Summer 8-7-2012

Alzheimer's Disease and Intimacy: A Content Analysis of Resources Avaliable through the Alzheimer's Association and the National Institute on Aging

Danelle S. Hubbard
Georgia State University

Recommended Citation

Hubbard, Danelle S., "Alzheimer's Disease and Intimacy: A Content Analysis of Resources Avaliable through the Alzheimer's Association and the National Institute on Aging." Thesis, Georgia State University, 2012.
https://scholarworks.gsu.edu/gerontology_theses/29

ALZHEIMER'S DISEASE AND INTIMACY:

A CONTENT ANALYSIS OF RESOURCES AVAILABLE THROUGH THE ALZHEIMER'S ASSOCIATION AND THE NATIONAL INSTITUTE ON AGING

by

DANELLE HUBBARD

Under the Direction of Candace Kemp

ABSTRACT

An estimated 5.4 million individuals in the United States have Alzheimer's disease, and the number is expected to rise exponentially over the next 50 years. Content analysis was used to examine the availability and content of online resources accessible through the Alzheimer's Association and the National Institute on Aging (NIA) that addressed emotional and physical intimacy for a marital unit. The analysis resulted in ten documents from the Alzheimer's Association's website, seven from the NIA's website, and four additional documents produced from external links that met these criteria. Five major themes emerged from these documents regarding the subject of emotional and physical intimacy. These categories included: (a) defining sexuality and intimacy, (b) changes that occur in the relationship due to a dementia diagnosis, (c) reasons for the change in the relationship, (d) responses to a dementia diagnosis, and (e) strategies for managing the changes due to a dementia diagnosis.

INDEX WORDS: Alzheimer's disease, Intimacy, Alzheimer's Association, National Institute on Aging, Couples, Aging, Spousal relationships, Sexuality, Content analysis

ALZHEIMER’S DISEASE AND INTIMACY:
A CONTENT ANALYSIS OF RESOURCES AVAILABLE THROUGH THE ALZHEIMER’S ASSOCIATION AND THE NATIONAL INSTITUTE ON AGING

by

DANELLE HUBBARD

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

Master of Arts

in the College of Arts and Sciences

Georgia State University

2012

ALZHEIMER’S DISEASE AND INTIMACY:
A CONTENT ANALYSIS OF RESOURCES AVAILABLE THROUGH THE ALZHEIMER’S ASSOCIATION AND THE NATIONAL INSTITUTE ON AGING

by

DANELLE HUBBARD

Committee Chair	Candace Kemp
Committee:	Ann Pearman
	Jaye Atkinson

Electronic Version Approved:

Office of Graduate Studies

College of Arts and Sciences

Georgia State University

August 2012

DEDICATION

I would like to dedicate this thesis to my mother, Priscilla Hubbard, who has been my life-long encouragement, inspiration, and supporter. You have been the cornerstone of my pursuit for higher education. Without your continual love and support, completing this monumental task would not have been possible. Thank you and I love you!

ACKNOWLEDGEMENTS

In my 11 years of working with persons with dementias and their families, I have seen the devastating impact of Alzheimer’s disease and other dementias. I would like to begin by acknowledging those families for inspiring this body of work and my hopes for a cure!

Heartfelt thanks goes to my committee members. First, a deeply indebted thanks to Dr. Candace Kemp, chair of my thesis committee, for her on-going support, mentoring, patience, and countless hours of assistance. I would also like to thank Dr. Jaye Atkinson and Dr. Ann Pearman for providing their guidance and input.

Within the Gerontology Institute, I would like to acknowledge previous and current staff for all of their support over the years: Dr. Elisabeth Burgess for introducing me to the Gerontology Institute and providing the spark of inspiration to pursue a Master’s degree in this field, Dr. Frank Whittington for his encouragement and support of all gerontology professionals, Dr. Sharon King, for being one of my earliest mentors in gerontology, Mary MacKinnon for her cheerful and caring reassurance, and Dr. Yong “Tai” Wang for being an advocate and mentor. A special thanks to all who contribute to the success of the Gerontology Institute!

I would like to acknowledge the Alzheimer’s Association, Georgia Chapter for their support in my pursuit of higher education. In addition, my sincerest thanks goes to Ginny Helms and Suzette Binford for granting the flexibility needed to work full time while pursuing my Master’s degree and never doubting my ability to successfully accomplish both.

Finally, overwhelming gratitude goes to my biological and chosen family, who sustained me during the most challenging of times. I would also like to acknowledge all of my friends, co-workers, and classmates for your endless words of encouragement and support. I am truly grateful to have such a wealth of family and friends!

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

An estimated 5.4 million individuals in the United States have dementia of the Alzheimer’s type (DAT), and that number that is expected to rise exponentially over the next 50 years (Alzheimer’s Association, 2011). This anticipated growth is related to increasing longevity as advanced age is one of the primary risk factors for developing Alzheimer’s disease (Alzheimer’s Association, 2005). Until a cure is found, more families, including couples, will be required to navigate the changes in cognitive function their loved ones experience as a result of DAT and learn to cope with the accompanying emotional and physical challenges.

Among those who have been diagnosed with DAT, 25% are married (Alzheimer's Association and National Alliance for Caregiving, 2004). An estimated 6% of caregivers for those with Alzheimer’s disease are spouses (Alzheimer’s Association, 2011). Caring for a person with Alzheimer’s disease can present challenges because of the cognitive and physical changes associated with DAT. Spousal caregiving may be accompanied by additional challenges because of the intimate nature of the relationship compared to other caregiver-care recipient relationships (Connidis, 2010). For example, a spouse with Alzheimer’s disease may exhibit severe mood swings, poor judgment, bizarre behavior early in the disease process and sometimes long before the well-spouse is aware of DAT, may place strain on the marital relationship even prior to a diagnosis (Stephens & Qualls, 2007). Because Alzheimer’s disease has implications for both emotional and physical intimacy, upon diagnosis both spouses may need education about DAT and support through the care process. However, the majority of support tends to be needed by the well spouse, as caregiving demands increase alongside the risk of decline in emotional and physical health (Alzheimer’s Association, 2005).

Highly relevant information and tools aimed at helping couples cope with Alzheimer's disease are available in scientific journals. For example, Davies, Zeiss, Shea, & Tinklenberg, (1998) identify several intervention techniques such as counseling specific to couples coping with an Alzheimer's diagnosis which may be particularly helpful for spousal caregivers. In the past, persons with Alzheimer's disease were perceived as unable to benefit from intensive therapy (Davies et. al., 1998, pg.201). Davies and colleagues state, "…many older couples would be amenable to interventions that address successful adaptation to changes in sexuality caused by Alzheimer's disease" (Davies et. al., 1998, pg.195). In addition, emotions surrounding cognitive changes could be addressed (Davies et. al., 1998). Yet, health literacy, which is the comprehension of health care information, may be a barrier to accessing and understanding information in academic or clinical resources. For example, a cross-sectional cohort study of 414 independently living older adults age 60 or older, found that health literacy scores in individuals that had reduced cognitive ability, as measured by the mini-mental status examination, were significantly lower than people with higher mental status scores (Federman, Sano,Wolf, Siu, & Halm, 2009).

Although academic journals have quality content, this information is usually not transmitted to the lay population. Spouses are more likely to seek information and support from sources other than academic or clinical journals. A little over half of the people who care for someone with Alzheimer's draw on print materials (e.g.books), while many others look to the internet for caregiving information and to learn about Alzheimer's disease (Alzheimer's Association and National Alliance for Caregiving, 2004). Indeed, it is clearly a growing trend among older adults to use the internet to search for medical information and support (Birren & Schaie, 2006). Recent estimates find that two-thirds of internet users in the United States seek health information online, which exceeds the number of persons who actually visit a physician for health information. Although this trend does signify the growing importance of the internet as a source for medical information (Birren & Schaie, 2006), many families may still seek the counsel of a professional in person or by phone (Alzheimer's Association and National Alliance for Caregiving, 2004).

A recent patient handbook developed by *Geriatrics*, a peer-reviewed medical journal of physicians, identified both the National Institute on Aging (NIA) and the Alzheimer’s Association (AA) as resources considered to provide reliable health information for patients (Patient Handbook: Reliable health information at NIHSeniorHealth.gov., 2005). Both institutions also meet the credibility standards set by the Successfully Preparing for Retirement Years (SPRY) Foundation, such as affiliation with established universities and health care organizations (Benbow, 2002). SPRY is a government organization dedicated to aiding older adults entering retirement years. SPRY suggested that both AA’s and NIA’s respected and respective positions in the health industry add to their credibility (Benbow, 2002).

The Alzheimer’s Association has worked in partnership with researchers and professionals in the medical community in the areas of advocacy, staff training, and consumer education (Maslow & Heck, 2005). Reuben and colleagues (2010) examined the success of a referral program to the Alzheimer’s Association. In their pre-post intervention study of ten physicians and 1,179 patients over an 11-month period, referrals to the Alzheimer’s Association resulted in an increase in the quality of dementia care for the 17% of patients (Reuben, Roth, Frank, Hirsch, Katz, McCreath, et al., 2010).

Although the Alzheimer’s Association and NIA are common organizations on which caregivers refer, the materials they provide relating to issues of emotional and physical intimacy and Alzheimer’s have not been scientifically evaluated for content. Identifying what materials are available and how they address issues of intimacy and dementia is an important and essential first step in assessing and ultimately improving information available to couples living with Alzheimer’s disease.

Overall Aims

The overall aim of this research was to conduct a content analysis of resources available through the Alzheimer’s Association and National Institute of Aging that address emotional and physical intimacy for couples affected by Alzheimer’s disease. More specifically, the aims of my proposed thesis were:

1) To identify the online resources available through the Alzheimer’s Association and the NIA that relate to understanding emotional and physical intimacy and Alzheimer’s disease; and
2) To examine the content of the available print and on-line resources, identifying the key patterns, themes, assumptions, and messages conveyed to spouses and couples.

My thesis contains five chapters. Following an introduction, Chapter 2 establishes the background for my research and includes a review of literature which: covers the topics of Alzheimer’s disease, marital couples, sexuality and older adults, defining intimacy, and intimacy and Alzheimer’s disease. Next, Chapter 3 discusses the methods for launching this investigation. Chapter 4 contains my findings, and Chapter 5 contains my discussion.

Gerontological Significance

Currently, Alzheimer’s disease is the 6th leading cause of death (Centers for Disease Control and Prevention: Aging - Healthy Brain Initiative, 2010) and its growing prevalence means more families and couples will be touched by DAT. With advanced age as one of the primary risk factors for developing Alzheimer’s disease and an estimated 13.5 million will have

DAT by 2050, marital couples will be faced with possibility that one will be diagnosed with Alzheimer’s disease at some point in later life (Centers For Disease Control and Prevention: Aging - Healthy Brain Initiative, 2010). Persons with Alzheimer’s disease are among the oldest and frailest of populations needing care (Alzheimer's Association and National Alliance for Caregiving, 2004). Caregiving spouses are also apt to be older and frailer than other family caregivers, such as daughters and/or sons. This fact, paired with the challenges of caring for an intimate partner with Alzheimer’s disease, makes this population particularly vulnerable and in need have support. In the later stages of DAT, spouses often describe their relationships as a marital limbo, in which they no longer have a spouse but are not widowed either (Stephens & Qualls, 2007). These concerns are reflected in the findings of various researchers of marital caregivers of persons with dementia (see Connidis, 2010).

Due to the changes that occur with Alzheimer’s disease, “couples frequently grapple with adaptation to changes in sexuality” (Davies et. al., 1998, pg.201). According to Adams, Oye, & Parker, (2003), “the Internet may be especially suited for sex education because, without the risk of being shamed or socially sanctioned, older adults may feel freer to have open and frank discussions about issues they have been trained to avoid” (pg.411). Thus, the internet has been identified as a possible tool for information about sexual relationships (Adams, Oye, & Parker, 2003). Emotional intimacy discussion and support are also available to couples via the internet (Alzheimer's Association and National Alliance for Caregiving, 2004). My research was designed to evaluate the amount and quality of internet information available to couples on the topic of emotional and physical intimacy. This knowledge will, hopefully, be a start to the development of guidelines for enhancement of existing literature aimed at improving quality of life for the ever-growing number of couples affected by Alzheimer’s disease.

CHAPTER 2: LITERATURE REVIEW

The overall aim of my research was to conduct a content analysis of resources available through the Alzheimer's Associate and NIA that address emotional and physical intimacy for couples affected by Alzheimer's disease. This chapter provides information on existing research relating to couples facing a diagnosis of Alzheimer's disease within their marital relationship. The chapter establishes the context for my thesis work and is organized according to five general areas. First, Alzheimer's disease will be described including changes that occur with the onset of DAT and possible treatments. Second, I will discuss marital couples through a life course perspective including life transitions and caregiving. Third, I will define intimacy taking care to consider both physical and emotional components. Fourth, I will examine intimacy among couples in which one spouse is diagnosed with Alzheimer's disease. I will conclude with a summary statement presenting my research aims and specific questions.

Alzheimer's Disease

According to the DSM-IV Alzheimer's disease falls under the category of dementia (American Psychiatric Association [APA], 2000). Dementia is defined as a loss of cognitive function due to neurological changes in the brain (Mendez & Cummings, 2003). This diagnosis is a persistent impairment that is not the result of a delirium, a psychological, or pharmacological cause (Mendez & Cummings, 2003). Dementia compromises three or more of the nine spheres of mental activity (APA, 2000). These spheres include: "…memory, language, perception, (especially visuospatial), praxis, calculations, conceptual or semantic language, executive functions, personality or social behavior, and emotional awareness or expression" (Mendez & Cummings, 2003, p.69). Although many conditions can cause a dementia, including Parkinson's disease, Lewy Bodies, and Huntington's disease, Alzheimer's disease is the most common cause of dementia (Mendez & Cummings, 2003).

