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#### Adult Children as Possible Barriers to Parental Sexuality in Nursing Homes:

A Literature Review

BY

Crystal D. Wanek

#### **THESIS**

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

Master of Arts in Clinical Psychology

IN THE GRADUATE SCHOOL, EASTERN ILLINOIS UNIVERSITY CHARLESTON, ILLINOIS

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I HEREBY RECOMMEND THIS THESIS BE ACCEPTED AS FULFILLING THIS PART OF THE GRADUATE DEGREE CITED ABOVE

Sexuality in nursing homes ii

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#### Abstract

Sexual interest and activity continue across the entire lifespan, but multiple barriers make sexual behavior difficult for those in nursing homes. With increases in nursing home populations occurring during the last three decades, the anticipation of the baby boomers entering retirement and beginning to enter nursing homes over the next 10 to 30 years suggests that more knowledge is needed to assist nursing homes with making policies that are protective and reverential of sexuality. This literature review seeks to take a comprehensive look at the issue of sexuality for the elderly in nursing homes and identify whether adult children serve as one of the many barriers to elderly parents' sexual expressions. In the process of the literature review, it will become apparent that studies have already confirmed that institutional, physiological, psychological, and social barriers exist towards sexuality in nursing homes. Unfortunately, research findings specific to adult children's attitudes, behaviors, and roles regarding their parents' sexuality in nursing homes is lacking. Therefore, this review concludes and makes suggestions of how future research can assess the attitudes, behaviors, and roles of adult children and their parents in nursing homes more thoroughly. It is hoped that the suggestions made will serve as a guide, so that future research will lead to improved relationships among nursing home staff, residents, and adult children of the residents, and to the development of nursing home policies that will safely allow more sexual freedom to residents.

#### Dedication

I am thankful for the support that my husband, Brett Anderson, and thesis committee have provided me throughout this process. Brett's love, encouragement, and urgings to complete this project were instrumental to the process. Dr. Caridad Brito was patient, kind, and knowledgeable during every aspect of the creation and completion of this thesis. Dr. Sharma and Dr. Snyder's belief in this project and support of it, despite the IRB's reservations, reassured me that putting this information out there is purposeful. Finally, my parents, brothers, sister-in-law, and friends all assisted in helping me to believe that I could complete this thesis and supported me along the way. From my heart, thanks to all of you.

#### Acknowledgements

The foundation for this project began when I was an undergraduate working as a pharmacy technician. The interactions that I had with elderly individuals opened my eyes to an older generation who sometimes lost their voice. Perhaps the outspoken gravitate towards taboo topics, but I tend to think positively and suggest that I advocate for others when they cannot or do not know how. I want to acknowledge the research of Charles White and all the others who dare to ask about sex in the nursing home. Thank you, again, to my committee for giving me this opportunity to address a barrier that not many wish to speak about.

#### Table of Contents

Title Page	p. i
Copyright page	p. ii
Abstract	p. iii
Dedication	p. iv
Acknowledgements	p. v
Table of Contents	p. vi
Chapter I	p. 1
Definition of Terms.	p. 4
Chapter II	p. 5
Section I- Sexual Ac	tivity across the Lifespanp. 5
Section II- Barriers t	o Sexual Activity in Late Lifep. 8
The Aging Body, Se	xual Response Cycle, and Other Physiological Changesp. 8
Psychologica	ıl Barriersp. 10
Social Barrie	rsp. 12
When Menta	l and Physical Barriers Meet Social Barriersp. 13
Section III- Attitudes	s toward Sexual Activity in the Elderly and Resulting
Sexual Behaviors	p. 13
Students and	/or Young People's Attitudesp. 13
Staff Attitude	esp. 14
Older Adult A	Attitudes on Sex in Nursing Homesp. 15
Family Mem	bers' Attitudes, Nursing Homes Responses, and the
Paucity of Re	esearch Supportp. 18

#### Sexuality in nursing homes vii

Chapter III					p. 2	
				search		
References	·····	is and the			p. 27	

#### Chapter I

Sexuality does not simply end when adults become "old." In fact, most people express sexual interest and engage in sexual activities across the entire lifespan (Gussaroff, 1998; Kaplan, 1990; Masters & Johnson, 1966). Carroll and Wolpe (1996) helped to clarify the definition of sexual behavior as any form of intimacy which may either be motivated by a desire to reproduce or taking pleasure in sexual gratification. The general term of sexuality may simply represent the feelings and behaviors of a person concerning sex. Age appears to change the expression of sexuality and it has been suggested that older people define and express their sexuality in varied ways from younger cohorts (Starr & Weiner, 1981). Studies looking at cognitive functioning in later life (Payne, LaPorte, Deber, & Coyte, 2007; Small & Baackman, 1999) suggest that there is a relationship between cognitive decline and end of life, but supports no specific age at which decline occurs and suggests that elderly clients may maintain their cognitive functioning across most, if not all, of their life. Since intimacy may be considered more brain than body, such positive information about continued functioning in late life adds credence to the idea that sexuality does not cease when one becomes "old." Looking closely, one may see that the terms "late life" and "elderly" have been defined as applying to individuals at or over the age of retirement, age 65. Interestingly, however, the growing population of people over ages 70, 80, and 90 in the United States population means that this late life period refers to a cohort that spans over 30 years. Thus, not only one cohort is being referred to, as this group can include both parents and their children. This suggests that two generations of the same family may be facing quite similar challenges when it comes to late life sexuality (Sharpe, 2006). Additionally, this suggests

