A GROUNDED THEORY STUDY EXPLORING LESBIAN PATIENT SELF-DISCLOSURE OF SEXUAL ORIENTATION IN ACUTE CARE

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M. Ruth Neese, MSN, RN, CEN
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by

M. Ruth Neese

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APPROVED BY:

Sandra Walsh, PhD, RN, FAAN Chairperson, Dissertation Committee

Carolyn LePage, PhD, ARNP Member, Dissertation Committee

Viessie Colin, PhD, RN, FAAN Member, Dissertation Committee

Claudette Spalding, PhD, ARNP, CNAA
Chair, Division of Nursing

Pegge Bell, PhD, RN, WHNP-BC Dean, College of Health Sciences

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Abstract

Background: Lesbians are a vulnerable population that has experienced discrimination in health care. Evidence-based strategies for supporting lesbian self-disclosure of sexual orientation have been developed for primary care, but not for acute care settings.

Purpose: The purpose of this study was to develop a grounded substantive theory to describe the process involved in lesbian self-disclosure of sexual orientation in acute care settings.

Philosophical Underpinning: The philosophical underpinning was grounded theory as described by Strauss and Corbin (1998).

Methods: Twelve lesbians who had been hospital inpatients or Emergency Department patients within the previous twelve months were individually interviewed about the process of self-disclosure of sexual orientation to acute care providers. Interviews were audiotaped and transcribed verbatim by the researcher and analyzed using open, axial, and selective coding.

Results: The Neese Theory of Lesbian Self-Disclosure in Health Care was identified that consisted of antecedent conditions, the core category of *personal risking*, and the causal condition of *fear*. Personal risking was a two-stage process used by participants to manage the fear of self-disclosure and consisted of an anticipatory and interactional phase. Participants calculated the risk of self-disclosure and selected one of four interactional stances in encounters with acute care providers.

Conclusion: The Neese Theory of Lesbian Self-Disclosure in Health Care could be used to guide more inclusive acute care nursing practices for lesbian clients.

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Dedication

I wish to dedicate this dissertation to two people, my sister Laura and my mother Patsy. My sister first sparked my interest in lesbian health with her requests for referrals to nonjudgmental physicians. Without Laura's presence in my life, I would never have chosen this research topic. My mother instilled in me the value of education and the importance of striving for excellence. Though not my loudest cheerleader, Patsy is my strongest supporter.

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CHAPTER ONE

Background of the Study

Every nurse has encountered innumerable female clients. Women seek health care for a wide range of needs, from dysmenorrhea to cardiogenic shock. The female population is quite diverse, encompassing many different age, ethnic, cultural, and spiritual subgroups. Increasing the diversity of female clients is a subgroup invisible to many nurses: lesbians.

To become visible, lesbians must reveal their sexual orientation. This process has been described two ways in the professional literature. Cass (1979) and Coleman (1982) detailed a process of homosexual identity development that began with self-identification as gay or lesbian and progressed as an iterative lifelong process of "coming-out" to friends, family, coworkers, and associates. The phrase "coming-out" has been most closely associated with social revelations of sexual orientation in the professional literature. The phrase "self-disclosure" was used when sexual orientation was revealed within the context of a professional therapeutic relationship (Farber, 2006). Since lesbians encounter acute care nurses in the context of a therapeutic nurse-client relationship, self-disclosure will be used in this study.

Women are major recipients of acute care, accounting for almost 60% of hospital admissions (Merrill & Elixhauser, 2005), and lesbians have been found in all subpopulations of women when researchers have requested information on sexual orientation (Dean et al., 2000). Depending on the source quoted, between 1.4% and 10% of women in the United States identified as lesbian or reported same-sex sexual experiences (Aaron, Chang, Markovic, & LaPorte, 2003; Dean et al.). U. S. employment

statistics revealed that registered nurses (RNs) are the largest group of licensed health care practitioners (Bureau of Labor Statistics, 2008) with 56.2% of RNs employed by hospitals (Steiger, Bausch, & Peterson, 2006). Based on these demographics, every hospital-based nurse has cared for lesbian patients. Despite the likelihood of encountering lesbians in practice, the health needs of lesbians have only recently been a major focus of nursing and the health care industry (Bradford, Ryan, & Rothblum, 1994; Dean et al., 2000; Solarz, 1999).

The first major publication to focus sustained attention on the diversity of lesbians, their health care needs, and directions for future research was the Institute of Medicine (IOM) report on lesbian health (Solarz, 1999). Highlights of the report included the prevalence of heterosexist bias in health care situations and a lack of culturally competent health care providers (HCPs) for lesbian clients. These factors interfered with an effective client-provider relationship. The report emphasized a need for research on how lesbians coped with heterosexist bias in various settings and discussed whether this bias interfered with health-seeking behavior. Following the IOM report, the Gay and Lesbian Medical Association (GLMA) issued a document in 2001 calling for more research on preventive health care for lesbians. The GLMA also advocated the identification of best practices for reducing homophobia in HCPs and insuring equal treatment of sexual minorities across all health care settings. Given this context, a wide range of investigative topics addressing lesbian health care and how to best support self-disclosure in different health care settings would be expected in the literature.

An explosion of lesbian health care research followed the release of the IOM report (Solarz, 1999), but investigations focused on primary care settings. Research

targeted provider-client relationships (Saulnier, 2002); lifestyle risk factors, such as smoking (Gruskin, Greenwood, Matevia, Pollack, & Bye, 2007); reproductive health concerns (Dibble, Roberts, Robertson, & Paul, 2002); mental health problems (Roberts, Grindel, Patsdaughter, Reardon, & Tarmina, 2004); and barriers to obtaining health care (Heck, Sell, & Gorin, 2006). The GLMA (2005) published guidelines for practitioners who wanted to make medical office environments gay- and lesbian-friendly by supporting self-disclosure. Lesbians were absent from acute care studies, with the exception of one group of nurse researchers in Sweden who explored hospital nurses' attitudes toward homosexuals (Röndahl et al., 2004a, 2004b, 2006, 2007).

Röndahl et al. (2004a, 2004b) found that Swedish nurses expressed generally positive attitudes toward homosexuals on surveys, but as many as 36% of nurses surveyed preferred to avoid caring for gay men or lesbians. When homosexual patients and their partners were queried on nurses' attitudes toward self-disclosure of sexual orientation, participants described nurses as fearful of behaving incorrectly, perplexed by self-disclosures, and reluctant to move beyond heteronormative assumptions about patients or their partners (Röndahl et al., 2006). Participants reported that nurses' behavior interfered with communication and care and described some nurses as openly hostile to life partners. The few studies conducted in the United States found that lesbians in hospital obstetrical settings reported similar discriminatory behavior on the part of nurses (Buchholze, 2000; Renaud, 2007).

Research in primary care has indicated that self-disclosure of sexual orientation by lesbians is associated with lower levels of anxiety and greater reported self-esteem (Jordan & Deluty, 1998). Women who more strongly self-identified as lesbian were more

likely to self-disclose to a primary HCP (Polek, Hardie, & Crowley, 2008), especially if that provider was perceived as gay-friendly (Steele, Tinmouth, & Lu, 2006). Having a receptive primary HCP was strongly associated with regular health care use (Steele et al.). Distant or detached provider behavior inhibited disclosure and interfered with lesbian health care use (Polek et al.; Steele et al.). It is not known whether these associations are relevant to lesbian clients in acute care. However, recent anecdotal reports indicated that homosexual clients who fail to share their sexual orientation with acute care providers may be discharged to tertiary care settings or home care services that are hostile to gay men and lesbians (Bennett, 2008; Gross, 2007).

The lessons learned in primary care on how best to ameliorate HCP homophobia, assure equal treatment of sexual minorities, and support self-disclosure of sexual orientation have yet to be applied uniformly in acute care settings. Self-disclosure is a dynamic, interactive social process that is context-bound. Self-disclosure of sexual orientation is further complicated by existing societal stigma related to homosexuality. The researcher aimed to learn how lesbians manage the process of self-disclosure as it evolves through interaction with hospital HCPs.

Statement of the Problem

Recent nursing research (Buchholze, 2000; Renaud, 2007; Röndahl et al., 2004a, 2004b, 2006) has shown that lesbians who disclose their sexual orientation may experience discrimination and marginalization by hospital nurses. Unpredictable provider response to instances of lesbian self-disclosure fostered distrust and impaired relationships with nurses and physicians (Buchholze; Renaud; Spidsberg, 2007). Though systematically studied in primary care, no nurse researcher has explored the process used

by lesbians to manage self-disclosure of sexual orientation in hospital settings. As the researcher explored the social process of self-disclosure, she hoped to also uncover how awareness of vulnerability in an acute care setting affects disclosure, under what conditions lesbians choose to self-disclose, what strategies are used in deciding whether to disclose, and the consequences experienced after self-disclosure.

Purpose of the Study

The purpose of this study was to develop a grounded substantive theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to describe the process involved in lesbian self-disclosure of sexual orientation in acute care settings. Understanding the self-disclosure process may provide the opportunity for nurses to modify practice and potentially reduce heterosexist bias and the marginalization of lesbian clients.

Research Question

The primary research question is, What is the process of lesbian self-disclosure of sexual orientation in acute care settings? Other questions guiding this study are:

- 1. How does the process of lesbian self-disclosure unfold?
- 2. What are the critical influences that govern lesbian self-disclosure?
- 3. What strategies are used by lesbians during the process of self-disclosure?
- 4. What are the outcomes or consequences of lesbian self-disclosure of sexual orientation as perceived by participants?

Significance of the Study

Assuming a conservative 2% prevalence of lesbians in a female population of 152,962,259 (U.S. Census Bureau, 2007), there are slightly more than 3 million lesbians in the United States. The Bureau of Labor Statistics (2008) estimates there are 2.5 million

RNs in the United States, meaning that there are at least as many lesbians as there are RNs living in this country. In 2006, more than 36 million Americans were admitted to hospitals for acute medical and surgical care (American Hospital Association, 2008). Women were hospitalized more frequently than men; in 2005, 59% of hospitalizations were for women (Agency for Healthcare Research and Quality [AHRQ], 2005). With three million lesbians in the female population, some of those hospitalized women were lesbians. Acute care nurses deliver care to lesbians on a daily basis, and it is crucial that this care be effective, humane, and respectful. The aim of this study was to develop a grounded theory that identified the process involved in lesbian self-disclosure of sexual orientation to acute care providers. Such a theory could guide nursing care and improve the care of lesbians in hospital settings. This study has implications for nursing education, nursing practice, research, and public policy.

Implications for nursing education. Nursing students are required to professionally render physical care and emotional support to clients in a color-blind, class-blind fashion (Culley, 2006; Gustafson, 2005), and some of these clients will be homosexual. Despite this, acculturation into the nursing profession is heteronormative because nursing is reflective of the society in which it is practiced, and American society is heterosexist (Gray et al., 1996; Misener, Sowell, Phillips, & Harris, 1997). Nursing students may enter school with preexisting negative attitudes toward lesbians (Eliason & Raheim, 2000; Röndahl et al., 2004b), and sexual minorities are often omitted from cultural diversity education. Older texts on culturally competent care did not mention sexual orientation (Purnell & Paulanka, 1998), and even the most recent texts give sexual orientation only a few sentences within each ethnic group (Lipson & Dibble, 2005).

Nurse educators need evidence-based exemplars to promote student reflection and transformative unlearning. This study could provide one of those exemplars through increasing nurses' and students' understanding of the process of lesbian self-disclosure.

Implications for nursing practice. Effective, respectful care that promotes healing is an essential feature of nursing (American Nurses Association [ANA], 2003). Thus, a major goal of nursing practice is to ameliorate patient fear and anxiety, not to enhance distress through discriminatory or stigmatizing behaviors. Nursing's code of ethics explicitly prohibits discriminatory or prejudicial behaviors in delivering care (ANA, 2001). Failing to treat lesbians with dignity and respect violates nursing's prima facie ethical duties of beneficence and nonmaleficence (Beauchamp & Childress, 1997). If hospitalized lesbians do not disclose their sexual orientation out of fear, nurses lose valuable opportunities for preventive health teaching, and lesbians may receive inappropriate referrals during discharge planning, further marginalizing an already vulnerable population. The data generated by this study described whether lesbians who acknowledge their sexual orientation experience less discomfort in encounters with acute care providers than those who maintain the appearance of heterosexuality. Understanding the process of lesbian self-disclosure in acute care could enable nurses to increase patient comfort, to promote trust, and to improve nurse-patient communication, thereby enhancing quality of care and maintaining ethical practice.

Implications for nursing research. An acute care nursing perspective on lesbian self-disclosure of sexual orientation and on how disclosure affects nursing care is missing from current nursing knowledge. This study may be the first step in filling that

knowledge gap. Understanding the process of lesbian self-disclosure in acute care could stimulate investigation of best-practice strategies for supporting lesbian self-disclosure.

Grounded theory is used to construct an abstract explanatory schema for an interactive social process using data from participants who have experienced the phenomenon (Strauss & Corbin, 1998). In nursing, grounded theory has been used to inductively develop middle range theories that are anchored in daily professional practice (Liehr & Smith, 1999; Peterson & Bredow, 2004; Smith & Liehr, 2003). A grounded theory of lesbian self-disclosure in acute care could stimulate research that eventually constructs a theory of self-disclosure applicable in multiple situations. Subsequent studies could examine causal conditions, strategies, context, and intervening conditions of self-disclosure in other populations and in different nursing care settings.

Implications for public policy. Lesbian health disparities that could result in hospitalization are a consequence of "homophobia fallout" (O'Hanlan, Dibble, Hagan, & Davids, 2004, p. 229) and accompanying stigma. Lesbians constitute a vulnerable population due to their marginalized sociocultural status and gender variance (de Chesnay, 2005). State law may withhold legal recognition of same-sex partnerships, meaning lesbians can be denied hospital visitation rights and prevented from making health care decisions for an incapacitated partner. Lack of legal protection interferes with obtaining health insurance for lesbian partners and their children. Institutional policies often mirror state law, encouraging discrimination and placing lesbians at risk of emotional and financial harm during an acute health crisis. Discrimination based on sexual orientation is essentially a social policy, and the health effects resulting from this

social policy are within the purview of nursing and the profession's social justice mandate (ANA, 2001, 2003).

This study illuminated some of the homophobia fallout in acute care by describing the process of lesbian self-disclosure. Nurses could then modify institutional policies to support beneficial self-disclosure. At the state level, nurses could inform legislators of the self-disclosure process and encourage them to consider changing discriminatory laws.

Philosophical Underpinnings

Grounded theory refers to a method of analysis in qualitative research developed by Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). Glaser and Strauss stated that they developed grounded theory to close a perceived gap between grand theory and empirical research in sociology; they sought to make theory relevant to the needs of sociological research and practice. Glaser was influenced by Paul Lazarsfeld at Columbia University and focused on empirical discovery and on inductively deriving theoretical concepts from real-world data (Strauss & Corbin, 1998). Strauss, who came from the University of Chicago School of Sociology, emphasized the constantly changing process of human interaction and of understanding meaning from the perspective of human actors (Strauss & Corbin). Thus, the roots of grounded theory lie in pragmatism, through concern for the union of theory and practice, and in symbolic interactionism, with its emphasis on the social process of human interaction and the meanings generated through interaction.

Pragmatism. Pragmatism originated as a philosophical theory of meaning in the U.S. in the 1870s and has since evolved several theoretical perspectives (Schwandt, 2001; Thayer, 2006). The perspective salient to grounded theory contends that humans are self-

aware purposive actors who experience material reality by interacting with their social and physical environments. This interaction is active, not a reflexive response to external stimuli or to internal psychological factors. Humans then use an interpretive process to create meaning and to define their reality, which situates knowledge and meaning historically and socially. Human action is provoked by diverse problems in everyday existence and by a subsequent search for practical solutions. Inquiry is used to examine these problematic situations reflectively and to transform indeterminacy to certainty by applying pertinent existing knowledge and inductively generating theory. As temporal and social contexts change, practical outcomes are constantly re-evaluated. Pragmatic inquiry can be described as an iterative process of reflective problem assessment, inductive exploration, and reflective evaluation of outcome that can initiate further inquiry.

Pragmatist philosophy was a great influence on the first American school of sociology at the University of Chicago, sometimes known as The Chicago School (Strauss & Corbin, 1998). Meaning conveyed in human communication and group life became a focus of scholarly inquiry at the Chicago School of Sociology due to the presence of the pragmatist psychologists John Dewey and George Herbert Mead (Gerhardt, 2000). Mead's contributions included the concept of a self-aware independent mind that developed through social interactions (1913) and through human use of significant symbols to convey meaning in communication (1922). These ideas became the foundation of symbolic interactionism.

Symbolic Interactionism. Symbolic interactionism (SI) is a sociological theory anchored in pragmatism and derived from the work of Herbert Blumer (1969), who

taught at The Chicago School. Blumer identified three tenets of SI: (a) human beings interact with physical objects, other entities, and abstract concepts on the basis of meanings attached to the object, individual, or thought; (b) these meanings arise in the context of social interaction; and (c) these meanings are modified through an interpretive process used by people to master their social environments. The tenets of SI are grounded in several assumptions that illustrate the nature of human society, social interaction, objects, humans as actors, human action, and the interrelationship of individual actions.

Nature of human society. Human society consists of and is created by humans engaged in action. Culture and social structures are outcomes of human interaction.

Nature of social interaction. Social interaction involves an interchange of meaning between humans. Social interaction may be non-symbolic or symbolic. Non-symbolic interaction does not require interpretation for comprehension, such as a reflex response to a threat. Symbolic interaction requires human actors to interpret each other's meaning and respond to the interpretation. Symbolic interaction is conveyed by gestures, which are any actions that humans use to convey meaning. Mead (1922) originally conceived of symbolic gestures as linguistic devices; Blumer (1969) extended the concept to include visual, physical, and auditory gestures. For understanding to occur, the individual making a gesture and the person receiving the gesture must attribute the same meaning to the gesture. According to Blumer, full comprehension of meaning is possible when each party involved in an interaction cognitively grasps the role played by the other individual and anticipates his or her response to the gesture.

Nature of objects. An object is anything that can be specified, whether physical, social, or abstract. Objects are social creations arising from social interactions and

negotiated meanings that are relevant to particular individuals or groups. Each individual attributes personal meanings to objects that are influenced by interaction with others. Humans view their environment as consisting of familiar objects coupled with attendant meanings. This environment is not static, as the nature and meaning of objects change over time as a result of human group life.

Human as actor. Humans are self-aware and recognize themselves as objects.

Individual behaviors emerge through interaction with the self and others. Self-interaction occurs through reflection and awareness of influences that direct action. Self-interacting humans assess their environment, make an object of what is perceived, determine the meaning of that object, and use the meaning to direct subsequent action.

Nature of human action. Humans confront a world that must be interpreted instead of an environment to which they respond based solely on inherent psychological factors. An interpretive process using self-interaction and social interaction is used to guide action individually and collectively. This interpretive process must be understood in order to fully comprehend human action.

Interrelationship of individual actions. Human group life permits societal understanding of specified concepts of communal action; for example, marriage, education, work, or war. Blumer (1969) referred to these concepts as joint actions and described joint actions as holistic interlinkages of individual actions. Joint actions are normed, networked, and grounded. Joint action is normed by humans acting according to established meanings. Accepted group meanings are dynamic and subject to change over time. Networked joint action permits the formation of societal and cultural institutions, which are modified by shifts in individual and group interpretation of meanings. Joint

action arises from the backgrounds and experiences of individual participants, meaning group action is grounded historically, temporally, and socially.

For Blumer, humans are active participants in their social, cognitive, and emotional environments. Through action, humans create and define an empirical world with a material reality that can be apprehended intellectually and emotionally through an interpretive process of meaning-making. Each individual brings presuppositions into every social interaction because each individual possesses preexisting personal and group meanings. These preexisting meanings influence perceptions of any novel social interaction, including scientific inquiry. Investigators possess presuppositions that bring bias to problem selection, study design, data collection, and interpretation of results. Blumer recommended that investigators not use a priori theory to frame studies of human group life to avoid introducing bias. He asserted that scientific inquiry was best served by meticulous study of human social life and the empirical world created by the group of interest. Functional theories highly relevant to sociological and psychological practice would result from close study of human social interaction.

Influences on Grounded Theory. Pragmatism promotes seeking useful change and inductively exploring problematic human social situations, a major focus of grounded theory. Symbolic interactionism contends that humans interact to create socially contextualized meanings that describe their empirical world and that direct action.

Grounded theorists must attend to the mutable nature of socially derived meanings and to how this variability influences human behavior.

There is currently no explanatory framework for how lesbians experience selfdisclosure of sexual orientation in acute care. Self-disclosure is an interactive social process carrying socially contextualized meanings that affect behavior. Grounded theory is an approach that inductively creates an explanatory framework for a social process that is grounded in situational context (Creswell, 1998). Thus, grounded theory was an appropriate method to use in this study.

