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“It's Always in the Back of your Mind”:
LGBTQ Partners' Experiences of Discrimination in Health Care for Serious Illnesses

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Abstract

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Purpose: This dissertation examines the experiences of lesbian, gay, bisexual, transgender, or queer (LGBTQ) adults caring for a partner receiving healthcare for a serious illness. Although discrimination in health care and health inequities experienced by LGBTQ people are well-documented, less is known about healthcare for serious illness. This study aims to help fill that gap by analyzing partner reflections on their experiences, focusing on the influences of socio-political factors, such as heteronormative culture, relationship recognition laws, and healthcare organization policies guiding the identification of legal next of kin.

Methods: Data include a purposive sample of interviews with LGBTQ caregiving partners (n=57) who described either experiences of discrimination or anticipatory concerns about discrimination prior to healthcare interactions. The data were gathered from April 2012 through

June 2013. Study participants received care in 20 states plus the District of Columbia. Data were analyzed using interpretive description and thematic analysis qualitative methods.

Results: Two analyses were conducted in this study. First, legal consciousness was used as a theoretical framework to examine reciprocal social processes in which partners and clinicians create, interpret, comply with, and resist law within healthcare interactions. This analysis yielded three themes: 1) awareness of legal status and expectations of (il) legality, 2) presumptive political (un)safe zones, and 3) legal grey areas. Second, perceived discrimination provided a theoretical framework to analyze how partners identify and interpret discrimination or potential discrimination in interactions with clinicians. Partners were found to experience three types of discriminatory communications or behaviors: 1) overt and intended, 2) covert and duplicitous, and 3) covert and unconscious. Further, nonverbal communication was identified as one way in which discriminatory attitudes were expressed by clinicians.

Discussion and Implications: This study demonstrates that LGBTQ partners experience discrimination in healthcare interactions in both overt and covert ways. Partners' efforts to anticipate, mitigate, identify, and interpret discrimination in the already difficult setting of healthcare for serious illness represent undue burden on LGBTQ partners compared with their heterosexual married counterparts. The results indicate that policy and practices should be improved to better support LGBTQ partners and reduce health inequities.

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Dedications

To the people who participated in the Caring for Partners Study, and to the many people whose experiences of discrimination have not been shared, who all deserve unwavering acceptance, care, respect, dignity, and health.

Also, in memory of my grandfather, Dante Coscia, who, though unable to witness my completion of this degree, has been with me all along the way.

CHAPTER 1

INTRODUCTION

“...LGBT people have been so systematically discriminated against, misunderstood, and (at best) ignored within the health system that when we walk into a practitioner's office or a hospital room we don't assume that we're starting at neutral in the interaction, because we know better.”

(Dunham, 2014, para. 6)

“For some, vulnerability is a cage, which traps their bodies and the all too confining perception of others. For others, [vulnerability] is a lens, through which differences can be appreciated and diversity embraced. Although it might be too much to ask, perhaps you might want to consider vulnerability as a mirror. In seeing your own reflection, you may discover that, similarly to that of your patients, your path is no less fragile, no less tenuous, and no less uncertain.”

(Chochinov, 2012, p. 1)

This dissertation examines the experiences of lesbian, gay, bisexual, transgender, or queer (LGBTQ)¹ adults in healthcare settings where their partners are receiving care for a serious illness or injury (hereafter referred to as serious illness). Although the impact of discrimination on the health and healthcare experiences of people who identify as LGBTQ is well-documented (Daniel & Butkus, 2015; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013; Institute of Medicine, 2011; Krehely, 2009; Lambda Legal, 2010; U.S. Department of Health and Human Services, n.d.), research focused on the needs and experiences of LGBTQ people

¹ I recognize the limitations of the LGBTQ acronym as a “catch-all” for a range of sexual orientations and gender identities. The acronym is used in this dissertation with an understanding of its inadequacies and the intention to have it represent the fullness of non-heteronormative sexual orientations and gender identities. Recruitment materials for the study from which the data for this dissertation were derived, used the acronym “LGBT” in outreach materials. I added the “Q” to the acronym to broaden its scope to include people who identify as queer or gender queer. Some references and quotations used in this dissertation use only LGBT. Importantly, one participant in the study identified as two-spirit.

receiving health care for serious illnesses is limited. The data in this study were collected prior to the federalization of marriage equality but during a time of rapid change regarding relationship recognition laws (April 2012-June 2103). Further, the analyses and writing of this dissertation was completed during a particularly rancorous political period of backlash against the LGBTQ community, i.e., the 2016 Presidential campaign and after the election of the current President. Over this period, explicitly discriminatory agendas have been emboldened by rhetoric and political actions from the highest levels of U.S. government (Lichtblau, 2016; Walsh, 2017). Examples of efforts to discriminate against LGBTQ people have taken three primary forms: 1) introduction of “bathroom bills,” which would restrict the use of public space by transgender people (Kralik, 2017; Landsbaum, 2017); 2) passage of so-called “religious freedom” laws allowing private businesses and organizations to discriminate based on religious beliefs (Cason, 2017; Sanchez, 2016); and 3) attempts to repeal the federal mandate requiring states to recognize same-sex marriage (Cadei, 2017), including a particularly robust case that will be heard by the Texas Supreme Court, which argues that the City of Houston should be able to refuse spousal benefits to city employees (Ura, 2017). These efforts to roll back social and political gains make the future of LGBTQ rights and inclusion uncertain. This context for partners’ experiences and my analyses will be covered in more depth in Chapter 3 in a section on the study context, and serves as the sociopolitical backdrop for the dissertation results.

Denzin (2017) recently declared a need for critical qualitative scholarship that morally informs disciplines and interventions that help transform injustices. This dissertation engages that call by using qualitative methods to elucidate the burden carried by LGBTQ partners with the aim of sensitizing clinicians to the fact that interactions with LGBTQ people occur along the trajectory of their (and the people in their social networks) past experiences, discriminatory and

not, with the healthcare system. Therefore, interactions with clinicians do not occur in isolation, and are necessarily interpreted through a cloud of ambiguity. The multiple ways that discrimination can be expressed (overtly, covertly, intended, or unconscious) contribute to the ambiguity. In the context of uncertainty, partners are exposed to both overt and covert communication and behaviors from clinicians that force them into a space where questions about their legitimacy and authority as caregivers and decision-makers must be negotiated within themselves and in relationship to clinicians. Understanding more about this interpretive process of recognizing (or not) experiences of discrimination provides rich insight into partners' experiences. Discrimination is central to this study because without a focus on the communication and behaviors through which it is expressed, it might otherwise go unnoticed and unaddressed in healthcare settings.

Given the rapid shifts in social acceptance and legal rights for LGBTQ people, along with the political debate and backlash that have accompanied them (Drake, 2013; Krehely, 2009), identifying and understanding ways in which discrimination emerges and persists is important. Discrimination in healthcare settings for patients with serious illness provides a meaningful site for examination: first, macro-level relationship recognition laws relate to the inclusion of LGBTQ people in the care of their partners and propagate mezzo-level organizational policies identifying legal next of kin, which have to be rapidly interpreted and applied in healthcare settings for serious illness (Chapter 4); and second, at the micro level, biases held by clinicians²

² In this dissertation, I use the term “clinicians” in a very broad manner. I am most interested in partners’ experiences with healthcare staff with clinical responsibilities, such as doctors, nurses, nursing assistants, emergency medical technicians, and social workers. However, I also recognize the ways in which administrative staff provide important functions at the frontline of the clinical setting, sometimes being the first person partners interact with upon arrival at the hospital. Because I see all personnel as integral to healthcare institutions and partners’ experiences within them, I use the term clinicians in reference to all staff working in the clinical setting.

regarding the legitimacy of LGBTQ partnerships are revealed through the questions and ruminations that linger for caregivers in reflections on clinical interactions (Chapter 5).

In this dissertation, I analyze interviews with 57 LGBTQ adults about their experiences caring for seriously ill partners in healthcare settings. The perspectives of participants provide insight about how people in the vulnerable position of having a partner who requires care for a serious illness perceive their risks for and experiences of discrimination. Although participants also described supportive actions by clinicians, the primary focus of this dissertation is on discrimination. Without their perspectives, knowledge of discrimination in health care is hampered, and interruption of practices that contribute to health inequities is impossible. Additionally, without these caregiver insights, even well-intentioned clinicians might be unaware of how deeply clinical interactions are embedded in sociopolitical contexts and biases about LGBTQ people and their relationships. Clinicians might be unaware of how these contexts influence the starting point of interactions with LGBTQ people, as Dunham (2014) points out in the quote at the beginning of this chapter.

Motivation for the Study

The impetus for this study came after the tragic experience of Charlene Strong in Seattle, WA (Chansanchai, 2009; Labella & Singh, 2008; Strong, 2007). In 2006, Kate Fleming, Strong's partner of 10 years was brought to Harborview Medical Center (HMC) after she drowned in the basement of their home due to a flash flood. When Strong arrived at HMC, she was told by a social worker that she was not permitted to see Fleming or receive medical information about her condition because she was not biological family or a designated legal next of kin. It took hours until clinicians could reach Fleming's sister who gave permission for Strong to be included in Fleming's medical care. After being transferred to an intensive care

unit, Fleming's heart stopped. The care team attempted to resuscitate her for 2 hours before Strong had to make the difficult decision to discontinue resuscitation efforts. A physician involved with Fleming's care recalls nurses questioning "the validity of Charlene's role in decision-making," given that she was "not even family" and "just [Kate's] partner" (Labella & Singh, 2008, p. 971).

Strong's experience struck a personal chord for me, a queer-identified social worker living in Seattle, a city with a progressive reputation. I was also employed by University of Washington, which operates HMC. My place of work was at HMC, as a member of a research team focused on improving end-of-life care and communication. The fact that Strong had this experience at HMC, a teaching hospital that is known to handle a high volume of complicated cases, did not fit with my expectations or assumptions. Furthermore, the fact that it was a social worker who excluded Strong was irreconcilable with my understanding of social work's professional codes of ethics (International Federation of Social Workers, 2012; National Association of Social Workers, 2008). For me, social work's ethical principle of social justice precluded such an overt act of discrimination, particularly when clinical colleagues at HMC were assuring me that it was not standard practice to exclude LGBTQ partners unless there was a reason to think that doing so was in the best interest of patients. Also, the time during a serious illness or before death is particularly difficult for those close to the patients receiving care. The context of serious illness makes decisions about the legitimacy of LGBTQ partnerships even more ethically salient, adding moral weight to decisions that risk patients dying without the people closest to them or increasing stress on caregivers. Surely risking Fleming dying without her partner beside her could not be deemed in her best interest, even if hospital policy restricted Strong's right to be present. In this unsettled space, the question that arose for me was: If this

happened at an academic hospital in Seattle, what are LGBT people's experiences like in more conservative places in the U.S.?

My assumptions that an academic clinical setting in a city with a progressive reputation would be relatively insulated from such overt discrimination were quickly doused. A Google search yielded another case at another hospital operated by the University of Washington. In 2005, Sharon Reed was prevented from being with her dying partner JoAnn Ritchie by a nurse who said that Reed's presence was agitating Ritchie (Sullivan, 2010). The nurse prevented Reed from being with Ritchie despite legal documentation establishing Reed as Ritchie's durable power of attorney for health care (DPOA) and the approval of Ritchie's physician for Reed to be included in her care. Reed was not able to be with Ritchie when she died.

The story of Janice Langbehn and her partner Lisa Pond more explicitly represents the biases that underlie clinician decisions to reject the legitimacy of LGBTQ partnerships (Parker-Pope, 2009). Also from Washington State, Langbehn and Pond were vacationing in Miami, Florida in 2007 when Pond collapsed because of a hemorrhagic aneurysm. Langbehn was informed by a hospital social worker that she was "in an antigay city and state" and would need to provide her DPOA paperwork to see Pond or receive information on her condition. Despite her Washington-based physician faxing the legal paperwork to the Florida hospital and the doctor's advocacy on behalf of Langbehn and Pond, she and their children were only allowed a 5-minute visit with Pond while last rites were administered. She was not with Pond when she died. The fact that these women were excluded from the care of their partners, even with documentation of their status as legal next of kin in two of the cases, raises the question about the degree to which legally recognized relationships provide protection against heteronormative biases that are deeply embedded in society in general and in healthcare institutions specifically.

The data for this study were collected before federalized marriage equality was established through a U.S. Supreme Court ruling on *Obergefell v. Hodges* (Liptak, 2015), and not all the participants in this study had legal documentation. However, participants' reflections on their experiences demonstrate that they enter healthcare interactions with law- and policy-based concerns about whether their partnerships will be recognized and individual-level fears that they will not be respected.

These multi-dimensional concerns represent an undue burden on partners to prepare for healthcare interactions and advocate for their inclusion. The concept of undue burden is taken from The Belmont Report (1978) on research ethics and applied to discrimination in health care. The Belmont Report states that justice should be assessed based on the extent to which equal individuals are treated equally and that an injustice has occurred when a burden is unduly imposed because of an individual's identification with a social group. Participants in this study described burdens placed on them that would not be required of their heterosexual married counterparts. For example, partners were asked to retrieve documentation of their legal status (e.g., marriage certificate or DPOA), sometimes before they were given information about their partners' medical status, and in one case, before a participant could consent for his partner's urgently needed medical treatment. The fact that it is highly unlikely that a heterosexual married partner would be asked to retrieve a marriage certificate before being included in care demonstrates that LGBTQ partners are not being treated as equals and that obstacles to their inclusion in care represent undue burdens. Participants' awareness of differences in how clinicians perceive their legal status and their legitimacy as legal next of kin provides the foundation for the analyses in Chapter 4 based on the concept of legal consciousness.

The ways in which macro- (e.g., LGBTQ partner legal status) and mezzo- (e.g., hospital policies regarding the identification of legal next of kin) level factors influence micro-level clinical interactions and individual experiences require analyses framed using an ecological person-in-environment perspective (Bronfenbrenner, 1977; Kondrat, 2002; Spencer & Grace, 2016; Ungar, 2002). Spencer and Grace (2016) emphasize the socio-structural influences on clinical interactions by modifying a socioecological model for healthcare interactions to include four sources of influence on interactions: 1) state and policy (e.g., health policy), 2) organizational (e.g., practice culture, location of organization), 3) patient-provider communication (e.g., racial concordance, assessments of social worth), and 4) individual (e.g., patient and clinician gender, race age, socioeconomic status) (p. 103). Importantly, in this model clinicians and patients are framed as individuals who are independently embedded within wider social contexts and whose interactions are also embedded and influenced by the social environment.

Discriminatory policies, and social norms about gender, sexuality, and family all influence clinical, and ultimately the health and well-being of LGBTQ people (Daniel & Butkus, 2015; Farmer & Yancu, 2015; Krehely, 2009; Lambda Legal, 2010; Meyer & Northridge, 2007; van Ryn, 2002). Important to this analysis is the idea that for members of marginalized groups, awareness of one's social and political position in relation to their environment is a constant. Laws regarding relationship recognition and organizational policies guiding the identification of legal next of kin represent macro and mezzo expressions of discrimination for LGBTQ people through their institutionalization of heteronormative family structures. A long history of discrimination in healthcare settings creates context for clinician perceptions of the legitimacy of

LGBTQ partnerships and LGBTQ partners' healthcare experiences (Farmer & Yancu, 2015; Harvey & Housel, 2014; Institute of Medicine, 2011; Lambda Legal, 2010).

Drawing on interviews with LGBTQ adults whose partners received health care for a serious illness, I examine the influence of macro-, mezzo-, and micro-level influences on LGBTQ partners' experiences in healthcare settings. This dissertation analyzes partners' experiences in the context of multi-dimensional sociopolitical influences. In the following chapter, I will provide an overview of the theoretical framework and concepts guiding this study, including ecological approaches to the social determinants of health, and scholarship on heteronormativity and discrimination in health care. In Chapter 3 I discuss the methods utilized in this study, focusing on the study context and methods of data analysis. Chapters 4 and 5 describe the study results. Chapter 4 utilizes the concept of legal consciousness to examine partners' perceptions about how law and policy function in their lives and influence their experiences of health care for serious illness, demonstrating that participants describe substantial awareness of their legal status and related concerns about their vulnerability to exclusion. The results in Chapter 5 demonstrate how partners interpret discrimination (overt and covert types, and the role of nonverbal communication) and frame partners' efforts to identify and interpret discrimination. Finally, in Chapter 6, I summarize the study findings and discuss related policy and practice implications.

CHAPTER 2

THEORETICAL FRAMEWORKS

The current chapter provides the theoretical and empirical foundation for the dissertation in four sections. First, I present a brief rationale for examining discrimination against LGBTQ partners in the interest of informing more inclusive and equitable health policies and healthcare practices. The second section includes summaries on literature about general LGBTQ health inequities and LGBTQ health inequities related to serious illnesses, using empirical literature on the topic to inform this dissertation. Third, I discuss ecological approaches to the social determinants of health (SDOH) to emphasize political determinants of health (PDOH), which provide the theoretical basis for my critical approach to analyzing partner experiences in the context of laws and organizational policies and practices informed by heteronormativity. The fourth section focuses on discrimination in health care. The chapter concludes with a summary of the theoretical lens that guided the analyses in this dissertation.

Ethics and Health Inequities

My perspective on this study was deeply informed by my training in social work and bioethics. Social work has clear ethical obligations to work for social justice (International Federation of Social Workers, 2012; National Association of Social Workers, 2008), which extend to social welfare research related to inequities in health (Rine, 2016; Uehara et al., 2013). The professionalization and ethical obligations of the newer field of bioethics are less established, but it is well-accepted that bioethical practice and scholarship must address social injustices (Azétsop & Rennie, 2010; Brazg, Dotolo, & Blacksher, 2014; Danis, Wilson, & White, 2016). In a call for bioethicists to speak out against race-based health inequities, Danis, Wilson,

and White (2016) have stated that, “Concern for justice has been one of the core commitments of bioethics. This commitment is manifest in an obligation to promote health equity... Differences in health that are avoidable, unfair, and unjust represent inequitable health” (p. 5).

Understanding inequities in health that are avoidable and unfair as social injustices is central to SDOH frameworks and applications of SDOH aimed at reducing inequities (Marmot, 2005; Rine, 2016; Ruger, 2004).

Discrimination is an example of one such cause of health inequities (Foglia & Fredriksen-Goldsen, 2014; Krieger, 1999; Nuru-Jeter, 2015; Williams & Mohammed, 2009; Williams, Yu, Jackson, & Anderson, 1997). The source of discrimination against LGBTQ people is heteronormativity. Heteronormativity refers to social norms that assume and reify heterosexual partnerships as the normal or natural foundation of familial relationships (Hebl, Law, & King, 2010; Utamsingh, Richman, Lattanner, & Chaikind, 2016; Yep, 2003). Yep (2003) stated that because heteronormativity is integrated into the central values and expectations of our society, it functions as “the quintessential force creating, sustaining, and perpetuating the erasure, marginalization, disempowerment, and oppression of sexual others” (p. 18). It is ubiquitous and reified socially, politically, discursively, and acts as a marginalizing mechanism for those who do not fit within the scope of heteronormative assumptions (Yep, 2003; Mink, Lindley, & Weinstein, 2014).

The ubiquitous nature of heteronormativity ensures that clinicians embedded in a socio-cultural set of norms about heterosexuality are influenced by these norms; resulting in conscious and unconscious biases, discrimination, and ultimately health inequities. Partners’ attempts to navigate a healthcare setting fraught with heteronormativity requires what Furlotte, Gladstone, Crosby, and Fitzgerald (2016) identified as an extra “expenditure of energy” (p. 7) in their study

of Canadian LGBTQ older adults' experiences with long-term care. Furlotte, et al. (2016) described extra energy expended by LGBTQ older adults, compared with their heterosexual counterparts, to ensure their well-being in long-term care settings. These expenditures are represented in three types of activities: 1) hiding their identity, 2) assessing environments for discrimination, and 3) placating discomfort with or educating others about LGBTQ people. Participants in this study described similar expenditures, such as preparing for clinical encounters with the anticipation of discrimination, demonstrating their legitimacy as partners, and identifying and interpreting discriminatory or potentially discriminatory interactions with clinicians. To emphasize the ethical valance of the phenomenon of energy expenditures as an injustice based on heteronormativity, I refer to it as an undue burden.

Heteronormativity influences the lives of LGBTQ people at all levels of social life. At the macro and mezzo levels, it informs presumptions and legal definitions about who ought to be recognized as “family” and “spouse,” and legal next of kin in healthcare settings. Because health care providers rely on legal hierarchies for determining who is able to receive medical information about a patient or provide surrogate medical decision-making when patients are incapacitated (Beauchamp & Childress, 2009), partners who do not have a legally recognized relationship (e.g., marriage or durable power of attorney for health care) are at risk of exclusion from the care of patients who are not able to request the involvement of their partners. Such exclusion based on heteronormative biases, particularly when it results in increased stress and suffering for partners near the end of life, represents a failure to provide ethical or equitable care.

LGBTQ Health Inequities

A significant amount of research has demonstrated that people who identify as LGBTQ are at greater risk for several illnesses and worse health outcomes than are their heterosexual and

cisgender counterparts (Fredriksen-Goldsen et al., 2013; Harvey & Housel, 2014; Institute of Medicine, 2011; Northridge & Meyer, 2007; U.S. Department of Health and Human Services, n.d.). Examples of such evidence include higher risks for smoking and its concomitant illnesses (Upton et al., 2009; Youatt, Johns, Pingel, Soler, & Bauermeister, 2015), mental health issues (Balsam, Molina, Beadnell, Simoni, & Walters, 2011; Hoy-Ellis & Fredriksen-Goldsen, 2017), some types of cancer (Burkhalter et al., 2016; Quinn, Sanchez, et al., 2015), and other chronic diseases (Garnero, 2010; Institute of Medicine, 2011; Kates, Ranji, Beamesderfer, & Dawson, 2015).

More proximal to the topic of this dissertation is research focused on LGBTQ people's experiences with care for serious illness and at the end of life. As recently as 2006, Smolinski and Colón (2006) noted that, aside from the AIDS literature from the 1990s and early 2000s, little was known about the healthcare experiences and especially the end-of-life care needs of LGBTQ people. An exception is the work of Boehmer and Case (2004) that focused on the experiences of lesbian and bisexual women who were treated for breast cancer (n=39). They found that the participants described apprehensive relationships with clinicians due to concerns about discrimination. Clinicians did not ask the women about sexual orientation, missing an opportunity to decrease some of the apprehension and provide more comprehensive care. In a 2012 review of the literature, Harding, Epiphaniou, and Chidgey-Clark (2012) found that available studies (n=11) focused primarily on lesbian and gay patients receiving treatment for cancer, with limited inclusion of people identifying as bisexual, and no studies inclusive of transgender care needs. They concluded that the literature focused on the needs of clinicians to ask about sexual orientation, "avoid heterosexist assumptions, and recognize the importance of partners in decision making" (Harding et al., 2012, p. 602).

Much of the more recent literature about end-of-life care includes qualitative, interview-based research focused on the need for and challenges to advanced care planning in the LGBTQ community. It describes the need to be legally designated as next of kin to circumvent exclusionary relationship recognition laws that up until 2015 did not universally allow federal recognition of same-sex marriages, as well as the relatively low prevalence of advanced care planning by LGBTQ people (Cartwright, 2011; Cartwright, Hughes, & Lienert, 2012; Hash & Netting, 2007; Hughes & Cartwright, 2014; Lawton, White, & Fromme, 2013; Rivera, 2011; Stein & Bonuck, 2001; Wahlert & Fiester, 2013). This literature has informed the current study by explaining the link between relationship recognition laws, advanced care planning (e.g., via establishing DPOA), and the risk of exclusion for LGBTQ caregivers in healthcare settings. This body of research, however, minimally incorporates reflections from LGBTQ people on their experiences with discrimination in healthcare settings. Rather, the focus has largely been on the need for advanced care planning, and attitudes, facilitators, and barriers to advanced care planning in the LGBTQ community.

A smaller body of literature addresses the unique caregiving needs of LGBTQ people due to alternative family structures (e.g., families of choice created because of rejection from biological families) and a need to recognize partners and close friends as significant caregivers (Brotman et al., 2007; Rawlings, 2012). Studies regarding the relationship between LGBTQ people's caregiving needs, limitations in the law, and practice competencies that would facilitate partner inclusion, provide an important foundation for this study. Collectively, this literature examines macro, mezzo, and micro influences on partner inclusion informing the ecological approach to this study. Inherent in all the literature related to LGBTQ health inequities is a concern for discrimination against LGBTQ people based on heteronormativity. This dissertation

aims to fill gaps in the literature on the broader experiences and needs of LGBTQ partners when receiving care for serious illness. This dissertation further contributes to the literature by including the voices of LGBTQ caregivers about policies and practices related to the care of those with serious illnesses.

Ecological Approaches to Social Determinants of Health

SDOH is a useful and increasingly utilized framework for analyzing multi-dimensional influences on individual and population health. The widely referenced World Health Organization's (WHO) report on SDOH (2008) is an institutional recognition of theoretical perspectives that have long considered multi-dimensional influences on health (Krieger, 2001; Link & Phelan, 1995; McLaren & Hawe, 2005; Navarro, 2009a; Pearlin, 1989). The SDOH as defined by the WHO are, "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" (World Health Organization, n.d., para. 1). Examples of social determinants include a range of resources and living conditions that have been shown to influence health (Centers for Disease Control and Prevention, 2014; Marmot, 2005; Navarro, 2009b; Raphael, 2006), most often focusing on issues regarding access to life-sustaining resources or safe and healthy human living conditions. Life-sustaining resources would include the availability of and access to food and safe housing, for example. These resources are "social" in the sense that inequities in access to resources for good health are the result of differentiation of the social status of individuals and groups based on socially salient characteristics, such as race, income, or gender. These differences in access to prerequisites for health demonstrably contribute to poorer health outcomes for groups with less social status (Wilkinson & Pickett, 2006). More specifically, people with less social status have less access to determinants that contribute to good health (e.g., nutritious food, safe housing) and

more exposure to determinants that contribute to poor health (e.g., environmental toxins, unsafe drinking water).

Political Determinants of Health

More than 10 years ago Raphael (2006) critiqued approaches to research utilizing the SDOH framework that focus on individual causes of poor health, such as genetic predisposition or health behaviors, rather than investigating larger sociopolitical processes that contribute to inequities. Looking at the social “causes of the causes” (Braveman & Gottlieb, 2014, p. 19) requires emphasis on the macro-level SDOH, which are addressed in the second half of the WHO’s definition and identified as the structural “forces and systems” that influence living conditions and inequities (World Health Organization, n.d., para. 1). Scholars interested in investigating the macro-level have termed them PDOH and defined them as the policies and social processes that affect health (Kickbusch, 2015; Mackenbach, 2014; Martyn, 2004; Raphael, 2006). These range from broad, diffuse aspects of sociopolitical contexts, such as welfare regimes or political ideologies (e.g., comparisons of population health between predominantly capitalist and socialist nations), to measuring the outcomes of more delimited policies intended to influence health (e.g., taxing sugary beverages or increasing funding for tobacco cessation campaigns).

Regardless of the scale of the policies or processes of interest, research attentive to PDOH contrasts with research myopically focused on individual-level influences on health. Emphasizing structural-to-individual influences on health, driven by empirical evidence of structural inequities, renders untenable theories that rely heavily or exclusively on altering individual behaviors to improve disparate health outcomes. Attention to PDOH enriches

research and research-informed praxis by adding important variables that contribute to and maintain inequities.

