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A culture of change: Taking a person-centered approach to understanding sexual expression among long-term care residents

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A culture of change: Taking a person-centered approach to understanding sexual expression among long-term care residents

by

Merea Diann Bentrott

A dissertation submitted to the graduate faculty in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies

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Iowa State University
Ames, Iowa
2012

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CHAPTER 1

GENERAL INTRODUCTION

Over the next two decades, the United States will experience a substantial increase in the number of people reaching age 65 and older. This growth may be attributed to increased life expectancy resulting from medical advances (Cassel et al., 2001) as well as aging of the Baby Boomer generation, comprised of approximately 78 million Americans (Institute of Medicine, 2001). Compounding the sizable increase in this population are 8.8 million people in need of long-term care, with an expected growth to 12 million by the year 2000 (Cahill, South, & Spade, 2000). Considering these statistics, society must prepare for the changes that will occur as a result of these shifts in composition and forthcoming increases in life expectancy.

While older adults today have more options when planning retirement or choosing a care facility than in generations past, as a society, we must prepare for the healthcare and housing needs of this sizable population, and the challenges that accompany them. Long-term care facilities (LTCFs), also referred to as freestanding nursing facilities/skilled nursing facilities (NF/SNF), provide medical or non-medical assistance for people with chronic illness or disability (Medicare.gov, 2009). The state of Iowa is comprised of 400 facilities with a total capacity of 28,884 residents (Iowa Department of Inspections and Appeals, 2008). The state’s definition of free-standing NF/SNF facility is “a stand-alone distinct part nursing facility is a designation of bed and by floor, wing or contiguous room designation that denotes an organizational and physical space” (dia.iowa.gov, 2008). The majority of residents in this type of care facility suffer from chronic illnesses that affect the ability to perform activities of daily living (ADLs; e.g., dressing, bathing) or instrumental activities of
daily living (IADLs; e.g., managing finances or cooking meals) (National Center on Caregiving, 2005).

Traditional and authoritarian LTC environments of generations past have done little to encourage people to relocate loved ones to these settings or enter this lifestyle themselves. However, in recent years there has been a movement toward increased quality of care in long-term care (LTC) settings, and a shift towards whole-person wellness. Whole-person wellness considers multiple elements of influence within residents’ lives (e.g., physical, spiritual, social, emotional), and their independent and collective influence on residents’ overall well-being, contributing to an overall culture change in LTCFs (Center for Successful Aging, 2008). According to the Doty and colleagues (2008, p. 1), the culture change movement is currently underway, working “to radically transform nursing home care, and help facilities transition from institutions to home.” This process involves modifications to facilities’ physical and cultural environments to make them appear more home-like, and less sterile and institutional. Privacy and autonomy are often limited in LTCFs, proving it necessary to consider facilities’ physical and cultural characteristics (e.g., shared rooms for residents, level of involvement with residents, approachability of caregivers, ease of access to caregivers) (Bentrott & Margrett, 2011). Many LTCFs are making efforts to modify their environments from institution-like settings (e.g., long, wide corridors, hospital-like rooms) to comfortable, home-like atmospheres where residents’ choices prevail and older adults can enjoy many of the freedoms they were afforded while residing in their homes (Doty et al., 2008).

One key component in progressing towards cultural change in the LTC environment is preserving residents’ rights to freedom of sexual expression. Although, the topic of
sexuality among the aging, particularly in the context of LTC has often been neglected, it is gaining recognition as an important factor in the lives of older adults (Doll, 2011; Hajjar & Kamel, 2003; Hillman, 2012). Greater understanding is required of current policies and practices that address sexual expression and intimacy, and protect residents’ rights in long-term care settings. Clear institutional strategies and caregiver training in addressing sexual expression are necessary to establish consistent and ethical professional response policies.

**Literature Review**

Throughout history, sexuality has been an ever-present topic that permeates nearly every aspect of life. From the media and advertising industries to the academic disciplines of biology, religion, literature, and the fine arts, sexuality has remained a fascinating, if not controversial topic. Despite early recognition of the importance of sex throughout the various levels of human development (Kinsey et al., 1998; Shafritz et al., 2005), only recently has it gained recognition as a natural part of the aging process (Katz & Marshall, 2003) and a healthy component of whole-person wellness. Theorist Abraham Maslow’s (1943) research on human motivation illustrated the importance of sex in his well-known hierarchy of needs model, which places sex in a category of immediate physiological needs among the most basic of them all (e.g., food, air, and water) (Shafritz et al.). Maslow’s theory compliments the concept of whole-person wellness in that multiple levels of human motivation are considered, including sexuality, and no single need is isolated, as every need is related to the state of another (Shafritz et al.). Applied to the current study, if residents’ sexual needs are ignored, ridiculed, or degraded, other areas of their lives (e.g., “belongingness,” “love needs”) will be negatively affected (Shafritz et al.).
Discussions of sexual expression among the older adult population elicit a variety of responses. Traditionally, sexuality among older adults has been regarded as unnatural, unnecessary, or inappropriate (Hubbard et al., 2003). Recent studies highlight the physical and psychological benefits associated with sexual expression (Béland et al., 2005; Miles & Parker, 1999; Tenenbaum, 2009), and indicate, “regardless of age, sex is generally beneficial to one’s physical health” (Casta-Kaufteil, 2004, p. 72). However, sexuality, particularly among residents in the LTC environment, has proven difficult to define. Sexual intercourse, oral sex, masturbation, touch and stimulation, and signs of companionship, flirting, and romantic affection have all been included in previous definitions of sexuality (DeLamater & Karraker, 2009; Hajjar & Kamel, 2003).

Considering that caregivers’ responses to certain forms of sexual expression among LTC residents are inconsistent, with responses ranging from acceptance to eviction (Reingold & Burros, 2004), it becomes increasingly important for caregivers to gain awareness of residents’ cognitive status to differentiate among behaviors. The definition of sexual expression requires reconsideration when applied to cognitively impaired residents (e.g., persons with Alzheimer’s Disease) who may exhibit a number of sexually related behaviors considered inappropriate by mainstream society (e.g., hyper-sexuality, public displays of sexuality) (Dhikav, Anand, & Aggarwal, 2007).

Today, sexuality is gradually gaining recognition as a healthy need of older adults and a natural part of the aging process (Katz & Marshall, 2003). This shift in social attitudes may be attributed, in large part, to the Baby Boomers. Baby Boomers are a generation experienced in change. They have reshaped each decade as they have lived it—through antiwar protests and riots, civil rights movements, and social experimentation—which mark
events such as the Vietnam War, Woodstock, and the Sexual Revolution (Kindrick Patterson, 2007). This cohort’s momentum will carry throughout future decades via calls for political, technological, consumer, cultural, and healthcare change. As the Boomer generation grays, and drives cultural change, the historically taboo topic of sexuality as related to the older adult population will gradually lose its stigma.

Empowering older adults and prolonging sexual vitality

The recent impetus for cultural change and acknowledgment of the reality and value of sexuality in the lives of older adults are reflected by social media’s messages of vitality and empowerment in the later stages of life. Accompanying these messages are advances in medicine, including Viagra and Cialis (National Center for Biotechnology Information, 2012), which extend males’ abilities to remain sexually expressive by prolonging the duration of physical sexual capability.

Within the context of LTC, it is important for administrators to anticipate that residents will require health services and resources for managing sexual functioning. Administrators must be adept in understanding the physiological aspects of sex and the aging body, as well as the effects of disease and medication on sexual competency. Care plans for maintaining and regaining sexual competency must be considered, as well as effective methods for educating residents on sexually-transmitted infections and tools for protecting themselves from risky sexual behavior (Tessler Lindau & Gavrilova, 2010.) In return, residents may realize the benefits of maintaining their health (e.g., exercising, ceasing habits, such as smoking) as these changes positively impact sexual competency and prolong the duration of their sex life (Tessler Lindau & Gavrilova.)
Adapting environments

The growing recognition of sexuality as a natural and healthy need of older adults, as well as increasing demands for services and resources for managing sexual functioning, poses significant implications for the long-term care industry. LTCFs will be pressed to recognize that “older adults remain interested in sexual activity and continue to participate in sexual behavior, while residing in such settings,” and adapt their physical and cultural environments accordingly (Bentrott & Margrett, 2011, p. 402). A 2007 National Survey of Nursing Homes conducted by the Commonwealth Fund described a facility that employs culture change as one that takes a resident-centered approach and crafts the residents’ environments in ways which “care and all resident-related activities are decided by the resident; living environment is designed to be a home rather than institution; close relationships exist between residents, family members, staff, and community; work is organized to support and allow all staff to respond to residents' needs and desires; management allows collaborative and group decision making; and processes/measures are used for continuous quality improvement” (Doty et al., 2008, p. 4). Results revealed only 5% of 1,435 nursing homes surveyed perceived themselves as adopters of culture change as defined by the study, while 25% reported they met the definition "for the most part" (Doty et al., 2008, p. 4). The benefits of managing a facility from a resident-centered approach are apparent to these facilities, as they evidenced “higher occupancy rates, better competitive position, and improved operational costs,” compared to 43% of facilities whose administrators perceived their facilities as traditional and “not at all” or “somewhat” fitting the study definition of culture change (Doty et al., 2008, p. vii). These advantages demonstrate the importance of achieving balance between the cultural and physical
environments to better serve residents in these settings. Yet, the resident-centered movement has not been embraced by all facilities. Even where residents are influential (e.g., presence of residents’ boards), facilities may not consistently operate based on the fundamental idea that residents’ desires must be accommodated. Residents’ wishes must be acknowledged as a driving factor when determining policies and rules for LTCFs. Ignoring sexuality among residents in the context of LTC impacts each level within a residents’ system of influence.

The current study suggests the systems, bioecological, and critical theoretical approaches are well suited for understanding sexual expression in later life and driving policy, recognizing the value of sexual contact and intimacy for older adults residing in long-term care facilities.

*Theoretical perspectives for assessing openness to sexuality in LTC*

**Systems Theory.** The core assumptions of systems and bioecological theories, which emphasize wholeness and interconnection, are particularly suitable for examining sexuality among LTC residents. LTC residents’ systems are comprised of multiple members, including direct care workers (CNAs), administrators, policymakers, family members, environments, and residents. Through continual interaction, these members begin functioning as a self-regulated group. Therefore, an entire system must be assessed as a whole to be understood, as changes within one part of the system impact the other system parts (White & Klein, 2002). For example, training sessions aimed at educating Certified Nursing Assistants (CNAs) on proper response strategies for addressing sexuality among LTC residents promotes cultural change and positively impacts other members of the system. Conversely, resistance to acknowledging sexuality in the context of LTC and refusal to provide CNAs skills to address sexual expression discourages cultural change, negatively
impacting system members.

According to systems theory, members of a system determine relationships by establishing agreements with other members. Certain rules result from these agreements, and shape members, setting expectations for roles within the system (Morgaine, 2001). Based on these rules, maintaining a continual pattern of expected behavior can establish balance within the system or cause difficulties. For example, a CNA who considers same-sex relationships unacceptable, may discourage sexual expression between two male residents or two female residents, and attempt to limit their time spent together; thus, limiting their behaviors, regardless of whether the resident or his/her family members support the relationship.

**Bioecological Theory.** The person-centered approach of bioecological theory is also relevant to explore sexual expression among LTC residents. The individual is the focal point of this theory, while surrounding influences are considered (White & Klein, 2002). However, the environment is more than merely an immediate setting. Ultimately, the resident is a product, as well as a producer of his/her environment. To demonstrate the importance of environmental influences on LTC residents, Zeisel and colleagues (2003) developed an environmental checklist, which included items such as individual privacy, environmental character, and autonomy support to evaluate the concepts of wholeness and interconnectedness among parts of 15 separate nursing home systems’ special care units (SCUs) which provide healthcare and resources for treating the needs of residents who require special accommodations (e.g., Alzheimer’s disease and other dementias). Zeisel et al. reported the usefulness of this checklist to determine associations between physical and cultural environmental design and residents’ behaviors, including “episodes of agitation, aggression, psychotic symptoms, depression, and social withdrawal” (Zeisel et al., 2003, p.
Zeisel et al. determined factors associated with decreases in aggression, psychological problems, and expressions of agitation, including “privacy and personalization in bedrooms, residential character, and an ambient environment that residents can understand” (p. 709). Environmental factors “associated with reduced depression, social withdrawal, misidentification, and hallucinations included common areas that vary in ambiance and exit doors throughout the SCU that are camouflaged” (Zeisel et al., p. 709).

Bioecological theory posits that humans rely on one another, as well as their environment to meet their needs and provide support (White & Klein). Applied to LTC, residents rely on CNAs, nurses, administrators, activities directors, other residents, and family members in their environment to meet their physical, mental, and social needs. With regard to sexual expression in this context, support is necessary at the federal and state government levels, in the LTCF from administrators and staff, and from residents’ family members (Figure 1) (Bentrott & Margrett, 2011, p. 405). Breakdown at one level negatively impacts the relationships among and within other levels, decreasing the likelihood of successful outcomes overall (Bentrott & Margrett). Through application of this theory, problems that affect residents’ sexual expression can be identified.

Among caregivers who lack knowledge or skills to properly address sexual expression among LTC residents, barriers will emerge and residents’ rights will be violated. Administrators’ roles must be considered, as they interpret laws and implement policies, which may influence facility needs and determine caregiver access to training. Statewide policies must also be examined via interviews with LTC ombudsmen. Federal law requires representation by LTC ombudsmen in each U.S. state to advocate on behalf of LTC residents for quality care and preservation of rights in LTC facilities (www.ltcombudsman.org, n.d.).
The National LTC Ombudsman program is managed by the Administration on Aging (AOA), which requires representation by LTC ombudsmen in each U.S. state (www.ltcombudsman.org, n.d.). The laws enacted at this level facilitate administrator and caregiver behaviors, and oftentimes affect responses, which directly impact residents’ rights.

**Staff perspectives: The microsystem**

The system level at which members engage in direct interaction and establish relationships with residents is called the microsystem (White & Klein, 2002). Within this system lies a multitude of influences, including frontline workers (CNAs), family members, and even facility activities, meal times, and residents’ room locations. CNAs are likely to interact with residents most frequently and regulate interactions with regard to activities and time spent with family members, visitors, other staff members, and residents (Bentrott & Margrett, 2011). This role can prove difficult for CNAs, who must set aside personal beliefs and opinions to observe the policies of the LTCF that preserve residents’ rights (Figure 1).
Figure 1, General Introduction. Guiding conceptual model for protecting rights and preserving well-being and quality of life for LTC residents (after Huston, 2001; Bentrott & Margrett, 2011.)
Previous research suggests the influence of CNAs’ religious beliefs and upbringing on responses to sexual expression (Hillman & Strieker, 1994). In addition, “counter-transference” may occur, in which CNAs compare residents with the older adults in their own lives (e.g., parents) (Heath & White, 2002, p. 143). The feelings associated with this phenomenon are important to consider, as caregivers may experience greater discomfort and heightened emotional responses, if they relate residents’ experiences to personal or familial relationships.

For CNAs, addressing sexual expression among residents may generate feelings of embarrassment or fear of reprimands for addressing the behavior (Archibald, 2002) and result in ignored sexual behaviors or inaccurate reports of appropriate sexual expression mislabeled as problematic. Oftentimes, caregivers ignore occurrences of sexual expression to avoid the discomfort of personally facing the issue (Roach, 2004). Residents bear the consequences of thwarting sexual expression in the forms of health declines and discontent (Figure 2).

Research conducted by Margret Baltes and colleagues (1987) demonstrates the influence of CNAs on residents, suggesting LTC residents’ dependency on caregivers to accomplish nonessential tasks or ADLs (e.g., assistance in cutting food) may “accelerate aging, leading to muscle atrophy, deteriorating strength, and diminished motor skills” (Baltes et al., 1987). Additionally, they posit this type of dependency is socially learned (Baltes et al.). Considering these assertions, to ensure residents are not negatively impacted by CNAs’ personal beliefs, it is important for CNAs to acknowledge and become comfortable with their views on sexuality and avoid allowing them to affect professional practices, as they are likely to impact residents (Heath & White, 2002).
Figure 2, General Introduction. Results of caregivers ignoring older adults’ sexual expression, health, and safety in long-term care facilities (after Roach, 2009, p. 377).
At the microsystem level, relationships are bidirectional. Therefore, residents’ attitudes and behaviors affect CNAs’ attitudes and behaviors, and CNAs’ attitudes and behaviors affect residents’ attitudes and behaviors. For example, a resident who believes he/she is being closely watched or judged by a CNA for being sexually expressive may limit his/her sexual behaviors. Conversely, a CNA may avoid being near or limit the amount of time spent caring for residents who sexually express themselves, due to personal values or feelings of discomfort, which, in turn, impact their job. Feelings of uncertainty regarding the types of behaviors considered sexual may prevent CNAs from recognizing, addressing, or responding to sexual expression or even documenting them properly in residents’ care plans (Heath & White, 2002).

Influences among systems

Oftentimes, members of a residents’ system influence one another, as in the case when CNA training, a higher-level influence of the mesosystem (comprised of policymakers), impacts CNAs’ skills and knowledge (influences within the microsystem). Currently, CNAs lack training opportunities for learning about residents’ rights to sexual expression in LTC, the types of behaviors considered appropriate versus inappropriate, and effective response strategies. At the federal level, the National Association of Health Care Assistants (www.nahcacaes.org, 2012), established in 1995, is a professional association of caregivers with membership numbers reaching over 36,000 across 29 states. This organization works to “recognize the contributions caregivers make to long-term care” and “assure the highest quality of care was provided to the nation’s elders living in nursing homes, achieved by elevating the professional standing and performance of nursing assistants” (www.nahcacaes.org, 2012). Training
development is a primary goal of the organization, as are mentoring programs, and advocacy for important issues related to the LTC industry (http://www.nahcacares.org).

While the association offers caregiver training on multiple relevant and important topics that should be considered when addressing sexual expression among residents (e.g., "Conflict resolution: Techniques for achieving optimal success," "Caregiver leadership: Moving the quality of care toward excellence," "Being a great nursing assistant requires having a great attitude"), there are currently no courses offered specific to sexual expression (www.nahcacares.org, 2012).

Within the context of the current study, at the state level the Iowa Direct Care Advisory Council (IDCAC), which sets forth guidelines for CNAs (also referred to as direct care professionals), has established the goal of “developing a direct care training and credentialing system that is nationally recognized, provides responsive and flexible training, promotes the highest quality of care, and develops career pathways to professionalize the direct care workforce in Iowa” (www.idph.state.ia.us, 2011). The IDCAC offers three levels of training certification for CNAs, and one advanced career track, which provides optional certification credentials to CNAs who wish to have further education. Certain coursework is mandated for all direct care professionals and includes education on person-centered care, “body mechanics,” “communication,” and “interpersonal skills,” the “direct care professional system”, and “infection controls” (www.idph.state.ia.us, 2011). Specialty endorsements designed by subject experts are also offered to CNAs on a variety of topics (idph.state.ia.us, 2011). These trainings require approval by the Iowa Board of Direct Care Professionals. However, endorsement is typically optional and based on specialty (idph.state.ia.us, 2011). Common
endorsement topics include Alzheimer’s/dementia, brain injury, and medication aide (idph.state.ia.us, 2011). While the course topics offered through the IDCAC are certainly applicable to the LTC environment and essential to successful caregiving, there is currently no course or policy requiring sexual education. Support in the form of access to education that outlines appropriate responses to residents’ sexual expression and resources that aid employees in understanding residents’ sexual needs and rights to sexual expression are crucial.

A second organization, which provides professional development advice and guidelines for Iowa care workers, The Iowa Caregivers Association, has embraced the training guidelines mandated by the Iowa Direct Care Advisory Council’s (iowacaregivers.org, 2011). This group has formed a partnership at the federal level with the National Association of Health Care Assistants (NAHCA). In November 2007, the NAHCA organized the Coalition to Protect Senior Care (CPSC) with the goal of “advancing policies that support and promote quality and help spur continuous quality improvement” (www.nahcacares.org, 2012). The coalition boasts 150,000 members, and is influential at the national, state, and local levels as a result of educating older adults, family members, caregivers, federal and state policymakers, and the general public about the caregiving profession (www.nahcacares.org).

Higher-level systems: Administrator

Operating at the mesosystem level of residents’ systems are long-term care administrators. While the administrative role varies significantly, depending upon individual facility needs, administrators typically facilitate relationships between structures (e.g., relations between residents, relations between residents and CNAs) in the
residents’ microsystem (White & Klein, 2002). For example, an administrator may continually assign a CNA to provide care for a resident because they consistently demonstrate they work well together, which is likely to positively affect both the resident and the CNA.

Administrators face the difficult task of satisfying multiple layers of the residents’ system. While observing government laws and regulations, they must also meet the needs of CNAs and other staff members, who are most likely to directly encounter sexual expression among residents. Administrators must promote training that addresses sexuality and aging in the LTC context and provide CNAs opportunities (privately or within a group setting) to openly communicate their feelings about their job.

Oftentimes, administrators face challenges presented by residents’ family members. With regard to the cognitively capable resident, the desires of family members must be heard and considered, as they typically have significant influence on their loved ones, but not allowed to obstruct residents’ rights. Administrators must adhere to laws which protect residents’ rights, regardless of threats of legal action against a facility presented by family members, who do not support sexual expression for their resident. A proactive approach to discussions of sexual expression with residents and family members must be used to address the topic upon residents’ admission to a facility. Continual communication among all systems is imperative to achieving a desired level of acceptance of residents’ sexual expression and promoting cultural change in the LTC environment (Bentrott & Margrett, 2011).

*Higher-level systems: Policy perspectives*

Policymakers comprise the exosystem or outer level of the residents’ system.
While policymakers do not directly interact with residents, they influence their functioning through associations with structures within residents’ microsystems (White & Klein, 2002). Policymakers develop laws that determine policies in LTCFs that affect the administrator, and CNA roles and responsibilities, residents’ and family members’ rights, facility activities, and resource allocation. The Federal Nursing Home Reform Act, established in 1987, mandates residents’ “right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits, and meetings of family and of resident groups” (www.law.cornell.edu, 2010). Additionally, the law specifies under the access and visitation rights clause, nursing home facilities must “permit immediate access to a resident, subject to reasonable restrictions and the resident’s right to deny or withdraw consent at any time, by others who are visiting with the consent of the resident” (www.law.cornell.edu). The subjectivity of the language of these laws results in varying opinions within the LTC industry over what is considered a “reasonable restriction” by “others who are visiting with the consent of the resident” (www.law.cornell.edu). Examples of reasonable restrictions are not provided and whether other residents within a facility are considered visitors is unclear, nor specified within the law. The language of this policy should be clearer and provide examples to further illustrate the meaning of the broad terminology. For example, the terms “visitors” (other residents?), “accommodations” (private spaces for sexual expression?), “access” to residents (admittance to the residents’ room?), and “reasonable restrictions” (determined by whom?) are unclear, and a resident may interpret their meanings differently than an administrator or CNA, leading to disagreements or infringement of residents’ rights (www.law.cornell.edu).
Critical Theory. Also relevant to the current study, are multiple assumptions within the critical qualitative paradigm. The researcher identified a particular area of concern, advocating for change in LTC with respect to residents’ rights to sexual expression, upon which assumptions have already been made. Another goal is to challenge these assumptions with the intent to broaden the population’s views and opinions on the topic, including those of older adults.

Critical theorists focus little on specific or identifiable variables that affect behavior, favoring rich interpretations of social interactions over distinguishable factors that determine cause and effect. The framework calls for social change through recognition of the roles of various systems (e.g., political, social, cultural) to restrict individuals’ attempts at betterment (Schofield-Clark, n.d.). Consistent with the current study objective to identify barriers to sexual expression for residents of LTCF, critical theorists aim to point out inconsistencies, problems, power differences, and biases, which impede efforts at improvement and emancipation (Schofield-Clark, n.d.).

Critical methodology involves the researcher posing questions to a group, organization, or culture and asking participants to reflect on their experiences with regard to a set of values or concepts applicable to their experiences. It involves multiple methods (e.g., interviews, observations, document analysis) of data collection, particularly dialogic in nature. These methods are used in the current study, which assesses the knowledge, experiences, and perceptions of LTCF administrators, CNAs, and LTC ombudsman through interviews, and examines the LTCF physical and cultural setting via observations and environmental checklists.
Study Purpose

The long-term goal of this research is to increase the consistency of responses to sexual expression among LTC residents, thereby alleviating caregiver frustration and stress, as well as increasing quality of life for older adults residing in these settings. The aforementioned papers are thematically and systemically linked, as evident when considering the levels ascribed within the bioecological framework. Additionally, they contribute to the study goals through examination of factors that impede sexual expression among residents, and identification of factors which support an environment conducive to freedom of privacy and sexual expression. Enhanced knowledge of residents’ rights and administrators’ expectations of caregivers, coupled with greater communication with residents and their families will increase the likelihood that caregivers make informed choices when responding to sexual expression among residents.

Table 1, General Introduction. Methodology guiding interaction with each constituent group.

<table>
<thead>
<tr>
<th>Constituent</th>
<th>Methodological Tool</th>
<th>Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrators</td>
<td>Interviews, Vignettes</td>
<td>Residents’ rights to sexual expression, caregiver and administrator response strategies, effectiveness of current laws and regulations, vignettes, and sexual education and training.</td>
</tr>
<tr>
<td>Certified Nursing Assistants (CNA)</td>
<td>Individual Interviews</td>
<td>Attitudes toward residents’ rights to sexual expression, barriers to sexual expression, and typical and recommended responses to sexual expression. Vignettes and policy examples with open-ended discussion questions, discussion of CNAs’ attitudes, opinions toward resident’s rights to sexual expression, barriers to sexual expression, and typical and recommended responses.</td>
</tr>
<tr>
<td>Ombudsman</td>
<td>Interviews</td>
<td>Current methods for assessing and grading LTCF on physical, social, and cultural environments, course of action for filed complaints, training and other materials for agencies/the public regarding sexuality and residents’ rights, policy and procedure recommendations.</td>
</tr>
</tbody>
</table>
Systems, bioecological, and critical approaches were used to guide the study and determine the suitability of the physical and cultural environments of LTC facilities. Perspectives of administrators and LTC ombudsmen were assessed, and guidelines and strategies for managing residents’ sexual behaviors identified. See Table 1 for the methodology guiding interactions with each of these constituent groups. Current policies were examined and suggestions for effective LTC facility responses were incorporated into policy and training recommendations to address sexual expression among residents.

**Ethnographic Methodology**

An ethnographic approach was utilized throughout the study to facilitate interpretive and descriptive analyses of the meanings and collective cultural patterns of the groups (Creswell, 2007). This methodology is particularly relevant to the current study’s objectives of interpreting, understanding, and describing the impact of LTC environments (physical and cultural) on residents’ sexual expression, as well as LTC administrators’ attitudes and opinions towards sexual expression among residents. Multiple methods, commonly incorporated in ethnographic studies (Creswell), were utilized for data collection, including face-to-face interviews using open-ended questions, environmental observations, and researcher observations. Interviews were audio taped and transcribed. Environmental (physical and cultural) observations were conducted at each participating LTCF. Additionally, the researcher wrote analytic memos to chronicle personal reflections, and field notes were recorded throughout observations and interviews.
Protection of Human Subjects

The Iowa State University Institutional Review Board (IRB) reviewed the research proposal and provided approval for data collection (Appendices A through E). Five nursing home administrators and two LTC ombudsmen voluntarily consented to individual interviews. None of the participants were members of a vulnerable population.

There were no major risks anticipated to participants, with the exception of the possibility of discomfort at disclosing information in response to some of the questions, as they are sensitive in nature. Information collected by the researcher remained confidential and only the primary investigator, major professor, and a limited number of trained research staff had access to actual identifying information. Pseudonyms were assigned to replace personal identifying information to further ensure confidentiality.

Participants were not coerced into joining the study, and prior to requesting signed consent and conducting interviews, they were notified of their rights to decline to answer questions or address certain topics, or terminate their participation in the study at any time throughout the research process without explanation. No costs to participants were incurred for participating in the study. Administrators were provided a $25 gift card to compensate for time and effort for their assistance with the study.

Ensuring Rigor and Trustworthiness

According to Golafshani (2003, p. 604), to achieve trustworthiness, quality, and rigor imperative to qualitative research, there must be an absence of bias and an “increase in researcher’s truthfulness of a proposition about some social phenomenon using triangulation.” Among qualitative researchers, it is widely recommended that a combination of strategies for ensuring rigor and trustworthiness is employed (Bowen,
The current study adhered to these suggestions, utilizing multiple methods of verification. Triangulation was employed through analysis and comparison of numerous data sources and methods, including interviews, observations, vignettes, field notes, and analytic memos. Rich, thick descriptions, and literal statements and quotations offered by participants have been included in study results to support the researcher’s assumptions, highlight experiences, and provide participants a voice, which illustrates the importance of their contributions to the research (McMillan & Schumacher, 2006; Sandelowski, 1994).

Researcher reflexivity was demonstrated through written accounts, recording personal reflections, experiences, and biases throughout the data collection process in the form of analytic memos and field notes. This was useful for informing studies on the researcher’s lens for interpreting data. These self-reflexive summaries were frequently added and revisited throughout the duration of the study, and analyzed to contribute to themes and categories.

Two colleagues were consulted to conduct a peer review of the study, which involved determining the accuracy and consistency of data collection, interpretation, coding, and analysis. Both reviewers were doctoral students in a College of Human Science with a background in Gerontology and previous experience with qualitative research. Additionally, an individual with a doctoral degree and qualitative research experience who is unrelated to the study was asked to analyze the research procedures and perform an external audit, upon which raw data, field notes, and summaries of the researcher’s procedures, strategies, expectations and rationale were utilized to record research processes, per recommendations by Halpern (1983) (as cited in Lincoln & Guba,
1985, p. 310-319). The auditor concluded that the information provided a fair and accurate framework for preparing and reporting the research. Member checks were also conducted to verify authenticity of participants’ input, and provide participants the opportunity to validate or dispute researcher’s interpretations and reportings. Participants were emailed copies of their interview transcripts and summaries of the researcher’s interpretations, and contacted by the researcher one week later to discuss questions, concerns, and comments. All participants indicated the transcripts accurately portrayed their interview and had no concerns regarding the validity of the content or summaries. One administrator asked the researcher to verify that he/she would not be personally identified as the provider of the information from the interview, upon which the researcher referred the administrator to the confidentiality clause of the Administrator Informed Consent document.

**Researcher’s Perspectives**

As the primary researcher in this study, it was my objective to accurately interpret and describe the meanings and shared cultural patterns of LTC staff, as well as the impact of LTC environments on residents’ sexual expression to inform current policy and training guidelines. The set of beliefs that I brought to the research are consistent with a social constructivist, advocacy/participatory, and pragmatic epistemological worldviews, which are compatible with one another and will best inform the study. Through a social constructivist lens, I focused the research on subjective meanings of participants’ interactions with one another, and relied on the context of the LTC facility to understand the cultural environment (Creswell, 2007). Consistent with the advocacy/participatory worldview, the study called for the improvement of the lives of LTC residents.
Additionally, through my research I aimed to positively impact study participants’ attitudes and opinions towards sexual expression among LTC residents through discussions promoting understanding of residents’ needs and rights, as well as the suitability of cultural and physical LTC environments echoing pragmatic principles (Creswell). A qualitative design was best suited to conduct the research, which consisted of a LTCF environmental checklist, as well as qualitative interviews with LTC CNAs, administrators, and ombudsmen.

The nature of qualitative research affords the researcher active participation in data collection. I embraced this opportunity for interactions and value the rich data outcomes of face-to-face communications. Because I had an interactive role in the qualitative data collection process, it was important to recognize the personal experiences and beliefs that influenced my interpretation of the data. I am a female, who earned a Bachelor’s of Art degree in Psychology and Sociology from a small, private college, and a Master’s of Science degree in Human Development and Family Studies from a research institution, where I was working towards completion of a doctoral degree in Human Development and Family Studies. Because I am a Caucasian, middle-class woman from the Midwest, pursuing a doctoral degree, I acknowledge that I may have encountered difficulties relating to the experiences of those from varying racial, socioeconomic status, and educational backgrounds. At the time of the study, I did not have a relative or friend residing in a LTCF, and have never worked directly with residents in a LTCF. However, throughout my early childhood, a close family member was employed as the activities director of a small, non-profit nursing home. This was my introduction to the population of older adults. My family member’s reasons for resigning from the nursing home were
related to the perceived mistreatment of residents by other employees and the lack of support he/she received from administration upon defending the residents. The disrespect of residents and disregard of their rights made an impact on me that influenced my evaluation of the research.

Without question my interpretation and subsequent writing of participants’ input and the overall culture of LTC were influenced by my sex, culture, social class, education, and religious and political views. As a qualitative researcher, it is critical to recognize the presence of such factors, and acknowledge the impact they may have on participants and readers. As a researcher, I continually evaluate my personal biases, experiences, and beliefs and question how this might affect the data collection process and my interpretations of these data. These personal reflections have been chronicled in memos and recorded in field notes that have been revisited throughout the duration of the study (Appendix F).

**Dissertation Organization**

Consistent with the non-traditional dissertation format, three papers were developed in response to the goals of the research study. Throughout the first paper, the suitability of the physical and cultural environments of LTC facilities and their impact on the scope of residents’ sexual expressions were determined, including barriers to sexual expression. Additionally, the article provides better understanding of cultural competency within LTCF by assessing adoption of cultural change as related to sexual expression among residents. The study will yield a publication submission to the *Journal of Applied Gerontology*, which publishes research articles relevant to the quality of life and healthcare for older adults. The current study contributes recommendations for culture
change in LTCFs as related to residents’ sexual rights, as well as practice implications to create suitable physical and cultural LTC environments.

The second paper explored the attitudes, barriers, knowledge, and practices of long-term care administrators regarding sexual expression in long-term care facilities. It is hoped that this research will provide administrators with information to aid them in enacting policies addressing resident’s sexual expression and assist them in providing training to caregivers to enable residents to appropriately express their sexual needs. It is expected the proposed study will yield a publication in the journal of Health Care Management Review (HCMR). The journal takes a multidisciplinary and theoretical approach to address relevant issues within health care systems with regard to leadership, administration, and management. This study contributes a theoretically-based commentary of LTC administrators’ leadership responsibilities to manage sexual expression among LTC residents. The discussion focuses on policies and procedures, influences on residents’ privacy and freedom of sexual expression, and strategy recommendations for addressing sexual expression in the LTC environment.