According to the DSM-IV, the criteria for a diagnosis of probable Alzheimer's disease is as follows: memory impairment, cognitive disturbances such as aphasia (language impairment), apraxia (disturbance of motor acts), agnosia (perceptual difficulty), or disturbances in executive functioning, impairment in social and/or occupational functioning, gradual onset with continuing cognitive decline and/or, impairments not due to other medical conditions or Axis I disorders (APA, 2000). An individual must have memory impairment and one other cognitive impairment (APA, 2000). These impairments must exist for six or more months and interfere with daily activities and/or social functioning (APA, 2000).

Alzheimer's disease is caused by the development of neurofibrillary tangles and beta-amyloid plagues that lead to neuronal loss and cortical atrophy (Mendez & Cummings, 2003). Usually, short-term memory is the first cognitive deficit that is exhibited (Alzheimer's Association, 2005). However, this is not always the case, and some individuals may notice other losses first such as mood disruption or shortening of attention span (Mendez & Cummings, 2003). "The disease leads to a gradual progression through three main stages: Early/Mild, Middle/Moderate, and Late/Severe, which leads to death" (Alzheimer's Association, 2005). The prognosis in the general population is that individuals live with Alzheimer's disease an average of 10 years from the time of diagnosis (Mendez & Cummings, 2003). However, individuals with the disease typically live from 2 to 20 years based on overall health factors (Mendez & Cummings, 2003).

There are two primary modes of treatment for Alzheimer's disease: pharmacological and non-pharmacological. Pharmacologic treatments are usually given upon diagnosis. Current medication regimens work to maximize the efficiency of the neurotransmitters and promote neuron health (Alzheimer’s Association, 2005). The goal of this type of treatment is to fully utilize healthy neurons in an effort to slow the disease’s progression. In addition to combating cognitive decline, behavioral issues tend to be the primary complaint of individuals with Alzheimer’s disease and their care partners. Medication is often prescribed also to reduce or eliminate these behaviors if possible. Antidepressant medications are administered for depressed mood and irritability (Alzheimer’s Association, 2005). For hallucinations, delusions, aggression, and agitation anti-psychotics are sometimes prescribed (Alzheimer’s Association, 2005). Anxiolytics may be used for anxiety, restlessness, and verbally disruptive behavior (Alzheimer’s Association, 2005). The severity of the behavior and physician’s discretion determine the type and frequency of medication given (Alzheimer’s Association, 2005). Non-pharmacological treatments focus on the management of behavior resulting from cognitive decline in conjunction with or as an alternative to pharmacological treatments. Psychosocial interventions such as behavioral therapy in the earlier stages have been proven effective in treating Alzheimer’s patients’ behavioral and psychiatric symptoms (Logsdon, McCurry, & Teri, 2007).

Marital Couples, the Life Course, Transitions, and Caregiving

From a medical perspective, the devastating effects of this disease are most apparent for the person diagnosed with Alzheimer’s disease and there are great efforts are being made to combat DAT for the individual. However, of those estimated 5.4 million diagnosed with Alzheimer’s disease, over 1.3 million have a spouse (Alzheimer's Association and National Alliance for Caregiving, 2004). Therefore, this disease becomes a shared experience in which both partners struggle as a unit with changes brought on by Alzheimer’s disease. Yet according to Epstein, Auclair, and Mittelman (2006), many of the previous interventions have been designed only for the caregiver and may negate the importance of the couple as a unit. In the Epstein, Auclair, and Mittelman (2006) study, a randomized wait-list control design in a six session counseling treatment of 12 couples with one spouse in the early stages of Alzheimer's disease, one of the goals was to interact with both the spouse with Alzheimer's disease and well spouse equally and validate both spouses' experiences. How a married couple copes with an Alzheimer's disease diagnosis is influenced greatly by the health of the marriage throughout its life course (Connidis, 2010).

Marital relationships change over time with major life events such as birth of children, purchase of first home, retirement, all shaping the relationship over the life course (Huyck, 2001). A couples' ability to cope with major life changes and stressors is often a determining factor of how a couple copes with changes later in life such as health (Huyck, 2001). Zarit utilizes Huyck's (2001) typology to identify various types of romantic relationships that can occur in later life such as, "…marriage, remarriage, partnership, cohabitation, abandoned relationships, absent relationship…" (pgs.9-10). Thus, Huyck (2001) highlights the variations that can exist in marital relationships such as one problematic type of relationship defined as "stable incompatible" where couples remain married but are unhappy in the relationship (Zarit, 2001). The onset of a major health crisis in a spouse could prove irrevocably damaging to this relationship (Zarit, 2001). Thus the "therapeutic challenge" is in understanding the couple's dynamics and starting point to craft an intervention from their current position (Zarit, 2001). While not all older couples will experience dementia over their life course, many experience health transitions that require negotiating individual and shared needs and abilities (Connidis, 2010).

As a result of some health transitions, one spouse may transition into the role of caregiver, especially when one spouse experiences health declines at a faster rate than the other (Connidis, 2010). While declining health in both spouses may lead to greater interdependence to meet the needs of daily living, the journey of a caregiver is clearly an experience different from the person with the Alzheimer's disease (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005). Caregiving can have consequences for those who care. Some of the risks for spousal caregivers include: (a) financial from the increasing expense of purchasing care supplies and prescriptions as the disease progresses or loss of income from the ability to work due to caregiving responsibilities, (b) emotional due to the strain of dealing with challenging behaviors and/or grief for the slow loss of a partner's ability to act as a spouse, and (c) physical from providing direct care activities such as bathing and toileting of a person with Alzheimer's disease or combative behaviors from the person with Alzheimer's disease (LoboPrabhu et. al., 2005).

Intimacy

An important function of a spousal relationship is the development and maintenance of intimacy. However, definitions of intimacy can be highly subjective and vary in the literature. In his pioneering book on improving marital intimacy, Waring (1988) defined intimacy as: "a multifaceted interpersonal dimension which describes the quality of a marriage relationship at a point in time" (p.23). Further, he describes intimacy as being comprised of eight factors, "affection, expressiveness, compatibility, cohesion, sexuality, conflict resolution, autonomy, and identity" (Waring, 1988, p. 23). Later, Harper and colleagues (2000) refer to these same definitions in their work on marital quality in later life as an illustration of the complexity of the term intimacy. However, for the purpose of their study, intimacy was defined according to the earlier work of Schafer and Olson (1981) in which intimacy is described in five main areas:

emotional, social, sexual, intellectual, and recreational as a process of sharing feelings of closeness through shared experiences (Harper et.al., 2000). These results were from an examination of the marital quality of 236 older couples from a random sampling of all 50 states (Harper, Schaalje, & Sandberg, 2000). Rheaume and Mitty (2008, p. 344) explore a wider definition of intimacy consisting of: "…5 distinct components: commitment, mutuality (interdependence), emotional intimacy (includes caring, positive regard), cognitive intimacy (includes thinking about the other; shared values), and physical intimacy (ranging from closeness to intercourse)." In Steinke's (2005) article which addresses the intimacy needs of individuals suffering from chronic illness, primarily cardiovascular disease, intimacy is defined as closeness with physical sexuality as a major component. For the purposes of the following investigation, intimacy will be defined as a relationship in which there is an exchange of both emotional disclosure and physical affection, including sexual expression within a married couple.

Researchers discuss the significance of intimacy stating that when intimacy needs are met a higher quality of life is experienced and that this is key in successful aging (Steinke, 2005). According to Meyer and Roseamelia (2007), love and intimacy needs never fade. In fact couples, in a research study on sexual relationships in long-term marriages expressed the importance of intimacy in their relationships (Hinchliff & Gott, 2004). Intimacy remains an important component regardless of whether couples continued to engage in sexual activities (Hinchliff & Gott, 2004). However, research on spousal caregivers finds that loss of intimacy over the course of caregiving can result in a decrease in marital satisfaction (Kuppuswamy, Davies, Spira, Zeiss, & Tinklenberg, 2007). In a study on social support in spousal relationships, intimacy was one of several factors shown to have the greatest bearing in decreasing perceived stress and depressive symptoms (Dehle, Larsen, & Landers, 2001). The Harper, et al. (2000) study concluded that an

"…increase in perceived intimacy is significantly related to an increase in marital quality for both husbands and wives in preretirement/retirement-aged couples."

Emotional Intimacy

Disclosure of emotion is a major component of intimacy in a marital relationship (Forgas, 2011). Marital communication becomes key in evaluating the health of a marital relationship. "The way emotion is communicated (or not communicated) is critical in romantic relationships" (Guerrero, 2009, pg.487). In Guerrero's study of attachment and marital satisfaction, emotional communication appeared to be a determining factor in whether couples experienced a relationship with secure attachment with high levels of relational satisfaction or dismissive attachment with low levels of relational satisfaction (Guerrero, 2009). In Garfield's work on utilizing therapeutic men's groups to enhance couples therapy, the development of emotional intimacy skills in men plays a crucial role in the successful outcome of couple's therapy (Garfield, 2010).

This pattern appears to hold true in relationship in which one partner has a dementia diagnosis. In Braun's investigation of marital communication between spouses of persons with dementia and caregiver depression, "…it is plausible to assume that relations between mental health and accordingly well-being, marital satisfaction, and communication in dementia caregiving dyads are concordant with the associations found in healthy couples" (Braun, 2010, pg.187). Braun goes on to emphasize the importance of not only examining the caregiver's communication style in communication research but also the person receiving the care (Braun, 2010). In observational coding of conversations of couples, there appears to be a relationship between positive and negative communication between couples and the depression scores of the well spouses (Braun, 2010). In some couples, positive communication of the care receiver appears to provide an emotional buffer and protect the well spouse (Braun, 2010). This illustrates the impact emotional communication has not only on the well-being of the relationship but also the emotional health of the couple.

Sexuality

Traditionally, marriage was the only social status that allowed sexual and erotic expression resulting in a sexual interdependence of couples to fulfill these needs (Connidis, 2010). These needs do not necessarily disappear with age. Unfortunately, studies regarding older adult sexuality have been very limited due to common prejudices and attitudes about older adults (Butler, Lewis, Hoffman, & Whitehead, 1994). What little research that exists indicates that the majority of older adults still engage in some form of sexual activity (DeLamater & Moorman, 2007). Yet, there appears to be gender differences in the rates of sexual activity.

In a national probability study sample of 3005 United States residents between the ages of 57 and 85, 83.7% of men and 61.6% of women age 57-64 years old and 67% and 39.5% of women age 65-74 years old self reported engaging in sexual activity with a partner with the past 12 months (Lindau et al., 2007). This study illustrates slight gender differences as the percentages for male sexual activity are higher. However, women are the least sexually active in increasing age due to the lack of available male partners (Lindau et al., 2007).

As with sexual activity, there appears to be another gender difference in views on sexuality. For individuals that stated they had no sexual activity in the previous three months, women overwhelmingly reported a lack of interest in sex, especially those in the older demographics without an intimate partner (Lindau et al., 2007). In AARP’s (2010) survey of sexuality of 1,670 English and Spanish speaking adults between the ages of 45 and 70 conducted by Knowledge Networks, a similar demographic occurs in the AARP study in which minority populations such as Hispanics had a similar outcome of sexual activity being unimportant in later life (AARP, 2010). In addition, men were far more concerned with sexual performance and the ability to maintain physiological functioning than women, which illustrates that both gender and cultural differences exist regarding sexual attitudes and behaviors (AARP, 2010).

Being married is one of the biggest predicators of sexual engagement (Connidis, 2010), and those with a sexual partner (primarily composed of married couples) report greater sexual satisfaction than other marital status groups (AARP, 2010). Yet, the lack of available male partners contributes to women being the least sexually active gender in increasing age (Lindau et al., 2007). According to Butler (1994), “If sexual activity was an important part of people’s early life…it definitely is part of their healthy later lives” (pg. 6). In the AARP (2010) study, an average of 72% of respondents stated that a satisfying sexual relationship was important for quality of life.

Aging can result in physical changes that make sexual forms of intimate expression more challenging (Roberto, 2001). According to Connidis (2010), “Although certain forms of sexual activity decline with age, sexual expression remains an important component of long term relationships” (pgs. 91-92). The experience of chronic pain may result in a lack of physical intimacy (Roberto, 2001) and potentially create a sense of loss for the well spouse (Connidis, 2010). In a similar category, Zeiss & Kasl-Godley (2001) find that medication can interfere with physical performance and sexual desire. The study’s focus is on how health (particularly sexual health) affected sexuality but the overall conclusion is the majority of older adults remain sexually active in some form in spite of various health conditions (Lindau et al., 2007). Similarly, the DeLamater and Moorman (2007) study, based on information from the AARP 1,384 surveys on sexuality, “diagnosed illnesses and their associated treatments exerted surprisingly little influence on frequency of sexual behavior" (pg. 941). These physical transformations may result in the need for a change in strategies for sexual activity such as varying sexual activities, change in positions, and greater communication within the relationship (Zeiss & Kasl-Godley, 2001).

Changes in sexual activities are not the only behavioral changes that can occur with aging. Psychosocially, an overall sense of well-being in the relationship increases sexual satisfaction regardless of the physical challenges (Zeiss & Kasl-Godley, 2001). However, culturally restrictive beliefs regarding acceptable sexual activity may limit sexual expression in couples when earlier forms of sexual activity are no longer possible (Zeiss & Kasl-Godley, 2001). Health providers should encourage communication between spouses regarding sexual health (Zeiss & Kasl-Godley, 2001). Often spouses may carry misconceptions about reasons for a decline in sexual activity within the relationship such as loss of desirability due to the physical transformations that occur with age instead of the partner's inability to perform due to a physical condition (Zeiss & Kasl-Godley, 2001). According to Steinke (2005), "Anxiety and fear are common reactions of older adults with chronic disease when considering return to sexual activity. They may fear that engaging in sexual activity may cause harm or relapse of their illness" (pg. 49).