In her historical account of social epidemiological theory, Kreiger (2011) places her own work in a scholarly trajectory toward more vigorously ecological approaches that consider multiple dimensions on individual and population health, calling her approach ecosocial. Krieger's ecosocial approach provides a good example of research that is deeply concerned with PDOH and illuminates the complex pathways from macro- to individual-level health indicators. Krieger's work on the multi-dimensional influence of racism on health identifies six levels of pathways for discrimination ranging from global conditions to individual characteristics and interactions. Importantly, she does not analyze differences in health outcomes based on race and ethnicity (individual characteristics), rather she focuses analysis on the social phenomenon of racism (macro), expanding perspective on the causes of poorer population health outcomes (from genes and behaviors) to the social construct of race as well as the social pathways by which racism influences health outcomes.

Research on PDOH, however, presents methodological challenges. These challenges primarily involve difficultly defining and measuring broad social processes and complex social policies. Much of the research done on SDOH has been conducted by public health researchers who have employed quantitative approaches to identify influences on health at the population level. When political determinants are considered, they have been constructed as categorical variables such as type of welfare regime, amount of political participation by citizens, or level of income inequality. For example, one aspect of a study conducted by Herian, Tay, Hamm, and Diener (2014) examined the relationship between the predominant ideologies in state governments in the U.S. and the health of its citizens. Their findings showed that state ideology

influenced health, with more liberal state governments being positively related to better health. At the finest scale, albeit a less frequent type of analysis, researchers have measured the effects of individual policies on health (Crossland, 2016; Pega, Kawachi, Rasanathan, & Lundberg, 2013; Raifman, Moscoe, Austin, & McConnell, 2017). A recent example that is relevant to this dissertation is the work of Raifman and colleagues (2017) who found a significant correlation between decreases in adolescent suicide attempts and states with policies allowing LGBTQ partners to be legally married. Conceptualizing PDOH as categorical and/or quantitative variables, however, risks missing opportunities to understand political processes and their influences on health from the perspective of those affected by the PDOH of interest, suggesting a need for qualitative methodologies that can provide needed insights from those perspectives. Mackenbach (2014) states that analyzing the relationship between multidimensional influences on health requires an interdisciplinary approach and a combination of qualitative and quantitative methodologies.

Fit with Social Work

Consideration of the social conditions that influence health have been an enduring part of health-oriented social work practice. Seen as a foremother of medical social work, Ida Cannon was hired in 1905 by Dr. Richard Cabot, a physician at Massachusetts General Hospital who was concerned that the social situations of patients was interfering with their medical treatment (Bartlett, 1975). Due to his service with a children's agency, Dr. Cabot had had some previous exposure to the ways in which social workers based their interventions on social assessments. He envisioned embedding social workers in health care settings to assist patients for whom their living conditions were complicating their medical care, particularly those with tuberculosis, neurological issues, venereal diseases, injuries related to occupational hazards, and pregnancies

among unwed women (NASW Foundation, n.d.; Praglin, 2007). Many of these patients were immigrants with limited ability to speak the English language and lived in overcrowded housing. Although Cannon's work preceded development of contemporary theories and ecological models of broad social determinants of health, her orientation to practice and the multi-dimensional social influences on health were clearly prescient. Maintaining a holistic view of the multidimensional influences on health and well-being continues to be central to the practice of social work (Brazg et al., 2014; Craig, Bejan, & Muskat, 2013; Moniz, 2010; Moore et al., 2017; Rine, 2016). Although developed in the field of public health, ecological approaches to understanding wide-ranging influences on health reflect social work's broad understanding of health and the conditions that contribute to health disparities.

Ecological approaches to SDOH that emphasize PDOH provide a structure to orient the analyses in this dissertation. The empirical literature documenting LGBTQ health inequities demonstrates the effect of discrimination on downstream health outcomes. While poor health outcomes for LGBTQ people provide a foundation for this study, the focus here is on multidimensional processes that at once create health inequities and represent inequities in the delivery of health care for serious illness. Informed by the modified social ecological model of medical decision-making developed by Spencer and Grace (2016), Figure 1 provides the framework for the analyses in this study. Macro- and mezzo-level factors are analyzed as influences on the perceptions of clinicians and partners as well as the context for their interpersonal interactions. In Chapter 4, legal consciousness is used as a conceptual tool to analyze participants' perceptions of clinicians' views about their legal status and the legitimacy of their partnerships, based on laws, social norms, and organizational policies and practices. Although the focus of Chapter 5 more deeply analyzes the interpersonal aspects of clinical

interactions, macro- and mezzo-level influences are identified as sources of assumptions and biases informing participants' interpretations of healthcare interactions.

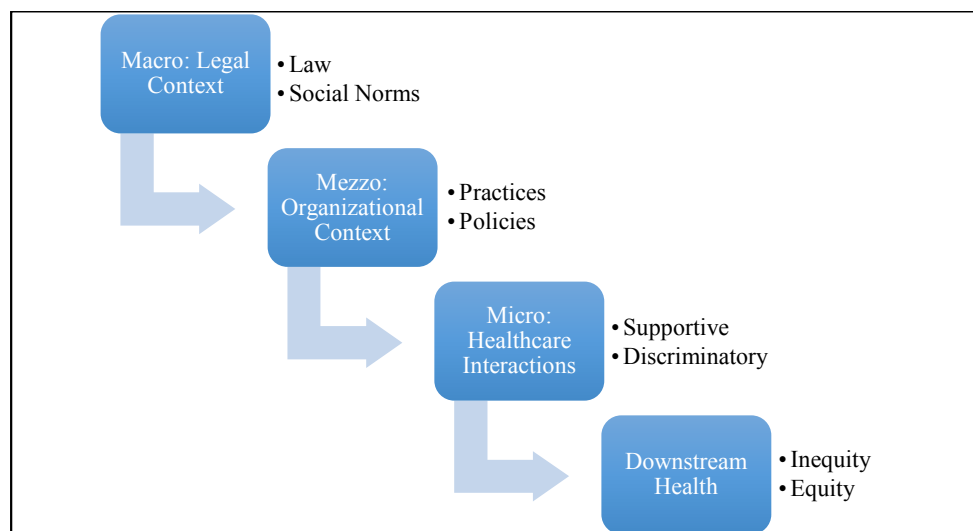


Figure 1: Macro-to-Micro Influences in Health Care

Sexual Orientation and Gender Identity

Before moving to a discussion of the literature on discrimination and health, it is important to note the failure to include sexual orientation and gender identity as social characteristics relevant to health. Despite substantial consideration of social characteristics that influence health and well-being, the inclusion of sexual orientation and gender identity (beyond dichotomous male/female conceptualizations of gender) as relevant characteristics is remarkably absent from SDOH literature. A key example of this absence is observable in the often-referenced final report of the WHO Commission on the Social Determinants of Health (2008), which made no mention of sexual orientation or gender identity as a social characteristic related to differential health outcomes. This omission stands in contrast to the “continuing, pervasive, violent abuse, harassment and discrimination” LGBTQ people experience in every region of the world (United Nations Human Rights Council, 2015, para. 2).

Commentaries in the *American Journal of Public Health* argue that the preponderance of evidence of increased health risks necessitates the inclusion of sexual orientation and gender identity as highly relevant to SDOH frameworks (Logie, 2012; Pega & Veale, 2015). In reference to the WHO final report, Logie (2012) urged the WHO to pay particular attention to the health-related disparities that have been demonstrated to be associated with sexual orientation. Similarly, Pega and Veale (2015) advocated for the WHO to include gender identity as a social determinant of health and to “develop and implement dedicated recommendations for addressing gender identity to improve health equity” (p. e61). As with other social determinants, research is needed to show the social conditions, from macro- to micro-level influences, that result in to health inequities for LGBTQ people.

Discrimination and Health

Discrimination is defined as inequitable treatment (van Ryn et al., 2011; Williams & Mohammed, 2009) based on biases or negative beliefs both conscious and unconscious, pertaining to social characteristics (van Ryn et al., 2011). Williams and Mohammed (2009) write that the ideology of racism (a predominant form of discrimination) “often leads to the development of negative attitudes and beliefs toward racial outgroups (prejudice), and differential treatment of members of these groups by both individuals and social institutions (discrimination)” (p. 21). The same is true of discrimination based on other socially salient characteristics, such as sexual orientation and gender identity. Systemic discrimination based on social characteristics is illustrative of pervasive discrimination LGBTQ people face globally (United Nations Human Rights Council, 2015). Important to the study of discrimination in health is consideration of the pathways through which discrimination affects inequities in health

outcomes. The following section describes some conceptual tools from the literature on discrimination in health that inform this study.

Conceptualizing Discrimination and Its Effects

Discrimination embodies a complex phenomenon that has been studied and conceptualized in overlapping and mutually informing ways. It is outside the scope of this dissertation to provide a comprehensive overview of the literature on discrimination. However, in this section I summarize some concepts relevant to this study, namely everyday discrimination, microaggressions, anticipatory stress, and vigilance. The pervasiveness of discrimination in the lives of people belonging to traditionally marginalized groups has led scholars to conceptualize and measure discrimination in its “everyday forms.” A notable contribution to this topic is the work of Williams and colleagues (1997) who developed a measurement scale for everyday discrimination. The scale has been adapted and applied to research on race- and ethnicity-based discrimination (LeBron et al., 2014; Lewis, Aiello, Leurgans, Kelly, & Barnes, 2010; Peek, Nunez-Smith, Drum, & Lewis, 2011), as well as discrimination based on sexual orientation (Gordon & Meyer, 2008). Although they did not make reference to the Everyday Discrimination Scale, Swim, Pearson, and Johnston (2007), tested a conceptually similar phenomenon they call “everyday heterosexism” in the lives of LGBTQ people (p. 31).

The everyday nature of discrimination compounds the difficulty of recognizing negative experiences, particularly covert discrimination, as notable or outside of one’s expectations. The theory of microaggressions similarly explores the complexity of discrimination, its presentation in both overt and covert forms, and the influence of these forms on the everyday experiences of the individual who is the subject of discrimination (Sue, 2010). The expectation for

discrimination represents an additional and chronic stressor with negative health effects for people regularly experiencing it.

In their seminal work on racial discrimination, Sue et al. (2007) defined microaggressions as “brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults” (p. 271). The authors also created a taxonomy of microaggressions including the following: 1) microassaults, which represent explicit and intended discriminatory actions (e.g., referring to someone with a derogatory racial slur); 2) microinsults, which are rude or insensitive communications that demeans a person’s identity (e.g., a teacher failing to acknowledge students of color in the classroom or implying a person of color did not obtain a job by their own merit by asking a question like, “How did you get your job?”); and 3) microinvalidations, which include communications that “exclude, negate, or nullify” the thoughts, feelings, or experiences of a person of color (e.g., a statement to a person of color reflecting “colorblindness” or claiming a person of color is “too sensitive” in response to a subtle discriminatory experience) (Sue et al., 2007, pp. 274-275). Microaggressions have also been shown to be experienced by LGBTQ people (Balsam et al., 2011; Nadal, 2013; Nadal, Rivera, & Corpus, 2010; Nadal, Whitman, Davis, Erazo, & Davidoff, 2016; Platt & Lenzen, 2013; Sue, 2010). Nadal, Rivera, and Corpus (2010) described eight ways in which LGBTQ people might be subjected to microaggressions: 1) use of heterosexist or transphobic terminology, 2) endorsement of heteronormative or gender-conforming culture or behavior, 3) assumption about a universal LGBTQ experience, 4) exoticization of LGBTQ people, 5) discomfort or disapproval of LGBTQ experiences, 6) denial that heterosexism or transphobia occurs, 7) assumption of sexual pathology or abnormality, and 8) denial of expressions of discrimination via heterosexism or transphobia (p. 491). Because

health care for serious illness represents a specific setting bound by professional and institutional prohibitions against discrimination, and because interactions between partners and clinicians tend to be limited to exchanges focused on matters pertaining to medical care, few forms of microaggressions are readily observable in the data for this study. However, microaggressions provide a useful way to conceptualize the everyday and sometimes subtle nature of LGBTQ partners' likely past exposure to discrimination.

Research focused on the adaptation and coping strategies that targets of discrimination employ illustrates some of the ill effects that chronic, everyday exposures to discrimination have on health and well-being (Nuru-Jeter et al., 2009; Nuru-Jeter, 2015; Williams & Mohammed, 2009). Williams and Mohammed (2009) have defined anticipatory stress and vigilance as two such stressors. Their research has demonstrated disproportionate psychological (stress) and physical burdens (poor health outcomes) experienced due to both anticipated and experienced racism. Vigilance involves a heightened feeling of being on guard and scanning for threats of discrimination. Anticipatory stress refers to worry or concerns about the threat of discrimination. Of the deleterious effects of stress-related discrimination, Nuru-Jeter (2015) noted that, "the 'wear' associated with chronic racial discrimination...is linked with poor health, especially among those who are vigilant about, or expecting, mistreatment" (para. 3). Therefore, when these stressors occur in healthcare organizations, these organizations contribute to health inequities, failing in their mission to improve health.

Policy as Context for Partners' Experiences

In the context of this dissertation, both formal and informal policies at the macro and mezzo levels provide the context within which partners are receiving and perceiving their health care. Relevant formal policy would include relationship recognition laws (macro) and hospital

policies (mezzo) regarding identifying legal next of kin. Relevant informal policy would include discretionary implementation of law and policies by clinicians regarding inclusion of LGBTQ partners as legal next of kin (mezzo).

As described in Chapter 1, the years in which the people who participated in this study received their health care was a time of rapid change regarding LGBTQ relationship recognition laws. Healthcare organizational policies were also enhanced to include explicit non-discrimination policies for LGBTQ people (Obama, 2010; The Joint Commission, 2014) and require cultural competency trainings to encourage equity in healthcare practices (Klein & Nakhai, 2016; Snowden, 2010). As evidenced by persistent health inequities based at least in part on discriminatory practices in health care, laws and policies insufficiently address recalcitrant biases and discriminatory actions.

The management of biases in healthcare practice within organizations is complex. The fact that policies are rarely specific enough for clinicians to unambiguously and uniformly apply them to all circumstances requires clinicians to use their discretion regarding how to interpret and implement policies (Hoyle, 2014; Lipsky, 2010; Tummers & Bekkers, 2014). Lipsky's (2010) work on street-level bureaucracy describes discretion as informal policy implementation by frontline workers in bureaucratic, hierarchical organizations. The concept of street-level bureaucracy has been applied to analyses of many social service and public sector contexts, often focusing on discrimination that results from clinician discretion. For example, Masters, Lindhorst, and Meyers (2014) and Watkins-Hayes (2009) utilized street-level bureaucracy to analyze the processes by which racial discrimination and moral judgements are formulated and expressed by social service employees in government offices. Healthcare organizations share

similar features with welfare offices, such as being overtly hierarchical and complex organizations that operate with varying levels of discretion allowed to frontline workers.

Although the literature on street-level bureaucracy has not explicitly intersected with work on PDOH, the concept of street-level bureaucracy has been applied to examine discrimination in healthcare settings (Hoyle, 2014; O’Sullivan, 2016). The most applicable example is Hoyle’s (2014) application of Lipsky’s work in a qualitative study examining how nurses in a Scottish urban hospital acted as front-line bureaucrats. She demonstrated that discretion is a notable “feature within the front-line practice of nursing staff” and that the discretion they exercised resulted in adaptations of policies to better meet the needs of patients and their work environment (p. 189). These adaptations are an example of informal policy implementation.

Similarly, the stories of women barred from being with their partners described in Chapter 1 illustrate how street-level decisions can be harmful to LGBTQ partners (Chansanchai, 2009; Parker-Pope, 2009; Sullivan, 2010). Stories about negative experiences become shared narratives in the community, contributing to realistic fears of discrimination in health care when a partner is seriously ill. Two of the three stories in Chapter 1 are notable because in both of these cases, the women barred from their dying partners’ bedsides had documentation of DPOA and lost lawsuits that alleged discrimination. In both cases, the court upheld clinicians’ rights to determine the best interests of patients over the rights of partners to be included in the care of their loved ones (Parker-Pope, 2009; Sullivan, 2010). All three cases demonstrate the role of clinical discretion in interactions. This present study contributes to the literature on discretion by analyzing partners’ reflections on situations in which clinicians used their discretion to advocate for and support partners, rather than focusing on discrimination alone. Partners’ perceptions of

discrimination and support from clinicians is the focus of the analyses presented in Chapter 5. Justification for this micro-level focus is provided in the following section.

Conclusion

The theoretical framework guiding this dissertation represents a unique intersection of theoretical work on PDOH, street-level bureaucracy, and discrimination in health. These three topics provide conceptual tools that will be used to consider how participants perceive multidimensional influences on their healthcare experiences. van Ryn and Fu (2003) emphasized the need for more research on the “interpersonal mechanisms or mediators of institutionalized discrimination” (p. 252). The analyses presented in this dissertation aim to contribute to this gap in the literature by examining how macro and mezzo level influences affect partners’ anticipation and experiences of discrimination in healthcare interactions. In the following chapter, I describe my specific research questions and the methods of analysis used to answer them.

CHAPTER 3

METHODS

Research Design

In this study, I applied interpretive description (ID) as a methodological approach to qualitative analysis of interview-based data. An interview-based design was chosen because of the rich data generated by interviews with participants who provided their interpretations of their experiences in the retelling of them. I chose interpretive description because of its utility as an applied approach to qualitative inquiry and its eclectic use of research methods. Thorne (2008) describes ID as an approach that:

straddles the chasm between objective neutrality and abject theorizing, extending a form of understanding that is of practical importance to the applied disciplines...ID arose from a need for an applied qualitative research approach that would generate better understandings of complex experiential clinical phenomena within nursing and other professional disciplines concerned with applied health knowledge or questions “from the field.” (p. 26-27)

Like the profession of nursing from which ID was developed, social work’s praxis involves an exchange “between practice and knowledge” (Thorne, 2008, p. 26). ID provides a pragmatic approach to answering applied questions about care received by LGBTQ patients and their families within a qualitative interview data collection format. This study aims to address a gap in the research and policy-level literature regarding healthcare services for seriously ill LGBTQ people and their partners.

In addition to its applied focus, ID includes the use of research methods from a variety of traditions, emphasizing that researchers should choose the methods that best suit an endeavor to understand phenomena in the clinical setting with the aim of improving practice. From this perspective, this study uses methods from thematic analysis (Attride-Stirling, 2001; Braun &

Clarke, 2006) to describe partners' experiences with the ultimate goal of sensitizing clinicians to the overt and covert ways in which partners might be perceiving discrimination.

Research Questions

The analyses in this dissertation were guided by the following research questions:

Analysis 1 (results in Chapter 4)

1. How do LGBTQ people describe experiences of legal consciousness in healthcare settings when caring for seriously ill partners?
2. How do discriminatory policies or discrepant policy implementation in clinical settings influence partners' legal consciousness?

Analysis 2 (results in Chapter 5)

- How do LGBTQ people identify and interpret discrimination or potential discrimination by clinicians in healthcare interactions?

Study Context

The publicized experience of Charlene Strong at the institution where I worked (Chansanchai, 2009) was the initiating event for this inquiry into partners' experiences with serious or end-of-life care. An initial review of the literature on the needs and/or experiences of LGBTQ partners with end-of-life care revealed scant research on the topic, including few studies of first-person accounts of healthcare experiences. This dearth of research led to the development of the Caring for Partners: LGBT Study (referred to hereafter as CFP), which was funded by the National Palliative Care Research Center (PI: Ruth Engelberg, PhD). This study was a mixed-methods approach aimed at the following: 1) identifying barriers and facilitators to

decision-making, 2) describing psychological symptoms associated with decision-making, and 3) assessing the feasibility and effectiveness of using innovative recruitment strategies for a hidden population. The data analyzed in this dissertation were collected in the context of this larger study. My involvement in the development and implementation of the study is discussed in more detail below (see Reflexivity).

Also mentioned in Chapter 1, the period during which this study was developed and data were collected was a time in U.S. history during which relationship recognition laws were changing rapidly. Massachusetts was the first state to legalize same-sex marriage in 2003, with federal recognition established in 2015. In the time between, rights afforded to LGBTQ partners varied greatly depending on their states of residence. In Washington State, for example, due to the advocacy work of Charlene Strong and others (Labella & Singh, 2008), a state domestic partner registry was established in 2009 that provided all the benefits of marriage within Washington State – referred to as the “everything but marriage” law. In February 2012, the state legislature passed a bill that created marriage equality. However, an injunction was established on the issuance of marriage licenses for same-sex couples due to the submission of a referendum requiring a public vote. In November 2012, Washington State became the first location in the country to put same-sex marriage to a popular vote, and voters approved marriage for same-sex couples, finally allowing the issuance of marriage licenses. Table 1 provides a snapshot of the legal landscape the year in which data collection was initiated. The bolded state abbreviations indicate that at least one study participant received health care in that state.

Table 1

State Relationship Recognition Laws in 2012

<i>States with marriage</i>	<i>CT, DC, IA, MA, ME, MD, NH, NY, VT, WA</i>
<i>States with marriage equivalence</i>	<i>CA, DE, HI, IL, NV, NJ, OR, RI</i>
<ul style="list-style-type: none"> <i>e.g., civil unions, registered domestic partnerships allowing all the rights of marriage within the state</i> 	
<i>States with limited rights</i>	<i>CO, WI</i>
<ul style="list-style-type: none"> <i>e.g., registered partnerships for dependent coverage on health insurance policies</i> 	
<i>States with no rights</i>	<i>AL, AK, AZ, AR, FL, GA, ID, IN, KS, KY, LA, MI, MN, MS, MO, MT, NE, NM, NC, ND, OH, OK, PA, SC, SD, TN, TX, UT, VA, WV, WY</i>

(see Knauer, 2012, p. 753)

Bold = states with at least one study participant

Human Subjects Considerations

The CFP study was approved by the University of Washington Human Subjects Division. I was listed as an investigator on the study. However, because data collection is complete and interview transcripts are de-identified, the study is closed and no longer under review.

Methods

Study sample

Participants were eligible for the CFP study if they self-identified as someone who was in a same-sex relationship with someone who had experienced a serious illness, during which they were unable to make their own care decisions within the 5 years prior to participation. Recruitment relied on a variety of outreach efforts. Participants were recruited through LGBTQ-specific (n=9) and non-LGBTQ-specific (n=1) organizations, online and social media (e.g., Craigslist, Facebook, Yahoo Groups) (n=28), print media (n=1), healthcare providers (n=5), as well as word-of-mouth through friends and partners (n=12). One participant did not recall how they had learned about the study.

My study sample is based on two criteria. First, the sample includes participants from the CFP study who chose to be interviewed in-person or via telephone (n=66), rather than by completing an online survey. Second, only those who were interviewed and described concerns about or experiences of discrimination in their interviews were ultimately included in the study sample (n=57, 86%). The study sample includes two sub-samples: 1) participants who described anticipatory concerns about discrimination prior to healthcare interactions but did not experience discrimination (n=14, 25%), and 2) participants who described any form of overt or covert discrimination (n=43, 75%). Thorne (2008) described purposive sampling as an effort to identify a group of individuals in a specific setting who “by virtue of some angle of the [experience of

interest] that might help us better understand” the phenomenon under study (p. 90). In this case, in-person or telephone interviews allowed for a deeper analysis of partners’ experiences of discrimination (anticipated and experienced) in the context of health care for serious illnesses.

Semi-structured interviews were conducted in-person or by telephone by a research coordinator who is a social worker and identifies as queer (see Appendix 1: Interview Guide). Interviews were transcribed verbatim by a professional transcriptionist, leaving in vocalized pauses such as “umm” and “well.” When needed, I also reviewed the audio recordings to attempt to clarify information or participants’ tone of voice to better understand the conversation between the interviewer and participants.

Participants were mailed a questionnaire following the interviews, which requested demographic information on the participants and their partners (patients). Participants could check multiple responses as well as provide open-ended responses to indicate their racial, sexual orientation, and gender identities. Additional open response options were available for all three of these items. Most of the participants (70.2%) identified as white and non-Hispanic (75.4%). The participants primarily identified their sexual orientation as either gay (40.4%) or lesbian (33.3%), with most participants identifying their gender as female (42.1%) or male (38.6%). Few participants identified as bisexual, queer, two-spirit, or transgender. Participants were relatively well-educated with over half (57.9%) completing a 4-year college or graduate degree (Table 2).

Table 2

Participant Demographics

<i>Participant Demographics (n=47)</i>	<i>N (%)</i>
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Age*	<i>Mean (SD)</i>	50.3 (14.0)
	<i>[range]</i>	[52]
Ethnicity	<i>Not Hispanic</i>	43 (91.5)
	<i>Hispanic</i>	4 (8.5)
Race**	<i>White</i>	40 (85.1)
	<i>Black or African American</i>	7 (14.9)
	<i>American Indian or Alaskan</i>	
	<i>Native</i>	3 (6.4)
	<i>Other</i>	2 (4.3)
Sexual	<i>Gay</i>	23 (48.9)
	<i>Lesbian</i>	19 (40.4)
Orientation**	<i>Bisexual</i>	4 (8.5)
	<i>Queer</i>	2 (4.3)
	<i>Two-spirit</i>	1 (2.1)
	<i>Transgender</i>	1 (2.1)
Gender**	<i>Female</i>	24 (51.1)
	<i>Male</i>	22 (46.8)
	<i>Transgender</i>	2 (4.3)
Education***	<i>High School</i>	3 (6.5)
	<i>Some college or trade school</i>	10 (21.7)
	<i>4-year college</i>	13 (28.3)
	<i>Graduate school</i>	20 (43.5)

Missing=10 for items, unless otherwise indicated

**n=57 for this item only*

***Multiple responses included*

****n=46 for item*

Participants were also asked demographic information about their partners who were the patients being treated in this context. The majority of them were identified as white and non-Hispanic (78.9%) with sexual orientation as either gay (35.1%) or lesbian (38.8%), and female (45.6%) or male (38.6%). Only a few were identified as bisexual, queer, or transgender. A smaller proportion of partners than participants had completed a 4-year college or graduate degree (38.6%) (Table 3).

Table 3

Partner Demographics

<i>Partner Demographics (n=48)</i>		<i>N (%)</i>
<i>Age*</i>	<i>Mean (SD)</i>	<i>55.8 (17.5)</i>
	<i>[range]</i>	<i>[66]</i>
<i>Ethnicity</i>	<i>Not Hispanic</i>	<i>45 (93.8)</i>
	<i>Hispanic</i>	<i>3 (6.3)</i>
	<i>White</i>	<i>38 (79.2)</i>
	<i>Black or African American</i>	<i>6 (12.5)</i>
<i>Race**</i>	<i>American Indian or Alaskan Native</i>	<i>2 (4.2)</i>
	<i>Asian</i>	<i>2 (4.2)</i>
	<i>Biracial</i>	<i>1 (2.1)</i>
	<i>Gay</i>	<i>20 (41.7)</i>

Sexual Orientation**	<i>Lesbian</i>	22 (45.8)
	<i>Bisexual</i>	6 (12.5)
	<i>Queer</i>	1 (2.1)
Gender**	<i>Female</i>	26 (54.2)
	<i>Male</i>	22 (45.8)
	<i>Transgender</i>	1 (2.1)
	<i>Gender queer</i>	1 (2.1)
Education	<i>Some high school</i>	2 (4.2)
	<i>High school</i>	6 (12.5)
	<i>Some college or trade school</i>	18 (37.5)
	<i>4-year college</i>	13 (27.1)
	<i>Graduate school</i>	9 (18.8)
Deceased	<i>Yes</i>	19 (39.6)

Missing=9 for items, unless otherwise indicated

**n=47 for item*

***Multiple responses included*

In addition to personal demographic information, participants were asked for information about their relationships. Participants overwhelmingly reported that they were in long-term relationships with their partners. Most relationships were 10 years or longer (50.9%), with 28.1% being over 20 years. Notably, only 28.1% of participants indicated that they had some form of legal relationship recognition. However, 60.4% endorsed having DPOA or healthcare proxy, a rate higher than those found in a recent study of LGBTQ baby boomers (34%)

(American Society for Aging, 2010). See Table 4 for additional detail on participants' relationship characteristics.