Scope and Limitations of the Study

Several limitations could affect this study: (a) lack of generalizability, (b) researcher bias, (c) selection bias, (d) reliance on self-report and on respondent recall of past events, and (e) difficulty recruiting participants. Low minority participation and sociological variables like a lesbian-friendly political climate or a homophobic environment could affect generalizability. When the researcher is the data-collection instrument, researcher bias is always a concern (Schreiber, 2001; Speziale & Carpenter, 2007). Lesbians are a hidden, vulnerable population requiring the use of snowball or chain sampling techniques (Platzer & James, 1997; Wuest & Merritt-Gray, 2001). The use of snowball sampling increases the possibility of selection bias and the overrepresentation or underrepresentation of subgroups in the sample (Platzer & James, 1997; Heckathorne, Semaan, Broadhead, & Hughes, 2002). Relying on self-report and respondent recall of past events opens research data to inaccuracies and to respondents providing what they think researchers want to hear (Creswell, 2007; Patton, 2002). Finally, lesbians do not always self-identify as lesbian, which could result in difficulty recruiting participants.

Summary

Lesbians are a marginalized, vulnerable population that has experienced discrimination in health care. Evidence-based strategies for supporting lesbian self-

disclosure of sexual orientation have been developed for primary care, but not for acute care settings. This grounded theory study aimed to explore the process of lesbian self-disclosure of sexual orientation in acute care. Findings from this study could enhance cultural diversity instruction in nursing education, raise awareness of supportive nursing interventions for this population, and spur advocacy for changing discriminatory policies.

CHAPTER TWO

Review of the Literature

Historical context. Despite research spurred by the IOM report on lesbian health (Solarz, 1999) and despite the possibility of encountering lesbians in hospitals, few studies in the United States have focused on caring for lesbians in that setting. Stevens' (1994, 1995) landmark qualitative studies included some descriptions of lesbians' hospital experiences, but research related to acute care of homosexuals centered on managing AIDS crises. Lesbians have been mostly invisible in acute care nursing literature until quite recently. The experience of lesbians giving birth in hospitals has been the focus of two recent nursing studies (Buchholze, 2000; Renaud, 2007).

A search of relevant literature was conducted across disciplines to explore lesbian self-disclosure in acute care. Citations were limited to English-language articles published in peer-reviewed journals from 1995 through 2008, and no published information related to the process of lesbian self-disclosure in acute care was returned. To provide context for this study, the literature review traces the history and evolution of lesbianism, or female homosexuality, including current demographic information on the lesbian population in the United States. Health issues for lesbians are discussed from a women's health perspective to permit incorporation of physical health concerns and the societal-level problem of sexual prejudice. The health concerns reviewed increase the likelihood that lesbians will encounter an acute care setting and include childbirth, obesity, and smoking. Sexual prejudice contributes to patterns of discrimination and stigmatization experienced by lesbians and other sexual minorities (Herek, Chopp, & Strohl, 2007).

History of lesbianism. Homosexuality did not exist as a word or as a social construct of identity in Western society until the late-19th century (Dean, 1996; Weeks, 1996). There were laws prohibiting deviant sexual acts, but sodomy laws targeted behaviors, not a sexual identity. Male sexual deviancy was proscribed because unregulated male sexual behavior was believed to cause moral decay and social dissolution (Weeks). Female sexual behavior other than prostitution was limited to the domestic sphere and its associated procreative requirements (Dean). Women were assumed to be passive recipients of male sexual desire. This assumption made lesbian behavior ideologically impossible and invisible; it implied that women were simply incapable of active sexual desire. Sexual deviancy was a moral failing defined strictly in terms of male behavior (Dean; Weeks).

The word "homosexual," coined in 1869, gradually became a label for individuals exhibiting same-sex desire (Dean, 1996; Weeks, 1996). After 1885, medical and psychological discourses began to define same-sex desire as an internal individual trait rather than a sexually deviant act (Weeks). These discourses medicalized homosexuality, shifting the condition from a moral problem to a disease entity or pathology subject to diagnosis and treatment (Weeks). Havelock Ellis (1897/2004) is credited as being the first to medicalize homosexuality, to define it as an individual anomaly, and to codify the condition in terms of male behavior (Dean). Homosexuality became a socially constructed deviant identity.

The term "lesbian" was derived from the Greek isle of Lesbos, home of the poet Sappho, who was famed for writing love poems to other women (Cardozo, Marsden, Klinger, & Rothblum, 2006). Coined in the 17th century, the word lesbian did not enter

general use until the 1880s (Cardozo et al.). Physicians and psychologists referred to lesbians as "inverts" until well into the 1900s (Dean, 1996).

Female same-sex desire remained largely invisible to the medical community until the early-20th century. After 1903, lesbianism appeared more often in medical discourses as a dangerous condition requiring intensive treatment (Adam, 1987; Dean, 1996). Physicians and psychiatrists used hypnosis, hysterectomies, electroshock therapies, drugs, and hormones in an attempt to "cure" lesbians of homosexuality (Adam). Lesbians were deemed dangerous because they actively participated in sexual deviance, destabilized rigid gender boundaries, and disrupted dominant constructions of "normal" sexuality. The deviant label became cemented as cultural bias in the West between World Wars I and II (Adam; Weeks, 1996).

Widespread political activism in the United States in the early 1970s prompted the lesbian community to seek greater social acceptance, to de-medicalize lesbianism, and to redefine the meaning of "lesbian" politically (Aldrich, 2004; Holmberg, 1998; Streitmatter, 1995). Gay activism prompted the American Psychiatric Association to remove homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders* in 1973 (Cardozo et al., 2006). In the 1970s, feminists championed the women's health movement and demanded that female reproduction and sexuality be perceived as normal, not pathological (Nichols, 2000). Political activity in urban centers did make lesbians more visible to the general public but did not succeed in removing the stigma of deviance from a lesbian identity.

In the 1990s, gay activism in urban centers succeeded in fracturing the monolith of "lesbian identity" (Phelan, 1993); many lesbian subcultures formed and the meaning of

the word "lesbian" was contested (Elwood, 2000; Esterberg, 1996; Fingerhut, Peplau, & Ghavami; Lo & Healy, 2000; Love, 1999). Racialized minorities defined what "lesbian" meant to them (Anzaldua, 2002; Dworkin, 1997; Chan, 1997) and challenged white hegemonic discourses regarding sexual identity (Anzaldua; Lo & Healy; Love). Gender became a continuum instead of a male/female dichotomy. Attempting to neutralize negative connotations associated with those labels, young women embraced labels and appearances that older generations of lesbians found repugnant (Holmberg, 1998). This postmodern diversity has created a problem for researchers interested in lesbian health—how to define "lesbian." For the purposes of this study, the term *lesbian* will be defined as a woman whose primary emotional, social, and sexual relationships are with women (American Psychological Association, 2008) and who self-identifies as lesbian or gay.

Current demographics of the lesbian population. The primary sources of population-based lesbian demographic information are the United States Decennial Census (USDC) and the American Community Survey (ACS). Data on same-sex unmarried partner households were collected in the 1990 and 2000 USDCs. The Census Bureau conducts the ACS yearly to provide population estimates between USDC surveys (U.S. Census Bureau, 2006). ACS results are based on responses from a stratified random sample of all housing units in the United States and Puerto Rico; approximately three million households are sampled annually (U.S. Census Bureau).

Census data revealed an increase in reporting same-sex partnership status between 1990 and 2000, with 63,787 lesbian families counted in 1990 and 297,061 lesbian families reported in 2000 (Smith & Gates, 2001). This data represented a 365% increase in reported lesbian households from 1990 to 2000. In 2000, 33% of lesbian couples

reported children living in the home (Gates & Ost, 2004). Florida ranked ninth among states in coupled gay and lesbian households (Smith & Gates), with Gulfport and Wilton Manors reporting the largest numbers of coupled lesbian households (Gates & Ost).

ACS data also demonstrated increased reporting of same-sex unmarried partner households from 2000 to 2005 (Gates, 2006). Florida was ranked as the No. 2 state in gay, lesbian, and bisexual couples, with an estimated 24,391 female same-sex couples (Gates). Approximately one quarter of these lesbian couples reported membership in a racial or ethnic minority (Romero, Baumle, Badgett, & Gates, 2007). The Miami-Fort Lauderdale-Miami Beach Metropolitan Statistical Area (MSA) reported 5,765 lesbian couples; this MSA included Wilton Manors. Female same-sex couples in Florida had an average yearly income of \$30,241 (median \$25,000), which is less than the average for married men and male same-sex couples (Romero et al.). Women in lesbian couples were more likely to have a college degree and to be employed than married heterosexual women (Romero et al.).

Unfortunately, the USDC and the ACS do not provide a means of identifying single lesbians or those who are in a relationship but not living in the same household. Demographers have expressed reservations related to undercounts of gays and lesbians in the general population (Black, Gates, Sanders, & Taylor, 2000; Smith & Gates, 2001). Undercounts were estimated at 71% for lesbians in the 1990 census (Black et al.) and at 62% for the 2000 census (Smith & Gates). Assuming a 50% undercount, lesbians constitute an estimated 2% of the female population (Gates & Ost, 2004). Lack of lesbian-specific data in reports based on these national surveys is also a concern. Results are often presented as "gay and lesbian," as if the demographics of gay men and lesbians

were equivalent (Romero et al., 2007; Smith & Gates). This practice renders lesbians invisible to policy makers, advocacy organizations, and the news media, and it does little to contradict societal biases contributing to health issues or sexual prejudice.

Making use of this demographic data, an adequate sample of lesbian participants was found for this study. Focusing on lesbians in this study foregrounded their presence in acute care and permitted the researcher to uncover the process of self-disclosure of sexual orientation. This study could make lesbians more visible to acute care nurses and policy makers.

Women's health. The phrase women's health was formerly confined to issues related to female anatomy—pregnancy, childbirth, and menopause. Beginning in the 1960s, the exclusive focus on reproduction was replaced by a broader conception of women's health (Nichols, 2000). A wide range of social, economic, and health-related factors that affect women differently from men have been included under the umbrella of women's health (Nichols). Recent nursing and medical research findings have indicated that lesbians may experience health issues differently from heterosexual women, and some of these concerns increase the chance that lesbians will present in an acute care setting. Three of these health concerns are childbirth, obesity, and smoking.

Childbirth. The assumption that lesbians never have children has been a common one regarding this population. Reports in the maternal-child health nursing literature have challenged that supposition (Buchholze, 2000; Renaud, 2007; Spidsberg, 2007). More than one in three lesbians have experienced childbirth, either in a previous heterosexual marriage or through donor insemination (Gates, Badgett, Macomber, & Chambers, 2007; Marrazzo & Stine, 2004). Increasing numbers of lesbians have chosen to become

pregnant through donor insemination and to involve their partner as co-parent (Renaud; Spidsberg).

Renaud (2007) conducted a critical ethnographic study of lesbians, partnered or single, who had given birth and lived in the Pacific Northwest. The ethnography described participants' personal and health care experiences with conception, perinatal care, childbirth, and becoming mothers and co-mothers. The article cited reported themes from conception to childbirth. Twenty-one women completed in-depth interviews; six women participated in a focus group; and the researcher completed a 6-month observation of a support group for lesbian mothers. All the participants chose donor insemination and delivered in a hospital. Themes identified were (a) "preparing the way: becoming ready," (b) "conception: you can't just fall into it," (c) "you can hear a heartbeat: pregnancy," and (d) "birthing our babies" (Renaud, p. 195). Participants used a word-of-mouth network to identify lesbian-friendly hospitals for delivery, and many incorporated their sexual orientation and how they wished to be treated into their birth plans. Despite extensive preparation and many positive outcomes, some participants reported discrimination, nurses' refusal to acknowledge the co-mother, and perceived lack of support and caring from nurses. The author urged nurses to become familiar with lesbian issues and advocated for lesbian-friendly perinatal policies and settings.

Obesity. Lesbians have been noted to have higher rates of obesity than heterosexual women. Case et al. (2004) reported on data obtained from the Nurses' Health Study II, a prospective cohort study that began collecting information on sexual orientation in 1995. Case et al. were interested in associations between sexual orientation and health risk factors, in mental health status, and in health-related functioning. For

obesity, the outcome variable was body mass index (BMI). Overweight was defined as a BMI of 25.0 to 29.9 kg/m 2 , and obesity was defined as a BMI \geq 30.0 kg/m 2 . Covariates were age, race (White/Black/other), and region of residence in the United States. Multivariate prevalence ratios were calculated to compare sexual orientation subgroups (lesbian, bisexual, other) with heterosexuals using binomial regression to adjust for covariates. Results showed that lesbians had a 50% greater prevalence of obesity (95% CI = 1.4-1.7) and a 20% greater prevalence of overweight (95% CI = 1.1-1.4) than heterosexual women.

Boehmer, Bowen, and Bauer (2007) used data from Cycle 6 of the National Survey of Family Growth (NSFG) to determine if lesbians had higher rates of overweight and obesity than heterosexual or bisexual women. Conducted in 2002, Cycle 6 of the NSFG was the first survey to ask questions about sexual orientation. The investigators' outcome variable was BMI in kg/m 2 with covariates of age, parity, race/ethnicity, medical insurance status, residence (urban/nonurban), nativity, household income, and education. Using a multinomial logistic regression model, researchers found that lesbians between the ages of 20 and 44 were more likely to be overweight (OR = 2.69, 95% CI = 1.40-5.18) and obese (OR = 2.47, 95% CI = 1.19-5.09) than heterosexual women after adjusting for the covariates. The World Health Organization (2003) has declared obesity a global epidemic and has linked obesity with multiple chronic illnesses such as breast cancer, colon cancer, Type II diabetes, and heart disease. Treatment or exacerbation of any of these conditions could result in acute hospitalization for obese or overweight lesbians.

Smoking. Research spurred by the IOM report on lesbian health (Solarz, 1999) has indicated that lesbians are more likely to smoke cigarettes than heterosexual women. Smoking has well-known health consequences, including asthma, chronic lung disease, and heart disease. Heck and Jacobson (2006) investigated the prevalence of asthma and correlates of asthma diagnosis in a population-based sample of individuals in same-sex relationships (SSRs) compared with individuals in opposite-sex relationships (OSRs). Data were obtained from the National Health Interview Survey, a nationwide probability survey of the adult population in the United States. Weighted chi-square tests were used to compare male and female SSRs and OSRs with respect to asthma prevalence, smoking status, stress frequency, and medical insurance status. Women in SSRs were significantly more likely to be current smokers (p < .0001) and to report an asthma diagnosis (p < .03) than women in OSRs. Sanchez, Hailpern, Lowe, and Calderon (2007) found that one or more emergency department visits by lesbian, gay, or bisexual individuals were associated with treatment for asthma (p < .05).

Tobacco use in the sexual minority population of California was compared with the general population of that state by Gruskin, Greenwood, Matevia, Pollack, and Bye (2007). A disproportionate, stratified random-digit-dialing sample design was used to recruit respondents. Cigarette use, age, race/ethnicity, education, and personal income for lesbians, gay men, and bisexuals were compared with male and female respondents from the general population. Lesbians were significantly more likely to report being smokers (28%, 95% CI = 21.1-38.0) than women from the general population (12%, 95% CI = 11.9-12.4). This trend persisted across age stratums from 18 to 44 years (p < .017). The greater prevalence of smoking puts lesbians at risk for lung disease, heart disease, and

stroke. Cigarette smoking has also been linked to several cancers, including lung, bladder, kidney, and pancreatic cancers (American Cancer Society, 2009). Exacerbations of asthma certainly initiate contact with acute care providers, and complications of cancer therapy may necessitate hospitalization.

Population studies have identified health risks in lesbians that could trigger a need for acute care. Lesbians are choosing to have children, and qualitative investigations have shown that lesbians prefer to deliver in a hospital setting. Yet, the acute care nursing literature is nearly silent on this population, with the exception of maternal-child nursing. This silence renders lesbians invisible in acute care. This study could increase awareness of the lesbian presence in acute care and could inform nurses of possible strategies to use in supporting this patient population.

Sexual prejudice. American society has demonstrated biases against lesbians and gay men by denigrating their existence; enforcing heterosexist policies; discriminating in employment, housing, and health care; and harassing them with tactics ranging from verbal abuse to physical assault (Adam, 1987; Dean, 1996; Weeks, 1996). The psychologist George Weinberg coined the term homophobia in 1969 as shorthand for societal-level biases with the accompanying rejection of homosexuals as an out-group (Herek, 2004). Homophobia has been heavily critiqued in psychology; its critics contend that the word implies a character flaw rather than animosity and insist that homophobia fails to encompass the sociopolitical factors that contribute to antigay hostility (Herek, 2000, 2004). Sexual prejudice has been offered as a replacement term for homophobia and refers to negative attitudes based on sexual orientation that are influenced by individual factors and sociopolitical power dynamics (Herek). Sexual prejudice would

encompass negative attitudes toward people based on their sexual-group membership rather than individual attributes. Negative attitudes toward homosexuals can result in stigmatization, discrimination, avoidance, abuse, or violence depending upon characteristics of the immediate situation and social norms (Herek). Sexual prejudice is a social phenomenon that can affect the health of lesbians, which brings sexual prejudice under the women's health umbrella.

Stigmatization occurs when society labels certain individual traits, behaviors, or attributes as shameful or undesirable (Herek, 2004). These labels evolve meanings in social interactions, constructing social roles and expectations (Herek et al., 2007). A stigmatized individual is allotted an inferior social role, accorded less power, and targeted for attack if role expectations are violated (Herek et al.). Stigmatization is used to induce feelings of shame, self-loathing, and anxiety in those who are marginalized (Herek; Herek et al.). Sexual prejudice stigmatizes homosexuality, meaning lesbians are labeled bad, sick, or abnormal (Herek et al.). In heterosexuals, this labeling can generate negative attitudes toward homosexuals. Nursing research has identified the presence of negative attitudes toward homosexuals in nursing students and practicing nurses.

Eliason and Raheim (2000) used a researcher-developed survey to assess prenursing students' exposure to and comfort with 14 culturally diverse groups, including lesbians. A convenience sample of 196 White, heterosexual (173 female, 23 male) prenursing students completed the survey; 13 non-White students were excluded from analysis. A pilot of the instrument demonstrated a test-retest correlation of .94. Forty-four percent of respondents reported that they would be uncomfortable working with lesbians. Experience with a particular sexual minority was positively and significantly associated

with comfort in working with clients from that group (lesbians r = .35, p < .001). Written narrative comments were used to determine students' attributions for their discomfort in working with diverse groups. The most negative emotionally charged comments were made toward sexual minorities and included the responses "gross," "disgusting," and "immoral." No other racial or ethnic group elicited such negative attitudes, and the authors speculated that students expressed more negative attitudes because lesbians and gays are not identifiable by external characteristics.

One group of researchers in Sweden has been investigating nurses' and nursing students' attitudes toward homosexuals. In an initial study using the Affect Adjective Checklist and Nursing Behavior Questionnaire, Röndahl et al. (2004b) surveyed a convenience sample of nurses and nursing students in Sweden. The purpose of the study was threefold: (a) to investigate the emotions of practicing nurses and nursing students toward homosexual clients, (b) to determine whether practicing nurses and nursing students would choose to avoid caring for homosexual patients if the option existed, and (c) to discover how refrainers expressed their wish to avoid caring for homosexual clients. Practicing nurses (48 nurses and 37 assistant nurses) were recruited from one infectious disease clinic. Assistant nurses are equivalent to licensed practical nurses in the United States (Kapborg, 1998). Nursing students and assistant nursing students were recruited from single programs in central Sweden. The response rate for practicing nurses was 67% (n = 57), and the response rate for nursing students was 62% (n = 165). Assistant nursing students expressed significantly more homophobic anger ($F_{3,217}$ = 6.058, p = 0.0006) than all other groups. Thirty-six percent of practicing nurses and 9% of students stated that they would avoid caring for homosexual patients if the option

existed. Reasons for refraining included social desirability, insecurity, negative attitudes, and fear. The authors attributed assistant nursing students' more negative attitudes to lower levels of education and lack of experience with homosexual clients. Investigators expressed surprise at the percentage of practicing nurses who wished to avoid caring for gay and lesbian patients but voiced optimism that the low percentage of students wishing to abstain indicated a general shift in societal attitudes toward homosexuals.

Röndahl et al. (2006) also conducted a qualitative interview study of lesbians and gay men who had experienced nursing care in hospitals as patients or partners in a variety of specialty areas. Seventeen women and 10 men were recruited using snowball sampling and agreed to participate in face-to-face interviews. Interviews were analyzed using phenomenographic techniques, which focus on the participant's perspective of an experience, not on an interpretation of the meaning of an experience. The primary theme identified was heteronormativity. Informants reported being treated as heterosexual even after disclosing an alternate sexual orientation. Assuming that nurses would respond negatively, others were afraid to reveal their homosexuality. Nurses were described as perplexed by disclosures of a gay or lesbian sexual orientation, with some nurses distancing themselves from the patient or ignoring the partner. All participants reported that nursing behavior interfered with clear, open communication in the hospital setting. Nurses seemed to be unaware of the heterosexual norms communicated by their verbal and nonverbal behavior, and several lesbian participants were distressed by encounters related to reproductive health.

