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The long-term care decision making of older lesbians: a narrative analysis

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THE LONG-TERM CARE DECISION MAKING OF OLDER LESBIANS: A NARRATIVE ANALYSIS

by

Marcena Lynn Gabrielson

An Abstract

Of a thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Nursing in the Graduate College of The University of Iowa

May 2009

Thesis Supervisor: Associate Professor Janet K. Pringle Specht

ABSTRACT

This qualitative study used narrative analysis of interviews with 10 older lesbians (aged 55 and over) who have made a financial commitment to live in a continuous care retirement center (CCRC) specializing in lesbian, gay, bisexual and transgender (LGBT) care. The specific aims were to:

1. Describe what has impacted older lesbians' decisions to live in an LGBT-specific CCRC.
2. Describe factors that both positively and negatively impact older lesbians' perceptions of elder care.

The study combined two qualitative strategies (across-case, thematic analysis and narrative analysis) and used a convenience sample.

Themes identified in across-case analysis were interpreted in the context of patterns in the narrative analysis. Categories, topics and subtopics were organized temporally. This within and across case strategy facilitated the ability to view the whole as well as individual and identify salient themes and representative stories across cases.

Stories of past negative experiences with family (resulting from the participants' sexual orientation) as well as past positive experiences within the gay community were widespread across cases. Presently, the participants are caring for older heterosexual family members and realizing that in their lesbian friendship circles they have experienced this type of care and support and not in their biological family relationships. Additionally, they are increasingly aware of their own aging and realizing that at some point they might not be able to support themselves and each other in ways that preserve their dignity and prevent discrimination, as they generally can now.

The participants' past experiences (as well as expectations stemming from them) coupled with present experiences and realizations, have led to the decision to live in an LGBT CCRC. They have concluded that the only way to be assured of dignity and respect in elder care is to decide on the LGBT CCRC. Positive perceptions regarding the decision to live in this elder care option were straightforward and directly reflected the findings for Aim I. It is important to understand older lesbians' elder care decision making because continued lack of knowledge may potentially undermine optimal care delivery of elder lesbians across settings.

Abstract Approved: _____

Thesis Supervisor

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Title and Department

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CERTIFICATE OF APPROVAL

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PH.D. THESIS

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This is to certify that the Ph. D. thesis of

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has been approved by the Examining Committee for the thesis requirement for the Doctor of Philosophy degree in Nursing at the May 2009 graduation.

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Frank Beck

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CHAPTER I

INTRODUCTION, SPECIFIC AIMS

An estimated one to three million Americans over the age of 65 are lesbian, gay, or bisexual (Cahill, South, & Spade, 2000). The Lesbian and Gay Aging Issues Network (LGAIN) of the American Society on Aging undertook the first U.S. national survey of lesbian, gay, bisexual, and transgender baby boomers—1,000 self-identified lesbian, gay, bisexual and transgender (LGBT) people ages 40 to 61—in November of 2006 and found some alarming information with respect to the LGBT population's expectations for older age. Specifically, the results revealed that one in five respondents, and particularly one-third of respondents without partners, had significant worries about who will take care of them when they grow older. Twenty-seven percent of the respondents feared discrimination in old age, with less than half of them expressing confidence that health care professionals will treat them with respect. These fears were particularly strong among older lesbians, 12% of whom had no confidence at all that they will be treated respectfully by health professionals as they age (LGAIN, 2006). Other research studies on LGBT persons have suggested that expectations of discrimination may be rooted in experience. For example, in their sample of 416 older gays, lesbians, and bisexual adults, Grossman, D'Augelli, and O'Connell (2001) found that 63% had experienced verbal abuse, 29% threats of physical violence, 20% employment discrimination, 16% assault, and 7% housing discrimination within their lifetimes. In another study, LGBT older adults expressed belief that discrimination in retirement care facilities exists (Johnson, Jackson, Arnette, & Koffman, 2005) and that this may greatly affect their potential choices for elder care.

The identity development of current older lesbians occurred against significant external homophobia and often discrimination and trauma. It is important to keep in mind that until 1973 homosexuality was listed as a mental illness in the *Diagnostic and Statistical Manual of Mental Disorders*. The removal of the diagnosis from the manual

took years of challenge by gay activists and their allies. However, it is also critical to be mindful of the fact that sodomy laws, criminalizing homosexual behavior and providing a means to justify discrimination against LGBT people (Lambda Legal Defense and Education Fund, 2002), were only finally overturned by the U.S. Supreme Court in 2003 (Harcourt, 2006).

Past experiences relating to homophobia, internal homophobia, and lesbian invisibility may be influencing elder care expectations and choices among the aging lesbian population. It should be noted that the first members of the baby boom generation are now reaching their 60s and that these baby boomers and the others who will follow have experienced increased visibility stemming from the gay rights movement. Their past experiences and expectations about their future elder care are likely to be very different from elder lesbians who have preceded them.

It is likely that the past experiences and new expectations regarding future elder care of gay and lesbian baby boomers will have an enormous impact on the current health care system. For example, it is unlikely, given their past increased openness, that it will be acceptable to gay and lesbian baby boomers to have to return to secrecy about their sexual orientation in order to receive needed elder care services (something that has been the norm until now). It is therefore also unlikely, given their concerns about elder care and expectations for mistreatment in older age by those providing services, that the population will continue to access elder care services that they deem culturally insensitive to them.

We may be seeing the result of these past experiences and new expectations in the growth of LGBT-specific retirement communities in the United States. There are currently only a few of these, and they are concentrated in Arizona, New Mexico, Florida, Massachusetts, and California. They range from basic retirement to continuing care models. This study is a narrative analysis of older lesbians who have made the

decision and commitment to live in a continuing care retirement center (CCRC) that specializes in services for the LGBT population.

Not unlike their heterosexual counterparts, LGBT baby boomers are clear about their desire to live out their old age and end of life in their own homes (LGAIN, 2006). Considerable benefits of *aging in place* (remaining in your own home) with in-home health care supports have been noted.

Marek, Popejoy, Petroski, Mehr, Rantz, & Lin (2005) found that their sample of participants who were aging in place stabilized or improved on all outcome measures (cognition, depression, incontinence, functional status, and pressure ulcers) compared to the declines in outcomes seen in a matched nursing home comparison group.

Almost 40% of respondents in the LGAIN study (2006) believed that their sexual orientation has helped them prepare for some of the challenges of aging. They specifically believed that the importance they have placed on support networks as a consequence of their sexual orientation will help them in their older age. More than 75% identified that they currently rely on the support of non-family support networks. There is a growing consensus regarding the importance of social ties to older adult well being. Social ties have a significant impact on not only the mental but also the physical health of older adults (Lubben & Gironda, 2003). The emergence of LGBT-specific retirement facilities may be resulting not only from the experiences and elder care expectations of LGBT baby boomers but also as a strategy for securing social ties and natural supports as they age.

LGBT elders are among the most invisible of all Americans. We continue to know little about them because of the widespread failure of researchers to include questions about sexual orientation or gender identity in studies of the aged (Cahill et al., 2000). To date, there has been an inadequate amount of nursing research devoted to the aging and health experiences of older LGBT adults (including older lesbians) and the factors that impact those experiences. This study represents a significant and logical

move forward. Given the lack of research on the topic and the significance of the issue, both in terms of policy and service delivery implications for the current health care system, descriptive exploratory studies are called for as a starting point. This descriptive exploratory study gives rise to questions about and aspects of elder care of older lesbians that can be studied in larger ethnographic studies and ultimately, in intervention studies.

This qualitative study combines across-case thematic analysis and within-case narrative analysis of interviews with 10 older lesbians who have decided to live in a LGBT-specific CCRC. It investigates themes in the accounts of these older lesbians regarding what has impacted their decision.

This research is innovative because it addresses an issue and a population largely overlooked in health and nursing research, revealing important information regarding the elder care planning and expectations of older lesbians. It is significant not only because of its potential to increase care providers' sensitivity to and knowledge about older lesbians with respect to elder care but also because of its potential to increase the dignity, respect, and quality of life experienced by older lesbians in elder care across settings. It is critical to better understand this phenomenon because the continued lack of knowledge potentially undermines optimal elder health care for older lesbians.

Specific Aims

The specific aims of this study are to:

- Describe what has impacted older lesbians' decisions to live in a lesbian, gay, bisexual, and transgender (LGBT)-specific continuing care retirement center (CCRC).
- Describe factors that both positively and negatively impact older lesbians' perceptions of elder care.

This dissertation thesis addresses these specific aims, discusses related supporting literature, identifies policy and practice implications, and provides this recommendations as well as recommendations from nationally recognized LGBT organizations, for

addressing the identified policy and practice implications.

CHAPTER II

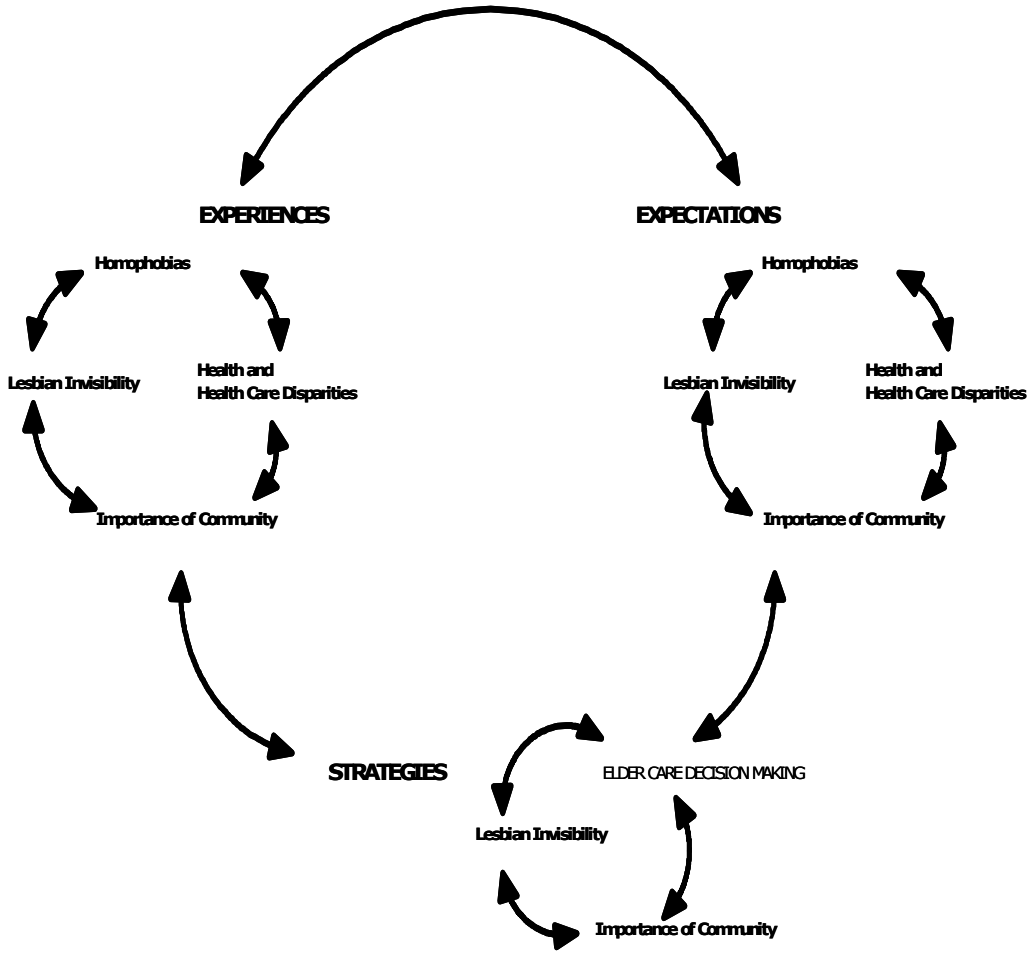
REVIEW OF RELATED LITERATURE

The purpose of this chapter is to provide background for and clarification of the conceptual framework (Figure 1.) prompting the study, as well as to discuss the body of literature providing support to the investigation. The conceptual framework prompting the study is depicted in Figure 1. It conveys that the expectations and strategies of older lesbians regarding their long term care are a consequence of all the older lesbians' life and health experiences that have come before it and that these experiences are interrelated and cumulative in their effect on later expectations, strategies, and decisions. Specifically, this emerging framework was based on my pre-analysis assumptions and depicts that homophobia (internal and external) is an antecedent to lesbian invisibility. Homophobia and lesbian invisibility are assumed to be antecedents to health and care disparities. Health and care disparities are assumed to be antecedents to the importance placed on social ties. Finally, all are posited by me to be antecedents to expectations, strategies, and decisions of older lesbians regarding their elder care.

While I assume that these variables are related to one another as stated above, the framework itself illustrates that the variables are likely to influence one another in a multidirectional fashion. This emerging framework is a modification of Ayres' caregivers' process of meaning making (2000).

The review begins with a general presentation of lesbian elders in the context of other elders within the United States and continues with a discussion of scholarly literature regarding decision making. Figure 1 depicts long-term care decision making as a consequence of all the older lesbians' life and health experiences that come before it. The review discusses the concept of homophobia (internal and external) as well as lesbian invisibility, emotional health, health and care disparities, aging, and the importance of social supports and community.

Figure 1. Proposed Framework: Older Lesbians' Process of Elder Care Decision Making



Lesbian Elders in the Context of All Elders in the United States

There are 37 million adults over the age of 65 in the United States (Federal Intra-agency Forum on Aging Related Statistics, 2008). An estimated one to three million Americans over the age of 65 are lesbian, gay, or bisexual (Cahill et al., 2000). There are

similarities in concerns about aging between homosexual older adults and their heterosexual counterparts. An American Association of Retired Persons survey in 2000 revealed that more than 90% of seniors aged 65 and over want to remain in their own homes indefinitely **(**Bayer & Harper, 2000). A recent survey of 402 seniors aged 65 and older indicated that it is very important to 89% of them to remain in their own homes, and 53% of the sample worry about their ability to do so indefinitely (Prince Market Research, 2007). When asked what they worried about most in aging, the sample identified loss of independence. It is the basis for concerns about remaining in their own homes and worries about losing independence that may be very different for LGBT elders.

I have already identified the fears that LGBT elders have about homophobia, discrimination, and mistreatment in aged care. Yet there are additional striking differences between homosexual and heterosexual elders in terms of support for aging. For example, LGBT seniors are twice as likely to age single, more than twice as likely to live alone, and more than four times as likely to have no children to call upon in times of need as compared to heterosexuals. For LGBT elders this potentially means a disparity in natural supports (NGLTF, 2005). Factors I am seeking to explore indirectly in my study include perceived and actual differences in terms of aging supports for older lesbians and how these differences affect their expectations for and ultimately their decision making regarding elder care.

Decision Making

Our decision making processes are generally attempts at gaining the best possible outcomes for particular issues or problems that we might face. The best possible outcome is generally based on some standard of good or bad and is likely to be subjective. Issues and problems we face range from very simple, non- significant, day-to-day decisions (such as what television program to watch) to complex, significant, long- term decisions (such as choices regarding retirement).

Early problem solving theorists suggested that decision making is generally sequential in nature. Seminal work in this area includes the problem solving framework postulated by Dewey (1910). Dewey suggested that there is a sequence of stages for making a decision regarding a problem. This sequence includes: (a) perceiving a difficulty, (b) defining the character of the difficulty, (c) suggesting possible solutions, (d) evaluating the suggestion and, (e) accepting or rejecting the suggestion based on observation and experience.

Later problem solving theorists identified the limiting nature of Dewey's sequence. These later theorists offered decision making models that included similar components for making decisions as that found in Dewey's model, but were notably non-sequential. They suggested that the components of decision making occur in a parallel (Witte, 1972) or cyclical (Mintzberg, Raisinghani, & Theoret, 1976) format.

Regardless of the sequence of decision making, most if not all decisions include valuing of probable outcomes (Hansson, 1994). Relational valuing can be visualized in a simple example of choosing one outcome over two others:

A is better than B

B is better than C

A is better than C

Since A is better than all the other alternatives, A would be chosen. In relational valuing, we compare alternatives and may use phrases such as "better than," "worse than," "equally good," or "at least as good" to determine the best decision (p. 14).

Decision makers also commonly apply numerical valuing (utilities). The basic rule in the numerical valuing of potential outcomes is to choose the outcome with the greatest or highest utility and the decision most likely to achieve that outcome (Fishburn, 1970).

Counters to simple utility theory include the works of Ellsberg (1961) and Tversky and Kahnerman (1981). Ellsberg (1961) demonstrated the *ambiguity effect*.

Ellsberg's work suggested that people prefer to bet on clear rather than vague events (Heath & Tversky, 1991). For example, Ellsberg asked subjects to draw a ball out of a box and without looking, guess its color. He postulated that individuals would prefer to draw from a box containing an even distribution of red to green balls versus another box in which the distribution was unknown. This pattern of preference has been confirmed in many experiments. One of the most well known, respected, and widely cited modern conceptualizations of decision making is prospect theory (Tversky & Kahneman, 1981). Tversky and Kahneman (1981) suggested that people exhibit patterns of preference incompatible with simple utility valuing (p. 454). They suggest that outcomes are seen as gains or losses from a reference point that is judged by the decision maker as neutral.

A seminal work by Tversky and Kahneman (1974) reveals that we judge probability (and thus make decisions) based on the ease with which mental operations of retrieval, construction, and association can be performed. Over the lifespan, more significant and frequent events are recalled much easier than less significant or frequently occurring events (p. 1127-28).

Regarding future care planning and decision making, Sorensen and Pinquart (2000) discuss a four-component process. The components of future care planning and decision making that they identify include (a) awareness and anticipation of future care needs, (b) information gathering, (c) determination of preferences, and (d) making specific plans (S358). Awareness of vulnerability is a strong predictor for future care planning and having resources enhances planning for those with awareness of need (Sorensen & Pinquart, 2000, p. 275).

An important issue in decision making concerns the relationship between actions and outcomes. It is generally assumed by decision makers that actions decided upon cause outcomes. In certain circumstances, however, our actions may be more diagnostic of an outcome than causal (Quattrone & Tversky, 1984). In other words, the outcome could be independent of the decision. This may be an important consideration for the

participants making the decision of interest in this study. For example, it is highly likely that the participants believe that the action of living in a LGBT-specific CCRC will provide beneficial outcomes for their old age. What the participants view as beneficial may vary to some degree across cases, and yet it is likely that all will believe the action to have a causal relationship to beneficial outcomes. The question then is: Are these beneficial outcomes explained by an associated factor rather than a LGBT-specific CCRC itself? This could be problematic for the decision makers in this situation as they may be making critical trade-offs (financial, for example) to achieve an outcome that perhaps their decided-upon action does not in fact cause. They may ask themselves whether the beneficial outcomes are associated more with congregate living with other older gays and lesbians instead of living in a specific CCRC. Because some outcomes are likely to not be independent of choice, the value of a particular outcome for the participants may be weighted by the likelihood that it is dependent upon or conditional to the decision (Jeffrey, 1965). Therefore, certain outcomes that are absolutely critical to the participants and most associated with living in a specific CCRC versus those outcomes associated with factors irrespective of location are likely to be the keys to the participants' decision to live in a particular LGBT CCRC.

The potential influence of peers on decision making should not be underestimated. Seminal work by Leon Festinger (1954) revealed the influence of social comparisons upon our opinions and attitudes. Festinger suggested that individuals are driven to evaluate their attitudes and opinions against the attitudes and opinions of comparable peers (others they feel are like them). More recent work has supported the continuing influence of social comparison theory (Suls & Wheeler, 2000; Suls & Wills, 1991). Some researchers have suggested that individuals attempt to reduce uncertainty through social comparison. Specifically, it has been suggested that uncertainty among individuals arises when similar peers disagree with them. Likewise, uncertainty is

reduced when individuals believe that similar peers agree with them or they can see themselves agreeing with similar peers (Abrams, 1996; Turner, 1991).

It should also be noted that this study directly asked what the participants perceive to be their reasons for deciding to live in an LGBT-specific CCRC. People may have hidden objectives for their decisions unknown even to them (Keeney, 1992). Given that, narrative analysis was strategically used for this study because it may help to uncover underlying motivations for the decision that may be unknown even to the participants.