Table 4

Relationship Characteristics

<i>Relationship Characteristics (n=48)</i>		<i>N (%)</i>
	<i>6 mo to 1 year</i>	<i>2 (4.2)</i>
	<i>1 to 4 years</i>	<i>8 (16.7)</i>
	<i>4 to 7 years</i>	<i>6 (12.8)</i>
<i>Length</i>	<i>7 to 10 years</i>	<i>3 (6.3)</i>
	<i>10 to 15 years</i>	<i>8 (16.7)</i>
	<i>15 to 20 years</i>	<i>5 (10.6)</i>
	<i>20 years or more</i>	<i>16 (33.3)</i>
	<i>Registered domestic partner</i>	<i>12 (25.0)</i>
<i>Legal Recognition*</i>	<i>Civil union</i>	<i>1 (2.1)</i>
	<i>Married</i>	<i>3 (6.3)</i>
	<i>Yes</i>	<i>29 (60.4)</i>
<i>DPOA</i>	<i>No</i>	<i>16 (33.3)</i>
	<i>Don't know</i>	<i>3 (6.3)</i>

Missing=9

**Multiple responses included*

Data Collection

Data were collected from April 2012 through June 2013. The data include interviews with people who received their health care in 20 states plus the District of Columbia.³ Data regarding the state in which the participants' partners received care was collected via a post-interview, mailed questionnaire, or was obtained from the interview audio when questionnaire data were not available. Most partners received their health care in Washington State (n=28); however, participants represented each of the four U.S. regions, as designated by the U.S. Census Bureau (n.d.). See Table 5 for the number of interviews by U.S. region.

Table 5

Interviews by U.S. Region

<i>Region</i>	<i># of Interviews (%)</i>
<i>Northeast</i> <i>(NJ, NY, PA, VT)</i>	5 (8.8)
<i>Midwest</i> <i>(IL, IN, MN, MO)</i>	5 (8.8)
<i>South</i> <i>(AL, DC, FL, GA, LA, MD, NC, TX)</i>	12 (21.1)
<i>West</i> <i>(AZ, CA, CO, UT, WA)</i>	34 (59.6)
<hr/>	
<i>Missing = 1 (1.8)</i>	

³ Data on the states in which partners had their healthcare experiences is missing for one participant.

The high number of interviews from Washington State increased the proportion of interviews with people who received health care in the West. However, in 2012, Washington State and California were the only two western states in the sample with marriage or marriage equivalence available (see Table 1). Therefore, even the interviews collected in the West represent experiences within a range of legal contexts. The Northeast is the only region that uniformly had marriage or marriage equivalence available in all the states represented in the study in 2012. Maryland, District of Columbia, and Illinois are the only places with marriage or marriage equivalency in the states represented from the Midwest and the South. Fifteen interviews were conducted with people who received care in states with no legal relationship recognition rights available. Additionally, one person received care in Colorado, which only had a limited option for partners to register for joint insurance.

Data Analysis

Transcripts were stored, coded, and analyzed in Dedoose (versions 5.1.20-7.5.9), an online mixed-methods analysis program (www.dedoose.com). I familiarized myself with the data by reading the transcripts and creating an initial unstructured coding scheme. Through this process, I inductively identified a theoretical framework for an analysis of a case study from the data to meet the requirements of my doctoral qualifying exam (Dotolo, Lindhorst, Kemp & Engelberg, in progress). The research questions driving the analyses in this dissertation were developed inductively through these activities, subsequent re-reading of the transcripts, writing of case summaries, and a deepening of my understanding of the theoretical literature applied to analyses.

Thematic analysis was used to analyze the data. This approach aims to understand a phenomenon by identifying and analyzing patterns captured in participants' experiences (Attride-Stirling, 2001; Braun & Clarke, 2006; Vaismoradi, Turunen, & Bondas, 2013). It is descriptive

and inductive, which generally keeps analysis close, or more immediately observable in the data, identifying themes “within the explicit or surface meanings of the data” (Braun & Clarke, 2006, p. 84). However, thematic analysis also allows for interpretation or the identification of latent themes (Braun & Clarke, 2006). Thematic analysis of latent themes “starts to examine the underlying ideas, assumptions, and conceptualizations – and ideologies – that are theorized as shaping or informing the semantic content of the data” (Braun & Clarke, 2006, p. 84). Latent themes can be contextualized within larger sociopolitical processes, such as heteronormativity and public discourse regarding the legitimacy of LGBTQ partnerships.

My interest in partners’ experiences with discrimination developed throughout the research process. Prior to data collection for CFP, I conducted a literature review and wrote a paper on the topic of LGBTQ surrogate decision-making for a medical ethics class. In that paper, I framed the exclusion from relationship recognition laws in the context of end-of-life care as an ethical issue because of the added burden placed on LGBTQ partners to legitimize their relationships (e.g., prepare legal paperwork, retrieve legal paperwork in an emergency), a theme that carried through to this study. At the outset, I expected that CFP interviews would yield a larger proportion of cases in which partners described overt discrimination and exclusion from their partners’ care. As I immersed myself in the data, the more covert ways partners perceived discrimination, the anticipatory fears of discrimination they described, and their interpretations of how they were treated by clinicians arose as important facets of the interviews. I became increasingly interested in the subtler ways that partners were affected by their legal standing and how it was that they identified and interpreted discrimination. Based on these observations, I identified theoretical and empirical work that provided useful frameworks for this analysis. These theories are reviewed in greater depth in the introductions for each results chapter.

Transcripts were coded to identify negative partner experiences, partners' responses to those experiences, as well as contextual information, such as text that discussed their anticipatory fears, preparations, and reflections on law or politics (see Appendix 2: Code List).

The results discussed in Chapter 4 were developed through an iterative process of moving between theory, empirical literature, and the data (Sandelowski, 1993). After initial coding, legal consciousness (described in Chapter 4) was identified as an explanatory theory that seemed to fit with the general themes that were created. I then developed more specific themes by continuing to compare theoretical ideas with the data, "testing" the fit (Thorne, 2008, p. 142), and identifying new contributions to the literature on legal consciousness. Coded excerpts were then organized according to the identified themes and reviewed for consistency.

Conversely, theory on perceived, overt, and covert discrimination was identified and used as sensitizing concepts for the analysis in Chapter 5 before data coding. Data that involved anticipated or experienced discrimination were coded. Codes were used to identify specific types of discriminatory experiences and to categorize them into types of discrimination, informed by the literature on overt and covert forms of discrimination. Also, I identified nonverbal forms of communication (e.g., looking at me funny, not looking me in the eye, dismissive body language) from participants' reflections as a topic for further analysis after a review of the literature revealed a relationship between nonverbal communication and discrimination in health care.

Trustworthiness and Reflexivity

In order to enhance the quality of interpretive results, Thorne (2008) suggested that researchers "learn to see beyond the obvious, rigorously testing out that which we think we see, and taking some ownership over the potential meaning and impact of the visions that we

eventually present as our findings” (p. 142). Trustworthiness and “testing out” of observations in this data, occurred through co-reviewing transcripts with Dr. Lindhorst, and meeting with her to discuss coding ambiguities, observations, and results. During the analytic process, I would also memo about my observations, coding, and interpretations of the data. Rather than aiming to negate my biases, I strived to remain self-aware and transparent about how and when my biases influenced my research process. For example, my involvement in this area of research for 10 years has heightened my awareness of the risks of discrimination and exclusion partners face in this context. I met with Dr. Lindhorst on multiple occasions to discuss the theory informing my analyses, my initial observations, and to clarify my interpretations of the data. These meetings functioned to broaden my thinking and improve the trustworthiness of my observations. This type of collaboration in research is referred to as group analysis. Gilgun (2015) described the benefits of such collaboration by stating, “If we do analysis with others, we increase the likelihood that we will identify multiple dimensions of informants’ accounts and have checks and balances on our individual perceptions” (p. 744).

The quality of my analyses was also enhanced by the integration of reflexivity. Reflexivity is an important element in rigorous qualitative research that acknowledges and values the researcher’s role in creating knowledge (Denzin & Lincoln, 2011; Gringeri, Wahab, & Anderson-Nathe, 2010; Stige, Malterud, & Midtgarden, 2009). Stige et al. (2009) noted that “reflexivity is not a matter of methodological control but about articulating questions tacitly underlying and motivating research” (p. 1508). My experiences and perspective influence this research in two important ways. First, living as a queer woman in a heteronormative society provides me with a sensitized lens through which I can identify and investigate discrimination, as well as critically examine participant statements that seem to highlight or minimize their

experiences of discrimination in the context of this study. For example, out of context, a clinician questioning a partner about the nature of her relationship to a patient might seem innocuous. However, as a queer woman I am sensitized to the fact that this question might require a queer person to “come out” in a setting that has historically discriminated against LGBTQ people, thereby potentially increasing risk of discrimination or feelings of vulnerability.

Second, my research experience and deep exposure to the clinical settings relevant to this study have allowed me to contextualize participants’ experiences within the ideals and limitations of care for seriously ill patients and their families. Through these experiences, I recognized that clinical interactions occur in very complex healthcare settings. Given the high level of physician specialization and challenges regarding continuity of communication between clinicians, it seems plausible that study participants could have been repeatedly asked about their relationship to the patient, particularly in a hospital setting, without any conscious or unconscious biases motivating the question. Because this was a retrospective interview-based study, healthcare interactions and clinician behaviors were not observed, and clinician intent is not knowable. This analysis relies upon partners’ reflections on discrimination because research has shown that perceived and chronic discrimination are stressors that influence health for traditionally marginalized groups (Abramson, Hashemi, & Sánchez-Jankowski, 2015; Doyle & Molix, 2015; Nuru-Jeter et al., 2009; Pascoe & Smart Richman, 2009). Aside from these pragmatic reasons for relying on partner perceptions, given the study data, doing so fits with my epistemological stance, which will be discussed in the following section.

Epistemological Stance

I have taken a constructivist approach in this dissertation (Creswell, 2009; Denzin & Lincoln, 2011), meaning that I understand the development of the results to occur through

interactions between participants' interpretations of their own experiences and my interpretation of their reflections, informed by my practice experiences, research training, and personal perspective. In this view, research is a "joint product" that is "co-constituted" by participants and the researcher (Finlay, 2002, p. 531). Implicit in my constructivist approach is an appreciation for the (un-, semi- or conscious) selection processes participants go through to choose responses to interviewer questions. Due to their experiences as people with LGBTQ identities, as well as the oftentimes lengthy illnesses of their loved ones, the study participants' reflections on their experiences with health care are drawn from and embedded within the entire trajectory of their life stories. Although some of the discrimination that partners described seemed minor within the whole range of their healthcare experiences, I place value on the fact that partners recalled and chose to share those experiences in the context of this study. I interpret their recollection of seemingly small details, like non-verbal communication that they interpreted to signal potential discrimination, sometimes years after their healthcare experiences, as indicators of their importance. Their recollections allow me to then place them in conversation with the theoretical and empirical literature regarding discrimination and the larger political context of heteronormativity.

Explicitly and transparently recognizing my interpretive process of analyzing participant reflections through the lens of my own identity and experiences is informed by feminist theory and representative of the intrinsically political perspective of the analyses that follow. Scully, Baldwin-Ragaven, and Fitzpatrick (2010) stated that feminist bioethics "has been able to spot the nuances of gendered and raced relationships – between different kinds of patient or doctor – and how social positioning inflects the ethics of their interactions" (p. 3). My current study represents precisely that type of effort via research of partner experiences in the uniquely

vulnerable time of being involved with the healthcare system during a loved one's serious illness, and during a time in U.S. history in which the legitimacy of LGBTQ partnerships has been highly politicized.

CHAPTER 4

RESULTS: LEGAL CONSCIOUSNESS DURING A TIME OF CHANGE

This chapter discusses how the concept of legal consciousness applies to partners' perceptions of their legal statuses in the context of health care for a serious illness of loved ones. Legal consciousness refers to subjective experiences of the functions of law in everyday life (Harding, 2006, 2011; Hull, 2016; Knauer, 2012; Sarat, 1990; Sarat & Kearns, 1995). The analyses in this chapter represent iterative movement between data and theory (Sandelowski, 1993). Themes related to legal consciousness emerged inductively, motivating a review of the literature, from which I generated a list of associated sensitizing concepts for further analysis of the relationship between theory on legal consciousness and participants' experiences (Sandelowski, 1998). This study contributes to the literature on legal consciousness by applying the concept to LGBTQ experiences with health care for serious illness, a setting in which law and policies guide formal identification of legal next of kin for inclusion in medical care processes and decisions, as well as informal estimations of who is recognized as a legitimate family member.

This chapter includes three sections. First, I summarize the scholarship on legal consciousness and describe its application to LGBTQ relationships. Second, I provide an overview of the current shifting U.S. legal landscape in relation to LGBTQ people. Third, I present three themes that derive from my analysis: 1) awareness of legal status and expectations of (il)legitimacy, 2) presumptions about political (un)safe zones, and 3) uncertainty in "legal grey areas." A brief summary of the results and their contribution to the literature concludes this chapter.

Legal Consciousness

The concept of legal consciousness refers to the way law functions in the people's everyday experiences, and it is born out of scholarship at the intersection of sociology and law (Ewick & Silbey, 1998; Harding, 2006, 2011). In this study, "law" refers to both macro-level LGBTQ relationship recognition laws and related mezzo-level organizational policies regarding the identification of legal next of kin that influence healthcare interactions and partners' experiences of them (micro level). Important epistemological and ontological assumptions are embedded in the concept. Knowledge about the role of law in ordinary life is derived from the individuals' perceptions in references to their own lives (Hull, 2003; Hull, 2016). Also, legal consciousness, as it will be applied in this study, is a constitutive process in which law is viewed as "an emergent feature of social relations" (Ewick & Silbey, 1998, p. 17), that both affects and is affected by society (Harding, 2011). Reciprocal influences between law and society are created through social processes in which people create, interpret, comply with, and resist law. Oswald and Kuvallanka (2008) noted that legal consciousness "attends to both the constraints and opportunities of law and the ways in which people negotiate their lives within these parameters," and "shows how people challenge and eventually change those parameters, for example, by resisting the rule of law to protest injustice" (p. 1053). From this perspective, law can then be understood as fluid, socially bound, and subjective. Applied to this analysis, legal consciousness provides a conceptual tool to assess how partners perceive their sense of legality; interpret clinicians' perceptions of their legality and legitimacy as legal next of kin and family members; and navigate legal contexts, accepting and resisting their limitations by "using" the law to their advantage (Merry, 1990, p. 5).

Empirical research applying legal consciousness to LGBTQ people is limited and for the most part very recent. The earliest work on this topic was by Connolly (2002) who conducted

interviews with 20 gay and lesbian parents who successfully petitioned courts to recognize a second-parent adoption, before marriage or marriage equivalence was widely available.

Although she does not reference Merry (1990), Connolly's work demonstrates the idea of partners using the law by petitioning the courts to accommodate their family structure.

Identifying partners' use of the law in the context of legal consciousness is important for recognizing the reciprocal relationship between people and their environments, demonstrating in this study that legal consciousness functions as a mechanism for partners' maintenance of their agency as caregivers as well as an indicator of their marginalization within heteronormative legal constructs of legal next of kin and family. She noted that, "The voices of these petitioners tell us that they presented themselves in the legal system in a self-conscious manner and used this system to their advantage to obtain formal recognition for their families of choice. They did so with dignity and with resistance to unacceptable formulations of their lives" (Connolly, 2002, p. 343). Subsequent research on legal consciousness for LGBTQ people has focused on the role of law and consciousness in parenting decisions (Park, Kazyak, & Slauson-Blevins, 2016); the influence on legal relationship recognition laws (via civil unions or marriage) and perceptions of the cultural import of marriage in the United States and the United Kingdom (DiGregorio, 2016; Harding, 2006, 2011; Hull, 2003; Hull, 2016; Park et al., 2016; Richman, 2013); and, most recently, the ways in which legal consciousness shaped the experiences of those who were the earliest to dissolve civil unions in the United States (Auchmuty, 2016). These authors highlight the relevance of legal consciousness in the lives of LGBTQ people and critique the ways that heteronormativity has historically been institutionalized in the law.

The Shifting Legal Landscape

LGBTQ people have historically been subject to a variety of laws that have pathologized, criminalized, and excluded them from fundamental social institutions such as legally recognized marriage and parenting (Farmer & Yancu, 2015; Foglia & Fredriksen-Goldsen, 2014; Harding, 2011). The morality of LGBTQ people and the legitimacy of LGBTQ partnerships remain “hotly contested” making LGBTQ “lives and families...uniquely politicized” (Knauer, 2012, p. 749). Recent developments, such as marriage equality, represent unprecedented advancements in the social acceptance and legal rights of LGBTQ people (Drake, 2013; Goldsen et al., 2017). Although the changes are recent, some research has already demonstrated improvements in the health and well-being of LGBTQ people due to increased rights to legal relationship recognition (Goldsen et al., 2017; King & Bartlett, 2006; Raifman et al., 2017; Riggle, Wickham, Rostosky, Rothblum, & Balsam, 2016). In a study of long-term LGBTQ relationships, comparing states with and without relationship recognition laws, Riggle et al. (2016) found that living in a state with legal recognition was associated with lower levels of identity concealment, improved individual identity acceptance, and less vigilance and isolation. Raifman et al. (2017) found that state marriage equality was correlated with fewer high school students reporting suicide attempts. While it is perhaps too soon to claim causal relationships between these policies and improvements in health and well-being, these early studies suggest that legal relationship recognition rights potentially have far-reaching health consequences.

Recent advances, however, have also heightened public debate and backlash, including a push to pass state “religious freedom” laws to allow private business owners to deny services to LGBTQ people based on their religious beliefs that marriage should only be between one man and one woman (Cadei, 2017; Cason, 2017; Kralik, 2017; Wright, 2017). The type of discrimination these laws are intended to allow is exemplified by the refusal of a Mississippi

funeral home to perform cremation services for Jack Zawadski's husband because he was gay (O'Hara, 2017). Public backlash against transgender-specific gains toward equality is apparent in state "bathroom bills," which would require people to use public restrooms according to the gender to which they were assigned at birth, functionally restricting access to public space for transgender people (Kralik, 2017; Landsbaum, 2017). These attempts to rollback changes created by the Supreme Court ruling *Obergefell vs. Hodges* (Liptak, 2015), which made same-sex marriage legal across the country, show the fragile nature of legal changes and the need for continued research on the relationship between changes in laws and the experiences of people and communities.

Shifts in macro-level relationship recognition laws have been paired with advances in mezzo-level organizational policies enhancing the rights of LGBTQ people regarding hospital visitation and surrogate decision-making. In 2010, President Obama issued a Presidential Memorandum mandating that healthcare facilities receiving federal funding must honor legal documentation of decision-making authority for LGBTQ people (Obama, 2010). Immediately after the issuance, President Obama called Janice Langbehn to express sympathy for what she endured and later awarded her with the Presidential Citizen's Medal for her advocacy work on the topic (Lambda Legal, n.d.; The White House, 2011). President Obama's memorandum set the course for modifications to The Joint Commission's hospital accreditation standards and the release of a field guide for LGBTQ inclusion from the organization (American College of Healthcare Executives, 2013; The Joint Commission, 2014).

As with all policies, effectiveness in solving the problems for which they were intended depends on how clearly and consistently they are implemented. It is outside the scope of this study to summarize and integrate the vast literature on policy implementation. However, I use

the concept of street-level bureaucracy from that literature to contextualize the influence of law and related organizational policies on partner experiences. As described in Chapter 2, Lipsky's (2010) work formulates policy implementation as formal (law and policy) and informal (in situ policy implementation and discretionary decisions by frontline workers). In the context of this study, these policy processes are identified as influences on healthcare interactions and participants' perceptions of them.

Results: Partners' Legal Consciousness

Awareness of Legal Status and Expectations of (Il)legality

In this section, I will focus on two subthemes that demonstrate the presence and influence of legal consciousness on partner experiences: awareness of legal status and expectations of (il)legitimacy. The central characteristic of legal consciousness is self-awareness of one's relation to the law, particularly when law functions as a mechanism for marginalization. As Connolly (2002) has noted, the law operates differently for "those within its bounds and those outside of it" (p. 328). In the context of this current study, LGBTQ partners maintain legal consciousness and concern about perceptions of their legitimacy because of their history of exclusion from relationship recognition laws, an awareness that is not required of historically included heterosexual married partners. For some LGBTQ participants, this awareness positions them to approach the healthcare system with concerns about how their legal status will influence their inclusion in care. In this context, relationship recognition laws influence healthcare organizations' policies and practices regarding the identification of legal next of kin, which in turn, drives the identification of surrogate decision-makers and recipients of medical information.

Definitions of legal next of kin reflect heteronormative biases in the way in which legal and biological relationships are ranked. Legal next of kin are identified via a hierarchy of biological relationships, showing deference to heterosexual nuclear families by placing married spouses at the top of the hierarchy, followed by parents and then adult children. Because healthcare providers rely on legal hierarchies for determining who is able to make decisions (Beauchamp & Childress, 2009), partners who do not have a legally recognized relationship (e.g., marriage) or have prepared legal documents such as DPOA are at risk of being excluded from the care of patients who are too ill or incapacitated to request the involvement of their partners.

“Consciousness” relates to participants’ awareness of how their LGBTQ relationships have historically fallen outside of socio-legal definitions of family and how historic marginalization and recent legal changes influence partners’ approaches to interactions with clinicians. The results described below demonstrate that partners were not only aware of their legal status but that their awareness also influenced their expectations of whether clinicians would view them as legitimate legal next of kin.

Sixteen study participants had legal relationship recognition (e.g., state registered domestic partnerships, civil unions, or marriage), and 29 had legal documentation of DPOA for their partners. Participants in this study were aware of the laws that guided definitions of family and identified legal next of kin. Often, their knowledge of the law was established through past negative experiences in healthcare settings, the upsetting experiences of friends and family members, as well as through the sharing of stories about the experiences of others in the LGBT community, such as Strong’s and Langbehn’s stories.

Bob,⁴ whose partner was hospitalized for a critical complication from a chronic disease, reflected on how hearing the stories of others created some concern that his status as DPOA would be challenged. He and his partner lived in a liberal city in a conservative state where Bob said, “being gay isn’t such a big deal.” They had had positive healthcare experiences previously, yet he noted anticipatory concerns about his legal status:

“I guess, always in the back of your mind, you have some apprehension that something...if I have to assert medical power of attorney, are they going accept it because you’ve heard horror stories of people not being accepted for medical power of attorney, so...there’s a natural...because you’ve heard stories to the contrary, there’s a natural anxiety, I suppose.”

Bob’s concerns show that stories like Strong’s, Langbehn’s, and Reed’s create a consciousness in which fear of discrimination paired with awareness of a legal status that is not as secure as heterosexual marriage informs partners’ perceptions of risk, even if it is only “in the back your mind.” Additionally, Bob retained some level of concern despite his legal documentation and a history of positive experiences with health care, representing an additional stressor for him as a caregiver.

Maggie also noted that one source of her anticipatory concerns arose from stories of other people’s bad experiences. She did not have a legally established relationship or DPOA when her partner was seriously injured in an accident. She stated:

“I haven’t really been in the hospital very much at all...to like visit people, but uh, I’d just heard, you know, stories about people, who are in relationships that aren’t like heterosexual relationships, having trouble or just not being able to see their partner at all. Um, so I just was scared that that might be the case. And also, I’m from [home state], which is a lot like, more conservative and so, I don’t know if it had something to do with being in [current state], and it being maybe a more liberal place, but I was like preparing myself, kind of, for experiencing maybe discrimination or maybe just a little bit of a runaround.”

⁴ Pseudonyms have been used for all participant and partner names to protect confidentiality.

In Maggie's case, concerns based on the stories of others' negative experiences were compounded by her previous experiences living in a conservative state, presumably making her familiar with negative rhetoric regarding LGBTQ partnerships. The influence of partners' perceptions of the politics in the place they live will be discussed in more detail below; however, the reflections on location by Bob and Maggie show that their consciousness is based on their experiences with public debate as well as law. Both partners remained concerned about how clinicians would view the legitimacy of their relationships regardless of whether they had legal documentation.

On the other hand, Adam and his partner Dwight resided in a state where registered domestic partnerships were available, in part due to the political advocacy of Strong after her experience (Labella & Singh, 2008). Adam and Dwight were not registered as domestic partners when Dwight unexpectedly became very ill. However, Adam could participate in his care decisions during Dwight's long-term care. Under state law, in the absence of Adam's legal standing via DPOA, Dwight's adult daughter would be designated as his decision-maker. Although she did not live in the same state, the daughter visited Dwight at the skilled nursing facility where he was receiving care. Despite the daughter's standing as the de facto legal decision-maker, clinicians turned to Adam for decision-making. Expressing his surprise at being recognized as a legal next of kin and decision-maker, he said:

“And as I said, I'm not registered as his domestic partner. So, legally, I had no right to [make decisions]. And legally, they had no obligation to follow [my decisions]. But pragmatically, you know, it only made sense because he wasn't able, at that time, to understand what he was doing...Um, and like I say, I was a little bit surprised that, in the absence of domestic partnership they...both [hospital] and [nursing home] just automatically, you know, turned to me to...for decision-making.”

Unlike Bob and Maggie, Adam's legal consciousness comes from living in a state where legal relationship recognition was available, but he and his partner had not acquired it or a DPOA.

Yet clinicians in this state were also influenced by these changing laws and debate to the extent that they integrated Adam into his partner's care even without the couple having obtained formal legal sanction for their relationship.

Anticipatory concerns about discrimination drove some partners to prepare legal documents in the absence of available relationship recognition laws with the goal of ensuring their role as legitimate legal next of kin. Some partners went to great lengths to try to guarantee that they were shielded from exclusion, if not discrimination. These efforts represent an undue burden placed on LGBTQ partners to try to protect their inclusion in care. The following are example statements from partners who exemplify this proactive strategy:

“we didn't ever have to show [documentation]...I mean, we are registered domestic partners and we also have, from before the 2009 law, we had, you know, powers of attorney and health directives and, you know, all of that stuff lined up, in the event that we would face some challenge to my role as needing to represent her interests.” (Jan)

“Like I said, we were living in [Mid-Atlantic state] at the time and the surgery and hospitalization were taking place in [same Mid-Atlantic state]. Knowing that the surgery was coming up, was one of the reasons that we decided to register a civil partnership in [same Mid-Atlantic state]....So as part of our preparation for the hospitalization, even though we already had powers of attorney, we also registered our civil union...and that was a decision we had to make in every single place we had lived...some of the places that we'd lived before, we'd had domestic partnerships or, you know, sort of the equivalent in others, we hadn't it had depended a lot on both legislative law and case law in those jurisdictions.” (Emily)

“I had power of attorney for everything and everything in this house, everything we owned, was joint. And we had...not only did we have our plots, we had our burial, we had everything already paid for...We had the lawyers draw up everything cuz we live in [Southern state] and they're so homophobic that we knew we had to protect each other.” (Bruce)

In these cases, partners demonstrated substantial knowledge of the law. Their expectations followed from that knowledge in the form of concerns of discrimination and proactive preparation for healthcare interactions. Although the excerpts from interviews with Jan, Emily, and Bruce did not indicate demonstrated discrimination by clinicians, they illustrated the way in which legal consciousness and inequities in legal status generated concerns about potential barriers that participants addressed by covering legal bases as much as possible.

