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Sex, Dementia, and Long-Term Care: Public Perspectives

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SEX, DEMENTIA, AND LONG-TERM CARE: PUBLIC PERSPECTIVES

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the College
of Agriculture, Food and Environment at the University of Kentucky

By

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ABSTRACT OF DISSERTATION

SEX, DEMENTIA, AND LONG-TERM CARE: PUBLIC PERSPECTIVES

The current mixed methods study utilized an ecological framework to examine public perspectives toward sexual behaviors among long-term care residents with dementia. Analyzing attitudes of the public is an integral component of understanding the entire ecological system that affects the development and overall well-being of a long-term care resident. Attitudes were examined using a multiple segment factorial vignette with a probability sample of 329 respondents from a southern state. Results indicate that attitudes were not statistically affected by sex or the elapsed time since diagnosis, and age, spousal disposition, and degree of intimacy predicted attitudes. A respondent's education level also predicted attitudes across segments; those who attained higher levels of education were consistently more accepting of sexual behaviors, less likely to expect staff intervention in adulterous relationships, and were supportive of the healthy spouse beginning a new relationship. An ecological perspective provided a framework for guiding and informing future research on the influences of long-term care on sexual development and, in turn, for the development of relevant long-term care policy.

KEYWORDS: aging, attitudes, long-term care, sexual behaviors, sexuality

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Chapter One: Introduction and Overview of the Dissertation

At the center of a human ecological system is the individual, whose development is directly and indirectly influenced by the continuously evolving reciprocal interactions of environment, persons, and symbols surrounding them (Bronfenbrenner 1979; 1989; 1995; Bronfenbrenner & Crouter, 1982; Bronfenbrenner & Crouter, 1983; Bronfenbrenner & Morris, 2006). Within long-term care (LTC), the center of the ecological system is purportedly the resident, and his or her development, including biological capacities, quality of life, and overall well-being are largely influenced by the facility, or environment. In order to better understand public perspectives toward sex and dementia within the context of LTC, it is imperative to conceptualize the environmental influences such a facility has on a resident's life and development. One aspect of a LTC resident's environment, the culture change movement, has provided motivation for understanding attitudes toward sex and dementia in LTC.

Culture change is a movement within LTC that aims to protect autonomy and put the resident first, including their right to make choices and direct their care and life in institutional facilities (National Long-Term Care Ombudsman Resource Center, 2015). Similar to Bronfenbrenner's ecological model in which a person is centered among interacting environmental contexts, the resident takes center stage within the culture change movement. The main objective of culture change is to reform the institutionalized culture of LTC facilities by creating environments *for* residents. An optimal environment, as seen by culture change advocates, focuses on person-directed values such as "choice, dignity, respect, self-determination and purposeful living" (Pioneer Network, 2015, para. 1) and boasts more resident-centered, home-like qualities. Culture change stresses that

quality of care and quality of life are equally integral to a resident's overall well-being. Within this ideal LTC environment, residents and caregivers "are able to express choice and practice self-determination in meaningful ways at every level of daily life" (Pioneer Network, n.d., para. 2). This may include residents being able to define their own schedules, be served cooked-to-order meals, freely consume alcohol, and even have sex (e.g., Button & Panosh, n.d.; Oregon Long-Term Care Ombudsman, 2013). Because of the person-centered environment culture change promotes, we are left to question how sexuality among residents with dementia fits into this new milieu. I would argue that it is crucial to understand and examine the role of LTC, and ultimately culture change, on resident sexuality, especially as future generations of LTC residents will demand resident-friendly policies surrounding sexuality.

Sexuality is a fundamental component of life from birth until death and healthy intimate relationships are essential to overall well-being (Esterle, Sastre, & Mullet, 2011; Thompson, Charo, Vahia, Depp, Allison, & Jeste, 2011; Zeiss & Kasl-Godley, 2001). Although the frequency of sexual behavior declines as one ages (DeLamater & Moorman, 2007), sexual abilities and desires can persist, even after admission to a LTC facility (DiNapoli, Breland, & Allen, 2013; Elias & Ryan, 2011; Katz, 2013; Reingold & Burros, 2004). In fact, the majority of LTC residents engage in intimate behaviors such as holding hands, embracing, and kissing at least once per month (Ginsberg, Pomerantz, & Kramer-Feeley, 2005). Some scholars (e.g., Burgess, 2004) have suggested that future aged generations, particularly the upcoming baby boomers, will be more sexually active compared to previous cohorts. This is because the baby boomers have pioneered the liberalization of sexual attitudes (Thornton & Young-DeMarco, 2001) by singlehandedly

leading the sexual revolution, challenged the traditional nature of LTC, and established the culture change movement. Because the boomers will be future LTC inhabitants, administrators must be prepared to answer their demands and expectations, as they will desire the resident-friendly policies emphasized by culture change.

An important characteristic of the baby boom generation to consider, in the context of this study, is the prevalence of dementia related disease, as the boomers have also become known as Generation Alzheimer's (Alzheimer's Association, 2011). It is currently estimated that 11% of adults over the age of 65 have Alzheimer's disease (Alzheimer's Association, 2014), the predominant source of dementia. By 2025, it is estimated that the prevalence of Alzheimer's will increase 40%, affecting 7.1 million people (Alzheimer's Association, 2014). Because of dementia's debilitating effects, many individuals will require some degree of LTC. Although 60% of LTC residents have some form of dementia (Alzheimer's Association, 2015a), intimacy and sexual desires are still commonplace within LTC (Frankowski & Clark, 2009; Katz, 2013). Further, one's ability to engage in meaningful, intimate relationships does not necessarily directly diminish with a dementia diagnosis, and many dementia sufferers are still able to engage in healthy relationships (Kamel & Hajjar, 2004; Loue, 2005; Tabak & Shemesh-Kigli, 2006). Among dementia sufferers, competence and autonomy are increasingly threatened and basic human rights, such as sexuality, can be threatened. Because dementia does not directly preclude sexual desires or abilities, it is important to initiate the discussion on sex, dementia, and LTC when implementing culture change. Specifically, the following questions may be asked: Can persons with dementia have sex in LTC? Should LTC staff stop an adulterous relationship between two married residents with dementia? What role

does the spouse's opinion have on whether LTC should stop this relationship? Finally, should a healthy spouse engage in a new relationship after their spouse's mental deterioration due to dementia?

A key component of understanding sex, dementia, and LTC is analyzing public perspectives toward this issue, as Bronfenbrenner (1979) suggests ecological influences, such as public attitudes, are likely to effect a developing individual. The public will first need to accept sexuality as a component of a resident-friendly policy, as proposed by culture change, in order to facilitate its progression. In order to assess these public perspectives, participants in this study were asked their opinions on various aspects of sexuality and dementia within a LTC context. Specifically, a vignette illustrating a plausible trajectory of sexual relationships for a person with dementia in LTC was introduced in this study; a person with dementia having a sexual relationship with their spouse in a LTC facility, then developing a new relationship with another resident of the facility who also has dementia, and finally a cognitively healthy spouse developing a new relationship.

Purpose and Research Aims

The purpose of this dissertation is to examine public perspectives toward sex, dementia, and LTC from an ecological perspective. It should be noted that for the purposes of this study, sexual behavior will be conceptualized in various ways (e.g., intimate behavior among a couple or between two individuals ranging from flirtation to sexual intercourse), though the respondent is largely left to interpret whether they deem a behavior as 'sexual'. Further, various types of dementia will not be discerned, rather, they will be grouped as a single term, 'dementia', encompassing all forms of Alzheimer's

disease and related disorders. Analyzing attitudes of the public is an integral component of understanding the entire ecological system that affects the development and overall well-being of a LTC resident. The general public can likely influence how the sexuality component of the culture change movement will move forward; negative attitudes have the ability to hinder sexual autonomy, while supportiveness will likely propel its acceptance. Regardless of disposition, attitudes of the public are a key component of one's macrosystem influences as described by Bronfenbrenner, which will be discussed further in Chapter Two. Furthermore, examining public perspectives toward the potential pathways of intimacy and dementia allows researchers to understand what these opinions are and hypothesize how they may potentially impact policy at the institutional, state, or federal levels. Because of the current number of LTC residents and future estimates of LTC need, it is likely that many adults will have experience with LTC at some time, whether directly or indirectly through themselves, a family member, or friend. This project provides foundational knowledge related to sex, dementia, and LTC and will allows researcher to gain an understanding of what are, perhaps, core societal values toward this topic.

Dissertation Organization

The remainder of this dissertation is organized as follows: Chapter Two provides a detailed review of the relevant literature, the conceptual framework that motivated this study, and describes the research questions and hypotheses in detail. Chapter Three describes the methodological and analytic approach. Chapter Four comprises the results of the data analyses and the findings of the present study. Finally, Chapter Five provides

a discussion of the results in relation to the research questions and hypotheses, limitations of the dissertation, and recommendations for future research.

Chapter Two: Review of the Literature

Review of the relevant literature begins with a discussion of key concepts associated with the present study, an overview of the theoretical perspectives, followed by review of the independent and dependent variables. Finally, pertinent research questions and hypotheses are identified and a brief review of the methodology is given.

Aging America and Long-Term Care

In 2011, 3.65 million baby boomers turned 65, and an estimated 10,000 boomers will turn 65 every day until the year 2030 (Pew Research Center, 2010). Currently, 3.6% (1.5 million) of adults age 65 and older reside in LTC facilities (Administration on Aging, 2012) and it is estimated that 46% of adults over the age of 65 will require LTC at some point in their lives (Spillman & Lubitz, 2002). Because an estimated 72.1 million people will be over the age of 65 in 2030 (Administration on Aging, 2012), Spillman and Lubitz's projections ultimately suggest that an estimated 33 million individuals could reside within LTC at any given time.

Currently, the state of Kentucky is comprised of 310 LTC facilities with a total capacity of 27,477 residents (Kentucky Cabinet for Health and Family Services, 2014). Generally, there are three types of care homes in Kentucky: assisted living, personal care, and skilled nursing facilities. Continuum of Care Retirement Communities (CCRC) offer all service levels under one roof or campus and many facilities are now offering memory or Alzheimer's special care units as well. Assisted living facilities offer numerous services, such as 24-hour assistance, meals, housekeeping, laundry, and activities, but provide minimal health care service. Personal care homes provide care to ambulatory persons able to manage most activities of daily living, such as supervision of residents,

basic health services, personal care, and social and recreational activities (Kentucky Protection and Advocacy, 2011). Skilled nursing facilities are based on a medical model and provide 24-hour nursing care, medication management, various therapy and social services, nutrition programs, and access to medical supplies and equipment in addition to all aspects of daily care (Centers for Medicare and Medicaid Services, 2014). Further, an estimated 17% of residential care communities in the United States offer dementia special care units (Park-Lee, Sengupta, & Harris-Kojetin, 2013). Memory care or Alzheimer's units provide specified services to individuals with various types and stages of dementia.

In addition to the facilities already discussed, The Green House® Project is an example of a model that embraces culture change and the systems of the ecological model. As a way to transform LTC, this evidence-based model is designed to enhance quality care through state-of-the-art, smart, home-like facilities, and innovative staffing. In the ideal pioneering model, residents receive quality care in an environment that supports autonomy within a group setting. Staff members have universal roles, meaning they help with direct nursing care, laundry, cooking, and housekeeping – just as one would in a traditional home, and a large emphasis is placed on ensuring each resident has a meaningful life in their later years. The Green House® project was most recently estimated to be active in 32 states, with 144 open homes and 120 in development (The Green House Project, 2014); Kentucky has zero operating homes and one community in development. However, many facilities try to renovate and embrace the Greenhouse values and culture of care.

It is difficult to discuss LTC without mentioning the increase in value placed on home and community-based care. Many people desire to stay in their own homes and

states have responded by providing home and community based care for individuals and families, including those with low incomes (Fox-Grage & Walls, 2013). Ultimately, these trends may delay the need for institutionalized LTC and/or reduce the proportion of individuals who will require some form of institutionalized LTC. Regardless, the massive increase in the number of aging adults that America is currently experiencing will more than likely cause a drastic increase in the number of individuals requiring LTC services. Additionally, because LTC has evolved to offer a continuum of care that spans all levels and intensity of healthcare, a greater number of adults, especially those who can afford it, are better able to identify and live within a LTC facility that best suits their needs, including living with progressive memory loss caused by dementia.

Dementia

Dementia "is a syndrome of gradual onset and continuing decline of higher cognitive functioning" (Adelman & Daly, 2005) that can affect memory, thinking, judgment, behavior, personality, and language. In some cases, dementia can be the result of disease (e.g., Alzheimer's disease, Parkinson's disease, or Huntington's disease) and in others, it can stem from various physical changes in the brain (e.g., vascular dementia or dementia with Lewy bodies). The most common form of dementia is Alzheimer's disease, which accounts for 60-80% of dementia cases (Alzheimer's Association, 2015b). Individuals with early-stage Alzheimer's typically have difficulty recalling recent events or names and can experience depression. As Alzheimer's progresses, symptoms can include impaired communication, inability to make sound decisions, confusion, and disorientation. Eventually, Alzheimer's can lead to mobility decline, difficulty eating and swallowing, and death. More specifically, Reisberg and colleagues (1982) developed the

Global Deterioration Scale (GDS) that outlines seven stages of cognitive functioning for individuals suffering from a degenerative dementia, such as Alzheimer's disease. Stage one, *no impairment,* represents completely normal functioning. Stage two, *very mild decline,* consists of age associated memory impairment, such as misplacing an item or briefly forgetting a name. Subsequent stages are more indicative of more serious cognitive decline. For example, an individual in stage three, *mild decline,* may get lost more easily, have poor job performance, or have a noticeably difficult time remembering words or names. Stage four deficits, or *moderate decline,* can consist of not recognizing familiar people or places or having decreased knowledge of current events. This then progresses to stage five, *moderately severe decline,* where sufferers can no longer survive without some assistance. They may be unable to recall their address or telephone number and may dress inappropriately for current weather conditions. Individuals in stage six, *severe decline,* are generally unable to recognize or identify their spouse, the current year or season, and will begin to need assistance with activities of daily living, such as toileting. It is within this sixth stage that many personality changes can occur; some individuals may exhibit delusional behavior, obsessive tendencies, and anxiety. Finally, the seventh stage, *very severe decline,* consists of incredible deterioration in all aspects of life; there is frequently no speech or communication, psychomotor skills are rapidly declining, and assistance with eating and toileting is needed. Concerning sexuality, it can be assumed that sexual desires or behaviors will be absent in the stage seven and strongly limited by stage six. Until then, it is probable that some individuals will retain some degree of desire and ability to engage in intimate or sexual relationships while others will

experience reduced sexual interest at early stages (e.g., Alzheimer's Society, 2013; Post, 2000).

Sex, Dementia, and Long-Term Care

Regardless of one's age or living situation, intimacy and sexuality continue to be an essential aspect of physical and psychological health, healthy aging, and overall well-being (Esterle, Sastre, & Mullet, 2011; Thompson, Charo, Vahia, Depp, Allison, & Jeste, 2011; Zeiss & Kasl-Godley, 2001). The importance of sexuality cannot be suppressed once an individual chooses to live within or requires LTC housing. In fact, admission to and progression within long-term care does not directly prevent sexual interest (DiNapoli, Breland, & Allen, 2013; Elias & Ryan, 2011; Katz, 2013) or preclude one's sexual ability (Reingold & Burros, 2004), regardless of cognitive status. Studies have overwhelmingly revealed that sexual behaviors, including intercourse but particularly intimate touch, hand holding, and other less physically strenuous sexual activities, are both integral to a resident's identity (Lennox & Davidson, 2013) and are common occurrences within LTC settings (Frankowski & Clark, 2009; Katz, 2013). Specifically, over a period of 12 months, 60% of cognitively competent residents engaged in touching or holding hands, 62% reported embracing or hugging, and 57% indicated they had kissed a partner daily to at least once per month. Notably, all respondents conveyed that they craved the opportunity to engage in more aspects of physical and sexual experiences (Ginsberg, Pomerantz, & Kramer-Feeley, 2005).

Sexual desires are not limited to the cognitively competent. Healthy sexual expression is prevalent among individuals with dementia (Kamel & Hajjar, 2004; Loue, 2005; Tabak & Shemesh-Kigli, 2006) as cognitive decline does not always reduce the

desire to engage in sexual behavior. In fact, 54% of reported sexual contact in LTC is between a heterosexual couple where both individuals suffer from dementia (Di Napoli, Breland, & Allen, 2013). Another study discovered that among couples where at least one individual has Alzheimer's disease, 70% report continued engagement in sexual activity (Davies, Sridhar, Newkirk, Beaudreau, & O'Hara, 2012).