The Experience of Homophobia as Antecedent to Long-Term Care Decisions

Homophobia is the unreasonable fear of, hatred toward, and intolerance of homosexuality (Weinberg, 1972). The identity development of today's older lesbians occurred against significant external homophobia and often discrimination and trauma. Homophobia and discrimination continue to be a part of lesbians' life experiences and expectations. Older lesbians (as do all gays and lesbians) have to navigate through and function within systems that are generally heterosexist. Heterosexism is an ideology promoting the denial, denigration, and stigmatization of non-heterosexual behavior, identity, relationships, or communities (Herek, 1992).

Homosexual and bisexual individuals report more lifetime and day-to-day experiences with discrimination than their heterosexual counterparts (Mays & Cochran, 2001). In a sample of 416 older (aged 60-91) gays, lesbians, and bisexuals, D'Augelli, Grossman, Hershberger, and, O'Connell (2001) found that 63% had experienced verbal abuse, 29% threats of physical violence, 20% employment discrimination,16% assault, and 7% housing discrimination within their lifetimes. Herek, Cogan, and Gillis (2002) found that 94% of their survey sample had been victims of hate crimes related to sexual orientation. D'Augelli and Rose (1990) found that 75% of the participants in their study had experienced verbal abuse and almost all expected future experiences of homophobia and harassment based on their sexual orientation.

Anti-gay behavior may not in fact be intended to cause harm to homosexual people. Heterosexual people who use anti-gay language for example are not always strongly anti-homosexual (Burn, 2000). Even when anti-gay language is not used to be intentionally harmful to homosexual people, it may still be experienced as harassment and contribute to stress in homosexual people (Burn, Kadlec, & Rexer, 2005).

Expectations of Homophobia

Expectations of experiencing homophobia and discrimination can affect homosexual persons' life experiences and choices. Two strong contributors to the fear of victimization are past experiences of personal and/or property victimization and homonegative environments (Otis, 2007). Most lesbians experience some form of discrimination during their lives as a result of their sexual orientation and are quite vulnerable to stressors related to that (Brooks, 1981; diPlacido, 1998; Lewis, Derlega, Bernd, Morris, & Rose, 2001; Meyer, 2003). Homosexual persons actively assess the levels of homosexual prejudice in the heterosexual people they encounter. Positive contact with heterosexuals has been associated with increased levels of comfort and openness by homosexual people (Conley, Devine, Rabow, & Evett, 2002). Researchers have found that subtle or perceived heterosexist attitudes are associated with a decreased openness of homosexual people (Burn et al., 2005). Fear of homophobia and discrimination has caused many lesbians to remain closed about their identities over the years.

The Experience of Internal Homophobia as Antecedent to Long-Term Care Decisions

Internal homophobia can be understood as the negative feelings (resulting from homophobia) that homosexuals might experience and manifest towards themselves relating to their homosexuality. In a systematic review of research on internal homophobia, Williamson (2000) used the term to represent the negative and distressing thoughts and feelings experienced by lesbians and gay men about their sexuality, which

are attributed to cultural heterosexism and victimization. Szymanski and Chung (2001) stated that for lesbians, internalized homophobia is comprised of five dimensions: (a) connection with the lesbian community, (b) public identification as a lesbian, (c) personal feelings about being a lesbian, (d) moral and religious attitudes toward lesbianism, and (e) attitudes toward other lesbians. They also pointed out that high levels of internalized homophobia have psychological results for lesbians such as lower self-esteem and greater loneliness. In a survey study of 116 lesbians, Fingerhut, Peplau, and Ghavami (2005) found that lesbian identity was significantly and negatively associated with internalized homophobia ($r = -.42$, $p < .01$). Specifically, lesbians who had explored the meaning their lesbianism held for their lives and who held positive feelings about the lesbian community and participated actively in it scored lower on internalized homophobia. Possibly due to continuing and pervasive effects of homosexual stigma and heterosexism, lesbian shame is present even in those who are well-educated, successful, and have high levels of lesbian identity integration (Wells & Hansen, 2003).

Lesbian Invisibility as a Strategy for Coping with Homophobia and Discrimination

Fear of experiencing discrimination can reinforce social isolation, placing the older LGBT adult at higher risk for self-neglect, decreased long term quality of life, and increased mortality. For many older lesbian couples, choosing to remain invisible may have seemed and may still seem a safer option than being open about their relationships and risking harm. Lesbian invisibility contributes to increased vulnerability, and this has been associated with decreased societal and environmental resource availability, social connectedness, and access to health care (Saunders, 1999). The increased vulnerability manifests itself in risks of violence, HIV, cancer, and addiction.

Emotional Health, Stress, Depression:

Areas of Potential Health Disparity

Past researchers have suggested that lesbians are at increased risk for mental health issues (Diamant & Wold, 2003; Koh & Ross, 2006; Matthews, Hughes, Johnson, Rozzano & Cassidy, 2002; Oetjen & Rothblum, 2000; Rothblum, 1990). Matthews et al. in their regression analyses showed a clear, direct, and independent association of lesbian sexual orientation to four indicators for depression (Ever Received Therapy $P < .001$, Treated for Depression $P < .001$, Suicidal Ideation $P < .001$., Suicide Attempts $P < .01$). Matthews et al. suggested that other factors not included in the model (internal homophobia, self esteem, levels of support) may contribute to or mediate depression in lesbians and that continued research is needed. Discrimination has been found to be related to mental health issues for lesbians (Mays & Cochran, 2001). Mays and Cochran specifically found that the odds of having any psychiatric disorder were significantly increased in individuals reporting any lifetime discriminatory event (adjusted OR = 1.60; 95% CI = 1.29, 1.99) or any day-to-day experiences with discrimination (adjusted OR = 2.13; 95% CI = 1.69, 2.68), after adjustment for possible confounding demographic variables.

A mediator for mental health issues among lesbians is social support. Oetjen and Rothblum (2000) found that lack of social support from friends for lesbians was a significant predictor for depression. Their regression analysis showed that as the levels of social support from friends increased for their sample, depression decreased ($n = 167$, $r^2 = -.301$, $p = <.0001$).

Other Potential Health and Health Care

Disparities of Older Lesbians

One of the overarching goals of Healthy People 2010 is the elimination of health disparities (United States Department of Health and Human Services, 2000). Sexual orientation as a nonheterosexual woman has been associated with increased rates of poor

physical and mental health (Diamant & Wold, 2003), but the exact relationship is poorly understood and therefore more research is needed. Length and quality of life is the second overarching goal of Healthy People 2010 (United States Department of Health and Human Services). The potential health disparity is significant because length and quality of life may be seriously affected for older lesbians. It has been shown that lesbians have higher rates of alcohol use and smoking (Burgard, Cochran, & Mays, 2004; Cochran, Keenan, Schober, & Mays, 2000; Diamant, Wold, Spritzer, & Gelberg, 2000; Rankow, 1995; Valanis et al., 2000,) as well as obesity (Cochran et al, 2001; Yancey, Cochran, Corliss, & Mays, 2003). Higher rates of smoking, alcohol use, obesity, and lower parity rates, were found to increase lesbians' risks for a wide range of cancers and chronic disease (O'Hanlon, Dibble, Hagan, & Davids, 2004).

The Relationship of Prevention to Health Disparities for Older Lesbians

Lesbians are less likely to seek out and use preventive health care and screening than heterosexual women (Aaron et al., 2000; Bergeron & Senn, 2003; Cochran et al., 2001; Ellingson & Yarber, 1997; Hutchinson, Thompson, & Cederbaum, 2006; Lauver et al. 1999; Marrazzo, Koutsky, Kiviat, Kuypers, & Stine, 2001; O'Hanlan, 1995). This has been shown to include such critical screenings for women as pap smears and mammograms (Bergeron & Senn, 2003; Lauver et al., 1999). Delays in seeking care are serious as they can result in the unnecessary experience of more debilitating illnesses and thus significant health disparities for the lesbian population. Access to providers, as well as experiences and interactions with them, are antecedents to lesbians' low rates of using preventive care services and screening compared to rates of heterosexual women (Hutchinson et al., 2006).

The Relationship of Risk to Health Disparities for Older Lesbians

Lesbian women have demonstrated different patterns of health risk than those of their heterosexual counterparts (Cochran et al., 2001; Solarz, 1999; Valanis et al., 2000). For example, lesbian women were found to have a potentially double to triple risk of breast cancer compared to other women (Solarz, 1999; Valanis et al., 2000)). Despite this potential health disparity, lesbian women were less likely to receive mammograms (Cochran et al., 2001; Lauver et al., 1999). In terms of risk factors for cancers, lesbian women demonstrated lower parity rates as well as lower rates of birth control use and because of this were less likely to have gynecological examinations (Cochran et al., 2001). Cochran et al. (2001) found that lesbian women were less likely to have had a pelvic examination in the last two years than that of the general population of women. Marrazzo et al. (2000) are among the researchers who have also reported that lesbians may not have adequate screening for cervical cancers. Many researchers have reported that the lack of gynecological examination and cervical cancer screening stems from the misperception on the part of both lesbian women and their care providers that they are not at risk and do not need the screening because they do not have sex with men (Marrazzo et al., 2000; Phillips-Angeles et al., 2004,).

Compared with estimates for the general population, lesbian women have a greater prevalence of obesity (Cochran et al., 2001; Yancey, Cochran, Corliss, & Mays, 2003). Lesbians also were shown to have higher rates of alcohol and tobacco use (Burgard, Cochran, & Mays, 2004; Cochran, Keenan, Schober, & Mays, 2000; Diamant, Wold, Spritzer, & Gelberg, 2000; Rankow, 1995; Valanis et al., 2000).

Higher rates of smoking, alcohol use, and obesity as well as lower parity rates were reported to increase lesbians' risks for a wide range of cancers and chronic disease (O'Hanlon, Dibble, Hagan, & Davids, 2004), and therefore are potential antecedents to health disparities. Deevey's (1990) sample of women over the age of 50 revealed similar

health issues of "infrequent breast self examination, high alcohol consumption, extra weight, and skepticism toward both traditional health care and health promotion" (p. 36-37).

Access and Health Care Disparities for Older Lesbians

Deevey, (1990) pointed out that older lesbian women experience a triple minority status (age, gender, sexual orientation) that renders them marginalized.

Stevens (1993) stated that:

> Access to care implies services that are affordable, geographically available, and culturally appropriate. Access for groups placed in society's margin by gender, race, income, sexual orientation, illness, disability, or age has not been guaranteed (p. 315).

Lesbians are significantly at risk for poor health care access (Heck, Sell, & Gorin, 2006). Lesbians were also found to be less likely to have health insurance or a primary health care provider and to be more likely to have health needs that are not met (Heck et al., 2006; Rankow, 1995). Fear of discrimination and homophobia, whether based on previous or current experience with health providers, has been shown to keep many gay, lesbian, bisexual and transgendered persons from seeking care (Clark, Lander, Linde & Sperber, 2001).

Financial constraints impose yet another barrier to health care utilization for older lesbian women. Many rely heavily on Medicare, and much of their health care expenses are out-of-pocket costs such as for prescription drugs. The history of limited or no health insurance also contributes to disparity in the utilization of preventative health care. Lack of health care insurance has been associated with lesbians' low use of preventative health care services (Cochran et al., 2001; Lauver et al., 1999; Marrazzo et al., 2001; Rankow & Tessaro, 1998). Cochran et al. (2001) found that lesbians who had health insurance were

more likely to have had a pelvic examination in the last two years than lesbians who had no health insurance. Additionally, health care insurance coverage for lesbian couples was found to be generally more expensive because in most cases they still have to have separate health insurance versus experiencing the discounted premiums most providers extend to married heterosexual couples and their children (Denenberg, 1995; Roberts et al. 1998). Considering the career-long differences women have experienced in earnings compared to the earnings of men, it is not surprising that lesbian women would experience greater financial impediments to quality health care (Diamant et al., 2000; Orel, 2004). These financial impediments can be particularly problematic for older adult lesbian women with limited financial resources and on fixed incomes.

Communication and Health Care Disparities for Older Lesbians

An open and supportive health care environment has been demonstrated to be highly important to and valued by lesbians (Lauver et al., 1999; Stevens, 1994; Stevens & Hall, 1988). Past research has found that disclosing and discussing important personal health-related information with care providers was particularly difficult for lesbians as compared to gay males (Klitzman & Greenberg, 2002). Lesbian's perceptions of practitioner's attitudes toward their sexual orientation were found to be antecedents to self disclosure with health practitioners (Barbara, Quandt, & Anderson, 2001). Older adult lesbians may be particularly closed with their health care providers about their orientation because of experiences with "homophobic violence, legal or medical discrimination, religious condemnation, or family rejection" (Deevey, 1990, p. 35). Since older gays and lesbians grew up in an era when few dared to venture out of the closet,

they may carry on an aura of secrecy (Brower, 1995). Lack of communication is also a potential consequence of provider behaviors and attitudes. Prejudicial attitudes of health care professionals toward the LGBT population and perception of such prejudice are both identified as barriers to care. Providers' attitudes and lesbians' perceptions of providers' attitudes have a great impact on help-seeking and preventive care-seeking, as well as quality of care (Bergeron & Senn, 2003; Millman, 1993; Stevens,1996; Rankow & Tessaro,1998;).

The lack of access to and communication with health care providers has serious potential health ramifications for older lesbians. This can be easily amended through culturally sensitive and competent care. Many lesbians feel unable to trust their provider's judgment when they do not give the provider a complete picture of themselves (Barbara et al., 2001). Many lesbians would prefer to be open with their providers, but the barriers are great. Orel (2004) stated that members of her focus groups reported having more positive health care experiences when they shared their orientation with their providers. However, it should be noted that according to the participants, they had to initiate that area of discussion because in their experience the providers never would (p. 64). Providers continue to demonstrate misconceptions and attitudes that produce barriers to caring for their lesbian clients.

Health Care Providers and Health Care Disparities for Older Lesbians

The attitudes, knowledge and cultural competence of providers in delivering care to lesbians are antecedents to lesbians' health care practices and levels of health. Provider attitudes toward homosexuality impact the quality and range of services provided to gay

and lesbian clients (O'Hanlan, Cabaj, Schatz, Lock, & Nemrow, 1997; Schwanberg, 1996). According to reports by participants in Saulnier's (2002) study, providers' attitudes toward lesbians ranged on a continuum from least to most positive, including: homophobic, heterosexist, tolerant lesbian sensitive, and lesbian affirming. Expectations and experiences with these health provider attitudes affected lesbian's choices about who to see as a provider. Even in Canada, where civil unions between lesbians are recognized by the governments, and there are no financial barriers to preventive care for lesbians, Mathieson, Bailey, and Gurevich (2002) revealed that lesbians avoided care to keep themselves from having to deal with any mental and physical harm from potentially homophobic providers. They also found that while study participants recognized screenings such as breast exams and pap smears as important, they rated general physical exam as the most important preventive practice. This would indicate that providers' may have an opportunity in the general physical exam to exert significant influence over lesbians' health care decision making.

Dibble and Roberts (2003) stated that:

> For women who may put off health care for fear of having their sexual orientation discovered and recorded or because they have found hostility within the healthcare system because of their sexual orientation, the use of specialized educational programs is vital (E77).

This means that targeted health care programs focusing on the health and needs of lesbians are a critical component in increasing lesbians' health care access and decreasing potential health disparities. Dibble and Roberts (2003) studied a lesbian-specific educational program on preventive cancer screening led by a lesbian physician. Follow-up data revealed an increase in mammograms, self-breast exams, and pelvic exams in the targeted members suggesting that lesbian-specific interventions can increase positive

health behaviors (E78). This culturally innovative model could be used to address many other health issues for lesbians including but not limited to obesity, alcohol issues, smoking, and setting up legal rights and protections for health care decision making.

Respondents in Hash's (2006) qualitative study of the experiences of midlife and older gay men and lesbians caring for same-sex partners expressed that while attributing some poor health care treatment to homophobia, much was believed to result from a health care system that has become far too impersonal. Additionally, these respondents experienced further discrimination based on race, age, mental health status, and HIV status.

Providers' knowledge of the unique risks and health behaviors of lesbians as well as the delivery of culturally sensitive and competent care could be critical in preventing health disparities for the lesbian population. More research in terms of provider outreach interventions with the lesbian population is definitely needed. While health disparities are potential consequences of lesbian risk and prevention behaviors, health care access limitations, and the impact of providers on lesbian health decision making, health disparities are antecedents to issues regarding lesbian aging and elder care.

Aging Issues Surrounding the Elder Care Decision Making of Older Lesbians

Many studies have examined perceptions and concerns about aging among older gays and lesbians. One concern among many LGBT seniors is that they will not have access to caregiving when needed (LGAIN, 2006). Orel (2004) found in a sample of 25 gay men and lesbians that all participants were concerned about future care. Pride Senior Network (1999) found that 64% of their 98 New York City gay and lesbian survey

respondents under age 50 were able to identify someone they could rely upon for help and care in a time of need, and 68 % of those over age 50 could not. Rural older lesbians have expressed particular concerns about isolation from social and health care resources as mobility decreases (Comerford, Henson-Stroud, Sionainn & Wheelter, 2004).

Despite these varied concerns about lack of access to care, many LGBT seniors were found to refuse to consider assisted living, long term care facilities, or even adult day care services due to the belief that staff at such facilities would not be adequately knowledgeable about issues of concern for older LGBT adults (McFarland & Sanders, 2003). Gay, lesbian, bisexual and transgendered older adults were shown to perceive that discrimination in retirement care facilities exists and that nondiscrimination policies in retirement care facilities do not exist (Johnson, Jackson, Arnette & Koffman, 2005).

There are only a limited number of elder care facilities and services that have established policies to address homophobia, and this has left many LGBT elders vulnerable to life in hostile and dangerous environments (Cahill, Ellan, & Tobias, 2002). A 1994 survey found that 96% of 24 different area agencies on aging did not offer any services specifically designed for gay and lesbian elders and did not target outreach efforts to lesbian and gay seniors. Only 17% of those agencies reported staff training in the area of sexual orientation (Behney, 1994). A survey of social workers at 29 different nursing homes in the state of New York revealed negative attitudes toward LGBT residents among nursing home staff. Specifically 34% of the social workers said staff's attitudes toward sexuality in general were mixed, and 45% said they were negative. When explicitly asked about staff attitudes toward homosexuality, 52% said staff attitudes were intolerant or condemning, and they offered specific comments such as

"homosexuals are very much in the closet…staff would be horrified" and "we don't allow partners of the same sex into the home." Only one of the 29 care facilities had cultural competency training regarding sexual orientation (Fairchild, Carrino, & Ramirez, 1996).

De Vries (2005) found that gay and lesbian elders are more likely to be guarded in communications with health care providers, have higher levels of illness and disability bringing them into contact with providers, and have concerns about future care. Fear of discrimination by health care providers has been found to cause many lesbians to avoid needed health care services (Lauver et al., 1999; Mays & Cochran, 2001). Avoidance of needed health and elder care services may serve to widen potential health disparities between lesbian and heterosexual women as they age.

Provider's attitudes and behaviors can be antecedents to the experience of elder care for older lesbians. If providers take the position that the sexual orientation of a resident is a "private matter" and "none of my business," the concept of privacy in this context has been shown to serve as a barrier to understanding clients and their life experiences and understandings (Harrison, J., 2001, p. 143). Gay and lesbian older adults are showing an interest in gay friendly aging care. Gay-exclusive retirement communities are sprouting up in different parts of the country in response to this interest. Not unlike their heterosexual counterparts, LGBT baby boomers are clear about their desire to live old age and end of life in their own homes (LGAIN, 2006). Considerable benefits of aging in place (remaining in your own home) with in-home health care supports to do so, have been noted. Marek et al. (2005) found that their sample of participants who were aging in place stabilized or improved on all outcome measures (cognition, depression,

incontinence, functional status, and pressure ulcers) compared to declines in outcomes seen in their matched nursing home comparative group.

Cahill et al., (2000) provided an excellent context for the concerns surrounding gay and lesbian aging:

> As GLBT people grow older and rely more and more on public programs and social services for care and assistance, they may have less independence from heterosexist institutions. The fear of experiencing discrimination can reinforce social isolation, placing people at higher risk for self-neglect, decreased long-term quality of life, and increased mortality risk. (p. 17).