In some cases, legal preparations supported partners' advocacy for their inclusion and their "use of the law" to secure that end (Merry, 1990, p. 5). In response to an interviewer question about his experience with clinicians, Bruce demonstrated his "use of the law" when he said:

"Well, you know, I had the power attorney and I threw it in their face. Every time I went in, I carried a new one. And...they would ask me, 'What's your relationship?' and I said, 'Partner. Forty. One. Years. Here's my power of attorney.'"

Bruce's reflection is important because it illustrates the fact that awareness of legal status can function as a source of legitimacy for partners to utilize in the interest of maintaining their agency as legitimate legal next of kin and family members to their partners.

Partners' concerns about exclusion sometimes translated into expectations for discrimination. Even though receiving health care free of discrimination and having legal documents honored should be a standard expectation, partners implicitly revealed lower expectations of their care. Partners described feeling "lucky," "fortunate," or "blessed" that clinicians honored their legal status or treated them as legal next of kin in the absence of legal documentation, despite the fact that doing so would be consistent with the standard practice of including patients' closest family members in care (Beauchamp & Childress, 2009). The following two excerpts exemplify partners' statements about good "luck":

"I think I was lucky because even though...we weren't sure if [the out-patient doctor] approved [of the relationship] or not, she did not, however, question my right

to [make decisions]. And certainly, the doctor that took over [in the hospital] did not question that. Nor did the Hospice people. Even when she died, the funeral home...didn't question my right or ask me for any proof that I was the partner, legally or whatever...I think we were lucky in that...I was not questioned.”
(Carmen)

“I've been, I think, very blessed that I've been able to [make decisions] and that people have respected my speaking for her, understanding that these are our wishes.”
(Cynthia)

On the surface words such as “lucky,” “fortunate,” and “blessed” seem to represent only partners' gratitude for positive experiences. The words, however, also indicate partners' low expectations for care. Feeling “lucky” for not being questioned as a legal next of kin when legal documentation, policy, and practice standards support the legitimacy of partners' roles reveals a concerning discordance. Considering partners' grateful responses against expected responses from heterosexual married counterparts provides a helpful heuristic, since heterosexual married people are unlikely to feel “lucky” for not being asked to produce a marriage certificate to make decisions for a spouse. In fact, heterosexual married people are unlikely to be aware of the advantages of their legal status and fit with heteronormativity when interacting with clinicians. When viewed from this angle, partners' gratitude actually refers to their expectation for discrimination via exclusion not being realized.

Presumptive Political (Un)Safe Zones

Partners referenced the political climate of the geographic areas in which they received care as a presumptive protective factor against legal uncertainty and clinician discretion. Statements about political climate revealed an assumption that a local or geographic culture of social acceptance for LGBTQ people increased the chances of being treated fairly, regardless of whether relationship recognition laws were available. Partners identified urban and politically liberal locations as safe zones and yet were still subject to forms of discrimination, such as being

required to show legal paperwork or being looked at “funny” by clinicians. The following excerpts discuss advantages related to political climate:

“I live in an area that’s pretty progressive with this...if this situation happened in, you know, Mississippi I think it would’ve been a wa-a-ay different experience, right? But, you know, I live in the greater [liberal metropolitan] area.” (Robert)

“Any hospital in [liberal city] is going to be pretty progressive.” (Adam)

“...we were...visiting my parents, well, my step mother, and [partner] had fallen and we found a medical clinic...and that was fine. But again, that was in [upscale city in liberal state], as opposed to being out in [more conservative large city in the same state].” (Lily)

These assumptions are maintained despite experiences of discrimination, references to friends’ and other community members’ bad experiences in health care, and for the people in Washington State, Strong’s highly publicized story that occurred in a large, urban, academic hospital in Seattle.

Danny’s story shows that presumptive safe zones are not immune from discriminatory practices. Danny, whose partner died after a hospitalization for a serious injury, described a kind of dissonance between his expectations of being in a notably gay-friendly, liberal city and his lived experience. He received a call letting him know that his partner was injured and that he should come to the hospital because it was “pretty bad.” Although he and his partner were married, their marriage was only legally recognized in the adjacent county where they lived, but not in the county where the hospital was located. Even though his married status did not grant him legal standing in the jurisdiction where his partner was receiving care, he was asked to go home to retrieve a copy of their marriage certificate, was assured that his partner was stable at that moment, and that Danny would receive “a little more” information with the documentation. He recalled his response to the request:

“And I’m in a panic, I didn’t know where to find it, but I...you know, it’s something that’s precious and I didn’t remember where it’s at, so I rushed back home.”

The clinicians gave him some information after the retrieval of the document. However, he felt that a heterosexual married spouse would not have been burdened with locating and retrieving a marriage certificate under the circumstances. Additionally, clear recognition of his role in decision-making was never provided. He experienced the clinicians as “going back and forth” and being without a “game plan” about how much information he could receive which increased his stress. He said:

“...it caused a lot of frustration and I would yell at them sometimes. And, I didn’t mean to yell at them. It’s just my partner is dying and I just didn’t know what to do.”

Reflecting on the discordance between his perception of the area in which he lived and his actual experience, he said:

“...because it is a little bit different in [city of residence and surrounding area], in terms of more acceptance, I would think, of partners and kind of the legality of stuff, they were able to release a little bit more information to me. But it always seems like it’s a little bit of a grey area there...even though there’s quite a few gay couples out here...I guess they’re still trying to figure out what they can release, even though we’re, you know, it’s a grey area, like in [county], they recognize us as partners, but since it’s not in that [the hospital’s county]...”

Danny’s reflection shows an unsettled reaction to the pain of his experience and the way in which his exclusion was not consistent with his expectations. He expected that the liberal political leanings of the area in which he lived would provide some protection against the risk of discrimination. His situation also highlights the importance of discrepancies between legal jurisdictions, which will be discussed below.

Legal Grey Areas

Although partners were very aware of the law and their legal standing, their experiences took place amid rapid changes regarding social acceptance and legal recognition of LGBTQ partnerships. These shifts have created an inconsistent legal landscape for partners to navigate. Although same-sex marriage is now federally recognized, legislation prohibiting discrimination against LGBTQ people has not been passed in many states and continues to be a matter of public debate (Broverman, 2017). Knauer (2012) noted that, “In the absence of federally mandated civil rights, the individual states are free to provide whatever level of safeguards they choose,” extending discretion from individual clinicians up to state jurisdictions (p. 750). Partners’ experiences reflect this sense of fluctuation and politicization.

In unsettled times, partners either lacked status as legal next of kin because they were not legally married or lacked clarity about whether clinicians would recognize the legal status (e.g., DPOA) they did have. Like Danny, other participants described how disparities between jurisdictions affected their sense of security and contributed to the sense that their legal status was transient or unreliable. For example, Teresa explained the way in which she and her partner traversed the boundaries of their legal standing in their travels across state lines. She said:

“We travelled a lot and so we knew that, in certain places, if something had happened to one of us, we would have no legal right.”

Partners also described being subject to variability depending on geographic boundaries. In reference to a short period in which marriage was available in a county prior to a statewide ban on same-sex marriage, Teresa said:

“We got legally married in [county] until they took it away.”

Although legal relationship recognition did not provide fail-safe protection from discrimination, partners described legal recognition as a source of social recognition and a source of legal

protection in circumstances in which clinicians were willing to recognize and honor their legal standing.

The shifting legal terrain also presented challenges for the implementation of new or revised policies in clinical settings. Sandra, provided an example of this point. She was a legally registered domestic partner due to a recently passed domestic partner law. In a reflection on why she might not have been allowed to ride along when her partner was transported to a hospital in an ambulance for care for a suspected stroke, she stated:

“But looking back, you know, that was the year that [domestic partner law] passed. And so maybe policies hadn’t been updated to be consistent with the law.”

Sandra’s statement reflected not only the changing laws, but also the role that clinician discretion played in partners’ experiences. Presumably major changes in law trigger equivalent changes in policy and staff training to implement these changes. Sandra’s reasoning suggests that because EMTs might not have been clear on recent changes in the law, they used discretion to decide what to do and erred on the side of not allowing Sandra to ride in the ambulance.

A sense that recognition and inclusion is tentative and dependent on clinician discretion is present in other partners’ recollections as well. Participants frequently recalled being told that they were not legal family members and, in some cases, were repeatedly told they were not a family member and not allowed to participate in care, even after showing documentation of either a legally recognized relationship or status as an authorized medical decision-maker. In an extreme case, one participant reported being excluded from receiving information even after the patient confirmed their relationship. Joe, who did not have a legal relationship with his partner or a DPOA, remembered an interaction in which a clinician recognized his relationship with his partner, but did not view the relationship or the patient’s claim of the relationship as equivalent to a legitimate legal status. He said:

“...my partner... assured [the clinician] that we lived at the same address, [the clinician would] go like, ‘Oh, you know, this is confidential and, you know, some of this I can’t reveal to you and I realize you are partners, but you know, unless [patient] signs something, then, you know, I can’t reveal some of this stuff to you, cuz you know, you’re not a legal partner,’ or whatever.”

It is important to note that when patients can speak for themselves, their statements about whom they would like to be involved in care should trump requirements to have a legally documented relationship. In healthcare settings, legal documentation is required for cases in which patients are not able to make their preferences known (Beauchamp & Childress, 2009). In this case, the clinician is either remarkably uninformed and practicing outside of typical standards, or is using discretion to create a barrier for Joe’s inclusion in his partner’s care, consciously or not.

Another example provides a clearer illustration of the role of clinician discretion. Before the availability of legal relationship recognition in his state of residence, Ken went to the hospital to be with his very ill partner who had been admitted to an acute care unit. When he arrived, he encountered a nurse who refused to allow him into the room with his partner. He did not have documentation of a legal relationship with his partner, but described his partner as very ill and alone. As he recalled, she said, “I’m sorry, sir, you don’t have any legal right.” In response Ken demanded to be able to see his partner, when a senior nurse overheard the exchange. The senior nurse told the initial nurse, “Any time this man shows up, day or night, he’s allowed to go in there.” In this case, discretion was used in conflicting ways. The initial nurse used it to exclude Ken while the senior nurse used it to ensure that Ken was able to visit his partner despite the lack of legal documentation. This inconsistency could have left Ken feeling uncertain about whether he would be able to visit his partner the next time he came to the hospital if this senior nurse was not on duty.

Like the senior nurse, participants mentioned other clinicians who acted as buffers against discrimination in a “grey area.” These clinicians’ actions and professional knowledge minimized

legal uncertainty for partners, as was the case with the senior nurse who intervened on Ken's behalf. In order to do so, clinicians must be aware of the risk of exclusion LGBTQ partners face. Emily and Joan, who had a registered domestic partnership and a DPOA, initiated a conversation with their physician in advance of Joan's planned surgery to discuss "the best way to handle things as a same-sex couple." Although very supportive, Emily recalled the physician's surprise about their concerns:

"And then we had a conversation...about how to make sure, if my partner couldn't make decisions for herself, that I would be the person to make those decisions. And like I said, he seemed kind of startled. It didn't occur to him...that anybody would ever challenge that or that would be a problem."

Without awareness of the concerns LGBTQ partners carry or the risks they face, even supportive clinicians might miss opportunities to alleviate those concerns and advocate on partners' behalf.

Partners were supported by clinicians who suggested strategies to avoid being excluded from their partner's care. Interestingly, although the EMTs did not allow Sandra to ride in the ambulance with her partner, when she arrived at the hospital, one of the responding EMTs gave Sandra her partner's room number. Sandra noted that the EMT who gave her the room number was the one who did not allow her to ride in the ambulance. This EMT said that he gave her the room number so she could bypass the nurses' station and go directly to her partner's room, to "avoid any grief." Sandra recalled mixed feelings about the interaction:

"I felt supported because I think he was basically trying to give me the skinny on how to avoid issues. But I also, for the first time, felt afraid that I wasn't going to be able to be a part of things because I was gay. Like it hadn't even occurred to me...It didn't occur to me until that moment."

More often, however, partners unequivocally valued proactive engagement by clinicians. For example, Marc, who described anticipatory concerns about his inclusion after his partner was

diagnosed with an advanced form of cancer, was grateful to clinicians who told him to keep his documentation handy. He said:

“I was informed by the folks at the cancer center, you know... They were like, ‘Every time you go, you should give them this, so that they know who you are, in case anything happens.’ And also, so that they have it on file. They’re like, ‘Even though it’s going to be there multiple times,’ they were like, ‘That’s okay.’”

Nicole, whose partner was seen by a palliative care team, received similar instruction. She appreciatively remembered the palliative care team’s recommendation:

“I was very glad that I actually had the physical healthcare proxy. And in fact, it was the care team that actually prompted me to make sure it was in the front of the chart. And they photocopied it and gave me a copy to carry around with me, in case anybody gave us a hard time.”

Reflections on clinicians who offer support in this way provide some insight into the ways in which partners could be better supported. They also reveal the complexity of the healthcare system, and the lack of confidence clinicians themselves may have in the consistency and reliability of laws, organizational policies, and practices. These concerns expressed by clinicians mirror those of partners and acknowledge the vulnerability of LGBTQ partners to discrimination and exclusion.

In some cases, the vulnerability of partners is clear and requires direct clinician engagement. For example, Benjamin received the assistance of a social worker who intervened to “mediate” legal concerns about Benjamin making decisions for his partner. Benjamin’s partner, Richard, was unconscious due to a hemorrhagic stroke, which ultimately caused his death. Benjamin and Richard had initiated DPOA paperwork with an attorney and received a copy of the paperwork to sign shortly before Richard was hospitalized, but they had not yet signed these documents. Because Benjamin did not have complete legal documentation, the social worker contacted Richard’s biological sister who verified that Benjamin knew what

Richard would want and should be able to make decisions. Of the social worker's intervention, Benjamin said:

“The social worker just kind of mediated it with, I guess, their legal people so that everybody was on the same page about what was being decided...she was just kind of being a facilitator to make sure there weren't any grey legal areas”

Ultimately Richard's sister travelled to the hospital, and she and Benjamin made the difficult decision to withdraw Richard's life support together.

It is significant to recognize that Benjamin's recognition as a partner and his inclusion in decision-making were dependent on many factors. These factors included the social worker being willing to “mediate” the grey area, Richard's sister being willing to acknowledge Benjamin as a significant person in the family, and other clinicians being willing to accept the accommodation established by the social worker and Richard's sister. The unique circumstances of Benjamin's experience made him feel protected against a legal grey area. However, his feelings of security were tenuous. He was subject to the discretion of others and not able to act as an autonomous agent with legal standing.

Danny's experience provides an unfortunate illustration of this point. Although he was confident that his partner would not want to be kept alive with life-supporting interventions, he was not able to make the decision to withdraw those interventions against the wishes of his partner's family. Describing the emotional consequences of his inability to make decisions on behalf of his partner, he said:

“...it was a constant battle back n' forth, but ultimately...I kind of just let them do what they wanted to do...and keep him on life support. Unfortunately, he didn't make it...and you know, I didn't have to suffer through that decision for a very long time.”

These participant reflections demonstrate that legal grey areas are not only composed of jurisdictional differences in law, but also that their legality and consequent inclusion in care are

subject to clinician discretion. In this context, partners must anticipate and prepare for resistance to their inclusion and reluctance to respectfully recognize their relationships.

Conclusion

The results presented in this chapter fill a gap in the literature on legal consciousness by extending the concept to the healthcare setting, with a focus on care for serious illness. In this context, partners' legitimacy as legal next of kin and family members, formally or informally recognized, is crucial to their inclusion in care. In addition to applying the concept in a novel setting, this study contributes by extending the literature on legal consciousness from proximal analyses of family and relationship recognition laws to more downstream effects of those laws in clinical practice.

In an analysis of human geography and social and special exclusion, Sibley (1995) wrote:

The simple questions we should be asking are: who are places for, whom do they exclude, and how are these prohibitions maintained in practice? Apart from examining legal systems and the practices of social control agencies, explanations of exclusion require an account of barriers, prohibitions and constraints on activities from the point of view of the excluded (p. x).

This current study engages with Sibley's questions by examining partners' perceptions of how law, organizational policy, and healthcare practices create "barriers, prohibitions, and constraints" on their activities as caregivers. However, partners' reflections reveal that legal consciousness is a multifaceted phenomenon. It can represent the effects of exclusionary law and policy infiltrating interpersonal healthcare interactions, and it can be a motivation to prepare for healthcare interactions by using law to bypass "barriers, prohibitions, and constraints" on partners' inclusion in care (e.g., through obtaining DPOA). Regardless of how legal consciousness functions in partners' perceptions, by its presence, it reveals that LGBTQ partners are burdened by the concerns "in the back of their minds" and the need to navigate in this

heteronormative setting. The results demonstrate that partners maintain substantial awareness of their tenuous legal status and their vulnerability to clinician discretion, both of which compound stresses normally associated with caring for a seriously ill partner.

The fear of loss, stressors, and responsibilities associated with caring for a seriously ill loved one is an experience many can relate to or imagine happening to them. Chochinov's (2012) reframing of vulnerability as a mirror (as noted in the epigraph at the beginning of this dissertation) suggests that clinicians ought to be able to empathize with the experiences of caregivers in these circumstances. The results of this chapter, however, demonstrate added layers of vulnerability for LGBTQ partners concerned about perceptions of their legitimacy or being excluded from care. These results show how macro- and mezzo-level influences infiltrate micro-level interactions and experiences. In the following chapter I will focus in on clinical interactions and take a closer look at how discrimination is identified and interpreted by partners.

CHAPTER 5

RESULTS: IDENTIFYING AND INTERPRETING DISCRIMINATION

IN HEALTHCARE INTERACTIONS

The results in this chapter represent an analysis of how partners identify and interpret attitudes related to discrimination that underlie clinician communication and behavior. Noting the importance of research examining healthcare interactions, van Ryn and Fu (2003) stated that a “lack of attention to interpersonal mechanisms or mediators of institutionalized discrimination may undermine the effectiveness of our strongest policy and organizational-level strategies” to reduce health inequities (p. 252). In this chapter, I contribute to this call by identifying cues partners notice in interactions with clinicians, as well as the ways in which they infer meaning from those cues in clear and not so clear interpersonal exchanges.

The analyses in this chapter, like those in Chapter 4, represent an iterative process of moving between data and theory. The analysis of data represented in this chapter are the result of an initial inductive, open coding process in which I observed recollections of covert forms of discrimination, including participants describing nonverbal communication, as well as explicit attempts to interpret the intent of clinicians expressing discriminatory or potentially discriminatory attitudes. I utilized theoretical and empirical work on perceived discrimination, covert discrimination, and nonverbal communication to inform the coding. This chapter includes two sections: 1) an overview of theory and research related to discrimination in interpersonal interactions generally and its effects on clinical interactions specifically; and 2) results illustrating three forms of discrimination: a) overt and intended, b) covert and duplicitous, and c) covert and unconscious. A focus on how partners identify and interpret the “unsaid,” or

nonverbal, aspects of interactions with clinicians is woven into the results because of the unique way in which nonverbal communication relates to discrimination, particularly its covert forms. The chapter ends with a brief conclusion summarizing the findings and their contributions.

Identifying and Interpreting Discrimination: Theory and Research

Perceived Discrimination

Perceived discrimination is utilized as a conceptual framework for analyzing partners' experiences. Hausmann et al. (2011) defined perceived discrimination as, "the perception of differential and negative treatment because of one's membership in a particular demographic group" (p. 627). A strength of applying perceived discrimination to this study is the way in which the concept explicitly centers individual interpretations of lived experiences. Pascoe and Richman (2009) noted that because of exclusive reliance on self-report rather than "verification of actual events," the validity of perceived discrimination is a subject of some debate in the literature; however, current research on discrimination is increasingly focused on individual "perceptions of discriminatory treatment" (p. 533) as valid sources of empirical information. Although participants in this study were not explicitly asked about discrimination, they described experiences that mirror those previously identified in empirical literature on perceived discrimination, suggesting that the concept provides language to recognize common experiences. Our participants described discriminatory experiences (e.g., being avoided, ignored, receiving disparaging glances) similar to experiences of perceived discrimination identified in studies of Vietnamese (Mellor, 2004), indigenous (Mellor, 2003), and LGBTQ (Rojas-Lizana, 2014) people in Australia, and indigenous people in Chile (Merino, Mellor, Saiz, & Quilaqueo, 2009).

Perceived discrimination has also been applied to research on health inequities and patient-provider communication in healthcare settings (Abramson et al., 2015; Bogart, Landrine, Galvan,

Wagner, & Klein, 2013; Doyle & Molix, 2015; Hausmann et al., 2011; Lee & Turney, 2012; Pascoe & Smart Richman, 2009). Pascoe and Smart Richman (2009) conducted a meta-analysis of perceived discrimination and confirmed the association between perceived discrimination and negative mental and physical health outcomes. While quantitative examination of the pathways and influences of perceived discrimination on health are invaluable sources of knowledge about the concept and its effects, examining qualitative reflections on perceived discrimination in interpersonal interactions is required to better understand how to recognize and remediate discrimination in health care.

Schmitt and Branscombe (2002) note that “attributions of prejudice” by members of disadvantaged groups are important because they are “likely to be internal, stable, uncontrollable, and convey widespread exclusion and devaluation of one’s group” (p. 167). Historical experiences of discrimination might be particularly salient for older adults who have lived through times in U.S. history in which LGBTQ sexual orientations and gender identities have been pathologized and criminalized (Foglia & Fredriksen-Goldsen, 2014). Seeking to understand discrimination from the vantage of those affected is an empowering methodology, with the potential to provide richer understandings of the “extent and impact” of discrimination in society than could be provided if knowledge was derived solely from an observer (Merino et al., 2009, p. 805). This approach is also consistent with strengths-based social work practice perspectives, which center the expertise of individuals on their own lived experiences (Saleebey, 2006).

Overt Discrimination

Overt discrimination is defined as observable, easily recognized, and intended (Jones, Peddie, Gilrane, King, & Gray, 2013; Van Laer & Janssens, 2011). Contemporary theorists have

described a shift toward more covert forms of discrimination due to changes in social norms discouraging overt discrimination and growing awareness in the general population about discrimination and its deleterious effects (Bonilla-Silva, 2013; Burgess, van Ryn, Dovidio, & Saha, 2007; Nadal, 2013; Pager & Shepherd, 2008; Shelton & Delgado-Romero, 2011; Sue et al., 2007; Williams & Mohammed, 2009). As discussed above, it must be noted that in the current political climate, acts of overt discrimination and violence against LGBTQ people, religious minorities, immigrants, and people of color have risen (Hauslohner, 2017; Lazar, 2017; Lichtblau, 2016). Also, overtly exclusionary legislation targeting LGBTQ people continues to be proposed (Cason, 2017; Kralik, 2017; Wright, 2017).

Covert Discrimination

Covert forms of discrimination might be particularly intractable and difficult to detect because they are subtle and indirect (Bonilla-Silva, 2013; Coates, 2011; Pager & Shepherd, 2008). Coates (2011) states that the “plausible deniability” of covert discrimination “benefits perpetrators by allowing them to deny responsibility and culpability while simultaneously undermining its victims ability to claim damage(s)” (p. 2). This type of discrimination can occur when the person exhibiting discriminatory behavior consciously holds biases and is intentionally duplicitous about their actions based on those biases. At other times, covert discrimination can represent unconscious biases, about which a well-intentioned person is unaware (Castelli, Carraro, Pavan, Murelli, & Carraro, 2012; Coates, 2011; Fallin-Bennett, 2015; Sabin, Riskind, & Nosek, 2015; Sabin, Rivara, & Greenwald, 2008). Bonilla-Silva describes conscious covert discrimination as “smiling face” discrimination, which is exercised by an individual who appears to be friendly and concerned, but who acts to undermine or disrupt a person’s opportunities, engagement, or success (p. 3). An example of smiling face discrimination is a congenial white

woman office manager who kindly tells a person of color that there are no positions available even though jobs are indeed available because she has racial animosity towards the person of color and is acting to prevent their access to employment (Bonilla-Silva, 2013). Covert discrimination, conscious or unconscious, can be challenging to disrupt since undoing biases requires self-awareness as well as willingness to take a critical view of one's own socialization and privileges. In healthcare settings, covert discrimination, whether conscious or unconscious, has been shown to harm the health and well-being of its targets (Blair, Steiner, & Havranek, 2011; Dovidio & Fiske, 2012; M. van Ryn, 2002; Williams & Mohammed, 2009). In the following analyses, healthcare interactions will be examined as the primary site within which covert expressions of discrimination are perceived by LGBTQ partners.

Discrimination and Nonverbal Communication

In an editorial on racial discrimination and health, Dovidio (2009) described the ability of nonverbal communication to rapidly transmit information between individuals. He noted that, "...nonverbal signals can be especially effective in transmitting social attitudes because they can be spontaneously understood with minimal effort and are perceived as a source of valid information" (Dovidio, 2009, p. 1641). Nonverbal communication that has been examined in the context of clinical interactions includes a range of behaviors, such as eye contact and gaze, head nodding, and body positioning (Beck, Daughtridge, & Sloane, 2002; Lorie, Reiner, Phillips, Zhang, & Riess, 2017; Robinson in Manusov & Patterson, 2006; Gerd Røndahl, Innala, & Carlsson, 2006; Stepanikova, Zhang, Wieland, Eleazer, & Stewart, 2012). On the one hand, nonverbal communication can enhance clinical relationships. For example, in a review of literature related to nonverbal communication and physician-patient interaction, Robinson (2006) found that patient-oriented physician body positioning and gaze is related to positive assessments

of physician likeability and patients' willingness to disclose personal information. Similarly, in a systematic review of literature on culture, nonverbal communication, and clinical relationships, Lorie et al. (2017) found that nonverbal communication, including "body posture, smile, and demonstrations of warmth by facial expression," played an important role in communicating empathy, fostering trust, and improving care (p. 421).

On the other hand, nonverbal communication has also been associated with the expression of discrimination, conscious and unconscious, which is related to poorer clinical communication and health inequities (Castelli et al., 2012; Elliott, Alexander, Mescher, Mohan, & Barnato, 2016; Hausmann et al., 2011; Lovaas, 2003; G. Røndahl, 2009; Stepanikova et al., 2012). Elliott et al. (2016) conducted a randomized trial to study verbal and nonverbal communication between physicians and white and African-American patients about end-of-life care. The authors scored physicians' verbal and nonverbal communication, comparing communication with African-American and white patients. The verbal communication scores did not differ between the patient groups. However, physicians' nonverbal communication scores, measured by interaction time with patients and families, open or closed posture, touch, and physical proximity to patients, "were significantly lower with black patients vs white" (Elliott et al., 2016, p.1). Along with those of other related studies, these findings suggest that biases are differentially expressed and perceived.