Cognition is largely considered essential to ensuring consensual sexual activity and in its absence, an array of issues can be encountered (Elias & Ryan, 2011). Sometimes, sexual expression by an individual with dementia is considered a problematic behavior and merely a symptom of the dementia (Elias & Ryan, 2011; Rheaume & Mitty, 2008). Some dementia sufferers can exhibit disturbing sexual behavior such as increased sexual expression, inappropriate sexual behaviors, or sexual aggression (Alagiakrishnan et al., 2005; Kamel & Hajjar, 2004). This is not always the case and "it is possible to differentiate between healthy and unhealthy or wanted versus unwanted sexual behavior" (Frankowski & Clark, 2009, p. 27) by considering the behavior and the social context in which it was carried out. Despite this, attitudes toward intimacy and sexuality among persons with dementia are rather ambiguous.

Previous research has indicated that resident sexuality is often considered acceptable if it occurs between two married, heterosexual, cognitively competent adults (Yelland, Hosier, & Hans, 2014), but public attitudes toward individuals with dementia are generally negative. One study has demonstrated that attitudes of the public are substantially less favorable toward LTC residents with dementia compared to those with full cognitive competency (Yelland, Hosier, & Hans, 2014). From an ecological perspective, attitudes of the public are a component of one's macrosystem and have an

indirect effect on one's development. Attitudes toward residents with dementia are also less positive among LTC employees (e.g., Alzenberg, Welzman, & Barak, 2002; Bauer, McAuliffe, Nay, & Chenco, 2013; Bouman, Arcelus, & Benbow, 2007). From an ecological perspective, because of staff's proximity to and frequency of contact with a resident, their attitudes, regardless of disposition, will have a direct influence on LTC residents. Additional macrosystem influences enhance the negativity surrounding dementia and sexuality in LTC; nearly 31% of LTC administrators report that their facility does not have a policy regarding resident sexuality and an additional 46% report that they are unsure if a policy exists. Among the 23% of facilities with a policy specific to resident sexuality, only 14% report that their policy specifically addresses sexual activity among residents with diagnosed dementia (American Medical Directors Association, 2013). More broadly, the residents' rights manual for LTC residents of Kentucky states,

> If a resident is married, privacy shall be assured for the spouse's visits and if they are both residents in the facility, they may share the same room unless they are in different levels of care or unless medically contraindicated and documented by a physician in the resident's medical record (Kentucky State Long-Term Care Ombudsman, 2014, para. 9).

While this ensures privacy for a married couple of unknown cognitive status, there is a dearth when considering other issues and types of intimate relationships in Kentucky's LTC facilities. Nationally, because there are limited guidelines regarding such behavior (Cornelison & Doll, 2012; Shuttleworth, Russell, Weerakoon, & Dune, 2010), sexual expression among individuals with dementia is largely considered a worrisome issue by

LTC staff. Further, it is commonly cited as a behavior problem that needs to be managed or eliminated (Cornelison & Doll, 2012; Hajjar & Kamel, 2003; Rheaume & Mitty, 2008).

Although some couples can continue to have a healthy relationship despite dementia's effects, cognitive impairment also has the potential to impose a great deal of stress and imbalance on a relationship, specifically concerning marital intimacy and satisfaction (Baikie, 2002; Evans & Lee, 2013). Dementia's negative influence on many marital relationships stems from one common characteristic: attenuation in the quality of communication between the couple (Baikie, 2002; Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010; De Vugt et al., 2003; Evans & Lee, 2013). Further exacerbating dementia's effects on a marital relationship is the propensity for dementia sufferers to begin a new relationship with another individual, particularly if the other person also has a diagnosed dementia. Right or wrong, such a relationship is considered adulterous, and comes with its own unique set of issues, especially those rooted in law and policy. First is the concept of acceptable adultery, specifically, whether or not adultery is both understandable and permissible in the context of dementia. While 21 states have laws against adultery and competent adults, only two, Alabama and New York, have statutes in place that protect persons with dementia who technically commit the crime of adultery (Adultery, §13A-13-2; Unlawfully procuring a marriage license, bigamy, adultery: defense §255.20). Aside from legality, concerns also lie in how LTC staff members should respond to an adulterous relationship and whether they should inform a cognitively healthy spouse.

The Hebrew Home, located in Riverdale, New York, is a pioneer in sexual rights for LTC residents. The Hebrew Home has identified their own method of addressing with

the healthy spouses an intimate relationship between two individuals with dementia. In short, the Hebrew Home promotes acceptance and understanding, and upon spousal refusal of the relationship (i.e., the spouse wanting the relationship to cease), staff will attempt to intervene and discourage the adulterous relationship (Hebrew Home at Riverdale, 2013; Tenenbaum, 2009). One study even highlights that although the reactions of cognitively healthy spouses and family members are difficult to generalize, positive responses to an adulterous relationship by the healthy spouse do occur and are often characterized by understanding and even joy (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). In fact, retired Supreme Court Justice Sandra Day O'Connor's husband, a dementia sufferer, began a new companionship with another resident of the LTC facility in which he lived. The family reported that they were happy he had "found rays of contentment in the darkness of his disease" (Parker-Pope, 2007, para. 5). Although reliable data estimating the prevalence of adulterous relationships initiated by a person with dementia does not exist, its impact can be measured by scholars who have identified the topic as one that needs to be both acknowledged and addressed (e.g., Tenenbaum, 2009), as well as the testaments of the Hebrew Home and two state laws protecting these individuals from prosecution.

Another matter that needs to be considered is the possibility of a cognitively healthy spouse forming a new relationship following marital breakdown due to a spouse with dementia. Especially considering that cognitive impairment can begin at such early ages in one's life, between 7% and 45% of dementia sufferers are diagnosed with early-onset dementia (Fujihara, Brucki, Rocha, Carvalho, & Piccolo, 2004; Garre-Olmo et al., 2010; Vieira et al., 2013), the propensity for a cognitively healthy spouse to engage in a

new, intimate relationship should not be ignored. Davies and colleagues (2010) reported that spouses of dementia sufferers often express ambiguity toward a future relationship with their spouse, and the majority are open to beginning a new relationship with a person other than their spouse. Although otherwise vaguely addressed in the academic literature, popular new media outlets such as *Psychology Today*, *AARP Bulletin,* and *The Wall Street Journal* have addressed a spouse's option to engage in a new relationship and the benefits it may have (Foster, 2011; Gadoua, 2010; Ramnarace, 2010) as well as whether or not the new relationship constitutes adultery (Mundy, 2009). Because dementia has the potential to disrupt one's ability to maintain a positive and mutually rewarding relationship with their spouse, it is plausible to expect that marital expectations will diminish or change and a healthy spouse's desire to satisfy these deficiencies with a new partner will follow.

A review of the literature clearly indicates that numerous sources affect sexuality and persons with dementia residing in LTC facilities. Thus, an ecological systems perspective serves as an appropriate lens through which to analyze sex, dementia, and LTC as human ecologists suggest that human development and behavior is influenced by the interplay of various environmental systems. Spouses, LTC staff, LTC policy, culture change, and the LTC care facility itself are all examples of various entities of person, process, context, and time that influence the phenomenon at hand.

Theoretical Foundation: An Ecological Perspective of Process-Person-Context-Time

Urie Bronfenbrenner (1979) postulates that in order to understand human development, one must first understand the subject's entire ecological system in which growth and development take place. His first framework, *Ecological Systems Theory,*

emphasizes the environment's effects, ranging from micro to macro levels, on development and the "interrelationships among subsystems, especially during periods of transition" (Bretherton, 1993, p. 286). Bronfenbrenner emphasizes that "contexts are always defined from the viewpoint of the developing person" (Bretherton, 1993, p. 286) and that conceptualizing these environmental contexts is critical to understanding an individual's development within their own environment. After realizing that his ecological model lacked the incorporation of biological influences, Bronfenbrenner developed the bioecological model as an extension to his original work (Bronfenbrenner, 1995; Bronfenbrenner & Morris, 2006). The bioecological model added emphasis to the individual and their genetics in addition to the effects one's environment has on his or her own development. In the case of the current study on sexuality and dementia, one's sexual ability and cognitive status, for example, are incorporated as aspects of the individual. Later, Bronfenbrenner further transformed his bioecological perspective and developed the process-person-context-time (PPCT) model, which places greater emphasis on the interaction of proximal processes and the individual. PPCT is considered "an operational research design that permits [the] simultaneous investigation [of] *Process-Person-Context-Time"* (Bronfenbrenner & Morris, 2006, p. 798). This model is ultimately based on two, foundational propositions (Bronfenbrenner & Morris, 2006, p. 797-98):

> *Proposition I: Especially in its early phases, but also throughout the life course, human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment. To be effective, the interaction must occur on a fairly regular basis*

over extended periods of time. Such enduring forms of interaction in the immediate environment are referred to as proximal processes.

Proposition II: The form, power, content, and direction of the proximal processes affecting development vary systematically as a joint function of the characteristics of the developing person, the environment – both immediate and more remote – in which the processes are taking place, the nature of the developmental outcomes under consideration, and the social continuities and changes occurring over time through the life course and the historical period during which the person has lived.

Now considered the foundation of his ecological model, PPCT focuses on the interaction of the four key concepts affecting how a person and environment changes over time.

Process. The process aspect of bioecological development focuses on bidirectional interactions, called *proximal processes,* between a person and their environment and the person and other people that occur over time. Although proximal processes are the "primary mechanism producing human development", their degree of influence is presumed and can vary among "the developing *person*,…the immediate and more remote environmental *contexts*, and the *time* periods, in which the proximal processes take place" (Bronfenbrenner & Morris, 2006, p. 795).

Generally, Bronfenbrenner's conceptualization of proximal processes refers to the bidirectional interaction of genes and environment and those effects on a developing person. Bronfenbrenner focuses on the development of children and such processes have generally not been related to adults, especially concerning their sexuality. In the context of adult sexuality in LTC, I would propose that proximal processes exist in numerous contexts, first of which is the interaction of genes (or sexual ability) and environment (the

LTC facility) on one's sexual development. Perhaps in this context, though, we can conceptualize sexual development not as the development of an emotional and physical foundation for sexuality, but rather as the manifestation of sexual behaviors in complex environments alongside probable physical and cognitive decline. If an individual retains both the ability and desire to engage in sexual activity, yet their environment disallows such behavior, their sexual development is stifled. Conversely, if their environment supports sexual behavior and their ability persists, sexual development can occur. Regardless of the environment, if an individual's sexual ability is diminished, sexual development does not cease as it is also manifested in emotional connections and less physical behaviors (e.g., handholding, kissing).

A second way in which proximal processes are manifested in adult sexuality in LTC is through the interaction of others with the developing person, who in this case is the resident. We can assume that the proximal processes of a LTC resident are also going to include LTC staff workers, family members and friends (if such relationships exist), and other residents. As such, the interaction of these people with the resident will play a role in their sexual development. It can further be assumed that these interactions will be primarily based on the attitudes and belief systems of the individuals with which the resident is interacting. For example, if a LTC staff member is approving and supportive of one's sexual development, such behaviors will likely be supported and thus continue, and vice versa. However, as in the case of the LTC staff, their attitudes and beliefs can be compounded by the policy of the facility in which they work, thus emphasizing the complex nature of proximal processes.

Person. Person relates to three characteristics of persons that are "most influential in shaping the course of future development through their capacity to affect the direction and power of proximal processes through the life course" (Bronfenbrenner & Morris, 2006, p. 795): resource, disposition, and demand. Resource characteristics are one's "ability, experience, knowledge, and skill…required for the effective functioning of proximal processes at a given stage of development" (Bronfenbrenner & Morris, 2006, p. 796). Dispositions are those that "can set proximal processes in motion in a particular developmental domain and continue to sustain their operation" (Bronfenbrenner & Morris, 2006, p. 795). Finally, demand characteristics are those that act as an instantaneous stimulus in any social situation, such as age, sex, race, or physical appearance. Such characteristics are often associated with socially defined expectations (e.g., expecting a female to be feminine or an elderly person to be disabled) and can influence interactions, beliefs, and attitudes about an individual. This concept is particularly relevant in the current study, as differences in attitudes toward two demand characteristics, sex and age, will be assessed.

Context. The context component of Bronfenbrenner's PPCT model includes the four systems of his original ecological systems model: the micro-, meso-, exo-, and macro-systems. In the context of a LTC resident, the microsystem is inclusive of one's self and their immediate environment, including family, LTC staff, LTC residents, and so forth. The mesosystem is the interaction of an individual's microsystems; this could include the interaction between LTC staff and a resident's spouse, for example. Next is the exosystem, which includes aspects of one's microsystem that have an indirect impact on the individual. For example, LTC staff member's beliefs and attitudes or policy within

the LTC facility would be examples relevant to the current discussion. The macrosystem is comprised of laws, customs, attitudes, and values in which the individual lives. In the context of LTC, the concept of culture change and attitudes of the public toward issues in LTC are considered a part of a resident's macrosystem.

Time. Finally, Bronfenbrenner emphasizes the impact of time and timing on development, as explained by the four principles of life course theory (Bronfenbrenner & Morris, 2006; Elder, 1998; Elder & Shanahan, 2006). The first principle, historical time and place, states, "the life course of individuals is embedded in and shaped by the historical times and events they experience over their life time" (Bronfenbrenner & Morris, 2006, p. 821; Elder, 1998). In the current study, the culture change movement in LTC is a prime example of historical change. This movement has singlehandedly altered the previously sterile and institutionalized culture of LTC to one that is home-like and emphasizes person-valued choices and resident autonomy.

The second principle, the timing of lives, emphasizes timing of events and states: "the developmental impact of a succession of life transitions or events is contingent on when they occur in a person's life" (Bronfenbrenner & Morris, 2006, p. 821; Elder, 1998). In reference to the current study, the appropriateness of a spouse of a person with dementia developing a new relationship after considerable cognitive deterioration will be examined. As suggested by this second principle, we are motivated to question if there is an appropriate time for a spouse to move on, and if so, when that time occurs (the current study asks about months versus years after a dementia diagnosis).

The third principle of the life course, linked or interdependent lives, "asserts that lives are lived interdependently and social and historical influences are expressed through

this network of shared relationships" (Bronfenbrenner & Morris, 2006, p. 822; Elder, 1998). This concept ultimately explains cross-generational human relationships, such as those between a parent and child, though its effects will not be a focus of this current study. The fourth principle, human agency, states, "individuals construct their own life course through choices and actions they take within the opportunities and constraints of history and social circumstances" (Bronfenbrenner & Morris, 2006, p. 822; Elder, 1998). This concept suggests that macro-level events and influences, such as LTC policy, can effect individual behaviors (e.g., LTC policy allowing private, sexual contact and one's frequency of sexual expression).

In sum, Bronfenbrenner's ecological model provides a lens through which sexual issues specific to LTC residents can be conceptualized. Next, the literature review will continue with a discussion of the independent and dependent variables inherent to this study.

Review of the Independent Variables

Perspectives toward sex. Studies have shown that LTC staff reactions to resident-initiated sexual activity and intimacy can be swayed by the initiator's sex. LTC staff are more likely to develop a concern for safety when a male resident initiates intimate or physical contact with a female (Archibald, 1998; Tzeng, Lin, Shyr & Wen, 2009). This concern is perhaps fueled by the fact that LTC staff report that more men than women exhibit problematic sexual behavior (Alagiakrishnan et al., 2005) and are generally the initiators of sexually based interactions (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Studies analyzing the public's perspectives toward sex have not found a statistical difference in attitudes between men and women; there is roughly a 3%

difference, with more support for males engaging in sexual behaviors than females (Yelland, Hosier, & Hans, 2014; Yelland, Hosier, & Werner-Wilson, 2015). A review of the literature also revealed that there are substantial differences in both the frequency and type of intimate behaviors between males and females residing in LTC facilities. Overall, males more frequently express the desire for sexual contact than females (Hajjar & Kamel, 2003), are nearly twice as likely to report sexual intimacy as *very important* (Yelland, Hosier, & Hans, 2014), and generally indicate lower levels of sexual satisfaction compared to their female counterparts (Hajjar & Kamel, 2003). The types of sexual behaviors that men and women engage in are also different; 79% of men aged 65-74 compared to 85% of women report having sexual intercourse and 53% of men report masturbating compared to 22% of women (Lindau et al., 2007). Studies highlighting sex differentiation in sexual behaviors more commonly expressed in LTC, such as handholding or less strenuous sexual touching, have not been performed. For the purpose of this study, sex will be presented as either male or female. It is hypothesized that sex will follow previous trends (e.g., Yelland, Hosier, & Hans, 2014; Yelland, Hosier, & Werner-Wilson, 2015) and will not statistically predict respondent's attitudes. Regardless, the resident's sex is an important aspect to consider from an ecological perspective as such demand characteristics (i.e., sex or age) significantly influence proximal processes across the lifespan.

