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Sexuality and Dementia: Assisted Living Staff Negotiate the Autonomy of Residents' Sexual
Needs

by

Josephine Misaro

Under the Direction of Erin Ruel, PhD

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2023

ABSTRACT

Assisted Living (AL) communities are residential care settings designed to offer support and assistance to adults aged 65 or older who demonstrate a physical or mental impairment that makes it difficult for them to care for themselves. These communities provide support with activities of daily living (ADL) without the level of medical care typically found in nursing homes. By offering housing, personal care services, and social engagement opportunities tailored specifically to older adults' needs, AL aim to promote independence while improving quality of life. Apart from care, AL provide an environment where social relationships, intimacy, and sexuality for residents are negotiated.

Administrators of these communities face challenges when developing and implementing policies and processes that govern residents' behavior. These challenges are compounded by the physical and cognitive decline of the residents such as dementia frailties. AL administrators face difficult decisions on balancing the sexuality and intimacy needs of older adults with health and consent needs. Existing theoretical and empirical research on sexuality and intimacy among residents living with dementia is not sufficient, especially regarding how providers negotiate to balance the autonomy of residents' sexual needs against ensuring residents' health and safety as well as the expectations of their respective families using structured interviews and qualitative thematic analysis, I examine how administrators and care workers in AL define, understand, balance, and negotiate the sexuality and intimacy behaviors of residents with dementia.

Administrators are gatekeepers, policy-makers, and culture influencers in a setting. The level of protection entrusted to administrators and their role in governing sexual relations amongst residents while understanding the potential side effects of dementia is worth studying. Administrators informal policies regarding residents' sexual needs are shaped by many factors that tend to stifle the residents' sexual autonomy. The health, safety, and family

expectations often trumped the intimacy needs of AL residents. Findings highlight oversight strategies, such as surveillance, redirecting, and reporting, that careworkers employ, undermine residents' privacy, dignity, and respect. In this dissertation, I expand on earlier studies on sexuality and older adults by examining the complex ways in which administrators negotiate and balance sexual autonomy using strategies within the AL communities.

INDEX WORDS: Dementia, Sexual autonomy, Assisted living, Policies

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DEDICATION

I dedicate this work to assisted living community administrators and direct care workers who work towards the quality of life of residents with dementia.

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LIST OF ABBREVIATIONS

AL - Assisted Living

IRB - Institutional Review Board

Ph.D. - Doctor of Philosophy

LGBT - Lesbian, Gay, Bisexual, Transgender

ADL - Activities of Daily Living

HIPAA - Health Insurance Portability and Accountability Act

CNA - Certified Nursing Assistant

EOL - End of Life

DSM - Diagnostic and Statistical Manual of Mental Disorders

NPI - National Provider Identifier

PPE - Personal Protective Equipment

CMS - Centers for Medicare and Medicaid Services

HIV - Human Immunodeficiency Virus

PT - Physical Therapy

OT - Occupational Therapy

1 INTRODUCTION

1 Background and Rationale

With an aging population rapidly expanding and dementia becoming more commonplace, a growing proportion of the U.S. population faces many unique challenges such as cognitive decline, dependence on caregivers, and loss of autonomy (Kolodziejczak et al., 2019). One under-studied challenge is the sexuality and intimacy need of older adults—especially those with dementia—mainly due to the cultural taboos regarding older adults and sex. Such attitudes can impede the creation of thoughtful, caring policies and processes designed to meet the sexual needs of older adults living in assisted living (AL). As a result, AL residents' sexual rights and autonomy remain inadequately addressed leading to inconsistent practices or possible violations of residents' rights (Rheaume & Mitty, 2008).

The lack of policies also creates an environment where residents lose autonomy, resulting in frustration, isolation, and reduced well-being (Kolodziejczak et al., 2019). Being deprived of sex or intimacy may cause some residents with dementia to experience behavioral issues, such as anxiety, depression, and diminished social connections. Further, this denial of intimacy is contradictory to philosophy of AL which includes a homelike environment that emphasizes consumer choice, autonomy, privacy, and control; services designed to maintain independence and aging in place; and 24-hour watchful oversight of (Burgess et al., 2018; Barmon et al., 2017, Carder & Hernandez, 2015).

Staff members may encounter difficulties addressing and supporting residents' sexuality due to limited training or guidelines. This could be a result of the nature of current policies and practices within ALs which may hamper negotiations of residents' sexual needs. Effectively bridging these gaps may require comprehensive policies and training for staff.

1.1 Sexuality and Intimacy

Beliefs and norms surrounding sexuality and intimacy start from childhood and apply throughout the life course. Current practices regarding sexuality and intimacy are predicated on Judeo-Christian norms in that sex should only take place in the marital bed and for the purposes of procreation. Extramarital sexual relations also violate the norms of appropriate sexuality. Americans strongly believe it is wrong for a married person to have sexual relations with someone other than their marriage partner (Ashdown et al., 2019; DeRose et al., 2021). Yet, it is estimated that more than half of married men and women commit adultery by having sex with someone who is not their spouse at some point in their marriage (Newport, 1997). So, while norms are accepted within general society, their enforcement is inconsistent. Reasons for engaging in extramarital sex vary depending on the situation. It could be caused by dissatisfaction with the primary relationship, desire for more sex, and, in some cases, falling in love with the extramarital partner (Allen & Atkins, 2012).

Most conversations on sexuality focus on the younger population and ignores older adults. Rheume and Mitty (2008) argued that sexual activity among older and frail individuals often draws criticisms and outrage in society due to ageism and stereotyping associated with older adults' sexuality. Society generally believes that older individuals, particularly those living in AL communities, should no longer engage in sexual activity due to ageist assumptions about them being incapable or the notion that sexual expression is inappropriate for them. Perceptions about abstaining from sexual activity may lead them to neglect their sexual needs, depriving them of the opportunity for intimacy, connection, and pleasure that are essential elements of human experience. This neglect can contribute to feelings of isolation, loneliness, and diminished sense of self-worth in older adults (Rheume & Mitty, 2008).

Consensual sex between two individuals is also a norm in society today. Americans and other societies believe that consent prior to sexual relations should be freely given, reversible, informed, enthusiastic, and specific (Douglass, 2019). Freely given means that an individual makes the choice without coercion or manipulation. Reversible means that parties could change their minds about what they feel like doing at a given time. Informed and specific mean that all parties are informed of the sexual activity. Enthusiastic refers to the freedom to do what an individual wants, not what they are expected to do (Douglass, 2019). Consent is not defined by past behavior and should be clearly articulated.

An individual is deemed legally incapable of consent if intoxicated, asleep, physically or mentally disabled, or younger than the acceptable age (Douglass, 2019). The law is explicit on what consent means in cases involving younger victims. However, there is not a clear framework for consent in cases involving older adults.

Older adults living in AL who desire to have sex may violate the above-stated norms of premarital and extramarital sex. As some residents in AL have cognitive issues, consent adds another layer of complications. Sexuality and intimacy become more complicated when older adults without dementia live in AL with other older adults with dementia or other conditions that might affect their normal cognitive processes (Rheaume & Mitty, 2008). Residents living with dementia can express themselves in an inappropriate manner, which might be awkward and embarrassing for other residents and staff. Pinho and Pereira (2019) found that older adults living with dementia engaged in various passive aggressive behaviors when attempts at intimacy failed.

In some cases, these older adults who were not able to achieve intimacy displayed violent behavior like breaking dishes or being abusive, and, in other cases, they were embarrassed by the difficulty of engaging in heteronormative penile-vaginal sex. These instances illustrate the need

to balance protecting older adults and allowing for freedom that might improve their quality of life. It is also important to note that attitudes, perspectives, principles, culture, and religion might positively or negatively influence how people interact and treat each other in different circumstances (Pinho & Pereira, 2019).

Beyond cultural norms, research has found that societal institutions like hospitals and AL staff in AL communities have concerns over older adults engaging in sex due to their greater health risks. These risks include cardiovascular and metabolic diseases and the health consequences of using medicines to resolve sexual dysfunctions (Kolodziejczak et al., 2019). While research exists on the sexuality of older adults, it has not effectively addressed the effect of conditions like dementia on intimacy (Erens et al., 2019). Previous studies by Ricoy-Cano et al. (2020) only discussed the impact of culture, beliefs, and traditions on sexual relations among older adults. Conversely, Bender et al. (2017) identified a need to discuss the impact of dementia on sexuality and intimacy among AL residents.

1.2 Research Problem

In my dissertation, I focused on how AL administrators negotiate the sexual autonomy of AL residents with dementia. While sexuality is an integral aspect of the human experience, it can be monitored and repressed among older adults with dementia. Problematic AL communities lack comprehensive policies and processes that support residents' sexual autonomy (Burgess et al., 2018, 2021; Kolodziejczak et al., 2019). Policies often fail to effectively address dementia-specific needs and challenges, leading to inconsistent practices among staff and a lack of clarity about residents' rights. Such negative attitude can hinder open discussions, hamper inclusive policy development, and perpetuate notions that sexuality is no longer relevant or appropriate for older individuals with dementia.

AL administrators face the issue of balancing the sexual autonomy and needs of AL residents with dementia with issues of consent, as well as, the health and safety of all residents. In this study, I investigate how policies and training are applied to improve residents' sexual autonomy while improving overall well-being. Further, I aimed to understand challenges, identify gaps, and make recommendations in order to improve care provided to people living with dementia in ALs (Rheaume & Mitty, 2008).

1.3 Research Objectives

This research was motivated by the fact that many Americans are expected to move to AL as the U.S. population ages making this a timely and significant study. According to American Geriatrics Society, as of 2020, approximately 800,000 people in the United States were living in more than 28,000 AL communities (American Geriatrics Society, 2020). There is a need to understand how administrators in AL communities address the sexual desires and consent needs of residents. Understanding the root cause of the issues affecting the communities and how they operate would help structure appropriate interventions and policies, ensuring that residents' needs will be met while protecting against anticipated risks.

1.4 Research Questions

My research questions are: How do AL policies and procedures shape the administrators' management of sexuality and intimacy needs of residents living with dementia? How do administrators negotiate and balance the autonomy of residents and the extended families' concern over safety and protection?

To investigate these issues effectively, I used semistructured interviews with three levels of administrators in seven AL communities . Additionally, I utilized qualitative thematic analysis

methods (Braun & Clarke, 2006) to deconstruct the various issues that administrators face surrounding sexuality and dementia among older adults in AL.

1.5 Significance of Research

Research on sexuality and aging cuts across different bodies of knowledge; therefore, this study will contribute to the fields of sociology, gerontology, and gender and sexuality studies. The findings may also contribute to policies aimed at managing sexuality among older adults living in AL with and without dementia.

1.6 What's to Come

In this chapter, I provided an overview of research problems and the goals and implications of my research. What follows is a traditional dissertation format with five chapters. The second chapter, titled “The Life Course Perspective” examines the life course perspective (LCP), which informs this dissertation, introduces Bender et al.’s model of “negotiating lack of intimacy assisted living”, which is modified to consider dementia, and a review of the extant literature. In the third chapter, I layout the research methods used. In Chapter Four, I provide the results of my research, and in chapter five, I discuss the findings in relation to the literature before ending with a limitation section and conclusions.

2 THE LIFE COURSE PERSPECTIVE (LCP)

The Life Course Perspective (LCP) shows how chronological age and life transitions shape life spans as well as the social, mental, and physical health of individuals or groups (Elder, 1998). The sequences, experiences, and roles taken up over time define the normative life course trajectory. The Christian-Judeo cultural norms regarding sexuality shape life course trajectories, and these trajectories might change with transitions that alter individuals' statuses or identities (Elder et al., 2003; George, 1993; Hutchison, 2011; Settersten, 2006). Changes in societal norms and acceptable practices form part of the narrative of the life course and can be used to explain attitudes, policies, and feelings toward specific issues.

The typical life course refers to what is expected over time as people transition through different life course stages, from childhood to emerging adulthood, mature adulthood, and, finally, older adulthood. The standard trajectory for a typical life course includes childhood, education, work, marriage, parenting, and retirement. The transitions between these stages also have long-term implications for the nature of the life course of an individual (Crosnoe & Elder, 2002; Elder et al., 2003; Elder & Johnson, 2018; George, 1993). This typical life course trajectory has been extensively used in investigating and studying various sociological phenomena and how they shape lived experiences.

Aging, another key element of the life course, is a dynamic and progressive process experienced throughout one's life (Pinho & Pereira, 2019). Aging comes with physiologic changes such as illness or treatments which might result in outcomes like fatigue, pain, or incontinence, impacting an individual's confidence and interactions with the world. Additionally, interpersonal and psychological changes may eventually impact mood and energy levels, which would also affect the possibility of engaging in sexuality and intimacy (Kelemen et al., 2022;

Rheaume & Mitty, 2008).

