VOICES OF HUSBANDS: POSITIVE ASPECTS OF CAREGIVING FOR WIVES WITH DEMENTIA

Mackenzie Hiemstra

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Committee:

Laura Landry-Meyer, Advisor
Nancy Orel
Wendy Watson
ABSTRACT

Laura Landry-Meyer, Advisor

The purpose of this mixed method study was to explore the voice of husbands to learn about the positive aspects of caregiving for a wife with dementia. The study utilized a semi–structured interview guide with open-ended questions and the Gain in Alzheimer’s Care INstrument with a sample of ten husbands. The husbands on average were caring for a wife with dementia for 7.45 years and averaged 77.8 years old. While listening to the audio–recorded interviews, themes were transcribed focusing on the positive aspects of caregiving and the overall caregiving experience. All husband participants stated at least one positive aspect of caregiving and eight of the ten husbands stated more than one positive aspect of caregiving. The most common positive aspect of caregiving for a wife with dementia that was found was still being able to do things with her and spend time with her and seven of the ten husbands stated this. Knowing their wives are getting proper and personalized care and their wives still knowing who they are were the second most mentioned positive aspects with five of the ten husbands stating these. Other positive aspects included things like growing closer to their wives and seeing them happy. All husbands stated that there was a change in the relationship with their wife. There were no linkages found between characteristics of husbands (e.g. age, length of time caregiving, length of marriage) and likelihood to increase or decrease the chances of them finding positive aspects of caregiving. This research used a strengths–based approach to the examination of caregiving from the perspective of the husband caregiver contributing to the gaps in the current literature while building upon the recently created Gain in Alzheimer’s Care INstrument.
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CHAPTER I: INTRODUCTION

According to the National Alliance for Caregiving (2009), there are about 65.7 million caregivers representing about 29% of the population in the United States. It is estimated that seven in ten caregivers care for someone over the age of 50 (National Alliance for Caregiving, 2009). Spouses are the most common caregivers over the age of 65 than in other age groups (Bookwala & Schulz, 2000). The greatest risk factor for dementia, specifically Alzheimer’s disease, is advanced age and it is estimated that 44% of the United States population between age 75-84 and 38% of the United States population age 85+ have Alzheimer’s (Alzheimer’s Association, 2014).

There are an estimated 5.2 million Americans currently diagnosed with Alzheimer’s disease, 210,000 in Ohio (Alzheimer’s Association, 2014). More women than men have some form of dementia, 3.2 million women compared to 1.8 million men (Alzheimer’s Association, 2014). Husband caregivers of wives with dementia are more common based on these demographics. It is estimated that one third of caregivers are men and 38% of the recipients being cared for by a spouse were women (National Alliance for Caregiving). In their study, Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbè and Caron (2006) found that 44% of caregivers are men and the majority are husbands caring for wives with a diagnosis of dementia.

Age ranges of husband caregivers in the literature have been as young as 48 (Baker, Robinson & Connelly, 2010) and as old as 96 (McLennon, Habermann & Rice, 2011). The estimated average age based on caregiving studies is about 72 years old (Baker et al., 2010; Cahill, 2000; Calasanti & King, 2007; Ducharme et al., 2006; Kramer, 1997; Kramer 2000; McLennon et al., 2011; Rose-Regó, Strauss & Smyth, 1998). Length of marriage for husband caregivers has not been studied specifically, but is included in sample descriptions (Baker et al.,
Ranges have been from 5 years (Baker et al., 2010) to 66 years (Kramer, 1997). More relevant is the length of time for husbands being in the caregiving role (Cahill, 2000; Ducharme, 2006; Kramer, 1997; Kramer, 2000; McLennon et al., 2011; Shim, Barroso & Davis, 2011; Shim, Barroso, Gillis & Davis, 2013; Siriopoulos, Brown & Wright, 1999). Length of time caregiving for wives ranges from less than a year (Siriopoulos et al., 1999) to 17 years (Kramer, 1997).

Husbands caring for wives with dementia spend more hours providing care than those who care for wives without dementia (Ducharme et al., 2006). Husband caregivers help wives with any and all activities from mowing the grass to incontinence care (Cahill, 2000; Ducharme et al., 2006). Husbands cope with caregiving in different ways ranging from journaling about their experience and taking a managerial approach in caregiving to self-medicating (Cahill, 2000; Calasanti & King, 2007; Siriopoulos, Brown & Wright, 1999; Raschick & Ingersoll-Dayton, 2004). Some husbands use formal services including adult day services, support groups and home care while others do not use these services and believe that it is an admittance of weakness to use services (Ducharme, et al., 2006; McFarland & Sanders, 1999; Siriopoulos et al., 1999).