Intimacy and Alzheimer's Disease

As previously suggested, the emotional and physical components of intimacy are vital to the well-being of the couple and relationship. Research suggests that many older adults continue to desire physical intimacy even if that individual is diagnosed with an illness such as Alzheimer's disease (Connidis, 2010). Davies and colleagues (1998) found that caregivers "…want to maintain an intimate relationship with their partners because they find sexual intimacy to be a source of support, reassurance, and a means of coping with their partner's devastating illness" (p.195). Yet, upon the progression of Alzheimer's disease, there is a decrease in quality of marital relationship, communication, joint activities, and shared experiences (Epstein, et al., 2006). As Stephen and Qualls (2007) suggest, couples will "need to renegotiate intimacy. Dementia impairs a person's ability to plan, execute, and follow up actions with sensitivity to context and social nuance" (p.55). This can interfere with the "sequencing of behaviors" needed to physically perform sexual acts (Kuppuswamy et. al., 2007, pg. 77).

Physical intimacy for couples in which one partner has Alzheimer's disease has its unique challenges (Connidis, 2010). According to Davies, Zeiss, Shea, and Tinklenberg (1998), "The subject of sexuality in older adults is especially difficult to confront due to the conjunction of two strong beliefs: 1) sex is for the young, and 2) sex is for the cognitively intact" (p.196). In a healthy couple, these beliefs may act as a barrier to discussions on this topic among couples. With the addition of a cognitive impairment, the challenge is even greater. Although limited, researchers have explored specific topics of sexual function, activities and satisfaction for partners of persons with dementia (Davies, et al., 1998). This type of research is an effort to open discussion among couples and assist persons with dementia maintain physical intimacy.

The issue of consent is an important one in discussions of physical intimacy and dementia. Davies, Zeiss, Shea, and Tinklenberg (1998) found that caregivers of spouses with Alzheimer's disease voiced concerns about the ability of their partner to consent. This issue becomes more problematic as DAT progresses and at later stages the person with Alzheimer's disease may no longer recognize the spouse. In fact several strategies have been developed to help with this concern such as using a sexual permission system in which a clinician asks specific questions regarding sexual activities and assisting well spouses both verbal and nonverbal communication skills based on their partner's level of impairment (Davies, et al., 1998). However, researchers voice concern over the implementation of such intervention stating, "Although several models of intervention are available, few health care professionals directly address the subject. Cultural taboos, personal beliefs, and inadequate professional training contribute to the lack of existing help" (Davies, et al., 1998, p. 202).

In some marital relationships, the well spouse might experience a decline in physical intimacy needs. The increased burden of caregiving can decrease the well spouse's interest in pursuing physical intimacy with their partner caused by various factors such as fatigue and increasing responsibility for maintaining spouse's hygiene (Hayes, Boylstein, & Zimmerman, 2009). In Hayes, Boylstein, and Zimmerman's (2009) qualitative study of 28 spousal caregivers, some expressed feelings that the "child-like" care they provide to their spouse also decreased desirability during their interview.

In a longitudinal study of sexuality and Alzheimer's disease, researchers found that well spouses who maintain sexuality activity reported better health and less depression (Wright, 1998). In addition, rejection of physical intimacy can have a negative emotional impact on the person with dementia. According to Davies et al. (1998):

> The onset of the illness does not erase sexuality, but rather alters the way in which love is given and received. For some patients, remaining sexually active provides one of the few remaining ways in which they feel they can maintain their role identity and provide something of value to their partners. (p.195)

Well spouses may experience a myriad of emotions: frustration as cognitive decline impairs their partner's ability to perform, guilt when a partner no longer recognizes by name, or anger when the impaired spouse rejects sexual advances (Davies, et al., 1998). For couples in a traditional monogamous relationship, the absence of physical intimacy can be a huge loss as no other physical outlets involving another person are permissible due to self-imposed moral and social pressures regarding sexual acts with someone that is not your spouse. For some caregivers, this dilemma has been describes as being a “married widow” (Baxter, Braithwaite, Golish, & Olson, 2002).

Zarit (2001) argues that as the disease progresses, a shifting in the type of intimacy from emotional to physical or vice versa may occur. According to Kuppuswamy and colleagues (2007), caregivers have a myriad of emotional response including but not exclusive to: “anger, denial, acceptance, satisfaction, humor, fantasy, and feelings of victimization” (pg.80). Some participants in Hinchliff and Gott’s (2004) study expressed feelings of being close without having sex, suggesting the significance and continued relevance of emotional intimacy. LoboPrabhu et al., (2005) theorizes that some repetitive behaviors that may perceptive by the well spouse as clingy are an attempt regain closeness with the spouse. This behavior illustrates that the person with dementia maintains a desire to be connected to the spousal partner. In stark contrast to the need of some persons with dementia to maintain a physical connection, others may reject any attempts of emotional or physical intimacy.

Summary

The review of literature presented above indicates Alzheimer’s disease is proven to be a devastating disease for both the person with DAT and their spouse. There is a clear need for information and tools to assist couples with addressing the topic of emotional and physical intimacy. The subject of intimacy is complicated by a variety of definitions, but a common theme is the importance of both emotion and physical intimacy for marital couples. Further complicating matters is the fact that older adults and sexuality is an understudied area. This combination of factors creates greater trepidation for martial couples coping with Alzheimer's disease to discuss intimacy concerns.

My research examines two existing resources for marital couples by following a step-by-step procedure:

1) To identify the online resources available through the Alzheimer's Association and the National Institute on Aging that relate to understanding emotional and physical intimacy and Alzheimer's Disease

    a) What materials are available?
    b) To whom (e.g., professional vs. non-professional, and well-spouse or diagnosed spouse or marital unit) are materials targeted?

2) To examine the content of the available online resources, identifying the key patterns, themes, assumptions and messages conveyed within materials targeted to well spouses, diagnosed spouses, and/or the marital unit.

    a) What patterns, themes, assumptions, and messages are conveyed in the materials targeted to spouses regarding emotional intimacy?
    b) What patterns, themes, assumptions, and messages are conveyed in the materials targeted to spouses regarding physical intimacy?

CHAPTER 3: METHODS

This chapter outlines my research design and methods in five sections. I begin with a discussion of the research design and methods used in my study. This leads into a discussion of the organizational sources used for the text. Following this section, I identify my data sources including my justification for the sample selection and text classification. Next, I discuss the data set including descriptive charts of my final documents followed by the procedure for my content analysis.

Design and Methods

Research methods are tools that permit exploration of the world in a systematic way. The two primary research techniques for evaluating data are the use of quantitative and qualitative methods. Quantitative analysis focuses on the frequency or duration of observable data while qualitative analysis examines patterns of forms (Berg, 1995). Qualitative methods are useful in gathering of preliminary data of relatively unexplored topics (Berg, 1995). The use of the qualitative method allows examination of the form in which information is communicated in the context of a social/cultural environment (Berg, 1995). Content analysis is a common strategy for analyzing print materials and can be conducted using quantitative and qualitative approaches; the latter technique gives researchers the ability to identity themes within literature (Patton, 2002). As will be discussed, this type of analysis provides a window into information the researcher can chose to study on a directly observable and/or “manifest” level and underlying phenomenon or “latent” level (Boyatzis, 1998).

Organizational Sources for Texts

For purposes of this study, materials provided by websites for the Alzheimer’s Association and NIA will be the data sources. As mentioned earlier, both the Alzheimer’s

Association and the NIA are listed as important resources for patient information referrals (Patient Handbook: Reliable health information at NIHSeniorHealth.gov., 2005).

The Alzheimer's Association is a private, non-profit organization founded in 1980 (Alzheimer's Association, 2009). The National Headquarters is located in Chicago, Illinois with 77 chapters nationwide (Alzheimer's Association, 2009). Their mission is:

> To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health (Association, 2005, p.1).

The organization has two primary functions. The first function is to support the community by providing education and services to individuals and care partners facing Alzheimer's disease and other dementias (Association, 2009). The organization's second function is to fund research for Alzheimer's disease prevention, treatment, and ultimately a cure (Association, 2009). In their last fiscal year of 2008-2009, the Alzheimer's Association reported 5,617,875 visits to their website and 250,000 calls to their helpline (Association, 2009).

Second, the NIA is one out of 27 departments under the National Institute of Health (NIA, 2009). The institute was given authority by Congress in 1974 to provide leadership in aging research, programs, and serve as a primary Federal agency on Alzheimer's disease research (Aging, 2009).

Their mission is to:

> Support and conduct genetic, biological, clinical, behavioral, social, and economic research related to the aging process, diseases and conditions associated with aging, and other special problems and needs of older Americans; foster the development of research and clinician scientists in aging; communicate information about aging and advances in

> research on aging to the scientific community, health care providers, and the public. (Aging, 2009)

The Alzheimer's Association and NIA are resources on which caregivers draw both in terms of calling and requesting information and visiting their websites.

Aim 1: Sample Selection and Text Classification

Information was collected emulating the approach spousal caregivers and/or persons newly diagnosed with Alzheimer's disease might use to search for information for couples regarding physical and emotional intimacy. Each website was visited using the following web addresses: www.nia.nih.gov for the National Institute on Aging, and www.alz.org for the Alzheimer's Association. I conducted multiple keyword searches using the search engines available on these pages. In my searches, a total of 39 keyword searches were conducted (see Table 3.1). Keywords were chosen based on terminology used by caregivers and persons with Alzheimer's disease in transcribed interviews from research such as in those conducted by Hayes, Boylstein, & Zimmerman, (2009) and Baxter, Braithwaite, Golish, & Olson, (2002) as well as previous knowledge of the literature. Words such as intimacy, Alzheimer's, and relationship were used as initial keywords. Data collection occurred simultaneously for both websites over a four-day period. The first day a total of 32 initial keywords were chosen and based on initial results some keywords were combined (see Table 3.2). This process will be discussed later in the methods section. The second day the keyword searches for both websites were conducted and all results were printed thus allowing for the preservation of the records collected. The third and fourth days were used for reviewing and charting the search results.

Table 3.1

Initial Keyword Search Results

		Alzheimer’s Association		National Institute on Aging	
	Keywords	Initial Results	Google Refined Results	Initial Results	Google Refined Results
1	Intimacy	20	13	43	43
2	Intimate	18	9	45	45
3	Emotional Intimacy	12	9	28	28
4	Physical Intimacy	11	8	30	30
5	Marriage	50	15	64	64
6	Married	127	22	91	58
7	Partner	131	41	319	165
8	Couple	59	16	256	117
9	Spouse	107	34	262	136
10	Husband*	679	N/A	137	94
11	Wife*	539	N/A	122	81
12	Feelings	126	31	268	137
13	Emotion	30	15	251	123
14	Emotional+	227	53	409	N/A
15	Connect+	133	45	199	N/A
16	Connection+	93	36	780	N/A
17	Closeness	8	5	14	12
18	Confidant	4	2	3	3
19	Sharing+	203	38	655	N/A
20	Sex	54	23	402	171
21	Sexuality	18	11	65	44
22	Sexual	35	15	180	97
23	Desire*+	55	10	183	100
24	Attraction*+	1	1	5	5
25	Physical*+	439	N/A	1020	N/A
26	Touching	47	19	163	163
27	Affection	10	8	22	18
28	Relationship+	245	62	717	N/A
29	Alzheimer’s *+	12600	N/A	3200	N/A
30	Confide	0	0	0	N/A
31	Confiding	0	0	0	N/A
32	Confided	0	0	0	N/A

*Denotes keyword was combined for Alzheimer’s Association
+Denotes keyword was combined for the National Institute on Aging
N/A Denotes results did not undergo Google refinement process

Table 3.2

Initial Combined Keywords Results

		Alzheimer’s Association		National Institute on Aging	
	Combined Keywords	Initial Results	Google Refined Results	Initial Results	Google Refined Results
1	Husband and Intimacy	4	4	N/A	N/A
2	Wife and Intimacy	5	5	N/A	N/A
3	Emotional and Intimacy	N/A	N/A	22	22
4	Physical and Intimacy	11	8	30	24
5	Connect and Intimacy	N/A	N/A	34	20
6	Connection and Intimacy	N/A	N/A	28	17
7	Sharing and Intimacy	N/A	N/A	30	20
8	Desire and Attraction	0	0	3	3
9	Relationship and Intimacy	N/A	N/A	28	22
10	Alzheimer’s and Intimacy	20	13	40	25

A database was created using a multi-stage approach. A broad preliminary search was conducted for information containing any portion or form of the keyword. However, a function of the Google search application used by both websites omits duplicate entries thus reducing the total number of results per keyword (see Table 3.1). In addition, some keywords produced tremendous results. An example of this phenomenon was that the keyword “Alzheimer’s” that produced 12,600 results on the Alzheimer’s Association’s website. Therefore some keywords were combined with the word “intimacy”, the focus of the analysis, in an effect to refine the results (see Table 3.2). In contrast, some keywords yielded no results and were thus removed from the second stage of the data selection process.

The next stage, of the sample selection and data sorting, involved examining data sources. Many types of information surfaced as a result of the keyword search, including press releases, conference notes, research grant information, town hall meeting transcripts, resource lists, scientific journal articles, reports, blogs, message boards, multimedia resources such as videos or DVD's, advertisements, personal stories, documents in languages other than English, and various health-related information. These types of information were divided into seven major exclusionary categories in two separate charts for each organization: multimedia, personal stories/ messages/blogs, documents in other languages, materials related to the organization's operations, scientific journal articles, and materials unrelated to the proposed aims (see Appendix A and Appendix B).

The final stage involved examining the remaining materials and dividing them into three categories: professional audience, resource lists, and duplication (see Appendix C and Appendix D). Keywords that produced no remaining materials were removed in this stage. Documents that specifically addressed professional audiences such as physicians or professional caregivers or used language indicating instructional use for professionals were excluded to address the second aim of examining materials targeted to spouses. However, their numbers were recorded to answer a portion of the first aim (see Appendix C and Appendix D). Lists of journal articles targeted to researchers were also excluded. Lastly, materials that were duplicated in the results were also excluded.

Aim 2: Sample Selection and Text Classification

The exclusionary categories were selected based on the focus of the second research aim, for materials targeted to a spouse, and produced by one of the two organizations. To address the second part of the first research aim, the materials were examined for target audience (see

Appendix C and Appendix D). A final exclusionary category was created as a result a preliminary examination of the remaining materials that excluded three documents. These articles fit the inclusionary criteria but failed to discuss either physical or emotional intimacy.