Older adults experience issues such as retirement, which can lead to a lack of purpose or a gaining of new purpose, or the death of a spouse, possibly leading to loneliness, emotional isolation, and a lack of opportunity to engage in sexual activity (Luhmann & Hawkley, 2016). However, AL residents who experience these issues are also likely to expand their social network within an AL community, receive more social support, and increase the probability of sexual activity (Freak-Poli et al., 2017). The life course perspective articulates how temporal changes affect perceptions of sexuality and intimacy, their influence on care workers, and the policies they apply when negotiating intimacy and sexuality in AL communities.

Dementia, which is caused by neurodegeneration and results in memory loss and declines in other cognitive abilities, afflicts older adults more than younger ones. Aging also causes hormonal declines of estrogen among women and testosterone among men (Cappelletti & Wallen, 2016; Kolodziejczak et al., 2019; Pinho & Pereira, 2019). The human desire for intimacy may endure despite the cognitive decline caused by dementia and the various changes related to the aging process (Freak-Poli et al., 2017; Seng, 2017). Older adults living with dementia, however, are often unable to exercise these desires due to multiple limitations that can reduce the achievement of orgasms, limit masturbation, and make sex physically challenging, painful, and even unsafe (Rheaume & Mitty, 2008). Administrators in AL communities understand these effects and are more likely to take a precautionary approach aligned with the existing stereotypes surrounding the sexuality of older adults.

Institutional guidelines in AL communities depart from the norms accepted by society on marriage and sexuality. Pinho and Pereira (2019) noted that few institutions are proactive in minimizing barriers, even for married older adults living in the same community. In their study, a

nurse stated that couples were not allowed to sleep in the same bed, regardless of how long they have been married. The best they could do is put the beds together to have more closeness. Privacy is non-existent in many AL communities, which means that residents do not have a chance to engage in intimate behavior (Pinho & Pereira, 2019). Despite understanding the implications of such guidelines, Pinho and Pereira found that direct care workers (DCWs) do little to address the issues.

2.1 Sexuality and Intimacy in Later Life Stages

Sexuality and intimacy among married older adults are often impacted by the disengagement from sex, age-related losses in reproductive capacity, and a reduction in sexual desires (Kolodziejczak et al., 2019). These changes can be magnified if either partner lives in AL communities or has dementia. AL policies and staff are required to address sexuality and intimacy within the resident community while considering life course transitions and any potential physiological hindrances. For instance, widowed older adults might develop an attraction to married older adults who have been separated by the AL guidelines. Policies should help AL administrators negotiate such incidences to address the emotional and intimacy needs of the members of their AL community (Cook et al., 2021; DeLamater & Koepsel, 2015; Fileborn et al., 2017).

While sexual interest does not disappear with the onset of dementia, decision-making capacity—which is very important during intimacy—could be affected. In instances where this effect has been established, AL staff must protect vulnerable older adults (Archibald, 2003). A resident might mistake another person for their spouse and engage in unwelcome intimate behavior towards them (Rheaume & Mitty, 2008). They might accuse their partner of doing

something to them without their consent even though they could have forgotten whether or not consent was granted due to their cognitive status.

AL staff might be conflicted about addressing non-normative sexual relations between residents with dementia. They have to consider issues of consent alongside issues of safety and resident abuse. Furthermore, Rheume & Mitty find that administrators hold gendered assumption about sexuality, which treats men as predators and women as victims, which leads to a belief that if the woman later states that she was hurt, that the man took advantage of her (2008). The pressure from society to ensure that sexual abuses do not occur can be one reason why administrators apply 24-hour oversight on residents in AL.

2.2 Societal Pressure Because of Life Course Transitions

Each generation is raised in a different time under different circumstances leading to period and cohort effects, which may lead to differing understandings and stereotypes regarding life course transitions such as marriage, divorce, and widowhood, and how that impacts sexuality at older ages (Hutchison, 2011). This can lead AL applying specific policies and procedures. For example, for newly widowed older adults prone to depression because of loss, anxiety, loneliness, and a longing for intimacy (Aizenberg et al., 2002), AL staff are inclined to be more protective, especially when the adults are living with dementia (Rheume & Mitty, 2008; Saj et al., 2022). Over time, these perspectives can be adopted at the societal level, creating social pressure. Each generation is shaped by a range of cohort and period effects,.

Using the LCP, I explain how these norms vary between administrators who have experienced different life trajectories. LCP details how different factors shape life trajectories (George, 1993; Hatch, 2018). I also describe AL staff' development in social, cultural, and

environmental contexts, as well as their educational background, and how these factors influence their negotiation of sexuality and intimacy among older adults with dementia.

2.3 Assisted Living Residences

2.3.1 Background of Assisted Living Communities

AL is a living arrangement in group quarters designed for the long-term care of older adults or people with disabilities who need regular care (Zimmerman et al., 2003). Because these parties need regular care, it is also a workplace that is staffed 24/7. Additionally, family members visit their loved ones in these communities. The services offered by AL communities include meals, personal care, emergency care, social activities, and recreational activities. According to Zimmerman et al. (2003), AL was developed to fill the gap between independent senior housing and nursing homes. They were modeled as settings meant to provide an “invisible support system” in a residential setting.

AL staff are guided by the goals of providing residents with a homelike environment, independence, autonomy, and privacy (Kemp et al., 2021; Zimmerman et al., 2003). This setup creates an environment where caregivers and residents may become friendly. In some cases, residents may want an intimate relationship with a caregiver or a fellow resident (Kemp et al., 2012). Depending on the context and the norms surrounding a specific AL community, these advances might either be labeled as inappropriate or as harassment, or, in the case of two residents, allowed as normal behavior.

2.4 Sexuality, Intimacy, and the LCP

An analysis of literature on the nature of AL and its fundamental characteristics provided insight into how administrators negotiate sexuality and intimacy among residents living with dementia. According to Zimmerman and Sloane (2007), AL varies in the programs offered, the

services provided to residents, and the policies governing residents' stay. These variations arise because the processes and policies applied in AL depend on advisory boards' suggestions, clients' demands, and, in some cases, the consensus of AL staff.

Kemp et al. (2009, 2021) observe that the differences in policies applied can impact the quality of the care process. Family members of residents can be appreciated as supportive, but they may make demands about the nature of relationships the residents can have within the community. These demands can affect the conduct of care workers and the quality of lives of residents (Kemp et al., 2009). Centering these demands around sexuality and intimacy raises the question of whether the residents have the freedom to express themselves freely.

AL administrators prioritize protecting residents from victimization or harassment over their quality of life and the perceived freedom to engage in sexuality and intimacy (Beldon et al., 2009; Teaster et al., 2015). They do this by increasing oversight and controls over daily activities of the residents. To have control over their own decisions, residents need to show that they can be independent, make sound choices. Residents living with dementia are likely to lack such control, in which case, AL staff must take charge of the decision-making process (Ball et al., 2009; Burgess et al., 2021; Fitzroy et al., 2022; Kemp et al., 2021; Zimmerman et al., 2003).

According to Dobbs et al. (2009), residents' humanity and quality of life depends on internalized norms, ageist beliefs, and even discriminatory actions of AL staff as previously noted. AL staff are also more inclined to focus on physical care rather than social and emotional needs (Fitzroy et al., 2022), which should go together when it comes to upholding humanity and quality of life within an AL. Other studies noted that AL still lacks meaningful engagement for residents living with dementia (Kemp et al., 2021), which would allow them to better address the issues they face with sexuality. As a solution to these issues, Burgess et al. (2021) suggest

adopting more comprehensive metrics that address different populations and incorporate multiple perspectives to understand better how intimacy issues can be handled. AL administrators, staff and fellow residents should have an operational framework driven by policy and training that will aid in ensuring resident autonomy and staff knowledge as it pertains to intimacy amongst residents.

Bender et al. (2017) observed that AL residences are designed to cater to the needs of financially secure White older adults. These needs are broken down by Kemp et al., (2012), who noted that a typical resident is an 87-year-old White woman who needs assistance with two activities of daily living. Approximately 50% to 67.7% of the residents also live with Alzheimer's or other forms of dementia, a characteristic that further influences the nature of care provided. In contrast, DCWs are predominantly lower SES, female and non-White (Ball et al., 2009, 2010). The differences in race, gender, and SES status between residents and care workers are some of the factors that influence their relationships and negotiation of issues such as sexuality. The norms adopted by different communities and religions, or the general attitudes of society towards sexuality, also have an impact on these relationships.

2.5 Relationship Between Workers and Residents in AL

Existing studies provide a framework to investigate how relationships between workers and residents vary when considering residents with dementia (Engel et al., 2006; Kemp, 2008; Kemp et al., 2009; Sloane et al., 2005). The framework examines AL communities as a home for residents, but a workplace for AL staff (Burgess et al., 2018). The workers are intimately involved in the lives of the residents and are required to control aspects of their lives, including nutrition, hygiene, and decision-making on social interactions.

According to Ball et al., (2009), the fact that the staff who work in AL residences are predominantly non-White means that they are often subjected to unequal treatment and low pay. Most AL staff describe their work as demanding, both physically and emotionally. Socio-economic challenges caused by low pay are compounded by residents' harassing behaviors, such as inappropriate jokes, sexual comments, and physical touch (Ball et al., 2009; Burgess et al., 2018). When faced with these experiences, AL staff redirect the residents' actions and reframe the sexual comments so that they can perform their tasks (Vik & Eide, 2012). Based on these factors, AL staff are more likely to have a negative attitude toward issues of residents' sexuality.

AL staff still act as the immediate circle to provide the social ties needed to improve residents' quality of life. Some of the residents exclusively depend on those who work and live in AL residences for interaction, while others have a wider care circle, including pre-existing relationships with family and friends, formal care workers, and potentially co-residents (Ball et al., 2005; Fitzroy et al., 2022; Kemp, 2021; Kemp et al., 2009, 2012, 2021, 2022). However, AL staff have little time to socialize with residents due to their work responsibilities (Ball et al., 2010). The relationships maintained within AL residences often depend on the processes and policies of the institution such as the admission and discharge policies applied (Burgess et al., 2021; Kemp et al., 2012). Subsequently, the relationships often manifest as impersonal, neglecting the social and emotional needs of the residents (Fitzroy et al., 2022).

AL staff are also likely to give more autonomy and freedom of choice to the residents without dementia regarding sexuality and other decisions. However, residents face challenges with sexuality because their agency and self-determination are compromised. Often, they cannot make decisions independently, because of interruptions like workers opening doors without knocking to check on the residents. Those with dementia have even less autonomy and

opportunity for social interactions and intimacy that could improve the quality of life within AL settings (Burgess et al., 2021; Fitzroy et al., 2022; Kemp et al., 2012). These characteristics point to the need to delve deeper into the dynamics of dementia and how they influence care interactions within AL residences.

2.6 Dementia

2.6.1 Societal Perception of Sexuality and Intimacy in Dementia Patients

Lichtenberg (2014) argues that administrators of long-term residences frequently fail to assess the sexual needs of older adults suffering from dementia in their communities on an ongoing basis. This oversight is attributed to various factors, including social discomfort around discussing the sexuality of older adults, limited awareness of its significance, and the lack of clear policies and guidelines addressing this concern. Without regular assessment, administrators overlook the sexual desires, preferences, and challenges facing older residents, leading to inadequate support and neglect of their sexual needs.

Older adults, like any other individuals, are likely to desire intimacy (Rheaume & Mitty, 2008). However, their desires suffer challenges depending on their life course experiences and the conditions of AL in which they spend the rest of their lives. Administrators are likely to set up sex-restrictive policies depending on their experiences and beliefs about sexuality among older adults.

Previous research on sexuality and intimacy among AL residents living with dementia focus on debunking myths of sexlessness or the perception of the asexual nature of older adults (Hillman, 2012). Existing research fails to expound upon how these situations affect the policies and procedures applied by AL staff to manage sexuality and intimacy in AL communities. As

there are approximately 10 million cases of dementia recorded each year, most of which are in older adults, this is a salient issue (WHO, 2020).

2.6.2 Dementia and Care Interactions in AL

Dementia influences the nature of provided care as well as the negotiation of issues the residents face in AL (Dilworth-Anderson et al., 2020). As the rates of dementia continue to rise, the need to devise proper care mechanisms has grown commensurately (Dilworth-Anderson et al., 2020; Shiells et al., 2020). As dementia progresses with worsening neuropsychiatric symptoms, residents experience a reduced quality of life, and higher levels of depression which impacts care interactions (Aud, 2002; Kemp et al., 2009).