Research has shown that people are more conscious of, and therefore better able to control, their verbal communication and behaviors than their nonverbal communication (Hausmann et al., 2011; V. Manusov, personal communication, April 24, 2017). Verbal communication and behaviors are more likely to be consistent with social norms restricting overt discrimination. Nonverbal communication, however, is more vulnerable to the expression of unconscious biases.

The relationship between nonverbal communication and discrimination may be particularly relevant to healthcare settings where organizational policies, professional codes of ethics, and practice norms prohibit explicit expressions of discrimination (Hausmann et al., 2011; V. Manusov, personal communication, April 24, 2017).

It is clear that nonverbal communication is an important aspect of good quality clinical care and that nonverbal communication is a means by which both conscious and unconscious discrimination is expressed in clinical relationships. What is less clear is how people interpret nonverbal aspects of communication. The results in this section contribute to research in this area by integrating scholarship on discrimination and nonverbal communication with the experiences of LGBTQ partners in the context of health care for serious illness.

Influences of Discrimination on Clinical Interactions

In Chapter 2, Figure 1, healthcare interactions were described as a site through which social policies influence health. Good communication between patients and clinicians is commonly recognized as a hallmark of quality health care (Barrier, Li, & Jensen, 2003; Curtis et al., 2016; Curtis, Engelberg, Nielsen, Au, & Patrick, 2004; The Joint Commission, 2014). It has also been identified as a mechanism that may result in inequities in health outcomes (Agénor, Bailey, & Krieger, 2015; Hausmann et al., 2011; Johnson, Roter, Powe, & Cooper, 2004; Smedley, Stith, & Nelson, 2003; M. van Ryn, 2002). Importantly, patients' perceptions of discrimination from their healthcare providers have been associated with poor patient-provider communication. Hausman et al. (2011) conducted a study to measure the effects of perceived racial and class discrimination on patient-provider communication. They found that when African Americans perceived discrimination (based on either race or class) they were less likely to indicate positive communication with the clinician. Perceived discrimination might also

influence utilization of health care. Burgess, Ding, Hargreaves, van Ryn, and Phelan (2008) analyzed cross-sectional data from adults who identified as white, U.S.-born black, African-born black, American Indian, Hispanic, and Southeast Asian to assess whether perceived discrimination was associated with underutilization of medical care. Their results showed that even when controlling for access to health care and overall health, “people who reported perceived discrimination from within healthcare settings had significantly higher odds of delaying or avoiding seeking healthcare” (Burgess et al., 2008, p. 902).

Clinical communication concerns specific to LGBTQ people relate to a fear of disclosing sexual orientation or gender identity due to historic (and current) discrimination, concerns about negative biases, and a lack of culturally sensitive medical resources (Brotman et al., 2007; Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emler, & Hooyman, 2014; Furlotte et al., 2016; Institute of Medicine, 2011; Quinn, Sutton, et al., 2015). Fear of disclosure to healthcare providers also relates to concerns that coming out will increase vulnerability and the possibility of mistreatment (Mollon, 2012; Quinn, Sutton, et al., 2015; Roberts & Fantz, 2014; Stanton et al., 2010). These concerns about exposure to heterosexism from clinicians are well-founded. In addition to the high profile media reports already described, studies of clinicians and clinicians-in-training show that they do not receive adequate training to provide culturally competent care to LGBTQ patients and families and that, like the general public, physicians and nurses hold negative biases about LGBTQ people (Burke et al., 2015; Carabez et al., 2015; Fallin-Bennett, 2015; Hayes, Blondeau, & Bing-You, 2015; Lim, Brown, & Jones, 2013; Obedin-Maliver, Goldsmith, Stewart, & et al, 2011; Sequeira, Chakraborti, & Panunti, 2012; Snowden, 2010; K. L. Strong & Folse, 2015).

Even clinicians who do not hold overtly negative beliefs about LGBTQ people must contend with their unconscious biases that are derived from the cultural milieu. Clinicians are often unaware of how or when they express unconscious biases, and how their interactions with LGBTQ patients and partners might be interpreted. Further, the findings of a study conducted by Hausman and colleagues (2011) shows that perceived discrimination in health care has both immediate and long-term influences on “patients’ interactions with the healthcare system by fostering less positive medical encounters in the future” (p. 634). Avoiding such negative effects on healthcare interactions requires data about the types of interactions that might be perceived as discriminatory so that clinicians can be more aware of the ways in which they might be inadvertently marginalizing patients and partners or affirming fears of discrimination in health care.

Results: Experiences of Overt and Covert Discrimination

Because professional codes of ethics and policies guiding practice prohibit discrimination, and likely adequately discourage abusive or derogatory behavior in healthcare settings, partners rarely described aggressive or outright derogatory expressions of discrimination. However, they did describe direct and easily interpreted experiences of overt discrimination via communication and actions. Partners also provided examples of covert, or indirect, discrimination. In some cases, partners interpreted these experiences to be conscious discrimination. In other cases, clinicians seemed to be acting out biases unconsciously. The results of this section are organized according to those three types of discrimination: 1) overt, 2) covert and duplicitous, and 3) covert and likely unconscious.

Overt and Intended: Message Received Loud and Clear

Overt and unambiguous examples of discrimination were easily identified and interpreted by partners. The intent of the clinician seemed clear and were conveyed through overt statements of disapproval of LGBTQ people and/or an invalidation of their relationships. An example of an overt experience of discrimination expressed verbally by a clinician was described by Marc whose reflections were also included in Chapter 4. He encountered a clinician who explicitly stated her disapproval of LGBTQ relationships. Prior to the statement, Marc felt very supported by this nurse who advocated for his right to get medical information and make medical decisions for his partner against the wishes of his partner's confrontational parent. She told the parent that Marc's partner was an adult who designated Marc as his DPOA, and therefore it was up to Marc about whether to share medical information with the parent or allow the parent's involvement in decision-making. In response to Marc's gratitude for the support, the nurse told him:

“I'm a Christian woman. I don't understand [your relationship]...It's not what I believe. It's not what's in the Bible, but you know, I have to do what I need to do as a nurse.”

Marc said that he was shocked by the nurse's response, which made him feel like she had entirely discounted his relationship with that one statement. Her statement destabilizes his feelings of being supported and reifies concerns about discrimination, which Marc had because his partner was receiving care in the southern U.S. Marc's shock about the inconsistency he perceived between her professional behavior and her statement of personal beliefs reveals that biases can be veiled and are not always readily visible. Yet verbal statements overtly expressing discrimination have the power to disrupt partners' feelings of acceptance or safety and confirm underlying fears as Marc indicated after hearing this nurse's statement of her religious beliefs.

Partners also reflected on behavioral examples of overt discrimination. For example, Jaime, whose partner required an ambulance transport to the hospital due to concern about a blood clot in his leg, told the EMT that his partner was HIV positive. Jaime remembered the EMT's response after that disclosure:

“...he would not touch him. He would not talk to him. All the way to the emergency room. And he...wouldn't do anything for him. He wouldn't look at his leg.”

But, as soon as they arrived at the emergency room, Jaime noted that the clinicians assessed his partner with some urgency and a concern that should have been matched by the EMT. Although the EMT did not verbalize his biases against Jaime's partner, his behaviors were easily interpreted by Jaime. Also, Jaime understood the EMT's inaction and failure to assess his partner to be an atypical practice, particularly with concern for a blood clot. Jaime's belief that the EMT should have acted with urgency is supported by the contrasting swift action taken by the emergency room clinicians. Importantly, Jaime's perception that the EMT was unwilling to touch his partner matched the stigma and discrimination historically and currently experienced by people living with HIV (Lambda Legal, 2010). This historical frame contextualizes Jaime's perceptions of discrimination and provides another example of how LGBTQ people do not enter clinical interactions on neutral ground (Dunham, 2014).

As discussed above, nonverbal communication is an important factor in clinical interactions. It can enhance clinical relationships or function as a mechanism for expressing conscious and unconscious biases, both overtly and covertly. Common references to nonverbal communication in the data that were more easily interpreted as negative expressions by clinicians related to eye contact, clinician gaze, or “looks” given by clinicians. In the literature, eye contact has been positively associated with patient satisfaction with health care and

negatively associated discrimination (Bergman & Connaughton, 2013; Hebel, Law, & King, 2010; Dovidio, Hebl, Richeson, & Shelton, 2006; Dovidio & Robinson, 2006; Rood et al., 2016). Although there are important cultural differences in preferences and interpretations of eye contact, reflections from the participants in this study suggest that they viewed eye contact as a positive indicator of clinician engagement and considered other gazes by clinicians, such as “funny looks” and “double-takes” to be cues for overtly discriminatory attitudes. The following are examples of partner reflections on eye contact or looks in which clinician intent appeared clear:

“[The clinicians] were very brusque, very...they were rude, you know, they wouldn’t even look me in the eye when she was talking.” (Sheila)

“Uh, the head nurse at [facility] is a mean little trick. She has a really hard job and when I said...when Liz was being discharged into my care, [the head nurse] gave me really dirty looks that I was the partner.” (Nance)

“...sometimes people look at you weird, but people do that all the time. You know, stare at you like, ‘Oh, what’s up with them?’ or something, but I really don’t pay them too much attention...” (Jasmine)

In these examples, the lack of eye contact given to Sheila, or the looks given to Nance and Jasmine were indicators to each partner of a lack of respect for their relationships. Their reflections illustrate Dovidio’s (2009) claim about the rapid transmission of social attitudes through nonverbal communication. In the cases above, the partners were clear about clinician attitudes of disapproval or in some cases dislike. Even though partners like Jasmine, may have minimized these negative experiences, being watchful for and subject to this type of nonverbal communication added to partners’ stress.

Covert and Duplicitous: Plausibly Deniable

Covert and duplicitous examples of discrimination include those that are delivered in a way that is not objectively problematic, in that the words said or actions taken might fit within the bounds of practice standards, but partners suspect or are able to detect discriminatory intent. An example of such an experience involved Bridgette and a nurse who had been caring for Bridgette's partner after a suicide attempt. Bridgette, who had presented legal documentation of her DPOA status to the nurse, remembered the nurse asking if her partner had family each time Bridgette requested information (despite her DPOA status). Bridgette recalled an exchange with the nurse during which she told the nurse she was going home for the night and asked the nurse to call if there were any changes with her partner's medical status:

“[The nurse said,] ‘Well, we can only give that information to family.’ And she kept asking, ‘Well, doesn't she have any family nearby that we can talk to?’ And you know, I finally said, ‘Well, it doesn't really matter who I am because I'm medical power of attorney.’ ...You know, I could be, you know, her lawyer, basically...but I have the right. So that was very frustrating... She was focused a lot on the word ‘family’ and that she didn't recognize us as family.”

Because policies so clearly identify DPOAs as legitimate recipients of medical information and decision-makers, and because deference to patient DPOAs is a common feature of healthcare practice, the nurse's comments demonstrate a barely veiled challenge to Bridgette's legitimacy as a family member. Although obviously based in heteronormative biases about who ought to be recognized as family, the nurse's comments also illustrate challenges with confronting covert discrimination. If Bridgette complained about the nurse's comments, the nurse could simply declare ignorance about the reach of DPOA status. For example, she could say that she thought DPOAs were only consulted when urgent medical decisions were required. Further, this type of covert discrimination could leave Bridgette feeling uncertain about whether the nurse would call her if her partner's medical status changed. It is of course impossible to know the nurse's intent,

but the repetition of the word “family” in the face of policy and practice regarding DPOAs provided a clear signal to Bridgette that the nurse did not consider Bridgette to be a legitimate family member.

Partners also described covert discrimination expressed through action or inaction that they interpreted to be based in clinician biases. Examples of discriminatory (in)actions that partners discussed included clinicians providing lower quality care, delaying care to LGBTQ patients, or not being sensitive, gentle, or attentive to patients. For example, Marc described the ICU nurses as not being supportive or attentive to him or his partner. He recalled:

“[They were] just kind of there, going through the motions...shove this tube here, shove this tube there, do this...”

Although the clinician’s actions are observably impersonal and inattentive as with Bridgette’s reflection above, the ICU nurses could simply credit their behavior to a heavy workload or a desire to give Marc and his partner privacy. This quality of being not easily proven as examples of discrimination exemplifies the challenges inherent in identifying covert forms of discrimination. Bridgette went on to describe these challenges:

“...at another hospital one time, when she had her back surgery, there were, you know, little things where it was hard to know... Well, one nurse was just outright, you know...kind of hostile, I guess... She was subtle enough about it, that it wasn’t really something we could complain specifically about. But you know...she did not want to recognize me as next of kin, things like that. And then there were just little things that it was hard to know if they were particularly discrimination or if it was just that the nurses were not good at their job. You know, not bringing her pain medication promptly, responding to the bell with some delay, things like that.”

In these types of discriminatory experiences, although relatively easy for partners to identify, clinicians do not reveal the motivations behind their communication and behavior. In these circumstances, partners often reflect feelings of frustration about difficulty in providing evidence for the poor care that they or their loved one have received.

Examples of nonverbal communication also included covert and duplicitous discrimination, again often focusing on gaze or eye contact. “Funny” looks were referenced when partners reflected on interactions that left them uncertain about what such looks meant, but suspicious that clinicians were disapproving of them or their relationships. For example, Adam recalled:

“On a couple of occasions, you know, I had the sense that some of them were looking at us or looking at me kind of funny. They didn’t say anything.”

Partners did not describe the body language that accompanied “funny” looks, but did clearly interpret such looks negatively, which suggests that the looks might have been delivered in combination with other forms of communication or behaviors. A general sense of discomfort or disapproval was all Adam, and others, could glean from such interactions. The interpretive work of noticing nonverbal communication and making meaning of clinician intent is further evidence of LGBTQ partners’ sense of vulnerability and the burden placed on them when navigating within heteronormative healthcare settings.

Covert and Unconscious: Heteronormative Blind Spots

The last type of unambiguous discrimination represents, like the two above, expressions that partners find easy to interpret. However, they are covert in the sense that, although based in heteronormative biases, they are not necessarily expressions of disapproval of LGBTQ people or their relationships. Instead, these represent inadvertent discrimination, of which the clinicians might not even be aware. For example, partners often reflected on statements made by clinicians that seemed to be evidence of clinicians’ attempts to make sense of relationships that were clearly intimate but did not fit heteronormative expectations of partners or spouses (e.g., opposite

gender identity and expression). The following are examples of reflections on these types of clinician assumptions:

“People be sayin’, ‘Oh, you’re sisters?’ We say we live with each other... But some people say we similar, we look alike, or something... We say okay and we just leave it alone.” (Jasmine)

“Kay was prematurely grey-haired. A lot of people assumed that she was my mother. And we didn’t tend to dissuade people. We didn’t insist on being a lesbian couple, necessarily. We were just good friends, or whatever they thought we were and we learned to kind of go with the flow. People came up with their own answers for their own comfort level.” (Cynthia)

“There’s a large age difference between us... So they, a lot of times thought I was his son... But we would correct them on it. And, took a little guff in the ICU, a little bit. I don’t remember a lot of it, kind of purposely just blocked it out...it’s just traumatic and I just wasn’t going to take any guff. I was just like...you know, they would’ve had to drag me outta there.” (Pat)

These excerpts show that partners strategized about whether to correct these types of assumptions but also recognized that doing so might jeopardize their ability to stay involved in their partners’ care or risk incurring additional or more overt discrimination. Regardless of whether the clinicians making these statements intended to be discriminatory, these remarks have consequences, including direct emotional responses to them (e.g., “traumatic”), making partners feel unsafe to come out, or signaling to them that clinicians do not recognize the importance of their relationships with their partners.

At other times it was less clear that clinician communication was driven by unconscious heteronormative biases, particularly when nonverbal communication was identified as the cue for discrimination or potential discrimination. For example, Maggie, who was not a DPOA for her partner, recalled an interaction with a physician:

“I remember another thing that kind of bothered me was after Jen did get out of surgery and the surgeon was talking to her sister...about how...the surgery went and explaining now what to expect in the future...he was like totally friendly, but when

he was talking to us, like 85% of the time, he was addressing her sister. Like, he was looking at her sister. He was talking to her sister.”

She went on to try to make meaning of the physician’s behavior by positing that the physician might have been talking to the sister because Maggie was not the DPOA and the sister was biological family. She did not attribute his behavior to overt discrimination, but did conclude that the physician should have at least acknowledged Maggie as the partner. Without acknowledging the significance of Maggie in Jen’s life, the physician, potentially inadvertently, illegitimated their relationship and Maggie’s inclusion in Jen’s care, and functionally excluding Maggie from Jen’s care.

Interpreting Unclear Cues

Sometimes partners described less easily identifiable cues that clinicians might be expressing discrimination and more complex interpretations of clinician communication and behavior. Feeling disregarded by clinicians is one example of a broader interpretation made by partners. The concept of being disregarded or not acknowledged was perceived by partners through verbal and nonverbal communication as well as other behaviors from clinicians. For example, Anna provided a rich description of her perceptions and interpretations:

“And it was almost like they felt like I was just making stuff up. I felt like I was just disregarded, like...I don’t know. And then I saw the doctors looking at each other at the corner of their eyes...you know, like it was a joke. Like it’s...it’s almost like the unsaid ...it’s hard to... It’s hard to explain it, but it’s like the unsaid, like, ‘How dare me?’ or, ‘Who do I think I am?’... They treated me like I-I shouldn’t be there, like I should’ve been a man. If I was her husband, it would’ve been different.”

What is interesting about Anna’s reflection is that she struggled to detail or explain how the doctors made her feel disregarded. Although she did not name specific aspects of communication, she was able to describe the general experience of being disrespected and

disregarded. It is likely that she compiled information through multiple forms of communication to develop her assessment of the “unsaid” attitudes of the clinicians.

Emily, on the other hand, identified at least some of the reasons she felt disregarded by a nurse. She used the behavior of the rest of the nurses as a reference to assess the behavior of a “daytime nurse” with whom she did not feel comfortable. She also noticed verbal and nonverbal cues indicating differences between the daytime nurse’s attitude and the others’. She recalled:

“So, some of it was body language and some of it was how she handled, you know, verbalizing in conversation. And also, you know...if one of the nurses stuck their heads in and Joan’s eyes were closed or something like that, they would communicate with me. You know, they would look at me or they would ask me, ‘How are things going? How is this thing that was talked about before?’ and the daytime nurse just never did. So, she never initiated conversation with me. And it was...it took effort to get myself into conversations with her, when she was, you know, talking to Joan.”

In this reflection, Emily identifies three ways in which the daytime nurse behaved differently from the other nurses. First, she would not look at Emily to check in with her when Joan was asleep. Second, the nurse did not ask Emily how things were going like the other nurses did. And finally, Emily felt as though she must work to be included in conversations with this nurse when Joan was awake. These three cues indicated to Emily that she was not being cared for by the nurse and that she was not seen as a legitimate person to include in Joan’s care. In this excerpt, Emily described a scenario in which she was acutely aware of the subtle behaviors of the nurse, and that she was burdened by having to insert herself into conversations to be acknowledged.

Conclusion

Examining the many facets of interpersonal interactions from which partners gather information to assess whether they will be respected and included in the care of their partners

demonstrates an additional layer of stress placed on partners. In their reflections, partners communicate alertness to multiple modes of communication and forms of discrimination that might be directed their way. Through this analysis, vigilant responses to chronic discrimination described by Williams and Mohammed (2009) become readily visible. The results presented in this chapter contribute to the literature in three ways. First, the theoretical framing of this study brings together literature on perceived discrimination with work on overt and covert discrimination to frame perceived discrimination as a factor in health inequities. The results demonstrate that even when outright derogatory and aggressive statements of discrimination are not present in partner accounts, more nuanced forms of overt and covert discrimination persist.

Second, analyzing nonverbal forms of communication adds nuance to studies of perceived discrimination. Whereas published typologies of perceived discrimination (Mellor, 2003, 2004; Merino et al., 2009; Rojas-Lizana, 2014) include references to nonverbal communication, nonverbal communication has not received examination apart from other forms of communication and behaviors in this literature. Also, studies specifically focused on nonverbal communication have shown that it contributes to health inequities, but no studies examined nonverbal communication in the context of health care for serious illness. This study shows that nonverbal communication is a feature of healthcare interactions that cues partners to discrimination or the potential for it.

The third contribution of this study is that it situates LGBTQ partners' experiences within health care for serious illness, a type of care associated with storied and tragic accounts of partners being excluded from visitation and decision-making for their loved ones. Cultural norms that construct an ideal death as one in which people dying are with their closest family also increase the ethical valence of partners being separated when death is possible or imminent.

It is therefore an important setting in which the reflections by partners detailed here can inform interventions to increase clinicians' sensitivity to communication and behaviors that make partners feel excluded or at risk for exclusion.

CHAPTER 6

DISCUSSION, IMPLICATIONS, AND CONCLUSION

Discussion

The starting point for this dissertation was my distress about Strong's experience in Seattle. I initially engaged with this study assuming participants would widely report overtly discriminatory experiences in health care, and the purpose of the research would be to demonstrate the challenges faced by LGBTQ people. I was anticipating stories about partners being denied the right to visit their partners and/or make medical decisions. Through the process of this dissertation research, my initial assumptions about overt discrimination diminished as curiosity about more subtle experiences of discrimination increased. Interest in the ways that partners described and interpreted their experiences motivated the identification of frameworks that helped me interpret the ways in which people make meaning of the "everyday" function of law in their lives and the "everyday" types of discrimination they experience. This "everyday" focus allowed me to frame the subtler forms of discrimination to consider how partners contextualized those experiences in the sometimes long-term and profound healthcare experiences they had over the trajectory of their loved ones' illnesses. As I became deeply immersed in the data, the amount of work partners did to navigate in healthcare settings to anticipate, avoid, identify, and interpret discrimination came to the forefront. It is not individual experiences of discrimination that are of primary interest here, but how collectively, the sociopolitical context of LGBTQ partnerships informed partners' approaches to healthcare interactions and their perceptions of clinician communication and behavior, both supportive and discriminatory.

This study contributes to the wider literature on SDOH by showing the persistence of discrimination against LGBTQ people and validating that sexual orientation and gender identity must be explicitly incorporated in SDOH frameworks. Likewise, PDOH are highly relevant to studies of health inequities. Given the already noted health inequities experienced by LGBTQ people (Logie, 2012; Pega & Veale, 2015; United Nations Human Rights Council, 2015), as well as the findings of this study, sexual orientation and gender identity should consistently be included as characteristics that relate to SDOH, with particular focus on discrimination and its consequent health outcomes. Incorporating gender identity in SDOH frameworks would support efforts to research the unique needs of people with non-binary or non-heteronormative gender identities in healthcare settings, which is remarkably lagging in the current research literature. Theoretically supported by scholarship that focuses on political aspects of discrimination as a determinant of health, this study maintains an inherently political approach. As in Krieger's (2011) upstream focus on racism as a determinant of health (p. 287-288), this study positions heteronormativity as the sociopolitical source of LGBTQ health inequities, via the influence of discriminatory policies and practices in healthcare interactions. Derived from qualitative data, the results point to ways in which upstream influences on health are reflected in sometimes subtle and nuanced interactions in healthcare settings.

In addition to contributing to SDOH frameworks, the results of this study underscore that LGBTQ people often do not assume a neutral starting place with clinicians (Dunham, 2014), which denotes both the history of discrimination in health care and a health inequity in and of itself. Health inequity is created when partners experience burdens related to preparing for healthcare encounters, scanning environments for risks of discrimination, having to continually interpret their interactions with clinicians to assess for discrimination, and making decisions

about how to respond to potentially unsafe or discriminatory situations. These efforts might go unnoticed by clinicians who, for the most part, do not intend to discriminate or make partners feel excluded. Clinicians are potentially unaware of the ways in which LGBTQ people's past experiences, stories of experiences of others in the LGBTQ community, and the politicization of LGBTQ relationships creates a lens through which partners assess healthcare environments and interactions. This dissertation illuminates the burdens experienced by LGBTQ people exposed to discriminatory practices so that with this information clinicians might be better able to support LGBTQ partners, particularly in health care for serious illness.

Implications for Policy and Practice

The results of this study have implications for policy and practice. Policy implications include both macro- and mezzo-level policies and policy implementation. Although positive policy changes at the macro level by no means represent uniform social change, as is evident in the current backlash of "freedom of religion" laws and "bathroom bills," they represent values of equity and inclusion. Discrimination against LGBTQ people is deeply ingrained into the social and cultural norms of U.S. society, so public policy at the federal and state levels is needed to create a legal structure that provides more tools for LGBTQ people and allies to "use" the law to advocate for equality in relationship recognition. The findings of this study related to the legal consciousness of partners demonstrate that, while not fail-safe, relationship recognition laws provide partners with some sense of protection against exclusion from their partners' care. The social valuing of LGBTQ people and their relationships can also be expressed through anti-discrimination laws. The inclusion and safety of partners in healthcare settings is contingent on social acceptance and broader legal protections.

The findings in this study also show that legal documentation of a relationship (marriage or DPOA) is not enough to protect partners from discrimination. In order to enhance inclusion at the mezzo level and improve the consistency of policy implementation, organizations must develop policies and inculcate practices that more robustly assess institutional barriers to inclusion, as well as strategies for enhancing inclusion. The Joint Commission's field guide titled *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community* (2014) provides comprehensive checklists for healthcare administrators. The "Leadership Checklist" (p. 35) includes content that addresses discrimination *and* disrespectful behavior toward LGBTQ people. This focus on creating a culture of respect, rather than focusing only on discrimination and basic access for partners, provides an emphasis on a broader range of discriminatory practices, including covert expressions of disrespect. The field guide suggests the development of assessment and accountability processes to create structure for shifting culture in a way that sensitizes clinicians and gives partners clear avenues to report the subtler forms of disrespect they experience. The emphasis on culture change is important because engagement with this type of organizational change has the capacity to penetrate more deeply into underlying attitudes and practice habits than routine policy shifts have. Also, considering the full range of organizational staff that interact with LGBTQ patients and their partners (that have broadly been referred to as "clinicians" in this dissertation) requires that assessment and accountability processes be attentive to organizational hierarchies, facilitating input from all levels of staff.

Partner reflections on their experiences also reveal problems at the practice-level, with healthcare interactions not adequately alleviating concerns about potential discrimination, or more problematically, being a site in which discrimination is expressed. To address practice-

related improvements to health care for LGBTQ people, the Joint Commission field guide also provides a detailed checklist for the “Provision of Care, Treatment, and Services.” The checklist focuses on the creation of a welcoming and inclusive environment (via strategies such as inclusive forms and signage), avoiding heteronormative assumptions (in written and verbal communication), facilitating disclosure of sexual orientation and gender identity while recognizing that “coming out is an individual process,” and providing resources for LGBTQ people when appropriate (The Joint Commission, 2014, p. 36). The results of this study show that while these types of organizational improvements are important, anticipatory concerns might be heightened in the context of health care for serious illness. Therefore, the clinical settings of emergency rooms, intensive care units, and other units that regularly care for seriously ill patients must establish standards for care that expressly notify partners of their rights and the organization’s standards regarding the recognition of LGBTQ partnerships, and respect for patients’ identification of their family members and support people. Simple strategies such as having clinicians wear rainbow stickers on their name tags have been employed at hospitals, including the University of Washington Medical Center, to communicate safety and inclusion to LGBTQ patients and their families.

