Exploring Staff Perspectives About Interpersonal Relationships Among Persons in Assisted Living Facilities in Franklin County, Ohio: A Pilot Study

Dissertation

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By

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Abstract

As the number of older adults in the United States increases, there will be more and more individuals with functional limitations that requiring long-term care support and services. Understanding how to deliver services that support older persons’ health and well-being, including intimate and sexual expression, is important to providing a high quality of care. Facilities that provide assisted living services are one of the largest service settings in aging person care systems. Ten staff members from four assisted living facilities in Franklin County, Ohio were interviewed for approximately 60 minutes each to learn about their experiences with resident intimate and sexual expression and the related policy-making process in their facility. Naturalistic inquiry methods informed the process of data collection that resulted in the following themes: informal policy, reliance on events, pre- and post-event climates. Overall, results indicate that facilities frequently avoid the development of facility-level policy to address resident intimacy and sexuality favoring a case-by-case evaluation that often lacks standardized evaluation tools. Perceptions of the aging process are influenced by the larger negative societal views of the aging process. There are substantial needs for comprehensive training to empower
staff to make consistent, wellness-aimed decisions for residents. Practice, education, policy, and research implications are proposed.
Dedication

James Russell Lanning 1918 – 1967

&

Cedes 2001 – 2015
Acknowledgments

This accomplishment would have never been possible without the assistance of my committee, the support of my family, and the time of my participants.

Simply put, I have the best committee of any student. Each member has been an invaluable mentor, confidante, and friend. Sharvari taught me the art of qualitative research. Randi pushed me when I wanted to give up. Denise kept me true to my future dreams. Holly stepped in to be my chair, and has become such a trusted ally and friend. Thank you to each of you from the bottom of my heart.

My family is incredible. They have supported me every step of the way. They have waited patiently for this day. I hope I have made them proud.

My dog, Cedes, was the best writing partner I could have ever had. She had to leave me when I was almost done. I will remember, miss, and love my ‘little bug’ forever.

Each of my participants provided me access to their time and thoughts. I hope I did their words justice.
Vita

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Publications


Fields of Study

Major Field: Social Work
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Chapter 1: Statement of the Problem

Introduction

Assisted living (AL) facilities are one of the biggest sectors of service provision for aging people who need assistance as they navigate changing abilities during the aging process. AL services focus primarily on maintaining the autonomy of aging people, providing assistance with activities of daily living (i.e., food preparation, making beds) on an as-needed basis. Residents in AL also typically do not need constant medical monitoring services usually provided in nursing home settings. Understanding one critically important aspect of resident quality of life, intimate and sexual expression (ISE), is all but ignored in stated policy on management of resident behavior. This research explored the meaning made of these expressions, and the policy-making process in facilities. ISE is something that is considered important across the lifespan and is correlated with positive health benefits for those who experience ISE. The beginning understandings gained from this research can inform future research with the aim of improving the resident experience in AL by educating staff and creating environments that safely support AL resident ISE.
Statement of Problem

A number of groups have formed to represent AL facilities and address various issues of importance (e.g., facility amenities, resident feedback utilization) to them, and their families. One such group is the National Center for Assisted Living (NCAL). While NCAL is primarily a trade group, representing the setting of AL facilities more than individual residents they do provide valuable insight into AL settings. They describe long-term care as more than a mere setting, but as more of a “philosophy of care” (NCAL, 2008). The NCAL provides insight into their operational philosophy in a statement of resident rights that includes specific items of importance such as privacy, and being treated with dignity and respect at all times. Further, they recognize the importance of the freedom to interact with other people not only within the facility, but also the larger community. Missing from their statement is any specific right to ISE. This omission, as some have pointed out, contributes further to ageist-fueled myths that older people are asexual (Connolly, Breckman, Callahan, Lachs, Ramsey-Klawsnik, & Solomon, 2012).

Given the increasing need for AL services in the United States, as the baby-boom generation ages, a comprehensive understanding of the situation of intimacy and sexuality in these settings is needed. The reality of intimacy and sexuality is a constructed one that relies on the meaning made by multiple players, including the staff, residents, and family members of residents. Exploring what meaning is made of the experience of resident ISE behaviors from all involved parties is the first step in creating climates that respect resident autonomy and choice. Very little research describes what behaviors residents engage in most commonly. Research into typical staff response is often
understood in ageist and prohibitive terms. The policy development process must be understood better so as to develop best practices on how to create policy that respects maintaining optimal resident autonomy, while address facility and family concerns. Gaining an understanding of the relative importance of resident, family, and staff member input is a first step into informing an effective and respectful policy-making process. Establishing what the primary concerns of residents, family, and staff is also critical in understanding how to bring the various parties into conversations aimed at productive policy for facilities to implement. This research is a first step into developing this understanding.

Research Statement

Research has shown that intimate and sexual feelings are considered an essential part of the human experience (Delameter, & Sill, 2005; Doll, 2012; Elias, & Ryan, 2011; Miller, 2004), and extend for most, if not all, of one’s lifespan (Langer, 2009). While some research has found that the reported frequency of all kinds of sexual and intimate behaviors actually decreases over the lifespan, sexuality and intimacy remain essential components of the lived experience (Bretscheider & McCoy, 1988). Research has also shown that when someone’s sexuality is promoted, a number of general quality of life indicators realize positive gains, and depression and anxiety actually decrease (Heath, 1999). Of particular importance to long term care settings, Heath found increases in general social engagement when someone felt they were supported in expressing themselves sexually; so the positive effects of supporting sexuality extend to overall socialization for all residents, even those not engaged in sexual activity themselves.
Bretschneider, and McCoy (1988) explored the sexual interest of over 200 respondents living in residential retirement facilities and discovered a number of interesting findings. Primarily, there was a gendered effect in desire and engagement in reported sexual and intimate feelings in their sample. Men tended to report more desire and engagement in sexual behavior than did women across all age groups. They also found that there was a slight decline in the frequency and pleasure derived from touching and caressing without sexual intercourse. Of particular interest was their finding that 37% of their sample reported the current setting “some of the time” prevented them from engaging in sexual activity, or “that it did prevent them” from engaging in sexual activity. Further, 58% indicated that the setting did not increase their chances of engaging in sexual activity. There were no differences between men and women in their sample on these measures.

Hajjar and Kamel (2004) point out the issue of sexuality and intimacy in the aging population should not be narrowly defined. The body of research into aging persons’ sexuality that exists tends to focus on a few key areas; the first being the management of sexuality in partnerships where one or both partners is experiencing dementia. A second focus is on the state of care-providers’ attitudes and beliefs about aging people’s sexual desire, sexual needs and benefits, and management of displays of sexuality in long-term care settings. Previous studies have found that restrictive attitudes and beliefs in staff equate to a more punitive approach to the management of aging-resident sexuality (Bentrott & Margrett, 2012). This includes such things as physical restraint, isolation, and even medicinal intervention. While many agree that the current approaches are not acceptable, what most fail to agree on is how to specifically address the issue. Of central
importance is the maintenance of safety of residents needing protection (e.g., declining cognitive decision-making ability due to dementia), respecting family (who are often involved in care decisions) wishes, while also maintaining order and civility in the facilities.

Despite all of these findings that may suggest sexual activity does not happen frequently, there are dramatic increases in sexually transmitted infections such as syphilis, and even HIV in older individuals. According to Jameson (2011) the CDC recorded that in the years from 2005 to 2009 the rate of chlamydia and syphilis was up 43 percent in older age individuals. In some popular retirement areas like Phoenix, Arizona, the respective rate is twice that of the national average. According to Jameson, the government funded health care program for all older Americans, Medicare, is even considering including sexual health screening as part of their standard office-visit protocol for sexually active seniors.

This knowledge calls for the greater examination of issues related to older people’s sexuality in AL facilities from the most broad basis; including more levels of analysis than currently exists in most of the literature. Evidence shows that a lack of any type of training related to sexuality in facilities further contributes to more negative attitudes towards it among staff (Hajjar & Kamel, 2004). There is sufficient evidence that training at all levels of staffing is necessary (Chau, Lee, Low, & Thompson, 2005) that can transfer usable knowledge and skills that improve clinical care (Arnetz & Hasson, 2006; Hallin, Henrikksen, Dalen, & Keissling, 2011; Aylward, et al., 2003) may be an advantageous place to begin.
Methodology Overview

Existing research is piece-meal in its approach, often looking at one (e.g., social, care-taker) perspective or rules and regulations surrounding managing sexual behavior in AL facilities (Bouman, Arcelus, Benbow, 2006). This study used a qualitative exploratory approach that collected data intended to develop themes for future research. Qualitative research is appropriate methodologically because it provides the basis for understanding the process as it occurs, in context. The Narrative Inquiry (NI) approach of qualitative data analysis integrates the researcher role, with that of staff in AL facilities in Franklin County to begin to explore typical expressions, standard responses, and methods of input for policy development in the setting of AL in Franklin County, Columbus Ohio.

Elias & Ryan (2006) in their review of the literature found a focus on the specific area of managing sexuality in dementia patients, and call for research that incorporates the view of multiple levels of facility staff, as included in this study. The literature consistently cites ageist beliefs and assumptions, and a lack of privacy (Elias, & Ryan, 2011; Gilmer, Meyer, Davidson, & McLain, 2010) as being major barriers to supportive policy and practice toward resident’s expression of their intimate and sexual selves. In the absence of any training into sexuality’s importance throughout life, these ageist views may inform the approach taken by staff in some cases. This work used a naturalistic qualitative methodological approach to determine the meaning made from experiences in the setting of AL, and the policy making input from various stakeholder groups.
Naturalistic Inquiry

Naturalistic methodology considers inseparable the relationship between data collection and data analysis. This study aimed to explore and to describe the meaning made of expressions of intimacy and sexuality among residents from the perspectives of staff working in AL Facilities in Franklin County, Columbus, Ohio. The study resulted in the development of themes for future research including the typical portrayals of intimacy and sexuality, how facilities manage these expressions, and the policy that either results from, or stands separate from these experiences and meanings. This interactive and dynamic approach to data collection responded to early observations that informed refinements in later data collection methods.

Qualitative interview data was obtained from 10 convenience-selected staff members employed in AL facilities in Franklin County. While interviews with residents and family members would have been preferred, the interviews were conducted with staff members for feasibility concerns. This choice was also made because staff members were considered to be the role that interacted with the resident, facility policy, and involved family simultaneously. Staff members would therefore be best able to provide a broad view of ISE in AL facilities. Individual semi-structured 60-minute interviews were conducted. Questions focused on facility climate towards resident intimacy and sexuality; agency policy and procedures regarding ISE behavior in the facility, intimate and sexual policy development processes, and staff member portrayals of typical resident displays of staff response to ISE behavior in the facility. Conducted interviews were recorded and transcribed by the Co-I. The Collaborative Institutional Training Initiative (CITI) provides human subjects research training through Ohio State University. The
The investigator who conducted the research is CITI certified as well as trained in the techniques of qualitative data collection. Committee members are also CITI trained, supervised the investigator while collecting qualitative data on previous projects, and provided guidance on methods used for this research. Results are reported aggregately with no interview participants being identified. This is done out of a concern by the Institutional Review Board that no participants be individually identifiable given the sensitive nature of information provided. The results reported intend to inform an exploratory description of the overall intimate and sexual situation in settings of AL in Franklin County.

The research conducted presented low risk to professional staff members because data collected aimed to describe standard policy and practice across the setting of AL facilities. Results are not individually identifiable by respondent, or respondent facility. The benefits to staff participation were expressed feelings of contribution to improvement of quality of life of the residents in their facility.

**Stakeholders**

The research I conducted had three primary groups of interest. The first group of interest is the residents of AL facilities. Residents of AL are typically highly autonomous with limited, or sporadic needs for assistance in activities of daily living. The second group of interest is the related family of residents in AL. Also considered part of this group are persons, who may or may not be related, but who retain various powers’ of attorney to assist in making decisions for an aging person unable to make their own
decisions. The third group of interest is the staff and administration of AL facilities. This group of employees has a wide range of educational preparation to work in this setting.

**Research Aims**

This study had two main aims:

1. Exploration of staff members’ perceptions of policy and practice regarding intimate and sexual expression of residents in settings of AL.

2. Exploration of staff members’ understandings of the facility climate pertaining to interpersonal relationships and contribution of various stakeholders (i.e., resident, family members, facility/staff) into policy regarding intimate and sexual expression of residents in AL settings.

**Limitations**

This exploratory work was a first step in developing an understanding of the situation of intimate and sexual expressing for aging residents of AL facilities in Franklin County, Columbus, Ohio, as research in this area is in its infancy. This descriptive work portrayed the experience of staff members’ view of their residents’ experiences and the policy in their facility at the point of time we conducted their interview. It also explored the facility climate related to interpersonal relationships and the various stakeholders contributions to the policy making process. As such it should not be considered an exhaustive explanation of the situation and policy development process across all settings. The research conducted used a purposive sample, so findings may not be generalizable. A common criticism of qualitative research is the ability of researcher involvement in the data collection process, as well as researcher bias and assumptions, to
influence the analysis of data. This research incorporated the Naturalistic Inquiry method that intentionally includes the researcher as part of the creation of meaning concerning the variables of interest. The Institutional Review Board review of this project delayed commencement of recruiting efforts until early December. When initial contacts were established with EDs to seek facility participation, it was very close to the holiday time period, which may have impacted what facilities agreed to participate. Facility EDs that may have agreed to participate in the research may have lacked the time to respond to the recruitment emails because of holiday vacations, or other staffing issues. Non-participation in the research should therefore not be read as not supporting the research.

As such with these limitations, the aim of this work was the development of themes that will inform future research projects, advocacy efforts, and overall awareness. The overall qualitative approach was methodologically appropriate because there is so little known about ISE in AL settings in the existing research. Being that I am a member of the LGBT community it was also important to me to select a qualitative approach that acknowledged the meaning that I would make of the experiences of residents expressing ISE. NI enabled me to process the meaning that I made in the context with the staff member participant. This was a strength of the approach I selected. However, there are a number of limitations with qualitative research, particularly the inability to establish a causal relationship. So, while my model includes ageist and discriminatory views towards disability as potential causes of the reactions that staff members portrayed, future research will have to test these relationships using appropriate methodology.
Definitions

Intimacy and sexuality are often viewed as similar things in many social contexts, and even used interchangeably in conversation. However, sexuality and intimacy are thought to be two distinct sets of behaviors and patterns of interaction that have very different importance across one’s lifespan. Sexual and intimate feelings are also considered non-essential life functions by some facility staff members, instead of a normal part of a person’s interaction throughout their life. There may be some staff who do not believe this ISE is appropriate among this populations for a variety of reasons. Because of this, ISE is typically not addressed as a concern in how to plan resident care in the facility unless the resident is affected by a decision-making deficit and the activities should not be engaged in at all. In those cases more precautions may be taken to protect the wellbeing of this type of patient. Though both words have been defined in myriad ways, the operational definition for this project will be as follows.

Intimacy is understood as the relational and social interactions that comprise the desire to be close to someone, without being physically sexual. This would include verbal flirtations, facial expressions of interest, and possibly hand contact to another person’s hands, arms, face, or head/hair. Expressions or caresses that do not lead to sexual intercourse are considered intimate behaviors.

Sexuality would be the more privately-engaged set of behaviors, such as kissing, ‘heavy petting’, or actual sexual intercourse (e.g., penis/vagina penetration). Sexual behaviors may include intimate behaviors, but they may also be stand-alone means of physical gratification.
Long-term Care Settings

Long-term care settings are the package of different residential service settings that present a range of available service levels. They are another important definitional consideration in this project. For this project there are considered to be three primary settings for services (independent housing, AL, and nursing home/skilled care) that cater to an aging client (Adapted from Doll, 2012). The focus of this research will be facilities in Franklin County, Columbus, Ohio that provide AL services. Below are the explanations of the different service types.

Independent Living Facilities.

The most basic level of service is independent living facilities. Independent living facilities provide a modified residence aimed at being accessible for someone with deteriorating ability to function independently. In these facilities physical modifications may be made to areas like the kitchens and bathrooms, with an emphasis on maintaining the independence of the resident as long as possible. Residents in these settings experience the highest level of privacy and autonomy.

Assisted Living Facilities.

AL facilities is the next level of service setting. In AL facilities the resident is challenged with some, or some parts of, activities of daily living (e.g., preparing meals, dressing). In these facilities the physical environment is modified to maintain as much independence as possible, with supervision and assistance provided with challenges. Residents in these settings experience a high level of privacy and autonomy, with
minimal interruptions. Residents may share common spaces, but usually maintain private sleeping quarters.

Nursing Home/Skilled Care.

The highest level of services provided is in facilities known as nursing home/skilled care facilities. In this setting, residents experience many challenges with a majority or all activities of daily living, and must also be monitored closely for medical conditions. Residents in this setting often experience the lowest level of privacy and autonomy in this setting. Often residents share rooms of communal gathering, as well as sleeping quarters.

Overview of Chapters

Chapter 1 provides the introduction to this research. In this chapter I have provided a statement of the problem, and research statements that guided this work. Then a methodological overview I introduce the methodological approach and the use of Naturalistic Inquiry that informed my data collection process. Research aims, and limitations are then discussed. Finally I provide useful definitions for the reader as they progress through this document.

Chapter 2 is a comprehensive review of the literature. In Chapter 2 you will be introduced to aging in the United States, and provided information about the setting, climate, and philosophy of AL. The next section of the chapter covers the regulatory and professional environment for staff, and social workers in AL. Lastly a discussion of ageism and the current research paradigm is provided.
Chapter 3 explains the methodology used in this research. Beginning with an introduction to my data sources and data collection, I then provide the reader with the sample characteristics, consent and data collection process, and analytic plan I followed. The chapter concludes with a discussion of the limitations of this research.

Chapter 4 reports the findings of the interviews conducted with staff members of AL. After reviewing the semi-structured interview plan that I utilized I then present my thematic understandings of my data.

Chapter 5 is a discussion of the findings, including social practice, policy, and research implications. The overall importance of family is discussed first and then I present my discussion in relation to the two climates that my data revealed operate in AL settings concerning ISE among residents from the perspective of staff members.

Lastly, Chapter 6 discusses the implications in a similar format to Chapter 5 utilizing the two operating climates to structure implications I have drawn from my data.
Aging in the U.S.