The third paper is a perspectives piece that examined existing legislation and institutional policies regarding sexual expression in LTC settings, utilizing input from LTC ombudsmen to inform recommendations to enhance current policies, and provide feedback for effective training guidelines for LTC staff. The paper contributes to a publication in a top-tier journal such as Sexuality Research and Social Policy, which takes a multidisciplinary, international platform dedicated to sexuality research and the implications of this research on social policies related to “sexual health, sexuality education, and sexual rights in diverse communities” (http://www.nsrc.sfsu.edu, n.d.).
The publication addressed current legal policies and training guidelines for administrators and CNAs in long-term care settings, and offer policy and training recommendations, which proactively address sexual expression among LTC residents with administrators, CNAs, residents, and their family members.
Chapter One References


CHAPTER 2. IMPACT OF PHYSICAL AND CULTURAL ENVIRONMENTS ON LONG-TERM CARE RESIDENTS’ SEXUALITY: MARKERS OF CULTURAL CHANGE

A paper to be submitted to the Journal of Applied Gerontology

Merea D. Bentrott¹, Jennifer Margrett², MaryJane Brotherson³

Abstract

Research recognizes the considerable influence of environment on individuals’ quality of life, of which sexual expression is an important component. Regardless of the living environment, older adults remain interested in sexuality. Therefore, the physical and cultural environments in which they live are important to consider in relation to sexual expression. Utilizing environmental observations, administrator interviews, and researcher observations this qualitative study assessed five Midwestern long-term care facilities and aimed to (1) identify barriers to LTC residents’ sexual expression (2) provide better understanding of the suitability of the physical and cultural environments of the LTC facilities for sexual expression among residents and (3) provide better understanding of cultural competency within LTCF by assessing adoption of cultural change for sexual expression among residents. LTCFs demonstrating resident personalization, offering individual privacy, and presenting high residential character (homelike qualities) faced fewer barriers to promoting successful environments for aging and sexual expression, and were considered more culturally responsive environments. A LTCF was considered to have a culturally responsive environment when it had

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² Associate Professor, Department of Human Development and Family Studies, and director of gerontology program, Iowa State University.
³ Professor, Department of Human Development and Family Studies, Iowa State University
characteristics, including protection of residents’ privacy, autonomy support, and policy implementation. These characteristics were considered indicative of a culturally responsive environment and aided the researcher in determining a facility’s ‘ability to embrace cultural change. One participating facility was considered hesitant to embrace cultural change, one facility deemed neutral, two facilities ranked between neutral and strivers, and one facility between strivers and adopters of embracing cultural change.

**Introduction**

Designing optimal physical and cultural environments, conducive to the challenges that accompany aging, remain crucial in preserving quality of life for the rapidly growing population of older adults. While the majority of U.S. older adults continue to live in their homes for as long as possible through the aging process (Morley, 2012), many have illnesses and/or needs that cannot be met in the home by family members or loved ones, and necessitate greater measures of healthcare that can be provided in long-term care (LTC).

The benefits of creating living spaces, which promote “choice and control, community, physical support, normalness/authenticity, cognitive support, comfort and personalization,” are profound (Parker et al., 2004, p. 960). Multiple physical and cultural characteristics of the LTC environment, including “unit layout, supportive features and finishes, reduced noise, as well as access to outdoor spaces,” have been positively associated with residents’ “improved sleep, better orientation and way-finding, reduced aggression and disruptive behavior, increased social interaction, and increased overall satisfaction and well-being” (Joseph, 2006, p. 3). Homelike features, resident personalization, and a “culture that encourages spontaneity and close relationships
between staff and residents and gives residents more choices and control over their lives” has also been linked to improved quality and overall resident satisfaction (www.ahrq.gov, 2012). The impact of LTC staff has also been demonstrated by research, suggesting “The attitude, competence and helpfulness of the staff creates the atmosphere of the ward regardless of layout, furnishings, equipment and décor” (Rowlands & Noble, 2008, p. 768).

While some long-term care facilities (LTCF) are making efforts to modify their environments from institution-like settings to home-like atmospheres (Doty et al., 2008), many LTCFs face barriers to adapt their environments, particularly with regard to matters of residents’ rights to privacy and sexual expression. The purpose of this study was to (1) identify barriers to LTC residents’ sexual expression (2) provide better understanding of the suitability of the physical and cultural environments of the LTC facilities for sexual expression among residents and (3) provide better understanding of cultural competency within LTCF by assessing adoption of cultural change for sexual expression among residents.

Understanding cultural responsiveness

The topic of sexuality among residents in the LTC environment often elicits uncomfortable or embarrassed responses from professional caregivers (e.g., CNAs), who are most likely to directly encounter instances of sexual expression in this setting. Despite stigma associated with sexuality in this context, previous research suggests many older adults would embrace the opportunity to discuss their sexual health, needs, and desires (Nusbaum et al., 2005). Their desire for disclosure demonstrates the need for LTCFs to address sexuality through a person-centered lens, asking residents their opinions, needs,
and wants with regard to sexual expression in the LTC setting.

According to the National Association of School Psychologists (as cited in Davis, 1997), cultural competence is defined as “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services; thereby producing better outcomes.” Furthermore, cultural context is “created and mediated by the development of shared meaning by both professional caregivers and residents” (Hubbard et al., 2003, p. 110). For administrators and CNAs, this means demonstrating attitudes of awareness, acceptance, and respect of the conditions and influences surrounding residents’ sexual needs and desires, and communicating this understanding to residents. Topics, that have previously been avoided or ignored, require increasing recognition in the context of LTC today. Media coverage of medicinal interventions for treating sexual impairment (e.g., Viagra) have heightened awareness of older adults as sexual beings and decreased stigma surrounding the topic, and must be considered in the context of LTC. Sexual diversity among this population (e.g., same-sex relationships) is also being recognized with greater frequency. Today’s population of lesbian, gay, bisexual, and transgender (LGBT) older adults are considered “the last generation to have lived their adolescence and young adulthood in hiding” (Hunter, 2005, p. 13). This is largely due to growing acceptance at both the legal and social levels related to greater demonstrations of openness in living among the LGBT population (Knauer, 2012). Still, there is progress to be made, as the LGBT population continues to “face significant discrimination from senior care providers, including in places where we are most vulnerable, such as assisted living facilities and end-of-life care” (hrc.org, 2009).
Therefore, cultural responsiveness is dependent upon multiple factors, which collectively determine how proficiently LTCFs apply knowledge and understanding of older adults to caregiving standards.

The fundamentals of cultural change are driven by person-centered care, defined as “the assurance of individuality, choice, privacy, dignity, respect, independence, a sense of being part of a community and connected to the larger community, and a home environment in which to reside” (www.achca.org/, 2010). Multiple factors related to these care objectives must be examined, as they affect residents’ rights to sexual expression. The Pioneer Network is a multidisciplinary professional group that promotes cultural change and advocates for older adults in a multitude of living environments. This organization asserts that oftentimes, “the basic need for excellent service has been overshadowed by a single-minded adherence to numerous state and federal regulations, medical regimens and cost pressures, even though service and an environment conducive to healthy living were stated objectives of the organizations” (www.pioneernetwork.net, 2012). Thus, the mission and basic principles of LTCFs and the goal of person-centered care are largely unmet.

*Creating respectful physical environments*

Previous research has established the importance of physical design for LTCFs and its significant impact on quality of life for residents in these settings (Joseph, 2006; Parker et al., 2004). The LTC environment has proven implications for residents’ cognitive and physical health, and abilities to participate in social and recreational activities (Joseph, 2006; Kayser-Jones et al., 2003). Features within the built environment, such as indoor and outdoor spaces, room size, status (shared versus
private), location, and even dining ambiance and food presentation have been found to impact residents’ well-being and social participation (Mathey et al., 2001; Parker et al., 2004). The effects of these and other environmental factors are particularly evident with regard to residents’ personal rights to privacy and sexual expression.

Typically, residents’ rights to sexual expression are encompassed in privacy and dignity issues, and tangible features within the built environment supportive of sexual expression are not contemplated. Therefore, accommodating sexual expression is more often considered the residents’ personal issue to be resolved independent of LTCF, rather than facilitated through it. The importance of providing physical surroundings to accommodate residents’ sexual expression was emphasized in one Long-Term Care Ombudsman’s recount of a legal complaint regarding residents’ continual use of a “sex bench.” The complainant cited excessive use of a bench, mostly concealed from public view, but still sitting in a public location that had become well-known to residents as a place they could go to sexually express themselves with another resident. This space was not private, nor accommodating to some of the physical limitations of the residents; however, because they were not provided a private space to sexually interact, it was considered the only option residents had if they wanted to sexually interact with another resident. Such examples illustrate the need for LTCFs to be constructed with factors, such as privacy and space, for residents to interact (Kayser-Jones et al., 2003), opportunity for personalization in residents’ rooms and “residential character” (e.g., perceived crowdedness, homelike qualities) in mind.

This study examined several aspects of LTCFs. First, it identified barriers to LTC residents’ sexual expression. Secondly, it provided better understanding of the suitability
of the physical and cultural environments of the LTC facilities for sexual expression among residents. And third, the study examined the cultural responsiveness of the LTCF to understand the cultural context and examined how facilities embrace cultural change towards sexual expression among residents. The overall aim of this study was to understand how LTCs support the role of sexuality in the lives of older adults.

Design and Method

Participating long-term care facilities

Five LTCFs participated in this study. Participating LTCFs consisted of two Midwestern urban LTCFs, one non-profit status (Site A), the other for-profit ownership (Site B), and three rural LTCFs, one non-profit, church-related status (Site C) and two for-profit ownership (Sites D and E). At the time of the study, the three rural facilities were certified for 50, 60, and 180 number of beds, and the two urban sites were certified for approximately 120 and 140 beds. All facilities offered skilled nursing care and restorative nursing services, while Sites B and E offered respite care as well. Sites B and C (both rural) and Site E (urban) offered residents hospice care. However, only Sites A and B had memory care Alzheimer’s units. Sites A and B, as well as the largest rural facility (Site C), offered assisted living and independent living. All facilities accepted Medicare and Medicaid and were privately owned. Sites A and C were religiously affiliated, offering community and individual church services throughout the week. Average age of the population for the majority of LTCFs was between 75 and 80 years, with the exception of Site C. It represented a slightly older population (e.g., 80 years and over) of “very frail” older adults. Sites C and E reported 90% or a majority of female residents, while Site D said females represented roughly 75% of their population. Sites A
and B reported having approximately 70 and 64%, respectively, female residents.

Resident ethnicity at four of the LTCFs was primarily Caucasian, with a small percentage of African American, Hispanic, and Asian residents. At the time of the study, Site A consisted solely of Caucasian residents (Table 1).
Table 1, Chapter 2. Long-term care facility demographics

<table>
<thead>
<tr>
<th></th>
<th>SITE A</th>
<th>SITE B</th>
<th>SITE C</th>
<th>SITE D</th>
<th>SITE E</th>
</tr>
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<tbody>
<tr>
<td>Overall CMS ranking Stars</td>
<td>***</td>
<td>New facility-no ranking</td>
<td>****</td>
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</tr>
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<tr>
<td>Population Average age</td>
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<td>Population % female</td>
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<td>50</td>
</tr>
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</table>

Note: X indicates “Yes”, Absence of X indicates “No”
Procedures

Upon receiving approval for the research study by the university Institutional Review Board (IRB), participating LTCFs were recruited from the Centers for Medicare and Medicaid Services (CMS) Five-Star Quality Rating System list of Iowa Skilled Nursing Home Facilities ratings which contains data assessing the adequacy of 443 certified Iowa Medicare and Medicaid nursing homes in the areas of health inspections, staffing, and quality measures (medicare.gov, n.d.). This rating system was developed to help individuals, families, and caregivers recognize specific areas of importance to assist them in making comparisons among long-term care facilities and ultimately choosing a facility (medicare.gov, n.d.). Prior to selection, facilities were placed in either a rural or urban sample list, depending on their locale. Using systematic random sampling procedures, the researcher selected three facilities from the rural list and two from the urban list were identified for participation in the study. The study included facilities that earned higher scores (i.e., better performing facilities) as well as those with lower scores on the CMS Five-Star Quality Rating System of Iowa Skilled Nursing Home Facilities. One participating facility scored four stars on the CMS Quality Rankings, one facility scored three stars, two facilities scored two stars, and one facility had not yet received a ranking because it opened within the past year and had not yet been evaluated by CMS. It is important to note the quality ratings for each LTCF selected were expected to relate to the physical and cultural environments, qualifications of administrators and caregivers employed, frequency, availability, and adequacy of training, and also whether policies are developed and executed at these LTCFs.
Upon selection, LTCFs administrators at each site were called by the researcher and approval was requested for a guided tour of the facility and interview with the administrator on occasion, as well as researcher observation of the LTCF’s physical and cultural environments. Administrators at the first three rural LTCFs randomly selected agreed to participate in the research. Administrators at the first two urban LTCFs selected declined the researcher’s invitation to participate in the research. Therefore, the two urban facilities that followed in the random selection process were contacted, upon which the administrators agreed to participate.

*Environmental observation.* Throughout facility tours, the researcher identified specific environmental characteristics which were interpreted as indicative of the suitability of the physical and cultural environments of the long-term care facilities. Physical characteristics such as the types of services offered (e.g., skilled nursing, memory care/Alzheimer’s unit), facility (e.g., urban or rural location, public or private ownership) and resident (e.g., ethnicity) demographics, and written policies regarding residents’ rights, sexual expression, safety and physical health were noted. (Table 2).
### Table 2, Chapter 2. Environmental and Cultural Observation Characteristics

<table>
<thead>
<tr>
<th>Physical Environmental Characteristics</th>
<th>Cultural Environmental Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Types of services offered:</strong></td>
<td><strong>Privacy</strong></td>
</tr>
<tr>
<td><strong>Facility and Resident Population</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Written policies regarding residents’ rights, sexual expression, safety and physical health</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Independent Living</strong></td>
<td><strong>INDIVIDUAL PRIVACY</strong></td>
</tr>
<tr>
<td>Admissions criteria</td>
<td>• Private bedrooms Y/N</td>
</tr>
<tr>
<td>• Accept Medicare/Medicaid?</td>
<td>• Semi private rooms Y/N</td>
</tr>
<tr>
<td>• Public/Private?</td>
<td>• If yes, describe any privacy measures (e.g., curtain)</td>
</tr>
<tr>
<td>Residents’ rights Policy? Y/N</td>
<td>• Larger number of private bedrooms</td>
</tr>
<tr>
<td>• If Yes, posting location?</td>
<td>• Bedrooms with entrances away from common spaces</td>
</tr>
<tr>
<td>• Policy description</td>
<td>• Presence of private spaces that are not bedrooms</td>
</tr>
<tr>
<td></td>
<td>• Privacy signs</td>
</tr>
<tr>
<td></td>
<td>• Ability for residents to lock their doors</td>
</tr>
<tr>
<td></td>
<td>• Opportunity for residents to interact privately</td>
</tr>
<tr>
<td></td>
<td>• Guest facilities or a room for residents to check out similar to a hotel</td>
</tr>
<tr>
<td></td>
<td>• Describe other privacy measures enacted</td>
</tr>
<tr>
<td><strong>Assisted Living</strong></td>
<td><strong>RESIDENT PERSONALIZATION</strong></td>
</tr>
<tr>
<td>Non-profit or Profit?</td>
<td>• Availability of adequate space for sexual expression</td>
</tr>
<tr>
<td></td>
<td>• Encouragement of personal items (e.g., furniture, photos, personal objects)*</td>
</tr>
<tr>
<td></td>
<td>• Resemblance to “home-like” bedroom</td>
</tr>
<tr>
<td><strong>Skilled Nursing Home</strong></td>
<td><strong>COMMON SPACE</strong></td>
</tr>
<tr>
<td>Religious affiliation</td>
<td>• Appropriate number common spaces considering capacity*</td>
</tr>
<tr>
<td></td>
<td>• Opportunity for interaction</td>
</tr>
<tr>
<td></td>
<td>• Ease of access/use of common spaces for interaction*</td>
</tr>
<tr>
<td></td>
<td>• Comfort of common space environment (noise levels)</td>
</tr>
<tr>
<td></td>
<td>• Access to outdoor common spaces for resident interaction*</td>
</tr>
<tr>
<td>Table 2. Chapter 2. (continued)</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td><strong>Memory Care/ Alzheimer’s Unit</strong></td>
<td><strong>Urban or Rural</strong></td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospice Care</strong></td>
<td><strong>CNA Rotation? (How often, same area or different?)</strong></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respite Care</strong></td>
<td><strong>Mission statement?</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Population served</strong></td>
</tr>
<tr>
<td></td>
<td>• Average age</td>
</tr>
<tr>
<td></td>
<td>• % female</td>
</tr>
<tr>
<td></td>
<td>• Average education</td>
</tr>
<tr>
<td></td>
<td>• Ethnicities represented</td>
</tr>
<tr>
<td></td>
<td>• Number of residents per unit</td>
</tr>
</tbody>
</table>

* Items adapted from Zeisel et al., 2003
Researcher observations. Researcher observations recorded in the forms of analytic memos and field notes were also utilized in the overall analysis of LTCFs’ cultural competency. The use of analytic memos prompted the researcher to critically think and rethink the purpose of the study, and challenge personal assumptions, considering how thoughts and opinions may influence observations (Saldana, 2009, p. 33). Documentation of environmental observations and interpretations of characteristics of the LTC environment through field notes also provided insight into the cultural competency of each facility and informed the researcher’s decision of LTCF levels of cultural competency. For example, the researcher noted at one facility, “The physical atmosphere is very medical and old-fashioned, but I can see that they have made efforts to modernize and ‘soften’ the environment. There are plants everywhere and sticker quotes (e.g., biblical quotes and inspirational sayings), which later the administrator tells me are used to try and soften the “old institutional” model of LTC. The lighting is poor in some areas, the ceilings are very low, and there is a tremendous need to update the institutional feel in some wings of the facility. However, the recently renovated areas are warm, light, and very personalized for residents.” The aforementioned characteristics described by the researcher indicated that, although this facility was structurally outdated and faced barriers for making for cosmetic changes to the environment (e.g., lack of funding), they recognized the need for efforts towards cultural change and improvised where possible (e.g., paint, inspirational wall stickers), which suggested progress towards cultural competency.

Administrator Interviews. Throughout guided tours, the researcher utilized an informal conversational approach, relying on interactions with administrators to guide the
interview process and gain greater understanding of the LTC environment (McNamara, 2008). This informal interview design encouraged participants to freely offer information, and LTCF administrators provided a wealth of detail regarding their facilities (McNamara, 2008). Physical characteristics, such as size and location of resident rooms, dining areas, libraries, entertainment areas (e.g., for watching television, listening to music, or playing cards) were pointed out by administrators. The administrator at one facility expressed his excitement over a new common space recently remodeled to accommodate residents who require dining assistance (e.g., being fed). These residents had communicated their discomfort dining in front of residents who do not require assistance. In response, the facility built a dining area specifically for the residents so they could be assisted with their meals privately, or among residents with similar needs. The facility’s attempt to accommodate residents by providing a private location for dining was symbolic of their consideration of residents’ feelings in meeting their needs. This resident-centered approach to care was interpreted by the researcher as progress towards cultural competency.

Cultural characteristics (e.g., joking with residents, pointing out residents’ personal artwork displayed in the hallway, ignoring an employee who is not abiding by facility policies,) also became evident through informal conversational interviewing and tours of facilities. Several administrators addressed residents by first name and appeared to have knowledge of residents’ conditions (e.g., “Hello, James, how’s your knee coming along?”), suggesting that administrators invested time getting to know residents. In the midst of the tour at one facility, the administrator stopped to assist a CNA who appeared to be struggling in her attempt to return a resident to her room. Though the CNA did not
request assistance, the administrator recognized the need and stepped in to help. This gesture coupled with the CNA's gratitude expressed toward the administrator, indicated cultural responsiveness among leadership at this facility.

Changes in administrators’ actions, language, feelings, and expressions throughout tours were noted by the researcher. For example, in the midst of one facility tour, the researcher recorded that the administrator notably changed his/her demeanor “from pleasant and talkative to defensive” when asked about the number of common spaces available for residents to interact. The facility offered limited common spaces for residents, but the administrator stressed that it was “adequate enough”. The researcher interpreted that the subject was sensitive and the administrator’s sudden change in demeanor was considered resistant to change. Such visibility in participants’ emotions provided insight into administrators’ desires to progress towards cultural change and offered a more comprehensive picture of the cultural competency of the physical and cultural environments (Saldana, 2009, p. 99).

**Analyses**

*Environmental observation analysis*

The coding process began with thorough evaluation and re-evaluation of the data produced by the environmental observation for the purpose of familiarization and better understanding of the data. Each facility’s data were analyzed individually, not compared to the other facilities participating in the study. The researcher utilized an evaluation approach to analysis, differentiating among characteristics of the physical and cultural environments which were indicative of progress toward cultural change and those which were not. Each facility’s levels of individual privacy, resident personalization, common
space, residential character of the LTCF, and level of autonomy were collectively considered, as not just one item would result in a label of overall cultural change status. For example, privacy measures were observed in rooms which were shared by residents. Where privacy measures were present in rooms (e.g., curtains or dividers), facilities were considered receptive towards cultural competency, and where multiple privacy measures were present, the facility was considered progressive towards cultural change. Conversely, the researcher interpreted facilities that lacked any privacy measures as closed or cautious to cultural change, and those with minimal privacy measures hesitant or resistant.

Facilities that maintained formal written policies which addressed residents’ rights, sexual expression, safety, physical and/or mental health were considered progressive towards cultural competency. Facilities that did not have such policies or those who poorly displayed or failed to implement policies were considered less progressive towards support cultural responsiveness. Based on a comprehensive analysis of these characteristics and the aforementioned definition of cultural competence proposed by Davis (1997), the researcher determined the level of cultural responsiveness at each facility.

Researcher observation analysis

Analytic Memos. Analytic memos were coded using a line-by-line method, and served to validate the researchers’ interpretations of the data and aid in generating codes and categories. For example, the following memo excerpt was assigned the code “BARRIER TO RESIDENTS’ SEXUAL EXPRESSION”: “I can’t help but notice the overwhelming presence of barriers (both physical and cultural) in these facilities.
Between lack of privacy measures and private spaces, thus opportunity for personal or private interaction, barriers are an obvious issue. One facility indicated they offered privacy for residents to be sexual if they wished—on a metal bench. Benches aren’t exactly comfortable nor are they accommodating for private physical interaction (for anyone!) Not a reasonable solution in my mind. While it may still be too early to say for certain, I can see barriers standing out as a potential major theme.”

Field Notes. Field notes were recorded by the researcher to document personal insight and responses to participant observations. Notes were coded using descriptive methods to analyze the data’s most basic topics and aid in understanding the nature of the observations (Saldana, 2009, p. 70). The following example illustrates this method, demonstrating the researcher’s view on what was seen and heard during one facility observation.

<table>
<thead>
<tr>
<th>Field Notes</th>
<th>Descriptive Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>As I approach the building, I notice a “Wanderguard” system in place. I had to buzz three times before anyone would let me into the facility. There’s a strong odor inside. There are four residents sitting around the nurses’ station in wheelchairs. Staff seems to be buzzing about them quickly, only occasionally glancing down at them. None of them acknowledge my presence as I wait to speak with the administrator.</td>
<td>SECURITY MEASURE\nSTAFF BUSY/IGNORING\NEG CULTURAL CHAR\RESIDENT QOF (QUALITY OF LIFE)</td>
</tr>
<tr>
<td>OC: The odor in the building is pungent and makes me a little sick to my stomach. It bothers me that these four residents are sitting around, seemingly, being ignored.</td>
<td>NEG CULTURAL CHAR\STAFF BUSY/IGNORING\RESIDENT QOF (QUALITY OF LIFE)</td>
</tr>
</tbody>
</table>

Administrator interview analysis

Administrators’ responses to questions posed through informal interviews throughout guided facility tours were recorded by the researcher in the form of written
notes. These notes were reviewed multiple times, recorded in a single Word document, and then coded using detailed, line-by-line open-ended coding to identify key concepts (Saldana, 2009, p. 81). These distinct parts of the data were highlighted and written in margins, then sorted and relabeled into categories. The second cycle of coding included focused coding techniques, which decreased the number of categories from first cycle coding through identification of the most frequent and significant initial codes. From this process, categories emerged as data which were similar in nature and/or content were clustered together and reassessed. The following excerpt illustrates this process.

| P: You know it’s just more of a wow, surprise shock. But if somebody has been in that instance before, at that point they go, ‘oh, excuse me,’ pull the curtain, shut the door, make sure their roommate if they have one, if it’s a spouse. You know, just depends on the situation. Again Dementia is the biggest key factor in these, and I know you’re going off of if they are in their right state of mind. | RESPONSE: SURPRISE RESPONSE: STAFF EXPERIENCE RESPONSE: SUPPORTIVE RESPONSE: SUPPORTIVE BARRIER: ROOMMATE RESPONSE: SITUATIONAL BARRIER: DEMENTIA |

*Cultural competency continuum*

To identify barriers to LTC residents’ sexual expression and provide better understanding of the suitability of the physical and cultural environments of the LTC facilities for sexual expression among residents, the cultural responsiveness of each facility was examined. To achieve this, the researcher considered the aforementioned factors that would prove indicative of each facility’s level of cultural responsiveness. These factors were selected due to their capacity to demonstrate progress towards cultural change and promotion of residents’ rights. Through the process of triangulation, utilizing environmental observation, researcher observation, and administrator interviews, cultural responsiveness placement was determined. Facilities were placed on the cultural
responsiveness continuum based on the researcher’s interpretations of whether the facility lacked presence of cultural competency, demonstrated some presence, demonstrated moderate presence, demonstrated neutral presence, or demonstrated strong presence with regard to the multiple characteristics demonstrated in Table 3. LTCFs that demonstrated greater cultural responsiveness were placed higher on the continuum as they promoted and/or transformed acquired knowledge of older adults and sexuality, and applied it to attitudes, policies, practices, and response strategies in their cultural settings, which, in turn, improved the quality of services and resulted in better overall outcomes. Facilities at the low end of the continuum demonstrated fewer characteristics indicative of cultural responsiveness.

Results

Three major themes emerged from data analysis, including barriers to resident sexual expression, supports for residents’ sexual expression and staff involvement in residents’ sexual expression. Several categories were identified in each theme and are discussed below.

Theme: Barriers to residents’ sexual expression

Category: Physical characteristics that negatively influence sexual expression.

Multiple physical characteristics of the LTC environments may have negatively influenced residents’ rights to sexually express themselves. Placement of the residents’ rights policy in a highly visible location proved important for reminding staff, visitors, and residents of their rights. Therefore, noncompliance emerged as a barrier to residents’ right to sexually express themselves.
Table 3, Chapter 2. Long-term care facility characteristics indicating adoption of culture change.

<table>
<thead>
<tr>
<th>Cultural Competency Ranking</th>
<th>SITE A</th>
<th>SITE B</th>
<th>SITE C</th>
<th>SITE D</th>
<th>SITE E</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Between strivers and strong adopters</td>
<td>Between neutral and strivers</td>
<td>Hesitant</td>
<td>Between neutral and strivers</td>
<td>Neutral</td>
</tr>
</tbody>
</table>

**Physical Environmental Characteristics**

<table>
<thead>
<tr>
<th></th>
<th>SITE A</th>
<th>SITE B</th>
<th>SITE C</th>
<th>SITE D</th>
<th>SITE E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing residents’ rights policy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Where is existing residents’ rights policy posted?</td>
<td>In resident and visitor hallway- little visibility</td>
<td>Nurses’ station, only visible upon leaving the main entrance and proceeding down a long corridor</td>
<td>Nurses’ station- highly visible</td>
<td>Nurses’ station- highly visible</td>
<td>Front entrance- highly visible</td>
</tr>
<tr>
<td>Existing sexual expression policy</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Existing safety policy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Existing physical health policy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Existing mental health policy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Common space (appropriate number of common spaces considering resident capacity)</td>
<td>Multiple common spaces</td>
<td>Multiple common spaces</td>
<td>Multiple common spaces</td>
<td>Very few common spaces</td>
<td>Very few common spaces</td>
</tr>
<tr>
<td>Ease of access/use of common spaces for interaction with other residents</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Table 3. Chapter 2. (continued)

<table>
<thead>
<tr>
<th>Cultural Environmental Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Resident personalization of living space</strong></td>
</tr>
<tr>
<td><strong>Comfort of common space environment</strong></td>
</tr>
<tr>
<td><strong>Opportunities for interaction among residents</strong></td>
</tr>
<tr>
<td><strong>Resident-Staff Interaction</strong></td>
</tr>
<tr>
<td><strong>Access to outdoor common spaces for resident interaction</strong></td>
</tr>
<tr>
<td><strong>Residential character (low perceived crowding, room décor, lighting)</strong></td>
</tr>
<tr>
<td><strong>Autonomy support (ease of staff accessibility, independent accessibility to erotic content and materials presence of barriers preventing access to adult content and materials)</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td><strong>Offer individual privacy</strong></td>
</tr>
<tr>
<td><strong>Provide support and resources for couples to room together</strong></td>
</tr>
<tr>
<td><strong>Provide support and resources for same-sex couples</strong></td>
</tr>
</tbody>
</table>
Table 3. Chapter 2. (continued)

| Hold regular meetings with staff members to discuss caregivers’ roles and convey administrators’ expectations | Yes | Rarely | Yes | Periodically | Yes |
| Require staff training that includes discussion of resident activity sexuality | Sexuality training is included in training of new employees | None | None | None | None |
| Barriers to sexual expression | Funding due to private ownership; mission, religious values | Administrator resistance to awareness involvement | Limited funding and resources; inaccessibility to current technology; funding due to private ownership; mission, religious values | Limited funding and resources; inaccessibility to current technology | Limited funding and resources, inaccessibility to current technology |
| Presence of resident’s council | Yes | Yes | Yes | Yes | Yes |
| Presence of family council | No | Yes | No | Yes | No |
With regard to facility structure, many LTCFs fell short of accommodating residents’ rights. Data indicated that lack of common spaces limited resident interaction. While each LTCF provided common spaces (e.g., recreational rooms, group seating areas), as well as opportunity for interaction with other residents, Site A provided the greatest number. These spaces were also easily accessible (unlocked areas, spacious entries and exits). Sites B and C, however, had slightly fewer common spaces considering resident capacity, and Sites D and E offered even less.

Lack of individual privacy also emerged as a barrier to resident sexual expression. The majority of bedrooms at each LTCF were designed with entrances away from public or common spaces. However, not all rooms were privately located. Site E had bedrooms that opened into a very public hallway passage to the dining area, offering little privacy unless the door was closed. All of the participating facilities offered both private and semi-private bedrooms. However, none had a greater number of private than semi-private rooms. Discussion with rural site administrators of Sites C, D, and E revealed lack of funding for considerable design modifications to facilities, particularly residents’ rooms. Therefore, major structural modifications that would better accommodate residents’ privacy were not possible. Thus, privacy measures proved an important component in compensating for shared rooms, as data revealed that LTCFs which lack multiple privacy measures (e.g., inadequate curtain dividers in semi-private rooms) fall short of preserving residents’ rights to sexual expression.

None of the facilities were at full occupancy capacity, yet, private spaces for residents to interact outside of personal bedrooms (e.g., guest rooms similar to hotel rooms) were not provided. The Site D administrator said their facility was in the process
of converting a room into such a privacy space, but lamented it may be temporary, if it is
determined the room is needed for resident occupancy and money could be made by
occupancy.

**Category: Cultural characteristics that negatively influence sexual expression.**

Several characteristics of the LTC cultural environment which may have negatively
impacted residents’ sexual expression were also revealed through data analysis. Foul
odors were present at some facilities, despite administrators’ reports that controlling for
odors was important. Crowding also appeared problematic at some facilities, limiting
room for resident privacy. Despite not being filled to resident capacity, Site C, the largest
rural facility, appeared crowded, as the researcher noted “a significant numbers of
residents in the common areas and hallways throughout.” Sites C, D, and E demonstrated
less “cosmetically” modernized physical environments, particularly at Sites D and E,
where efforts were made to compensate for poor lighting. Administrators at these sites
utilized natural light, keeping curtains open in common spaces and residents’ rooms.
They brought in portable lamps when windows were not present.

Variations in staff responses to sexual expression among residents were also
evident, particularly regarding attitudes towards resident purchase and/or possession of
erotic content (magazines, movies, and music). The religiously affiliated Site C indicated
this type of content would be frowned upon and the facility would not become involved
in making these purchases. Family member resistance, funding for the material, and
discomfort were reported as barriers preventing access to adult content and materials at
each LTCF. Ownership resistance possibly related to personal attitude or values was
reported by the privately owned facilities, and Site C stated the religious mission
prevented provision of erotic materials.

*Theme: Supports for resident sexual expression*

**Category: Physical characteristics that positively influence sexual expression.**

Tours of LTCFs revealed several physical characteristics that could positively impact
residents’ sexual expression. Encouragement of resident personalization through the
presence of furniture, photos, and personal objects were visible at each site. Sites A, B,
and C were in the midst of continuous, obstructive stages of remodeling, which included
converting residents’ rooms from institutional-like spaces to warmer, home-like
environments. Efforts toward updates were noticeable at many of the facilities through
modern paint colors, décor, artwork, motivational quotes, and fabrics in curtains and
furniture.

Curtain dividers were common privacy measures in semi-private rooms. Site E
provided a curtain around each individual bed, in addition to a room divider. Site C built
tall, wooden bookcase dividers to separate spaces between residents, while Site A offered
residents the option of using privacy signs and allowed cognitively intact residents to
lock their doors.

Despite that Sites B, C, D, and E had few common spaces considering resident
capacity residents in these facilities appeared to have regular and easy access to the areas
to interact with other residents. While private spaces for residents to interact were limited
in the majority of facilities, some administrators indicated they would provide a space
outside of personal bedrooms (e.g., guest rooms similar to hotel rooms) upon residents’
request.
Category: Cultural characteristics that positively influence sexual expression.

Low perceived crowding was found to contribute to residents’ opportunities for privacy. Sites D and E had smaller numbers of residents and low perceived crowding, and the urban locations appeared sprawling and spacious, conveying the impression of low crowding. Efforts to provide comfortable, personalized, and home-like atmospheres were noted at each LTCF. Resident personalization was visible in facilities through residents’ photographs, personal memorabilia, and artwork placed in entrances and hallways. Also noticeable upon entering were fresh scents and pleasant perfume-like odors, and the smell of cleansing agents. Administrators explained that controlling for odor was an important objective, as they felt nursing homes in the past had stigma surrounding foul odors and they were concerned about portraying this image themselves.

Most of the LTCFs set aside space for collections of books, magazines, and games for residents to obtain at their leisure, and several facilities used a portable “library” or book cart to visit each resident’s room. However, erotic content and materials in the forms of magazines, movies, and music were not provided to residents at any of the participating sites. The majority of sites indicated they would purchase erotic materials for individual residents upon request, to be kept in their personal possession, using residents’ personal funds, or advise residents to ask family members to order such items.

The importance of opportunities for extracurricular activities and social interaction became evident throughout analysis of the data. At Site C, residents were interacting with pets (birds and puppies) and were also offered the options of playing cards and board games. A musical guest was entertaining at Site E, and residents were
singing along to songs from their past. At Site A, CNAs were prepping for their weekly happy hour celebration. Tables were set with seasonal centerpieces and the administrator told the researcher that female residents were offered beautician services (e.g., make-up and hair styling) prior to such events. These types of services were not uncommon among LTCFs. Site E set aside a room (a former janitorial closet) for beautician services twice weekly. Other facilities regularly brought barbers and hair stylists to residents’ rooms upon request. Site A presented “coupled” residents (described as those who are married or regularly dating) upscale dinner dates to commemorate anniversaries. Overall, these facilities were bustling with activities and opportunities for interactions among residents.