The investigation conducted by Röndahl et al. (2006) indicated that lesbians do self-disclose their sexual orientation in hospital settings and that these self-disclosures

received mixed reactions from nurses. Sexual prejudice, stigma, and heterosexist bias could contribute to emotional distress and impaired communication between lesbian clients and their nurses, but the self-disclosure process has not been examined in the acute care setting. This study sought to reveal the process of lesbian self-disclosure in acute care including factors that influence self-disclosure and that strategies lesbians use in self-disclosing.

Experiential context. The idea for undertaking this study grew out of my personal and professional experience with lesbians seeking health care. I am a 54-year-old, White, middle-class, heterosexual female and feminist reared in the southern United States. I have a lesbian sister, who has experienced discrimination in health care and has sought my advice on providers and other matters. She recently underwent surgery for ovarian cancer. Professionally, I am an Emergency Department (ED) nurse who has witnessed homophobic and affirmative provider reactions to lesbian clients. I have also been witness to the lesbian word-of-mouth referral network sending individuals into the ED on the night shift because the nurses were considered more gay-friendly. These observations and experiences intrigued me and triggered my desire to investigate the factors that influence lesbian self-disclosure of sexual orientation in acute care settings.

Maintaining an objective stance. Strauss and Corbin (1998) referred to mitigating biases by the investigator attempting to maintain an objective stance. They said being objective did not mean controlling confounding variables; rather it meant remaining open and being willing to actively listen to the voice of participants without imposing a researcher's preconceived ideas on the data. No investigator comes to a research setting without individual biases, preexisting knowledge, and suppositions; these

must be acknowledged and controlled. I remained aware of my feelings and used a personal reflective journal to record my reactions to the research process. I believe I remained neutral in interviews, concentrating on the voices of my participants and their perspectives of self-disclosure. I constantly compared my interpretations with the data and asked myself, "What is going on here?" to avoid imposing my suppositions on the data. I sought out various viewpoints on lesbian self-disclosure through conducting multiple interviews and consulting other data sources as needed to enhance my perspective. I did "wave the red flag" (Strauss & Corbin, p. 97) whenever I suspected that any preexisting assumptions or beliefs were intruding into the analysis. This intrusion was signaled by totalizing words and phrases like *always, never, everyone does*, and *no one*. These red flags signaled a need for further exploration rather than simple acceptance.

Summary

Lesbians constitute approximately 2% of the population of women in the United States, and Florida has several metropolitan areas with large numbers of lesbian residents (Gates & Ost, 2004). Despite these numbers, lesbians are a hidden marginalized minority subjected to sexual prejudice and its accompanying stigmatization. A recent example of discrimination occurred in Miami when a lesbian was denied visits to her dying partner at a local hospital (Figueroa, 2009). The woman, a tourist from Washington State, was denied access to her partner despite having documents granting her legal guardianship and medical power of attorney; she filed suit against the hospital for intentional infliction of emotional distress (Figueroa). The lawsuit was dismissed by a federal district court judge in 2009 (Parker-Pope, 2009). Florida statutes related to health care advance

directives and guardianship do not read "except for homosexuals" and are written to accommodate documents executed in other states (Health Care Surrogate, 2008; Types of Guardianship, 2008). Where were the nurses to advocate for this couple?

In addition to sexual prejudice, lesbians face health concerns that increase their chance of needing acute care. Lesbians are choosing to become pregnant and to deliver babies in hospitals. They are more likely to be overweight or obese and smoke, which increases their risk of many chronic diseases that can manifest acute symptoms. Most women's health research including lesbians has focused on primary care settings and lesbian health risks; very little research exists related to lesbians in acute care. The existing studies were all qualitative, conducted in obstetrical settings, and focused on lesbian *experiences* in acute obstetric settings (Buchholze, 2000; Renaud, 2007). As illustrated by this literature review, some lesbians choose to self-disclose in acute care, but the process of lesbian self-disclosure remains unexamined. Understanding the self-disclosure process in acute care was the goal of this study.

CHAPTER THREE

Method

A grounded theory approach is useful when a researcher seeks to develop a theory or framework that explains human behavior in a social context. The purpose of this study was to develop a grounded substantive theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to describe the process involved in lesbian self-disclosure of sexual orientation in acute care settings. Understanding the self-disclosure process may provide the opportunity for nurses to modify practice and to potentially reduce heterosexist bias and the marginalization of lesbian clients.

Research design. A qualitative method was appropriate for this study because the phenomenon under investigation is complex, dynamic, and constantly influenced by social and individual contexts. Self-disclosure of sexual orientation is a subjective experience with perceptible social consequences. Qualitative research methods allow for the exploration of subjective experience and the examination of process.

Grounded theory does not begin with a pre-established theoretical framework; instead, a grounded theory researcher seeks to generate a theory that explains a process of human behavior or a social interaction that is anchored in social and situational context (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Since the focus is human behavior, individuals who have experienced the interaction of interest are sought as participants. Nursing research uses a narrower problem lens and requires more detailed analytic procedures than described by Glaser and Strauss (Benoliel, 1996), so the grounded theory method outlined by Strauss and Corbin (1998) was used in this study.

Strauss and Corbin (1998) portray grounded theory inquiry as having two primary aspects: asking questions and making comparisons. Asking questions is a multifocal process consisting of collecting data from participants through questioning and interrogating the data to build categories, concepts, process, and theory. The researcher constantly questioned the data and sought to learn as much as possible through sensitizing questions that helped determine who, what, where, when, how, and with what consequences. One sensitizing question would be: What is your definition of "selfdisclosure?" Guiding questions were used to structure interviews and gave direction to data analysis. Guiding questions changed over time as the theory developed. An example of a guiding question was: Have you ever self-disclosed to a nurse, and if so, what was that experience like for you? *Practical questions* provided direction for sampling and assisted in identifying underdeveloped concepts and category saturation. A very practical question was: Have I interviewed anyone who had a positive or negative self-disclosure experience? Theoretical questions highlighted process and helped the researcher connect concepts to make relational statements. One potential theoretical question was: How does self-disclosure change over the course of a hospitalization? Questioning was intimately linked to analysis through making comparisons.

Constant comparative analysis is used to make comparisons between available data, the structure of the evolving theory, and data needed to further theory development (Strauss & Corbin, 1998). By making comparisons, a researcher identifies process and links concepts to form a grounded theory. Process is identified through coding, which surfaces the core phenomenon, the causal conditions related to the core phenomenon, the strategies used during interaction, and the consequences of strategies. The final outcome

of coding is a delineation of the process of interest, often written as a "storyline memo" (Strauss & Corbin, p. 150). Comparisons are used to uncover variation and patterns in categories, to link concepts in the emerging theory, and to trigger researcher reflexivity. Asking questions of the data and making comparisons culminate in the generation of a theory grounded in social and situational context.

Grounded theory researchers must remain open to what the data reveals and sensitive to the words and actions of participants (Strauss & Corbin, 1998). The elements of Strauss and Corbin's approach that were applied to this study of lesbian self-disclosure of sexual orientation in acute care are depicted in Figure 1.

Grounded Theory Inquiry

Lesbian Self-Disclosure of Sexual Orientation in Acute Care Asking Questions Guiding questions: What is the process of **Making Comparisons** lesbian self-disclosure of sexual orientation in acute care? Interviews **Identify process:** Core phenomenon Causal conditions Strategies Sensitizing questions from: Consequences Previous interview data "Story" of process Code notes Personal journal Accessing literature Constant Comparative **Analysis Practical questions from:** Link concepts: Previous interview data Form substantive-level Sampling theory of lesbian self-Memos disclosure Diagrams Theoretical questions from: Previous interview data Theoretical notes Diagrams Accessing literature

Figure 1. Neese, R. (2009). Grounded theory approach to lesbian self-disclosure of sexual orientation in acute care. Adapted from Strauss and Corbin, 1998.

Ethical considerations. Ethical considerations are integral to any qualitative study and require careful attention when participants are from a vulnerable population. The researcher must remain open to multiple voices and avoid intentional or unintentional exploitation of marginalized participants. This researcher obtained Institutional Review Board (IRB) approval for this study and obtained informed consent (Appendix A) prior to study participation. She informed individuals that participation was completely voluntary, that they might withdraw from the study at any time without penalty, and that confidentiality would be maintained. Consent forms were kept in a locked file cabinet in a home office separate from demographic surveys and transcripts. Participants selected a pseudonym. Pseudonyms were attached to consent forms or demographic surveys to prevent linking a particular participant to specific data. Data from this study were reported in aggregate form to maintain participants' confidentiality.

Audiotapes were transcribed verbatim by the researcher. Due to the sensitive nature of investigating self-disclosure of sexual orientation, data handling and storage were given high priority. Audiotapes were transcribed exclusively by the researcher and destroyed immediately after transcription was complete. The researcher checked each completed transcript for accuracy by listening to the audiotapes and making corrections to the text. Transcripts, field notes, memos, and survey data will be stored for three years in a locked file cabinet in the researcher's home office. All data will be destroyed by shredding at the end of the three-year period.

After the debriefing, each participant was asked about interest in confirming study findings. If interest was expressed at three months post-interview, the participant was offered a choice of receiving preliminary findings by email or via postal mail in a self-

addressed stamped envelope. Any contact information provided was stored separately from transcripts and demographic surveys in a locked file in a home office. An email account established exclusively for this study was password-protected and closed at the study conclusion.

The participants' risks of involvement in this study were minimal and included emotional upset from unpleasant memories of health care experiences, emotional upset from thinking about what one did or did not tell the researcher, unintentional outing if news of participation left the sampling network, and feeling tired after the interview. The following procedures were used to minimize these risks: conducting the interview at a time and place convenient for participants, briefly stopping taping, debriefing after the interview, telephone contact from the investigator three days after the interview, providing a written list of community counseling services, referral for support if needed, and strict observance of privacy.

The only direct benefit to study participants was the receipt of a \$25 grocery gift card for keeping a scheduled interview appointment. The study findings may benefit lesbians as a whole through modifications in acute care nursing practice prompted by this substantive-level theory development. Participants who kept a scheduled interview appointment received a \$25 grocery gift card regardless of whether they completed the interview. After they signed the informed consent, participants received a free list of available community referral sources (Appendix B) in the event they experienced emotional difficulty at the three-day follow-up.

Sample. Purposive and theoretical sampling methods are used in grounded theory (Strauss & Corbin, 1998). Purposive sampling is used to obtain participants who have

experienced the domain of the study, and theoretical sampling is driven by the concepts identified in the emerging theory. Theoretical sampling allows the researcher to "densify" (Strauss & Corbin, p. 158) or identify all the relevant properties and dimensions of a category, to maximize variation, and to increase the explanatory power of the emerging theory. Through theoretical sampling, the researcher strives to increase the depth and breadth of data used for comparative analysis.

During theoretical sampling, the researcher strove to find different perspectives on lesbian self-disclosure of sexual orientation in acute care. Individuals with a variety of acute care experiences were sought, including those with inpatient hospital admissions for childbirth, illness, injury, surgery, or mental health issues and those who made visits to an Emergency Department (ED) for any reason. Initial participants were encouraged to refer individuals who did and did not self-disclose during an acute care experience so that a greater depth of data could be achieved. The interview guide was modified based on emerging concepts and categories. While the general overview question remained the same, follow-up probes asked of later participants were guided by the results obtained from coding previous interviews. Data included in theoretical sampling included interviews, observational notes, relevant hospital policies, and the professional literature.

Recruitment. The initial participants were a purposive criterion sample of four women known to the researcher prior to the initiation of this study (Creswell, 2007). Using snowball sampling, initial participants were asked to refer other individuals who met the study criteria (Speziale & Carpenter, 2007). Each initial participant was provided with three cards that gave the researcher's name, contact information, and study purpose (Appendix C). These same cards were given to the referrals by the initial participants.

The referrals were then free to contact the researcher or to dispose of the card. Detailed recruitment flyers with the study criteria and the researcher's contact information (Appendix D) were posted in a local lesbian organization, two chapters of Parents, Families, and Friends of Lesbians and Gays (PFLAG), and a variety of public places, such as Publix and Winn-Dixie supermarkets. The local lesbian organization is found at Compass: The Gay & Lesbian Center of the Palm Beaches in West Palm Beach. The PFLAG chapters are in Vero Beach, FL and Port Saint Lucie, FL. A sample letter requesting permission to post or distribute recruitment flyers is located in Appendix F.

Potential participants were able to contact the researcher by telephone or email.

Once contacted by a potential participant, the researcher provided preliminary information regarding the study via telephone or email and ascertained the individual's desire to participate. If an individual expressed an interest in participating in the study, a mutually agreeable time and location (university conference room, community center) for data collection were established.

Before data collection began, each individual received full verbal and written information regarding the study. Participants were allowed to ask any questions.

Informed consent forms (Appendix A) were obtained once the potential participant was fully informed and verbalized a desire to participate in the study. Each participant received a copy of her informed consent. A list of relevant community referral sources was provided to the participant after the consent form was signed (Appendix B).

The researcher planned to interview a maximum of 25 individuals and to gather data until category saturation was achieved. Category saturation is reached when no new information surfaces during coding (Strauss & Corbin, 1998). The planned sample of 25

individuals was within the number of participants recommended for a grounded theory study (Creswell, 2007).

Inclusion criteria. Participants were women over 18 years of age who self-identified as lesbian or gay, who spoke English, who lived in southeastern Florida, and who were interested in participating in the study. Participants had personally experienced inpatient acute care hospitalization or an ED visit. The hospitalization or ED visit was within 12 months prior to this study to allow the individual to vividly recall experiences of self-disclosure of sexual orientation.

Exclusion criteria. Exclusion criteria included men, individuals under 18 years of age, women who did not self-identify as lesbian or gay, individuals who could speak English, individuals who did not live in southeastern Florida, individuals who had not experienced inpatient hospital admission or visited an ED, and individuals who were hospitalized or had an ED visit more than 12 months prior to the study.

Interview questions. Strauss and Corbin (1998) view the purpose of interviews in grounded theory as a means of accessing knowledge about a process through participants who have experienced the process. Interviews are one of many data collection methods cited by the authors as appropriate for grounded theory. Strauss and Corbin do reiterate that questioning is crucial to theory development, whether the questions are posed to a participant during an interview or are pondered as the researcher analyzes data. Interviews are used to follow the conceptual threads of the emerging theory, and questions put to participants will change over time depending upon the stage of analysis.

The constantly shifting iterative process of analysis makes the researcher as instrument a prominent characteristic of grounded theory. The researcher is interviewer,

observer, analyst, and theory developer and participates in all aspects of the study. The researcher must maintain an objective stance while using questions to surface process, variation, concepts, and interrelationships among concepts. Initial participants tell a broader story or their experience, while theoretical sampling and guiding questions lend a different focus to later interviews. A semi-structured face-to-face interview process was used. Open-ended, neutral, clarifying questions facilitated the interview process. The interview guides used to assist participants in describing their self-disclosure experience are provided in Appendix E. As analysis and theoretical sampling progressed, interview guide questions evolved. To encourage the participant to describe the experience of lesbian self-disclosure, the researcher used probing techniques such as silence, motivating phrases and gestures, asking for examples, and nonverbal attending skills.

Demographic data. Participants were asked to provide limited demographic data upon completion of the informed consent. Information on participant age, ethnicity, and level of education; presence of children in the household; whether participant had a hospital admission or an ED visit; and the number of a participant's admissions or visits was obtained (Appendix G). The data were used to describe the sample.

Data collection procedures. The researcher completed a Barry University

Institutional Review Board (IRB) application. Data collection began upon IRB approval.

Eligible individuals were informed of the study and asked to complete a consent form

(Appendix A). After written informed consent was obtained, the participant was asked to complete the demographic questionnaire. When the questionnaire was completed, interviewing began.

A semi-structured face-to-face interview was conducted with each participant in a mutually agreed-upon setting. The anticipated length of the interview was individually driven but did not last more than two hours. Data were collected by audiotaping the interviews. Observational field notes were used to capture the context and conditions of the interview. Additional data sources from professional literature were added during the study as determined and directed by the emerging theory.

Each interview began with a general question about the participant's acute care experience. Following this general disclosure, the researcher questioned the participant regarding experiences with acute care and health care providers (HCPs), particularly those relating to disclosure or nondisclosure of sexual orientation. The interview guides (Appendix E) and topics that emerged during the interview directed questioning. The interview guides evolved and questions were added as analysis showed a need for gathering more information about a concept or category.

A debriefing was offered at the conclusion of the interview. The debriefing script is in Appendix H. Each participant was asked if the researcher might contact her by telephone or email at three days post-interview to inquire if any uncomfortable feelings or emotional distress had occurred since the interview. If a participant reported emotional or psychological distress at the three-day post-interview contact, she would have been urged to follow up with a personal mental health provider or one of the resources provided when the consent form was signed. No participants reported any distress after the interview.

After the debriefing, each participant was asked about interest in confirming the study findings. If interest was expressed, at three months post-interview the participant

was offered a choice of receiving preliminary findings by email or via postal mail in a self-addressed stamped envelope. Any contact information provided was stored separately from transcripts and demographic surveys in a locked file in a home office. An email account established exclusively for this study was password-protected and closed at study conclusion.

Audiotapes were transcribed verbatim by the researcher. Due to the sensitive nature of investigating self-disclosure of sexual orientation, data handling and storage were given high priority. Audiotapes were transcribed exclusively by the researcher and destroyed immediately after transcription was complete. The researcher checked each completed transcript for accuracy by listening to the audiotapes and making corrections to the text. Transcripts, field notes, memos, and survey data will be stored for three years in a locked file cabinet in the researcher's home office. All data will be destroyed by shredding at the end of the three-year period.

Data analysis. Data analysis begins as soon as data collection starts in grounded theory studies (Strauss & Corbin, 1998), and analysis for this study through code notes, memos, and reviewing the field notes began at the conclusion of the first interview. Memos were used to augment the data with analytical ideas, to record researcher ideas and pre-existing assumptions, and to record the data analysis process. Figure 2 depicts the analytic process planned for this study.

Data Analysis Pathway

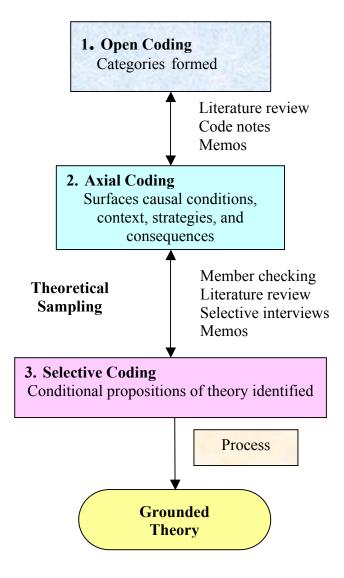


Figure 2. Neese, R. (2009). Data analysis pathway for a grounded theory study adapted from Strauss and Corbin (1998).

The researcher transcribed each interview verbatim and reviewed each transcript line-by-line using the constant comparative method while listening to the audiotape to initiate open coding. A qualitative perspective suggests that silences, hesitancies, emotion, and intensity in speech are just as important as words (Creswell, 2007). These

strategies were used to identify the concepts used by participants to label phenomena associated with disclosure or nondisclosure of sexual orientation in acute care. As concepts proliferated, analogous concepts were grouped into categories using the words of participants as labels. Categories represent matters of importance to participants. Categories were examined for properties, or attributes. Properties were then dimensionalized, or placed on a continuum of "more-less, is-is not." Data collection and coding continued until category saturation was achieved.

As the interviews and memo writing continued, open codes proliferated, allowing the start of axial coding. This level of coding assembles the data in new ways to allow a central phenomenon to emerge from the data and explores causal conditions, context, strategies, and consequences surrounding the central phenomenon (Strauss & Corbin, 1998). Incoming data was constantly compared with existing data to determine similarities, differences, and gaps in the data. Additional literature review was incorporated here, and emergent fit was used when a concept from the literature that fit the data was identified (Schreiber, 2001; Strauss & Corbin). Member checking commenced by having willing participants confirm the "fit and grab" (Wuest & Merritt-Gray, 2001, p. 168) of findings during axial coding. Member checking began three months after the first interview was transcribed.

As axial coding defines the core phenomenon, selective coding will begin to establish conditional propositions of the theory (Strauss & Corbin, 1998). Selective coding was used to identify the process of lesbian self-disclosure of sexual orientation in acute care. Theoretical sampling was used to test propositions in the emerging theory and identify negative cases. When selective coding was complete, a theory that fit the data,

that was recognizable to participants, and that explained the process of lesbian self-disclosure in acute care settings was generated. The theory was shared with study participants to check for "fit and grab" (Wuest & Merritt-Gray, 2001, p. 168) in an ongoing process that began with axial coding.