The study findings also demonstrate that inclusive health care requires deeper awareness from clinicians about potential concerns for LGBTQ people and about biases that might manifest in interactions with LGBTQ people (conscious or unconscious). Therefore, opportunities to develop the self-awareness of staff at all levels and a wider culture of sensitivity and accountability is needed. There are a range of frameworks for developing clinician capacity to practice across cultural differences (understood broadly to include sexual orientation and gender identity), including cultural competence, cultural fluency, cultural humility, and cultural

consciousness. What these frameworks share is a motivation to provide clinicians and administrators with tools nimble enough to navigate many, and ever-changing, types of cross-cultural practices. Cultural competency frameworks are suggested as antidotes to discrimination in health care (Arthur, 2015; Conlon & Aldredge, 2013; Dearing & Hequembourg, 2014; Fredriksen-Goldsen et al., 2014; Garner, 2010; Klein & Nakhai, 2016). Cultural competency frameworks focus on the development of professional skills that challenge assumptions about individuals based on their identities while also recognizing differences between group experiences. Cultural fluency frameworks similarly focus on developing facility for communicating across difference by focusing on assumptions and discomfort that arise in cross-cultural settings (Oyserman, 2011). The concept of cultural competence is often critiqued for have an inherent implication that a level of competency that resembles an endpoint for professional development is attainable, and that the locus for change is too narrowly on individuals, ignoring structural factors that create the conditions that make cross-cultural practice difficult (e.g., social constructions of race, heteronormativity) (Danso, 2016). Cultural fluency is vulnerable to the same critiques. Cultural humility frameworks attempt to address some of these limitations by describing humility as an approach to practice that acknowledges power dynamics and moves away from the notion that competence is possible. However, structural critiques are generally understated or missing from these cultural humility frameworks as well.

The underlying challenge for any framework is that culture is “slippery and untameable for any single framework” (Danso, 2016). Recognizing this challenge, cultural consciousness frameworks draw from theories of critical consciousness, which blend a focus on individual awareness and social change (Azzopardi & McNeill, 2016; Sakamoto & Pitner, 2005; Suárez, Newman, & Reed, 2008). It is an example of an approach to ethical practice across cultural

differences that incorporates a more open approach, supportive of patient strengths and knowledge, and therefore consistent with the strengths-based perspective in social work, and that provides a useful framework for skill development that requires clinicians to become self-aware of biases, recognize the history of discrimination experienced by the LGBTQ community, and consider structural contributions to discrimination (e.g., heteronormativity). Cultural consciousness is “an ongoing and dynamic developmental process with no endpoint” in which clinicians maintain “a continuous, mindful awareness of culture and diversity, including the complex ways in which they construct meaning and experience” to promote “effective and ethical practice” (Azzopardi & McNeill, 2016, p. 287). Developing an approach to practice that integrates cultural consciousness requires development of a broader clinical ethic that continually evolves practices in the interest of improving inclusivity and equity amidst rapidly changing sociopolitical influences.

Limitations

The study limitations relate to recruitment and the study sample. First, participants were volunteers and therefore the sample was selective, including only those people who were comfortable talking about their experiences as they cared for their seriously ill partner. A number of individuals contacted the study but ultimately declined to participate, saying that they were fearful of being exposed in their communities or that the topic was too disturbing to discuss. These individuals may have provided quite different reflections of their experiences. Similarly, because recruitment materials targeted people who identified as “same-sex” partners or “LGBT,” it is likely that the sample does not include people who do not identify with those terms, but who might have otherwise been eligible for the study (National Resource Center on LGBT Aging, 2013). However, in preparation for the study, CFP staff ran a focus group and

consulted experienced researchers and community members about the most easily identifiable language to use in recruitment materials. Focus group participants acknowledged the limitations of language, but agreed that LGBTQ people recognize and understand what is intended by the acronym, making it the most pragmatic language to use in recruitment materials. Recruitment for CFP utilized some innovative techniques, strategically not relying exclusively on LGBTQ organizational- or media-based outreach. By using internet-based platforms like Craigslist and Yahoo, recruitment efforts may have reached people who are not generally out and/or are not connected with any LGBTQ-specific organizations or media.

Another limitation relates to the geographic regions represented in the sample. Respondents to the outreach efforts overwhelmingly represent Washington State and were generally concentrated in the west. This is likely due to increased opportunities for in-person outreach efforts in Washington State because the CFP study was in Seattle, and because four LGBTQ-identified staff members (myself included) were affiliated with the larger research group and distributed recruitment materials within their social networks. Despite national outreach efforts and an added in-person recruitment effort in Boston, the sample included only 1 participant from the Northeast region. A more geographically balanced sample might have provided additional insights into how sociopolitical contexts influence partners' expectations and experiences.

Finally, as described in Chapter 3, participants in this study overwhelmingly reported their and their partners' sexual orientation as lesbian or gay and gender identity as female or male. Therefore, the results of this dissertation do not adequately represent the experiences of people who identify with sexual orientations other than lesbian or gay, or gender identities other than female or male. The same is true regarding the experiences of people of color. The participants

in this study primarily described their and their partners' racial identity as white and their ethnic identity as not Hispanic. Participants were not asked about physical disabilities, mental health issues, or religion, although participants might have also experienced discrimination based on any of these characteristics. My future research on this topic will engage with these limitations and consider methods to reach a wider sample so that an intersectional approach to analysis might be possible.

Directions for Future Research

To address some of the limitations described above, future research efforts should utilize community outreach strategies as well as anonymous methods to enhance the inclusion of people who may be reluctant to participate. I would also like to design outreach materials and methods to more sensitively recruit people who identify as bisexual and transgender, as well as people with a range of non-binary sexual orientations and gender identities. The inclusion of people who experience discrimination based on their racial and/or ethnic identity is also a necessity. Through enhanced outreach efforts to recruit a broader sample of LGBTQ people, intersectional analyses would be possible. Intersectionality refers to a body of theoretical work that aims to resist essentializing notions of social characteristics, such as race, sexual orientation, and gender, as though they were distinguishable influences on one's lived experiences. Instead, intersectional theory aims to understand social identities and the positionality experienced due to those identities as complex, interrelated, and overlapping aspects of individual realities (Crenshaw, 1991; Mehrotra, 2010). The integration of intersectionality in analyses of the experiences of LGBTQ patients receiving health care for serious illnesses and those of their partners is needed to have a fuller understanding of partners' experiences, including the ways

that people experience discrimination due to social characteristics other than sexual orientation and gender identity.

Finally, observational studies and interviews with clinicians and healthcare administrators are needed. Such research would allow for analyses of the pathways from policy to practice through which discrimination is transmitted and could be interrupted. Institutional ethnography (Smith, 2005) has been successfully applied to analyses of healthcare processes and contributors to health disparities (e.g., Quinlan, 2009; Sinding, 2010). Smith (2005) describes institutional ethnography as a method that “begins in the local actualities of the everyday world, with the concerns and perspectives of people located distinctively in the institutional process” (p. 34). As such, institutional ethnography is well-suited to examine the influences of policy on organizational processes, and clinician and LGBTQ patient and partner experiences. An empirical analysis of institutional processes could also be paired with interview-based studies with administrators, clinicians, patients, and family members to understand how institutional processes are interpreted, implemented, and experienced by individuals located differently within institution structures. Insights gained from multi-dimensional approaches to research could yield multi-dimensional interventions to improve the experiences of LGBTQ patients and their partners, and to potentially reduce current levels of health inequities.

Conclusion

As the epigraph from Chochinov (2012) at the beginning of this dissertation suggests, ethical practice in serious illness requires that clinicians are willing to see the fullness of patients’ vulnerabilities and strengths. In the case of LGBTQ people receiving health care for serious illness, the usual vulnerabilities are compounded by anticipatory concerns about whether their relationships will be recognized and respected, as well as experiences of discrimination.

Participants in this study demonstrated considerable burdens created by unjust laws, organizational policies that did not reliably support their inclusion, and clinician communication and behavior that expressed discrimination. Partner reflections also provided a clear picture of the agency, commitment, and determination partners demonstrated while caretaking and navigating healthcare settings during difficult times. At times partners also identified ways in which knowledgeable and sensitive clinicians provided support. For healthcare organizations and clinicians to reliably support partners, administrators and clinicians must be willing to look at the way in which heteronormativity influences what partners carry when they walk in the door, as well as how heteronormativity infiltrates healthcare organizations and their own biases. This type of awareness is essential for ethical practice with seriously ill LGBTQ people and their partners (National Association of Social Workers, 2004, p. 4). In hospitals that treat the concerns of LGBTQ families seriously, we can hope to avoid the tragic ends faced by Charlene Strong, Janice Langbehn, and Sharon Reed.

REFERENCES

- Abramson, C. M., Hashemi, M., & Sánchez-Jankowski, M. (2015). Perceived discrimination in U.S. healthcare: Charting the effects of key social characteristics within and across racial groups. *Preventive Medicine Reports, 2*, 615–621. <https://doi.org/10.1016/j.pmedr.2015.07.006>
- Agénor, M., Bailey, Z., & Krieger, N. (2015). Exploring the cervical cancer screening experiences of black lesbian, bisexual, and queer women: The role of patient-provider communication. *Women & Health, 55*, 717–736.
- American College of Healthcare Executives. (2013). The healthcare executive's role in fostering inclusion of LGBT patients and employees. Retrieved from <https://www.ache.org/policy/inclusion-lgbt.cfm>
- American Society for Aging. (2010). *Still out, still aging: The MetLife study of lesbian, gay, bisexual, and transgender baby boomers*. American Society for Aging. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-still-out-still-aging.pdf>
- Arthur, D. (2015). Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective. *Journal of Social Work in End-of-Life & Palliative Care, 11*(2), 178–201. <https://doi.org/10.1080/15524256.2015.1074141>
- Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*(3), 385–405. <https://doi.org/10.1177/146879410100100307>
- Auchmuty, R. (2016). The experience of civil partnership dissolution: Not “just like divorce.” *Journal of Social Welfare and Family Law, 38*(2), 152–174. <https://doi.org/10.1080/09649069.2016.1156884>
- Azétsop, J., & Rennie, S. (2010). Principlism, medical individualism, and health promotion in resource-poor countries: Can autonomy-based bioethics promote social justice and population health? *Philosophy, Ethics, and Humanities in Medicine, 5*, 1. <https://doi.org/10.1186/1747-5341-5-1>
- Azzopardi, C., & McNeill, T. (2016). From cultural competence to cultural consciousness: Transitioning to a critical approach to working across differences in social work. *Journal of Ethnic & Cultural Diversity in Social Work, 25*(4), 282–299. <https://doi.org/10.1080/15313204.2016.1206494>
- Balsam, K. F., Molina, Y., Beadnell, B., Simoni, J., & Walters, K. (2011). Measuring multiple minority stress: The LGBT people of color microaggressions scale. *Cultural Diversity & Ethnic Minority Psychology, 17*(2), 163–174. <https://doi.org/10.1037/a0023244>

- Barrier, P. A., Li, J. T.-C., & Jensen, N. M. (2003). Two words to improve physician-patient communication: What else? *Mayo Clinic Proceedings*, *78*(2), 211–214. <https://doi.org/10.4065/78.2.211>
- Bartlett, H. M. (1975). Ida M. Cannon: Pioneer in medical social work. *Social Service Review*, *49*(2), 208–229.
- Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics*. New York, NY: Oxford University Press.
- Beck, R. S., Daughtridge, R., & Sloane, P. D. (2002). Physician-patient communication in the primary care office: A systematic review. *Journal of the American Board of Family Medicine*, *15*, 25–38.
- Bergman, A. A., & Connaughton, S. L. (2013). What Is patient-centered care really? Voices of Hispanic prenatal patients. *Health Communication*, *28*(8), 789–799. <https://doi.org/10.1080/10410236.2012.725124>
- Blair, I. V., Steiner, J. F., & Havranek, E. P. (2011). Unconscious (implicit) bias and health disparities: Where do we go from here? *The Permanente Journal*, *15*(2), 71–78.
- Boehmer, U., & Case, P. (2004). Physicians don't ask, sometimes patients tell: Disclosure of sexual orientation among women with breast carcinoma. *Cancer*, *101*(8), 1882–1889. <https://doi.org/10.1002/cncr.20563>
- Bogart, L. M., Landrine, H., Galvan, F. H., Wagner, G. J., & Klein, D. J. (2013). Perceived discrimination and physical health among HIV-positive Black and Latino men who have sex with men. *AIDS and Behavior*, *17*(4), 1431–1441. <https://doi.org/10.1007/s10461-012-0397-5>
- Bonilla-Silva, E. (2013). *Racism without racists: Color-blind racism and the persistence of racial inequality in America* (4 edition). Lanham, MD: Rowman & Littlefield Publishers.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braveman, P., & Gottlieb, L. (2014). The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports*, *129*(Suppl 2), 19–31.
- Brazg, T., Dotolo, D., & Blacksher, E. (2014). Finding a seat at the table together: Recommendations for improving collaboration between social work and bioethics. *Bioethics*, n/a-n/a. <https://doi.org/10.1111/bioe.12106>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513–531. <https://doi.org/10.1037/0003-066X.32.7.513>

- Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cormier, R., Julien, D., ... Richard, B. (2007). Coming out to care: Caregivers of gay and lesbian seniors in Canada. *The Gerontologist*, 47(4), 490–503.
- Broverman, N. (2017, May 1). Dems re-introducing LGBT rights bill. *The Advocate*. Retrieved from <http://www.advocate.com/politics/2017/5/01/dems-re-introducing-lgbt-rights-bill>
- Burgess, D. J., Ding, Y., Hargreaves, M., van Ryn, M., & Phelan, S. (2008). The association between perceived discrimination and underutilization of needed medical and mental health care in a multi-ethnic community sample. *Journal of Health Care for the Poor and Underserved*, 19(3), 894–911. <https://doi.org/10.1353/hpu.0.0063>
- Burgess, D., van Ryn, M., Dovidio, J., & Saha, S. (2007). Reducing racial bias among health care providers: Lessons from social-cognitive psychology. *Journal of General Internal Medicine*, 22(6), 882–887. <https://doi.org/10.1007/s11606-007-0160-1>
- Burke, S. E., Dovidio, J. F., Przedworski, J. M., Hardeman, R. R., Perry, S. P., Phelan, S. M., ... van Ryn, M. (2015). Do contact and empathy mitigate bias against gay and lesbian people among heterosexual first-year medical students? A report from the medical student CHANGE study. *Academic Medicine: Journal of the Association of American Medical Colleges*, 90(5), 645–651. <https://doi.org/10.1097/ACM.0000000000000661>
- Burkhalter, J. E., Margolies, L., Sigurdsson, H. O., Walland, J., Radix, A., Rice, D., ... Maingi, S. (2016). The National LGBT Cancer Action Plan: A white paper of the 2014 National Summit on Cancer in the LGBT Communities. *LGBT Health*, 3(1), 19–31. <https://doi.org/10.1089/lgbt.2015.0118>
- Cadei, E. (2017, March 15). A new strategy may have opened for states opposed to gay marriage. Retrieved from <http://www.newsweek.com/state-religious-freedom-laws-568299>
- Carabez, R., Pellegrini, M., Mankovitz, A., Eliason, M., Ciano, M., & Scott, M. (2015). “Never in all my years...”: Nurses’ education about LGBT health. *Journal of Professional Nursing*, 31(4), 323–329. <https://doi.org/10.1016/j.profnurs.2015.01.003>
- Cartwright, C. (2011). Ethical challenges in end-of-life care for GLBTI individuals. *Journal of Bioethical Inquiry*, 9(1), 113–114. <https://doi.org/10.1007/s11673-011-9345-8>
- Cartwright, C., Hughes, M., & Lienert, T. (2012). End-of-life care for gay, lesbian, bisexual and transgender people. *Culture, Health & Sexuality*, 14(5), 537–548. <https://doi.org/10.1080/13691058.2012.673639>
- Cason, M. (2017, April 18). Alabama senate passes bill protecting faith-based adoption policies. *AL.com*. Retrieved from http://www.al.com/news/birmingham/index.ssf/2017/04/alabama_senate_passes_bill_pro.html

- Castelli, L., Carraro, L., Pavan, G., Murelli, E., & Carraro, A. (2012). The power of the unsaid: The influence of nonverbal cues on implicit attitudes. *Journal of Applied Social Psychology, 42*(6), 1376–1393. <https://doi.org/10.1111/j.1559-1816.2012.00903.x>
- Centers for Disease Control and Prevention. (2014). NCHHSTP social determinants of health. Retrieved from <https://www.cdc.gov/nchhstp/socialdeterminants/definitions.html>
- Chansanchai, A. (2009). The end of an ordinary life. Retrieved from <http://www.seattlepi.com/local/article/The-end-of-an-ordinary-life-1301899.php#src=fb>
- Chochinov, H. M. (2012). Vulnerability and palliative care. *Palliative & Supportive Care, 10*, 1–2.
- Coates, R. D. (2011). *Covert racism: Theories, institutions, and experiences*. Boston, MA: BRILL.
- Conlon, A., & Aldredge, P. A. (2013). Department of Health and Human Services changes: Implications for hospital social workers. *Health & Social Work, 38*(1), 19–27.
- Connolly, C. (2002). The voice of the petitioner: The experiences of gay and lesbian parents in successful second-parent adoption proceedings. *Law & Society Review, 36*(2), 325–346. <https://doi.org/10.2307/1512179>
- Craig, S. L., Bejan, R., & Muskat, B. (2013). Making the invisible visible: Are health social workers addressing the social determinants of health? *Social Work in Health Care, 52*(4), 311–331. <https://doi.org/10.1080/00981389.2013.764379>
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review, 43*(6), 1241–1299. <https://doi.org/10.2307/1229039>
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd edition). Thousand Oaks, CA: SAGE Publications, Inc.
- Crossland, J. (2016). Exploring the Care Act’s potential for anti-discriminatory practice with lesbian, gay, bisexual and trans older people. *Quality in Ageing and Older Adults, 17*(2), 97–106. <https://doi.org/10.1108/QAOA-05-2015-0026>
- Curtis, J. R., Engelberg, R. A., Nielsen, E. L., Au, D. H., & Patrick, D. L. (2004). Patient-physician communication about end-of-life care for patients with severe COPD. *The European Respiratory Journal, 24*(2), 200–205.
- Curtis, J. R., Treece, P. D., Nielsen, E. L., Gold, J., Ciechanowski, P. S., Shannon, S. E., ... Engelberg, R. A. (2016). Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *American Journal of Respiratory and Critical Care Medicine, 193*(2), 154–162. <https://doi.org/10.1164/rccm.201505-0900OC>

- Daniel, H., & Butkus, R. (2015). Lesbian, gay, bisexual, and transgender health disparities: Executive summary of a policy position paper from the American College of PhysiciansLGBT Health Disparities. *Annals of Internal Medicine*, 163(2), 135–137. <https://doi.org/10.7326/M14-2482>
- Danis, M., Wilson, Y., & White, A. (2016). Bioethicists can and should contribute to addressing racism. *The American Journal of Bioethics*, 16(4), 3–12. <https://doi.org/10.1080/15265161.2016.1145283>
- Danso, R. (2016). Cultural competence and cultural humility: A critical reflection on key cultural diversity concepts. *Journal of Social Work*, 1468017316654341. <https://doi.org/10.1177/1468017316654341>
- Dearing, R. L., & Hequembourg, A. L. (2014). Culturally (in)competent? Dismantling health care barriers for sexual minority women. *Social Work in Health Care*, 53(8), 739–761. <https://doi.org/10.1080/00981389.2014.944250>
- Denzin, N. K. (2017). Critical qualitative inquiry. *Qualitative Inquiry*, 23(1), 8–16. <https://doi.org/10.1177/1077800416681864>
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The SAGE handbook of qualitative research* (4th Edition). Thousand Oaks, CA: SAGE Publications.
- DiGregorio, N. (2016). Same-sex marriage policies and lesbian family life. *Sexuality Research and Social Policy*, 13(1), 58–72. <https://doi.org/10.1007/s13178-015-0211-z>
- Dotolo, D., Lindhorst, T., Kemp, S., & Engelberg, R.A. Conceptualizing social justice: Contributions of recognition theory to just social work practice. Manuscript in progress.
- Dovidio, J. F. (2009). Racial bias, unspoken but heard. *Science*, 326(5960), 1641–1642. <https://doi.org/10.1126/science.1184231>
- Dovidio, J. F., & Fiske, S. T. (2012). Under the radar: How unexamined biases in decision-making processes in clinical interactions can contribute to health care disparities. *American Journal of Public Health*, 102(5), 945–952. <https://doi.org/10.2105/AJPH.2011.300601>
- Dovidio, J.F., Hebl, M., Richeson, J.A., & Shelton, J.N. (2006). Nonverbal communication, race, and intergroup interaction. In Manusov, V. L., & Patterson, M. L. (Eds.). (pp. 481-500). *The SAGE handbook of nonverbal communication* (1st edition). Thousand Oaks, CA: SAGE Publications, Inc.
- Doyle, D. M., & Molix, L. (2015). Perceived discrimination and social relationship functioning among sexual minorities: Structural stigma as a moderating factor. *Analyses of Social Issues and Public Policy: ASAP*, 15(1), 357–381. <https://doi.org/10.1111/asap.12098>

- Drake, B. (2013, June 25). How LGBT adults see society and how the public sees them. Retrieved from <http://www.pewresearch.org/fact-tank/2013/06/25/how-lgbt-adults-see-society-and-how-the-public-sees-them/>
- Dunham, K. (2014, November 21). In the hospital, there's no such thing as a lesbian knee. Retrieved from <http://www.npr.org/blogs/health/2014/11/21/365469968/in-the-hospital-theres-no-such-thing-as-a-lesbian-knee>
- Elliott, A. M., Alexander, S. C., Mescher, C. A., Mohan, D., & Barnato, A. E. (2016). Differences in physicians' verbal and nonverbal communication with black and white patients at the end of life. *Journal of Pain and Symptom Management, 51*(1), 1–8. <https://doi.org/10.1016/j.jpainsymman.2015.07.008>
- Ewick, P., & Silbey, S. S. (1998). *The common place of law*. Chicago, IL: University of Chicago Press. Retrieved from <http://www.press.uchicago.edu/ucp/books/book/chicago/C/bo3615912.html>
- Fallin-Bennett, K. (2015). Implicit bias against sexual minorities in medicine: Cycles of professional influence and the role of the hidden curriculum. *Academic Medicine: Journal of the Association of American Medical Colleges, 90*(5), 549–552. <https://doi.org/10.1097/ACM.0000000000000662>
- Farmer, D. F., & Yancu, C. N. (2015). Hospice and palliative care for older lesbian, gay, bisexual and transgender adults: The effect of history, discrimination, health disparities and legal issues on addressing service needs. *Palliative Medicine and Hospice Care, 1*(2), 36–43.
- Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4), 531–545. <https://doi.org/10.1177/104973202129120052>
- Foglia, M. B., & Fredriksen-Goldsen, K. I. (2014). Health disparities among LGBT older adults and the role of nonconscious bias. *The Hastings Center Report, 44*(0 4), S40–S44. <https://doi.org/10.1002/hast.369>
- Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emlet, C. A., & Hooyman, N. R. (2014). Creating a vision for the future: key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of Gerontological Social Work, 57*(2–4), 80–107. <https://doi.org/10.1080/01634372.2014.890690>
- Fredriksen-Goldsen, K. I., Kim, H.-J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health disparities among lesbian, gay, and bisexual older adults: Results From a population-based study. *American Journal of Public Health, 103*(10), 1802–1809.
- Furlotte, C., Gladstone, J. W., Cosby, R. F., & Fitzgerald, K.-A. (2016). “Could we hold hands?” Older lesbian and gay couples' perceptions of long-term care homes and home care. *Canadian Journal of Aging, 35*(4), 432–446.

