intersex, nonbinary, something else (LGBTQ+) status holds a host of ramifications for both the patient and the provider. Those identifying in any of the LGBTQ+ categories (including subgroups of agender, gender diverse, gender queer, non-binary individuals, and others) have specific health needs that should be properly addressed by medical personnel. Unfortunately, beliefs held by both patients and providers can limit the level of disclosure provided by the patient, and potentially place that patient at risk by not being thoroughly assessed by their provider. Efforts to normalize sexual orientation and gender identity (SOGI) status discussions in the healthcare setting have been made by major organizations such as the Centers for Disease Control and Prevention (CDC), The National Academy of Medicine (NAM, formerly the Institute of Medicine), The Fenway Institute, the International Lesbian, Gay, Bisexual, Trans, and Intersex Association (ILGA), The Joint Commission (TJC), and others in recent years. However, these conversations are not always commonplace and, as will be discussed shortly, SOGI status is an often overlooked topic during the health visit.

There can be a general hesitancy to openly discuss SOGI status in the healthcare system which leads to a general lack of data reporting for LGBTQ+ individuals. Despite the use of national surveys like the Behavioral Risk Factor Surveillance Survey (BRFSS), National Health and Nutrition Examination Survey (NHANES), the Youth Risk Behavior

Survey (YRBS) and others, information regarding the LGBTQ+ population remains unreported and underutilized. Even though the State of Michigan has been asking individuals to disclose their SOGI status on the Michigan Behavioral Risk Factor Surveillance Survey (MiBRFSS) since 2011, this information has yet to be included in an annual report. Without accurate collection and reporting, there is no data to help develop a profile for the population, which means there are no delineation of needs and no resources allocated to this population for health improvement. The Healthy People 2020 (n.d.) initiative summarizes the unique needs of the LGBTQ+ population as a result of a series of “societal stigma, discrimination, and denial of civil and human rights” which disproportionately predisposes these individuals to issues of psychiatric disorders, substance abuse, homelessness, among others (para 3). Healthy People 2010 (n.d.) highlighted the need for more information to “document, understand, and address the environmental factors that contribute to health disparities in the LGBT community” which is something that we are still striving for well over ten years later (para. 4).

Background and Significance

Issues regarding SOGI disclosure for LGBTQ+ patients involve patient comfort and understanding, provider knowledge, practice, and attitude (Kitts, 2010). Interestingly, research shows that one of the biggest reasons that patients do not disclose their sexual orientation is because they are not directly asked about it by their medical provider (Kitts, 2010; Rossman et al., 2017). Depending upon the medical setting, this lack of direct questioning can arise from provider discomfort or an attitude that sexual orientation does not apply to the medical issue at hand. However, the link between sexual orientation, sexual health, and mental illness is very intricately woven and if left

unaddressed can have drastic effects on the rest of the body (Manzer et al., 2018). Rossman, Salamanca, and Macapagal (2017) note that the NAM and the World Professional Association for Transgender Health (WPATH) recommend “inclusion of LGBTQ identities into paperwork and electronic records” (p. 1403). Including basic questions about sexual orientation, preferred gender pronouns, and identifying gender gives the patient the freedom to list their information without having to verbally disclose this information multiple times to multiple people. Research has shown that patients are more likely to disclose their sexual orientation to medical providers if they are simply asked (Kitts, 2010). It is also important to include a question about birth sex as the biological sex can have important implications in the plan of care. Biological males and females require different preventive care plans in terms of disease screening (i.e. mammograms, PSA tests, etc.). As the WPATH outlines, most of the screening guidelines established by different colleges and professional organizations address body systems that are not affected by hormone therapy. However, “in areas such as cardiovascular risk factors, osteoporosis, and some cancers (breast, cervical, ovarian, uterine, and prostate), such general guidelines may either over- or underestimate the cost-effectiveness of screening individuals who are receiving hormone therapy” (WPATH, n.d., p. 65-66). Therefore, specially tailored preventive care regimens, as well as open and safe SOGI disclosure, are necessary to take appropriate care of these patients.

Additionally, some patients and providers alike do not believe that sexual orientation has anything to do with the chief complaint. Patients may feel that their sexual orientation is private, not related to their health concern, and may fear the response of the provider if they disclose their sexual orientation or gender identity (Rossman et al.,

2017, p. 1392). Patient reasons for not disclosing their status to the provider vary from fear of response, general distrust or dislike of the provider to a sense of fear of the response. Rossman et al. (2017) continues to say that patients are also afraid of being labeled and stigmatized, especially if they themselves are continuing to struggle with their identity. If patients are not sure how to label themselves, they certainly do not want a label forced upon them by the medical community.

Purpose of Project

The purpose of this DNP project is to explore how answering SOGI questions on a general intake form impacts patient attitudes regarding the impending visit. Peripheral benefits to including this type of information on general intake paperwork are multifold: to contribute to the overall data collection of those individuals identifying as LGBTQ+, increase inclusivity, sensitivity of office staff and medical providers, improve individualized care, and most perhaps importantly to normalize discussions regarding SOGI status among patients with their medical providers (CDC, 2020; Healthy People 2020; Kitts, 2010; Mulé et al., 2009; Schmidt, 2010). The research question guiding this project is: *How does answering sexual orientation and gender identity (SOGI) questions on a pre-visit form impact the patient experience in a Midwestern, rural university healthcare setting across different sexual orientation and gender identities?* The overall goal is that all patients can find comfort in disclosing their SOGI status on intake paperwork and avoid feeling unfairly “outed” during face-to-face interactions with their provider or with front office staff. Essentially, asking all patients about their SOGI status allows the healthcare staff to treat individuals with dignity and respect.

Methods

This study was conducted using a post-intervention survey among patients who visited a student health center during the traditional school year in winter semester of 2020 and fall semester of 2020. The general health history intake forms for the health center were modified in the fall semester of 2019 to include SOGI status in the demographic section as an aid for health care staff to be aware of preferred names and genders to be updated in the patient's electronic health record (EHR). This project utilized non-probability convenience sampling (using all eligible students who visited the health center during the specific time frame, those 18 years and older) and consecutive (over two academic semesters) styles. Students visiting the health center during this time frame were emailed a post-visit survey asking about their perceptions of answering SOGI questions before seeing the provider. The survey design maintained all Health Insurance Portability and Privacy Act (HIPAA) and anonymity laws with only age, sex assigned at birth, and SOGI status as the identifying markers. The questions have a variety of pre-set answers to choose from and a few spaces for participants to write in additional information if desired. Thematic analysis was performed for answers written in on specific questions. IRB approval was obtained through Northern Michigan University.

Theoretical Framework

The first step in normalizing conversations regarding SOGI status in the healthcare setting is to stop assuming that every patient is a cisgender heterosexual individual. First, we must *queer* our personal practice to include space for those who do not fit *our norm*. Teresa de Lauretis coined the term *queer theory* in a conference speech in 1990 when she decried that the field of LGBTQ+ studies needed to shift the focus from

the “heteronormative underpinnings of theory and research” and instead “queer” the norm by exploring other viewpoints and identities (Schmidt, 2010, p. 317). During this time, de Lauretis was working on guest editing an issue of *d i f f e r e n c e s : A Journal of Feminist Cultural Studies* and was writing the introduction called “Queer Theory: Lesbian and Gay Studies: An Introduction.” In this introduction de Lauretis (1991) writes:

The conference was based on the speculative premise that homosexuality is no longer to be seen simply as marginal with regard to a dominant, stable form of sexuality (heterosexuality) against which it would be defined either by opposition or by homology. . . . Instead, male and female homosexualities—in their current sexual-political articulations of gay and lesbian sexualities in North America—may be reconceptualized as social and cultural forms in their own right, albeit emergent ones and thus still fuzzily defined, undercoded, or discursively dependent on more established forms. (p. iii)

From this notion of “queering the norm,” the politics of identity and how people categorize themselves as gay, lesbian, male, female, transgender, heterosexual, homosexual, bisexual, pansexual, nonbinary, etc. comprise the very basic core of queer theory. In addition, queer theory examines how the categories of LGBTQ+ came to be and how these individuals identify and are identified (Schmidt, 2010). Queer theorists argue that the act of labeling individuals as gay/straight, male/female does more than categorize people, they place regulations on behavior and identity in ways that laws and religion have controlled behavior in the past. By labelling individuals based on a certain characteristic, we create norms regarding those behaviors and we begin to associate

correct behavior by what is normal and *incorrect behavior* by what is abnormal. As Schmidt (2010) explains, the term heterosexual is not just a label, but is a way of categorizing people based upon a pre-conceived set of expectations and behaviors that determine *normal* characteristics from *other* characteristics and we learn about *homosexuality* by the negative in terms of what it is not. When behavior is continuously biased against the LGBTQ+ community this is known to as *heteronormativity* or *cisnormativity*, which contributes to a worldview that privileges this identity (Knutson et al., 2019).

Knutson et al. (2019) provides a basic primer of LGBTQ+ specific terminology by introducing terms such as *non-binary*, *genderqueer*, *gender variant*, *gender fluid*, *gender expansive*, among others, which are sometimes adopted by individuals as a way to self-identify without using binary terms of male/female. Most importantly, these terms allow the individual to identify themselves in terms of what they are (i.e. gender fluid) instead of terms they are not (i.e. male or female). Accepted heteronormativity is problematic because it leads to policies and procedures that end up reinforcing heterosexuality as the norm by the mere act of ignoring other sexualities (and identities for that matter) (Schmidt, 2010). Jagose (1996) offers that the term *queer* describes the behaviors that create inconsistencies with contemporary traditional associations between biological/chromosomal sex, gender, and sexual desire. The word queer has also become an inclusive term to include analytical framework for other behaviors such as cross-dressing, gender ambiguity, gender-corrective surgery, and intersex individuals (Jagose, 1996). It is important to note here that some of the terms used by Jagose in 1996 are no longer considered appropriate or acceptable. A discussion regarding the evolution of

terminology and language will be found later in this paper. Flexibility and sensitivity regarding the evolution of terminology and language is critical to have open discussions regarding SOGI status in medicine.

Chapter 2

Introduction

Concern regarding specific health needs of the LGBTQ+ community is relatively new in terms of healthcare. As Cochran and Mays (2017) describe, collecting SOGI data on the general population was not considered necessary until the beginning of the 21st century when there was a push for health surveillance in terms of sexual risk factors. Researchers began to identify major differences in the health needs of men and women in regards to sexual orientation (Cochran & Mays, 2017, p. 497). Additionally, focus has often been placed on the health risks of gay men as opposed to the LGBTQ+ community as a whole. Obviously, the lived experiences of gay men differ greatly from the lived experiences of lesbian women, whose lived experiences differ greatly from those who identify as bisexual, whose lived experiences differ greatly from those who are transgender, and so on (Cochran & Mays, 2017). It is not enough to collect data on the LGBTQ+ population, but care must be taken to individualize health recommendations for the various groups that comprise this community. For example, lesbian women are twice as likely to smoke as heterosexual women, while this disparity does not exist between straight and gay men (Cochran & Mays, 2017). Additionally, those who are transgender have a very unique set of health concerns that go far beyond identifying as the opposite gender including access to insurance and specialized healthcare (National LGBT Health Education Center, n.d., p. 5). Coverage for medical services like hormones, implants, and injections may not be covered by insurance, forcing these individuals to pay out of pocket or to search for these treatments from other less safe and sanitary options. As Baldwin et al. (2018) explains, these individuals are dependent upon the medical system

to help affirm their authentic gender through procedures such as “hormone replacement therapy, gynoplasty, facial feminization surgery, mammoplasty” and others (pp. 1310-1311). These treatments literally save lives and should not be considered cosmetic treatments, but rather medical necessities (Baldwin et al., 2018). The irony here is that these individuals are dependent upon a medical system that barely recognizes their existence. As the National LGBT Health Education Center (n.d.) notes, denying transgender individuals access to appropriate care can lead to higher rates of morbidity and mortality and complicate access to competent and specific health care which is already quite limited for these patients. Future research should focus on the specific health needs of each group in the LGBTQ+ community to thoroughly address these specific health disparities. The LGBTQ+ community is recognized as a very diverse collection of individuals with varied interests, identities, and needs. An appropriate and adequate discussion of each subgroup in the LGBTQ+ spectrum is beyond the scope of this DNP project, and regrettably the LGBTQ+ community will be discussed as a whole, with specific issues for each subgroup mentioned at appropriate times.