Final documents selected contained one or more of the keywords were publications created by the organization, and their target audience was a general or lay population, caregivers, and/or persons with DAT (see Table 3.3, Table3.4, and Table 3.5). Based on the aforementioned criteria, ten documents were selected from the Alzheimer's Association's website and seven from the National Institute on Aging's website (see Table 3.3 and Table 3.4). In addition, four documents were produced from external links that met the inclusionary criteria with the exception that they were not produced by the organizations. However, these documents were highly relevant to the overall aim and were cited as references by the NIA and Alzheimer's Association thus were included in the results (see Table 3.5). Each article was then transcribed into a word document for analysis. From the articles selected, a descriptive chart was created with the URL, typed of material, target audience, stage of Alzheimer' s disease addressed, and summarization of each article (See Table 3.3, Table 3.4, and Table 3.5).

Data Set

After all inclusionary and exclusionary criteria were considered, ten documents were selected from the Alzheimer's Association's website and seven from the NIA's website (see Table 3.3 and Table 3.4). Four additional documents were produced from external links that met the inclusionary criteria. Two of the articles are from online caregiver support websites from the United Kingdom, while one is from a U.S. caregiver website, and another from an Australian website. A total of 21 materials comprised the data set for the content analysis to address the second aim. The sample size was smaller than initially anticipated due to the repetitive use of materials within both websites. For example, the inclusionary criteria produced the article *Early Stage Issues*. However upon further examination, the material was taken verbatim from the broader brochure *Living with Alzheimer's*. Thus, only the original article was included in the data set. The majority of the articles were brochures produced by the organizations that could be viewed in PDF on the website (see Table 3.3, Table 3.4 and Table 3.5). In addition, each website references two articles from their resource lists exclusively addressing the subject of intimacy and Alzheimer's disease.

Table 3.3

Alzheimer's Association Descriptive Chart

Title	**URL Location**	**Type of Material: Brochure/Web Based**	**Target Audience: Persons with Alzheimer's disease/Caregivers/General Audience**	**Stage of Alzheimer's Disease Addressed: Early/Middle/Late/All Stages**	**Document Summary**
Behaviors	http://www.alz.org/living_with_alzheimers_behaviors.asp	Brochure	Caregivers and General Audience	All Stages	This brochure focuses on common problematic behaviors that may be exhibited by a person with Alzheimer's disease and strategies for responding to these behaviors.
Changes in Relationships	http://www.alz.org/living_with_alzheimers_changes_in_relationships.asp	Web-Based	Caregivers	All Stages	This article is designed to assist caregivers with preparing for the changes in different relationships including marital due to a spouse's diagnosis of dementia.
Families and Friends	http://www.alz.org/living_with_alzheimers_families_and_friends.asp	Web-Based	Person with Alzheimer's disease	Early Stages	This article addresses how the person with dementia can cope with the evitable changes brought on by the progression of Alzheimer's disease through greater communication with loved ones and planning.
Grief, Mourning, and Guilt	http://www.alz.org/living_with_alzheimers_grief_and_loss.asp	Brochure	Caregivers and General Audience	All Stages	The purpose of this brochure is to normalize many of the emotions that may be felt by caregivers and provided steps for coping with each stage of grieving along with supportive resources.
Late Stage Care	http://www.alz.org/living_with_alzheimers_late_stage_care.asp	Web-Based	Caregivers and General Audience	Late Stages	This article is a guide for providing physical and emotional care for a person with Alzheimer's disease in the later stages.
Living with Alzheimer's: A Resource Guide for Families and Caregivers	http://sitesearch.alz.org/search?q=a+resource+guide+for+families+and+caregivers	Brochure	Caregivers and General Audience	All Stages	This is a comprehensive guide that addresses all areas of dementia from diagnosis to death with a focus on Alzheimer's disease including education about Alzheimer's disease, behavioral changes, coping strategies, and supportive resources for the caregiver.
Monitoring Abuse	http://www.alz.org/living_with_alzheimers_monitoring_abuse.asp	Web-Based	Caregivers and General Audience	Middle and Later Stages	This article focuses on the vulnerability of persons with dementia, defines abuse, emotional conditions that may lead to abuse, and resources for addressing this issue.
Sexuality	http://www.alz.org/living_with_alzheimers_changes_in_relationships.asp	Brochure	Caregivers and General Audience	All Stages	This document is designed as a fact sheet that discusses how intimacy and sexuality are affected by dementia, behavioral changes in the person with dementia, and supportive resources for the caregiver.
Take Care of Yourself	http://www.alz.org/stresscheck/answers.asp	Brochure	Caregivers	All Stages	This brochure designed to assist caregivers in recognizing symptoms of excessive caregiver stress, exploring strategies for coping with stress, and identifying supportive resources.
Younger-Onset Alzheimer's	http://sitesearch.alz.org/search?q=younger+onset+brochure&btnG.x=0&btnG.y=0&btnG=Google+Search&ie=&restrict=core_national_office&site=core_national_office&output=xml_no_dtd&client=alz&lr=&proxystylesheet=alz&oe=	Brochure	Persons with Alzheimer's disease and General Audience	Early Stages	This brochure addresses the unique concerns of persons with younger onset, planning for the future, and coping strategies.

Table 3.4

National Institute on Aging Descriptive Chart

Title	URL Location	Type of Material: Brochure/Web Based	Target Audience: Persons with Alzheimer's disease/Caregivers/General Audience	Stage of Alzheimer's Disease Addressed: Early/Middle/Late/ All Stages	Document Summary
Alzheimer's Disease: Unraveling the Mystery	http://www.nia.nih.gov/Alzheimers/Publications/Unraveling/ (PDF) Alzheimer's Disease: Unraveling the Mystery	Brochure	General Audience and Caregivers	All Stages	This brochure is designed to explain the biology of an Alzheimer's disease diagnosis, treatment, and research as well as discuss Alzheimer's disease's impact on the person with DAT and caregiver.
Caring for a Person with Alzheimer's Disease: Your Easy-to-use guide from the National Institute on Aging	http://www.nia.nih.gov/Alzheimers/Publications/caregiverguide.htm (PDF) Caring for a Person with Alzheimer's Disease: Your Easy-to-use guide from the National Institute on Aging	Brochure	General Audience and Caregivers	All Stages	A comprehensive guide for the care of someone with Alzheimer's disease including: education about Alzheimer's disease, caregiving strategies, self-care for the caregiver, and supportive resources.
Challenging Behaviors: Special Issues for Family Care	http://www.nia.nih.gov/Alzheimers/Publications/challenging.htm	Web-Based	Caregivers	All Stages	This brochure focuses on common problematic behaviors that may be exhibited by a person with Alzheimer's disease and strategies for responding to these behaviors.
Connections Vol. 13 No.1-2	http://www.nia.nih.gov/Alzheimers/ResearchInformation/Newsletter/	Brochure	General Audience, Persons with Alzheimer's disease, and Caregivers	Early Stages	This community publication discusses Alzheimer's disease in the early stages and the need for the person with Alzheimer's disease to have support.
End of Life: Helping with Comfort and Care	http://www.nia.nih.gov/HealthInformation/Publications/endoflife/ (PDF) End of Life: Helping with Comfort and Care	Brochure	Caregivers	Late Stages	This brochure is a guide for providing physical and emotional care for a person with Alzheimer's disease in the later stages.
Sexuality in Later Life	http://www.nia.nih.gov/HealthInformation/Publications/sexuality.htm (PDF) Sexuality in Later Life	Brochure	General Audience	Early Stages	This brochure addresses changes and possible issues that affect sexual activity in later life, the importance of addressing these changes, and coping strategies for maintaining sexual health.
Talking with Your Doctor: A Guide for Older Adults	http://www.nia.nih.gov/HealthInformation/Publications/TalkingWithYourDoctor (PDF) Talking with Your Doctor: A Guide for Older Adults	Brochure	General Audience	Early Stages	This comprehensive guide is designed to assist older adults with establishing better communication with their physician by providing older patients with educational tools and communication techniques.

Table 3.5

External Links Descriptive Chart

Title	URL Location	Type of Material: Brochure/ Web Based	Target Audience: Persons with Alzheimer's disease/Caregivers/General Audience	Stage of Alzheimer's Disease Addressed: Early/Middle/Late/ All Stages	Document Summary
Dementia: Sexuality and Intimacy	www.betterhealth.vic.gov.au	Web-Based	General Audience and Caregivers	All Stages	This document is designed as a fact sheet that discusses how intimacy and sexuality are affected by dementia, behavioral changes in the person with dementia, and supportive resources for the caregiver.
Intimacy, Marriage and Alzheimer's Disease	http://www.ec-online.net/Knowledge/articles/intimacy.html	Web-Based	Caregivers	Middle and Late Stages	A conversational style article that discusses dementia's impact on sexual relationships and how caregivers can cope with these changes to maintain a loving relationship.
Sex and Dementia	www.alzheimers.org.uk/factsheet/514	Web-Based	General Audience and Caregivers	All Stages	This document is an academic overview of healthy sexual intimacy, changes due to dementia, and coping strategies. The material also addresses issues of consent and abuse in persons with dementia.
Sexuality and Dementia: Coping with Changes in Your Intimate Relationship	www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=782	Web-Based	Caregivers	Early and Middle Stages	A conversational style article written from the perspective of a caregiver that discusses changes in a relationship due to a dementia diagnosis, coping strategies, and resources for educational and emotional support.

Content Analysis

Qualitative thematic analysis and coding, a form of content analysis mentioned above, was used to analyze the publication materials. Qualitative thematic analysis is the process of using inductive methods to observe patterns or themes within qualitative data (Boyatzis, 1998). The use of inductive methods is typically used to generate information from raw information and since no known prior research specifically on this topic exist this appears to be the most appropriate method (Boyatzis, 1998). Topics may not be directly stated but it is plausible to assume the authors wish to convey a message to the reader and thus becomes an example of a latent code (Boyatzis, 1998). Latent coding would include statements of advice or phrases that place judgment upon an occurrence.

The first stage is to look for themes and repeated statements within the materials (Luborsky, 1994). Therefore every article from the data set was read and re-read multiple times and a chart was made with the initial broad observations from each reading including direct quotations. From these broader observations, patterns emerged and the second stage consisted of classifying the information into units and then organizing them into categories by a constant comparative method thus allowing categorical themes to emerge (Rudestam & Newton, 2007). The results of this comparative method produced sub-categories of themes found throughout the article and charts were created demonstrating which sub-categories were contained in each article. Thus, using the above example, several statements reflecting upon a caregiver’s feelings as their spouse decline could be placed the categorical theme of a sense of loss. The third stage was assigning prospective categorical themes, common subjects that can be grouped under broader themes, within each document. For example, statements about the importance of communication and sexuality as a problematic behavior were seen in many of the articles and became a visible pattern during the analysis. As the primary aim of this research was to examine both forms of intimacy, an additional analysis further categorized the sub categories as related to physical or emotional intimacy. Therefore several statements reflecting upon a caregiver’s various feelings experienced due to the cognitive changes in their partner could imply that caregivers will experience many responses to the dementia diagnosis were categorized as an emotional response. The last stage was the finalization of categorical themes and assignment under each of the broader themes. This process involved the identification of five broader themes or latent codes in which the sub-categories were organized.

CHAPTER 4: RESULTS

This chapter addresses my research aims of identifying the online resources available through the Alzheimer's Association and the National Institute on Aging that relate to understanding emotional and physical intimacy and Alzheimer's disease. The chapter begins with a discussion of the observable data such as target audience and stage of Alzheimer's disease represented. Afterwards, I move into the portrayal of emotional and physical intimacy. Next, I address the overarching themes (including their sub-categories) that emerge regarding these topics. Last, I discuss overall observations and provide comparisons between the two websites and external links.

Aim 1: Target Audience and Stages of Alzheimer's Disease Represented

Examination of the exclusionary data, illustrated that materials targeting professional audiences were in the minority (see Appendix C and Appendix D). Thus the majority of materials on both websites were targeted to non-professional audiences. Only 3% from the Alzheimer's Association's 75 remaining articles and 31% from the National Institute on Aging 152 remaining articles were designed exclusively for professionals. The data set provided the materials available regarding the subject of Alzheimer's and intimacy targeted to non-professionals. Of these remaining materials, fifteen of the articles address the needs of the caregiver with only a total of three, two articles from the Alzheimer's Association and one article from the NIA's website, of the twenty-one articles solely addressing the person with dementia. Only in the articles *Living with Alzheimer's*, *Younger Onset*, and *Connections* is the person with dementia directly addressed. In addition, emotional intimacy issues for persons with dementia were primarily addressed in articles in which they were the target audience which are the three previously mentioned articles.

A similar pattern held for the stages of Alzheimer's disease addressed in the materials. Most of the articles from both websites addressed all stages of DAT; but a total of five pieces focused solely on the early stages of Alzheimer's disease while only three address solely or in part the later stages of Alzheimer's disease. Half of the articles from the external links included all stages and the remaining two articles addressed middle and early or late stages.

Aim 2: Emerging Themes: Latent Coding Results

Five major themes emerges among both websites (and their external links) that address the subject of emotional and physical intimacy on a latent level. These categories include: (a) defining sexuality and intimacy, (b) changes that occur in the relationship due to a dementia diagnosis, (c) reasons for the change in the relationship, (d) responses to a dementia diagnosis, and (e) strategies for managing the changes due to a dementia diagnosis. In what follows, I discuss each theme in detail beginning with emotional and physical intimacy followed by the five broader themes.

As shown in Tables 4.1, 4.2, and 4.3, three separate charts were created for the Alzheimer's Association website, National Institute on Aging websites and the external links. The top horizontal column lists the articles from the data set. Directly underneath each article a "P" and "E" are listed representing a category for physical and emotional intimacy. The determination of physical or emotional intimacy was based on the choice of language used to communicate a message to the reader within each selected statement. In some instances, both could be communicated at the same time. The vertical columns represent each of the five broad categories with the sub-categories for each broad theme listed underneath. In some of the themes, sub-categories were duplicated.

Therefore every sub-category can be viewed in relation to physical or emotional intimacy and in which articles within the dataset contained the sub-category (see Table 4.1, Table 4.2, and Table 4.3).