**Category: Facility compliance with laws.** Results of data analysis indicated that each LTCF adhered to the federally mandated posting of the residents’ rights policy, which requires placement at a location with high resident and employee visibility. However, differences among facilities in the degree to which the laws were followed were observed. For example, maximum adherence to the law were noted at Sites C and D where residents’ rights policies were posted at front entrances, and also at Site E (rural) where policies were posted on a corkboard at the primary nurses’ station. At each of these sites, policies could easily be seen by residents, employees, and visitors, indicating full compliance with the law. Site B (urban) posted residents’ rights at a nurses’ station, only visible upon leaving the main entrance and proceeding down a long corridor. When questioned by the researcher about the visibility of the policy, this facility’s administrator stated they also distribute hard copies of the residents’ rights policy to residents and family members upon admission, in the case that the policy is overlooked upon visiting.
Site A (urban) posted the policy in a hallway around the corner from the main entrance where it was difficult to see unless directed to it. This facility suggested the policy is visible enough to residents, visitors, and employees, as all are allowed to openly walk throughout the facility. The researcher interpreted this as minimal compliance with the law. In compliance with state and federal guidelines, adjacent to each LTCFs’ posting of residents’ rights were phone numbers for government agencies, and contact information for filing grievances and reporting elder abuse and neglect. Each facility also had formal residents’ safety, and physical and mental health policies, but lacked a sexual expression policy. With respect to privacy, interviews with administrators revealed that residents’ rights to sexual expression were, generally, classified within the federally defined residents’ rights to proper “privacy, property, and living arrangements” (Medicare.gov, n.d.). Administrators also pointed to the policy’s clause directed at residents’ rights to spend time with visitors. These rights include, “spending private time with visitors. Having visitors at any time, as long as you wish to see them, as long as the visit does not interfere with the provision of care and privacy rights of other residents. Seeing any person who gives you help with your health, social, legal, or other services may visit at any time” (e.g., doctor, a representative from the health department, and your long-term care ombudsman, among others) (Medicare.gov, n.d.). These vaguely stated regulations fail to acknowledge sexual interest or the possibility of resident sexual interactions.

**Theme:** Staff involvement in resident sexual expression

**Category:** Staff characteristics that may influence residents’ sexual expression. Staff interaction with residents and their involvement in residents’ sexual expression emerged as an important theme throughout observations and administrator
interviews. Caregivers at each facility were dressed in scrubs and appeared to interact in a friendly and approachable manner with residents. Residents were seen casually joking with CNAs at many of the facilities, and the social interactions were particularly noticeable at Sites A and E where CNAs were seen playing cards and dining with residents. The administrator at this location indicated it was a common occurrence and encouraged friendly relationships between residents and staff.

While CNA-resident interaction was supported at each LTCF, autonomy support was also a priority recognized by administrators. Staff demonstrated understanding of residents’ desire to purchase and possess erotic materials was recognized as a positive way to enable to residents to be sexually expressive.

**Category: Cultural competency and adoption of cultural change.** LTCFs that embraced culture change to a greater degree exhibited features, such as posted written policies related to residents’ rights (safety, physical, mental), and offered individual privacy in the form of private bedrooms and privacy signs. These facilities were likely to demonstrate greater acceptance of resident personalization through encouragement of personal items (e.g., furniture, photos, personal objects) and were more open to providing resident accessibility to erotic content and materials, such as magazines, movies, and music. They demonstrated greater willingness to make provisions to residents’ rooms for adequate space for sexual expression, as well as ease of access to an appropriate number of common spaces to provide opportunities for interactions with other residents. Facilities that indicated greater acceptance of culture change extended equal support and resources to heterosexual and same-sex couples. Administrators at these facilities held regular meetings with staff members to discuss caregivers’ roles and convey
administrators’ expectations. They also required staff training that included discussions of resident activity sexuality. LTCFs that did not demonstrate culture change to a greater degree exhibited contrasting features from those facilities which embraced it.

Privately-owned facilities cited ownership resistance to providing funding for sexually-related items (e.g., paraphernalia, movies) as a barrier, while church-related facilities suggested their mission, guided by religious values, prevented certain modifications to their environment. Long-term care facilities that offer individual privacy, post written policies related to residents’ rights, and demonstrate greater acceptance of resident personalization reportedly face fewer barriers to promoting successful environments for aging and ranked higher on the cultural continuum.

Figure 1 displays the distribution of participating LTCFs on the continuum of adoption of cultural change. The two types of LTCFs on the left side of the curve demonstrate resistance or hesitancy to cultural change in their LTCFs. These facilities may lack the funding, knowledge, initiative, or leadership support necessary to begin or maintain cultural change in their facility. None of the participating facilities were placed within the resistance category. However, Site C was categorized as hesitant to embrace cultural change. Similar to other participating facilities in the study, Site C did post the residents’ rights policy, but lacked a formal policy specific to sexual expression. The absence of a family council to represent the needs and opinions of residents’ family members was also noted in this facility. Site B ranked highly in the areas of resident personalization of living space, and ease of access and use of common spaces for interactions with other residents. However, this site only moderately demonstrated comfort of common spaces, and ranked poorly in the categories of residential character
(low perceived crowding, “home-like” qualities of caregivers, facility and room décor, lighting) and autonomy support (ease of staff accessibility in common and private spaces, independent accessibility to erotic content and materials, such as magazines, movies, music, presence of barriers preventing access to adult content and materials). While support and resources for couples to room together were observed at Site C, these benefits were not afforded to same-sex couples. Other factors contributing to continuum placement of Site C included reports of barriers to sexual expression, such as limited funding and resources due to private ownership and mission, inaccessibility to current technology (iPads® which could be privately used by residents to fulfill sexual needs), and religious values.

The middle of the distribution represents LTCFs neutral to cultural change. Based on current research suggesting today the meaning of culture change is “recognized by and familiar to almost all providers” and “if the first step to change is awareness of a problem and the availability of an alternative, then the field of nursing home care is indeed poised for transformation” (www.commonwealthfund.org, 2007). The researcher posits that most LTCFs would fall into this portion of the curve. These facilities demonstrate understanding the need for cultural change, but may lack direction, leadership support, or funding to progress towards strong adoption of cultural change—thus, remaining stagnant. Site E was placed in this section of the continuum. Similar to Site C, this LTCF did not have a residents’ policy specific to sexuality or a family council. They provided moderate access to outdoor common spaces for resident interaction and autonomy support. Adequate opportunities for residents to interact were reported. However, the facility lacked common spaces considering resident capacity
(including spaces for private interactions outside of residents’ rooms). This LTCF was considered supportive of heterosexual couples rooming together and also provided moderate levels of support and resources for same-sex couples. The administrator at Site E reported limited funding and resources, and inaccessibility to current technology as barriers to adoption of cultural change with regard to residents’ sexual expression. Although they conveyed understanding of the importance of cultural change and indicated a desire to eventually take action towards making cultural changes, Site E was not planning for change in the immediate future and appeared somewhat stuck in traditional ways.

Adoption of Cultural Change which Supports LTC Residents’ Sexual Expression Cultural Continuum

Adapted from Fagan-Smith at ROI; Commonwealth Fund, 2007

Figure 1, Chapter 2. Adoption of cultural change which supports LTC residents’ sexual expression cultural continuum

LTCFs that strive towards cultural change are placed slightly to the right of neutral facilities. Striving facilities acknowledge the benefits of progressing towards
cultural change in the LTC environment and have successfully modified their facility in some ways. Site B was placed between the neutral and strivers sections on the cultural continuum. This facility demonstrated progress towards cultural change with ample opportunities for interaction among residents, ease of access and use of common spaces for interaction with other residents, residential character, and access to outdoor common spaces for resident interaction and maintains a residents’ council and a family council. Despite being a new facility, they scored moderately on comfort of common space environment and autonomy support. While sufficient support and resources were provided for heterosexual couples to room together, same-sex couples received less support, as resistance to recognizing relationships and providing residents with opportunities to spend private time together were noted. Barriers to cultural change, which support residents’ sexual expression, were particularly noticeable in the administrator’s role. Regular meetings with staff members to discuss caregivers’ roles and convey administrators’ expectations were rarely held by the administrator at Site B, and researcher questions regarding sexuality and direct interaction with residents were deferred to frontline caregivers. This implied lack of involvement, knowledge, and/or desire on the administrator’s part to address or facilitate sexual expression among residents.

Site D was also ranked between neutral and strivers of cultural change on the distribution. This LTCF had the presence of residents’ and family councils, and provided sufficient opportunities for interactions among residents, ease of access, and use of common spaces for interactions with others. Access to outdoor common spaces for resident interactions, autonomy support, and residential character were also very good,
and equally high levels of support were offered to both heterosexual and same-sex couples. The administrator at Site D cited barriers, as limited funding and resources, and inaccessibility to modern technology. However, this facility was clearly striving towards cultural change.

LTCFs at the far right side of the continuum are considered strong adopters of culture change. These facilities are at the forefront of the cultural change movement in LTC. Site A was placed between the strivers and adopters marks on the continuum. While this site did not have a family council or an existing policy related to residents’ rights to sexual expression, this facility demonstrated high levels of cultural change supportive of residents’ sexual expression in nearly every category. Resident personalization was visibly high at this LTCF, as well as ease of access to an appropriate number of common spaces to provide opportunities for interactions with other residents, and availability of adequate space for sexual expression in bedrooms. Additionally, this facility stated they would be open to providing residents accessibility to erotic content and materials. Barriers preventing this facility from placement on the adoptive mark related to lack of family council and a policy related specifically to sexual expression.

**Discussion**

The current study suggests LTCFs that recognize the value of the aforementioned characteristics and incorporate them into their physical environments are more likely to provide residents with opportunities for privacy and freedom of sexual expression. The study highlights the importance of the physical and cultural LTCF environments that influence residents’ rights to sexual expression. Informed by environmental observation, researcher observation, and interviews with LTC administrators, the suitability of the
physical and cultural environments of LTCFs for sexual expression among residents is determined. Key principles for reducing negative influences of the physical and cultural environments on residents’ sexual expression will be identified.

**Implications of a residents’ rights policy**

Providing suitable physical and cultural environments for LTC residents to sexually express themselves is challenging, but not impossible, considering the factors associated with adoption of cultural change supportive of residents’ sexual expression. The significance of residents’ rights policies is emphasized throughout this study. Policies gain momentum in LTCFs, where administrators demonstrate openness in compliance with guidelines and procedures. Adherence to government requirements to publicly post residents’ rights in a highly visible location in LTCFs was demonstrated by all of the study’s participating facilities, except one, positively demonstrating the majority of the administrators’ willingness to comply with legal guidelines. However, missing from residents’ rights policies is information specific to the right to sexual expression. Rather, the subject of sexuality is eluded to and intertwined within the clauses of residents’ rights to make independent choices, rights to privacy and confidentiality, and rights to dignity, respect, and freedom. Under this clause, residents maintain the rights to “personal belongings and property as long as they don’t interfere with the rights, health, or safety of others. To have private visits, and to make and get private phone calls” (Medicare.gov, n.d.).

Changes are necessary at the policy level, where resident sexuality must be formally recognized as an inherent need of LTC residents, and definitions of responsible and acceptable sexual behavior identified. Here, guidelines must be established for
managing sexual expression in the LTC environment, and training on sexual rights, cultural competency, and privacy, mandated for administrators and staff. The implementation of such policies are reflected in caregiver practice, thereby, increasing residents’ quality of life.

*Directing cultural change*

CNAs must be offered support to address sexual expression (Bentrott & Margrett, 2011), and empowered with authority to make decisions in response to certain needs of residents. Not only should administrators hold regular meetings with staff members to discuss caregivers’ roles and convey administrators’ expectations, they must ensure competency for CNAs through consistent training that equips them with the skills and resources necessary for properly managing sexual expression. The cultural change movement is further advanced when CNAs approach residents’ sexuality with an open mind. Casual, social interaction and friendly relationships among residents and LTC staff (e.g., CNAs) should be encouraged in the LTC environment. This is achieved when CNAs understand their impact on residents, consider residents’ circumstances individually, and are knowledgeable about the role of sexuality in the process of aging.

Additionally, administrators must initiate discussions with residents and family members. Facilities should observe resident and family councils, which represent the voices of these parties, and advance conversation regarding sexuality in LTC upon residents’ admission into the facility. Residents’ rights policies should be distributed to residents and family members, and thoroughly discussed prior to admission, to ensure each party’s expectations have been communicated and recorded in residents’ care plans.
Multiple factors with respect residents’ rights to privacy require consideration in the LTC environment. Common privacy measures in LTCFs are found in the forms of room dividers, privacy signs, and rules for staff to knock on residents’ doors prior to entering. These practices were observed in several LTCFs in the study. Facilities must make efforts to designate more private rooms and offer greater privacy measures in shared rooms. Administrators at participating LTCFs pointed to insufficient funding and barriers related to the significant number of residents utilizing Medicare and Medicaid, as factors which prevent them from offering residents greater numbers of single occupancy rooms. However, they recognized the need to increase the number of privacy measures to compensate for the lack of private rooms.

Because cultural responsiveness is a continual process, LTCFs must frequently evaluate their environments and practices to ensure they offer choices to residents and encourage autonomy with regard to certain personal decisions. Evidence of cultural competency was apparent at participating LTCFs through efforts to create a sense of hominess through personalization of residents’ rooms, comfortable furniture and décor, fragrant smells, proper lighting, and use of warm colors. Additionally, spas, libraries, pubs, restaurants, and other spaces for socialization are increasingly becoming a part of today’s LTC experience. Future residents will live longer and be more active, and are more technically savvy than residents in years past. LTCFs must recognize the modern needs and abilities of this generation and provide access to technology, which may fulfill the sexual desires of some residents through sexually-related Internet material and/or online social interactions, sexual or otherwise (e.g., Facebook®, OurTime.com®). It is
crucial to acknowledge these factors as components of whole-person wellness and consider how they may contribute to residents’ sexual expressions.

Study results revealing common spaces and opportunities for resident interactions within participating LTCFs were encouraging, and a wide range of activities, including musical shows, spa days, exercise classes, and church services, were observed. Missing, however, were opportunities for privacy and personal spaces for residents to interact outside of their personal rooms. Because the majority of LTC residents receive assistance from Medicare, most are required to share rooms with other residents, limiting privacy for sexual expression or interactions with other residents. Additionally, facilities must be aware that privacy levels of even single occupancy resident rooms can be diminished by the location within the facility. As a means of comparison, hotel visitors rarely request rooms located near the front desk, elevators, stairwells, or swimming pools. These locations can be loud, intrusive, and disruptive to personal activity. Similarly, LTCFs must consider room location a potential barrier to residents’ privacy and right to sexual expression, and provide privacy options outside of residents’ personal rooms. If privacy cannot be offered in rooms, arrangements for private time must be made.

Conclusions

Outcomes of this examination of barriers to residents’ sexual expression and the physical and cultural environments for LTCFs highlight evidence the facilities that participated in the study were making efforts to modify their environments to reflect cultural change supportive of residents’ rights to sexual expression. Cultural characteristics, including protection of residents’ privacy, autonomy support, resident personalization, opportunities for social interaction, and employee training on sexuality
indicated a greater likelihood of adoption of cultural change in participating LTCFs. Characteristics of the physical environment of the LTCFs participating in the study, which indicated a greater likelihood of adoption of cultural change, included adequate common spaces, spaces for privacy apart from residents’ rooms, tangible privacy measures, and posted residents’ rights policies. Barriers to protecting residents’ rights to sexual expression exist in the forms of funding, lack of employee training, and current federal government regulations, which fail to acknowledge sexual interest or the possibility of resident sexual interactions. Collaboratively, policymakers, administrators, caregivers, residents, and family members must work towards establishing responsive cultures in LTC environments that acknowledge and support the role of sexuality in the lives of older adults.

The current study adds to the field of gerontology research identification of strengths and weaknesses within physical and cultural environments of LTCFs as related to cultural change. LTCFs wishing to adhere to guidelines for adopting cultural change must consider the influence of their environments.

Limitations

Within any study utilizing a limited number of participants, the researcher must refrain from generalizing study results to the larger population. The current study assessed five LTC facilities. Therefore, the researcher was cautious not to make assumptions regarding these LTC environments and apply them to all LTCFs. Future research conducted with a greater number of LTCFs, particularly outside the Midwest would prove beneficial, as attitudes in several domains are likely to vary by location (e.g., resident ethnic diversity and religious, political, and economic climates). The study
considers the influences of funding sources, status, and location, and includes for-profit, non-profit, privately funded, in environmental assessments. However, ethnic or cultural diversity of participants and LTCFs are not considered, and, therefore, impede comparisons among facilities with regard to these characteristics. Inclusion of these characteristics could contribute to identification of differences between residents and facilities with regard to various factors, such as religious views based on culture.

The current study methods were consistent with ethnographic research and the study of individuals in their environment (e.g., observation, interviews), however, the research would have benefited from prolonged engagement which would produce rich data and descriptions which may be observable only over time.

Future longitudinal studies may determine broader perspectives of the residents’ larger networks over greater periods of time by assessing residents’ rights to sexual expression from a Systems or Bioecological perspective. Each system of influence must be closely considered, particularly, the influence of family members and legal guardians. Additionally, environmental observations may benefit from a more detailed, dynamic and interactive tool developed to systematically measure the physical and cultural environments of LTCFs.

Despite evidence from the study’s results suggesting many LTCFs are unaware of the magnitude of influence by the physical and cultural environments on residents’ rights to sexually express themselves in the LTC environment, the overall results of this study are encouraging. The study is unique because it considers the level of adoptive cultural change supportive of residents’ sexual expression. Outcomes suggest high levels of
interest in cultural change by administrators through efforts to adapt the LTC environments to meet the needs and wants of residents.
Chapter Two References


CHAPTER 3. ADMINISTRATORS’ PERSPECTIVES OF THEIR ROLES IN MANAGING SEXUAL EXPRESSION AMONG RESIDENTS IN LONG-TERM CARE

A paper to be submitted to *The Health Care Management Review*

Merea D. Bentrott$^4$, Jennifer Margrett$^5$, MaryJane Brotherson$^6$

Abstract

*Background:* Inconsistencies exist within long-term care facilities with regard to sexual expressions among older adult residents. At the administrative level, the importance of understanding and refining policies regarding residents’ rights to privacy and sexual expression are crucial to successfully implement person-centered care.

*Purpose of the Study:* This qualitative study explored the attitudes, barriers, knowledge, and practices of long-term care administrators regarding sexual expression in long-term care facilities. It is hoped that this research will provide administrators with information to aid them in enacting policies addressing residents’ sexual expression and assist them in providing training to caregivers to enable residents to appropriately express their sexual needs.

*Design and Method:* Qualitative interviews were conducted with administrators at five Midwestern long-term care facilities (LTCF). Administrators responded to vignettes that described LTC residents’ engaging in sexual expression and a series of questions aimed at five primary categories related to residents’ sexual expression. They were asked to

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rank their personal levels of knowledge in several key areas regarding the elderly population.

**Findings:** Results indicated administrators’ acknowledgment of sexual expression as a need of residents in long-term care facilities. Presently, formal government policies specific to managing sexuality in long-term care facilities do not exist. Therefore, sexual expression is addressed on a situational basis. Administrators agreed no single response strategy would suffice to cover all scenarios of sexual expression. However, they were supportive of opportunities for training staff on the topic of aging and sexuality, and providing staff with a range of appropriate response strategies.

**Practice Implications:** Underlined throughout this study is the importance of addressing residents’ sexual expression at the highest level of leadership within long-term care settings. The primary implication of this research is that administrators must enforce guidelines for managing sexually expressive behaviors, which can be achieved through administrator involvement in policy development and implementation, and facilitation of staff training and education.

**Introduction**

Research has established that increases in numbers of older adults, due in part to advances in technology and medicine, have altered the country’s standards of aging by enabling people to live longer (Institute of Medicine, 2001; Walker Smith & Clurman, 2007). These changes are particularly evident in the long-term care (LTC) environment, where an anticipated 40% increase is expected in the utilization of long-term care facilities (LTCFs) between 2000 and 2020, with an expected 27 million entering some form of long-term care facility by 2050 (American Healthcare Association, 2012).
This growing population is comprised of Baby Boomers, who will no doubt have significant influence on the process of aging in the future (U.S. Department of Health and Human Services, 2005). This generation may best be described by statements such as “Boomers may be aging, but they don’t see themselves as getting old, no matter how many candles get crammed onto their birthday cakes with each advancing year” (Walker Smith & Clurman, 2007, p. xiv) and “Boomers will bring a particularly argumentative and even feisty attitude” into their later years (Whittington, 2009, p. 313). These quotes characterize the Baby Boomer cohort and signify the changes that lie ahead for this sizable and influential aging population, as well as the society that will serve them.

Significant levels of overall influence are expected of Baby Boomers, supported by the generation’s marked concern “for leaving behind values, attitudes, and an intact world to their children and grandchildren” (Frumkin et al., 2012, p.1434). This concern for passing on legacy, coupled with the open-minded orientation of this cohort, is driving cultural change towards an approach to care that places individuals’ needs and desires at the core (person-centered care), and considers the physical, spiritual, social, and psychological elements of individuals (whole-person wellness), as well as the impact of surrounding influences in the physical environment (privacy curtains, spaces for social interaction). Recently, a cultural movement has gained momentum in LTCFs, demonstrated by gradual progress in the number of facilities adopting cultural change and implementing person-centered care initiatives which support social relationships in these contexts (Commonwealth Fund, 2007). The image of skilled nursing care is being reshaped, and older adults are calling for greater LTC options at a higher quality than in the past. According to the U.S. Administration on Aging (2010), 1,167 staff members
and 8,813 certified volunteers addressed 157,962 complaints in 2010, among them 18,587 regarding violations of residents’ rights, including autonomy, choice, preference, exercise of rights, and privacy. A total of 33,946 complaints related to quality of life were reported, comprised of 8,991 activities and social services complaints, and 14,560 complaints were associated with the LTC environment (U.S. Administration on Aging). Complaints launched at administration totaled 8,747, which consisted of issues related to policies, procedures, attitudes, resources, and staffing concerns (U.S. Administration on Aging). These statistics highlight the importance of leadership at the administrative level in providing adequate LTC environments (physical and cultural), employing competent, quality staff, and addressing residents’ needs, desires, and concerns, which, in turn, alleviate residents’ problems before they escalate to formal complaints to a LTC Ombudsman. Furthermore, the Baby Boomer generation holds expectations, which differ from past cohorts of older adults. The Boomer generation possesses a modern means for comparison of LTCFs through use of technology. They have greater access to tools (e.g., Internet) for locating information and determining the types of facilities available (levels of care provided, amenities, staff-to-resident ratio), as well as comments, complaints, and rankings provided by the Centers for Medicare and Medicaid Services (CMS) (medicare.gov, n.d.). Accordingly, LTCFs, who aim to best serve this group, must adopt culture change and practice person-centered care to ensure quality of life for their residents and remain competitive among LTCFs (Steel et al., 2009).

Acknowledging Sexuality in LTC

The current study aims to determine what are the attitudes, barriers, knowledge, and practices of long-term care administrators regarding sexual expression in long-term

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care facilities. It is hoped that this research will provide administrators with information to aid them in enacting policies addressing resident’s sexual expression and assist them in providing training to caregivers to enable residents to appropriately express their sexual needs.

The positive impact of social relationships among LTC residents and their family members and peers, on residents’ overall quality of life has previously been addressed in research (Hubbard et al., 2003). Though infrequently discussed, researchers are beginning to acknowledge the role of sexuality in social relationships within LTC settings, and recognize it as a key component of person-centered care (Bentrott & Margrett, 2011; Doll, 2011). The course for recognizing the sexual needs and desires of older adults begins at the highest level of LTCFs, initiated by administrators, who are responsible for regulating the physical and cultural environments which impact social relationships among residents.

Administrator commitment has proven paramount to facilitate cultural change in LTC environments in the past (The Commonwealth Fund, 2007). Currently, many LTCFs are deemed “strivers” of culture change (The Commonwealth Fund, 2007). Although they are not considered “adopters” of culture change, their leadership strives to support cultural change and person-centered care initiatives, and emphasizes the importance of government and administrative leadership, and involvement in protecting residents rights at the highest level (www.commonwealthfund.org, 2007). What is clear is administrators must establish consistent institutional strategies, and provide caregivers the knowledge and skills for addressing sexual expression among residents (Bentrott & Margrett, 2011).
**Bioecological Theory**

A bioecological lens is utilized in the current study to examine LTC administrators’ roles in recognizing residents’ rights to privacy, and developing policies and response strategies for addressing sexual expression among residents, as well as implementing staff training (White & Klein, 2002). Several key assumptions of bioecological theory support the person-centered care concept, imperative for honoring residents’ privacy and rights to sexual expression in the LTC environment. Within the theory, the inherent social nature of individuals and their reliance on others is recognized, as well as the impact of physical and cultural surroundings (White & Klein). The context of the network of relationships, that collectively become an individual’s environment, is an important indicator of the residents’ rights to sexual expression. In the LTC setting, where residents are partially dependent upon others for personal care and well-being, administrators must communicate with each level of residents’ networks, from immediate influence to the remote, including policymakers, certified nursing assistants (CNAs), residents, and family members, as each level has influence on residents’ rights to sexual expression.

The LTC administrator plays a crucial role in alleviating resident, caregiver, and family member embarrassment and discomfort surrounding the topic of older adults and sexuality. Ultimately, it is the administrator’s responsibility to determine the wants and needs of the resident, and ascertain the expectations of all parties. This can be achieved through continual communication with policymakers, discussions with residents and families, and CNA training and instruction on appropriate response strategies. The sensitivity of the topic is compounded by challenges, such as resident cognitive
impairment and rate of decline, and the personal values and belief systems of staff at each level of residents’ care, which can pose difficulties determining how to best address sexuality among residents. Administrators must be cognizant of such factors, when determining best practices, and developing and implementing policies regarding residents’ sexual expression.

Method

An ethnographic approach is useful to interpret the meanings of “cultural patterns of groups” (Creswell, 2007, p.78) and aided the study’s objectives of understanding the role of administrators with regard to residents’ sexual expression in LTC. Consistent with ethnographic practices, multiple methods were utilized for data collection (Creswell, 2007), including face-to-face interviews with open-ended questions, vignettes, and analytic memos, which chronicled personal reflections throughout observations and interviews.

As a qualitative researcher with a background in human development and family studies and gerontology, it was important to recognize how my personal experiences and values influenced my interpretation of the data. At the time of the study, I did not have a relative or friend residing in a LTCF, nor have I previously been employed by a LTCF. However, I do have personal volunteer experience with older adults in the community and in the LTC environment. Therefore, I acknowledge that my interpretation of participants’ input and the LTC environments were influenced by these experiences, as well as my sex, culture, social class, education, and religious and political views.
Participants

Upon obtaining approval for data collection from the university Institutional Review Board, purposeful sampling strategies, commonly employed in ethnography studies (Creswell, 2007, p. 120) were utilized to gather a sample of five administrators from the Centers for Medicare and Medicaid Services (CMS) list of LTCF rankings. Two of the selected administrators had over 20 years experience, one administrator had seven years of experience, and two administrators had one year of experience. Based on the Skilled Nursing Home Facilities Five-Star Quality Rating System, this system assigns a higher score to facilities that meet the quality standards and practices established by CMS (medicare.gov, n.d.). Administrators were randomly selected and contacted to participate in one sixty-minute, individual, face-to-face interview at the administrator’s LTCF. Inclusion criteria for administrator participation included: (1) all participants have been employed by their LTC facility for greater than six months and (2) spoke English. All participants provided informed consent. Honoraria included a $25 gift card.

Data collection

A combination of strategies to ensure rigor and trustworthiness were employed, and the current study applied multiple methods of verification. Triangulation was utilized through analysis and comparison of numerous data sources and methods, including interviews, analytic memos, and vignettes (Bowen, 2005; McMilan & Schumacher, 2006).

Interviews

Administrators provided demographic information for themselves and their facility (e.g., administrators’ length of employment, types of services offered by the
facility, percentage of males/female residents) and were asked a series of questions aimed at four primary categories: (1) residents’ rights to sexual expression, (2) caregiver and administrator response strategies, (3) the effectiveness of current laws and regulations, and (4) sexual education and training opportunities. For example, administrators were asked to “Describe some of the ways in which residents sexually express themselves in your long-term care facility” and “Describe any policies or strategies of the LTCF when becoming aware of sexual expression among residents.”

Administrators were also asked to verbally rank their personal levels of knowledge in several areas of content regarding the elderly population. Using a Likert-type scale with the following options: 1- No knowledge, 2- A little knowledge, 3- A moderate amount of knowledge, and 4- A great deal of knowledge. The categories included whole person wellness, sexuality in later life, diverse ways of expressing sexuality, heterosexual relationships between residents, homosexual relationships between residents, cognitive impairment (e.g., dementia) and mental illness (e.g., depression), and adverse effects of medication.

*Vignettes*

Through use of vignettes developed by the researcher, administrators responded to four hypothetical situations that may occur in LTCFs (e.g., same-sex sexual expression, masturbation) (Appendix G). Questions related to the vignettes focused on administrators’ opinions on whether a particular situation needed addressed, why/when the situation might be considered inappropriate, who should determine whether the situation is appropriate and should continue, what might be achieved to best serve all residents of the LTC facility and the staff, and ideal staff response strategies. For
example, one vignette posed the following situation: “Juanita is an 85-year-old widowed resident at a long-term care facility. Juanita spends a great deal of time with Carmen, who is also a widowed resident. Frequently, the women hold hands at mealtimes and various social events, and recently have begun openly expressing themselves in a sexual way (e.g., kissing, flirting, touching one another).” Administrators were asked: “In your opinion does this situation need to be addressed? Why? When? With whom should this relationship be addressed?”

Analytic memos

Analytic memos were recorded to explore the researcher’s thoughts regarding the data, coding process, and developing categories (Saldana, 2009, p. 34). The following excerpt reflects how the researcher personally related to the administrator at one facility who indicated his/her role involved mostly fiscal and quality assurance responsibilities. “It strikes me as interesting (and a bit disappointing) how administrative roles can vary so drastically. This administrator is clearly uncomfortable and can barely utter the word “sex” without turning red. I can’t imagine being the administrator at a facility and being uncomfortable with this topic!” As a researcher I hold a professional position that allows me to advocate for the rights of aging individuals. Using analytic memos allowed me to examine my own biases and emotions as I analyzed the data and developed interpretations.

Ethical considerations

Due to the sensitive nature of the research topic, it was important to consider individuals’ feelings and reactions when approached about participation in the study. The goals and potential outcomes of the research were clearly and thoroughly explained,
as well as the role and rights of participants. This preliminary disclosure appeared to alleviate feelings of discomfort and aided in establishing rapport with participants.

Information collected by the researcher remains confidential, including names and site-specific details, and only the researcher and an IRB trained transcriptionist were given access to information. Pseudonyms were assigned to replace personal identifying information to further ensure confidentiality. Summaries of researcher interpretations of the data and results, which include group-level data, were shared with administrators of facilities who agreed to participate in the study. All participants were informed of their option to respond to researcher summaries.

**Data Analysis**

Data were analyzed throughout the study, and served to enhance the researcher’s understanding of the context of events and provide rich descriptions that may not be measurable quantitatively (Sofaer, 1999). A feasibility study, as well as the researcher’s knowledge of data saturation, assisted in determining the number of participants in the study.

The open-ended initial coding technique (Saldana, 2009, p. 81) was used as a first cycle coding method to break down administrators’ interview transcript data and responses to questions related to the vignettes into distinct parts for further examination and identification of similarities and differences among codes (Saldana, 2009, p. 81). Detailed, line-by-line coding aided in identifying key concepts provided by participants in interviews, which were highlighted and written in margins, then sorted and relabeled into categories. Focused coding was utilized in the second cycle of coding. This method involved decreasing the number of categories from first cycle coding by identifying the
most frequent and/or important initial codes to “develop major categories from the data” (Saldana, 2009, p. 155). Coded data which were similar in nature or content were then clustered together and reassessed to form categories. The following excerpt illustrates this process.

<table>
<thead>
<tr>
<th>P: We had a married couple here once and they, you know wanted their beds pushed together, which we did, you know they liked sleeping together and always tried to give ’em privacy. Um, he had the call light cord wrapped around his leg one time during it… it went beep, beep, beep.</th>
</tr>
</thead>
</table>
| **STATUS:** MARRIED COUPLE  
**RES NEEDS:** CLOSENESS  
**DESIRED**  
**LTCF EFFORTS:** SLEEP TOGETHER  
**LTCF EFFORTS:** PRIVACY  
**BARRIERS TO SEXP:** CALL LIGHT  
**ADMIN RESPONSE:** LAUGHTER |

**Analytic memo analysis**

The researcher’s analytic memos served as an additional “code and category-generating method” (Saldana, 2009, pg. 157), and were coded using a line-by-line method. For example, the following excerpt was assigned the code “PROTECTING RESIDENTS’ RIGHTS”: “I’m pretty confident in the category “protecting the resident” based on everything I’ve heard in interviews. Most of the administrators truly seem to want to do what’s in the residents’ best interests and protect their right to sexual expression (and everything else). Whether this actually happens off the record, when I’m not there to conduct an interview, is unknown.”

Member checks were conducted for verification of the authenticity of administrators’ interviews, and to allow participants the opportunity to validate or dispute researcher’s interpretations. Copies of interview transcripts and summaries of the researcher’s interpretations were emailed to participants. The researcher then contacted participants one week later to discuss question or concerns. All administrators agreed the
transcripts accurately portrayed their interview with the researcher.

**Findings**

Four themes emerged upon analysis of interviews with administrators, vignettes, and researcher analytic memos. Table 1 displays these themes, which included protecting residents’ rights to sexual expression, increasing knowledge and opportunity for sexual expression among LTC residents, barriers to sexual expression, and responses to sexual expression among residents, and their subsequent categories (Table 1).