- Garnero, T. L. (2010). Providing culturally sensitive diabetes care and education for the lesbian, gay, bisexual, and transgender (LGBT) community. *Diabetes Spectrum*, 23(3), 178–182. <https://doi.org/10.2337/diaspect.23.3.178>
- Gilgun, J. F. (2015). Beyond description to interpretation and theory in qualitative social work research. *Qualitative Social Work*, 14(6), 741–752. <https://doi.org/10.1177/1473325015606513>
- Goldsen, J., Bryan, A. E. B., Kim, H.-J., Muraco, A., Jen, S., & Fredriksen-Goldsen, K. I. (2017). Who says I do: The changing context of marriage and health and quality of life for LGBT older adults. *The Gerontologist*, 57(suppl_1), S50–S62. <https://doi.org/10.1093/geront/gnw174>
- Gordon, A. R., & Meyer, I. H. (2008). Gender nonconformity as a target of prejudice, discrimination, and violence against LGB individuals. *Journal of LGBT Health Research*, 3(3), 55–71. <https://doi.org/10.1080/15574090802093562>
- Gringeri, C. E., Wahab, S., & Anderson-Nathe, B. (2010). What makes it feminist?: Mapping the landscape of feminist social work research. *Affilia*, 25(4), 390–405. <https://doi.org/10.1177/0886109910384072>
- Harding, R. (2006). “Dogs are ‘registered’, people shouldn’t be”: Legal consciousness and lesbian and gay rights. *Social & Legal Studies*, 15(4), 511–533. <https://doi.org/10.1177/0964663906069545>
- Harding, R. (2011). *Regulating sexuality: Legal consciousness in lesbian and gay lives*. New York, NY: Routledge.
- Harding, R., Epiphaniou, E., & Chidgey-Clark, J. (2012). Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *Journal of Palliative Medicine*, 15(5), 602–611. <https://doi.org/10.1089/jpm.2011.0279>
- Harvey, V., & Housel, T. H. (Eds.). (2014). *Health care disparities and the LGBT population*. Lanham, Maryland: Lexington Books.
- Hash, K., & Netting, E. (2007). Long-term planning and decision-making among midlife and older gay men and lesbians. *Journal of Social Work in End-of-Life & Palliative Care*, 3(2), 59–77. https://doi.org/10.1300/J457v03n02_05
- Hauslohner, A. (2017, February 15). Southern Poverty Law Center says American hate groups are on the rise. *The Washington Post*. Retrieved from https://www.washingtonpost.com/national/southern-poverty-law-center-says-american-hate-groups-are-on-the-rise/2017/02/15/7e9cab02-f2d9-11e6-a9b0-ecee7ce475fc_story.html?utm_term=.4c149e630545
- Hausmann, L. R. M., Hannon, M. J., Kresevic, D. M., Hanusa, B. H., Kwoh, C. K., & Ibrahim, S. A. (2011). Impact of perceived discrimination in healthcare on patient-provider

- communication. *Medical Care*, 49(7), 626–633.
<https://doi.org/10.1097/MLR.0b013e318215d93c>
- Hayes, V., Blondeau, W., & Bing-You, R. G. (2015). Assessment of medical student and resident/fellow knowledge, comfort, and training with sexual history taking in LGBTQ patients. *Family Medicine*, 47(5), 383–387.
- Hebl, M., Law, C., & King, E. (2010). Heterosexism. In J. Dovidio, M. Hewstone, P. Glick, & V. Esses (Eds.), *The SAGE handbook of prejudice, stereotyping and discrimination* (pp. 345–360). Thousand Oaks, CA: SAGE Publications.
- Herian, M. N., Tay, L., Hamm, J. A., & Diener, E. (2014). Social capital, ideology, and health in the United States. *Social Science & Medicine* (1982), 105, 30–37.
<https://doi.org/10.1016/j.socscimed.2014.01.003>
- Hoy-Ellis, C. P., & Fredriksen-Goldsen, K. I. (2017). Depression among transgender older adults: General and minority stress. *American Journal of Community Psychology*.
<https://doi.org/10.1002/ajcp.12138>
- Hoyle, L. (2014, April). ‘I mean, obviously you're using your discretion’: Nurses use of discretion in policy implementation. *Social Policy and Society*, 13(2), 189–202.
- Hughes, M., & Cartwright, C. (2014). LGBT people’s knowledge of and preparedness to discuss end-of-life care planning options. *Health & Social Care in the Community*, 22(5), 545–552. <https://doi.org/10.1111/hsc.12113>
- Hull, K. E. (2003). The cultural power of law and the cultural enactment of legality: The case of same-sex marriage. *Law & Social Inquiry*, 28(3), 629–657.
- Hull, K. E. (2016). Legal consciousness in marginalized groups: The case of LGBT people. *Law & Social Inquiry*, 41(3), 551–572. <https://doi.org/10.1111/lsi.12190>
- Institute of Medicine. (2011). The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding. Retrieved from <http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>
- International Federation of Social Workers. (2012). Statement of ethical principles. Retrieved from <http://ifsw.org/policies/statement-of-ethical-principles/>
- Johnson, R. L., Roter, D., Powe, N. R., & Cooper, L. A. (2004). Patient race/ethnicity and quality of patient–physician communication during medical visits. *American Journal of Public Health*, 94(12), 2084–2090.
- Jones, K. P., Peddie, C. I., Gilrane, V. L., King, E. B., & Gray, A. L. (2013). Not so subtle a meta-analytic investigation of the correlates of subtle and overt discrimination. *Journal of Management*, 149206313506466. <https://doi.org/10.1177/0149206313506466>

- Kates, J., Ranji, U., Beamesderfer, A., & Dawson, L. (2015, July 30). Kaiser Family Foundation: Health and access to care and coverage for lesbian, gay, bisexual, and transgender Individuals in the U.S. Retrieved from <http://kff.org/disparities-policy/issue-brief/health-and-access-to-care-and-coverage-for-lesbian-gay-bisexual-and-transgender-individuals-in-the-u-s/>
- Kickbusch, I. (2015). The political determinants of health— 10years on: Public health professionals need to become more politically astute to achieve their goals. *British Medical Journal*, 350(81). <https://doi.org/10.1136/bmj.h81>
- King, M., & Bartlett, A. (2006). What same sex civil partnerships may mean for health. *Journal of Epidemiology and Community Health*, 60(3), 188–191. <https://doi.org/10.1136/jech.2005.040410>
- Klein, E. W., & Nakhai, M. (2016). Caring for LGBTQ patients: Methods for improving physician cultural competence. *International Journal of Psychiatry in Medicine*, 51(4), 315–324. <https://doi.org/10.1177/0091217416659268>
- Knauer, N. J. (2012). Legal consciousness and LGBT research: The role of the law in the everyday lives of LGBT individuals. *Journal of Homosexuality*, 59(5), 748–756. <https://doi.org/10.1080/00918369.2012.673947>
- Kondrat, M. (2002). Actor-centered social work: re-visioning “person-in-environment” through a critical theory lens. *Social Work*, 47(4), 435–448. <https://doi.org/10.1093/sw/47.4.435>
- Kralik, J. (2017). “Bathroom bill” legislative tracking. National Conference of State Legislatures. Retrieved from <http://www.ncsl.org/research/education/-bathroom-bill-legislative-tracking635951130.aspx>
- Krehely, J. (2009, December 21). How to Close the LGBT Health Disparities Gap. Retrieved from <https://www.americanprogress.org/issues/lgbt/report/2009/12/21/7048/how-to-close-the-lgbt-health-disparities-gap/>
- Krieger, N. (1999). Embodying inequality: A review of concepts, measures, and methods for studying health consequences of discrimination. *International Journal of Health Services*, 29(2), 295–352. <https://doi.org/10.2190/M11W-VWXE-KQM9-G97Q>
- Krieger, N. (2001). Historical roots of social epidemiology: Socioeconomic gradients in health and contextual analysis. *International Journal of Epidemiology*, 30(4), 899–900.
- Krieger, N. (2011). *Epidemiology and the people’s health: Theory and context*. New York, NY: Oxford University Press.
- Labella, A., & Singh, D. (2008). Turning loss into legislation. *American Journal of Public Health*, 98(6), 971–973. <https://doi.org/10.2105/AJPH.2007.123745>
- Lambda Legal. (2010). *When health care isn’t caring: Lambda Legal’s survey on discrimination against LGBT people and people living with HIV*. Retrieved from

http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf

- Lambda Legal. (n.d.). President Obama issues memo on LGBT health issues: Calls Janice Langbehn from Air Force One [2010]. Retrieved from http://www.lambdalegal.org/news/us_20100415_president-obama-issues-memo-on-lgbt-health-issues-7
- Landsbaum, C. (2017, February 24). Laverne Cox explains what anti-trans bathroom legislation is really about. *The Cut*. Retrieved from <https://www.thecut.com/2017/02/laverne-cox-explains-what-bathroom-laws-are-really-about.html>
- Lawton, A., White, J., & Fromme, E. K. (2013). End-of-life and advance care planning considerations for lesbian, gay, bisexual, and transgender patients. *Journal of Palliative Medicine*, 17(1), 106–108. <https://doi.org/10.1089/jpm.2013.9457>
- Lazar, K. (2017, March 22). LGBT community top target for hate acts in Boston. *The Boston Globe*. Retrieved from <https://www.bostonglobe.com/metro/2017/03/22/lgbt-community-top-target-for-hate-acts-boston/6jgvxACsmfMSculSgACGBO/story.html>
- LeBron, A. M. W., Valerio, M. A., Kieffer, E., Sinco, B., Rosland, A., Hawkins, J., ... Spencer, M. (2014). Everyday discrimination, diabetes-related distress, and depressive symptoms among African Americans and Latinos with diabetes. *Journal of Immigrant and Minority Health*, 16(6), 1208–1216. <https://doi.org/10.1007/s10903-013-9843-3>
- Lee, H., & Turney, K. (2012). Investigating the Relationship between Perceived Discrimination, Social Status, and Mental Health. *Society and Mental Health*, 2(1), 1–20. <https://doi.org/10.1177/2156869311433067>
- Lewis, T. T., Aiello, A. E., Leurgans, S., Kelly, J., & Barnes, L. L. (2010). Self-reported experiences of everyday discrimination are associated with elevated C-reactive protein levels in older African-American adults. *Brain, Behavior, and Immunity*, 24(3), 438–443. <https://doi.org/10.1016/j.bbi.2009.11.011>
- Lichtblau, E. (2016, November 14). U.S. hate crimes surge 6%, fueled by attacks on muslims. *The New York Times*. Retrieved from <https://www.nytimes.com/2016/11/15/us/politics/fbi-hate-crimes-muslims.html>
- Lim, F., Brown, D., & Jones, H. (2013). Lesbian, gay, bisexual, and transgender health: Fundamentals for nursing education. *Journal of Nursing Education*, 52(4), 198–203.
- Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior*, 80–94. <https://doi.org/10.2307/2626958>
- Lipsky, M. (2010). *Street-level bureaucracy: Dilemmas of the individual in public service* (30 Anv Exp edition). New York, NY: Russell Sage Foundation.

- Liptak, A. (2015, June 26). Supreme Court ruling makes same-sex marriage a right nationwide. *The New York Times*. Retrieved from <https://www.nytimes.com/2015/06/27/us/supreme-court-same-sex-marriage.html>
- Logie, C. (2012). The case for the World Health Organization's Commission on the Social Determinants of Health to address sexual orientation. *American Journal of Public Health, 102*(7), 1243–1246.
- Lorié, Á., Reiner, D. A., Phillips, M., Zhang, L., & Riess, H. (2017). Culture and nonverbal expressions of empathy in clinical settings: A systematic review. *Patient Education and Counseling, 100*(3), 411–424. <https://doi.org/10.1016/j.pec.2016.09.018>
- Lovaas, K. E. (2003). Speaking to silence: Toward queering nonverbal communication. *Journal of Homosexuality, 45*(2–4), 87–107. https://doi.org/10.1300/J082v45n02_04
- Mackenbach, J. P. (2014). Political determinants of health. *European Journal of Public Health, 24*(1), 2–2. <https://doi.org/10.1093/eurpub/ckt183>
- Marmot, M. (2005). Social determinants of health inequalities. *The Lancet, 365*(9464), 1099–1104. [https://doi.org/10.1016/S0140-6736\(05\)71146-6](https://doi.org/10.1016/S0140-6736(05)71146-6)
- Martyn, C. (2004). Politics as a determinant of health. *British Medical Journal, 329*(7480), 1423–1424.
- Masters, N. T., Lindhorst, T. P., & Meyers, M. K. (2014). Jezebel at the welfare office: How racialized stereotypes of poor women's reproductive decisions and relationships shape policy implementation. *Journal of Poverty, 18*(2), 109–129. <https://doi.org/10.1080/10875549.2013.833159>
- McLaren, L., & Hawe, P. (2005). Ecological perspectives in health research. *Journal of Epidemiology and Community Health, 59*(1), 6–14. <https://doi.org/10.1136/jech.2003.018044>
- Mehrotra, G. (2010). Toward a continuum of intersectionality theorizing for feminist social work scholarship. *Affilia, 25*(4), 417–430. <https://doi.org/10.1177/0886109910384190>
- Mellor, D. (2003). Contemporary racism in Australia: The experiences of aborigines. *Personality and Social Psychology Bulletin, 29*(4), 474–486. <https://doi.org/10.1177/0146167202250914>
- Mellor, D. (2004). The experiences of Vietnamese in Australia: The racist tradition continues. *Journal of Ethnic and Migration Studies, 30*(4), 631–658. <https://doi.org/10.1080/13691830410001699496>
- Merino, M.-E., Mellor, D. J., Saiz, J. L., & Quilaqueo, D. (2009). Perceived discrimination amongst the indigenous Mapuche people in Chile: Some comparisons with Australia. *Ethnic and Racial Studies, 32*(5), 802–822. <https://doi.org/10.1080/01419870802037266>

- Merry, S. E. (1990). *Getting justice and getting even*. Chicago, IL: University of Chicago Press.
- Meyer, I. H., & Northridge, M. E. (2007). *The health of sexual minorities: public health perspectives on lesbian, gay, bisexual, and transgender populations*. New York, NY: Springer.
- Mink, M. D., Lindley, L. L., & Weinstein, A. A. (2014). Stress, stigma, and sexual minority status: The intersectional ecology model of LGBTQ health. *Journal of Gay & Lesbian Social Services, 26*(4), 502–521. <https://doi.org/10.1080/10538720.2014.953660>
- Mollon, L. (2012). The forgotten minorities: Health disparities of the lesbian, gay, bisexual, and transgendered communities. *Journal of Health Care for the Poor and Underserved, 23*(1), 1–6. <https://doi.org/10.1353/hpu.2012.0009>
- Moniz, C. (2010). Social work and the social determinants of health perspective: A good fit. *Health & Social Work, 35*(4), 310–313.
- Moore, M., Cristofalo, M., Dotolo, D., Torres, N., Lahdya, A., Ho, L., ... Fouts, S. (2017). When high pressure, system constraints, and a social justice mission collide: A socio-structural analysis of emergency department social work services. *Social Science & Medicine, 178*, 104–114. <https://doi.org/10.1016/j.socscimed.2017.02.014>
- Nadal, K. L. (2013). *That's so gay!: Microaggressions and the lesbian, gay, bisexual and transgender community*. Washington, DC: American Psychological Association.
- Nadal, K. L., Rivera, D. P., & Corpus, M. J. (2010). Sexual orientation and transgender microaggressions in everyday life: Experiences of lesbians, gays, bisexuals, and transgender individuals. In D. . Sue (Ed.), *Microaggressions and marginality: Manifestations, dynamics, and impact*. New York, NY: Wiley.
- Nadal, K. L., Whitman, C. N., Davis, L. S., Erazo, T., & Davidoff, K. C. (2016). Microaggressions toward lesbian, gay, bisexual, transgender, queer, and genderqueer people: A review of the literature. *The Journal of Sex Research, 53*(4–5), 488–508. <https://doi.org/10.1080/00224499.2016.1142495>
- NASW Foundation. (n.d.). Ida Cannon (1877-1960). Retrieved from <http://www.naswfoundation.org/pioneers/c/cannon.htm>
- National Association of Social Workers. (2004). *NASW standards for social work practice in palliative and end of life care*. National Association of Social Workers. Retrieved from <https://www.socialworkers.org/practice/standards/Palliative.asp>
- National Association of Social Workers. (2008). Code of Ethics (English and Spanish). Retrieved from <http://www.socialworkers.org/pubs/code/code.asp>
- National Resource Center on LGBT Aging. (2013). *Inclusive questions for older adults: A practical guide to collecting data on sexual orientation and gender identity*. Retrieved from http://www.sageusa.org/files/InclusiveQuestionsOlder%20Adults_Guidebook.pdf

- Navarro, V. (2009a). History of the social determinants of health: Global histories, contemporary debates (review). *Bulletin of the History of Medicine*, 83(3), 620–622. <https://doi.org/10.1353/bhm.0.0261>
- Navarro, V. (2009b). What we mean by social determinants of health. *International Journal of Health Services: Planning, Administration, Evaluation*, 39(3), 423–441.
- Northridge, M. E., & Meyer, I. H. (2007). *The health of sexual minorities : Public health perspectives on lesbian, gay, bisexual, and transgender populations*. New York, NY: Springer.
- Nuru-Jeter, A. (2015, January 15). “I can't breathe”: Racial injustice as a determinant of health disparities. Retrieved from http://www.rwjf.org/en/culture-of-health/2015/01/_i_can_t_breather.html
- Nuru-Jeter, A., Dominguez, T. P., Hammond, W. P., Leu, J., Skaff, M., Egerter, S., ... Braveman, P. (2009). “It’s the skin you’re in”: African-American women talk about their experiences of racism. *Maternal and Child Health Journal*, 13(1), 29–39.
- Obama, B. (2010). Presidential Memorandum - Hospital visitation. Retrieved from <http://www.whitehouse.gov/the-press-office/presidential-memorandum-hospital-visitiation>
- Obedin-Maliver, J., Goldsmith, E., Stewart, L., & et al. (2011). Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA*, 306(9), 971–977. <https://doi.org/10.1001/jama.2011.1255>
- O’Hara, M. E. (2017, May 2). Gay man sues funeral home that refused his 82-year-old husband’s body. *NBC News*. Retrieved from <http://www.nbcnews.com/feature/nbc-out/gay-man-sues-funeral-home-refused-his-82-year-old-n753856>
- O’Sullivan, D. (2016). Power, politics and the street-level bureaucrat in Indigenous Australian health. *Journal of Sociology*, 52(4), 646–660. <https://doi.org/10.1177/1440783315575170>
- Oswald, R. F., & Kivalanka, K. A. (2008). Same-sex couples: Legal complexities. *Journal of Family Issues*, 29(8), 1051–1066. <https://doi.org/10.1177/0192513X08316274>
- Oyserman, D. (2011). Culture as situated cognition: Cultural mindsets, cultural fluency, and meaning making. *European Review of Social Psychology*, 22(1), 164–214. <https://doi.org/10.1080/10463283.2011.627187>
- Pager, D., & Shepherd, H. (2008). The sociology of discrimination: Racial discrimination in employment, housing, credit, and consumer markets. *Annual Review of Sociology*, 34, 181–209.
- Park, N. K., Kazyak, E., & Slauson-Blevins, K. (2016). How law shapes experiences of parenthood for same-sex couples. *Journal of GLBT Family Studies*, 12(2), 115–137. <https://doi.org/10.1080/1550428X.2015.1011818>

- Parker-Pope, T. (2009, May 19). Kept From a Dying Partner's Bedside. *The New York Times*. Retrieved from <http://www.nytimes.com/2009/05/19/health/19well.html>
- Pascoe, E. A., & Smart Richman, L. (2009). Perceived discrimination and health: A meta-analytic review. *Psychological Bulletin*, *135*(4), 531–554. <https://doi.org/10.1037/a0016059>
- Pearlin, L. I. (1989). The Sociological Study of Stress. *Journal of Health and Social Behavior*, *30*(3), 241–256.
- Peek, M., Nunez-Smith, M., Drum, M., & Lewis, T. T. (2011). Adapting the everyday discrimination scale to medical settings: Reliability and validity testing in a sample of African American patients. *Ethnicity & Disease*, *21*(4), 502–509.
- Pega, F., Kawachi, I., Rasanathan, K., & Lundberg, O. (2013). Politics, policies and population health: a commentary on Mackenbach, Hu and Looman (2013). *Social Science & Medicine* (1982), *93*, 176–179. <https://doi.org/10.1016/j.socscimed.2013.06.007>
- Pega, F., & Veale, J. F. (2015). The case for the World Health Organization's Commission on Social Determinants of Health to address gender identity. *American Journal of Public Health*, *105*(3), e58-62. <https://doi.org/10.2105/AJPH.2014.302373>
- Platt, L. F., & Lenzen, A. L. (2013). Sexual orientation microaggressions and the experience of sexual minorities. *Journal of Homosexuality*, *60*(7), 1011–1034. <https://doi.org/10.1080/00918369.2013.774878>
- Praglin, L. J. (2007). Ida Cannon, Ethel Cohen, and early medical social work in Boston: The foundations of a model of culturally competent social service. *Social Service Review*, *81*(1), 27–45. <https://doi.org/10.1086/511013>
- Quinlan, E. (2009). The “actualities” of knowledge work: An institutional ethnography of multi-disciplinary primary health care teams. *Sociology of Health & Illness*, *31*(5), 625–641. <https://doi.org/10.1111/j.1467-9566.2009.01167.x>
- Quinn, G. P., Sanchez, J. A., Sutton, S. K., Vadaparampil, S. T., Nguyen, G. T., Green, B. L., ... Schabath, M. B. (2015). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA: A Cancer Journal for Clinicians*, *65*(5), 384–400. <https://doi.org/10.3322/caac.21288>
- Quinn, G. P., Sutton, S. K., Winfield, B., Breen, S., Canales, J., Shetty, G., ... Schabath, M. B. (2015). Lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) perceptions and health care experiences. *Journal of Gay & Lesbian Social Services*, *27*(2), 246–261. <https://doi.org/10.1080/10538720.2015.1022273>
- Raifman, J., Moscoe, E., Austin, S. B., & McConnell, M. (2017). Difference-in-differences analysis of the association between state same-sex marriage policies and adolescent suicide attempts. *JAMA Pediatrics*, *171*(4), 350–356. <https://doi.org/10.1001/jamapediatrics.2016.4529>

- Raphael, D. (2006). Social determinants of health: Present status, unanswered questions, and future directions. *International Journal of Health Services: Planning, Administration, Evaluation*, 36(4), 651–677.
- Rawlings, D. (2012). End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. *International Journal of Palliative Nursing*, 18(1), 29–34.
<https://doi.org/10.12968/ijpn.2012.18.1.29>
- Richman, K. D. (2013). *License to wed: What legal marriage means to same-sex couples*. New York, NY: New York University Press.
- Riggle, E. D. B., Wickham, R. E., Rostosky, S. S., Rothblum, E. D., & Balsam, K. F. (2016). Impact of civil marriage recognition for long-term same-sex couples. *Sexuality Research and Social Policy*, 13(2). <https://doi.org/10.1007/s13178-016-0243-z>
- Rine, C. M. (2016). Social determinants of health: Grand challenges in social work's future. *Health Social Work*, 41(3), 143–145.
- Rivera, E. (2011). Long-term care and life planning preferences for older gays and lesbians. *Journal of Ethnographic & Qualitative Research*, 5(3), 157–170.
- Roberts, T. K., & Fantz, C. R. (2014). Barriers to quality health care for the transgender population. *Clinical Biochemistry*, 47(10–11), 983–987.
<https://doi.org/10.1016/j.clinbiochem.2014.02.009>
- Robinson, J.D. (2006). Nonverbal communication and physician-patient interaction: Review and new directions. In Manusov, V. L., & Patterson, M. L. (Eds.). (pp. 437-460). *The SAGE handbook of nonverbal communication* (1st edition). Thousand Oaks, CA: SAGE Publications, Inc.
- Rojas-Lizana, S. (2014). Perceived discrimination in LGBTIQ discourse: A typology of verbal discrimination. *PORTAL Journal of Multidisciplinary International Studies*, 11(1). Retrieved from <https://epress.lib.uts.edu.au/journals/index.php/portal/article/view/3303>
- Röndahl, G. (2009). Students inadequate knowledge about lesbian, gay, bisexual and transgender persons. *International Journal of Nursing Education Scholarship*, 6, Article 11.
<https://doi.org/10.2202/1548-923X.1718>
- Röndahl, G., Innala, S., & Carlsson, M. (2006). Heterosexual assumptions in verbal and non-verbal communication in nursing. *Journal of Advanced Nursing*, 56(4), 373–381.
<https://doi.org/10.1111/j.1365-2648.2006.04018.x>
- Rood, B. A., Reisner, S. L., Surace, F. I., Puckett, J. A., Maroney, M. R., & Pantalone, D. W. (2016). Expecting rejection: Understanding the minority stress experiences of transgender and gender-nonconforming individuals. *Transgender Health*, 1(1), 151–164.
<https://doi.org/10.1089/trgh.2016.0012>
- Ruger, J. P. (2004). Ethics of the social determinants of health. *The Lancet*, 364, 1092–1097.

- Sabin, J. A., Riskind, R. G., & Nosek, B. A. (2015). Health care providers' implicit and explicit attitudes toward lesbian women and gay men. *American Journal of Public Health, 105*(9), 1831–1841. <https://doi.org/10.2105/AJPH.2015.302631>
- Sabin, J. A., Rivara, F. P., & Greenwald, A. G. (2008). Physician implicit attitudes and stereotypes about race and quality of medical care. *Medical Care, 46*(7), 678–685. <https://doi.org/10.1097/MLR.0b013e3181653d58>
- Sakamoto, I., & Pitner, R. O. (2005). Use of critical consciousness in anti-oppressive social work practice: Disentangling power dynamics at personal and structural levels. *British Journal of Social Work, 35*(4), 435–452. <https://doi.org/10.1093/bjsw/bch190>
- Saleebey, D. (2006). *The strengths perspective in social work practice*. Boston, MA: Pearson/Allyn & Bacon.
- Sanchez, R. (2016, April 7). Why the onslaught of religious freedom laws? *CNN*. Retrieved from <http://www.cnn.com/2016/04/06/us/religious-freedom-laws-why-now/index.html>
- Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in Nursing & Health, 16*(3), 213–218. <https://doi.org/10.1002/nur.4770160308>
- Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health, 21*(4), 375–382.
- Sarat, A. (1990). “.. The law is all over”: Power, resistance and the legal consciousness of the welfare poor. *Yale Journal of Law & the Humanities, 2*(2), 343–379.
- Sarat, A., & Kearns, T. R. (Eds.). (1995). *Law in everyday life*. Ann Arbor, MI: University of Michigan Press.
- Schmitt, M. T., & Branscombe, N. R. (2002). The meaning and consequences of perceived discrimination in disadvantaged and privileged social groups. *European Review of Social Psychology, 12*(1), 167–199. <https://doi.org/10.1080/14792772143000058>
- Scully, J. L., Baldwin-Ragaven, L. E., & Fitzpatrick, P. (Eds.). (2010). *Feminist bioethics: At the center, on the margins* (1 edition). Baltimore, MD: Johns Hopkins University Press.
- Sequeira, G. M., Chakraborti, C., & Panunti, B. A. (2012). Integrating lesbian, gay, bisexual, and transgender (LGBT) content into undergraduate medical school curricula: A qualitative study. *The Ochsner Journal, 12*(4), 379–382.
- Shelton, K., & Delgado-Romero, E. A. (2011). Sexual orientation microaggressions: The experience of lesbian, gay, bisexual, and queer clients in psychotherapy. *Journal of Counseling Psychology, 58*(2), 210–221. <https://doi.org/10.1037/a0022251>
- Sibley, D. (1995). *Geographies of exclusion: Society and difference in the west* (1 edition). London, UK: Routledge.

- Sinding, C. (2010). Using institutional ethnography to understand the production of health care disparities. *Qualitative Health Research, 20*(12), 1656–1663. <https://doi.org/10.1177/1049732310377452>
- Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2003). *Patient-provider communication: The effect of race and ethnicity on process and outcomes of healthcare*. Washington DC: National Academies Press. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK220354/>
- Smith, D. (2005). *Institutional ethnography: A sociology for people*. Lanham, MD: AltaMira Press. Retrieved from <https://rowman.com/ISBN/9780759105027/Institutional-Ethnography-A-Sociology-for-People>
- Smolinski, K. M., & Colón, Y. (2006). Silent voices and invisible walls. *Journal of Psychosocial Oncology, 24*(1), 51–64. https://doi.org/10.1300/J077v24n01_05
- Snowdon, S. (2010). The medical school curriculum and LGBT health concerns. *AMA Journal of Ethics, 12*(8), 638. <https://doi.org/10.1001/virtualmentor.2010.12.8.medu1-1008>
- Spencer, K. L., & Grace, M. (2016). Social foundations of health care inequality and treatment bias. *Annual Review of Sociology, 42*, 101–120.
- Stanton, M. V., Jonassaint, C. R., Bartholomew, F. B., Edwards, C., Richman, L., DeCastro, L., & Williams, R. (2010). The association of optimism and perceived discrimination with health care utilization in adults with sickle cell disease. *Journal of the National Medical Association, 102*(11), 1056–1064. [https://doi.org/10.1016/S0027-9684\(15\)30733-1](https://doi.org/10.1016/S0027-9684(15)30733-1)
- Stein, G. L., & Bonuck, K. A. (2001). Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *Journal of Palliative Medicine, 4*(2), 173–190. <https://doi.org/10.1089/109662101750290218>
- Stepanikova, I., Zhang, Q., Wieland, D., Eleazer, G. P., & Stewart, T. (2012). Non-verbal communication between primary care physicians and older patients: How does race matter? *Journal of General Internal Medicine, 27*(5), 576–581. <https://doi.org/10.1007/s11606-011-1934-z>
- Stige, B., Malterud, K., & Midtgarden, T. (2009). Toward an agenda for evaluation of qualitative research. *Qualitative Health Research, 19*(10), 1504–1516. <https://doi.org/10.1177/1049732309348501>
- Strong, C. (2007, August 9). Add your voice to the chorus calling for equality and dignity. *The Seattle Times*. Retrieved from http://seattletimes.com/html/opinion/2003827542_charlenestrong09.html
- Strong, K. L., & Folse, V. N. (2015). Assessing undergraduate nursing students' knowledge, attitudes, and cultural competence in caring for lesbian, gay, bisexual, and transgender patients. *Journal of Nursing Education, 54*(1), 45–49.