While there is a wide range of estimates about the number of older adults living in long-term care, it is estimated that 37 million live in some type of long-term care (Benz, 2013), and 1 million reside in assisted-living facilities (AL) (NCAL, 2008). It is estimated that 70% of people over 65 can expect to spend at least some time in some form of long-term care during their life (USDHHS, 2013). The number of people living in the most service-intensive setting, nursing homes, is estimated to be around 5% of those over 65 years of age, and 20% of those over 85 (Hajjar & Kamel, 2004).

There are nearly 77 million baby boomers entering into an age where the need for long-term care may become reality (Connolly, Breckman, Callahan, Lachs, Ramsey-Klawsnik, & Solomon, 2012). Estimates are that 12 million people will be in need of long-term care by 2020 (Castle & Stadtlander, 2009). The baby-boomer cohort represents many people responsible for the lesbian, gay, bisexual and transgender (LGBT), women’s, and “sexual revolution” movements. This cohort therefore presents a possible challenge to the current under-researched, and often avoided topic of intimacy and sexual expression (ISE) in long-term care settings. As this cohort begins to replace the current consumer of AL facilities, the socio-cultural context of AL is expected to change.
drastically, making the topic of managing resident intimacy and sexuality a very important one at this time (Bouman, Arcelus, & Benbow 2005). AL facilities have become a critical industry to address the needs of aging persons (Castle & Stadtlander, 2009) so issues important to these consumers must be determined and comprehensively addressed at all levels of the service provision.

Assisted Living

Assisted living (AL) provides housing with services when an aging person needs assistance with activities of daily life change. AL aims to maximize the time spent in this setting, helping elders “age in place” by maintaining resident autonomy to the highest levels possible (NCAL, 2013). Often there is a range of choices of activities from outings in the community, to social activities within the facility to keep residents interacting socially. The setting is designed to be aware of and responsive to resident needs as they change. This means that over time care providers may have increasingly frequent, and likely intimate (i.e. dressing and bathing), contact with residents as the residents’ needs change. The care providers employed in AL settings are typically administrative, nursing, care coordinators (i.e, social workers), medication assistants, and personal care staff. AL facilities also employ dining, custodial, maintenance, and activities coordinators.

The costs for services vary on a number of dimensions including location of the facility, amenities, and apartment size (NCAL, 2013). There are often entrance fees to buy into the facility and monthly service charges to maintain residence in the facility. These fees are most often paid out of retirement, funds from selling a home or other personal investment funds.
AL settings today reflect massive change in how we care for aging people over the last 100 years in the United States. Whereas aging people were sent to “old folks” homes in the past, there are now a range of options to care for an aging person (Doll, 2012). One such service provision is AL, in AL facilities the resident is challenged with some, or some parts of, activities of daily living (e.g., preparing meals, dressing). In these facilities the physical environment is modified to maintain as much independence as possible, with supervision and assistance provided for the challenges. Residents in these settings experience a high level of privacy and autonomy, with minimal interruptions. Residents often share common spaces, but usually maintain private sleeping quarters. Residents are able to age in place as their changing needs are addressed over time, delaying entry into nursing home care.

Climate/Philosophy of AL

Overall in the field of aging, there is a movement from the medical model to the humanistic approach to care (Hamilton & Tesh, 2002), which is reflected in AL settings. The medical model dominated care in nursing home settings. This model of care emphasizes managing disease. The humanistic approach is a shift to emphasizing the whole person’s wellness to include biological, medical, social, and other domains when considering how to manage an aging person (Doll, 2012).

AL facilities with more explicit policies regarding a humanistic approach to interaction of facility staff, residents, and family members tend to be corporate-owned (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009). The Eden Alternative is one of the only, but also the most complete resource for changing from the medical model to a
holistic one that approaches care from a multitude of important areas (Hamilton & Tesh, 2002). There is growth in the number of facilities that are implementing systemic change models like The Eden Alternative (Bergman-Evans, 2004) that encourages this type of approach (Thomas & Sterner, 1999; Hamilton & Tesh, 2002). However, the gap of comparison regarding freedom and self-determination associated with community living to that of aging care is widening. Things like guest monitoring, designated meal times, and even medicinal intervention, often used to suppress intimate and sexual expression, occurs in these settings frequently (Bergman-Evans, 2004).

The environments of AL facilities have also been described by some as boring and lonely, and often residents feel helpless to change this environment (Bergman-Evans, 2004). Ice (2002) found that residents in their study spent a majority of their time isolated and alone in their rooms. The lack of companionship experienced in aging care settings is experienced differently among residents with family filling some of the gap, but a lack of other interactions for time and interest may negatively impact residents (Slettebo, 2008). Where there are matches in cultural background, including race, there are more positive interactions, based in trust (Slettebo, 2008; Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009) that can help. Overworked staff, however, may not always have time to interact with residents as much as anyone may like (Slettebo, 2008). Residents also desire to minimize the burden they present and may avoid interaction, especially if it is aimed at improving the level of service they are experiencing (Slettebo, 2008).
Lack of Regulation in AL

The external regulatory oversight provided by Federal or State level policies is limited for AL in general, and is unlikely to provide more oversight in the future, by way of resident protections for issues such as intimacy and sexuality rights. Mollica (2008) points out that most existing policy at the Federal level emphasizes broad consumer protections and protection of facilities from legal claims. The state level, in some states at least, does provide further definitional regulations such that ‘privacy’ is mandated to include things like one resident bed per sleeping room. Again, though the regulation related to specific issues of any kind, much less intimacy and sexuality rights, are almost completely absent (Mollica, 2005). Lack of information available to consumers in a readable and accessible format can lead to significant risks for the resident in terms of their care (Castle & Stadtlander, 2009).

This lack of regulatory oversight into typical daily issues relegates management of them to the facility, and care-provider level resulting in significant variation by state, locality, and facility (Kane, Wilson, & Spector 2007). Following larger societal trends to avoid topics of sexuality, most research suggests that preparatory safety and consent conversations are not being had. Further when intimate and sexual activity is actually present, most staff in facilities that provide AL services have not been trained in ISE in aging populations (Langer, 2009). This leaves staff ill-prepared to handle a complex conversation (Kennedy, Haque, & Zaranow, 1997), in an increasingly competitive
marketplace for consumers of these services (Sampsell, 2003), which increases the chances that the conversation may be avoided altogether.

Castle & Stadtlander (2009) assert that given this lack of regulatory oversight, trusted groups should work to provide important information to consumers so they may make an informed decision about care. North Carolina, in 1996, was the first state to address the issue of environmental change, moving from a medical model to a more humanistic approach, with their North Carolina Eden Coalition (Hamilton & Tesh, 2002). Since that time, a few groups have formed to represent residents and address various issues of importance (e.g., facility amenities, resident feedback utilization) to them, and their families. One such group is the National Center for Assisted Living (NCAL). They describe long-term care as more than a mere setting, but as more of a “philosophy of care” (NCAL, 2008). The NCAL provides guidance into their operational philosophy in a statement of resident rights that includes specific items of importance such as privacy, and being treated with dignity and respect at all times. Further, they recognize the importance of broadly stated freedom to interact with other people not only within the residence, but also the larger community. Missing from their statement is any specific right to intimate or sexual expression, however. This omission, as some have pointed out, contributes further to ageist-fueled myths that older people are asexual (Connolly, Breckman, Callahan, Lachs, Ramsey-Klawans, & Solomon, 2012).

The Internet has emerged as a significant provider of consumer information for people making decisions about long-term care (Castle & Stadtlander, 2009). Though many residents move to AL out of necessity for assistance with activities of daily living, it does come with relief from the anxiety of living alone (Slettebo, 2008; Jungers, 2010).
Consumers need to be proactive in planning for long-term care services (Castle & Stadtlander, 2009) because those residents who engage the most actively in the process of selecting their AL facility experience the most positive transition (Jungers, 2012).

Generally speaking all states provide some level of service provision information online, though it varies greatly by state as the comprehensiveness of this information (Castle & Stadtlander, 2009). Ohio provides overall quality ratings online, which their research seemed to find as one of the more important pieces of information for consumers to make decisions. Only 20 states posted a version of the Resident’s Bill of Rights, a document that all states are thought to have a version of (Castle & Stadtlander, 2009).

None of the information the research team gathered included information about sexuality or intimacy related policies, practices, or other information (Castle & Stadtlander, 2009). The other important consideration is that of the relationship between consumers of AL services and service providers. Service providers and consumers (whether defined as resident themselves, or family members) may often have different priorities (Kane et al., 2007), which complicates issues further when considering how decisions are made. However, the relationship is viewed as important (Gregory, Gesell, & Widmer, 2007).

Paying for AL services can oftentimes require large amounts of cash to be on hand, as well as a reliable source of a sustained income. Medicare does not cover extended care services, and Medicaid only steps in when all other assets a person had are depleted (NCAL). However, there is wide variation in these circumstances based on the state the consumer lives and myriad other variations. This means that someone finding themselves needing AL services must explore options, often in a very short window of
time as services are needed immediately, and no two situations are likely to be identical. Veterans and those with a pension are somewhat better off, as these sources of income are sometimes able to pay for the services. A few states offer Medicaid-waiver programs, and some facilities offer a limited number of beds for such programs. There is also long-term care insurance, but that must be purchased earlier in life by someone planning ahead. Another option is a reverse mortgage that enables someone to use the equity in a home to generate income. Again, many times consumers are forced to make these decisions in a very short period of time after an incident that necessitates AL services for themselves or a loved one.

While the position of this author is that a positive approach be adopted in the training and maintenance of environments of aging care, there are significant challenges in including related to residents being able to actively consent to any intimate and/or sexual behavior. Lichtenberg (2014) provides a succinct explanation as well as tools for facilities to consider using for assessing the ability of residents to consent to ISE. Without exploration of the issue of intimate and sexual expression, it is unclear whether these considerations are a subset of broader contextual areas (i.e., social wellbeing), or are in fact their own area of consideration (Brownie & Horstmanshof, 2012).

**Social Work and The Aging Population**

The field of social work was founded, and is guided by core values of recognizing the dignity and worth of all persons, and the importance of human relationships regardless of functioning level, age, gender, or sexual orientation. Additionally, the social work core values of service and social justice call upon those working in the profession to
identify, create awareness around, and ultimately aim to change the conditions of under-represented and/or oppressed groups (NASW, 2013). Aging individuals in facilities that provide long-term care may be considered one such group of people in the United States in terms of the management of their intimate and sexual lives when they interface with service providers of AL.

Social workers in AL settings are perfectly situated to champion the cause of bringing a voice to an underserved population such as AL residents, particularly in the area of intimacy and sexuality, important parts of residents’ lives. Social workers creating awareness around the issue of intimate and sexual expression in AL facilities would not only be a natural extension of the social work mission, it would also further groups like NCAL’s philosophy of care. Most researchers however have suggested that this is an issue of under-research despite its importance on a number of prevalence and importance on quality of life indicators (Bentrott & Margrett, 2011; Chau, Lee, Low, Lui, & Thompson, 2005; Connolly, Breckman, et al., 2012).

Supporting the Wellness of Residents

Wellness is a term that encompasses a holistic look that goes beyond a person’s physical health to include mental, spiritual, relational, and other domains (Myers, Sweeney, & Witmer, 2000). Wellness has caught on in medical and social service settings in a large part due to a backlash against other paradigms focus on managing the expenses associated with care (Coleman, 2004). There is also an assembling evidence base for wellness’s use in settings like counseling (Myers & Sweeney, 2008), geriatric rehabilitation (Resnick, 1996), and in managing the aging process in retirement.
communities (Myers & Degges-White, 2007).

The Whole Person Wellness Model developed by Montague (1994) includes six dimensions of wellness demonstrated by personal gains in choice, self-directedness, and optimistic outlooks on life and the future. The six domains are:

1. Vocational – recalling past life roles and duties.
2. Social – activities that encourage and support interaction with other people.
3. Spiritual – subscribing and practicing to belief in larger powers.
4. Intellectual – processing information and creatively expressing oneself.
5. Physical – health of body, and activity that encourages immune functioning.

The particular domain of interest to this research is that of emotional wellness, as expressed through intimacy and sexual activities. As explained in Myers, Witmer, & Sweeeny (2000), love is the mutually committed to state of long-term and sustained intimate interaction with another person. Love, through committed relationships, is attributed to protecting people from various diseases, and extends life expectancy. Healthy, loving relationships also provide the basis for social support, which is attributed to many of these same indicators (Sarason, Shearin, Pierce, & Sarason, 1987).

**Older Adult Sexuality and Intimacy Part of Wellness**

The field of gerontology is one that is relatively new (Ranzijn, 2002) and there is debate about the terminology with some considering an approach that emphasizes the person holistically over a medical management of illness emphasis *successful aging*, with others advocating for a *positive aging* term for this approach (Ranzijn, 2002). Whatever
term is adopted, initial efforts at certification and training towards a successful or positive approach to aging care have failed to produce results throughout the organizational structure, with front-line service providing individuals the least likely to be certified by some certification-granting entities (Sampsell, 2003) such as NCAL. Further, coalitions and groups aimed at changing the environments of care, lack the ability to regulate, and are therefore mostly service- referring bodies that provide awards despite being very positively received by people presented with their ideas for change (Hamilton & Tesh, 2002). Some researchers suggest that using a positive approach to the aging process may be able to positively impact psychological and physical health of elders (Ranzijn, 2002).

**Ageism**

The general feelings of AL staff towards family members is often ambiguous with some staff reporting very ageist views, while other staff report very positive views of the aging process and aging people (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009). Dobbs et al. (2008) ethnographically studied stigma and ageism in AL. They found that significant stigma exists, including by nature of the setting itself being stigmatizing. Other themes their work uncovered revealed that larger societal views, often negative, find their way into the setting of AL, that disease or illness stigmatizes, and that social class also informs conceptions of care provided.

Relationships in facilities described as interactional and caring are instrumental in improving psychological health are important in nursing home residents (Guse &Masesar, 1999). In order to foster these types of relationships workers in settings of aging care need to first assess their views of aging people (Jungers, 2012). A focus on the
abilities and opportunities for growth should be adopted (Meddaugh & Peterson, 1997). Starting in the transitional period at in-take researchers feel that a strength-based approach is needed (Koenig, Lee, Fields, & Macmillan, 2011).

**Current Long Term Care Research Paradigm**

Overwhelmingly, the emphasis in research into long-term care settings focuses on a few key considerations. One is an overemphasis of research into the setting of nursing homes with a void where AL research remains unstudied (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009). This setting is the most expensive of services that an aging person, or their family access. It is also the time where residents report the most feelings of powerlessness over their situation, often leading to apathy and ultimately depression and chronic illness (Meddaugh, & Peterson, 1997). This displays the importance of focusing on the setting of AL, which is a less expensive option, and one where residents typically retain more autonomy.

There is a debate into the competing interests of whether to improve quality (Beerens, Zwalhaalen, Verbeek, & Ruuward, 2013; de Rooij, et al., 2012; Guse, & Masesar, 1999), or extend quantity of life (Luo, Hawkley, Waite, & Cacioppo, 2012; Cacioppo et al., 2002; Holt-Lunstad, Smith, & Layton, 2010). However there does seem to be a general agreement that the true definition of a life well lived balances quality and quantity (Brownie & Horstmannhof, 2012) and that more mixed-methods research is needed across the various relationships and settings to gather valuable perspectives (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009). The resultant body of literature is therefore robust into a specific service setting (see Kane, Wilson, & Spector, 2007), but
fails to address adequately many issues that have been altogether avoided, such as other settings, or intimate and sexual expression behaviors.

Given the rapidly and dramatically increasing average lifespan, viewing the last half of one’s life, during the post-work/retirement period of life as one solely marked by the decay in quality of life does not make much sense (Ranzijn, 2002). The process where a person’s ability to manage activities of daily living decreases to the point of needing AL services is usually gradual, with an event occurring that necessitates movement into an AL facility. Once they enter the AL facility, the period of time spent in this setting is one of the more affordable options for aging people (Ball, Perkins, Hollingsworth, Whittington, & King, 2009). In Ohio, for instance, the cost of AL services on average is about half the cost of nursing home services (Craft, 2015). The complex web of interactions, both positive and negative, in cognition and sociability domains on physical and mental health are emerging in research as important to study (Ranzijn, 2002). The link of these domains to physical health and recovery are also thought to be significant (See Ranzijn, 2002).

Lastly, the overall tone of aging research is at best maintaining the status quo, rarely emphasizing gains or growth (Belsky, 1999), and usually on the aging process as one of only loss (Ranzijn, 2002; Luo, Hawkley, Waite, & Cacioppo, 2012). The pathologizing of the aging process makes the emphasis on negative aspects reasonable to predict. It also leaves no space to respect the interactional nature of different aspects of aging, some of which may produce positive gains, (Meddaugh & Petereson, 1997). Even instruments developed for physicians that address intimacy and sexuality in aging people are biased towards a decline in ability with questions like “what health problems have
affected your ability to be physically intimate?” (p.44, Lichtenberg, 2014). As this illustrates the assumption is that there has been a decline that must be explained. What if the resident has not experienced a decline? The process of aging, though dynamic, can be viewed as a positive process (Meddaugh, & Peterson, 1997).

Much has been written about the experience of nursing home residents, and resident issues of loneliness and isolation (Cacioppo et al., 2002; Luo et al., 2012; Slettebo, 2008; and Cacioppo & Hawkley, 2003). However, little is known about the life of AL residents, climates, and policies that encourage intimate and sexual interaction while protecting the interests of residents, families, and facilities. This research had two main aims to explore these critically understudied areas of research.

Aim 1: Explore the staff member perceptions of policy and practice regarding intimate and sexual expression of residents in settings of AL.

Aim 2: Explore staff member understandings of the contribution of various stakeholders (i.e., resident, family members, facility/staff) into policy regarding intimate and sexual expression of residents in AL settings.
Chapter 3: Method

This exploratory and descriptive study with employees of assisted living (AL) facilities employed qualitative methods informed by Lincoln and Guba’s Naturalistic Inquiry. The primary aim of this work was to describe the issue of resident intimacy and sexuality, the response to it by staff, and the method of policy creation addressing it in settings of AL. The Institutional Review Board at the Ohio State University approved the methods, procedures, and interview guides used in this research in December 2014.