**Positive Aspects of Caregiving**

Caregiving for a spouse with dementia can be an uplifting, fulfilling, and an emotionally close experience with many positive aspects and gains (Cahill, 2000; Ducharme et al., 2006; Hogstel, Curry & Walker, 2005; Kinney & Stephens, 1989; Kramer, 1997; Sanders, 2005). Focusing on the positive aspects is better for the health of the caregiver (Cohen, Colantonio & Vernich, 2002). Cohen and colleagues (2002) state that caregivers who define more positive aspects of caregiving might be shielded against negative effects of caregiving for themselves and the care recipients. Positive aspects of caregiving can buffer the negative effects of caregiving,
putting less stress on the caregiver, in turn creating a better environment for the care receiver (Cohen, Colantonio & Vernich, 2002; Liew, Luo, Ng, Chionh, Goh & Yap, 2010).

More positive aspects are associated with fewer depressive symptoms and greater subjective well-being for caregivers. Cohen et al. (2002) found in their study that 73% (N=211) of their participant caregivers could find at least one positive aspect of caregiving and another 6.9% could find more than one positive aspect of caregiving. Ducharme et al. (2006) state that in their study, 59% of husbands experienced a large or moderate amount of personal gratification from their caregiving role. McFarland and Sanders (1999) found that one of the male caregivers in their study believed that he lessened the burden by thinking about the fact that he was being educated throughout the disease. As the number of positive aspects rises, there are fewer burdens and less negative reaction to care receiver problems (Carbonneau, Caron & Derosiers, 2010). A husband participant in a study conducted by Shim et al. (2013) stated the importance of looking at the positives: “not to overlook the negative aspect, but if all you hear is caregiver stress and this and that, if that’s all you hear that’s what you’ll expect. But there are humorous times. There are positive things, and an opportunity to give back. So people should know that” (p.126).

The positive aspects of caregiving for a relative with dementia have not been investigated very thoroughly (Andrén & Elmståhl, 2005). Research and discussion about caregiving is doused in negativity and caregiver burden with a focus primarily on women as the caregivers (Carbonneau et al., 2010; Pinquart & Sorensen, 2011; Andrén & Elmståhl, 2005; Baker et al., 2010; Cohen et al., 2002; Kramer, 1997; McLennon et al., 2011). Caregiver burdens such as physical, emotional and financial strain, role stress, time restraints, and effects on work life are commonly stated (Ory, Hoffman, Yee, Tennstedt and Schulz, 1999).

Overall, caregiving research has lacked attention to husband caregivers of wives with
dementia from a strengths-based approach. A strengths–based approach acknowledges the toughness, but accentuates the importance of exploring personal characteristics, such as geographic location and influences in order to identify and focus on their strengths. Caregiving research is primarily focused on women’s experiences of caregiving, not men’s (Carbonneau, Caron, & Derosiers, 2010; Pinquart & Sorensen, 2011). With most research focusing on the women’s experiences and negativity, it is important to investigate the positives in order to improve the experience of caregivers, especially men. Exploring the positive aspects from the view of husband caregivers will shed more light into their caregiving experience (Yap, Luo, Ng, Chionh, Lim & Goh, 2010).

The purpose of this mixed method study is to explore the positive aspects of caring for a wife who has dementia from a husband caregiver’s view while utilizing a semi-structured interview combining qualitative questions with a quantitative instrument. This research will add to the current literature, giving voice to husband caregivers age 65 and older whose wives have dementia including Alzheimer’s. The research question that guided the investigation was: What are the positive aspects of caregiving for a wife with dementia? This research used a strengths-based approach to the examination of caregiving from a husband caregiver’s perspective contributing to the gaps in the current literature and it builds upon the use of a recently created quantitative instrument called the Gain in Alzheimer’s Care INstrument (GAIN) by Yap and colleagues (2010). GAIN was developed to identify the gains when caring for a person with Alzheimer’s Disease.

**Definition of Terms**

The following definitions refer to terms that are used throughout this research study.

*Husband* – any man legally married to a woman. For the purpose of this research,
heterosexual marriage will be the focus of the study.

*Caregiver* – A person who is unpaid that assists an older adult with activities of daily living.