In the past, older adults with dementia had been excluded from research, making it difficult to devise policies to improve their overall well-being (Ciofi et al., 2022). As a result, residents continued to suffer from communication and memory problems reducing further their ability to effectively share their experiences and communicate their needs, or even live in the care environment while maintaining connections with families and the surrounding community (Ciofi et al., 2022; Shiells et al., 2020). Despite these concerns, studies on the care needs of residents living with dementia state that meaningful relationships are essential for comfort and enhancement of the residents' quality of life in AL.

Residents who are neglected by their families or are barely visited are prone to depression and anxiety (Cohen-Mansfield et al., 2000). For residents living with dementia, these effects are magnified as some suffer from memory loss to the point that they forget they have been visited and feel abandoned, resulting in depressive symptoms. In recent years, other factors like the COVID-19 pandemic have presented an even bigger threat to the quality of life in AL settings, causing anxiety, depression, and isolation (Kemp et al., 2020; Kemp et al., 2021). It may also

have increased staff concerns regarding how to handle intimacy while maintaining the health and safety of the residents.

2.6.3 Dementia and the Expression of Sexual Desires

According to Wang and Kyomen (2020), an estimated 63.4% of caregiving residences lack policies for negotiating the sexual health of residents with or without dementia. The lack of clear policies presents challenges when determining the sexual consent capacity of residents and negotiating appropriate or inappropriate sexual behaviors among residents diagnosed with a major cognitive disorder (Wang & Kyomen, 2020). Other key considerations are the different factors underlying the determination of what counts as appropriate sexual behavior within the work setting. Such policies require clinical, legal, and ethical considerations, all of which play a role in the decision-making process of providers and care staff.

According to Kelemen et al. (2022), older adult patients have been known to want to discuss issues concerning intimacy and sexuality with their clinicians. However, physicians do not initiate these conversations because they feel that they lack the training to effectively address the issues facing older adults (Kelemen et al., 2022). They prefer to focus on treating diseases occurring within older adults and hesitate to engage in discussing issues that they might have with their sexuality. As a result, bias, norms, and conventions dominate when dealing with such issues in healthcare settings and AL communities. Thus, having formal policies regarding resident sexuality may benefit AL staff who, like doctors, are not trained sex experts.

Deterioration of cognitive ability results in changing roles, identity, self-esteem, satisfaction, sexual activity, and reciprocity (Holdsworth & McCabe, 2018). Whether the changes are abrupt or progressive, they impact relationships and social interactions among couples as they age. The nature of social interactions affects how residents communicate and express their sexual desires.

For residents with dementia, the quality of social and intimate interaction is comparatively lower compared to their more well-functioning counterparts (Abbott et al., 2017).

2.6.4 Consent and Dementia

In the United States, aging individuals who develop neurocognitive disorders might lose the capacity to consent to sex and intimacy. Capacity is an individual's physical or mental ability to perform a specific task. There is an overall assumption that each person can make personal decisions unless adjudicated as lacking capacity (AMDA, 2016). A court can legally determine capacity when individuals cannot make personal decisions. The legal standard on sexual consent capacity is interpreted using the criteria of knowledge, understanding of reasoning, and voluntariness (The American Bar Association [ABA]/The American Psychological Association [APA], 2016). Individuals should have relevant information, including risks and benefits, to reason based on their values and make decisions free from undue influence or coercion (ABA/APA, 2016). The ABA/APA handbook does not explore diagnostic considerations in detail, but dementia—which does not necessarily indicate incapacity—is one of the diagnoses listed. There are some types of dementia, such as frontotemporal dementia, that have been associated with hypersexuality or even inappropriate sexual behavior (ISB; AMDA, 2016). Capacity is assessed by examining the cognitive performance of an individual (Boni-Saenz, 2015). The courts assess cases of sexual assault by considering the various factors that influence the ability to give consent. These factors include understanding and communicating the decision to engage in sexual behavior; broad evidence of the ability to reason; one's capability to understand the nature of sex, its consequences, and physical mechanics; and the ability to acknowledge its meaningfulness and moral dimensions (Boni-Saenz, 2015; Graves, 2015).

While conservative approaches to sexual competency might protect vulnerable individuals, like older adults living with dementia, they could also eliminate the possibility of intimate interactions. Even in cases where older adults with dementia manifest a desire for sexual interaction, they are often considered legally incompetent to consent to such an activity. An individual having intimate physical contact with a cognitively impaired person may be subject to criminal prosecution if there are allegations that the victim did not give consent or was found unable to consent (Wilkins, 2015).

Medical settings also have no agreement on assessing sexual capacity, even though people with dementia still seek intimacy and companionship and should be allowed to enjoy relationships and privacy. On the flip side, they also have a right to be protected against abuse (Joy & Weiss, 2018). According to the American Medical Directors Association (AMDA; 2016), residents living with dementia have three fundamental rights--regarding sexual activity, protection, and capacity determination. All persons who have reached the age of consent have a right to consensual sexual activity and are presumed to have the capacity to consent when there is no evidence to the contrary.

As a show of respect to individuals, AL communities are expected to allow resident autonomy and privacy to accommodate consensual sexual relationships (AMDA, 2016; Joy and Weiss, 2018). Community members also have the right to not consent to intimacy or unwanted sexual aggression. There have been cases where communities have been found liable as third parties in cases involving resident-to-resident sexual aggression (RRSA; Joy & Weiss, 2018).

2.6.5 Dementia Care Interventions

Most of the public believe that sexual relationships should be permitted for residents living with dementia (Yelland et al., 2018). Individuals who disagree with this notion cite consent

issues as the primary cause for concern. Responsive care interventions for residents living with dementia needs an understanding of care processes and how they operate when health changes occur to enhance communication even in such instances (Kemp et al., 2020, 2021). Health changes, especially when they involve dementia, require AL staff to consult, collaborate, assess, and respond appropriately to improve residents' quality of life. These actions can eradicate the social stigma linked to dementia and sexuality within ALs (Holdsworth & McCabe, 2018). They may also allow the AL staff to draft more responsive interventions to facilitate better resident care and expression.

2.7 Negotiating Intimacy in AL Communities for Residents with and Without Dementia

While the life course situation of residents provides context for understanding what is happening in AL communities in regard to intimacy and sexual relations, it doesn't help us understand how administrators and DCWs negotiate residents' autonomy and intimacy needs. Figure 1 presents the model developed by Bender et al. (2017) that directly addresses how AL staff address the intimacy needs or desires of residents and the barriers that stop residents from achieving intimacy. Finally, they include the strategies AL staff use to negotiate intimacy. Bender et al. determined that in terms of desire, residents express a range of intimate desires from none to desiring a relationship. They also find that residents thought there are a unique set of barriers limiting their ability to express their desire for intimacy. In particular, they find access to desirable partners a problem, the lack of privacy, and the rules and norms of the AL community impede their ability to achieve their desired level of intimacy. Finally, Bender et al. found that residents use various strategies to negotiate their lack of desired intimacy in AL communities. Excuses are used by residents to minimize desire and then deny responsibility for it. They instead, focus on age and health concerns. Or, residents justify their lack of intimacy by

citing a concern about being a burden. Finally, they use a dismissal strategy when bumping up on barriers to eliminate the need for intimacy.

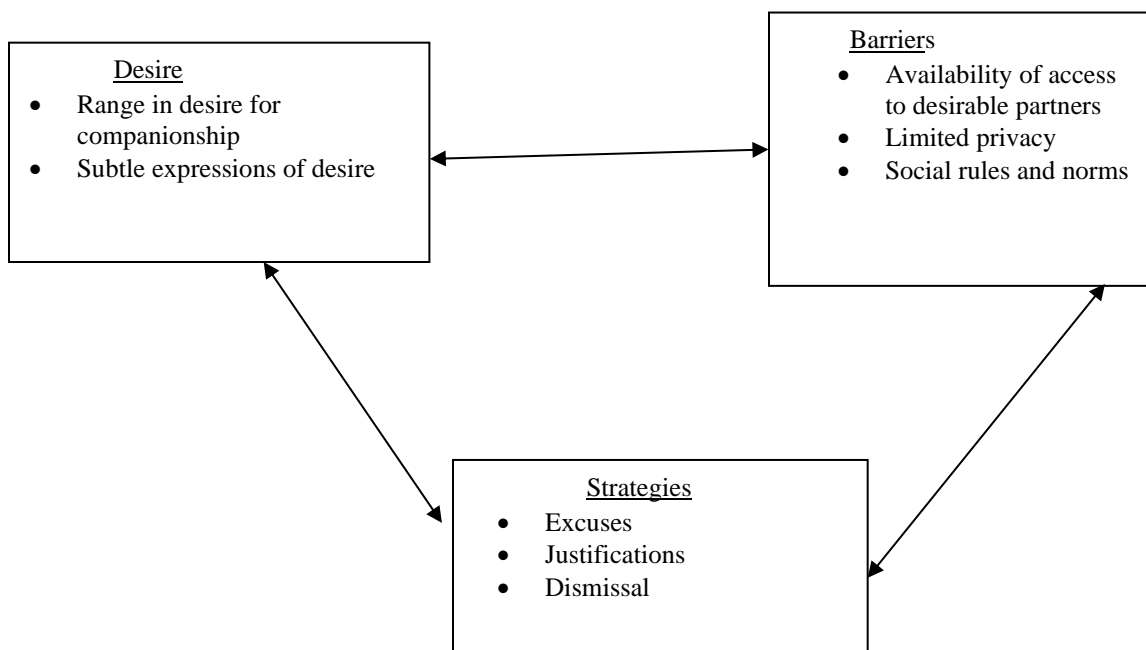


Figure 1 Negotiating the Lack of Intimacy in Assisted Living

Bender, A. A., Burgess, E. O., & Barmon, C. (2017). Negotiating the Lack of Intimacy in Assisted Living: Resident Desires, Barriers, and Strategies. *Journal of Applied Gerontology*, 39(1), 28–39. <https://doi.org/10.1177/0733464817746756>

Bender et al.'s (2017) model examines the situation from the perspective of residents. The residents do not seem to acknowledge the role of AL staff in creating and maintaining the barriers they face to achieving their intimacy needs. In this study, I used a modified form of this framework to understand how AL staff negotiate residents' intimacy needs particularly in the case of residents with dementia. What strategies do staff use and what barriers do these strategies raise or lower?

2.8 Training vs Experience

The debate over whether training or experience is more important for staff in assisted living communities remains a complex and multifaceted one. Both training and experience bring

unique strengths to AL staff, and their relative importance can depend on various factors, including the specific roles within the AL and the needs of the residents.

Having trained staff with the appropriate skills is vital for understanding and delivering care to residents (Maas & Buckwalter, 2006). Proper training may also ensure that staff members have a solid theoretical foundation in negotiation of health and safety of residents. Further, many regulatory bodies mandate specific training and certification requirements for staff in AL to safeguard the well-being of residents (Carder & Hernandez, 2015). Compliance with these regulations is crucial. Additionally, it seems training can provide specialized skills that are necessary for addressing the unique needs of residents in AL, particularly those with cognitive impairments.

However, even with a lack of training, most DCWs claim to provide holistic care to residents (Maas & Buckwalter, 2006). Exposure to numerous residents over a lengthy period allows DCWs to familiarize themselves with the day-to-day requirements thereby building a knowledgebase that allows them to perform the job. The specific roles within the assisted living facility will determine the weight given to negotiation of health and safety. DCWs, who interact closely with residents have been found to rely more on experience (Maas & Buckwalter, 2006). However, relying on experience promotes unequal treatment with residents' sexual needs dealt with on a case-by-case basis (Burgess et al., 2016).

2.8 The Research Gap

Research on assessing and meeting the sexual needs of older adults living in AL communities remain scarce. There is a gap in understanding how AL staff negotiate the complexities associated with supporting residents' sexual well-being and autonomy in AL (Rheume & Mitty, 2008). No clear guidelines exist to develop policies and training for

negotiating sexuality in AL. My study will specifically examine the formal and informal policies that administrators and AL staff implement to negotiate both bridges and barriers to the intimacy needs of older adults with dementia.

3 RESEARCH METHODS

3.1 Research Design

I employed a descriptive qualitative research approach to explore how the structure of AL (i.e., policies and procedures) impacts residents' sexual autonomy. Overall, the qualitative research design enables an exploration of AL administrators' experiences and perspectives when negotiating residents' sexuality and intimacy issues (Rheume & Mitty, 2008).