Degree of intimacy. Research has repeatedly revealed that the degree of intimacy and sexual desires transform with age (Bullard-Poe, Powell, & Mulligan, 1994; Ginsberg, Pomerantz, & Feeley, 2005; Gott & Hinchliff, 2003). While younger individuals predominantly engage in and value sexual intercourse, whether it be for procreation or

otherwise, older adults are more likely to value, and desire non-coital sexual activity (Bouman, Arcelus, & Benbow, 2007; Katz, 2013), especially when their health prohibits them from engaging in more strenuous sexual activity. Although sexual intercourse does take place in LTC, more common expressions of sexuality include flirtation, physical proximity, maintenance of physical appearance, intimate touch, hand holding, and kissing (Frankowski & Clark, 2009; Hubbard, Tester, & Downs 2003; Katz, 2013).

Research has shown that LTC staff members are more accepting of less physical displays of affection, which are often perceived as caring or loving behaviors, compared to more erotic or implied sexual behaviors, such as intercourse or viewing pornographic material (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Frankowski & Clark, 2009; Hajjar & Kamel, 2003). Further, younger and/or less experienced LTC workers report more negative and restrictive attitudes toward sexuality in LTC (Bouman, Arcelus, & Benbow, 2007). Because sexual intercourse and heavy petting is often considered taboo, it is hypothesized that a greater proportion of respondents will expect LTC staff intervention for residents who engage in sexually physical behaviors and will be more accepting toward less physical sexual behaviors, such as handholding or flirting. For the purpose of this study, degree of intimacy has been classified into two categories: flirtatious conversation and intimate physical contact.

Spousal disposition toward an adulterous relationship. Spousal disposition is a key variable of interest for one important reason; the opinions of a spouse have been shown to affect LTC staff responses toward intimate relationships (e.g., Frankowski & Clark, 2009; Tenenbaum, 2009). While empirical research is lacking, some studies have shown that spouses are comfortable with their husband or wife engaging in new

relationships. Some LTC policies even encourage cognitively healthy spouses to be open and accepting of the new relationship (Tenenbaum, 2009). A different study by Frankowski and Clark (2009) found that LTC providers will ultimately respect familial or power of attorney wishes. If family members or powers of attorney are unhappy with the relationship, then staff will strive to discourage the relationship, and conversely, if family members are supportive, LTC staff will respect their opinion and will not make advances to interrupt the adulterous relationship. For the purpose of this study, spousal dispositions are either portrayed as comfortable or distressed. Based on the review of the research, it is hypothesized that a greater proportion of respondents will expect LTC staff intervention if a spouse is opposed to the adulterous relationship, and vice versa. From an ecological perspective, the spouse's opinion is crucial to understand. Bronfenbrenner states "the belief systems of…spouses…may be especially important…as belief systems of such "others" can function as instigators and maintainers of…the developing person" as they have "potent" influence on an individual's behaviors and development (Bronfenbrenner, 1995, p.638).

Length of elapsed time since diagnosis. The length of time after a dementia diagnosis is a key variable of interest because relationships are likely to change over time, particularly when an individual suffers from a health condition requiring daily assistance, such as dementia. Changes in a marital relationship due to dementia are commonly characterized by changing, reversal, and loss of roles, dependency, shifting intimate and sexual norms, and a general imbalance in the relationship (Harris, 2009). Particularly as one's cognitive capacities decline, the quality of communication can deteriorate within a relationship, ultimately affecting overall relationship quality as

perceived by the cognitively healthy spouse (De Vugt et al., 2003; Evans & Lee, 2013). Although negative alterations tend to overshadow positive ones, positive changes within one's relationship and self can also occur. For example, some caregivers report experiencing personal growth and commitment toward their spouse and some dementia sufferers report the development of a greater appreciation for their spouse (Harris, 2009). Ultimately, because some degree of change is likely to occur over time, and the magnitude of change is likely to increase as the dementia progresses, it is hypothesized that a longer elapsed time since diagnosis will breed more accepting attitudes toward the healthy spouse developing a new, intimate relationship. In this study, the length of elapsed time since diagnosis was presented as either months or years. This distinction of time is important to understand from an ecological perspective because "a major factor influencing the course and outcome of human development is the timing of…social transitions as they relate to culturally defined…role expectations, and opportunities" (Bronfenbrenner, 1995, p. 641). In sum, the length of elapsed time after diagnoses may alter the culturally perceived role of a spouse in the context of LTC and dementia, and thus one's opinion toward their beginning a new relationship.

Review of the Dependent Variables

Sexuality among LTC residents with dementia. Cognitive impairment does not directly preclude sexual interests, desires, or abilities (DiNapoli, Breland, & Allen, 2013; Elias & Ryan, 2011; Katz, 2013; Reingold & Burros, 2004) and intimate and sexual relationships maintain crucial importance throughout all stages of life (Esterle, Sastre, & Mullet, 2011; Thompson, Charo, Vahia, Depp, Allison, & Jeste, 2011; Zeiss & Kasl-Godley, 2001). Despite this, LTC staff attitudes toward sexual behavior among residents

with dementia in LTC are generally neutral to unfavorable, while public perspectives remain understudied. Previously, adults have had a generally unfavorable disposition toward sexual expression in later life (DiNapoli, Breland, & Allen, 2013), yet the magnitude of negative attitudes has reportedly decreased over recent decades (Heron & Taylor, 2009; Mahieu, VanElssen, & Gastmans, 2011; Walker & Harrington, 2002). When coupled with dementia, attitudes become even more convoluted due to one's cognitive circumstance (Allen, Petro & Phillips, 2009). Further, regardless of cognitive capacity, the type and degree of sexual or intimate interaction can sway attitudes. LTC staff members are generally more accepting of behaviors perceived as loving and caring as they typically respond to romantic behavior in ways that range from humor to the infantilizing of the resident, and react to eroticism with anger and objection (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Although the influence of the type and degree of sexual or intimate behavior has on attitudes of the general public has not yet been studied, more general attitudes have been reported as substantially less favorable toward LTC residents with dementia compared to those with full cognitive capabilities (Yelland, Hosier, & Hans, 2014). Specifically, the degree of support for the expression of sexual behaviors within LTC decreased from 68% to 36% once a hypothetical vignette character received a dementia diagnosis, with the majority of respondents indicating that one's consent capacity was ultimately compromised due to the dementia. Research has indicated that healthy sexual expression can be distinguished from unhealthy and/or unwanted sexual contact among individuals with dementia (Davies, Sridhar, Newkirk, Beaudreau, & O'Hara, 2012; Di Napoli, Breland, & Allen, 2013; Frankowski & Clark, 2009; Kamel & Hajjar, 2004; Loue, 2005; Tabak & Shemesh-Kigli, 2006). There are

generally two methods of determining one's consent capacity: a case-by-case basis or the use of the Mini Mental State Examination (MMSE) (White, 2009). Specifically, the Hebrew Home follows the case-by-case approach and offers a series of questions to ask a resident in order to determine their consent capacity regarding a sexual relationship. Such questions include "What are your wishes about this relationship?", "Do you enjoy sexual contact?", "Do you know what it means to have sex?", and "What would you do if you wanted it to stop?" (Hebrew Home at Riverdale, 2011). Still, others opt for the standardized MMSE, which requires the achievement of a minimum score for an individual to be deemed suitable to make conscious decisions.

Staff intervention in intimate relationships. Experts readily agree that LTC staff members' should balance their responses to resident sexuality by responding in a professional, yet comfortable, manner while ensuring that residents are protected from unwanted or potentially abusive sexual situations (White, 2009). Generally, garnering a positive response requires sufficient staff training, particularly regarding sexual development among aging adults and ensuring consensual sexual activity. Providing training to LTC staff members elucidates more positive and appropriate responses to future encounters of resident sexuality (Walker & Harrington, 2002). In fact, DiNapoli and colleagues (2013, p. 1097) reported that LTC staff members consistently cite that "clinical staff working with demented residents should receive specific instructions for dealing with resident sexuality and sexual expression". Unfortunately, few LTC providers deliver such sensitivity training; Doll (2013) reports that only 40% of LTC staff members are given some degree of training on how to appropriately respond to resident's sexual

expression, yet many staff still perceive resident sexuality to be concerning or problematic.

The type and degree of staff intervention to resident sexual expression is varied and appears to be largely dependent on a situational basis. In one study, the majority of staff members (70%) reported that they would avoid direct intervention and notify a supervisor and others said that they would "try to respectfully help the resident" (51%) (Doll, 2013, p. 33). In a separate study, 37% of LTC staff members reported that they would directly intervene, while 24% said they would call the family and 11% would initiate a staff meeting (DiNapoli, Breland, & Allen, 2013). In sum, evidence suggests that there is neither a preconceived method of addressing issues regarding sexuality in LTC nor is there sufficient and consistent staff training on the topic, both of which need to be thoroughly addressed in order to encourage and sustain appropriate and positive staff-patient interactions regarding sexuality.

Obligation to inform spouse of an adulterous relationship. Previous study by Doll (2013) showed that the majority of LTC staff indicate that family members must be notified of sexual relationships, as care plans often state that "a person of interest needs to be aware of…any…significant change in the life of their loved one" (p. 34). Doll also reported that staff were generally hesitant and would not report had the resident asked them not to, but felt obligated otherwise due to the loose interpretation of their facility's policy. Notably, sexuality was never defined as a significant change, but was perceived by some employees to be such. Although some vague policies exist, as in the previous example, there is a scarcity of well-defined policy that addresses how to approach adulterous relationships. The Hebrew Home enacts a policy on which to base future

discussion. Simply stated, the Hebrew Home will first contact the spouse to inform them of the new relationship and will ultimately encourage them to respond with acceptance. Upon refusal despite counseling, the LTC facility will then take actions deemed appropriate to discourage the relationship, such as relocating the resident to a different wing or floor of the facility to ultimately promote spatial separation of the adulterous couple (Tenenbaum, 2009).

Appropriateness of a healthy spouse moving on. Generally, the propensity for a healthy spouse of a dementia sufferer to desire and perhaps engage in a satisfying intimate relationship, sexual or otherwise, should not go unnoticed. As literature has consistently stated, maintaining healthy intimate and sexual relationships are an integral component to one's life satisfaction and overall well-being (Esterle, Sastre, & Mullet, 2011; Thompson, Charo, Vahia, Depp, Allison, & Jeste, 2011; Zeiss & Kasl-Godley, 2001). As a spouse's dementia progresses, maintaining a mutually satisfying intimate relationship, whether emotional or physical, can prove considerably daunting as communication, memory, and overall functioning decline. Although there has been little empirical discussion on the topic, Esterle and colleagues (2011) pointed out that after the death of a spouse, many individuals are willing to form new, satisfying intimate relationships and Carr (2004, p. 1066) states, "boomers are less likely than past cohorts to adhere to the model of having only one lifelong romantic relationship". Within the popular news media, a 2011 *New York Times* article discussed the issue as the popular television evangelist, Pat Robertson, likened dementia to death and said it was acceptable for a healthy spouse to begin a new relationship, but that the individual should also pursue divorce (Parker-Pope, 2011).

There are two concepts relevant to the discussion of a healthy spouse moving on – ambiguous loss and social death. These ideas align with this discussion because although a person with dementia is physically present, their mind will be progressively absent.

***Ambiguous loss*.** Ambiguous losses are defined as "physical or psychological experiences of families that are not as concrete or identifiable as traditional losses such as death" (Smith, Hamon, Ingoldsby, & Miller, 2009, p. 111). Physical death is a part of life and is a normal and recognizable loss; although terribly difficult to lose a loved one, grief resulting from death is normalized and has even been conceptualized into stages (e.g., Kubler-Ross, 1969). Ambiguous loss has much different characteristics and is manifested in various ways, largely dependent upon what is perceived as lost. There are two types of ambiguous loss: physically absent but psychologically present (i.e., a soldier who is missing in action) and physically present but psychologically absent (i.e., a dementia sufferer) (Boss, 1999). Individuals and families who experience ambiguous loss are subject to immense stress as the ambiguity surrounding the loss ultimately prohibits normalized grieving patterns (Boss, 1999). In an ecological context, the intensified stress experienced by a family member can affect the resident.

***Social death*.** Previously, social death has been attributed to those who are not accepted as fully human by society (e.g., slaves and ostracized individuals during the holocaust) or are considered non-human (e.g., comatose patients) (Sweeting & Gilhooly, 1997). A more recent definition of social death has broadened to include individuals who no longer possess the ability to communicate with others. More specifically, those who are considered socially dead are often deposited into three distinct groups: lengthy

terminal illness, the very old, and those who are without their personhood (Sweeting & Gilhooly, 1997), as in the case of those suffering from dementia.

Sweeting and Gilhooly (1997) argue that prolonged care in non-institutionalized settings often leads to intensified anticipatory grief and may encourage the development of social death, or a situation in which individuals act as if the sufferer was already deceased. Social death among the very old is characterized by actions that "devalue, stereotype, and exclude old people" (Sweeting & Gilhooly, 1997, p. 96; Rosow, 1974) and can offer limited interruption in functioning in the deceased's family system. Loss of personhood, or having minimal meaningful human interaction, can also lead to social death, although this is not always the case. In the context of dementia, a loss of personhood does not always lead to social death as friends and loved ones may still hold value in that person and continue to be involved in their lives. Calkins (1972) might argue that an individual with dementia who recognizes their spouse only some of the time cannot be considered socially dead, but one that no longer has any recognition could be. Findings in Sweeting and Gilhooly (1997) show that 57% of caregivers of dementia sufferers perceive the individual to be socially dead, though there is variation in which group a dementia sufferer belongs in – terminal illness, very old, or lacking personhood. Ultimately, the concept of social death deserves further attention in the literature as a deeper understanding would be relevant to a spouse of a dementia sufferer beginning a new intimate relationship.

Research Questions and Hypotheses

The purpose of this study is to examine public perspectives toward sex, dementia, and LTC from an ecological perspective. Given the review of the literature presented in

Chapter Two, the following research questions (identified as RQ) and hypotheses (identified as H) were investigated:

RQ1: How does age and sex affect one's opinion toward sexual expression by a married couple in which one individual has dementia and resides in LTC?

H_1: Age and sex will not statistically predict attitudes.

RQ2: How does the degree of intimacy affect one's opinion toward whether LTC staff should attempt to stop a non-marital, adulterous relationship in which both residents of LTC suffer from dementia?

H_2: A greater proportion of respondents will expect LTC staff intervention for residents who engage in sexually physical behaviors.

H_3: A greater proportion of respondents will not expect staff intervention for residents who engage in flirtatious conversation.

RQ3: How does a cognitively competent spouse's disposition affect one's opinion toward the degree of influence LTC staff should have in a non-marital, adulterous relationship in which both residents of LTC suffer from dementia?

H_4: A greater proportion of respondents will expect LTC staff intervention if a spouse is opposed to the adulterous relationship.

H_5: A greater proportion of respondents will not expect LTC staff intervention if a spouse is supportive of the new relationship.

RQ4: How does the elapsed time after diagnosis affect one's opinion toward whether or not the community-dwelling, cognitively healthy spouse can begin a new relationship?

H_6: The largest proportion of respondents who hear about a new relationship beginning years, versus months, after the dementia diagnosis will indicate that the new relationship is appropriate versus inappropriate.

Chapter Three: Methodology

Brief Description of the Methodology

To answer the research questions, this dissertation utilized a mixed-methods approach to research design. First, quantitative analyses incorporated logistic and ordinal regression analyses to explore the relationship that contextual circumstances and respondent characteristics have with one's response to the quantitative questions. Then, a qualitative analysis of respondent's open-ended responses followed; inductive coding of rationales sheds a light on the foundation of one's quantitative response. An intensive description of the methodology continues below.

Sample

The sample consisted of 329 respondents, ranging in age from 18 to 94 years (M = 55.8, SD = 16.5). The majority of respondents were female (69.9%), married (56.1%), White (92.6%), and had children (79.5%). The level of formal education was diverse: 34.1% received a high school diploma or less, 28.3% completed some college, 22.2% had a bachelor's degree, and 15.4% had a post-bachelor's degree. The most commonly reported religious affiliations were non-Baptist Protestant (42.6%), Baptist (32.6%), and Catholic (14.8%). Overall, 48.4% indicated they were *very religious*, 38.2% classified themselves as *somewhat religious*, 6.5% were *slightly religious*, and 6.9% were *not very religious*. The median annual household income was between $30,000 and $50,000. Reported importance of sexual intimacy was also diverse: 39.5% said sexual intimacy was *very important* to them, 29.6% said it was *somewhat important*, 10.9% said *not very important*, and 19.6% said sexuality was *not at all important* to them at this point in their lives. Finally, 66.5% of respondents reported knowing or having known someone with dementia. Complete

respondent characteristics are presented in Table 3.1.