that the age ranges for adult children of nursing home clients might be quite diverse, with ranges beginning around age 30 and ending at over age 70. With such a large age range, it is a possibility that both parents and adult children may require nursing care. This literature review will focus on attitudes and behaviors that adult children have with respects to their parents in *nursing homes* and will generally define the term as residential facilities where people live due to disability or illness.

Sexual activity in nursing homes brings up many questions and concerns. Understanding the role that adult children of elderly nursing home patients play with respect to their parents' sexuality, and understanding the attitudes and behaviors of adult children concerning their own sexuality is very important for several reasons. First, the increase in life expectancy and the anticipation of the baby boomers entering into retirement and then nursing homes in higher numbers during the next 10 to 30 years has sparked many questions concerning sexuality in elderly clients. The increase in the nursing home population may be seen when comparing the 1.28 million residents in nursing homes in 1977 to the 1.63 million in 1999, a growth of 27 percent (Decker, 2005). Additionally, interest in geriatric sexuality research has been renewed by the introduction of medications that treat sexual dysfunctions (Hillman, 2000; Waltz, 2002) and concerns about the possibility of sexually transmitted infections (STIs) increasing in the elderly population (Hillman & Stricker, 1998). Although a recent British metaanalysis, which included American research, suggested increasingly positive attitudes toward sexuality in older adults (Bouman, Arcelus, & Benbow, 2006), literature regarding historical attitudes revealed that elderly sexuality has been seen negatively (Covey, 1989; Hillman, 2000). With this information in mind, nursing homes are trying

to make policy changes that are protective and reverential of their approximately 1.6 million clients, as of 2003, and in anticipation of the additional baby boomer clients (Johnson & Scelfo, 2004). Information gathered by this literature review concerning the attitudes and behaviors of adult children toward their parents' sexuality in nursing homes and their own sexuality may be very useful as nursing homes make structural changes. Specifically, this review will provide foundational information concerning parental and child relationships and suggest that adult children may fulfill different roles, such as barriers, supporters, or neutral observers, to the care that is provided to their elderly parent(s) regarding sexuality in nursing homes.

The possible roles that adult children of nursing home residents play is an understudied area of research and specific future research questions will be suggested. Several subsidiary areas of research knowledge will be investigated first, to provide a sufficient foundation for the hypotheses that can be posited and questions that were generated. These areas of knowledge will be elucidated in a series of sections. Section one will begin the literature review with an examination of the redefinition and continuation of sex across the lifespan. Section one is simply meant to be informative and reveal that elderly individuals in and out of nursing homes are generally interested and engage in sexual activities, however varied, until the end of life. The second section will continue the literature review by providing foundational information on physiological, psychological, and social barriers to late life sexuality. The second section is very important, since social factors play a large role in the attitudes and behaviors of staff, adult children, and their parents which affect the expression of sexual behaviors in nursing homes. The third section will look more intensively at attitudes towards sexual

activity in the elderly. This section also focuses on adult children possibly serving a role as barriers to parental sexuality. The state of the research will suggest that nursing home staff give credence to the adult children's negative attitudes towards parental sexuality over the parents' desires (Burnside, 1973; Wallace, 1992) and that a "lack of geriatric sexual education among nursing home staff and family members often results in a negative attitude toward sexual behaviors expressed by residents" (Hajjar & Kamel, 2003, p. 154). The fourth and final section of this review will consist of information specifically pertaining to prior foundational studies and presenting the state of combined knowledge and suggestions for research. This literature review will gather information and make suggestions regarding further research that needs to be done and questions that need to be addressed.

#### Definition of Terms

Throughout this literature review there will be several terms that are used similarly. As reported above, *sexual behavior* will be used to describe any form of intimacy which may either be motivated by a desire to reproduce or taking pleasure in sexual gratification. The general term of *sexuality* will be used similarly, but will more simply represent the feelings and behaviors of a person concerning sex. The terms *elderly* and *older adult* will be used interchangeably to mean adults at or over the age of 65. Similarly, the terms *nursing home* and *long term care facility* will be generally defined as residential facilities where people live due to disability or illness.