Data Collection and Representation

While increasing education and adding SOGI status to a health history intake forms may seem like a trivial task, this method of data collection adds to the major issue of adequate representation for the population as a whole. Mulé et al. (2009) summarizes: “In health promotion research and practice, representation matters. It matters which populations are being targeted for health promotion interventions and for what purposes, and it matters which populations are being overlooked” (para. 1). Interestingly, approximately 4.5% of the U.S. adult population identified themselves on the LGBTQ+

spectrum in 2018, and those born after 1980 were more likely to identify as LGBTQ+ than their older counterparts (Lawlis et al., 2019).

As previously discussed, the LGBTQ+ population has frequently been omitted by mainstream research agendas, health promotion, policies, and practice guidelines as evidenced by the general lack of reporting from the MiBRFSS and other national health surveys (Mulé et al., 2009). Failing to report, or readily publish, results from these government led surveys contributes to the systemic discrimination of the LGBTQ+ population through rendering those individuals as underrepresented, non-existent, or *invisible*. When a specific group is continually rendered invisible by those in control, a domino effect of erasure from research, denial of resources, and barriers to health resources quickly follow suit (Mulé et al., 2009). As Mulé et al. (2009) explains, without adequate representation, research, and knowledge, those identifying as LGBTQ+ have been excluded from holistic treatment, and instead emphasis has become focused on treatment for specific diseases (e.g. HIV/AIDS) instead of targeted health promotion strategies. When a group becomes associated with a specific disease in the way that gay men have become almost synonymous with AIDS, the individual needs of those identifying as LGBTQ+ become irrelevant or invisible and the intricate needs of the population cease to exist. Or put another way, “Public policy developed in this climate of homo-negativity implicitly normalizes and naturalizes heterosexuality, resulting in a circular process and continued invisibility of the needs of gender and sexually diverse people” (Mulé et al., 2009, para. 10.).

Recent legislation and public health policy have worked to combat the lack of representation for the LGBTQ+ community as organizations such as the NAM, TJC, and

the Center for Medicare and Medicaid Services have begun to require all electronic health records to address SOGI status and other related topics. As Grasso et al. (2019) explains, the Meaningful Use Stage 3 Incentive Program through Medicare has incorporated SOGI information into its data bank as a way to monitor and adequately represent the LGBTQ+ community's use of healthcare services. Additionally, the United States Department of Health and Human Services has initiated several new efforts aimed at the health improvement of the LGBTQ+ community, and major national surveys continue to help contribute to the data bank and resource allocation for these individuals (Ceres et al., 2018). Unfortunately, SOGI related questions were not included in the 2020 census questionnaire, which severely limits the potential national resources which could have been allocated to the health needs of this population.

Literature Review

Knowledge Gap and Barriers

Stigma and discrimination are, unfortunately, very real barriers for some LGBTQ+ patients. Quinn et al. (2015) outlines a few major barriers for disclosure of SOGI status which includes fear of discrimination, lack of provider knowledge, provider bias, and lack of access to LGBTQ+ resources and referrals. Rossman et al. (2017) reports that “10% of LGB and 21% of transgender patients [have experienced] harsh or abusive language and 8% of LGB patients and 27% of transgender patients [have] been refused care” (p. 1392). Even if patients do not face direct hostile or abusive reactions from disclosing their SOGI status, non-affirming care (care based on the presumption that patients are heterosexual, or addressing patients in a heteronormative way), can create an unwelcome environment for LGBTQ+ patients (Rossman et al., 2017). In concrete

terms, failure to disclose SOGI status can result in sub-par health care through provider failure to screen, diagnose, and treat relevant medical issues (Manzer et al., 2018, p. 158). In interpersonal terms, the ability for LGBTQ+ individuals to self-disclose their SOGI status impacts the relevance of information shared with the provider and can impact the patient's perception of the provider (Rounds et al., 2013). In professional terms, this is a practice of cultural competency. Cultural competency is a set of behaviors, attitudes, and practices that influences how providers care for those of different backgrounds (Manzer et al., 2018). Cultural competency is considered a basic, entry level skill for nurses and physicians, and requires balancing the provider's personal culture with the culture of their patient (Manzer et al., 2018, p. 158). When providers fail to address a patient's sexual orientation or gender identity, or when providers assume sexual orientation or gender identity does not apply to the patient's current health concerns, they are implicitly reinforcing heteronormativity. This constant reinforcement of heteronormativity sets up a potentially dangerous situation where the provider is not fully aware of the patient's health status or able to provide adequate care for the patient.

There is a well-established link in the literature regarding LGBTQ+ adolescents and higher rates of depression, mental illness, and suicide, and yet in Kitts (2010) study, only 57% of physicians acknowledged this association. In fact, Kitts (2010) found that the majority of physicians would not discuss sexual orientation with their patients (especially adolescents) when taking a sexual history, and they would also not address sexual orientation for patients who were presenting with depression, suicidal thoughts, or who had attempted suicide. This lack of specific questioning represents a significant disconnect between proper patient care, current research, and cultural competency.

Feelings of sexual orientation typically arise during adolescence and this vulnerable group is at an increased risk of “depression, suicidal behaviors, homelessness, familial rejection, dropping out of school, substance abuse, sexually transmitted diseases . . . and victimization” (Kitts, 2010, p. 731). Additionally, these risk factors can follow individuals into adulthood and without proper care and resources, patients can suffer true harm.

A general lack of knowledge and discomfort in addressing issues of sexual and gender identity can be blamed for the deficits in provider care for this population of patients. As Parameshwaran, Cockbain, Hillyard, and Price (2017) identify, practitioners may not provide appropriate care because they do not know what treatments or resources are available to individuals with specific LGBTQ+ health needs (p. 368). In the Parameshwaran et al. (2017) study, almost 85% of medical students surveyed reported a lack of LGBTQ+ education, with deficits in clarifying unfamiliar SOGI terms, locating support resources, discussing domestic and substance abuse, and deciding appropriate places of treatment for LGBTQ+ patients. This confusion and lack of confidence directly reflects a long-term issue in medical education. While there is typically a discussion regarding cultural sensitivity (i.e. Jehovah’s Witness patients not wanting blood transfusions) the discussions regarding LGBTQ+ patients is inconsistent and clearly lacking. Parameshwaran et al. (2017) asked medical students 66 questions about their medical training, clinical experience with LGBTQ+ patients, and their personal attitudes toward these patients and found that LGBTQ+ specific education is inconsistently imbedded into the student’s curriculum. Baldwin et al. (2018) cites that one-third of medical school in the United States do not require any educational hours directed toward

LGBTQ+ specific needs. This leads many medical professionals feeling unprepared to care for these patients following medical school. By failing to appropriately educate practitioners regarding the importance of LGBTQ+ patient status, the medical establishment perpetuates the heteronormative status quo and assumes that sexual orientation and gender identity are not influential in a person's overall health status.

Johnson and Nemeth (2014) conducted a qualitative study addressing the gap in research focused specifically on lesbian women (LB). One statement made by a participant in the Johnson and Nemeth (2014) study highlighted a disconnect between the education of the provider and the expectations of the patient: "I just went there under the assumption that they are going to be understanding because they have to learn about this in school and they're going to know exactly what I'm talking about" (p. 637). This is a very important statement because some patients believe that LGBTQ+ specific needs are addressed and taught in our medical and nursing education programs, which as is previously discussed, is certainly not the case. Patients look to medical providers for answers, comfort, and understanding, and it is apparent that our current education system is failing some of our most vulnerable patients. However, another statement made by a participant in the Johnson and Nemeth (2014) study is equally troubling: "Sometimes I just literally assume that they're going ahead on heteronormative what-not because that's what they know and that's what they're familiar with" (p. 637). A positive rapport and sense of trust can never truly be established between patient and provider if the patient enters into the experience with the assumption that they will not be appropriately treated. As Johnson and Nemeth (2014) conclude, many medical and nursing schools lack LB specific curriculum in their programs, but post-graduation educational interventions to

improve practitioners skills in practice were effective. Johnson and Nemeth (2014) summarize to say that their study strengthens the call to medical, nursing, and other health care training schools to include LGBTQ+ content and to require continuing education for LGBTQ+ specific needs.

Health Disparities

It can be argued that a lack of visibility has led to significant health disparities for the LGBTQ+ population including issues of morbidity and mortality (Stall et al., 2016, p. 787). As Stall et al. (2016) postulates, it is entirely plausible that there is a variety of undetected health needs in the lesbian, bisexual, and transgender population due to the overall lack of investment in health research for these groups. Additionally, the impact of racial and ethnic minority factors layered upon LGBTQ+ individuals raise important issues regarding health disparities (Stall et al., 2016). For example, how do the health needs of a Latino lesbian differ from those of a bisexual black man, and how do those health needs differ from that of a transgender Asian woman? While a discussion of how race, ethnicity, class, and power dynamics has rendered many minority groups invisible in mainstream culture is outside the scope of this project, the point is that when an already invisible group (LGBTQ+) has other layers of invisibility (race) the individual health needs of these individuals become even more difficult to discern. In theoretical terms, these complexities are known as *intersectionality* and examine how multiple social identities influence health disparities (Agénor, 2020). The study of intersectionality has roots in black feminist theory and calls for multi-level analysis in terms of examining the effect of intersecting categories of social inequality, racial inequality, sexual inequality, gender inequality, gender, politics, historical processes, structural and social constraints,

and power on the health of those that are marginalized by multiple categories (Agénor, 2020; Stall et al., 2016). Stall et al. (2016) explains that once theorists publish interventions for researching this population, trials can be developed to test these interventions in a clinical setting and recommendations can be made for individualizing care for public health practice. However, it is important to remember that these theories and interventions will never reach the testing stage without adequate representation and allocation of resources. Stall et al. (2016) reminds us that the inclusion of SOGI information and behavior in all major health surveys are likely to reveal important findings and relevant research topics for this population, but only if these results are reported and appropriately utilized.