Reflexivity is a dynamic process of continuous critical self-reflection used to acknowledge researcher bias and positionality, to make values explicit, and to embrace the subjectivity of knowledge construction throughout every stage of the research process (Finlay, 2002; Lincoln & Guba, 2000; Patton, 2002). Reflexivity requires a conscious examination of how an investigator's perspective influences problem choice, participant selection, data analysis, and reporting findings. Engaging in reflexive process enhances rigor and prepares the researcher for recognizing and coping with ethical tensions that arise from interpersonal interactions in the research setting (Guillemen & Gillam, 2004). Reflexivity was addressed through several avenues. A personal reflective journal was used to record the researcher's feelings and reactions to interviews. Memos were used to record and challenge my suppositions. The researcher attended closely to the voice of participants and used their words as coding labels. Before writing the findings, the researcher carefully considered how words can be used to support or repress sexual minorities.

Research rigor and trustworthiness. Rigor and trustworthiness in qualitative research have recently been sources of extended debate (Creswell, 2007; Speziale & Carpenter, 2007). Postmodern and poststructuralist perspectives have called for transgressive validities that simultaneously acknowledge multiple realities and deny the possibility of a knowable "truth" (Lincoln & Guba, 2000). With its roots in pragmatism

and symbolic interactionism, grounded theory does not accommodate postmodern concepts of validity. Therefore, this study used the types of rigor and criteria for trustworthiness described by Lincoln and Guba (1985; 2000).

Rigor. Rigor has been defined as the cogency of findings, or how well results represent the thoroughness of methods and the reality described by participants (Lincoln & Guba, 2000). Lincoln and Guba defined two types of rigor: methodological and interpretive. Methodological rigor refers to how well the researcher followed the process of a chosen qualitative method. Some requirements include a naturalistic setting, purposive sampling, the researcher as instrument, emergent design, and an iterative process of data collection and analysis. To meet methodological rigor, this study used face-to-face engagement with participants, purposive sampling of lesbians who have experienced acute care, the researcher as instrument, constant comparative analysis, and an emerging sampling design. Interpretive rigor requires authenticity, or that results be recognizable as a reality to both the researcher and the participants. This study paid meticulous attention to analysis through accurate transcription of audiotapes, code notes, memos, and diagrams to enhance interpretive rigor. Member checking of preliminary results and engaging in reflexive process by the researcher were used to facilitate interpretive rigor.

Trustworthiness. Lincoln and Guba (1985) considered trustworthiness a way to evaluate qualitative research. Trustworthiness refers to the confidence that a reader of a research report may have in applying the findings. It is the judgment of consumers of research that determines the trustworthiness of a study. Investigators may enhance the

trustworthiness of a qualitative study by attending to four criteria—credibility, transferability, dependability, and confirmability (Lincoln & Guba).

Credibility. Credibility means results are convincing and plausible, or that the researcher has woven a compelling case that findings accurately represent a co-created reality recognizable to participants. Methodological and interpretive rigors affect the credibility of qualitative research. Credibility is enhanced by prolonged engagement with the data, persistent observation used to discover variation, and triangulation of data sources (Lincoln & Guba, 1985). The rigorous analytic process of grounded theory was used in this study to provide prolonged engagement with data; to facilitate persistent observation through coding and theoretical sampling; and to access multiple data sources including interview transcripts, memos, observational notes, and the professional literature. To further enhance the credibility of findings, two qualitative techniques referred to as member check and negative case finding were used (Lincoln & Guba). Member check was accomplished by having willing participants review preliminary results for accuracy of representation of the process of self-disclosure of sexual orientation. Negative case finding builds explanatory power and is an integral part of axial and selective coding in grounded theory analysis (Strauss & Corbin, 1998). Participants were encouraged to refer others whose acute care experiences may not have matched their own encounters.

Transferability. Transferability refers to the likelihood that qualitative study findings can be applied to another similar situation (Lincoln & Guba, 1985). It is incumbent upon the consumers of research to determine whether findings fit their context. Thick description of the research context and underlying assumptions facilitates

transferability. Direct quotes were used to support researcher-identified causal conditions, strategies, and consequences. Thick description was used to provide conceptual detail and tell the story of the theory. A diagram of the theory was included in the final report.

Dependability. Dependability is closely linked to credibility in qualitative research and refers to the process of research as manifested in a particular study (Lincoln & Guba, 1985). If attention to rigor produces credibility, attention to process enhances dependability. The research process must be logical, traceable, and documented (Schwandt, 2001). Grounded theory as described by Strauss and Corbin (1998) requires exhaustive documentation with discrete, progressive steps traceable through the analytic process. To establish dependability, audit trails were made available to the dissertation committee. Data trails included observational notes, code notes, memos, interview transcripts, diagrams, documents, and the text of the final product.

Confirmability. Confirmability is analogous to the quantitative concept of objectivity (Lincoln & Guba, 1985). Confirmability refers to neutrality, or the degree to which biases, assumptions, values, worldviews, and theoretical orientations influence data interpretation and research findings. Although the biases of the researcher are an important consideration, Lincoln and Guba remind investigators that participants also bring biases, assumptions, and values to the research context and that these presuppositions must be acknowledged. All external influences on interpretive rigor must be subjected to critical reflection and to an assessment of whether another researcher would obtain the same results. Confirmability was established through the researcher's use of a personal reflective journal and documentation of all grounded theory activities. Negative case finding was used to examine the range of variation in concepts and

potential participant biases. The dissertation committee served as expert consultants to guide the researcher in theory development.

Summary

The design of this grounded theory study was based on the method described by Strauss and Corbin (1998). The researcher asked questions of participants, interrogated the data, and made comparisons to generate a substantive-level grounded theory of lesbian self-disclosure of sexual orientation in acute care. Purposive and theoretical sampling guided data collection and analysis. The researcher used code notes, memos, diagrams, and the professional literature to assist in surfacing causal conditions, context, strategies, and consequences of lesbian self-disclosure. The researcher's reflexivity was aided by the use of a reflective journal and memos. The researcher attended to rigor and trustworthiness during the research process in an effort to generate a theory of lesbian self-disclosure of sexual orientation in acute care that fits the data, grabs participants as an accurate portrayal of the process they experienced, and works when used to explain the behavior encountered in this study (Glaser & Strauss, 1967).

CHAPTER FOUR

Findings of the Inquiry

The purpose of this study was to develop a grounded substantive theory to describe the process involved in lesbian self-disclosure of sexual orientation in acute care settings. A central category of personal risking was identified. Personal risking was a two-stage process used by lesbians in acute care settings to manage fear surrounding self-disclosure.

During the analytic literature review, the researcher found a grounded theory study by Hitchcock (1989) that investigated the process used by lesbians in deciding whether to self-disclose sexual orientation to primary health care practitioners (HCPs). Many of the terms used in the current study were adapted from Hitchcock's work as the concepts and categories uncovered were comparable to those she defined. While not recommended by Strauss and Corbin (1998), the authors stated that a concept might so closely fit the data that it is acceptable to use a concept used by another researcher. In this study, attempting to apply a different label often felt more forced than using Hitchcock's term. This chapter presents a descriptive profile of the participants and describes the central category of personal risking.

Descriptive profile of the participants. This study included 12 women who self-identified as lesbian and had recent acute care experiences, either as a hospital inpatient or in the emergency department (ED). Despite a general assumption that South Florida is gay-friendly, recruitment was more difficult and required more time than originally anticipated. Recruitment flyers were posted on a lesbian social forum; were posted in two gay community centers, one in West Palm Beach and the other in Wilton Manors; and

were distributed at meetings of Women In Network. This researcher passed out flyers at six gay-pride festivals and provided recruitment cards to participants. A grassroots lesbian health organization was identified in Broward County—ARROW: Area Resource and Referral Organization for Women: Targeting LBT Health (Targeting LBT Health is part of the organization's name for itself). This researcher attended three health fairs sponsored by ARROW. All of these recruitment activities met with limited success. Only two participants lived in the northern portion of the geographic area, St. Lucie County, and none were recruited from Martin County. Four participants lived in Palm Beach County, four in Broward County, and two in Miami-Dade County. Two participants were recruited by purposive sampling, and subsequent participants were recruited via snowball sampling.

Twelve interviews were conducted face-to-face in either the researcher's home or the participant's home and were tape-recorded. Participants chose to be identified by number, and sessions were numbered sequentially. Verbatim transcripts were sent to participants for member checking within three months of transcription. Only four participants responded to their transcripts. Those four participants did not request anything be deleted or corrected. Feedback comments consisted of "Yep, that's what I said" and "It all looks correct to me."

Participants represented a variety of demographics and health care experiences. Their ages ranged from 25 to 69 years. Demographic survey responses were detailed in aggregate form to protect confidentiality and to prevent identification of individual responses. Tables 1 through 4 detail participants' demographic characteristics. Table 1 depicts participants' age and ethnicity.

Table 1

Participants' Age and Ethnicity (n = 12)

Characteristic	Frequency	Percent
Age		
25-34	1	8.3
35-44	1	8.3
45-54	5	41.6
55-64	3	25.0
65 or above	2	16.0
Ethnicity		
African-American	2	16.6
White	10	83.4

Participants reported their highest level of education, their annual level of income, and whether they had children. Those with children were asked to report the number of children. All participants had attended college, and nine participants (75%) had earned a baccalaureate degree or higher. The majority of participants had yearly incomes above \$45,000 (83.3%). As expected, some participants (41.6%) reported having children, while others (58.3%) were childless. Table 2 depicts participants' level of education, level of income, and number of children.

Table 2

Participants' Level of Education, Level of Income, and Number of Children

Characteristic	Frequency	Percent
Highest Level of Education		
Some college (less than 2 years)	3	25.0
Baccalaureate	5	41.6
Masters	2	16.6
Doctorate	2	16.6
Level of Income		
\$20,000 to \$34,000	1	8.3
\$35,000 to \$44,000	1	8.3
\$45,000 to \$54,000	2	16.6
\$55,000 to \$64,000	1	8.3
\$65,000 to \$74,000	3	25.0
\$75,000 and above	4	33.3
Number of Children		
None	7	58.3
One	1	8.3
Two	2	16.6
Three	2	16.6

Participants were asked to report on the type of acute care they had experienced in the past 12 months—inpatient hospitalization or ED visit. Most participants reported single episodes of hospital admission or ED use, but others reported multiple episodes.

One participant indicated three ED visits and four hospitalizations in the previous 12 months. Table 3 details the number of ED visits and hospitalizations reported by participants.

Table 3

Participants' Number of ED Visits and Inpatient Hospitalizations in Past 12 Months

Characteristic	Frequency	Percent
Emergency Department Visits		
One	4	33.3
Two	2	16.6
Three	1	8.3
Not applicable	5	41.6
Inpatient Hospitalizations		
One	5	41.6
Two	2	16.6
Three	1	8.3
Four or more	1	8.3
Not applicable	3	25.0

Since many different types of HCPs may be encountered in acute care, participants were asked to detail the types of providers they had encountered during their acute care experience. Nurses were the most frequently encountered HCPs (91.6%), followed by physicians (83.3%). Participants were asked to write in providers who were not listed as choices under "Other." Three types of providers were listed under "Other: physician's assistant, occupational therapist, and anesthesiologist. Table 4 depicts the types of acute care providers that participants' encountered in acute care.

Table 4

Types of Acute Care Providers Encountered by Participants

Characteristics	Frequency	Percent
Nurse	11	91.6
Physician	10	83.3
Respiratory Therapist	2	16.6
Radiology Technician	5	41.6
Physical Therapist	2	16.6
Unlicensed Assistive Personnel	3	25.0

The final survey question asked participants if they were able to choose a hospital in advance of their visit based on the institution's reputation for being gay-friendly. Gay-friendly refers to an environment that is open, welcoming, nonjudgmental, and supportive of sexual minorities. Despite evidence in the maternal-child health nursing literature indicating that lesbians seek out gay-friendly hospitals (Renaud, 2007), 100% of

participants said they had not selected the hospital based on a gay-friendly reputation.

One participant explained her choice of hospital as: "I go where my doctor goes."

Another participant stated, "I'm lucky because I live in an area where the closest hospital is gay-friendly." The consensus was that participants went to hospitals where their primary care physicians had privileges, regardless of whether the institution was known to be gay-friendly.

In the following sections, the researcher discusses the substantive theory that emerged from the data. The Neese Theory of Lesbian Self-Disclosure in Health Care is presented. The theory has the central category of personal risking, which consists of the context of personal risking, the causal and intervening conditions, the central category, and the consequences of personal risking.

The context of lesbian self-disclosure in health care includes personal attributes of the participants and characteristics of the hospital domain and providers within that domain. The context is followed by descriptions of the causal and intervening conditions, which interact with the context and are antecedent to the central category. The central category of this theory, *Personal Risking*, is discussed using a schematic that depicts the two stages of *Personal Risking*, the anticipatory phase and the interactional phase. A discussion of the consequences of *Personal Risking* follows. Excerpts from participants' verbatim transcripts are included throughout the discussion to provide confirmation of the conclusions drawn by this researcher.

The Theory of Lesbian Self-Disclosure in Health Care. As used in this study, the term "agency" is defined as "the socioculturally mediated capacity to act" (Ahearn, 2001, p. 118), or the ability to personally assert power in a social interaction. As a

marginalized minority, lesbians lack power in many heterosexual social settings. Acute care settings are heteronormative in nature, meaning that lesbians are at a power disadvantage. Feeling powerless engenders fear of being seen as less than human.

Therefore, revealing a stigmatized identity is a risk. The working title for this theory was originally the theory of protecting agency. The title was revised during the dissertation defense.

According to *Merriam-Webster's Collegiate Dictionary*, "risk" is a noun that means the "possibility of loss or injury" (2001, p. 1008), so "risking" would mean engaging in an activity that could endanger the actor in some fashion. As used in this study, "personal risking" refers to actions taken by lesbians to mitigate their fear of self-disclosure. Through the process of personal risking, lesbians attempt to decrease their vulnerability to personal rejection and medical reprisals, to enhance psychological comfort, and to increase the likelihood of a safe acute care experience. The stages of personal risking are key to understanding the process of lesbian self-disclosure of sexual orientation in acute care.

The theory of lesbian self-disclosure in health care encompasses several areas that affect the process and outcome. These areas are components of the theory and are discussed sequentially. The context, the intervening conditions, and the causal condition interact—the context and the intervening conditions affect the magnitude of the causal condition. The conditions are antecedents to the two-stage process of personal risking. Through the process of *Personal Risking*, lesbians anticipate the possibility of self-disclosure, plan their interactional stance, and evaluate the interaction. Strategies to manage each stage are detailed, and the consequences of interactional stances provide

feedback that is incorporated into the anticipatory stage for the next episode of provider contact. The ultimate outcome of the process of personal risking is *Protecting Agency*.

According to Strauss and Corbin (1998), the conditions are circumstances that create the milieu surrounding a phenomenon and that provide a limited explanation for individual or group actions. Labels placed on the conditions, such as context, intervening, and causal are ways to delineate influence on actions or interactions. The contextual conditions are "the specific sets of conditions (patterns of conditions) that intersect dimensionally at this place and time to create the set of circumstances or problems to which persons respond through actions/interactions" (Strauss & Corbin, p. 132).

Context. The context in this study was provided by personal attributes of the participants and factors within the hospital domain. Several personal attributes that influenced the process emerged from the data. These were personal comfort with sexual orientation, relationship status, profession, and age.

Personal comfort with sexual orientation. Participants who were secure with a lesbian identity were more likely to self-disclose. Participant One described comfort with sexual orientation this way:

I learned a long time ago that people are not going to attack you because if you're comfortable with yourself and you put that out there, now let *them* be uncomfortable with that. Now it's not my problem, it's your problem. If you're yourself, then who's to judge you?

Participant Two stated "I am forthright with that information" in relation to her sexual orientation, and Participant Three asserted "I never was 'in the closet.' Never have a problem telling anyone my sexual orientation." In contrast, Participant Ten insisted, "I

would never disclose my sexual orientation. I wouldn't have told you if you hadn't asked. It's just not something you talk about." Participant Ten disclosed only to her primary physician and to no other HCP. No participants expressed a belief that being lesbian was sick or immoral, and most were comfortable with their sexual orientation. While interviewing participants who had disclosed to acute care providers, it became obvious that relationship status influenced disclosure.

Relationship status. Participants who were in an active relationship were more likely to self-disclose, especially if they were committed to a life partner. One of the first things Participant Eight did was present her marriage certificate to this researcher and state, "I've had a partner for thirty-seven years and she's always with me in the hospital. We have all the papers, including this marriage certificate. So far, we've never had a problem." Participant Nine illuminated the difference between being partnered and being single, "Having a partner would make disclosure more likely, otherwise you have to lie about who they are. Being single, I don't feel compelled to disclose my orientation. It would depend on the situation." All partnered participants were very clear that their partner was a significant other equivalent to a spouse; "She's not here as a friend, she's not here as a girlfriend, she's my partner," stated Participant Two. Disclosure was essential if the partner was to be accorded "family member" status and given access to protected health information and decision-making authority. As is explained in the next section, only the participant's profession inhibited self-disclosure if she had a life partner.

Profession. Participants had varied professional backgrounds. Two were nurses currently working in hospitals, two described themselves as homemakers, and one each was a lawyer, veterinarian, police officer, senior companion, president of a women's

sporting organization, middle-school teacher, accountant, and retired military officer.

Only the middle-school teacher and the retired military officer mentioned specifics of how their profession interfered with self-disclosure to HCPs. The teacher, Participant Nine, had disclosed only to her primary care physician and had requested that this information not be included in her chart:

I'm a middle-school teacher, so I have to be very careful at work or with anything that could get back to my job. My sexual orientation could be a source of disruption in my classroom and that could cost me my job.

Participant Twelve was a retired U.S. military officer who had never disclosed while she was on active duty because of the potential repercussions, "You know, it's just unacceptable in the military up until this point," she stated, "There's nothing they're gonna do to me, what are they gonna do—nothing. I'm retired, so that really has changed my outlook because there's nothing anybody can do to me because I don't work."

Participants who worked in professions where being known as lesbian would result in dismissal did not disclose in any health care setting where their employer could potentially have access to that information, even if they had a life partner or were middle-aged.

Age. Age had an influence on self-disclosure of sexual orientation in acute care settings. Generally, older women were more willing to self-disclose. According to Participant Eleven, "The closer I get to forty the less I care." There was some interaction between age and personal comfort with sexual orientation. Participant Seven phrased this as, "I think as you age you become more comfortable with who you are. You know, just being yourself." A similar sentiment was provided by Participant Eight. "Oh, I think

being older makes it easier to disclose. You get more comfortable in your own skin as you age, and you find that you just don't give a damn what other people think."

Participants were split on whether disclosure was easier for younger lesbians. The nurses and teacher believed that younger lesbians were less likely to self-disclose due to fear of ridicule or rejection, while other participants believed it was much easier for younger lesbians to self-disclose. Participant Ten stated, "The young ones today make too much out of it, running around telling everyone they're gay. Ridiculous."

Older lesbians who had a life partner were comfortable with their sexual orientation, and if they were in a profession that did not penalize sexual minorities, they were more likely to self-disclose their sexual orientation. Even the women who usually self-disclosed acknowledged that situational factors could influence their decision. The hospital domain presented situational factors related to provider characteristics and the health care environment.

The hospital domain refers to intrinsic attributes of the hospital environment.

These attributes included provider characteristics and the health care environment.

Subcategories of provider characteristics were personal and professional attributes of providers and familiarity of providers. Subcategories of health care environment were geographic location of the hospital, size of the hospital, and presence of heterosexism.

Personal and professional attributes of providers. Participants did not express a gender preference in relation to provider characteristics. Most of them described their primary care physician as male, and none mentioned gender in reference to nurses. No participant expressed a preference for lesbian HCPs. The personal provider attributes that emerged as important were verbal and nonverbal behaviors that conveyed acceptance of

the participant by the provider. Verbal behaviors included statements that indicated a nonjudgmental attitude, concern for the individual's dignity, and acknowledging the risk taken in revealing an alternate sexual orientation. Participant Eleven recounted her first visit with a new primary care physician:

I disclosed to him. What he said to me was, "Thank you for sharing that information with me, but that's not relevant to your file and I'm not going to write it down. If ever you or I think it's relevant to your care, we'll discuss it at that time." He wasn't saying it was off-limits to the discussion, and he certainly was very warm and open about it; but he just decided he wasn't going to write it down and shield me from any sort of office scuttlebutt. That was very thoughtful.

Participants also looked for providers' verbal overreaction or under-reaction to disclosure as indicative of acceptance. Ignoring the disclosure or one-word answers of "Oh" or "OK" were *not* viewed as accepting. Stuttering, stumbling over words, and other indicators of verbal stress were perceived as overreactions. Participants were looking for "professional behavior," verbal acknowledgment of the risk they took. They also expected providers to speak to a partner if one was present in the room as if the partner were a heterosexual spouse. Participant Two described one interaction in the ED, "The PA didn't even flounder when I informed him we slept in the same bed, he just kept talking to [partner]. The nurse stumbled and very quickly and abruptly left the room."