Table 4.1

Content Analysis Emerging Themes and Sub-Categories of Alzheimer's Association Website Articles

Emerging Themes	Younger Onset Alzheimer's		Taking Care of Yourself		Sexuality		Monitoring Abuse		Living with Alzheimer's		Late Stage Care		Grief, Mourning, and Guilt		Families and Friends		Changes in Relationships		Behaviors	
P=Physical and E= Emotional	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**
Defining Sexuality and Intimacy																				
Sexual Activity as a Healthy Part of a Relationship	♦																			
Sex, Intimacy, and Touch are Basic Human Needs					♦	♦			♦	♦	♦	♦					♦	♦		
Changes that Occur in the Relationship Due to a Dementia Diagnosis																				
Sexual Relationship Can Continue with a Partner with Alzheimer's Disease	♦				♦										♦					
Role Change of Spouse	♦	♦				♦									♦		♦	♦		
Reasons for the Change in the Relationship																				
Changes in Sexual Functioning	♦				♦				♦						♦		♦	♦		
Behaviors as Part of DAT or Associated with factors Unrelated to the Character of the Person DAT					♦				♦					♦	♦		♦		♦	
Changes in Behaviors as an Expected and Inevitable Part of DAT Process	♦		♦		♦		♦		♦					♦	♦			♦	♦	
Sexual Expression as a Problematic Behavior					♦		♦		♦								♦		♦	
Inability to Communicate Verbally					♦				♦	♦	♦	♦								
Responses to Dementia Diagnosis																				
Normalizing Feelings and Expression of Emotions		♦		♦		♦		♦		♦		♦		♦		♦		♦		♦
Anticipatory Emotions		♦		♦		♦		♦		♦		♦		♦		♦	♦	♦		♦
Feelings of Loss		♦				♦		♦		♦		♦		♦		♦		♦		
Strategies for Managing the Changes																				
Permission Giving		♦				♦		♦		♦				♦		♦		♦		♦
Spiritual Support								♦		♦										
Sensory Experience									♦	♦	♦	♦								
Normalizing Feelings and Expression of Emotions		♦		♦		♦		♦		♦		♦		♦		♦		♦		♦
Medicalization of Changes Related to Alzheimer's Disease					♦				♦									♦		
Caregiver Coping is Necessary and Should be Personalized	♦	♦			♦	♦		♦	♦	♦				♦						
Importance of Maintaining a Sense of Independence for the Person with Alzheimer's Disease		♦								♦						♦				
Importance of Maintaining a Sense of Empowerment		♦								♦						♦				
Importance of Touch					♦				♦	♦	♦	♦					♦	♦		
Importance of Communication		♦						♦		♦				♦	♦	♦		♦		
Inability to Communicate Verbally					♦					♦	♦	♦								
Emotional Support and Well-Being		♦				♦				♦		♦		♦		♦	♦	♦		
Formal Support		♦		♦		♦		♦		♦		♦		♦		♦		♦		♦
Informal Support		♦		♦		♦		♦		♦		♦		♦		♦		♦		♦
Adjustment Strategies	♦	♦		♦	♦	♦		♦	♦	♦	♦	♦	♦	♦	♦		♦	♦		♦

Table 4.2

Content Analysis Emerging Themes and Sub-Categories of National Institute on Aging Website Chart

Emerging Themes	Talking with Your Doctor		Sexuality in Later Life		End of Life		Connections		Challenging Behaviors		Caring for a Person with Alzheimer's		Unraveling the Mystery	
P=Physical and E= Emotional	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**
Defining Sexuality and Intimacy														
Sexual Activity as a Healthy Part of a Relationship	♦		♦											
Sex, Intimacy, and Touch are Basic Human Needs			♦	♦					♦		♦	♦		
Changes that Occur in the Relationship Due to a Dementia Diagnosis														
Sexual Relationship Can Continue with a Partner with Alzheimer's Disease	♦	♦	♦	♦							♦			
Role Change of Spouse												♦	♦	♦
Reasons for the Change in the Relationship														
Changes in Sexual Functioning	♦		♦											
Behaviors as Part of DAT or Associated with factors Unrelated to the Character of the Person DAT			♦	♦					♦	♦	♦	♦		♦
Changes in Behaviors as an Expected and Inevitable Part of DAT Process					♦				♦		♦	♦	♦	
Sexual Expression as a Problematic Behavior			♦						♦		♦		♦	
Inability to Communicate Verbally					♦				♦					
Responses to Dementia Diagnosis														
Normalizing Feelings and Expression of Emotions		♦		♦		♦		♦		♦		♦		♦
Anticipatory Emotions		♦		♦				♦				♦	♦	♦
Feelings of Loss		♦		♦				♦		♦	♦	♦		
Strategies for Managing the Changes														
Permission Giving		♦						♦		♦		♦		
Spiritual Support						♦						♦		
Sensory Experience						♦			♦					
Normalizing Feelings and Expression of Emotions		♦		♦		♦		♦		♦		♦		♦
Medicalization of Changes Related to Alzheimer's Disease	♦		♦						♦		♦		♦	
Caregiver Coping is Necessary and Should be Personalized	♦		♦	♦		♦			♦		♦	♦	♦	
Importance of Maintaining a Sense of Independence for the Person with Alzheimer's Disease								♦						♦
Importance of Maintaining a Sense of Empowerment		♦						♦						♦
Importance of Touch			♦								♦	♦		
Importance of Communication				♦		♦		♦		♦		♦		♦
Inability to Communicate Verbally					♦	♦			♦					
Emotional Support and Well-Being		♦		♦		♦		♦		♦		♦		♦
Formal Support		♦	♦	♦		♦		♦		♦		♦		♦
Informal Support						♦				♦		♦		♦
Adjustment Strategies	♦	♦	♦	♦		♦			♦	♦	♦	♦	♦	♦

Table 4.3

Content Analysis Emerging Themes and Sub-Categories of External Links Website Chart

Emerging Themes	**Sexuality and Dementia**		**Sex & Dementia**		**Intimacy: Marriage, & AD**		**Dementia: Sexuality and Intimacy**	
P=Physical and E= Emotional	**P**	**E**	**P**	**E**	**P**	**E**	**P**	**E**
Defining Sexuality and Intimacy								
Sexual Activity as a Healthy Part of a Relationship	♦	♦	♦	♦	♦		♦	♦
Sex, Intimacy, and Touch are Basic Human Needs	♦	♦	♦	♦	♦	♦	♦	♦
Changes that Occur in the Relationship Due to a Dementia Diagnosis								
Sexual Relationship Can Continue with a Partner with Alzheimer's Disease	♦	♦	♦	♦	♦			
Role Change of Spouse		♦						
Reasons for the Change in the Relationship								
Changes in Sexual Functioning	♦		♦	♦	♦		♦	
Behaviors as Part of DAT or Associated with factors Unrelated to the Character of the Person with DAT	♦	♦		♦	♦	♦		♦
Changes in Behaviors as an Expected and Inevitable Part of the Disease Process	♦	♦	♦	♦	♦	♦	♦	♦
Sexual Expression as a Problematic Behavior	♦		♦		♦	♦	♦	♦
Inability to Communicate Verbally	♦		♦	♦				
Responses to Dementia Diagnosis								
Normalizing Feelings and Expression of Emotions	♦	♦		♦	♦	♦	♦	♦
Anticipatory Emotions	♦	♦		♦	♦	♦	♦	♦
Feelings of Loss		♦		♦		♦		
Strategies for Managing the Changes								
Permission Giving		♦		♦		♦		♦
Spiritual Support		♦						
Sensory Experience			♦	♦		♦	♦	♦
Normalizing Feelings and Expression of Emotions		♦		♦		♦		♦
Medicalization of Changes Related to Alzheimer's Disease	♦		♦					
Caregiver Coping is Necessary and Should be Personalized	♦	♦	♦	♦		♦		
Importance of Maintaining a Sense of Independence for the Person with Alzheimer's Disease								
Importance of Maintaining a Sense of Empowerment								
Importance of Touch	♦	♦	♦	♦	♦	♦	♦	♦
Importance of Communication	♦	♦		♦		♦		♦
Inability to Communicate Verbally		♦	♦	♦				
Emotional Support and Well-Being		♦		♦		♦		♦
Formal Support		♦		♦		♦		♦
Informal Support		♦		♦		♦		♦
Adjustment Strategies	♦	♦	♦	♦	♦	♦	♦	♦

Emotional Intimacy

In the emotional category, two themes were contained in every article. Responses to the dementia diagnosis and strategies for managing changes were found in 100% of the articles (see Figure 4.1). The bulk of information regarding emotional intimacy primarily refers to changes in physical strategies that a caregiver must make to maintain an emotional connection such as an emphasis on touch. For instance, Alzheimer's Association's article, *Late Stage Care,* suggested that, "Touch can be a powerful connector. Hold your loved one's hand. Give a gentle massage to the hands, legs, or feet. Give a kiss. Gently brush his or her hair." Emotional issues are widely discussed for persons with Alzheimer's disease, in articles targeted to that population such as in the *Younger Onset* brochure. The theme of emotional responses to a dementia diagnosis, from the articles of both websites and external links, was also found in 100% of all articles in contrast to its physical intimacy counterpart that had the lowest percentages (see Figure 4.1 and Figure 4.2). Another important observation is that the emotional sub-categories of this theme had the greatest prevalence within the articles. An example of this pattern is in recurring messages normalizing emotions that a caregivers and persons with dementia may experience. In the NIA's, *Challenging Behaviors*, this is illustrated by, "…difficult or frustrating situations will occasionally arise for the person with dementia and their caregiver." The lowest percentages were found in the theme of, changes that occur in the relationship, with the articles from the external links having the approximately 25% of the sub-categories (see figure 4.1).

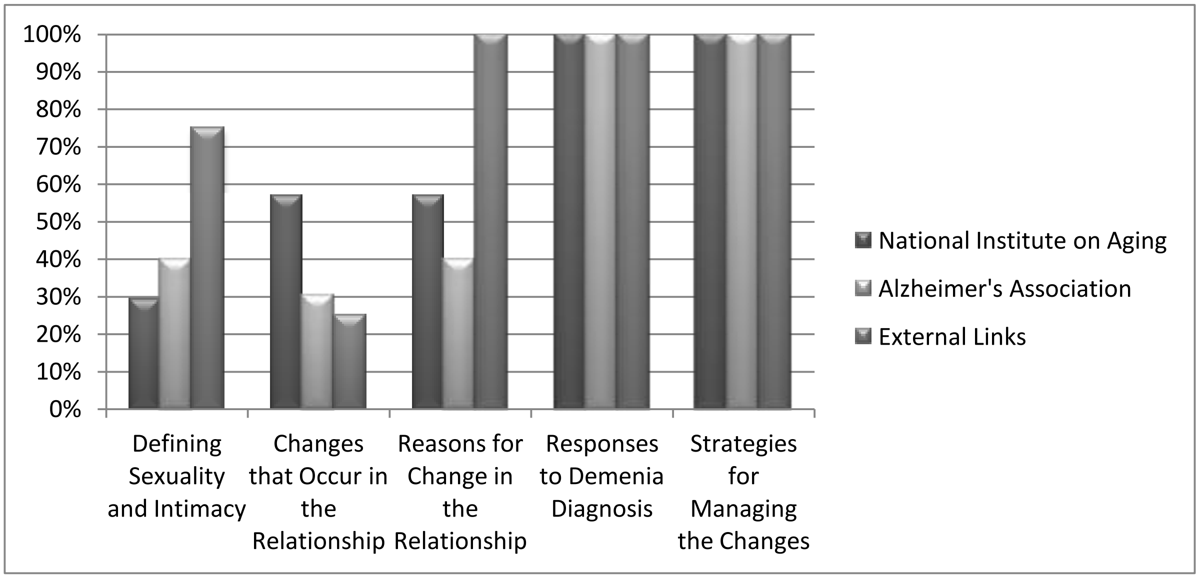

Figure 4.1
Percentages of Website Articles Per Theme Addressing Emotional Intimacy

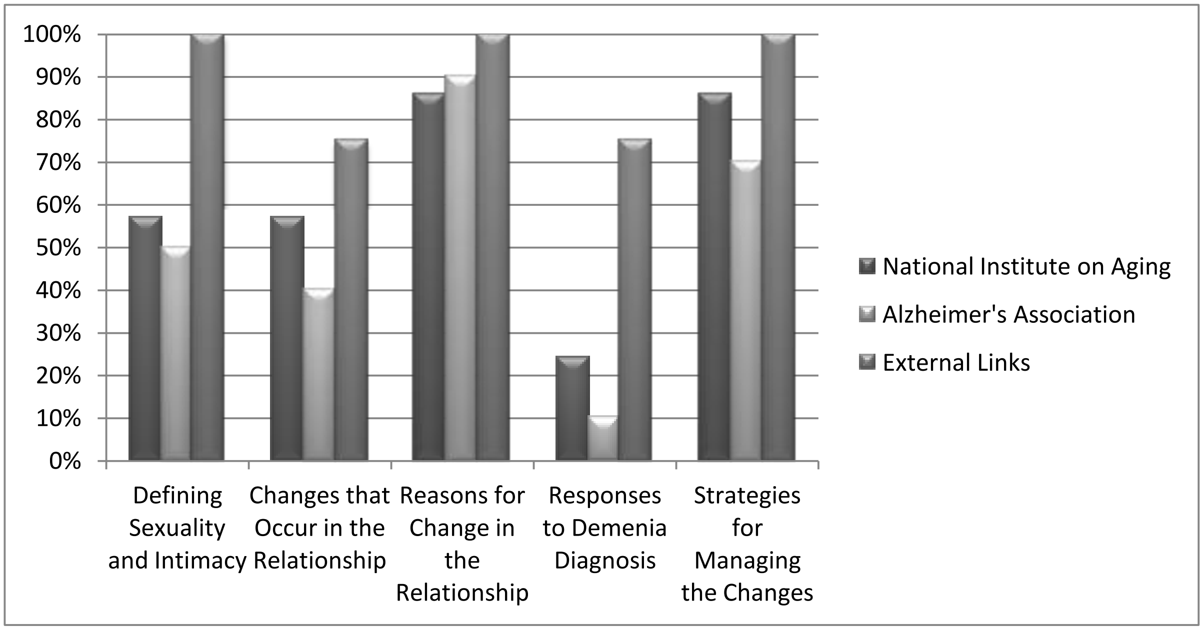

Figure 4.2
Percentages of Website Articles Per Theme Addressing Physical Intimacy

Physical Intimacy

The overall percentages for information within the websites regarding physically intimacy are significantly lower than measures for emotional intimacy (see Figure 4.1 and Figure 4.2). Again the topic of physical intimacy is not directly addressed in many articles. For example, the Alzheimer's Association's article, *Sexuality* explains, "…knowledge that your (physical) relationship will change." However, no detailed information is given regarding how the relationship will change. In contrast, the Alzheimer's Association's, *Living with Alzheimer's Disease* gives caregivers specific methods of response to sexual situations and behaviors such as, "Increase the level of appropriate physical contact. Give the person plenty of physical contact in the form of stroking, patting and hugging." In the NIA's article, *Challenging Behaviors*, a discussion on counseling includes the statement, "They may also suggest alternative forms of intimacy, other than intercourse." However, sexual activity as a part of a healthy relationship is not directly mentioned. Again, the reader is left with incomplete and ambiguous messages regarding physical intimacy.