*Theme: Protecting residents’ rights to sexual expression*

**Category: Facility demographics that impact sexual expression among older adults.** Facility location (i.e., urban or rural setting) may have influenced residents’ rights to sexual expression with regard to privacy measures, as characteristics of urban facilities were considered more conducive to residents’ sexual expression than at rural facilities, which were “more restrictive of residents’ sexual expression”. Administrator reports of CNAs’ positive attitudes towards older adults and high levels of CNA/resident social interaction are encouraging and demonstrate progress at the direct care level. Differences in rural and urban reports of CNAs’ attitudes towards sexual expression, particularly towards instances of same-sex relationships, revealed the need to recognize influential factors, which differ by location. CNAs were considered more open and supportive of residents’ sexuality and same-sex coupling in urban LTCFs than in rural locations.
Table 1, Chapter 3. Themes and Categories of Residents’ Rights to Sexual Expression

**THEMES**

<table>
<thead>
<tr>
<th>Protecting Residents’ Rights to Sexual Expression</th>
<th>Increasing knowledge and opportunity for sexual expression among LTC residents</th>
<th>Barriers to sexual expression</th>
<th>Responses to sexual expression among residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility demographics which impact sexual expression among older adults</td>
<td>Aging &amp; sexuality in LTCF training</td>
<td>Family members</td>
<td>Residents’ Responses</td>
</tr>
<tr>
<td>Facility characteristics which are supportive of sexual expression among residents</td>
<td>Policies</td>
<td>The administrator role</td>
<td>Policymakers Responses</td>
</tr>
<tr>
<td>Administrator characteristics which are supportive of sexual expression among residents</td>
<td>Opportunities for social interaction</td>
<td>Spaces/opportunity for sexual expression</td>
<td>Administrators’ Responses</td>
</tr>
<tr>
<td>Factors impacting staff attitudes towards older adults’ sexual expression</td>
<td></td>
<td>Cognitive and physical health</td>
<td>CNAs’ Responses</td>
</tr>
<tr>
<td>Privacy measures</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**CATEGORIES**

Facility demographics which impact sexual expression among older adults
Aging & sexuality in LTCF training
Family members
Residents’ Responses

Facility characteristics which are supportive of sexual expression among residents
Policies
The administrator role
Policymakers Responses

Administrator characteristics which are supportive of sexual expression among residents
Opportunities for social interaction
Spaces/opportunity for sexual expression
Administrators’ Responses

Factors impacting staff attitudes towards older adults’ sexual expression
Cognitive and physical health
CNAs’ Responses

Privacy measures
Privately owned LTCFs reportedly restricted residents’ sexual expression more than public LTCFs through resistance to cultural and environmental modifications. Administrators indicated that private owners were less likely to spend money on many of the structural changes that would better accommodate residents’ privacy and opportunities for sexual expression (e.g., private rooms).

The impact of LTCF religious affiliation on residents’ rights to sexual expression was most evident among demographic characteristics evident in discussions with administrators, as religiously affiliated LTCFs indicated their mission, guided by religious values, would prevent modifications to an environment that would accommodate residents’ sexual expression. Despite evidence that residents have a voice within these LTCFs (e.g., personal photos and furniture, spaces and opportunity for residents to interact privately, presence of residents’ councils), their religious missions may compete with a key objective of person-centered care, accommodating residents’ sexual needs. This finding was not surprising to the researcher, as religiosity has previously been determined a factor of influence on “knowledge, attitudes, and practices of long-term care staff as related to elderly sexuality” (Walker, 1998, p. 3). Accordingly, religiously-guided missions, which govern LTCFs’ values, leadership, and staff, were expected to impact residents’ rights to sexual expression, further illustrating the influence of each level within residents’ systems, and consistent with bioecological theory.

The impact of religious values and attitudes on residents’ rights to sexual expression were reflected in privately owned and religiously affiliated LTCFs. These demographics were influential in restricting residents’ sexual expression through resistance to cultural and environmental modifications, particularly with regard to same-
sex sexual expression. Although instances of same-sex sexual expression among residents were reported more frequently in urban facilities, administrators managed same-sex couples similarly, extending them the same rights as heterosexual couples, with the exception of one religiously-affiliated LTCF. The administrator at this location discussed the challenges associated with being a faith-based organization and addressing certain situations that he/she considered sensitive. With regard to the topic of same-sex relationships, he/she stated, “You know, our challenge is dealing with a whole bunch of people living under one roof and everybody has different needs (/and everybody/), and again we are a faith-based organization so probably, realistically, we would try and encourage people to use their rooms for lots of different things because then it can be done without potentially offending others. And that’s maybe not right or fair, but in the world that we’re living in here, um, it might be what would have to happen.”

Category: Facility physical and cultural characteristics that are supportive of sexual expression among residents. The impact of physical and cultural characteristics of LTCFs on residents’ quality of life emerged from the data as a category, and has gained increasing consideration among researchers throughout the past decade (commonwealthfund.org, 2007; Cox Curry et al., 2008; Zeisel et al., 2003). According to a 2007 National Survey of Nursing conducted by the Commonwealth Fund, cultural change must be reflected in modifications by healthcare providers to “resource management, the physical environment, and care delivery”—considered “the hallmarks of resident-centered care” (www.commonwealthfund.org, 2007). Consistent with these assertions, LTC administrators in the study said their facilities recognized how the physical and cultural characteristics of their LTCFs were influential in preserving or
hindering residents’ rights. Each facility promoted resident personalization by encouraging residents to bring personal items (e.g., furniture, photos) into rooms, autonomy by empowering residents, and vocalization through active residents’ councils. Administrators also demonstrated facility support by promoting positive interactions among LTC staff and residents, which was evident through partnerships with constituents in residents’ lives, and the endorsement of multidisciplinary care teams and family councils. Each administrator conveyed the importance of sustaining married couples through attempts to keep married residents together in rooms whenever possible. All but one facility indicated support for same-sex coupling among LTC residents.

**Category: Administrator characteristics that are supportive of sexual expression among residents.** The importance of the administrative role became clear throughout analysis as certain characteristics revealed were deemed supportive of sexual expression among residents. Administrators’ self-perceived levels of knowledge in several key areas revealed that confidence in understanding of adverse effects of medication, cognitive impairment, mental illness, whole-person wellness, and knowledge of same-sex relationships between LTC residents were characteristics which positively contribute to understanding and acceptance of sexual expression among residents.

**Category: Factors impacting staff attitudes towards older adults’ sexual expression.** While administrators can foster a culture of openness and acceptance, and train employees on various forms of sexual expression and proper response strategies, employees’ personal values and beliefs (e.g., religious and political views), and background (personal upbringing) are not easily altered. Roach (2004, p. 375) supports this assertion in her research of staff perceptions of sexuality among nursing home
residents, stating, “staff members are a product of their education, religious and cultural beliefs as well as their life experiences.” Prior research supports the likelihood that some CNAs are influenced in the workplace by their upbringing, traditional beliefs, and/or religious principles which do not support sexual expression independent of a marital relationship or for reasons other than reproductive purposes (Hillman & Strieker, 1994). Such views can lead to less-permissive treatment of residents involved in sexual expression and infringement on residents’ rights. According to administrators, CNAs’ age and experiences in the LTC environment, and with older adults often dictate responses to sexual expression. Younger and less experienced CNAs are more likely to become uncomfortable upon encountering sexual expression and respond impulsively or inappropriately (Pierre Bouman et al., 2007). One administrator stated: “I think it depends on which staff member encounters it and their level of expertise. Um, the young aides, especially the ladies you know giggle or are grossed out or don’t know how to react. And uh you know they’re trained to simply turn and walk out of the room. Give the individual their privacy, shut the door, um you know, not intervene but allow that to occur. Um and so that’s the way they’re trained. Now that’s easier for some than others.”

This administrator’s response implies that youth and inexperience in employees often determine their response strategies. Therefore, administrators should view these characteristics as opportunities to promote a culture of tolerance and openness in attitudes and responses to resident’s sexual expression.

**Category: Privacy measures.** While privacy measures were implemented at each LTCF in the form of curtains and/or bookshelf room dividers in residents’ personal living
spaces, differences were noted between rural and urban locations. One large, rural facility offered privacy with curtains that wrap directly around residents’ beds, in addition to room dividers. Another urban LTCF gave residents the option to indicate the need for privacy in their personal room via signs, which hang outside residents’ doors. Locks were not present on residents’ doors at the majority of locations. However, each administrator indicated they require employees to knock on residents’ doors and request residents’ permission prior to entering.

**Theme: Increasing knowledge and opportunity for sexual expression among LTC residents**

**Category: Aging & sexuality in LTCF training.** All participating LTC administrators indicated their support for inclusion of staff training on sexuality, however, four of the facilities did not offer training specific to sexuality among residents or address the physiological changes that accompany aging which might impact sexual expression. One facility made a point to inform CNAs of the possibility of sexual behaviors occurring among residents, but the information was provided as a “heads up” and response strategies were not discussed. Administrators admitted they were unaware of current trainings that address sexual expression, but added that trainings would not only benefit staff in understanding and accepting sexual behavior, but also residents’ friends and family members.

**Category: Policies.** Federal law mandates public posting of residents’ rights and several other legal documents in a location visible to residents, staff, and visitors in LTCFs. Administrators at participating facilities adhered to state guidelines, placing policies in visible locations. However, federal or state laws specifically related to
residents’ rights to sexual expression do not exist. Thus, administrators relied on privacy and dignity clauses within the general residents’ rights policy when addressing these matters (Iowa Department on Aging, 2012). Additionally, the presence of residents’ rights policies does not guarantee compliance and administrators stated that ensuring employees adhere to policies is often difficult.

**Category: Opportunities for social interaction.** Throughout interviews administrators emphasized the importance of providing a multitude of opportunities for residents to socially interact. Each facility offered at least one common area or space for resident to spend time visiting with family members or friends. Pedicures and manicures, musical entertainment, movies, games, and even happy hour at two facilities, were offered to residents for extracurricular activities. All five facilities offered religious services at least once per week. Outdoor spaces including walking paths, public benches, and gardens were provided and residents. Two facilities celebrated residents’ anniversaries with special “romantic” dinners and birthdays were marked with parties and social events.

*Theme: Barriers to sexual expression*

**Category: Family members.** Family members are an integral part of residents’ lives and may pose significant influence on residents’ sexual expressions. Administrators indicated resistance in the majority of situations, where family members learned of instances of sexual expression involving their loved one. Frequently, family members expressed disbelief or disapproval of loved ones’ interest in sexuality and may condemn LTCFs for supporting residents’ right to privacy and sexual expression. One administrator recalled an incident and described the proactive measures necessary for
protecting the LTCF: “the family member was threatening us with lawsuits, with you know taking things to the state. And we had, of course, had already contacted the ombudsman’s office just quite honestly to protect ourselves… To let them know what was going on and to observe the rights of both parties.”

Further demonstrating the impact that family members can have on residents’ sexuality, this resident was transferred out of the LTCF by family members in disagreement with the LTCF’s policy of residents’ rights to privacy, despite determination that both residents involved in the relationship were deemed cognitively intact and consenting individuals.

**Category: The Administrator Role.** Administrators’ knowledge and attitudes of sexuality in later life, and same-sex relationships between LTC residents proved influential in residents’ sexual expression in LTC. Administrators were asked to self-report their level of knowledge on a series of domains, including whole-person wellness, sexuality in later life, diverse ways of expressing sexuality, homosexual relationships between residents, adverse effects of medication, and cognitive impairment and mental illness. The majority of administrators indicated fear of infringing on the rights of others, but believed they possessed a moderate or great deal of knowledge in the areas of cognitive impairment (e.g., dementia) and mental illness (e.g., depression), adverse effects of medication, and whole-person wellness. Many administrators were moderately confident in their knowledge of sexuality in later life and had strong perceptions of understanding heterosexual relationships between residents. However, low levels of confidence in knowledge of homosexual relationships between residents were disclosed.
One urban facility administrator expressed little knowledge of sexuality in later life, diverse ways of expressing sexuality, heterosexual relationships between residents, and homosexual relationships between residents. A second administrator declined to assign a number to his/her knowledge. Notably, the administrator who declined to assign a number to his/her degree of knowledge in any of the domains, instead replied: “I can say that I’m probably not...I don’t know, the most knowledgeable with most of the things we deal with. That’s why we have regulating guides. You have the ombudsman available, you have Department of Inspections and Appeals, you have colleagues, you have coworkers, you have everybody who’d probably experienced it. You just have to find the right person to shine the light on stuff.” This administrator’s philosophy on the importance of partnering with constituents of the residents’ life exemplifies the bioecological approach to person-centered care. Conversely, admission of the lack of perceived knowledge in these domains may imply the absence of personal responsibility in his/her role.

Variability among administrators’ perceived knowledge persisted when scenarios describing a LTCF employee disgruntled over sexual expression between two residents were presented to administrators. Reactions were divided on whether CNAs should be reassigned to a new resident or reminded of their professional responsibility to provide person-centered care for residents, which includes respecting their right to sexually express themselves. The administrator at one facility stated the situation should be addressed by reassigning the CNA to another resident, “So that they wouldn’t be in the same section that, or the same area, that those patients are located.” Conversely, a second LTCF administrator stated that he/she would remind the CNA, “one of the...
advantages of living in a free society is that we do not have, we do not have authority over our neighbors or the ability to present our will upon them. And so while you may or may not agree with the choices that they’ve made, that’s the advantage of living here, is that we are not subject to that. We have personal rights, personal responsibilities, and so, I would probably begin with just reminding them of that. And secondly, I would remind them of their duty as a caregiver, that as a caregiver their job is not to, stop their (residents’) behavior or intervene. Their job is to continue to nurture and to provide support so that an individual can live the life they want to live for as long as they can live it. That is their choice. Your job here is to promote that choice, to… to substantiate and to fulfill their desire to move forward. And if that is the way they want to move forward, then I don’t think you really have the right to impose your will.”

The vast difference in these administrators’ responses illustrates the importance of establishing policies that provide administrator and CNAs specific response strategies and calls attention to variations in the roles of administrators with regard to professional duties and interaction with residents. Despite equivalency in training and state licensure, administrators in rural locations appeared to play multiple roles, including those outside the realm of administrator. At one rural location, the administrator also served as chief executive officer. An administrator interview at a second rural facility was briefly interrupted when the administrator attended to a resident with dementia and escorted him back to his room. In the urban LTCFs, administrators reported being more heavily involved in managing the business and financial aspects of the LTCF. One administrator relayed that “keeping the doors open” was his/her primary responsibility. This administrator referred the majority of the researcher’s questions concerning residents’
sexual expression to the facility’s “social services,” indicating little personal interaction with residents and, largely, upper management and financial duties.

**Category: Spaces and opportunity for sexual expression.** Consistent opportunities for private interaction were minimal at most facilities, as they were unable to provide private spaces outside of residents’ rooms where residents could spend time together one-on-one. This proved problematic for residents who wished to be sexually expressive as the majority of residents shared rooms with at least one other person, but sometimes two, or even three other people. Semi-private rooms and, oftentimes, roommates’ behaviors and attitudes were cited as barriers which hindered resident’s sexual expression

**Category: Cognitive and physical health.** At the center of the controversial topic of sexuality are the residents, themselves, who face multiple barriers outside the levels of their systems of care. Evidence of the impact of residents’ cognitive health emerged throughout data analysis as administrators continually noted cognitive capabilities, as the most important factor to consider when addressing sexual expression among residents. Questionable cognitive capabilities (e.g., Alzheimer’s Disease) cause concerns over residents’ abilities to consent and require reassessment of mental status, which can prevent instances of sexual abuse.

Physical health issues which are commonly challenging in older adulthood, including hip and back injuries, arthritis, osteoporosis, incontinence, bedsores, and other ailments can leave residents bedridden or physically unable to sexually express themselves were revealed throughout analysis. Drugs and medical interventions used to
treat certain ailments were cited as inhibitors of sexual interest and ability to remain sexual.

Theme: Responses to sexual expression among residents

Category: Residents’ Responses. According to administrators, residents exhibited a variety of responses to sexual expression. If prevented from being sexual, or physically and intimately close to someone, many residents became lonely or depressed. Residents who did attempt to have their sexual needs and desires met, typically expressed embarrassment if “caught” in acts of sexual expression. However, administrators did cite a smaller number of incidences where residents were indifferent to staff responses. One administrator noted that residents are sometimes confused by staff reaction to their behavior, recalling a time when a young CNA hastily left a resident’s room because she encountered two residents “making out”. When the CNA informed her supervisor of the incident, the supervisor visited the residents to discuss the situation, where she was informed that the CNA “may be able to learn a little something is she had stayed and watched.”

Category: CNAs’ Responses. Immediately influential on residents’ sexual expression are CNAs who have consistent, direct contact with residents. Discussion with administrators revealed staff attitudes towards older adults were generally positive. CNAs were described as caring and friendly with residents, often playing games, dining, and visiting with them. However, CNA attitudes towards sexual expression varied among LTCFs. Participating administrators from urban facilities expressed CNAs appeared more aware and open to understanding the sexual needs and health of older adults, in general, and these facilities experienced less “shock” over sexual expression
among residents. Administrators from rural facilities indicated less CNA understanding and acceptance of the sexual needs and desires of older adults.

Category: Administrators’ Responses. Typical behavioral responses expressed by administrators and CNAs include separating or verbally discouraging residents from public acts of sexual expression, diverting residents’ attention to other activities, or providing residents privacy in personal rooms to complete an act of sexual expression, while monitoring their safety (e.g., periodically checking on them, knocking but not entering and asking if everything is ok). All administrators agreed that responses should be carried out in whatever manner best protects residents. Ultimately, it was agreed upon by all that if a resident’s cognitive functioning is questionable, family members should be contacted and sexual activity should be prohibited pending further examination of ability to consent.

Administrators expressed a variety of responses, both emotional and professional, to seeing or learning of sexual expression among residents. They admitted to feeling somewhat uncomfortable when faced with these instances, but mostly showed concern regarding residents’ cognitive state and ability to consent to sexual interaction with other residents. One administrator suggested it is best to notify family members, if residents are sexually expressive. Few were flustered by these forms of expression, nor believed residents should be prevented from being sexually expressive, as long as their cognitive capabilities were deemed intact and their expressions were not public or infringing on the rights of others. Nonetheless, administrators revealed responses that contradict these views when they were presented the following scenario: “Malcolm is a 75-year-old male resident, who shares a room that is divided by a moveable curtain with another male
Malcolm occasionally masturbates in his room, sometimes when his roommate is present. Malcolm’s roommate has complained about these occurrences.” Four participating administrators indicated they would relocate the complainant to another room, and replace him/her with a less cognitively aware or capable resident. This response contrasts administrators’ earlier statements that sexual expression should be supported, but not at the expense of other residents’ rights.

Several implications emerged from the administrators’ attempt to preserve Malcolm’s right to sexual express himself in his room. Moving the complainant might put an end to the problem, but will be disruptive to the resident, who is forced to relocate and readjust to a new environment and, potentially, a new roommate. Additionally, the solution infringes on the less cognitively intact residents’ rights to privacy and living arrangements. One administrator disagreed with the others and suggested instead, “I think we need to provide better privacy, um, for the gentleman who is self-pleasuring. If we’re unable to do that or if we’re having other privacy-related issues or there’s embarrassment, I think we need to give someone the opportunity to relocate or move.”

While the option of relocation is still proposed, this response more broadly considers how best to preserve the rights of all parties involved.

**Category: Policymaker Responses.** Consistent with the bioecological perspective, administrator interviews revealed influences on sexual expression at multiple levels of residents’ environments. Although policymaker involvement with residents is indirect (Bentrott & Margrett, 2011), its influence is valid. This is evidenced by the government’s current presence in LTC, via laws which require continual data collection for Minimum Data Set (MDS) and the Resident Assessment Inventory (RAI) (National
Clearinghouse on the Direct Care Workforce, 2008), which offers LTCFs a holistic picture of residents, as it considers “quality of life and quality of care mutually significant and necessary” (www.medicare.gov, n.d.). The RAI is used as an interdisciplinary tool which “helps to support the spheres of influence on the resident’s experience of care, including: workplace practices, the nursing home’s cultural and physical environment, staff satisfaction, clinical and care practice delivery, shared leadership, family and community relationships, and Federal/State/local government regulations” (www.cms.gov, 2012). Sexual expression falls into the realm of residents’ experience of care and the aforementioned levels of influence impact residents’ rights to sexually express themselves.

**Discussion**

Regardless of apparent inconsistencies in the role of LTC administrators, sexuality is a key component of residents’ quality of life. Physical and cultural LTC environments, multilevel responses within residents’ systems, and other important factors which impact residents’ sexual expression must be acknowledged and required as a part of administrators’ education, licensing, and accreditation to establish consistent expectations across roles. Discussion of major findings, followed by recommendations for addressing issues which emerged from the data will be presented.

**Rural versus urban LTCFs**

According to the U.S. 2000 Census, approximately 22% of older adults in the United States live in rural areas (U.S. Census Bureau, 2000). These statistics are concerning, as rural-residing older adults demonstrate greater physical and mental health needs and have less access to resources, compared to older adults residing in urban areas.
(Crowther et al., 2010), resulting in fewer personal care and long-term living options, increased crowding in LTCFs, and greater mental and physical health demands. Rural facilities are typically smaller in size and have fewer beds and, therefore, less space to accommodate residents’ privacy and sexual interactions with others (Dalton et al., 2002). Additionally, residents of rural facilities may be more likely to enter LTC in the town or nearest to the town where they resided in their home. Therefore, residents may be familiar with staff, or even have family members or friends working or living in the facility. This familiarity may cause feelings of discomfort, embarrassment, or fear of gossip or mistrust, and prevent residents from sharing their sexual needs and desires.

**Religious affiliation**

Religious affiliation of LTCFs proved highly influential in restricting residents’ sexual expression, particularly through cultural resistance to accept certain types of sexuality. In many religiously-affiliated facilities, sexual expression outside of marriage and same-sex relationships conflicted with faith-based missions. LTCFs must communicate their mission and values, particularly with regard to sexuality among residents, prior to admission so residents and their families are aware of facilities’ expectations for resident relationships, and therefore, can determine goodness of fit accordingly.

**Respecting the rights of LGBT residents**

The Gay and Lesbian Elder Housing (GLEH) group is a nonprofit organization pioneering housing options for homosexual older adults (Gay & Lesbian Elder Housing, 2012). The goal of this organization is to “improve the life experience of lesbian, gay, bisexual and transgender seniors by developing affordable housing, providing
comprehensive care, and ensuring, through advocacy and education, a brighter future for the LGBT elder community” (http://gleh.org, 2012). In 2007, the GLEH opened the first non-profit housing facility for LGBT older adults in Hollywood, CA, called Triangle Square. While the facility will not deny anyone residence, they outwardly promote an attitude of openness and acceptance of LGBT individuals. Today, it is estimated approximately 25 LGBT-focused retirement communities have been developed, primarily in locations such Florida, Arizona, and New Mexico (gilbertguide.com, 2012).

Recognizing the needs and desires of the LGBT population is increasingly important, considering statistics on LGBT older adults. According to the U.S. 2010 Census, there are roughly three million gay and lesbian adults over age 55 (U.S. Census, 2010) and, approximately, 10,000 American LGBT elderly nearing retirement age per week (National Resource Center on LGBT Aging, 2012). It is estimated LGBT Americans over the age of 65 will increase from 3 to 7 million in the next 25 years (Grant, 2009).

Administrator Knowledge

Self-reports of administrator knowledge revealed moderate to high levels of understanding of cognitive impairment, mental illness, adverse effects of medication, and whole-person wellness. Administrators’ confidence in these areas is not surprising, as training requirements traditionally focus on these matters. Additionally, these issues are formally and legally regulated in LTC; whereas, sexuality and forms of residents’ sexual expression are not. Moderate levels of confidence in administrators’ knowledge of sexuality in later life and, particularly, heterosexual relationships between residents are encouraging, and suggests these topics are being recognized in the LTC. Low rankings
and inconsistencies reflected in administrators’ knowledge of same-sex relationships among older adults, as well as diverse ways older adults express sexuality, indicate the need for education inclusive of these topics as they apply to the LTC environment. Same-sex relationships between LTC residents is becoming increasingly relevant as many of the Baby Boomers, a generation more likely to openly express their sexual orientation, grow older and transition to LTC. Thus, the importance of the LTC industry in acknowledging the growing LGBT populations and diversity in sexuality is increasingly important and administrator training on the subjects should be mandated.

*Staff attitudes towards sexual expression in LTC*

Personal values and beliefs are difficult to alter, and each CNA’s background and prior experiences and exposure to older adults impacts their current attitudes and responses to residents’ sexual expression. Administrators must screen for competent individuals to work with residents, and compensate for the effects of some CNAs’ youth and lack of experience through training and clarification of facility policies and role expectations. Ongoing training related to sexuality in the LTC environment, which presents a variety of scenarios, must be provided to staff at all LTCFs and not only to larger or urban facilities.

The profession of caregiving (CNAs) has traditionally experienced problems with recruiting qualified and reliable applicants, and high turnover (Pioneer Network, 2008). Previous research suggests a number of factors contribute to these issues, including inadequate screening processes to detect qualified applicants, the absence of or poor training, unrealistic expectations of CNA duties, and disrespect by management (Pioneer Network, 2008). A screening tool comprised of questions and vignettes related to older
adults and sexuality would be useful to evaluate prospective CNAs. The Aged Sexuality Knowledge and Attitudes Scale (ASKAS) (White, 1982) is a measurement tool utilized to assess the impact of older adult sexuality education on the attitudes of older adults, family members, and caregivers in LTCF. A prescreening process could identify attitudes and opinions most compatible with the CNA role in LTC, and decrease the future likelihood of reports of problematic sexual behaviors, inappropriate responses to sexual expression, incidences of resident sexual abuse by CNAs, and employee turnover.

Confronting barriers to sexual expression

While common spaces for social interactions were present in each LTCF participating in the study, less importance was placed on securing private spaces and opportunities for sexual expression. Two of the participating facilities provided private locations for residents to interact outside of their rooms; however, this was only possible due to a low census at the time of the study. Both facilities indicated the spaces would be reallocated as residents’ rooms in the near future for incoming residents. Not only should privacy measures in LTCFs must be observed (e.g., knocking on residents’ doors before entering, honoring privacy signs) but spaces provided for personal time and resident interactions. Where space is not available, residents may benefit from scheduled opportunities for privacy where roommates are removed for a designated time period.

At the resident level, it is important for administrators to consider physical and cognitive health, as well as adverse effects of medication, on residents’ sexual capacity. Continual assessments and health checks must be conducted, and doctors notified of changes in behavior and well-being. Accommodations are recommended for residents through provision of videos, computers, iPads®, or other forms of technology that may
be used privately to alleviate embarrassment and serve as an outlet for sexual expression for residents who are unable to physically express themselves or lack partners.

*Facilitating communication between residents’ networks to promote positive responses*

Consistent with the researcher’s assumptions, study findings confirmed the importance of the LTC administrator role in facilitating communication between and among residents’ networks and promoting positive responses. Incidences of change at one level impact other levels, ultimately, affecting residents. Therefore, to fully understand residents’ rights to sexual expression, one must apply a bioecological approach, considering not only the resident and his/her environment, but also the network of relationships and their interactions. Administrative best practices for facilitating residents’ sexual expression involves not only respecting residents’ rights, but also reaching out to residents’ multiple levels of care to understand the most effective policies and response strategies which ensure person-centered care.

In the earliest stages of employment, administrators must have conversations with CNAs to clarify both the LTCF’s and CNA’s opinions, expectations, and levels of comfort in addressing sexuality among residents. Administrators may be able to alleviate anxiety and discomfort related to sexuality among residents through communication with residents and staff on the importance of preserving the right to sexual expression, thus normalizing the occurrence. Where administrators demonstrate they are comfortable discussing the topic, residents and staff may be more comfortable, and more likely to execute proper response strategies or ask questions when uncertainty arises regarding sexuality among residents.
Family members frequently serve residents at the direct care level, and are highly involved and influential figures in residents’ decision-making. Family members’ views of residents’ capabilities and rights may be imposed and, subsequently, regulate the behaviors of administrators, CNAs, and residents. The current study reported administrators rarely initiated discussions with family members regarding sexuality among residents. However, it is crucial for administrators to discuss potential scenarios and commonly occurring situations regarding residents’ sexuality with family members at residents’ intake meetings. An open dialogue will assist all parties to communicate expectations, and will ultimately aid in the preservation of residents’ privacy and rights to sexual expression.

Because informal policies for managing sexual expression vary, administrators must sift through existing policies to determine what is missing with regard to sexuality. Do residents have the right to order or access erotic movies, magazines, books, paraphernalia and Internet sites? Are residents provided adequate time, space, and opportunity to interact with other residents in ways afforded to persons outside long-term care settings (e.g., becoming acquainted, in a flirtatious or sexual manner with another resident)? Is a separate location provided for residents to interact alone? Administrators can demonstrate to policymakers the need for continuous support by identifying holes in the current residents’ rights policy and utilizing evidence-based research to communicate the importance of recognizing sexuality as a natural part of the lives of older adults.

The MDS and RAI legal guidelines are aligned with bioecological theory, and indirectly assist LTC residents by determining quality measures and ensuring proper use of resources. Therefore, policymakers must be informed of changes (e.g., in residents’
demographics) and trends (e.g., increases in sexually transmitted infections) occurring in LTC to best meet the needs and preserve the rights of residents. Trends over time may provide insight into determining future LTC needs and influence policymakers to provide funding and/or resources directed at these needs (e.g., funding for programs which educate LTC staff on sexually-transmitted infections.)

Promoting sexual education

Previous studies conclude that staff training on sexuality among older adults is effective to diminish negative stereotypes (Hillman & Strieker, 1994; Mayers & McBride, 1998), and positive correlations have been identified between knowledge and attitudes toward older adults’ sexual expressions (Hillman & Strieker). Only one of the five participating facilities provided training to CNAs specific to sexuality health and aging or response strategies to sexual expression among residents. Formal training on sexuality in LTC was briefly addressed with CNAs at only one larger, urban LTCF, where new employee orientations were conducted weekly. This finding implies administrators are not actively promoting education on the topic, which would aid in developing consistent professional response strategies, and enable residents to appropriately express their sexual needs and desires.

Administrators have determined one particular response strategy is not suitable for addressing every situation related to sexuality, and despite the absence of formal policies, training guidelines would be useful to direct CNAs in proper resident-centered responses. According to administrators, sexual expression is addressed on a situational basis and recommendations for responses vary. Administrators agreed no single response strategy would suffice in covering every possible scenario related to residents’ sexual
expressions, due to differences in cognitive and physical health, and varying stages and rates of decline. However, all were receptive of opportunities for training CNAs on the topic of aging and sexuality, and providing them response strategies to apply in the workplace.

Equipping CNAs with knowledge and skills to address sexual expression in the LTC environment aids them in recognizing inappropriate or abusive sexual expression, defined by the National Center on Elder Abuse (2012) as, “non-consensual sexual contact of any kind with an elderly person. Sexual contact with any person incapable of giving consent is also considered sexual abuse. It includes, but is not limited to, unwanted touching, all types of sexual assault or battery, such as rape, sodomy, coerced nudity, and sexually explicit photographing” (www.ncea.aoa.gov, 2012). Residents must be protected from unwanted sexual contact. Thus, residents, who exhibit excessive or aggressive sexual behaviors, must be closely monitored. When incidences of sexual abuse occur, they must be immediately disclosed to administrators, who are required to follow legal protocol. Failure to report allegations of sexual abuse or misconduct to legal authorities can result in serious legal fines and penalties.

One such training is the “Pioneering Change to Promote Excellent Alternatives in Kansas Nursing Homes” (PEAK) program (Center on Aging, 2008). This training program provides a foundation for educating those who interact with residents at every level of care. PEAK guides LTCFs in establishing best practices and policies with the goals of diminishing feelings of discomfort, and improving CNA competency through effective response strategies. The principles applied in PEAK training equip CNAs with the skills and knowledge (e.g., respect, understanding, communication) required to
successfully facilitate sexual expression, and encourage LTCFs to remain open-minded and embrace this movement in LTC toward culture change.

**Conclusions**

This study utilized a multilevel approach to consider administrators and CNAs’ attitudes and opinions regarding influences on residents’ sexual expressions in the LTC environment. Additionally, a broad understanding of LTCFs’ training and policies regarding sexual expression among residents was presented. Study results are positive in their indication that administrators acknowledge the importance of sexual expression in the lives of LTC residents. The administrator’s role is key to ensuring residents are afforded privacy, respect, opportunity, and available spaces, which enable them to appropriately express their sexual needs. One way in which this can be achieved is through formal recognition of sexuality in residents’ individual care plans. Formal documentation sends the message to staff that sexuality is a rightful need of residents and should be recognized accordingly.

At the direct care level, the administrator’s role is to transfer knowledge to those who interact daily with residents (e.g., CNAs, activities professionals) and, therefore, are more likely to encounter incidences of sexual expression. It is essential to CNAs’ understanding of the sexual capacity of older adults to equip them with effective and reasonable response strategies. Although it may be understood that residents have the right to privacy, it cannot be assumed the definition of sexuality is the same, nor considered a standard component of privacy, by everyone. A multitude of factors, including personal values, beliefs, and upbringing, may influence staff members (e.g., CNAs, administrators, nurses, and volunteers) and their perceptions of sexuality, privacy,
and residents’ rights. Despite these factors may be out of an administrator’s realm of management, they cannot be ignored and must be contemplated when determining goodness of fit between employee and environment.

Training for staff on proper response strategies to sexual expression must be actively promoted and consistently provided throughout employment. Opening lines of communication on such a sensitive topic and equipping staff with knowledge would serve to alleviate caregiver frustration and stress, and possibly diminish staff turnover, in turn, improving quality of life for residents.

The current study would gain greater comprehensive insight into the administrators’ role through prolonged engagement in the LTC environment, which would result in rich data and description that are observable only over time. Pre and post-training assessments of staff members’ responses to sexual expression among residents would enhance the study, as well as perspectives from individuals at each level of residents’ care. Further analysis of administrators as facilitators of communication among caregivers, family members, and residents would also prove beneficial (Tenenbaum, 2009) as well as assessment of policymakers’ perspectives of incidences of sexual expression among LTC residents.
Chapter Three References

Adapted from “Pioneering Change to Promote Excellent Alternatives in Kansas Nursing Homes,” 2003-2008, Center on Aging, Kansas State University, Manhattan, KS. Used by permission.


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CHAPTER 4. PROTECTING RESIDENTS’ RIGHTS TO SEXUALITY IN THE LONG-TERM CARE ENVIRONMENT: STAFF TRAINING, POLICIES, AND RESPONSE STRATEGIES

A paper to be submitted to the journal of *Sexuality Research and Social Policy*

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Abstract

Escalating numbers of older adults requiring long-term care are prompting public health officials to reevaluate current legislation regarding standards of long-term care (LTC) and residents’ rights to services and healthcare. It is estimated that LTC facilities in the United States will experience a 40% increase in occupancy between the years 2000 to 2020 (American Healthcare Association, 2012). Whole-person wellness embodies multiple elements of well-being, among which sexuality and the choice to remain sexually expressive, a basic human right for older adults, should be included. However, this right is largely ignored in the context of LTC, and oftentimes, sexual expression among LTC residents is mislabeled as problematic behavior. Utilizing systems and bioecological theories as a basis for examining multiple levels of influence on residents’ sexual expression, the current article addresses the issue of preserving residents’ choice to be sexually expressive and examines existing laws and policies regarding sexual expression in LTC settings. Input from LTC Ombudsmen was utilized to inform recommendations to enhance current policies and contribute feedback for effective training guidelines for LTC staff in addressing residents’ sexual expression. Therefore,

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universal legal guidelines are necessary to broaden understanding of the meaning of sexuality in older adulthood and aid in consistent response strategies which preserve residents’ rights to sexual expression.