Nonverbal provider behaviors also conveyed rejection or acceptance. Abruptly leaving the room was perceived as rejection. The most common negative nonverbal behavior participants encountered was distancing, with a HCP becoming "standoffish" or

"hands-off." This behavior was described most often in nurses. When recounting interactions with the ED nurse caring for her, Participant Two stated, "As soon as she realized [partner] and I were a couple, she became a very hands-off, stand-backish type of a nurse and had very little direct patient contact with me. Very disturbing." Distancing behavior also included "taking extra precautions [gowns and masks in addition to gloves] like you're gonna give em AIDS."

Participants were very attuned to facial expressions. Direct eye contact, warm tone of voice, and smiling were perceived as accepting. Participant Eight stated, "I expect them to look at *me*." Participants described a range of facial expressions that conveyed rejection from open-mouthed gaping and frowning to "looking at you like you have horns coming out of your head, like you're not a normal person."

The important professional attributes that emerged were type of provider and participants' familiarity with HCPs. All participants had disclosed to their primary care physicians and gynecologists. Participant Three indicated self-disclosure was necessary and reasonable:

I would think that, uh, for health reasons it could possibly make a difference in decision-making, uh, knowing who your sexual partner is, you know, that it's crucial you let them know your sexual orientation. I highly recommend for health reasons that people disclose what their sexual orientation is. That you would want everyone to know as much about you as possible so that they could make good decisions about you, for the diagnosis.

Participant Five stated she had disclosed to her physician and surgeon "So they would talk to [partner] while I was under anesthesia in case anything went wrong. I want her to be able to make decisions without question or argument."

Nurses were notable by their absence from participants' narratives, despite nurses being the most frequently encountered acute care providers. If nurses were mentioned directly, it was as a source of anxiety or obstruction. Nurses were considered "unknowns" with unpredictable responses to self-disclosure. Participant Eleven shared. "I typically don't discuss my sexuality unless I have to with unknown health care providers. I always tell my family doctor and any specialists I have to see, the gynecologist, but I just don't do it with the unknowns." Nurses were viewed as enforcers of restrictive visitation policies that must either be tricked into allowing non-family visitors or be confronted with legal documents. Participant Seven described a common ploy used to circumvent restrictive visiting practices:

Like every hospital restricts visitors to family only, so I tell them my sister, Linda, will be visiting. One time, there were four friends in my room and the nurse came in and said, 'You sure have a lot of sisters named Linda.,' but she let everyone stay.

Participant One characterized the recurring narrative involving confronting nurses with legal documents in order to be with a partner:

She was hospitalized twice and my protocol is, because this is how we live our lives, I go to the safe in my house and get the documents. She goes to the hospital, I walk in, and they say 'You can't go in.' I go, 'Nope, here it is, here's

my medical power of attorney. She's unable to make decisions; I make it for her.' So they look at this and it's legal and they get kinda scared and go ok. I hate to use the phrase "beat them at their own game," but you know, it doesn't have to be that hard.

When nurses received positive recognition, the terms used were very general—"good," or "they did their job." Positive comments were very few, even when the participants were directly questioned about interactions with nurses.

knew at least some of the HCPs. The nurses and the police officer went to EDs where they were well-known to the staff. Participants who had scheduled elective surgery went to hospitals where their surgeons were well-respected and often had their "own nurses." Participant Five traveled to New York City for an orthopedic procedure because she was comfortable with the surgeon and his staff. When Participant Four was injured while out of town, she selected an ED where staff knew the friends who accompanied her. Participant Two stated, "I prefer providers that *know* me. My biggest fear is being away from my friends and my hospital and my people and having a situation, especially out of state. That's a big fear." The greatest fears were fear of rejection and fear of exclusion or being denied access to a partner labeled as "not family." Knowing at least some of the acute care providers provided a source of reassurance and comfort that participants would be treated professionally.

Participants were more likely to self-disclose to HCPs who maintained a warm, professional demeanor with appropriate eye contact, touch, and body language.

Providers' facial expressions and tone of voice were closely monitored for any indication

of rejection or disapproval. No preference for provider gender or sexual orientation was expressed. Participants had disclosed to their physicians, but disclosed to nurses only when questioned directly or when forced to confront restrictive visitation practices.

Familiarity with acute care staff was comforting, while encountering unknown staff was viewed as anxiety-producing and potentially threatening.

Factors within the health care environment of the hospital domain influenced participants' decision to self-disclose. These factors were the geographic location of the hospital, the size of the hospital, and heterosexism.

Geographic location of the hospital. When possible, participants went to a hospital in a geographic area reputed to be gay-friendly. In this study, that meant hospitals in Broward County; no other southeastern Florida locales had the same reputation. Participants also preferred hospitals in larger towns and cities to those in small towns. Even then, a location's gay-friendly reputation was no guarantee that a hospital would be open to alternative sexualities. Participant Twelve summarized geographic hindrances to self-disclosure: "One of them is a veteran's hospital and one of them is a small one in a small, close-minded town, and one of them is [hospital]. Although [city] is supposed to be so open-minded, it's not as progressive as it seems."

Size of the hospital. Hospital size and geographic location interacted. Though generally perceived as more open, large hospitals could be unfriendly to lesbians and small hospitals could be perceived as more supportive if participants were comfortable with the staff. Participants did view larger (300 plus beds) hospitals as more likely to be supportive of self-disclosure. Participant Seven stated, "I'm not comfortable with small

hospitals. Too easy for people to hear things you don't want them to hear. I prefer the larger one where my doctor goes, they seem to be more open-minded."

Heterosexism. Heterosexism refers to the patterns and rules used by institutions to reinforce stigma and its accompanying power differentials to oppress nonheterosexuals and to make sexual minorities invisible or targets for attack (Herek, Chopp, & Strohl, 2007). This condition was not identified in Hitchcock's (1989) original work. Items in the hospital physical setting were viewed as indicative of a supportive or a repressive environment. Registration demographic forms were condemned as not inclusive of sexual minorities; participants laughed when questioned about the forms. Participant Seven stated, "I would like to see admission forms that have 'partner' or 'significant other' as a choice." Participant Eight pointed out, "What would I say to some clerk if I was widowed [participant has a marriage certificate with her partner]? The next question is always 'What was your husband's name?' Well, my 'husband' is a woman!"

Participants wanted to see medical literature or educational brochures that acknowledged the existence of lesbian partnerships, especially for breast and ovarian cancer. "Even a photograph on one page of a female couple would be something!" according to Participant Nine. Participant Seven had a critique of post coronary angioplasty patient information. She had been hospitalized several times with cardiac issues and said, "The discharge pamphlets go on and on about when to safely resume sex, yet the assumption is it will be heterosexual intercourse! There is no printed information on when it's safe for lesbians to start having sex after a cardiac procedure."

Participants stated they would feel more comfortable if they saw a "gay cultural icon" somewhere in the hospital environment. As detailed by Participant Six:

When my friends and I are out around town, if we have a choice between two restaurants and one has a rainbow flag in the window, I'll say let's go here. I know if there's a rainbow flag there, I will be treated well. Seeing something like that in a hospital door or registration window would make me feel more at ease—even a nurse wearing a rainbow flag pin.

Other participants concurred that the presence of a rainbow flag would mark the environment as gay-friendly and provided several other comforting icons. The middle-school teacher mentioned the logo from an organization named GLSEN: the Gay, Lesbian & Straight Education Network, a stylized black-and-white figure with a hand raised as if answering a question. Participants Eleven and Twelve mentioned logos from the Human Rights Campaign (yellow equal sign on a square navy-blue background) and Equality Florida (green equal sign inside a green circle). Participants Six, Seven, Eight, and Eleven also included the pink triangle as an icon.

In summary, the context in this study was provided by personal attributes of participants and elements of the hospital domain. The personal attributes that emerged were personal comfort with sexual orientation, relationship status, profession, and age. Factors within the hospital domain were personal and professional attributes of providers and the health care environment. Older women who were comfortable with their sexual orientation, had a partner, and worked in a profession that did not penalize sexual minorities were more likely to self-disclose. Warm, professional providers who maintained good eye contact, a friendly tone of voice, and open body language encouraged self-disclosure. Participants looked for verbal responses that directly acknowledged the risk they took in self-disclosure and in requesting the presence of their

partners. Large hospitals in larger cities that displayed less heterosexism were considered safer for self-disclosure.

Intervening conditions. Intervening conditions "are those that mitigate or otherwise alter the impact of causal conditions on phenomena" (Strauss & Corbin, 1998, p. 131). The intervening conditions that interact with the causal condition in this study of personal risking are relevancy and sexual stigma.

Relevancy. Every participant used the word *relevant* when asked what factors affected their decision to self-disclose. Relevant meant that revealing their sexual orientation was pertinent to their health care needs or to guarantee a partner's participation in care planning. Participant Four stated, "I only disclose to people I don't know if my sexual orientation is relevant to my diagnosis or care, like a gynecological issue. Disclosing is not necessary in every health care situation." Participant Seven echoed this sentiment, "It would have to be relevant to my condition, like a gynecological problem. Not everyone on the cardiac floor needs to know I'm gay." Two participants defined relevant as "the need to know." Participant Ten insisted, "Only my doctor needs to know," while Participant Twelve stated, "That information is relevant if it applies to my medical treatment. It's not relevant if it doesn't apply to my care." Participants with life partners would disclose if met with staff resistance to permitting partner visitation or to including the partner in care planning. Participant Two was very matter-of-fact when explaining this: "She is my lifetime partner and anybody who comes in contact with me, caring for me, needs to know that she needs to be told and included in everything and not excluded." Figure 3 on the next page illustrates a sample audit trail for the category of relevancy.

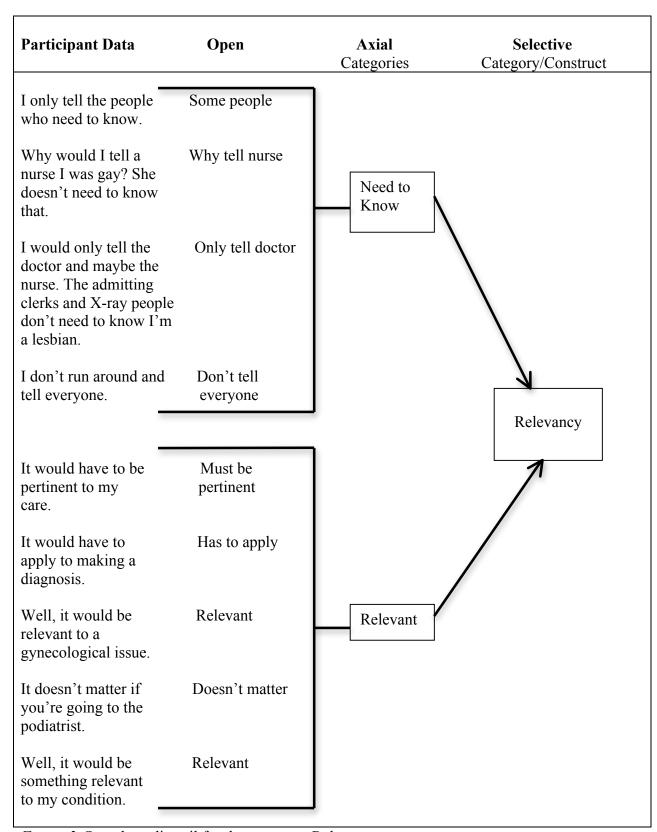


Figure 3. Sample audit trail for the category: Relevancy.

Sexual stigma. Sexual stigma refers to a societal-level belief system through which homosexuality is denigrated, discredited, and constructed as invalid relative to heterosexuality (Herek, Chopp, & Strohl, 2007). Heterosexism is the institutional enactment of sexual stigma. When heterosexuals internalize sexual stigma, it is called sexual prejudice, and when homosexuals internalize sexual stigma, it is called internalized homophobia (Herek et al.). This condition was not identified in Hitchcock's (1989) original work but emerged in this study. Sexual prejudice in HCPs and internalized homophobia in participants influenced the decision to self-disclose.

No participants reported direct verbal or physical confrontations with heterosexual HCPs in acute care. Instead, subtler nonverbal and verbal behaviors were perceived as indicating sexual prejudice and disapproval. As described previously, distancing and avoidance were viewed as evidence of heterosexual prejudice. Verbal minimizing of health concerns, refusing to verbally engage a partner in care-related discussions, and delays in meeting individual health care needs and information requests were considered signs of sexual prejudice. Participant Two explained her perception of sexual prejudice:

It's a problem in a health care setting, in an emergency room, where you should not be discriminating against anybody who comes through the door. It's still very much a problem. I think that you get, for some reason I think that we get—I don't want to say less consideration. It's almost as if your illness isn't as important to that person had you been a straight person in there experiencing the same thing. Participant Eleven recounted previous ER experiences similar to episodes witnessed by

this researcher in practice:

I have had bad experiences in the past in ERs, you know, where they ask you if you are sexually active and you say, "yes" and they say, "Well, let's give her a pregnancy kit or test her for STDs. And I'm thinking, yah, OK, pregnancy's not possible and STDs are unlikely. Um, and they fail to account for the fact that you could be a lesbian, you could be sexually active but not pregnant. That really seems to throw them for a loop. So I typically answer that question differently.

She went on to say that typically she answers no to avoid any hassle from ED staff.

Participant Twelve had experienced delays in care. "I had some instances where, um, they didn't want to move that fast. You know, they just didn't want to move. I wouldn't say that they mistreated me, but it was like I don't get equal treatment."

Internalized homophobia. Internalized homophobia implies an awareness of negative societal attitudes toward homosexuality, accepting these attitudes as deserved, and consequently feeling shame or embarrassment toward the self or other homosexuals (Herek, Chopp, & Strohl, 2007). All participants were aware of pervasive sexual stigma in society, but only one unquestioningly accepted the negative attitudes. Participant Ten vowed to "go to my grave without people knowing I'm lesbian." While not naming homophobia, Participant Three described it: "[Self-disclose] for psychological reasons, 'cause if you're holding back, it seems like you might have some kind of guilt or embarrassment or something. That you don't feel comfortable. I would think that you wanna feel comfortable." For Participant Two, her children and supportive coworkers helped her gain a measure of self-acceptance, "My children told me to just move on with my life and be happy." Many informants described feeling fearful of revealing their sexual orientation due to anticipated negative consequences from HCPs—"scorn,"

"judgment," "stereotyping," "ridicule," or "not getting the care I need." Negative feelings were grounded in perceptions of being viewed as an "other" or as "not normal."

Other participants related that they were aware of their own homophobia towards other homosexuals, those who were more "flamboyant" or "blatant." Participant One declared, "I am totally against all these people who are in your face about being gay. It's just not necessary." Another stated, "I just don't understand why these young girls have to run around wearing the 'lesbian uniform' [short hair, tattoos, masculine clothes] and pushing their gayness on you. I'm tired of it. It makes us look pushy and obnoxious."

The intervening conditions of relevancy and sexual stigma influenced participants' decisions to self-disclose. They were more likely to disclose if they believed sexual orientation was relevant to obtaining accurate diagnosis and effective treatment or to insuring the participation of a partner in their care. Sexual stigma impacted self-disclosure through sexual prejudice and internalized homophobia. Participants who perceived more sexual prejudice from HCPs or described more internalized homophobia in themselves were less likely to self-disclose.

Causal condition. Causal conditions "usually represent sets of events or happenings that influence phenomena" (Strauss & Corbin, 1998, p. 131). In this study, the causal condition of fear heavily influenced the personal risking process.

Fear. The word fear appeared frequently in participants' narratives—fear of ridicule for being a lesbian, fear of homophobia, fear of stereotyping, fear of ostracism, fear of receiving subpar nursing or medical care, and fear of revealing a stigmatized identity. Participant Two stated, "There is a fear of retribution, a fear of not getting the same kind of care a heterosexual is going to get." Participants described contemplating

the need for self-disclosure as anxiety-provoking and a decision that required very careful situational evaluation. Participant Six advised, "You need to be truthful, but careful at the same time. Always assess the setting before you disclose because sometimes it's just not safe." *Safe* and *unsafe* were words participants used when quantifying fear. Safe meant contextual and intervening conditions were optimal for self-disclosure—a warm, accepting HCP in a supportive setting where self-disclosure was relevant, sexual stigma was minimal, and information disclosed about sexual orientation would be treated with discretion. Participant Twelve defined safe as:

When I go in for treatment I don't have to worry about monitoring the medications I'm being given and I don't have to worry about whether the doctors are treating me fairly because of my race, my ethnic background, or my sexual preferences. And they are sensitive to my sexual orientation and what my preferences are religiously and otherwise. And it just doesn't happen all the time. It hasn't happened.

Unsafe meant contextual and intervening conditions did not support self-disclosure—scornful or judgmental HCPs in a heterosexist setting where self-disclosure was irrelevant or might garner retribution due to pronounced sexual stigma. Participant Eight referred to this latter instance as "running across some psycho" and advised that lesbians in that setting should lie about their sexual orientation to maintain their safety.

Core category. A participant's level of fear directly influenced her perception of whether it was safe to disclose her sexual orientation. The core category of personal risking was used to manage the fear of self-disclosure to acute care providers. This two-stage process consists of an anticipatory phase where a participant would calculate the

risk involved in self-disclosure and an interactional phase where an interactional stance was chosen and the results of this choice were evaluated.

Anticipatory phase. In the anticipatory phase, the risk of self-disclosure is calculated using imaginative and cognitive strategies. Lesbian participants may not have been conscious of all of these strategies but used them on an unconscious level. The imaginative strategy was the development of *imagined scenarios*.

Imagined scenarios. Lesbians first developed imagined scenarios, a mental image of the acute care environment, of the providers they were likely to encounter, and of what might happen if they disclosed their sexual orientation. These imagined scenarios were often difficult to articulate and seemed to be dichotomized into positive and negative expectations. Participants who were secure in their sexual identity were more likely to envision positive outcomes to self-disclosure. For example, Participant Five said, "I just go in there with a positive outlook, that everything will be fine and everyone will be professional." In contrast, Participant Eleven stated, "I assume they will treat me differently, like I'm unusual or not normal and avoid me or start whispering about me to other staff;" and Participant Twelve recounted, "I get it in my head that they are going to be difficult and give me grief about my partner coming in where I'm being prepped."

Not every lesbian in this study used imagined scenarios. All participants used cognitive strategies. Three major cognitive strategies were employed: *formalizing*, *screening*, and *rallying support*.

Formalizing. In formalizing, lesbians worked within the existing legal system to give legitimacy to a long-term relationship. All participants with a life partner used formalizing by obtaining all legal documents available to them to guarantee the

recognition of their right to make medical decisions for an incapacitated partner.

Documents included medical power of attorney, health care surrogate, living will, and in one instance, guardianship papers. Participant One said, "We went to an attorney and we literally paid out \$1,000 to make sure all those loops and holes were covered, and the documents are safe in my house." Participant Eight and her partner had traveled to Massachusetts for their wedding because that state grants a marriage certificate to gay and lesbian couples that is identical to the certificate issued to heterosexual couples. The overarching concern was being barred from making health-related decisions for a partner or even prohibited from visiting a critically ill loved one. Participant Five was emphatic when she said, "We signed guardianship papers for each other because I want there to be *no* question that we are a couple and expect to be treated like any other married couple in a hospital." Even with all legal documents in place, some lesbians had experienced instances of resistance to allowing a partner to visit or to make decisions for them.

Participant One summarized why formalizing was so important to lesbians:

This was part of a conversation I had with somebody at the hospital last night. When we were discussing civil unions or gay marriage, I said you need to realize why we are fighting so hard for this is the legality of the thing. Because if I was critically injured and put in the hospital, my partner could not come in according to the standards and laws of the hospital and Florida. So that's why my life is a little bit different, and thank God I think about all this stuff.

Screening. When using screening, lesbians interviewed providers regarding their attitudes toward lesbians and whether an alternative sexual orientation would interfere with their ability to deliver safe, effective care. In this study, participants screened only

primary care physicians and relevant specialists prior to hospital admission whenever possible. Nurses and other ancillary health care providers were not screened prior to hospital admission or ED visits. Overall, participants had positive experiences with screening physicians. All had disclosed their sexual orientation to their primary care physician, and many had disclosed to specialists, such as general surgeons, orthopedic surgeons, rheumatologists, gynecologists, cardiologists, and fertility specialists. Participant Eleven recounted an experience with her new fertility specialist. She had changed physicians after having a negative encounter with her previous specialist:

I told the gentleman I had to switch; he shared with me that's very common.

That sometimes women just have different realities than doctors and I shouldn't be at all—upset at all. It happens all the time, and he didn't want me to give it a second thought.