Table 3.1
Respondent Characteristics (*N* = 329)

Characteristic	n	%
Age (18-94; *M* = 55.8, *SD* = 16.5)		
Sex		
Male	99	30.1
Female	230	69.9
Marital status		
Married	174	56.1
Widowed	47	15.2
Divorced	43	13.9
Single (never married)	41	13.2
Separated	5	1.6
Race		
Caucasian	286	92.6
African American	13	4.2
American Indian	4	1.3
Asian American	2	0.6
Parenthood status		
Has children	245	79.5
Does not have children	63	20.5
Highest education level completed		
High school diploma or less	106	34.1
Some college	88	28.3
Bachelor's degree	69	22.2
Post-Bachelor's degree	48	15.4
Religious affiliation		
Protestant (non-Baptist)	132	42.6
Baptist	101	32.6
Catholic	46	14.8
Something else	28	9.0
Religiosity		
Very religious	148	48.4
Somewhat religious	117	38.2
Slightly religious	20	6.5
Not very religious	21	6.9
Importance of sexual intimacy		
Very important	123	39.5
Somewhat important	92	29.6
Slightly important	34	10.9
Not at all important	61	19.6
Knows someone with dementia		
Yes	212	66.5
No	107	33.5

Procedure

Respondents were contacted using a list-assisted random-digit dialing method that gave all household telephone exchange in Kentucky an equal probability of being contacted. Telephone numbers were purchased from the University of Kentucky's Survey Research Center. To reduce within-unit sampling bias, the oldest or youngest individual of a given sex living within the household was selected. Multiple call attempts were made to each household telephone number in the sample and one conversion attempt was made for each initial refusal. These procedures resulted in a cooperation rate (Pew Research Center, 2012) of 34%, which is comparable to current telephone response rates (Chang & Krosnick, 2009).

Prior to being read the vignette, respondents verbally consented to participate in the study after hearing a brief introduction and description of the study. Each respondent was read a single version of the vignette in which variables were randomly chosen by the electronically programmed survey. Research assistants recorded all responses electronically and verbatim.

Design

Multiple-segment factorial vignettes (MSFVs) are an experimental design that combines the contextual richness of multiple segment vignettes with the random manipulation of key variables of interest within the vignette (Ganong & Coleman, 2006). Utilizing a MSFV approach allows researchers to analyze the degree of influence contextual variations as well as sequential details have on attitudes or beliefs toward a particular phenomenon. A MSFV is composed using multiple segments, which incorporate randomly manipulated variables, to tell a single story. Following each segment

of the vignette, the respondent is asked a series of questions about what should be done given the circumstances presented in the story. In this particular study, a four-segment vignette portrayed a possible trajectory of sex, dementia, and long-term care – a married couple in which one person suffers from dementia engaging in an intimate relationship inside of the facility, the individual with dementia developing a new relationship with another resident of the facility who also has dementia, and the healthy spouse beginning a new relationship. Various contextual variables – age, sex, degree of intimacy, spousal disposition, and length of elapsed time since diagnosis – were introduced into the vignette in order to assess the impact that they may have on participant's responses. After hearing each segment of the vignette, respondents were asked to provide a forced-choice answer (should or should not) followed by an open-ended response. Forced-choice answers were then analyzed to determine the effects that the contextual variables had on responses, and open-ended data helped rationalize the respondents' beliefs.

The vignettes. Prior to being read the vignettes for the current study, one separate vignette segment was read to respondents. Because this data was analyzed for a different study, its results will not be included. For purposes of explaining the entire vignette in complete detail, the vignette has been provided for your review (independent variables are italicized):

> David and Amy are both *65/95* years old and have been married for most of their adult lives. While *David/Amy* is cognitively competent, *he/she* has recently developed several health complications that require extra care so *he/she* now lives in a private room in a nursing home. *Amy/David* is healthy and continues to live in their home, but visits *David/Amy* often. Although *David/Amy* suffers from health

In the first vignette segment analyzed for the current study, one independent variable was randomly manipulated: sex of the individual living with the retirement home (male or female). In the following vignette example, the hypothetical character was male (the independent variable is italicized):

> Several months later, *David* develops dementia, meaning that *he* has lost intellectual and social abilities that affect daily functioning, and no longer recognizes *his* spouse but seems content when s*he* visits, and they still occasionally engage in sexual relations during visits. Typically, residents of nursing homes are allowed to have consensual sexual relationships in their private rooms, but the rules are unclear about whether this is allowed for those with diminished cognitive functioning, as in *David's* case given the dementia.

After hearing the scenario, respondents were asked, "Given the situation, do you think *David* should or should not be allowed to engage in sexual behaviors with *his* spouse in the nursing home?" and were then asked to "Briefly explain in your own words why you chose that answer."

The story continued in the second segment of the vignette by revealing a new independent variable: degree of intimacy (flirtatious conversation or intimate physical contact). In the following example, the couple was engaging in intimate physical contact:

> Due to dementia, *David* no longer realizes that *he* is married and has developed an intimate relationship with another resident of the nursing home who also has dementia. The two have been *seen having intimate physical contact.*

Respondents were then asked, "Given this information, do you think the nursing home staff should or should not attempt to stop the new relationship?" and "How obligated are

nursing home care staff to inform *David's* spouse of *his* new relationship: would you say *highly obligated, somewhat obligated, slightly obligated,* or *not at all obligated?* Then, respondents were prompted to provide the rationale for their responses.

In the third segment of the vignette, an additional independent variable was revealed as the story continued: spouse's disposition (comfortable or distressed). In the following example, the spouse is distressed:

> The nursing home care staff explain to *Amy* that it is common for people with dementia to develop new intimate relationships even if they were happily married for many years. *Nevertheless, Amy is distressed about* David having a new intimate relationship**.**

Following this segment, respondents were asked, "Given his/her spouse's response, do you think the nursing home staff should or should not attempt to stop the new relationship?" and "Briefly explain in your own words why you chose this answer."

In the final vignette segment, the final independent variable was introduced: the length of elapsed time since the dementia diagnosis (months or years). In the following example, several months had gone by:

> Now a few *months* have passed and they have grown distant; *David's* dementia has worsened to the point that *he* does not even recognize *Amy* anymore. *Amy* has been lonely but recently developed a close friendship and fondness for a widowed neighbor. Given the circumstances with *David*'s dementia, *Amy* is considering the possibility of starting a new relationship with the widowed neighbor.

Following this final segment, respondents were asked, “Given the circumstances, do you think it would be appropriate or inappropriate for *Amy* to have a relationship with *her* new friend?”, “Would you say it is *highly, somewhat, or slightly* (in)appropriate?”, and “Briefly explain in your own words why you chose those answers.”

Analytic Approach

Three logistic regression models and two ordinal regression models were created to analyze the main effects of the independent design variables and respondent characteristics. In all five regression models, the main effects of the independent design variables were forced into the models and respondent characteristics were forced into the models in the final entry block. The closed ended, dichotomous response option questions served as the dependent variables for the logistic regression and the independent variables included age (65 or 95), sex (male or female), degree of intimacy (flirtatious conversation or intimate physical contact), and spouse’s disposition (comfortable or distressed). The categorical questions that asked respondents to rate obligation or appropriateness on a scale served as the dependent variables for the ordinal regression analyses; the two questions asked after the final vignette segment were combined, recoded, and analyzed as a 6-point ordinal regression. Within these analyses, the independent variables were age (65 or 95), sex (male or female), degree of intimacy (flirtatious conversation or intimate physical contact), spouse’s disposition (comfortable or distressed), and length of elapsed time since dementia diagnosis (months or years). Additional respondent demographics – age, sex, importance of sexual intimacy, knowledge of a person with dementia, education,

parenthood status, religion, and religiosity – were incorporated into the model to determine how much sway these characteristics had in a respondent's decision.

Respondent's open-ended rationales were typed verbatim and coded inductively; that is, the codes emerged from the participants' responses. The coding unit was a unique rationale, so a single response may have been coded into multiple categories. All of the responses were coded by a second coder to test for inter-rater reliability, which resulted in almost perfect agreement (kappa = .86) between the two coders (Landis & Koch, 1977). Ultimately, the categories of responses that emerged were used to help understand and interpret responses to the closed-ended questions.

Human Participants and Ethics Precautions

The Institutional Review Board (IRB) at the University of Kentucky approved this study in February of 2013. Human participants and ethics precautions were taken to ensure informed consent and minimize potential risk or harm to all participants. To obtain informed consent, research assistants read the following script to all participants before any data collection commenced:

> Hello. My name is [first name] with the University of Kentucky's family sciences research group and we are conducting a survey to better understand attitudes toward sexuality in older adults. The survey should only take about 10 minutes to complete and your phone number was randomly selected from all households in Kentucky, so your answers will remain anonymous. Participation is voluntary and can be discontinued at any time.

My instructions are to speak with the [youngest/oldest] [male/female], 18 or older, living in your household. [Would that be you? OR Would you call that person to the phone please?]

To ensure that respondents had an outlet to voice complaints, suggestions, or questions about their right as a research volunteer, all research assistants had the University of Kentucky's Office of Research Integrity's toll-free telephone number available on their computer screen at all times. If a complaint or other issue arose, research assistants were instructed to give the telephone number to the participant.

Chapter Four: Results

This chapter provides detailed results from the statistical analyses used to address the research questions and hypotheses. All hypotheses were tested at a significance level of $p = .05$. First, each vignette segment and corresponding questions are reviewed. Then, quantitative results are presented and are followed by a discussion of the qualitative rationales participants gave for their responses. All tables are provided at the end of the chapter and implications for these findings are presented in Chapter Five.

Segment One

The first segment of the vignette incorporated age (65 or 95 years old) and sex as independent variables. Participants were read the following:

> Several months later, *David/Amy* develops dementia, meaning that *he/she* has lost intellectual and social abilities that affect daily functioning, and no longer recognizes *his/her* spouse but seems content when s*he/he* visits, and they still occasionally engage in sexual relations during visits. Typically, residents of nursing homes are allowed to have consensual sexual relationships in their private rooms, but the rules are unclear about whether this is allowed for those with diminished cognitive functioning, as in *David's/Amy's* case given the dementia.

After being read the vignette segment, respondents were asked, "Given the situation, do you think *David/Amy* should or should not be allowed to engage in sexual behaviors with *his/her* spouse in the nursing home?"

Quantitative results. Overall, 58% of respondents indicated that a married couple in which one person suffers from dementia and resides in a LTC facility should be allowed to have sexual relations in the LTC facility. The two independent variables

presented in this vignette segment, age and sex, had different impacts on respondent's opinions; age was a statistical predictor of responses and sex was not. Support for a 65 year-old was higher than for a vignette character portrayed as being 95 years-old; of those who said *should*, 65% heard about a 65 year old versus 52% who heard about a 95 year old. Participants were 1.8 times more likely to say *should* when they heard about a 65 year-old versus a 95 year-old vignette character. There was no statistical difference between those who heard about a male versus a female vignette character. However, support was slightly higher for males (61%) compared to females (55%). Complete descriptive results are found in Table 4.1 and logistic regression results are presented in Table 4.2.

Respondent characteristics. Of the respondent characteristics analyzed for this segment – age, sex, importance of sexual intimacy, education, parenthood status, religiosity, knowledge of someone with dementia, and religion – only one was a statistical predictor of respondent's attitudes. Respondent education was positively associated with stating that a married couple in which one person suffers from dementia *should* be allowed to have sexual relations in a LTC facility. Specifically, for each unit increase in a respondent's education level, respondents were 1.3 times as likely to say the vignette characters *should* be allowed to have sexual relations.

Qualitative rationales. Although age was a statistical predictor of attitudes, respondents cited numerous other rationales supporting their response to the first vignette. Among those who said *should*, the largest proportion of respondents said "it's their decision", "if they want to", "they should be able to make the choice" and similar statements indicating adult autonomy. Of those who provided such a rationale, the

Table 4.1

Percentage of Responses Within Each Level of the Independent Variables: Segment One (n = 318)

	Should or should not be allowed?			
	Should		Should not	
Variable	*n*	%	*n*	%
Independent variables:				
Age				
65	97	64.7	53	35.3
95	87	51.8	81	48.2
Sex				
Male	90	60.8	58	39.2
Female	94	55.3	76	44.7

Table 4.2

Logistic Regression Predicting Whether Sexual Relations in Long-Term Care Should Be Allowed (n = 286)

Predictor	*B*	*SE*	*p*	*OR*	95% CI
65 (95)	0.59	0.25	.020	1.80	[1.10, 2.96]
Male (female)	0.19	0.25	.459	1.21	[0.74, 1.98]
Respondent characteristics					
Age	0.00	0.01	.910	1.00	[0.98, 1.02]
Male (female)	0.34	0.29	.241	1.41	[0.79, 2.50]
Importance of sexual intimacy	0.02	0.12	.892	1.02	[0.80, 1.29]
Education	0.28	0.12	.025	1.32	[1.04, 1.68]
Never had children (has had children)	-0.27	0.35	.439	0.76	[0.38, 1.52]
Religiosity	-0.07	0.16	.661	0.93	[0.68, 1.28]
Does not know someone with dementia (does)	-0.14	0.27	.618	0.87	[0.51, 1.49]
Religion					
Baptist (protestant)	-0.55	0.29	.058	0.58	[0.33, 1.02]
Catholic (protestant)	-0.01	0.38	.987	0.99	[0.47, 2.09]
Catholic (Baptist)	0.55	0.39	.159	1.73	[0.81, 3.70]

Note. Reference category in parentheses. CI = confidence interval for odds ratio (*OR*). Should = 57.9%.

majority knew someone with dementia (75%). Then, 16% of respondents cited that the couple *should* be allowed to have sexual relations because they are married. Others said that if the couple consents, they should be allowed to have sex; one respondent said "if she can intellectually make the decision, they should [have sex]." Those respondents who reported knowing someone with dementia were four times as likely to provide this rationale compared to those who did not know someone with dementia. Some respondents cited both marriage and consent as their rationale; one participant said, "They are still married and that is still his wife. As long as she agrees to it." Still, other respondents placed the responsibility on the healthy spouse to decide whether it was appropriate for the couple to have a sexual relationship. One respondent said, "It is up to the husband to take a responsible role to determine if they should have sex." A small proportion of respondents (7%) even acknowledged the importance of sexuality in regard to physical and emotional well-being. One person said, "It's [sex] proven to be healthy" while another said, "it [sex] makes them [the couple] happy, so why not?"

Compared to those who were supportive of the couple, respondents who said the couple *should not* have sex in the LTC facility frequently cited consent and dementia-related issues. Most respondents said that the person has an inability to consent (41%). This perspective was primarily held by those who identified as *somewhat* or *very religious* (88%). Then, 13% of respondents cited that the couple should not have a sexual relationship because the person with dementia cannot recognize their spouse. Eleven percent of respondents stated that no one should be having sex in a LTC facility, regardless of cognitive status. Some respondents said "it is not a polite place to have it [sex]", "nursing homes is [sic] not the place for sexual relation [sic]", and "don't think it

is appropriate in nursing home." Sixty percent of those who said sex was generally inappropriate in a LTC facility did not cite an additional reason why the couple should not be permitted (i.e., consent). Then, a compelling issue is raised, as 6% of respondents indicated that having sex with an individual with dementia would constitute rape. Many respondents cited something similar to "she isn't in her right mind, it could be rape" or "she may think he's a stranger raping her." Complete qualitative rationales are presented in Table 4.3.

Research question and hypothesis. The specific research question in this segment was: *How does age and sex affect one's opinion toward sexual expression by a married couple in which one individual has dementia resides in LTC?* Results showed that attitudes are statistically influenced by the vignette character's age, and there is more support for a 65 year old versus someone who is 95. Ultimately, the hypothesis, which stated that age and sex would not statistically predict attitudes, was not supported by the data.

Segment Two

The second segment of the vignette incorporated one new independent variable: degree of intimacy (flirtatious conversation or intimate physical contact). The vignette was read as follows:

> Due to dementia, *David/Amy* no longer realizes that *he/she* is married and has developed an intimate relationship with another resident of the nursing home who also has dementia. The two have been *seen having intimate physical contact/overheard having flirtatious conversations.*

Table 4.3

Most common Rationale for Whether Sexual Relations Should or Should Not Be Allowed in the Retirement Home

Rationale	*n*	*%*
Should		
Adult autonomy	52	21.2
Married	40	16.3
If both consent, sex is okay	38	15.5
Sex is an integral component of life and relationships	16	6.5
Spouse is responsible to decide	15	6.1
If person with dementia recognizes their partner, sex is okay	14	5.7
LTC should have no say on sexual relationships	9	3.7
Sex is okay if it occurs in private	8	3.3
Should not		
Inability to consent	65	41.1
Inability to recognize partner	20	12.7
Sexual behaviors should not be permitted in LTC	17	10.8
Rape	10	6.3

After hearing the vignette, respondents were asked, "Given this information, do you think the nursing home staff should or should not attempt to stop the new relationship?" and "How obligated are nursing home care staff to inform *David's/Amy's* spouse of *his/her* new relationship: would you say *highly obligated, somewhat obligated, slightly obligated,* or *not at all obligated?*"

Quantitative results. After hearing the second vignette segment, 78% of respondents indicated that LTC staff members *should* attempt to stop the relationship between two residents with dementia whom are not married to each other (complete descriptive results are found in Table 4.4). The new independent variable introduced in this segment – degree of intimacy – had little bearing on attitudes. There was only slightly more support for stopping the relationship (54%) when a respondent heard about a physical relationship versus a flirtatious one. The two independent variables introduced in previous segments – age and sex – also had no statistical impact on respondents' attitudes.