**Introduction**

Throughout the next four decades, the number of older adults entering some form of long-term care facility (LTCF) is expected to reach 27 million (American Healthcare Association, 2012). This influx is driven by Baby Boomers, a generation influenced by political rights and civil activism, including the Sexual Revolution and advancements in methods of contraception. Traditionally, this cohort has demonstrated greater openness and tolerance in their attitudes towards sexuality (Hillman, 2012) than past generations and, no doubt, these attitudes will persist throughout the boomers’ lifespan. Sexuality is a significant contributor to whole-person wellness, and LTCFs can anticipate among future residents increases in frequency of sexual expression, sexual diversity (e.g., same-sex relationships, intergenerational relationships), and use of medicine to treat sexual dysfunction (e.g., Viagra®). Additionally, LTCFs will face greater needs and demands for resources (e.g., education) and materials (e.g., condoms) related to sexuality. Particularly, those associated with prevention of sexually-transmitted infections (STIs)—projected to increase among the future population of older adults (Cloud et al., 2003). Accordingly, current policies regarding sexuality among older adults residing in LTC settings must be contemplated and amended to reflect the expectations of this generation. Despite the discomfort, denial, embarrassment, or resistance that may accompany discussion of the topic, policymakers must take a second look at existing laws that protect residents’ rights to determine where the right to sexual expression fits.
Within this article we will first establish the importance of sexuality as a basic right in the lives of LTC residents. Next, the role of government and the importance of formal acknowledgment of sexuality as an inherent need of older adults, as well as recognition of the value of sexual expression among residents in the LTC environment, are then illustrated at the international, federal, and state levels. Finally, guided by input from LTC Ombudsmen institutional policies and recommendations for best practices, tools for determining effective response strategies, and training guidelines for administrators and certified nursing assistants follow.

Establishing sexuality in older adulthood as a human right

“The assumption that sexuality is the province of the young is more than just an outdated idea relegated to media clichés; it is simply wrong” (www.cregs.sfsu.edu/, 2012). Older adults are proving this declaration true, observing sexuality as an important factor of life (Tesslar Lindau et al., 2007) and remaining interested in sexuality well into older adulthood (Gott & Hinchliff, 2003). While evidence supports that sexuality is inherent throughout the aging process (American Association of Retired Persons, 1999) and even associated with good health (Addis et al., 2006; American Association of Retired Persons, 1999), multiple barriers exist which prevent the sexual needs and desires of older adults from being acknowledged and accepted in the LTC setting. Ageist attitudes and society’s obsession with youthfulness and beauty, as well as caregiver difficulties separating the identity of residents from their own parents or grandparents (i.e., “counter-transference”; Heath & White, 2002, p. 143), contribute to stereotypes regarding sexuality among the population, particularly in the context of LTC.
International regulations

Sensitivity surrounding discourse of sexuality and older adults unquestionably contributes to the absence of any form of legal recognition of sexuality as a normal component of aging, or formal guidelines for addressing instances of sexual expression among LTC residents. At the international level, laws do not exist which specifically address the sexual rights of residents in LTC environments. Instead, the majority of countries abide by a basic human rights policy. For example, the United Kingdom’s Human Rights Act of 1998 [HRA], an extension of the European Convention on Human Rights Act, includes “the right not to be discriminated against” and the “right to privacy and family life guaranteed under Article 8, which is particularly relevant in care homes, and recognises the fundamental ethical and legal principle in health care of human autonomy – that is, the right of the individual to make decisions and choices about his or her life without undue interference by others” (www.legislation.gov.uk, 1998).

Canada’s Residents’ Bill of Rights as described within the Long-Term Care Act of 2007 (LTCHA) falls short of specifically mentioning sexuality, but does address residents’ privacy, dignity, and choice through recognition of the following residents’ rights: “to be treated with courtesy and respect in a way that fully recognizes the residents’ individuality and respects the resident’s dignity; to communicate in confidence, receive visitors of his or her choice and consult in private with any person without interference; to form friendships and relationship and to participate in the life of the long-term care home; to have his or her lifestyle and choices respected; to meet privately with his or her spouse or another person in a room that assures privacy; and the rights to share a room with another residents according to their mutual wishes, if appropriate
accommodation is available” (www.e-laws.gov.on.ca, 2010).

The World Health Organization (WHO, 2010), is the “directing and coordinating authority for health within the United Nations system; responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends” (WHO 2010). The organization recently published a list of sexual rights, recommending: “Sexual rights embrace human rights that are already recognised in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to decide to be sexually active or not; engage in consensual sexual relations; choose their partner; have respect for bodily integrity; seek, receive and impart information related to sexuality; receive sexuality education; achieve the highest attainable standard of sexual health, including access to sexual health care services; pursue a satisfying, safe and pleasurable sexual life” (WHO, 2010), while emphasizing that “the responsible exercise of human rights requires that all persons respect the rights of others” (WHO, 2010). Though not specific to LTC residents, this list of sexual rights is applicable to all older adults including those who reside in a LTC environment.

Federal regulations

History documents the governments’ clear and profound presence in the sex life of Americans. According to the Center for Research and Education on Gender and Sexual Equality (CRGS), “whether appreciated or not, our governments’ elected officials and legislators have much say in how we live out our sexual lives” (www.cregs.sfsu.edu/, 2012). They further assert that, “housing benefits, sexuality education standards, and
(non-judgmental, relevant) healthcare services are just some of the decisions left to policy makers that impact our access to, and understanding of, healthy sexuality” (www.cregs.sfsu.edu/, 2012). Recently, this influence on sexuality has gained increasing recognition, largely due to controversy over gay rights and civil union laws. Yet, sexuality among older adults remains an uncomfortable, if not taboo, topic and the frequency of sexual expression among LTC residents remains undocumented.

In 1965, the Older Americans Act was passed, which provides federal funding for community social services for older adults, as well as “research and development projects, and personnel training in the field of aging” (www.aoa.gov, 2010). One component of this act requires that each U.S. state maintain a LTC Ombudsman program to field complaints related to LTCFs (www.aoa.gov, 2010). The Ombudsmen play an integral role in advocating for LTC residents’ rights and the provision of guidelines for understanding and managing sexual expression at the administrative, CNA, resident, and family member levels in order to aid in preserving residents’ rights without restricting or regulating residents’ behaviors.

According to the National Long-term Care Ombudsmen, residents must legally be provided the following rights, among which the right to sexual expression is not included: the right to “citizenship, dignity, privacy, personal property, freedom, residence, and expression,” and the rights to care and information (e.g., costs for services rendered) (www.ltcombudsman.org, 2012). When formal complaints related to sexuality are reported to the Ombudsman, classification is determined on a situational basis by the LTC Ombudsman receiving the complaint. Due to subjectivity, complaints which are sexual in nature may fall into a variety of categories of residents’ rights violations. For
examples, a complaint related to prevention of a resident’s right to own erotic or
pornographic material may be considered a violation of a resident’s right to privacy, right
to expression, right to dignity, right to citizenship, or right to personal property. However,
such labels do not accurately describe the type of behavior precipitating the complaint.
Missing from the National Long-Term Care Ombudsman’s definition is a clause specific
to residents’ rights to sexual expression (www.ltcombudsman.org, 2012) causing concern
over whether certain forms of sexual expression are mislabeled problematic behaviors,
rather than inherent expressions.

Determining cognitive capacity

Communicating sexually-related policies and understanding residents’ attitudes
towards sexuality is crucial to preserve residents’ rights, but, ultimately, cognitive
capacity is key to determining whether a sexual relationship is consensual. While a
resident may indicate the desire to participate in a sexual relationship, if he/ she is
deemed cognitively incapable of consenting, the LTCF must determine the proper
response strategy and discuss it with the resident’s guardian. The Resident Assessment
Instrument (RAI) is a federally-mandated assessment for Medicare or Medicaid certified
residents of LTCFs (CMS, 2012). The RAI is comprised of data collected by the
Minimum Data Set (MDS), which informs the Care Area Assessment (CAA) through
identification of responses to specified items on the MDS. The CAAs “reflect conditions,
symptoms, and other areas of concern that are common in nursing home residents and are
commonly identified or suggested by MDS findings” to determine care areas and aid in
development of an individualized care plan (CMS, 2012). Together, they provide
understanding of residents’ overall functional status, weaknesses, strengths, and
preferences and provide insight into future assessments warranted by discovery of new problems. The MDS provides a standardized, comprehensive evaluation of residents’ information, which includes assessment of cognitive processes conducted via Brief Interview Mental Status (BIMS). This tool is useful for determining residents’ “attention, orientation, and ability to register and recall new information” (CMS 2012). If significant changes are noted in a resident’s demeanor, ability, or behavior, including sexual behavior, reassessment is necessary, as type and rate of decline in this population vary and may determine residents’ cognitive capabilities to consent to sexual expression.

*State level involvement*

Each U.S. state is required to adhere to guidelines set forth in the Older Americans Act, which describe the rights of LTC residents. Because sexuality is not explicitly included in this list, much of the issue in addressing circumstances related to sexual expression lies in the subjectivity of its meaning and interpretation. Subsequently, variations in institutional and staff responses result within and across states. Most non-abusive, sexually-related complaints fall into the categories of “Autonomy, Choice, Preference, Exercise of Rights, and Privacy” and “Policies, Procedures, Attitudes, and Resources”. In 2010, 157,962 complaints were reported to Ombudsman nationally, with 18,579 filed under “Autonomy, Choice, Preference, Exercise of Rights, and Privacy” (www.aoa.gov, 2010). Amending the definition of residents’ rights to recognize sexual expression as a right of cognitively intact residents and assigning a category specific to sexually-related complaints would aid in differentiating between natural and expected forms of sexual expression and problematic behaviors (e.g., sexual harassment, unwanted touching by one resident on another), and serve to alleviate mislabeling and complaints.
Interviews conducted with Local LTC Ombudsman in one Midwest state revealed, although sexual expression commonly occurs, nationally it is infrequently recognized and formally underreported by LTCFs. Even where facilities are asked to report merely the frequency and/or types of sexual expressions occurring in their facility -not only those behaviors considered problematic--administrators remain hesitant. Results of a study conducted by Frankowski and Clark (2009) assessed residents’ perspectives on sexuality in thirteen assisted living environments over a nine-year period and indicated support of this assertion. Compared to LTCFs, assisted living facilities have been equally criticized for “paying only modest attention to the sexual needs of their clients—even as the field moves toward a holistic, person-centered approach to care” (de Vries, 2009, p. 2). Administrators may have an awareness of sexual expression occurring in their facility, but “dealt with sexuality issues only when confronted by specific incidents” (de Vries, 2009, p. 2). Additionally, acknowledgment of certain types of sexual expressions (e.g., same-sex physical touching) were “reportedly rarely expressed—or acknowledged” (de Vries, 2009, p. 2). The Ombudsman interviewed for the current article cited fear of government involvement and the possibility of imposed sanctions against facilities as possible explanations for underreporting. Occurrences of sexual expression in the LTC environment are more frequently evidenced in informal conversations among CNAs, administrators, residents, and families. Lack of data and state policies specific to residents’ rights to sexual expression leads to varied interpretations at the institutional level.

**Institutional Regulations**

At the institutional level, LTCFs should recognize sexuality as part of residents’
lives and first consider the resident’s wishes above those of the facility or family. Some LTCFs have embraced sexuality in the LTC environment and proactively established policies and response measures to protect residents’ rights. Hebrew Homes, in Riverdale, New York, is a non-profit facility that provides a variety of services to older adults, including nursing care, rehabilitation, and Alzheimer’s care (hebrewhomes.org, 2012). One goal of this facility is “to provide care in a warm, homelike environment and in a manner, which preserves and enhances independence and dignity” (hebrewhome.org). Additionally, Hebrew Home communications suggest “such care should be provided on the basis of a continuum of care in which older people can live, learn and flourish” (hebrewhome.org). This facility has laid the groundwork for policymakers to develop a universal policy that holds all LTCFs to a similar person-centered standard of care.

Recommendations for increasing awareness and advancing knowledge

Efforts to decrease discomfort among LTC administrators and staff and normalize sexuality among LTC residents begin with clarification of residents’ sexual rights, increased educational efforts, and effective communication among multiple levels of influence (e.g., federal, state, institutional, micro). We recommend inclusion of a clause which indicates residents have “The right to sexual expression: Residents of long-term care facilities have the right to responsibly exercise their rights to sexual privacy, freedom, and autonomy, sexual materials and paraphernalia, sexual counsel, and sexual health care, provided the rights of other residents are not infringed upon and cognitive capabilities have been determined.” This definition calls for resident accountability through clarification of the conditions of sexual expression, and charges LTCFs with providing counsel and sexual health resources to residents. Additionally, the clause
ensures consent, protecting residents from having their rights violated by co-residents’
sexual expression and cognitive impairment.

Despite the magnitude and variety of scenarios that may involve sexuality in
LTCFs, inclusion of a clause specific to residents’ rights to sexual expression will (1)
publicly acknowledge sexuality as an inherent and normal component of aging and,
consequently, aid in desensitization and increased acceptance of the phenomena; (2)
clarify legal expectations and confirm LTCFs’ accountability for managing sexual
expression; (3) aid LTC administrators, staff, and Ombudsmen in differentiation between
natural and expected behaviors, and those which are problematic; and (4) assist in
determining best practices and response strategies, when incidences of sexual expression
occur among residents in LTC settings.

Government efforts toward normalizing sexual expression among LTC residents
involves promoting awareness of sexuality throughout the middle and later stages of life.
Sexual expression should not be considered merely a physical act associated with
youthfulness, but a rightful need of older adults including LTC residents, who should be
afforded the freedom and dignity to privately carry out forms of sexual expression
(Bentrott & Margrett, 2011). This concept, as well as clear explanations of
administrators’, CNAs’, residents’, and family members’ boundaries with regard to
residents’ rights, must be communicated to residents and their families prior to admission
to LTCFs to avoid potential conflicts and complaints, and protect residents’ rights.
**Similarity of environmental contexts and individual circumstances: Parallels between persons with disabilities and older adults**

Many parallels can be drawn between attitudes towards the sexuality of persons with disabilities and older adults, particularly with regard to sexual expression and institutional living environments. A 2010 article by Rembis demonstrates society’s attitudes towards sexuality and the disabled population, stating, “Their inability to perform gender and sexuality in a way that meets dominant societal expectations is seen as an intrinsic limitation, an ‘unfortunate’ but unavoidable consequence of inhabiting a disabled body.” Similar attitudes persist towards older adults, and contradict laws which intend to preserve the rights the older adult population. Older adults are protected under the Older Americans Act (www.aoa.gov, 2010) state what the act ensures. The rights of persons with disabilities are outlined in the United Nations’ Declaration on the Rights of Disabled Persons (www.un.org/disabilities/, 1975). According to this declaration, “Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible” (www.un.org/disabilities/, 1975). Additionally, “Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive there-from. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living
conditions therein shall be as close as possible to those of the normal life of a person of his or her age” (www.un.org/disabilities/, 1975). The vague language used in the Declaration, similar to the Older Americans Act, fails to specifically address sexual expression, leaving room for subjectivity in interpretation of what sexuality entails. Clarification of sexual expression in language specific to the rights of the two populations is necessary for normalizing sexuality and promoting consistent response strategies where necessary.

Informing Residents of their Rights

The process of moving into a LTCF can be emotionally challenging and stressful for older adults, as they experience disruption from normal routines, separation from the familiarity of their community or loved ones, and face the task of establishing a new lifestyle in an unfamiliar environment (caregiverslibrary.org, 2012). LTCFs must recognize these stressors and, consistent with person-centered care, make every attempt to involve residents in decision making, as higher levels of resident satisfaction have been associated with teamwork and involvement in the decision-making process (Sikorska-Simmons, 2006). Despite evidence of heightened efforts towards recognizing residents as the foci of person-centered care in LTCFs (Leutz et al., 2008), the opinions of residents themselves are often overlooked in favor of realizing the needs of facilities, which considerably impact their residents’ quality of life (e.g., choosing not to report to a complaint related to sexual expression to avoid government investigation) (Kane, 2001).

Despite the sensitivity of the topic, conversations with residents regarding sexual expression must take place to determine the conditions surrounding relationships between residents. Residents must be informed of their rights to determine their personal and
sexual needs and desires, and afforded opportunities to share their opinions of sexuality, independent of family members. Residents may be uncomfortable sharing their feelings on sexuality with family members or embarrassed by their desires, and may even purposely mislead family members into believing they are uninterested in sexuality. While residents may still hesitate to discuss sexuality with administrators, directors of nursing, or CNAs, we advise administrators to ask residents asked about their feelings and needs regarding sexuality and recommend inclusion of such questions in standardized intake forms upon admittance.

LTC Ombudsman interviewed for the article suggested sexual expression and residents’ relationships should be documented within residents’ care plans, as inclusion of this information would aid administrators and CNAs in recognizing unusual or unexpected behavior, and identifying problems or changes in residents’ health and/or cognitive ability. Care plans must be updated consistently throughout the duration of the resident’s stay to ensure documentation that the resident recognizes the meaning of sexual expression. Documentation would also serve as a record, which may be particularly useful where discrepancies in knowledge exist between family members and LTCFs.

Fact Sheets for Families

Researchers have long recognized the importance of family members in the lives of older adults residing in group-home settings (Port et al., 2000) and found that family members typically remain involved and influential in their loved ones’ life following placement (Gaugler et al., 2004). Admittance into a LTCF requires completion of multiple legal, financial, medical, and personal forms (e.g., basic daily rate for Medicaid
residents, authorization for disclosure of medical information, residents’ bill of rights). However, discussions of sexuality in the long-term care environment are not currently required between residents, family members, and administrators upon admission. Despite feelings of discomfort, embarrassment, or denial, which may prevent family members from initiating discussion of sexual expression pertaining to their resident, the conversation is still imperative to residents’ rights.

The LTC Ombudsman illustrates the importance of communication with family members in a complaint reported by the adult child of a cognitively intact resident, who recently lost her spouse and became sexually involved with another resident. The family member learned of the relationship through the resident and was angry the LTCF did not inform the family of the circumstances. Despite the resident’s wishes to remain in the sexual relationship, the family member considered it inappropriate and lodged a complaint with the state, threatening to sue the LTCF if the relationship was not terminated. According to the Ombudsman, complaints where family members perceive they have rights or authority over their residents’ rights are not uncommon. The situation would likely have been avoided, if the administrator at this facility would have presented the family a list of residents’ rights to sexual expression, and addressed possible scenarios and response strategies. If these conversations are not legally required, they are unlikely to occur.

Considering input from LTC Ombudsman regarding complaints related to sexuality and the significant level of involvement of many residents’ family members, the authors propose government-mandated dissemination of a sexuality fact sheet issued to family members and residents upon admission to LTCFs. This fact sheet must describe
sexuality throughout the adult lifespan, as younger and middle-age adults also reside in LTCFs, explain residents’ rights to sexual expression, and differentiate between acceptable and unacceptable forms of sexual expression. The fact sheet must include terminology consistent across LTCFs (e.g., definitions, explanation of cognitive capabilities to consent), but also information specific to each facility (e.g., response strategies to certain forms of sexual expression). Due to variances in LTCFs’ missions, statuses, and affiliations, clarification of ethical stances on key issues related to sexual expression (e.g., homosexual relationships, extramarital relationships) is necessary. For example, a religiously-affiliated LTCF may not support sexual expression between two cognitively capable residents who are married to other people, due to religious values, which regard the relationship as an extramarital affair. Incoming residents and their family members must be informed of situations such as these, which are not aligned with a facility’s mission or values. These measures are necessary to establish a culture of openness and awareness that fosters positive interaction among residents’ levels of care, and serve to diminish the likelihood of future “surprises” and miscommunications. Ultimately, residents will benefit from opportunities for all parties to clarify expectations, exchange ideas, and offer feedback to one another.

*Training*

Subjective interpretations of sexual expression, impacted by personal values and beliefs, upbringing, and cultural attitudes, and variations in responses to sexual expression among residents’ various levels of care, necessitate government mandates for education on the topic at each level. Lack of acknowledgement or hesitancy to ask questions or report incidences of sexual expression may lead to serious and unhealthy
practices (e.g., sexually transmitted infections), each of which would be alleviated by knowledge through training on sexuality and aging throughout administrators’, nurses’, CNAs’, and activity professionals’ education and professional careers. Discussions of physiological changes associated with aging that affect sexuality, potential scenarios of sexual expression, and proper response strategies would promote understanding and aid in normalizing sexual expressions among LTC residents; thus, minimizing hesitation and discomfort when addressing the topic.

The National Association of Long Term Care Administrator Boards (NAB) is the professional organization that provides guidance and resources for certification and licensing requirements to agencies that grant licensure to LTC administrators within the United States (2012). According to the NAB (2012), each state requires licensure for LTC administrators, which includes successful completion of a state-approved training program and licensing exam. Administrators must complete coursework in the areas of gerontology, business, finance, and nursing home administration (e.g., management in senior care services, aging services, health care human resources) (DMACC, 2012).

CNA certifications are earned at state-approved postsecondary training programs through completion of clinical rotations and approximately 200-230 hours of coursework on topics, such as medical terminology, nutrition, body mechanics, and anatomy (although, federal guidelines require only a minimum of 75 hours of state-approved coursework) (National Clearinghouse on the Direct Care Workforce, 2008). CNAs must also pass a state-regulated written exam. While some state-approved training programs currently address sexuality and aging within other courses (e.g., Issues in Aging) (DMACC, 2012), sexuality is not offered exclusive of other coursework.
The authors argue that inconsistencies in LTC administrators’ and staff knowledge regarding sexuality and aging exist because licensure requirements vary by state and training related to sexuality is not required. Therefore, to establish consistency in attitudes and response strategies towards residents’ sexual expressions, universal guidelines for education on the subject must be established and mandated by governing boards. Based on the aforementioned factors, the authors proposes a stand-alone course, dedicated solely to issues related to sexuality among residents in LTCFs, as well as integration of whole-person wellness and the impact of sexuality on social and emotional well-being into current coursework. A comprehensive curriculum must be designed to broaden understanding of the meaning of sexuality in older adulthood and address common stereotypes, judgments, and assumptions regarding sexuality and aging. Coursework must promote a person-centered approach to addressing sexuality in this environment, and assess the influence of physical and cultural environments, including barriers to sexuality in older adulthood (e.g., chronic illness, medication, sexual dysfunction). Changes in the human body that occur throughout aging and impact sexuality in older adulthood must be addressed, as well as sexual diversity and the impact of culture, gender, and orientation on aging. Future administrators and LTC staff would also benefit from insight into the roles of family, institution, government, technology, and policy in sexuality among the older adult population.

Some LTC administrators or CNA training programs offer continuing education courses specific to sexuality among residents (e.g., Indian River State College’s “Critical Issues in Aging and Sexuality for Long-Term Care Professionals”) (www.irsc.edu, n.d.). However, administrators and CNAs must be provided continual opportunities to learn of
changes, trends, and medical advances related to sexuality and aging, as well as current research, so they can remain competent in their knowledge.

Conclusions

The future of residents’ rights in the LTC environment is dependent upon the advocacy of those who call for reevaluation of current policies and guidelines, and consider the needs and desires of incoming generations, as well as the modernity of today’s LTCFs. Policymakers are at the forefront of societal influence, possessing the legal authority to develop policies and certify compliance, and the public visibility to curtail negative misjudgments that damage the image of older adults. According to Roach (2004, p. 379), “Both staff and nursing home managers need to work toward developing a home environment that is supportive of residents’ sexuality rights, that permits sexuality expression and promotes a culture where all people concerned are comfortable with sexuality issues.” The authors support this recommendation and offer administrators guidance for initially determining how best to address sexual expression among residents.

Throughout this paper, we have established the importance of formally recognizing sexual expression as an inherent and legal right of LTC residents. Currently, existing legislation and institutional policies do not effectively view sexual expression as a formal need in LTC. Research appeals for reevaluation of current definitions of residents’ needs and recommends modification of policies to include sexual expression. Education guidelines must also be amended to consider training at the administrative and direct-care worker levels, and proactive measures to address resident sexuality with family members and residents must be established.
Chapter Four References


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CHAPTER 5
OVERALL DISCUSSION

The topic of sexuality among the older adult population has long been ignored and too commonly elicits disapproving or incredulous reactions, particularly in the context of long-term care. Researchers, personnel, and advocates in the field of gerontology strive to bring attention and credibility to the topic, while considering the history and composition of incoming LTC residents, and the impact they will have on society. Bioecological, systems, and critical theories provide fitting theoretical frameworks to study factors contributing to and inhibiting residents’ sexual expressions.

Establishing the role of policy in residents’ rights to sexual expression

The influence of government on LTC residents’ rights to sexual expression has been strongly established throughout each paper in this dissertation. While policymakers do not typically have direct access to LTC residents, the policies and guidelines enforced at the federal and state levels determine residents’ access to funding, resources, activities, privacy, and visitors. A law that addresses residents’ rights to sexual expression would provide a basis for recognizing and understanding sexual expression among older adults in the context of LTC, and present guidelines for managing residents’ sexually expressive behaviors at the administrative and CNA levels. Policies that protect residents’ rights do exist. However, the broad and subjective language they incorporate regarding matters such as privacy, visitors, and independent choice are left to interpretation. These rights and multiple others (e.g., confidentiality, dignity, respect, property) comprised within the general LTC residents’ rights policy come closest to addressing sexuality in the LTC
environment, but fall short in specifically declaring sexual expression a right of LTC residents (Medicare.gov, n.d.)

The principles of critical theory, which promote change within an specified area of concern upon which assumptions have previously been made, were utilized to support the researcher’s assertion that policymakers are charged the responsibility of advocacy, and developing guidelines and boundaries that protect LTC residents, and therefore, must present a lawful and factual portrayal of older adults. This can be achieved by amending the current LTC residents’ rights policy to formally recognize sexuality as a natural part of the aging process. Critical theory further guided the study in challenging current assumptions regarding sexuality among LTC residents, with the goal of broadening society’s views on the topic.

Because difficulties exist in determining the types of behaviors that might be considered sexual within the LTC environment, a clause specific to residents’ rights to sexual expression would assist in identifying and normalizing sexual expression in LTC in a number of ways as noted in paper three, (1) publicly acknowledge sexuality as an inherent and normal component of aging and, consequently, aid in desensitization and increased acceptance of the phenomena; (2) clarify legal expectations and confirm LTCFs’ accountability for managing sexual expression; (3) aid LTC Ombudsmen in differentiation between natural and expected behaviors, and those which are problematic; and (4) assist in determining best practices and response strategies when incidences of sexual expression occur among residents in LTC settings. Based on these strategies, the researcher advises policymakers to include the following clause in the existing residents’ rights policy. This clause, more clearly than the general residents’ rights policy, defines
residents’ sexual rights and addresses the critical question of cognitive capabilities, while clarifying the LTCFs’ roles to provide residents sexual health resources.

LTCF administrators, who participated in the current study, demonstrated compliance to government guidelines which mandate public posting of residents’ rights policies, phone numbers for government agencies, and other relevant information (e.g., processes for filing grievances and reporting abuse) in a location with high resident, visitor, and employee visibility. On the surface, this suggests LTCFs will comply with further legal guidelines, such as implementation of a residents’ sexual rights policy. However, observing laws where harsh penalties may be inflicted for noncompliance may prove easier than modifying and maintaining changes within the culture of a facility.

Currently, there is little evidence of existing LTCFs that have formally recognized the importance of implementing an institutional policy that outlines sexual expression for residents. The facilities that do adhere to such policies operate on the knowledge that human beings remain sexual well into their older adult years. Policymakers should consider the processes and practices of these LTCFs, as well the effectiveness of the policies.

*Conversations across systems*

The principles of bioecological and systems theories, applied to LTC residents’ sexual expressions, are resident-centered, beginning with an examination of the residents’ experience across settings (White & Klein, 2002). Consistent with these theories, one key objective of person-centered care is to involve residents in decision-making through consideration of their needs and desires prior to developing laws and regulations. Unfortunately, residents’ desires are often overlooked in favor of what may prove easiest
for other parties involved and not what is best for the resident. Residents must be provided opportunities to communicate their thoughts and opinions on sexual expression, which should be formally observed in care plans, periodically re-visited, and modified as necessary. To encourage an environment supportive of residents’ sexual expression, LTCFs must respect residents’ choices and encourage autonomy in decision-making.

Residents must also take a proactive approach to their personal care and declare their desires, needs, and expectations to administrators, CNAs, and/or family members upon entering a LTCF. In practice, this may not always be possible, due to variations in residents’ health and abilities, and oftentimes, residents require representation in the form of family members or legal guardians to convey their thoughts. Additionally, broaching the sensitive topic of sexuality may be intimidating, uncomfortable, or awkward, thus avoided by residents, even when questioned on the topic. However, residents must understand that to develop successful care plans and respect residents’ rights to sexual expression, they must be honest and open with their LTCF staff prior to admission. This upfront communication will aid residents to determine goodness of fit between their personal expectations and those of the LTCF staff.

Resident and Family Councils

Maintaining consistent, open lines of communication between residents, family members, CNAs, administrators, and policymakers is paramount to preserving residents’ rights. Resident advisory boards, also called residents’ councils, are comprised of LTCF residents, and any resident can choose to become a member. Councils are not regulated by LTC administration, but instead state LTC Ombudsman. According to the Federal Nursing Home Reform Act (www.law.cornell.edu, 2010), residents’ councils have the
following rights (a) “to serve in an advisory capacity to the respective administrators and to the director in all matters related to policy and operational decisions affecting resident care and life in the facility, to include, but not be limited to, input into the biennial budget making process and facility supplementary policies and procedures,” (b) “to actively participate in development of choices regarding activities, food, living arrangements, personal care and other aspects of resident life,” and (c) “when so requested by a resident, serve as an advocate in resolving grievances and ensuring resident rights are observed” (carewatchers.org, 2012). Residents must be made aware of their right to membership on resident councils, where they can voice their opinions and represent themselves and other residents.

Family councils consist of relatives and friends of LTCF residents, as well as a designated staff liaison or advisor of the LTCF (carewatchers.org, 2012). Family councils are federally mandated at Medicare and Medicaid certified LTCFs and provided the following rights (a) “to meet in the facility with the families of other residents in the facility; (b) the facility must provide a family group, if one exists, with private space; (c) staff or visitors may attend meetings at the group’s invitation; (d) the facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings; and (e) when a family group exists, the facility must listen to the views and act upon the grievances and recommendation of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility” (carewatchers.org, 2012). Family boards are powerful platforms for exchanging ideas and providing feedback to LTCFs. Where these boards exist, family members can choose to participate in meetings and activities to
represent their resident, and where they do not exist, families can request the development of a family board or increase their involvement at the facility.

*Discussing the details with family members*

The role of family members and their level of influence (legal or otherwise) in LTC residents’ lives must be recognized, as their personal beliefs of what is best for their resident may be imposed on administrators and regulate the behaviors of employees. Considering this influence, it is paramount that administrators initiate discussions with residents and their families regarding sexuality as related to their resident, and present possible scenarios involving sexual expression with all parties.

While family members’ influence varies, as some families are more regularly involved than others in residents’ lives, if conversations are not initiated by administrators, family members must initiate discussion with residents, CNAs, and administrators regarding residents’ care. Despite the difficulty of discussing a topic this sensitive in nature, conversations with residents that identify their needs and desires, as well as assessment of residents’ family members’ expectations, should take place prior to choosing a LTCF. Residents should be accompanied by loved ones on visits to facilities where questions, concerns, and suggestions can be presented and expectations clarified.

Crucial to successful implementation of a sexual expression policy is dissemination of information related to sexuality in the LTC environment among LTC residents’ levels of care. Fact sheets (e.g., literature, brochure) that describe the residents’ rights to sexual expression policy, sexuality in older adulthood, acceptable and inappropriate forms of sexual expression, and response strategies should be distributed to family members. The PEAK (Promote Excellent Alternatives in Kansas) program is an
initiative developed by the Kansas Department for Aging and Disability Services that has demonstrated success in aiding residents’ family members to understand sexuality in a LTC (Center on Aging, 2008). PEAK developed a Guide for Families of Long-term Care Residents to address LTC residents’ sexual needs, which describes forms of sexual expression and the process of aging, offers resources, and discusses benefits, challenges, and feelings associated with the topic. The literature explicitly states, “being old and/or living in long-term care does not automatically diminish sexual needs” and “this guide is intended to help you think more comfortably about this subject” (Center on Aging, 2008, p. 2). Despite embarrassment, discomfort, or denial expressed by residents and family members, discussions of sexuality must occur to assess all parties’ expectations and preserve residents’ rights. Thus, dispersing literature, such as the aforementioned, may be useful to initiate these discussions. Conversations with administrators should be held with residents independent of family members, and family members independent of residents. Clear communications of what natural and expected sexuality among LTC residents entails will alleviate uncertainty regarding the types of sexual expressions which are problematic, resulting in a decrease of mislabeled behaviors and, in turn, the number of complaints. If these conversations are not legally required, they are unlikely to occur.

*Training caregivers*

A second goal of the PEAK program focuses on providing training to individuals who work in various geriatric care facilities, assisting them to: “Understand the meaning and functions of sexuality for older adults; Identify barriers for residents’ sexual needs; Identify strategies to help residents appropriately express their sexual needs; Identify
inappropriate sexual expressions and strategies to respond to them; and identify fundamental elements for effective staff training on sexuality” (Center on Aging, 2008, p. 2). Competency is demonstrated and maintained, and best practices are delivered to residents by CNAs who employ these objectives. The principles of the training equip CNAs with knowledge of diverse ways of expressing sexuality by LTC residents, attitudes of residents and family members, and successful response strategies.

Promoting sexual education

Preparing individuals working in the LTC setting for situations they are likely to encounter involving residents’ sexual expression is crucial to preserving residents’ rights and retaining employees. Administrators and CNAs must be offered opportunities to learn about issues that will aid their understanding of sexuality among LTC residents. Physiological changes that accompany aging and their impact on sexual health, sexuality within the LTC environment, sexual expression and disabilities, medicine and sexuality, cognitive capabilities for consent to sexual expression, privacy, and cultural competency are topics necessary for administrators and CNAs to comprehend to successfully manage sexual expression among residents. Recent studies on sexually-transmitted infections demonstrate an increasing need for awareness of the risks associated with sexual expression among the older adult population. Reports of rising numbers of sexually-transmitted infections among adults age 50 and older (Minichiello et al., 2012) may best be explained by the populations’ lack of need for contraception (perhaps due to absence of pregnancy concerns) and increased use of medicine to treat sexual dysfunction (Jena et al., 2010). Additionally, there is an absence of health programs and initiatives directed at educating older adults on risky sexual behavior and protective measures.
High incidences of resident abuse (sexual, verbal, physical, emotional) by residents, caregivers, and visitors in LTCFs point to the need for training on the topic. Researcher Claudia Cooper and colleagues (2008) compiled a summary of evidence related to the abuse of older adults, gathered by multiple researchers in the gerontology field. The summary reports (a) “about 16% of long-term care staff reported committing significant psychological abuse in the only study using a valid and reliable measure (b) about 10% of staff admitted physical abuse and 40% any psychologically abusive act in the last year in a study with a well-defined representative population and standardized data collection methods and (c) over 80% of nursing home staff have observed abuse occurring, but rates of abuse actually reported to home management were low (2%)” (Cooper et al., 2008, p. 158). The National Elder Abuse Incidence Study estimated that “for every one case of elder abuse, neglect, exploitation, or self-neglect reported to authorities, about five more go unreported” (www.ncia.aoa.gov, 1998). Certification and training regulations, which include coursework on sexuality in LTC, would help maintain awareness of incidences of sexual expression and response strategies, and aid staff members in recognizing sexual abuse.