#### Chapter II

#### Section I- Sexual Activity across the Lifespan

Sexual activity continues and changes across the lifespan. Mulligan and Pulguta (1991) found that although the majority of the 61 men ages 41 to 100 years old in their study, both subjects with and subjects without partners, preferred vaginal intercourse, 21% of the sample also favored caressing and hugging, 5% favored kissing, and 2% favored masturbation. Hinchliff and Gott's (2004) study of married adults ages 50 to 86 living in the United Kingdom, helps us to understand these results by identifying that the redefinition of "sex" for long-term (i.e., 20 years or more) marriages was highly based upon different types of physical intimacies (i.e., touching, hugging, and fondling) when intercourse was no longer possible or desirable. Although a decline in sexual intercourse with age has been shown to occur for both sexes (Edwards & Booth, 1976; Keller, Eakes, Hinkle, & Hughston, 1978; Palmore, 1981) researchers should be more careful when drawing conclusions about the sexual interest and practices of women, as their behaviors often depend upon access to and the interest of male partners (Pfeiffer, Verwoedt, & Davis, 1972). The United States Census Bureau gathered statistics in 2002 using noninstitutionalized participants and reported that the gender imbalance of more women to men increases steadily as the genders age past 55 years old. Between ages 55 to 64, the imbalance reveals 94 men for every 100 women. Steadily the discrepancy grows until 46 men for every 100 women exists among participants 85 years and older (Smith, 2003). This gender imbalance is likely to increase with the baby boom generation, as they are living even longer than prior generations.

The baby boom generation consists of those born between 1946 and 1964, so members from this generation began entering into adulthood in the 1960's during the sexual revolution. The size and changes in social ideologies of this generation has and is continuing to change the sexual climate of the United States, as they move through middle age and enter later life. Katz and Marshall (2003) discuss the consumer society that the United States has become and point out that people of the aging baby boomer generation are being sold products based upon ideas that suggest sexual dysfunction is an unnatural process. Products like Viagra and other sex linked bodily rejuvenating products are now being marketed to the aging audience. It is no wonder that such products are being marketed to older generations, when a Sexuality Education and Information Council of the United States (SEICUS) "Fact Sheet" for 2004 compiled surveys done by organizations such as the Association of Reproductive Health Professionals (ARHP) from 1999 and the National Council on Aging (NCOA) from 1998 reveals that sixty to eighty year old adults are still maintaining enjoyable sex lives. The ARHP Sexual Activity Survey (1999) reported that, of people 60-69 years of age, 52% of men and 9% of women considered themselves "sexually active." Of individuals 70 years and older surveyed, 36% of men and 18% of women considered themselves "sexually active" (Sexuality Education and Information Council of the United States [SEICUS], 2004). Not only does this statistic reveal a drastic gender difference for those defining themselves as "sexually active", but it also reveals an odd discrepancy between the female age groups; wherein the older women (i.e., those 70 years and older) reported being 2 times more sexually active than 60-69 year old women. Several alternative explanations are possible: perhaps the weighing of variables such as gender and age caused unequal numbers of individuals

in the 60-69 and 70+ groups resulting in the skewed outcomes; perhaps the populations studied in the national sample were quite different; perhaps trends in sexual beliefs varied across age groups; or perhaps the older group of women were more comfortable admitting to their sexual activity. Whatever the case, the difference is quite interesting and very different from the number of individuals that reported having sexual intercourse during the Starr and Weiner (1981) study of 800 participants aged 60 to 91. Of those individuals who reported on the frequency of their sexual relations, 60% of women and 86% of men reported sexual relations that were placed in 8 different frequency categories which varied from "when in the mood," "three times a week or more," to "less than once a month" (Starr & Weiner, 1981). Unfortunately, the number of "No Response," were not included on the table that divided the frequencies of sexual activities into age classes, so only how many of those reporting a frequency of sexual relations or no relations is available. Looking at the statistics very basically, one will notice that 83% of the 60-69 year old age group, 73% of the 70-79 year old age group, and 60% of the 80-91 year old age group reported sexual activity.

In summary, discrepancies between the SEICUS (2002) report findings that 36% of men and 18% of women 70 years or older and Starr and Weiner (1981) findings that 73% of elderly between ages 70 and 79 are sexually active or consider themselves sexually active, suggest that either more elderly adults were having sex in the 1980's, that there are large discrepancies between the populations surveyed (i.e., possibly due to societal changes across time), that discrepancies existed in the definitions of sexual activity used, or the flaws in the studies make the findings not valid. This writer posits that definitional differences in sexual activity, the differing methods used to collect data,

and the differing populations studied can explain the differences in the amounts of sexual activity reported for the two studies. At a basic level, however, the findings both show that elderly individuals are interested in sex and in having sex.

#### Section II- Barriers to Sexual Activity in Late Life

#### The Aging Body, Sexual Response Cycle, and Other Physiological Changes.

In addition to the gender imbalance, as mentioned above with reference to the continuation of sexuality across the lifespan, there are multiple physiological barriers that contribute to decreases in sexual activity in late life. These barriers include fears of sexually transmitted infections (STIs), which may be considered non-normative physiological problems. Several studies reveal that the aging body experiences many other sexually negative, but natural, changes across time (Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, & Martin, 1953; Masters & Johnson, 1966; Starr & Weiner, 1981). If one accepts that, as Kaplan's (1990) meta-analysis of other studies revealed, 70% of "healthy people" aged 70 have "sex" once a week or more often, then the continuation of sex in late life makes it important to talk about the natural changes that occur to the sexual response cycle with age.