Naturalistic methodology informed the data collection process. This application of grounded theory considers inseparable the relationship between data collection and data analysis. This study aimed to begin to explore and to describe the meaning made of expressions of intimacy and sexuality among residents from the perspectives of staff working in AL Facilities in Franklin County, Columbus, Ohio. This interactive and dynamic approach to data collection responded to early observations that informed refinements in later data collection methods.

Chapter Overview

This chapter begins with an explanation of the data sources I used to explore the issue of resident intimacy and sexuality in AL, including the sample strategy I employed, and the ethical considerations in exploring such a topic. There is then an explanation of
my data collection plan and a brief explanation of the sample characteristics. The analytic plan that I followed is discussed. Lastly, the limitations of my methodology are discussed.

Data Sources

Sampling Strategy

This study utilized a cross-sectional design with a convenience, purposive sample of employees in AL facilities in Franklin County, Columbus, Ohio. The website ltcohio.org compiles information for consumers interested in care for aging persons. In the Franklin County area, fifty (n = 50) facilities were listed as providers of AL services for aging persons. Approximately 14 of the facilities included on this website did not have contact information listed, or the contact information was not current resulting in returned emails. These facilities were then contacted using information found on their respective facility webpages. For approximately nine facilities no successful email address was found. As a result, they were in turn contacted using a webpage contact form. Alternate contact methods outlined previously did not result in any facilities participating in this research. All facilities that participated did so through an email sent in reply to direct email recruitment. The Executive Director was contacted via email with an explanation of the research and a short survey that gathered contact information for employees they identified as ‘able to speak to the policy and practice pertaining to resident interpersonal relationships in [their] facility best’. Employees selected by the Executive Director of their facility (n=10) were then recruited using email contact information provided by the Executive Director of the facility. An initial recruitment
email was sent describing the research, providing informed consent documentation, and asking to provide possible meeting times. A similar follow-up was sent after 5 business days elapsed in the case of non-reply to first message. Finally, phone calls were utilized after another 5 business days elapsed to meet recruitment goals. Employees who agreed to participate were interviewed at a time identified by them, at their facility in areas that met the privacy requirements of the participant. Participants who were non-English speaking people were not eligible to participate. There was no compensation provided for participation. The consent form for this research reiterated that study participation was voluntary, and that identification by the participant’s Executive Director in no way obligated the participant to provide the interview. Respondents were also advised that they could stop participation at any time, and data collected would be kept confidential and no identifying information about them would be used in the manuscripts and documents that emerged from the research.

All participants of this research study were over 18 years of age and study involvement reflected minimum risk to participants. The date, time, and location for conducting the interviews were selected by the respondents. All interviews were conducted by me, with data accessible to Dr. Holly Dabelko-Schoeny and Dr. Sharvari Karandikar-Chheda who both provided expert opinion and data interpretation assistance. The respondents are not identified in any way that may identify them. Only aggregate results of the study are shared and discussed.
Ethical Considerations

This study was reviewed and approved by the Institutional Review Board at The Ohio State University under an expedited review by the behavioral and social sciences section. The participants were guaranteed anonymity and confidentiality. The Executive Director selected staff participants eligible for participation. The staff members were then contacted for participation in the research and provided signed consent prior to commencement of the interview. The participants could decline participation entirely, or cease participation at any point during the recruitment, consent, or interview. It was important to stress that selection by the Executive Director of their facility in no way obligated participation by the staff member.

Data Collection

Instruments

A semi-structured interview was conducted using an interview guide that included possible probes to each question. Questions and probes were developed in consultation with the dissertation chair, an expert on the setting of AL, and a committee member whose expertise is in qualitative study design. Of central concern is the resident experience and staff member responses to ISE. Therefore the interview began with resident concerns, and continued on through various levels of the setting of AL. No individual facility was analyzed; instead the setting of AL broadly was the focus. Therefore, questions remained at the level of climate, existing policy, and typical behaviors by residents/responses by staff. Probes aimed to gather further information at
the level of ‘the typical staff member’, without being so specific as to identify the particular role of the interview participant. This was done to maintain the privacy and confidentiality of participant data as many AL facilities employ a single person in any particular role (i.e., Director of Nursing, Activities Director).

Interviews began with participants being asked two grand-tour questions. These questions were aimed at collecting information about the overall climate related to interpersonal relationships, and the awareness of any policy concerning the same. The first question asked the respondent to describe the climate in their facility concerning intimate and sexual expression among residents. The next question was about the respondent’s awareness of the policy addressing the management of such behavioral expressions by residents in their facility. I began with these questions to gather overarching climate and awareness contexts. Both of these contextual backgrounds are important to begin with because it establishes the settings establishment of culture through policy and then adherence to policy among staff. Through the process of defining the study with my dissertation chair it became apparent that these two things may be operating in differential ways, so these questions explored whether this was the case in the facilities that I visited. In all cases, probes were used to explore the participant’s meaning made of particular statements. For instance, if the participant said there was value in some interaction among residents, a standard probe would then be “how would you describe what value it had?” this would allow the participant to construct the meaning and provided important contextual information for thematic analysis.

Participants were then asked a series of questions related to the resident, family-member/care-partner, and facility/staff concerns regarding intimate and sexual expression
in their assisted facility. In terms of resident experiences and concerns, participants were asked to explain the methods of input into policy that residents have, and the typical displays in the facility by residents of an intimate or sexual nature.

Family-member/care-partner concern questions were similar. First, the participant was asked about the method of input the family-member or care-partner had into policy regarding intimate or sexual expression by their resident family-member. The participant was then asked who the typical family-member/care-partner was to the resident (i.e., daughter, son). Lastly, participants were asked about the intake process for new residents and any expressions of concern that these care partners may express about their resident.

The participant was then asked about the concerns of facility/staff members. Beginning with a similar policy questions regarding facility and staff member methods of input into policy regarding intimate or sexual expression in residents. Typical probes included how someone might voice a concern anonymously, and how often intimate or sexual expression issues arise in the facility. Then the participants were asked to describe the typical response by the facility or individual staff members regarding observation of resident expressions of ISE behaviors. Typical probes included whether the participant felt these responses were positive or negative for the resident, and the appropriateness of the response. They were then asked a pair of questions to gather information about the various levels of administration in the facility. The first asked the participant about their perception of concerns that administrators have in expressions of intimate or sexual expression; the latter was about the bedside care providers concerns about such expressions. Typically, probes in this part of the interview included clarifying whether staff member’s personal relationships with residents impacted these concerns, and the
degree to which liability concerns influenced these concerns. Lastly, the participant was
asked about training in the facility regarding intimate and sexual expression among
residents. Typically participants were also asked if they felt training would be a good
thing, and to expand on a suggested implementation plan for such training in their
facility.

Sample Characteristics

The majority of the sample was female. Nine interviews were conducted with
females, and one with a male. A total of 10 individuals participated in 9 interviews. Two
participants elected to be interviewed together in one interview. There were two
established criteria for participation: identification by the Executive Director of the
agreeing facility; voluntarily agreed to participate in the research.

Executive Directors were used as the gatekeepers for facilities per the
recommendation of the dissertation committee members. Specific employee groups were
not targeted because most assisted-living agencies employ one person in each specific
role, and therefore the confidentiality of participants would have been compromised. No
identifying information about the participant was gathered to further protect the
anonymity of the participants. This was particularly important given the sensitivity of the
information collected. To further limit identification the large geographical area of
Franklin County was selected to recruit from because of its large number of AL facilities.

Consent and Data Collection

Staff members were asked to provide signed consent prior to the interview
commencing. After the consent form was read to the participant, a sufficient amount of
time was allowed to answer any questions about the research. No participants had any questions during this allowed time period. It was emphasized that identification by the Executive Director was in no way an obligation for the staff member to participate, and that they could decline to answer any question, and discontinue participation at any time. No staff members expressed feeling undue pressure to participate, nor did any elect to not answer, and/or discontinue their interview.

Institutional Review Board approval was obtained for the semi-structured interview protocol that explored the issue of interpersonal relations in AL facilities. All interviews were audio taped, and transcribed by a professional transcription service. A second researcher reviewed the transcriptions for accuracy. In approximately two cases the interview recordings were referred to in order to further clarify word, phrasing, and other unclear areas of transcriptions. There was a high level of agreement in the original transcriptions with all minor issues clarified through consensus. Probing questions such as “what is the value of this behavior” were used to provide clarity of meaning in initial answers. As part of the audit trail for the research general demeanor information was also recorded for each participant. Notes were also used on these documents to remind the interviewer to probe further, or simply as a checklist to ensure I included all questions.

**Researcher Assumptions and Biases**

As a researcher I did have assumptions and biases as I engaged in this study. Particularly being a member of a sexual minority and having experienced discriminatory responses to public displays of affection. A primary assumption of mine was that those residents who engaged in ISE in AL settings were experiencing discriminatory responses.
This certainly informed the processing of experiences as I interviewed staff members. This assumption necessitated my selection of NI to guide much of my data collection. Additionally I believe ISE should be supported in such a way that is safe and respects individual autonomy and choice. This bias is important to consider when viewing the implications that I offer from my research results.

**Analytic Plan**

Each audio-taped interview was transcribed into a Microsoft Word document. Each interview was written in the form of a narrative and each narrative was analyzed using the grounded theory approach. The analysis consisted of reading the qualitative data line-by-line, identifying themes, coding categories, developing matrices and drawing cluster diagrams to uncover relationships between themes and categories (Straus & Corbin, 1990, 1997).

Multiple layers of data analysis occurred in this endeavor. Naturalistic Inquiry significantly informed the conduction of this study. As such my experience as the observer data-collector who collaborated with the participants on the meaning created with each interview was explored at the same time as the phenomenon was explored. Through the use of member checking at the end of each interview, the meaning intended by the participant was confirmed with me. After the completing each interview, I used a reflective journal that included questions about parts of the experience that stood out for me, how the experience affected my views on the issue of resident intimacy and sexuality, and how these reflections would change future interviews with participants. Early themes were identified and probed for confirmation with later participants. This
constant, iterative processing of analysis allowed the unit of analysis to remain at the setting level, while exploring the meaning created by the individual actors, including the researcher.

I maintained a notebook where I recorded notes at each of the facilities I visited while I waited for staff to sit down for the interview. Things that I wrote down included general impressions of the facility cleanliness and location. I also noted any interactions I observed involving residents. For instance, on one visit I observed an adult child joining a resident to a medical appointment and I noted the interaction and the actors involved. I would also take notes about the general demeanor of the person I was interviewing. In one case, a staff member was very fidgety and nervous appearing throughout our interview. These notes were then combined with a thorough review of the transcripts. Using transcripts of the interview, I went through each line of the interview to confirm the transcription accuracy. In three cases I went back to tapes and confirmed words that were unclear. I would also make notes on the side of the transcript as to things I remembered about the interaction. For example, if someone was emphatic about what they were saying I would record this in the margin of the transcript. Using the transcripts I then identified key words and concepts. Most interviews were conducted with two staff members (individually) during one visit to the facility. As NI informed the data collection significantly, this meant that my notes were important as I needed to check with the second interview any reflections that were unclear, or potentially an emergent theme. Between facility visits I conducted a thorough review of the transcripts, my notes, and refined my probes for the next facility visit. NI allowed my role as a researcher to interact
with the interview participants to understand the meaning made in the context of the concepts I was interested in on this research.

Because this was a modest project, with specific aims, and in a narrow setting, Chamraz (2006) states that saturation may be reached quickly. This was true in this research as clear patterns emerged relating to both of the two aims of the research. It is important to note that saturation was not achieved on the entire topic of intimacy and sexuality in aging people, but specifically on the aims of the research and the specific experiences of those I interviewed.

After I read each transcript twice for accuracy, I then began to code my data. Coding is the identification of segments of the data that “simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz, 2006, p.43). I began this process with small segments (i.e., phrases, keywords, lines of data) that then were assembled into larger data pieces. Cluster diagrams were used to develop themes. This iterative and intensive process working with my data allowed me to begin to apply analytic interpretation of the phenomena my research explored. The entire data collection process, and note taking was done on printed Microsoft Word printouts of transcripts, supplemented by notepads with memos and researcher notes that included my reflections of emergent meanings and modifications to the data collection process in keeping with a NI approach. No qualitative software (i.e., ATLAS.ti) was used for coding. I would instead extract the small passages of data from transcripts and place them into a Microsoft Word document that evolved into themes presented in this dissertation with supporting quotes from the staff members I interviewed.
The themes that emerged from the interviews with the staff of AL facilities formed the main body of this research. Staff experiences with intimate and sexual expression among residents were detailed. These experiences were also analyzed by examining the contribution of these experiences to the policy-making process in these facilities.

The study fills a gap in the literature on the experience of AL facilities in terms of resident intimate and sexual expression and the policy-making process in these facilities. The study results inform recommendations for changing the climate of AL facilities in terms of management of intimate and sexual expression among residents. The study also captures and narrates the voices of staff workers in defining and explaining intimate and sexual expression in AL facilities. As participants in the interpretation and policy-making concerning intimate and sexual expression of aging persons in AL, voices from the field, presented in this research, produce empirical evidence to inform policy, practice, and research decisions regarding this phenomenon.

**Limitations of the Study**

While the study achieved admirable diversity in terms staff employed by various setting type, size, and range of services offered in the facility, the majority of those interviewed were also presumed to be management-level staff. A more diverse population of workers, in a wider variety of facilities would increase the variation in the data. Additionally, the participants were all from facilities that operate in the Franklin County area of Ohio. While this is a large, diverse county in this Mid-western state, and the
facilities were from four distinct areas of the county, interviewing facility staff in other county, state, or other areas could produce increased variation.

The majority of the study participants were female. While this is actually representative of staff in this setting, who are often female, this does mean that the results are not able to inform the meaning made by males in this setting. It may be that males in this setting make entirely different observations into ISE expression and policy. This work reached saturation on the salient aims of this research, however, future research should endeavor to explore the male perspective on this issue.

When I visited one facility there was some sort of event that was causing disruptions in staffing coverage and one of my participants was leaving later that day for an indeterminate amount of time. In this case, the option was offered by the participants to conduct their interviews together in one session immediately, or the facility would not be able to participate. I elected to conduct the two-person interview, however it is not known if the answers of one or both of the participants were influenced by the presence of the other person during our interview. There may have also been other events recalled providing more breadth of experiences. However, the two-person interview did result in good depth of discussion.

This study recruited from 50 facilities in the geographical area selected, and received four agreements to conduct research at their respective facility. The sample was a self-select group of Executive Directors who may have had more accepting views of ISE among their residents. Given the low response rate, a few observations should be considered. One, the recruitment strategy relied on a publicly available listing of AL services. This information may not have been accurate. To account for this limitation,
facility websites, and other publicly available contact information was gathered, which yielded no additional facilities. Secondly, there may have been hesitation by the Executive Directors to discuss this issue with their staff in these facilities. Many of the interview participants expressed that there was no formal policy, and that prior to our interview the issue had not been a prevalent conversation in the facility. Lastly, the review by Ohio State’s Institutional Review Board was delayed so that initial participation emails were sent during the month of December. In fact most of the major recruitment for this research had to occur during the Christmas/ New Year time period, so the participation level may have been reflective of inability to respond to my request because of factors not related to the research, or its aims.
Chapter 4: Results

Introduction

Chapter 4 presents the findings of the face-to-face interviews conducted with staff identified by the Executive Director of facilities that agreed to participate in this naturalistic, grounded-theory, qualitative study. The participants were all volunteers identified by their facility Executive Director/General Manager in a purposive sample of assisted living (AL) facilities in Franklin County, Ohio. The researcher established contact with Executive Director/General Managers through email using publicly available contact information via the Internet. Follow-up emails were sent in the cases of non-response to the first message. Non-response to either of these messages was considered to be declining to participate in the research. Ten staff members in four AL facilities in Franklin County were interviewed. Participants were identified from 51 AL facilities in Franklin County who were invited to participate in the study. Four facilities provided letters of support to conduct research interviews in their facility. Interview participants provided signed consent after assurances that the information they provide will be held in confidence, and that there is non-obligation to participate. The interviews were conducted at times and in spaces of the interview participants’ choice.
Initially, the recruitment strategy was to interview two participants at each agreeing facility. However, despite following the recruitment protocol, few facilities agreed to participate. In addition, those Executive Directors who did agree to support the study, suggested participation by more than two staff members. This lack of response by many facilities and enthusiasm by a small number may be the result of the topic of the study. Implications of the challenges of recruiting facilities to participate will be discussed in Chapter 5. Initial data collection revealed utilizing three interviews in each setting would be feasible. This enabled the researcher to use triangulation in each facility (Padgett, 2008) enhancing the rigor of the study from not only each facility, but also across the setting of AL, which is the setting of interest for this research.

Institutional Review Board approval was sought for this change, and Executive Directors were asked to provide email acknowledgement that conducting a third interview was agreeable. Three of the four facilities initially agreed to provide a third interview for the research. Subsequently one facility had to decline to provide a third because of concerns regarding staff coverage. The Executive Director canceled via email, expressing the burden that the third interview would place on the staff of the facility. In my follow-up email regarding the cancellation, an offer was made by me to visit at any time that was conducive, and no reply was received to this request. Another facility I visited elected to conduct one interview with the two participating individuals from the facility at the same time. This facility expressed concern that a staffing shortage would result from the interviews being conducted individually. This same facility also declined to provide access to a third interview when asked. This modified recruitment yielded two additional interviews from two facilities.
The following table outlines the facility type, size, interviews conducted, and number of participants at each facility. The diversity of the sample in terms of setting size and type is illustrated. It should be noted that many facilities that provide aging care do so in a range of service types. I conducted interviews with staff at two facilities that provided such a range of service types. For our interviews, I emphasized to participants that I was interested in the AL setting among residents who retained decision-making capacity.

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<tr>
<th>Facility</th>
<th>Facility Type</th>
<th>Size</th>
<th>Interviews</th>
<th>Participants</th>
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<td>B</td>
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Table 1: Facility/ Facility Type / Size / Interviews / Participants

My researcher notes were reviewed to provide general context information. All of the facilities that I visited were very pleasant and had residents, staff, and other people interacting in common spaces that I visited. I observed many loving, caring interactions involving residents in all the facilities that I visited. The chart above intends to provide some context, while not identifying the facilities that I visited. Small size facilities were one to two floor facilities with a single wing. Medium provided additional wings in the complex and was three stories tall. The large facility was a campus type physical setting.
Every participant acknowledged that there was no written policy in their facility related to intimate and/or sexual expression (ISE) by their AL (AL) residents. Many replied that there was, however, an informal policy regarding intimate and/or sexual expression by residents. Most participants replied that this informal policy began with assessing that both residents were able to actively consent to such interaction with one another. For individuals able to actively consent, there was little intervention on the part of most of those interviewed. However, if either resident was unable to actively consent, then an intervention was often necessitated. This often involved care-planning meetings conducted by staff with the family to determine the best course of action for the resident.