*Husband Caregiver* - a man who is legally married to a wife and provides unpaid assistance with activities of daily living. Caregiving must have occurred for at least a 6 month duration while residing together, but does not have to currently be residing together.

*Activities of Daily Living* – actions of self-care that are typically done every day by individuals such as dressing, bathing, eating, etc.

*Dementia* - a progressive impairment of memory and intellectual functioning; characterized by advancing declines (that last over six months) in cognitive functioning such as memory, attention, the ability to process new information and problem solving abilities (Shagam, 2009). Alzheimer’s disease is considered a type of dementia.

*Positive Aspects of Caregiving (PAC)* – any event, discovery, realization or moment that provides satisfaction, benefits or rewards as a result of caregiving.

*Wife with dementia* - a woman who is legally married to the husband participant and has a current diagnosis of dementia, including Alzheimer’s disease.

*Strengths-Based Approach* – A theoretical approach that focuses on the strengths of a person or family. This approach accentuates the importance of exploring personal characteristics, such as geographic location and influences in order to identify and focus on their strengths.
CHAPTER II: REVIEW OF THE LITERATURE

Recently there has been an increase in caregivers and in cases of dementia. Those suffering from dementia are typically over the age of 65, with some experiencing early onset dementia starting at about age 50. With women more likely to have dementia, their husbands are more likely to be caregivers. Husbands are neglected in the research, but hearing their voice is extremely important. It is important because being a caregiver is typically out of their comfort zone since women have been known to be more prepared for the caregiving role due to their child rearing and house managing experiences (McFarland & Sanders, 1999). However, these typical gender roles and responsibilities are changing. When the topic of caregiving arises, the burden of it is the most common theme (Andrén & Emståhl, 2005; Bastawrous, 2013; Carbonneau, Caron & Derosiers, 2010; Hellström, Nolan & Lundh, 2007; Hogstel, Curry & Walker, 2005; Kramer, 1997; Sanders, 2005). This is why it is important to look at this topic from a strengths perspective and to look at the positive aspects of caregiving. The topics that will be covered in this chapter include the theoretical framework guiding the research, husband caregivers, reasons husbands provide care for their wives, relationship changes that occur after diagnosis of dementia, caregiving tasks that husbands help their wives with and the impact/burden and support husbands receive.

Theoretical Framework

Theory is extremely important in guiding all research to help guide research questions and to help explain findings (Alley, Putney, Rice & Bengston, 2010). The strengths based perspective acknowledges that there are negative experiences, but uses these to focus on an individual’s strengths. It also acknowledges the idea that people can grow and change. People’s motivation is created through their own strengths that they see in themselves. It is important to
help them find these strengths. This theory was chosen because it stresses the importance to understanding the strengths of husband caregivers and the need to view caregiving using positives, rather than negatives (Saint–Jacques, Turcotte & Pouliot, 2009).

The strengths based approach accentuates the importance of exploring each characteristic of a person including where they live and who influences them in order to focus on their strengths (Saint-Jacques, Turcotte, & Pouliot, 2009). Using a strengths-based approach allows the exploration of husbands’ strengths as they provide care for their wives. This theoretical lens provides the opportunity to explore husband characteristics, the husband-wife relationship within the caregiving context focusing on the positives and strengths of that relationship.

Linking the strengths perspective and the research on husbands, the husband is the expert of his life and he must be empowered. Husbands are able to grow and change through learning and whether or not a husband is going to grow and change is based on his own determination. The strengths based approach says that the community is a source of resources and that a person should always focus on their strengths (Saint-Jacques et al., 2009). DeFrain and Asay (2007) state that by only focusing on the problems and failures, the need for a positive approach to succeed in life is ignored. The strengths based approach stresses the importance of looking at one’s strengths instead of failures in order to benefit the person more. This strengths–based theory is the lens that will be used to guide the research design, analysis and interpretation of the results.