Respondent characteristics. Of the respondent characteristics analyzed for this segment, three proved to have an impact on respondents' opinions – education, religiosity, and religion. Specifically, for each unit *decrease* in a respondent's attained education, respondents were nearly 1.5 times as likely to say that LTC staff members *should* intervene in an attempt to stop the relationship; the less educated a respondent was, the more supportive they were of staff intervention. Further, for each unit *increase* in reported religiosity, respondents were 66% more likely to say that the staff should intervene. Finally, Catholics were half as likely to say *should* when compared to non-

Table 4.4

Percentage of Responses Within Each Level of the Independent Variable: Segment Two (n = 317)

	Should or should not stop the relationship?			
	Should		Should not	
Variable	*n*	%	*n*	%
Independent variable:				
Degree of intimacy				
Flirtatious conversation	115	78.2	32	21.8
Intimate physical contact	133	78.2	37	21.8

Baptist Protestant respondents. Complete logistic regression results are presented in Table 4.5

Ordinal regression. Overall, 53% of respondents indicated that LTC staff members were *highly obligated* to inform the spouse of the new relationship and 84% of respondents indicated that LTC staff had at least some degree of obligation to inform the spouse. Only 16% said that staff members were *not at all obligated*. Of those who said that the relationship *should not* be stopped by LTC staff, 77% of respondents still indicated that staff members were obligated to inform the spouse of the relationship. Among those who said that the staff *should* intervene, 86% indicated that staff members were obligated to tell the spouse. Regardless of the degree of obligation reported by respondents, the majority always supported stopping the relationship (complete descriptive results are presented in Table 4.6 and Table 4.7). The three independent variables analyzed in this segment – age, sex, and degree of intimacy – had little bearing on attitudes. Only one respondent characteristic, religion, predicted attitudes; respondents who identified as non-Baptist Protestant reported twice as much obligation to inform the spouse versus their Baptist counterparts. Complete ordinal regression results are presented in Table 4.8.

Qualitative rationales. The qualitative responses generally substantiate the quantitative results in that most respondents did not cite the vignette character's degree of intimacy as a rationale for their opinion. Instead, the largest proportion of those who said that the relationship *should* be stopped (16%) simply cited that the spouse had a right to know. Of those who gave this rationale, all respondents indicated that the LTC staff were obligated to some degree to tell the spouse. One respondent said "I just think his wife

Table 4.5

Logistic Regression Predicting Whether LTC Staff Should Intervene to Stop the Adulterous Relationship: Segment Two (n = 284)

Predictor	*B*	*SE*	*P*	*OR*	95% CI
65 (95)	0.13	0.31	.674	1.14	[0.62, 2.08]
Male (female)	-0.05	0.31	.884	0.96	[0.52, 1.75]
Flirtatious conversation (intimate physical contact)	0.06	0.31	.834	1.07	[0.58, 1.95]
Respondent characteristics					
Age	0.02	0.01	.070	1.02	[1.00, 1.04]
Male (female)	0.44	0.36	.232	1.54	[0.76, 3.15]
Importance of sexual intimacy	0.01	0.15	.935	1.01	[0.75, 1.37]
Education	-0.41	0.15	.006	0.67	[0.50, 0.89]
Never had children (has had children)	-0.12	0.41	.770	0.89	[0.40, 1.98]
Religiosity	0.50	0.19	.009	1.66	[1.13, 2.42]
Does not know someone with dementia (does)	0.41	0.35	.243	1.50	[0.76, 2.96]
Religion					
Baptist (protestant)	-0.02	0.37	.950	0.98	[0.47, 2.02]
Catholic (protestant)	-0.82	0.42	.050	0.44	[0.19, 1.00]
Catholic (Baptist)	-0.81	0.44	.065	0.45	[0.19, 1.05]

Note. Reference category in parentheses. CI = confidence interval for odds ratio (*OR*). Should = 78.2%.

Table 4.6

Percentage of Responses Within Each Level of Obligation to Inform the Spouse (n = 316)

	Should or should not stop the relationship?			
	Should		Should not	
Variable	*n*	%	*n*	%
Obligation to inform spouse				
Highly obligated	141	83.4	28	16.6
Somewhat obligated	44	71.0	18	29.0
Slightly obligated	28	82.4	6	17.6
Not at all obligated	35	68.6	16	31.4

Table 4.7

Percentage of Responses Within Each Level of the Dependent Variable: Segment Two (n = 316)

	Should or should not stop the relationship?			
	Should		Should not	
Variable	*n*	%	*n*	%
Obligation to inform spouse				
Highly obligated	141	56.9	28	41.2
Somewhat obligated	44	17.7	18	26.5
Slightly obligated	28	11.3	6	8.8
Not at all obligated	35	14.1	16	23.5

Table 4.8

Ordinal Regression Predicting Degree of Obligation for Staff to Inform Spouse of Relationship (n = 290)

Predictor	*B*	*SE*	*P*	*OR*	95% CI
65 (95)	0.29	0.23	.217	1.33	[0.85, 2.09]
Male (female)	0.04	0.23	.877	1.04	[0.66, 1.62]
Flirtatious conversation (intimate physical contact)	0.00	0.23	.998	1.00	[0.64, 1.56]
Respondent characteristics					
Age	-0.00	0.01	.745	1.00	[0.98, 1.01]
Male (female)	-0.01	0.26	.957	0.99	[0.60, 1.65]
Importance of sexual intimacy	0.10	0.11	.366	1.11	[0.89, 1.38]
Education	-0.81	0.11	.465	0.92	[0.74, 1.15]
Never had children (has had children)	0.41	0.33	.205	1.51	[0.80, 2.86]
Religiosity	-0.02	0.15	.892	0.98	[0.73, 1.31]
Does not know someone with dementia (does)	-0.09	0.25	.722	0.92	[0.57, 1.48]
Religion					
Baptist (protestant)	-0.71	0.27	.008	0.49	[0.29, 0.83]
Catholic (protestant)	-0.26	0.35	.461	0.78	[0.39, 1.53]
Catholic (Baptist)	0.46	0.35	.192	1.58	[0.80, 3.13]

Note. Reference category in parentheses. CI = confidence interval for odds ratio (*OR*).

needs to know what's taking place with her husband" while another said "she is his wife and she should be told". Next, 15% of respondents cited that the LTC staff should stop the relationship because the person "is married and should abide by that", and the like. Nearly 12% of respondents cited that individuals with dementia lack the mental competency to have intimate or sexual relationships. One respondent said, "I just know when you lose your mind you don't know what you are doing. I mean, my husband was a brain injury person and it's just not right" and another said "they [persons with dementia] lose their ability to think rationally". In regard to how respondents think LTC staff should respond, 13% said staff should attempt to discontinue the relationship, 10% said they were obligated to tell the spouse about the relationship, and only 6% said staff should not tell the spouse about the relationship.

Among those who said the LTC staff should not stop the relationship, a large proportion of respondents still focused on the need for LTC staff to tell the spouse (26%) and many cited that the relationship was adulterous and/or inappropriate for persons with dementia (26%). Only 11% of those who said the staff should not stop the relationship cited adult autonomy as a rationale for their response. The majority (63%) of those who cited adult autonomy indicated that the LTC staff was obligated to some degree to inform the spouse of the relationship. Concerning the independent variable, degree of intimacy, only four respondents said that their response was dependent upon the degree of relationship occurring between the two unmarried persons with dementia. Complete qualitative rationale results are presented in Table 4.9.

Research question and hypotheses. The research question associated with this vignette segment asked, "How does the degree of intimacy affect one's opinion toward

Table 4.9

Most Common Rationale for Whether LTC Staff Should Stop the Adulterous Relationship and Degree of Obligation to Inform Healthy Spouse

Rationale	*n*	*%*
Should		
Spouse has the right to know	55	15.9
Person is married and is committing adultery	52	15.0
LTC staff should attempt to discontinue relationship	45	13.0
Persons with dementia lack competence to have an intimate relationship	41	11.8
LTC staff is obligated to tell the healthy spouse	34	9.8
LTC should not inform the spouse; they could get upset	20	5.8
Relationship is morally wrong	10	2.9
Spouse is paying for care, and therefore has the right to know	8	2.3
Intimate relationships for a person with dementia are a health and safety risk	7	2.0
Should not		
Spouse has the right to know	15	16.1
Person is married and is committing adultery	12	12.9
Persons with dementia lack competence to have an intimate relationship	12	12.9
Adult autonomy	10	10.8
LTC is obligated to tell spouse about the relationship	9	9.7
LTC should not inform spouse because they could get upset	6	6.5
Depends on LTC policy	4	4.3
Dependent upon degree of relationship	4	4.3

whether LTC staff should attempt to stop a non-marital, adulterous relationship in which both residents of LTC suffer from dementia?" The results indicate that the degree of intimacy does not statistically affect responses. The findings support the second hypothesis which states that a greater proportion of respondents will expect LTC staff intervention for residents who engage in a physical, versus flirtatious, relationship; 78% of respondents indicated as such. The third hypothesis stated that a greater proportion of respondents will not expect staff intervention for residents who engage in flirtatious conversation. The data did not support this hypothesis; 78% of respondents expected staff intervention in a flirtatious relationship.

Segment Three

The third vignette segment introduced spousal disposition as a new independent variable. Participants were read the following vignette:

> The nursing home care staff explain to *Amy/David* that it is common for people with dementia to develop new intimate relationships even if they were happily married for many years. *After learning this, Amy/David is comfortable with / Nevertheless, Amy/David is distressed about David/Amy* having a new intimate relationship**.**

After hearing this vignette segment, respondents were asked, "Given his/her spouse's response, do you think the nursing home staff should or should not attempt to stop the new relationship?"

Quantitative results. After hearing about the spouse's disposition, 64% of respondents indicated that LTC staff should attempt to stop the adulterous relationship; prior to hearing the spousal disposition, in segment two, 78% of respondents gave the

same response. Both degree of intimacy and spousal disposition had a statistical impact on respondents' opinions. Respondents were twice as likely to say that the LTC staff *should* intervene when they heard about a physically intimate relationship versus a verbally flirtatious one. In addition, respondents were seven times more likely to say *should* intervene after hearing that the cognitively healthy spouse was distressed by the new, adulterous relationship. Overall, 83% of respondents who heard about a distressed spouse said that the staff *should* intervene. Conversely, only 46% of respondents said that staff *should* attempt to stop the relationship after hearing about a supportive spouse. Complete descriptive results are found in Table 4.10.

Respondent characteristics. Of the respondent characteristics analyzed for this segment, only one was a statistical predictor of respondent's attitudes. Respondent education was positively associated with stating that LTC staff *should not* intervene to stop the new relationship. Specifically, for each unit increase in a respondent's achieved education level, respondents were nearly 1.5 times more likely to say that the LTC staff *should not* attempt to disrupt the adulterous relationship. Complete logistic regression results are presented in Table 4.11.

Qualitative rationales. The qualitative rationales among respondents who said the staff *should* stop the relationship were generally consistent with those in the previous segment. The majority of respondents (40.8) cited that the relationship was adulterous and immoral or that persons with dementia are incapable of sustaining intimate or sexual relationships. The qualitative responses also aligned with the quantitative results in that 17% of respondents cited the healthy spouse's disposition in their rationale.

Table 4.10

Percentage of Responses Within Each Level of the Independent Variables: Segment Three (n = 312)

	Should or should not stop the relationship?			
	Should		Should not	
Variable	*n*	%	*n*	%
Spousal disposition				
Comfortable	71	45.5	85	54.5
Distressed	130	83.3	26	16.7

Table 4.11

Logistic Regression Predicting Whether LTC Staff Should Intervene to Stop the Adulterous Relationship: Segment Three (n = 284)

Predictor	*B*	*SE*	*p*	*OR*	95% CI
65 (95)	-0.39	0.29	.181	0.68	[0.38, 1.20]
Male (female)	0.02	0.29	.942	1.02	[0.58, 1.81]
Flirtatious conversation (intimate physical contact)	-0.57	0.29	.048	0.56	[0.32, 1.00]
Comfortable (distressed)	-1.96	0.31	< .001	0.14	[0.08, 0.26]
Respondent characteristics					
Age	0.01	0.01	.288	1.01	[0.99, 1.03]
Male (female)	0.11	0.33	.740	1.12	[0.59, 2.12]
Importance of sexual intimacy	-0.17	0.14	.243	0.85	[0.64, 1.12]
Education	-0.36	0.15	.013	0.70	[0.52, 0.93]
Never had children (has had children)	0.34	0.39	.382	1.40	[0.66, 2.98]
Religiosity	0.36	0.19	.055	1.44	[0.99, 2.08]
Does not know someone with dementia (does)	-0.22	0.31	.473	0.80	[0.43, 1.47]
Religion					
Baptist (protestant)	-0.33	0.35	.339	0.72	[0.37, 1.41]
Catholic (protestant)	-0.66	0.43	.124	0.52	[0.23, 1.20]
Catholic (Baptist)	-0.33	0.43	.453	0.72	[0.31, 1.69]

Note. Reference category in parentheses. CI = confidence interval for odds ratio (*OR*). Should = 64.4%.

The responses among those who said the staff *should not* stop the relationship generally substantiated the quantitative results; the largest proportion (43%) indicated that their response was based on the spouse's positive disposition toward the relationship. The next largest proportion of responses (23%) cited rationales of adult autonomy. One person even said, "Anything that makes people happy in those poor nursing homes. It aint gonna [sic] go nowhere. How can you stop a person from liking someone anyway?" Finally, 6% of respondents indicated that it was not the responsibility of the LTC facility or staff members to stop the relationship; one person said, "It is not their responsibility. They are there to take care of health not the moral laws." Complete qualitative rationales are presented in Table 4.12.

Research question and hypotheses. The research question for this segment asked, "Does a cognitively competent spouse's disposition affect one's opinion toward the degree of influence LTC staff should have in a non-marital, adulterous relationship in which both residents of LTC suffer from dementia?" Results showed that a spouse's disposition does, in fact, statistically affect respondent's opinions. Hypothesis four posited that a greater proportion of respondents would expect LTC staff intervention if a spouse is opposed to the adulterous relationship. Ultimately, the data supported this hypothesis, as 83% of those who heard about a spouse who was distressed indicated that LTC staff should attempt to stop the relationship. Hypothesis five stated that a greater proportion of respondents would not expect LTC staff intervention if a spouse is supportive of the new relationship. This, too, was supported by the data, as 55% of those who heard about a spouse who was comfortable with the new relationship said LTC staff *should not* attempt to stop the new relationship.

Table 4.12

Most Common Rationale for Whether LTC Staff Should Stop the Adulterous Relationship

Rationale	*n*	*%*
Should		
Relationship is adulterous and immoral	59	25.9
Persons with dementia lack competence to have an intimate relationship	34	14.9
If spouse is upset, LTC should attempt to stop the relationship	24	10.5
If spouse is comfortable, LTC should not attempt to stop the relationship	15	6.6
Should not		
If spouse is comfortable, LTC should not stop relationship	51	42.5
Adult autonomy	27	22.5
Not the responsibility of LTC to stop the relationship	7	5.8

Segment Four

The final segment of the vignette revealed the last independent variable: the length of elapsed time since the dementia diagnosis (months or years). The vignette was read to respondents as follows:

> Now a few *months/years* have passed and they have grown distant; *David's/Amy's* dementia has worsened to the point that *he/she* does not even recognize *Amy/David* anymore. *Amy/David* has been lonely but recently developed a close friendship and fondness for a widowed neighbor. Given the circumstances with *David*'s/Amy's dementia, *Amy/David* is considering the possibility of starting a new relationship with the widowed neighbor.

After hearing the final segment, respondents were asked, "Given the circumstances, do you think it would be appropriate or inappropriate for *Amy/David* to have a relationship with *her* new friend?" and "Would you say it is *highly, somewhat, or slightly* (in)appropriate?"