**Semi-Structured Interview Schedule**

There were three overarching research questions posed to staff members in this study:

1. What is the organizational culture around ISE in your AL facility?
2. What policy exists concerning ISE in AL facilities?
3. What are the patterns of behavior in various stakeholders (resident, family, staff) in response to ISE in your facility?

In order to explore the staff members’ perceptions and experiences of ISE among residents, a list of questions were developed for semi-structured interviews. The questions began with two grand tour questions about the climate in the facility related to ISE, and about the policy that exists in the facility related to intimacy and sexuality among residents. Staff member participants were then asked to define the words “intimacy” and “sexuality”. The remaining questions for staff members involved the experiences and concerns of the residents, families, and staff related to the ISE of their...
related residents. Wrap-up questions gauged the respondent’s perceptions of the overall concerns of administrators and direct care providers related to ISE among residents, and any training the participant is aware of related to such behaviors.

Naturalistic inquiry informed the entire process of data collection and analysis, particularly the interview process. Adjustments were made to the interview protocol, according to NI processes to triangulate early findings and where appropriate move triangulated phenomena to categorical themes. One such example was the issue of informal care taking that occurred among residents. An early participant portrayed a story of two same-sex residents taking care of each others’ physical needs in their facility. The intent of this activity was not to escalate to sexual involvement, but was intimate in nature. Later participants confirmed that this was a very common behavior in the setting of AL. This same-sex informal care-taking became a theme of inquiry in later interviews.

Questions were also added to clarify important contextual understandings of concepts of interest to the research. For example, a question was added at the end of the grand-tour questions to explore how staff member participants defined the terms intimate and sexual. Early in the data collection process it became clear that underlying working definitions of these terms were shaping responses to questions throughout the interview protocol.

The specific open-ended, main questions are below:

- Overall how would you describe the climate in your facility related to interpersonal relationships among residents in your facility?
  - Probes: do you have “town hall” meetings in the facility? Who attends these meetings from the administrative staff? Who attends from the residents? Is there a ‘feedback box’?
• Tell me about the policy in your facility regarding the management of intimate and sexual expression by residents.
  
  o Probes: Do residents “snuggle” in common spaces? Do you hear of residents who are in couples? Are there dances or socials aimed at relational experiences?

• In 1-2 sentences define: Intimate & Sexual
  
  o Probes: Is touching of any kind sexual? Is kissing more intimate than sexual? Is only the act of intercourse sexual?

• Resident Experiences and Concerns
  
  • Explain the methods of input that residents have into policy in the facility around intimate and sexual expression.
    
    o Probes: do you have “town hall” meetings in the facility? Who attends these meetings from the administrative staff? Who attends from the residents? Is there a ‘feedback box’?

• Describe typical resident expressions of intimacy and sexuality
  
  o Probes: Do residents “snuggle” in common spaces? Do you hear of residents who are in couples? Are there dances or socials aimed at relational experiences?

• Describe any care taking you have observed between residents of the facility.
  
  o Probes: Is this caretaking more same-sex, or opposite sex oriented? Is their value to this behavior? Explain the value of the behavior.

• How do care issues that are behaviors by residents get care planned.
  
  o Probes: What is the flow of information regarding events? Why do things get escalated? Where is this information stored? How is it referenced?

• Family Experiences and Concerns
• Explain the methods of input that families of the residents have into policy in the facility around intimate and sexual expression.
  
  o Probes: if they exist, do town hall meetings include family members? Is there a feedback box for families? Do admin/other staff meet with family members?

• Of those family members who advocate on behalf of their related resident, who are they in the family (daughter, DIL, granddaughter, physically close relatives, financial/pay decision makers, etc)
  
  o Probes: are they mostly any of the demographics above? Is there a gendered effect to who in a family talks about this topic?

• Describe any concerns that are expressed at intake/maintenance by families about their family member resident and their intimate and/or sexual expression.
  
  o Probes: is the topic avoided? Who brings it up? Is it part of care planning?

• **Facility/Staff Experiences and Concerns**

• Explain the policy input level that staff and/or management have into policy in the facility around intimate and sexual expression.
  
  o Probes: how are staff concerns voiced? Is there confidentiality?

• Describe the typical response by staff to expressions in the facility of intimacy or sexuality.
  
  o Probes: are there escalation procedures? Do certain staff avoid this issue? Do certain staff handle all the issues?

• Describe how issues identified by this staff rise to administration concern as
opposed to a 'this is our job, do it' type response at gate keepers

- Probes: Do you think there is a different level of "acceptable" physical contact in this setting? Why do staff work in this setting?

- Describe administrators’ concerns about intimacy and sexuality of residents.

  - Probes: Are they primarily related to any people we have discussed? Are they primarily legal concerns? Are they informed by any other affiliations your facility has?

- Describe bedside care providers’ concerns about intimacy and sexuality of residents.


- Describe the training in your facility related to intimacy and sexuality among residents.

  - Probes: is the training extensive/brief? Stand-alone/part of new employee, recurrent, etc?

The length to complete each interview ranged from 30-60 minutes. All interviews were conducted in a private setting of the participant’s choice in the facility. Each interview was recorded, and then transcribed. Prior to any coding of the transcripts, I reviewed each transcription for accuracy two times prior to reading for overall impressions and to familiarize myself with the interview. In two of the three interviews, the recordings were referred to in order to further clarify word, phrasing, and other unclear areas of transcriptions. Two participants interviewed were native speakers of
languages other than English, so there were issues with accents that made things less than clear. A third participant spoke frequently during my prompts so there was confusing overlap that made it necessary to listen to the recordings during certain sequences. There was a high level of agreement in the original transcriptions with all minor issues clarified through consensus. I took brief notes prior to the interview as to observations I saw in the waiting room, during the interview to assist with estimating demographics of the participant, intended clarifying probes that I would use, and also for general impressions of facility, interviewee, or interaction during the interview session.

The facilities that I visited varied in size and services offered in the setting and in my notes I recorded that each facility waiting area was very clean and orderly. In all the facilities there were staff, residents, and visitors present in the waiting area. Many times the interactions I observed were very caring and physical. Staff often caressed the residents as they spoke to them and the speech was often very cheerful and upbeat. The staff I met with were all very welcoming and often offered me tours of the facility.

**Thematic Results**

The respondents recognized that ISE behavior occurred in their respective facilities. Managed informally, and differentially based on a number of factors, the thematic understandings of the experiences and contributions of residents, family members, and staff into policy are reported in the discussions outlined below.

Thematic results are presented in the order of the semi-structured interview, beginning with participant’s reports of the general inter-personal climate of the facility, explanations of ISE policy in their facility, and the participants’ definitional...
understandings of the terms intimate and sexual. Next, participants were asked about the respective experiences of residents, family, and staff into ISE policy development. Then participants were asked what they perceived that administrators and fellow staff members’ overall primary concerns were in relation to ISE among residents. The interview concluded with the participant explaining any training they received in regards to resident ISE, and providing any other final reflections they had before they were thanked for their time and the interview concluded.

Climate

Casual

Participants described the inter-personal climate of most facilities in terms of casual relationships among the residents. Residents were described as “willing to exchange pleasantries”, and “look out for one another” in “very friendly” and “homely” environments in the facilities. The residents themselves were described as “happy”, “pleasant”, and “warm” by the participants. Participants attributed this general description to an attention to resident rights, referring to state-level statute into the bill of rights that residents may legally enjoy when they choose to reside in AL facilities.

Resident’s rights in Ohio (see http://codes.ohio.gov/orc/3721.13) are included in an easy-to-read guide for consumers by the Health Care Management Group (HCMG). The document covering resident rights is approximately 18 pages of definitional, and procedural guidance concerning the administration of facilities that provide AL services. Included in this section of the document are the responsibilities of the various parties (i.e., facility director, resident proxy where applicable) and grievance procedures in the
course of transfer or involuntary relocation of the resident. Also enumerated are over 30 rights specific to the daily life of the resident. Included in this list are rights to unopened correspondence, to rise and rest on their own schedule. More broadly covered rights are things like safe, and clean environments, and appropriate medical care. More specific items outlined are rights to consume alcohol and tobacco in “reasonable amount[s]”. However, ISE is not specifically addressed. The only specifically outlined right that may apply to ISE is provided below.

(22) The right to assured privacy for visits by the spouse, or if both are residents of the same home, the right to share a room within the capacity of the home, unless not medically advisable as documented in the resident’s medical record by the attending physician;

In this case, the resident right applies to a recognized spouse, most likely through marriage. There are no other rights that apply to relational, or ISE for AL residents in the full bill of resident rights.

One participant went further to explain that their particular facility subscribed to a specific philosophy in their facility that emphasizes a person-centered approach to aging care. In that particular facility, the initial training, and ongoing “in-service” training emphasizes this level of “strong interpersonal relationships” that inform the service to residents that the staff provides. This participant therefore described their facility climate as “superb” and fabulous.

A number of the participants used terms that suggested a predominance of casual type relationships among the residents in their facilities. One participant explained that residents “got along very well together”. However, another participant said that frequently “fights and rifts” would break out among the (mostly female) residents. When
further asked about the reason for the fights, the same participant stated that “strong personalities” often were the cause of such disagreements.

Care-Taking

Two participants discussed the climate in terms of the residents providing care for one another. In the one participant’s case, the behavior was explained as “they look out for one another” while another participant used the term “mothering” to refer to the level of interaction that surpassed “pleasantries” that another participant described. This “mothering” type activity caused further exploration of the term “intimate”. Upon further reflection, intimate was expanded to include activities that were separately termed ‘informal care taking’ in future interviews to make inquiry into this level of relationship, thought to be deeper than mere friendship.

One participant offered a description of a relationship that was possibly an intimate relationship when the questions about climate were being asked. This participant said “we’ve had some [residents] that have been considered…you would think are best friends so to speak almost to the point of sisters uhm but beyond that no. No.”. This particular participant was very uncomfortable during most of their interview, including uncomfortable laughter and the participant also played with a name-badge holding lanyard during the entire interview. Additionally this participant used the term ‘married couple’ extremely frequently to describe any relationships that surpassed the friendship level.
Informal Policy

The policy regarding intimate and sexual expression among residents in all the facilities that participated was informal in nature. None of the facilities where interviews were conducted had any written policy regarding relationships among residents at all. One participant, prior to concluding the interview, asserted that our research would not find any facility that had written policy regarding relationships among residents stating “I’d be hard-pressed to hear that you go to these places and they have policies. That will surprise me. I’ve never, in any [emphasis added] building had a policy on sexual health. Never. And I been doing this 20 years.” This was despite that same participant stating that policy would probably “be a good idea” because the primary concern of administrators, in this staff member’s perception, was “liability” related concerns. Another participant stated that they “could not really think of any [policy] off the top of their head” in their facility.

When participants referred to a policy related to intimate or sexual expression among residents, they often cited the resident bill of rights. One participant used terms that vaguely referred to this document at first, before remembering its formal name. A number of the participants spoke immediately, and specifically, about the bill of rights in terms of resident rights to “privacy” and “dignity”. While these may be related to one resident engaging in a relationship with another resident, they are not specifically addressing the intimate or sexual relationships. The resident rights document includes privacy rights examples that are aimed at the requirement for announced entry, and allowance for residents to maintain closed doors to their residence. It also covers that medical interactions and conditions be kept confidential. Dignity rights are specifically
covered in the resident rights documents in terms of the decision-making capacity of residents being retained, unless there is a medical determination that this is not safe for the resident. It also includes protections of conducting religious practices, and rising and resting on their own preferred schedule. Both sets of resident rights are specific and directive, however there exists no specific rights to the conduction of ISE behavior.

Since there was no instance of a written policy in any facility explicitly about ISE among residents, I also asked each participant if there was an informal policy regarding ISE among residents in their facility. While one participant emphasized there was ‘no written, no unwritten’ policy in their facility, there did emerge a pattern of response by the facility when two residents appeared to be engaging in courtship-type behaviors (i.e., holding hands, sitting close to one another). Overall, everything is based on events in this setting, and events are dealt with on a “case-by-case” basis, beginning with some assessment of decision-making ability.

Yes, definitely and it has to be a case by case in my opinion just because there are so many other factors that contribute. Somebody can have mild dementia and still be able to make their own decisions for themselves versus somebody that has moderate to severe dementia or cognitive deficits.

In this same facility the staff member portrayed this assessment process as using standardized instruments as part of determining whether both residents are able to consent to intimate or sexual activity. If family, or persons acting as power of attorneys due to limited decision-making capacity, are not involved and both residents are able to choose then one participant put it this way about two residents establishing a relationship “and they wanted to engage in some sort of sexual behavior. That would be completely fine. They would set up their own schedule, [and do] whatever they wanted to do.”
Structured Response

Somewhere between explicit, written policy being non-existent, and intimate and sexual expression being managed albeit informally but in a structured way, were responses that the policy in the facility was similar to that in the broader community. One participant stated:

I would say it would be the same out in the community as far as what people are socially allowed to do without making other people uncomfortable. If somebody gives a hug or kiss, of course that’s fine, but if it’s to a point where they’re really kissing, then we would have to step in. If it’s making other people feel uncomfortable.

In many cases participants were somewhat confused recalling any written or unwritten policy regarding intimate and sexual expression. This confusion appeared to confirm that ISE is handled on a case-by-case issue by the staff in the facilities represented by the interview participants. Comments were typically reconciled with statements about the resident rights document. However, one participant remained confused and then began recounting policy in the facility regarding staff interaction with residents. In this particular facility, there was a policy regarding that type of interaction, but not a policy addressing the interactions entirely among and between residents. In this case, the participant also emphasized “that one is mostly between two families. The facility might say no, but if the families approve and they are mentally okay – nothing is wrong with them – you allow them”. In this case, the suggestion is made that the facility makes a determination about the situation but that the family is the one that ultimately decides. The resident does not seem to have any input, at least in some cases per this respondent. While this interview participant was emphatic throughout the conversation that intimate
and sexual expression was something she “[doesn’t] care about, that’s not my concern”, there were examples throughout her interview that other staff did carry feelings about this type of resident interaction, and they were often negative. This participant seemed to be very supportive of the interaction however, in one place recounting a story of how the participant assisted a resident to wrap a gift (in toilet paper) for another resident. The difference for this participant was any staff member’s motivation being “from the heart” as opposed to being in the work “for the paycheck”.

**Resident Experiences of Facility Climate & Policy**

During the interview with staff-member participants explaining the climate and policy in the facility regarding interpersonal relationships and intimate and sexual expression, respectively, a number of important resident experiences were conveyed. Overall, one participant summed up the experience of a resident in their facility as “some people do, if they don’t see anybody, hold hands. If they notice people are watching, then they stop”. So there is awareness among residents that staff members are watching them, and the resident’s reaction is to this is to stop the behavior. This participant also shared that motivation to work in the setting was important, and talked about why the residents’ reactions may be to stop their behavior. In this participant’s case, when ISE is observed, staff report this behavior to supervisors immediately stating “This is what I saw between these two people. Do you know anything about what is going on?”. This is reported to supervisors only as she “will never take it to my coworkers because it’s a private thing. You never do that because it is like you’re violating their privacy. I would talk to my supervisors about it”. At that point “trust me. That one is private between the family
members and the supervisor….when they finish everything, they will just tell us, “you
guys just leave those two. They are allowed to be together. Whenever you see them, just
walk off.” That’s all they will say to us [about the situation]”. In this case, the situation is
escalated and managed, apparently between family and supervisors, and does not appear
to routinely involve the wishes of the resident.

Another passage from an interview illustrates the swift and decisive action taken
according to another participant

Interviewer: Okay lets just say that two staff members walk up on Mrs.
Smith and Mr. Roy and they’re cuddling in the couch, what do you think
the typical staff response to that would be – what will be there physical
response?
Participant: Ops sorry, and shut the door.
I: Okay, in the public spaces, how do you …
P: No. They’re gonna send them to their apartment. We aint tolerate’n
nothing out here. I mean other than hold hands.

Another reason that the resident may stop the behavior is what appeared to be a
common response by those interviewed including laughing, infantilizing, or otherwise
making light of observing two people getting together. One participant identified the
“line staff” as the ones their community who “would probably need to be educated…[to]
feel more comfortable with…relationships. I don’t feel this is the case necessarily with
most of the supervisory types.”. Another participant echoed this sentiment about
“younger staff” who often react “oh, gross. They shouldn’t be doing that, they’re old
people” and “that type of [reaction]”. This participant also said “And its just education”
that is needed to re-direct these types of reactions.

While most participants portrayed some level of staff discomfort regarding the
intimate and sexual expression of residents, one participant said “well, no one has ever
expressed an interest in their father, mother having a partner here” in regards to this issue coming up during the intake process with family. Further, when asked about the resident communicating anything regarding relationships to staff, one participant replied “well they’re doing that with whoever their ultimate partner is. They’re not talking to us about it”. So ISE appears to be uncomfortable to everyone to some degree, for varying reasons. This discomfort is portrayed by a negative reaction by staff, and not talked about among family with staff at intake, or residents with staff members. There is essentially complete silence regarding ISE in the setting.

Interviewer: Describe to me a typical resident expression of intimacy and sexuality. So walking around the halls. Describe to me a typical exchange that you see that is either intimate or sexual.

Participant: There's nothing typical. Right now I don’t think we have any partners going on here, but it is fun to watch, you know, someone who, you know, that been very friendly with a certain person and they got an extra jump and hop in their step and they glow a little bit more and … I mean you pick up on little things like that too but, I mean there’s nothing typical.

I: The glow and the pep in their step, do you think that there’s value to that.

P: Yes.

I: What value do you think that is?

P: That the person has better feeling about themselves they feel good, they feel accepted, they feel loved, they you know just the same thing human touch does for anybody.

I: And in this setting, do you think that as especially important.

P: I think it’s, it’s very important to some people. Other people are, they were all about their one spouse and they’re not interested.