Participant Twelve provided a lengthy story about how much she liked one of her surgeons because he always treated her kindly, spoke to her partner, and returned phone calls personally, "And he knows when he sees me, he's gonna see her and he's gonna ask about her and so it makes a difference." If physicians had overtly negative reactions to self-disclosure or seemed cold, participants looked for a new, more accepting doctor.

Rallying support. This strategy was used by lesbians who were not in a long-term relationship to insure that they would not be alone in the hospital. In rallying support, single lesbians informed many of their friends that they were to be hospitalized and arranged ways to circumvent restrictive visitation policies. As described previously, Participant Seven arranged for all her friends to call themselves her sister, Linda. Having female friends listed as "sisters" or "aunts" was the most common strategy used to bypass

limits on visitors. These friends could be other lesbians or heterosexuals, as long as they served as an advocate or a companion. Participants felt that support was vital because hospitals were "scary places" and being there alone as a stigmatized minority was just too frightening. Participant Six described this situation: "I'm terrified of being alone in a hospital anywhere! I need someone with me to feel safe." Participant Nine stated, "I need my friends around me to keep the negative people at bay. It's so important to have someone there." Friends assumed even greater importance if a single lesbian chose to self-disclose in an acute care setting.

Regardless of which identified strategies were used and of whether the process was conscious, at the conclusion of the anticipatory phase, lesbians had calculated their risk of self-disclosure. This information was then used to determine an initial *interactional stance* that was carried into exchanges with HCPs, where the interactional phase of personal risking begins.

Interactional phase. In this study, the interactional phase began with determining an interactional stance, or how the lesbian would approach self-disclosure with providers. Four interactional stances were identified. These stances were situational and could change to another interactional stance during a subsequent encounter with a different provider. Thus, the stances used by lesbians are not static but very dynamic, shifting based on antecedent conditions and calculated risk of each self-disclosure opportunity.

The four stances identified were (a) active self-disclosure, (b) passive self-disclosure, (c) passive nondisclosure, and (d) active nondisclosure. The majority of participants in this study used either active disclosure or passive disclosure when interacting with acute care providers. In active disclosure, a lesbian verbally affirms her

sexual orientation. With passive disclosure, a lesbian does not directly confirm or deny her sexual orientation, but provides clues that indicate her sexual orientation. Clues are also provided to the HCP with passive nondisclosure, but the clues are very subtle and the lesbian does nothing to assist the provider in deciphering the clues. Active nondisclosure involves "passing" as heterosexual; the lesbian actively hides her sexual orientation from providers.

Active self-disclosure. The majority of participants with life partners chose active disclosure as a stance. In active disclosure, a lesbian verbally states her sexual orientation to an acute care provider. The behavior usually occurred when legal documents were presented to confirm the legitimacy of a partner as a health care surrogate. Active disclosure could also be a self-initiated behavior if a lesbian was directly questioned about her sexual orientation. Participant Two provided an example of active disclosure:

I'm proud of being in a same-gender relationship. I'm not ashamed of it. I'm not going to hide it from anybody. It is what it is. I have no problem telling people right off the bat this is my significant other. If they know right up-front, ahead of time, it seems to alleviate all the uncomfortable feelings.

Participants Four and Five, who were partners, expressed similar sentiments. "We are very up-front about being partners. It saves time and grief." Other participants waited to self-disclose until nursing staff challenged a partner's presence. Participant One chose to self-disclose in response to questions. "Just lay it out there, ask me, and I'll tell you. Most people are afraid to ask."

Active disclosure did have situational elements, with most participants preferring to self-disclose to physicians prior to acute need and in a private, controlled setting.

Participant Eleven explained:

Probably, privacy made it easier. You know where you don't feel like you're telling the entire staff. It's pretty uncomfortable to do with just curtains drawn. I think for me it was being able to sit down with my doctor initially in a visit in the privacy of an office as opposed to, you know, no privacy and a curtain drawn. I've had that experience with my ex many times and it's just very uncomfortable. And sometimes I may have other family members in the room, and that becomes more uncomfortable to have conversations. Health care providers don't seem to know when it's appropriate. They'll ask your partner to leave the room, but they never think to ask your mother or your cousin to leave, you know.

Passive self-disclosure. Several study participants used passive self-disclosure as an interactional stance. In passive self-disclosure, a lesbian provides clues to her sexual orientation without straightforward verbal confirmation. A classic example was Participant Seven's four sisters named Linda as visitors; she never directly self-disclosed to the nursing staff. Participants choosing passive self-disclosure assumed that others could determine their sexual orientation from the way they lived or from the people who accompanied them. Participant Six stated, "I had my girlfriend with me the entire time and I never let go of her hand unless I had to. I'm sure the nurse must have known I was gay." Participant Seven explained: "You know, just being yourself. That's all you have

to do, just be yourself. You don't need to come out and say 'I'm gay,' you just be yourself."

Passive self-disclosers also assumed others could identify them as lesbians by their clothing or other body adornment. For some subcultures in the lesbian community, identification is possible because they may have similar short hairstyles, wear masculine clothing, have visible tattoos, and have multiple body piercings (Esterberg, 1996). This "uniform" applied to only one study participant. "In my younger days, you know, my clothes, my haircut would tell. But these days I think I'm pretty benign."

Passive self-disclosers would provide assistance to HCPs who could not decipher the clues if provider comprehension was relevant to further diagnostic testing or therapy. For example, in the vignette previously recounted by Participant Eleven, ED providers had assumed that she could be pregnant because she had admitted to being sexually active. A passive discloser would repeat that pregnancy was not possible until understanding dawned in the provider or until the lesbian became frustrated and self-disclosed. Frustration could also override a passive self-disclosure stance if staff were extremely resistant to a partner. This happened to Participant Twelve, who preferred passive self-disclosure. "I had to do that [self-disclose] one time in order to get treatment. She's my health care surrogate and power of attorney, so I don't usually have to say that. But one time they were so unreasonable I had to."

Passive nondisclosure. Passive nondisclosure closely resembles passive self-disclosure in that lesbians provide clues to their sexual orientation. In passive nondisclosure, lesbians will not provide hints to providers or aid provider comprehension of clues. Participant Eleven was the sole participant who used passive nondisclosure with

hospital providers. She was with her partner, who had power of attorney, but never openly discussed her sexual orientation with acute care providers. When asked to define passive nondisclosure, she stated, "Oh, just not saying much about my sexuality and not correcting any assumptions that are made." After her ED experiences, when questioned about being sexually active, she "answers that question differently" by denying she is sexually active. Participant Twelve defined passive nondisclosure as:

They just kinda walk around in a bubble hiding, and they never talk about it.

Not proactive, they're just not proactive about disclosing any information about their sexuality, and they don't believe that they play any role in how they have to live life. They don't take any ownership for their sexuality. They aren't bearing any responsibility for having to express who they are as a person.

Active nondisclosure. In active nondisclosure, lesbians engage in pretense by deliberately presenting themselves as heterosexuals or by not correcting HCP assumptions about their sexual preference. Participants Nine and Ten preferred this stance. Participant Nine chose this stance because of being employed as a teacher. She would have preferred another stance, but "being a teacher makes self-disclosure more difficult. I have to be very careful." She assumed a heterosexual identity whenever she was hospitalized. Participant Ten never used any other stance except when disclosing to a primary physician. She insured that her appearance met heterosexual expectations and never discussed her sexual identity with any HCP except her primary care physician. "I never discuss my sexual orientation with anyone in the hospital; it's none of their business." No one knew she was a lesbian except a very small circle of close friends who

had promised not to mention her sexual orientation to anyone else. Participant Twelve had been an active nondiscloser while on active military duty because disclosing as a lesbian would have meant losing her career and pension. Now retired, she was active in lesbian social activities and lobbied for equal rights for sexual minorities.

Evaluating interactions. All of these interactional stances could be situational, depending upon the calculated risk of self-disclosure and the lesbian's perception of safety. Positive provider interactions could prompt participants to use a more open stance, while negative provider responses often led to less self-disclosure by participants. Active self-disclosers were least likely to choose another stance unless they were convinced that their sexual orientation was irrelevant to the health care situation.

Scanning. Concurrent with determining an interactional stance but before actual provider interaction, participants used a scanning strategy. Scanning involved observing the health care environment and looking for indications of heterosexism or gay cultural icons. The physical environment and the people working in that environment were scanned for verbal and nonverbal cues connoting a safe or unsafe environment and/or provider. Cues included gay-oriented literature in waiting areas, the presence or absence of gay cultural icons, providers who made eye contact, and provider body language. Participant Eleven described scanning for a particular cue:

You know, I happen to be a Christian, but sometimes, you know, I'm a little bit loath to disclose if there are too many overtly Christian paraphernalia because it just seems to be, uh, a right-leaning mentality that is not accepting. So, I try. You know as a Christian I am not offended by these images, but it always makes me wonder if these are really welcoming health care providers.

Participant Twelve looked for posted declarations that stated "Proud to serve all people, regardless of race, gender, color, creed, or sexual orientation. She added, "It would mean the same thing even if there wasn't a rainbow flag."

Participants indicated that scanning was limited by acuity of need in a hospital or an ED setting. Severe illness or pain interfered with scanning, and participants with partners depended upon the partner's assessment of safety. Participant Eight stated, "My partner is a doctor and she's always with me, keeping an eye on them and making sure I get everything I need."

Monitoring. After an interactional stance has been implemented, monitoring starts. A lesbian observes and checks the responses of providers and the health care environment during the interaction to determine if it is safe or unsafe to disclose.

Monitoring is a continual process that is used during an entire hospital stay or ED visit. Participant Eleven described cues she watched for during monitoring:

Reactions which are either overly influenced by my disclosure or maybe reactions that are under-influenced, you know, by my disclosure. So I look to see if there's too much, you know. Because, you know, I hate to say it, but, you know it's kinda like people say, oh, you know, I'm not racist because some of my friends are Black. [Laughs]. I think the same thing in this case.

Several participants spoke of observing staff for distancing or avoidance behaviors.

Participant Twelve listened for "loud remarks to other staff members in the hallway."

Reevaluating stance. Information gathered during monitoring is used to reevaluate the interactional stance, and a decision is made whether to maintain a stance or change to another interactional stance. A lesbian who initially approached acute care

providers through active self-disclosure has no choice but to maintain the stance during the immediate interaction and has limited options in subsequent provider interactions during the same acute care episode.

Maintaining or changing stance. If an interactional stance effectively managed a lesbian's fear of self-disclosure and enhanced her perception of safety, she maintained that stance in subsequent provider interactions. If monitoring indicated a change in circumstances, with interactions becoming safe or unsafe, the interactional stance was modified. Providers that proved more accepting than originally anticipated could prompt a shift from passive nondisclosure to a self-disclosure stance. Strong staff resistance to permitting a partner to be present could shift passive self-disclosure to active self-disclosure as previously described by Participant Twelve. Judgmental or negative staff reactions to passive self-disclosure could result in a lesbian choosing one of the nondisclosure stances, as Participant Eleven chose to do in response to ED provider questioning.

Interactional stances could also change over time based on a lesbian's becoming more familiar with providers or a change in profession. Participant Twelve changed her interactional stance from active nondisclosure to passive self-disclosure after retiring from the military. Acute care settings became safer for self-disclosure because her career and pension were no longer at risk. The same participant has become more familiar with nursing staff on a particular hospital floor due to frequent surgical admissions by the same surgeon. She is more open with these staff members, "We tease and we laugh. I feel very secure when I am under [my surgeon's] care and I don't have to worry about treatment."

Lesbians who chose active or passive self-disclosure had to manage the consequences of their disclosure. This experience was then incorporated into the anticipatory phase to inform future interactions. Lesbians who did not disclose experienced consequences from remaining silent.

Managing consequences. The majority of participants viewed consequences as advantages or disadvantages, regardless of the interactional stance used in acute care. No participant experienced negligence or mistreatment as a result of disclosure. Most participants related positive outcomes to self-disclosure.

Advantages of self-disclosure were primarily psychological. Participants who self-disclosed viewed this choice as "being true to who you are." Participant Twelve described it as being "satisfied and happy in my own skin and then living in and walking in that skin as comfortably as I can." Self-disclosure relieved anxiety that surrounded hiding part of the participant's identity, "Not telling them I'm a lesbian is more stressful than telling them" according to Participant Eight. Disclosure also guaranteed the presence of a partner, regardless of initial staff resistance.

Self-disclosure brought advantages to medical diagnosis and treatment and to nursing care planning. Disclosure guaranteed that abdominal symptoms would not be attributed to pregnancy or the sexually transmitted diseases most common in heterosexuals. Participants were unanimous in stating that disclosing to a gynecologist was beneficial because "they can rule out certain things if you don't sleep with men." Self-disclosure permitted health counseling more closely attuned to lesbian health risks. For lesbians with partners, self-disclosure insured the inclusion of their partner in nursing care planning, patient teaching, and discharge planning.

The disadvantages of self-disclosure were psychological and care-related.

Psychological disadvantages were distress and disappointment when disclosure was met with scorn, rejection, disapproval, or sexual prejudice. Care-related disadvantages were delays in care because staff "just didn't want to move" and distancing or avoidance.

Sometimes, nurses became "standoffish" or "hands-off" after participants' self-disclosure. Two participants described having to change physicians when their self-disclosure was met by disapproval and reluctance to provide services. No participants reported requesting a change in nurses or a transfer to another unit after noting avoidance behavior.

The major consequence for nondisclosers was the stress of maintaining the charade. Participant Nine detailed the issues:

You have to be so careful about how to talk to visitors and what you talk about. You can't go on about so-and-so's partner and who went on vacation or who just bought a house together. I have to remember which name I told my friends to use and then remember to use it if there's a nurse in the room. And I have to make *very* sure there's no hint of homosexuality in relation to my job! Sometimes it's so hard. I can't wait to retire so I can be more open.

Summary

This chapter presented the characteristics of the study sample and the core category of personal risking that describes how lesbians manage the decision to self-disclose to HCPs in acute care settings in order to manage their fear, to maintain a perception of safety, and to obtain needed health care. Personal risking is a two-stage process with antecedent conditions that affect the decision to self-disclose.

Antecedent conditions were divided into two contextual conditions, two intervening conditions, and one causal condition. The two contextual conditions were (a) personal attributes of the individual lesbian and (b) factors within the hospital domain. Intervening conditions were (a) relevancy of the disclosure to health care needs and (b) sexual prejudice. The causal condition was fear; higher levels of fear decreased a lesbian's perception of safety and reduced the likelihood of self-disclosure. Lower levels of fear enhanced a lesbian's perception of safety and increased the likelihood of self-disclosure. The two-stage personal risking process was used to manage the fear of self-disclosure.

The first stage was the anticipatory phase, where the lesbian calculated the risk of self-disclosure using imagined scenarios and the cognitive strategies of formalizing, screening, and rallying support. Using the information and support gathered in the anticipatory phase, the lesbian moved into the interactional phase by determining a preliminary interactional stance.

In the interactional phase, there were four possible interactional stances: (a) active self-disclosure, (b) passive self-disclosure, (c) passive nondisclosure, and (d) active nondisclosure. Concurrently with selecting an interactional stance, a lesbian would be scanning the hospital environment and providers present within that environment for cues as to whether the HCPs would be open to her self-disclosure of sexual orientation. After the initial interaction with an HCP, a lesbian began monitoring provider reactions to reevaluate the preliminary interactional stance and to determine if that stance should be maintained or changed. She then had to cope with the consequences of her self-disclosure

decision. Figure 4 on the next page presents a detailed schematic of the Neese Theory of Lesbian Self-Disclosure in Health Care.

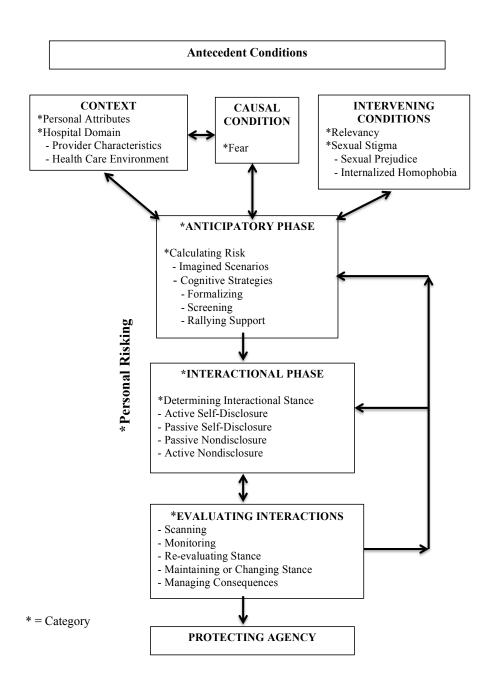


Figure 4. Theory of Lesbian Self-Disclosure in Health Care

CHAPTER FIVE

Discussion and Conclusion of the Inquiry

In this chapter, the researcher discusses the findings as they relate to the existing literature and the nursing profession. Consistent with the grounded theory method, the researcher returned to the literature to support analysis and to examine the analysis for comparisons and contrasts with the emerging theory. This chapter explores the meaning of the study. The grounded theory work of Hitchcock (1989) and a theory of stigma from psychology are described to put this research study in context. Implications of the findings and their significance to nursing, including the relevance for nursing education, practice, research, and public policy, are explicated. Strengths and limitations of the study are discussed and suggestions are provided for future study.

Exploration of the meaning of the study. In exploring the meaning of this study, the researcher viewed the investigation through a feminist research lens. Grounded in feminist theory, the tenets of feminist research are: investigators must self-identify as a feminist, and studies should be participatory in nature, should benefit women, should identify oppressive structures, and should have the potential to benefit participants (Parker & McFarlane, 1991; Reinharz, 1992). In feminist research, the oppressive structure of interest is gender relations. or the male/female dichotomy. The issue of gender relations is very broad in scope and influences interpersonal relations, values, social and political institutions, health care, art, literature, and indeed every facet of a culture defined by gender (Slife & Williams, 1995; Tong, 1998). Hierarchical power relationships, difference, context, and marginalized conditions linked to gender relations

are of particular interest to feminist investigators (Arslanian-Engoren, 2002; Francis, 2000; Liamputtong, 2007; Rosenau, 1992; Tong; Waugh, 1998).

Women have collectively suffered discrimination in health care (Ashley, 1980), so marginalized groups of women would have endured greater prejudicial treatment. Harding (1991) stated that lesbian lives are appropriate standpoints to guide research activity because they are marginalized and devalued, and because "the struggles that lesbians must engage in for survival can reveal regularities of social life that are invisible from the perspective of heterosexual lives" (p. 265). One of these regularities is the process involved in lesbian self-disclosure of sexual orientation to acute care providers.

This study did reveal a regularity of lesbian social life—the women's struggle to protect agency when interacting with the oppressive heteronormative power structure inherent in hospitals. Participants were exquisitely aware of the presence of heterosexism and sexual prejudice and used the personal risking process as a defense against oppression in interactions. A minority of participants never abandoned their active nondisclosure stance; only one acknowledged the oppressive nature of this stance. The self-disclosers seemed to recognize the power hierarchy that constructed a lesbian identity as inferior to a heterosexual identity and used self-disclosure as creative action. Through this action, self-disclosers positioned themselves and their partners as legitimate actors in interactions with acute care providers. By choosing to engage in self-disclosure with acute care providers, these women created a lesbian identity as something of value and shifted the heteronormative power balance (Hoagland, 1992).

Participants ascribed different meaning and value to self-disclosure. For the self-disclosers, the choice meant protecting agency through establishing an authentic presence

with acute care providers and thus enabling the women to be themselves. For the nondisclosers, the choice meant protecting agency through avoiding detection by oppressive individuals and through averting potential discriminatory actions. Both self-disclosers and nondisclosers viewed the interactional stances as avenues of self-preservation in a threatening environment.

Interpretive analysis of the findings. Upon returning to the literature, the researcher located a dissertation by Hitchcock (1989) that explicated a Glaserian grounded theory of lesbian self-disclosure of sexual orientation to health providers. Hitchcock's study was conducted in the San Francisco area in the late 1980s and included 30 lesbians who had encountered health providers in various care settings. The majority of her participants related primary care experiences with physicians, and some described disturbing instances of physical abuse and neglect. Using a grounded theory approach, Hitchcock identified a two-stage process of personal risking used by lesbians to manage the basic social-psychological problem (BSPP) of fear. In the anticipatory phase, lesbians calculated the risk of self-disclosure by using imaginative and cognitive strategies to determine a disclosure stance. In the interactional phase, scanning and monitoring permitted reevaluation of the initial stance. Hitchcock described three conditions that determined the personal risking process: personal attributes, health care context, and relevancy.

The Neese Theory of Lesbian Self-Disclosure in Health Care is similar to the process of personal risking identified by Hitchcock (1989). This researcher found a two-stage process in participants' narratives, as well as four interactional stances. Due to the use of a different grounded theory approach (Strauss & Corbin, 1998) in this study,

antecedent conditions were labeled context, intervening conditions, and causal conditions. The causal condition of fear matched the BSPP reported by Hitchcock. This grounded theory differed from Hitchcock in aspects of context, intervening conditions, and cognitive strategies.