The desire phase is affected by changes in the levels of testosterone in both aging men and women (Kaplan, 1990). Rates of men and women who suffer from lowered testosterone vary, but Kaplan (1990) reported that particularly women who surgically undergo menopause and "in approximately 15-20% of (non-surgical) postmenopausal women" testosterone levels are insufficient to maintain sexual desire (p. 191).

Additionally, males who experience a period similar to the female menopause may have decreased testosterone levels resulting in lower levels of sexual desire.

During the excitement phase, when the genitals become erect in males and lubricated in females, age related changes also occur. A loss of estrogen in females after menopause has been found to lead to vaginal atrophy and a lessened amount of lubrication, which in turn increases the incidence of physical trauma to female genitalia during sexual intercourse without additional nonsteroidal lubricants (Kaplan, 1990). Despite this finding, however, Starr and Weiner (1981) reported that few of their female respondents reported experiencing any discomfort or pain during intercourse. Males suffer, reportedly to a lesser degree, changes in the excitement phase, as their need for genital stimulation increases and erectile softening occurs with age (Wagner & Green, 1983). In healthy males with good penile circulation and blood pressure, the maintenance of penile rigidity needed to perform intercourse often exists until the end of life.

Finally, during the orgasm phase, healthy women generally maintain their ability to experience repeated orgasms across the lifespan, because their refractory period (i.e. the amount of time needed between orgasms) does not increase the way that males' refractory periods do. Males in later life cannot be stimulated to orgasm as quickly after a previous orgasm as young males. Kaplan (1990) reported that the refractory period for 17 year olds may be only a few moments, but that this period may lengthen to as much as 48 hours for 70 year olds.

Thus far the normative changes in the sexual response cycle have been reported for healthy individuals, however, geriatric women and men may suffer from a plethora of difficulties mentally, socially, and physically that disrupt their sexual functioning. For example, Haddad and Benbow (1993a; 1993b) and Benbow and Jagus (2002a; 2002b) reveal dementia to be an important disorder to consider when examining sexual problems

in late life. Camacho and Reyes-Ortiz (2005) suggest that some common disorders related to sexual dysfunction in the elderly are diabetes, depression, cardiovascular disease, and lower urinary tract symptoms. Sexually transmitted infections (STIs) are also of concern. Gott (1999) used data from the National AIDS Behavioral Study (NABS) to look at risk factors for HIV infection in participants over age 50 and found that approximately 10% of individuals sampled presented at least one risk factor for infection of HIV. For example, it was discovered that risk taking participants aged 50 and over used condoms one-sixth as often and had been tested for HIV one-fifth as often, as participants in their 20's. Unfortunately, CDC and Illinois state surveillance are not monitoring the spread of HIV/AIDS and other STIs in the elderly as closely as in other groups, which is a concern and a barrier to more effective education, monitoring, and treatment of STI transmission among the elderly in general and aged nursing home clients, in particular. The lack of this monitoring may be due to focus on younger groups, which have higher rates of contracting HIV/AIDS and STIs. Prevailing social attitudes that stigmatize and make sexual activity in older adults taboo may also play a role in the lack of surveillance.

Psychological Barriers. Dementia is highly prevalent among nursing home residents and serves as an important barrier to sexual behavior. Jorm (1990) reported that the prevalence of dementia in the elderly ranges from 2% in people ages 65 to 69 and upwards to 40% in those aged 90 and older. Haddad and Benbow (1993a, 1993b) suggest that sexuality for individuals and/or partners with dementia bring to bear many difficult ethical questions and dilemmas for care providers, family members, and partners of the demented individual. Denial of patient sexuality when the patient has dementia may

simply serve to protect the patients and care facility from lawsuits. Even though the federal law Omnibus Budget Reconciliation Act of 1987 (Turnham, 2001) requires nursing homes to allow choice in activities to nursing home residents and the residents have rights to privacy, nursing homes have difficulties implementing policies that respect nursing home residents' rights, especially those with dementia, while protecting the nursing home from lawsuits. With elder abuse laws in place mandating the reporting of suspected elder abuse and the high costs of legal judgments if/when nursing home staff are found to be at fault, it seems appropriate to suggest that nursing home staff are more likely to avoid, bar, or stop, rather than address, the sexual needs and behaviors of nursing home residents. The Illinois Department of Public Health (2009), for example, produces a quarterly report that provides information on nursing home violations, such as elder abuse, and the consequences and costs associated with the abuse. This report provides a foundation for understanding the fears that nursing home operators may have concerning the financial and other repercussions for poor care. In a sense, the natural psychological barrier of dementia has been paired with an institutional barrier to sexuality for many nursing home residents. Dementia, however, is not the only psychological barrier to sexual activities, as other mental illnesses, such as depression, also negatively affect sexuality in late life.

Birrer and Venuri (2004) report that depression is more prevalent among elderly persons and Rovner, German, Brant, Clark, Burton, and Folstein (1991) have revealed that depression negatively affects mortality in nursing home residents. In fitting with this study, Benbow and Jagus (2002a; 2002b) report that the loss of sexual desire is a

symptom of depression. Additionally, pharmacological treatments for depression may have negative effects on sexual functioning in both males and females.