Meal times were reported as the most prevalent time to observe residents coming together, potentially in an intimate or romantic way. Participants conveyed stories of residents arranging seating in order to be next to one another. This often causes staff to notice “I can see where the table setters have changed. All of a sudden Treva is sitting with John – hmmm wonder what is going there?”, and “ohhhh, this is interesting wonder
what’s go[ing to] happen, you know?”. This expression of piqued curiosity was echoed in many of the interviews.

Re-Directing Intimate and Sexual Expression

Participants outlined a set of behaviors that I believe constitute a category known as re-directing behaviors when the staff member encountered an intimate and/or sexual expression that was viewed as needing addressed. Most often this meant stopping the encounter altogether. The reasons for addressing the behavior through re-direction varied. The respondent suggested the behavior needed to be addressed because of staff discomfort, resident family objections, and maintenance of community decorum standards. The re-directing behaviors followed two distinct patterns; those that re-directed the behavior to non-sexual interactions; and those that allowed for safe, comfortable intimate or sexual expression.

In some cases, when family members were made aware of a new relationship between two residents, the family met with staff and ultimately the order was given to “keep them separated”. The decision-making process was very siloed with nursing being the main actor with Executive Directors and families. To enact this separation plan the respondent expanded on the situation.

You know. If you bring one in to an activity, park him where he’s already got some people around him, so that when she comes in, so she can’t sit beside of him. And don’t rearrange the room, which is what you have to do sometimes for those that are a couple.

In this case, the participant is told to perform re-directing behavior of putting the resident in the position to establish general social interaction with other people in the facility. This
would aid in the resident avoiding the target of their intimate or sexual desires during the activities time.

Another participant discussed the case of a resident who “exhibits these behaviors. All of a sudden one day, maybe they weren’t before” – in this case he was appearing to make sexual advances towards other residents (and staff?), and it was revealed that the resident was experiencing a urinary tract infection, which are common in the setting and residents often “have a lot of confusion, can really just mess up, and it can promote behaviors like that actually occurring.” In response, the resident “had meals in his room for a few days”. I was concerned that this re-directing behavior was isolating, and that is not something that would be typically promoted in this setting. However upon further probing, I was told “it wasn’t that we made him but it was kind of mutually agreed upon”. Other residents were told this resident “just wasn’t feeling well enough to come down for dinner”.

Another participant shared,

It would depend on the situation at hand. If something occurred, a staff member could be like, “Hey, Mr. Smith. It’s time for bingo. Why don’t we go start this? Or can I offer you a snack?” Not necessarily stopping them from doing it, but steering away from the situation. I don’t want to use the word “distract” them, but redirect them.

In this case, the re-directed behaviors were recreational activities, or eating a snack. Though the participant stated that the intent was not to stop them, stopping the behavior was at least one possible consequence of the intervention.

A few participants described re-directing behaviors that were intended to release intimate or sexual needs through alternative means. One participant discussed a resident who was using their motorized cart to transport themselves to a nearby stripper club. The
Another participant described the story of a resident who was using "nurse call buttons, and other unsafe items" to sexually stimulate herself because "she missed that intimate level with someone". The resident initially asked the participant to "set her up with a man" which prompted the staff member to reply that "that’s not the way it works". As the staff member went on, the trouble was that "[the resident] had needs and she was doing things inappropriately that could have potentially harmed herself. So we as a care team came up with ‘well we’re gonna have to get her something to help those needs’ and so we did have to go purchase a vibrator for her to help those needs.” In describing this process further, the participant said

And it you know there was a bit of a challenge for those of us who were like oh my gosh 1. Explain how to use the thing 2. How to take care of it and all of that. Plus go buy it for her…that, that was an interesting experience because it was myself and the unit manager at the time were both standing in the store with this whole wall loaded down with vibrators. I’m like what the heck do you buy a 90-something year old? I mean never in my wildest imagination, would I have thought, in my career that’s what I would be doing as part of my job. But you know we had to make sure that need was taken care of for her, cause otherwise she was gonna hurt herself with the things that she was trying to use to take care of that need. So and that was a horrifying conversation that I then had to have with family, because the money that we needed to use needed to come from her personal account. But we also had to make them aware that ‘this is what this is going on, this is what were about to do’. So if they came to visit and they see this actually there and are like ‘what the heck is going on?’
...which I have to say that the family was quite relieved that I was the one taking care of it not them.

The previous passage illustrates a common theme of discomfort among staff, which often began with simple requests from residents for companionship that are not left alone, but instead the resident is persistent and the staff responds. Later in the interview with the participant we revisited this issue.

When we had the situation with the lady with a vibrator we had some staff that had a really hard time with that some of them were just appalled by it but by the same token others were like yeah do what you gotta do. I mean we can't have her in an unsafe situation – so for some people that was harder for them to deal with that uh but we approached it with its her right, we gotta do what we need to do for her. You may not like it suck it up move it on. If you really can't deal with that then we look at changing assignments for somebody.

This case illustrates how addressing ISE needs in the AL setting can be complicated. This passage also shows how the re-directing behavior may still not be fully accepted by some staff, if not completely rejected.

Another participant described one particular resident that was making unwanted advances to staff. In this case the participants outlined a rather comprehensive plan for the resident to safely and courteously engage in intimate or sexual expression.

Participant A: We have one gentleman that, he's very sexual. We have to, he'll say stuff to the staff, so we had to say listen, you have to keep those thoughts in your head, you can't say them to the staff. But what can we do to help you out? So, do we need to get you magazines? Videos? That type of thing, so you can express yourself without taking it a step further and harassing the staff.

In discussing the same case the other facility participant said

Participant B: So what we did was we actually gave him a tablet of paper and told him if he feels like he wants to express himself, could he write it on paper instead of saying it to the girls?
In this case the resident did use the paper tablet to write things down instead of verbalizing them. In addition “some of the staff brought him in movies”. It was summed up that this resident’s “urge is taken care of. He’s still getting his needs met without overstepping” “or being disrespectful of the girls”. So in this case the facility seems to have had buy-in from other staff members into the re-directing behaviors that made for a successful resolution where the resident is getting the specific needs met, and community cohesion is maintained.

Barriers to Intimate or Sexual Expression

Beyond re-directing behaviors designed to encourage residents to behave in a non-intimate or sexual ways, a number of participants described barriers to resident intimate or sexual expression. For instance, most of the facilities that I visited employ an activities person to perform weekly shopping duties. This often entails the collection of any number of personal items that a resident may need. The list is collected all week, and on a designated day/time, as one activities director put it, “if they put something on my shopping list, I will go get it but I’m not offering.” The last part of that statement is key to this being considered a barrier because it illustrates that items making the list are subject to some level of scrutiny, and possibly judgment by the designated shopper for the facility.

Another participant was asked about possible trips to places such as a strip club. While another participant raised this as an example in my conversation with them, it was used in subsequent interviews to member check the information gathered. In response to the possibility that a resident may request this type of outing, the participant stated that
So if there’s a gentleman that says hey, I want to go to a strip club for an outing, well, she’ll ask the other gentlemen if this is something that they would want to do. If we can get a group that wants to go, we’ll certainly take them and then have staff help so that if they need to be wheeled in or moved to, from a wheelchair to a chair, that’s something that we can do. If it’s just an individual person that wants to go, then we might at that point try to talk to the family and say they’ve expressed interest in doing this. We, as a facility, don’t have enough people to make it like an outing, but we wanted to make you aware in case you guys could facilitate that.

In this case, while the staff is clearly open to this type of outing, there must be a group of individuals who are interested in participating in the outing, or it is relegated to the resident to try and figure out a plan to engage in this activity.

Perhaps the most blatant barrier to intimate or sexual expression portrayed in the interviews was portrayed in the following exchange.

Participant: They wanted to get married and the general manager—or the administrator then said, okay but the only couple rooms we have are upstairs. You got be able to climb the steps if you’re going to share room. And that little lady got out of her wheelchair made it up that flight of steps to share the room with her new husband.
Interviewer: Do you think that the stairs thing was a meant to be an obstacle by that general manager? Or was it a challenge to try and improve her [physical] condition?
P: I think it was a challenge to prove to me if this is what you really want, tell me you understand because she was also the one that will have us put vaseline on her banana because that makes it ripen faster. Because back then, we gave fruit away for bingo prizes, yeah.

The rationale of this condition being imposed on the residents was unclear to the participant. In follow up questions that sought whether the condition was aimed at being a way to improve the resident’s physical mobility, or was intended to deter these residents from relational interaction the participant was uncertain.

The use of NI to inform data collection means that the meaning I am assigning to an event should be analyzed. In member checking whether this experience was as
negative as I perceived it was another participant said “I would look at it as a way to say it’s not going to happen. They’ll never do that, so I don’t have to worry about it. That’s what I would look at it as. Because there’s better ways to offer enticements.” So while this could be seen as a way to improve the physical condition, or mobility, of a resident – the actual intention is at best unclear, and may be a barrier intended to avoid dealing with the circumstance.

**Policy Development Input**

Following the grand-tour questions, each participant was asked about the input process into ISE policy development in facilities from three groups of people; residents, family members or other decision-makers of residents, and the facility staff. Because none of the facilities had written policies addressing the intimate and/or sexual expression in their facility (to their recollection or understanding during our interview) this discussion covered the informal policy, and primarily explored the likelihood/feasibility of each group’s input into someday developing a written policy specific to intimate and sexual expression.

**Policy Development Input: Residents**

As mentioned previously a theme that crossed themes was the flow of communication – identified as a barrier, but also illustrative of resident input into policy. All the facilities employed the use of resident councils to facilitate resident input into the management of the facility. One participant described “Resident council is nursing home only and folks are invited by the activity director to come participate and have a voice and anything they wanna talk about. It’s free and open and no specific agenda”, most
facilities described a similar situation in AL settings as a resident council, neighborhood council, or similar. These groups typically elected a leader that would maintain order during the meetings. Participants described leaders of such groups in a variety of ways by participants. While one participant said they are typically rebel rousers who are “curmudgeonly” and who advance more “personal views” than group member concerns. Another participant described the leader in their facility as “very friendly. She doesn’t bump heads with anybody, so I think people feel very comfortable. Because the residents were the ones that voted her [in].” This facility also incorporated a “grievance committee” to provide residents another avenue for input which will be further discussed in the family input section. So, all the facilities I visited used a resident council type meeting, but the leaders varied, and the issues they were likely may or may not be representation of resident concerns.

In light of this reliance on a very public forum to air desires about ISE, I asked each respondent to tell me about how a private matter, or any concern that a resident may not feel comfortable raising would be addressed. Many had no idea when asked how a resident would anonymously raise an issue such as ISE. “That’s a great question…*long pause*…if they randomly had a concern about something and they wanted to be anonymous I’m not sure what they would do…. “. When participants did provide an answer it was consistently the “comments box” often found in the entrance area of the facility. This area is also one of high-traffic and intentionally well-monitored for safety and security concerns of the residents. So even the most anonymous way to raise concerns, may not be very anonymous.
Staff members who were senior management offered that they had “open-door policies” whereby anyone in the community could come in and talk to them about concerns. This policy was true of not only for residents, but for the family of residents, and staff members. However, no participants recalled issues of intimate and/or sexual expression being raised during such an open-door meeting with a resident.

Policy Development Input: Family

During the conception of this research, through expert consultation, it was assumed that family members carried the significant amount of weight in developing policy in the facilities. Staff members I spoke to stated there was no formal policy regarding ISE, and further that felt that family should not possess power over policy in the setting generally speaking, favoring resident wishes and maintenance of resident autonomy in making policy. What emerged instead was family’s informal influence on practice in the setting, reinforcing the case-by-case approach favored over a formal policy in the facilities I visited. The incorporation of family into this case-by-case practice development was also very difficult to pattern. One participant’s description of the family member involvement sums up a consistently found theme.

Into policy? There’s not necessarily … I mean we make policy they [family members] have input, well they don’t have much input because really it’s about the resident. Now that aside if you have a guardian and we’re trying to come to some agreement…for a particular policy, you know we might engage the guardian in the question. We’re very big on surveys because we’ve tried to get as much consensus as possible on issues, so it could potentially go to a guardian if necessary, but were really careful when you know someone says well I’m your POA and we know that person can make a choice. We’re very very careful about that because we’re here for the best interest of the resident, not the family and although [the family members] play a part and we’re a glad that they are partners in care at times and all of that, if someone can truly tell me you know I feel,
or my team feels like [the resident is] truly expressing what they want and need, we’re going with that. Everyday we’re going with that and those families are made aware you know prior to whatever that decision is…’hey this is what your mother wants I don’t really care what you say this is very clear in her mind, his mind,’ whatever. So [family members] don’t have as much power in policy making. I mean they may be able to share some ideas ‘hey have you ever thought of this?’ OK we’ll look at it you know but I don’t see them having that kind of power in input.

As this passage illustrates, contrary to our initial inkling into the level of importance given to family input, the picture is much less clear when residents are able to make their own choices. Especially when those resident choices run contrary to family wishes on the matter. When pressed that family could, in theory, extract their family member from the facility in such cases as where the staff goes with the resident choices in defiance of family wishes the participant stated “Sure. Absolutely. That’s never happened but – well yeah they could”. So in the case of this participant, while it could happen that a family removes a resident for essentially disobeying wishes, it has not happened to this participant’s knowledge.

**Family “Awareness”, not “Authorization”**

What emerged in the cases where a resident retains cognitive ability to make clear decisions; families were made aware of the situation. The family of the resident was not brought into the conversation for authorization. This was made clear in the conversation with the participant who explained the vibrator scenario for a resident. In that case, there were two issues that family needed to be made aware of. The first awareness issue for the family of the resident was the withdrawal of personal funds to purchase the vibrator for the resident. “We also had to make the[ family] aware that this is what is going on. This is what we’re about to go do [purchase a vibrator for the resident]. So [that] if they came
to visit and they see this actually there and are like ‘what the heck is going on!’ or otherwise shocked by something that the family was completely unaware of, stated that participant. In this statement was the other awareness issue for the family of the resident, however. At the end of the statement is the issue of whether a family member during a visit ever saw the item, then they would have been made previously aware of the issue prompting this item’s presence in the resident’s room. In this case, the participant felt that the family was “quite relieved that I was the one taking care of [purchasing the vibrator] not them [the family members].” The awareness conversation began with the family as a ‘this is what we are doing’ framed conversation, and in fact this is what the facility did.

However, other times families appear to have been drawn into the conversation pre-emptively in order to “handle” situations where one or both partners may not retain ability to consent, as would be expected in such cases out of concerns for resident safety. This often came up in facilities where the resident need to be moved from the a lower service-needed setting of AL to more intensive care provided in a nursing home setting. At those times of

movement in the facility, and again when we’re looking at more confusion more cognitive impairments because generally we try to stay based off what the individual wants to do. Because it is still their right to say they still have the mind to be able to say ‘now this is what I want’. But then family can interject and we can try to see ok what is the best way to handle this?

So at those times of renegotiation of resident needs resulting in moving the resident to other service areas or facilities, families were brought into the conversation for awareness and authorization purposes and facilities balanced needs and wants, and decision-making ability. As one participant at another facility stated, “we promote, once you move in here
we do everything we can to keep you here so you don’t have to go to a nursing home.” in response to a generalized anxiety in the setting regarding having to relinquish even more control over their personal circumstances as represented by nursing home level of care.

This same participant explained their facility’s use of what they called a “grievance committee” which seemed to be a further step to ensure that residents could remain in their setting as long as possible. This participant cited a trend confirmed by a participant in a separate facility

[a] trend in AL is because people are going to the nursing homes sicker, we are getting people that are sicker. So ten years ago when you thought of AL, you thought of people, you know, they still were driving, they just needed maybe reminders or meals cooked for them. Well now, we might have somebody that needs total assistance. So the trend, I mean, we’re getting a lot more higher acuity and sicker residents.

In this facility the grievance committee includes family member participation (whereas their resident council is restricted to residents only) in meeting to voice concerns about care. In that facility the grievance committee

Usually they meet about once a month, or as somebody passes or something is going on. And particularly there’s family members on there and residents on there. And so they just meet, I think it’s on a monthly or like every three months, quarterly, just to touch base to see if anything’s going on, any concerns or questions, and they just go from there

This was the only facility to have such a level of family involvement in voicing concerns of resident family members. The facility in this case also had a very open policy of trying to keep residents in the facility as long as possible (before moving to nursing home care). The grievance committee seemed to be a further demonstration of this philosophy to their resident by reconciling family issues as much as possible to retain the resident in the facility.
Two of the participants had markedly different views from all other interviews conducted in terms of their perceptions of the family’s input into policy regarding their related resident intimate and/or sexual lives. Whereas most of the other participants relegated family input to simple awareness, and only in cases of inability of the resident to make choices, some type of negotiated authorization level where family input was weighed by staff in relation to what the staff member knew the resident’s wishes to be. One participant when asked about resident intimacy and/or sexual expression initially replied

It's sometimes between the families. Sometimes families allow their loved ones to be intimate with someone. That one is mostly between two families. The facility might say no, but if the families approve and they are mentally okay—nothing is wrong with them—you allow them.

Suggesting that in their facility, at least, according to their perception, this resident expression was managed by the facility according to family wishes. However, once further probed for clarity, what emerged was less clear.

You have to be mentally okay, and the two families have to come together and approve it, only if the person appeals for himself or herself. If I appeal for myself, nobody can make any decision for me. I make my own decision. If the facility doesn't like it, they make the argument and say, “Well, the other family doesn't like that, so you can't do it.” That's how it is. Intimacy is between family members. The facility can say no, but the family members said yes, we have to go ahead and approve them. You're not involved in their intimacy. You leave them to do whatever they want to do. It's their own way. If you meet them in any way, you have to leave them, and that's not your business to say it to anybody.

The participant’s response appears to include contradictory statements about whether the resident actually gets to choose whether or not to be in a relationship. In the initial statement the participant made, the choice is the resident’s if they are able to make clear decisions; however the next passage reveals that this may not be the case.
Another participant when specifically and repeatedly asked about relationships entirely among residents, kept referencing relationships of staff members with residents and those relationships being forbidden.

Yeah. That is a no-no. It’s a no-no, you can’t do it. Even generally, you just can’t do that. Because you cannot do any sexual expression in front of the residents, and you cannot do, you cannot say verbally. You’re supposed to give them the respect. They’re here for you to take care of them, help them, direct them. Not for you to abuse them, because that’s like an abuse.