3.2 Sample Selection

I utilized a purposive sampling approach to select seven AL communities across the metropolitan Atlanta region with the assistance of the Director of the Gerontology Institute, as summarized in Table 3.1. This sampling strategy ensured a variation of AL communities by encompassing urban, and suburban, as well as corporate small, medium, and large communities (Charmaz, 2014). The variation of ALs was vital to assessing potential differences among them and detailing them properly for inclusion in my dissertation (Rheume & Mitty, 2008).

From the seven communities, I purposively selected 3 administrators or careworkers from three levels of management for a total of 22 respondents. I recruited 7 top management level administrators, 8 middle management administrators, and 7 direct care workers (DCWs). Top management included chief executive officers, chief administrators, chief operations officers, and executive directors (i.e., senior managers). Middle management included department heads, supervisors, or coordinators overseeing specific departments (i.e., middle management), while DCWs are staff directly involved with providing direct care and support to residents (Rheume & Mitty, 2008). My target was 21 participants, but due to the large size of one of the homes (Retirement Haven), I selected two middle management representing different sections. I

conducted three different interviews in each AL and four interviews in Retirement Haven [pseudonym].

By including different levels of administrators within each AL, I sought to capture diverse insights and perspectives and thus increase the comprehensiveness of the findings (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2017; Kemp et al., 2020). Further, I explored decision-making processes related to residents' sexuality and intimacy. I determined sample sizes based on data saturation (Corbin & Strauss, 2015), when interviews would no longer produce new information. I have provided demographic data of participants in Chapter Four.

Table 3.1 Assisted Living Sampling Strategy

	Urban	Suburban	Total
Corporate large	2	1	3
Corporate medium	1	1	2
Corporate small	1	1	2
Total	4	3	7

(Note: AL pseudonyms are categorized by capacity and location in Chapter Four)

3.3 Data Collection

I utilized a semistructured interview guide for data collection, which is summarized in Table 3.2. Due to the overall health risks in AL homes that limited accessibility, I conducted virtual semistructured interviews through Zoom (Rheaume & Mitty, 2008).

Table 3.2 Administrator Interview Guide

Main question	Topics for probe
1. Tell me about your daily routine	Probe for involvement; interaction with residents
2. What is it like to work here	Satisfaction; resident interactions; staff cohesion
3. What are your thoughts on dating and intimacy for residents with dementia	Freedom of residents' expression of intimacy; autonomy of sexual behavior, privacy; opinion
4. Have you been trained in negotiating sexual and intimate behaviors of residents	Formal training; informal training; on-the-job experience
5. Have you noticed people form romantic relationships here	Sexual or dating behaviors, areas in which relationships develop; frequency, consequences
6. Are there residents who lack the opportunity to get involved in a sexual or intimate relationship	Resident reactions; organization policy; barriers
7. Do you involve families in the approval of sexual and intimate relationships of residents	Family approval, family barriers; consequences
8. What do you think are appropriate/inappropriate sexual or intimate behaviors in AL	Perception of agreement from other residents; what should happen when perceived inappropriate behaviors occur; safety; risks
9. What kinds of freedoms of sexual expression do you think residents should have?	Family approval; Residents with dementia; differences in cognitive function between two residents
10. Does your community allow residents to have sexual autonomy	Sexual rights; privacy; consultation with family; barriers; safety; risks
11. Do you have policies that govern sexual and Intimate desires of residents	Formal policies; informal policies
12. How do you negotiate sexually inappropriate behavior of residents	Policies in place to govern inappropriate sexual behavior
13. Have your approaches to negotiating sexuality changed since you move here?	Reasons for change; reasons for not changing
14. Is there anything you would like to add to what we have discussed	Additional information; determine the viability of the research scope

3.4 Human Subjects

My dissertation research methodology was reviewed and approved by the Institutional Review Board of Georgia State University (# H23362). I assigned AL homes and administrators pseudonyms to protect participant confidentiality and anonymity and secured informed consent.

Informed consent requires that subjects know enough about the research to decide whether to participate, so that they could agree to participate voluntarily. I informed participants that they were not required to answer any questions they did not want to answer and that they could end the interview at any time.

3.4.1 Privacy and Confidentiality

I saved the data on an encrypted, password-protected computer. I concealed any identifying information in this report.

3.4.2 Potential Risks

No significant risks were associated with participating in the research. However, some potential risks included physical discomfort, which may have resulted from the communication, psychological risks from anxiety, and loss of confidentiality. Privacy and confidentiality were some of the issues that were effectively addressed. I avoided any breach of confidentiality, as well as the release of confidential, personal, or sensitive information to the public.

3.5 Data Analysis

I digitally recorded, reviewed, and transcribed verbatim all the interviews before importing them to NVivo 12 (QSR International). I used a qualitative thematic analysis method to analyze the transcripts. This method involves reading through the transcripts and identifying patterns in meaning across the data to derive themes (Braun & Clarke, 2006). I created initial codes by reading and re-reading transcripts and independent line-by-line coding (Kemp et al., 2020). I grouped the codes into potential themes that captured a central idea, summarized in a single sentence. I searched for similarities, differences, and developed trends in the data and labeled similar concepts and categorized them into codes until saturation was reached. I continued

reviewing the manuscript and, in the process, added codes and deleted other codes throughout the remainder of the coding process to capture all participant statements within the codes.

During the coding phase, I collapsed and expanded codes until distinct conceptual categories emerged to derive significant themes and sub-themes related to sexual autonomy in AL (Braun & Clarke, 2006). I explored connections between the themes in a bid to produce a holistic representation of residents' rights in AL as they pertain to sexuality and intimacy. The themes I identified include policies and procedures, safety of residents, family concerns, and the quality of life of older adults in AL. The next step involved focusing on specific care cases based on the administrators' feedback. For instance, what were the specific conditions under which certain procedures were applied, and how did they affect the residents' perceptions of sexual rights? I then linked these contexts and outcomes to negotiating and balancing the residents' autonomy. I used the qualitative analysis software, NVivo 12, to aggregate, store, manage and facilitate the coding and analysis of data.

I applied the codes to narrow the notes into themes surrounding how administrators negotiate and understand issues of sexuality and intimacy for AL residents with and without dementia. The themes identified include training, policies, consent, safety/risk, family concerns, reporting and redirecting. I organized these codes by identifying how they are linked to other open codes such as family involvement in handling sexuality issues and the existence of policies governing the negotiation of sexuality issues.

I identified connections between the AL characteristics, gender, marital status, and the policies applied when negotiating cases where one resident developed an interest in another. For example, DCWs embraced their professional experience as the most substantial training regarding intimacy issues in AL (Burgess et al., 2021). They cared more about the safety and

well-being of the residents and focused on residents understanding the risks that could emerge when they got involved in sexual relationships. The gender of the AL residents also emerged as one of the major themes. Females were considered more vulnerable and more likely to be at risk in the relationship than men.

3.6 Conclusion

Residents' care management is shaped by various factors, including the AL, relationship dynamics, the influence of stakeholders, and administrator characteristics (Burgess et al., 2021). My analysis identified procedures which inhibit residents to engage in sexual relationships drawn within different contexts, and the variations in practices depending on the AL.

4 RESULTS

4.1 Characteristics of AL Homes

Table 4.1 summarizes characteristics of ALs, residents, and availability of policies.

Although selected ALs varied in capacity, size, ownership, and location (i.e., urban, suburban), they had similarities in other areas, such as gender ratio of residents (i.e., predominately female), race (i.e., predominately White), and the level of care. ALs ranged in capacity from 25 to 100 residents. All homes were below their licensed capacity and had, on average, 28 empty beds. Good Living Home had almost half its capacity unoccupied, registering 52 occupants from a capacity of 100. Retirement Haven, with the lowest licensed capacity, had the highest occupancy percentage, registering 76% occupied beds. Both Good Life Gardens and Golden Place had 20 empty beds.

The lowest recorded monthly fee paid by residents was \$4,300 and the highest was \$13,000. The respondents clarified that the fees varied according to the level of care provided and the nature of the accommodation (i.e., rooms) provided by the AL. Rooms with garden views cost more than standard rooms. Before admission into the AL, the staff evaluated the residents based on age, cognitive impairment, and ambulatory status. The evaluation was useful for assessing residents' eligibility for admission. For example, four of the seven ALs required that residents should be ambulatory to be able to transfer within the AL. Other ALs had age limit for admission, requiring residents to be 65 and above. All residents in this study were above 65. Cognitive impairment was assessed for ALs that had both memory care and assisted living. The assessment guides the administrators regarding where the resident would be admitted.

4.1.1 Gender

The number of female residents far outweighed the number of men in all the ALs. The most considerable disparity was observed in Good Life Gardens, a large urban AL with seven men and 53 women. Cardinal Home had 51 women and eight men. Good Living Home, the second largest urban AL, had the third lowest number of men, nine and 44 women. Golden Place reported 10 men and 40 women; Silver Springs had nine men and 34 women; and Retirement Haven recorded nine men and 31 women. Century Court, a small urban AL reported the highest number of men, 16, and 29 women.

4.1.2 Race

Another critical variable observed during the data collection was the residents' race in the AL. On average, most of the residents were White, while Blacks formed the minority. Two homes, Good Living Home, and Retirement Haven did not provide demographic data, with the former describing their racial distribution as “mixed.”

4.1.3 Dementia Diagnosis

My goal was to investigate the number of residents diagnosed with dementia within the various ALs. The initial of my investigation showed that a significant number of residents within the AL had been diagnosed with dementia. In Silver Springs, 81% of the residents had been diagnosed with dementia, followed by Golden Place with 70%. The rest of the ALs had lower percentages; Century Court reported 62% and Cardinal Home had 53%. In Good Living Home, the respondents stated that they had an estimated 46% of their residents showing early stages of dementia and 54% with a mixture of middle and late stages.

4.1.4 Sexual Autonomy of Residents

Administrators from three of the seven AL did not report whether they allowed residents to engage in sexuality and intimacy freely (i.e., Century Court, Golden Place, Good Life Gardens). The remaining four administrators reported allowing residents the autonomy to engage in sexuality and intimacy if both residents consented.

4.1.5 Family Approval of Sexual Intimacy

I aimed to determine if ALs had to consult family members before allowing sexual relationship. Inquiries were also made whether family concerns changed over time and whether the administrators found them reasonable. I added this question because family members were likely to request constant updates on the activities of residents, including sexuality and intimacy. Five AL demonstrated that family members of their residents approve of them have sexual relationships. When families expressed reservations, some AL staff attempted to educate them about the importance of these relationships for the residents. This meant that family members were likely to change their perspective on sexuality following advice from the administrators. There was consensus from administrators on residents' sexual relationship. Given its impact on the findings, I also went into more detail about family approval as a theme.

4.1.6 Formal Policies and Informal Practices Regarding Intimacy

Policy regarding intimacy is one of the key questions of this research. I recorded mixed responses on the existence of policies within different ALs. Staff from three ALs, Cardinal Home, Golden Place, and Good Living Home, say they have informal practices, rather than formal policies, that are occasionally applied when negotiating the intimate and sexual behaviors of residents. The informal practices apply in most contexts allowing residents the freedom to engage in sexuality and intimacy activities if both parties consent and if there is no risk involved.

Most administrators stated they had extensive experience dealing with intimacy among older adult residents and had standard informal practices for negotiating sexual behaviors.

Staff from Century Court, Silver Springs, the Retirement Haven, and the Good Life Gardens stated they had no policies that negotiated sexuality and intimacy in their varied ALs. They relied on work experience gained for several years.

Table 4.1 Characteristics of ALs, Residents, and Policies

Characteristics of Als							
	Good Life Gardens (Urban large)	Good Living Home (Urban large)	Cardinal Home (Suburban large)	Golden Place (Urban medium)	Silver Springs (Suburban medium)	Century Court (Urban small)	Retirement Haven (Suburban small)
Capacity	100	100	70	80	63	42	25
Residents during the study	80	52	59	60	36	29	19
Monthly fee range (US\$)	6190 - 6970	4300 - 5000	4300-6000	5000 - 7000	11000 - 13000	7565 - 11890	5000 - 7000
% Men	13	17	14	20	21	35	22
% Black	5	Mixed (Not specific)	0	8	3	7	No response
Demographic Characteristics of Residents							
	Good Life Gardens (Urban large)	Good Living Home (Urban large)	Cardinal Home (Suburban large)	Golden Place (Urban Medium)	Silver Springs (Suburban medium)	Century Court (Urban small)	Retirement Haven (Suburban small)
% below age 65	0	0	0	0	0	0	0
% married couple living together	Not reported	4	0	10	11	7	11

%Widowed	Not reported	8	15	33	14	35	Not reported
% with a dementia diagnosis	Not reported	46 mild**	53	70	81	62	Not reported

Formal Policies Regarding Intimacy

Sexual autonomy of residents	Not reported	Yes	Yes	Not reported	Yes	Not reported	Yes
Family approval of sexual intimacy	Yes*	Not reported	Yes*	No	Yes	Yes	Yes
Sexuality and Intimacy Policy	No	No**	No**	No**	No	No	No

*Contradictory information on whether there truly is a formal policy

**Early stage of Dementia

4.1.7 Characteristics of Administrators

I recorded the characteristics of administrators to provide a thorough outlook based on their positions (See Table 4.2). Most DCWs are women and Black (seven) while most residents are women and White. Most senior managers (seven) are White, or Asian (two). Staff work experience ranges from five to 37 years. Most administrators have an associate, bachelor's, or master's degree while DCW have lower educational attainment. Nine respondents were in the age range of 35 to 44, six were 45 to 54, and one was 65 to 74. Seven are single, and twelve are married. Two respondents are widowed and one did not to answer the question on marital status. Most middle management have higher qualifications than upper management. In fact, one upper manager had trade/vocational training..