Social Barriers. One of the main social barriers to sexual activity in nursing homes is the lack of privacy (Hajjar & Kamel, 2003; Richardson & Lazur, 1995; Wallace, 1992; White, 1982b). White (1982b) found that among the participants described as being sexually inactive during the last month, 17% reported interest in sexual activity but that they lacked the opportunity (i.e., regarding lack of privacy or partner). Despite federal regulations meant to insure resident privacy, often the design (i.e., the unlocked doors and access to residents for care) of nursing homes and functional requirements of the care provided lower the amount of privacy that residents receive.

As reported in White's (1982a; 1982b) studies above, another social barrier to the sexual expression of elderly nursing home residents is the lack of an able partner. Wasow and Loeb (1979) reported that 27% of men and 33% of the women in their study declared lack of a partner as their reason for being sexually inactive. United States Census Data from 2002 as analyzed by Spraggins (2003) revealed that there are, per 100 women, approximately 91.6 men for ages 55 to 64, 83.5 men for ages 65 to 74, 67.5 men for ages 75 to 84, and 46.3 men for ages 85 and older. Looking at sheer numbers alone, it is no wonder that nursing home ratios of women to men may average around 4 to 1 or even 5 to 1. Especially when taking into account the social factors of men continuing to be married into late life and it being more acceptable for men to date or remarry as widowers, but not for women to date or remarry as widows, the pool of men available for sexual relations with late life females appears quite small (McIntosh, 1981; Portonova, Young, & Newman, 1984).

When Mental and Physical Barriers meet Social Barriers. When examining sexual function and dysfunction in the later years, it is important to look at how physical, mental, and social aspects interact and serve as barriers to sexual functioning. For example, when discussing physical or psychological reasons for many elderly men's difficulties to maintain erections, Starr and Weiner (1981) reported that some men may overreact to the failure to maintain a firm erection with age and may interpret such a change as the lessening of their masculinity or worth. Additionally, Kaplan (1990) suggested that couples who do not communicate well or lack intimacy or compassion for one another may have minor impairments in their sexuality which can increase to more debilitating sexual disabilities. Some couples may not be able to adapt to healthy sexuality in their elderly years, due to antisexual social messages that were imparted to them in their youth by cultural traditions or religious beliefs. These social messages or attitudes, with reference to sexuality and the elderly, will be examined in more detail in the next section.

## Section III- Attitudes toward Sexual Activity in the Elderly and Resulting Sexual Behaviors

Despite the apparent interests in sexual practices by elderly individuals, research has noted differences between the attitudes held toward elderly sexuality and expression of those attitudes by the elderly, their caregivers, and their adult children (White, 1982a).

Students and/or Young People's Attitudes. Story (1989) completed a study in Iowa that compared the Adult Sexuality Knowledge and Attitude Test scores of 133 retirement home elderly to 133 students at a university and found that overall attitudes of both groups were positive toward elderly sexuality; however, specific behaviors like

fellatio and sex without marriage were seen as less positive by the elderly participants than the students. The studies covered in the Nottingham Study of Sexuality and Aging I (NSSAI) (Bouman et al., 2006) revealed that youth and students in some studies took negative stances, while in other studies students took positive stances towards sexuality in late life. The dates of the literature reviewed (i.e., Golde & Kogan, 1959; and LaTorre & Kear, 1977) revealing negative attitudes towards elderly sexuality by college students occurred earlier than the research revealing positive attitudes (i.e., Damrosch, 1982; Damrosch & Fischman, 1985; Quinn-Krtach & Van Hoozer, 1988; and Hillman & Stricker, 1996). This may suggest that students and/or young people's attitudes towards elderly sexuality have become increasingly positive across time due to social changes and/or education or this may simply reflect differences in the populations and focuses of the studies. These findings suggest that the adult children of current nursing home clients may hold more positive attitudes and be more supportive than prior researchers have hypothesized.

Staff Attitudes. Kaas (1978) found that nursing home staff accepted sexual expression of the handicapped, learning disabled, and mentally ill more so than aged nursing home clients. However, Dupras and Poissant (1987) found that hospital settings, including nursing homes, tend to inhibit the sexual expression of their residents, as those settings seek to maintain smooth functioning of public facilities. This often means that clients' rights to privacy, which is needed for the sexual act, receive less respect and rules are imposed to keep sexual encounters from disturbing the order that the hospital relies on to function well. Roach's (2004) study echoed similar findings in that the staff studied in Sweden and Australian nursing homes revealed that staff members guard themselves

against the discomfort of sexuality issues within nursing home's by having more restrictive ethos. The NSSAI (Bouman, et al., 2006) revealed restrictive and negative, as well as permissive and positive, attitudes of care staff towards late life sexuality. It is important to note, that White and Catania (1982) found that with increased knowledge concerning sexuality in late life, following an educational program, the staff in the institutions revealed a greater amount of permissiveness. A more recent study at Kansas State University (Barcomb-Peterson, 2008) continued to support the idea that educating nursing home staff helps staff members feel more confident about dealing with residents' sex related issues in the nursing home. The surveys given prior to the educational workshop revealed that there were marked attitude changes by the staff on the surveys following the workshop and further follow up suggested that knowledge was applied to solving patient intimacy dilemmas in a more positive way. Perhaps the differences between permissive and positive versus restrictive and negative attitudes of care staff in the NSSAI (Bouman, et al., 2006) can be linked with staff who are either more and less educated about how to handle sexuality issues with residents.