Many LGBT adults may age with crisis competence. They have experienced a great deal of crises and pain in their lives as a result of homophobia and discrimination, and because of those experiences have learned life skills to help them with the challenges of life, particularly ones they may face in old age (Cahill & South, 2002; Wahler & Gabbay, 1997). Crisis competence among some LGBT older adults may lead to creative problem solving and solutions to fears and concerns that they may have regarding many issues of aging, including elder care. Almost 40% of respondents in the LGAIN study (2006) believed that their sexual orientation had helped them prepare for some of the challenges of aging.

The Impact of Policy and Legal Issues

Many federal laws, including health care legislation, are designed to financially aid American couples but actually discriminate against homosexual couples (Bennett & Gates, 2004; Cahill et al., 2000; Cahill et al., 2002; Human Rights Campaign, 2008). For example, LGBT seniors are at significant risk of losing their home when the partner enters a nursing home. Federal Medicaid law permits a married spouse to remain in the couple's home yet does not grant unmarried couples the same right (Bennett & Gates, 2004; Cahill et al., 2000;). Additionally, same sex couples are currently ineligible for

social security survivor benefits when one of them dies (Cahill et al., 2000; Human Rights Campaign, 2008). Federal tax laws also discriminate against LGBT couples (Badgett, 2007; Cahill et al., 2000). Unlike the protections afforded to heterosexual widowers, LGBT seniors are denied the right to roll over an inherited retirement plan into their own. Instead, they are forced to take the entire payout of the funds in a lump sum, be subject to immediate taxation, and therefore are pushed into a higher tax bracket (Human Rights Campaign, 2008). These laws are discriminatory because heterosexual unmarried couples may be legally married while LGBT couples are not allowed to be in most states.

Unless legal marriage or some sort of comparable alternative is recognized in states, there are generally no legal protections afforded to lesbian couples. This is significant, because it depends on the couple to seek out their own legal protections in the form of living wills, power of attorney, etc. In situations where couples have not made these arrangements, their involvement in each other's care can be seriously compromised leading to unnecessary stress and often tragic experiences. The informed and culturally competent health care provider has a great opportunity to make a significant impact on the lives of older lesbians by providing education and making appropriate referrals to address these important disparities in aging.

Social Networks as Experience of and Strategy for Support

The formation of support networks has been found to be basic to lesbian living (Comerford, Henson-Stroud, Sionainn, & Wheeler, 2004). These support networks are critical for lesbians (Aronson, 1998; Grossman, D'Augelli & Hershberger, 2000;

Weinstock, 2000) and are likely to become more so as a lesbian ages. When lesbians are in caregiving roles, unsupportive professionals and family members may add to the strain of caregiving, while supportive professionals and family were found to serve as buffers to caregiver stress (Hash, 2001, p. 93).

Social support and social stressors specifically linked to sexual identity are associated with psychological wellbeing for lesbian women as well. High levels of identity support result in higher self-esteem and life satisfaction as well as lower levels of depression for lesbians (Beals & Peplau, 2005).

Beals and Peplau (2005) expressed well the significance of social support for lesbians:

> Of special significance for lesbians may be interactions relevant to a woman's socially stigmatized identity as a sexual minority person. Feeling that other people understand and support her identity should enhance a lesbian's mood, self-esteem, and satisfaction with life. In contrast, feeling that people are uncomfortable or negative about her being a lesbian should detract from a woman's well-being (p. 140).

Specifically, Beals and Peplau (2005) found that, among their sample of 34 self-identified lesbian women, identity support was indeed significantly positively associated with concurrent life satisfaction ($r = .44$, $p < .01$) and overall well-being ($r = .66$, $p < .0001$), and identity devaluation was negatively correlated with concurrent life satisfaction ($r = -.41$, $p < .05$) and overall well-being ($r = -.48$, $p < .01$) (p. 143-144).

This may be particularly true in relation to support from family for lesbians. Lesbian couples have reported experiencing more stress compared to gay male couples relating to family rejection and lack of understand and support (Todosijevic, Rothblum, & Solomon, 2005). In fact, gay men in civil unions have reported more closeness to their families of origin compared to lesbian couples (Solomon, Rothblum & Balsam, 2004). Lesbian and gay elders were shown to specifically believe that the importance they have

placed on support networks as a consequence of their sexual orientation will help them in their older age (LGAIN, 2006). More than 75% of the sample in the LGAIN (2006) study stated that they currently rely on the support of nonfamily support networks.

There is a growing consensus regarding the importance of social ties on older adult well-being. Social ties have a significant impact not only on the mental but also the physical health of older adults (Lubben & Gironda, 2003). The recent emergence of LGBT retirement facilities may result not only from the experiences and elder care expectations of LGBT baby boomers but may also be a strategy for securing social ties as they age.

Summary

This literature review provided an overview of the framework prompting this study. It discussed my pre-analysis assumption that older lesbians use their experiences and expectations to interpret their potential future elder care circumstances within the context of their lives. The pre-analysis assumption is that those experiences and expectations include homophobia, discrimination, invisibility, health and care disparities, and the significance of social support networks. In addition to drawing from those experiences and expectations, older lesbians also use the aging issues they are experiencing to identify those circumstances that require interventions as they relate to future elder care, to make decisions about elder care strategies to manage those circumstances, and to predict the outcomes of those elder care decisions.

CHAPTER III

RESEARCH DESIGN, METHODS AND ANALYSIS

Research Design

This study combined two qualitative strategies (across-case thematic analysis and within-case narrative analysis) to investigate themes in the accounts of older lesbians regarding what has impacted their decisions to live in a continuing care retirement center (CCRC) that specializes in services for the lesbian, gay, bisexual, and transgender (LGBT) population. Themes that were identified in the across-case analysis were interpreted in the context of patterns in the narrative analysis. A convenience sample of older lesbian women who have registered to live in a CCRC specializing in LGBT care was used. These were information-rich cases, and they provided extensive data regarding the phenomena of interest.

Methods

Setting

The setting in which the participants for the study have committed to live is an LGBT specific CCRC in Western United States. A CCRC is a retirement arrangement in which residents have a range of services available to them on site from independent to assisted living and nursing home care. This assures residents that they can remain in the same setting regardless of a future change in their care and support needs. The project is still under construction with an unknown completion date. Currently, interested individuals can secure a unit by making a substantial monetary reservation. The older lesbian participants in my study have made the commitment to live in the CCRC by making this monetary reservation. Between 100 to 150 units of varying styles and sizes, as well as an assisted living care center are planned as part of the project. Depending upon the style and size of the chosen independent living unit, entrance fees can be anywhere from approximately three hundred thousand to a million dollars, making it unaffordable for many seniors of middle to lower income. Monthly fees are additional

and can range from approximately two thousand to five thousand dollars, depending upon the style and size of the chosen unit as well as the amount of care support needed at any point. Monthly fees change with increasing care support. The projected costs of this living arrangement are comparable to that of an existing non-LGBT specific CCRC designed and owned by the same company.

Sampling

Qualitative researchers are interested in and sample for meaning, frequently working with small samples of participants nested in their context and studied intensely and in depth (Holloway & Wheeler, 2002; Miles & Huberman, 1994; Morse, 2007; Sandelowski 1995, 1993, 1991; Tesch, 1990). The intent in this study is not to provide generalizability in a positivist empirical sense (Denzin & Lincoln, 2005; Lincoln & Guba, 1985; Patton, 2002; Sandelowski 1995, 1993, 1991) but an in-depth understanding of what has impacted the decision making of a group of older lesbians who have decided to live in an LGBT CCRC. While prepared to recruit and interview as many participants as needed, ten was the number recommended by a narrative analysis nurse researcher who was an insider to the community from which the sample was being drawn and was experienced in conducting qualitative research with lesbians. Her recommendation held as data saturation was indeed reached with ten participants.

Sandelowski (1995) states that people participate in qualitative studies because they have direct and personal knowledge of a phenomenon and they want to communicate that. This was a convenience sample of lesbian adults who have committed financially to living at a specific CCRC. The participants were selected because they met both experiential fit (they are experts undergoing the experience of interest) (Morse, 2007) and were willing to be interviewed and participate in the study. It was a convenience sample in that the participants were recruited by a member of the advisory committee of the CCRC and were only those older lesbian future residents of the CCRC who volunteered to participate.

This strategy provided direct access to the specific location and group of potential participants I was interested in. While convenience sampling is considered a weakness in quantitative empirical studies, and even some qualitative researchers have argued against its use (Patton, 1990), there are situations in which convenience samples are an acceptable way to proceed (for example, when studying marginalized populations that are difficult to access, instances in which a population is a rarity, or for populations and phenomenon that have not been studied previously) (Phua, 2004; Weiss, 1994). These were all factors in this study. Older lesbians are a marginalized, often difficult-to-access population, and the sample was unusual in that all participants had a commitment to live in an LGBT-specific CCRC. Further, this has not been studied previously. Something unanticipated but very remarkable happened with this group of participants. This sample, in fact, was found to be quite homogenous with similar backgrounds and described experiences. Additionally, all the participants were either known acquaintances or close friends who had been discussing the issue of retiring together for years. The closeness of the sample members and their homogeneity in terms of background, described experiences, and shared stories helped to strengthen the analysis.

All 10 potential participants volunteered for the study. They ranged in age from 55 to 68. They were homogeneous racially and economically. All were self-identified as well-educated and middle to upper middle class in income. Nine participants were white. One participant was African American (see Table 1).

Inclusion Criteria

Inclusion criteria were: (a) self-identified lesbian women, (b) age 55 or older, and (c) committed future residents of the CCRC.

Exclusion Criteria

Exclusion criteria were: (a) self-identified bisexual and transgender women. Table 1 displays the demographic characteristics of the sample.

Table 1. Demographic Characteristics of the Sample

Characteristic	Of 10
Lesbian (self-identified)	10
Partnered	10
Age 55-60	2
Age 60-65	6
Age 65 >	2
Middle income (self-identified)	8
Upper middle income (self-identified)	2
College educated	10
Biological children	0
White	9
African American	1

Procedures

Human Subjects Protection

This is a marginalized population that has faced homophobia and discrimination as a result of their sexual orientation. Potential breeches of confidentiality that would reveal their identity were the primary risks of being in the study that they identified. Therefore, the Institutional Review Board of the University of Iowa was asked and agreed to waive the requirement of a signed informed consent. In this way, no proper names or specific identifying information will be attached to the study records.

Recruitment

Potential participants were identified by an advisory member of the CCRC facility. This advisory member approached known persons who met the inclusion criteria and provided them information about the study. Those potential participants who were interested provided me with their contact information (Appendix C).

I then mailed each interested participant a packet of study materials including a project information sheet and a subset of the interview questions (Appendix D). Finally, I telephoned each potential participant to further describe the study, answer questions, and set the date for the study interview if they were interested in proceeding (Appendix E). All of the 10 potential participants volunteered to be in the study. Participation in the interview constituted consent.

Interviews

Face-to-face interviews of participants were conducted by me in their homes or other locations of their choosing. Eight of the 10 participants were interviewed in their homes. Two chose to be interviewed in a private location at their place of employment. The interview began with a description of the study and the statement that proceeding with the interview would constitute consent. They were asked to confirm that they understood and were willing to proceed.

The interviews were based on a semi-structured interview guide (Appendix F) so that each participant was responding to the same set of questions. I used open-ended questions to give the participants the opportunity to respond with their individual stories. The interview guide was specific enough to seek essential information regarding what had affected informants' decisions to live in an LGBT-specific CCRC and yet was broad enough to encourage individual variation. While they contain the structural elements of the original conceptual framework, the questions go beyond the conceptual boundaries of that framework in order to allow for discovery and the emergence of a new framework.

A multipart example question from the interview guide that specifically addressed both Aim I (to describe what has impacted older lesbians' decisions to live in an LGBT CCRC) and Aim II (to describe factors that both positively and negatively impact older lesbians' perceptions of elder care) was:

1. How did you come to decide to retire here?

What things did you consider in making that decision?

What other options have you considered?

What are the hopes that have influenced the decision?

What are the concerns that have influenced the decision?

What has had the greatest influence on this decision?

This question explores Aim I by not only asking directly what participants felt has had the greatest impact but by exploring in depth other options that they may have considered as well as their hopes, experiences, and expectations surrounding the decision. It also indirectly addresses Aim II by exploring the participants' hopes and concerns about the decision to live in the LGBT CCRC.

An example question from the interview guide that specifically addressed an aspect of the original conceptual framework for the study was:

1. Tell me stories about you and your relationships with family and friends.

This question specifically addressed the potential role of support and community in the participant's life.

Example questions from the interview guide that went beyond the boundaries of the original conceptual framework and allowed for the emergence of ideas never considered by this investigator were:

1. Can you think back to the time when you began to think you might be lesbian? Tell me the story of when you first realized you were a lesbian. Tell me any stories you can think of regarding that time.
2. What did I not ask that you think I should know about?

These questions do not address the aims directly, nor do they address in a direct way any aspect of the original framework. What they do attempt to allow for is the free expression on the part of the participant to tell their story beginning in a temporal manner. All interviews actually began with the first question, evolving from that point. The interviews all concluded with the second question.

Neutral probes were also used to give participants the opportunity to illustrate their answers with additional stories or to provide evidence for particular conclusions they drew. Examples of neutral probes that provided this opportunity for the participants were statements such as: “Tell me more about that,” “What happened then?” and “What was that like for you?”

The interview guide was intended to support the integrity and validity of the study’s results. The range and depth of the questions were aimed at preventing a scenario of simply eliciting confirmation of the original conceptual framework of the study. Instead, a strategic effort was made to facilitate the emergence of ideas and a new framework that I might have never considered prior to hearing the participants’ stories.

Data Security

All interviews were digitally tape recorded. These recordings were immediately backed up onto a password-secured laptop. The interviews were also transferred from the laptop to CDs. These were kept in a locked portable cabinet where I kept all hard copies of documents pertaining to the study. These were temporary measures to provide data security while traveling to and from the locations for the interviews. All interviews were transcribed verbatim. As a more permanent measure of data security, all digital and hard copy data files were stored on the secure server at Illinois State University and were not

kept in my home office or on my home computer. Illinois State University was used because I am a faculty member of the College of Nursing at Illinois State and do not live in Iowa City, making data storage on the University of Iowa server impractical.

All participants were identified by a numeric code (1-10) that was used to label interviews. Any proper names in the text (for example, names of children, providers, or institutions) were extracted and/or changed to neutral terms (for example "my partner" instead of the individual's proper name). The interviews were transcribed by a professional transcription service.

Analysis

Narrative Analysis

Narrative inquiry is a form of qualitative research in which the stories of participants are the focus of analysis. The telling of stories about their lives is considered a primary way by which people make sense of, give meaning to, and share their experiences (Bruner, 1991; Duffy, 2007; Reissman, 2002; Sandelowski, 1991).

A narrative is the created structure chosen by each narrator for the telling of the narrator's own story. Narrative analysis is an interpretive strategy focusing on and attending to plot. In other words, the narrative analyst is concerned with the structuring of the story and how events told by the narrator in story unfold temporally. How narrators plot their stories gives us clues to the meaning their stories have for them (Poirier & Ayres, 1997). The narrative researcher has been given the privilege of being entrusted with participants' stories. Therefore, it is imperative that we provide an interpretation that is at once trustworthy and also recognizes that privilege and the responsibility attached to it and is true to each participant's unique story (Ayres & Poirier, 1996).

Narrative research explores both the meaning that individuals give to their experiences (Sandelowski, 1991) and the "interface of personal and social identity" (Duffy, 2007, p. 401). Because decisions result from personal and social processes and probably reflect individuals' perceptions of personal and social identity, narrative

analysis is a particularly useful method for exploring the phenomenon of decision making, as in this study.

The goals of the analytic process were to find commonalities as well as variations within and among the stories of the respondents. To that end, a within-case thematic analysis and an across-case narrative analysis approach were used (Poirier & Ayres, 1997). In the within-case analysis, there was a focus on implicit meaning rather than only the explicit meaning in the interview text. This was accomplished through a technique of narrative analysis known as overreading (Kermode, 1981). This is a deliberate act of interpretation (Poirier & Ayres,1997) where the investigator looks for meaning that is implicit rather than only explicit in the interview text (Ayres, 1998; Ayres, Kavanaugh, & Knafl, 2003, Poirier & Ayres, 1997) demonstrating a sensitivity to unspoken or indirect statements and attending to inconsistencies, endings, repetitions, and silence (Poirier & Ayres, 1997). In this way, rather than taking the truth and reality of what has affected the participants' decision making to be a matter of what the participants say it is at face value only, I instead undertook an intense and iterative process of coming to understand the participants' decision making. Overreading in this study, as for that of previous narrative investigators, was the rigorous process by which the topics and subtopics that were initially separated from the context of the original stories were compared across cases and reintegrated (Ayres, 1998). They were essentially decontextualized and ultimately recontextualized.

I attempted to identify repetitions in which particular words or phrases recurred in interviews, omissions in which salient topics were avoided (for example, a respondent answering an interview question with a story on another topic), and incongruencies in which assertions or beliefs stated in one portion of the interview were contradicted in another portion. Repetitions, omissions, or incongruencies occur within the boundaries of an individual account (Ayres, 2000), and the analysis was grounded in a close reading of individual cases and extended by thematic comparisons across cases.

Data Management

The analysis occurred in many cycles beginning first with a process of total immersion in the data by reading each individual interview multiple times. After the first several readings, and with each subsequent reading, the data were reduced and further reduced to categories with topics and subtopics emerging from constant comparative analysis (Lincoln & Guba, 1985). Table 2 displays the categories, topics, and subtopics I identified. I then used categories, topics, and subtopics from individual interviews to track themes and patterns across cases. At the same time, I conducted within-case comparisons on each topic within each informant's account.

It is important to note that narrating is a creative act. Narrators choose the details, events, characters, and perspectives for the stories they tell about their lives. These decisions reflect the meanings that the narrators give their stories. In narrative research, the narrative analyst interprets these stories and decisions by the participant narrators and invests them with further meaning (Sandelowski, 1991). This iterative process of meaning-making by both the narrator and narrative analyst and the comparisons made by the analyst at all levels in all accounts is what is known as the *hermeneutic spiral* (Ayres, 1998; Poirier & Ayres, 1997; Sandelowski, 1991; Tesch, 1990). The analyst's role in this process was first described by Tesch when she explained that in the hermeneutic spiral "the analyst moves back and forth between individual elements of the text and the whole text in many cycles" (p. 68). This rigorous process of reflection and reinterpretation enabled me to track thematic variation as well as commonality across cases without stripping away the individual context essential to narrative inquiry (Ayres et al., 2003).

The integration of these analyses led to identifying the significance of past experiences (positive and negative) related to the participants' sexual orientation. As their decision making with respect to retirement is something centered in the future, I began to organize the previously identified categories, topics, and subtopics in a temporal fashion of past-, present-, and future-oriented narratives (Table 2).

Table 2. Topics, Subtopics, and Categories of Responses: Examples

Topic	Subtopic	Category
Denial of Past Negative Experiences		
Past Negative Experiences		
	Past Experiences with Family	Homophobia
	• Experiences of Being Ignored	Homophobia
	• Experiences of Being Rendered Invisible	Homophobia
	• Experiences of Being Ostracized	Discrimination
	Invisibility of the Gay and Lesbian Culture (Past)	Homophobia
	Knowledge of Lives Being Ruined	Homophobia
	Choosing to Be Invisible and Silent (Past)	Homophobia
	Additional Experiences of Homophobia	Homophobia
	• Experiences of Discrimination	Discrimination
	• Discrimination in Health Care	Discrimination
	• Health Care Discrimination Fears	Discrimination
	• Health Care Discrimination Expectations	Discrimination
	• Paradox	
Past Positive Experiences		

	Experiences of Friends as Family	Support
	Experiences of Immersion in the LGBT Community	Inclusion

Table 2, continued

Present Life		
	Experiences, Beliefs, and Expectations	
	• The Desire to Be Open	Homophobia Discrimination
	• Anger Regarding Not Having Equal Rights	Homophobia
	• Lesbian Seniors Subjected to Homophobia	Aging
	• Caring for Elder Heterosexual Family Members	Aging
	• Developing Concerns Regarding Own Aging	
	The Decision to Live in an LGBT CCRC: Controlling the Outcome	
	• Planning Ahead and Making Decisions to Exercise Control	

In doing so, I was able organize the stories and narratives in a large-scale matrix of ten columns (one column for each participant). The columns of stories (organized by past, present, and future around the categories, themes, and subsequent subthemes) were color coded using a different color for each participant (Appendix G).