When I asked the clarifying probe “What about between residents? So two residents decide that they’re going to go into a relationship. Do you know any policy about that?” to get at the intended question of relationships entirely among residents the participant then said

Well, to my understanding, to what I understand, if they decided to go into a relationship it’s up to the two families if they’re going to accept something like that to happen. If they have kids, and if they don’t have like wives or girlfriends outside, they have kids, those two families can, if they have, how you say, power of attorney, then they have the right to give the power and say if it’s good for them they can go ahead.

This participant’s views ISE as a decision by family members, or the designated Power of Attorney for the resident.

**Family Responses to Resident Intimacy or Sexuality**

During this part of the interview staff members described responses that families typically experienced in regards to their related resident establishing an intimate and/or sexual bond with another resident. Overall the establishment of formal relationships (i.e., marriages of residents) was very rare. One participant stated “they [are] very rare, in fact”. Another participant, who relayed the story of the resident’s ability to climb the
stairs to allow a marriage to occur between two residents, was asked about the uniqueness of such a marriage in the facilities and she responded “pretty unique”.

Families most often rejected relationships that emerged among residents. Many participants cited family concerns about confusion that may result from such relationships. One participant summarized typical family responses as “No no no that’s our dad. That’s our stuff, you know. You’re gonna take our stuff. It’s really more money driven inheritance driven between the kids. It’s interesting”.

Another typical family response of rejection was not wishing to see their mom or dad replaced and/or engaging in this intimate behavior with a new partner. One participant, who described very siloed management of resident issues, remembered “There’s only been one time….where we have a family ..[say].. oh no, that’s awful” . When asked to describe how that came to be known, the participant said “I didn’t know that was nursing.” This was the same participant who further explained “no one ever expressed an interest in their father, mother having a partner here” suggesting that this is the furthest thing from families’ minds.

Policy Development Input: Staff

The next group of interest concerning input into the policy development process was that of the staff members in facilities. As previously mentioned there were no facilities with written policy, leaving ISE behaviors to be handled in a case-by-case manner. Many of the participants were also adamant about this approach to managing the issue. Two themes emerged as mechanisms for staff member input into policy. The first was staff meetings, of various sizes and frequency. The second was escalation of events.
Staff Meetings

For issues that rose above simple management during the event, the most common way to gather information from staff members was through employee meetings. One facility noticed that staff members were very uncomfortable speaking in front of large groups, so they decided to have a small-scale (i.e., department only), and large-scale (i.e., entire facility staff) meeting on an alternating monthly schedule explained in the passage below.

However, they have discovered that everybody is comfortable in a big group setting, so now, so on the other months, every other month, they have small meetings, like six up to ten. Small groups where this is your time and really, management conveys very little what they want to be known for. They say OK, what’s your beef? What is wrong, what’s right? And so they are very much in tune with the employees that way.

So issues are brought up from the front-line workers to management for handling.

Other participants explained that they had open-door policies where staff (or residents, or family members) could stop in and talk.

I encourage all kinds of suggestions from staff, all times. Almost every day, ‘Hey, if this isn’t working, let me know. We can change it.’ It’s all about trial and error.

This participant further explained “we have to involve the staff. If we don’t involve the staff and keep the morale up, it’s going to be a revolving door.”

Escalation

The most common theme of handling ISE was also escalation as illustrated by this participant’s response to the question of how staff has input into policy development.

So what I would imagine would happen is there would be folks that have a relationship where something like that would happen. There would be an event. So it would come through social work or healthcare worker like a
director of nursing or someone like that and then that would go to our senior leadership team ....and we just throw it out on the table

So again, an event is escalated through front line workers to supervisors, and then to a senior leadership team who develops a policy. In this particular facility, the participant then explained what would happen next

So ... an issue that would go to that team and we would sit down and hash it out and actually write a policy together. And everyone would bless it. Everyone would be comfortable – we’d fight about it probably, but we come to some kind of an understanding and agreement. We’ve done that over and over when issues come up. And we send it down to the next group and we say ‘here’s what we came up with’ – poke holes in it – and then it ultimately we have a policy and that’s the end of it.

So these two examples display that a single event, or coupling can rise to the level of the senior management team for handling.

Unspoken in any of these examples are any disagreements on the parts of any involved parties (i.e., family of resident, staff members). When there were disagreements among the parties things got more interesting. In addition to the escalation of the issue or relationship, there was communication with the family. This case-by-case approach means that the staff member has to negotiate many variables when considering how to proceed. This is especially true when the resident and family are not agreeing on what should happen. This passage below illustrates how it can play out in such cases. In this passage I asked the participant about their comfort level buying a sex toy for genital stimulation of a resident. The participant when asked if this was part of their job said

They are still independent in the sense that, if this is what you want to make happen and you’re smart enough to make this happen then you need to make smart enough and cognitively able to make the right choices, to make that happen too.”
When further probed about what would happen if the family was not ok with this purchase the participant said, "You don’t want her to have it then you go tell her. I did my job, and told you what she’s asking for. You, you get it for her, or you tell me to get it for her, or you could tell her she can’t have it.

So in this case, the resident had an ally in the process of procuring an item they wanted. In the case of a familial objection this participant put it right back to the family to settle that with the resident.

Overall Concerns

In an effort to triangulate findings among the participants and add rigor to the study, all the participants were asked their perceptions of the overall concerns of two groups of facility employees. This allowed me to verify themes developed through the participant interviews in terms of concerns of different groups in the setting. The first was administration and what the participant felt was administrators’ primary concern in regards to resident ISE. Then they were asked the same thing about fellow staff members. These questions were asked to everyone regardless of their identified, or assumed, role in the organization. A high level of verification occurred and those results are presented below.

Administration – liability, safety

The most commonly perceived concern of facility administration regarding ISE, per our staff member participants, was “liability”. One participant further explained where these liability concerns originate,

Yes and I’ll tell you that’s partly because of the children. The children imagining their parents having sex freaks them out. But like really? So that’s huge. And I believe that they would come after [an] organization if
they were completely freaked out about it, you know? And, that’s why I say …it would be picking up the phone because you have POA of healthcare, POA of finance, POA...I don’t care that you’re in your right mind today, were you when you consented? And were you -oh my gosh – you could see that all unfolding! So its fortunate or unfortunate.

The concerns about liability may also be well-founded when considering Magsi and Malloy (2005) who found that despite over half of the AL residents in their study had cognitive impairments, a significant portion were undiagnosed. In my research there was also evidence that cognitive impairments were prevalent and that their monitoring may be hampered by attention to things like retaining the resident in the setting, as opposed to moving them to nursing care. The potential for residents to be harmed because one of both residents may not be identified as having cognitive impairments to the level of not being able to actively consent to ISE is present in this setting. Despite many of the facilities I visited having a similar structured response, a firm policy could protect from this happening by providing staff with explicit guidance on how to handle these situations.

Staff – safety, family

Safety of the resident was mentioned most commonly regarding what their perceptions of staff members’ overall concerns regarding ISE. While one participant put it this way,

We can't do anything about it. We, the staff, don't have anything to do about it. All this is up to the higher people and the family members. We don't have anything to do about it because it's none of our concern. They always tell us what to do.

Most staff members described it as more of an issue of taking care of the resident. One participant stated “It really is taking care of the concerns of the resident. It really is all
about them”. Other overall concerns were more related to the work environment of the staff member. Some concerns were about the conduct of certain levels of service, for instance the religiously objecting woman. But other concerns were described by one participant as “… maybe they’ll walk in on something and see something that they wouldn’t expect to see. Actually, they probably worry about their safety, as well.” Another participant said “I kind a see where, you know hearing little things that someone said that they really, really feel that a lot of things are inappropriate said towards them” So the concerns of staff seem to be around workplace safety and comfort for the staff member. In the case of one facility that had issues with a resident inappropriately expressing him/herself sexually to a staff member, the facility instituted the notepad policy for the resident to express themselves sexually without offending the staff. This plan worked well and demonstrates that re-directing behavior that is still venting related desires works in this setting, at least in that case. This was a unique circumstance, and warrants further study.
Chapter 5: Discussion of Findings

Chapter five presents the discussion of findings of this exploratory qualitative study. The research had two main aims: exploring staff perceptions of intimate and sexual expression (ISE) in assisted living (AL) residents; and, exploring staff understandings of various stakeholders (i.e., resident, family members, facility/staff) into policy regarding intimate and sexual expression of residents in AL settings. In order to develop best practices in healthy ISE of AL residents, researchers must first understand how the issue is interpreted, and managed by staff. Because of the sensitive nature of communication about sexuality, developing an understanding of how input occurs in policies associated with ISE of AL residents is critical to understanding this issue.

Ten AL staff members participated in qualitative interviews that were recorded, transcribed, and analyzed. Using naturalistic inquiry throughout the analysis of tapes, transcripts, field notes, and memos enabled the construction of themes. Beginning with a thorough review of the transcripts, key words and constructs were assembled into broader themes that informed the theory developed through this research. The themes that emerged were universal across the interviews and saturation was reached on the narrow aims of this research. Variability in setting size, range of other services offered in the facility, and urban/suburban setting were apparent in the sample of participants.
The figure below demonstrates how ISE in AL facilities being managed on an event-based system means that there are two climates created. The first climate is created prior to the ISE event. Described below, this climate is made up of the atmospherics and overall concerns related to ISE in AL facilities according to the participants I interviewed. This pre-ISE climate operates to prevent ISE events from ever occurring. There is then the ISE event, most often in a public space in view of others. Everything that occurs after constitutes a secondary climate. This post-ISE event climate includes considerations of the staff involvement and response, the escalation process, and barriers the facility enacts. While many residents never enter into this cyclical system, those who do tend to cycle through repeatedly according to our participants. It was expressed by one respondent that “the love of their life is gone, and there is no interest in anything else” and so consequently that resident, regardless of climates, is not interested in ISE with another resident. However, it appeared that there were residents who did seek this type of interaction, and often repeatedly.
Resident ISE in AL

- Climate: Pre-ISE Event
- Atmospherics
  - No facility policy
  - No specific resident right
  - No communication
- Overall concerns
  - Administration: liability & safety
  - Staff: safety & family

ISE Event

- Climate: Post-ISE event
- Staff Involvement & Response
- Escalation
- Barriers

Figure 1: Resident ISE in AL

Pre-ISE Event Climate

The first climate created in the AL settings I visited is the result of a number of factors that are in existence prior to an ISE event including a lack of facility policy for ISE, a lack of recognition of ISE as a resident right, poor communication, liability and safety concerns, and family wishes.
Lack of Facility Policy

None of the staff interviewed worked at facilities that had formal, written policy in place to follow when managing ISE among residents. This passage below illuminates how the regulatory environment is interpreted in the absence of explicit policy.

Assisted living is interesting because I’ve worked [in] the nursing center for a long time and they’re so heavily regulated. You have policy in every single thing and because they’re federally regulated. Assisted living - I mean truly, it's like a piece of cake compared to what nursing home like regulations are, and it's not federally regulated. It’s just state regulated and the regulations can be loosely interpreted.

Recommendations in Kane, Brown-Wilson, and Spector (2007) are that the regulatory environment be studied more empirically. However, their recommendations fail to highlight the study of regulation as it relates to ISE. The trouble with this ‘loosely interpreted’ regulatory environment is that harmful views, such as ageism or disabilityism, brought from the larger society into the facility could be impacting care in differential ways. Consistent with Dobbs et al. (2008) my research did find ageist views either demonstrated personally, or recounted in portrayals of other staff members’ responses to viewing resident ISE in the AL facilities. Passages like one participant stating “I think a lot of the staff, especially younger staff, you know, it’s like ‘oh, gross, like they shouldn’t be doing that. They’re old people’, that type of thing.” suggests that deeply negative, and possibly prohibitory feelings towards resident ISE may be pervasive in their AL setting. Other participants suggested more subtle versions of staff reactions where some staff may be “more uncomfortable” with resident ISE. During one of the interviews the participant was very physically uncomfortable, fidgeting with a neck lanyard the entire interview. This participant also portrayed staff interactions in a
“juvenile context” when discussing the situation of two residents establishing a romantic bond.

The lack of any formal policy also means that directives that the facility develops in response to an ISE event for any resident may, or may not be followed by individual staff. For instance, one participant who recounted the story of purchasing a vibrator for a female resident explained that a particular staff member refused to follow the facility policy enabling the woman to safely, and sanitarily use the item. Another participant from the same facility, familiar with the situation, explained that “she just, and I don’t know if it was ever clearly stated, but she just believed that this was wrong in the eyes of God, and in some religions masturbation is not a welcome thing.” when asked to elaborate on the religious objections by a staff member when the facility instructed staff to assist in the cleaning and storage of the vibrator. Outside of the scope of this research, this same participant described an exchange between a staff member and resident where the resident was attempting to “pray the gay away” of the staff member who identified as a gay person. The power and impact of the outside societal views of sexuality, sexual identity, and in this case – ageism, and other more directly-related “isms” should not be underestimated in this setting. This participant said it best in regards to my inquiry about whether they believed a policy would be a good idea “You can’t go wrong with written policy. If there’s something there that says hey, this is OK and we need you to understand it.”. In this participant’s case their experience is that ISE occurs in the setting and like any other behavior in the setting, policy ensures consistency of response. Given the participant’s description of the ‘praying gay away’ story, this may be even more important to respect residents, as well as staff, who may identify as gay or lesbian.
Lack of Explicit Resident Right

One place to start with emphasizing the need for facilities to recognize and address the issue of ISE among AL residents would be to develop a specific resident right to ISE. Each state codifies the rights of AL residents individually. The Ohio resident rights that enumerate proxies for this level of interpersonal relationships fall mainly under the broader categories of privacy. They include things like the right to a closed door, and staff knocking before entering private spaces, and a specific ISE resident right would set the tone for the setting to address this issue. Resident rights are also something that are referred to frequently, almost all my interviews included at least one mention of them at some point in time. However, when asked about their specific content, the exchange below illustrates how well their specific content is retained by staff.

Participant: I in turn have kind of made my office or my space an open door policy. I have a lot of residents that frequently come in and talk to me about either personal issues or things going on in their lives. Certainly that and then upon admission, all of the residents are provided copies of the resident's rights. And in there it talks about having the right to sexual freedom, participate in any sexual activities, so it is consensual and so forth. That is provided to them in writing upon admission.

Interviewer: Awesome.

P: For their resident and it’s part of the residents’ right.

I: Excellent, okay. That’s new.

P: That you’ve heard about resident's right, yeah.

I: That it’s actually in writing at least.

P: I hope it is. I think it is.

In fact, though this would be an excellent thing to be included, specific ‘sexual freedom’ is not included in the Resident’s Rights document. Further, the words ‘sex’, ‘sexual’, nor ‘intimate’ are found anywhere in the Ohio Resident Rights document despite intimacy and sexuality being understood as life-long influencers of quality of life (Doll, 2012; Lichtenberg, 2014; Antonucci, Akiyama, & Takahashi, 2004).
Lack of Communication

Overall, in every facility that I visited, there is almost a complete silence around the issue of ISE among the residents prior to their being an event where the staff and facility must then respond. All participants were asked whether the topic came up at two points in time: intake and regularly scheduled care-planning meetings. Further, when asked about how residents would express concerns regarding ISE anonymously, the only means were resident council-type meetings, or the suggestions box in the lobby. Both have been discussed previously in this manuscript, but it is worth repeating the passage below.

Interviewer: Starting with residents, how do residents have input into the policy in the facility inter mental sexual expression?
Participant: I would say that they can bring it up at the resident council but it’s not necessarily something I think they would do.

No participant stated that the issue was brought up at either intake or scheduled care-planning meetings, unless there had been an event prior to entry, or during their residence. For example, when participants were asked during interviews whether ISE came up during intake the standard answers were “No. Not at this facility”, “Not at this facility that I know of”, and “no one ever expressed an interest in their father, mother having a partner here”. Again this runs contrary to research (Antonucci, Akiyama, & Takahashi, 2004) that shows attachment and close relationships occur throughout a person’s life. The only time the issue does come up is when there has been some sort of event and it is often portrayed as “Usually families will seek out one of us and say ‘hey’ heads up’ this is what they are usually doing”. Staff appeared to minimize that this is a regular occurrence, and when ISE was raised, it was most often seen as negative and
needing intervention. There were relatively few tones of addressing the ISE of residents in a safe, supportive way in any of my interviews. One example was a resident who was inappropriately verbalizing sexual expressions to staff members. In this case the staff members purchased a notepad for the resident to write down these thoughts. The staff went further to provide pornographic books and videos so the resident could express their physical needs. Another example was the purchase of a vibrator for a resident who was using unsafe/unsanitary items to self-gratify. Excepting these examples, there were no other examples of safe, supportive resolutions to ISE events.

Ageist Responses

When communication does occur among the staff, many participants described it in terms like “juvenile”, and “gross”. One participant also stated “In places like this, there’s a lot of gossips, I’m telling you.” So the setting is impacted by broader societal views of the aging process as one that does not include ISE as a normal part of the process, and is the object of scrutiny among staff. One participant put it this way “again, they come from the younger ones that don’t realize that older people can have feelings, too, as far as sexual feelings. They’re very good to the people they take care of, but they just put them in this pigeonhole and don’t think of them as an entire person a lot of the times. “ The ‘pigeon-hole’ this staff member refers to is a sexless existence that residents are assumed to have. In fact, many participants agreed that it’s “because for a lot of the younger staff it’s, they have a hard time with it and it’s just education”. Yet another participant echoes similar sentiment “knowing my community that would be the group that would probably need to be educated, and … feel more comfortable with
relationships.” So the need for education in the direct line staff, according to the participants in my study, is apparent. This is consistent with this employee group being one of the lowest paid, least empowered, and feeling the least appreciated in many facilities (Kemp et al., 2009; Ball et al., 2009; Bauer & Nay, 2010).

**Reliance on Events of ISE**

In all the facilities that I visited there was a complete and adamant reliance on managing events of ISE as opposed to developing a facility policy regarding them. Given the discussion up to this point concerning under-identification of cognitive impairment (despite its repeatedly acknowledged prevalence), and research evidence of this occurring (Magsi & Malloy, 2005) concern about liability to the facility, and the often negative ageist views of staff, there is still a hesitance to develop across the board policy or practice standards in facilities.