#### Older Adult Attitudes on Sex in Nursing Homes

The NSSAI (Bouman et al., 2006) supports that there is a lack of research concerning attitudes towards sex in residential living facilities and/or nursing homes. Multiple studies in the paragraphs above were used to provide a numerical sense of the rates of sexual activity in the elderly both in and out of nursing homes, but few studies have reported on attitudes held by the elderly toward late life sexuality in nursing homes. This makes it difficult to generalize many of the findings to the population of this review, as there continues to be a lack of sexual attitude studies examining nursing home

participants. Still, the studies below provide some insight into the perceptions, attitudes, and behaviors of the elderly regarding sexuality in nursing homes.

Attitudes and perceptions of attitudes about older adult sexuality play a role in the beliefs older adults hold regarding their own sexuality. Kaas (1981) developed a theory of Geriatric Sexuality Breakdown Syndrome, which suggests that social actions and attitudes play a role in the negative re-definition of sexuality for some elderly, as their sexual behaviors and self perceptions change across their life span. Bond and Tramer (1983) completed a study of the attitudes of 273 married people between the ages of 56 and 75 broken up into five age related reference groups and six social reference groups. They found that older adults believed that the younger the person, the less favorable the person would perceive late life sexual behaviors. The results from the older adults indicated that friends, clergy, and **children** were perceived to hold less favorable attitudes toward elderly sexuality than a spouse, doctor, or the participants themselves. Elderly women also viewed sex among the elderly less favorably than did elderly men and their attitudes were seen as less positive than the adult, middle aged, and elderly male reference groups.

The attitudes towards late life sexuality that female elderly hold are of particular interest. McIntosh (1981) found evidence to support a double standard during her study of 100 women between the ages of 60 and 94 years of age in independent congregate residences for elderly not in need of nursing care. High percentages of the women responded to the Sexual Attitudes Scale items in a very non-permissive way. When asked about whether it was alright for a man aged 60 to marry or have an affair with a 25 year old woman, 50% of the women reported that it was. When the question was changed to a

60 year old woman and 25 year old man, 78% did not believe that it was okay for an affair or marriage to occur. Additionally, McIntosh (1981) found that most of the women did not think that older women considered themselves to be attractive. Weinstein and Rosen (1988) found similarly that the women feel a double standard in that they become less sexually attractive at an earlier age than men. Such personal and social perceptions may act as hindrances to the sexual expressions of older women.

Portonova et al. (1984) studied women's attitudes toward elderly sexuality in 120 women 60 to 90 years old. The study made use of eight different vignettes and the outcomes revealed that the females had more positive attitudes toward sexually active married older adults and widowed people living in apartments, than widowed individuals residing in nursing homes. In general, these findings suggest elderly social perceptions exist that contribute to stigmatizing sexual activities in nursing homes.

White (1982b) further illuminated the difficulties related to elderly attitudes and sexual behaviors in nursing homes when he interviewed 250 nursing home residents. This study found that, despite sexual desires, only 8% of the participants had engaged in intercourse and/or masturbation in the previous month. It was reported that 17% of White's (1982b) sample had desired to be sexually active, but did not have access to a partner or privacy in the nursing homes studied.

Looking at several of the aforementioned studies' findings overall, one may note that elderly women hold attitudes towards sexuality that are less positive than other age and gender groups (Bond & Tramer, 1983; McIntosh, 1981; Portonova et al., 1984; Weinstein & Rosen, 1988). Elderly women also hold social perceptions about the appropriateness of sexual activities in nursing homes that suggest less positive/permissive

attitudes (Portonova et al., 1984). Finally, positive attitudes held by elderly individuals do not necessarily indicate sexual behaviors, as multiple barriers exist in association with nursing home living (White, 1982b). This literature review seeks to examine if more evidence exists to support that adult children of nursing home residents may be one of those barriers.

Family Members' Attitudes, Nursing Home Responses, and the Paucity of Research
Support

Positive attitudes toward sexuality were found among adult children and their older parents (aged 65 years or older) in a Canadian study done by Poulin and Mishara (1994). The researchers suggested that a cohort effect may have been present, as the adult children were shown to have significantly higher positive attitudes towards their parents' sexuality than the parents held toward their own sexuality. This was explained by suggesting that the lifelong attitudes towards sexuality of the parents were less positive than the attitudes of their children (Poulin & Mishara, 1994). Such a finding suggests that positive changes in attitudes about sexuality across different cohorts may reveal that some adult children of nursing home residents serve supportive or neutral roles, rather than roles as barriers to their parent's sexuality.