Quantitative results. After hearing the final vignette segment, 61% of respondents indicated that it was inappropriate for the spouse to begin a new relationship; 50% said *highly inappropriate* versus 14% of respondents who indicated it was *highly appropriate*. The majority of respondents indicated that the spouse beginning a new relationship was inappropriate regardless of the length of time that had passed since the dementia diagnosis; 60% of respondents said it was inappropriate after months had passed versus 62% that said inappropriate after hearing that years had passed (complete descriptive statistics are presented in Table 4.13). The five independent variables analyzed in this segment – age, sex, degree of intimacy, spousal disposition, and length of time after dignosis – had no statistical bearing on attitudes. Only one respondent

Table 4.13
Percentage of Responses Within Each Level of the Independent Variable: Segment Four (n = 314)

	Inappropriate or appropriate to begin a new relationship?			
	Inappropriate		Appropriate	
Variable	*n*	%	*n*	%
Length of time post-diagnosis				
Months	97	59.9	65	40.1
Years	94	61.8	58	38.2

characteristic, religiosity, had statistical influence on a respondent's opinion; for each unit increase in religiosity, respondents were half as likely to say it was highly appropriate for the vignette character to begin a new relationship. It should also be noted that though respondent education was statistically nonsignificant ($p = .056$), the confidence interval for the effect size [1.00,1.54] suggests that education may still have influenced attitudes in similar directions as the previous segments; for each unit increase in respondent education, respondents were more likely to say that the healthy spouse should be allowed to begin a new relationship. Though there was not a statistical difference, crosstabulation analysis revealed that those who identified as separated or divorced were twice as likely to suggest that starting a new relationship was appropriate than those who were married or widowed. Further, the largest proportion of those who said the new relationship was *inappropriate* reported that sexuality was *not at all important* to them. Of those who indicated the healthy spouse beginning a new relationship was *inappropriate*, the majority (56%) said the sexual relationship between a married couple in which one person sufferes from dementia *should* be allowed. Complete ordinal regression results are found in Table 4.14.

Qualitative rationales. The largest proportion of respondents who indicated that it was appropriate for the cognitively healthy spouse to begin a new relationship (43%) cited so because of adult autonomy or the freedom for one to make their own decisions. One respondent said, "he should not be expected to be tied to her after she has developed dementia" while another said, "she shouldn't be forced by society to go without a relationship". One respondent powerfully said, "The spouse of the patient suffering from dementia should not be forced to suffer any more than the patient himself." Still, others

Table 4.14

Ordinal Regression Predicting the Degree of Appropriateness for Spouse to Move On (n = 287)

Predictor	*B*	*SE*	*P*	*OR*	95% CI
65 (95)	0.25	0.23	.276	1.29	[0.82, 2.03]
Male (female)	-0.07	0.23	.765	0.93	[0.60, 1.46]
Flirtatious conversation (intimate physical contact)	0.06	0.23	.812	1.06	[0.67, 1.66]
Comfortable (distressed)	0.07	0.23	.769	1.07	[0.69, 1.66]
Months (years)	0.08	0.23	.723	1.09	[0.69, 1.71]
Respondent characteristics					
Age	0.01	.001	.391	1.01	[0.99, 1.02]
Male (female)	-0.16	0.26	.552	0.86	[0.51, 1.43]
Importance of sexual intimacy	0.01	0.11	.964	1.00	[0.80, 1.26]
Education	0.21	0.11	.056	1.24	[1.00, 1.54]
Never had children (has had children)	0.24	0.31	.452	1.27	[0.69, 2.34]
Religiosity	-0.75	0.15	< .001	0.47	[0.35, 0.63]
Does not know someone with dementia (does)	-0.08	0.25	.736	0.92	[0.57, 1.49]
Religion					
Baptist (protestant)	-0.39	0.27	.144	0.68	[0.40, 1.14]
Catholic (protestant)	-0.31	0.34	.370	0.74	[0.38, 1.44]
Catholic (Baptist)	0.08	0.35	.812	1.09	[0.55, 2.17]

Note. Reference category in parentheses. CI = confidence interval for odds ratio (*OR*). Appropriate = 39%.

were approving of the relationship but presented some indication of uneasiness. To that effect, one respondent said, “it isn’t really right…but it’s okay”. Other responses were slightly more detailed; 21% of respondents said that due to their partner’s dementia, their marriage was essentially void. Much smaller proportions of respondents cited that beginning a new relationship was okay because the healthy spouse would certainly be lonely (5%) or because the person with dementia also had a new relationship (4%). In the case of the latter, one respondent said, “it would be fair for both to have a relationship”. Still, another said, “Amy is no longer a companion. She's developed her own relationship as well, and people deserve a friend. Not saying abandon her, but he should be able to choose.” Then, nearly 4% of respondents indicated that the healthy spouse should begin a new relationship because of their age, often indicating that they should enjoy what life they have left. Three percent of respondents indicated that the healthy spouse engaging in a new relationship was appropriate, but conditioned their statement by saying that they should first get a divorce.

Among respondents who said it was *inappropriate* for the healthy spouse to move on, the majority (51%) indicated so citing adultery and morality. One respondent said, “Your [sic] married. No. That’s how it is…I’m sorry but you have to wait it out I guess” and another said, “Dementia or not it’s still adultery.” Twelve percent of respondents cited marriage vows, particularly the “till death do us part” portion, as their rationale; the majority of those who provided this rationale also identified as *very religious* (79%). Again, divorce was cited by some respondents (9%). One respondent even said, “It’s inappropriate, just because someone has a mental problem, there’s no reason to cheat on them. If you can’t deal with it then divorce them.” One person even indicated that using

the vignette character's dementia was an "excuse" and said that the healthy spouse has no justification for beginning a new relationship, and therefore should seek divorce. Lastly, 9% of respondents indicated a general sentiment regarding religion as to why beginning a new relationship was inappropriate. Some respondents referenced the bible's teachings while others stated that it "don't [sic] agree with my religious beliefs." Complete qualitative results are presented in Table 4.15.

Research question and hypothesis. The research question for this segment asked, "How does the elapsed time after diagnosis affect one's opinion toward whether or not the community-dwelling, cognitively healthy spouse can begin a new relationship?" The results indicate that, statistically, elapsed time does not affect responses. There is slightly more acceptance for a relationship beginning months (40%) after the diagnosis compared to years (38%). The final hypothesis proposed that the largest proportion of respondents who hear about a new relationship beginning years after the dementia diagnosis will indicate that the new relationship is appropriate versus inappropriate. Ultimately, the data did not support this hypothesis.

Summary of Results

Participant's initial reactions to sexual behaviors among a married couple in which one person suffers from dementia trended toward favorable; 58% of respondents said the couple should be allowed to have sexual relations. As the proposed trajectory of intimate relationships and dementia continued and an adulterous relationship was introduced, support experienced a sharp decline. Only 22% of respondents felt as though staff members *should not* intervene in an attempt to stop the adulterous relationship between two residents with dementia who were not married to each other. Then, the

Table 4.15

Most common Rationale for Whether The Healthy Spouse Should Begin a New Relationship

Rationale	*n*	*%*
Appropriate		
Adult autonomy	73	42.7
Marriage no longer exists because of dementia	36	21.1
Loneliness	9	5.3
Relationship is okay because person with dementia also has new relationship	7	4.1
Relationship is okay because of age	6	3.5
Close friendship is okay, but no sexual behaviors	5	2.9
Competent person should seek divorce	5	2.9
Inappropriate		
Adultery/Immoral	119	51.5
“Till death do us part”/Marriage vows	28	12.1
Competent person should seek divorce	21	9.1
Religious doctrine	21	9.1

spouse's disposition was introduced into the vignette. After hearing their stance, support (indicated by the respondent saying the staff *should not* intervene) increased by 14%. Perceived acceptability for the healthy spouse to begin a new relationship was largely unfavorable; 39% of respondents supported the spouse initiating an intimate relationship with a widowed neighbor.

Consistencies among independent variables across segments. Throughout the segments, consistencies among statistical differences in the independent variables were unremarkable. Out of the five regression analyses, only two exhibited a statistical difference in independent variables. In the first analysis (segment one), age was a statistical predictor and there was more support for a 65 year old versus a 95 year old. Then, the logistic regression in the third segment, after spousal disposition was introduced, elicited two independent variables with statistical differences – degree of intimacy and spousal disposition. Briefly, there was more support for staff intervention if the relationship was physical and/or if the spouse was distressed about the relationship.

Regardless of significance, results across segments followed expected patterns. There was more support for a younger and male vignette character and more respondents expected staff intervention after hearing about a disapproving spouse. Unexpectedly, there was an inconsistent pattern in support for those who heard about a physical versus flirtatious relationship. When the relationship was first introduced the type of relationship had no bearing on attitudes, but after hearing the spouse's disposition, there was a statistical difference in attitudes toward a physical versus flirtatious relationship. Lastly, there was little difference in attitudes regarding the elapsed time since diagnosis before the healthy spouse contemplated beginning a new relationship.

Consistencies among respondent characteristics across segments. For every vignette segment, regardless of statistical significance, there was a pattern between respondent education and perceived acceptance of sexual behavior. Those who attained higher levels of education were consistently more accepting of sexual behaviors, less likely to expect staff intervention, and were supportive of the spouse beginning a new relationship. Having known an individual with dementia also affected responses across segments; generally, those who know someone with dementia were more supportive of sexual relationships, less supportive of staff intervention, and slightly more supportive of the spouse moving on and beginning a new relationship. Thirdly, those who reported higher degrees of religiosity showed similar patterns of beliefs. Those who said religion was *very important* were more likely to support stopping intimate relationships and reported higher degrees of obligation to inform the spouse. Profoundly, 75% of those who identified as *not very religious* said the healthy spouse beginning a new relationship was appropriate; 27% of those who identified as *very religious* expressed the same attitude.

Consistencies among respondent's rationales across segments. Respondent rationales across the four segments also followed expected patterns. Generally, those who supported the relationship or discouraged staff intervention consistently cited adult autonomy as their rationale for support. A pattern of concerns occurs among those who were unsupportive of relationships and those who encouraged staff interruption of relationships. Unsurprisingly, issues of consent and competence appeared across all segments in large proportions. In segments where an adulterous relationship was

occurring or had the potential to occur, concerns of immorality, adultery, and religious conflict were prominent.

Chapter Five: Discussion

The objective of this dissertation was to examine public perspectives toward sex, dementia, and LTC from an ecological perspective. In this study, participants were read vignettes that allowed researchers to assess their opinions regarding a plausible trajectory of relationships affected by dementia – a person with dementia having a sexual relationship with their spouse in a LTC facility, then developing a new relationship with another resident of the facility who also has dementia, and finally the cognitively healthy spouse developing a new relationship with a neighbor. Consistent with a previous study (Yelland, Hosier, & Hans, 2014), the results suggest that the majority of the public is supportive of married couples in which one person has dementia engaging in sexual activity (58%), but that attitudes change drastically once an adulterous relationship is introduced into the vignette. For example, a large proportion of respondents indicated that LTC staff members were obligated to both intervene in an attempt to discontinue the adulterous relationship between two residents with dementia and inform healthy spouses of such relationships. Results also demonstrated public disapproval for the spouse of a dementia sufferer developing a new relationship with another healthy individual, regardless of the elapsed time since the dementia diagnosis.

Overall, the contribution from the current study confirms and adds to the already intricate nature of sex, dementia, and LTC and provides a perspective, that of the public, which has been largely understudied until this point. Understanding public perspectives from an ecological standpoint is important because macrosocial influences, such as public perspectives, can greatly influence sexual development. In fact, socially constructed attitudes are more influential on sexual desire and expression than biomedical factors,

such as illness or disease (Doll, 2012). Public attitudes are also likely to influence the progression of culture change or resident-centered facilities and the development of relevant policy; negative perceptions are likely to hinder progression and policy development, while public support can propel acceptance and resident-centered policy. As the longevity revolution continues and more sexually permissive generations enter their later years, issues regarding sex, dementia, and LTC will gain unprecedented importance. This study initiated discussion on sex, dementia, and LTC and provided a glimpse of understanding on the societal values toward this topic.

The remainder of this chapter will discuss the results within the context of the research questions, hypotheses, and previous research, and themes emerging from this study will be highlighted. Then, the limitations of this dissertation will be discussed.

Hypotheses and Implications

The vignette created for this dissertation sought to tell the story of a proposed trajectory of intimate relationships and dementia within LTC. Along the way, numerous contextual circumstances were introduced and manipulated in an attempt to understand the degree of influence such characteristics had on the public's perspective of the hypothetical story. The first research question asked how age and sex affect one's opinion toward sexual expression by a married couple in which one individual has dementia and resides in LTC, and it was hypothesized that neither of these characteristics would sway respondent's answers. Among the ecological influences he describes, Bronfenbrenner highlights how an individual's demand characteristics (i.e., those that are immediately apparent to others) are commonly associated with and substantially influenced by socially defined expectations and how they have the capacity to influence attitudes toward other

individuals. Focusing on the demand characteristics, sex and age, this study found that age was a statistical predictor of attitudes, with more support for a younger vignette character to engage in sexual activity, and a larger proportion of respondents were supportive of a male character. A previous study (Yelland, Hosier, & Hans, 2014) found that attitudes toward sexual behaviors in LTC are statistically affected by a vignette character's sex. The contrast in studies implies that one's demand characteristics can have some degree of sway in respondent's opinions, but that statistical demand characteristics are not consistent between studies.

The second research question sought to identify whether or not the degree of intimacy between a couple with dementia engaged in an adulterous relationship influenced a person to say that LTC staff members should intervene in an attempt to stop the relationship. The hypotheses suggested that staff intervention would be expected more so for a physical versus a verbally flirtatious relationship. Statistically, there was little difference between the two degrees of contact, but the perceived obligation of LTC staff involvement was strong. Between 64% and 78% of our sample indicated that LTC staff *should* stop the relationship. This is an interesting finding when compared to existing literature and guidelines for intervention. Guidelines generally suggest that there needs to be some degree of intervention in order to assess competence and risk (e.g., Steele, 2012), but that staff should not intervene to stop a relationship unless a resident is clearly refusing the encounter and the staff perceive it as "an unwanted invasion of personal space" (p. 11), even if the individual is married. There is clearly a large disconnect between how LTC administrators suggest to respond to such relationships and

what the public seems to expect. Regardless of the degree of relationship, the consensus from this sample is that any adulterous relationship needs to be stopped.

This study also questioned whether a competent community-dwelling spouse should be informed by LTC staff of the adulterous relationship. Previous literature has suggested that LTC staff members generally feel obligated to inform the spouse and some policies even explicitly state that spouses must be told of adulterous relationships (e.g., Doll, 2013). The results from the current study validate these ideas and policy; 53% indicated that LTC staff members were *highly obligated* to inform the spouse and 84% of respondents indicated that LTC staff had at least some degree of obligation to inform the spouse. In this context, it appears that some existing policy and opinions among LTC administrators align with the public opinion – spouses of individuals with dementia need to be informed by LTC staff of an adulterous relationship.

The third research question asked if a cognitively competent spouse's opinion of the new, adulterous relationship influenced public expectations of staff intervention. It was hypothesized that a supportive spouse would elicit less expectation for intervention, and vice versa. Aligning with the researcher's expectations, this study suggested that society values a spouse's opinion toward a resident's sexual behaviors and ability to remain sexually autonomous. This finding has several implications for both implementing culture change and developing relevant LTC policy. Being that culture change emphasizes resident autonomy and resident-centered care and living, how does a family's wishes fit into this model? Furthermore, should policy on resident sexuality, be developed with a degree of flexibility in order to accommodate for the preferences of family members? Or, should family members' opinions even be considered? This study

illustrates that even when spousal attitudes and expectations challenge the values of resident-centered living, their opinions may ultimately be paramount to a resident's sexual autonomy.

The final research question in this dissertation asked how the elapsed time since the dementia diagnosis affects opinions toward whether the healthy, community-dwelling spouse should be able to begin a new relationship. It was hypothesized that a longer elapsed time since diagnosis would elicit greater support, and vice versa. Interestingly, there was no statistical difference and results generally showed that there was little difference in attitudes. Among those who said the new relationship was appropriate, 53% heard about months versus 47% who heard about years since diagnosis. This data does not support the hypothesis that there will be more support for years versus months and introduces a thought-provoking theory. Perhaps timing simply has nothing to do with one's opinion toward the spouse's new relationship and has everything to do with the spouse's new relationship itself. This is further evidenced by the fact that the majority of those who said that a new relationship was inappropriate referenced adultery, breaking of marriage vows, or opposition of religious doctrine. Even among those who said the relationship was appropriate, not a single respondent said their opinion was based on the amount of time that had or had not passed.

The results from this study have elicited three additional themes that warrant continued discussion: consent, the need for policy and gerontological literacy.