The external links contain the highest percentages of sub categories on this subject and clearest definition of physical intimacy with three of the five themes addressed in 100% of the articles. An attempt at defining physical intimacy is made in every article. Coping strategies are explained in explicit terms. The UK's *Sex and Dementia* article suggests, "There are a number of ways to relieve pent up sexual tension-for example, taking exercise and other energetic activities can help reduce the physical tension, as can masturbation", when the partner with DAT loses the ability to perform coitus. This direct approach sends the message that sexual needs are normal.

Defining Sexuality and Intimacy

A recurring subject within many of the articles is the issue of defining intimacy and sexuality within the context of a relationship. Statements such as “intimacy is a special bond we share with a person we love and respect” and “sexuality is one type of intimacy” in the NIA’s, *Caring for a Person with Alzheimer’s disease* illustrate this point. However this was the only article in which intimacy is discussed on both emotional and physical levels. In most articles attempting to define intimacy, the focus of the definition is on the physical aspects of the relationship, with the emotional aspect only implied or briefly discussed such as in the Alzheimer’s Association’s *Younger Onset Alzheimer’s* which states, “continue to find ways for you and your spouse or partner to fulfill the need for intimacy” or in the NIA’s *Talking with your Doctor*’s statement “sexuality remains important in later life.” Considerable attention is given to the sub-category of sex, intimacy, and touch as basic human needs (see Table 4.1, Table 4.2, and Table 4.3). Every article that attempts a definition mentions the importance of physicality within a relationship such as in the Alzheimer’s Association’s *Sexuality* article which states, “realize that sexuality and the need for touching are very human drive” under the heading for caregivers of “understand causes of behavior.”

Changes that Occur in the Relationship Due to a Dementia

An additional prevailing theme involves physical and emotional changes in relationship for both the caregiver and person with Alzheimer’s disease. Articles within the Alzheimer’s Association’s websites, such as *Changes in Relationship,* concentrate more on the concept of role change for the spouse with statements such as, “You may find yourself taking on a new role in your relationship as your partner’s memory declines” and NIA’s, *Unraveling the Mystery,* “Many caregivers must assume new and unfamiliar roles in the family, and these changes can be both difficult and sad" illustrate this point. However, the NIA's website overall focuses more on the continuation of a sexual relationship with a partner with Alzheimer's disease. In the NIA's, *Younger Onset* brochure, awareness of possible changes to promote continuation of a sexual relationship is stressed for persons with Alzheimer's disease in statements such as, "Continue to find ways for you and your spouse or partner to fulfill the need for intimacy." However, this theme had the least number of supportive sub-categories among all articles (see Table 4.1, Table 4.2, and Table 4.3).

Reasons for the Change in the Relationship

Another common thread in the materials is educating caregivers and persons with dementia regarding reasons for the changes in the relationship brought on by Alzheimer's diagnosis. A major sub-category describes the changes as expected and inevitable thus illustrating that the relationship will be affected. In the Alzheimer's Association's, *Changes in Relationship*, the statement is made that, "Changes caused by the disease may cause the person with the disease to exhibit inappropriate behavior" and "The person with Alzheimer's disease may no longer be able to perform certain tasks, such as balancing the checkbook, doing the taxes, handling financial and legal matters." In NIA's, *Challenging Behaviors* article, a detailed description of the type of changes that may occur is given such as, "a loss of physical inhibitions." These all directly relate to changes in behaviors as part of DAT or associated with factors unrelated to the character of the person as the article goes on to explain that judgment of social norms can become impaired. This message is illustrated in NIA's, *Sexuality in Later Life,* by the statement, "Some people with dementia show increased interest in sex and physical closeness, but they may not be able to judge with is appropriate sexual behavior." The

Alzheimer's Association's article, *Behaviors*, directly states, "Alzheimer's disease and related dementias can cause a person to act in different and unpredictable ways."

In the Alzheimer's Association's, *Families and Friends* changes is sexual functioning by suggesting, "Seek professional counseling to discuss new factors in your relationship and changes in sexual relations" thus encouraging marital couples seek professional counseling to address sexual issues. Another common category is sexual expression as a problematic behavior as a reason for negative change in the relationship. In the NIA's, *Caring for a Person with Alzheimer's disease*, the concept of hypersexuality is explained,

> Sometimes, people with AD are overly interested in sex. This is called "hypersexuality." This person may masturbate a lot and try to seduce others. These behaviors are symptoms of DAT and don't always mean that the person wants to have sex.

This statement implies a problematic change in the relationship. In contrast to the excessive sexually behavior, NIA's, *End of Life*, discusses the later stages of DAT when a person may not be able to verbally communicate with "While you may not be able to communicate with the person through words, you can use other way to show the person reassurance and love." The Alzheimer's Association's *Sexuality* article encompasses all of the sub-categories under this theme again stating solid examples of the changes (see Table 4.1, Table 4.2, and Table 4.3). These categories all give explanation for the change in the relationship.

Responses to Dementia Diagnosis

A prevalent pattern seen throughout the articles is how both caregivers and persons with Alzheimer's respond to the diagnosis and changes associated with DAT. This area primarily focuses on the emotional aspects of intimacy especially for the caregivers (see Table 4.1, Table

4.2, and Table 4.3). The majority of the articles discuss loss in varying forms ranging from the potential loss of both physical and emotional connection. For the well spouse in the Alzheimer's Association's, *Sexuality* the article states, "realize that it's common for a caregiver to loss sexual desire because of the demands of caregiving…" and for the person with dementia "consider the possible reasons for reduced sexual desire: physical illness, hormonal imbalance, side effect of medication, depression and sensing a partner's emotional withdrawal." In the external links, *Sexuality and Dementia*, "The loss of the sexual relationship is a major part of the grief and sense of loss that caregivers experience while caring for a loved one." This emotional loss is also seen in the Alzheimer's Association's, *Changes in Relationship*, which states, "Given your partner's cognitive decline, you may no longer be able to have the same emotional or physical intimacy that you once shared."

Anticipatory emotions are also a common theme as many of the articles seek to normalize feelings. In NIA's, *Connections*, brochure for persons with the dementia, "many diagnosed people and their family members acknowledge the need to connect with others who are facing similar challenges, loss, anxiety, confusion, depression, isolation, and grief… ." In the Alzheimer's Association's *Grief, Mourning and* Guilt, both anticipatory emotions and loss are discussion in concert, "Alzheimer's gradually takes away the person you know and love. As this happens, you'll mourn him or her and experience the phases of grieving: denial, anger, guilt, sadness and acceptance." For caregiver's, the subject is addressed in the NIA's, *Unraveling the Mystery*, states that "all caregivers do not have the same emotional or physical responses to caregiving." For persons with dementia, the *Family and Friends* article from the Alzheimer's Association directly states that "you may be coming to terms with the diagnosis yourself or fear that others may feel uncomfortable around you."

This theme is most inclusive of both caregivers and persons with Alzheimer's disease addressing both audiences, and normalizing the emotions experienced by both (see Table 4.1, Table 4.2, and Table 4.3).

Strategies for Managing the Changes

The overwhelming message of all the articles is that new strategies will be needed to manage the changes brought on by Alzheimer's disease for both caregivers and persons with DAT. All of the articles give some form of advice or coping strategy such as in the articles from the Alzheimer's Association that all recommend some form of formal support (see Table 4.1, Table 4.2, and Table 4.3). Another example of advice giving is in the Alzheimer's Association's brochure, *Monitoring Abuse*, which suggests, "If you are having difficulty dealing with a stress related to caregiving, talk to someone for support." Thus, this theme had the greatest number of supportive sub-categories among all articles (see Table 4.1, Table 4.2, and Table 4.3). In the NIA's articles, physical and emotional adjustment strategies are mentioned in all but two of their materials. This pattern is illustrated in the sub-category caregiver coping is necessary and should be personalized in NIA's, *Unraveling the Mystery*:

> AD caregivers do not all have the same psychological and physical response to caregiving. For example, caregivers who have strong support systems and well developed coping skills may be able to weather the stresses of caring for a loved one with AD. Others who have few breaks form caregiving responsibilities and/or have preexisting illnesses may be more vulnerable to the physical and emotional stress associated with dementia care. Caregiver research is beginning to discover effective ways to ease the burden of caregiving.

This statement addresses how and why caregivers may differ in their coping needs.

In the Alzheimer's Association's article, *Living with Alzheimer's disease,* all sub-categories related to emotions were captured in phrases such as addressed to people with DAT, "after the diagnosis, you may be going through a range of emotions", "express your frustrations and emotions. Don't keep your feelings to yourself" and "you can still find comfort in your family and friends." These phrases also tie into the importance of communication is another area of emphasis both verbally and non-verbally. In *Families and Friends*, from the Alzheimer's Association, several strategies are shared for both the well spouse and person with Alzheimer's disease. As in the previously cited quotes, persons with Alzheimer's are encouraged to talk with their partner, share their emotions with friends, and let others know how to support them. These statements all imply the importance of maintaining a sense of empowerment for the person with dementia. Other examples of statements of empowerment and maintaining independence for the person with dementia are in the Alzheimer's Association's articles, *Younger Onset* stating, "Living with Alzheimer's was not what you planned. But you have the power to make a new plan with Alzheimer's in the picture" and *Families and Friends*, "Continue to participate in as many activities as you can."

As stated in previous theme, in the Alzheimer's Association's article, *Families and Friends,* well spouses are encouraged to share educational information and seek professional counseling regarding changes in sexual relations. However, non-counseling related, medical interventions are suggested as a solution in a total of ten articles. The primary suggestion is the use of prescriptions for the person with Alzheimer's disease such as in the external link's, *Sex and Dementia*, that suggests, "Medication might be considered as a last resort…" or discussions of institutionalization as in *Unraveling the Mystery* which discusses, "One of the hardest decisions that many families face is whether and when to place a loved one with AD in a nursing home or other type of care facility.” However, the overall message regarding strategies for managing the changes due to Alzheimer’s disease is positive and encourages couples to take proactive measures.

Overall Observations

Within both websites and external links, the majority of the sub-categories were included in at least one article on the website. In addition, all four articles from external links contain nearly of the sub-categories and all of the five major themes of the originating websites (see Table 4.3). This conveys that more commonalities than differences exist in the messages conveyed regarding physical and emotion intimacy. An example of this pattern is that both websites recommending formal and informal support as a coping strategy, this phenomenon was illustrated. However, the Alzheimer Association’s website recommended formal and informal support in every document. The target audiences for most of the articles were caregivers.

Even with the many commonalities between the websites, there were areas of substantial difference. The starkest contrast exists between the articles in the external links and information found on both websites. The external link articles have the highest percentages of sub-categories of all articles (see Figure 4.1 and Figure 4.2). They also provide the most concrete and direct language. In many of the articles originating from the two websites, issues around intimacy are implied instead of directly stated. The subtle message is that sexuality remains a somewhat taboo subject especially in later life. However, no singular article contains of all the sub-categories pertaining to both physical and emotional intimacy. Thus, there is an opportunity for improvements in the materials available to both well and impaired spouses to be made.

CHAPTER 5: DISCUSSION

The previous chapter fulfills my research aims to identify what materials are available and to whom through the Alzheimer's Association and the National Institute on Aging that relate to understanding emotional and physical intimacy and Alzheimer's disease. The sub-categories and emerging five major categories of information answer in part what patterns, themes, assumptions, and messages are conveyed in the materials targeted to spouses regarding emotional and physical intimacy. However, broader analysis is needed to examine these findings in a social context.

As previously mentioned, many commonalities exist between the two websites. Information for caregivers was available in abundance for suggesting strategies for managing the changes brought about due to Alzheimer's disease in a spouse. Information provided in both websites stressed the importance of seeking support both formal and informal. Emotional health and well-being are at the center of this advice. Researchers' such as Davies discuss the need for supportive interventions for both well spouse and person with dementia (Davies, et al., 1998). However, there were areas of substantial differences in approaches to conveying health information. The NIA's website provided a broader scope of materials that focused not only on issues related to dementia but issues related to aging in general. Sexuality and aging are discussed in two out of its seven documents thus reflective of a previous researcher's findings that the majority of older adults remain sexually active in some form in spite of various health conditions (Lindau et al., 2007). In contrast, the Alzheimer's Association's website targeted issues related to dementia. Therefore, one would assume that the topic of intimacy and Alzheimer's disease would be thoroughly expounded. However, the one article with intimacy as a focal point *Sexuality*, Alzheimer's Association, primarily focused on the physical and problematic changes related to the person with Alzheimer’s disease. This article would have been a prime opportunity to address both physical and emotional intimacy in detail. Again, this finding could support research regarding the potential barriers that cultural taboos could limit discussion of this topic (Davies, et al., 1998).