To combat the invisibility of the LGBTQ+ community, Mulé et al. (2009) offers three solutions: first, the community must be able to define itself using the language of its choosing; second the medical community must shift how standard care is provided; and third the surrounding society must become knowledgeable and sensitized to these issues in order to combat phobia, heterosexism, and cis-genderism. It is arguable that over ten years after the publication of the Mulé et al. (2009) article, these three goals have not become fully realized, and are even in jeopardy in our current socio-political climate (i.e. the reported lack of SOGI status on the 2020 census questionnaire). Public health policy desperately needs to address holistic needs and create visibility to those in the LGBTQ+ population.

The specifics regarding health disparities for the LGBTQ+ community involve a wide range of issues ranging from substance abuse, mental health, poverty, and reproductive health, among others. Incorporating SOGI questions into the electronic

health record is essential to identify risk factors specific to the LGBTQ+ community. For example, transsexual individuals are at higher risk for certain cancers as a result of hormone replacement therapies used in transitioning (Mule et al., 2009). Without knowledge that an individual has transitioned and has taken hormone replacement therapies, a provider would not be able to recommend critical screenings. Additionally, poverty and lack of access to resources is a strong reality for some LGBTQ+ individuals depending on their geographic location and individual support system. Socioeconomic factors heavily influence the ultimate well-being of the LGBTQ+ population and appropriate medical care can be cost-prohibitive to many individuals (i.e. access to HIV/AIDS medications, hormone replacement therapies, gender reassignment surgeries, etc.) (Mulé et al., 2009). Awareness of these risk factors will allow providers to promote the appropriate preventative care measures and encourage positive health behaviors.

Provider Education and Patient Interventions

In an effort to bridge the gap between medical training and the realities of personalized care, various national health organizations including the CDC and the Fenway Institute have created guidelines and informational materials for providers to increase their knowledge base regarding patient interactions with LGBTQ+ individuals. It is important for providers to remember that not all patients are heterosexual and sexuality is not a concrete fixture. Some individuals self-identify as having a fluid sexuality and although they may currently be in a same sex relationship, that does not mean that they do not need to discuss birth control options for future relationships. Despite the resources provided by these organizations, it is important to recognize that mistakes in terminology and interviewing will occur, and these events should be

acknowledged and dealt with appropriately. As Knutson et al. (2019) delicately states, “when [terminology] errors occur, it is important for [practitioners to be] self-compassionate, appropriately apologetic, and receptive to feedback” (p. 219).

Relationships between providers and patients are built over time and, as with any relationship, mistakes and missteps happen. Providers must remain open and receptive to the feedback of their patients as these relationships are navigated together (Knutson et al., 2019). In certain circumstances, LGBTQ+ patients may end up serving in multiple roles during a medical visit: patient, educator, and advocate (Knutson et al., 2019). This multi-function of the patient as both an advocate for a population and an educator to the provider can provide an additional source of stress for the patient, on top of their current medical concern. When these inevitable missteps in terminology, language, or other interactions are made, the provider must work to maintain a safe space both for feedback from the client in correcting the wrongdoing and for the patient to continue disclosing pertinent information related to their medical concerns. As Brown et al. (2020) adds, this correction can come in the form of self-recognition and acknowledgment by the practitioner, verbal reminders by the patient, and/or suggestions by the patient to make changes to existing processes (i.e. including pronouns on intake forms). Mistakes should be recognized and corrected, and the conversation should continue.

There is a clear need for continued education to all those that work in the medical practice setting: physicians, nurse practitioners, physician assistants, nurses, front office staff, laboratory technicians, and others as a way to provide affirming, non-judgmental, and personal care to each and every patient (Baldwin et al., 2018; Selix et al., 2018). This continued education is imperative especially for the transgender population as

specific and culturally appropriate care is not as readily available to the transgender and gender-variant population (Selix et al., 2018). One aspect of continued necessary education on the part of the provider includes ways to speak to those whose gender may not match their outward appearance or those whose sexual lifestyle may be different from what the provider may assume. Reisner, Hopwood, Goldhammer, and Makadon (n.d.) offer a variety of real-world talking points and sample conversations geared toward helping providers navigate these delicate conversations. First, it is important to establish a good rapport with all patients, whether they identify with the LGBTQ+ community or not by simply asking individuals what name they would like to use: “I would like to be respectful—how would you like to be addressed?” or “What name would you like me/us to use” (Reisner et al., n.d., p. 7). Additionally, instead of using terms such as *Sir* or *Ma’am*, getting into the practice of addressing all patients with a general question of “How may I help you today?” is one way to make language more inclusive and avoid potential embarrassment by calling a patient by the wrong gender (Reisner et al., n.d., p. 6).

Paperwork, Language, and Terminology

The consensus across the body of research is that simple questions addressing SOGI status should be included on health history intake forms as a way to simplify and streamline the disclosure process (Baldwin et al., 2018; Bradford et al., n.d.; Knutson et al., 2019; Quinn et. al., 2015). The importance of including these questions on intake forms is two-fold: it saves time during the patient interview if the information is readily available on paper and allows an opportunity for engagement if the questions are left

blank. It is very important for practitioners to periodically ask about SOGI information as these may change over the lifespan (Bradford et al., n.d.).

Having this information easily available on intake forms can help the provider be better prepared for the patient visit, and also save the patient from having to disclose this information verbally if they are uncomfortable vocalizing this information. Regardless of how the information is disclosed, it is imperative for providers to have this information because of the connection between same-sex behavior and health disparities (Bradford et al., n.d.). Thoughtful, inclusive, and well-formulated paperwork can create the beginnings of a positive therapeutic alliance (Knutson et al., 2019). Donatone and Rachlin (2013) posit that a provider's competency is communicated by the questions they ask and the language that they use during the patient interview. The wording for these SOGI questions is very important as the answers may be complicated for certain individuals (Donatone & Rachlin, 2013). Additionally, practitioners should be aware of how gathering this SOGI information will affect the patient in the future. As Donatone & Rachlin (2013) caution, medical records with this information could potentially threaten patient privacy, limit future access to health care, and cause future issues in terms of insurance coverage, etc. However, this information is obviously relevant and valuable to the overall respectful and holistic treatment of the patient.

While the academics and the researchers have both theorized and demonstrated that clients prefer to disclose their SOGI information on intake forms, some providers continue to believe that patients (presumably non-LGBTQ+) may find these questions offensive and intrusive (Cahill et al., 2014; Maragh-Bass et al., 2017; Rullo et al., 2018; Knutson et al., 2019). However, Rullo et al. (2018) notes that 97% of their participants

were not “distressed, upset, or offended” by answering SOGI questions on an intake form. As Quinn et al. (2015) expands, disclosure of SOGI information is widely regarded as having a positive impact on the health of LGBTQ+ patients. Quinn et al. (2015) describes the Austin (2013) study in which those researchers found that lesbian women chose to disclose this information in an effort to continue building a positive rapport with their providers. Additionally, this disclosure increases overall satisfaction with the treatment provided by the practitioner and created a greater coverage of appropriate health screening (Quinn et al., 2015). Baldwin et al. (2018) incorporated a section in their discussion dedicated to the importance of treating *all* SOGI identity disclosure as routine. To summarize, patients experienced greater comfort and sense of ease when they felt as if these SOGI directed questions were a routine part of the healthcare visit. When SOGI questions were asked and answered, practitioners and support staff who affirm, acknowledge, and noted the answers were remembered with greater appreciation than those who unnecessarily dwelt on the information. If a non-applicable question was asked the information is recorded and the interview continues such as ““When asked when I had my last period, I told the nurse that I do not get a period because I am transgender. She simply entered that information into the computer in the place of a date”” (Transgender woman, 27 years old) (Baldwin et al., 2018). This statement displays a developing relationship between the patient and the provider where the provider is open and receptive to feedback, but the misstep is not dwelt upon.

In spite of the acknowledgement that paperwork and intake forms offer an immediate positive impact of inclusion in a medical setting, the terminology and specific language to be used on these forms remains a work in progress. While organizations

such as the CDC, the Fenway Institute, the ILGA and others have published language guidelines, it is important to recognize that there is no perfect blueprint for the terminology or language used on intake forms, and that some clients will need space to discuss their reactions to these forms and processes. A revised form should never take the place of a face to face discussion regarding SOGI status, especially for a patient who may be struggling to label themselves (Knutson et al., 2019). What *is* known is that there should be more options than traditional binary choices (i.e. male/female, homosexual/heterosexual, cisgender/transgender) to allow patients adequate space for self-identification. Forcing patients to choose an option that may not fully encompass their identity can cause significant emotional distress and contributes to an overall invisibility in society (Knutson et al., 2019; Scheffey et al., 2019). Walker (2014) noted in their study that a common theme throughout the literature was the absence of terminology that allowed patients to self-categorize their identities without using medical diagnostic terminology. Knutson et al., (2019) reinforces the Walker (2014) observation when they note that 1 in 5 respondents from their study identified themselves with different terminology than what their healthcare provider used. This is significant because it highlights the fact that healthcare may be using outdated, insensitive, or inappropriate terminology or may not be allowing space for the patient to identify themselves. Walker (2014) draws on the tenets of Narrative Theory when they discuss language as a instrument people use to create their sense of self-concept. According to theorists such as Derrida (1995) and Hansen (2006), Walker (2014) mentions that language has an immeasurable impact on how we see ourselves and others, how we

interact with the world around us, and how these words create a system in which our social roles are delineated.

What researchers can agree upon is that there is a loose set of guidelines that facilities should follow in order to achieve the desired welcoming effect when inquiring about patient SOGI status. Knutson et al. (2019) recommends avoiding the phrase *other, please specify* when providing space for the patient to write in how they identify. While this phrase seems appropriate as it acknowledges a difference and allows the patient to specify exactly how they identify, it creates an othering effect on the client that can be alienating and isolating. While Scheffey et al. (2019) agrees that *other* is not a preferable term, they found in their research that patients would prefer to write in an answer in the *other* section than to be forced to select a box that is inaccurate. Lawlis et al. (2019) also recommends that gender neutral terms such as partner/spouse and parent should be used in place of heterospecific terms like husband/wife and mother/father. Additionally, separating questions regarding sexual orientation from gender identity and birth sex, and asking for personal pronouns and preferred names can help the practitioner to collect all relevant information quickly and easily (Lawlis et al., 2019). Heck et al. (2013) expands on the issues surrounding husband/wife and partner/spouse terminology and notes that intake paperwork should avoid the term *marital status* because not all states allow LGBTQ+ couples to marry. It is an unfortunate fact that many LGBTQ+ individuals have been denied certain rights (i.e. marriage, health insurance) and the use of non-inclusive language can work to reinforce those social stressors even if the intent was well-meaning. In summary, not providing patients the opportunity to self-identify on

medical paperwork creates an environment where the patient's true self is non-existent and unimportant (Knutson et al., 2019).

One of the most important aspects of inclusive language and terminology on paperwork involves the use of personal pronouns and preferred names. These two items are, arguably, the most central items to self-identification for any patient presenting to the health visit. Best practice guidelines promote the use of these self-chosen identifiers to help promote a sense of respect and appropriate care provided by the practitioner (Brown et al., 2020; Knutson et al., 2019). Baldwin et al. (2018) includes the following qualitative statement from their research study as a way to reinforce the importance of proper pronoun usage:

“I understand why health care providers need to know about the health of my vagina, but as a trans man, I don't like being given a form that says, “For women” on the top in order for them to get the info they need. It's discouraging and already sets up the atmosphere of not being trans friendly or trans sensitive. . . affirming and respecting my gender identity is important, especially using proper pronouns (Transgender man, 28 years old).” (p. 1310)

Patients present to healthcare facilities for a variety of reasons and it is imperative that practitioners trust in the patient's self-perception of their identity by allowing for the expression and adoption of personal pronouns and preferred names (Knutson et al., 2019).