Consent

Respondents have clearly indicated that consent is perhaps the principle concern regarding dementia and sex; 41% of respondents cited consent as a concern. However,

there is often struggle with the logistics of ensuring that residents with compromised cognition are consenting to sexual activity. The way in which laws and policies address this issue is not concrete. Although some facilities will utilize a cognitive assessment tool, such as the Mini Mental Status Examination (MMSE), to determine cognition (e.g., Stimson, 2011; White, 2009), the extent and frequency of which this or other methods are used across the nation is unknown. As it stands, there are no federal or state laws for assessing mental capacity to ensure a consensual intimate or sexual relationship and many institutional policies are lacking or do not exist at all. There have been some suggestions, though, that assessing the mental status of a resident is far more complicated than completing a single cognition test. Stimson (2011) asserts that, in addition to assessment tools such as the MMSE, an observation of six hours or more, interviews with staff, partner(s), family members, and the resident, and a complete medical and social history should be considered before allowing a sexual relationship, assuming that it consists of acceptable methods of sexual expression. While important, these steps seem largely impractical for any one facility to perform on any of their residents that appear or acknowledge to be in an intimate relationship. Furthermore, it can be argued that these guidelines ignore the typical spontaneity of sexual encounters, as they often are not planned and/or discussed with medical staff for approval prior to their occurrence. Although the results of this study can help promote policies on this matter, it is also recognized that such guidelines need to be achievable.

Not only is *how* consent should be measured an issue, but also *how often* it should be measured. Because dementia is a progressive decline in cognitive functioning, a cognitive assessment may have differing results weeks, month, or years down the road,

depending on the individual. Because assessing one's capacity to consent to a sexual relationship is an intricate process, the fact that it needs to be repeated due to progressive decline adds to its complexity. The purpose of this dissertation was not to solve these issues; however, it does confirm that the public recognizes consent as an unresolved and significant issue in the realm of sexuality, dementia, and LTC. This study strengthens the argument that procedures for consent need to created and implemented as several respondents argue that LTC facilities and their policy are ultimately responsible for the safety of residents.

The Need for Policy

This study furthers the need for consistent, fair policy concerning sexuality in LTC. Because intimate relationships are an integral component of well-being and happiness, and sexuality continues to be a normal and natural part of life, creating and sustaining policy that supports resident's choices while protecting them from unwanted sexual attention is important. Such policy may include guiding LTC staff members to respond to sexual desires and expression in appropriate ways and encouraging staff to initiate an open dialogue regarding sexual needs of residents (e.g., a private room, condoms, or pornographic materials), for example. The development of such policy can evoke a sexually supportive environment for residents, LTC staff, and family members, and highlights the commitment to all quality of life issues, including sexuality. In fact, Doll (2012) suggests that by fostering a sexually supportive environment and encouraging healthy sexual expression, some inappropriate sexual behaviors can even be suppressed. Additionally, it is not uncommon that personal beliefs and values among residents, family members, and LTC staff will differ. Without a guiding policy, personal

biases may affect decision making and "staff and family may decide on a management response that disregards the preferences of the residents involved" (Christie et al., 2002, p. 6). In order to create effective policy, conversations within and across the various environmental systems of a LTC resident must be initiated.

LTC residents are the heartbeat of LTC facilities, and the concept of culture change has strived to create facilities *for* them. A key objective of culture change and person-centered care is to allow residents to be involved in decision-making processes and to consider their needs and wishes prior to formulating policy. Thus, understanding resident's perspectives and rights is at the forefront of need. LTC administrators, conversely, are responsible for initiating and sustaining the various aspect of culture change, including sexuality. Administrators have the ability to create and implement resident-centered environments and sexual-friendly policies as well as determine if, how, and when spouses will be informed of adulterous relationships. Ultimately, administrators have the power to foster the person-centered environment that culture change promotes through the development of person-centered policy. Lastly, public perspectives are an additional aspect to consider when developing policies; the public's perception is likely to influence policy and law, which indirectly affect the resident, and can influence LTC facilities directly through family members, friends, or LTC employees. The results from this study can serve as a starting point for initiating conversation across various ecological contexts (i.e., residents, administrators, and the public) and developing

effective and practical policy that can be applied to a variety of facilities across the nation.

Education and Gerontological Literacy

A final theme that emerged from the results of this study is the need for education and enhancing gerontological literacy. Results consistently indicated that education was a statistical predictor of attitudes; respondent education was positively correlated with the perceived acceptability of all intimate behaviors. Regardless of attained formal education, we can make real-world efforts to establish non-ageist ideologies surrounding sexuality in the LTC population, among residents with or without dementia related disease. Educational efforts need to first begin in facilities themselves; residents, staff, and administrators can ultimately determine the culture of sexuality within their own facility. Beyond them, family members of LTC residents should also be provided with educational materials so that they may better understand the sexual development of older persons, and understand that intimate and sexual relationships are normal well into later life. By initiating conversations and distributing educational messages across all of the ecological systems of a resident, uncertainty, concern, and discomfiture among residents, family members, and staff can be lessened and support of sexual development and expression in LTC can be fostered.

Limitations

The current study has several limitations centered on the sample and recruitment strategy. First, although the sample accurately represented the state of Kentucky, the sample lacks sociodemographic diversity. Participants were overwhelmingly White (92.6%), female (69.9%), and a large proportion identified as highly religious (48.4%).

The findings reported in this dissertation may not generalize to other races, men, or less religious individuals. Because this study questioned topics such as sexuality and adultery, it is also suspected that a less-religious sample might have demonstrated different perspectives.

Second, this study recruited participants by calling landline telephones. This methodology may have influenced the generalizability of results because of the participants that were ultimately recruited. The "proportion of Americans who rely solely or mostly on cell phones for their telephone service" has grown. Ultimately this "[poses] an increasing likelihood that public opinion polls conducted only by landline telephone will be biased" (Keeter, Christian, & Dimock, 2010, para. 1). Generally, "young people [under 30] are difficult to reach by landline phone, both because many have no landline and because of their lifestyles" (Keeter, Christian, & Dimock, 2010, para. 15) and "people younger than age 30 who are cell phone only can have different…attitudes than those who are reachable by landline phone" (Keeter, Christian, & Dimock, 2010, para. 16). However, part of the sampling strategy was to ask for the youngest/oldest male/female living in the household. Because cell phones are assumed to be personal devices, "no effort is made to give other household members a chance to be interviewed" (Pew Research Center, 2015, para. 6) when using a list of cell-only phone numbers. Therefore, there are both limitations and positive elements of using a landline only recruiting strategy.

Furthermore, this study asked participants to respond to hypothetical vignettes centering on a character unrelated to them. It can be suggested that if the participant had

been asked about themselves or their family members, different responses may have been given.

Future Research

Despite the preceding limitations, this study has revealed how complex the issue of sex, dementia, and LTC is. Future research should highlight how the experience of dementia influences a married couple and should include how intimacy between couples changes after a dementia diagnosis. A second area of exploration is examining infidelity and dementia. The question, is it adultery if the spouse has Alzheimer's, should be examined within a national sample and an effort should be made to understand why perceptions toward this question differ. It is also important to explore how extramarital relationships are perceived differently by spouses, LTC staff, LTC resident's family members, and the public when a spouse has Alzheimer's. Building on the ecological perspective, further exploration can also pursue the ecology of sexuality within LTC. Examining how marital relationships and concerns of infidelity are different when an individual with dementia resides in a specialized dementia care facility versus a facility that also houses cognitively aware individuals would be beneficial. Comparisons within continuing care retirement communities (e.g., independent living, assisted living or personal care, and skilled nursing) would also help to gather a complete understanding of how attitudes toward sexuality in LTC change as abilities decline. Finally, understanding attitudes toward culturally and sexually diverse populations would be helpful, as perceptions of appropriateness are likely to change across groups. The findings from this study have helped to paint a picture of public attitudes and much needed future

exploration can help to achieve inclusive understanding of sex, dementia, and long-term care.

Conclusion

This dissertation aimed to explore public perspectives toward sex, dementia, and LTC from an ecological perspective. This study demonstrates that each level of a resident's ecosystem affects their overall well-being, behavior, and development and, more specifically, affects their rights and abilities to sexual expression. The results from this study have real-world implications, particularly for LTC policy. Regardless of living environment and cognitive status, each resident should be afforded the right to engage in a safe and consensual loving relationship. Although not all older adults will become "sexy oldies" (Gott, 2005, p. 2), LTC facilities need to be prepared to facilitate, fairly and consistently, the sexual needs of those that will, while also protecting residents and staff from unsolicited sexual advances.

References

Adelman, A. M., & Daly, M. P. (2005). Initial evaluation of the patient with suspected dementia. *American Family Physician, 71,* 1745-1750.

Administration on Aging. (2012). *A profile of older Americans: 2012*. Washington, DC: U.S. Department of Health and Human Services.

Adultery, Code of Alabama §13A-13-2.

Alagiakrishnan, K., Lim, D., Brahim, A., Wong, A., Wood, A., Senthilselvan, A.,…Kagan, L. (2005). Sexually inappropriate behaviour in demented elderly people. *Postgraduate Medical Journal, 81,* 463–466.

Allen, R. S., Petro, K. N., & Phillips, L. L. (2009). Factors influencing young adults' attitudes and knowledge of late-life sexuality among older women. *Aging and Mental Health, 13,* 238-245.

Alzenberg, D., Welzman, A., & Barak, Y. (2002). Attitudes toward sexuality among nursing home residents. *Sexuality and Disability, 20,* 185-189.

Alzheimer's Association (2011). *Generation Alzheimer's: The defining disease of the baby boomers.* Retrieved from http://www.act.alz.org/site/DocServer/ALZ_ Boomers Report.pdf?docID=521

Alzheimer's Association (2014). 2014 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia, 10*(2), 1-75.

Alzheimer's Association. (2015a). *Special care units.* Retrieved from http://www.alz.org/join_the_cause_special_care_units.asp

Alzheimer's Association. (2015b). T*ypes of dementia.* Retrieved from http://www.alz.org/dementia/types-of-dementia.asp

Alzheimer's Society. (2013). *Sex and dementia.* London, England: Author.

American Medical Directors Association. (2013). Elder care sex survey finds caregivers seeking more training. *American Medical Directors Association.* Retrieved November 15, 2013 from http://www.amda.com/news/Bloomberg_ infographic.pdf

Archibald, C. (1998). Sexuality, dementia, and residential care: Manager's report and response. *Health and Social Care in the Community, 6,* 95-101.

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy, 17*(3), 289-299. doi:10.1080/14681990220149095

Bauer, M., McAuliffe, L., Nay, R., & Chenco, C. (2013). Sexuality in older adults: effects of an education intervention on attitudes and beliefs of residential aged care staff. *Educational Gerontology, 39,* 82-91.

Boss, P. G. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge, MA: Harvard University Press.

Bouman, W. P., Arcelus, J., & Benbow, S. M. (2007). Nottingham Study of Sexuality and Ageing (NoSSA II). Attitudes of care staff regarding sexuality and residents: A study in residential and nursing homes. *Sexual and Relationship Therapy, 22,* 45-61.

Braun, M., Mura, K., Peter-Wight, M., Hornung, R., & Scholz, U. (2010). Toward a better understanding of psychological well-being in dementia caregivers: The link between marital communication and depression. *Family Process, 49*(2), 185-203.

Bretherton, I. (1993). Theoretical contributions from developmental psychology. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.).

Sourcebook of Family Theories and Methods: A Contextual Approach. New York, NY: Springer.

Bronfenbrenner, U. (1979). *The ecology of human development.* Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1989). Ecological systems theory. In R. Vasta (Ed.), *Annals of Child Development* (197-249). Greenwich, CT: JAI Press.

Bronfenbrenner, U. (1995). Developmental ecology through space and time: a future perspective. In P. Moen, G. H. Elder, Jr., & K. Luscher (Eds.), *Examining lives in context: Perspectives on the ecology of human development* (p.619-647). Washington, DC: American Psychological Association.

Bronfenbrenner, U., & Crouter, A. (1982). Work and family through time and space. In S. B. Kamerman & C. D. Hayes (Eds.), *Families that work: Children in a changing world* (39-83). Washington, D. C.: National Academy Press.

Bronfenbrenner, U., & Crouter, A. (1983) The evaluation of environmental models in developmental research. In P. H. Mussen (Ed.), *Handbook of Child Psychology: Vol I. History, Theory and Methods* (W. Kessen, vol. Ed., 357-414). New York, NY: Wiley.

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner, & W. Damon (Eds.). *Handbook of Child Psychology* (6th ed.). Hoboken, NJ: John Wiley & Sons, Inc.

Bullard-Poe, L., Powell, C., & Mulligan, T. (1994). The importance of intimacy to men living in a nursing home. *Archives of Sexual Behavior, 23,* 231-236.

Burgess, E. O. (2004). Sexuality in midlife and later life couples. In J. Harvey, A. Wenzel, & S. Sprecher (Eds.), *The handbook of sexuality in close relationships* (p. 437-454). Mahwah, NJ: Erlbaum.

Button, J., & Panosh, A. (n.d.) *Sexuality and Intimacy in Long Term Care Facilities.* Retrieved from http://www.ltcombudsman.org/sites/default/files/norc/sexuality-presentation-2nd-addition_0.pdf

Calkins, K. (1972). Shouldering a burden. *Omega, 3,* 23-36.

Carr, D. (2004). The desire to date and remarry among older widows and widowers. *Journal of Marriage and Family, 66,* 1051-1068.

Centers for Medicare and Medicaid Services. (2014). *Skilled Nursing Facility Care.* Retrieved from http://www.medicare.gov/coverage/skilled-nursing-facility-care.html

Chang, L., & Krosnick, J. A. (2009). National surveys via RDD telephone interviewing versus the internet comparing sample representativeness and response quality. *Public Opinion Quarterly, 73,* 641-678.

Christie, D., Botham, L., Gilbert, S., Hall, B., Latner, L., Luchsinger, G.,…Treen, B. (2002). *Intimacy, sexuality and sexual behaviour in dementia: How to develop practice guidelines and policy for long term care facilities.* Retrieved from http://www.piecescanada.com/pdf/Resources%20-%20Sexuality.pdf

Clay, R. A. (2012). Sex in long-term care. *Monitor on Psychology, 43,* 44.

Cornelison, L. J., & Doll, G. M. (2012). Management of sexual expression in long-term care: Ombudsmen's perspectives. *The Gerontologist, 53,* 780-789.

Davies, H. D., Newkirk, L. A., Pitts, C. B., Coughlin, C. A., Sridhar, S. B., Zeiss, L. M., & Zeiss, A. M. (2010). The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships. *International Psychogeriatrics, 22*, 618-628.

Davies, H. D., Sridhar, S. B., Newkirk, L. A., Beaudreau, S. A., & O'Hara, R. (2012). Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being. *Aging & Mental Health, 16*, 89-101.

De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I.,…Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry, 18*(2), 149-154. doi:10.1002/gps.807

DeLamater, J., & Moorman, S. M. (2007). Sexual behavior in later life. *Journal of Aging and Health, 19,* 921-945.

Di Napoli, E. A., Breland, G. L., & Allen, R. S. (2013). Staff knowledge and perceptions of sexuality and dementia of older adults in nursing homes. *Journal of Aging and Health, 25,* 1087-1105.

Doll, G. A. (2012). *Sexuality and long-term care: Understanding and supporting the needs of older adults.* Baltimore, Maryland: Health Professions Press, Inc.

Doll, G. M. (2013). Sexuality in nursing homes: Practice and policy. *Journal of Gerontological Nursing, 39,* 30-37. doi:10.3928/00989134-20130418-01

Ehrenfeld, M., Bronner, G., Tabak, N., Alpert, R., & Bergman, R. (1999). Sexuality among institutionalized elderly patients with dementia. *Nursing Ethics, 6,* 144-149.

Elder, G. H. (1998). The life course as a developmental theory. *Child Development, 69*(1), 1-12.

Elder, G. H., & Shanahan, M. J. (2006). The life course and human development. In R. M. Lerner, & W. Damon (Eds.). *Handbook of Child Psychology* (6th ed.). Hoboken, NJ: John Wiley & Sons, Inc.

Elias, J., & Ryan, A. (2011). A review and commentary on the factors that influence expressions of sexual by older people in care homes. *Journal of Clinical Nursing, 20,* 1668-1676.

Esterle, M., Sastre, M. T. M., & Mullet, E. (2011). Acceptability of sexual relationships between elderly people residing in nursing homes. *Sexuality and Disability, 29,* 157-164.

Evans, D., & Lee, E. (2013). Impact of dementia on marriage: A qualitative systematic review. *Dementia, 13,* 330-349.

Foster, J. (2011, November 9). The vicar who has found love as his wife fights dementia: Selfish betrayal or a very human response to a cruel dilemma? *The Daily Mail.* Retrieved from http://www.dailymail.co.uk/femail/article-2059162/Vicar-finds-love-new-lover-wife-fights-dementia.html

Fox-Grage, W., & Walls, J. (2013). *State studies find home and community-based services to be cost-effective.* Washington, DC: AARP Public Policy Institute.

Frankowski, A. C. & Clark, L. J. (2009). Sexuality and intimacy in assisted living: Residents' perspectives and experiences. *Sexuality Research & Social Policy, 6,* 25-37.