Even with potential barriers to information, emotional intimacy is widely communicated throughout both websites. In Guerrero’s study of attachment and marital satisfaction, emotional communication and the importance emotional communication is indeed emphasized as a coping strategy (Guerrero, 2009). Although not directly stated, reoccurring categories such as the importance of communication and touch suggest that an emotional connection is vital to the health of the relationship. Indeed Braun’s investigation of the connection between marital communication among spouses of persons with dementia and caregiver depression, is echoed in the Alzheimer’s Association’s article, *Changes in Relationships* when discussing the importance of reassuring touch as a form of communication when a person with dementia losses the ability to verbally communicate. The article goes on to discuss how vital this form of non-verbal communication is to the well spouse as a means of remaining emotionally connected.

The idea of maintaining a physical connection in a sexual form also is addressed, though not as directly. Sexuality is primarily addressed in terms of coping with problematic behaviors. These articles are targeted to the well spouses with suggestions of how to handle and explanations for possible causes of various scenarios such as undressing in public. By primarily framing this subject in a negative light, the underlying message is sexuality is problematic. Very few references are made on how to negotiate sexuality as a martial Alzheimer’s disease progresses. As stated by previous researchers older adult sexuality have been very limited due to common prejudices and attitudes about older adults (Butler, Lewis, Hoffman, & Whitehead, 1994). The beneficial effects of couple's therapy is absent from the articles as well.

The external links provided by far the most comprehensive information. Most articles touch on each of the major themes. However, it should be noted that even with the article's broader coverage, one article did not contain all of the sub-categories. The most striking difference was in language usage. A direct approach to the topic of physical intimacy is missing from most of the articles. As Davies discussed, this would imply that cultural taboos regarding physical intimacy exist in professional training as presumably all articles were created by professionals (Davies, et al., 1998). Specifically these taboos would apply to the United States' cultural as most of the external links were produced this country.

Omissions and Assumptions

As anticipated from the literature review, sexuality for older adults continues to be marginalized. The majority of articles addressing sexuality did so in terms of a problematic behavior or in medical terms. Fewer sections within the articles address sexuality in terms of enjoyment and fulfillment for a healthy relationship. Even though Alzheimer's disease is a medical condition, the positive aspects of sexuality and relationships could be discussed in greater detail. The overwhelming latent message is that sexuality in later life is problematic even without a dementia diagnosis. An example of this phenomenon is the statement within the article *Talking with your Docto*r from the NIA that"...sexuality remains important in later life." However, the entirety of the piece is centered on all the problems that can occur to impede sexuality.

In fact, sexuality is defined as a "sensitive subject", within the article *Talking with your Docto*r from the NIA, thus again framing it in a precarious light. When Alzheimer's disease is discussed, the subject is examined separately from sexuality in a section on discussing memory problems with your physician. The compartmentalization continues as sexuality is often isolated in the article from discusses of sexual behaviors in persons with dementia. As discussed earlier, the starkest contrast is within discussions of sex and Alzheimer’s disease is in the use of direct language regarding sexuality. The articles in the external links had the most progressive approach to subject of sexuality by using concrete terminology and specific examples of sexual expression. The omission of direct language implies a stigma attached to the subject of sexuality.

The issue of consenting to physical intimacy for both the caregiver and person with dementia varied greatly throughout the dataset. Some articles originating from both websites briefly discussed that a person with dementia may have a diminished capacity for understanding sexual acts or that a person with dementia may become overly sexual. Again this places physical intimacy within the context of a medical or clinical lens thus negating the benefits of physical intimacy in maintaining a healthy relationship. However, the topic of consent is never directly addressed. Even the word “consent” is only used in the Alzheimer’s Association’s article *Monitoring Abuse*, but this is not specific to spouses and generally implies a non related person and as a problematic behavior of the caregiver. This could send the underlying message that within a marriage, spouses are always expected to consent to their partners’ sexual advances, and when one spouse experiences a disease process such as Alzheimer’s, this is the only time when sexual advances can be questioned.

In contrast, capacity to consent to sexual relations is directly addressed in *Sex and Dementia*, from the external links, in a separate section dedicated to this subject alone. This topic is missing within both websites. The article broadens this issue for caregivers by a discussion on how a history of sexual aggression may promote more aggression upon onset of Alzheimer’s disease and a more proactive strategy may be needed to cope with this change. This directly relates to the discourse in the literature review of how the previous marital health of the relationship affects the dynamics and coping strategies for challenging behaviors. For the caregiver in the same article, specific instructions are given on what to look for regarding consent including “nonverbal cues.” The direct approach to this discussion is missing from most of the articles as well as the emotional concern of the well spouse that sexual expression is a consensual act with their partner. The article *Intimacy, Marriage, and Alzheimer’s disease*, expands the idea of emotional distress in the well spouse by frankly stating the fear of “raping their spouse.” The use of the word “rape” is exemplifies the model of addressing issues candidly. This is reflective in Davies, Zeiss, Shea, and Tinklenberg (1998) findings that caregivers of spouses with Alzheimer’s disease voiced concerns about the ability of their partner to consent.

For persons with dementia, the high volume of information directed to caregivers could have the underlying message that their needs are not as important as the person providing care. For example, *Families and Friends*, from the Alzheimer’s Association, directly addresses the individual with dementia in sections. However, the majority of the information discusses the challenges the person with dementia will have and various coping strategies for these changes. In addition, the language used within many articles labels sexual behaviors as primarily problematic in persons with dementia. The unintended latent message for persons with dementia could be one of becoming a burden to their loved ones. This limited quantity of information could be the result of historically persons with DAT being diagnosed in the later stages of Alzheimer’s disease. However, as persons with dementia are diagnosed at earlier ages and stages of Alzheimer’s disease, the demand for information within this population will grow. Hopefully, this will result in an increase of materials for this audience

The awareness of diversity within the populations of persons faced with the Alzheimer's disease is acknowledged in some of the articles and should be mentioned. The target population for the purposes of the analysis is heterosexual married couples. However same sex relationships are mentioned in the *Sex and Dementia* article from the external links. In addition, a discussion of cultural differences among caregivers is presented in NIA's *Unraveling the Mystery*. However the issue of cultural sensitivity is not raised specific to the subject of intimacy.

Strengths, Limitations, and Future Directions

This content analysis was a novel attempt to examine the availability and content of online resources accessible through the Alzheimer's Association and the National Institute on Aging that address emotional and physical intimacy for a marital unit. Until now this subject had not been examined through scientific means. In addition, one of the strengths of conducting a content analysis is the ability to study environments over different time periods (Berg, 1995). Therefore this study could be duplicated and reexamined repeatedly for changes in thematic content.

The major challenge existed in the process of gathering data. Every effort was made to emulate a spouse conducting a web search. However, my professional knowledge may have produced more materials than an average user would have received. Using numerous keywords, from the previously mentioned transcribed interviews, provided the closest representation of materials that would be assessed by the general public. The coding of materials was an additional challenge. The use of qualitative thematic analysis is dependent upon the perspective of the individual conducting the analysis and intra-rater reliability can be problematic (Whitley, 2002). Due to limited time and resources only one person coded the data collected. Lastly, history may have been a threat to internal validity by conducting the research in an environment (internet) that is subject to possible changes over time. As a preliminary study of materials available to spouses, making broader generalizations of the availability or composite of materials of other websites on the topic of emotional and physical intimacy is not appropriate.

Within articles from both websites, the topic of physical and emotional intimacy is touched on in varying degrees. However, neither website has an article exclusively discussing both subjects in their entirety. A document could be created combining the information throughout both websites. Ideally the material would be written in a unifying language for couples addressing both the person with dementia and the care partner. In addition, equal weight would be given to both the topic emotional and physical intimacy. Ideally a document that addressed intimacy would contain the following:

- A clear title that directly states the issues using words such as: dementia, intimacy, sexuality, partner, or marriage
- Inclusive language that addresses both the well and impaired partner as well as applying to unmarried and/or homosexual couples
- Physical and emotional intimacy would be defined and each addressed in separate sections including the benefits of each in a relationship
- A discussion on the impact of dementia in relationships both physically and emotionally
- The issue of consent would be addressed in a separate section for both the well spouse and spouse with dementia
- Adjustment strategies for both the well and impaired spouse such as:
    - Alternative forms physical expression
    - How to remain emotionally connected to your spouse

- A worksheet or questionnaire for couples to aid in discussions regarding intimacy issues addressing both the well spouses and person with dementia. Examples of potential questions would be:
    - Person with Dementia: Under what circumstances or physical/mental conditions would sexual contact with me would no longer be acceptable? If I no longer recognized you as my spouse, I exhibited fear or discomfort, etc.?
    - Well Spouse: Could I seek to have my physically intimacy needs met outside of the relationship? If so, at what point in the progression of Alzheimer's disease and/or number of years in a specific stage?
- Recommendations for interventions such as couples' therapy or support groups

Ideally these materials would be presented upon diagnosis, as part of an informational packet given to couples requesting resources, or in conjunction with involvement with a support group for persons in the early stages of dementia. In addition, this document would be listed as part of any key word search related to intimacy, sexuality, marriage, or relationships on both websites.

Results from both websites demonstrate that the topic of emotional intimacy needs further attention to assist couples with beginning a dialogue of how Alzheimer's disease will impact their relationship. As more couples are affected by this devastating disease, more information will be needed to assist them through their journey. Information that can assist spouses with beginning a dialogue regarding intimacy could provide vital support. As the findings demonstrate, other aspects of caregiving are addressed in great detail, such as changing communication styles, but intimacy, both physical and emotional, are not as widely addressed. By providing materials about the topic of emotional and physical intimacy from the onset of diagnosis, caregivers could be made aware of the possible challenges they may face. In addition, this could assist them with making different choices in how they cope with the changes in their spouse instead of being faced with a difficult situation and have no point of reference as to how to address the issue. In fact, many caregivers may not know that other spouses struggle with similar issues such as sexual consent. Access to this information would allow caregivers to recognize their commonalities with other spousal caregivers and perhaps gain confidence to discuss issues that are considered social sensitive.

As with caregivers, spouses with a dementia diagnosis will need education and tools for coping with the changes due to Alzheimer’s disease. As mentioned by Epstein, Auclair, and Mittelman (2006), persons with the dementia in the early stages can benefit from learning about coping strategies and participating in interventions such as counseling. These strategies can serve to assist the person with dementia in the early stages adapt coping strategies for the changes brought on by Alzheimer’s disease and thus empower the spouse with dementia. While the person with dementia is able to participate in dialogue regarding the future, this knowledge could kindle conversations regarding the impaired spouse’s wishes for how to manage intimacy issues throughout the disease process including how the spouse with dementia wishes the well spouse to care for their own intimacy needs. These types of conversations would also assist couples with navigating intimacy issues more successfully. In addition, these discussions could greatly reduce the stress in the well spouses as Alzheimer’s disease progresses in their partners by giving them more confidence in many of the decisions they will eventually have to make on their spouses’ behalf.

By examining the existing information, we have the opportunity to create a higher quality of information that will provide better counsel and support to spouses. Better comprehensive tools can also begin to address concerns some researchers' concerns over the implementation of interventions, such as couples' therapy, regarding this subject (Davies, et al., 1998) these interventions when introduced early in the diagnosis can help minimize the negative emotional impact of changes brought on by DAT. Professionals would also receive the information to begin the development sensitivity needed when issues regarding intimacy arise. This information would support professionals in their work of providing guidance to couples throughout this journey.

As the 6th leading cause of death (Centers for Disease Control and Prevention: Aging - Healthy Brain Initiative, 2010), Alzheimer's disease and its growing prevalence means more families and couples will be touched by Alzheimer's disease. These findings demonstrate that greater work needs to be accomplished to successfully address the topic of intimacy and the development of comprehensive materials. In so doing, this knowledge can be used to pursue guidelines for enhancement of existing literature aimed at improving quality of life for the ever-growing number of couples affected by Alzheimer's disease.

REFERENCES

2011 Alzheimer's Disease Facts and Figures. (2011). Alzheimer's Association, Chicago, Illinois. Retrieved November 7, 2011, from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

AARP (May, 2010). Sex, Romance, and Relationships: AARP Survey of Midlife and Older Adults. Washington, D.C. Retrieved November 7, 2010, from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

Adams, M., Oye, J. & Parker, T. (August, 2003). *Sexuality of older adults and the internet: From sex education to cybersex.* Sexual and Relationship Therapy. 18(3). 405-415.

Alzheimer's Association (2005). Basics of Alzheimer's Disease: What it is and what you can do. *Alzheimer's Association*. Chicago, Illinois: Alzheimer's Association.

Alzheimer's Association (2009). Alzheimer's Association Annual Report Fiscal Year 2009 (July 1, 2008 - June 30, 2009) (pp. 30). Chicago, Illinois.

Alzheimer's Association and National Alliance for Caregiving. (2004). Families care: Caregiving in the United States. Retrieved November 7, 2010, from http://www.alz.org/national/documents/report_familiescare.pdf.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders : DSM-IV-TR* (4th ed.). Washington, DC: American Psychiatric Association.

Baxter, L., Braithwaite, D., Golish, T., & Olson, L. (2002). Contradictions of interaction for wives of elderly husbands with adult dementia. Journal of Applied Communication Research, *30*(1), 1-26.

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. *Familly Process*, 49(2), 185-203.

Benbow, A. E. (2002). *Evaluating health information on the World Wide Web: a hands-on guide for older adults and caregivers*. SPRY Foundation, Washington, DC.

Berg, B. L. (1995). *Qualitative research methods for the social sciences*, 2nd edition. Boston, MA: Allyn and Bacon.

Birren, J. E., & Schaie, K. W. (2006). *Handbook of the psychology of aging*. (6th ed.). Burlington, MA: Elsevier Academic Press.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.

Centers For Disease Control and Prevention: Aging - Healthy Brain Initiative, (2010). Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion. Retrieved November 7, 2010, from http://www.cdc.gov/aging/aginginfo/alzheimers.htm

Coggan, J. M. (2003). AARP: Evaluating Health Information on the Internet Retrieved November 7, 2010, from <http://www.aarp.org/confacts/health/wwwhealth.html> *Journal of Consumer Health on the Internet*, *7*(4), 61-66.