Positive Aspects of Caregiving

The strengths based approach is the companion to the gerontological literature term of Positive Aspects of Caregiving (PAC). Positive aspects of caregiving are “the extent to which the caregiving role is appraised to enhance an individual’s life space and be enriching. It may
include any positive affect or practical return experienced as the direct result of becoming a caregiver such as the satisfactions, rewards, gratifications, or benefits that are perceived” (Kramer, 1997, p. 240). Focusing on the positive aspects has been found to be better for the health of the caregiver. Peacock et al. (2010) state that PAC are important in the context of caregiving despite the perception of the stress and burden often associated with caregiving. Cohen, Colantonio and Vernich (2002) state that caregivers who define more positive aspects of caregiving might be shielded against negative effects of caregiving for themselves and the care recipients. Positive aspects of caregiving can buffer the negative effects of caregiving, putting less stress on the caregiver, in turn creating a better environment for the care receiver (Cohen, Colantonio & Vernich, 2002; Liew, Luo, Ng, Chionh, Goh & Yp, 2010). Bekhet (2013) states that positive cognitions or the ability to think in a positive way when faced with challenging situations enhances individual’s mental health and it allows them to manage their daily activities with better ability. It can minimize the effects of some adverse elements such as depressive symptoms as compared with those who do not reframe their situation in a positive way (Bekhet, 2013).

Some PAC can be growing closer to the care recipient, increasing patience level, or making the caregiver a stronger, more resilient person. Peacock et al. (2010) and Shim, Barrosso and Davis (2011) found that husbands specifically believed that a positive aspect of caregiving was being able to pay their wives back for past care. Shim and colleagues (2011, 2013) as well as Siriopoulos et al. (1999) report that husbands found special meaning in being able to love their wives back in return for the way they loved them during their marriage and becoming closer to their wives through caregiving as part of their caregiving experience.

Cahill’s (2000) twenty-six husbands reported several satisfying aspects of their
caregiving role. Twenty-seven percent of husbands were satisfied with seeing their wife happy, smiling and comfortable, 23% percent were satisfied with seeing her remain healthy. Twenty-three percent also reported satisfaction from being together with their wife and being able to have her there with him. Only four percent did not find anything satisfying in their caregiving role (Cahill, 2000). Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbé and Caron (2006) report that 59% of their 323 husbands said they received a large or moderate amount of personal gratification from being a caregiver. The most common positive aspect mentioned was learning new things. Ninety-one percent of husbands in Sanders’ (2005) study reported feeling a sense of accomplishment and mastery as a gain in caregiving and 86% of husbands reported personal growth as positive aspects of caregiving.

Yap, Luo, Ng, Chionh, Dip, Lim, Sci and Goh (2009) designed an instrument called the Gain in Alzheimer’s care INstrument (GAIN). It is a survey with ten positive statements about caregiving. Yap et al. (2009) designed this survey because they discovered that in the literature, there was an extreme focus on the caregiver burden, but not on the positive outcomes or gains in caregiving. The researchers wanted to explore what factors are associated with the experience of gains in caregiving for a person with dementia. The questions developed for this instrument were based on qualitative interviews with caregivers of people with dementia and were gains that were commonly mentioned.

**Husband Caregivers**

Almost 45% of caregivers are men and the majority of these men are husbands caring for wives with a diagnosis of dementia (Ducharme et al., 2006). The estimated average age based on caregiving studies is about 72 years old (Baker et al., 2010; Cahill, 2000; Calasanti & King, 2007; Ducharme et al., 2006; Kramer, 1997; Kramer 2000; McLennon et al., 2011; Rose-Regos,
It is often assumed that the husband-wife relationship is long-term, but studies have found length of marriage to range from 5 years to 66 years (Baker et al., 2010; Kramer, 1997). Although the sample was mixed, women and men, Rapp and Chao (2000) and Siriopoulos et al. (1999) found no association with gain or strain based on caregivers’ age, health status, years spent caregiving, education, gender, marital status or relationship to the care recipient. Sanders’ (2005) research shows differently. Sanders (2005) studied 85 spousal and adult child caregivers of people with Alzheimer’s disease or another related dementia and found that husbands reported the highest percentages of gain.

According to Lin, Fee and Wu (2012), male caregivers were more likely than female caregivers to find positive meaning from caregiving in their study of 1552 caregivers. Baker, Robertson and Connelly (2010) found some interesting things about men’s characteristics and likeliness of reporting positive aspects not mentioned by any other authors. They discovered that the more traditional a man was about emotional closeness with another man and about success, power and competition, the more likely they were to find more gain. This emotional closeness with another man and views about success, power and competition is related to gender role conflict. Baker, Robertson and Connelly (2010) found that these gains reported by men with traditional views, but not nontraditional views could be due to males with less traditional views possibly already experiencing caregiving situations and because of this may not appraise high levels of gain. Men with these more traditional views may not want to admit that they are feeling burdened (Baker, Robertson & Connelly, 2010).