**Public**

In public spaces, the most common portrayal of ISE among the residents was “pecks on the cheek” and “holding hands”. The staff response was fairly bifurcated with more frontline staff responding in ways that were informed by ageist views, and prohibitive responses. The management countered this with expressions of respect and dignity about these ISE. As one participant stated

We are looking at two grown adults, who are much older than we are and that. [They are] in the end parts of their life, and they are here in this setting. Let’s have a little more respect – let’s quit going with the little chatter here and there. Just, like oh my god, grow up. That is my take on just what I have seen and that. …for the married couples, you know, it is we look at that as ‘Wow! Look how many [years] they’ve been together and they can still sit and hold hands and things like that.
So in this case, the participant is reverent towards the couple engaging in ISE as a way to counter what the participant saw as negative responses by other staff. It also presents a double standard as those residents who enter married seem to fall under a rule where this is acceptable, however residents who meet someone in the facility may not be managed similarly.

Private

When staff became aware of ISE among residents in private settings, the situation was handled much more discreetly. One participant described two situations that occurred in resident private spaces in this passage:

One was the Census Bureau was here to just do a random survey, and definitely had a lady on her list. And when I knocked on the door, I heard two voices. They both said “come in,” which I thought uh oh, at the time. And then as I entered the apartment, the bed, the foot of the bed is in vision but the rest of the bed is not, so I saw two pairs of feet like this. So I stopped and said, I’m here with the Census Bureau. If you could, in the near future, step out of your apartment and meet this lady down at the end of the hall. And both voices said, “Of course,” acting like nothing was wrong.

The other time was when I went to get somebody from Bingo and I knew that the gentleman had been seeing a neighbor of his. And this was in assisted living. So I knocked on the door, getting ready to go in, and the aide cautioned me, you don’t want to do that. And I said oh? It’s time for Bingo. And then she explained the circumstances of what she had just observed, that there were two pairs of Depends over a chair and they were enjoying themselves immensely, so that I probably would not want to go in there and remind them of Bingo, to which I agreed.

In these cases the encounters were met with discretion and nothing more was done at the facilities about them.
Response to ISE Events

Staff

This study revealed staff in facilities I visited were aware of situations where the response to ISE by residents was influenced by ageist views and stereotyping of aging people as sexless, and their behavior as undesirable. In one facility, there was a refusal to serve the resident in the name of religious views. This situation is very troublesome as it relates to other issues such as possible resident homosexual identity, or alternative sexual preferences. Absent any direct, explicit right and/or facility policy where might the line be drawn on such matters? With the current method of pay for these services being primarily restricted to private individuals paying for care, the choices for consumers of these services may be limited in some cases. What if a resident finds themselves in a facility with a staff predominantly in religious objection to something that is core to their person?

Mid level Management

Many participants agreed that education was needed in the setting in order to lessen the impact of broader societal views like ageism, and other stereotyping on resident experiences in AL facilities. At least two participants from different facilities expressed similar views about the need for education regarding ISE among residents. In the first case, the participant recognized the need for education of the families, stating “sometimes there’s a conflict, and all we can say is we can keep them safe. If [the family] need[s] education or certain things, we can provide that for them. But if [the residents] are both consenting, then we have to respect that”. Another participant recognized the need for training in staff members. As this participant stated, “knowing my community that would
be the group that would probably need to be educated, and … feel more comfortable with relationships. I don’t feel that is the case necessarily with most of supervisory types”.

**Escalation as the Initial Systemic Response**

The initial response in most facilities to ISE among residents is to stop the behavior and then escalate the issue to mid-level managers for handling. Once this occurs, addressing ISE follows two main paths.

**Stop**

Using expressions like “we ain’t having none of that here. Take it to your rooms”, some facility staff felt empowered enough to stop the behavior. In the case of this passage, the statement was made in response to the participant sensing that others were being made uncomfortable. The trouble with handling situations like this is that some in the facility may not have noticed anything occurring, but were made aware of it through the reaction. The reaction also then sends the clear message that such behavior will not be tolerated, and will be shared in a very public way.

**Care-planning**

Another route is the staff member sees the ISE in the facility and walks off during the event, but then escalates the situation after observing ISE. The following passage sums up this response. “We meet them in the room. They are doing their own things. You can't say anything. You can't talk to them, just walk off. You will tell you supervisor. If they approve of it, they will tell you, ‘No, they're fine. Everybody knows what is going on between them.’” In this case there isn’t much made of the event itself publicly. Instead
the participant relayed that they reported it to their supervisor who, based on knowledge of the situation, issues a determination of how this situation should be handled. I asked a few participants where all this institutional knowledge about residents and the allowance for their interpersonal relationships resides, there was no known place where this information was stored. The closest answer was that this information may be found in the nursing team notes.

Consistent with the research that residents’ social lives are important (Kemp et al., 2012) in these facilities, the best scenario for a response may be somewhere in the middle of these two extremes. While the first response theme draws negative attention to the event, and further stigmatizes ISE among the residents, the second ignores the event altogether. Ignoring entirely the situation at hand could increase the chances that a resident is being victimized if either resident is not properly identified as having cognitive impairment.

Post-ISE Event Climate

The combination of these typical responses creates the secondary, Post-ISE event climate for residents. While the initial Pre-ISE event climate is one that prohibits ISE among residents from ever occurring, the post-ISE event climate is effective at deterring it from ever happening again for those residents did express intimate and sexual behaviors. Aside from these communicative devices that implicitly prohibit ISE, a number of facilities employed other tactics that actually prevented ISE. This response was absent of any apparent discussion of cognitive impairment, or any other substantial rationale for prohibiting such interaction.
Barriers

A number of barriers emerged in the thematic analysis of the interviews. One important barrier to consider is the flow of information, specifically complaints, in the facility. Most of the facilities that I visited employed a Resident Council, or similar type of group to air concerns in the community. When asked where a resident could raise an issue related to ISE, the resident council in the participant’s facility was mentioned, but in the same statement the participant stated that “it’s not necessarily something I think they would do”, so participants acknowledge that this is not the place where a resident would feel comfortable expressing these concerns. I asked another participant how someone could raise an anonymous issue and was told “that’s a great question…I am not sure what they would do” suggesting that little emphasis has been placed on understanding how to solicit any concerns considered sensitive. Another participant stated “we also have a suggestion box” referring to a box in the lobby where residents could insert notes. This sounds like an excellent idea until you consider the amount of traffic in this area of the facility. It is also an area generally watched over well out of safety and security concerns in the facility.

Another suggestion a participant had was to use other residents to speak up about the issue instead of more reserved resident. This again sounds like a good idea, until you consider the specific issue of ISE that is not likely to fall in the same social acceptability as less than appetizing meal preparations.

Another type of barrier were facility level things like designated an individual to purchase relevant items, the requirement of multiple residents attending an event of interest, room selections, and other built environment barriers employed to prevent ISE.
Designated shopping people are used in most of the settings I visited. Residents follow a scheduled process in order to get needed items on the shopping lists, and on the designated day a facility employee buys items on the list. In at least one facility, the participant used the process of getting items on the list as a way of determining if a person “really wanted the item”, stating that “If they put something on my shopping list, I will go get it but I’m not offering”. In this case, for any items that may require more discreet consultation, that will not occur. The item must be put on the list with everyone else’s items.

Many of the facilities also required that there be a group of people interested in going to an activity. For instance, I inquired about a hypothetical resident wanting to go to a stripper club as this was a request another facility had honored for residents. I was told

So if there’s a gentleman that says ‘hey, I want to go to a strip club for an outing’, well, [the activity director will] ask the other gentlemen if this is something that they would want to do. If we can get a group that wants to go, we’ll certainly take them and then have staff help so that if they need to be wheeled in or moved to, from a wheelchair to a chair, that’s something that we can do. If it’s just an individual person that wants to go, then we might at that point try to talk to the family and say they’ve expressed interest in doing this. We, as a facility, don’t have enough people to make it like an outing, but we wanted to make you aware in case you guys could facilitate that.

so in this case the requirement of a group wanting to do an activity may be a barrier. In this case, the participant expressed that they would then let the family know of the request for consideration of accommodation.

All facilities have built environment issues and are limited by the number of rooms, and the level of privacy built into the facility environment. Where the facilities do
exercise greater control in is who rooms together, and changes are allowed to be made as needed. The facilities would sometimes limit room movement in order to prevent relationships from occurring. Similarly the built environment in one facility presented a unique barrier that a staff member devised. In that case, the requirement of a first-floor resident climbing the stairs to the second floor where the object of their desire resided was used as a barrier to ISE occurring between those residents. In the end, the participant relayed that the residents indeed did couple, despite this barrier being presented to them.

Re-direct

A secondary theme is re-directing activities. Examples of re-directing tended to take two forms: non-sexual diversion activities; and, other sexual outlet activities. When I asked one participant whether they were aware of any resources to refer to when faced with ISE their response was “Absolutely not. There are no policies, there is nothing. I mean we were just trying to go with ‘what is the right thing?’ you know? And, and what’s my liability? Unfortunately, I have to think about that.” so staff in these settings are operating without any formal policies or procedures of what to do, with little guidance on a best practice. This makes the re-directing activity inconsistent and may or may not be resident-centered.

Family’s Involvement

Underlying all of these discussions is the complicated relationship that involved family adds to the equation. Research has found family input is important (Gaugler & Kane, 2007) and all of our participants at some point in their interview at least implicitly, and sometimes explicitly, discussed the importance of involving family in care decisions.
My research also consistently found that the involved family members has always tended to be the daughter, and more commonly, the daughter-in-law. While people familiar with the industry, and most participants in my research identify the family caretaker as most often female, this understanding is contrary to some research that suggests this role is not clearly understood (Castle & Stadtlander, 2009) in terms of collecting and interpreting information that aids in choice of facilities for an aging person.

You have all the way from the ground up level. Some residents' family members, they'll come in every day, the entire family. Kids will come by after school, see their grandparents. Some might come by once a month. Then there are situations where, I've seen in the past, family members are completely involved with the admission process, everything. They'll stop by for the first couple days after they move in, and then boom, they just, more or less, lack of a better word, dump them in here.

And contrary to our initial belief that family would be the greatest influencer of policy, another participant succinctly describes the typical family input into policy as this “Into policy? Uhm…they’re not necessarily [involved in] policy. I mean we make policy. They have … input. They don’t have much input, because really it’s about the resident”. These passages really describe very well the consistent themes my research uncovered regarding family involvement in care, and policy formation. It’s all ranges of family involvement, with little understanding of why one family is involved while another is not. Also very difficult to understand is what input family really has into policy.
Chapter 6: Implications

Chapter 6 presents the practice, policy, education, and research implications derived from this exploration into the issue of intimate and sexual expression (ISE) in assisted living (AL) facilities. The implications of my research will be discussed in terms of the two climates described in detail in Chapter 5. Consistent with the NASW Code of Ethics document, the issue of ISE in AL is perfectly suited to being addressed by the field of social work. Social work simultaneously aims to make the person fit better into society, while also changing society to work better for the person. AL settings are simply a microcosm and with their aim to respect the dignity and autonomy of the person for as long as medically safe, they are an excellent setting for social workers to create systemic change. Specific guiding social work principles of respecting personal autonomy, empowerment, and the importance of human relationships are inherent specific to the issue of ISE. Koenig et al. (2011) argues for the importance of having gerontological social workers in AL facilities to empower staff to effectively address and to meet the needs of the whole person. Social workers can ensure that resident wellness needs are identified, addressed, and met.

As previously stated, this research had two main aims:

1. Exploration of staff members’ perceptions of policy and practice regarding intimate and sexual expression of residents in settings of AL.
2: Exploration of staff members’ understandings of the facility climate pertaining to interpersonal relationships and contribution of various stakeholders (i.e., resident, family members, facility/staff) into policy regarding intimate and sexual expression of residents in AL settings.

Ageism

Underlying much of the context surrounding ISE in AL settings is the impacts of ageism and how it shaped both climates this research discovered. Most of the interviews that I conducted with staff members contained multiple examples of ageism impacting the resident experiences in AL facilities as it relates to ISE. The silence surrounding ISE often originates in the belief that aging persons should not engage in ISE at all. Further many staff members see the resident as ‘grandmotherly’ or otherwise similar to their own relatives and do not wish to see the resident engage in ISE. A number of staff also described discriminatory reactions to residents who engaged in ISE in their facility. These discriminatory responses took multiple forms, from gossiping among staff to direct obstruction of ISE being conducted among residents.

The pre-ISE event climate is built upon ageist-informed views that aging people do not want ISE experiences as part of their life as they age. It is further perpetuated by many of the staff members who I interviewed expressing views summarized as people generally not wishing to think of their own aging relative in such a manner (that engages in ISE). This results in projection on the residents of the AL facility and precludes many residents from being allowed to engage in ISE events.
The post-ISE climate often makes trivial, or otherwise infantilizes, the ISE event observed by staff. Many staff members I interviewed expressed that staff members gossip about observed ISE events frequently. They also stated that many times the staff employ a variety of tactics to avoid ISE among residents, sometimes in response to supervisor instructions, but sometimes out of personal-level reactions.

Addressing and dispelling ageist-informed negative views of the need for, and prohibitory reactions to, ISE experiences is therefore an important consideration as one considers the implications discussed below.

**Importance of Family**

It also cannot be overstated that the role of family is critical to understanding how residents experience care in AL in general. However, as it relates to ISE in AL among residents, the role of family is very difficult to pattern. In general, my research findings were consistent that female family members were the most involved in care of residents. Some current research suggests that it is unclear as to who is involved in information gathering, facility selection, and family involvement (Castle & Stadtlander, 2009). Future research should empirically explore the level of involvement and differential involvement by family relation in ISE in AL settings. This understanding could have important impact on how facilities advertise themselves to recruit residents. It also could influence the conceptualization, design, implementation, and evaluation of programming aimed at addressing the issue of well-being and specifically ISE in AL.

All the participants I interviewed also described very sporadic contact with family, and as it related to ISE events, the family was often caught by surprise with the
conversation. In many of the cases, the family was really not required to be involved but was being brought in out of paternalistic feelings on the part of staff. Educational programs aimed at dispelling myths and stereotypes about the aging process, and clear and direct communication about the importance of relationships formed in the setting from recruitment through maintenance of care activities should be employed to family of residents.

Implications discussed through the rest of this chapter need to be explored in a manner that includes family in the most meaningful and appropriate way. Social workers are uniquely experienced to champion this cause as our focus is the person in context. Contextually speaking, the family is important, however determining the most appropriate way for them to understand the importance of ISE among residents, and inform policy to manage it safely is something that future research should attempt to do. During my interviews many of the participants specifically named social work professionals as the ones that were likely to be involved in such conversations with family. Social workers were also thought by many to be the person in the facility used to having difficult conversations, so there is facility staff support for such ideas informally currently.

Pre-ISE Event Implications

There are a number of implications from this research that could inform the Pre-ISE event climate in AL settings. Facilities could approach ISE in AL as normal, expected, and supported in several ways. This would improve the overall social condition
of AL residents, and begin to change some of the dialogue around life in the setting and ageing in general.

Practice

Reforming the intake process by asking general questions about the relational status of residents entering AL facilities should be considered. Questions do not need to be intrusive, or unnecessarily disclosing, but provides an opportunity to establish that the inter-personal relationship experiences in the setting are completely normal and not only expected, but anticipated. The intake process could include residents expressing their hopes and desires in regards to interpersonal relations. Participants in my research often portrayed rather abrupt discussions with family after an ISE event. Not surprisingly these abruptly conducted conversations were met by a variety of uncomfortable feelings among residents and family members. Adding a short set of questions to the intake process with attention to not adding to the already over-burdened process would establish an awareness of the potential of inter-personal relationships developing. This would also empower residents by acknowledging this essential component and their choice in what it looks like as they age in the setting. Social isolation among residents of long-term care is commonly reported (Slettebo, 2008). Negative health impacts are correlated to this isolation, yet the exact mechanisms related are not clearly understood (Cacioppo & Hawkley, 2003; Cacioppo et al., 2002). Those mechanisms need to be studied for better understanding so known negative health impacts could be avoided.

Care planning meetings should similarly incorporate inter-personal relationships of residents. As this research has found, there are informal care taking, supportive
networks operating in the setting of AL, as well as ISE. Participants recognized these as beneficial to those who engage in them in my interviews, so this should be brought into the care planning conversation. In cases where this type of interaction exists, fostering its continuance is perhaps advisable. In cases where it is not occurring for a resident, discussions with family involved in care could find potential connections among residents in the facility. For instance, former occupational roles, and military service were common themes around which these informal care networks were formed. Residents recalled memories of time in service with other residents and established deep bonds through these interactions.

Recognizing that there are myriad criteria used when considering an AL facility (i.e., look of the facility, amenities offered at the facility) in addition to cost, examining the impact of facility choice by the level of support or lack of support for resident relationships and ISE is needed. Of particular interest was the instance where a participant described a resident attempting to ‘pray the gay away’ from a staff member who was gay/lesbian identifying. In this case, it was resident to staff, but in cases where this may occur against a resident, their ability to change facilities or feel empowered to speak up may be influenced by the level of choice they have based on ability to pay the costs of a facility. Particularly in cases where the person may rely on a Medicaid-waiver for payment, it is important for this issue to be better understood.

Education

Educational programs for family, staff, and residents appear to be needed. The programs should include broad issues of ageism, the process of ageing, human sexuality
across the lifespan, healthy relationships, and other such topics. For family, the educational programs could be informational pamphlets not only made available, but specifically included in recruitment materials so that family receive the message that ISE is a completely normal part of aging.

Numerous examples of inappropriate responses by staff to ISE among residents were described in almost all of the interviews I conducted. The most common rationale offered was ‘this is not our job’. When faced with this, I would probe the participant as to how, in a setting that includes such incredibly intimate care of residents, that ISE was somehow established as a part or not a part of the job. In no case was I given a clear answer. Most often I was met with silence. This suggests that sensitivity training for all staff may be needed.

Accordingly, social workers employed in AL settings should develop and coordinate training classes about ISE among older adults for all levels of staff. One participant was asked about a training plan in the exchange below.

Interviewer: So a program that was aimed at sexual health and wellness that was put into place in the AL in your mind may actually start at the place of ageist beliefs and stereotypes and myths about aging. Participant: Yes. Absolutely. Absolutely.

So, at least according to this participant, there may be facility buy-in to such a plan.