Displaying the participants' stories temporally was part of the recontextualization of themes. It made it possible to identify variations and to organize stories into typical and representative ones for each group. These stories provided insights into experiences that have significantly affected the participants' expectations and reflect the meaning they give to their present experiences, all of which impacts their decision making. This within- and across-case strategy allowed me view the whole and the individual at the same time and thus ultimately to identify salient themes as well as significant and representative stories across cases

Trustworthiness and Rigor

Reissman (2002) posited that traditional applications of reliability standards do not and should not apply to narrative study. Validation, the process through which we make claims for the trustworthiness of our interpretations, is the critical issue. "Trustworthiness" not "truth" is a key semantic difference (p. 258).

In any qualitative analysis there are no techniques or procedures that will generate complete objective truth (Lather, 1986; Lincoln & Guba, 1985; Philips, 1990). Validity in qualitative research is not a commodity that can be purchased with techniques (Brinber & McGrath, 1985). Understanding is a more elemental notion for qualitative research than validity (Wolcott, 1990). Existing categories of validity are situated in positivist assumptions underlying quantitative and experimental realms of research (Maxwell, 1992). Traditional conceptions of validity, techniques, and typologies as standards for judging the importance and value of a study do not resonate with those of understanding and purpose as keys for evaluating qualitative research. Therefore, a dilemma is presented to the interpretive researcher in trying to establish the validity of a narrative

analysis. It is the challenge that Sandelowski (1991) referred to as “the inherently contradictory project of making something scientific out of everything biographical” (p. 161), and Ayres and Poirier (1996) call attempting to “make science out of stories” (p. 164).

I support and will reflect the model of Maxwell (1992) for understanding validity within this qualitative research realm and for addressing threats to validity in the analyses for this study. Further, I support and will reflect my belief in the positions stated by Sandelowski and Barroso (2002) and Ayres and Poirier (1996) regarding the importance of reader response in assessing the value and quality of qualitative reports. Maxwell provided dimensions of validity (descriptive, interpretive, and theoretical) that are not so much a typology or criteria for establishing the completeness or exactness of any results as they are a guide or checklist for attempting to address potential threats to validity.

Descriptive Validity

Descriptive validity refers to the factual accuracy of the account itself (Maxwell, 1992). As applied in this case to a narrative analysis, I have reflected word-for-word the exact statements of the participants in constructing the final analysis. No words were distorted or changed except in cases where proper names were used by the participants, in which case the term “partner” was substituted for the proper name or “CCRC” for the name of the facility.

According to Maxwell (1992), descriptive validity also includes avoiding the error of omission of critical elements of the account. Again, in this narrative study, the participants words were the focus of the analysis, and the statements were reflected verbatim until the points on a particular topic were concluded.

Interpretive Validity

Interpretive validity is concerned with meaning. In this case, the concern is the meaning that the participants' accounts and stories have for them and that it is more a reflection of the participants' perspective than the researcher's perspective (Maxwell, 1992). I attempted to reflect as often as possible specific statements in which the participants indicated that something was, from their perspective, significant to their decision to live in an LGBT CCRC. In narrative analysis the researcher's interpretation and engagement with the participants is an important part of the process. Yet, narrative analysis inherently gives voice to the participant's perspective. I attempted to remain true to each participant's views and voice.

Theoretical Validity

Theoretical validity refers to an account's validity as a theory of a phenomenon. It refers to the validity of the concepts applied to the phenomenon as well as the relationships among them (Maxwell, 1992). The rigorous iterative analytic process used (in this case, both within-case and across-case analyses and the hermeneutic spiral), inherently prevents any threats to errors in theoretical validity. The chosen analytic method of narrative analysis then (as distinct from phenomenology or concept analysis, for example) minimizes threats to theoretical validity.

Reader Response

Sandelowski and Barroso (2002) called for a new understanding of the qualitative research report as a dynamic vehicle that mediates between researcher/writer and

reviewer/reader, rather than as a factual account. They contended that it is more suitable to treat qualitative research reports as tools designed to persuade readers of the merits of a study than as mirror reflections of a study. They promoted the application of reader response theory to support the significance of a qualitative report. Reader response theory views the text as the *vehicle* for meaning; yet meaning only occurs when the text interacts with the mind of the reader (Ayres & Poirier, 1996). Reader-response theory represents a scholarly rebellion against the strictures of positivism. Reader response theory holds that the merit of the work is apparent in the reader's response to it. As Ayers and Poirer stated, "From reader response theory, we rebel against the idea of one right answer, and we understand that there can be multiple valid interpretations" (p. 167).

Sandelowski (1993) and Iser (1980) also discussed the fluidity of narratives, meaning that understandings and perceptions revealed in the narrative on the day of the original data collection can evolve and change for both the narrator and analyst with the passage of time. Further, the practice of overreading does privilege the investigator. In narrative analysis the final interpretation emerges in the mind of the investigator. The investigator earns this special privilege by holding all of the participants' stories, the research literature, and the knowledge to fuse them together (Ayres, 1998).

Ayres and Poirier (1996) pointed out that a clear and transparent description of all methods and means used to come to the final presentation is the best evidence for demonstrating the trustworthiness of the work, given the potential for multiple interpretations and meanings. The construction of meaning is never finalized, because readers will themselves respond to it from their own contexts and in that response will give meaning and worth to the work. If a study is conducted transparently and

responsibly and is faithful to the methods and data, the final interpretation must be accepted as one but perhaps not the only valid interpretation.

To that end, I have fully described the methods by which the interpretations were produced. Specifically, I made representations visible and presented processes in full clarity. The rigorous and iterative process leading to the final interpretation was delineated step-by-step. Finally, the full transcripts will be kept indefinitely for requested viewing by other researchers.

CHAPTER IV

FINDINGS

Purpose

The purpose of this chapter is to describe the findings of the study in detail using the narratives of the participants. Salient themes as well as significant and representative stories across cases are discussed in relation to the study aims and the conceptual framework that emerged (Figure 2). This framework relates to Specific Aim I, which is to describe what has impacted older lesbians' decisions to live in a lesbian, gay, bisexual, and transgender (LGBT)-specific continuing care retirement center (CCRC).

Findings

Specific Aim I

The participants are self-identified college educated, middle to upper middle class lesbians, who are in long term committed relationships, and who are without biological children. They deny past histories of negative experiences related to their sexual orientation, yet provide many stories of negative past experiences related to it. They have been ignored, rendered invisible, or ostracized by family and have maintained a code of silence with family about their sexual orientation. Their stories reflect the hurt and pain of that. Choosing to be invisible and silent in the past may have stemmed from internal homophobia and was used to elicit some control over outcomes.

Invisibility of the gay and lesbian culture was something that, in the past, the participants experienced as the norm. They expressed knowledge of lives being ruined due to homophobia. Yet they believe in the importance of being open about sexual orientation in the present time.

In the past they have experienced homophobic reactions from multiple sources in multiple settings, and they refuse to experience discrimination in long-term care. They describe themselves with adjectives such as “privileged.” They state that they have not experienced discrimination yet are angry about not having the same rights as heterosexual married couples and about the added difficulties that goes along with that for them. They say that in most areas of their lives and for most of their lives they have not experienced marginalization. The denial of experiencing discrimination may reveal a condition of *privileged guilt* in which because of the perceived privileged status in most areas of their lives the participants feel guilty calling attention to their marginalization and discrimination experiences related to their sexual orientation. This calls for further exploration in future studies.

The participants have experienced friends as family in the past. They stated that the comfort, support, and security they experience within the gay and lesbian community is what they are looking for and expecting from retirement in the LGBT CCRC. They stated that are tired of worrying about regulating their behavior for the comfort of the heterosexual population. As they are in the position of taking care of elder heterosexual family members, the participants realize that it is in their lesbian friendship circle and the experience of friends as family where they have received this type of care and support rather than from their biological families.

The participants’ past negative and positive experiences, as well as the beliefs and expectations that have stemmed from them, have led to the decision to live in an LGBT CCRC. They have concluded, based on these experiences, beliefs, and expectations, that the only way to control the outcome—in terms of preserving their dignity and preventing

the experience of homophobia and discrimination when old and less able to stand up themselves—is to decide on an LGBT CCRC. It is their way of knowing for certain that they will not have to worry, maybe for the first time in their lives.

Denial of Past Negative Experiences

The majority of participants (six out of 10) denied that homophobia and/or discrimination were issues that they had to deal with to any great extent in the past or that homophobia and/or discrimination had any major impact on their lives to date. An example follows:

> I haven't felt a lot of discrimination in my life, so I can't really address that, but I know other people have, so it should be a concern of mine. I've been lucky—most people don't discriminate against me.

Past Negative Experiences

Despite the participants' denial of experiencing any serious homophobia or discrimination from others in their lifetimes resulting from their sexual orientation, stories of negative past experiences were widespread across cases. Most notable of their stories were those related to homophobia demonstrated toward them by family members. Paradoxically, they deny that family members ever did anything harmful to them, but in their narratives reveal that they were ignored, rendered invisible, or ostracized by family. Their stories reflect the hurt and pain of those experiences.

Past Experiences with Family

In the following accounts, one participant expressed the understanding that her siblings and parents knew she was lesbian before she did. She moves from a light-hearted statement about being the only one who had not "figured it out" to the revelation that her mother had ignored her from an early age:

They all had figured it out

> When I got home from the service, I knew that I was a lesbian. There was not a doubt in my mind, even though my father had pretty well convinced me anyway. So I came out to my brothers and sisters and my mother. They said they all had figured it out a long time ago. I was the only one that hadn't figured it out in the family!

She had figured it out

> My mom told my dad one time that she knew I was going to be a lesbian when I was, I guess 8 years old. She had figured it out, and so she just ignored me from then on.

Experiences of Being Ignored

In the following account, we see that the same participant moves from describing the experience of being ignored by her mother (in terms of the participants' sexual orientation) to taking the position of turning to friends in times of need rather than family:

She just ignored me

> My mother is 80, so she may be settling in for a while. She's horribly homophobic. Really trying to get over it. She never treated me bad. She just ignored me. No, but she was never mean or cruel like that. I guess psychologically cruel, but no, she never beat me. She never sent me to psychologists about it. I think maybe there is some of it in her, and she recognized it or something. My mom's a big, strong, powerful woman, and she overcompensates for, I think, maybe she had some close friends. It's weird family dynamics there too. I think her older sister was gay, I got a feeling. Anyway, she learned to be very homophobic at a very young age, saw me, and then just ignored me from then on. We're still ignoring each other. No, we're getting better. But we don't talk much. We don't like each other much. I find her very shallow. When my partner got hurt, the only person that called to see if they could help with anything was my older brother, and then my mother sent a postcard that said "hope she gets better soon." I mean, this woman almost lost her life and then, you know, her entire life was changed, and that's just the way the family dynamics got. That was just reborn-again Christians and my homophobic mother, and it was at that point I just let go. I don't need this. I just don't want to be part…this doesn't need to be part of my life. I love my brothers and sisters because they're family, not because I would want them in my life a whole lot more. A lot of women up here call this

> their family, and I'm one of those. Yeah. These are the people that I would turn to in time of need.

Another participant with a similar past of being ignored by her mother, discussed some of the effects that these early family experiences have had on how she lives her life and conducts herself:

The way I feel people should be treated

> So many things influence who we are and how we act and how we interact with people. The fact that I was a lesbian and the fact that I decided to be truthful and that I came out in the world and the way that I was treated by my family and maybe other people, sure, it did something to who I am or how I am, but I can't separate that from difficulty with mom or always not feeling loved by her way before she knew I was a lesbian. She loves me, but she doesn't really like me. She doesn't like the kind of person I am, that I bite my nails, that I was tough, that I was athletic, that I looked Italian and she was Irish and my dad was Italian. So that is why I am, as you can tell, I am a very thoughtful person and very wordy. I have thought about all of this stuff. So it is intermixed like that. You can't separate it and say, well this was because I was this way. I mean yes when I was younger being an athlete I was kind of like other people might describe me as kind of tough and I was, but I was also protecting a soft heart too, which I didn't learn until later. But, some of the ways that I have been treated actually had the opposite effect on me in that I feel very, very strongly about treating people, not the way they treat me, but the way I feel people should be treated.

Experiences of Being Rendered Invisible

In the following account, a participant provides a story revealing that while her family understood her sexual orientation, they never wanted to discuss it. In the same account she states that they were "okay with it" yet "didn't want a daughter who was a homosexual." She was given mixed messages in that they demonstrated acknowledgment of her partner, yet never wanted to discuss her identity and all maintained a code of silence. She states that because they were not "disowning" her, she didn't care and conceded to the silence:

Could you get out of the way of the television?

> We had a huge 40th birthday party for my partner. Softball team was all there, you know, friends from her youth were there. My parents were there. I mean, it was a whole group of people there. And if anything weird could have happened, it

> had happened at that point. So the next morning, my parents don't live here, so they spent the night with my sister and her little boy. And the next morning we were having this huge breakfast. My partner takes off, because she doesn't want to be any part of this “let's come out to the family” part. She goes off with some friends, right? So she left, and I was trying so hard to tell them. And we sat down to breakfast and I said "Oh my golly gosh, wasn't that an interesting group of people last night?" And my father said "Yeah, they were. Could you get out of the way of the television?" So, he knew what was coming. He never wanted any labels put on it. He didn't want a daughter who was homosexual. However, if I went home without my partner, there was always "Are you sure she's not in the car?" They gave us joint Christmas presents. They totally had no problem whatsoever with her, but they never ever wanted to talk about it. I had given them numerous chances to bring it up, and I figured that as long as they didn't hate me and disown me, which I didn't want to happen, then I didn't care. They just didn't want a label on it, and they didn't want to talk about it. But it was okay with them. Even later when I was doing some things for my stepmother, she said "You tell her I will get you back to her right away," because I had to go up and do some things for her. You know, so it was like they knew and they didn't care, so I never tried to browbeat them with putting labels on it, and I just left it that way because they were comfortable with that.

Another participant offered an account of maintaining codes of silence with family members about her sexual orientation. In this account we see that in addition to the previous participant’s stance of conceding to silence in order to make family more comfortable, the following participant also maintains the code of silence to avoid discord and negative outcomes:

Why rile the cart?

> It was a known unknown. If anybody then asked, then I always told them. My parents did not ask, but they knew. My aunt the nun, she would call me and say that she missed my partner. Maybe the words were never said but everybody knew. So, I figured why rile the cart? They understood, and they were pretty clear.

Experiences of Being Ostracized

When participants were directly open with family members in the past, some were ostracized by both parents and siblings:

Banned from the house

> The difficult thing was when I told my parents was that I was basically was banned from the house. It was when Billy Jean King was to have the palimony thing and all the other stuff and, you know, my mom was talking something about, you know, those people are so terrible. I said, "Well, those people are me." I mean it was dead. I was allowed to come back as my mother was dying of breast cancer, so I could come back and take care of her. But my partner wasn't allowed to come. So that was difficult.

In the following account, one participant voices perceptions about the relationship between the Christianity of her siblings and their homophobia toward and ostracizing of her:

Hate and judgment

> My little brother and my sister became born-again Christians and wouldn't really have anything to do with me for a while, but it's getting better. I think maybe they're learning that Christian means tolerance and love instead of hate and judgment. Because, when it started out, it started out as the hate and judgment, so my sister and I are starting to have a pretty good relationship again. But my older brother has always just accepted me for who I am. But he didn't become a born-again Christian either, so that helped.

A revealing account was offered by a participant on her perception of the difference between the discrimination experienced by gays and lesbians and that of other minority groups:

Ostracized by their own family

> I was the apple of my dad’s eye for years and years and years because I was the firstborn, but once he found out he ostracized me from the family for 20 years. So I have those personal scars, my mother and my father and all the stuff I missed. My father said he was sorry before he died. He erased 20 years by just saying “I’m sorry.” I took care of him before he died, and I take care of my mom now too. But, I feel that our group, gay people, is the only group of people that are ostracized by their own family. If you really think about it everybody else that is prejudice towards a group, it’s not within their own family usually. It’s really the outsiders. So we have to deal with the outsiders and for many of us the inside too.

Invisibility of the Gay and Lesbian Culture (Past)

Invisibility of the gay and lesbian culture was something that in the past, participants experienced as the norm. One participant discussed in the following account how, in general, the environment she grew up in was very intolerant of anything outside of the norm:

You'd be ostracized

> I wasn't very sexual. I didn't even think about it. I was really into sports and things like that and I never even really thought about it. And everybody was WASP. I didn't even know black people existed. I mean, I was naïve, and I was naïve sexually, I was naïve socially, I was naïve culturally. I was one naïve…all I saw was, it was like the Stepford Wives in the 70's—you saw the same old, same old. All the kids were, everybody had the same politics. It was unhealthy, looking back, but it was fun for a kid. I wouldn't want to be an adult in that town. If you had any other ideas than what the general town thought, my God, you'd be ostracized.

Several accounts were provided by various participants regarding the difficulty of connecting with the gay and lesbian culture and in finding any information to help them explore their sexual identities in the past.

I didn't know where to go

> Well, there wasn't a lot of information out there. You didn't know who to talk to. You ended up in bars, everybody just drinking and getting drunk and that was like the community center was the bar, and it just, outside of that, you just, you felt like you really had no way to get information. As I've gotten older, I'm finding there are bookstores now, and if there were some before, I didn't know about them. I didn't know where to go and find them.

Always kind of hidden

> During that time it was not forbidden, but it wasn't open. I'm from the Midwest. So, it was like, it was all very kind of, you know, not talked about. And if you read a magazine about it, you know, it was always kind of hidden a little bit, you know. I met some people and discovered that there were a lot of people like me, you know. I wasn't the only one.

I didn't know there were any others

> We were not part of the lesbian scene. I didn't know there were any others. I didn't know there was a culture. I didn't know there was women's music. I mean, none of that stuff. When she left me for a guy, I sat there and said, “I want the butchest, dykiest person that I can go date.” So I found one and that was a big mistake. She was way too pushy. But I got some exposure to women's music and some exposure to more feminist thought processes, and I was liking it a lot. Well, I decided that I really wanted to go back to school and met all these women in the doctoral program. And it was cool. Because then I got really a lot of exposure to feminist, lesbian, being out there music, that there was a culture that was a whole movement that, you know, I had no idea about.

Knowledge of Lives Being Ruined

One participant discussed knowledge of lives being ruined through expression of sexual identity to homophobic people. She moves from discussing the jailing of her gay and lesbian compatriots to her position on the importance of being open about sexual orientation in the present time. This is a paradox, as while the participant believes in being open and the emotional freedom that openness can give a gay or lesbian person, she has chosen in the past and continues to choose in many circumstances currently, to remain silent and invisible.

They’d ruin their lives

> We came from a world where, they used to, the cops, believe it or not, used to raid gay bars and put everybody in jail. This was in the 50's and 60's, just so their names would be in the paper and they'd ruin their lives. These were teachers, and they would just ruin their lives. So a lot of lesbians have learned to keep that well hidden and from my age group up. And it's gotten better and better and better, so now more people are open, but I think once you just start with that, you can turn around some soul tearing apart that you had done if you can just come out and say it and just get past the fear of the establishment ruining your life. And I think it affects you in every way. I really do.

Choosing to Be Invisible and Silent (Past)

The participants’ stories revealed experiences of rejection and being ostracized when they were open in the past and known examples of the negative outcomes of openness. They report being open about sexual orientation in most areas of their lives

presently and indicate that they have been out for many years. This is a paradox in that some continue to choose not to be visible and open in specific situations. This coping strategy of choosing to be invisible may stem from internal homophobia and has been used as a coping strategy and protective mechanism and a way to elicit some control over outcomes:

I couldn't control the output

> I never came out to my husband. That's one of the things that I have some, I have guilty feelings around that. I wasn't, I didn't have a lot of integrity around that. What I told him was true in that I no longer felt like I could be in that kind of, that I could be married to him, but I didn't tell him the whole truth. And so, I mean, I think. Well, I certainly have paid a price for non-integrity in my life and that's, you know, not a thing that I'm proud of. I wish I had the guts to stand up and say here's who I am and that's why I can't be married to you, but I didn't say that. I hadn't come out to my family yet. My birth family. I couldn't control the output, you know.