**Reasons for Providing Care**

Reasons for providing care have been studied. Several studies have found that the main reason husbands provide care is relational, focusing on love. According to Cahill (2000) and
Mullin, Simpson and Froggatt (2011), the husbands who cared for their wives with dementia mainly did so because they love them (35%), were married to them (27%), a combination of feeling a duty, loving them and being married to them (20%), just because they felt a duty for them (7%) and for other reasons (11%). In addition to this sense of commitment and devotion as well as responsibility, Russell (2001) found that husbands believed their care was best for their wives as opposed to being in a long-term care facility. Siriopoulou, Brown and Wright (1999) qualitatively studied eight husbands caring for wives with dementia. The reason these husbands provided care was because they wanted to reciprocate all the love and care they had been given throughout their marriage to their wives.

**Relationship Changes**

Within the relational context for the reasons to provide care, there are also changes in the husband-wife relationship that occur. Hellström, Nolan and Lundh (2007) studied the ways spouses experience dementia over time in their interpersonal relationships. They discovered that to sustain the “couple” relationship, four things must happen: talking things through, making the best of things, keeping the peace and being appreciative and affectionate (Hellström et al., 2007). Talking things through represents the pattern of communication within the relationship and willingness to have open communication. Making the best of things means that each part of the dyad perform their best to ensure that their lives are as good as possible, enjoying life’s little pleasures by making sure some joy is experienced each day. In order to make the best of things, couples must search for the positives by looking on the bright side and live for today by giving more thought to today and less thought on the future. Keeping the peace involves knowing each other’s triggers and not responding to them. Appreciativeness and being affectionate involves a special effort to maintain each person’s attractiveness and continue to show affection and be
appreciative (Hellström et al., 2007).

As a person’s dementia gets more severe, there becomes a lack in communication (Ducharme et al., 2006; Mullin, Simpson & Foggatt, 2011; Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert & Henderson, 2010; Shim, Barroso & Davis, 2011).

Ducharme et al. (2006) found that nearly half of the husbands in their study experienced great or moderate losses in exchanges with their wives. They found that nearly 2/3 of the male caregivers lost the practical things that their spouses used to do for them (e.g. their wives could no longer cook for them) as well as the chance to do things they had planned together. For instance, they could no longer travel together like they had planned.

**Caregiving Tasks**

According to Ducharme et al. (2006), in their study of 323 husband caregivers, 60% spent at least 84 hours caregiving per week. Another 36% spent 21-24 hours per day caregiving for their wives. Ducharme et al. (2006) report an even higher mean number of hours spent caring for wives with memory problems. Activities of daily living (e.g. self-care activities like eating, showering, etc.), including instrumental activities (e.g. the activities one does to remain independent such as cooking meals and housework, etc.) are part of the caregiving role.

Husbands help wives with any and all activities from mowing the grass to incontinence (Cahill, 2000; Ducharme et al., 2006).

Calasanti and King (2007) reported that husbands approach caregiving by “picking it up like you do a trade.” Many studies, including Raschick and Ingersoll-Dayton (2004), found that husbands approached the caregiving tasks in this manner, in a managerial way. Calasanti and King (2007) said that some husbands used this managerial approach by delegation. Husbands paid others and coordinated with others to help with certain tasks. McFarland and Sanders (1999)
also state that men look at caregiving as a second job or as an extension of their job. Russell (2001) studied 14 husbands who were caregivers to their wives with dementia and stated that husbands use a style that joins management and nurturing. This meant that they used masculine workplace values with efficient care for their wives or doing what needs to be done, with care.

According to Calasanti and King (2007), when dealing with their wives and trying to complete tasks such as personal care for their wife or household chores such as mowing the lawn, husbands sometimes used force, restraint and intimidation. Husbands in this study sometimes used padlocks on doors in order to keep their wife from wandering. One husband even tried to confine his wife inside the car with the windows down in order to keep her safe while he was mowing the grass. Another husband tied a leash from her ankle to his so he would be awoken during the night if she got out of bed so she was not left unsupervised. Other husbands used shouting to gain compliance from their wife (Calasanti & King, 2007).