The reality of language is that it continually evolves, and terminology regarding the LGBTQ+ experience is no different. Words that were commonly used decades ago have come in and out of favor as the LGBTQ+ community works to define the language

that defines themselves. Appropriate and accepted language for describing the LGBTQ+ existence is most certainly on a continuum and it is important to recognize that there are limited accepted words to describe these experiences (Drill et al., 2019). Academics have been attempting to identify appropriate language and terminology since the 1990s and the works of scholars such as Judith Butler (1990), Nestle, Howell, and Wilchins (2002), Anna Corwin (2009) and Lynda Johnson (2016) are representative of the discussion of LGBTQ+ terminology in their specific timeframes (as referenced in Scheffey et al., 2019). Likewise, inclusive and open terminology and language on medical paperwork empowers the patients and provides holistic care regardless where the patient is on their continuum of development to self-discovery (Scheffey et al., 2019).

The performance of identity is a concept well known in the world of theatre scholarship and is well applied in this context as well. The basic tenet is that individuals are different people in different settings, and their personas are merely performances of their authentic selves (Walker & Caprar, 2020). In the Scheffey et al. (2019) study, the researchers reported that up to 47% of participants would change how they describe their SOGI status depending on the situation. The concept of role flexing is introduced here, where individuals might highlight certain characteristics while downplaying other characteristics depending on the context in an effort to fit in, reduce stigmatization, and work to ensure their personal safety (Bry et al., n.d.)

Summary

The literature clearly shows that one of the easiest ways for medical settings to convey inclusivity and openness is to incorporate this type of language on paperwork given to all patients. As Baldwin et al. (2018) summarizes, medical visits “went well

when providers and staff used inclusive language, demonstrated their experience and education, and treated identity disclosure as routine. Negative interactions were characterized by misgendering, unfamiliarity with [LGBTQ+] people and health issues, and transphobic practices” (p. 1300). Essentially, not allowing space for inclusive language and paperwork creates an environment of bias against the LGBTQ+ community.

The space that allows individuals the freedom of identity is created in part by the paperwork distributed to patients, the relative education of the provider, the attitudes of other staff, and the resources available in the physical office (i.e. posters, pamphlets, stickers representative of the LGBTQ+ population). These signifiers work together to create a sense of orientation toward or against LGBTQ+ individuals, much in the same way as the lack of ramps or elevators may go unnoticed by those able to use steps. Likewise, those that easily fit into *straight spaces* (i.e. school dances, romantic restaurants) may not notice the lack of inclusion for those who do not fit as nicely in these spaces (Heyes, Dean, & Goldberg, 2016). The Heyes et al. (2016) study cited a participant who described the ample availability of condoms but absence of dental dams as an example of a non-inclusive health environment that recognizes multiple sexual practices. Additionally, an Allies or rainbow sticker on the window does not necessarily communicate LGBTQ+ inclusivity on its own, but coupled with other specific items in the physical space can indicate that LGBTQ+ patients are not only welcome, but are *expected here* (Heyes et al., 2016).

Significance for Population and Conclusion

It is important for providers and practitioners to educate themselves and their patients on the importance of LGBTQ+ status disclosure by creating a warm, nurturing, safe, and expected environment in which patients feel comfortable discussing personal issues. Through education and inclusion efforts on the part of providers, this vulnerable population will receive thorough health assessments that will address their whole-body needs. By incorporating the basics of queer theory and the minority stress model in daily practice, providers can begin to look at the ways in which medicine creates a heteronormative and potentially harmful environment for some patients. Simply thinking about the norms imposed on our practice and being aware that not every patient fits each norm, providers will become more competent providers for our wide variety of patients.

Theoretical framework

One can trace the origins of queer theory from feminist, racial, gay and lesbian equality movements of the 1970s and 1980s as well as theoretical discussions surrounding sex and gender by academics such as Simone de Beauvoir, Michel Foucault, Monique Wittig, and others. The idea that the masculine was the general to which the feminine was the other translates to the basic tenet of early queer theory that the heterosexual is the general to which all other sexual orientations (and later gender identities) are traditionally measured against (Wittig as cited in Butler, 2007). Queer theory, in basic terms, works to breakdown this binary system of male/female, heterosexual/homosexual, etc. to include a more fluid nature of identification that allows for alterations and changes over time in terms of how individuals choose to name and label themselves. Queer theory works to debunk the pre-conceived notions set by society

and enforced through politics, to allow the individual the freedom to create and adopt their own system of naming and coding. As Hennessy (1993) contributes: “Queer theory calls into question obvious categories (man, woman, latina, jew, butch, femme), oppositions (man vs. woman, heterosexual vs. homosexual), or equations (gender = sex) upon which conventional notions of sexuality and identity rely” (p. 964).

In the late 1980s, discontent was growing among the materialist feminist movement regarding the binary categorization system in society and politics. Frustrated with the current state of thought, theorists began to develop ideas outside of the traditional definitions of gender, race, socioeconomic class, nationality, and sexual orientation system to incorporate a space between what is *sex* and what is *gender* (Sedgwick, 1990). At this time, the distinction between sex and gender was not well-defined and as Corwin (2009) explains, sex is typically considered to be defined by biology (i.e. body parts) while gender is a spectrum of masculinity and femininity. Hennessy (1993) adds that as early as the 1970s, feminists such as Charlotte Bunch, the Furies, the Pu September Staff, and Monique Wittig began to call for a more critical analysis of heterosexuality arguing that current discourse addressed sexuality in terms of personal or civil rights as a way to avoid the inherent politics of heteronormativity. In terms of *orientation*, Heyes et al. (2016), explains that this word became accepted terminology in the 1970s as a way to describe the relationship between gender and sexual desire. The term orientation shifted from a measurement of direction or trajectory, to a representation of a person’s basic attitude, beliefs, and connection to a certain topic (Heyes et al., 2016).

Societal shifts in the 1950s initiated this change and shifted focus toward *harmful* sex in terms of prostitution and masturbation, and later toward *sex offender*, *child molester*, and eventually *homosexual menace* (Rubin, 1993, p. 100). In 1952 the American Psychological Association (APA) published the first version of the Diagnostic and Statistical Manual (DSM-I) and it listed all conditions that were accepted as psychiatric illnesses at the time. The term *homosexuality* was included in this manual and was described as a “sociopathic personality disturbance;” in DSM-II, published in 1968, homosexuality was reclassified as a *sexual deviation* (Drescher, 2015, p. 569). Following pressure from various academics and social movements including the Stonewall Riots in 1969, the APA removed the diagnosis of *homosexuality* in the revised DSM-II in 1973 (Drescher, 2015). While the term *homosexual* was removed from the DSM, it was replaced with *sexual orientation disturbance* (SOD) which considered homosexuality a diagnosis if the individual experienced distress and requested assistance (Drescher, 2015). This new diagnosis was dangerous as it legitimized sexual conversion practices and therapies (Drescher, 2015). The SOD diagnosis was eventually replaced in the DSM-III by a diagnosis of *ego dystonic homosexuality* which allowed space for those unhappy about their sexuality to be diagnosed with a mental illness. This diagnosis never quite fit into the standards of typical psychiatric diagnoses as it questioned whether people who are unhappy with any part of themselves (skin color, hair color, sex, height, etc.) should be diagnosed with a mental illness and was removed from the DSM-III-R in 1987 (Drescher, 2015). In 1990, the WHO removed *homosexuality* from the International Classification of Diseases (ICD), which, along with the materialist feminist movement of the 1980s and theorists mentioned in this paper, shifted the discussion of

homosexuality out of the medical/psychiatric arena into the social sphere (i.e. political, moral/religious, governmental) (Drescher, 2015, p. 572).

In February 1990, a conference was held at the University of California, Santa Cruz, in which scholar Teresa de Lauretis read some of her work from the introduction of the journal *differences* and queer theory was introduced into mainstream academia. Expanding on the choice of terminology:

Today we have, on the one hand, the terms “lesbian” and “gay” to designate distinct kind of life-styles, sexualities, sexual practices, communities, issues, publications, and discourses . . . In a sense, the term “Queer Theory” was arrived at in the effort to avoid all of these fine distinctions in our discursive protocols, not to adhere to any one of the given terms, not to assume their ideological liabilities, but instead to both transgress and transcend them.

(de Lauretis, 1991, p. v)

The choosing of the term *queer* had long-reaching implications in the early 1990s. Jagose (1996) summarizes an etymological evolution of the terms gay, lesbian, and queer from George Chauncey (1994) and notes that the term *queer* predates the acceptance of *gay* among the early 20th century gay male community. The term *gay* began to gain more acceptance in the 1930s and became solidified during the following decades. In the 1960s, leaders of the LGBTQ+ movement broke with the term *homosexual* and reclaimed the term *gay* which had previously been used to describe “women of dubious morals” (Jagose, 1996, p. 72). The term *gay* was adopted to counter the political and social differences between demonized *homosexuals* and moral *heterosexuals*.

Since the early 1990s, queer theory has changed and adapted as theorists grapple with the tenets, terminology, and the essence of what it means to be *queer*. Theorists such as Judith Butler, Eve Sedgwick, Gayle Rubin, Michele Foucault, and many others have contributed much of their professional lives to the work of sex and gender politics. Gayle Rubin, a cultural anthropologist, published “Thinking Sex” in 1984 and revisited that seminal work in 2011 in her article “Blood under the Bridge: Reflections on ‘Thinking Sex.’” As the vantage of time often offers many insights and reflections, Rubin (2011) writes, “Despite initial controversy and some persistent arguments, the major assumptions of social construction now form the familiar ground on which most queer scholarship takes place” (p. 18). Kemp (2009) adds that *queer* implied both imitating the norm and exploring alternatives to what is traditionally accepted.

In 1993, Rubin posited that one must recognize the impossibility of a full analysis of social and political constructs of sex and gender if biology was to remain the primary axis on which it is measured. Rubin (1993) further explains her concepts of the construction of sex and gender when she states, that *sexuality* is a creation of society similar to social norms, transportation, division of labor, and methods of oppression. Hennessy (1993) adds that the primary objective of queer theory is to provide another discourse regarding how we think about sexuality (i.e. outside of limited binary terms of *straight* and *gay*). By focusing on the social construction of these identities and labels, queer theory incorporates a variety of critical frameworks to conceptualize symbols and relationships as a matter of representation (Hennessy, 1993). The mere act of incorporating of the term *queer* in discourse functions as a reclaiming of a previously derogative term (used to refer to sexual deviants cast out by society and demonized in the

1950s) and creates an air of rebellion against societal pressure to be either normal, invisible, or apologetically abnormal (Hennessy, 1993). Despite the variations of theories attributed to queer theory in the last 30 years, the early versions of queer theory focused on some common themes including queer identities, symbolism in society, and the eroticism of sexuality (Hennessy, 1993). These themes summarized in 1993 will form the basis for the following discussion of queer theory and how it relates to this DNP project. The basic tenets of queer theory are fundamental to understand in order for the medical community to realize why routine disclosure of SOGI status for all patients is essential to appropriate and patient-centered care.