White and Catania (1982) also found that the attitudes of family members of elderly people toward sexuality in later life are generally positive. Collecting pre and post data using the Aging Sexuality Knowledge and Attitudes Scale (ASKAS) and two groups with participants randomly assigned using a block procedure, one group received a three week educational program on sexuality in the aged and the other received no information, White and Catania (1982) found that the attitudes towards sexuality in the aged among

community residing aged people, adults with elderly family members, and caregivers of aged people became more permissive as knowledge was increased. Looking specifically at the pre and post attitude scores for the adults with elderly family members in the group that received the educational information, one may see that the attitudes held were already categorized as permissive. Thus, the positive experimental effect for the post attitudes score was less pronounced than the substantially more positive knowledge score during the post test. White and Catania (1982) suggested that post scores on attitudes for the family members of elderly people may have revealed a ceiling effect due to the already held permissive attitudes. There are problems with White and Catania's (1982) study, however, as the experimental group of family members of elderly people held significantly greater knowledge and more permissive attitudes than the control group, which suggests that, despite the use of the randomized block procedure, the same population was not tested. The less permissive attitudes of the family and staff control groups, pre and post test, lend credibility to the Hajjar and Kamel (2003) study, which suggested that a lack of knowledge in staff and family members may result in negative attitudes toward the expression of sexuality in late life nursing home residents.

A smaller study, of 57 health care providers at several different nursing homes, also used White's instrument, the ASKAS, to assess existing knowledge and attitudes toward sexuality in the aged. Glass, Mustian, and Carter (1986) found that as existing staff knowledge increased, permissive attitudes toward elderly sexuality decreased (Glass et al., 1986). Glass et al. (1986) suggested that the personnel with the most knowledge of geriatric sexuality are those with supervisory powers and are often interested in simplifying their positions by avoiding legal and other problems via limiting the sexual

expressions of the institutionalized elderly. In essence, increased knowledge of geriatric sexuality alone does not suggest increased permissive attitudes, as there are multiple other factors or "hurdles". One of the "hurdles" suggested by Glass et al. (1986), which supervisors may have wished to avoid, was having problems with the family members of the elderly residents concerning their sexual practices.

Nursing home personnel may be more interested in the desires of family members (i.e., adult children, legal guardians, or bill payers) than in the sexual desires of the elderly nursing home residents (Burnside, 1973; Wallace, 1992). As noted previously, attitudes of care staff were only one of the barriers to sexual expression found during the Richardson and Lazur (1995) study. Richardson and Lazur (1995) found research support for a number of barriers: lack of privacy, lack of a partner, loss of interests, chronic illness, attitudes of care staff, lack of knowledge concerning sexuality, and feelings of unattractiveness. Interestingly, however, in prior studies either no mention or no measurement was made of adult children as barriers to sexuality (Hajjar & Kamel, 2003; Richardson & Lazur, 1995). Studies like the Kansas State University study (Barcomb-Peterson, 2008) suggest that adult children may be concerned about their parents engaging in sexual activities in the nursing home for safety reasons or because the relationships may affect their inheritance. Gayle Doll, a researcher and faculty member at Kansas State University, suggested that adult children fear their parent(s) in the nursing home(s) being exploited and/or that the parent's roles will change (Barcomb-Peterson, 2008).

Multiple research articles mention the attitudes or behaviors of adult children of nursing home residents (Barcomb-Peterson, 2008, Burnside, 1973; Glass, et al., 1986;

Hajjar & Kamel, 2003; Poulin & Mishara, 1994; Wallace, 1992; White & Catania, 1982), but none of the research found and reviewed actually investigated the possible roles that adult children play, with reference to their attitudes and behaviors, concerning the expression of their parents' sexuality in nursing homes. Specifically, no studies looked at the relationship of adult children's attitudes towards parental sexual behaviors and the possible effect those attitudes have on parental sexual behaviors. If anything, many researchers simply posit that adult children may regard sexuality for their parents in the nursing home negatively based upon their experiences in working with families and nursing home personnel. Although personal accounts provide a wealth of knowledge, it is time that a more scientific approach is taken to the topic so that knowledge can be gained and positive changes proposed.

#### Chapter III

#### Section IV- Conclusions and Needs for Additional Research

The literature reviewed in Chapter II provides a basic overview of the facts that individuals in nursing homes continue to desire sexual activity and that sexual activity is a normal part of life across the entire lifespan. Institutional barriers such as lack of privacy, negative attitudes of care staff, and policies to deter sexual activity of residents, due to liabilities related to difficulties assessing mental functioning or ability to consent to sexual activities by residents have been researched. Social barriers like lack of a partner, lack of knowledge concerning sexuality, and feelings of unattractiveness, along with medical barriers of chronic illness, and psychological barriers of dementia and loss of interest (i.e., sometimes due to depression) reveal research support. Attitudinal, behavioral, and role related research is still lacking, though, with respects to adult children and their parents in nursing homes.