Cahill’s (2000) study with 26 husbands caring for wives with dementia showed that husbands perform many caregiving tasks for their wives. Ninety-six percent of the husbands did housework and meal prep; 100% took care of the finances; 77% did all of the driving; 88% helped their wives with medication; 81% of husbands supervised; 58% of husbands assisted their wives in showering or bathing; 50% assisted with dressing; 46% helped their wives with grooming; 27% helped with feeding; 23% helped their wives walk. When it came to toileting, 42% of husbands assisted their wives, 50% with urinary incontinence and 31% with fecal incontinence (Cahill, 2000). According to Cahill (2000), 71% of the husbands he studied dealt with the difficult task of incontinence by looking at it as a routine aspect of care that was just like any other job that needed to be done. Ducharme et al. (2006) also discussed many of the same tasks husbands helped their wives with including help with medication, dressing and undressing,
meal prep, housekeeping, grocery shopping or running errands as well as instrumental tasks.

**Caregiving: Impact and Support**

Caregiving impacts a caregiver’s life dramatically, especially when caring for someone with dementia. It is a high stress, overwhelming, and thankless, and exhausting 24/7 “job.” Often times it is unexpected by husbands because husbands typically die before their wives. This leaves them unprepared and in need of assistance. Some people do it alone while others receive help. Some receive informal help such as assistance with meals and caregiving tasks from family and friends. Others receive help formally such as adult day care, respite stays, long-term care or Meals On Wheels from organizations.

**Impact and Burden**

In her study of 43 husbands, Kramer (2000), found that husbands who continued caring for their wives within the community appraised their wives’ memory and behavior problems as well as activities of daily living less stressful over time. Kramer (2000) also found that husbands reported less depression over time when caring for their wives within the community while those whose wives were institutionalized reported an unchanged level of depression over time. Perhaps the reason for this is due to types of coping strategies they used that helped them adapt to caregiving. Russell (2001) states that men are very adaptable and resilient. Some coping strategies that Calasanti and King (2007) reported from their research with husbands include focusing on specific tasks and doing what needs to be done, blocking out their emotions like shame and fear to be able to get done what has to be done, minimizing disruption and trying not to let the disease affect the continuance of their lives together. Siriopoulos, Brown and Wright (1999) mentioned trying to continue their lives together without interference by establishing and maintaining a routine. Studies done by McFarland and Sanders (1999) and Calasanti and King
(2007) found that men focused on the tasks involved in caregiving while blocking out their emotions, tried to distract attention of the problems by keeping themselves busy and self-medicated with alcohol in order to relieve their stress. McFarland and Sanders (1999) also looked at ways men coped and one strategy they used was journaling to keep track of their wives personal care needs as a way of staying in control.

Husbands in Siriopoulos et al. (1999) coped in similar and different ways. Husbands used humor as a coping strategy; they tried to hold onto the memories and let go in order to overcome the loss and they used breaks from caregiving activities. Husbands also utilized assistance from formal and informal support (Siriopoulos et al., 1999).

Support

Almost two thirds of the husbands in Cahill’s (2000) research received help from their adult daughters. Ducharme et al. (2006) did not specifically report who the help was from, but they did say that husbands received more emotional support from their family and friends than instrumental support. Husbands in Siriopoulos et al.’s (1999) study reported that they utilized support from family and friends and used it as a coping and support method.

Siriopoulos et al. (1999) state that husbands in their study felt they needed assistance. They used assistance as a coping and support method. Many husbands utilize adult day services, support groups, housekeeping and home care the most (Cahill, 2000; Ducharme et al., 2006; Siriopoulos, et al., 1999). However, Ducharme et al. (2006) research shows that 12% of their 323 husbands received no support services at all. McFarland and Sanders (1999) said that men in their study felt that using resources was an admittance of weakness.

Summary

This strengths based lens allows the husband to be the expert of his life and empowers the
husbands by pointing out the strong aspects of themselves that gives them the ability to give care. Some positive aspects of caregiving have been found in caregiving for a wife with dementia including being able to be with their wife, seeing her remain healthy, learning new things and personal growth. The Gain In Alzheimer’s Care INstrument is a tool to use when assessing the positive aspects. Many people think of women when they hear “caregiver,” but there are also many men caregivers. This seems to be neglected in the literature. The most common men caregivers are those that are caring for their wives with dementia and they provide many different reasons for providing care such as feeling a duty, loving their wives and because they are married. Changes within the relationship of a caregiving dyad are common and the most common change is a decrease in communication. Although husbands are not typically thought of when thinking of a caregiver, they are not shy when it comes to the tasks involved with it like bathroom assistance. Often, husbands receive help, formal and informal, when caregiving in order to buffer the impact of caregiving.
CHAPTER III: DESIGN AND METHODOLOGY

The purpose of this study was to explore the positive aspects of caregiving for wives with dementia. This chapter describes the researcher’s lens, research design, data collection method, and results. Other studies have used this approach, including Cahill (2000), Cohen, Colantonio and Vernich (2002) and Kramer (2000) and have found it to be effective.