Mesosystems: Higher-level training for policymakers

Policymakers must work hand-in-hand with organizations, such as the National Association of Long Term Care Administrator Boards (NAB, 2012), which provides certification resources and licensing requirements to U.S. LTC administrator licensing agencies. At the federal level, policymakers can mandate coursework on the topic of sexuality in LTC for administrators through requirements within each state’s government-approved training program and licensing exam. The current study results,
which indicated moderate levels of confidence in administrators’ knowledge of sexuality in later life and heterosexual relationships between residents, were encouraging. However, administrators’ knowledge of diverse ways of expressing sexuality and homosexual relationships suggests a need for training on the topics.

The implementation of federal regulations is also necessary to establish consistency in CNAs’ skills and knowledge, and response strategies to sexual expression among residents. In the current study, the researcher postulated that inconsistencies in LTC administrators’ and CNAs’ knowledge regarding sexuality and aging exist because licensure requirements vary by state and training related to the topic is not required. Currently, CNA certifications are earned through postsecondary, state-approved training programs, which vary per state. While anywhere from 75 – 230 hours of coursework may be required, courses specific to sexuality and LTC residents are not consistently offered. Policymakers must become involved in defining the CNA role at the federal level through implementation of universal guidelines that require training on the topic through stand-alone courses, offered exclusive of other required coursework. Course content should utilize a person-centered lens to address the natural process of aging and how it affects sexuality, as well as the influences of government, family, health, sexual diversity and orientation, and the physical and cultural environments. Barriers to sexuality in older adulthood must also be identified, and response strategies offered to sexual expression among LTC residents. The skills and knowledge obtained from coursework must be considered in the CNA state-regulated written licensure exam. Additionally, continuing education courses (CEUs), specific to sexuality among
residents, must be offered frequently to provide CNAs the latest in research, medical
advances, and trends associated with LTC, and to maintain their skills and knowledge.

**Microsystems: Administrator training**

Administrators must also be held accountable for their personal knowledge of
sexual expression in LTC. The low levels of administrators’ knowledge in the domains
of diverse ways of expressing sexuality and homosexual relationships suggest the need
for training related to the topics in the context of LTC. Same-sex relationships between
LTC residents is becoming increasingly relevant as many of the Baby Boomers, a
generation more likely to openly express their sexual orientation, grow older and
transition to LTC. Paper one emphasizes the importance of the LTC industry in
acknowledging the growing LGBT population, and mandating training for administrators
and CNAs working in the LTC environment.

In paper two, recommendations are outlined for proficiency in the healthcare
industry provided by the Institute of Medicine, among which included “focusing on
quality improvement”, “delivering patient-centered care”, and “working as part of
interdisciplinary teams” (www.iom.edu, 2012). For administrators to effectively deliver
patient-centered care, deep understanding of the diversity of sexual preferences and the
ways in which residents sexually express themselves are required. Administrators must
also consider the varying degrees of residents’ physical and cognitive health, and the
impact of medicine on sexual capabilities.

Addressing sexual expression in LTC requires an understanding by administrators
that each resident differs in their needs, desires, and capabilities. Along this vein, one
particular response strategy will not adequately apply to every situation that arises.
Therefore, training should encompass a multitude of situations and guidelines that direct resident-centered responses. One crucial function of administrators is to provide support to CNAs and other staff members, who are likely to encounter sexual expression among residents. CNAs must be trained in differentiating between intimacy and inappropriate or risky sexual behaviors, and empowered to recognize situations that need addressed, so they can make informed decisions in managing behaviors. Regularly scheduled meetings must be offered by administrators to continually communicate the goals, responsibilities, rules, and expectations of administrators, policymakers, and CNAs. An administrative “open door policy” for CNAs would encourage open communication and provide a place for CNAs to receiving counseling, venting, or debriefing when necessary.

**Microsystems: Empowering CNAs through training**

To empower CNAs to consistently demonstrate professional response strategies, administrators must proactively promote training on residents’ sexual expressions. Without proper training and understanding of the topic, CNAs’ personal values, attitudes, beliefs, and upbringing may influence their decisions when addressing incidences of sexual expression. Administrators cannot change these factors, but cannot ignore the possibility of their influence in CNAs perceptions of residents’ sexuality. Interpretation of the terms “sexuality” and “privacy” varies; therefore, a universal definition applicable to the LTC environment must be introduced to CNAs early in their career. A screening tool, similar to the one utilized in the current study (the Aged Sexuality Knowledge and Attitudes Scale, White, 1982), which assesses attitudes related to older adults and sexuality in the context of LTC, would be useful to determine goodness of fit between
CNAs and LTCFs. Additionally, it may serve to decrease mislabeling or reports of problematic behaviors, and undesirable responses to incidences of sexual expression.

Varying levels of skill, competence, and experience exist across CNAs working in LTCFs. It is crucial that CNAs communicate questions and concerns regarding sexual expression to administrators, if they are uncomfortable or uncertain how to respond to these types of incidences. Increased knowledge empowers CNAs to make rational decisions in response to residents’ needs and execute proper response strategies. When CNAs indicate interest in learning how to better serve residents, they improve the quality of care residents receive and advance cultural change in their LTCF. Administrators have a responsibility to support CNA requests for education and resources that aid their understanding sexuality in LTCF.

Adapting physical and cultural environments to reflect cultural change

Training and education are highly effective in adapting the cultural LTC environment, including attitudes and processes surrounding sexual expressions among residents (Low et al, 2005). Additional support from policymakers, which requires inclusion of certain features of both the physical and cultural environments, would further benefit residents by formally recognizing the impact of modified environments. Opportunities for personal time and social interaction (e.g., exercise classes, musical shows, church services) must be furnished in comfortable settings, where residents are engaged and can build meaningful relationships with others. The importance of socialization among the older adult population has a history among researchers (Hubbard et al., 2003). Geriatrician Bill Thomas took residential care to new heights in 1989 when he formed The Eden Alternative® (2009). The goal of this movement was to change the
aging experience worldwide through efforts to de-institutionalize residential care facilities (www.edenalt.org, 2009). The Eden Alternative “provides a new way of thinking and new values that become the foundation for dramatic and sustainable transformation of the organization and the people who come in contact with the organization” (www.edenalt.org, 2009). Eden Alternative communities provide residents a sense of purpose through interaction with animals, children, and plant life to alleviate feelings of boredom, loneliness, and powerlessness. The philosophy is currently implemented in approximately 225 facilities across the United States, Canada, Europe, and Australia, and serves as an exemplar for LTCFs which aim to enhance residents’ quality of life through modification of their cultural and physical LTC environments (www.edenalt.org). The success of this principle-based philosophy of care is evident in statistics that boast decreases in needs for antidepressants and “psychotropic prescriptions, average number of medications per resident, staff absenteeism, resident irritability, and incidents of pressure sores, skin tears, and incontinence, and increased revenue and net operating income and census in Eden Alternative facilities” (www.edenalt.org).

The majority of LTC residents in the United States are required through Medicare to share rooms with another resident. Therefore, residents’ access to privacy is restricted and alternative arrangements for private time must be made. Specified numbers and/or types of opportunities for residents to spend time together, designated spaces for residents to privately interact outside of their rooms, and access to erotic movies, magazines, and paraphernalia could be legally required. To compensate for the lack of private rooms, federally-mandated privacy measures, such as room dividers and privacy signs, would be
beneficial where double occupancy rooms are necessary. Rules that require CNAs to knock prior to entering residents’ rooms, and schedules that offer time alone to residents, who share rooms or time to interact privately with other residents without interruptions, would also advance cultural change and preserve residents’ rights.

Administrators are at the forefront of the adoption of cultural change in their duties to manage multiple influences that surround residents. Administrators have the leadership capacity to observe the law, and enforce rules and guidelines, and adapt environments to best accommodate residents. The cultural change process is continual, and administrators are responsible for evaluating their physical and cultural environments, and practices to determine their level of cultural change. Within the physical environment, administrators must make efforts towards creating a homelike atmosphere that encourages warm colors, pleasant odors, comfortable and natural lighting, and resident personalization through use of personal photographs, artwork, furniture, and collections. Privacy signs, curtains, and room dividers contribute to greater feelings of privacy in shared rooms. However, residents should be offered privacy in spaces separate from their rooms—shared or private.

As technology becomes increasingly prevalent in LTCFs and residents demonstrate greater technical abilities, administrators must evaluate access to technology they provide to residents and modify their environments to include computer centers, libraries, and wireless access that could be used to meet the sexual needs of residents. For example, a resident who cannot (due to physical or cognitive difficulties) or wishes not to sexually express themselves with another resident, may be capable of utilizing technology to meet his/her sexual needs. Where lack of funding and reluctance at the private ownership
and/or government levels to acknowledge or support sexuality in the context of LTC pose challenges to LTCFs in establishing environments conducive to sexual expression, administrators can utilize fact-based evidence to support requests for modifications to physical and cultural LTC environments, and inform policymakers and other decision-makers. The Green House Project® is an organization that creates warm, inviting, and smart homelike group living spaces that contribute to vitality and independence for older adults. Residents in green house environments receive quality professional and personal care backed by research that suggests these settings “help elders to live happier, more satisfying lives” (thegreenhouseproject.org, 2011). This model successfully demonstrates the feasibility of preserving residents’ autonomy within a group setting and provides the framework for adapting LTC environments to support the needs, sexual and otherwise, of residents and further their independence in decision-making.

Due to frequency of interaction with residents, CNAs are best positioned of all levels of influence within a resident’s system, to promote positive social interaction and a culture supportive of residents’ sexual rights. Certified nursing assistants interact daily with residents and must strive to establish positive and comfortable relationships, while maintaining their professionalism. CNAs must operate on the basis that a resident-centered approach considers the needs and desires of the resident first. Many residents experience discomfort or embarrassment discussing sexuality, but may feel comfortable having these conversations with a CNA who appears open and approachable. While CNAs have some level of control over residents’ physical environments (e.g., closing residents’ doors to allow for privacy), they are most effective through their actions. CNAs can foster an environment of acceptance by demonstrating respect and
understanding of residents’ sexual needs, even asking residents to share their feelings about sexuality, and discuss their needs and wants. Additionally, these feelings should be documented in personal care plans and observed with the equivalence of other important elements in care plans to ensure these rights are respected. Despite the sensitivity of the topic, conversations with residents regarding sexual expression must take place to determine the conditions surrounding relationships between residents.

Cognitive capability is an important factor to determine whether sexual expression is consensual between LTC residents. Administrators and CNAs must have the skills and knowledge to adequately assess the cognitive capabilities of residents to protect residents’ rights and prevent those who are not cognitively capable of consenting from being taken advantage of the situation. CNAs must adhere to federal guidelines, which mandate assessment of Medicare and Medicaid certified residents in LTCFs using the Resident Assessment Instrument (RAI) (CMS, 2012), and modify care plans accordingly. Residents’ cognitive capabilities should be reassessed frequently as changes in health, ability, behavior, or demeanor may indicate decline or illness, which impact the ability to consent to sexual expression.

Comparisons of profit status and rural vs. urban LTCFs

An extensive search for literature on cultural change comparisons among rural and urban LTCFs has highlighted a dearth of information available on the topic. Research by LaSala (2000) (as cited in Sultz & Young, 1999), illustrates the “rural nursing workforce has been greatly impacted by the cultural environment in which it is practiced, including some of the broader trends related to rural occupational and economical foundations as well as political influences that have had a significant impact on rural health care.”
However, missing from current research are comparisons regarding attitudes, barriers, and response strategies of administrators and CNAs in rural versus urban, and for-profit versus non-profit LTCFs. In the current study, funding restrictions for modifying LTC environments to accommodate residents’ sexual expression was cited as a barrier in both urban and rural facilities, but particularly due to private ownership. Non-profit, religiously-affiliated LTCFs reported their missions, guided by religious values, limited certain forms of sexual expression (e.g., masturbation) and were considered barriers to residents’ rights to sexually express themselves. Inaccessibility to current technology (e.g., computers, movies), which could aid some residents in sexual expression, stood out as a restriction in rural LTCFs. Rural facilities indicated that urban locations have access to modern technology sooner and rural locations often receive what is “left over.” Administrator resistance to awareness of sexual expression and involvement in response strategies was noted at one urban LTCF, possibly due to variations in administrative roles in the two locations.

Administrative duties are based on a cross-section of knowledge of business and healthcare. Administrators at smaller or rural facilities may have multiple duties (supervisory, financial, socially through interaction with residents); whereas, administrators at larger or urban facilities may largely have one key responsibility (e.g., attending to financial matters). Great understanding of similarities and differences between the types of facilities would aid in addressing barriers, allocating resources, and determining fairness in LTCFs.
**Limitations**

Despite the strengths of the study to identify influences on sexual expression at various levels of residents’ systems and providing strategies for normalizing sexuality among older adults, limitations exist herein. Lack of ethnic or cultural diversity between LTCFs and among study participants in the current study limits generalization of results, as greater diversification would aid in comparisons among facilities with respect to these characteristics and promote broader assumptions. Evaluation of the physical and cultural environments across a broader spectrum of LTC would contribute greater knowledge of residents’ rights to sexual expression. Therefore, the current study would benefit from research conducted in various regions throughout the United States. Despite the resident-centered focus of this paper, direct input from residents is not included. Additionally, residents’ family members are represented within residents’ systems; yet, did not participate in the study. Consideration of residents and family members’ perspectives would strengthen the evidence which advocates for residents’ rights to sexual expression presented in this paper.

**Conclusions**

This dissertation study is directed towards policymakers, LTC administrators, CNAs, family members, and residents who (knowingly or unwittingly) influence sexual expression among residents in the LTC environment. The researcher developed an environmental checklist as a new method to assess the physical and cultural LTC environments, and a cultural continuum measure useful for LTCFs in determining the degree to which they are adopting cultural change in their facility. Qualitative interviews conducted with administrators, CNAs, and LTC Ombudsman, utilizing questionnaires,
vignettes, and researcher observations, produced rich, detailed information, which aided in determining outcomes to the research questions. The researcher successfully determined the suitability of the cultural and physical environments of five LTCFs, and presented discussions of formal and informal policies regarding sexual expression among residents. The attitudes, knowledge, and practices of LTC administrators regarding sexual expression among residents, as well as efforts to actively promote sexual education for caregivers, enact policies addressing residents’ sexual expression, and provide training recommendations to aid in developing consistent professional response strategies have also been evaluated. Finally, existing legislation and institutional policies regarding sexual expression in LTC settings were explored, utilizing input from LTC Ombudsmen to inform recommendations for enhancing current policies and LTC staff training guidelines (Table 1).

The study demonstrates each level within the LTC residents’ system has influence on residents’ rights to sexual expression, and a role in preserving these rights. Collectively, these systems can make a difference in the way sexuality is viewed in relation to older adults, and alter response strategies to better suit the needs and desires of LTC residents. Regardless of age and living environment, everyone should be afforded the right to privacy and the choice to be sexual.

Future Directions

The studies comprised in this dissertation are expected to lead to future research on influences surrounding sexual expression among older adults and barriers, which affect residents’ sexual rights in residential care facilities.
Table 1, Chapter 5. Overall study key findings and implications among residents’ systems

<table>
<thead>
<tr>
<th>Paper</th>
<th>Study Aims</th>
<th>Key Findings</th>
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| Paper 1 | Utilizing environmental observations, administrator interviews, and researcher observations this qualitative study assessed five Midwestern long-term care facilities and aimed to (1) identify barriers to LTC residents’ sexual expression (2) provide better understanding of the suitability of the physical and cultural environments of the LTC facilities for sexual expression among residents and (3) provide better understanding of cultural competency within LTCF by assessing adoption of cultural change for sexual expression among residents. | • LTCFs that participated in the study were making efforts to modify their environments to reflect cultural change supportive of residents’ rights to sexual expression.  
• Cultural characteristics including protection of resident’s privacy, autonomy support, resident personalization, opportunities for social interaction, and employee training on sexuality indicated greater likelihood of adoption of cultural change in participating LTCFs.  
• Characteristics of the physical environment of the LTCFs participating in the study indicated a greater likelihood of adoption of cultural change included adequate common spaces, spaces for privacy apart from residents’ rooms, tangible privacy measures, posted residents’ rights policies.  
• Barriers to protecting residents’ rights to sexual expression exist in the forms of funding, lack of employee training, and current federal government regulations, which fail to acknowledge sexual interest or the possibility of resident sexual interaction. | • Residents- Adoption of cultural change means improved conditions to physical and cultural LTC environments that include residents in decision-making, accommodate sexual expression and protect residents’ rights to remain sexual. This results in more positive living atmospheres and improved quality of life.  
• CNAs- Adoption of cultural change and modifying physical and cultural LTC environments to accommodate sexual expression results in greater knowledge of residents’ sexual needs, which empowers CNAs in decision-making and response strategies, in turn, creating a more positive work atmospheres.  
• Administrators- Adopting cultural change and adapting physical and cultural LTC environments to accommodate sexual expression will result in fewer resident complaints, decreased staff turnover staff, higher occupancy rates, and greater competitive advantage over LTCF that do not promote cultural change.  
• Policymakers- Investments in the culture change movement at the policy level will mean increased collaboration, thus communication, with various relevant government agencies, LTC providers, various LTC associations, and residents and their families. Residents and CNAs will be happier and more satisfied with living and working conditions, resulting in fewer formal complaints. |
<table>
<thead>
<tr>
<th>Paper 2</th>
<th>This qualitative study explored the attitudes, barriers, knowledge, and practices of long-term care administrators regarding sexual expression in long-term care facilities. It is hoped that this research will provide administrators with information to aid them is enacting policies addressing resident’s sexual expression and assist them in providing training to caregivers to enable residents to appropriately express their sexual needs.</th>
</tr>
</thead>
</table>
|  | • The administrator’s role is crucial to facilitate communications between and among residents’ networks, yet role varies by LTCF.  
• Inconsistencies exist in administrators’ knowledge regarding residents’ sexual expression in long-term care facilities.  
• Administrators report lower levels of knowledge on same-sex relationships among older adults, as well as diverse ways that older adults express sexuality.  
• The majority of participating facilities do not provide training to CNAs specific to sexual health and aging or response strategies to residents’ sexual expressions.  
• Differences exist between rural and urban LTCFs in resident demographics, healthcare needs, and barriers to residents’ sexual expressions. |
|  | • **Residents**- Sexual education for LTCF employees will decrease incidences of residents’ needs being unmet, violations of residents’ rights, poor communications between residents and family members, and mistrust of CNAs and administrators.  
• The implementation of government policies specific to resident sexuality are reflected in caregiver practice, thereby, increasing residents’ quality of life.  
• **CNAs**- Sexual education for LTCF employees will alleviate uncertainty regarding role responsibilities and how to meet LTCF expectations. Training current employees provides opportunities to improve existing knowledge and clarify expectations.  
• **Administrators**- Sexual education for LTCF employees will reduce uncertainty regarding roles and misunderstandings related to proper response strategies to residents’ sexual expression. CNAs will better comprehend LTCF expectations with regard to sexual expressions. Therefore, frustration, conflicts, mistakes, decreased productivity, and turnover are less likely. |
<table>
<thead>
<tr>
<th>Paper 3</th>
<th>This article is a perspectives piece that examined existing legislation and institutional policies regarding sexual expression in LTC settings, and utilized input from LTC Ombudsman to inform recommendations for enhancing current policies, and provided feedback for effective training guidelines for LTC staff.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Questions:</strong></td>
<td></td>
</tr>
<tr>
<td>• Do certified nursing assistants working in LTCF receive adequate training regarding residents’ sexual behaviors and rights to sexual expression and appropriate response strategies?</td>
<td>• A federally-mandated residents’ rights policy specific to sexual expression does not exist. Therefore, responses to sexual expression among residents vary.</td>
</tr>
<tr>
<td>• Based on identified training results, is there a need to amend policy at the legislative and institutional policy level to formally include sexual expression as a need and right of residents in LTCFs?</td>
<td>• Training requirements for administrators and CNAs do not require education specific to sexuality in LTC.</td>
</tr>
<tr>
<td>• Based on identified training results, is there a need to update training guidelines to include effective response strategies for LTC staff?</td>
<td>• LTCFs are currently not required to have conversations regarding sexual expression with residents or their family members. Therefore, many families are unaware of the possibility of sexual relationships.</td>
</tr>
<tr>
<td></td>
<td>• CNAs’ responses to sexual expression among residents are impacted by personal values and beliefs, upbringing, and cultural attitudes.</td>
</tr>
<tr>
<td></td>
<td>• Residents- Residents will have no question about their rights to sexual expression upon entering LTC.</td>
</tr>
<tr>
<td></td>
<td>• CNAs- Clarification of residents’ sexual expression and universal guidelines outlining proper response strategies will broaden understanding of the meaning of sexuality in older adulthood and aid in consistent response strategies, which preserve residents’ rights to sexual expression.</td>
</tr>
<tr>
<td></td>
<td>• Administrators- Straightforward, standard explanations of what sexuality in LTC entails will make identifying violations of residents’ rights to sexual expression less challenging. Specific definitions of sexual expression among residents and applicable response strategies will aid in training employees.</td>
</tr>
<tr>
<td></td>
<td>• Policymakers- A universal policy that holds all LTCFs to a similar standard of care will ensure residents’ rights to sexual expression. Violations of residents’ rights to sexual expression will be more easily identifiable, resulting in decreased numbers of complaints associated with sexuality.</td>
</tr>
</tbody>
</table>
Pre- and post-training evaluations of administrator and CNA attitudes and practices could provide insight into the effectiveness of various training methods, as well as the influence of education on LTC physical and cultural environments. Longitudinal assessment of policies that protect LTC residents’ rights, particularly with regard to sexually expressive behaviors, could aid in supporting results of the current study by further demonstrating the extent to which a policy specific to sexual expression is necessary. Inclusion of resident and family member opinions would also strengthen understanding of the knowledge and expectations surrounding sexuality among LTC residents, and aid in determining response strategies. Comparisons between various types of residential living environments for older adults (e.g., assisted living, independent living) would also prove beneficial in determining differences in attitudes and responses to sexual expression, as variations in constraints, freedoms, and outcomes are likely in these contexts. Sexual expression among older adults of culturally-diverse populations should be examined, as interpretations of what sexuality entails varies across cultures, and therefore expectations and response strategies may differ. In the meantime, the tools and information provided in this study can guide LTCFs in determining best practices and strategies for protecting residents’ rights to sexual expression in LTC.
Chapter Five References

Adapted from “Pioneering Change to Promote Excellent Alternatives in Kansas Nursing Homes,” 2003-2008, Center on Aging, Kansas State University, Manhattan, KS. Used by permission.


APPENDIX A: ORIGINAL INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL FOR RESEARCH

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515-294-6546
FAX: 515-294-4587

Date: 7/1/2011
To: Meeza Bentrott
4380 Palmer

CC: Dr. Jennifer Merrett
4380 Palmer

From: Office for Responsible Research

Title: Sexual Expression among Residents of Long-Term Care: Perspectives of Staff and Administrators

IRB Num: 11-393

Approval Date: 8/29/2011
Continuing Review Date: 8/20/2012
Submission Type: New
Review Type: Full Committee

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 50), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Obtain IRB approval prior to implementing any changes to the study by submitting the "Continuing Review and/or Modification" form.
- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/irb/forms/ or available by calling (515) 294-4586.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
### INSTITUTIONAL REVIEW BOARD (IRB) Application for Approval of Research Involving Humans

**SECTION I: GENERAL INFORMATION**

<table>
<thead>
<tr>
<th>Principal Investigator (PI): Mena D. Bentrott</th>
<th>Phone: 515-371-5282</th>
<th>Fax:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degrees:</td>
<td>Correspondence Address: 60 L.e.Haron, ISU</td>
<td></td>
</tr>
<tr>
<td>Department: Human Development and Family Studies</td>
<td>Email Address: <a href="mailto:mbeany@iastate.edu">mbeany@iastate.edu</a></td>
<td></td>
</tr>
<tr>
<td>Center/Institute:</td>
<td>College:</td>
<td></td>
</tr>
<tr>
<td>PI Level:</td>
<td>Faculty</td>
<td>Staff</td>
</tr>
<tr>
<td>Alternate Contact Person: Dr. Jennifer Margrett</td>
<td>Email Address: <a href="mailto:margrett@iastate.edu">margrett@iastate.edu</a></td>
<td></td>
</tr>
<tr>
<td>Correspondence Address: 2754 Palmer, ISU</td>
<td>Phone: 515-394-3028</td>
<td></td>
</tr>
<tr>
<td>Title of Project: Sexual Expression among Residents of Long Term Care: Perspectives of Staff and Administrators</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Project Period (include Start and End Date):</td>
<td>Name/Date: [5/1/11] to [5/1/12]</td>
<td></td>
</tr>
</tbody>
</table>

#### FOR STUDENT PROJECTS

<table>
<thead>
<tr>
<th>Name of Major Professor/Supervising Faculty:</th>
<th>Signature of Major Professor/Supervising Faculty:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone: 515-394-3028</td>
<td></td>
</tr>
<tr>
<td>Department: Human Development and Family Studies</td>
<td>Email Address: <a href="mailto:margrett@iastate.edu">margrett@iastate.edu</a></td>
</tr>
<tr>
<td>Type of Project (check all that apply):</td>
<td></td>
</tr>
<tr>
<td>□ Research</td>
<td>□ Thesis</td>
</tr>
<tr>
<td>□ Independent Study (490, 590, Honors project)</td>
<td>□ Other. Please specify:</td>
</tr>
</tbody>
</table>

#### KEY PERSONNEL

List all members and relevant experience of the project personnel. This information is intended to inform the committee of the training and background related to the specific procedures that each person will perform on the project.

<table>
<thead>
<tr>
<th>NAME &amp; DEGREE(S)</th>
<th>SPECIFIC DUTIES ON PROJECT</th>
<th>TRAINING &amp; EXPERIENCE RELATED TO PROCEDURES PERFORMED, DATE OF TRAINING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mena D. Bentrott, M.S.</td>
<td>Principal Investigator</td>
<td>Trained in qualitative interviewing techniques and knowledgeable in content area (human sexuality, adult sexuality, gerontology).</td>
</tr>
<tr>
<td>Jennifer Margrett, Ph.D.</td>
<td>Supervise Principal Investigator in data collection, analysis, and reporting</td>
<td>Ten plus years of research experience is everyday functioning, competency, and cognitive aging in adulthood and later life.</td>
</tr>
<tr>
<td>Sarah French</td>
<td>Coordinate and assist in data collection and entry, interview transcription</td>
<td>Taken content and method courses, proficiency with SPSS, member of Gerontology lab group.</td>
</tr>
</tbody>
</table>

Office for Responsible Research: IRB 09/12/10
FUNDING INFORMATION

| Internally funded, please provide account number: |
| Externally funded, please provide funding source and account number: |
| Funding is pending, please provide OSPA Record ID on GoldSheet: |
| Title on GoldSheet if different from above: |
| ☒ Other: (e.g., funding will be applied for later) PI will apply for dept. dissertation funding in September |
| ☒ Student Project—no funding or funding provided by student |

SCIENTIFIC REVIEW

Although the assurance committees are not intended to conduct peer review of research proposals, the federal regulations include language such as “consistent with sound research design,” “rationale for involving animals or humans” and “scientifically valuable research,” which requires that the committees consider in their review the general scientific relevance of a research study. Proposals that do not meet these basic tests are not justifiable and cannot be approved. If an assurance review committee(s) has concerns about the scientific merit of a project and the project was not competitively funded by peer review or was funded by corporate sponsors, the project may be referred to a scientific review committee. The scientific review committee will be an ad hoc and will consist of your ISU peers and outside experts as needed. If this situation arises, the PI will be contacted and given the option of agreeing that a consultant may be contacted or withdrawing the proposal from consideration.

☑ Yes ☐ No Has or will this project receive peer review?

If the answer is “yes,” please indicate who did or will conduct the review: The proposed project was part of a larger grant proposal submitted to the Borchard Foundation in November 2010 and another proposal currently under review by the National Institute of Justice. The Graduate Education Committee of the Department of Human Development and Family Studies will review an abbreviated proposal when the PI applies for dissertation funding.

If a review was conducted, please indicate the outcome of the review:

COLLECTION OR RECEIPT OF SAMPLES

Will you be: (Please check all that apply.)

☐ Yes ☒ No Receiving samples from outside of ISU? See examples below.
☐ Yes ☒ No Sending samples outside of ISU? See examples below.

Examples include: genetically modified organisms, body fluids, tissue samples, blood samples, pathogens.

If you will be receiving samples from or sending samples outside of ISU, please identify the name of the outside organization(s) and the identity of the samples you will be sending or receiving outside of ISU. If the outside organizations have not been identified, please check no for both questions above.

Please note that some samples may require a USDA Animal Plant Health Inspection Service (APHIS) permit, a USPHS Centers for Disease Control and Prevention (CDC) Import Permit for Etiologic Agents, a Registration for Select Agents, High Consequence Livestock Pathogens and Toxins or Listed Plant Pathogens, or a Material Transfer Agreement (MTA) EH&S Website.

Office for Responsible Research: IRB 9/13/10
ASSURANCE

- I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies.
- I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subject or welfare of animal subjects are protected. I will report any problems to the appropriate assurance review committee(s).
- I agree that I will not begin this project until receipt of official approval from all appropriate committee(s).
- I agree that modifications to the originally approved project will not take place without prior review and approval by the appropriate committee(s), and that all activities will be performed in accordance with all applicable federal, state, local and Iowa State University policies.

CONFLICT OF INTEREST

A conflict of interest can be defined as a set of conditions in which an investigator's or key personnel's judgment regarding a project (including human or animal subject welfare, integrity of the research) may be influenced by a secondary interest (e.g., the proposed project and/or a relationship with the sponsor). ISU's Conflict of Interest Policy requires that investigators and key personnel disclose any significant financial interests or relationships that may present an actual or potential conflict of interest. By signing this form below, you are certifying that all members of the research team, including yourself, have read and understood ISU's Conflict of Interest policy as addressed by the ISU Faculty Handbook (http://www.provost.iastate.edu/faculty) and have made all required disclosures.

☐ Yes  ☐ No  Do you or any member of your research team have an actual or potential conflict of interest?
☐ Yes  ☐ No  If yes, have the appropriate disclosure form(s) been completed?

SIGNATURES

[N. Name]
Signature of Principal Investigator  Date: 6-2-11

[Signature]
Signature of Department Chair  Date: 7-2-11

The Major Professor/Supervising Faculty member must sign the cover page in the section entitled "For Student Projects".

PLEASE NOTE: Any changes to an approved protocol must be submitted to the appropriate committee(s) before the changes may be implemented.

Please proceed to SECTION II.
SECTION II: IRB SECTION - STUDY SPECIFIC INFORMATION

Please complete all of the following questions.

STUDY OBJECTIVES

Briefly explain in language understandable to a layperson the specific aim(s) of the study.

The primary study aim is to examine the cultural and physical environments of long-term care facilities, including formal and informal policies regarding sexual expression among residents. Perspectives of administrators and certified nursing assistants will be assessed. In addition, a checklist of relevant information will be gathered about each long-term care facility.

BENEFITS TO SOCIETY AND PARTICIPANTS

Explain in language understandable to a layperson how the information gained in this study will advance knowledge, and/or serve the good of society. Please also describe the direct benefits to research participants; if there are no direct benefits to participants, indicate that. Note: monetary compensation cannot be considered a benefit to participants.

No direct benefits may occur for the current study participants. However, findings are expected to provide benefits to staff members by increasing communication among caregivers, administrators, residents, and families. The project will increase recognition of barriers that influence sexual expression and aid in establishing adequate environments and consistent response strategies across long-term care facilities.

PART A: PROJECT INVOLVEMENT

1) □ Yes ☒ No Is this project part of a Training, Center, Program Project Grant?
   Director Name: Overall IRB ID:

2) □ Yes ☒ No Is the purpose of this project to develop survey instruments?

3) □ Yes ☒ No Does this project involve an investigational new drug (IND)? Number:

4) □ Yes ☒ No Does this project involve an investigational device exemption (IDE)? Number:

5) □ Yes ☒ No Does this project involve existing data or records?

6) □ Yes ☒ No Does this project involve secondary analysis?

7) □ Yes ☒ No Does this project involve pathology or diagnostic specimens?

8) □ Yes ☒ No Does this project require approval from another institution? Please attach letters of approval.

9) □ Yes ☒ No Does this project involve DEXA/CT scans or X-rays?

PART B: MEDICAL HEALTH INFORMATION OR RECORDS

10) □ Yes ☒ No Does your project require the use of a health care provider’s records concerning past, present, or future physical, dental, or mental health information about a subject? The Health Insurance Portability and Accountability Act established the conditions under which protected health information may be used or disclosed for research purposes. If your project will involve the use of any past or present clinical information about someone, or if you will add clinical information to someone’s treatment record (electronic or paper) during the study, you must complete and submit the Application for Use of Protected Health Information.
PART C: ANTICIPATED ENROLLMENT

| Estimated number of participants to be enrolled in the study Total: 70  |
|-----------------------------|-------------|
| Males: 20                   | Females: 50 |
| Check if any enrolled participants are: |
| □ Minor (Under 18)          |
| □ Age Range of Minors:      |
| □ Pregnant Women/Fetuses    |
| □ Cognitively Impaired      |
| □ Prisoners                 |
| Check below if this project involves either: |
| □ Adults, non-students      |
| □ Minor ISU students        |
| □ ISU students 18 and older |
| □ Other (explain)           |

List estimated percent of the anticipated enrollment that will be minorities if known:

<table>
<thead>
<tr>
<th>American Indian:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaskan Native:</td>
</tr>
<tr>
<td>Asian or Pacific Islander:</td>
</tr>
<tr>
<td>Black or African American:</td>
</tr>
<tr>
<td>Latino or Hispanic:</td>
</tr>
</tbody>
</table>

PART D: PARTICIPANT SELECTION

Please use additional space as necessary to adequately answer each question.

11. Explain the procedures and rationale for selecting participants, including the inclusion and exclusion criteria (e.g., where will names come from, what persons will be included or excluded and why, etc.).