Table 4.2 Characteristics of Administrators

		Upper management	Middle manager	Direct care worker
Job title	Executive director	4	0	0
	Chief Operations Officer	2	0	0
	Regional Vice President	1	0	0
	Director of Nursing	0	1	0
	Head of Nursing	0	1	0
	Assisted Living Director	0	1	0
	Primary Care Manager	0	1	0
	Resident Care Manager	0	1	0
	Administrator	0	2	0
	Resident Services Manager	0	1	0
	Direct Care Worker	0	0	7
Age (years)	25-34	0	2	1
	35-44	2	4	3
	45-54	3	1	2
	55-64	2	1	0
	65-74	0	0	1
Gender	Male	2	1	0
	Female	5	7	7
Race	Black	1	3	7
	White	6	3	0
	Asian	0	2	0
Marital Status	Married	5	4	3
	Single	2	3	2
	Widowed	0	1	1
	No response	0	0	1
Training	Master's Degree	1	3	0
	Bachelor's Degree	4	3	0
	HS Diploma*	0	0	3
	Some College or associate degree	1	2	2
	Trade/Vocational	1	0	0
	No response	0	0	2

*High School Diploma

Summary

Although there are variations in structural characteristics, capacity, location, and level of administration, staff responses are remarkably consistent. DCWs are women from minority groups with low levels of education. While administrators assert they have formal policies and informal practices, they did not share the policies with me and the data contradict these assertions. Unfortunately, I only asked administrators about formal policies, rather than all respondents, which is a limitation of my study. Next, I will discuss my findings in Chapter 5.

5 FINDINGS

Given the large number of informants by level of management and by assisted living (AL) communities, Table 5.1 presents the pseudonyms used for each AL and job level to provide a bit of clarity when seeing the data. In addition, the capacity (large, medium, or small) and the location (urban or suburban) is included to help the reader make sense of the data. Again, there was little to no variation in policies and procedures negotiating sexual autonomy based on capacity or location.

Table 5.1 Pseudonyms for Staff

	Good Life Gardens (Urban large)	Good Living Home (Urban large)	Cardinal Home (Suburban large)	Golden Place (Urban medium)	Silver Springs (Suburban medium)	Century Court (Urban small)	Retirement Haven (Suburban small)
Upper management	Josephine	Anna	Kelly	Leroy	Robert	Jennie	Alison
Middle management		1.Sheila					Denicia
DCWs	Lorraine Yvette	2.Ann Goosby	Melissa Beatrice	Marie Norida	Arianna Esi	James Sarah	Sunita

In fact, beyond admission and discharge policies, there were no other formal policies, really. That means staff had no formal policies to rely on when addressing the intimacy needs of residents. As I will discuss later in this chapter, staff additionally prefer to rely on work experience over training when it comes to addressing any intimacy needs of the residents. Therefore, any intimacy issues raised tend to be handled on a case-by-case basis inclusive of residents with dementia. Overall, I identify four themes or forms of strategies that staff utilize in either raising barriers or lowering bridges to intimacy as presented in Figure 2, my modification of the Intimacy Negotiation Model found in Bender et al. (2017). These strategies are watchful oversight or over surveillance, redirecting, and reporting.



Figure 2 Negotiating Sexual Autonomy in Assisted Living Communities.

5.1 Bridges and Barriers to Intimacy

Since AL communities continue to be a strong option for residential long-term care for growing numbers of older adults with or without dementia, it is critical to determine residents' expectations and experiences of sex and intimacy in these communities. The context of AL provides the potential for both bridges and barriers (Bender et al., 2017) to intimacy for residents with dementia. Bridges allow for intimacy while barriers restrict it. Themes that fall into these categories are family concern, training/experience/formal policies, and consent. The same theme can operate as either a bridge or a barrier.

5.1.1 When Family Concerns Lead to a Bridge

Staff treat family concerns as vital. Family concerns most often regard the health and safety of the loved one in AL, but can also concern resistance to parental sexuality. As intimacy may raise health and safety issues, family concern, as noted in Figure 2 can operate as either a bridge or a barrier. Goosby and Robert shared their experiences:

When family was consulted, their concern was only if their mother was happy with it. We explained that she is comfortable. We told them how they hold hands and sit together all the time. This made the family happy. In fact the daughter talked to the male resident and assured him that it was okay that they were friends (Goosby, DCW, Good Living Home)

We had a situation in our community where we were not comfortable. Although both residents were consenting to the relationship, something seemed not right. First there was a huge gap in age and again he was a big guy. So, we did reach out to the family one time just to make them aware. We just wanted to cover our bases, I guess, to make sure the family was also aware of that. But family was okay with it. They were happy that their mother had a partner. (Robert, upper management, Silver Springs)

Family involvement is a key to the goals of AL communities. Whether sexual relationships are discouraged, promoted, or ignored is a decision forged by a resident's family along with AL staff, often independent of the residents' choice. Administrators value family for two reasons: First, family reinforces an environment that is homely. This is crucial for a good working relationship between the staff, residents, and family. Second, AL communities are a business and family members are the clients. A cordial working relationship ensures continuity of the business and referral of future residents. Finally, family approval makes it easier for staff to negotiate sexual relationships without reservations.

5.1.2 When Family Concerns Lead to a Barrier

Despite family concerns sometimes being a bridge, these concerns may also act as a barrier if a family member does not approve of the sexual relationship. Some family members struggle with the idea that their relative is in a relationship. Leroy and Jennie told their stories:

I stopped involving family in issues of my community. Family don't understand what happens here. They are quick to argue how their mother can never do this or that. Tell you what, if you involved family, we may end up having separate common areas for female residents. For example, there is this female resident who is widowed and had something good going with a male resident who was divorced. When the family found out, they were furious. I tried to explain to the son how intimacy was a good thing for his mother's mental health. The following day, he came to transfer his mother to another facility (Leroy, upper management, Golden Place)

And so, intimacy may sometimes end up in a sexual act, which is okay with us. Someone's towards the end of their life, and they've met somebody else that makes them feel fulfilled, and the families want to get involved and say, oh, my mother! My father would never! And we try to take the time that's necessary to help them understand that it's okay and good for the resident. But sometimes we don't, we just let it slide. We have a job to do and we use the best means to get the job done (Jennie, upper management, Century Court)

These quotes signify three points. First, despite the residents being the consumer of AL services, administrators aim to satisfy family over residents' needs. Second, administrators selectively notified families of residents' sexual behavior. This might be because there are no formal policies that uniformly deal with family concerns in regard to different types of residents' behavior. Finally, from administrators' illustrations, it appears that residents' families, who are mostly the children of residents, become paternalistic by protecting their parents against sexual activities, something their parents did to them when they were growing up. Consequently, cultural and family norms appear to override residents' rights to sexual autonomy.

5.1.3 Training/Experience/Formal Policy

Bridges and barriers resulting from training, experience and formal policies were closely related. In this regard, I present these themes jointly. However, I will discuss each of the themes separately, first as a bridge and as a barrier where the theme operated as either a bridge or a barrier.

5.1.3.1 When Training Leads to a Bridge

Training is the act of teaching employees skills that empower them to carry out their tasks efficiently. Despite its significance training in negotiating sexuality and intimacy is limited. However, some AL have training programs. These communities illustrate how training can empower staff to improve residents' quality of life. This includes staff having a positive attitude

towards work and towards intimacy for residents. For example, Josephine, an upper manager at Good Life Gardens, describes the “model of care” training.

And so spiritual training is all about our model of care. It’s about the household model of care. But it’s also about how you show up at work every day and how your attitude and personality show up at work. And so, we talk a lot about how people affect the workplace. We talk about diversity and inclusion. We also talk about death and dying because, you know, we are creating a home for people. So, we do talk about sexuality. We do a little bit of training on that. We could probably expand on that a little bit. And I know that a lot of our model of care training, especially in memory care, is a very high-touch environment. So, providing intimacy between humans is what we do. You know, people think sexuality and intimacy are synonymous. I see intimacy as very different. I see that you know more about connection. People’s spiritual needs and need for connection with other people. Eye contact, touch, and hugs, and all those things are included in our training module.

This quote demonstrates positive attitudes towards training while also showing a lack of relevant training modules. Sexuality and intimacy seem to be an area that is not given training priority. In fact there are no federal standards for staff training in AL communities (Pitz, 2020, IOM, 2008). Consequently, Georgia’s regulations do not directly talk about sexuality and intimacy but rather highlight residents’ rights (Carder & Hernandez, 2015). Regulations that are specific to sexual and intimate needs of residents may be useful. Further, some of the decisions DCWs make, are born out of negative attitude towards sexuality and ageism. Training staff on these issues, as it appears in the above quote may lead to better attitudes. There is a need for additional research on training of staff in negotiating the sexuality of residents.

5.1.3.2 When Training Leads to a Barrier

I identify training as a barrier when administrators do not encourage training in their communities. Further, most staff prefer experience to training. Leroy, an upper manager at Golden Place, discusses the lack of training and use of experience in his AL:

I tell you what, training isn’t as necessary as experience, wisdom and common sense. Do you know how someone dies? We have a lot of unique cases. Residents

leave their apartments without clothes and walk through the building with dementia. Or when a male resident walks into the dining room with only his shoes and socks. Can you deal with that? It's hard to get prepared for. It's hard to put down on paper. Could you train for that? I'm sure you can't, but academics only think of training. I would take someone's common sense, experience, good judgment, and discernment.

There is a lot going on in this quote. One could easily see creating a training document that specifies how to handle death, considering the clientele are older and all will eventually die. Likewise, how to handle uncomfortable scenarios such as having an undressed resident in public spaces could also easily be included in training documents. So, his rationale for preferring experience to training doesn't hold up. It turns out, Leroy does not have a college education. He got where he is through years of practical work experience. This may play into his disparagement of training and education.

Secondly, the hands-on DCWs tend to be low-paid women who are thought to have empathy, to be 'caregivers (IOM, 2008; White & Cadiz, 2013). Is that what Leroy is suggesting by saying common sense and discernment? In reality, experience allows staff to have discretion concerning residents' intimacy, which in turn, can be arbitrary and vary from staff member to staff member even within the same facility. A third explanation is that perhaps the training for working in assisted living is subpar. In their research, Institute of Medicine (2008) noted, "the education and training of the direct-care workforce is insufficient to prepare these workers to provide quality care to older adults" (p. 204). Extant research (White & Cadiz, 2013; Burgess et al., 2016; Barmon et al., 2017) also observe a lack of training regarding sexuality. Perhaps until training improves, experience actually is better, but we cannot know this without additional research.

5.1.3.3 When Experience Leads to a Bridge

Work experience is the application of past practical knowledge in negotiating sexual needs of residents. Whereas experience is mostly used by DCWs to distract residents' sexual desires, there were incidents when work experience is used as a bridge. Sarah, a DCW at Century Court illustrates how experience can be used as a bridge to intimacy.

Through experience, we know how to deal with it. Sometimes we report to the administrators but sometimes we just deal with it because even if you tell the managers they will tell you to deal with it. So I do it using my past experience. Sometimes I allow them to interact, like, I mean have intimacy to calm them down. You, know some of them get messy if you deny them little things. I just allow them to make it easier for everyone.

Administrators, DCWs and family members work together as a unit. This collaboration is intended to ensure quality of life for the residents. But DCWs are the staff that directly interact with residents. In this regard, they are central to lowering a bridge or raising a barrier. However, use of work experience results in inconsistencies. It also depends on how much work experience staff has in any given scenario, and potentially, what their beliefs and attitudes regarding intimacy are. Lack of formal policies in AL encourages treatment of sexual needs to be handled in this arbitrary, case-by-case manner.