I don't even want to put myself in that situation

> I have never had any really negative experiences. At work, I was out but I wasn't flaunting it, you know, so if someone asked me, I would tell them. I worked with a lot of older people, and their thing is a little different than, you know, when I was 35 and 40 and coming out, and I figured that they could care less. But “Guess what, I'm gay,” it never occurred to me to do that. But my partner always went with me to all work functions and it was never a problem. This is a very accepting place. You know, if we move to Kansas, two women living together could get their barn burned. You move to North Carolina, and two women living together can get their barns burned, and that has happened. We don't want to go to places where it is not very accepted. So, I have never really had any bad experiences, but I have never put myself, I don't even want to put myself, in that situation.

I got nothing to hide

> I don't think, you know, I didn't say, "Sit down. I'm gay." Or, you know, “Sit down, I want to tell you something.” It was more like, you know, well my partner and I have been together for however many years, and my brother’s been living with a woman for about the same amount of time and is still married to another woman. So, you know, it's like I got nothing to hide.

Additional Experiences of Homophobia

The participants have experienced homophobic reactions from multiple sources in addition to those they encountered with family members in the past:

I was just shocked

> I had a surprising experience with a woman that I had gone to high school and college with. And during this time, she was a very, kind of free spirited and in all sorts of open relationships. And so, she had come out here for a few-hour layover and I spent some time with her, and I came out to her at that time. I was so surprised by her reaction because she had turned to religion and just thought how horrible it was and what a sin it was. And I was just shocked. I mean, here is someone who lived free and easy, did drugs, did everything, you know. So, that was surprising. I haven't had any contact with her since. It's not like we had a lot of contact prior to that point either, but we were very close in high school and college. So, that was a surprise.

In the following narrative, one participant moves from describing what she has experienced in the past to her stance on the importance of LGBT-specific CCRCs:

These places are important

> I don't want people making fun of me. I don't want people calling me names. I have been in the past. It sure has happened to all of us or a lot of us. I think people that are our age have experienced more of the prejudice than maybe our sisters and our brothers in their 20s and 30s and 40s. They have a different experience. People like myself and people older than me carried a lot of the brunt of what happened as we broke through to allow the younger generations to be more who they are, to be more out, or just be themselves. It is not easy. Some of my friends are still in the closet. So these places are important. I support this even if I was never going to end up here, because it is important for people to be in a safe environment as they get older or as they get sick or you know to get what they need no matter who you are.

Experiences of Discrimination

Discrimination at Work

Participants provided additional accounts in which they interpreted experiences in the work setting as discrimination. They conveyed the belief that these directly resulted from their sexual orientation:

I would never get another promotion

> There were management and clinical staff that were trying to do some team building, and we were going to have a softball game. We had the administrative people versus the clinical people. We had hats and uniforms and pom-pom people. At the time when we were doing this event, our staff was short. My partner happened to be there to watch, so I asked her if she wouldn't mind playing. She said okay. Another person of very high influence in the institution was there, and he took one look at her and took one look at me, and that was it. After that, I was told I would never get another promotion. At that time, if I ever said that is what was told to me, they would deny it, because there really was nobody else there. Then I did apply, regardless, for another promotion and was told by the search committee that I was the most qualified but for some reason I wasn't getting the position.

Never had a chance

> I didn't get a job because I was a lesbian. Yeah, they were not happy. Even though I was very well prepared for the job, "No, you're not going to get it." I found that out afterwards. A friend of mine was on the committee. And she told me later, she said, "You never had a chance.

Discrimination in Health Care

There were many accounts in which participants described concerns regarding actual and potential health care discrimination. They have experienced health care discrimination in the past regarding their sexual orientation. They have also witnessed and internalized the fear of health care discrimination of homosexual people through known experiences of friends and through what they have witnessed in the media.

Health Care Discrimination Experiences

She obviously was not accepting

> My first job when I moved here was at this place where those two girls were and so it all, it all kind of happened. They did bring me in. I had my first slow dance with one of the gals and I thought, “Oh my God.” So, that was good. And, you know, I had started at the time when I had this conversation at work when I thought, “Oh my God this is who I am,” I think I was in therapy because things weren't going quite so well with my husband and I. So when I went to the therapist to tell her about this, she was just very uptight and said, “This can't be right.” You know, she obviously was not accepting of it at all, and so I immediately said, “Sorry this isn't for me. I don’t need this.”

The shock on their faces

> When my partner was injured, the medical world had a hard time with it. They didn't want to talk to me about her condition. I didn't have any paperwork. You didn't have it at that time. This is back in the 80's. I just said I was her significant other, and they just stared at me. They didn't even know what I was talking about. Domestic partner hadn't really come as a new verbiage. But I said, “I'm her partner. We're lesbians.” You could see the shock on their faces. Yeah. Anyway, still they didn't want to tell me. She couldn't speak for herself even for the first week. She was pretty well in and out of it. You know what I'm saying? I think even though they may have wanted to talk to me, some of them—not all of them—I don't think they felt legally like they could. Her mom got there a few days later. She made all the decisions. She was the only one that had legal right to. All she said was, “Do everything you can for my daughter.” My partner had asked me, oh gosh, six months, a year before, “Would you mind being durable power of attorney medically?” I said, “Well what does that entail?” and she goes, “Well, if something happens to me, decide if they can take me off life support,” and I said, “Honey, I don't know if I can make that decision.” So I hemmed and hawed around. We never got it done. After that, she got better, and I just said, “No problem. I can make that decision.” I just saw what her mother had gone through. Her mother couldn't make that decision. She would have kept her a vegetable if that's what she turned out to be. She would've done it. And my partner would have been pissed. A pissed-off vegetable!

Health Care Discrimination Fears

What effect that would have on your care of me

> I have some real concerns about health care. I have some physical challenges and I recently this last year had to change docs because my doc decided to go to a concierge practice where you would pay $3500 a year just for the privilege of seeing her. That doesn't include lab work, hospitalizations, nothing. And so, I was

> mighty terrified. I dragged my partner along with me, and the first question on my list of questions was, “It is critical to me to know how you feel about, I'm a lesbian and I need to know. I don't care necessarily what you personally think about it. I need to know what effect that would have on your care of me. I don't want to wait until I'm in an ICU and find out that you aren't going to talk to my partner.” And so, um, so that was a big scary. And she responded extremely well, and we have a very good working relationship now. But when we move to the home, as my partner and I lovingly call it, I've got to face that again.

Health Care Discrimination Expectations

In the following narrative the participant describes coming to the realization that discrimination of gays and lesbians exists in various long-term care settings as a result of exploring options for her aging mother. She pointedly expresses her refusal to experience discrimination in long-term care:

I will not be discriminated against

> We were looking at places for my mom. We went and looked at a lot of places. And one of the things that I came to understand about many places, including faith-based, but not limited to faith-based places, was that you had to, in order to live under, you know, in a unit with someone you had to either be connected to them by blood or contract. So they had to either be a sibling or they had to be a marriage partner. And I thought, “Holy s**t!” I had never thought about it, and there it was, smack in the face. And I also realized that many people in her age group would not be accepting of the fact that my partner and I are lesbians. And I will not be discriminated against. I will not be discriminated against.

Another participant reveals the comfort in knowing that she will not have to experience potentially being separated from her partner in the LGBT-specific CCRC:

Positive about this

> A lot of these assisted living places, unless you're married, will not allow two people to live in the same unit. So that's the one lesbian thing that was positive about this…….we're not going to be told we have to get two different units.

Paradox

In the following narrative, the participant contradicts herself with respect to experiencing homophobia in the work setting. She states that she had been lucky in her past work life, did not experience problems, and was aware of coworkers knowing of her

sexual orientation. Yet in the same narrative, she reveals that coworkers would also tell gay jokes in the work setting.

I didn't have any problems

> I didn't ever come out and say, "Well, yeah, and I'm a lesbian," when I was trying to get hired somewhere. I never went there. I just figured it shouldn't really be part of it. But when I got a job and I was working, everyone always figured it out. The gay jokes would start and, you know, the blonde jokes would start they go, "Oh God, I can't believe you don't think we know," so it was always like that. I've been really lucky in the workforce. I know other people that haven't. My partner wasn't lucky. She had some real problems. I always worked for very small companies, and you get to know people and all of a sudden it's like that shouldn't be a barrier. I think the larger the company, the harder that is. But, no, I didn't have any problems.

In the following narrative, a participant reveals a clear experience of homophobia in the work setting and discrimination in her spiritual life, yet moves from that to the statement that she is unable to identify how others' attitudes and beliefs toward her sexual orientation have had any effect on her:

None comes to mind

> There were a couple of times I worked in facilities and my partner would come there and some of the guys would make comments; so much of it that she felt uncomfortable coming there. I guess the one place that I've always felt discriminated against is in my church. In my everyday career life, I don't encounter that kind of discrimination. In my church and in my community, I think, I mean I've always lived out, you know. I think when you face discrimination it's oftentimes when you're in the closet and you're hidden. Of course people have attitudes and beliefs that have, perhaps, put up some barriers that I've had to go over in my life. But none comes to mind.

<u>Past Positive Experiences</u>

Across cases, the participants provided many stories and accounts of experiencing lesbian friends as family in the past. In addition to homophobia and discrimination, the previous narratives revealed past experiences of being ignored, ostracized, or invisible in relationships with biological family. In the following narratives, it is clear that in their

lesbian friendship circles and in immersion experiences in the gay community participants have experienced being recognized, supported, understood, and comfortable.

Experiences of Lesbian Friends as Family

In one account, a participant relates her firm belief that due to the experience of being ostracized by family, gay people have to create their own families:

We have to create family

> A lot of lesbians or gay people or anyone who has been ostracized by their family, I think we innately have to create, we have to create family. We have to do something around that.

Participants relate that it is in their lesbian friendship circles that they receive their support. The following participant moves from describing her positive experiences to her perceptions about how the experience of heterosexual women differs and is inferior to her own with respect to support. She says that a conversation started among her lesbian friendship circle many years ago of wanting to retire together:

Wanting to grow old together

> We are so fortunate that we have an incredibly supportive community. We have a great set of friends, absolutely great. We have dinner at least once a week with anywhere from, you know, 10 to 15 people. And we go traveling together. We do a lot of group traveling. We are so, so lucky. It's like nobody can go to a hospital without all of us being there. And we've had experiences in hospitals where, you know, the straight women, the husband drops the woman off, she's having a hysterectomy, it's very traumatic for her, and there's nobody there. And yet, one of us goes and you know, we're there and we're singing. It's just great. I know my sister, for example, is very jealous of the friendships that we have. Now, is it because we're lesbian? Probably. Because women just have those kinds of relationships better. The closeness. A group of us several years ago started this conversation about needing, wanting to grow old together.

In the following narratives, participants reveal their strong beliefs about friends as family and the need for lesbians to form friendship families in order to look out for one another, their perceptions of experiencing real support and acceptance for who they are, their experiences of support in times of need and celebration, and their perceptions about

how much more support they experience from their lesbian friendship family than they ever have in heterosexual circles:

The way a family does

> I feel like I have a circle of friends, and I don't see them all the time, but I know that I could pick up the phone and say, "Hey, I need some help," and they'd be here. You know. Stepping in and helping out the way a family does.

Look out for one another

> I think it's different. I think we kind of look out for one another in a different way. You know, being a minority and just being there for each other I think is different, you know, and that might be true too of new immigrants to the country and things like that. I don't know. But I know that we certainly feel like there's a community.

My family is here

> I feel my family is here, you know, my friends, the support group, the confidants, the, you know, whatever, are here. Versus, you know. And the family is the family and, in the sense that they're the biological but you know, they don't know who I am, you know? I think the people here know who I am.

They were all there

> We have a circle of friends that we've been friends and acquaintances for 20 years with some of them, 25 with some others, 30 with some others even. But, and you know, the first time that I had the surgery, they were all there. And you know, all there supporting my partner, supporting me, you know. The doctor came out and sort of stepped back when he saw all these women standing there all waiting to hear the answers.

Different than what I experienced in the straight world

> For my 60th birthday, I went on a trip with my partner. A total of 28 people came down. Now, I am very, very blessed and very lucky and very whatever you want to call it, but I have this wonderful family of friends that, you know, was willing to spend the money and come down and visit. So, you know, we had a great time. But that's what I think is so wonderful. It's that support when my partner was in the hospital. I had 15 women sitting in the waiting room. They didn't know what to do with us. You know, and that happened with every one of the angioplasties that she had. I mean, it's like, everybody was there. And even though, you know, it's getting repetitious after a while, I can still count on at least four or five people

> taking the day off. It is just different than what I had experienced in the straight world. I don't think folks expect non-blood relatives to really rally around each other.

One participant reveals in the following account her concerns about growing older and provides a telling example of the experience of friends as family in that she and her partner have been present at the death of many friends in the past:

There for the death

> I get scared. Right now I am a little scared after seeing my friend try to conquer this cancer, and she was a pretty healthy person when she started. This is our eighth friend that has died, and because we are very close to people, we have actually been there for the death three or four times. Some people never have. It is an awesome, but intense experience. But it has kind of made us go, "Whoa, I am going to be 60." My partner is going to be 64 this year. It is really different when you are 30 or 40. At 60, it can happen.

Experiences of Immersion within the Gay and Lesbian Community

Across cases, participants described many positive past experiences of immersion in the gay community and the comfort felt within it. They reveal that the decision making regarding living in an LGBT-specific CCRC stems, in part, from past positive experiences with immersion in the gay community.

Because the experience we had

> Here's what we'd think we'd like to do because the experience that we had. We went on an Olivia tour through Australia and it was just mind blowing the fact that you could be in the boat in Sydney Harbor and flying the gay flag and being surrounded by, you know, 90 lesbians. It was this energy. We went to this luncheon where there was probably, I don't know, 70 gay men and women at this luncheon and I said, "You know, the energy here is sooo terrific that, you know, wouldn't it be wonderful."

We just felt so included

> That whole idea of emotional comfort, it was there. We just felt so included in this group. All these people were there, and nobody cared that we were gay. Nobody gave a damn. And if you wanted to hold hands, you could hold hands, you know. Nobody was, but you could. Nobody was looking cross-eyed at anybody else.

In the following revealing account, the participant moves from describing past positive experiences of immersion in the gay community to the realization that she is tired of worrying about regulating self for the comfort of the heterosexual population:

I didn't have to prove myself

> I am tired of watching what I say in a group of straight people. We went on a cruise, a huge cruise, 1200 people on this ship. I think there were 6 gay people on this cruise. My partner came back to the room one day and she says, "I think I saw another gay couple." "Really? We should go look them up." It wasn't that we wanted to run around nude or do anything stupid, but you know, I am very, very comfortable in a group of gay people. So, I think it's just the comfort. The comfort that I felt on the Olivia trip, the comfort I felt in that luncheon. Like-minded people where I didn't have to prove myself. I don't have to prove myself, I don't have to explain myself. You have to constantly think about it. We were just gambling, and you know, if we won a lot of money, I want to give my partner a big hug, which we did. I also hugged my straight friend who was with us because she won a lot of money. It is something that you think about, where this straight couple over here can win a lot of money, and they can be kissing and holding hands and going crazy and there's nobody even looking at them. Nobody even looks at them, but two women or two men that get demonstrative, they stare at you. And, you know, you get tired of it.

Present Life

Experiences, Beliefs, and Expectations

The participants provided many accounts of how currently (within their lesbian relationships as well as friendships) they feel supported, understood, comfortable, and not afraid of losing self:

Heard and understood

> It's kind of a neat feeling of being in a special club. Sort of like I would imagine it is for born-agains. You know, you sort of meet up with somebody and you know that there's a vibe going on. And I'm not talking about a sexual attraction. That's another real plus for being a lesbian is that you, I have had the experience of really feeling like I was heard and understood.

A lot of deepness

> Women are so cool! They're just, they run deep. Men, I find, not all of them, but it's real superficial. Somewhere along in life they learn how to do superficial

> really well. Women don't. But on the other hand, women can talk you to death. Okay? I mean, they can. They like to process a lot, and that does drive me a little crazy, but there's just a lot of deepness to a woman. It's just—women are incredible. That's the other really positive side of being a lesbian. You get to be part of that.

Very supportive

> You're comfortable with yourself. You don't seem to have an agenda. Like, I was just talking to our neighbor and they're trying to sell their house, and he's a great guy. They're having to do their equity line because they're both retired, and she wants to go back to work, and she has a chance for a part-time job where she used to work. He doesn't want her to do it and I said, "Okay, is this some kind of guy thing?" You know, there's not a guy thing going on where you have to say, "I can't do that" because somebody doesn't want you to do that. I think, at least my experience with women, they're very supportive. They're very, um, nurturing, you know for you to do whatever you want to do versus "You've got a rule here."

Very comfortable

> Lesbian relationships are very comfortable. I think women just think differently than men. I think women are better problem solvers. You know, it used to be in the 1940s and 1950s there had to be the fem and the dyke. You had to have roles in the relationship. I don't think you have to have that now. So I think that has changed, and I think that is marvelous. I know some women who are gay that aren't out because of the business that they are in, and they are gorgeous, and they are always hit on by guys because they don't "look" gay, you know, and so I think that having roles isn't as important as it was 40 years ago. You can be yourself. You can be comfortable. You can have a good cry without being considered that you are weak.

You can be yourself

> And that doesn't mean that your partner isn't going to console you, but, you know, you can be yourself. I think a lesbian relationship allows me to totally be me. In the general whole, it is more difficult, but within the relationship, it is an easier place to be, I think.

One participant discusses her perceptions about the differences between lesbian relationships and heterosexual relationships for women. It is telling in that she identifies the perception that heterosexual women "cut themselves out" or lose themselves in relationships with men, yet in many of her narratives she discusses past experiences of

being ignored and invisible to others and in a sense losing self to keep relationships with others:

Cutting a little bit of themselves out

> I think to make a heterosexual relationship work, it's always compromise in any relationship, but I don't think men go to that emotional level much, and I think women need it a lot, so I think they start letting go because they do need it. If they want to make the relationship work, I think they have to start cutting a little bit of themselves out and get a little bit more superficial. I think they have the capability of going pretty deep again, but I don't think in a heterosexual relationship it fosters a woman's growth. I don't think so at all.

An example of the participant's inconsistency regarding this issue is provided in the following narrative. In it she moves from emphasizing the importance of openness to stating that if her neighbors want to remain silent about her sexual orientation it is "their business":

> A lot of lesbians have learned to keep that well hidden and from my age group up. And it's gotten better and better and better, so now more people are open, but I think once you just start with that, you can turn around some soul tearing apart that you had done if you can just come out and say it and just get past the fear of the establishment ruining your life. And I think it affects you in every way. I really do. All of our neighbors know we're gay. But I don't go over and say, "I'm a lesbian," but, well, everyone has always figured it out with me. They don't want to talk about it, that's fine. That's their business.

In the following narratives, the participants reveal that in the gay community overall and also in their lesbian support network, they perceive a common experience and bond as well safety and nurturing.

At ease with yourself

> It's a common experience. So it's safe. It's nurturing. It's all this other kind of stuff. Even though you may not agree on what you're talking about, and maybe it is that everybody has gone through that, you know, the being different. The being, you know, on the outside or, you know, whatever it is. Because we are on the outside. I mean, you know, it's, we are in the minority, the margins, or whatever. And some people may feel that, oh gosh you can change, but I think most people know they can't change. This is the way it is and we are extremely happy. And I think when you're at ease with yourself, then you're happy.

We have this common bond

> I don't think that lesbians have internalized those negative messages about women because if we had, then who would we go after to date? I also believe that there is a spirit of sisterhood that sort of goes beyond, sometimes it goes beyond class and race; although, class and race is certainly, you know, exists within the lesbian community as well as the other community. But we have this common bond, you know, as women that I think we can relate with.