Connidis, I. A. (2010). *Family ties & aging* (2nd ed.). Los Angeles: Pine Forge Press.

Davies, H. D., Zeiss, A. M., Shea, E. A., & Tinklenberg, J. R. (1998). Sexuality and intimacy in Alzheimer's patients and their partners. *Sexuality and Disability*, *16*(3), 193-203.

Dehle, C., Larsen, D., & Landers, J. E. (2001). Social support in marriage. *American Journal of Family Therapy*, *29*(4), 307-324. doi: 10.1080/01926180152588725

DeLamater, J. , & Moorman, S. (2007). Sexual behavior in later life. *Journal of Aging and Health*, *19*(6), 921-945.

Epstein, C., Auclair, U., & Mittelman, M. (2006). Couples counseling in Alzheimer's disease: first observations of a novel intervention study. *Clinical Gerontologist*, *30*(2), 21-35.

Federman, A., Sano, M., Wolf, M., Siu, A., & Halm, E. (2009). Health L

literacy and cognitive performance in older adults. *Journal of the American Geriatrics Society*, *57*(8), 1475-1480. doi:10.1111/j.1532-5415.2009.02347.x.

Flynn, K. E., Smith, M. A., & Freese, J. (2006). When Do Older Adults Turn to the Internet for Health Information? Findings from the Wisconsin Longitudinal Study. *JGIM: Journal of General Internal Medicine, 21*(12), 1295-1301. doi: 10.1111/j.1525-1497.2006.00622.x

Forgas, J. (2011). Affective influences on self-disclosure: Mood effects on the intimacy and reciprocity of disclosing personal information. *Journal of Personality and Social Psychology*, *100*(3), 449-461.

Garfield, R. (2010). Male emotional intimacy: How therapeutic men's groups can enhance couples therapy. *Family Process, 49*(1), 109-122.

Guerrero, L.,Farinelli,L., & McEwan, B. (2009). Attachment and relational satisfaction: The mediating effect of emotional communication. *Communication Monographs, 76*(4), 487-514.

Harper, J. M., Schaalje, B. G., & Sandberg, J. G. (2000). Daily hassles, intimacy, and marital quality in later life marriages. *American Journal of Family Therapy, 28*, 1-18.

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies, 23*(1), 48-59.

Hinchliff, S., & Gott, M. (2004). Intimacy, commitment, and adaptation: Sexual relationships within long-term marriages. *Journal of Social and Personal Relationships, 21*(5), 595-609. doi: 10.1177/0265407504045889.

Huyck, M.H. (2001). Romantic relationships in later life. *Generations, 25*(2), 9-17.

Kuppuswamy, M., Davies Helen, D., Spira Adam, P., Zeiss Antonette, M., & Tinklenberg Jared, R. (2007). Sexuality and intimacy between individuals with Alzheimer's disease and their partners: Caregivers describe their experiences. *Clinical Gerontologist, 30*(3), 75-81.

Maslow, K. & Heck, E. (2005). Dementia care and quality of life in assisted living and nursing homes: Perspectives of the Alzheimer's Association. *The Gerontologist: Dementia Care and Quality of Life in Assisted Living and..., 45*(1), 133-46. Retrieved October 5, 2010, from Research Library.

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. *The New England Journal Of Medicine, 357*(8), 762-774.

LoboPrabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia:How do they stay together "till death do us part"? *Journal of Gerontological Social Work, 44*(3-4), 161-174.

Logsdon, R. G., McCurry, S. M., & Teri, L. (2007). Evidence based interventions to improve quality of life for individuals with dementia. *Alzheimer's Care Today: Best Practices in Dementia Care, 8*(4), 309-320.

Mendez, M. F., & Cummings, J. L. (2003). *Dementia: A clinical approach* (3rd ed.). Philadelphia: Butterworth Heinemann.

Meyer, M. H., & Roseamelia, C. (2007). Emerging issues for older couples: Protecting income and assets, right to intimacy, and end-of-life decisions. *Generations, 31*(3), 66-71.

National Institute on Aging. (2009). About the National Institute on Aging Retrieved January 8, 2010, from http://www.nia.nih.gov/AboutNIA/.

National vital statistics reports: From the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System. (2010) (pp. 1-135). Hyattsville, Md.: National Center for Health Statistics.

Patient Handbook: Reliable health information at NIHSeniorHealth.gov. (2005). *Geriatrics, 60*(1), 38.

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Punch, K. (2005). *Introduction to social research: Quantitative and qualitative approaches*. London; Thousand Oaks, Calif.: SAGE.

Reuben, D. B., Roth, C. P., Frank, J. C., Hirsch, S. H., Katz, D., McCreath, H., et al. (2010). Assessing care of vulnerable elders—Alzheimer's Disease: A pilot study of a practice redesign intervention to improve the quality of dementia care. *Journal of the American Geriatrics Society, 58*(2), 324-329. doi: 10.1111/j.1532-5415.2009.02678.x

Rheaume, C., & Mitty, E. (2008). Sexuality and intimacy in older adults. *Geriatric Nursing, 29*(5), 342-349.

Roberto, K. A. (2001). Chronic Pain and Intimacy in the Relationships of Older Adults. *Generations, 25*(2), 65-69.

Rudestam, K. E., & Newton, R. R. (2007). *Surviving your dissertation: A comprehensive guide to content and process* (3rd ed.). Los Angeles: SAGE Publications.

Steinke, E. E. (2005). Intimacy needs and chronic illness: Strategies for sexual counseling and self-management. *Journal of Gerontological Nursing, 31*(5), 40-50.

Stephens, M., & Qualls, S. H. (2007). Therapy to help aging couples cope with dementia. *Generations, 31*(3), 54-56.

U.S. Census Bureau. (January, 2009). ‘‘America’s Families and Living Arrangements: 2008, Table A1. Marital Status of People 15 Years and Over, by Age, Sex, Personal Earnings, Race, and Hispanic Origin, 2008’’. Retrieved May 1, 2010 from http://www.census.gov/population/www/socdemo/hh-fam/cps2008.html.

Waring, E. M. (1988). *Enhancing marital intimacy through facilitating cognitive self-disclosure*. New York: Brunner/Mazel.

Whitley, B. E. (2002). *Principles of research in behavioral science*. New York, NY: McGraw-Hill.

Wright, L. K. (1998). Affection and sexuality in the presence of Alzheimer's Disease: A longitudinal study. *Sexuality & Disability, 16*(3), 167-179.

Zarit, J. (2001). A Tribute to adaptability: Mental illness and dementia in intimate late-life relationships. *Generations, 25*(2), 70-74.

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

APPENDICES

Appendix A

Alzheimer's Association Initial Results Based on Exclusionary Criteria

	Keywords	Initial Results	Multi-media	Personal Stories, Messages, & Blogs	Documents in Other Languages	Materials Related to Organization's Operations	Scientific Journal Articles	Materials Unrelated to Proposed Aims	Total Materials Remaining
1	**Intimacy**	13	1	0	0	2	0	0	9
2	**Intimate**	9	0	2	0	2	0	3	2
3	**Emotional Intimacy**	9	2	0	0	2	0	3	5
4	**Physical Intimacy**	8	2	0	0	3	0	0	3
5	**Marriage**	15	0	4	0	6	2	0	3
6	**Married**	22	0	4	0	11	3	3	1
7	**Partner**	41	1	0	0	31	1	5	3
8	**Couple**	16	1	3	0	8	3	0	1
9	**Spouse**	34	0	1	2	13	4	11	3
10	**Feelings**	31	1	1	2	11	3	8	5
11	**Emotion**	15	2	1	0	7	1	2	2
12	**Emotional**	53	0	4	2	24	3	17	3
13	**Connect**	45	0	2	0	20	2	15	5
14	**Connection**	36	0	0	1	21	2	10	2
15	**Closeness**	5	0	1	0	1	2	0	1
16	**Confidant**	2	0	1	0	1	0	0	0
17	**Sharing**	38	2	2	0	24	2	7	1
18	**Sex**	23	0	0	1	9	3	7	3
19	**Sexuality**	11	1	0	3	1	0	0	6
20	**Sexual**	15	1	0	3	3	1	2	5
21	**Desire**	10	0	0	0	6	0	2	2
22	**Attraction**	1	0	0	0	1	0	0	0
23	**Touching**	19	1	1	0	10	2	2	3
24	**Affection**	8	0	1	0	3	0	0	4
25	**Relationship**	62	1	0	1	44	4	7	5
26	**Husband and Intimacy**	4	2	0	0	1	0	0	1
27	**Wife and Intimacy**	5	2	0	0	1	0	0	2
28	**Physical and Intimacy**	8	2	0	0	3	0	0	3
29	**Desire and Attraction**	0	0	0	0	0	0	0	0
30	**Alzheimer's and Intimacy**	13	1	0	0	2	0	0	10

Appendix B

National Institute on Aging Initial Results Based on Exclusionary Criteria

	Keywords	Initial Results	Multi-media	Personal Stories, Messages, & Blogs	Documents in Other Languages	Materials Related to Organization's Operations	Scientific Journal Articles	Materials Unrelated to Proposed Aims	Total Materials Remaining
1	**Intimacy**	43	0	0	1	2	3	2	35
2	**Intimate**	45	0	1	1	17	7	8	11
3	**Emotional Intimacy**	28	0	0	0	5	3	0	19
4	**Physical Intimacy**	30	0	0	0	7	3	0	20
5	**Marriage**	64	0	0	0	24	17	0	5
6	**Married**	58	1	0	1	25	13	11	7
7	**Partner**	165	1	0	0	88	16	39	21
8	**Couple**	117	0	0	0	58	19	27	13
9	**Spouse**	136	2	1	2	54	17	35	25
10	**Husband**	94	0	3	0	30	12	33	16
11	**Wife**	81	0	4	0	22	8	32	15
12	**Feelings**	137	1	2	0	41	10	64	19
13	**Emotion**	123	1	0	0	78	6	22	16
14	**Closeness**	12	0	0	0	4	1	1	6
15	**Confidant**	3	0	0	0	1	2	0	0
16	**Sex**	171	1	1	0	66	37	51	15
17	**Sexuality**	44	0	0	5	9	4	7	19
18	**Sexual**	97	2	0	15	35	12	19	14
19	**Desire**	100	0	0	0	49	6	34	11
20	**Attraction**	5	0	0	0	4	1	0	0
21	**Touching**	163	5	2	0	41	14	75	26
22	**Affection**	18	0	0	0	8	2	0	8
23	**Emotional and Intimacy**	22	0	0	0	5	2	0	15
24	**Physical and Intimacy**	24	0	0	0	5	2	1	16
25	**Connect and Intimacy**	20	0	0	0	5	2	2	11
26	**Connection and Intimacy**	17	0	0	0	5	2	3	7
27	**Sharing and Intimacy**	20	0	0	0	5	1	1	13
28	**Desire and Attraction**	3	0	0	0	2	1	0	0
29	**Relationship and Intimacy**	22	0	0	0	5	1	2	14
30	**Alzheimer's and Intimacy**	25	0	0	0	3	1	2	19

Appendix C

Alzheimer’s Association Results Based on Final Exclusionary Criteria

	Keywords	Total Materials Remaining	Professional Audience	Resource List	Duplications	Final Materials List
1	**Intimacy**	9	0	1	2	6
2	**Intimate**	2	0	0	0	2
3	**Emotional Intimacy**	5	0	0	0	5
4	**Physical Intimacy**	3	0	0	0	3
5	**Marriage**	3	0	0	0	3
6	**Married**	1	0	0	0	1
7	**Partner**	3	0	0	0	3
8	**Couple**	1	0	0	0	1
9	**Spouse**	3	0	0	0	3
10	**Feelings**	5	0	0	1	4
11	**Emotion**	2	0	0	0	2
12	**Emotional**	3	0	0	0	3
13	**Connect**	5	0	1	3	1
14	**Connection**	2	0	0	0	2
15	**Closeness**	1	0	0	0	1
16	**Sharing**	1	0	0	0	1
17	**Sex**	3	0	0	0	3
18	**Sexuality**	6	1	2	1	2
19	**Sexual**	5	1	0	0	4
20	**Desire**	2	0	0	0	2
21	**Touching**	3	0	0	0	3
22	**Affection**	4	0	0	0	4
23	**Relationship**	5	0	0	0	5
24	**Husband and Intimacy**	1	0	0	0	1
25	**Wife and Intimacy**	2	0	0	0	2
26	**Physical and Intimacy**	3	0	0	0	3
27	**Alzheimer’s and Intimacy**	10	0	1	4	5

Appendix D

National Institute on Aging Final Results Based On Exclusionary Criteria

	Keywords	Total Materials Remaining	Professional Audience	Resource List	Duplications	Final Materials List
1	**Intimacy**	35	6	0	23	6
2	**Intimate**	11	3	1	5	2
3	**Emotional Intimacy**	19	1	1	8	9
4	**Physical Intimacy**	20	1	1	9	9
5	**Marriage**	5	2	0	1	2
6	**Married**	7	1	0	2	4
7	**Partner**	21	2	0	13	6
8	**Couple**	13	1	2	7	3
9	**Spouse**	25	2	4	10	9
10	**Husband**	16	2	1	7	6
11	**Wife**	15	0	1	8	6
12	**Feelings**	19	2	1	10	6
13	**Emotion**	16	2	4	5	5
14	**Closeness**	6	0	1	2	3
15	**Sex**	15	3	1	3	8
16	**Sexuality**	19	2	8	4	5
17	**Sexual**	14	3	2	4	5
18	**Desire**	11	2	1	5	3
19	**Touching**	26	2	4	11	9
20	**Affection**	8	0	1	2	5
21	**Emotional and Intimacy**	15	1	3	4	7
22	**Physical and Intimacy**	16	2	4	3	7
23	**Connect and Intimacy**	11	1	3	3	4
24	**Connection and Intimacy**	7	0	2	1	4
25	**Sharing and Intimacy**	13	2	2	1	8
26	**Relationship and Intimacy**	14	2	2	4	6
27	**Alzheimer’s and Intimacy**	19	2	7	5	5