Participants for the study will be recruited from the Iowa Department of Inspections and Appeals list of public and private Free Standing Nursing Facilities/Skilled Nursing Facilities (NF/SNF) in the state of Iowa which differ in religious affiliation and rural versus urban locations. Inclusion criteria for nursing home administrator participation in this study are: (1) all participants have been employed by their LTC facility for greater than 6 months (2) participants must be unrelated to any resident currently residing in the facility where they are employed (3) and be able to speak English. The investigator will also request permission from administrators to facilitate recruitment of the facility's Certified Nursing Assistants (CNA). Inclusion criteria for CNA participation in this study are: (1) all participants have been employed by their LTC facility for greater than 6 months (2) participants must be unrelated to any resident currently residing in the facility where they are employed (3) and be able to speak English. The investigator will also request permission from administrators to facilitate recruitment of the facility's Certified Nursing Assistants (CNA).

12. Describe the procedures for contacting participants (e.g., letter, email, flyer, advertisements, phone call, etc.). Attach copies of any letters, scripts, flyers, or advertisements that will be used. Recruitment materials should include a statement of the voluntary and confidential nature of the research.

Administrators at selected facilities will be called directly by the primary investigator who will describe the study and request their participation in one sixty-minute individual face-to-face interview to be conducted at their place of employment. CNAs will be recruited from each site in order to assess their attitudes toward residents' rights to sexual expression and barriers to sexual expression. Surveys are anonymous, however, tear-off sheets which voluntarily identify participants and indicate willingness to participate in a future focus group will be included with each survey. Survey participants will be told to fill out and tear off the sheet and return it to the researcher if they would like to volunteer to participate in a future focus group. From these sheets, female and male CNAs will be randomly selected and asked to participate in a focus group, assessed for one hour on one occasion during the participants' usual lunch period. Focus group sessions and interviews will be conducted at the participants' long-term care facility.

PART E: RESEARCH PLAN

Include sufficient detail for IRB review of this project independent of the grant, protocol, or other documents.
13. The information needed here is similar to that in the "methods" or "procedures" sections of a research proposal—it should describe the flow of events that will occur during your interactions with subjects. Please describe in detail your plans for collecting data from participants, including all procedures, tasks, or interventions participants will be asked to complete during the research (e.g., random assignment; any conditions or treatment groups into which participants will be divided, mail survey or interview procedures, sensors to be worn, amount of blood drawn, etc.). This information is intended to inform the committee of the procedures used in the study and their potential risks. Please do not respond with "see attached" or "not applicable."

Environmental checklists will be completed at participating facilities, surveys and focus groups held with certified nursing assistants, and one-on-one interviews conducted with administrators.

Environmental checklists will be completed at six participating facilities to determine the adequacy of the physical and structural environment of each LTC facility with regard to policy, privacy, and sexual expression (see Appendix for checklist).

Survey: Sixty Certified Nursing Assistants will receive a questionnaire prior to focus group meetings. Surveys are anonymous, however, tear-off sheets which voluntarily identify participants and indicate willingness to participate in future focus groups will be included at the back of the survey. From these sheets, 48 certified nursing assistants will be randomly selected and assigned to one of six focus groups. Questionnaires will assess demographics, attitudes toward resident's rights to sexual expression, barriers to sexual expression, and typical and recommended responses to sexual expression. Focus group sessions and interviews will be conducted at the participants' place of employment and take place over the participant's usual lunch period.

Focus Groups: Six focus groups consisting of eight Certified Nursing Assistants will be assessed for one hour on one occasion at the participant's long-term care facility. Focus group sessions will utilize this interactive format, including vignettes and policy examples, with open-ended discussion questions to generate discussion of CNAs' attitudes and opinions toward residents' rights to sexual expression, barriers to sexual expression, and typical and recommended responses to sexual expression.

Interviews: One sixty-minute individual face-to-face interview will be conducted with six Nursing Home Administrators at the participant's long-term care facility. Administrator interviews will be aimed at residents' rights to sexual expression, caregiver and administrator response strategies, the effectiveness of current laws and regulations, and sexual education and training opportunities.

14. For studies involving pathology/diagnostic specimens, indicate whether specimens will be collected prospectively and/or already exist "on the shelf" at the time of submission of this review form. If prospective, describe specimen procurement procedures; indicate whether any additional medical information about the subject is being gathered, and whether specimens are linked at any time by code number to the participant's identity. If this question is not applicable, please type N/A in the response cell.

N/A

15. For studies involving deception or where information is intentionally withheld from participants, such as the full purpose of the study, please explain how persons will be deceived or what information will be withheld. Additionally, a waiver of the applicable elements of consent will be needed. Please complete the "Waiver of Elements of Consent" form (available at the IRB website). If this question is not applicable, please type N/A in the response cell.

N/A

PART F: CONSENT PROCESS

A copy of any translated informed consent documents and an English version should be submitted with the application. Provide the name of the individual who translated the consent documents, their qualifications for translating documents, and in particular informed consent documents, below.
If the consent process does not include documented consent, a waiver of documentation of consent must be requested. If any information about the study is intentionally withheld or misleading (i.e., deception is used), a waiver of the elements of consent must be requested. Forms for requesting waivers are available at the IRB website.

16. Describe the consent process for adult participants (those who are age 18 and older).

All participants in the study will be age 18 or older. I will be contacting LTC facility administrators via phone to explain the research project and ask for permission to deliver a letter of consent for participation in a one hour interview conducted on one occasion at the participant's place of employment, as well as an environmental observation of their long-term care facility. Additionally, permission will be requested to assess the experiences of the facility's certified nursing assistants (CNAs) via survey. CNAs who agree to participate will be provided a letter of consent along with the option of voluntary participation in a focus group conducted on one occasion at the participants' place of employment.

17. If your study involves minor children, please explain how parental consent will be obtained prior to enrollment of the minor(s).

N/A

18. Please explain how assent will be obtained from minors (younger than 18 years of age), prior to their enrollment. Also, please explain if the assent process will be documented (e.g., a simplified version of the consent form, combined with the parental informed consent document). According to the federal regulations, "... means a child's affirmative agreement to participate in research. Mere failure to object should not, absent affirmative agreement, be construed as assent."

N/A

PART G: DATA ANALYSIS

19. Describe how the data will be analyzed (e.g., statistical methodology, statistical evaluation, statistical measures used to evaluate results).

The study is primarily qualitative, therefore qualitative data analysis techniques will be utilized simultaneously with data collection. Upon completion of each observation, interview, or focus group conducted, I will write summary sheets which serve as field notes to detail the conversations and events that took place, as well as my personal observations, insights, and reflections regarding the data. Audiotapes will be used to record interviews with administrators and focus groups and transcribed. I will use open coding and pattern coding data reduction techniques for coding the data, as well as my personal notes collected during the interviewing and focus group processes. Additionally, a methodological log will be kept to document my perceptions and reflections on the data collection process, analysis and the participant's reactions. Themes and patterns which emerge from the data upon coding will enable me to better understand the attitudes of the participants, as well as my own personal perceptions. In terms of quantitative data, analysis of variance will be utilized for comparisons of group means between urban versus rural long-term care facilities. Chi square analysis will be performed to determine relationships among variables.

PART H: RISKS

The concept of risk goes beyond physical risk and includes risks to participants' dignity and self-respect as well as psychological, emotional, legal, social or financial risk.

20. ☐ Yes ☑ No Is the probability of the harm or discomfort anticipated in the proposed research greater than that encountered ordinarily in daily life or during the performance of routine physical or psychological examinations or tests?
21. □ Yes  ☒ No Is the magnitude of the harm or discomfort greater than that encountered ordinarily in daily life, or during the performance of routine physical or psychological examinations or tests?

22. Describe any risks or discomforts to the participants and how they will be minimized and precautions taken. Do not respond with N/A. If you believe that there will not be risk or discomfort to participants, you must explain why.

There are no major risks anticipated to participants, with the exception of disruption of usual lunch plans for volunteering CNA focus group participants, which will be alleviated by arranging for catered lunch during focus group sessions and providing each participant a $10.00 gift card. Participants may experience some discomfort at disclosing information in response to some of the questions, as they are sensitive in nature. Participants will not be coerced into participating in the study, and prior to requesting signed consent and conducting interviews, surveys or focus groups, participants will be notified of their rights to decline to answer questions or address certain topics, or terminate their participation in the study at any time throughout the research process without explanation.

Participant information will not be shared with longterm care employees, nor made publicly available.

23. If this study involves vulnerable populations, including minors, pregnant women, prisoners, the cognitively impaired, or those educationally or economically disadvantaged, what additional protections will be provided to minimize risks?

The study does not involve participation by a vulnerable population.

PART I: COMPENSATION

24. ☒ Yes □ No Will participants receive compensation for their participation? If yes, please explain.

Do not make the payment an inducement, only a compensation for expenses and inconvenience. If a person is to receive money or another token of appreciation for their participation, explain when it will be given and any conditions of full or partial payment. (E.g., volunteers will receive $5.00 for each of the five visits in the study or a total of $25.00 if he/she completes the study. If a participant withdraws from participation, they will receive $5.00 for each of the visits completed.) It is considered undue influence to make completion of the study the basis for compensation.

Participating administrators will receive honoraria in the form of a $20.00 gift card on the one occasion they are interviewed. CNA volunteers for focus groups will receive a catered lunch during their focus group session and a $10.00 gift card on the one occasion they are interviewed.

PART II: CONFIDENTIALITY

25. Describe below the methods that will be used to ensure the confidentiality of data obtained. (For example, who has access to the data, where the data will be stored, security measures for web-based surveys and computer storage, how long data or specimens will be retained, anticipated date that identifiers will be removed from completed survey instruments and/or audio or visual tapes will be erased, etc.)

Information collected by the researcher will remain confidential and only trained research staff, including the primary investigator and major professor will have access to actual identifying information. Pseudonyms will be assigned to replace personal identifying information to further ensure confidentiality. Data will be kept in locked and/or password protected computer files and filing cabinets. Interviews will be audiorecorded and tapes will be destroyed immediately following transcription. Transcript and quantitative data will be retained for five years post last publication per guidelines of the American Psychological Association. Summaries of my interpretations of the data will be shared with the appropriate administrators and staff of the LTC facilities who agreed to participate in the study. I will not share confidential or identifying information, including names, with any participating LTC facilities or participants in the study. Group data are provided only and any uniquely identifying information, including site specific information, will not be included in summaries for participants or in future publications.
PART K: REGISTRY PROJECTS

26. To be considered a registry: (1) the individuals must have a common condition or demonstrate common responses to questions; (2) the individuals in the registry might be contacted in the future; and (3) the names/data of the individuals in the registry might be used by investigators other than the one maintaining the registry.

☐ Yes ☒ No Does this project establish a registry?

If "yes," please provide the registry name below.

Checklist for Attachments

Listed below are the types of documents that should be submitted for IRB review. Please check and attach the documents that are applicable for your study:

☒ A copy of the informed consent document OR ☐ Letter of introduction containing the elements of consent
☒ A copy of the assent form if minors will be enrolled
☒ Letter of approval from cooperating organizations or institutions allowing you to conduct research at their facility
☒ Data-gathering instruments (including surveys)
☒ Recruitment fliers, phone scripts, or any other documents or materials participants will see or hear

The original signed copy of the application form and one set of accompanying materials should be submitted for review. Federal regulations require that one copy of the grant application or proposal be submitted for comparison with the application for approval.

FOR IRB USE ONLY:

Action by the Institutional Review Board (IRB):

☒ Project approved. Date: 6/29/11

☐ Project is exempt. Date: 

☐ Project not approved. Date: 

☐ IRB approval is not required. Date: 

☒ Project is not research according to the federal definition.

☒ Project does not include human subjects as defined by the federal regulations.

[Signature]
IRB Approval Signature
Date 6/29/11
SECTION III: ENVIRONMENTAL HEALTH AND SAFETY INFORMATION

☐ Yes  ☒ No  Does this project involve human cell or tissue cultures (primary OR immortalized), or human blood components, body fluids or tissues?

PART A: HUMAN CELL LINES

☐ Yes  ☒ No  Does this project involve human cell or tissue cultures (primary OR immortalized cell lines/strains) that have been documented to be free of bloodborne pathogens? If the answer is “yes,” please answer question 1 below and attach copies of the documentation.

1) Please list the specific cell lines/strains to be used, their source and description of use.

<table>
<thead>
<tr>
<th>CELL LINE</th>
<th>SOURCE</th>
<th>DESCRIPTION OF USE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add New Row

2) Please refer to the ISU "Bloodborne Pathogens Manual," which contains the requirements of the OSHA Bloodborne Pathogens Standard. Please list the specific precautions to be followed for this project below (e.g., retractable needles used for blood draws):

N/A

Anyone working with human cell lines/strains that have not been documented to be free of bloodborne pathogens is required to have Bloodborne Pathogen Training annually. Current Bloodborne Pathogen Training dates must be listed in Section I for all Key Personnel. Please contact Environmental Health and Safety (294-5359) if you need to sign up for training and/or to get a copy of the Bloodborne Pathogens Manual (http://www.ets.iastate.edu/cms/default.asp?action=article&ID=214)

PART B: HUMAN BLOOD COMPONENTS, BODY FLUIDS OR TISSUES

☐ Yes  ☒ No  Does this project involve human blood components, body fluids or tissues? If “yes,” please answer all of the questions in the “Human Blood Components, Body Fluids or Tissues” section.

1) Please list the specific human substances used, their source, amount and description of use.

<table>
<thead>
<tr>
<th>SUBSTANCE</th>
<th>SOURCE</th>
<th>AMOUNT</th>
<th>DESCRIPTION OF USE</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g., Blood</td>
<td>Normal healthy volunteers</td>
<td>2 ml</td>
<td>Approximate quantity, essays to be done.</td>
</tr>
</tbody>
</table>

Add New Row

2) Please refer to the ISU "Bloodborne Pathogens Manual," which contains the requirements of the OSHA Bloodborne Pathogens Standard. Specific sections to be followed for this project are:
APPENDIX B: INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL
FOR RESEARCH MODIFICATION I

Date: 9/21/2011
To: Merea Bentoff
4350 Palmer

CC: Dr. Jennifer Margrett
4380 Palmer

From: Office for Responsible Research

Title: Sexual Expression among Residents of Long-Term Care: Perspectives of Staff and Administrators

IRB Num: 11-263

Approval Date: 9/20/2011
Continuing Review Date: 6/20/2012
Submission Type: Modification
Review Type: Full Committee

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Obtain IRB approval prior to implementing any changes to the study by submitting the "Continuing Review and/or Modification" form.
- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/office/ or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
**ISU HUMAN SUBJECTS CONTINUING REVIEW AND/OR MODIFICATION FORM**

**TYPE OF SUBMISSION:** □ Continuing Review  ☑ Modification  □ Continuing Review and Modification

**Principal Investigator:** Melan Diann Bennett  
**Degree:** M.S.  
**Correspondence Address:** 1369 Palmer Bldg, ISU

**Department:** Human Development and Family Studies  
**Project Title:** Sexual Expression among Residents of Long-term Care: Perspectives of Staff and Administrators

**IRB ID:** 11-263  
**Date of Last Continuing Review:** 6/26/2011

**Alternate Contact:** Dr. Jennifer Margrett  
**Phone:** 515-294-3028  
**Correspondence Address:** 2351 Palmer Bldg, ISU

**Email Address:** margrett@iastate.edu

**IF STUDENT PROJECT**

**Name of Major Professor:** Dr. Jennifer Margrett  
**Phone:** 515-294-3028  
**E-mail Address:** margrett@iastate.edu

**Department:** Human Development and Family Studies  
**Campus Address:** 2351 Palmer Bldg, ISU

**FUNDING INFORMATION:**

- External Grant/Contract  
- Internal Support (no specific funding source) or Internal Grant (indicate name below)
- Name of Funding Source: OSPA Record ID or Gold Sheet:
- Part of Training, Center, Program, Project Grant—Director: Overall IRB ID No:
- Student Project—No funding or funding provided by student:

**ASSURANCE**

I certify that the information provided in this application is complete and accurate and consistent with proposal(s) submitted to external funding agencies. I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any adverse reactions to the IRB for review. I agree that modifications to the originally approved project will not take place without prior review and approval by the Institutional Review Board, and that all activities will be performed in accordance with state and federal regulations and the Iowa State University Federal Wide Assurance.

**Signature of Principal Investigator:**  
**Date:** 8-25-11

**Student Projects:** Faculty signature indicates that this application has been reviewed and is recommended for IRB review.

**Signature of Supervising Faculty:**  
**Date:** 8-31-11

**IRB Approval Signature:**  
**Date:** 9-1-11

**For:** EXPEDITED per 45 CFR 46.116(b)  
**STUDY REMAINS EXEMPT per 45 CFR 46.101(b)  
**WAIVER OF SIGNED CONSENT per 45 CFR 46.116  
**WAIVER of ELEMENTS of Consent per 45 CFR 46.116  
**VULNERABLE POPULATION per 45 CFR 46.
DIRECTIONS: Section I: Key Personnel must be completed for all applications. Please complete Section II if this is an application for Continuing Review. If this is an application for continuing review and you will be modifying your project, please complete all sections of the form. If this application is only to request approval for a modification or change to your study, please complete Section I and Section III: Proposed Modifications or Changes. Please answer each question.

SECTION I: KEY PERSONNEL

List all current members of the project personnel, including any additions and excluding any deletions as described in Section III. This information is intended to inform the committee of the training and background of the investigators and key personnel.

<table>
<thead>
<tr>
<th>NAME &amp; DEGREE(S)</th>
<th>POSITION AT ISU &amp; ROLE ON PROJECT</th>
<th>TRAINING &amp; DATE OF TRAINING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marea D. Bentrott, M.S.</td>
<td>Principal Investigator</td>
<td>Trained in qualitative interviewing techniques and knowledgeable in content area (human sexuality, adult sexuality, gerontology). Date of Training: 1/7/2008</td>
</tr>
<tr>
<td>Jennifer Margrett, Ph.D.</td>
<td>Supervise Principal Investigator in data collection, analysis, and reporting</td>
<td>Ten plus years of research experience in everyday functioning, competency, and cognitive aging in adulthood and later life. Date of Training: 8/25/2006</td>
</tr>
<tr>
<td>Sarah French</td>
<td>Coordinate and assist in data collection and entry, interview transcription</td>
<td>Taken content and method courses, proficiency with SPSS, member of Gerontology lab group. Date of Training: 1/17/2011</td>
</tr>
</tbody>
</table>

If you don't know your training date, contact the Office for Responsible Research for assistance.

SECTION II: CONTINUING REVIEW

Part A: Enrollment Status

1. Yes [ ] No [ ] Is the research permanently closed to the enrollment of new participants?
2. Yes [ ] No [ ] Have all participants completed all research-related interventions?
3. Yes [ ] No [ ] Does research remain active only for long-term follow-up of participants (follow-up interactions that involve no more than minimal risk (e.g., "member checking") or follow-up interventions that would normally be performed for non-research purposes)?
4. Yes [ ] No [ ] Are the remaining research activities limited to data analysis? OR
5. Yes [ ] No [ ] Participant enrollment has not begun and no additional risks have been identified.

For definitions and guidance on how to determine enrollment, please see the document entitled Enrollment and Accrual of Study Participants on the IRB website.

Number of Participants Approved for Enrollment by IRB:

<table>
<thead>
<tr>
<th>Total Number of Participants enrolled in the study to date:</th>
<th>Male:</th>
<th>Female:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Screen Failures (participants who were screened and deemed ineligible) to date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check if any enrolled participants are:</td>
<td>Check below if this project involves:</td>
<td></td>
</tr>
<tr>
<td>□ Minors (under 18). Age Range of Minors:</td>
<td>□ Existing Data/Records:</td>
<td></td>
</tr>
<tr>
<td>□ Pregnant Women/Placenta</td>
<td>□ Secondary Analysis:</td>
<td></td>
</tr>
<tr>
<td>□ Cognitively Impaired</td>
<td>□ Pathology/Diagnostic Specimens:</td>
<td></td>
</tr>
<tr>
<td>□ Prisoners</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
List Below the Estimated Percent of the Total Enrolled That Are Minorities

<table>
<thead>
<tr>
<th>American Indian</th>
<th>Alaskan Native</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian or Pacific Islander</td>
<td>African American</td>
</tr>
<tr>
<td>Black (Not of Hispanic Origin)</td>
<td>Hispanic</td>
</tr>
</tbody>
</table>

1. □ Yes □ No Have any participants withdrawn or have you asked any participants to withdraw from the study? List number for each and reason for withdrawal:

Part B: Protocol Summary – Please use the amount of space needed to adequately address the questions.

1. Please provide a concise summary of the purpose and main procedures of the study.

2. Please provide a current summary of how the study is progressing (e.g., progress to date in terms of the overall study plan, success or problems encountered, reasons enrollment has not begun, progress since the last IRB review, etc.)

3. Is there any new information (positive or negative) from this study (e.g., interim analysis) or elsewhere (e.g., current literature) that might affect someone’s willingness to enroll or continue in the study? It is especially important for the investigator to notify the IRB of literature or information that’s relevant to the risks to participants in the study.

4. □ Yes □ No Have there been any modifications or amendments implemented since the last IRB review? If yes, please describe.

Part C: Adverse Events and Unforeseen Problems

1. □ Yes □ No Have there been any adverse events or unanticipated problems involving risks to participants or other people?

   If yes, please describe the event(s).

   □ Yes □ No Have there been any participant complaints?

   If yes, please describe.
Part D: Informed Consent

1. ☐ Yes ☐ No If a signed Informed Consent Form was required, was Informed Consent obtained from all participants?

If no, please explain.

2. ☐ Yes ☐ No Are all signed Informed Consent Forms on file with the PI?

If no, please explain.

3. Unless enrollment is permanently closed and remaining activities are limited to data analysis, please:

☐ Attached Submit an unstamped copy of the currently approved Informed Consent Document or informational letter so a current IRB approval stamp can be added. If changes have been made, please describe those changes in Section III and submit a copy with the changes highlighted, and a "clean" copy to be stamped with IRB approval.

☐ N/A

☐ Attached Submit an unstamped copy of all recruitment materials, so that a current IRB approval stamp can be added. Any changes to recruitment materials should be described in Section III. Please also submit a copy with the changes highlighted, and a copy to be stamped with IRB approval.

☐ N/A

Please Note: Any changes to the protocol, procedures, or study materials (e.g., survey instruments, interview questions, flyers, posters, etc.) must be described in detail as requested in Section III. Please also submit a copy with the changes highlighted, and a copy to be stamped with IRB approval.
SECTION III. PROPOSED MODIFICATIONS OR CHANGES

If this application is to request approval for modification or changes to your project, please complete Section I: Key Personnel and Section III.

The submission of a modification form is required whenever any changes are made to an approved project. This includes, but is not limited to, a title change, changes in investigators, resubmission of a grant proposal involving changes to the original proposal, changes in the funding source, changes to data collection materials and informed consent documents, advertisements, confidentiality measures, inclusion/exclusion criteria, reports from a data safety and monitoring board, addition of a test instrument, etc. NOTE: All changes must be submitted and approved by the IRB prior to their implementation unless the change is necessary to protect the safety of participants.

1. □ Yes ☒ No Does your project now require approval from another institution?
   If yes, please attach letters of approval.

2. The following modification(s) are being made (check all that apply):
   □ Change in protocol/procedures.
   ☒ Change in type or total number of participants. New anticipated total: 76
   □ Change in informed consent document.
   □ Change in co-investigator(s). New co-PI name:
   
   Signature of new Co-PI: ____________________________

   □ Change in funding source/sponsor. If federally funded, please attach copy of grant proposal.
   ☒ Other (e.g., change in project title, adding new materials, adding advertisement, etc.)

   □ Personnel/staff changes since the last IRB approval was granted? Please complete the following table as appropriate. NOTE: If the change involves a new Principal Investigator, a new Human Subjects Review form must be submitted.

<table>
<thead>
<tr>
<th>Add</th>
<th>Delete</th>
<th>Last Name</th>
<th>First Name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Describe the modification(s) indicated above in sufficient detail for evaluation independent of any other documents. Be sure to describe all changes in detail and provide a rationale for the changes. When submitting revised documents please submit one clean copy of the new document and a copy with the changes highlighted.

State-required long-term care ombudsmen will inform the current study from a policy perspective, providing information on resident rights and systemic advocacy, as well as state requirements and expectations of long-term care facilities. Inclusion of this information will strengthen the study by contributing to the theoretically holistic perspective of the research. Materials added to the study will include interview questions for ombudsmen, as well as informed consent documents (attached).
APPENDIX C: INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL FOR RESEARCH MODIFICATION II

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Date: 3/19/2012
Toc: Merea Bentrott
4380 Palmer

CC: Dr. Jennifer Margrett
4380 Palmer

From: Office for Responsible Research

Title: Sexual Expression among Residents of Long-term Care: Perspectives of Staff and Administrators

IRB ID: 11-263

Approval Date: 3/19/2012
Date for Continuing Review: 8/20/2012
 Submission Type: Modification
 Review Type: Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.
- Obtain IRB approval prior to implementing any changes to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.
- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.
- Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.

Please don't hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.
# INSTITUTIONAL REVIEW BOARD (IRB)
## Modification Form for Non-Exempt Research

**Title of Project:** Sexual Expression among Residents of Long-term Care: Perspectives of Staff and Administrators  
**Assigned IRB ID:** IE-12-03 
**RECEIVED**  
**PFF:** 2-2-2012 
**BY IRB**  

**Principal Investigator (PI):** Maree D. Benjott  
**University ID:** 63554041477  
**Phone:** 55-371-5292  
**Email Address:** mbenny@iastate.edu  
**Department:** Human Development and Family Studies 

**FOR STUDENT PROJECTS (Required when the principal investigator is a student):** 
**Name of Major Professor/Supervising Faculty:** Dr. Jennifer Margrett  
**University ID:** 104132522412  
**Phone:** 515-294-2028  
**Email Address:** margrett@iastate.edu  

**Alternate Contact Person:**  
**Correspondence Address:**  

Please notify the IRB Office if your contact information has changed since the last review.

## ASSURANCE

- I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies. Mispresentation of the research described in this or any other IRB application may constitute non-compliance with federal regulations and/or academic misconduct according to ISU policy.
- I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any problems to the IRB.
- I agree that modifications to the originally approved project will not take place without prior review and approval by the IRB.
- I agree that the project will not take place without the receipt of permission from any cooperating institutions, when applicable.
- I agree to obtain approval from other appropriate committees as needed for this project, such as the IACUC (if the research includes animals), the IBC (for research involving biohazards), the Radiation Safety Committee (for research involving x-rays or other radiation producing devices or procedures), etc.
- I agree that all activities will be performed in accordance with all applicable federal, state, local, and Iowa State University policies.

**Signature of Principal Investigator:** Maree Benjott  
**Date:** 2-22-12  
**Signature of Major Professor/Supervising Faculty:** Jennifer Margrett  
**Date:** 2-23-12  

(Required when the principal investigator is a student)

<table>
<thead>
<tr>
<th>For IRB Use Only</th>
<th>Full Committee Review</th>
<th>Review Date</th>
<th>March 14, 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Euch-PH 105 (469)</td>
<td>Approval Not Required</td>
<td>Approval/Determination Date</td>
<td>March 14, 2012</td>
</tr>
<tr>
<td>EXPERT-2013-34</td>
<td>Not Research</td>
<td>Approval/Expiration Date</td>
<td>June 20, 2013</td>
</tr>
<tr>
<td>NOTAPPROVED</td>
<td>Not Human Subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category: Letter</td>
<td>Risk: Minimal</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**IRB Reviewer's Signature:** Maree Benjott  
**Date:** March 14, 2012

Office for Responsible Research  
IRB Non-Exempt: Modification 8/26/11
Modification Information

The submission of a modification form is required whenever any changes are made to an approved project that requires expedited review or approval from the convened IRB. Modifications may include, but are not limited to,
- a change in the title;
- changes in investigators or key personnel;
- resubmission of a federal grant proposal involving changes to the original proposal;
- changes in the funding source (only when federal funding is involved);
- changes to data collection materials (e.g., informed consent documents, advertisements, survey or interview questions, etc.); or
- any other changes from the originally approved protocol (e.g., changes to confidentiality measures, inclusion/exclusion criteria, addition of an intervention or stimuli, etc.).

NOTE: All modifications must be approved by the IRB prior to implementation unless the change is necessary to protect the safety of participants.

Please provide answers to all questions, except as specified. The fields will expand as you type. Incomplete forms will be returned without review.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Was your project initially determined to be eligible for exempt review? This information can be found in the approval letter you received when the study was last reviewed.

If Yes, STOP! This is not the correct form! Please submit a Modification Form for Exempt Research form instead.

If No, please complete Parts A and B below.

Part A: Changes In Personnel

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Does the modification involve a change in Principal Investigator? If Yes, STOP! The new principal investigator must submit a completed new Application for Approval of Research Involving Humans.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Are you adding or removing members of the key personnel? If Yes, complete Table A.1 below.
<table>
<thead>
<tr>
<th>NAME</th>
<th>Interpersonal contact or communications with subjects, or access to private identifiable information?</th>
<th>Involved in the consent process</th>
<th>Contact with human research participants, or other behavioral research?</th>
<th>Other Roles in Research</th>
<th>Qualifications (i.e., special training, degrees, certifications, coursework, etc.)</th>
<th>Human Subjects Training Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sorenson, Karin</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>Data management, interview transcription</td>
<td>Taken content and method courses, proficiency with SPSS, member of Gerontology lab group.</td>
<td>1/11/2012</td>
</tr>
<tr>
<td>Pitlick, Alli</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>Data management, interview transcription</td>
<td>Taken content and method courses, proficiency with SPSS, member of Gerontology lab group.</td>
<td>1/9/2012</td>
</tr>
<tr>
<td>Imbleton, Kaela</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Assistance managing online survey responses and data</td>
<td>Extensive experience with surveygizms, data management</td>
<td>1/8/2011</td>
</tr>
</tbody>
</table>
Part B: Protocol Modifications

<table>
<thead>
<tr>
<th></th>
<th>1. Please specify whether or not either of the following changes apply:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes ☒ No</td>
<td>1.a. Changes in project title (specify new title):</td>
</tr>
<tr>
<td>☐ Yes ☐ No ☒ N/A</td>
<td>1.b. Change in funding source (applies only when federal funding is involved). Specify new source:</td>
</tr>
<tr>
<td></td>
<td>□ Attach a copy of the corresponding grant proposal with the IRB application.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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<th>2. Please complete items 2.a. through 2.f. below to identify and describe all proposed modifications to your research procedures or study materials.</th>
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<tr>
<td>☒ Yes ☐ No</td>
<td>2.a. Does the modification involve a change to the research procedures, such as the following? (Check all that apply.)</td>
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<td>☒ Method of data collection</td>
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<td>☒ Recruitment methods of procedures</td>
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<td>☐ Compensation plan (including awarding course credit)</td>
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<td>☐ Confidentiality measures or privacy protections</td>
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<td>☐ Other; please specify:</td>
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2.b. Please provide a detailed description of each change noted above in 2.a. The description should be complete, such that review of other documents (including attachments) is not required to understand the change.

*Method of data collection: The data collection method outlined in the study’s original proposal called for nursing home administrators to distribute KATES questionnaires to CNAs. Instead, the study will utilize a list of CNAs provided by the State of Iowa LTC Ombudsmen to recruit CNAs. Interested CNAs will complete an informed consent and the KATES survey online via SurveyGizmo. At the end of the survey, CNAs will be given the option to be contacted for a confidential, one-on-one follow-up interview with the researcher via telephone on one occasion, instead of the previously IRB approved mode of focus groups.

*Recruitment methods of procedures: CNAs will be recruited via e-mail and/or telephone instead of through long-term care administrators who are asked to distribute letters to employees which request participation.

*Number of participants: The original study called for 70 participants. Instead, 150 to 200
CNAs will be recruited via e-mail and/or telephone.

*For CNAs who take the survey and wish to be included in a raffle, there will be one drawing for every 25 participants for a $50 Target gift certificate to compensate for time and efforts in helping with the study. CNAs who agree to participate in a one-on-one interview with the researcher will receive a $20.00 gift card for their contribution to the study.

- Attach a copy of any revised materials or documents with all changes clearly marked.
- Attach a final, "clean" copy of any revised materials or documents for inclusion in the file and the addition of an IRB approval stamp.

2.6. Explain the rationale for each proposed change:

*Method of data collection: Utilizing a list provided by the LTC ombudsman will ensure that all registered CNAs in the state of Iowa have an equal chance of being selected for the study, and not only those where administrators were selected for interviews. The IRB previously approved content of the survey will not change, only the mode of data collection.

*Recruitment methods of procedure: Recruiting CNAs via email will allow the researcher to reach a greater number of participants than if recruitment was carried out by administrators at facilities which were chosen for interviews.

*Number of participants: The increase in the number of participants from 70 in the original study to 150 to 200 CNAs will improve the likelihood that survey results are representative.

*Due to the increase in the number of participants and the change in method of data collection from the focus group method to the online survey format, it was necessary to alter the compensation plan for participants to reflect these modifications.

□ Yes □ No 2.d. Does the modification involve a change to the study materials, such as the following? (Check all that apply)

- Recruitment materials
- Informed consent documents
- Survey instruments/questionnaires
- Interview or focus group questions or scripts
- Debriefing statements
- Other: please specify:

2.e. Please provide a detailed description of each change noted above in 2.d. The description should be complete, such that review of other documents (including attachments) is not required to understand the change.

*Recruitment materials: An email which describes the study and the role of the participant in the study will be used instead of a formal hard copy of a letter which describes the study and the role of the participant.

*Informed Consent: The CNA survey informed consent document will no longer describe the voluntary option to participate in the survey as, "Upon completion of the survey, you will have the option to fill out a form that is separate from the survey, which asks you if you would like to participate in the study."
are interested in participating in a 60-minute focus group on one occasion at your place of employment. If you indicate "yes", you will be asked to provide your name and contact phone number or e-mail. These forms will be collected separately from your survey responses. If interested, you may be randomly selected to take part in a focus group session. Information gathered at focus group sessions remains confidential and group-level data will be reported only. Identifying information, including names and site-specific information, shall remain confidential and will not be identified in summaries or future publications. Upon completion of the survey, you will have the option to participate in a 60-minute one-on-one interview with the researcher conducted by telephone on one occasion. If you indicate "yes", you will be asked to provide your name and contact phone number or e-mail and you may be randomly selected to take part in an interview. Upon selection, you will be contacted by me to and asked to schedule a convenient time and date to conduct the interview. Information gathered at the interview is confidential and group-level data will be reported only. Identifying information, including names and site-specific information, shall remain confidential and will not be identified in summaries or future publications.