5.1.3.4 When Experience Leads to a Barrier

Despite work experience sometimes being a bridge, it may also raise a barrier to intimacy. Administrators acknowledge DCWs work experience and empower them to make decisions in negotiating the health and safety of residents. In fact, most AL communities rely almost exclusively on the work experience of their staff. Alison and Esi share their experience.

It is based on their experience. Most of our DCWs have varied experience having worked in different ALs. I know what they must do, as far as the notification process, or what is required, as far as notifying whether it was deemed like a state reportable, or if it was something that we needed to notify the family about. But

they negotiate these issues well without notifying. And we have not had any problems with their negotiation except for one or two incidences when we had to come in and discourage the relationship. (Alison, middle manager, Retirement Haven).

I have more than 10 years of experience. That is a lot. I have also worked in four different facilities. Some things only complicate the work. For example, administrators or family ask too many questions like consent, abuse, anxiety issues that will be a health concern. We can choose to involve family and administrators and answer these questions or we can choose not to talk about it. When my shift is busy, I don't talk about it. But you know I could deny them today and tomorrow I give them a chance which is a good thing (Esi, DCW, Silver Springs)

These quotes highlight several issues. First there is the state and family. State regulations and family concerns require AL facilities to provide a peaceful homelike environment which will promote residents health and safety, rights, autonomy, independence, and quality of life. Staff strive to achieve these requirements by concentrating on having a peaceful environment with little or no conflicts. However, they ignore the residents rights and autonomy. Secondly, the DCW demonstrates how she inconsistently deals with residents' sexual desire. Intimacy is a continuing human need for most people. Staff misconceptions and negative attitudes about sexuality and aging pose a barrier to sexual fulfillment for residents. Finally, there is consensus between administrators and DCWs on handling residents' sexuality using past experience. This again plays to a lack of formal policies.

5.1.3.5 Lack of Formal Policies Leads to Barriers

The absence of formal intimacy policies is consistent across assisted living communities. Despite the growing recognition of the importance of fostering intimacy and social connections, a structured framework or set of policies to support and facilitate intimacy remains largely absent from the institutional landscape. Kelly and Sarah demonstrate:

We don't have formal policies written for residents' sexual freedom or rights except for sexual misbehavior, where it would be sexual harassment for staff. Of

course, we protect employees and staff from sexual harassment. Those are well written policies in our HR Manual. But again, we have very little in writing. We do a background check if anyone has anything in their background that would be more of a past inappropriate behavior sexually (Kelly, upper management, Cardinal Home)

We don't have policies. The companies that I've worked with, they have no policies on residents having sex or sexuality as you called it. That is taking the people's rights from them, so they didn't take the resident or the members right from them. If you want to do it, Yeah, that's your right as long as you're not in conflict with anyone and, Oh, I mean, your family knows about it (Sarah, DCW, Century Court)

Despite a growing recognition of sexuality in older adults, staff confirm that their ALs do not have policies and procedures to manage sexual needs of residents, which ultimately constitutes a disservice, if not a violation, of residents' rights. In fact, lack of policies creates an environment with little intimate human connections among residents. Apart from admission and discharge policies which administrators described as formal policies, the only other formal policy is an HR policy on sexual harassment of staff. Negotiation of sexuality and intimacy then, is handled informally on a case-by-case or staff-by-staff basis depending on prior experience. In the second quote, the DCW contradicts herself first intimating freedom then providing requirements that impede residents' intimacy when they don't compile.

5.2 How Consent Leads to Bridges or Barriers

Consent in this context demonstrates the approval given by a resident for a sexual relationship. Further probing reveals that consent is only expected from the female resident. Anna and Josephine describe how consent is a barrier.

It is all around sexual health and sexual relationship. I mean, we know basic resident rights like residents are allowed to have sex and allowed to have privacy and engage in intimacy and sexual practices as long as there is consent. If there is no consent, then we will not allow it to happen because that may lead to abuse of the woman. (Anna, upper management, Good Living Home)

As a CEO, I allow them the freedom to get into relationships. Our residents are not regulated. They make their own choices. When you pay attention to issues of exploiting residents, getting authorities to intervene in any way would take a lot of effort. So, we work with what is suitable for all of us. There are exceptions if one of the them doesn't consent, but the woman's consent is required. Both residents must consent to the relationship. Still, you know, cautioning residents, in my opinion, doesn't work because they do not always have the most nuanced understanding of things (Josephine, upper management, Good Life Gardens).

In principle, both quotes suggest that intimacy is possible with consent. But who is defining that consent and ensuring it is obtained? What does consent look like when at least one resident has dementia? These quotes appear to pay lip service to the idea of consent but in reality consent, as demonstrated by staff, is used as a barrier that denies residents sexual autonomy. Administrators choose what works for them and it often results in decisions that avoid conflict instead of honoring the residents' sexual needs. These decisions in most cases violate residents' rights. Further, staff discuss consensual relationships and justify raising a barrier to the relationship on the grounds of fear of exploitation and/or abuse.

If dementia is a concern for the staff, then protection from potential abuse takes precedence over the sexual needs of residents. Further, staff consensually insist on consent even with the knowledge that issues of consent for residents with dementia are complex. First, there is the inability for residents with cognitive impairment to consent to sexual relationships. This impediment may mean denied opportunity for companionship and intimacy. Second, AL environment runs counter to the cultural prescription that sex is a private act between consenting adults (Frankowski & Clark, 2009). Even with consent, staff find other reasons to inhibit intimacy. There is evidence of gendered social norms when it comes to consent, as illustrated by Anna especially for residents with

dementia (Burgess et al., 2016). Men are seen as predators and not needing protection while women are seen as the victims.

5.3 Negotiating Intimacy Strategies

Strategies are the conscious actions AL staff take in regards to residents' potential intimacy. Staff use different strategies to negotiate residents' sexual needs. Most of these strategies are influenced by the lack of formal policies which lead to inconsistencies. AL communities operate within a structured environment that provides oversight, rules and monitoring. Residents living in this environment are required to respect house rules. Whereas AL philosophy include residents' independence, rights and autonomy, there are still rules that are applied across the board. Earlier studies have shown that consequences of dementia can be, at times increased sexual expression, sexually inappropriate behavior or sexual aggression (Alagiakrishnan et al., 2005; Kamel & Hajjar, 2004). To combat such behavior, AL apply strategies that control sexual behavior to protect other residents and staff and foster a peaceful environment. I identify watchful oversight/surveillance, redirecting and reporting as strategies that emerged from my data. I will discuss each of the strategies and how they lead to barriers or bridges next.

5.3.1 Watchful Oversight/Oversurveillance

Watchful oversight and oversurveillance are closely related but differ in magnitude. Watchful oversight is the act of monitoring of residents' behavior. Watchful oversight involves regular observation, sometimes with intervals. For example, staff monitor residents' behavior on a 24-hour basis at regular intervals of one to two hours (Frankowski & Clark, 2009). This can include walking in on residents while they are in their rooms.

Oversurveillance involves continually monitoring residents' behavior beyond the interval inspections. Oversurveillance, as it presented in my study is about protecting residents and even

staff from another resident engaging in impulsive, inappropriate behavior. Staff justify oversurveillance as part of their responsibility to safeguard the health and well-being of residents. Responsibility is often referenced as a stand-alone word as it is a major aspect of AL communities' philosophy. Robert shares how watchful oversight as a strategy can lead to a bridge.

You know, we have varying levels of intimacy, and sometimes, like you said it is sexuality, sexual penetration. They just cohabit together, and, you know, enjoy each other's company. For example, watching TV together, holding hands all the way down to sexual intercourse, depending on the person. But this freedom is observed and whatever goes on is notified. We get a lot of notifications of residents found on top of each other in bed. But we have trained our staff not to interrupt. And it may just end with us. But we must know what is going on. (Robert, administrator, Silver Springs).

Robert acknowledges the many notifications received suggesting how pervasive watchful oversight is, and that it leads to a serious loss of privacy but does not necessarily lead to a denial of intimacy. He also uses the term “trained” which I found means informal practices of talking to staff on “dos” and “don'ts”.

Sunita, shares how the oversurveillance strategy can cause a barrier to intimacy—possibly for good reason as it introduces a scenario involving residents with cognitive impairment.

Some of them act on impulse. For example, there is this male resident who I can say acts on impulse. He just suddenly grabs a female resident's boobs or slaps their butt. He does that to staff as well. We as staff can deal with it but we have to protect residents from abuse...yes it is abuse. So, we have to constantly watch him and if you see him making a move, you quickly step in to distract his thoughts. Administrators tell us to have our eyes on him all the time (Sunita, DCW, Retirement Haven).

The second quote shows that the lack of privacy goes beyond watchful oversight at times and can include questioning of residents. .

Staff's watchful oversight practices are often contradictory to the stated values of AL. Decisions regarding residents' autonomy rest on evaluations and attitudes of staff—and

sometimes in consultation with family, ignoring residents' choice. Monitoring of residents was done both in common space (tv room) and in the private rooms. Other researchers found interferences included an unlocked-door policy, the presence of roommates, regular room checks by staff, and staff access to medical and health-related information (Calkins & Cassella, 2007).

Through watchful oversight and oversurveillance, residents' are likely to have difficulty adjusting to a shared environment especially one that mandates 24-hour oversight/surveillance. Almost every aspect of a resident's behavior is noted and recorded, even if only mentally by staff. Regarding sexuality, staff surveillance makes this value more ideological than practical. Residents' behavior is noted in logs and reported to families, and observations of behavior are discussed at staff meetings (Frankowski & Clark, 2009).

5.3.2 Redirecting

Staff use the redirecting strategy to deny residents opportunities for sexual relationships. Redirecting is the act of distracting residents' sexual desires. Staff use this strategy to make residents forget their intentions regarding sexual interactions. As staff monitor residents' behavior, they will redirect any sexual behavior to divert them. DCWs justify redirecting as a means of meeting AL's goal of responsibility, to satisfy both administrators and family members. Yvette and Goosby explain:

So, it is not frequent. I do have one resident who tells me about liking, well, loving another resident. But I just try to redirect him to something else. I have not notified it. The experience I have, I know what to do. But it is not that he physically touches them or does anything in their space. He also says it to other residents. When he says it, I will hear him like across the room expressing his sexual desire and looking at her. You know what I mean right? So yeah, I would step in and distract him. You know they forget easily because of their cognitive impairment. But if it continues, we will probably have to relocate one of them (Yvette, DCW Good Life Gardens).

What the administrators expect of us is to avoid issues that will disrupt peace. The same with family, they want their loved ones protected. So, we don't encourage anything that will get them excited. You know...sex...sex can be super exciting.

You don't want that. I deal with it by redirecting. This makes my work easy; family happy; administrators happy (Goosby, DCW Good Living Home)

It appears that DCWs' attitudes towards residents' sexual needs are primarily negative. It will disrupt the harmony of the facility and create more work for staff. These attitudes are also influenced by family and administrators. In fact, such attitudes often lead staff to perceive attempts at sexual expression as inappropriate behavior. Additionally, sociocultural and health biases may be present against older adults residing in AL communities who participate in sexual activity (Frankowski & Clark, 2009). This finding may be far from being reversed. Sexual expression varies from intimacy to intercourse. Sexuality and intimacy are manifested in various ways, including intercourse. But even the basic intimate behaviors like touch, hand holding, and other less physically intense expressions were redirected by staff denying residents opportunities to companionship.

5.3.3 Reporting

Reporting is a strategy that staff used to notify higher ups of residents' inappropriate behavior. DCWs report incidents of sexual behaviors to administrators, and administrators, report to family members. Reporting is intended to cover DCWs' or the administration's bases just in case. This strategy can lead to a bridge or a barrier depending upon the family.

We have house rules that control behavior. If the resident continues to have inappropriate behavior, I will notify the administrator. We must protect other residents. So, as direct care workers, that is what we do. We don't report to families. Administrators will decide (Sarah, DCW, Century Court)

We have procedures to follow. If you notice something inappropriate, you have to let administrators know. And they talk to the family members. We don't talk directly to family members. So, administrators know family has the final say to how far they want relationships to go. We only follow what family decides (Esi, DCW Silver Springs)

These quotes from different DCWs in different AL communities are quite similar. In fact, it confirms my findings that there are similarities in operations of varied ALs. Through surveillance, DCWs constantly monitor residents' behavior and notify to administrators what they label as inappropriate behavior. They described any attempt at sexual expression as inappropriate behavior. There are no policies to guide staff on "what should or should not" be allowable sexual expression. What they described as procedures in place are informal practices that can be changed on a case-by-case or staff-by-staff basis.