Researcher’s Lens

My lens for this research is guided by the strengths–based approach, specifically the Positive Aspects of Caregiving. My undergraduate degree is in Human Development and Family Studies, which is very focused on the strengths based approach and the positive aspects of caregiving. I come into this research with a bias that there are positive aspects of caregiving. I have worked with older adults with dementia in the long–term care setting for the past two years. I have seen the ups and downs of caregiving and I want others to see the ups, not just the downs.

I have been trained in active listening and felt that I gained very solid, respectable rapport with the participants in this study. In the interviews, I found that once the interview was over, the husbands did not want to stop talking. They enjoyed the interviews just as much as I did and I found it heartbreaking to leave when the interview was over. It is difficult to find people who want to open up to you when you are a total stranger and I found ten husbands willing to do this. That was very heartwarming.

Working in the long-term care setting with older adults suffering from dementia, I have seen many family members visiting their loved ones and it can be very difficult. The family members that caught my eye were the husbands. It was a very different environment when a husband was visiting a wife than when any other family member was visiting a loved one and I wanted to investigate this relationship more thoroughly.
Mixed Method

The overall design and methodology was a mixed method design with a semi-structured interview guide. This design and method was chosen because it allowed the results to be inclusive, meaning that all facets of the topic are focused on from all angles. This design was also chosen because the qualitative and quantitative portions are complementary of each other. There are only ten statements in the quantitative instrument. If only the quantitative instrument was included, it would leave no room for participants to state their own feelings about the positive aspects of caregiving. However, if only qualitative questions about positive aspects were included, it might put participants on the spot and would not give them the opportunity to state how they feel about common positive aspects of caregiving if they could not come up with any. It can sometimes be very difficult to come up with something when put on the spot. Providing the quantitative questions puts all of the participants on a level ground, making it easier to compare the results.

DiCicco-Bloom and Crabtree (2006) state that qualitative research provides more rich and in-depth information. It allows for the participant to be a bigger part of the process and to explain how they feel versus selecting one option of a few given. The qualitative approach of the semi-structured interview allows the researcher to receive a deeper meaning from the participants’ responses. It allows them to elaborate on their feelings. The information being researched is more than just a black or white response that needs to be answered by each individual in order to portray their own experience in their own words. There were five qualitative questions followed by GAIN, the Gain in Alzheimer’s care INstrument. The GAIN provides ten statements about caregiving for a person with dementia and the participant can respond with a Likert Scale response from 0 disagree a lot to 4 agree a lot (see Appendix F).
These two sections are then followed by six demographic questions (See Appendix E). The questions were developed from the research question and themes found in the literature.

The Gain in Alzheimer’s care INstrument is the quantitative instrument that will be used and it is directly associated with the research question and allowed the participants to classify whether or not they have experienced those things. Perhaps prior in the interview when asked what they felt the positive aspects were for caregiving, they could not think of any immediately. This instrument allows them to say how much each of these positive aspects is associated with their caregiving, even if they could not think of these or consider these positive aspects prior. This quantitative instrument is very complementary to the qualitative section. However, the GAIN is not an appropriate tool by itself.

Mixed method allows the quantitative and qualitative data to work well together in order to get a more holistic view of the data. Doyle, Brady and Byrne (2009) report many purposes of using a mixed method. One of these purposes includes completeness and they state that using both methods provides a more complete view of the research. Another reason is triangulation because it provides greater validity by corroborating the data found through the qualitative research with the data found through the quantitative research. Johnson and Onwuegbuzie (2004) also support mixed methods with these reasons as well as a few others. Johnson and Onwuegbuzie state that a mixed method is beneficial because the strengths of each method can overcome the weaknesses of the other. Using a mixed method is also beneficial in being able to generalize results. The qualitative approach can add meaning while the quantitative approach can add accuracy (Johnson & Onwuegbuzie, 2004).

There were a number of articles in the literature that used qualitative and a number that used quantitative (Andrén & Emståhl, 2005; Cahill, 2000; Carbonneau, Caron & Derosiers,
Both types of research articles utilizing qualitative methods and those utilizing quantitative methods are equally represented in the literature. However, there were very few that used a mixed method approach. This research will address the lack of mixed method data.