Judith Butler is a philosopher well-known for her work with feminism and sex and gender theory. Butler is one of the founding influential theorists in queer theory and is heavily influenced by other academics including Michel Foucault and Simone de Beauvoir. Butler's books *Gender Trouble: Feminism and the Subversion of Identity* (1990) and *Bodies That Matter: On the Discursive Limits of "Sex"* (1993) are considered foundational texts of early queer theory. The notion that gender is a social construct and not a biological assignment is central to Butler's theories in *Gender Trouble* (2007), which questions whether gender is something that we are said to *have* or is it something we are supposed to *be*? Butler (2007) questions how the construction of gender arises through forms of "social determinism" and postulates,

When the relevant "culture" that "constructs" gender is understood in terms of such a law or set of laws, then it seems that gender is as determined and fixed as it was under the biology-is-destiny formulation. In such a case, not biology, but culture, becomes destiny. (pp. 10-11, emphasis in original)

As Nagington (2016) explains, Butler's writings during the 1990s were a radical shift in thinking, especially in terms of feminist theory. Butler argues that the characteristics of the physical body cannot be delineated into male versus female, and that the need to understand gender in terms of physical anatomy is also a social construct. This social construction essentially begins at birth (or before, i.e. gender reveal parties), and examples such as the clothing that one wears, which bathroom they use, what toys they play with as children, etc. is influenced by those around them. Butler believes that individuals are not as free as they think they are to make many of these personal choices and instead are constantly policed by various social and political institutions that dictate what is and is not appropriate (Nagington, 2016). Butler (2007) expands to say that social scientists agree that gender is used as a dimension of analysis, and yet these terms also serve to mark persons with biological and cultural differences. Butler (2007) argues that the knowledge of a person's biology influences how society treats them in terms of gender expression and reinforces the male/female binary. This reinforcement delegitimizes deviations from the male/female binary especially in terms of intersex, transgender, other non-binary expressions (Jagose, 1996; Nagington, 2016).

As previously mentioned, the idea of performativity or role flexing is the incorporation of certain actions or attributes that a person exhibits depending upon the situation. Butler discusses the idea of performativity at length in her writing and says that performativity can be understood as a constant set of actions and discourses which are specifically designed to be observed and understood by outsiders in a particular way (Butler & Salih, 2004; Nagington, 2016). This performance is constantly repeated and reinforced by both the performer and the social sphere, and this concept helps dictate how

we act in certain social situations such as school, the doctor's office, the playground, work, etc. (Nagington, 2016). This constant policing by, and engagement with, the social sphere offers an insight into the conceptualization of minority stress theory which will be discussed later in this paper. Minority stress theory engages well with Butler's theories regarding social constructedness of binary gender and how non-binary individuals are thus unfairly minoritized and discriminated against (Nagington, 2016).

Butler, and others in the queer theory movement, were influenced by French philosopher Michel Foucault and his work with sex, power, and knowledge theory. Foucault, best known for his works *Discipline and Punish* (1975) and *The History of Sexuality* (1976), viewed the medical and psychiatric models of the *homosexual* (i.e. the DSM-I diagnosis) as a way for the state to expand power from the public realm into the private (Kemp, 2009). As Kemp (2009) explains, the policing of bodies and sexual desire extended into the bedroom and the invention of the *homosexual* was actually an artificial and constructed way to enforce accepted behavior. Additionally, Foucault argues that once the *homosexual* label was coined in the 1860s, a new psychology was invented that began to criminalize sex in new ways (Kemp, 2009). As Schmidt (2010) explains, "The criminalization of sex did more than delimit actions; it also named and categorized people. People did not merely engage in same-sex acts; people were homosexuals . . . Their meanings were solidified when people used the new terms to identify, categorize, and monitor themselves and others." (p. 317). Foucault (1988), in his third volume of the *History of Sexuality* series, questions this shift in thinking and posits these developments caused people to categorize themselves, their relationships, their desires, and their position in society in new ways. In essence, the shifts in how sex,

power, and knowledge are conceived, discussed, categorized, and performed influence every aspect of one's life from the personal to the political.

Eve Sedgwick is another founding philosopher of the queer theory movement, influenced by Foucault and a contemporary of Butler in the early 1990s. Sedgwick's works *Between Men: English Literature and Male Homosocial Desire* (1985) and *Epistemology of the Closet* (1990) helped lay the groundwork for the discussion of sex vs. gender and how the queer lens alters heteronormative readings. Like Butler, Sedgwick (1990) theorized that *chromosomal sex* (biological sex) is the base upon which the social construction of gender is built. In contrast to chromosomal sex, the meaning of gender is variable, relationable, and "inextricable from a history of power differentials between genders" (Sedgwick, 1990, p. 27). For Sedgwick, and other queer theorists, a discussion regarding sex and gender eventually leads to a discussion regarding physical intimacy and heterosexuality vs. homosexuality and here she introduces the *minoritizing* view, and the *universalizing* view. As Kemp (2009) explains, the minoritizing view suggests that homosexuality is of interest only to a select few, or the minority. However, the universalizing view sees homosexuality, as an issue of importance across the spectrum of sexuality (Sedgwick, 1990; Kemp, 2009). By thinking of sex and gender through the queer lens as described by Rubin, Butler, Foucault, Sedgwick, and others, one can easily see how society has actively worked to maintain a distinct separation between the heteronormative and the *other*. By changing the lens in which individuals and SOGI information is viewed, expected, and anticipated, a realm of other possibilities and identities is revealed, but only if medical professionals actively address it. As a way to ground the philosophical ruminations of queer theory for this DNP project, a second

theoretical framework will be introduced in the following paragraphs: minority stress model. The minority stress model fits quite nicely as a grounding theory to the work in the field of queer theory to translate these high-level philosophies into real, practical, examples of how the LGBTQ+ suffer grave health disparities.

The idea of the minority stress model, first theorized by Meyer in 1995, proposes that health disparities among minorities (i.e. high blood pressure in African Americans, mental health disturbances in LGBTQ+) can be at least partially explained by the constant stressors placed upon these individuals by systematic discrimination and homophobia leading to a constantly hostile living environment (Dentato, 2012). As Meyer (2013) explains, the basis for minority stress theory is grounded in several psychological and sociological theories. Meyer (2013) outlines LGBTQ+ health disparities (primarily mental health) in terms of the minority stress model and explains that the minority individual is likely to be at odds with society because the dominant culture, social expectations, and other norms are not inclusive of the minority group (i.e. inclusive options for homosexual marriage and child bearing/rearing). Meyer (2013) offers the following tenets of minority stress theory:

In developing the concept of minority stress, researchers' underlying assumptions have been that minority stress is (a) unique—that is, minority stress is additive to general stressors that are experienced by all people, and therefore, stigmatized people are required an adaptation effort above that required of similar other who are not stigmatized; (b) chronic—that is, minority stress is related to relatively stable underlying social and cultural structures; and (c) socially based—that is, it stems from social processes, institutions, and structures beyond the individual

rather than individual events or conditions that characterize general stressors or biological, genetic, or other nonsocial characteristics of the person or group. (p. 5)

From here, there are three processes of minority stress: (a) external, objective stressful events and conditions (chronic and acute), (b) expectations of such events and the vigilance this expectation requires, and (c) the internalization of negative societal attitudes (Meyer, 2013). Meyer (2013) notes that other researchers have added a fourth process to this list which is a disclosure of one's sexual orientation or gender identity. Others have theorized that concealment of one's SOGI status can be a proximal stressor due to internalized psychological stress (Meyer, 2013). Proximal stressors are subjective to each individual as self-identity plays a central role. Manzer et al. (2018) cites the American Psychological Association (2012); Mayer et al. (2008); Morrison (2011); and Rutherford, McIntyre, Daley, & Ross (2012) as evidence of minority stress theory in practice: There is growing evidence that the constant homophobia and sexism experienced by those in the LGBTQ+ community is the greatest cause for harm and leads to psychological stressors including anxiety, depression, substance abuse, violence, and suicidal ideation.

Minority stress theory is important to discuss as it grounds research focusing on self-disclosure of SOGI status. For example, a woman may be in a same-sex relationship but not self-identify as a lesbian (proximal stress). However, others may interpret her actions as *homosexual* and apply a minority label, thus contributing to distal minority stress (Meyer, 2013). These proximal and distal stressors in terms of SOGI status can have drastic effects on the LGBTQ+ individual, thus it is imperative for medical providers to provide safe space of disclosure with their patients. By queering the

heteronormative view of medicine and acknowledging the minority stress placed upon members of the LGBTQ+ community, it becomes obvious that incorporation of SOGI information in healthcare visits helps to provide for the universal care of these individuals across the lifespan.

Chapter 3

Introduction

In the fall of 2019, the student researcher contacted the health center at the university inquiring about potential DNP project topics. The office manager conveyed that a new physician was working on editing the health history intake forms to include SOGI data. The intent was to have the form finalized and in circulation at the beginning of the winter 2020 semester. This provided the perfect opportunity for this student researcher to become involved in measuring how the inclusion of SOGI questions on an intake form influence the patient experience. Data collection for this study was designed to be as quick and unobtrusive as possible. The use of an emailed survey through the Qualtrics survey system was agreed upon as the quickest and most efficient method for collecting data. The health center already used the Qualtrics survey system and was familiar with establishing anonymous links, emailing the survey, and obtaining the results. The survey was designed to assess the overall patient experience including attitude, preferences, and knowledge base regarding the collection of SOGI data.

Sample and Setting

Inclusion criteria for this study was the participant had to be 18 years of age or older, a student at the local rural midwestern university, and a patient at the student health center during the winter 2020 and fall 2020 semesters. Patients from the entire SOGI spectrum were invited to participate. The sampling technique for this study was convenience sampling, and the anonymous online survey was sent to all patients who fit the inclusion criteria. A minimum of 10 participants were necessary to fulfill the requirements of the DNP scholarly project.

IRB Process/Approval

Limited IRB approval was obtained at the university at the beginning of the winter 2020 semester (a copy of the IRB approval document can be found in Appendix A). Data was collected through the use of the Qualtrics survey system, which is currently used by the health center to collect patient satisfaction surveys. Qualtrics provides the researcher with an anonymous survey link to email to participants to maintain confidentiality and anonymity in results. The Qualtrics survey management system automatically de-identifies the participant data when results are made available to the researcher. This student researcher created the survey and provided the health center office manager with an anonymous link, who then included that link in an email to student patients who had visited the health center in the designated time period. The landing page of the Qualtrics survey included the consent, which was accepted and implied once the participant clicked the arrow button to proceed to the survey. A copy of the consent is found in Appendix B. The only identifying information from the surveys are questions regarding birth sex and age, which was delineated into check boxes for age ranges (i.e. 18-25, 26-35, etc.). A copy of the survey questions can be found in Appendix C.