One participant provided a revealing account in which she discussed that she is tired of continuing to regulate herself to accommodate the comfort of the heterosexual population. She expresses her frustration at heterosexuals who think that she has chosen to be lesbian and their justification of homophobia and discrimination relating to their belief that homosexuality is a choice. She finds it difficult to live as a lesbian but expresses that it is more difficult to live a lie:

You have to constantly think

> This whole thing, you know, that gay is a choice. You know, they are coming out now with there is some hormonal things and some things in your brain that you are born that way. Okay, but before that there was a lot of stuff, you know, you choose to be gay. No one would ever choose to be homosexual. They wouldn't choose. They can choose to not be true to themselves and stay in a straight marriage and wonder why that doesn't work, but no one would choose to be gay or lesbian because it is difficult. You have to watch what you say. You can't hold hands in public. You can, but you could offend someone. You have to constantly think about that. You have to constantly think. It is more difficult than being straight because friends totally accept you. You can reach across the table to your boyfriend and give him a kiss at the dinner table. You cannot do that in a lesbian relationship or a gay relationship. You can't do that. So, I find things more difficult. However, you know, living a lie is more difficult.

The Desire to Be Open

Some of the participants' current beliefs about openness contribute to their decision making to live in an LGBT CCRC as well. For example, participants express in the following accounts that they still feel uncertainty about what to expect in terms of how they will be treated by others because of their sexual orientation:

It is subtle

> I think it occurs in different tiny degrees. I mean it works both ways right? So how do you know in the little ways that people do things or don't do things? Let's say I am in a hospital. I get a little extra positive treatment. That is good. Or maybe they don't come in as often as they need to. It is subtle.

You just never know

> You never know. And that's the downside because you just never know. My feeling is that if you could meet with people on a face-to-face basis and they get to know you for who you are, then it's a nonissue.

Not knowing the expectation

> Meeting people in the world and not knowing the expectation and that there could always be a different take; whether they are going to accept you (not even to just accept or reject) or be violent. There are some people that would meet you in the street and say "dyke." Physical fear is probably the biggest thing. Lack of tolerance really irritates me.

The participants identified that the comfort, support and security they experience within the gay and lesbian community is what they are looking for and expecting from retirement in the LGBT CCRC:

I want to be comfortable

> One of the fears is ending up someplace where I can't be me, I have to watch what I say, I have to watch what I do, I can't be me. I want to be someplace where I can be me. Whether that's good or bad, you know, I just want to be me. I want to be with people that are comfortable. I want to be comfortable. And I don't mean physically comfortable, I mean emotionally comfortable. I mean, physically comfortable you can pay for. Emotionally comfortable you can't pay for. I think that this whole movement around LGBT retirement communities is, I mean, I'm assuming that most people understand it. Most people understand that people when they retire don't want to be bothered with a lot of "stuff." They just want to retire with some peace and some dignity and some grace. And so the issue of LGBT people wanting to retire with each other just makes perfect sense to me. People want to retire with their community. They want to retire in places that they can feel comfortable.

Out in the open

> Being gay is just who we are. It’s not like they have to have a gay night, you know what I mean. It's just like, the culture, the whatever. It's all gonna be just out in the open.

Anger Regarding Not Having Equal Rights

A participant contradicts herself in the following narrative. She describes herself with adjectives such as “privileged.” She states that she has not experienced discrimination, yet she is angry about not having the same rights as heterosexual married couples and the added difficulty that goes along with that for her and her partner:

Rights that I don't have

> I do not feel like I have been discriminated against because I'm a lesbian. I know I hear stories about people who feel that they haven't gotten jobs or whatever, and I absolutely get it that those are true stories. I've not experienced that in my life. I came out when I was 30, however, which means that there was, I mean I think it makes a big difference if you come out at 10, and you have that whole, you know, tumbling adolescence to go through. And it pisses me the hell off that we don't have the same rights, that we have had to spend thousands of dollars to get the legal documentation. So that angers me that, you know, in terms of those who shall remain nameless who are in office right now. I celebrate the fact that they have a deep Christian faith. I celebrate that they have that faith. What I don't celebrate is that they feel that it gives them the right and the arrogant privilege to tell me how to live my life, you know. I'm a feminist. I'm a dyke. There's a lot of things that don't fit into the little categories of boxes that you could check. And so I think that's a hard thing. I don't like it that there are rights that I don't have. And yet, I am a white, educated woman. I have no idea what it's like to live without privilege. And the little gnat-like bites of being a lesbian are tiny, tiny, tiny.

Knowledge of Lesbian Seniors Subjected to Homophobia

One person expressed awareness of elder lesbians who are currently being subjected to homophobia and discrimination in senior care:

No sense of community

> There are these two women who go to the senior citizens center in their neighborhood. They're two lesbians. They've been together for almost 50 years, and I've known them for a good 22 or 23 years. They are both in their, one is 76 I think and the other one is almost 80. The center that they go to has the reputation

> in the city for being the best center in the whole system for exercise. These women go into this center every day and exercise. And they've been doing it for years. So, they go to this center every day to exercise because they want to stay healthy as they age. And when they walk in, the people in the exercise room walk to the other side. They don't want to exercise by them. So they go to the exercise class and then they go home. And they've been doing this for years. And it's the same thing every day for them, you know. They have no sense of community out there. They're subjected to that. Does anybody say to them, “Oh, you know the free lunch is about to come in. Why don't you stay and have some lunch?” Or you know, “We're about to play some dominoes, why don't you stay and play?” You know. Nobody says any of that stuff to them.

Caring for Elder Heterosexual Family Members

In the participants’ present experience they are also in the process of caring for aging heterosexual family members. Stemming from that care taking role, they have identified that those support needs and caring, for them, have historically come from their lesbian friendship circle and the gay community and not from biological family. They have come to the realization that due to their childless status, there may be no one to assume the role that they are engaging in with their aging parents. They assert their position that this issue is a driving force behind the development of the LGBT CCRCs.

I wouldn’t have anyone

> My brother and I have certainly taken over the care of my mother. She has dementia, and so, you know, we're making a lot of decisions for her. And, you know, I wouldn't have anyone to make those decisions.

Who’s gonna care for you?

> As a lesbian, it's like, who's gonna care for you? You know, you don't have kids. I think, my partner and I have talked about this, you know. If we were in need of someone, would any of our family be able to step up and say, “Okay you can either come live with us or I'd come out and stay with you?” And I think that's a concern. We'll say, “Well, if I get that way, shoot me.”

Nobody for me

> Part of the issue is who is going to do for me what I'm doing. And that has been my driving force around trying to make an LGBT community happen, to make sure that I'm not going to be at the mercy of a caregiver…..You know, you want

> to be able to live, and you want to be able to know you're safe. And so when I recognized that, that there was nobody for me….So it's sort of like we have to plan for ourselves what is going to happen within our own community and family and friends.

Developing Concerns Regarding Own Aging

Not only are the participants spending time presently caring for their aging parents and realizing that they may not in the future have someone to provide the same care for them, they are also coming to the realization that they are growing older and are sensing that they may not be thinking as clearly or acting as strongly as they had in the past. They realize that they may not be able to act on their own behalf at some point as they have done for themselves in the past. In coming to these understandings they are finding the need to plan ahead to control outcomes for their own aging experience.

What are we going to do when we get dotty?

> So I think you spend a lot more time thinking about what are we going to do when. Because you don't just kind of let it go because, "My daughter will take care of it." And I think that straight people have more of a "My daughter and my granddaughter and my great-granddaughter will pitch in and deal with grandma when she is dotty." We don't have that, so we have to figure out what are we going to do when we get dotty? How are we going to do this? So you have to write more things down. And legally, I mean, up until the domestic partner thing, I had to have a piece of paper saying I could get into the ICU. I mean, a straight person can go into the ICU and see their loved one. A gay person cannot do that. So I think there is a lot more planning involved. There is inordinately more planning, I believe, that goes into my getting older.

The Decision to Live in an LGBT CCRC: Controlling the Outcome

The participants fear the vulnerability they could face in old age if they do not take the control that they are taking to prevent that. They reveal that the decision to live in the CCRC is largely impacted by these fears.

Planning Ahead and Making Decisions to Exercise Control

I can do less, and I forget more; who's going to help me out?

> As a person growing older, I can see where I can do less, and I forget more, and, you know, that's a concern. It's a concern because I'm not working anymore, you

know, I kind of watch those finances and planned as carefully as I could. You know, I mean it's not an overwhelming worry, but it's, you know, a concern. And as a lesbian, you know, I'm a lesbian with a partner so I think that helps to think about old age in those terms. You've got somebody kind of there beside you. If I were a single lesbian, I would probably be more concerned, and, of course, that's always a possibility too. Who's going to help me out if there are important decisions to be made? We've always helped each other with that, you know, since we've been together. But I think as you get older, you need more input to help you make decisions, and, of course, not that everybody always wants it.

My biggest fear

I don't think I would have ever expected my kids to want to take care of me, if I had kids. I don't think that would have been an expectation. I would think they would have their own life, and now it is definitely not an option. The taking care of business, I don't want to be around for that. I'm out of here. If I need to be that cared for, I want to be out of here into another level someplace, wherever that is. I don't mind a little help, but realistically, that is my biggest fear in getting older, is getting stuck in a mire of western medicine where they are in control and not knowing when to say enough is enough. Going beyond that point is a huge fear.

Moving a full decade to two decades earlier

Another thing that's different between me and most heterosexual women, I would think, is that I'm thinking about moving a full decade to two decades earlier because I want to make community. I'm pretty good at participating in community, and I want to do that. I want to get, I like to have established relationships, and this is true for people, you know, just sort of the riff-raff that hang out in your life on a daily basis. Before any strain gets on those relationships. Like, I don't want to meet my cardiologist in the emergency room. When I'm arguing with him or her saying, "Excuse me, this is serious. You need to pay attention to this." So, it's part of the planning thing, again. The part of me that plans ahead.

I want there to be stuff in place

You know, making sure that we can take care of each other. You know, I've been a caregiver all my life. I don't necessarily want the responsibility of caring for every single one of my friends. I want there to be stuff in place. Yes, I can do some of it, but I want to have the responsibility as I make it.

Making sure she's well taken care of

My thought process was almost exclusively around her ability to survive past me in an environment that would be good for her. I wanted her to be somewhere

> where friends would be that she knew and that, I don't think there's anything wrong with retirement communities, and I think that's what she will need if something happens to me. That was the thought process. It's really about her. That's my biggest concern is making sure she's well taken care of if something happens to me.

The participants express fear over being subjected to discrimination when they are older and may not be able to represent and defend themselves as well as in the past. In the following account one participant moves from the expression of that to saying that the resources she has enable her to take control over and not be subjected to that fate.

To make sure that I don't have to deal with that

> I don't want to deal with homophobia. I don't want to go to a senior center and have somebody move to the other side of the room. I just don't want to deal with that. When I'm 70 or 80 years old, I don't have the energy to deal with that kind of foolishness. So, I've worked really hard all my life, and I'm blessed to have the resources to be able to make sure that I don't have to deal with that stuff.

Another participant expresses the perception that she has control over her fate in old age and that her decision making is largely an exercise in controlling outcomes. In her mind, it is protection and defense. She states that other members of the elder lesbian community do not all have the same resources she does to enable them to "fix" their situations and keep their "record clean" of discrimination:

If I can fix it; I have options

> I want to keep my record clean. Because I don't have the experience of discrimination, I have a very low tolerance for it. People who have been kicked down all their life come to experience it as just sort of part of their life, and I haven't had that and I will not have that, you know. If I can fix it. If I have any option, and I do because we've been careful with money. Because, you know, we are who we are. I have options at the end of my life that most of my compadres don't. It doesn't make me feel smug. It just makes me feel so incredibly grateful.

One of the reasons I decided; I don't want to be subjected to it

> At this point, I guess the thing that bothers me most in terms, or that doesn't bother me, it worries me a little bit and disturbs me a little, is becoming more vulnerable as I age. I'm a fairly independent, fierce lesbian. Or have been all my

> life. Getting old and becoming vulnerable is what scares me a little bit. And knowing that someday I will need to be dependent on other folks for quality of life issues can be frightening. And so that's one of the reasons I decided on the CCRC, because I didn't want to leave my fate in the hands of somebody that I just didn't trust, you know. I think that when you're older that racism, ageism, homophobia, sexism all wound you much deeper than they do when you're younger. If I ever get to a point where I can't fight my own battles, I just can't see myself being in a place where I'm sort of left to the whims of other people's feelings or discriminations. I mean, that's part of why I got into the CCRC. Because I just didn't want to deal with that stuff. I just don't want to deal with it. I don't want to be subjected to it.

Summary of Aim I Findings

Because the participants are getting older and sensing that they are not as capable as they once were both physically and mentally, they are coming to the realization that in old age at some point they might not be able to decide for, represent, and stand up for themselves in ways that preserve their own dignity and do not subject them to serious discrimination, as they generally can now. It is again an exercise in control and at least knowing what to expect because they believe that they still can never count on what to expect regarding the response of others to their sexual orientation. However, in their lesbian relationships they have experienced being true to and not losing self, being supported and nurtured. In experiences with the gay community overall and in their lesbian friendship circles they have experienced support, feeling understood, and feeling safe. In their lesbian friendship circles, they have experienced friends as family. As they are in the position of taking care of their heterosexual family members, they realize that it is in their lesbian friendship circles and the experience of friends as family, that they have experienced this type of care and support and not from their biological families.

The participants' past negative and positive experiences, as well as their beliefs and expectations that have stemmed from them, have led to the decision to live in an LGBT CCRC. They have concluded, based on these experiences, beliefs, and expectations, that the only way to control the outcome in terms of preserving their dignity and preventing the experience of homophobia and discrimination when old and less able

to stand up for themselves is to decide on the LGBT CCRC. It is their way of knowing for certain that they will not have to worry and not have to think about it, maybe for the first time in their lives.

Specific Aim II

The purpose of Specific Aim II was to describe factors that both positively and negatively impact older lesbians' perceptions of elder care. In addition to data stemming from the overall analysis, participants were specifically asked to discuss their hopes for this elder care decision. This led to the derivation of specific data about the samples' positive perceptions of this elder care option. Finally, participants were also prompted to express any concerns or worries they have about the option and their decisions. This prompt led to the derivation of specific data about the samples' negative perceptions of this elder care option.

Positive Perceptions

Narratives discussed in the findings for Specific Aim I reveal factors that positively impacted the participants' perceptions of elder care. It should be therefore acknowledged that, in terms of the findings for Aim I and Aim II, the reader will note that there is significant overlap. Specifically, the participants identified that it is the sense of community and continuing friends as family, the protection from homophobia and discrimination, and the guarantee of support for their continued health, welfare, and relationships (all hallmarks of this elder care setting) that have led to their decisions to live in the LGBT-specific CCRC.

Sense of Community and Friends as Family

Having a sense of community and of friends as family were positive experiences for the participants in their pasts. Those positive experiences have had an impact on their beliefs about the importance of creating and maintaining families of choice and also on their decision making. Community and friends as family were identified as experiences they looked forward to in their future at the LGBT-specific CCRC:

Wouldn't it be wonderful

> Here's what we'd think we'd like to do because the experience that we had. We went to this luncheon where there was probably, I don't know, 70 gay men and women at this luncheon and I said, “You know, the energy here is sooo terrific that, you know, wouldn't it be wonderful.”

It is a built-in family

> It is a built-in family. It's the isolation that you don't get when you go to one of these retirement communities, which is really important.

Just a natural source of interactions

> And it's the access to each other that you, you know, when you become less mobile. See that tends to maybe affect other people's relationships because just like we talk about the person being shipped away, you know. The less mobile you become, maybe the less connected you become with this great support network of people. You know, because you can't drive to each other. It's like got to be a big planned-out thing or something. But this would make it much easier. Just a natural source of interactions.

One participant specifically conveyed being pleased that the LGBT-specific CCRC would allow her to establish community early. She also stated that not only would she be able to establish it early but she enjoyed the assurance of having community continue:

The community will continue; You don’t have to wait too long

> The community will continue. I’ll move into some place early enough to establish a community if I don't know a lot of people. You don't wait too long so that you don’t have that opportunity to establish that.

Another participant twice used support in conjunction with the idea that community would positively impact her perceptions of life at the LGBT-specific CCRC. She described it as a “supportive neighborhood” and expressed her beliefs that a real benefit of the LGBT-specific CCRC would be that she would “still have the same support in community, but it would all be kind of within walking distance." Additionally she

expressed that what will impact her positive perceptions of the LGBT-specific CCRC is that it will give her the ability “to be in a community, walking and being with people that are supportive of you and your lifestyle. So to me it would be kind of something that would be really neat.”

One participant reported that continuity in conjunction with community would positively impact her perceptions of life at the LGBT-specific CCRC. She stated that she both “loved the new idea of having a continuous community” and the perception that “You wouldn't have to totally lose all the connections that you have. And you're in a community where the entire community is growing old with you.”

Another participant was elated by the idea that she would have a community with people sharing the common bond of sexual orientation. She regarded this as potentially offering the sharing of common values:

A community of people who have a common bond

> I will have a community, you know. A community of people who have a common bond of being the same sexual orientation. And having hopefully some shared values one way or the other. I'm sure not all of us are going to have the same values, but at least there will be a community of folks that I can talk to.

Finally, the idea of having the choice to participate was highly valued. Knowing that the community will always be there was deemed important:

Distance isn't going to take you out of the scenario

> Your social group remains the same. I mean, you may choose to no longer participate, and then it wouldn't remain the same, but that's your choice not to participate. If you want to participate, distance isn't going to take you out of the scenario.

Protection from Homophobia and Discrimination

The participants experienced homophobia and discrimination in various arenas in their pasts, including the health care setting. They experienced and witnessed homophobia and discrimination based on sexual orientation in health care settings and are fearful about being vulnerable to both when they are older and less able to stand up for themselves. Therefore, one specifically positive aspect of living in the LGBT-specific CCRC, and an attested contributor to the decision, is that the option affords protection from homophobia and discrimination in health care in older age:

To make sure that I don't have to deal with that

> I don't want to deal with homophobia. I don't want to go to a senior center and have somebody move to the other side of the room. I just don't want to deal with that. When I'm 70 or 80 years old, I don't have the energy to deal with that kind of foolishness. So, I've worked really hard all my life and I'm blessed to have the resources to be able to make sure that I don't have to deal with that stuff.

If I can fix it; I have options

> I want to keep my record clean. Because I don't have the experience of discrimination, I have a very low tolerance for it. People who have been kicked down all their life come to experience it as just sort of part of their life, and I haven't had that and I will not have that, you know. If I can fix it. If I have any option, and I do because we've been careful with money. Because, you know, we are who we are. I have options at the end of my life that most of my compadres don't. It doesn't make me feel smug. It just makes me feel so incredibly grateful.

One of the reasons I decided; I don't want to be subjected to it

> At this point, I guess the thing that bothers me most in terms, or that doesn't bother me, it worries me a little bit and disturbs me a little, is becoming more vulnerable as I age. I'm a fairly independent, fierce lesbian. Or have been all my life. Getting old and becoming vulnerable is what scares me a little bit. And knowing that someday I will need to be dependent on other folks for quality of life issues can be frightening. And so that's one of the reasons I decided on the CCRC, because I didn't want to leave my fate in the hands of somebody that I just didn't trust, you know. I think that when you're older that racism, ageism, homophobia, sexism all wound you much deeper than they do when you're younger. If I ever get to a point where I can't fight my own battles, I just can't see myself being in a place where I'm sort of left to the whims of other people's

> feelings or discriminations. I mean, that's part of why I got into the CCRC. Because I just didn't want to deal with that stuff. I just don’t want to deal with it. I don't want to be subjected to it.

Where it is not very accepted

> We don't want to go to places where it is not very accepted. So, I have never really had any bad experiences, but I have never put myself, I don't even want to put myself in that situation.

Feeling safe about who we are; to not feel like I have to hide

> Feeling safe about who we are. Just being with like-minded people and feeling safe. I just want to be, you know, feel like I fit in and this is who I am. Just to really not have any change in my lifestyle that I have now. Just to not feel like I have to hide anything or feel afraid to not use the agenda.