This research study focused on the context of acute care, so contextual differences were expected. Hitchcock (1989) did not identify the participant's profession as an important determinant of an interactional stance, but profession was a strong influence in this study. Participants in professions hostile to sexual minorities and with severe consequences for self-disclosure did not disclose in acute care. Within the health care environment in this study, participants expressed a strong preference for hospitals where they were familiar with at least some of the acute care providers. The desire for familiarity did not emerge in Hitchcock's study. Finally, heterosexism and the perception of marginalization it created for participants were important contextual factors in this study; Hitchcock did not identify these antecedents.

Relevancy as an intervening condition emerged in the first interview in this study. Hitchcock (1989) also found relevancy to be a strong influence on self-disclosure. However, Hitchcock did not identify sexual stigma, also known by the earlier term *homophobia*, as an antecedent condition for lesbian self-disclosure. Sexual prejudice and internalized homophobia surfaced in this study as important determinants of self-disclosure. Participants in this study did not encounter any physical mistreatment or neglect, but still perceived the existence of discriminatory sexual prejudice in acute care providers.

Hitchcock (1989) found the cognitive strategy of *scouting out* to be a crucial tool for her participants. Scouting out involved gathering information about health care providers' attitudes toward sexual minorities in advance of their seeking care. Hitchcock's participants used two subcategories of scouting out: screening and networking. Only one subcategory of scouting out, screening, emerged in this study. Participants in this study screened primary care physicians and relevant specialists, but did not screen other acute care providers. Networking did not surface in this study. Participants did not seek referrals to gay-friendly hospitals from friends or gay media.

The researcher found new cognitive strategy, rallying support, in this study. Single lesbians used this strategy as a way to guarantee that their friends would have access to them while they were hospitalized. Rallying support did not appear in Hitchcock's (1989) study, possibly due to the preponderance of primary care experiences recounted by her participants. Rallying support was identified as a strategy used by lesbians seeking hospital-based maternity care in an ethnographic study by Renaud (2007). Participants in Renaud's study described bringing lesbian friends with them to serve as defenders and supporters in the perinatal setting.

In a comparison of Hitchcock's Theory of Personal Risking with the Neese Theory of Lesbian Self-Disclosure in Health Care, it is noted that the theories describe a continuum of lesbian responses to potential discriminatory behavior from HCPs. The Hitchcock Theory depicts the lesbian decision-making process in primary care, while the Neese Theory characterizes lesbian self-disclosure in acute care. Much of the basic process is shared, with notable contextual differences and the addition of rallying support in a more anxiety-inducing health care environment. In each setting, the personal risking

process is used by lesbians to maintain agency by calculating the risk of self-disclosure and by determining adaptive interactional stances best suited to managing that risk.

The use of coping strategies to manage a stigmatized identity has been described in the psychology literature. Scrambler and Hopkins (1986) proposed a differentiation between societal discrimination, or *enacted stigma*, and internalized feelings of shame at being labeled with a stigmatized identity, or *felt stigma*. In their model, Scrambler and Hopkins posit that felt stigma, and especially the fear of enacted stigma, prompted individuals to conceal a stigmatized identity or pass as normal. In coping with felt stigma, individuals employed proactive coping mechanisms to minimize the possibility of experiencing enacted stigma. The coping mechanisms used were situational and depended upon an individual's accurate calculation of the risk of discrimination. The most extreme coping mechanism was total concealment of the stigmatized identity, which was used by the majority of participants in Scrambler and Hopkins' study of epileptics. The effort of concealment exacted a serious emotional and psychological toll on their participants, making felt stigma more disruptive to participants' lives than enacted stigma.

Participants in this study also described managing a stigmatized identity, that of a sexual minority. The decision-making process of personal risking detailed how participants managed the felt stigma that accompanied being lesbian. In the Neese Theory, enacted stigma manifested as sexual prejudice in acute care providers, and felt stigma appeared as internalized homophobia in participants. Fear of enacted stigma was justified, given the legacy of rejection, avoidance, and actual physical harm of lesbian patients detailed in earlier nursing research (Hitchcock, 1989; Stevens, 1994, 1995). As

described by Scrambler and Hopkins (1986), some participants in this study chose total concealment of their lesbian identity through an active nondisclosure stance. Unlike the Scrambler and Hopkins model, the Neese Theory described additional disclosure stances that offered a range of possibilities for coping with felt and enacted stigma. The interactional stances were primarily proactive and were based upon a situational assessment of the risk of self-disclosure. This range of interactional stances was absent in the Scrambler and Hopkins model.

Nursing literature addressing lesbian self-disclosure in acute care remains limited primarily to perinatal nursing investigations (Lee, Taylor, & Raitt, 2011). The perinatal nursing area was the only care setting where nurses were not invisible in the published research on lesbian self-disclosure. Physicians were the default health care provider reported in multiple self-disclosure studies (Bjorkman & Malterud, 2007; Bonvicini & Perlin, 2003; Klitzman & Greenberg, 2002; Politi, Clark, Armstrong, McGarry, & Sciamanna, 2009; Steele, Tinmouth, & Lu, 2006). Even research published in nursing journals did not report findings specifically related to lesbian self-disclosure to nurses (Polek, Hardie, & Crowley, 2008) with the exception of Röndahl (2009), and Röndahl's study included gay men and lesbians.

Lee, Taylor, and Raitt (2011) conducted a small hermeneutic phenomenological study to investigate lesbian women's experiences of maternity care. Eight participants who had self-disclosed to midwives were recruited. The researchers noted that participants reframed negative care experiences in ways that distanced the negativity or rationalized the problem as belonging to caregivers or organizational factors. Only one participant openly acknowledged the possibility of sexual prejudice as a cause for her

negative experience, but reported that straight women had described similar negative experiences. Participants did not experience overt expressions of sexual prejudice, but expressed nagging suspicions that maternity care was not as accepting and inclusive as it appeared. The authors suggested that recent equality and diversity legislation could have eliminated homophobia in maternity care or caused providers to hide their homophobic responses to lesbian patients. Active self-disclosure did not provide a completely positive birthing experience for the participants in the study by Lee et al. Rationalizing negative experiences might be one protective coping mechanism that lesbians use to deal with internalized homophobia, a subcategory of the intervening condition of sexual prejudice in the Neese Theory.

Röndahl (2009) interviewed 27 gay or lesbian informants who had been hospital patients or the partners of patients in Sweden. The focus was on how sexual minority participants experienced nursing care. The majority of participants reported feeling insecure about self-disclosing to nursing staff because nurses were unknown and unpredictable in their attitudes toward gays and lesbians. Despite the insecurity, most participants described positive or neutral experiences of nursing care. A few participants witnessed distancing behavior or homophobic responses, but suggested that provider responses were the result of older age, less education, or religious prejudice. Partners of patients perceived being assigned outsider status and viewed as unimportant by nursing staff. The author stated that most nurses do not realize that their attitudes or behaviors could convey a sense of dislike to gay and lesbian patients and are likely unsure of how to interact with a gay or lesbian patient or partner. The insecurities of both parties in the interaction could be responsible for perceptions of dislike or distancing.

This research study clearly described distancing behavior, but participants were not as forgiving as those in the studies by Lee et al. (2011) and Röndahl (2009). In this study, participants directly ascribed distancing, avoidance, and other negative provider behaviors to sexual prejudice. Participants made no effort to reframe negative provider behavior in a positive manner or to attribute negativity to staff's "just having a bad day." No participants were relating a recent childbirth experience; most hospitalizations were for accidents or surgery. Thus, there was no psychological impetus for participants to have a positive experience, which Lee et al. cited as the rationale for reframing by participants in their study. Imagined scenarios described by participants in this study were largely negative; participants anticipated having problems with staff. This preconception could have interfered with interpreting distancing behavior as nurse insecurity instead of discrimination.

When comparing self-disclosure of sexual orientation to acute care providers and self-disclosure to other groups—friends, family, or coworkers—participants in this study stated that the only similarity was the anxiety inherent in self-disclosure. Participants had repeatedly used the phrases "anxiety-ridden process" and "risky business" when describing self-disclosure to acute care providers. Participants did not see themselves as having an interpersonal relationship with most acute care providers, which made self-disclosure feel unsafe. Research in psychology and sexual behavior has described the self-disclosure process as complex and never-ending; the decision must be made every time a lesbian meets a new person (Grov, Bimbi, Nanín, & Parsons, 2006; Morris, 1997; Radonsky & Borders, 1995). Although the psychological studies were referring to self-disclosure in a social, not a therapeutic, situation, the fluid nature of the self-disclosure

process was apparent in this study. The Neese Theory of Lesbian Self-Disclosure in Health Care captured this complex, iterative decision-making process for lesbian self-disclosure. The personal risking process was initiated with every new provider encounter and each time a lesbian interacted with a provider she had seen before. The risk of self-disclosure was calculated at each encounter, and the interactional stance selected was situation-specific. Active disclosers had fewer options available if their stance was met with a negative response from providers; the most common response was to change providers.

The Neese Theory of Lesbian Self-Disclosure in Health Care can be situated in previous nursing and psychological research. Investigations of lesbian self-disclosure of sexual orientation in acute care remain largely confined to perinatal settings, most likely due to lesbians' increased visibility and demand for services in these settings. The Neese Theory captures the complex process of lesbian self-disclosure in acute care and has implications for nursing education, practice, research, and public policy.

Implications for nursing knowledge. One of the key areas uncovered in this research is that lesbians do not always perceive acute nursing care as respectful and accepting, which interferes with self-disclosure of sexual orientation, impairs trust in the nurse-patient relationship, and impedes the delivery of patient-centered nursing care. Knowledge of the process of lesbian self-disclosure of sexual orientation is important for nurse educators at the academic- and staff-development levels, for nurses practicing in acute care settings, and for nurses advocating for social justice in public policy.

Nursing education. Almost every participant in this study stated that nurses needed more cultural sensitivity training related to creating more inclusive nursing care

environments for lesbians and other sexual minorities. Nursing research has revealed that pre-licensure nursing students often enter nursing programs with preexisting negative attitudes toward lesbians (Eliason & Raheim, 2000; Röndahl et al., 2004) that are not challenged due to a pervasive heteronormative environment (Gray et al., 1996). Nursing students could gain knowledge of the personal risking process since they will be encountering lesbian clients in practice. Being exposed to the contextual and intervening conditions that influence the calculation of the risk of self-disclosure could prompt greater student empathy for lesbian clients through reflection. Nursing faculty in academia have a role in emphasizing the importance of cultural competence in caring for lesbians and in challenging the stigma, myths, and stereotypes that accompany identifying as a lesbian across the curriculum. The Neese Theory of Lesbian Self-Disclosure in Health Care provides one way to demonstrate the impact that stigma and stereotypes have on lesbian clients and to urge that a more inclusive perspective be transmitted to students.

Authors and publishers of nursing textbooks should be encouraged to include content related to caring for lesbian clients, including the Neese Theory of Lesbian Self-Disclosure in Health Care. Lesbians and other sexual minorities continue to be absent from the majority of contemporary nursing textbooks. Two new nursing texts focused on lesbian health were published quite recently in an effort to fill this gap (Dibble & Robertson, 2010; Eliason, Dibble, DeJoseph, & Chinn, 2009).

Staff development educators in acute care can provide cultural sensitivity training to practicing nurses. Programs to help nurses successfully provide sensitive care to lesbians can be based on the findings. Culturally competent nursing care of lesbians and

other sexual minorities is a factor in patient-centered care. Patient-centered communication standards are now central to Joint Commission (2011) accreditation for hospitals and require proof that institutions prohibit discrimination based on sexual orientation or gender identity. In addition, the Joint Commission released a field guide for advancing culturally competent care of the lesbian, gay, bisexual, and transgender (LGBT) community to serve as a resource for hospitals. It is doubtful that all nurses practicing in acute care are aware of these new Joint Commission mandates. Acute care nurses need appropriate education to insure that lesbian patients have high-quality outcomes in a caring environment.

Nursing practice. A major goal of nursing practice is to ameliorate patient fear and anxiety, not to enhance distress through discriminatory or stigmatizing behaviors.

The Neese Theory of Lesbian Self-Disclosure in Health Care provides practicing nurses a framework for understanding provider characteristics that lesbians find supportive of self-disclosure. Being fully aware of a patient's lifestyle and home situation permits better health teaching and discharge planning. It is important for practicing nurses to ask inclusive questions about families and caregiving situations rather than to rely on heteronormative assumptions. Partners, biological families, and families of choice may need to be included in care planning. Many participants in this study spoke of how partners were excluded from discharge care teaching and planning. It was also disturbing that nurses were portrayed by participants primarily as obstacles or obstructions to care. Cultural sensitivity training could ameliorate this problem and could encourage practicing nurses to include lesbians' partners and support network in all phases of discharge

planning and teaching, especially those of older lesbians who may require rehabilitation or long-term care.

One simple step that practicing nurses can take toward decreasing lesbian perceptions of heterosexism in acute care is to wear a rainbow flag pin. Many participants stated they believed this symbol indicated an accepting environment. Nurses who are hesitant to wear a known gay cultural icon could wear a pin from the Human Rights Campaign or from other sexual minority advocacy groups. Another option would be prominently posting an institution's diversity or antidiscrimination policy in the nursing units within easy view of patients, staff, and visitors.

Nursing departments in hospitals can review human rights policies and ensure that these include sexual orientation and gender identity. Several study participants stated that this was an important indicator of an inclusive health care environment. Policies must be more than words on paper; the policies must be enforced and discriminatory behavior must not be tolerated. Two participants wanted to see statements inclusive of sexual orientation in hospital mission statements as an indication of a gay-friendly environment. Another organization advocating for LGBT equality in hospital care is the Human Rights Campaign. This organization has developed the *Healthcare Equality Index* (HEI) as a measure to rate hospital policies and practices related to the LGBT community and to serve as a benchmarking tool for best practices in LGBT hospital care. Currently, only three hospital systems in Florida participate in the HEI (Human Rights Campaign Foundation, 2011). The Neese Theory of Lesbian Self-Disclosure in Health Care can be used to raise awareness of health care equality needs in hospitals and to encourage acute

care nurses to urge their institutions to participate in the HEI and to meet Joint Commission patient communication standards.

Participants with life partners reported that nursing staff actively interfered with partner visitation. This position is now in direct violation of the Centers for Medicare and Medicaid Services (CMS) *Conditions of Participation* (2010). The change in the *Conditions of Participation* was directed by a presidential executive order after the outcome of the court case involving hospital denial of visitation to a lesbian partner (Figueroa, 2009) reached national news agencies. Hospital-based nurse educators can use the Neese Theory of Lesbian Self-Disclosure in Health Care to develop programs to sensitize nurses to lesbian rights to hospital visitation.

Nursing research. Lesbian experiences and social interactions in the acute care setting are still under-researched. More nurse-led investigations that specifically look at nurse-patient interactions with lesbians and other sexual minorities in acute care are needed. Only then will best practices for nursing the lesbian client in acute care emerge. Nurse researchers need to reach out to the LGBT community and to identify the care priorities in acute care for this community.

Similarities between the Hitchcock Theory (1989) and the Neese Theory of Lesbian Self-Disclosure in Health Care could indicate that the lesbian self-disclosure process has commonalities across care settings. Comparisons between the Neese Theory and the Scramble and Hopkins (1986) model of stigma could signify that psychology and nursing are describing the same process using different terminology. The next step in nursing research could be the development of a middle-range theory of self-disclosure inclusive of other stigmatized identities.

Recruitment difficulties were encountered in this study, despite using many of the recommended recruitment strategies for lesbian participants (Meezan & Martin, 2003). Since lesbians have been so poorly studied in acute care, it may be that new or revised recruitment strategies need investigation. Future investigations might need to consult gatekeepers in the lesbian community or to utilize action research methods to determine best practices for recruiting participants with acute care experiences.

The absence of nursing research related to lesbians in general-readership nursing journals was noted during the literature review and analysis of this study. All the studies including lesbians were confined to highly academic, very expensive journals that were full of jargon or to dissertations with limited access. The average practicing nurse will not read these sources of evidence, so translating the research findings into practice will be very slow. Editors of general-readership nursing journals or nursing specialty organization journals could assist with disseminating LGBT research findings by issuing calls for papers on LGBT health. They could also plan special issues on LGBT health; this step would be especially relevant for nursing specialty organizations. Every nursing specialty care area has lesbian patients who need knowledgeable nurses using the best research evidence in their practice. The Neese Theory of Lesbian Self-Disclosure in Health Care would be relevant to any general-readership or nursing specialty journal dealing with acute care.

Public policy. Participants in this study did report being denied visitors even when their partner had a medical power of attorney. They were keenly aware of their tenuous legal standing even when presenting all the legal documents they could muster. In Florida, biological relatives are granted primacy in health care decision-making; all

other individuals are secondary. If a biological relative appears and makes a claim of being a health care surrogate for a lesbian client, in Florida, it often takes a court decision to settle the issue. Participants desperately wanted this situation to change, which is why some of them campaigned in favor of gay marriage in Florida. They did not view having the same legal rights as the heterosexual majority as desiring special rights; they saw gaining legal rights as having the same rights as the majority enjoyed.

Lesbians and other sexual minorities deserve the same legal rights as the heterosexual majority. This social justice issue creates stress for lesbian patients and their partners while they are in an acute care setting. The cognitive strategy of formalizing in the Neese Theory describes lesbian attempts to insure their rights and the rights of their partner in acute care. Nurses can advocate at the state level for changes to Florida law to grant equal rights to lesbian partnerships. Admittedly, this will be a struggle in the current Florida legislative climate, but it is the appropriate ethical action based on nursing's foundational documents.

Nurses can also advocate at the state level for mandatory hospital participation in the HEI. This would help insure compliance with the CMS *Conditions of Participation* (2010) and the Joint Commission (2011) patient-centered communication standard. The Neese Theory of Lesbian Self-Disclosure in Health Care showed that insuring an accepting, nonjudgmental health care environment decreases lesbian anxiety in an acute care setting and increases the likelihood of self-disclosure. Universal hospital participation in the HEI would be one step toward creating inclusive acute care environments.

Strengths and limitations. This study has several strengths. First, it provided the first explanation of the process of lesbian self-disclosure of sexual orientation in acute care using grounded theory. Consistent with procedures outlined by Strauss and Corbin (1998), participants with a variety of acute care experiences were sought to enable the development of a substantive theory that remained close to the data collected. Five participants 55 years of age and older were recruited; older lesbian participants were lacking in previous studies. Second, this study captured unexpected results that indicated differences between lesbian self-disclosure in primary care and in acute care. Contextual factors varied from those in primary care, and a new cognitive strategy, rallying support, was identified. Researcher bias was addressed through the use of a self-reflective journal and member checking. Finally, the study generated ideas for future investigations into the process of lesbian self-disclosure to HCPs.

The study also has several limitations. First, despite every effort to recruit ethnic minorities and women from every level of education, the majority of participants were well-educated White women. Many initial contacts were made with African-American and Hispanic women at large gay and lesbian events, but only two African-American women followed through on scheduling and completing an interview. Additionally, no participants who had been inpatients for perinatal care or mental health issues were recruited. The self-disclosure process could be very different for these women, which limits the transferability of the Neese Theory of Lesbian Self-Disclosure in Health Care to those inpatient populations.

Second, recruitment was generally slow and difficult. This setback was not anticipated since demographic evidence indicated that a sizable pool of participants was

available. Every recruitment technique previously found useful with hidden populations was used—snowball sampling, visiting large venues and events, posting flyers in gay pride and counseling centers, becoming familiar with gatekeepers, working with grassroots health groups, and posting on lesbian forums. Still, very few women actually scheduled interviews. Those expressing interest yet never scheduling far outnumbered the actual participants. This researcher does not know why recruitment was so difficult. The limited number of participants limits the transferability of the Neese Theory of Lesbian Self-Disclosure in Health Care.

Third, reliance on respondent self-report of past events limits transferability.

Every effort was made to recruit participants with acute care experiences within the 12 months prior to interviews, but participant recall could still have been selective.

Participants could have been recounting older experiences instead of focusing on their most recent acute care episodes.

Finally, although participants were sought from the entire southeastern region of South Florida (Indian River County to Miami-Dade County), interviewees were clustered in Broward and Miami-Dade counties. These counties have large gay and lesbian populations due to reputations for a gay-friendly environment. This factor may limit the transferability of the research to the populations in those areas.

Recommendations for future study. More research is needed on the process of lesbian self-disclosure in acute care nursing specialty areas. Different contextual factors and intervening conditions may influence self-disclosure, and there could be additional strategies used by lesbians in the anticipatory or interactional phases of personal risking based on the specialty care area. Knowledge of the full range of antecedent conditions

and strategies used to manage fear of self-disclosure would enable the development of best nursing practices for lesbians in acute care.