Reporting also involves family. Administrators from various ALs illustrate that families hold the AL liable for residents' safety. To cover their backs, administrators report almost everything to family. Melissa explains:

I don't even know how to say that. Ha! Families get very protective and want their loved ones always to be safe. And they...you know...we try hard to talk with families about...not protecting and allowing people to do things that they want to do, that they need to do. But...it is what it is. For example we had this family that kept saying, my mother can't do that. I know my mother, She will never do that (Middle manager, Cardinal Home)

Children may not want to think of their parents as sexual beings. Some residents' children struggle to accept the idea that their mother may be intimate with someone new. However, family plays a big role in the continued stay of the resident in the AL. In protecting the privacy and autonomy of a resident, administrators risk alienating family members. This may lead to family members transferring their relative to another community, leaving the AL with a vacant bed. This scenario is avoided as it infringes into the financial intake of the community. Also, as family members help in marketing the AL by referring future residents, administrators will not want to risk alienating family. Finally, family involvement in AL help to enhance a homelike

environment which is good for residents. These factors influence staff's negotiation of intimacy. Clearly, staff use strategies that favor the family, and the AL community rather than the resident.

5.4 Summary

Despite residents' desire for intimacy, there were no formal policies that directly address sexuality. Lack of formal policies lead staff to address residents' sexual desires on a case-by-case and staff-by-staff basis. This is exacerbated by the reliance on individual work experience rather than training. Overall, while some strategies lead to bridges, the majority of strategies lead to barriers, though some themes emerged as both barriers and bridges.

My findings suggest that staffs' attitudes, concern for the safety and health of residents, and family concerns over parental intimacy, may bias against AL residents' right to sexuality. This is even though current cultural attitudes are shifting to encourage individuals to remain sexually active over the life course (Rheume & Mitty, 2008).

6 DISCUSSION AND CONCLUSION

The primary goal of this qualitative study was to explore how the structure of assisted living communities' policies and procedures impact the sexual autonomy of residents with dementia from the perspective of AL staff. I aimed to (a) understand how policies and procedures put in place by the AL communities shape decisions made by administrators in the management of the sexuality and intimacy needs of residents with and without dementia, and (b) to examine how AL administrators negotiate and balance the autonomy of residents living with dementia with the expectations of families' need for protection. To answer these questions, I collected primary data using semistructured interviews from 22 staff in 7 ALs. Each AL provided three levels of administrators ranging from senior management to DCW. One AL provided four administrators that included a senior manager, two middle management and one DCW.

I used the life course perspective, alongside a model of negotiating intimacy (Bender et al. 2017), and qualitative thematic analysis (Braun & Clarke, 2006) to analyze the data and structure my findings. In my findings, I modified extant research (Bender et al., 2017) by showing how the negotiating sexuality strategies that staff use can lead either to bridges or barriers to intimacy. Bridging intimacy is new and can be discovered due to discussions with the staff whom engage in these strategies rather than residents.

One major finding is that administrators depend upon DCWs' work experience rather than either training or formal intimacy policies to address resident intimacy needs. While extant research also found that AL operates without formal policies (Barmon et al., 2017; Burgess et al., 2016), the over reliance on work experience over training and education is new. Despite the fact that training is a foundational step to ensure that staff can do their work consistently and efficiently, there is little to no training relevant to sexuality and intimacy (IOM, 2008, White &

Cadiz, 2013). Two communities have “model of care” programs that trained their staff on work attitude and management of residents. However, these training modules did not include negotiation of residents’ sexual expression. It emerged that there could be lack of the relevant training modules for assisted living communities (IOM, 2008). Even with the little training provided in the model of care, staff were only trained on the acceptable attitude at work and the importance of intimate human connections.

Staff prioritize work experience over training, explaining how they utilize their work experience to efficiently deal with the delicate and complex scenarios of residents. It is possible, then, that two similar cases could be handled differently: one with a bridge and one with a barrier given the experience level or belief system of staff on hand. This dependence upon work experience creates inconsistencies that more often than not violate the rights of residents to privacy and autonomy. This finding is not inconsistent with prior research findings as older adults arrive at ALs with a life history of intimate experiences, preferences, needs, and desires which may be stymied under the influences of societal and internalized ageism (Fitzroy et al., 2022). Depending on experience rather than training or formal policies is especially surprising in the almost post-COVID-19 era given how harmful both COVID-19 and its resultant isolation were to residents.

The next major finding is how the same issue, family concerns or consent, can be both a barrier or a bridge depending upon how the staff use it. This can lead to confusion among residents and staff alike. The fact that administrators report residents’ inappropriate behavior (i.e., anything sexual) to family adds additional complications. Syme et al. (2017) observed that the perception of inappropriate behavior influences denying residents’ sexuality and intimacy in

ALs. Some of the perceptions that I found included scorn and stigma caused by ageism and bias against older adults.

Firstly, family members are the financiers of the residents stays in AL (Ball et al., 2005). This could mean managing the finances of the resident or financing the resident's from a family member's budget. Secondly, family plays a significant role in contributing to a homelike environment in AL, from which both the staff and residents benefit (Burgess, et al., 2016). Finally, family is valued by the AL as a business and as a marketing tool. In this regard, administrators notify family of almost everything concerning their relative's behavior.

In my findings, family concerns lowered a bridge to intimacy when they gave approval for sexual relationships after administrators notified them of their relative's desire. Some family members understand that their loved one need a companion—someone to hold hands, watch tv together or perhaps a pat on the back for reassurance on a bad day. Conversely, family concerns raise the barrier when they do not approve of a relationship because of concern over health and safety or propriety.

Finally, my research replicates decades-old findings regarding how AL communities operate (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016; Fitzroy et al., 2022; Frankowski & Clark, 2009; IOM, 2008). In other words, despite the many years of high-quality research on intimacy in AL settings, none of the findings have been translated into new practices, trainings, or formal policies.

Significant conflict between protection and sexual autonomy in assisted living communities persists. AL staff attempted to justify behavior that limited sexual autonomy, but their illustration was insupportable. A consensus of staff developed shared meanings regarding the residents' rights; these meanings were informed by the goals and values of AL. Further, staff applied the

beliefs and culture surrounding sexuality of older adults living with and without dementia. My dissertation explored extant research on understanding sexual freedom and autonomy in assisted living communities (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016)

Also conflict between protection (i.e., control) and autonomy still exists 12 years after data collection of extant research. Administrators and DCW's perceptions implied that ALs value their goals of responsibility and well-being of the residents more than residents' sexual autonomy (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2018). ALs are held responsible for the well-being of the residents by residents' families. State authorities also requires responsibility of residents before ALs are issued with a license. To meet this requirement, ALs must include a 24-hour watchful oversight for the well-being of the residents (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2018). Staff of two of the seven ALs confirmed the social model of care as well as 24-hour watchful oversight (Ball et al., 2004). It was troubling to learn of administrators' and DCWs' struggle to distinguish protection from control. They could not justify protection in the form of a 24-hour oversight, which was controlled behavior to either mitigate risk or to discourage residents' sexual autonomy (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016).

Despite these issues, most of the DCWs who were interviewed believed that sexual relationships should be permitted among residents with dementia. This finding supports extant research (Yelland et al., 2018). However, they justified a need to assess the risks and ensure that they are mitigated. I found that their justification echoed the findings of extant research (Ball et al., 2010; Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2018). A deeper look into the level of oversight revealed another dimension: DCWs discouraged sexual desires by redirecting residents' intentions. Redirecting involved distracting residents' sexual desires to discourage

sexual or intimate interaction. This finding also supported extant research (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016).

The AL environment creates opportunities for residents to develop relationships that may result in intimacy and sexuality (Kemp et al., 2020). Such an environment defines appropriate conduct through existing practices, including 24-hour oversight, which is imposed to justify responsibility. Family members of residents choose the AL environment that meets their concerns of safety and responsibility. Staff illustrate how ALs strive to meet this goal to continue having the residents reside in their AL and for marketing of future residents as referrals from existing family. The act of meeting family expectations raises the question: *Who is the consumer of AL services?* A 24-hour watchful oversight undermines residents' rights to privacy, respect, and dignity. However, staff chose to meet the family goals other than their consumers' (i.e., residents') rights.

I found that staff relied on experience rather than training to negotiate sexuality and intimacy. DCWs justified their experience and addressed incidents that occurred on a case-by-case basis without reference to policies or training. For residents with dementia, the main concern is that they are considered unable to process correct and acceptable actions from wrong, a concept better defined by the perceived capacity of the resident. Capacity entails the ability of an individual to reason based on their values and make decisions without coercion or undue influence (ABA/APA, 2016). The administrators' perceptions compliment extant research on the ability of residents with dementia to determine appropriate conduct and the responsibility of administrators to manage them (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016).

Another strategy DCWs utilized to reduce potential conflict was reporting. This strategy limited opportunities for residents to engage in sexuality and intimacy, but achieved

administrators' goals of discouraging sexual autonomy. The perceptions of the administrators influenced how DCWs balanced residents' sexual desire and family concerns of protection (Bender et al., 2017; Ciofi et al., 2022; Grigorovich & Kontos, 2018; Kemp et al., 2021, 2022; Simpson et al., 2018). Given that most staff were similar in their negotiation of sexuality issues, there was a shared consensus between staff on how they negotiate sexuality and intimacy issues. I highlighted consensus through themes like consent, watchful oversight, family concerns, redirecting, and reporting. If residents are freely consenting, they are allowed the freedom to engage in sexuality and intimacy. However, the DCWs remained responsible for ensuring their safety, which translated to watchful oversight.

While there is consensus between staff, I found that DCWs have the most interaction with residents while administrators have overall control of decisions. Administrators also have the least open permissive view of sexual autonomy. My findings support existing research (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2016).

Consensus does not extend to residents, meaning that even after chatting with the residents to confirm their attraction or consent to another resident, they do not influence the procedures the DCWs applied. Saj et al. (2022) noted that decision-makers are tasked with ensuring that residents are not exposed to situations that would put them at risk of abuse or accusations. This is especially true for cases where residents are living with dementia as it affects the nature of care offered and the negotiation of issues that residents face (Dilworth-Anderson et al., 2020; Saj et al., 2022). Lack of involvement of residents with dementia in workable policy also points to their inability to make value-consistent decisions or even have quality (i.e., safe) interactions. As such, oversight remains a key theme when administrators negotiate sexuality and intimacy issues.

Extant research also confirms the observations found in the literature on care interventions. For example, the concept of communicative competence, which requires DCWs to consult and collaborate about changes in the health of residents, was observed in cases where administrators consulted with the residents' families (Kemp et al., 2020). Talking to residents about consenting to a given relationship was a strategy that discounted sexual abuse and risks that could cause health complications.

Wilkins (2015) noted that an individual having intimate physical contact with a cognitively impaired person may be subject to criminal prosecution if it was established that the victim did not consent. The capacity to consent justifies the level of autonomy given to residents. Studies on dementia outline the capacity to consent as a primary determiner of whether they would be comfortable engaging in intimacy with their fellow residents (Barmon et al., 2017; Bender et al., 2017; Burgess et al., 2021). This applies to women, given their perceived vulnerability and the risk they face when they interact with men. This still poses the risk cited by Sorinmade et al. (2021) of unmet needs for people with dementia who cannot consent to intimacy and sexuality.

This study expands on the existing knowledge of sexuality and intimacy issues and how they affect residents living in ALs. The focus on residents with dementia counters the idea that older adults are likely to be asexual and sexless (Hillman, 2012). This research also expands Lichtenberg's (2014) observation that AL homes do not regularly assess the sexual needs of older adults. Monitoring relationships and nurturing them while ensuring that the residents are safe from harm is a better strategy (Lichtenberg, 2014). In addition, staff do not assess the sexual needs of their residents and feelings of residents' sexual desires are discouraged.

ALs vary in the programs offered, the services provided, and the procedures governing their admission and discharge of residents. Kemp et al. (2009) observed that these differences would

likely impact the care process. There are more similarities in the conduct of staff, starting from their application of experience to using informal policies to negotiate intimacy and sexuality issues. The administrators are tasked with ensuring that there is a balance between freedom and safety for the residents (Ball et al., 2009; Burgess et al., 2021; Fitzroy et al., 2022; Kemp et al., 2021; Zimmerman et al., 2003). They accomplish this task by limiting conflict in the AL, which, in most cases, inhibits sexual autonomy.

The study findings also reference the LCP (Elder, 1998), the key perspective reviewed regarding this research. I observed the application of the LCP from the perception of the staff and how they balanced and negotiated sexuality and intimacy issues.