Design and Procedures

The intake procedure at this particular health center involved patients filling out an updated health history form before their visit with the provider. This updated health history form asked for general information regarding chief complaint, medical and surgical history, allergies, personal habits/lifestyle practices, and other pertinent information. The goal was to collect SOGI information before the patient meets the

Table 1:

Updated SOGI questions on intake form:

Name:	Preferred Name:
Birth Sex:	Do you consider yourself to be: (patient able to choose multiple options)? Heterosexual, homosexual, bisexual, transgender, queer, something else
In a sexual relationship?	Partner(s) are: (patients able to choose multiple options) Men, women, both

provider so the practitioner would be able to review the information and address the patient with appropriate preferred names, personal pronouns, background information, and questions. This updated form (table 1) was given to both new and established health center patients as a way to update all medical records. Patients were able to write in answers as applicable, selecting multiple options or filling in additional options as necessary.

This was a mixed-methods research study that included two demographic questions, mostly nominal data in the form of yes/no questions, and two questions that allowed for qualitative answers. Data collection was originally set to occur only in the Winter 2020 semester with two rounds of surveys emailed to qualifying patients. The first round of surveys were emailed in late February to those students who had visited the health center during the months of January and February 2020. The second round of surveys were emailed to students in late April to cover those patients visiting the student health center in March and April 2020. However, this data collection timeline was modified to include the Fall 2020 semester, as the SARS-CoV-2 pandemic closed the university in which this study was taking place in March 2020. By May 2020, only nine

participants submitted answers to the survey which did not complete the minimum requirement of the DNP project. An extension through the IRB committee was approved for data collection to continue through the end of the Fall 2020 semester. Therefore, additional surveys were sent at the end of September and again at the end of November (memo of IRB extension can be found in Appendix D).

Measures

There is no established tool to collect data regarding this change in clinical practice, so all the research questions included on the patient survey were from the researcher. Some questions were modeled after forms used by organizations such as the State of Michigan, the Fenway Institute, and others. All questions were approved by the researcher's DNP project chair, the medical director of the health center, and the IRB committee of the university. Since these are new questions, there is no data regarding the reliability and validity of the survey instrument. This is a limitation of the study that will be discussed further in chapter four.

Data Analysis

Nominal data predominated the type of data collected for this study. Data analysis included the use of simple summary statistics in the form of frequency tables (means, frequencies, percentages). The answers for qualitative data were analyzed for common themes and recorded in quotation marks from participating respondents. All data is de-identified when made available to the researcher by Qualtrics, nevertheless, the data will be also stored on a password locked computer in the personal possession of the researcher for a period of seven years and then will be destroyed.

Because the sample size is small (23 participants) and the data is predominately nominal, classical statistical tests are most appropriate for this analysis. Chi-square tests are typically used for this type of data analysis as it allows the researcher to consider the distribution of observations between two groups and how they compare to expected outcome values. The problem with the traditional chi-square test in this instance is that the results can be unreliable when the sample size is small or there are values of one or zero in the contingency table. Thus, the Fisher's Exact test is more appropriate for analyzing the data in this study. The Fisher's Exact test allows the researcher to calculate all possible probabilities and works with data in almost all contingency tables.

Summary

Data collection for this project was sent by email through the Qualtrics survey system to all student patients visiting the university health center during the winter 2020 and fall 2020 semesters. The benefits of Qualtrics includes ease of use, anonymity and de-identification of the participant, basic analysis, among others. Data collection for this project was complicated by the SARS-CoV-2 pandemic and data collection was extended to include both the winter and fall semester of 2020. In order to adapt to quickly changing recommendations by the CDC and the Michigan Department of Health, the university health center shifted to a primarily telehealth-based source of access for providing care. While some patients continued to be seen in person, a large number of patients were seen by telehealth, which was not anticipated by the researcher at the beginning of the data collection period. A further discussion of the impact of the SARS-CoV-2 pandemic will be discussed in chapter four in the limitations section.

Chapter 4

Introduction

This DNP project was designed to assess how the patient experience is influenced by the addition of SOGI related questions on a health history intake form. In effect, does answering questions influence the impending encounter with the provider? Research questions included: *How does answering sexual orientation and gender identity (SOGI) questions on a pre-visit form impact the patient experience in a Midwestern, rural university healthcare setting across different sexual orientation and gender identities?*

- *Do patients feel a greater sense of inclusivity?*
- *Do patients feel a greater sense of openness to discuss SOGI and other sensitive topics?*
- *Do patients feel SOGI is important to their healthcare?*
- *Do patients generally disclose their SOGI status?*
- *Do patients prefer alternative methods of SOGI disclosure?*

This DNP project aims to gauge the perceptions of patients in terms of written SOGI disclosure before the healthcare meeting. Despite the vast research synthesized in this paper regarding the importance of acquiring this sensitive information, it is prudent for practitioners to understand what their patients believe in terms of their SOGI status and the disclosure of such status. By obtaining baseline data from a spectrum of ages and SOGI statuses, practitioners are able to understand their patient-base and begin the task of normalizing these conversations.

Results

The survey was emailed in four batches to patients who visited the student health center in the winter semester of 2020 and the fall semester of 2020. A total of 124 emails were sent to eligible participants, 23 surveys were started and submitted, 18 surveys were completed in full. The results and analysis discussion is divided into five sections, one for each of the research subsections and a final section for the other survey questions. Demographics will be discussed in each research subsection, but overall there were 16 females at birth, two males at birth, 11 individuals identifying as heterosexual, one identifying as homosexual, five identifying as bisexual, one identifying as transgender, one identifying as queer, and one identifying as something else. Due to the small sample size and for simplicity in analysis, the SOGI groups have been combined into the following four categories: heterosexual; bisexual; homosexual, transgender; and queer, something else. Combining these categories gives a clearer picture in terms of data presentation, however nuances between these different SOGI groups is lost and a full discussion of those identifying as homosexual, transgender, queer, something else is not provided. It is not the intent of this project to silence these voices and delete differences, but it is a byproduct of a small sample size and low participation in the overall project. There were two questions where respondents were able to write in answers which will be discussed further in a later section.

Table 2:

Demographic comparison of patient attitudes toward disclosing SOGI information.

Demographic characteristic	Yes	No
<i>Subsection question 1: Do patients feel a greater sense of inclusivity?</i>		
All participants (N= 18)	11 (61%)	7 (39%)
Age		
18-25	10 (58.82%)	7 (41.18%)
45-49	1 (100%)	0
Birth sex		
Female	10 (62.5%)	6 (37.5%)
Male	1 (50%)	1 (50%)
SOGI status		
Heterosexual	8 (66.67%)	4 (33.33%)
Non-heterosexual	3 (50%)	3 (50%)
Bisexual	2 (50%)	2 (50%)
Homosexual, Transgender	0	1 (100%)
Queer, Something else	1 (100%)	0
<i>Subsection question 2: Do patients feel a greater sense of openness to discuss SOGI and other sensitive topics?</i>		
All participants (N= 18)	12 (67%)	6 (33%)
Age		
18-25	11 (64.71%)	6 (35.29%)
45-49	1 (100%)	0
Birth sex		
Female	11 (68.75%)	5 (31.25%)
Male	1 (50%)	1 (50%)
SOGI status		
Heterosexual	8 (66.67%)	4 (33.33%)
Non-heterosexual	4 (66.67%)	2 (33.33%)
Bisexual	3 (75%)	1 (25%)
Homosexual, Transgender	0	1 (100%)
Queer, Something else	1 (100%)	0
<i>Subsection question 3: Do patients feel SOGI is important to their healthcare?</i>		
All participants (N= 18)	11 (61%)	7 (39%)
Age		
18-25	10 (58.82%)	7 (41.18%)
45-49	1 (100%)	0
Birth sex		
Female	10 (62.5%)	6 (37.5%)
Male	1 (50%)	1 (50%)
SOGI status		

Heterosexual	8 (66.67%)	4 (33.33%)
Non-heterosexual	3 (50%)	3 (50%)
Bisexual	1 (25%)	3 (75%)
Homosexual, Transgender	1 (100%)	0
Queer, Something else	1 (100%)	0
<i>Subsection question 4: Do patients generally disclose their SOGI status?</i>		
All participants (N= 18)	9 (50%)	9 (50%)
Age		
18-25	8 (47.06%)	9 (52.94%)
45-49	1 (100%)	0
Birth sex		
Female	8 (50%)	8 (50%)
Male	1 (50%)	1 (50%)
SOGI status		
Heterosexual	6 (50%)	6 (50%)
Non-heterosexual	3 (50%)	3 (50%)
Bisexual	1 (25%)	3 (75%)
Homosexual, Transgender	1 (100%)	0
Queer, Something else	1 (100%)	0

Subsection Question 1: Do patients feel a greater sense of inclusivity?

This research question correlates to the following survey question: *The NMU student health center has recently incorporated sexual orientation and gender identity (SOGI) status on their health history intake forms. Do you feel a greater sense of inclusivity by answering this question on the initial form for your healthcare visit?*

For this subsection question, 61% of participants agreed that they felt a greater sense of inclusivity from being asked these SOGI questions, and 39% felt they did not. In terms of demographic analysis regarding SOGI, there is a difference in agreement among heterosexual versus non-heterosexual participants. The Fisher's Exact test is used to estimate the strength of associations between SOGI status and the sense of inclusivity. For this analysis, the null hypothesis (the expectation if there is no difference between sexual orientation groups) is that SOGI status is not associated with a greater feeling of

inclusivity, and we would expect an odds ratio different from 1. The results of the Fisher's Exact test on this question gives a sample odds ratio of 1.922, with a 95% confidence interval of (0.173, 22.393), and a p -value of 0.627. This estimated odds ratio implies that the odds of a heterosexual patient feeling more inclusivity is 1.922 times greater than the odds of a non-heterosexual patient feeling the same. Another way to think about this is that the odds ratio is the estimated odds of a heterosexual participant feeling a greater sense of inclusivity is 92.2% larger than the odds of a non-heterosexual participant feeling the same. It creates an interesting question when considering this data—why do heterosexuals feel more included by answering their SOGI status on health forms when heteronormativity is so present in our society? Is there a sympathetic or empathetic response for SOGI inclusion among heterosexual patients? Are individuals in the LGBTQ+ community skeptical of these questions because of past negative experiences? Further research into these questions would be enlightening.

The p -value is the probability of seeing test results as more extreme than observed, so an odds ratio further away from one in either direction given the null hypothesis is true. Therefore, with $p = 0.627$ and a confidence interval containing 1, there is little to no evidence of an association between SOGI status and a feeling of greater sense of inclusivity. While there is a rather strong association present, there is not enough evidence to claim that there actually is a true association here.

For the remaining demographics for this question, the focus will be on descriptive analysis. For birth sex, there is a higher proportion of females than males saying they feel a greater sense of inclusivity, but it is important to note that there were only two males who completed the study. In terms of age demographics, there is a similar

distribution to birth sex, with disparate counts by age groups. The majority of those in the 18-25 age group agreed that they felt a greater sense of inclusivity, and the lone participant in the 45-59 age group agreed as well. It is worth noting that all participants fell into these two age brackets with no one in the 26-44 age group or 60+ age group. To conclude the analysis for this section, the responses for this question are disaggregated by all SOGI groups. These results are very similar to what was seen by considering orientation by heterosexual or not-heterosexual, so these results are included for completion, but not discussed. A follow up question asked participants *“If you answered ‘Something Else,’ please write what you consider yourself to be.”* A free text box was included to allow participants to write in their own answers. Two participants wrote in answers, one was non-sensical and is not included in this analysis. The other participant wrote that they identified as “Pansexual.”

Subsection Question 2: Do patients feel a greater sense of openness to discuss SOGI and other sensitive topics?