Fujihara, S., Brucki, S. M. D., Rocha, M. S. G., Carvalho, A. A., & Piccolo, A. C. (2004). Prevalence of presenile dementia in a tertiary outpatient clinic. *Arquivos de Neuro-Psiquiatria, 62*(3A), 592-595.

Gadoua, S. P. (2010, November 7). Dating someone while married to a spouse with Alzheimer's disease. *Psychology Today*. Retrieved from http://www.psychologytoday.com/blog/ contemplating-divorce/201011/dating-someone-while-married-spouse-alzheimer-s-disease

Ganong, L. H., & Coleman, M. (2006). Multiple segment factorial designs. *Journal of Marriage and Family, 68,* 455-468.

Garre-Olmo, J., Genis, B. D., del Mar Fernandez, M., Marquez, D. F., de Eugenio, H. R., Casadevall, T.,…Registry of Dementia of Girona Study Group (2010). Incidence and subtypes of early-onset dementia in a geographically defined general population. *Neurology, 75*(14), 1249-1255. doi:10.1212/WNL.0b013e3181f5d4c4

Ginsberg, T. B., Pomerantz, S. C., & Kramer-Feeley, V. (2005). Sexuality in older adults: Behaviours and preferences. *Age and Ageing, 34,* 475-480.

Gott, M. & Hinchliff, S. (2003). How important is sex in later life? The views of older people. *Social Science & Medicine 56,* 1617-1628.

Gott, M. (2005). *Sexuality, sexual health and ageing*. Maidenhead, Berkshire, UK: Open University Press.

Hajjar, R., & Kamel, H. (2003). Sexuality in the nursing home, part 1: Attitudes and barriers to sexual expression. *Journal of the American Medical Directors Association, 4,* 152-156.

Harris, P. B. (2009). Intimacy, sexuality, and early-stage dementia: The changing marital relationship. *Alzheimer's Care Today, 10,* 63-77.

Hebrew Home at Riverdale. (2011). *Abuse or intimacy: older adult sexuality.* Riverdale, NY: Author.

Hebrew Home at Riverdale. (2013). *Policies and procedures concerning sexual expression at the Hebrew Home at Riverdale.* Riverdale, NY: Author.

Heron, J., & Taylor, S. (2009). Nurse manager perceptions regarding sexual intimacy rights of aged care residents: An exploratory Queensland study. *Practice Reflexions, 4,* 16-25.

Hubbard, G., Tester, S., & Downs, M. (2003). Meaningful social interactions in institutional care settings for older people. *Ageing and Society, 23,* 1-16.

Kamel, H. K., & Hajjar, R. R. (2004). Sexuality in the nursing home, part 2: Managing abnormal behavior—Legal and ethical issues. *Journal of the American Medical Directors Association, 5,* S48–S52.

Katz, A. (2013). Sexuality in nursing care facilities: A personal choice or problem? *The American Journal of Nursing, 113*(3), 53-55.

Keeter, S., Christian, L., & Dimock, M. (2010). *The growing gap between landline and dual frame election polls.* Retrieved from http://www.pewresearch.org/2010/11/22/the-growing-gap-between-landline-and-dual-frame-election-polls/

Kentucky Cabinet for Health and Family Services. (2014). *Long-Term Care Directory December 2014* [Data file]. Retrieved from http://chfs.ky.gov/os/oig/directories.htm

Kentucky Protection and Advocacy. (2011). *Personal Care Homes in Kentucky.* Frankfort, KY: Author.

Kentucky State Long-Term Care Ombudsman (2014). Residents' rights for residents in Kentucky long-term care facilities. Frankfort, KY: Author.

Kubler-Ross, E. (1969). *On death and dying.* New York, NY: Touchstone.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33,* 159-174.

Lennox, R., & Davidson, G. (2013). Sexuality and dementia: Law, policy, and practice. *Practice: Social Work in Action, 25,* 21-39.

Lindau, S. T., Schumm, L. P., Laumann, E. O., Levinson, W., O'Muircheartaigh, C. A., & Waite, L. J. (2007). A study of sexuality and health among older adults in the United States. *New England Journal of Medicine, 357,* 762-774.

Loue, S. (2005). Intimacy and institutionalized cognitive impaired elderly. *Care Management Journals, 6,* 185–190.

Mahieu, L., Van Elssen, K., & Gastmans, C. (2011). Nurses' perceptions of sexuality in institutionalized elderly: A literature review. *International Journal of Nursing Studies, 48,* 1140-1154.

Mundy, A. (2009, November 3). Of love and Alzheimer's: When caregivers find new companions, is it adultery? *The Wall Street Journal.* Retrieved from http://online.wsj.com/news/articles/SB10001424052748704317704574503631569278424

National Long-Term Care Ombudsman Resource Center. (2013). *Culture change.* Retrieved from http://www.ltcombudsman.org/issues/culture-change

Oregon Long-Term Care Ombudsman. (2013). *Thinking outside the box (of wine): Alcohol use in long-term care facilities.* Retrieved from http://www.ltcombudsman.org/ sites/default/files/norc/or-presentation.pdf

Parker-Pope, T. (2007, November 14). Seized by Alzheimer's, then love. *The New York Times.* Retrieved from http://well.blogs.nytimes.com/2007/11/14/seized-by-alzheimers-then-love/?ref=weekinreview

Parker-Pope, T. (2011, September 16). Love, divorce, and Alzheimer's. *The New York Times.* Retrieved from http://well.blogs.nytimes.com/2011/09/16/love-divorce-and-alzheimers/?_php=true&_type=blogs&_r=0

Park-Lee, E., Sengupta, M., & Harris-Kojetin, L. D. (2013). Dementia special care units in residential care communities: United States, 2010. NCHS data brief, no 134. Hyattsville, MD: National Center for Health Statistics.

Pew Research Center. (2010). *Baby boomers retire*. Washington, DC: Author.

Pew Research Center. (2012). *Assessing the representativeness of public opinion surveys*. Washington, DC: Author.

Pew Research Center. (2015). *Random digit dialing – Our standard method.* Retrieved from http://www.people-press.org/methodology/sampling/random-digit-dialing-our-standard-method/

Pioneer Network (n.d.) *What is culture change?* Retrieved from https://www.pioneernetwork.net/CultureChange/

Post, S.G. (2000) Commentary on Sexuality and intimacy in the nursing home. *Journal of Clinical Ethics. 11,* 314-317.

Ramnarace, C. (2010, September 13). Till dementia do us part? *AARP Bulletin.* Retrieved from http://www.aarp.org/relationships/love-sex/info-09-2010/till_dementia_do_us_part.html

Reingold, D., & Burros, N. (2004). Sexuality in the nursing home. *Journal of Gerontological Social Work, 42,* 175-186.

Reisberg, B., Ferris, S. H., de Leon, M.J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139,* 1136-1139.

Rheaume, C., & Mitty, E. (2008). Sexuality and intimacy in older adults. *Geriatric Nursing, 29,* 342-349.

Rosow, I. (1974). *Socialisation to old age.* Berkeley and Los Angeles, CA: University of California Press.

Shuttleworth, R., Russell, C., Weerakoon, P., & Dune, T. (2010). Sexuality in residential aged care: A survey of perceptions and policies in Australian nursing homes. *Sexual Disabilities, 28,* 187-194.

Smith, S. R., Hamon, R. R., Ingoldsby, B. B., & Miller, J. E. (2009). *Exploring family theories* (2nd ed.). New York, NY: Oxford University Press.

Spillman, B. C., & Lubitz, J. (2002). New estimates of lifetime nursing home use: Have patterns changed? *Medical Care, 40,* 965-975.

Steele, D. (2012). Intimacy and sexuality in long-term care. A guide to practice: resource tools for assessment, response, and documentation. Retrieved from https://www.nccdp.org/SexualityPracticeGuidelinesLLGDraft.doc

Stimson, S. (2011). *Sexuality and intimacy: A guide for dementia patients in long term care and home care setting* [PowerPoint slides]. Retrieved from http://www.capcog.org/documents/Aging/Ombudsman /ContinuingEdu/DementiaSexualityandIntimacy.pdf

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness, 19,* 93-117.

Tabak, N., & Shemesh-Kigli, R. (2006). Sexuality and Alzheimer's disease: Can the two go together? *Nursing Forum, 41,* 158–166.

Tenenbaum, E. M. (2009). To be or to exist: standards for deciding whether dementia patients in nursing homes should engage in intimacy, sex and adultery. *Indiana Law Review, 49,* 675-720.

The Green House Project. (2014). *Evaluating The Green House® model.* Retrieved from http://thegreenhouseproject.org/doc/27/about-evaluation.pdf

Thompson, W. K., Charo, L., Vahia, I. V., Depp, C., Allison, M., & Jeste, D. V. (2011). Association between higher levels of sexual function, activity, and satisfaction and self-rated successful aging in older postmenopausal women. *Journal of the American Geriatrics Society, 59,* 1503-1508.

Thornton, A. & Young-DeMarco, L. (2001). Four decades of trends in attitudes toward family issues in the United States: The 1960s through the 1990s. *Journal of Marriage and the Family, 63,* 1009-1037.

Tzeng, Y. L., Lin, L. C., Shyr, Y. I. L., & Wen, J. K. (2009). Sexual behaviour of institutionalized residents with dementia – a qualitative study. *Journal of Clinical Nursing, 18,* 991-1001. doi:10.1111/j.1365-2702.2008.02708.x

Unlawfully procuring a marriage license, bigamy, adultery: defense, New York Penal Law, §255.20.

Vieira, R. T., Caixeta, L., Machado, S., Silva, A. C., Nardi, A. E., Carrion, O. A., & Mauro, G. C. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical Practice & Epidemiology in Mental Health, 9,* 88-95. doi:10.2174/1745017901309010088

Walker, B. L., & Harrington, D. (2002). Effects of staff training on staff knowledge and attitudes about sexuality. *Educational Gerontology, 26,* 639-654.

White, M. C. (2009). The eternal flame: Capacity to consent to sexual behavior among nursing home residents with dementia. *The Elder Law Journal, 18,* 133-158.

Yelland, E. L., Hosier, A., & Hans, J. D. (2014). *Attitudes of older adults toward sexual behavior in long-term care facilities.* Unpublished manuscript, Department of Family Sciences, University of Kentucky, Lexington, Kentucky.

Yelland, E. L., Hosier, A., & Werner-Wilson, R. (2015). *Attitudes toward sexual expression in long-term care.* Manuscript submitted for publication. Department of Family Sciences, University of Kentucky, Lexington, Kentucky.

Zeiss, A. M. & Kasl-Godley, J. (2001). Sexuality in older adults' relationships. G*enerations, 25*(2), 18-25.

Erin L. Yelland

EDUCATION

Graduate Certificate in Gerontology	University of Kentucky Lexington, Kentucky December, 2012
Bachelor of Science	YOUTH, ADULT, AND FAMILY SERVICES Minor: Organizational Leadership and Supervision Purdue University West Lafayette, Indiana May, 2010

RESEARCH EXPERIENCE

PUBLICATIONS

Hans, J. D., & **Yelland, E. L.** (2013). Posthumous sperm retrieval for cryopreservation and reproduction: Attitudes in context. *Journal of Clinical Research & Bioethics, S1: 008*. doi:10.417:10.4172/2155-9627

MANUSCRIPTS UNDER REVIEW

Yelland, E. L. Hosier, A. F., & Werner-Wilson, R. J. (2015). Public Attitudes Toward Sexual Expression in Long-Term Care: Does Context Matter? Accepted to *Journal of Applied Gerontology*. February, 2015.

MANUSCRIPTS NEARING COMPLETION

Frey, L. M., **Yelland, E. L.**, & Hans, J. D. (2013). Attitudes toward assisted suicide among older adults.

Hans, J. D., & **Yelland, E. L.** (2013). Abortion attitudes: How much does context matter?

Yelland, E. L., Hosier, A. & Hans, J. (2014). Attitudes of older adults toward sexual behavior in long-term care facilities.

EXTENSION PUBLICATIONS

Hosier, A., Traywick, L. S., & **Yelland, E. L.** (2015). *Keys to embracing aging: Attitude is everything…be positive.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., Traywick, L. S., & **Yelland, E. L.** (2015). *Keys to embracing aging 101.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Brain activity.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Eating smart and healthy.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Social activity.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Tuning into the times.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Know your health numbers.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Hosier, A., **Yelland, E. L.**, & Traywick, L. S. (2015). *Keys to embracing aging: Taking time for you.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Powell, E. L., & Hosier, A. (2011). *Sexual health in young adulthood: Protecting yourself from sexually transmitted infections (STIs)* (FCS7-197). Lexington: University of Kentucky Cooperative Extension Service.

Traywick, L. S., Hosier, A., & **Yelland, E. L.** (2015). *Keys to embracing aging: Physical activity.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Traywick, L. S., Hosier, A., & **Yelland, E. L.** (2015). *Keys to embracing aging: Practice being safe.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Traywick, L. S., Hosier, A., & **Yelland, E. L.** (2015). *Keys to embracing aging: Stress management.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Traywick, L. S., Hosier, A., & **Yelland, E. L.** (2015). *Keys to embracing aging: Sleep.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Traywick, L. S., Hosier, A., Connerly, L., & **Yelland, E. L.** (2015). *Keys to embracing aging: Financial affairs.* (FCS778-3-2015). Fayetteville: University of Arkansas Cooperative Extension Service.

Yelland, E. L., & Hosier, A. (2012). *Talking with your child about sexuality*. (FCS7-207). Lexington: University of Kentucky Cooperative Extension Service.

<u>EXTENSION PUBLICATIONS UNDER REVIEW</u>

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Collecting your important documents.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Planning ahead.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: What you should know about wills.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Ethical wills.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Pre-planning a funeral.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: A guide to probate.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Obtaining survivor's benefits.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Reworking personal finances.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Independently managing a household.

Flashman, R. H., Setari, R.R., & **Yelland, E. L.** Living with loss: Care of treasured objects.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Accepting the reality of your own death.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Anticipatory grief.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Death of a child.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Experiencing the loss of a friend.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Expressing kindness during grief.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Parental death.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Sibling death.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Spousal death.

Hosier, A., **Yelland, E. L.**, & Taul, J. Living with loss: Tips for friends of those dealing with loss.

Yelland, E. L. Living with loss: Death of a pet.

Yelland, E. L. Living with loss: HIV and AIDS: The grief process.

Yelland, E. L. Living with loss: How the dying react to death.

Yelland, E. L. Living with loss: Making sensitive end of life decisions.

Yelland, E. L. Living with loss: Suicide.

Yelland, E. L. Living with loss: The death experience.

Yelland, E. L. Living with loss: Violent death.

EXTENSION PROGRAMS AND CURRICULUMS

Hosier, A., & **Yelland, E. L.** *Living with loss.* Under review.

Hosier, A., Traywick, L. & **Yelland E. L.** (2015). *Keys to Embracing Aging.* Fayetteville: University of Arkansas Cooperative Extension Service.

CONFERENCE PRESENTATIONS

Powell, E. L. (2011, November). *Sexuality in aging adults from a biosocial perspective: A literature review.* Poster presented at the National Council on Family Relations Annual Conference. Orlando, FL.

Yelland, E. L., Hans, J. D., & Norman, J. L. (2012, November). Posthumous sperm retrieval for cryopreservation and reproduction: Attitudes in context. Poster presented at the National Council on Family Relations Annual Conference. Phoenix, AZ.

Frey, L., **Yelland, E. L.,** & Hans, J. D. (2013, November). Attitudes toward assisted suicide among older adults. Poster presented at the National Council on Family Relations Annual Conference. San Antonio, TX.

Westmoreland, A., **Yelland, E. L.,** & Hans, J. D. (2013, November). Sex in the nursing home: Does context matter? Poster presented at the National Council on Family Relations Annual Conference. San Antonio, TX.

Yelland, E. L., & Hans, J. D. (2013, November). Let's talk about sex…maybe? Studying sexuality among older adults. Poster presented at the National Council on Family Relations Annual Conference. San Antonio, TX.

GRANTS

Powell, E. L. (2011). Travel grant to present at the National Council on Family Relations Conference, Orlando, FL. *The Graduate School, University of Kentucky,* $400.

SERVICE AND RECOGNITION

REVIEWER SERVICE

Student Reviewer, *Family Relations* (2012-present)

Annual Conference Proposal Reviewer, *National Council on Family Relations* (2011-present)

SCHOLASTIC & PROFESSIONAL HONORS

Donovan Scholarship in Gerontology, 2012-2013

PROFESSIONAL AFFILIATIONS

National Council on Family Relations, 2009- Present

COMMITTEE EXPERIENCE

Family Action Council, University of Kentucky, 2010-Present

Consumer and Family Sciences Grade Appeals Board, Member, Purdue University, 2009-2010