Research is also needed on the process of lesbian self-disclosure in long-term care. Nursing research on this population is just beginning (Gabrielson, 2011) and suggests that this population will have special care needs that are not being addressed. Without further research, it cannot be known if the Neese Theory of Lesbian Self-Disclosure in Health Care applies in long-term care settings.

Another topic that should be addressed is the difficulty in recruiting lesbian participants with acute care experiences. Recruitment procedures that have been effective in studies of health risks and primary care practices were relatively ineffective in this study. Future investigations could focus on which recruitment procedures work best for lesbians who have been hospital inpatients or ED patients.

Additionally, investigations could examine connections between the personal risking process and patient outcomes. Provider behaviors and health care environments that foster a nonjudgmental atmosphere and promote self-disclosure have been linked to greater use of preventive health care by lesbians in primary care settings. Using the personal risking process to guide nursing care in acute care settings could positively affect patient outcomes for lesbians.

Finally, the Neese Theory could be used as a guide to further delineate provider behaviors that promote lesbian self-disclosure or as a tool to develop patient satisfaction measures for the LGBT community. The researcher could envision the development of measurement instruments. Such measurement tools could be used to demonstrate compliance with Joint Commission and CMS mandates related to the LGBT community.

Conclusions and Summary

The purpose of this study was to develop a grounded substantive theory to describe the process involved in lesbian self-disclosure of sexual orientation in acute care settings. The researcher sought to identify conditions that affected lesbian self-disclosure, the way in which the self-disclosure process unfolded in acute care, the strategies used by lesbians during the process of self-disclosure, and any consequences experienced as a result of the self-disclosure process. Following data collection and analysis consistent with procedures outlined by Strauss and Corbin (1998), the Neese Theory of Lesbian Self-Disclosure in Health Care was delineated. Contextual and intervening conditions were identified that indicated the continued presence of heterosexism and discrimination in acute care settings. The causal condition identified was fear, with the core category of personal risking used to manage the fear of self-disclosure. Personal risking is a twostage process involving an anticipatory and interactional phase. Lesbians use imagined scenarios and cognitive strategies during the anticipatory phase to calculate the risk of self-disclosure. In the interactional phase, lesbians select one of four initial interaction stances—active or passive self-disclosure or active or passive nondisclosure. Scanning and monitoring are used to reevaluate and modify the interactional stance if necessary. Consequences are used as feedback for the anticipatory phase during the next provider encounter. The desired outcome of personal risking is protecting agency, or maintaining a lesbian's ability to act independently instead of being acted upon by prejudicial others.

The Neese Theory of Lesbian Self-Disclosure in Health Care could be used to advance cultural competency education in academic and practice settings. The theory would also be useful in guiding inclusive acute care nursing practices and in encouraging

compliance with new Joint Commission and CMS mandates for LGBT hospital patients.

Recommendations for future research arose from the Neese Theory, and study participants suggested public policy efforts.

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Approved by Barry University IRB :

Date: 'JUL - '7 2009
Signature - Barry University
Informed Consent Form

Institutional Review Board Pretocol Form February, 00 10

Your participation in a research project is requested. The title of the study is "A Grounded Theory Study Exploring Lesbian Self-disclosure of Sexual Orientation in Acute Care." The research is being conducted by Ruth Neese, a student in the Division of Nursing at Barry University, and is seeking information that will be useful in the field of nursing. The aims of the research are to understand the self-disclosure process in order to modify nursing practice to reduce bias and promote better care for lesbians in an acute care setting. In accordance with these aims, the following procedures will be used: audiotaping of face-to-face interviews and note-taking. We anticipate the number of participants to be a maximum of 25.

If you decide to participate in this research, you will be asked to do the following: (1) answer questions about your experiences in acute care, which includes any hospital admission or Emergency Department visit within the last 12 months, in a face-to-face interview with Ruth; (2) be contacted by Ruth by telephone or email three days after the interview to inquire if any uncomfortable feelings came up for you; and (3) review study findings via email or postal mail three months after the interview. The interview will not last more than two hours.

Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects on your health care.

The risks of involvement in this study are minimal and include emotional upset from unpleasant memories of health care experiences, emotional upset from thinking about what you did or did not tell the interviewer, unintentional "outing" if news of your participation leaves the sampling network, and feeling tired after the interview. The following procedures will be used to minimize these risks: conducting the interview at a time and place convenient for you, briefly stopping taping, debriefing after the interview, telephone contact from the investigator three days after the interview, providing a written list of community counseling services free of charge, referral for support if needed, and strict observance of privacy. You will receive a \$25.00 grocery gift card. Your participation in this project may help our understanding of how lesbians interact within the acute health care system.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any hospital or healthcare provider name mentioned during the interview will not be reported. Any published results of the research will refer to group averages only and no names will be used in the study. Data will be kept in a locked file in the researcher's office. Immediately after transcription by Ruth, the audiotapes will be destroyed by shredding. Your signed consent form will be kept separate from the data. All data will be destroyed after three years.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Ruth Neese, at the point of contact, Barbara Cook, at the please signify your consent by signing this consent form.

Vol	luntary	Consent
V U	lumtary	Consent

I acknowledge that I have	been informed o	t the nature and purposes of	this study by
Ruth Neese and that I have r	ead and understar	nd the information presented	d above, and that
I have received a copy of thi	s form for my rec	ords. I give my voluntary of	consent to
participate in this study.	Ž		
1			
Signature of Participant	Date		
Researcher	Date	Witness	



OFFICE OF THE PROVOST INSTITUTIONAL REVIEW BOARD

11300 NE Second Avenue Miami Shores, FL 33161-6695 **phone** 305-899-3020 800-756-6000, ext. 3020 **fax** 305-899-3026 www.barry.edu

Research with Human Subjects Protocol Review

To: Ms. Ruth Neese

From: Doreen C. Parkhurst, M.D., FACEP

Chair, Institutional Review Board

Date: June 28, 2010

Protocol Number: 090611

Protocol Title: A Grounded Theory Study Exploring Lesbian Self-

Disclosure of Sexual Orientation in Acute Care

Dear Ms. Neese:

Thank you for sending the Modification Form indicating that you would like to make a change to your protocol regarding change of end date:

1. Extension of end date from July 5, 2010 to July 4, 2011.

The above changes have been accepted. You may proceed with your collection of data. The approval granted expires on July 4, 2011.

Sincerely,

Doreen C. Parkhurst, M.D., FACEP Chair Institutional Review Board Associate Dean, Program Director, PA Program Barry University Box SGMS 11300 NE 2nd Avenue Miami Shores, FL 33161

Cc: Dr. Sandra Walsh

If you have any questions, please contact Barbara Cook at: 305-899-3020



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11300 NE Second Avenue Miami Shores, FL 33161-6695 **phone** 305-899-3020 800-756-6000, ext. 3020 **fax** 305-899-3026 www.barry.edu

Research with Human Subjects Protocol Review

To: Ms. Ruth Neese

From: Doreen C. Parkhurst, M.D., FACEP

Chair, Institutional Review Board

Date: July 11, 2011

Protocol Number: 090611

Protocol Title: A Grounded Theory Study Exploring Lesbian Self-

Disclosure of Sexual Orientation in Acute Care

Dear Ms. Neese:

Thank you for sending the Modification Form indicating that you would like to make a change to your protocol regarding change of end date:

1. Extension of end date from July 4, 2011 to December 30, 2011.

The above changes have been accepted. You may proceed with your collection of data. The approval granted expires on December 30, 2011.

Sincerely,

Doreen C. Parkhurst, M.D., FACEP Chair Institutional Review Board Associate Dean, Program Director, PA Program Barry University Box SGMS 11300 NE 2nd Avenue Miami Shores, FL 33161

Cc: Dr. Sandra Walsh

If you have any questions, please contact Barbara Cook at: 305-899-3020

Appendix B Community Counseling Resources

If you experience any upset or distressed feelings after this interview or discover information about yourself that is upsetting, disturbing, or distressing, I encourage you to make contact with your mental health provider or the following agencies:

- Compass: The Gay and Lesbian Community Center of the Palm Beaches, (561)
 533-9699
- 2. 211Palm Beach/Treasure Coast, (561) 383-1112. In Palm Beach County, just dial
 211
- Parents, Family, and Friends of Lesbians and Gays—Vero Beach chapter,
 (772) 778-9835

Appendix C Recruitment Card Example

Front text:

You have been invited to participate in a nursing research study. This study is being conducted by Ruth Neese, a doctoral student at Barry University in Miami Shores, FL. Ms. Neese is investigating how lesbians interact with health care providers in hospitals. To participate in this study, you must:

- Be older than 18
- Describe yourself as lesbian
- Be willing to talk about a hospital admission or Emergency Department visit that occurred within the past 12 months

Participation is completely voluntary.

Back text:

If you are interested in learning more about this study, please contact:

Ruth Neese, (

Appendix D Study Flyer

Have you been admitted to a hospital or visited an Emergency Department in the last

Would you describe yourself as lesbian?

Would you be willing to discuss your hospital or Emergency Department experience with a nurse researcher?

If you are interested in participating in a research study that explores how lesbians interact with health care providers in hospitals and Emergency Departments, please contact Ruth Neese, MSN, RN for more details.

Phone number:	
Email:	

This study is being conducted by Ms. Neese in partial fulfillment of requirements for the PhD in Nursing from Barry University, Miami Shores, FL. Sandra Walsh, PhD is Ms. Neese's supervisor.

A maximum of 25 participants will be needed.

Your participation is completely voluntary and confidential.

Appendix E Interview Guides

Interview Guide: Interviews One Through Five

The interview will begin with the initial statement: Describe your hospital (Emergency Department) experience from your perspective as a lesbian. Some follow-up questions, if not initially addressed may include:

- 1. What was your experience with health care providers in the hospital or ED?
- 2. What were your perceptions of interactions with health care providers who provided your care?
- 3. What has been your experience in discussing your sexual orientation with health care providers in the hospital or ED?
- 4. When you were hospitalized or in the ED, what things influenced your decision to disclose or not disclose your sexual orientation?
- 5. What things caused you to worry?
- 6. What things made self-disclosure easier?
- 7. What things made self-disclosure more difficult?
- 8. What helped you feel comfortable?
- 9. What advice would you have for someone who is deciding whether to disclose sexual orientation to an acute care provider?
- 10. Is there anything else I should know about disclosing sexual orientation during hospitalization or an ED visit that I did not ask?
- 11. Is there anything else you would like to tell me?

Interview Guide: Interviews Six and Seven

- 1. What was your experience with health care providers in the hospital or ED?
- 2. What has been your experience in discussing your sexual orientation with health care providers in the hospital or ED?
- 3. What were your perceptions of interaction with health care providers who provided your care?
- 4. When you were hospitalized or in the ED, what things influenced your decision to disclose or not disclose your sexual orientation?
 - a. What influence would a life partner have on your decision to disclose?
 - b. What influence would being single have on your decision to disclose?
 - c. How would an institution's reputation for being "gay-friendly" influence your decision to disclose?
- 5. What things made self-disclosure easier?
 - a. Under what circumstances would you always disclose your sexual orientation?
- 6. What things made self-disclosure more difficult?
 - a. What things caused you to worry?
 - b. Under what circumstances would you never disclose your sexual orientation?
- 7. What helped you feel comfortable? Please describe.
- 8. What advice do you have for someone who is deciding whether to disclose sexual orientation to an acute care provider?

- 9. Is there anything else I should know about disclosing sexual orientation during hospitalization or an ED visit that I did not ask?
- 10. Is there anything else you would like to tell me?

Interview Guide: Interviews Eight Through Ten

- 1. What was your experience with health care providers in the hospital or ED?
- 2. What has been your experience in discussing your sexual orientation with health care providers in the hospital or ED?
- 3. What were your perceptions of interaction with health care providers who provided your care?
- 4. When you were hospitalized or in the ED, what things influenced your decision to disclose or not disclose your sexual orientation?
 - a. What influence would a life partner have on your decision to disclose?
 - b. What influence would being single have on your decision to disclose?
 - c. How would an institution's reputation for being "gay-friendly" influence your decision to disclose?
- 5. What things made self-disclosure easier?
 - a. Under what circumstances would you always disclose your sexual orientation? What does "relevant" mean to you?
 - b. What objects or tokens present in the healthcare environment would make you feel more comfortable?
 - c. How do you define "safe"?
- 6. What things made self-disclosure more difficult?
 - a. What things caused you to worry?
 - b. Under what circumstances would you never disclose your sexual orientation? How do you define "unsafe"?

- c. What is your experience with registration forms? Were these forms inclusive of alternative gender identities?
- 7. What helped you feel comfortable? Please describe.
- 8. How to you view the effect of age on willingness to self-disclose sexual orientation?
- 9. What advice do you have for someone who is deciding whether to disclose sexual orientation to an acute care provider?
- 10. Is there anything else I should know about disclosing sexual orientation during hospitalization or an ED visit that I did not ask?
- 11. Is there anything else you would like to tell me?

Interview Guide: Interviews Eleven and Twelve

- 1. What was your experience with health care providers in the hospital or ED?
- 2. What has been your experience in discussing your sexual orientation with health care providers in the hospital or ED?
- 3. What were your perceptions of interaction with health care providers who provided your care?
- 4. When you were hospitalized or in the ED, what things influenced your decision to disclose or not disclose your sexual orientation?
 - a. What influence would a life partner have on your decision to disclose?
 - b. What influence would being single have on your decision to disclose?
 - c. How would an institution's reputation for being "gay-friendly" influence your decision to disclose?
- 5. What things made self-disclosure easier?
 - a. Under what circumstances would you always disclose your sexual orientation? What does "relevant" mean to you?
 - b. What objects or tokens present in the healthcare environment would make you feel more comfortable?
 - c. How do you define "safe"?
 - d. Once you decide it is safe to disclose, do you monitor the setting and providers for a change in attitude or behavior? Please describe.
- 6. What things made self-disclosure more difficult?
 - a. What things caused you to worry?

- b. Under what circumstances would you never disclose your sexual orientation? How do you define "unsafe"?
- c. Once you have decided it is unsafe to disclose, do you monitor the setting and providers for a change in attitude or behavior? Please describe.
- d. What is your experience with registration forms? Were these forms inclusive of alternative gender identities?
- 7. What helped you feel comfortable?
 - a. Give me an example of a nonverbal provider behavior that helped you feel more comfortable.
 - b. Give me an example of a verbal provider behavior that helped you feel more comfortable.
- 8. What health care provider characteristics have helped you feel more comfortable or uncomfortable with disclosure (age, gender, specialty, level of licensure)?
- 9. How to you view the effect of age on willingness to self-disclose sexual orientation?
- 10. How do you view the effect of personal comfort with your sexual orientation on willingness to self-disclose?
- 11. What comes to your mind when I say active self-disclosure? Active non-disclosure?
- 12. What comes to your mind when I say passive self-disclosure? Passive non-disclosure?
- 13. What consequences have you experienced as a result of disclosing (or not disclosing) your sexual orientation to acute care providers?

- 14. What similarities do you see between disclosing your sexual orientation to acute care providers and other instances of disclosure (family, friends, co-workers)?
- 15. What is unique about disclosing your sexual orientation to acute care providers?
- 16. What advice do you have for someone who is deciding whether to disclose sexual orientation to an acute care provider?
- 17. Is there anything else I should know about disclosing sexual orientation during hospitalization or an ED visit that I did not ask?
- 18. Is there anything else you would like to tell me?

Appendix F Sample Request Permission to Post or Distribute Flyers Letter

PFLAG Port St. Lucie/Treasure Coast



Dear Ms. S.:

I am a nursing doctoral student at Barry University in Miami Shores, FL, and I am seeking permission to distribute a research study recruitment flyer on at a chapter meeting in July or August. The title of the study is *A Grounded Theory Study Exploring Lesbian Self-Disclosure of Sexual Orientation in Acute Care*, and I want to recruit lesbians who have been admitted to a hospital or visited an Emergency Department within the past 12 months. My goal is to describe the process lesbians use to decide whether to reveal their sexual orientation to health care providers in hospitals. My longrange goal is using study results to improve the care lesbians receive from nurses and other providers in hospitals.

I do not plan on collecting data at a meeting. I am only seeking to recruit participants for my study.

Participation would require a tape-recorded face-to-face interview with me that would last no more than two hours. I have included a copy of the recruitment flyer that I would like to post. I would be happy to provide you with a copy of the Barry University Institutional Review Board approval letter before posting the flyer.

If distributing a flyer is permissible, please return a letter indicating this permission in the enclosed SASE. I appreciate your time and consideration.

Thank you, Ruth Neese, MSN, RN

Appendix G Demographic Survey

Please circle the number next to the best answer.

What is your age?

- 1. 18 24
- 2. 25 34
- $3. \quad 35 44$
- $4. \quad 45 54$
- 5. 55 64
- 6. 65 or above

What is your highest level of education?

- 1. Some high school
- 2. High school graduate/GED
- 3. Some college (less than 2 years)
- 4. Associate degree
- 5. Bachelor's degree
- 6. Masters degree
- 7. Doctoral degree

Are you currently in a relationship with:

- 1. A woman?
- 2. A man?
- 3. Both?
- 4. Not currently in a relationship

How many times have you been a patient in How many times have you been a patient

an Emergency Department in the past 12

1. One

months?

- 2. Two
- 3. Three
- 4. Four or more
- 5. Not applicable

What is your race/ethnic group?

- 1. White
- 2. African-American
- 3. Hispanic
- 4. Asian
- 5. Caribbean Islander
- 6. Other: ____

Do you have children?

- 1. Yes
- 2. No

If yes, how many children do you have?

- 1. One
- 2. Two
- 3. Three
- 4. Four or more

What is your average yearly household income?

- 1. Less than \$20,000
- 2. \$20,000 to \$34,000
- 3. \$35,000 to \$44,000
- 4. \$45,000 to \$54,000
- 5. \$55,000 to \$64,000
- 6. \$65,000 to \$74,000
- 7. \$75,000 and above

in the hospital in the last 12 months?

- 1. One
- 2. Two
- 3. Three
- 4. Four or more
- 5. Not applicable

Which of the following healthcare providers interacted with you in the hospital or Emergency Department? (Circle all that apply)

- 1. Nurse
- 2. Physician
- 3. Respiratory therapist
- 4. Radiology technician
- 5. Physical therapist
- 6. Nurse's aide/ care technician
- 7. Other:

Were you able to choose the hospital in advance based on a reputation for the facility being gay-friendly?

- 1. Yes
- 2. No

Appendix H Debriefing Script

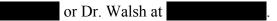
I want to thank you for participating in my study; your generous donation of your time and story are greatly appreciated.

Several studies have demonstrated that lesbians experience difficulties during health care if their sexual orientation becomes known to healthcare providers. I hope to use what I learn from your interview to identify the process used to manage self-disclosure of sexual orientation during your care in a hospital or Emergency Department. Called a grounded theory, this process could eventually be used to guide nursing actions and improve care for lesbians.

I would like to contact you by email or telephone in three days to ask how you are and if you are having any trouble managing any uncomfortable feelings triggered by this interview. If you are interested, I would also like to share the results of my analysis with you to ensure my conclusions represent your experience. I anticipate this will be two to three months after this interview. You may receive results via email or postal mail using a self-addressed stamped envelope.

If you were upset, disturbed, or distressed by topics covered in this interview or found out information about yourself that is upsetting, disturbing, or distressing, I encourage you to make contact with your mental health provider or any of the resources provided on the written list you received before the start of the interview.

Also, if you have any questions or concerns about the study, please contact Ruth Neese at



Appendix I Vita

VITA

June 7,	Born – Savannah, GA
1978	ASN, Armstrong State College, Savannah, GA
1978 – 1987	Staff Nurse, Hillcrest Hospital, Pittsfield, MA
1989	BSN, University of North Florida, Jacksonville, FL
1989 – 1996	Staff Nurse, Martin Memorial Medical Center, Stuart, FL
2003	MSN, University of Hartford, West Hartford, CT
2003 - Present	Staff Nurse, Jupiter Medical Center, Jupiter, FL

PUBLICATIONS

- Neese, R., Majka, G., & Tennant, G. (2006). The ultimate challenge: Three situations call American nurses to think and act globally. *Annual Review of Nursing Education*, *5*, 153-171.
- Neese, R. (2003). A Transformational Journey From Clinician to Educator. *Journal of Continuing Education in Nursing*, 34, 258-262.
- Heinrich, K. T., Pardue, K. T., Davison-Price, M., Murphy, J. I., Neese, R., Walker, P., & White, K. B. (2005). How can I help you? How can you help me? Transforming nursing education through partnerships. *Nursing Education Perspectives*, *26*, 34-41.

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- Heinrich, K. T., Cote, J. A., Solernou, S. B., Roth, K. A., Chiffer, D. K., Bona, G.,
 McKelvey, M. Carpenter, D. N., Bracken, C., Neese, M. R., Varholak, D.,
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 Scholars: Preparing Nurse Educators for the New Millennium. *Annual Review of Nursing Education*, 1, 109-132.