This research question correlates to the following survey question: *Do you feel a greater sense of openness to discuss SOGI and other sensitive healthcare topics by answering this question on the initial form for your healthcare visit?*

For this question, 67% of respondents agreed that they feel a greater sense of openness to discuss other sensitive health care topics when compared to 33% who said they did not. Comparing responses of participants by orientation, we see there is no difference in proportion on answer counts. As there is no difference in groups the Fischer’s Exact test will not be used. With birth sex, the male participants are split in their responses and there is a sizable proportion of females responding yes. For age

group, the majority of the participants in the 18-25 age group agree that they feel a greater sense of openness in discussing SOGI status, much like in the inclusivity analysis. Finally, in terms of all SOGI groups, bisexual participants had a higher rate of agreement with this question when compared to heterosexual participants. However, with the small sample size, the inference is limited.

Subsection Question 3: Do patients feel SOGI is important to their healthcare?

This research question correlates to the following survey question: *Do you believe that disclosing your SOGI status is an integral part of your healthcare background and visit?*

This question had a breakdown very similar to the other overall results that we have seen with the previous questions. There was roughly a 60/40 split in yes/no responses for this question. The first subgroup analysis on general sexual orientation breakdown shows the same results as seen in the first sub-question (*Do patients feel a greater sense of inclusivity?*) and therefore, the entire section of results and interpretations applies here as well. To review, the Fisher's Exact test gives us a sample odds ratio of 1.922, with a 95% confidence interval of (0.173, 22.393) and a *p*-value of 0.627. In terms of gender identity, there is a slight change in the views of birth females on the *importance* of disclosing their SOGI status when compared to their *openness* of disclosure, but it is still above 60%. The two birth males are once again split on the issue. Age demographics are a bit closer to a 50/50 split in the 18-25 age group on the importance of disclosing SOGI status, but essentially 60% of participants agree with the question overall. When the data is disaggregated by SOGI status, the bisexual participants did not think it was as important as the other non-heterosexual participants.

As has been the case through the rest of the data, the majority of heterosexual participants have been in agreement about the importance of SOGI status on the pre-visit questionnaire.

Subsection Question 4: Do patients generally disclose their SOGI status?

In this last question, there is an even split in those that typically disclose their SOGI status and those who do not. Surprisingly, this split continues through disaggregating the data by sexual orientation. Because there are equal counts for each group, there is an odds ratio of 1 and an uninteresting result from the Fisher's Exact test. Comparing responses by birth sex also results in a 50/50 split. The 18-25 age group almost repeats the pattern, but there is a slight preference to not disclosing SOGI status. We conclude the look at the survey results by comparing all SOGI groups and see that most bisexual participants do not disclose their status.

Table 3:

Comparison of preferred method of SOGI disclosure

Demographic characteristic	Intake form	Face to face	Another way	Not disclose
<i>Subsection question 5: Do patients prefer alternative methods of SOGI disclosure?</i>				
All participants (N= 18)	13 (72%)	2 (11%)	2 (11%)	1 (6%)
Age				
18-25	12 (70.59%)	2 (11.76%)	2 (11.76%)	1 (5.88%)
45-49	1 (100%)	0	0	0
Birth sex				
Female	13 (81.25%)	1 (6.25%)	2 (12.5%)	0
Male	0	1 (50%)	0	1 (50%)
SOGI status				
Heterosexual	9 (75%)	1 (8.33%)	1 (8.33%)	1 (8.33%)
Non-heterosexual	4 (66.67%)	1 (16.67%)	1 (16.67%)	0
Bisexual	3 (75%)	0	1 (25%)	0
Homosexual,	0	1 (100%)	0	0
Transgender				
Queer, Something else	1 (100%)	0	0	0

Subsection Question 5: Do patients prefer alternative methods of SOGI disclosure?

This research question correlates to the following survey question: *If you had the opportunity to disclose your SOGI status in a healthcare visit, how would you prefer to disclose that information?*

The data in this section was not notable in terms of the Fisher's Exact test, so only data summaries will be examined here. The overwhelming majority of participants chose the intake form as their preferred method of SOGI status disclosure. Not disclosing SOGI status was the least preferred option (which only one participant chose) and is a clinically significant finding that will be discussed a bit later. Breaking down responses by sexual orientation shows that the majorities of both heterosexual and non-heterosexual participants were in agreement that an intake form was their preferred method of

disclosure. In terms of birth sex, 80% of birth females preferred an intake form for SOGI disclosure while birth males were split between face-to-face disclosure and not disclosing this information at all. There is also a fairly even spread of responses across the 18-25 age group. In terms of gender identity, the one transgender participant is one of two individuals who prefer face to face disclosure, but the expected distribution of disclosure methods follows expectations from previous breakdowns.

A follow up survey question is *“If you answered that you prefer to disclose SOGI information in another way, please write how you prefer to disclose it”* and a free text box was provided to allow patients to type in responses. There were two responses, one was non-sensical and is not included in this analysis. The other response is insightful: *“If it arises in conversation or is pertinent to the medical issue I’m there for, I will tell the doctor. But I would rather them not know if it is not relevant to why I am visiting.”*

Discussion

This was an observational study and had neither a random sample nor random assignment, so the researcher can only claim that the effects seen are associations within the sample and should not say that this is representative of all patients at this rural university’s health care center. The self-selection of participants in this study means there are plenty of unaccounted for variables that could mean these individuals are not representative of the population of interest. What makes a random sample random is that within the sample, there is an equal probability for individuals to participate in the study. Since this study lacked randomness, the researcher cannot try to extend the statistical results of the study to patients outside of this study. Additionally, due to the lack of random assignment, the researcher can only claim the results shown here are associations

and not causal relationships. The statistical analysis of the data in this study is too narrow to offer generalizability beyond the participants in this study.

Interestingly, the survey analysis shows that the opinions of respondents were consistent through the series of questions as evidenced by similar breakdowns of responses on multiple questions. It is reasonable to think that based on the responses, asking these questions on a pre-visit intake form is something to at least track further depending on how the health care practitioner will use the information. An interesting observation is that heterosexual participants largely agreed with many of the questions asked, which was unexpected not in the sense that they would be opposed to these questions, but rather that they may not perceive this information as relevant to their overall health. As a group, it seems that these SOGI questions were more important to heterosexual patients than non-heterosexual patients and further research would be warranted to see why this is the case. In terms of birth sex, a significant limitation in this study is the fact that only two birth males participated. Birth females seemed to follow a distinct trend majority agreeing with most questions, but there is not enough data to understand how birth males would respond. Perhaps the most interesting question to follow up on would be the preferred disclosure method. The responses to this question were the most one-sided of all questions with 72% of participants preferring the intake form for disclosure. Further investigation into why this is the case would be warranted as health centers shift toward more inclusive language and environments.

Only one participant in the study indicated that they do not prefer to disclose their SOGI status at all. This is important in terms of clinical practice. As health centers and providers work on inclusivity, it is clinically relevant to understand that a majority of

patients believe this information is relevant to their health needs and are comfortable sharing that information with their healthcare provider. Therefore, barriers to disclosing this information do not lie with the patient, but rather with the health care system.

Clinical Implications for Practice

This DNP project contributes to the conversation regarding the importance of inclusive language in an institutional medical setting. Communication forms the basis of all human interaction, and that language can be both helpful and harmful. The incorporation of inclusive language into all intake forms, sets the precedent that patients are more than their chief complaint. Questions regarding SOGI status provide the patient with an opportunity to maintain control over their identity and dictate who is privy that information. Inclusive language also sets the tone that individuals from the spectrum of SOGI status are welcome and accepted in that particular practice. This DNP project specifically contributes information regarding patient perceptions of SOGI information disclosure. Most patients surveyed felt that their SOGI status was pertinent information to disclose during a healthcare visit (65% vs. 35%), which is in line with the research presented in this paper. The 35% of patients who did not feel as if their SOGI status was integral information is an important representation of society. Not everyone is comfortable discussing these intimate details of their lives, and that is important to recognize and respect as well. The important thing is to continue to normalize these conversations for all patients and should work toward normalizing these conversations in each and every patient encounter. It is important for practitioners to look inward and reconcile their own attitudes and perceptions of individuals on the SOGI spectrum. It is also imperative that practitioners work to maintain familiarity with adapting terminology

and incorporate inclusive language into their patient interviews. As more practitioners incorporate this inclusive language into their practice, patients will begin to expect to have these types of conversations and disclose this information on a regular basis.

Recommendations for Future Research

Recommendations for future research should focus on normalizing the disclosure and discussion regarding SOGI status. The results of this DNP project indicate that work needs to be done in terms of general education of the public. There is a disconnect between the researchers promoting SOGI disclosure during healthcare visits and the 35% of patients who do not believe that this information is relevant in this setting. Future work and research should be focused on educating the public in terms of why this information is important to collect on a health history intake form. Additionally, effort should be spent in establishing terminology that accurately and adequately describes those who identify on the SOGI spectrum. Work should also continue to focus on the standardization of wording on printed materials provided to patients. Further studies into the attitudes and perceptions of both practitioners and patients should continue as a way to monitor the gap between research and implementation as evidenced in this DNP project.

Strengths

Strengths of this study include the study design in terms of patient anonymity and sampling. All patients meeting the requirements (over the age of 18 and a student at the university) were invited to participate in the study through an email invitation. The medical office manager of the student health center managed the email list to potential respondents so there is no breach of HIPPA confidentiality both in terms of who attended

an appointment at the health center and who would potentially answer the survey. As a result, a larger spectrum of respondents were invited to participate. An additional strength includes the mixed method of responses that were available to the respondent. All questions allowed for multiple options to be selected, and two questions allowed for respondents to write in their own responses and expand on their answers to previous questions. Unfortunately, only two out of the 23 respondents wrote in any qualitative answers and only one of those individuals provided relevant answers. A more qualitative study would prove beneficial in terms of further understanding the reservations held by some individuals to disclose their SOGI status.

Limitations

Despite the sizable base for potential respondents (124 emailed surveys) only a small portion of patients completed their survey (18 were completed, 23 were submitted). This small response rate could be explained by a variety of factors including timing of the emailed surveys (twice per semester), method of survey engagement (lost in email, or easily deleted/forgotten), environmental (global pandemic), and academic stressors among other reasons. This small sample size (and only two respondents identifying as male) make it difficult to generalize responses in any meaningful way. As such, this study is only applicable to this rural midwestern university, and further research in other settings would prove prudent. Additionally, the SARS-CoV-2 pandemic surged in the same month when the first round of surveys were sent out. The first batch of surveys were emailed at the end of February 2020 to all patients who had visited the health center from the beginning of the semester (mid-January) to that point (about six weeks). The surveys were sent out the week before spring break as the United States was beginning to

realize the severity of the SARS-CoV-2 virus. It is reasonable to assume that some patients had already gone home for spring break and did not answer the survey when they returned to campus because they either did not want to, did not see the email in their inbox, or believed that the survey was no longer available for them to take. The home state for the university placed restrictions for mandatory quarantine in mid-March of 2020 and the university quickly closed all in person classes and transitioned to remote learning. As such, the health center also pivoted their interactions with patients, moving to mostly telehealth access. The second round of surveys were sent out during finals week of April 2020. Only nine patients responded to the survey following these two rounds. It is reasonable to assume that some potential respondents did not answer the survey questions for the reasons listed above. One also has to assume that the closing of the university had a significant impact on the number of students accessing care at the health center. Assuming that most students went home during this time, and were not local to the area, the available pool of potential patients and respondents was drastically cut. Because of the poor response rate, an extension through the university IRB was approved to extend the data collection period to the end of the fall 2020 semester. Unfortunately, the intake form that was sent to telehealth patients was different from the physical form that was given to patients at the beginning of the data collection period. Sections for preferred name and birth sex were not included on the telehealth form emailed to patients before their virtual visit. This change was made by health center staff without the researcher's knowledge. This change impacts the answers provided by patients with a virtual visit because they did not have an opportunity to answer those questions. This change creates obvious discrepancy in the standardization of the

procedures and process of the DNP project, but it also creates an environment where not all participants encountered an “inclusive” health history form. Therefore, when asked questions about inclusivity at the student health center, patients with virtual visits may not have felt it was an inclusive experience because they were not asked questions allowing them to identify birth sex and preferred name. Responses were not able to be stratified according to visit type because mass shutdowns caused immediate changes in the way the student health center operated, and the leaders had to pivot to provide care to those patients. The researcher did not find out about virtual visits and different telehealth forms until after data collection had begun. It is impossible to know how survey results and statistics could have changed had all students been given the same form before their visit.