The title of the Certified Nursing Assistant Focus Group Informed Consent will be changed to Certified Nursing Assistant Interview Informed Consent and will no longer say, "Because you have indicated interest in participating in the study, you have been randomly selected to participate in a 60-minute focus group on one occasion at your place of employment. You will be contacted by me and asked to attend a focus group session. Information gathered at focus group sessions remains confidential and group-level data will be reported only. Identifying information, including names and site-specific information, shall remain confidential and will not be identified in summaries or future publications. Your participation in focus groups is voluntary and your individually identifiable comments will not be shared with LTC facility employees, including your nursing home administrator, or made publicly available. Your name will not be used during focus group sessions and all participants will be asked to keep information shared in group sessions confidential. However, the researchers cannot control participants' actions beyond the focus group session. The focus group will be conducted over your typical work hours and discussion will be audio-recorded. Audio tapes will be transcribed and destroyed following transcription. Transcripts will be retained for five years post last publication per American Psychological Association guidelines. Instead it will say "Because you have indicated interest in participating in the study's one-on-one interview by completing an online survey form that provides your name and phone number or e-mail, you have been selected to participate in a 60-minute telephone interview with the researcher on one occasion at a date and time convenient to you. Information gathered at the interview remains confidential and group-level data will be reported only. Identifying information, including names and site-specific information, shall remain confidential and will not be identified in summaries or future publications."

*Survey Instruments/Questionnaires: The informed consent document is the first page that comes up when clicking on the online survey link. Currently, at the bottom of the consent form is a section that states "Do you agree to participate (response required)." I will add the following text to this question, "Clicking "Yes" indicates your consent to voluntarily agree to participate in this study. This means that the study has been explained to you, that you have been given time to read the document and that all your questions have been satisfactorily answered." Additional changes to the informed consent form at the beginning of the online survey are highlighted in green in the attached document and include: removal of the word "SIGNATURE" under PARTICIPANT'S RIGHTS; removal of Diane Amed's telephone number; and removal of the sentence "If you wish to keep a copy of this consent form, please print this page for your records", so that participants are told only to "Please print this page for your records."

*Interview or focus group questions or script: Demographic questions and hypothetical
Vignettes have been added to a series of previously IRB approved guiding questions to be used to interview CNAs. These guiding questions were previously IRB approved under the title "Focus Group and Administrator Guiding Questions." The title of this document is now "Certified Nursing Assistants Guiding Interview Questions".

- Attach a copy of all revised materials or documents with all changes clearly marked.
- Attach a final, "clean" copy of all revised materials or documents for inclusion in the file and the addition of an IRB approval stamp.

2.f. Explain the rationale for each proposed change:

- **Recruitment materials:** Because CNAs will no longer be recruited by administrators, and instead emailed/telephoned by the researcher, it is necessary to draft an email letter of recruitment.

- **Informed consent documents:** Because the method of data collection has been changed from CNAs completing the survey in hard copy form to the online survey method, it became necessary to update the informed consent documents to reflect these changes. The IRB previously approved content of the survey will remain the same, only the mode of collection will change.

- **Survey Instruments/Questionnaires:** Because the informed consent documents required modification due to method of data collection, it was necessary to update the informed consent document in the online survey to reflect these changes.

- **Interview or focus group questions or script:** Demographic questions and hypothetical vignettes were added to a series of previously IRB approved guiding questions to interview CNAs because they will capture rich data and provide supplemental information regarding the composition of the group of CNAs and their attitudes regarding the topic.

If you have any questions or feedback, please contact the IRB office at IRB@astate.edu or 515-294-4566.
APPENDIX D: INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL
FOR RESEARCH MODIFICATION III

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Date: 5/10/2012

To: Marea Benirott
4380 Palmer

From: Office for Responsible Research

CC: Dr. Jennifer Margrett
4380 Palmer

Title: Sexual Expression among Residents of Long-term Care: Perspectives of Staff and Administrators

IRB ID: 11-202

Approval Date: 5/9/2012
Date for Continuing Review: 5/9/2013

Submission Type: Modification
Review Type: Expected

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 50), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.
- Obtain IRB approval prior to implementing any changes to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.
- Immediately inform the IRB of (1) all serious and unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Please be aware that IRB approval means that you have met the requirements of federal regulations and ISU policies governing human subjects research. Approval from other entities may also be needed. For example, access to data from private records (e.g., student, medical, or employment records, etc.) that are protected by FERPA, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., schools, other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. IRB approval in no way implies or guarantees that permission from these other entities will be granted.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.

Please don't hesitate to contact us if you have questions or concerns at 515-294-4986 or irb@iastate.edu.
INSTITUTIONAL REVIEW BOARD (IRB)
Modification Form for Non-Exempt Research

Title of Project: Sexual Expression among Residents of Long-Term Care: Perspectives of Staff and Administrators

Principal Investigator (PI): Mena D. Beattret
University ID: 53654001417 Phone: 515-371-5392 Email Address: mbeattre@iastate.edu
Department: Human Development and Family Studies

FORSKUDENT PROJECTS (Required when the principal investigator is a student)
Name of Major Professor/Supervising Faculty: Dr. Jennifer Margret
University ID: 101322522412 Phone: 515-294-3028 Email Address: margretr@iastate.edu

Alternate Contact Person: Email Address:
Correspondence Address: Phone:

Please notify the IRB Office if your contact information has changed since the last review.

ASSURANCE

I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies. Misrepresentation of the research described in this or any other IRB application may constitute non-compliance with federal regulations and/or academic misconduct according to ISU policy.

I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any problems to the IRB.

I agree that modifications to the originally approved project will not take place without prior review and approval by the IRB.

I agree that the research will not take place without the receipt of permission from any cooperating institutions, when applicable.

I agree to obtain approval from the appropriate committees as needed for this project, such as the IACUC (if the research involves animals), the IRB (for research involving biohazards), the Radiation Safety Committee (for research involving x-rays or other radiation-producing devices or procedures), etc.

I agree that all activities will be performed in accordance with all applicable federal, state, local, and Iowa State University policies.

Signature of Principal Investigator: Mena Beattret 4/11/12

Signature of Major Professor/Supervising Faculty: Dr. Jennifer Margret 4/17/12

Office for Responsible Research
IRB Non-Exempt Modification 8/26/11

For IRB Use Only

| Full Committee Review: | Review Date: 4/9/12 |
| Approval not Required: | Approval/Determination Date: 4/9/12 |
| EXEMPT per 45 CFR 46.101(b): | Minimal Risk: Yes, more than Minimal |
| Not Research: | Approval Expiration Date: 4/9/13 |
| EXPEDITED per 45 CFR 46.101(b): | |
| Category Letter: | |
| Not Approved: | |

IRB Reviewer's Signature: 4/9/12

IRB Non-Exempt Modification 8/26/11
Modification Information

The submission of a modification form is required whenever any changes are made to an approved project that requires expedited review or approval from the convened IRB. Modifications may include, but are not limited to,

- a change in the title;
- changes in investigators or key personnel;
- resubmission of a federal grant proposal involving changes to the original proposal;
- changes in the funding source (only when federal funding is involved);
- changes to data collection materials (e.g., informed consent documents, advertisements, survey or interview questions, etc.); or
- any other changes from the originally approved protocol (e.g., changes to confidentiality measures, inclusion/exclusion criteria, addition of an intervention or stimuli, etc.).

NOTE: All modifications must be approved by the IRB prior to implementation unless the change is necessary to protect the safety of participants.

Please provide answers to all questions, except as specified. The fields will expand as you type. Incomplete forms will be returned without review.

☐ Yes ☐ No 1. Was your project initially determined to be eligible for exempt review? This information can be found in the approval letter you received when the study was last reviewed.

If Yes, STOP! This is not the correct form! Please submit a Modification Form for Exempt Research form instead.

If No, please complete Parts A and B below.

Part A: Changes in Personnel

☐ Yes ☐ No 1. Does the modification involve a change in Principal Investigator? If Yes, STOP! The new principal investigator must submit a completed new Application for Approval of Research Involving Humans.

☐ Yes ☐ No 2. Are you adding or removing members of the key personnel? If Yes, complete Table A.1 below.
Part B: Protocol Modifications

1. Please specify whether or not either of the following changes apply:

- [ ] Yes  [x] No  1a. Changes in project title (specify new title):

- [ ] Yes  [ ] No  [x] N/A  1b. Change in funding source (applies only when federal funding is involved). Specify new source:
  - [ ] Attach a copy of the corresponding grant proposal with the IRB application.

2. Please complete items 2a. through 2f. below to identify and describe all proposed modifications to your research procedures or study materials.

- [x] Yes  [ ] No  2a. Does the modification involve a change to the research procedures, such as the following? (Check all that apply.)
  - [ ] Method of data collection
  - [ ] Sources of data or records
  - [ ] Experimental design or conditions
  - [ ] Research interventions or stimuli
  - [x] Recruitment methods of procedures
  - [ ] Inclusion/exclusion criteria or characteristics of participants
  - [ ] Number of participants
  - [ ] Compensation plans (including awarding course credit)
  - [ ] Confidentiality measures or privacy protections
  - [ ] Other; please specify:

2b. Please provide a detailed description of each change noted above in 2a. The description should be complete, such that review of other documents (including attachments) is not required to understand the change:

```
Recruitment methods of procedures: The previously IRB approved modification indicated that CNA contact information would be provided by the State of Iowa LTC Ombudsmen. The researcher would also like to recruit participants by contacting known CNAs and contacts who are applicable to the research in the state of Iowa (e.g., instructors of gerontology, CNA educators, gerontology researchers) by phone number, email, and flyers which contain the previously IRB approved recruitment email information, including a description of the study and a link to the previously approved online KATES survey. Multiple copies of the flyer (attached) will be given to nursing home administrators throughout the state of Iowa, and thereby, distributed to the CNAs they employ.
```

- [ ] Attach a copy of any revised materials or documents with all changes clearly marked.
2. Attach a final, "clean" copy of any revised materials or documents for inclusion in the file and the addition of an IRB approval stamp.

2.c. Explain the rationale for each proposed change:

- Recruitment methods of procedure: The state of Iowa LTC Ombudsman are recently under new management and have indicated they are now uncomfortable providing a list of Iowa CNAs to the researcher as previously promised.

2.d. Does the modification involve a change to the study materials, such as the following? (Check all that apply)

- Recruitment materials
- Informed consent documents
- Survey instruments/questionnaires
- Interview or focus group questions or scripts
- Debriefing statements
- Other; please specify:

2.e. Please provide a detailed description of each change noted above in 2.d. The description should be complete, such that review of other documents (including attachments) is not required to understand the change.

- Recruitment materials: A flier which describes the study and the role of the participant in the study will be given to LTC administrators and used to recruit CNAs.

- Attach a copy of all revised materials or documents with all changes clearly marked.
- Attach a final, "clean" copy of all revised materials or documents for inclusion in the file and the addition of an IRB approval stamp.

2.f. Explain the rationale for each proposed change:

- Recruitment materials: Because CNAs will now be recruited via flyers distributed by administrators, it is necessary to draft a flyer for recruitment.

If you have any questions or feedback, please contact the IRB office at irb@iastate.edu or 515-294-4566.
Bentrott 11-261
Addendum: Per 5/9/2012 email

Reviewer question: The modification application notes that you plan to recruit participants by contacting third parties such as known CNA's and others (i.e., gerontology instructors and researchers, CNA educators) by phone, email, and flyers. What will these individuals (i.e., the known CNA's, gerontology instructors and researchers, CNA educators) be asked to do?

PI Response: The known third parties will be asked to distribute the flyers (e.g., place them in CNAs' mailbox at their facility or on the table in a break room where CNAs may see them) and/or forward the IRB approved email with the survey link to the CNAs they know are working in long-term care facilities.

Reviewer Question: Additionally, the approved email text/flyers provides instructions to the research subjects (i.e., the CNA's) on how to complete the online survey; there are no instructions for the third parties. Will the persons you contact simply be asked to share those emails/flyers with potential research participants? Will these third parties have any other roles in the research?

PI Response: The third parties will have no other role. They will only be asked to pass along the survey link via email or flyer.

Reviewer Question: Similarly, the modification application notes that you also plan to ask nursing home administrators to distribute flyers to CNA’s they employ. I want to confirm with you that these administrators will only distribute the flyers and will not have access to the CNA’s survey responses—that was part of the understanding when the study was initially approved, and I need to make sure we are still on the same page.

PI Response: Paper copies of the surveys are not being provided to CNAs, therefore, administrators will not be distributing or collecting the actual surveys, and will not have access to participants' responses. They will only have a paper copy of the IRB approved flyer that contains the survey link. Additionally, these flyers will be given to administrators in individual, sealed envelopes that contain no identifiers other than the ISU logo, preventing administrators from knowing if CNAs even complete the survey. Administrators will be asked to place these envelopes in CNAs’ mailboxes.
APPENDIX E: INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL FOR CONTINUING REVIEW

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Date: 5/13/2012
Te: Merea Bentrott
4380 Palmer

From: Office for Research
Title: Social Expression among Residents of Long-term Care: Perspectives of Staff and Administrators
IRB ID: 11-263

Approval Date: 5/9/2012
Date for Continuing Review: 5/8/2013
Submission Type: Continuing Review
Review Type: Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above as all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.
- Obtain IRB approval prior to implementing any changes to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.
- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.
- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Please be aware that IRB approval means that you have met the requirements of federal regulations and ISU policies governing human subjects research. Approval from other entities may also be needed. For example, access to data from private records (e.g., student, medical, or employment records, etc.) that are protected by 21 CFR 564, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. IRB approval in no way implies or guarantees that permission from these other entities will be granted.

Upon completion of the project, please submit a Project Closure Form to the Office for Research, 1138 Pearson Hall, to officially close the project.

Please don’t hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.
# INSTITUTIONAL REVIEW BOARD (IRB)

## Continuing Review Form

**Title of Project:** Sexual Expression among Residents of Long-term Care: Perspectives of Staff and Administrators

**Principal Investigator (PI):** Marea D. Rentrott  
**University ID:** 8368-9001-417  
**Degrees:** M.S.  
**Department:** Human Development and Family Studies  
**Phone:** 515-294-3028  
**Email Address:** mbrontott@iastate.edu

**FOR STUDENT PROJECTS (required when the principal investigator is a student):**  
**Name of Major Professor/Supervising Faculty:** Dr. Jennifer Margrett  
**University ID:** 1013523413  
**Phone:** 515-294-3028  
**Email Address:** margrett@iastate.edu

**Alternate Contact Person:**  
**Correspondence Address:**  
**Phone:**

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**ASSURANCE**

- I certify that the information provided in this application is complete and accurate and consistent with any proposal(s) submitted to external funding agencies. Misrepresentation of the research described in IRB or any other IRB application may constitute non-compliance with federal regulations and/or academic misconduct according to SU policy.
- I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any problems to the IRB.
- I agree that modifications to the originally approved project will not take place without prior review and approval by the IRB.
- I agree that the research will not take place without the receipt of permission from any cooperating institutions, when applicable.
- I agree to obtain approval from other appropriate committees as needed for this project, such as the IACUC (if the research involves animals), the IRB (for research involving biohazards), the Radiation Safety Committee (for research involving X-rays or other radiation-producing devices or procedures), etc.
- I agree that all activities will be performed in accordance with all applicable federal, state, local, and Iowa State University policies.

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**Signature of Principal Investigator**  
**Date:** 4/2/12

**Signature of Major Professor/Supervising Faculty**  
**Date:** 4/2/12

---

**IRB Reviewers’ Signature:**  
**Date:** 5/2/12

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**Office for Responsible Research**  
**IRB Continuing Review Form: 8/3/11**
### Continuing Review Information

Please provide answers to all questions, except as specified. The fields will expand as you type. Incomplete forms will be returned without review.

**Part A: Status of the Research:** Please respond to the following statements to describe the current status of your research.

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1. The remaining research activities are limited solely to data analysis (i.e., all contact with participants has ended and no additional data about participants will be collected).

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1.a. If Yes, have the data been de-identified, such that it is no longer possible to link the data with the identities of the persons to whom the data pertain?

If both 1 and 1.a are Yes, STOP! IRB oversight of your study is no longer required. Please complete the Project Closure Form and send it to the IRB Office (1138 Pearson).

If one or both are No, proceed to question 2.

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2. Recruitment and enrollment of new participants has begun and is ongoing.

If No, proceed to Question 3.

If Yes, proceed to question Part B. A current copy of the informed consent document(s) and recruitment materials must be submitted with the application.

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3. Recruitment and enrollment of new participants (or collection of private and identifiable data) has ended; no additional participants will be sought.

If Yes, proceed to question 4.

If No, proceed to Part B.

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4. All research activities involving participants (including collection of private and identifiable data about participants) have been completed; **OR**

Only long-term follow-up activities will continue, such as
- follow-up interactions that involve no more than minimal risk (e.g., “member checking”)
- follow-up interventions that would normally be performed for non-research purposes (e.g., blood draws at a routine physical exam, routine clinical monitoring for disease progression, routine cholesterol screening, etc.).

Please proceed to Part B.
Part B: Progress Report

Please provide a brief summary of your progress to date in conducting the research.

Data collection is currently in progress. Interviews with nursing home administrators are complete and data are being analyzed. Online surveys are in the process of being completed by CNAs and should be collected for analysis by the end of summer. Data from the Iowa LTC medication will also be collected by the end of summer.

Part C: New Information

☐ Yes ☐ No 1. Is there any new information available relevant to the risks or potential benefits of the research, such as the following? (Check all that apply.)

☐ Results from other relevant studies (published or unpublished)
☐ informal findings
☐ Data safety monitoring board (DSMB) reports
☐ Multi-center trial reports
☐ Other information that suggests a change, either positive or negative, in the risk to participants
☐ Other information that suggests a change, either positive or negative, in the expected benefits of the research

1.3. If any of the above are checked, please provide the following:

(i) a detailed description of the new information and how it is relevant to your study;
(ii) a complete description of any related changes to the research procedures or materials (including the informed consent process) that are needed to safeguard the rights and welfare of participants.

If none are checked, please proceed to Part D.

Part D: Protocol Changes

☐ Yes ☐ No 1. Do you wish to make any changes to research procedures, study materials, or key personnel with this application for implementation in the future?

[Signature]
[Date]

If Yes, please complete and attach a Modification Form for Non-Exempt Research or Amendment for Personnel Change form, as applicable.
2. Have there been any changes to the research procedures (e.g., methods of collecting data, sources of data, experimental design, interventions, stimuli, confidentiality measures, inclusion/exclusion criteria, consent process, etc.) implemented since the last IRB review? If Yes, please provide a detailed description of these changes, including when each change was implemented:

3. Have there been any changes to study materials (e.g., informed consent documents, data collection instruments, recruitment materials, etc.) implemented since the last IRB review? If Yes, please provide a detailed description of these changes, including when each change was implemented:

4. Have there been any changes to key personnel since the last IRB review? If Yes, please provide a detailed description of these changes, including when each change was implemented:

Part E: Enrollment

Please complete the following table related to the enrollment of participants in your study. For definitions and guidance on how to determine enrollment, please see the document entitled Enrollment and Accrual of Study Participants.

<table>
<thead>
<tr>
<th>Number of participants approved by the IRB: 210</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of participants enrolled in the study to date: 6</td>
</tr>
<tr>
<td>Estimated percent of the total enrolled by sex/gender (if known): Males: 3 Females: 2 Unknown:</td>
</tr>
<tr>
<td>Number of screen failures (participants who were screened and deemed ineligible) to date: 0</td>
</tr>
</tbody>
</table>

Check if any enrolled participants are:
- Minors (under 18)  Age Range of Minors:
- Pregnant Women/Fetuses
- Cognitively impaired
- Prisoners

List below the estimated percent of the total enrolled that are minorities (if known) Unknown: ☒

- American Indians: Alaskan Native:
- Asian or Pacific Islander: African American:
- Black (Not of Hispanic Origin): Hispanic:
Part F: Problems or Concerns

☐ Yes  ☒ No  1. Have there been any adverse events or unanticipated problems involving risks to subjects or others associated with the study? See guidance entitled Reporting Adverse Events and Unanticipated Problems for definitions and reporting requirements.

If Yes, please describe the event(s)/problem(s) as follows:

<table>
<thead>
<tr>
<th>Brief summary of adverse event(s) or unanticipated problem(s)</th>
<th>Approximate date incident occurred</th>
<th>Was a report submitted to the IRB?</th>
</tr>
</thead>
</table>

☐ Yes  ☐ No  2. Have there been any complaints from participants or others about the study?

If Yes, please describe the event(s)/problem(s) as follows:

<table>
<thead>
<tr>
<th>Brief summary of complaint(s) and how each was handled by research staff.</th>
<th>Approximate date complaint occurred</th>
</tr>
</thead>
</table>

Part G: Submission requirements

Unless enrollment is permanently closed and/or all remaining activities are limited to data analysis, please:

☒ Attached  ☐ N/A  Submit an unstamped copy of the informed consent document or informational letter so a current IRB approval stamp can be added. If you would like to modify these materials, please complete and attach a Modification Form for Non-Exempt Research.

☒ Attached  ☐ N/A  Submit an unstamped copy of all recruitment materials, so that a current IRB approval stamp can be added. If you would like to modify these materials, please complete and attach a Modification Form for Non-Exempt Research.

Please Note: Any changes to the protocol, procedures, or other study materials (e.g., survey instruments, interview questions, flyers, posters, etc.) must be described in detail as requested in Modification Form for Non-Exempt Research.
APPENDIX F: RESEARCHER’S FIELD NOTES

SITE 1

- I had to wait awhile to see the admin. He/she seemed a little flustered and a bit uncomfortable initially. I got the feeling he/she felt he/she was going to need to defend him/herself to me (he/she even printed out the facility’s copy of residents’ rights for me). However, as I explained the study, he/she became visibly more relaxed and we ended up having a nice, comfortable conversation.

- The facility, physically, is warm and inviting. The atmosphere is pleasant and there are decorations on tables and hanging from the ceilings. There appears to be a light and happy atmosphere and residents are greeting me and smiling. It gives the impression of a clean and pleasant environment.

- Administrator appears very young, and I’m not sure if this impacts how staff interact with him/her, but they seemed somewhat distant and a little quiet around him/her. While I was waiting to meet with the admin, I noted staff interacting lightly in conversation with one another and laughing with residents, joking around, etc., but their demeanor seemed to change around the admin. I have to admit, that I felt he/she (admin) was trying hard to demonstrate to me that he/she had a strong, comfortable relationship with staff and residents. As we toured the facility, he/she did mention several residents by name, but they didn’t seem to respond to him/her like they did to the caregivers. This made me wonder how often he/she comes out of his/her office to interact with the
residents and staff. He/she did tell me that he/she has been implementing some
new trainings and making a few changes and updates to the staff and schedules.
He/she didn’t elaborate and I didn’t pry, but I got the feeling it might be a source
of contention at the facility.

- There are photos of residents along with names outside of every resident's
  room. I love this touch of personalization. I can also see that, despite a somewhat
  medical feel in some of the older and non-updated areas of the facility,
  personalization of residents’ rooms is encouraged. The rooms truly look like
  bedrooms in a home. There are family photos and pictures and furniture that
  resemble a home. It appears that the residents are very happy.

- Although admin loosened up throughout my time with him/her, at the end of my
  visit, the administrator still joked about me “turning him/her.” He/she said that
  section of my informed consent scared him/her a bit. Because I saw nothing of
  concern there (at all- nothing even remotely close to abuse or neglect), I assured
  him/her that there was nothing to report.

**SITE 2**

- Very private, very separate entrance for guests. There is a reception area with a
gatekeeper and I had to sign in and wait for about ten minutes to see the admin.
This is a facility in an extremely affluent community. The décor/the feeling is one
of wealth and comfort. I can see there has been A LOT of money put into the physical environment. Very updated and aesthetically pleasing.

- Administrator appeared to be very busy and extremely uncomfortable meeting with me. I could easily sense that he/she didn’t want to discuss the topic and appeared to have trouble saying “sex” and “sexual expression”. He/she also indicated that he/she was sick the day before and had a million things to do-he/she said almost cancelled on me. Initially, a bit arrogant (he/she said he’s/she’s always happy to help students with their “little studies”), however, after I further explained the study and his role in it (although, he’d already read the informed consent) he/she seemed to relax a bit and open up. This was encouraging, as he/she was willing to share information. Unfortunately, he/she didn’t appear to have much with regard to my research topic.

- Admin kept referring to “social services” at the LTCF with regard to many of my questions and hypothetical vignettes. He/she told me social services were the social workers who really handle the situations that I was describing. He/she was visibly uncomfortable with my questions and, seemingly, unaware of acts of sexual expression (other than basic hand-holding, pecks on the cheek, etc) in the LTCF.
• It was a very quick interview, as he/she was in a hurry and didn’t really have much to offer. Indicated that he/she hadn’t seen or heard of much sexual interaction, they hadn’t had any “same sex” issues and he/she wasn’t aware of any occurrences of adultery at the facility. My honest impression of this admin is that he’s/she’s either unsure because he/she rarely interacts with residents and staff, or he’s/she’s in denial. I assume he’s/she’s there for financial purposes (to keeps the doors open). Responses (and lack thereof) provided me great insight into his/her job as administrator at this LTCF and will allow for nice comparisons with admin roles at other facilities!

• Admin raced me around the facility for my environmental checklist, as though he/she was in a hurry. On my way out, I saw a LTC ombudsman I know in the waiting room. Perhaps this was why he/she was nervous or in a hurry?

SITE 3

• This place is bustling with activity. There are people everywhere and events going on all over the place! In the main entrance (which was a bit hard to find) staff is throwing a “mani/pedi” party for residents. They set up a large display of fingernail polishes on a table and are painting residents’ nails. For the men, they’re clipping nails and doing foot soaks. Everyone seems very happy.

• The physical atmosphere is very medical and old fashioned, but I can see that they have made efforts to modernize and “soften” the environment. There are
plants everywhere and sticker quotes on walls (e.g., biblical quotes and inspirational sayings), which later the admin tells me are used to try and soften the “old institutional” model of LTC. The lighting is poor in some areas, the ceilings are very low, and there is a tremendous need to update the institutional feel in some wings of the facility. However, the recently renovated areas are warm, light, and very personalized for residents. There are pictures of the residents outside each door along with their name. In newly renovated areas, there are built-in bookshelves with glass doors. Each resident has one outside their room where they can display personal photos, awards, and special memorabilia. It’s very nice and I enjoyed looking at the displays, which told a story about each resident’s life. Also, inside each of these newly renovated shared rooms, instead of curtain dividers, there are gorgeous wooden shelves from floor to ceiling. It truly gives the impression of greater privacy and is very elegant and homelike.

- Staff are seen joking around with residents and laughing. There seems to be a lot of interaction and comfort among staff and residents. The administrator told me he/she takes pride in hiring people who “think outside the box”. He/she thinks they have unique ideas and they seem to contribute a lot to the facility, which other facilities don’t have because they hire traditional employees. I found this so interesting. I will admit that when I first entered the facility, I saw many young caregivers, some with brightly colored clothing and hair, some outrageous jewelry, and even piercings. I did note that this was a bit surprising to me, as
this is a religious LTCF. But this personal opinion, I suppose, is just my bias, and me buying into the traditional stereotype of the religiously affiliated facility.

Anyway, I could see and understood after speaking with the admin, his/her logic behind hiring non-traditional caregivers. Said he/she hires the kindest and most qualified people for the job, and the rest doesn’t matter. The residents love them and, he/she believes, they feel younger and more adventurous around them!

- On the other side of this coin, I can see that the admin works hard to preserve and uphold the religious tradition of the LTCF. As a religiously affiliated facility, there are pictures of Jesus and Biblical events, as well as scriptures all over the place. They have the most beautiful chapel I've ever seen inside a nursing home. It has gorgeous woodwork and stain glass windows and can seat about 200.

There's a huge open space in the center for residents in wheelchairs. Admin said they hold multiple services throughout the week and citizens from the community can attend as well. They’ve had multiple weddings there (between both residents and community members) and also several funerals. I think it’s wonderful for residents because they can attend the services for friends they’ve lost or that they’ve become acquainted with right there in the facility’s chapel whereas, otherwise, they may not have been able to.

- As I came in I saw two puppies in a large kennel that, I’m told, are learning their way around the facility. They’re too young to be let loose yet, but are being trained. I think it’s excellent that they’re bringing pets in to interact with
residents. As I was getting a tour, I also noticed two large bird boxes with
several types of birds in them (reminds me of Eden Alt). The residents really
seemed to like them and two of them were discussing how the birds interact
with one another.

- I notice there is a daycare directly next door to one of the wings of the facility. I
  think it’s a wonderful idea to bring children into the lives of older adults on a
  regular basis. It shows children the value of older adults and brightens residents’
days to spend time around such youthful innocence. The facility and daycare
used to interact quite frequently, however, due to funding, the daycare had to
close and the residents have been greatly affected by the children’s absence. :(
  Apparently, the residents frequently ask when the children are coming back. The
facility is working very hard to try to find ways for their residents to interact
with children.

SITE 4

- Warm feeling when coming in. Private entrance. Had to buzz several times
  before I was let in. They have a “Wander Guard” device on the door - not
  uncommon in facilities that serve Dementia residents.

- Waiting a LONG time to see the admin... but good because it gave me a chance to
  sit among the residents in the dining hall. Violinist is getting music out and
preparing for a musical show with a pianist. Residents are starting to gather.

Warm, friendly atmosphere- smells good (like chicken).

- While I was there, the buzzer went off, as a resident attempted to sneak outside for a “smoke”. I was getting a tour from the admin at the time and he/she, as well as several caregivers, quickly went to separate exits to find the location where the resident had left. They found resident quickly and he/she (a cognitively intact resident) sort of sheepishly smiled and said he/she just wanted a smoke before the concert. The admin gave resident a hard time and teased, then redirected him/her out the front door where he/she was buzzed out. Resident was clearly trusted to go outside alone, I think he/she was just embarrassed that he/she was going to smoke. He/she said he/she had forgotten that the door had an alarm on it.

- The mood seems light and residents are joking around with staff. There are a few residents sitting at tables playing cards. One resident in a wheelchair is browsing through books in an area of the dining hall that looks somewhat like a library. It’s nice because the bookshelves sit at “chair” height so residents in wheelchairs can easily reach them. They have quite a collection of magazines and books (nothing erotic in nature...)

- Later, I was told that a staff member acts as librarian at the facility and takes a portable bookshelf (on wheels) around to those residents who can’t or choose
not to come to the dining hall/library to check the books out. I think this is a wonderful service. I was also told that several of the books are ordered in large print, which is wonderful.

- There are puzzles sitting out and when I came in I saw one of the staff members putting a puzzle together with a resident. When I noted to the administrator that I thought it was nice that they had puzzles, games, etc sitting about for residents, he/she said that several staff members choose to take their breaks playing cards or putting together puzzles or even stopping by rooms to sit and visit with their “favorite” residents. I can see there is strong rapport among many of the staff and residents. That’s good!

- Administrator has long history here and takes a great deal of pride in the facility. He/she grew up in the community and, seemingly, takes a parental approach to the facility. Seems to have a lot of pride in his/her work.
  - I now understand why this facility is so personal to him/her. His/her family ran the facility before he/she did and they were both residents before their death.

- The administrator is not uncomfortable at all with discussion of sexuality in the facility. He/she is blunt and honest and says, yep it happens and we’ve seen it all! I found this refreshing, particularly in a rural setting. He/she cited multiple examples of situations that have occurred throughout his/her time there. I
guess I expected to hear that it didn’t happen much there, because it was small and rural. However, the length of admin’s experience there provided him/her with nearly every kind of experience or scenario I could present! Overall, I learned a lot at this facility and, found myself a little naïve about this “small town” rural LTCF.

**SITE 5**

*Despite the fact that this is a large facility with many beds and types of services offered, there is an extremely comfortable feeling as I walk in. I can see there are many renovations going on, and the areas that have already been updated are gorgeous. The setting of the facility is a wooded area and the facility takes advantage of this with TONS of huge windows that look out over the natural setting (trees, plants, animals, flowers—very pretty). It is a warm sunny day, so this helps my outlook!*

*Areas of the facility that are not yet updated are cold and institutional, but the LTCF has clearly made attempts at brightening things up (colorful paintings and wall sayings, bright signs, decorations, etc). They also have a very impressive painting on the exit door of their dementia unit that they are incorporating on the rest of the exits in the there. These paintings keep residents with dementia at ease and decrease incidents of residents wandering or leaving, as they don’t appear to be exits.*

*Admin gave me two full hours of time. Was very thorough and kind, offered tons of information. I can see through our conversation that he/she is organized, prepared, and
educated on LTC laws. Interacts with the staff very well and they seem to respect him/her. He/she acknowledges all of the residents by name (and we encounter many on our tour) and they all smile and respond to him/her by name. This is a relaxed atmosphere- it smells good and is warm and cozy.

*Admin takes me through each wing of the facility and describes the importance of having separate spaces for residents who can feed themselves and those who cannot. I think this is extremely important in preserving dignity and respecting the resident. They have created both private and public areas for these purposes. He/she indicated that families very much appreciate this option- nearly as much or more than residents.

*He discusses dignity and residents’ rights frequently throughout our conversation and I can see he places a great deal of importance on these. He offers conversation of person-centered care and acknowledges that he sees and has heard of multiple examples of sexual expression among cognitively intact residents.

*This LTCF offers new employee training each week (which is excellent), because there is, in this industry, high turnover. They are trying to cut back on this turnover by providing regular opportunities for training. Admin indicates interest in a specific training on sexuality in LTC.

*This facility is wonderful example of person-centered care. It appears to be a small community of friends. I may move into this place now...
APPENDIX G: VIGNETTES

Consider the following situations as they might occur in a long-term care (LTC) facility.

**Vignette 1**

Charlie is an 80-year-old widowed resident at a long-term care facility. Charlie lives in a room by himself. Recently, he has become intimate with a 76-year-old female resident. They frequently enter his room and close the door for long periods of time. Caregivers at the LTC facility have not addressed this situation.

**Vignette 2**

Malcolm is a 75-year-old male resident who shares a room that is divided by a moveable curtain with another male resident. Malcolm occasionally masturbates in his room, sometimes when his roommate is present. Malcolm’s roommate has complained about these occurrences.

**Vignette 3**

John is a 75-year-old married resident at a long-term care facility. John’s wife is not a resident at the facility, but visits him several times each week. Recently, staff learned that John is having sexual intercourse with a female resident who is not his wife. Caregivers at the LTC facility have not discussed this situation with John or his wife.

**Vignette 4**

Sharese is an 85-year-old widowed resident at a long-term care facility. Sharese spends a great deal of time with Bonita, who is also a widowed resident. Frequently, the women
hold hands at mealtimes and various social events, and recently have begun openly expressing themselves in a sexual way (e.g., kissing, flirting, touching one another).

Please respond to the questions below, addressing both hypothetical vignettes:

a. In your opinion does this situation need to be addressed?
   1. Why?
   2. When?
   3. With whom should this relationship be addressed?
   4. How should this relationship be addressed?

b. Why/when might this situation be considered inappropriate?
   1. What additional information would you like to know?
   2. What kinds of characteristics of the residents are important?
      i. Cognitively intact? Cognitively impaired? One or both?
      ii. Married?
      iii. Family response?

c. Who should determine whether this situation is appropriate and should continue?
   1. Why?

d. What might be done to best serve all residents of the LTC facility and the staff?

e. Ideally, how would you want staff to respond?
   1. CNAs
   2. Director of Nursing
   3. Administrators