Policy

Policy aimed at the issue of ISE should include programming in the facility that specifically supports couple interaction. One participant described how residents will sometimes make gifts in arts and crafts time for another resident. This was done because
of the resident’s initiative. Facilities should create programming that specifically promotes this type of behavior. Perhaps not in a romantic sense, but many of the participants described residents (or involved family of residents) bringing items to the facility for other residents who lacked involved family or resources to buy such items. In subtle ways this type of interaction could be promoted.

Unfortunately AL settings do not employ social workers in as clearly defined roles as in other settings such as nursing homes, and hospitals (Williams, 2002). However, the social workers who are employed in AL settings, should coordinate efforts with the NASW, to more forward an initiative to promote development of a specific resident right that speaks to ISE among residents. Establishing a specific resident right to ISE would formally recognize that ISE occurs in the setting. Establishing a specific resident right for ISE would also be a natural fit for social workers with our ethical principles and dual advocacy role. Being that the residents’ rights document was brought up in every interview, this document is familiar to all involved parties and its inclusion of this issue would bring clear and direct attention to the issue.

Perhaps in response to a shortage of higher education programs specifically focused on gerontology, the NASW has progressive credentialing for social workers interested in gerontological across all levels of general, advanced, and clinical social work practice. Known as the Social Worker in Gerontology (SW-G) certification, bachelor’s level social workers from accredited programs are able to receive specialized credentials. Information regarding ISE among older persons should be included in the curriculum. This would be a first step to begin increasing social workers employed in the setting, who may assist with promoting ISE among residents in AL.
Simultaneously these social workers should engage in policy change at the residents’ rights level. Resident rights were familiar to everyone I interviewed. These documents are written and codified in recognition of the fact that residents are in AL settings because they are vulnerable to various types of exploitation. However, they remain able to choose freely until determined unable. Each state maintains a residents’ rights in their respective states revised code and they should be reviewed for clarity on both ability to freely choose relationships, as well as freedom from sexual exploitation. Ohio’s Revised Code 3721.13 enumerates 32 rights of residents currently. Right number 22 as it is currently written is vague as to what it applies to. Adding the word ‘conjugal’ it would be clarified as written below

The right to assured privacy for [CONJUGAL] visits by the spouse, or if both are residents of the same home, the right share a room within the capacity of the home, unless not medically advisable…

The proposed addition of the word conjugal would add specificity in the intended application of this right. Additionally, written to reflect the similar right (number 27) to be “free from financial exploitation”, an additional resident right should be written that residents are “free from sexual exploitation”. In recognition that many staff members I interviewed felt a case-by-case approach was best, advocating for resident right policy change protects the integrity of facilities to implement maintenance of residents rights as they see best for their facility and residents. The resident right level policy change however simultaneously adds protections for residents in another known area of possible exploitation. The Hebrew Home at Riverdale, long recognized as a progressive facility in terms of policy it has developed, recognizes ISE as an issue and has developed facility policy that works in tandem with state resident rights to protect its aging residents.
Eventually perhaps more facilities would adopt similar policy in response to resident right change.

A number of barriers related to comfort communicating about this issue were present in this research. For instance, one participant expressed this in regards to speaking with a facility-employed psychologist concerning the care of a resident “the psychologist is probably close to my fathers age and I am standing there having sex conversations about somebody else with this person. And I am just like ‘oh dear god – this is just not right’.” Specifically related to ISE among residents, another participant said this

You know, I think that we always still want to pigeonhole this generation or these generations of people as, why are they doing that? Kind of a thing. But on the whole, I would have to say staff is like right on, good for you. I’d say there’s a few exceptions that people will say oh my gosh. And again, they come from the younger ones that don’t realize that older people can have feelings, too, as far as sexual feelings. They’re very good to the people they take care of, but they just put them in this pigeonhole and don’t think of them as an entire person a lot of the times.

Social workers are trained to engage in difficult conversations, so we should champion this cause and bring awareness to the issue on behalf of our clients.

Research

Research that aims to improve this Pre-ISE event climate should aim to understand a number of things. First, examining the intake and care-planning functions closely and identifying the nature of conversations regarding resident ISE and when they are best addressed. Next additional research should be conducted on the decision-making process by residents and family on how they select a facility for AL services. There are understandings about the entry into AL often being necessitated by some adverse health
event. However residents also move for other reasons, and understanding what impacts that decision is important. It should also be understood what choice there is should a resident not be satisfied. Do they move to other facilities, or manage the environment they are in?

In terms of educational programs, research should examine what programs of education work best, and under what conditions. When asked about the existing training, no one I interviewed was aware of trainings related to ISE in AL. The passage below elaborates

Participant: We do have computer courses that we are required to take, and they do touch on the topic. Nothing very detailed, but does pretty much tells you that you are to respect what people want, and you have to watch out for their safety as far as what’s going on, where it’s going on, who is it affecting, is it somebody that doesn’t want this done to them? But it’s a very short module.

Interviewer: Do you think that more training would be helpful?
P: I think so.

When asked about the best training approach, many advocated for a multiple level approach educating all in the facility on ISE.

I would start with doing it like the employee meetings, where it’s a mixture of, I have a feeling your social workers, your people in higher positions, are already pretty well versed in this. They’ve come from backgrounds of having to deal with all sorts of issues, and this would probably be something that they have run into before….I think probably the people that are giving the primary care would be the start. And have somebody there like the administrator and a social worker who could say, now if you have any questions you don’t want to ask in front of people, you want to come to one of us. But yeah, and maybe have the director, the medical director there also, might be a good idea.
There should also be explorations of the best ways to deconstruct complex issues of ageism and social stigmas around ageing to develop best practices in developing social interaction in the facility that is supportive and safe for residents to explore ISE.

**Post-ISE Event Implications**

There are also things that could be done to improve the condition of those residents who actively engage in ISE in AL. The participants I interviewed often relayed stories of a few residents who cycled through repeated ISE events, but relatively few of the participants discussed ways to manage that behavior safely. The issue was almost always escalated and then often re-directed to non-sexual behaviors. Facilities should be assessing consent ability on an on-going basis, and then educating residents on safe engagement in ISE so long as both partners retain consent ability. Consistent with maintenance of autonomy and respect of human relationships, re-directing should only be used when residents experience decline in ability to consent. Determining the precise mechanisms at play in how ISE events are escalated should be an emphasis of future research. Further exploration of the nature of bonds between resident and staff member may be an excellent place to start the exploration of understanding this process. Most of the participants I interviewed felt that the staff responded to ISE based on relationships with the residents, not concerns of liability to the facility. What characteristics of the relationship means should be more precisely identified. Does a staff member identifying a resident as someone who reminds the staff person of their grandmother impact the change of escalation? Similarly it was expressed that the relationship between staff member and resident family impacts decision-making. Does the relationship with the
family of the resident impacts the staff member’s decision-making more than their relationship with the resident? Exploring these intricate details and their differential impact on escalation of ISE events is critical.

Practice

The primary practice issue needing addressed, assuming a more supportive climate for ISE has been developed is determining resident ability to actively consent to such interaction. Only one facility that I visited had an informal policy in place that included standard instruments to assess choice, and a structure to develop a care plan based on this information for the resident. Given that so many residents in this setting experience cognitive impairments, developing valid and reliable assessment and care-planning tools is critically needed. The natural argument against such a plan would be that AL staff is already burdened with incredible responsibilities in the care of residents. However, it is also hard to argue that completely avoidable victimization, and sexually transmitted infections, their related cost to treat, and recovery time do not constitute a rationale for them being no different than any other training to avoid unnecessary suffering of residents.

Education

Educationally speaking, after active consent has been established, safe sexual expression could be covered in training classes. This could include alternative methods for sexual pleasure when a partner is not an option. It could also include adaptive sexual positions that decrease the chance of physical harm, while also addressing sexual health and safety could also be covered.
In my interviews the participants agreed that administration and staff both shared concerns for the safety of residents. Therefore educational efforts aimed at safe ISE engagement for those who participate in it would be appropriate. This would include educational programming for the resident on how, and why to use condoms. It would also address age-specific concerns to avoid over-exursion, or fall risks – that could contribute to health costs and other serious consequences.

Policy

None of the interview participants were aware of where information was kept in regards to resident ISE. This is very concerning given the amount of staff turnover in the facility, which would be assumed to hamper the ability to track resident issues like declining, or complete inability to actively consent to ISE. In the case of the participant who, when faced with ISE, and ignores it – this means that the informal policy of the facility could implicitly be to watch someone be victimized. Reforming the documentation of ISE and establishing clear standards to assess and track consent ability will stop ignoring the situation of ISE in AL facilities and decrease the chance of sexual victimization of residents.

The participants consistently identified the administration’s concerns for liability; therefore establishing a reporting format and repository would address these concerns. Families that had concerns could then be met with standardized, regularly conducted, and well-documented accountings for their related family member’s active consent to engage in such activities. It could also document educational engagement of the resident to
demonstrate the safest possible exploration of ISE by the resident to further allay concerns of family members.

Research

Lastly, in terms of research there needs to be a greater emphasis next on the resident of AL and their hopes, desires, and expectations as they relate specifically to AL residents’ ISE intentions while in residence. While there is an understanding that intimate and sexual desires are life-long, the ways that they change over time should be further explored. As previously mentioned, the generation of people aging into this type of care may be far more open to discussing these changes and advocating for change in the setting.

Because of feasibility issues, I collected data from AL staff members, so understandably the perspective of the resident was often lost in the staff member escalation, and facility response that were described. Building on my research, a future inquiry could re-visit the same facilities and begin to qualitatively explore the resident perspectives. One of the goals of this research was to discover what would be the best next inquiry for my future research career. My conversations with staff members consistently revealed that the issue of ISE resides among residents and the facility staff. Developing a better understanding of residents in this equation could inform years of future research.

Contrary to my initial assumption that family would occupy a more substantial role, our results were very unclear, so this would also be a next research inquiry. Generally speaking, family is important to the decision-making process as to what facility
to reside in, and family were involved in some ISE management, but this was not applicable in all cases. contradictorily, a lack of decision-making capacity didn’t necessitate family involvement, nor did this ability being retained preclude them from being involved. Understanding how, when, and why family is involved is a critical next step to understanding how to then bring them into the conversation of ISE specifically.

Large data sets that track things such as the frequency with which residents establish informal care-taking, intimate, and even sexual relationships in settings of AL are needed. While there is probably a lack of this data readily available, proxy measures could be used. For instance, tracking rates of STI’s or other reproductive health issues could provide estimates of who may be engaging in ISE. This would be particularly true in cases where known medical treatments or conditions do not presents risks for such health impacts in residents. Facilities could selected for participation in research based on significant rates of such health conditions in the facility. Beginning with understanding the frequency that ISE occurs in these settings is the first step. Then considerations like the health (i.e, mental, physical, emotional) benefits of such bonds could be tracked as well. This could lead to analyses of the healthcare savings that could be realized from utilization of these informal care systems that, at least in our data, was uncovered to have health benefits if managed properly among residents. That is, making sure that residents engage in physically safe interactions.

Conclusion

Chapter 6 presented the discussion of my results through the description of two operating climates in advance of, and in response to ISE events among residents of AL.
Prior to an ISE event there is a culture of silence regarding any aspect of resident ISE. This silence begins in larger society where ageist views, and stereotypes of the process of aging dominate public opinion. These ageist and stereotypical views further manifest themselves in a hesitance to address the issue of ISE at intake or during scheduled care-planning activities. Residents in AL care experience two distinct climates regarding their ISE. This first climate operates to discourage residents from engaging in ISE with other residents. In response to an ISE event there is the second climate that my results demonstrated. This climate was more aimed at managing the feelings of facility staff concerning resident. Most often the response was escalated, and very frequently the response was to re-direct the behavior to a non-sexual outlet. A relative few examples were given where the resident was re-directed in a manner that still allowed for ISE needs to be met. The common reason given for the escalation according to those I interviewed was a lack of education among staff that ISE is normal and expected.

In conclusion the recommendations offered are in line with the guiding principles of both the setting of AL, and the field of social work. Respecting autonomy, and empowering clients are essential functions of both fields. The interviews I conducted were incredibly awakening to the complexity of the many issues that inform the recognition and management of ISE in AL settings. This would be an important step towards respecting the value of human relationships. I believe this work was an incredible step to a long research career that aims to fully realize this goal.
Appendix A: Executive Director Participation Email

Dear Executive Director,

My name is James Carter from the College of Social Work at The Ohio State University. I am conducting my dissertation study to explore the issue of interpersonal relationships among residents of assisted living who possess decision-making capacity.

I am particularly interested in the perspectives of staff employed by assisted living facilities such as yours. We would like you to identify staff members who you feel would be able to speak to the policy and practice pertaining to resident interpersonal relationships in your facility best. Those staff members would be invited to participate in a 60-minute individual interview, during paid work hours, in a room or other private location in your facility this Autumn during a time the staff member arranges with me via email after we have obtained institutional approval at Ohio State.

Your agency’s participation is completely voluntary and will have no impact on your relationship with Ohio State in any way. All responses will be held confidentially. No data will be reported in such a way that your agency, or the staff member is individually identified.

I look forward to speaking with you about any questions you have. Please feel free to email me with any questions in the mean time at carter.684@osu.edu, or I may be reached via phone at 614.477.5125.

Thanks very much for your time,

James Carter
Appendix B: Semi-Structured Interview Schedule

Overall how would you describe the climate in your facility related to interpersonal relationships among residents in your facility.

Tell me about the policy in your facility regarding the management of intimate and sexual expression by residents.

In 1-2 sentences define Intimate Sexual

Resident Experiences and Concerns
- Explain the methods of input that residents have into policy in the facility around intimate and sexual expression.
- Describe typical resident expressions of intimacy and sexuality
- Describe any care taking you have observed between residents of the facility.
- How do care issues that are behaviors by residents get care planned.

Family Experiences and Concerns
- Explain the methods of input that families of the residents have into policy in the facility around intimate and sexual expression.
- Of those family members who advocate on behalf of their related resident, who are they in the family (daughter, DIL, granddaughter, physically close relatives, financial/pay decision makers, etc)
- Describe any concerns that are expressed at intake/maintenance by families about their family member resident and their intimate and/or sexual expression.

Facility/Staff Experiences and Concerns
- Explain the policy input level that staff and/or management have into policy in the facility around intimate and sexual expression.
- Describe the typical response by staff to expressions in the facility of intimacy or sexuality.
- Describe how issues identified by this staff rise to administration concern as opposed to a 'this is our job, do it' type response at gate keepers

Describe administrators’ concerns about intimacy and sexuality of residents.
Describe bedside care providers’ concerns about intimacy and sexuality of residents.

Describe the training in your facility related to intimacy and sexuality among residents.
Appendix C: IRB Consent Form

The Ohio State University Consent to Participate in Research

EXPLORING STAFF PERSPECTIVES ABOUT INTERPERSONAL RELATIONSHIPS AMONG PERSONS IN ASSISTED LIVING SETTINGS IN FRANKLIN COUNTY, OHIO: A PILOT STUDY.

Study Title:

Researcher:

Holly Dabelko-Schoeny, PhD, MSW
Associate Professor of Social Work,
The Ohio State University
College of Social Work
325 Stillman Hall, 1947 College Avenue, Columbus OH 43210
Phone: 614-292-8336

James R Carter, PhDc, MPH

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. The following information explains the objective, procedures, risks, benefits, restrictions, and requirements of this research study. Signing this form will indicate that this study has been explained to you, and that you agree to participate in it. The process of reading and signing this form is known as informed consent.

Your participation is voluntary.
Your participation in this study is completely voluntary and you may withdraw at any time. Your current and future employment will not be affected in any way.
Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

**Purpose:**
The purpose of this study is to explore the issue of interpersonal relationships among residents of assisted living facilities who possess decision-making capacity from the perspective of staff who work in these settings.

This study is being conducted at The Ohio State University College of Social Work. This study protocol has received approval by both the Ohio State University Institutional Review Board.

**Procedures/Tasks:**
You have been asked to participate in an individual interview because you are a staff member in a setting that provides assisted living services. Approximately 51 facilities that provide assisted living services were invited to participate in individual interviews conducted during this research study. Interview questions will gather demographic information about yourself, the nature of and response to interpersonal relationships among residents, and the policy development process relating to these interactions. The researchers will conduct one 60-minute interview session with you individually whenever is most convenient for your schedule. Basic descriptive data will be collected, including your age, gender, race/ethnicity, job title, degree/license and number of years working in the emergency room/hospital. To protect privacy, we will keep job title separate from other demographic information. Identifying information will be kept separate from analyzed data collected at all times in locked file drawers in the locked office of the PI. Recorded interviews will be transcribed. The recordings will be locked in separate files from analyzed transcripts.

**Duration:**
The interview will take approximately 60 minutes of your time, and will be conducted in a room or private location of your choice at your facility during a time that works for you and the research assistant.

**Risks and Benefits:**
*What are the possible risks, side effects, and discomforts of this research study?*
There is a possible risk that your identity or information will be required to be shared with others. In cases where a situation is revealed where a resident has been, or may be harmed, standard required reporting would occur. There is a possible risk that your identity or information may be revealed through a breach of data. Safeguards to prevent this occurrence are explained below. There are no known risks or discomforts in being interviewed.
What are possible benefits from taking part in this study?
There are no benefits to you in being interviewed, however, you may enjoy sharing your perspective with the researchers. Your participation may help understand and expand our knowledge about the topic of resident interpersonal relationships.

Confidentiality:
You will not be identified by name or identifying characteristics in the datafile or in any publication of research results. No identifying information will be disclosed in the publication or presentation of results. We will not share your identifying information or specific comments with anyone with whom you work.

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives:
You will not receive incentive for your participation in this research study. There will be no cost to you for participating other than approximately 60 minutes of your time.

Participant Rights:
You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at The University of Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:
For questions, concerns, or complaints about the study or if you are harmed as a result of participating in this study or for questions about a study related injury, you may contact the Principal Investigator, Dr. Holly Dabelko-Schoeny, at the numbers on the front page of this form.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you
may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.
Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject: ___________________________  Signature of subject: ___________________________  AM/PM

Date and time: ___________________________

Printed name of person authorized to consent for subject (when applicable): ___________________________  Signature of person authorized to consent for subject (when applicable): ___________________________  AM/PM

Relationship to the subject: ___________________________  Date and time: ___________________________

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent: ___________________________  Signature of person obtaining consent: ___________________________  AM/PM

Date and time: ___________________________


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