Additionally, the questions used on the survey sent to respondents were created by the student researcher and modeled after published surveys including the MiBRFSS, and those by the Fenway Institute, the CDC, and others. There is no established set of questions for assessing patient attitudes towards inclusive language and SOGI disclosure. Therefore, there is no way to establish validity and reliability for these questions in terms of reproducibility. Further research is warranted in creating a specific established set of questions used to gauge patient attitudes and perceptions to answering these types of questions on paper before meeting with a health care provider.

As previously discussed, this was a convenience sample, and as such participants were able to self-select to participate in the study, which was labeled as a study regarding SOGI disclosure status in the university health center. While the consent page explicitly mentioned that all responses were voluntary, anonymous, and would not affect current or

future care at the health center, it is not implausible to wonder if patients were uncomfortable answering the survey on the off-chance that it could be somehow linked to their health care visit. Because of the convenience sampling and the small sample size, the result of this study is very limited in terms of transferability of results. Individuals both within and without the educational, geographic, and generational cohorts discussed in this study may have different perspectives than those listed. The type of data provided by this study is also a limitation in the overall strength of the project. Finally, this study utilized nominal data which is considered the lowest level of data, and the fact that there was not a comparison group prevents more detailed statistical analysis from taking place. The student researcher was unable to survey patients regarding their attitudes of SOGI disclosure before the intake form was adapted and so the only group available to survey was those who had received the intervention. Thus, the available statistical analysis is limited to comparison tables and basic statistics of percentages of the whole.

Conclusion

Normalizing the conversation regarding SOGI information is a critical tool in the appropriate healthcare for all patients, but education needs to happen on both sides of the conversation. Not all healthcare providers believe that this is useful information to acquire, nor do all patients believe this is pertinent information to disclose. However, for those who believe in the importance of SOGI data collection, awareness and comfort with the language is critical. This terminology is ever evolving, and terms and phrases widely accepted a year ago may fall out of favor next year. Therefore, it is important that healthcare providers understand that this is a fluid spectrum of terminology that needs space and encouragement to change and evolve as thoughts and issues become identified

and resolved. As Drill et al. (2019) succinctly states “Inclusive language signals acceptance, recognition and welcome by the institution and thus, may decrease barriers to accessing health care, a notorious and documented obstacle for the LBGTQIA+ community” (p. 395). Normalizing these conversations decreases these barriers in a handful of ways. First, patients who may feel alone, marginalized, or left out of the mainstream may find comfort in seeing open space for them to establish their own identity outside of preconceived notions of appearance. Asking each patient how they identify in terms of SOGI status not only normalizes the conversation for the patient and the provider, but also for the office support staff. The background and education level of support staff in any medical office setting may not be in direct patient care so more inclusive language on paperwork in terms of SOGI status can help increase the comfort level of support staff interacting with patients from a variety of backgrounds. One small change in the daily practice of an office can have a profound impact on the system processes and policies through encouraging comfort and flexibility surrounding inclusive care. This shift in language affects not only office to patient interactions, but also influences interactions among office staff, providers, and administrators. This influence on support staff and providers may also help those individuals navigate their own SOGI status and bias, easing anxiety and discomfort around those topics of discussion.

In closing, this DNP project aims to contribute to the conversation regarding inclusive language in the health care setting and serves as a stepping off point for practitioners and patients to begin to normalize these delicate and sensitive conversations. The incorporation of SOGI inclusive language is warranted through multiple disciplines including health care, places of employment, schools, prisons, and others. These

conversations are intimate, complex, and fluid, but the concrete information provided by the addition of inclusive language on an intake form provides a starting point for all parties involved (Bjarnadottir et al., 2017). This DNP project responds to the charge set forth by the multitude of experts cited within this paper and contributes to the overall discussion regarding routine SOGI disclosure through inclusive paperwork in a healthcare setting.

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Appendix A

IRB Approval Letter

**Office of Graduate Studies and Research**

1401 Presque Isle Avenue

Marquette MI, 49855

906-227-2300

906-227-2315

www.nmu.edu/graduatestudies**Memorandum**

TO: Meghan Digneit
Nursing Department

CC: Melissa Copenhaver
Nursing Department

FROM: Lisa Schade Eckert
Dean of Graduate Education and Research

DATE: February 7, 2020

SUBJECT: IRB Proposal HS20-1093
“Representation Matters: An Examination Into How The Patient Experience is Impacted by the Inclusion of Sexual Orientation and Gender Identity Questions On a Health History Intake Form”
IRB Approval Date: 2/7/2020
Proposed Project Dates: 2/2/2020 – 5/1/2020

Your proposal “Representation Matters: An Examination Into How The Patient Experience is Impacted by the Inclusion of Sexual Orientation and Gender Identity Questions On a Health History Intake Form.” has been approved by the Northern Michigan University Institutional Review Board. Please include your proposal number (HS20-1093) on all research materials and on any correspondence regarding this project.

If you find that modifications of investigators, methods, or procedures are necessary, you must submit a Project Modification Form for Research Involving Human Subjects before collecting data. Any changes or revisions to your approved research plan must be approved by the IRB prior to implementation.

Appendix B

Consent Form

Informed Consent:

Investigator: Meghan Digneit, (906) 360-4333, mhawkins@nmu.edu

Dear NMU Health Center Patient:

I would like to invite you to participate in a research study. The purpose of this study is to explore the patient experience and attitude toward the addition of sexual orientation and gender identity (SOGI) questions to a health history intake form.

I am inviting you to participate in this study because you were a patient at the NMU Student Health Center in the Winter 2020 or Fall 2020 semester. All patients who had either a telehealth or an in-person visit to the health center during this time are invited to participate.

If you agree to participate, you will be asked to complete a brief 2-5-minute online survey that follows this consent information. This survey will be completely anonymous, with SOGI information as the only identifying information. All survey information is de-identified when made available to the investigator through use of the Qualtrics survey system. Additionally, all survey information will be kept on an encrypted hard drive and will be saved for seven years on a password protected computer. The goal is to publish the results of this study.

There are no major risks involved in participation. However, survey questions regarding SOGI status can bring to light a variety of strong emotions. Emotional distress is not intended by this study, and participation is completely voluntary and anonymous. You are not likely to gain direct benefits from participation in this study. You will not incur any costs as a participant in this research study and you will not be paid for being in this research study.

If you have any further questions regarding your rights as a participant in a research project, you may contact Dr. Lisa Eckert (leckert@nmu.edu) Dean of Graduate Education and Research at Northern Michigan University. Any questions you have regarding the nature of this research project will be answered by the investigator.

By completing the survey questions that follow, you acknowledge that you have read the above "Informed Consent Statement." You also acknowledge that the nature, risks, demands, and benefits of the project have been explained to you. You understand that you are able to ask questions and are free to cease answering survey questions at any time without incurring negative consequences.

Thank you very much for your consideration.

Sincerely,

Meghan N. Digneit, BSN, RN
Doctor of Nursing Practice Candidate
Northern Michigan University
mhawkins@nmu.edu, 906-360-4333

Dr. Lisa Eckert
Dean of Graduate Education and
Research
Northern Michigan University
leckert@nmu.edu, 906-227-2300

Appendix C

Survey Questions

1. Do you consider yourself to be:
 - a. Heterosexual (that is straight)
 - b. Homosexual (lesbian or gay)
 - c. Bisexual
 - d. Transgender
 - e. Queer
 - f. Something else
 - g. I prefer not to answer
2. If you answered “Something else” for question one, please write what you consider yourself to be: (space to write in answer)
3. The NMU student health center has recently incorporated sexual orientation and gender identity (SOGI) status on their health history intake forms. Do you feel a greater sense of inclusivity by answering this question on the initial form for your healthcare visit?
 - a. Yes
 - b. No
4. Do you feel a greater sense of openness to discuss SOGI and other sensitive healthcare topics by answering this question on the initial form for your healthcare visit?
 - a. Yes
 - b. No
5. Do you believe that disclosing your SOGI status is an integral part of your healthcare background and visit?
 - a. Yes
 - b. No
6. When visiting a healthcare provider, do you generally disclose your SOGI status?
 - a. Yes
 - b. No
7. If you had the opportunity to disclose your SOGI status in a healthcare visit, how would you prefer to disclose that information?
 - a. Indicating SOGI status on a health history intake form
 - b. Disclosing in a face to face conversation with medical staff/providers
 - c. Disclose this information in another way
 - d. I prefer not to disclose my SOGI status
8. If in question seven you answered that you prefer to disclose SOGI information in another way, please write how you prefer to disclose it: (space to write in answer)

Appendix D

IRB Modification Memo

**Office of Graduate Studies and Research**

1401 Presque Isle Avenue

Marquette MI, 49855

906-227-2300

906-227-2315

www.nmu.edu/graduatestudies**MEMORANDUM**

TO: Meghan Digneit
Nursing Department

CC: Melissa Copenhaver
Nursing Department

FROM: Lisa Schade Eckert
Dean of Graduate Education and Research

FROM: Lisa Schade Eckert,
Dean of Graduate Studies and Research

RE: Modification to HS20-1093
Original IRB Approval Date: 2/07/2020
Modification Approval Date: 9/10/2020
“Representation Matters: An Examination Into How The Patient Experience is Impacted by the Inclusion of Sexual Orientation and Gender Identity Questions On a Health History Intake Form”

Your modification for the project “Representation Matters: An Examination Into How The Patient Experience is Impacted by the Inclusion of Sexual Orientation and Gender Identity Questions On a Health History Intake Form” has been approved by the Northern Michigan University Institutional Review Board. Please include your proposal number (HS20-1093) on all research materials and on any correspondence regarding this project.

Any additional personnel changes or revisions to your approved research plan must be approved by the IRB prior to implementation. Unless specified otherwise, all previous requirements included in your original approval notice remain in effect.

Until further guidance, per CDC guidelines, the PI is responsible for obtaining signatures on the COVID-19 Researcher Agreement and Release and COVID-19 Research Participant Agreement and Release forms.