The Guarantee of Support

The guarantee of support for the participants’ continued health, welfare, and relationships (assured by the LGBT-specific CCRC option) is an aspect that the participants viewed positively and highly valued. They expressed feelings of comfort from the assurance of support and identified that their childless status made the support a particularly welcomed aspect of living at the LGBT-specific CCRC. Finally, the support for their relationships and the guarantee that their partners will be cared for competently were significant contributors to their decision making:

I want to be comfortable

> One of the fears is ending up someplace where I can't be me; I have to watch what I say; I have to watch what I do; I can't be me. I want to be someplace where I can be me. Whether that's good or bad, you know, I just want to be me. I want to be with people that are comfortable. I want to be comfortable. And I don't mean physically comfortable, I mean emotionally comfortable. I mean, physically comfortable you can pay for. Emotionally comfortable you can't pay for. I think that this whole movement around LGBT retirement communities is…I mean, I'm assuming that most people understand it. Most people understand that people when they retire don't want to be bothered with a lot of “stuff.” They just want to retire with some peace and some dignity and some grace. And so the issue of LGBT people wanting to retire with each other just makes perfect sense to me.

People want to retire with their community. They want to retire in places that they can feel comfortable.

These places are important

I don't want people making fun of me. I don't want people calling me names. I have been in the past. It sure has happened to all of us or a lot of us. I think people that are our age have experienced more of the prejudice than maybe our sisters and our brothers in their 20s and 30s and 40s. They have a different experience. People like myself and people older than me carried a lot of the brunt of what happened as we broke through to allow the younger generations to be more who they are, to be more out, or just be themselves. It is not easy. Some of my friends are still in the closet. So these places are important. I support this even if I was never going to end up here, because it is important for people to be in a safe environment as they get older or as they get sick or you know to get what they need no matter who you are.

Who's gonna care for you?

As a lesbian, it's like, who's gonna care for you? You know, you don't have kids. I think, my partner and I have talked about this, you know. If we were in need of someone, would any of our family be able to step up and say, "Okay you can either come live with us or I'd come out and stay with you"? And I think that's a concern. We'll say, "Well, if I get that way, shoot me."

Nobody for me

Part of the issue is who is going to do for me what I'm doing. And that has been my driving force around trying to make an LGBT community happen….to make sure that I'm not going to be at the mercy of a caregiver…..You know, you want to be able to live, and you want to be able to know you're safe. And so when I recognized that, that there was nobody for me…….So it's sort of like we have to plan for ourselves what is going to happen within our own community and family and friends.

The continuum- of-care model is really attractive

The continuum-of-care model is really attractive to me. And to start out on one end of that spectrum in an independent apartment, house of my own is really attractive to me. Having community, but yet being able to go in and close my door, you know. And feel like I'm living in any other housing development. Having sort of my own separate house. And again, depending on what happens, being able to graduate into something else. That was important to me.

Positive about this

> A lot of these assisted living places, unless you're married, will not allow two people to live in the same unit. So that's the one lesbian thing that was positive about this, we're not going to be told we have to get two different units.

Moving a full decade to two decades earlier

> Another thing that's different between me and most heterosexual women, I would think, is that I'm thinking about moving a full decade to two decades earlier because I want to make community. I'm pretty good at participating in community, and I want to do that. I want to get, I like to have established relationships, and this is true for people, you know, just sort of the riff-raff that hang out in your life on a daily basis. Before any strain gets on those relationships. Like, I don't want to meet my cardiologist in the emergency room. When I'm arguing with him or her saying, “Excuse me, this is serious. You need to pay attention to this.” So, it's part of the planning thing, again. The part of me that plans ahead.

My partner still could be taken care of

> One thing that I didn't mention. I have both of my aunts. My mother died at 62. So, I mean, who knows. But both of my aunts have memory problems galore. Dementia, Alzheimer's, whatever. And so I have some concerns that I may end up having that little genetic thing. And so I want to make sure that I am in a place that I can be taken care of and my partner still could be taken care of. That she would be okay and not have to spend all of her time taking care of me.

What would happen to my partner?

> If something happens to me, what would happen to my partner? She couldn't take care of this property. She couldn't do anything, so I wanted to be in a place where she knew some people and a place where they would come in and do the cleaning for her. I mean, she would still have her own place, but someone would come in and do the cleaning. I think they even do the laundry if you want. They have a cafeteria or a dining room where you can get meals. It's close to public transportation if she gets where she can't drive anymore..

Somebody there

> So if my partner needs care, or if I need care, that there's somebody there to back that up and to help with that. If one of us becomes incapacitated and the other gets into the caregiver role.for the caregiver to have the support of the community and to have resources.

Somebody's not going to take advantage of me

> Feeling safe that somebody's not going to take advantage of me . Actually feeling physically safe and feeling safe that somebody's not going to take advantage of me when I become feeble.

Negative Perceptions

In terms of negative perceptions about this elder care setting, some interesting findings are noted and may point to the need for future exploration and research. The participants conveyed that they are concerned about the lack of privacy that they may encounter. Additionally, they expressed concerns about the exorbitant costs involved in this elder care decision. Because of the participants' own concerns about homophobia and discrimination, it was striking and somewhat unexpected that they expressed qualms about having to live in the same setting as gay men.

Lack of Privacy

Lack of privacy is perceived as a negative aspect of long-term care settings, including their own long-term care choice. When asked what they regarded negatively in long-term care, narratives relating to privacy issues were expressed:

Will I still be able to feel like I have privacy?

> Well, privacy is important to me, you know. And so when you give up having a space and, you know, not having somebody's wall right next to yours. I have a little concern about will I still be able to feel like I have privacy?

Making sure that there's enough privacy

> Making sure that there's enough privacy. That it's quiet enough because I am just terrible about noise. I don't like it.

Hearing people through walls

> Living in a little apartment they're calling a house, and hearing people through walls…

That is the downside

> The only problem is the drama. That is the downside of any of the places is the drama. You can't get away when you get a big group of people. I don't care who they are. It doesn't have to be gay people or straight people.

Concerns Relating to Cost

The high expense of this elder care option is perceived negatively by the participants. When asked what they regarded negatively about this elder care decision, narratives relating to cost issues were expressed:

Very expensive

> It is very expensive on a monthly basis.

You have to pay more

> It's how CCRCs operate. I think they need all of that money because they're saying, you know, "We'll provide you with the health care." Although, if you need assisted living, you have to pay more than that. The monthly amount is included, I mean, is upped by that amount.

What happens if you run out of money?

> The financial aspect of it all. That has, to me, a little bit of concern of course, you know. Because I mean, even though we've looked at what our mortgage is and what the expenses are on a monthly basis, they require a very large entrance fee and then a monthly maintenance fee, you know. What happens if you run out of money? You know, what happens if you can't make it?

All these different financial structures

> Every now and then I think, "Oh my god. What am I doing?" You know, because it's a big change. You know, selling your home. They are being very good about how they said they will set it up financially. It's not easy to make a decision like this because financially, there are innumerable ways that you can do this. I mean, you know, you go to a facility, and they have this particular financial structure. All these different financial structures. So it's not easy to select that way. And it's also not easy to, especially for me. I'm not a particular planner, believe it or not after all of this, to say, "Okay. So at this point in my life now—you know, 64, 65,

> whatever—I'm going to move in here, and I'm going to stay here until I die." You know, it's like that could be a long time!

It could price us out of the market

> Money is a concern. As much as I said, you know, we've got our pensions and everything else. It could price us out of the market.

Can we afford it?

> We have talked to our financial planner, and we threw out what we knew about it. How much something is going to cost hasn't been out yet. They are still trying to figure out what all of this is going to cost. They have ballparks. So we threw the ballparks out to our financial planner, and she says if we don't plan to live to be 110, she thinks we can do it. And we are going to have to curtail some things; we're not going to be able to run out and buy toys all the time and that sort of things, but I think the biggest thing would be can we afford it?

Living with Gay Men

Throughout the narratives, feelings regarding strong connections with women and the preference of being in the company of women were expressed. However, considering the participants' specific concerns relating to homophobia and discrimination, I was somewhat surprised by their qualms regarding living with gay men. When asked their concerns about this elder care decision and what they perceived negatively about it, narratives relating to living with gay men were expressed:

Can I stand having all that gay male energy

> Living with a bunch of gay guys. Can I stand having all that gay male energy around me, you know?

I haven't lived around gay men

> I haven't lived around gay men very much. I have some concerns about how that is going to go. I am not concerned. Thoughtfulness about how that's going to go. I am not sure if it rises to the level of concern. And I'm sure that it goes the other way around.

A little bit of a concern

> We have heard things like, another friend of ours went to another gay/lesbian/transgender place, and she said all she saw were guys by the bar. I said, "Really, what is the incentive in that?" She saw all of these guys at the bar and guys doing the golf and guys out doing this. She wondered, "Where are the lesbians?" So, I will admit that is a little bit of a concern.

Men live in the world

> Living in a community that has men will be different for me. Of course men live in the world.

Summary of Aim II Findings

Positive perceptions regarding the decision to live in this elder care option were straightforward and directly reflected the findings for Aim I. These Aim I findings should also be noted as significant enough to override expressed negative aspects of the option (lack of privacy, financial burden and risk, and living in the same environment as gay men). The participants who expressed qualms about living in the same environment as gay men were somewhat of a surprise, given the concerns they have about homophobia and discrimination. I see this as an interesting finding and one calling for exploration in future research. The further exploration of relational issues between gay men and lesbian women could potentially provide important information for designing culturally specific and targeted elder care services for each of these populations.

CHAPTER V

DISCUSSION, STRENGTHS, LIMITATIONS, IMPLICATIONS

Discussion

Conceptual Frameworks

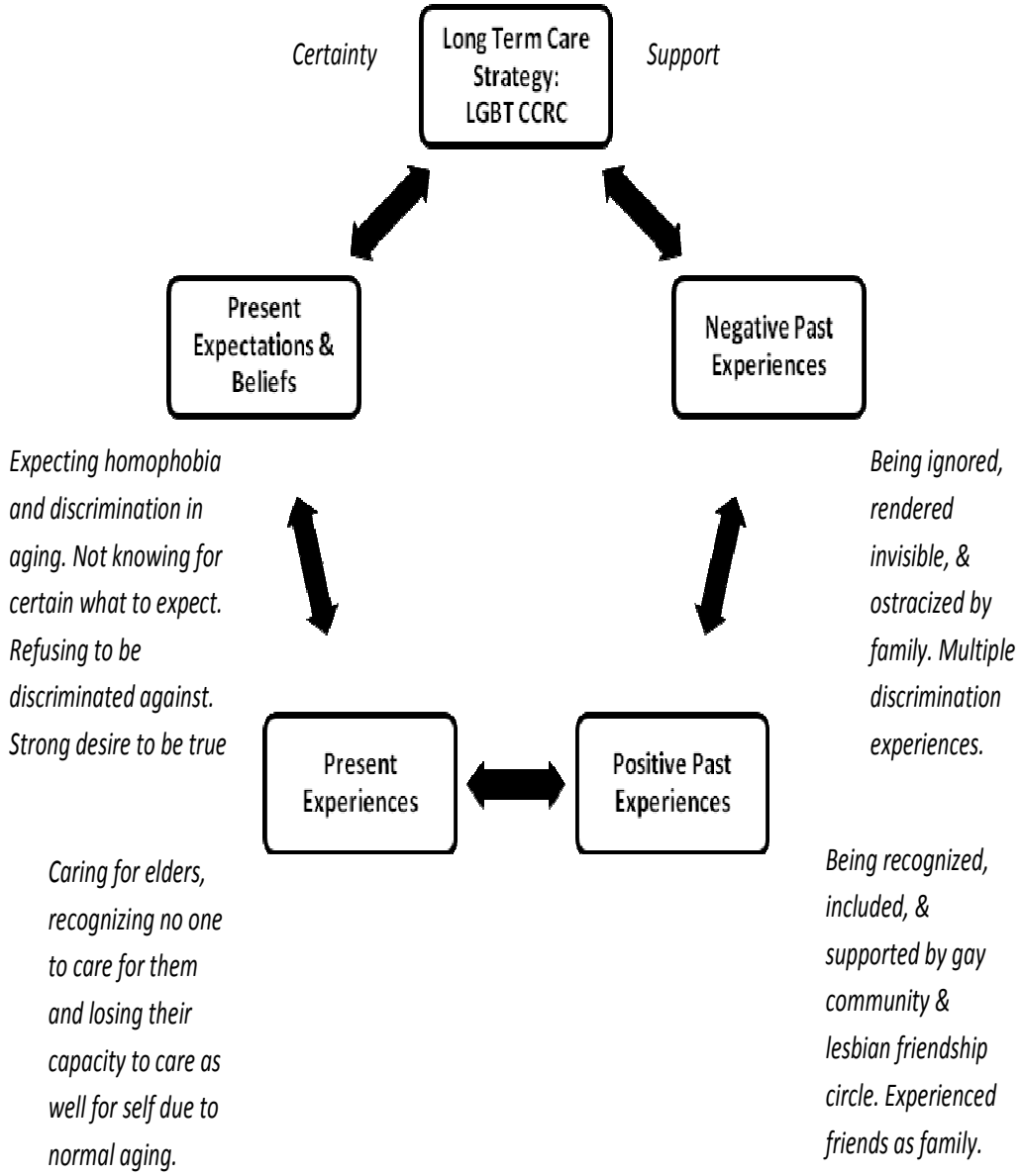
Many of the factors for the decision to live in the LGBT specific CCRC suggested in the proposed framework (Figure 1.) held true for the participants of this study. Specially, the findings revealed that the participants have used their past experiences (negative and positive), as well as expectations that have emerged from past experiences, to interpret potential future elder care circumstances within the context of their lives, identify those circumstances that require interventions as they relate to future elder care, select elder care strategies to manage those circumstances, and predict the outcomes of their selected elder care strategy. What emerged was a framework (Figure 2.) that revealed a broader and deeper contextual understanding of these factors impacting the participants' decision making.

Through the narrative analysis, I was able to understand the impact of caring for their own aging heterosexual parents. Through the participants' stories, I came to understand their growing realization that (because of their childless status) there would be no one to assume that caretaking role for them (except for their lesbian support network). Finally, through narrative analysis, I was able to see more clearly that the participants were developing insight about their own aging and decreased capacity to care for themselves as well as those in their lesbian support network. These present time variables also affect their future care expectations and concerns. Combined with the variables from the proposed framework (Figure 1.) these form the emerged framework (Figure 2.) for their long term care decision making.

Policy Implications

When compared to heterosexual older adults, lesbian, gay, bisexual, and transsexual (LGBT) seniors are twice as likely to age single, more than twice as likely to

Figure 2. Emerged Framework: Long Term Care Decision Making



live alone, and more than four times as likely to have no children to call upon in times of need. For LGBT elders this means a lack of traditional support networks (NGLTF, 2005).

The childless represent 20% of the population who are older than 65 years of age in the United States. The proportion of persons in the US between the ages of 70 and 85 who are both without spouses and children is expected to increase to 30% by the year 2030 (Wachter, 1997). Care of elders is generally a family affair with the implication that adult children are a natural, proper, and preferred form of social support (Gironda, Lubben & Atchison, 1999). Parenthood is considered a major contributor to social integration. Older childless adults have smaller social networks in old age than those older adults with children (Dykstra, 2006; Gironda, Lubben & Atchison, 1999). In addition, older, childless adults =have less financial security, poorer health outcomes, and less contact with extended family members. They do not substitute other family members for the children they do not have to support them when they age (Gironda, Lubben & Atchison, 1999).

There are important policy implications that need to be considered, particularly as the number of childless older adults increases over the next two decades. Public policy in the US, with regard to caring for the older adult population, encourages informal and discourages formal support. Efforts to improve access to and availability of formal support have been historically rejected based on the belief that increasing the focus on formal support undermines traditional family roles (Gironda, Lubben & Atchison, 1999). Health care professionals need to take a more proactive role in order to ensure adequate care and support for a substantial portion of the older adult population. In caring for older lesbians, helping professionals need to be cognizant of the historical tendency to

reinforce informal supports and maintain the status quo. It will be important for them to take a very active role with their older lesbian clients to explore formal aging supports that exist as well as to advocate for those that are needed and do not exist. Insufficient social and financial resources were found by Pinquart and Sorensen (2002) to be reasons for lack of future care planning. Helping professionals can contribute to the prevention of health disparities by exploring and developing interventions aimed at increasing the social and financial resources of elder lesbians. Future research to first explore and ultimately test such interventions is needed so that evidenced based practice guidelines can be recommended for all helping professionals working with this vulnerable population.

LGBT baby boomers worry about older age more than do their heterosexual counterparts (MetLife, 2005). In the LGAIN (2006) study, 74% of the participants identified fears of not being able to care for themselves in old age. Fifty-six percent of the sample expressed concerns about having to be dependent upon others, getting sick or becoming disabled, and living past their incomes. While three-quarters of the sample expect to become caregivers for someone else, almost one in five reported being unsure of who will take care of them when the need arises. Despite these significant fears, more than half of the sample had yet to create wills or living wills spelling out their long term care and end of life preferences. Participants in my study also expressed uncertainty and concern about who will take care of them in old age should they not live in the LGBT CCRC. My sample is different than the LGAIN (2006) study sample in that all of them are actively problem solving to allay their fears by planning their long term care.

Many health policies in the United States are designed to be helpful to older couples and families yet actually discriminate against older lesbian, gay, bisexual, and transgender (LGBT) couples and families. For example, older LGBT couples receive inequitable treatment under current Social Security policy, Medicaid regulations, and the Family and Medical Leave Act. In terms of Social Security, LGBT people in same-sex partnerships are not eligible for the spousal benefits or the survivor benefits that are afforded to their heterosexual counterparts (Cahill, Ellen & Tobias, 2002).

One health policy issue unique to LGBT older adults is unequal treatment of same-sex couples under Medicaid regulations. Current Medicaid regulations allow one member of a legally married heterosexual couple to retain a jointly owned home without jeopardizing his or her spouse's right to Medicaid coverage. Committed LGBT couples do not have a choice when it comes to marriage. According to the law in most states, they cannot be legally married. Medicaid regulations do not, however, make provisions for LGBT couples in long-term, committed relationships causing LGBT couples to potentially have to choose between getting medical coverage to meet one of the partner's health needs and retaining the home for the other partner (Cahill et al., 2000).

Cahill and colleagues (2002) summarized the discrimination against LGBT families inherent in the Family and Medical Leave Act as it is currently written:

> The Family and Medical Leave Act, a federal law passed in 1993, discriminates against LGBT families. It provides up to 12 weeks of unpaid leave after the birth or adoption of a child, to facilitate recovery from a "serious health condition," or to care for an immediate family member who is extremely sick. To qualify for family leave under this law, an employee must have worked for more than 1,250 hours in the previous 12 months in a company with over 50 employees. Most importantly, however, for gay men and lesbians, family is defined in very specific terms to exclude those headed by gay or lesbian individuals (p. 157).

This federal health care policy, despite its purpose of protecting and assisting families across the United States in times of need, prevents LGBT adults from caring for

their families on equal terms with their heterosexual counterparts. It is, in essence, federally mandated discrimination.

Given that LGBT older adults have significant concerns about aging, they may not have made solid plans or taken steps legally to ensure for adequate care and protection, and the federal government has yet to recognize same sex couples and families equitably under such areas as Social Security, Medicaid, and the Family and Medical Leave Act (to name a few), it is critically important for helping professionals to initiate the discussion of future care planning. Health care and other helping professionals need to take an even more active role with their older lesbian clients who have limited social and financial resources. Health care and other helping professionals should take more leadership in advocacy regarding these discriminatory federal policies. Also, LGBT organizations, business providers, financial institutions, and organizations working with LGBT elders must play a vital role in educating LGBT people about long-term care planning needs and options, as well as in developing targeted programs to assist LGBT people to prepare legal documents that will honor their wishes and protect their spouses and families in times of catastrophic illness and death (LGAIN, 2006, p. 17).