- Suárez, Z., Newman, P., & Reed, B. G. (2008). Critical consciousness and cross-cultural/intersectional social work practice: A case analysis. *Families in Society: The Journal of Contemporary Social Services*, 89(3), 407–417. <https://doi.org/10.1606/1044-3894.3766>
- Sue, D. W. (2010). *Microaggressions in everyday life: Race, gender, and sexual orientation*. Hoboken, NJ: Wiley.
- Sue, D. W., Capodilupo, C. M., Torino, G. C., Bucceri, J. M., Holder, A. M. B., Nadal, K. L., & Esquilin, M. (2007). Racial microaggressions in everyday life: Implications for clinical practice. *The American Psychologist*, 62(4), 271–286. <https://doi.org/10.1037/0003-066X.62.4.271>
- Sullivan, J. (2010, April 21). Jury rules nurse didn't violate rights of woman barred from partner's room. Retrieved from <http://www.seattletimes.com/seattle-news/jury-rules-nurse-didnt-violate-rights-of-woman-barred-from-partners-room/>
- Swim, J. K., Pearson, N. B., & Johnston, K. E. (2007). Daily encounters with heterosexim. *Journal of Homosexuality*, 53(4), 31–48. <https://doi.org/10.1080/00918360802101179>
- The Joint Commission. (2014). *Advancing effective communication, cultural competence, and patient- and family-centered care for the lesbian, gay, bisexual, and transgender (LGBT) Community*. The Joint Commission. Retrieved from <http://www.jointcommission.org/lgbt/>
- The White House. (2011). Janice Langbehn: 2011 Presidential Citizens Medal recipient. Retrieved from <http://www.whitehouse.gov/photos-and-video/video/2011/10/26/janice-langbehn-2011-presidential-citizens-medal-recipient>
- Thorne, S. E. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.
- Tummers, L., & Bekkers, V. (2014). Policy implementation, street-level bureaucracy, and the importance of discretion. *Public Management Review*, 16(4), 527–547. <https://doi.org/10.1080/14719037.2013.841978>
- Uehara, E., Flynn, M., Fong, R., Brekke, J., Barth, R. P., Coulton, C., ... Walters, K. (2013). Grand challenges for social work. *Journal of the Society for Social Work and Research*, 4(3), 165–170. <https://doi.org/10.5243/jsswr.2013.11>
- Ungar, M. (2002). A deeper, more social ecological social work practice. *Social Service Review*, 76(3), 480–497. <https://doi.org/10.1086/341185>
- United Nations Human Rights Council. (2015). *Discrimination and violence against individuals based on their sexual orientation and gender identity (summary)*. Retrieved from https://www.unfe.org/system/unfe-63-UN_Human_Rights_Council_Report_one-pager_GREY.pdf

- United States. (1978). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Bethesda, MD: The Commission.
- Upton, D., Reid, C., Dakota, R., Padilla, J., Quijada, A., Corinne, J., & Vanslyke, J. (2009). Exploring factors that influence tobacco use and cessation among lesbian, gay, bisexual, transgender and queer youth in New Mexico. *Journal of Respiratory and Critical Care Medicine*, 179, A3746. https://doi.org/10.1164/ajrccm-conference.2009.179.1_MeetingAbstracts.A3746
- Ura, A. (2017, March 1). Treat same-sex couples the same as others, Texas Supreme Court told. *The Texas Tribune*. Retrieved from <https://www.texastribune.org/2017/03/01/texas-supreme-court-hears-arguments-same-sex-marriage-benefits-case/>
- US Census Bureau. (n.d.). Geography Atlas - Regions. Retrieved from <https://www.census.gov/geo/reference/webatlas/regions.html>
- US Department of Health and Human Services. (n.d.). Healthy People 2020: Lesbian, gay, bisexual, and transgender health. Retrieved from <http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>
- Utamsingh, P. D., Richman, L. S., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner-patient interaction. *Health Communication*, 31(5), 566–574.
- Van Laer, K., & Janssens, M. (2011). Ethnic minority professionals' experiences with subtle discrimination in the workplace. *Human Relations*, 64, 1203–1227.
- van Ryn, M. (2002). Research on the provider contribution to race/ethnicity disparities in medical care. *Medical Care*, 40(1 Suppl), I140-151.
- van Ryn, M., Burgess, D. J., Dovidio, J. F., Phelan, S. M., Saha, S., Malat, J., ... Perry, S. (2011). The impact of racism on clinician cognition, behavior, and clinical decision making. *Du Bois Review: Social Science Research on Race*, 8(1), 199–218. <https://doi.org/10.1017/S1742058X11000191>
- van Ryn, M., & Fu, S. S. (2003). Paved with good intentions: Do public health and human service providers contribute to racial/ethnic disparities in health? *American Journal of Public Health*, 93(2), 248–255.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing Health Sciences*, 15(3), 398-405.
- Wahlert, L., & Fiester, A. (2013). A False Sense of Security: Lesbian, Gay, Bisexual, and Transgender (LGBT) Surrogate Health Care Decision-Making Rights. *The Journal of the American Board of Family Medicine*, 26(6), 802–804. <https://doi.org/10.3122/jabfm.2013.06.130130>

- Walsh, J. (2017, March 6). The real goal of Trump's travel ban Is to make America white again. *The Nation*. Retrieved from <https://www.thenation.com/article/the-real-goal-of-trumps-travel-ban-is-to-make-america-white-again/>
- Watkins-Hayes, C. (2009). *The New Welfare Bureaucrats*. Chicago, IL: University of Chicago Press.
- Wilkinson, R. G., & Pickett, K. E. (2006). Income inequality and population health: A review and explanation of the evidence. *Social Science & Medicine*, 62(7), 1768–1784. <https://doi.org/10.1016/j.socscimed.2005.08.036>
- Williams, D. R., & Mohammed, S. A. (2009). Discrimination and racial disparities in health: Evidence and needed research. *Journal of Behavioral Medicine*, 32(1), 20–47. <https://doi.org/10.1007/s10865-008-9185-0>
- Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health: Socio-economic status, stress and discrimination. *Journal of Health Psychology*, 2(3), 335–351. <https://doi.org/10.1177/135910539700200305>
- World Health Organization. (n.d.). WHO | Key concepts. Retrieved from http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/
- World Health Organization. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health*. Retrieved from http://www.who.int/social_determinants/thecommission/finalreport/en/
- Wright, J. (2017, February 16). Anti-LGBT lawmakers unveil slew of “religious freedom” bills despite business concerns. *The Texas Observer*. Retrieved from <https://www.texasobserver.org/anti-lgbt-lawmakers-unveil-slew-of-religious-freedom-bills-despite-business-concerns/>
- Yep, G. (2003). The Violence of Heteronormativity in Communication Studies. *Journal of Homosexuality*, 45(2–4), 11–59. https://doi.org/10.1300/J082v45n02_02
- Youatt, E. J., Johns, M. M., Pingel, E. S., Soler, J. H., & Bauermeister, J. A. (2015). Exploring young adult sexual minority women's perspectives on LGBTQ smoking. *Journal of LGBT Youth*, 12(3), 323–342. <https://doi.org/10.1080/19361653.2015.1022242>

APPENDIX 1: INTERVIEW GUIDE

Introduction: Thank you for taking time to talk with me today about your experiences with [your partner's] hospitalization [tailor to appropriate facility admission/stay]. In getting started, I'd like to find out a little more about **[your partner]**.

Prior to hospitalization/facility experience

Tell me a little about [your partner]

- Probe length of relationship with subject
- Attitudes, experiences with medical situations
- Relationship with partner's family

Did you and [your partner] ever talk about what he/she would want if he/she became ill or hospitalized?

- If yes, what were your partner's wishes?
- What was your role to be?
- How did you feel about this plan – were you in agreement with your partner?

Did you complete advanced directives or other paperwork formalizing these wishes?

- If yes, how were the wishes documented?
- Who were the wishes communicated with (medical staff, family, friends)?
- Did you live in a state that allowed same-sex marriage, civil unions or domestic partnerships? If so, did you decide to [marry/have a civil union/register]? What factors influenced your decision to/not to [marry/have a civil union/register]?

If long illness:

- Relationship of family with clinicians; role in medical communication
- Expectations of role as illness progressed
- Communication with clinicians re: these expectations

Admission to hospital/facility

- What happened to bring [your partner] into the hospital/facility?
- Probe nature of hospital/facility admission
- Shock vs more expected
- What family and patient thought would happen
- When/how did you find out and arrive?

Experiences in hospital/facility: Barriers

- What are the things that made it hard to play a role in your partner's medical care and pertaining to helping with or making care decisions on your partner's behalf?
- What did you want your role to be in decision-making and caregiving? Who else was involved (or wanted to be involved) in the decision-making and caregiving for your partner?
- What was your actual role? If not the preferred role, what kept that from happening as you would have liked?
- If life support was removed, how was the decision made to remove your partner's life support? What was your involvement in that decision? Were there obstacles to being part of that decision?
- Did you have the medical information you wanted? Why/why not?
- How did you/didn't you feel supported in this role (by clinical staff, other hospital staff, friends, family etc.)?
- Did you ever feel making the medical decisions for your partner was a burden?
- Were there conflicts with staff or family that made this harder?
- Were there aspects of the hospital/facility rules, procedures, organization that made it harder for you to play your preferred role in decision-making?

Experiences in the hospital/facility: Facilitators

We've talked a bit about things that may have made it harder to participate in your partner's medical care in the (hospital/nursing home/ED/ICU).

- What made it easier to play a role in your partner's medical care or make care decisions on your partner's behalf?
- Was a palliative care or spiritual care team, a social worker, or an ethics committee involved in the care of your partner?
- Did your relationships with the clinicians make things easier?
- Did your relationships with your partner's other family members make this easier?
- Did you feel supported by the hospital rules, procedures, organization?
- Did you have legal documents that made it easier to play the role you wanted to play?
- Did anyone in particular serve as an advocate for you? If so, was this helpful and in what ways?

Ethical Implications

We would also like your sense of how your experiences might be different from those of opposite-sex partners.

- Do you feel that you were treated less fairly or less equitably because you were a same-sex partner?
- Were you asked to show legal documentation of your legal relationship status?
- Do you feel you were denied a role in caring for your partner that would be afforded to opposite-sex partners?
- If you had been a legal spouse, do you think you would have had a different experience?

Recommendations

- If you could give advice to doctors, nurses or other care providers about how to improve the hospital/facility experience of a patient's same-sex partner, what would it be?
- If you could give advice to other same-sex partners to help them in a similar situation, what would it be?
- Is there anything else that you would like us to know about your experience?

APPENDIX 2: CODE LIST

Anticipatory stress/vigilance
Anticipatory strategy
Not being out
Prepare legal paperwork
Protective strategies by clinicians
Research queer-friendly or high quality providers
Retrieve paperwork, carry or show proactively
State relationship/advocate
Assumed protective factor/cue
Geography/political climate
Institution with a good reputation
Knew clinicians
LGBT clinicians
Assumed risk factor/cue
Religious
Military background
Conservative state/area
Lucky, surprised or fortunate
Negative experience
Acting suspicious
After death
Asked to alter physical affection/closeness
Asserting dominance
Being judgmental
Cited religious beliefs
Covert discrimination
Disregard, not acknowledged or look to others
Inconsistent application of rules
Inconsistent relationship recognition
Just friends
Look at us funny
Negative comments
Not family/who are you?
Not giving information
Not listening
Other familial relationship
Overt discrimination
Providing lower quality care
Pushing for partners to be "out"

Negative experience, cont.
Require paperwork
Rude, aggressive or not compassionate
Seeing differential treatment
Seemed uncomfortable or did not want to be physically close or involved
Separating partners
Unable to make decisions
Wanting partner to get care elsewhere/not admitting
Wouldn't look me in the eye
Reflections on law, politics or culture re: LGBTQ
Access to legal protection
Appealing to humane/enlightened professional
Critical of laws/marriage
Evidence of consciousness
Evidence of entitlement/recognizing heteronormative difference
Evidence of knowledge of the law
Legal grey area/jurisdictional disparities
Legal consciousness quote
Legality is public
Political action/political discourse
Past positive experiences
Past negative experiences
Stories of caution or exclusion

Danae G. Dotolo**Curriculum Vitae**

School of Social Work
University of Washington
danaed@uw.edu

4101 15th Ave NE 206-755-8852
Seattle, WA 98105-6299

EDUCATION

- | | | |
|-----|---|-----------|
| PhD | University of Washington, School of Social Work
Dissertation – Navigating end-of-life care: Lesbian, gay, bisexual, transgender and queer (LGBTQ) partner experiences
Committee – Drs. Taryn Lindhorst (chair), Susan Kemp, Helene Starks and Ruth Engelberg | June 2017 |
| MA | University of Washington, School of Medicine, Bioethics
Thesis – Intersections of recognition theory and social work: Justice, misrecognition and LGBTQ surrogate decision making | 2014 |
| MSW | Arizona State University, School of Social Work
Concentration – Planning, Administration and Community Practice | 1999 |
| BA | University of New Hampshire, College of Arts & Sciences
Major – English | 1994 |

AWARDS, HONORS & FELLOWSHIPS

- | | |
|--|-----------------|
| The Magnuson Scholarship, University of Washington Health Sciences (\$30,000 research funding) | 06/2016-06/2017 |
| Clinical Research Trainee, Institute of Translational Health Sciences (summer interdisciplinary training seminar and research funding) | 06/2013-9/2013 |
| Boeing Fellowship, UW School of Social Work (academic funding) | 03/2013-06/2013 |
| Top Scholars Fellowship, UW Graduate School (academic funding) | 09/2011-12/2011 |

PEER-REVIEWED PUBLICATIONS

- Dotolo, D.**, Neilsen, E.L., Engelberg, R.A., and Curtis, J. R. (2017). Strategies for enhancing family participation in research in the ICU: Findings from a qualitative study. *Journal of Pain and Symptom Management*. Online:
<http://dx.doi.org/10.1016/j.jpainsumman.2017.03.004>
- Moore, M., Cristofalo, M., **Dotolo, D.**, Torres, N., Lahdya, A., Ho, L., Vogel, M., Forrester, M., Conley, B., and Fouts, S. (2017). When high pressure, system constraints and a social justice mission collide: A social-structural analysis of emergency department social work services. *Social Science & Medicine*, 178, p. 104-114.

- Moore, M., Whiteside, L., **Dotolo, D.**, Wang, L., Ho, L., Conley, B., Glosson-Forrester, M., Vavilala, M., and Zatzick, D. (2016). The role of social work in providing mental health services and care coordination in the urban trauma center emergency department. *Psychiatric Services*. Online: Appi.ps.2015004.
- Moore, M., Robinson, G., Mink, R., Hudson, K., **Dotolo, D.**, Gooding, T., Ramirez, A., Zatzick, D., Giordano, J., Crawley, D., and Vavilala, M. (2015). Developing a family-centered care model for critical care after pediatric traumatic brain injury. *Pediatric Critical Care Medicine*, 16(8), 758-65.
- Brazg, T., **Dotolo, D.**, and Blacksher, E. (2015). Finding a seat at the table for social work: Recommendations for broadening the scope of bioethics. *Bioethics*, 29(5), 362-368.
- Long A.C., Engelberg R.A., Downey L., Kross E.K., Reinke L.F., Cecere Feemster L., **Dotolo D.**, Ford D.W., Back A.L., and Curtis J.R. (2014). Race, income, and education: Associations with patient and family ratings of end-of-life care and communication provided by physicians-in-training. *Journal of Palliative Medicine*, 17(4), 435-47.
- Muni, S., Engelberg, R.A., Downey, L., Treece, P.D., **Dotolo, D.**, and Curtis, J.R. (2011). The influences of race/ethnicity and socioeconomic status on end-of-life care in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine*, 139(5), 1025-1033.
- Curtis, J.R., Nielsen, E.L., Treece, P.D., Downey, L., **Dotolo, D.**, Shannon, S.E., Back, A.L., Rubinfeld, G.D., and Engelberg, R.A. (2011). Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: A randomized trial. *American Journal of Respiratory and Critical Care Medicine*, 183(3), 346-355.
- Engelberg, R.A., Downey, L., Wenrich, M.D., Carline, J.D., Silvestri, G.A., **Dotolo, D.**, Nielsen, E.L., and Curtis, J.R. (2010). Measuring the quality of end-of-life care. *Journal of Pain and Symptom Management*, 39(6), 951-971.
- Reinke, L.F., Shannon, S.E., Curtis, J.R., **Dotolo, D.**, Silvestri, G.A., and Engelberg, R.A. (2010). Nurses' identification of important yet under-utilized end-of-life care skills for patients with life-limiting or terminal illnesses. *Journal of Palliative Medicine*, 13(6), 753-759.

PUBLICATIONS IN PROGRESS

- Dotolo, D.**, Lindhorst, T., Kemp, S., and Engelberg, R.A. (in progress). Conceptualizing social justice: Contributions of recognition theory to just social work practice. Target journal: *Social Service Review*.

RESEARCH EXPERIENCE

Exploring Social Work Services in the Emergency Department 03/2014-present
Lead Research Assistant

University of Washington, School of Social Work, PI: Dr. Megan Moore
 Funded by the NIH National Center for Advancing Translational Sciences to investigate the role of social workers in emergency departments. Role: Code and analyze a large dataset of social work electronic medical records. Train new research assistants on project. Assist in the development of a conceptual model of social work services.

Social Work Intervention for Mild Traumatic Brain Injury (SWIFT) 04/2013-present
Lead Research Assistant

University of Washington, School of Social Work, PI: Dr. Megan Moore
 Funded by the NIH National Center for Advancing Translational Sciences to test a social work intervention with patients receiving care for mild traumatic brain injuries. Role: Supervise data collection. Train new research assistants on project. Collect, manage and analyze data.

The Family Experience after Pediatric Traumatic Brain Injury: From Acute Care to Discharge Planning and Rehabilitation 04/2013-12/2015
Research Assistant

University of Washington, School of Social Work, PI: Dr. Megan Moore
 Funded by NIH National Institute of Neurological Disorders and Stroke to explore family members' experiences after a child has experienced a traumatic brain injury. Role: Analyze qualitative data and collaborate to create a conceptual model of family centered care.

Family Communication Study: Ethics Supplement Study 12/2011-06/2012
Research Assistant

University of Washington, School of Medicine, PI: Dr. J. Randall Curtis
 Funded by NIH National Institute of Nursing Research to investigate barriers and facilitators to family member participation in critical care research. Role: Develop study protocol. Recruit and interview participants. Analyze data using qualitative content analysis methods.

Caring for Partners: LGBT Study 06/2011-06/2012
Research Staff

University of Washington, School of Medicine, PI: Dr. Ruth Engelberg
 Funded by the National Palliative Care Research Center to explore lesbian, gay bisexual and transgender and queer family members' experiences as surrogate medical decision makers for critically ill partners. Role: Assist with grant writing and study design. Facilitate focus groups to discuss recruitment methods.

Improving Clinician Communication Skills

04/2007-09/2011

Research Coordinator

University of Washington, School of Medicine, PI: Dr. J. Randall Curtis
 Funded by the NIH National Institute of Nursing Research to evaluate an intervention to improve end-of-life care delivered by medicine residents and nurse practitioner students. Role: Manage all aspects of the multi-site study activities. Develop institutional review board applications and reports. Supervise research assistants and student volunteers.

Integrating Palliative and Critical Care

04/2006-02/2008

Research Coordinator

University of Washington, School of Medicine, PI: Dr. J. Randall Curtis

Funded by the NIH National Institute of Nursing Research to evaluate the effectiveness of a multi-faceted intervention designed to improve the quality of end-of-life care in ICUs. Role: Supervise research assistants. Assist with training events at participating medical centers.

Improving Physician Skill at Providing End-of-Life Care

01/2004-04/2006

Research Coordinator

University of Washington, School of Medicine, PI: Dr. J. Randall Curtis
 Funded by the NIH National Institute of Nursing Research to evaluate an intervention to improve end-of-life care delivered by medicine residents and nurse practitioner students. Role: Manage all aspects of the multi-site study activities. Develop institutional review board applications and reports. Supervise research assistants and student volunteers.

Self-Sufficiency Standard

11/2001-11/2003

Research Coordinator

University of Washington, School of Social Work, PI: Dr. Diana Pearce
 Funded by various partner community organizations. Role: Responsible for producing state-specific cost-of-living reports to be used as an advocacy tool. Complete basic needs calculations.

PROFESSIONAL PRACTICE EXPERIENCE**Non-medical Reserve Corp Member**

01/2010-10/2014

King County Public Health Reserve Corps, King County Public Health, Seattle, WA

Register adults for autumn immunization clinics in several Seattle-area homeless shelters and meal programs.

Affiliated Scientist Institutional Review Board Member

09/2008-06/2010

University of Washington, Human Subjects Division, Seattle, WA

Review research protocols and status reports. Present review summary and potential regulatory and ethical concerns to committee. Communicate with researchers regarding research protocols and committee recommendations.

Field Instructor

08/1999-05/2001

Arizona State University, School of Social Work, Tempe, AZ

Supervised undergraduate and graduate social work students placed at ACADV for their field practicums.

Advocate-Consultant

04/2001-10/2001

National Electronic Network on Violence Against Women, Harrisburg, PA

Consult with Dr. Eleanor Lyon for her publication "Welfare and domestic violence against women: Lessons from research." Provide feedback about the practice implications of welfare reform policy on domestic violence service providers.

Public Policy Advocate (internship and 2+ years post-MSW)

08/1998-08/2001

Arizona Coalition Against Domestic Violence (ACADV), Phoenix, AZ

Advocate to improve systemic responses to intimate partner violence by meeting with elected officials, drafting legislation, testifying at committee hearings, and participating on governmental committees. Facilitate ACADV Legislative Committee meetings, legislative advocacy trainings and community forums.

Counselor

08/1998-12/1998

New Life Center Domestic Violence Shelter, Goodyear, AZ

Meet regularly with residents to provide support and resource referrals. Conduct intake interviews. Facilitate support groups for shelter residents and community members.

SCHOLARLY PRESENTATIONS**Peer-reviewed Presentations**

Dotolo, D., Lindhorst, T., and Engelberg, R. (January 2017). *Navigating end-of-life care: Lesbian, gay, bisexual, transgender and queer experiences*. Paper presentation at the annual conference of the Society for Social Work Research, New Orleans, LA.

Moore, M., Cristofalo, M., and **Dotolo, D.** (January 2017). *The Role of Social Work in Providing Mental Health Services and Care Coordination in the Urban Trauma Center Emergency Department*. Paper presentation at the annual conference of the Society for Social Work Research, New Orleans, LA.

Moore, M., Cristofalo, M., and **Dotolo, D.** (October 2016). *When high pressure, system constraints and a social justice mission collide: a social-structural analysis of emergency department social work services*. Oral presentation at the annual Qualitative Health Research Conference of the International Institute for Qualitative Methodology, Kelowna, BC.

Dotolo, D. Fantus, S. and Brazg, T. (October 2015). *The intersection of bioethics and social work: Teaching ethics and ethical decision-making*. Panel presentation at the annual program meeting of the Council on Social Work Education, Denver, CO.

Fantus, S., **Dotolo, D.** and Hoy-Ellis, C. (October 2015). *Ethical research across LGBTQ life course: Informing social work practice and education*. Panel presentation at the annual program meeting of the Council on Social Work Education, Denver, CO.

Lindhorst, T., Kemp, S., **Dotolo, D.**, and Brazg, T. (May 2015). *We're all in this together! Or are we? Integrating social work students into interprofessional education*. Panel presentation at the annual conference of the Association of Oncology Social Work, Seattle, WA.

Dotolo, D. (April 2015). *Recognition theory and social work: Justice, misrecognition and LGBTQ surrogate decision makers*. Paper presentation at the annual European Conference for Social Work Research, Ljubljana, Slovenia.

Dotolo, D. (January 2014). *'If anybody looked, I was always there': Recognition and participatory parity for LGBTQ medical surrogate decision makers*. Paper presentation at the annual conference of the Society for Social Work Research, San Antonio, TX.

Brazg, T., **Dotolo, D.** and Blacksher, E. (October 2012). *Social work and bioethics: A call for collaboration*. Panel presentation at the annual meeting of the American Society for Bioethics and Humanities, Washington, DC.

Other Invited Presentations

Dotolo, D. (April 2016). Moderator for a paper presentation at the Benjamin Rabinowitz Workshop in Medical Ethics titled "The Sickness of Society – What Kind of Equality Matters for Health?", University of Washington, Department of Philosophy, Seattle, WA.

Dotolo, D. (April 2014). Paper presentation titled, *'If anybody looked, I was always there': Recognition and participatory parity for LGBTQ medical surrogate decision makers* (April 2014). University of Washington, Cambia Palliative Care Center of Excellence annual conference, Seattle, WA.

TEACHING EXPERIENCE

BASW

Social Welfare Policy	01/2013-03/2013
Teaching Assistant (with Dr. Gunnar Almgren)	

MSW Foundation Year

Macro Practice: Organization, Community & Policy Practice	03/2016-06/2016
Sole Instructor	

History & Intellectual Foundations of the Social Work Profession	09/2015-12/2015
Sole Instructor	

History & Intellectual Foundations of the Social Work Profession	09/2013-12/2013
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Teaching Practicum (with Dr. Susan Kemp)

MSW Concentration Year

Policy Analysis 01/2015-03/2015
Co-Instructor (with Dr. William Vesneski)

Carol LaMare Oncology and Palliative Care Social Work 09/2013-06/2014 &
Doctoral Teaching Fellow (supervised by Dr. Taryn Lindhorst) 09/2014-06/2015

Inter-professional Education

Health Sciences Interprofessional Education Program 09/2013-06/2014 &
Instructor 09/2014-06/2015

ITHS Summer Biomedical Research Integrity Series 06/2013-09/2013
Facilitator

Social Work Continuing Education Course Development and Facilitation

*Ethical decision-making across the lifespan: Applying tools from
bioethics to social work practice*, two workshops at Vancouver
Coastal Health, Vancouver, BC 04/2015

*Applying tools from bioethics to social work practice in oncology
settings*, two workshops for the Association of Oncology Social
Workers, Seattle, WA 03/2013 & 09/2014

Bioethics for social workers: Ethical decision-making in health care, one
continuing education workshop for social workers in the
community, Seattle, WA 05/2014

Taking Your Pulse: Coping with Moral Distress in Clinical Practice,
facilitated an in service training for UW Medical Center social
workers, Seattle, WA 07/2013

Social Work Guest Lectures

Research Methods (MSW)

Research and rigor for qualitative methods (Winter 2016)
Research ethics for social work (Winter 2016)
Qualitative coding laboratory (Spring 2014)

Ethics (MSW)

Ethical theory and organizational policy (Winter 2015)
Tools for engaging in ethical deliberation in the healthcare settings (Autumn 2015)
Narrative ethics and social work practice (Autumn 2015)

Theory (BASW)

Feminist standpoint theory, Human Behavior and the Social Environment (Winter 2014)

SERVICE TO THE UNIVERSITY

UW Health Sciences Interprofessional Education Program, School of Social Work Planning Committee Member	09/2013-present
Doctoral Admissions Committee Member	09/2015-06/2016
Faculty Recruitment Committee Member	09/2014-06/2015
Doctoral Student Peer Mentor	09/2012-06/2013 & 09/2013-06/2014
Doctoral Awards Committee Member	09/2012-06/2013
Doctoral Student Speaker Series Planning Committee Member	09/2012-06/2013

REVIEWER ACTIVITIES

Reviewer for the *Journal of Palliative Medicine*

PROFESSIONAL AFFILIATIONS

Council on Social Work Education (CSWE), Member
 Society for Social Work Research (SSWR), Member
 Society for Social Work Leadership in Health Care, Member
 University of Washington Palliative Care Center for Excellence, Member