6.1 Summary and Conclusion

In conclusion, I identified themes of bridges and barriers to residents' intimacy and the strategies that staff use to either allow or impede that intimacy. Further I identified issues of conflict between the sexual autonomy and rights of residents with the responsibility and goals of AL communities to protect against risk. Staff applied strategies that hinder sexual freedom, rights, and privacy of residents, and these strategies are tactfully displayed to mask their contradictions of AL goals of residents' rights. In addition, policies were scarce. Staff handled issues on a case-by-case basis. Although some administrators struggled to justify admission and discharge procedures as formal policies, it was significant that none of the 7 ALs had formal policies regarding resident sexual behavior. Furthermore, I found that staff had no training regarding sexuality.

This study had some limitations. First, the impact of COVID-19 limited the opportunity for research as ALs were not open to having researchers in their communities. This factor prevented on-site visitation to witness the general environment and individual spaces where relationships

are negotiated. Second, the purposive sample of six assisted living communities in Metropolitan Atlanta is not generalizable to all ALs or different geographic regions. However, my goal was to develop an explanatory model for examining the negotiation of sexuality and intimacy in AL settings within limited resources. Future research can explore negotiation of sexual autonomy among a broader geographic sampling of assisted living communities that would be more generalizable. Finally, the study was limited in its basic nature as it was largely cross-sectional and did not factor the trends of how treatment of sexuality and intimacy have changed over time (Burgess et al., 2016). Examining the same outcomes longitudinally in future research would yield meaningful insight on the topic. In addition, I only asked administrators about formal policies in their varied ALs leaving out direct care workers. My understanding was that administrators are more involved in policy guidelines; as such this oversight limited DCWs' perceptions of policies.

Assisted living communities should implement their philosophy if they value residents' sexual autonomy and privacy. Despite assisted living communities having a philosophy that emphasizes maintenance of autonomy, AL staff struggle to balance autonomy and protection and ethical issues surrounding cognitive impairment and consent. Implementing the philosophy of residents' rights may make AL communities less likely to have conflicts of autonomy and protection. Second, policies that work towards fostering residents' sexuality and intimacy must be implemented. Such policies should be regulated and enforced, and care taken to encourage sexual autonomy without victimization of age or cognitive impairment. In addition, training regarding resident sexuality and intimacy must include issues of cognitive impairment and consent. AL staff are increasingly in demand as the population ages. These staff require support through a variety of organizational systems, including a training program that emphasizes

increased competence in caregiving, and relationship between staff and residents that promotes quality of life in all areas, including sexuality and intimacy.

Furthermore, although regulations in Georgia require training in residents' rights within the first 60 days of employment (Carder & Hernandez, 2015), there should be a follow up to ensure that AL staff are not just primed for the sake of getting hired. Continuous education and training of AL staff must be maintained and sufficient to prepare these staff to provide quality care to older adults. Future research should assess the relative impact of the factors that shape the barriers and training modules that must include sexual autonomy, rights, privacy, and negotiation of sexual needs for residents living with dementia in assisted living communities.

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APPENDICES

Appendix A

Informed Consent

Title: Sexuality and Dementia: policies and processes negotiating autonomy of residents' sexual needs by DCWs

Principal Investigator: Dr. Erin Ruel, Student PI, Josephine Misaro

Department of Sociology

Georgia State University

Introduction and Key Information

You are invited to participate in a research study. If you decide to participate, we will ask you to spend up to 60 minutes answering questions. This study is dissertation research for a student pursuing a PhD. The study is not funded. There will be no monetary appreciation. We are interested in your thoughts about policies and processes negotiated to balance autonomy and protection of sexuality and intimacy of residents living with dementia in Assisted Living (AL) homes.

If you decide to participate, we will ask you about the following:

- 1) The Assisted Living Facility that you serve.
- 2) Ideas related to policies governing sexual and intimate behaviors of residents living with dementia in the facility that you serve.
- 3) Training related to serving residents living with dementia.

A total of 20 people will be invited to participate in this aspect of the study.

In this study, you will not have any more risks than on a normal day. You will not benefit personally by participating in this study.

Participation in research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you can drop out anytime. You may skip questions or stop participation at any time. Whatever you decide, you will not lose any benefits you are entitled to.

Confidentiality

We will keep your records private to the extent allowed by law. Only Erin Ruel and Josephine Misaro will have access to the information you provide. Information may also be shared with those who ensure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP)). We will use a study number rather than your name on study records. The information you provide will be stored in a password-protected computer. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally. Call Erin Ruel at 404-413-6530 if you have any questions about this study.

Consent

You may keep this consent form for your records.

If you are willing to volunteer for this research, please verbally agree now.

Appendix B:**Administrators' In-depth Interview Guide**

Please provide me with this basic information about yourself.

Background:

Male Female _____

Are you of Hispanic or Latino origin? Yes No _____

What do you consider your race?

Black /African American White Hispanic/Latino _____ American Indian/Alaskan Native _____

Asian _____ Native Hawaiian or another Pacific Islander _____ Other Indicate what " other " means (e.g., Jamaican).

What is your age range?

18-24 25-34 35-44 45-54 55-64 65-74 75+ _____

What is your highest education level?

_____ Less than a high school diploma

_____ GED

_____ High school diploma

_____ Trade school or vocational certificate

_____ Some college or associate degree (2-year program)

_____ Bachelor's degree Specify Degree: _____

_____ Some post-graduate work

_____ Graduate degree, Specify Degree: _____

_____ Other

Are you married, separated, divorced, widowed, or have you never been married?

Married Widowed Single Divorced Separated_____

Facility Fact Sheet

BACKGROUND

What year did (name facility) begin operating as a personal care home?

Who owns and manages the facility?

Is the home affiliated with a religious denomination or organization?

How does this influence the home?

How does the home integrate religious beliefs and values into activities regardless of formal affiliation?

FEES

What is your current highest monthly rate? _____

What is your current lowest monthly rate? _____

How are these fees determined?

Resident Profile:

How many residents can you accommodate (are you licensed for)?

How many residents do you currently have?

About how many residents are in each of the following categories:

18-44 45-59 60-64 65-69 70-74 75-79

80-84 85-89 90+

How many residents are male, and how many are female

Male_____ Female _____

Please tell me the race of residents in your AL

Black/African American _____ White_____ American Indian/Alaskan Native _____

Asian _____ Native Hawaiian/Pacific Islander _____ Other _____

What is the marital status of residents in your AL?

Widowed _____ Married _____ Divorced _____ Single _____

How many units include married persons sharing living arrangements? Do you have any married residents who do not co-reside?

How many residents living with dementia, do you have in your facility?

ADMISSION AND DISCHARGE POLICIES

Admission

What are your criteria for admission?

Is there a specific type of resident you are trying to serve? (Elderly, Alzheimer's or other dementia, mentally retarded, Mental health problems)

Could you tell me what kinds of residents you won't admit?

Do you have an admission agreement?

How does a resident typically learn about your facility?

Description of admission procedures:

Level of family involvement

Resident assessment

Whether, when, and how are care needs assessed

after admission/before admission

who provides information about care needs

what information sought

whether care plans used

Discharge

Usual reasons for

How implemented

Type of notice given

How do you handle declines in residents' health status or functional abilities?

Could you tell me about any residents who have left your facility during the last year?

EMPLOYMENT HISTORY

Can you tell me about your employment history?

Probe for:

Length of time at this facility

Length of time in assisted living

Length of time in long-term care

TRAINING

Can you describe any training you have had regarding issues of older adult sexuality and intimacy?

(Clarify: When I use the term sexuality, I include actual sexual behavior (genital and non-genital contact), sexual attitudes and values, and sexual identity. I use intimacy to have romantic companionship, flirting, and dating).

Probe for:

Length of training, where provided, who provided

Attitudes about the quality of training

Is there any training you would like to have to help you do your job better? What? Why

Have your staff received training on issues of older adult sexuality?

Probe for:

Length of training, where provided, who provided**Attitudes about the quality of training****How did training address issues of dementia?**

Is there any training you would like the staff to have to help you do your job better? What? Why?

DAILY ROUTINES OF THE PROVIDER

I am interested in what a typical day is like for you. *In describing your activities and experiences, please avoid referring to people (residents, family members, or staff) by name. Instead, use initials or refer to them by generic terms (“ a healthy male resident” or “a long-term DCW”)*

Can you describe a typical day?

Probe for:

Time spent engaged in resident care activities

Time spent engaged in clerical/administrative activities

Other activities

ENVIRONMENT OF FACILITY

Describe the standard and social areas of the facility.

How often are these areas used? By whom? At what times?

What types of organized social events are available to residents? How often? Who attends? Does socializing ever lead to dating or romance between residents?

Do you have a map or floor plan of the facility?

How would you describe the social and emotional context of the facility? **SEX AND INTIMACY**

IN AL – EXPERIENCES IN THIS FACILITY

How do you think sexuality and intimacy differ in independent living or skilled nursing care?

Probe:

Physical Health and Well being

Mental health and Dementia

Access to Privacy

How often do issues about sexuality or intimacy come to your attention? What are the most common reasons for reaching your office?

What concerns do family members have about their loved ones' sexual and intimate behavior?

Probe:

Do their concerns change over time?

How accurate or reasonable are these concerns?

Can you describe what you would perceive as a healthy display of sexuality or intimacy for older residents?

Can you describe a specific incident around issues of sexuality or intimacy that created problems for your staff, residents, or family members of residents?

Probe:

Can you describe the events that led up to this incident?

Was anyone's safety at risk? How?

Were outside parties, such as family or community members, concerned about the situation?

How was the issue resolved?

Was everyone involved satisfied with the resolution?

What lessons did you learn from this incident?

Have there been other incidents? Describe as discussed above.

(Ask the following as needed to follow up)

Can you recall incidents when residents acted up toward staff?

How have you addressed concerns regarding the transmission of sexually transmitted infections?
 Are you concerned about the sexual and intimate behavior of residents living with dementia? Do the perceptions of the behavior of residents with dementia limit or alter the behavior of other residents? Staff? Residents' family members? How do residents, staff, and family members manage these concerns about the sexual expression of residents living with dementia?

POLICY

What formal policies do you have about residents' sexual health? Sexual Privacy?

Informal policy or practices?

What formal policies do you have regarding sexual harassment of staff or sexually inappropriate language or behavior directed at staff?

Informal policy or practices?

What formal policies do you have regarding sexual harassment of residents or sexually inappropriate language or behavior directed at other residents? Do you have separate policies/practices in the DCU (if applicable) or for residents living with dementia?

How effective are these policies or practices?

Thank you for your time. Is there anything else you would like to share with me on this issue?

DCW In-Depth Interview

Begin by reminding the interview subject: *In describing your activities and experiences, please avoid referring to people (residents, family members, or staff) by name. Instead, use initials ("J. L." instead of "John Lomax") or refer to them by generic terms ("a healthy male resident")*

1. As DCW, what experiences have you had with residents' sexuality and intimate behaviors in this facility?

Potential probes:

- What kinds of behaviors have you encountered?
- What do you think about these behaviors?
- How have you reacted to these behaviors?
- What concerns do you have about these behaviors?
 - How do you talk to residents about sexual and intimate issues? What type of language do you use?
 - What do you think are appropriate and inappropriate sexual behaviors for residents in ALFs?
 - Have your attitudes and approaches to issues of sexuality and intimacy changed over time? How so?

2. How do others in the facility respond to residents' sexual expressions and intimate behaviors?

Potential probes:

- What are the facility's policies regarding residents' sexual behaviors?
 - What rights to freedom of sexual expression do residents have in your facility?
 - What training have you received regarding sexuality and resident care?
 - What do you know about sexually transmitted infections among older people?
- Who gets involved in issues related to residents' sexual behaviors?
 - How do others define appropriate and inappropriate sexual behaviors for ALF residents? (i.e., administrators, members of the community, family members, other residents, and other staff members) How do they respond?

-How are behaviors identified as inappropriate handled? By whom?

-What roles do family members play? Other members of the community?

3. How do residents' sexual and intimate behaviors influence life in the facility?

Potential probes:

-What kinds of rights to freedom of sexual expression do you think residents should have?

-How do issues of residents' sexual behavior affect how you do your job?

-How does dementia factor into the sexual behaviors of residents?

-How do these behaviors affect other residents?

-How do these behaviors affect relationships with staff members?

-How do these behaviors affect relationships with family members?

-How do these behaviors affect relationships with those in the broader community?

4. How do concerns about dementia and the potential or actual behavior of residents with dementia influence perceptions about sexuality and intimacy in this facility?

Potential Probe:

- Do you have separate policies/practices in the DCU (if applicable) or for residents with dementia?

- How would you react differently to sexual behaviour if you knew a resident with dementia was involved?

- How do residents, staff, and family members manage these concerns about the sexual expression of demented residents?

Is there anything we haven't covered that you think is important to discuss or to know about regarding residents' sexual and intimate behaviours? If so, I'd like to invite you to discuss these issues.