Support Needs

Given older lesbians' often childless status and situations in which there is limited familial support, it is vitally important that health care providers and other helping professionals working with older lesbians seek to ask about and include their clients' families of choice. Most of the heterosexual population relies on the support of family members for care and assistance as they grow older. A history of rejection and strained relationships with family members, as well as frequently not having biological children of their own, leaves many older LGBT adults without the assurance of such support in their old age. Many older LGBT adults do not have adequate support systems available to assist in coping with the psychological and physical changes of aging nor do they have the financial resources to meet their needs as they age (McFarland & Sanders, 2003).

Successful aging of these adults is significantly impacted by the adequacy of the support systems available to them (Grossman, D'Augelli, & Hershberger, 2000). Some older LGBT adults may have spent much of their adult lives forming and creating their own "family of choice" (Orel, 2004). Those with a support system have typically done the work of creating it on their own, with little aid from community and social resources (Grossman, D'Augelli, & Hershberger, 2000). There are missed opportunities for meeting the health and support needs of older LGBT clients when providers do not include partners and families of choice.

Some individuals may take an active stance on their own behalf in terms of long term care planning, as is the case in my study of older lesbians. In some countries childless persons have found it necessary to form associations as a means to ensure basic entitlements, such as adequate housing. Examples are the *Centrum Individu en Samenleving* (CISA) in the Netherlands and the *Ensliges Landsforbund* in Norway (Dykstra & Hagestad, 2007). The results of my study of older lesbians' long-term care decision making, support the work of Rubin-Terrado (1994), who found that childless older women historically take more charge of their own situations, actively choosing housing and care alternatives for themselves. Older mothers in the Rubin-Terrado (1994) study tended to exhibit more passivity towards and reliance upon support for decision making regarding their housing and elder care options. My study participants referred to the importance of increased planning and documenting as strategies for dealing with the concern of childlessness as it relates to care and decision making support in old age. They specifically identified that because they could not be dependent on children, or for that matter other informal family support, it was important for them to think ahead and plan early to assure adequate care for themselves and their partners. Participants related the formation of support networks (also referred to as the "creation of family") to their experience of decision making and crisis support.

Despite recent increased openness and public acceptance of homosexuality, family and self-acceptance continue to have highly significant roles in the psychological health of gays and lesbians. For example, family support significantly reduces psychological distress among gay youth (Herschberger & D'Augelli, 1995). Herschberger and D'Augelli found that the less self-acceptance experienced by gay youth, the greater their psychological distress. My study participants discussed the distress that lack of family support has caused them in the past and specifically identified the acceptance and support received by their "family of choice" as psychologically enhancing.

Relationships between gay and lesbian adults and their parents have been characterized as ones of either loving denial (in which the parents are supportive but not open about their child's sexual orientation) or resentful denial (in which the parents actually limit contact with their child due to unhappiness with the sexual orientation) (Muller, 1987). Family relationship patterns discussed by the participants in my study tended to fall into the loving denial or resentful denial categories.

Crisis Competence

Cahill and South (2002) discussed a phenomenon called *crisis competence*. Crisis competence refers to how the stress and pain of living through years as the targets of homophobia and discrimination serve to prepare LGBT elders for the multitude of stressors they experience as part of the aging process. In this study, the formation of support networks of choice (or in the words of a participant of this study, "creating family") are a likely consequence of crisis competence.

The development of crisis competence among the LGBT population is substantiated by the previous LGAIN study (2006) in which almost 40 percent of the sample stated that their sexual orientation has helped them prepare for challenges in the aging process. Specifically, they felt the importance placed on support networks as a consequence of their sexual orientation will help them in their older age. Seventy-five

percent of that sample expressed current reliance on the support of non-family support networks. Additional studies support this practice. For example, Dorfman and colleagues (1995) conducted a study of lesbian, gay, and heterosexual older adults between the ages of 60 and 93. Their results suggested that the homosexual participants in their study received significantly more support from friends, while heterosexual participants received more support from members of their biological families. Beeler, Rawls, Herdt, and Cohler (1999) conducted a study of lesbians and gays between the ages of 40 and 90. They identified that 68% of their participants had a "family of choice" (non-biologically related friends that they considered family or analogous to family in their lives and upon whom they depended for support). Grossman, D'Augelli, and Hershberger (2000) found that lesbian and gay elders felt more satisfied with support received from people in their networks who knew their sexual orientation.

The deliberate construction of support networks is an essential feature of lesbian life (Comerford, Henson-Stroud, Sionainn, & Wheeler, 2004). Similar to my study, Comerford and colleagues had a sample consisting of lesbians aged 55 and older who frequently lacked family support relating to their sexual orientation. Their findings are consistent with my study in that participants in their sample reported finding it necessary to make a significant effort to develop other sources of support for their social, physical, emotional, and spiritual health.

Homophobia and Heteronormativity in Aging Services

Many LGBT baby boomers have been open about their sexuality for most of their lives and are increasingly unwilling to return to being closed about their sexuality when they encounter homophobia in aging services (Cahill & South, 2002). This finding is certainly substantiated by the results of my study.

Heteronormativity refers to the concept of viewing the heterosexual experience as the only, or central, worldview. In elder care, the concept of sexuality is generally viewed in terms of sexual activity, rather than as an aspect of identity with many facets, similar to

culture (Harrison, 2001). A heterosexual bias is widespread among elder care services. For example, 95% of long-term care staff surveyed in New York City supported the right to free expression of the sexual identity of their residents, yet only 13% of facilities offered sensitivity training on LGBT older adults and their needs. When accessing needed elder care services (for example, long-term care) LGBT older adults are presumed to be heterosexual and are separated from partners, faced with bigotry and discrimination if understood to be LGBT, and forced to go back into the closet to receive care (NGLTF, 2005).

The findings of my study support those of the LGAIN (2006) study in that these participants have no interest in becoming closed about their sexual orientation in order to receive services. While expressing that they have generally not experienced blatant or serious discrimination because of their lesbian sexual identity, they fear such discrimination and point to that as one of the significant factors in their decision making regarding LGBT-specific care.

Decision Making

Tversky and Kahneman (1974) stated that we judge probability and make decisions based on the ease with which we retrieve, construct, and associate past events and that more significant and frequent events are typically recalled with greater ease. The participants in this study recalled with relative ease and specificity multiple incidents of homophobia they have experienced over their lifetimes. Stories of maintaining silence about their sexual orientation and either being invisible to or ostracized by family were easily recalled and widespread across cases. Stories of feeling free to be open among, receiving support from, and feeling included among the gay community or in their lesbian friendship circles were also easily recalled and widespread. Words such as “safety,” “comfort,” and “security” were used to describe the feelings of being within the gay community.

Additionally, the decision may support the ambiguity effect postulated by Ellsberg (1961). Living in an LGBT CCRC would (despite some of the drawbacks) appear to be the best and most predictably safe choice for long-term care. It is a bet on clear rather than vague or ambiguous future events.

Sorensen and Pinquart (2000) suggested a four-component care planning and decision making process that includes having awareness and anticipation of future care needs, gathering information determining preferences, and making specific plans. The participants in my study are engaged in the process outlined by Sorensen and Pinquart (2000). The process is not sequential, and many components of the process are actually happening simultaneously. The participants have come to the decision to make specific plans to live at an LGBT CCRC. They also continue to engage in the earlier steps suggested by Sorensen and Pinquart:

1. They discuss a growing awareness about changing physical and mental capacity as they are aging and an understanding of the potential need for increasing future support.
2. They are gathering information by attending meetings regarding the ongoing development of the CCRC and are meeting with financial planners to determine their financial needs and risks.
3. They discuss the attributes they prefer for long-term care settings and expect to experience living in the CCRC.

An important consideration for the participants making the decision of interest in this study concerned the relationship between actions and outcomes presented by Quattrone and Tversky (2004). There was an outcome of interest to the participants that they felt was not likely to be independent of choice. That is the outcome of being free from vulnerability to discrimination, homophobia, and mistreatment in elder care based on sexual orientation. This outcome appeared to be absolutely critical to the participants

and was associated specifically with and therefore contributed to the decision to live in the LGBT CCRC.

Finally, social comparison theory emphasizes the considerable influence of comparable peers upon attitudes, opinions, and decisions (Suls & Wheeler, 2000; Suls & Wills, 1991). The suggestion that uncertainty arises when in disagreement and is reduced when in agreement with similar peers (Abrams, 1996; Turner, 1991) is noteworthy and may be an important factor for the participants of my study. All the participants in my study were either known acquaintances or close friends. This friendship network not only socialized with but also provided a support network for one another comparable to family. One participant referred to this group as her "ohana" (the Hawaiian term for family). This support network had been discussing the prospect of retiring together for many years. Their shared stories and discussions over the years likely influenced each other's attitudes and opinions about what they might experience in long term care and ultimately reinforced each other's decisions regarding the need to live in the LGBT specific CCRC.

Strengths and Limitations

A primary strength of this study was the dual method approach of across-case thematic and within-case narrative analysis. In this approach I engaged in what is known as the hermeneutic spiral. The hermeneutic spiral in my study was an iterative process of meaning making by both my participants (narrators) and myself (analyst). The hermeneutic spiral in this study involved for me the rigorous process of making comparisons at all levels in all accounts (Ayres, 1998; Poirier & Ayres, 1997). This strengthened the analysis providing a wider and deeper understanding of the participants' decision making.

An additional strength was that I provided explicit detail and description of the methods and procedures I used for the process of interpretation. The explicitness made the use of the method visible to readers and in this way will allow them to use their own

hermeneutic spiral. What this means is that readers can relate their own knowledge and experience with the findings, easily evaluate the trustworthiness of the analysis, and have a basis for conducting further investigations of their own (Ayres, 1998).

Finally, a strength of the study that was unanticipated but remarkable, was the homogeneity of the sample in terms of backgrounds and described experiences. All the participants were either known acquaintances or close friends who had been discussing the issue of retiring together for years. The closeness of this sample, as well as their homogeneity and shared stories, strengthened the analysis and findings.

While the sample has been identified as a strength, it may also be a limitation in this study. There are no established and required procedures for sample selection in narrative analyses. Without established procedures, studies such as this one in which the samples are convenient, small, and homogenous are limited in terms of transferability to other studies and groups.

Finally, it should be noted that a limitation for this study was the scarcity of related research. This limited the transferability of the findings to other research. It does add significance to this study and the need for further research. Existing related research was identified and any similarities with the findings of this study were noted.

Implications

Research Implications

Research regarding older lesbians is scarce. Studies that do exist are typically small and exploratory. Future nursing research relating to the health care issues, needs, and preferences of older lesbians is necessary to gain a better understanding of this important group. Continued lack of knowledge potentially undermines optimal elder health care for older lesbians. This study contributes to moving nursing research of older lesbians forward. Given the lack of research to date on the topic and the significance (both in terms of policy and service delivery implications for the current health care system), descriptive exploratory studies are necessary as a starting point. It is however

the intention of this study to raise questions about elder care for older lesbians that can be explored in other descriptive studies, in larger ethnographic studies, and ultimately in intervention studies.

Several issues that emerged from the analysis call for further exploration. First, across participants there was a denial of discrimination experiences, yet they discussed many stories of homophobia and discrimination. This may reveal "privileged guilt" in which the participants feel guilty calling attention to marginalization and discrimination experiences related to their sexual orientation due to the perceived status of privilege they feel in most areas of life. This calls for further exploration in future studies.

It will also be important for future nursing research to explore the elder care decision making of lower income LGBT adults. Most LGBT older adults do not have the means and resources of the participants in this study and yet may have experienced more difficult life experiences and may have greater needs. Geriatric nursing researchers have an obligation to address the needs of this very important elder aggregate.

Additionally, the participants expressed qualms about living in the same environment as gay men. This finding was a surprise to me, given the concerns participants had about experiencing homophobia and discrimination. Further research on this topic is warranted. The health care needs of gays and lesbians are naturally different just as the needs of heterosexual men and women are different. Exploration of relational issues between gay men and lesbian women as well as their specific needs and expectations for care could potentially provide important information for designing culturally specific and targeted elder care services for each of these populations.

Finally, it is my desire to return and complete an ethnographic study of this group when they are living in the LGBT-specific CCRC. I am interested in studying the degree of congruence between the participants' expected and actual experience of living in the LGBT-specific CCRC.

Implications for Education of Health Care Professionals

LGBT health issues need to become a mandatory part of the cultural competency education for all health professionals. This study focused on issues specific to the care of older lesbians. The health issues of lesbian elders should be an important part of geriatric health-related curricula. Accreditation bodies for health professions education (for example, the American Association of Colleges of Nursing) should require a LGBT cultural competence component in all programs. This education should be provided to and updated for the existing health care workforce through continuing education and should be ongoing in order to address staff changes and the evidence base provided by increased research.

Health care professional licensing examinations should include questions on LGBT health. Increased support should be offered by governmental health agencies and private foundations to researchers focusing on care of the LGBT population, including the care of lesbian elders. Efforts to create and disseminate standards of health care for the LGBT population should be supported both legislatively and financially by private foundations as well as governmental health agencies. For example, the John A. Hartford Foundation, the American Association of Colleges of Nursing, and colleges of nursing throughout the United States, in developing competencies, guidelines, and curricula for geriatric nursing care, should specify and include the unique needs of the LGBT population.

Nursing Practice Implications

At a macro-system level, nursing practice implications for addressing the health care needs of the elder lesbian population involve advocacy. Specifically, nurses should advocate for the inclusion of the LGBT seniors in federal and state health initiatives and policies. There is a significant opportunity for leading nursing experts in LGBT health and aging issues to partner with organizations such as the John A. Hartford Foundation to publish a template of policies for LGBT-friendly facilities. Organizations such as the

American Nurses Association should look for legislators in each state who support the rights of the LGBT population. Additionally, nurses should advocate for federal and state resources to target needs specific to the elder LGBT population. Finally, nursing can make a significant contribution to the health of this important and vulnerable population by broadly expanding research addressing high-risk problems for the LGBT population and also including large numbers of this population as subjects in interventions to test their effectiveness in this specific population.

At the micro-system level, practice implications for addressing the health care needs of the elder lesbian population involve actions that reflect and address the provision of culturally sensitive care. Examples of such practice implications include staff education programs, the enactment of LGBT patient non-discrimination policies, the use of LGBT-inclusive language on documents and in verbal communications, and the inclusion of partners and families of choice in care. Additional practice implications when working with lesbian elders include exploring existing support systems, identifying and assisting with the formation of acceptable support systems, investigating plans for elder care, discussing concerns about elder care and potential coping strategies, and examining with older lesbians, and educating them about, various elder care options.

Conclusion

Nurses must work actively toward the advancement of knowledge about and promotion of LGBT health. Our national health plan has, as one of its overarching goals, the elimination of health disparities. Nurses need to take leadership in all areas (nursing research, education and practice) in advancing nursing knowledge to prevent health disparities among vulnerable populations, including LGBT elders. Geriatric nursing researchers, for example, need to broadly expand research focusing on the health needs of the older LGBT population. More descriptive and exploratory research is needed immediately. Descriptive and exploratory studies should be directly followed by intervention studies that will ultimately provide the evidence base for translation to

nursing education and delivery of best nursing practices in the care of LGBT elders. There is a current lack of knowledge among nurses in terms of both health issues for and providing culturally competent nursing care to the elder LGBT population. A continued lack of nursing knowledge and limited evidence base regarding this group will potentially undermine optimal nursing care delivery and permit health disparities among this important and vulnerable population. This study was an intentional and logical move forward in advancing nursing knowledge about elder LGBT health.

APPENDIX A

SCRIPT FOR INFORMING SAMPLE POOL ABOUT STUDY TOPIC

There is a doctoral nursing student at the University of Iowa who is interested in conducting a study about the long-term care decision making of older lesbians. She would like to conduct interviews with older lesbians (age 55 and older) who have committed to living at a continuing care retirement center (CCRC) specializing in the care of the older lesbian, gay, bisexual, and transgender (LGBT) population. If you would like more information and/or are interested please contact:

Marcena Gabrielson

Phone: 309-262-5165

Email: marcena-gabrielson@uiowa.edu

APPENDIX B

STUDY INFORMATION LETTER

Date

Inside Address

Dear Potential Participant:

I am writing to invite you to be part of a research study. The purpose of the study is to explore the decision-making of lesbians (aged 55 and over) who have chosen to live in a lesbian, gay, bisexual, and transgender specific continuous care retirement center.

I am inviting you to be in this study because you have indicated an interest in this study.

If you agree to be one of the 10 participants, I will ask you to participate in an interview about your life and experiences including your relationships with your family and your access to health care and about the decisions you have made for your retirement. The interview will take about an hour, but I may want to talk with you a second time. A second interview will only take place if there is a need to clarify your responses from the earlier interview or if time does not allow for the interview guide to be completed in the first meeting. All interviews will be tape recorded. You may skip any questions you do not wish to answer.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records from this research. To maintain your privacy and complete confidentiality the following steps will be taken:

1) Your name and other identifying information will not be used in the study data. An ID number will be used in the order of your interview. If a second interview takes place it will be kept with your original interview ID number. The ID number assigned to you will be linked to your name. The list linking your name and your study identification number will be stored in a separate location that is accessible only to the researchers.
2) Any names you use in the interview (for example, names of children, providers, or institutions) will be edited out.
3) In addition to me, only my doctoral advisors, Dr. Janet Specht and Dr. Lioness Ayres, of the University of Iowa, will have access to a written record of your interview. I will be the only person with access to the tape recorded interviews.
4) The original tape recordings of your interview(s) will be kept in locked secured storage and will be destroyed after two years if not before.
5) The written transcriptions of the interviews may be kept for my use in publications and presentations.
6) If I write a report about this study we will do so in such a way that you cannot be identified.

You will be asked to discuss personal issues relating to your life experiences. This may recall difficult or stressful times in your life. You will not benefit personally from being in this study. However we hope that others may benefit in the future from what is learned. It is hoped that the information collected in this study will increase care providers' knowledge about older lesbians and therefore improve the care they provide.

It won't cost you anything to be in the study. You will not be paid for being in this study. Taking part is completely voluntary. If you decide not to be in the study, or if you stop participating at any time, you won't be penalized in any way.

If you have any questions about the study itself, please contact me:

Marcena L. Gabrielson, MSN, RN (309)438-2319, marcena-gabrielson@uiowa.edu or mlgabri@ilstu.edu. If you experience a research-related injury, please contact me at the number or e-mail addresses above.

If you have questions about the rights of research participants in general, please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 52242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research participant or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

Thank you for your interest in the study. I will follow up in one week with a telephone call to answer questions about all the information presented here. At that time, we will schedule an interview if you are interested. If you do not wish to participate in this study, please let me know when I contact you or e-mail this information to me before the phone call. Proceeding with an interview will demonstrate your consent to be in the study.

Yours Very Truly,

Marcena L. Gabrielson, MSN, RN

PhD Student, the University of Iowa

APPENDIX C

SAMPLE SCRIPT FOR TELEPHONE FOLLOW UP

Hello, this is Marcena Gabrielson. I am the doctoral nursing student with the University of Iowa who will be conducting a study about the long term care decision making of older lesbians. You requested an information sheet regarding the study that I will be doing in which I will conduct interviews with older lesbians (age 55 and older) who have committed to living at a continuous care retirement center (CCRC) specializing in the care of the older lesbian, gay, bisexual, and transgender (LGBT) population.

- Did you receive the study information letter?
- Do you understand the information? Do you have any questions?
- Are you interested in participating? If so, when and where would you like to schedule the interview?

APPENDIX D

INTERVIEW GUIDE

1. Tell me the story of when you first realized you were a lesbian.
2. If out, tell me the story of when you first came out as a lesbian.
3. If not out, tell me what has influenced that for you.
4. What are the most significant good things about being a lesbian?
    - Tell me stories about your experiences with those things.
5. What are the most significant bad things about being a lesbian?
    - Tell me stories about your experiences with those things.
6. Tell me stories about you and your relationships with family and friends.
7. What is it like to be growing older as a lesbian?
    - What are your hopes as well as concerns about growing older as a lesbian?
8. How did you come to decide to retire here?
    - What are the hopes as well as concerns that have influenced the decision?
    - What has had the greatest influence on this decision?
9. Can you think back to the time when you began to think you might be a lesbian?
    - Tell me any stories you can think of regarding that time.
10. What do you want to tell me about that I haven't asked you?
    - What do you think I should know?

APPENDIX E

LARGE SCALE MATRIX

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