So, what roles do adult children play regarding their parents' sexuality in nursing homes? Evidence from this literature review suggests that, in general, attitudinal studies of adult family members reveal positive attitudes towards parental sexuality (Poulin & Mishara, 1994; White & Catania, 1982). The Kansas State University study reported by Barcomb-Peterson (2008), however, suggested that adult children may be concerned about their parents engaging in sexual activities in the nursing home for safety reasons, or because the relationships may affect their inheritance, out of fear that their parents will be exploited, or that the parents' roles will change. Such concerns suggest that adult children may behave in a protective, avoidant, or an obstructive manner towards parental sexuality and relationships in nursing homes. Regardless of the adult children's attitudes towards

their parents' sexuality in nursing homes, Glass et al. (1986) suggests that supervisors avoid having problems with the family members of the elderly residents concerning the resident's sexual practices by limiting the resident's sexual behaviors. Thus, positive attitudes do not necessarily translate into positive behaviors with regards to parental sexuality. Future research studies might inquire how or whether or not adult children are expressing negative attitudes to nursing home supervisors or if supervisors are simply inferring the negative attitudes and making policies to protect the nursing home(s) from law suits. Unfortunately, although some information exists about adult children's attitudes and gives researchers a sense of why adult children may play the roles that they do, there is not enough research evidence to posit specifically what behaviors adult children engage in or how they act out their roles.

More research is needed to determine what terminology (i.e., barriers, supporters, or neutral observers) accurately identifies the roles that the adult children play for their parents in nursing homes regarding their parents' sexuality and to determine the main variables in the attitudes, behaviors, and roles that exist. Previous research has used the Aging Sexuality Knowledge and Attitudes Scale (ASKAS) (White & Catania, 1982), sexual behavior questionnaires (Starr & Weiner, 1981), and educational workshops (Barcomb-Peterson, 2008; White & Catania, 1982) to assess attitudes and behaviors towards sexuality. The Mini-Mental State Examination, available from Psychological Assessment Resources, Inc. (1975), also has found wide use in assessing nursing home residents for cognitive decline and screening out participants who may suffer from dementia. Focusing, initially, on sexual activity in a cognitively healthy aged population may lessen ethical concerns surrounding nursing home residents being studied with

regards to their sexual attitudes and behaviors. Future research may also make use of family assessment instruments in order to address variables that may have an impact on attitudes toward sexuality, such as family cohesiveness, problem solving, hierarchical structure, and culture (Sawin & Harrigan, 1995). Currently, research that looks at how culture impacts attitudes towards sexuality in nursing homes is lacking; and future researchers would benefit from being more sensitive to how culture may affect the interactions that occur between family members and staff at nursing homes. Additionally, instruments that assess role functioning via questionnaires or structured interviewing techniques would be useful to future researchers, as there is a lack of literature regarding the definition and development of roles for adult children with parents in nursing homes. The goal is for future researchers to have a clearer picture emerge of the terminology and variables regarding adult children's role development and expression of behaviors related to those roles, then policies or programs to improve the sexual lives of nursing home clients can be better implemented.

Future researchers should be cautioned, however, as researching the roles that adult children play regarding their parents' sexuality in nursing homes will likely require much care since the topic still may be regarded as "taboo" by some and pose ethical concerns. Efforts to reduce risk of harm to participants by using confidential settings and research procedures that ensure participant confidentiality of information provided and reported are very important. Several ways of implementing studies that are more protective of participant confidentiality include having separate and non-related groups of parents in nursing homes and adult children of nursing home residents. Internet studies, where participants may complete the study in a private location on a computer, may be

another option to obtaining a large sample size for parents in nursing homes and non-related adult children. Several barriers may exist to obtaining data from these populations in this way and problem solving by the researcher would need to occur, as computer access in nursing homes and adult children's homes along with lack of computer skills may make it difficult to obtain data.

Examining dyads of related adult children of parents in nursing homes may also be extremely beneficial by providing better data regarding variables such as relationships and roles. However, in order to maintain confidentiality from adult children finding out about their parents' attitudes and behaviors about sex and vice versa, either a very large sample size of participants would need to be used from one institution (i.e., over 50 dyads) or a large sample size (i.e., over 100 dyads) from multiple nursing homes would need to be used. With these samples, data collecting and reporting techniques will be able to guard participant identity of responses and lessen the possibility of a breach of confidentiality.

In conclusion, although many residents of nursing homes want and attempt to maintain sexual activity in nursing homes, multiple barriers to their sexuality exist.

Researchers and other individuals who have worked in nursing homes have posited that adult children are concerned and often wish to stop or avoid addressing their parents having sex while residing in nursing homes. Despite these reports, no qualitative or quantitative study has been found where adult children's roles regarding their parents' sexuality in nursing homes was studied. This research is important, as nursing home populations continue to grow and quality of life in nursing homes is of concern.

Additionally, the adult children of the current nursing home clients may be the clients of

the future and information about their sexual attitudes, behaviors, and roles played for their parents may be suggestive of what educational programs or policy changes are needed for future development and improvement of life in nursing homes. The suggestions made regarding research questions and study development considerations will hopefully serve as a guide for future researchers to enlighten adult children and nursing home coordinators about the roles that adult children play regarding their parents' sexuality in nursing homes. It is hoped that with more knowledge and understanding that change can ultimately occur.

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