Sample

Participant eligibility criterion included: husband is currently providing care for a wife with dementia. The participants will be husbands who are currently caregiving for their wives who have dementia. Husbands were included because there is a lack of research on them in the literature. Caregiving for a wife with dementia was chosen because with women being more likely to be diagnosed with dementia, husbands are likely to be their caregivers. Currently caregiving was chosen because it is important to be discussing current experience instead of looking back on a situation. If the wife has died, it will no longer be a current experience, but looking back on a situation and could result in different feelings about it.

Sample Recruitment

Prior to the start of the study, a formal collaboration was developed with the Northwest Ohio Alzheimer’s Association and Wood County Committee On Aging. These organizations agreed to assist with recruitment. Recruitment at the Wood County Committee On Aging located in Bowling Green, Ohio included hanging flyers at the Wood County Senior Center. Recruitment at the Alzheimer’s Association located in Toledo, Ohio included placing flyers at the front desk of the main office in Toledo, Ohio and attending support groups using the recruiting script (See Appendix A) in Lucas, Sandusky, and Wood Counties. I attended nine support groups that included 31 people. A sample flyer is located in Appendix B.

If interested in participating in the study, husbands contacted me. Two people contacted
me and I contacted eight people that wrote their information on the sign up sheet using the phone script (See Appendix C). After confirming eligibility (male caregiver, currently providing care to wife who has dementia), an interview time was established based on participant convenience. Locations were either at the participants’ homes, coffee shops or another location of their choosing. For two of the interviews, the wives were present. A total of eleven husbands were identified through the recruitment methods. Ten of those people met the participation criteria. Ten were interviewed and included in the results. Only ten husbands were needed because by the time the tenth husband was reached, pattern saturation had occurred (Marshall, Cardon, Poddar & Fontenot, 2013).

**Data Collection**

Prior to data collection, the Bowling Green State University Human Subjects Review Board approved the research study on March 25, 2014. Recruitment started on April 30, 2014. Data collection started on May 5, 2014 and lasted for nine weeks.

Prior to the start of the interview, participants received an informed consent form (See Appendix D). Time was allotted for them to review and ask any questions. Participants were informed that participation was voluntary and that they could discontinue participation in any activity at any time without penalty and that discontinuing participation would not affect their relationship with Bowling Green State University, the Wood County Committee on Aging or the Alzheimer’s Association. If participant did not consent, it was explained that there is no penalty or negative consequences. If participant consented, they signed the consent form and the interview proceeded. All participants consented, signed the informed consent and the interviews began using a semi-structured interview guide (See Appendix E). The interviews were all voice recorded with participant permission. Voice recordings were electronically saved.
Each husband was assigned a number in order to keep his responses confidential. On the voice recording and any notes that were taken, the husband was identified using that code, which only the researcher knew. Any identifying information as well as list of names matched with participant codes was kept confidential. Results will be given using participant codes.

**Semi-Structured Interview Guide**

The interview guide using open-ended questions (See Appendix E) was developed in order to allow the participants to answer in their own words. Open-ended allowed more of a perspective from each individual than a multiple-choice question where his options of answers would be limited. The questions were based on the research question, themes from the literature and how they were analyzed in order to determine how these topics might affect someone’s point of view of the positive aspects of caregiving for their wife with dementia. For instance, the description of a husband’s relationship with his wife provides a context and more insight into their relationship. The context of their relationship might influence whether or not he may find positive aspects in caring for his wife.

Relationship with wife was asked to identify length of marriage, characteristics of relationship, and decision to provide care. Participants were asked to tell the interviewer about their relationship with their wife. Prompts included how long were you married?, how did you meet? and how and why did you decide to be her caregiver? Other research studies have focused on the relationship with wife as a question as it is important to determine characteristics of the base of the relationship before caregiving began (Cahill, 2000; Shim, Barroso & Davis, 2011; Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004).

Change in relationship since inception of caregiving was asked to determine the impact of caregiving and their attitude towards caregiving. The question asked was: how has your
relationship changed? The prompt was: what are the biggest differences in your relationship pre and post dementia? Other research studies have focused on this question as it is important to determine the context of caregiving (Shim, Barroso, Gilliss & Davis, 2013; Siripoulos, Brown & Wright, 1999).

Positives Aspects of Care are defined as any event, discovery, realization or moment that provides satisfaction, benefits or rewards as a result of caregiving. Some of these positive aspects include growing closer to the care recipient, increasing the patience level and positive changes within the caregiver like being a stronger, more resilient person. Positive Aspects of Care was asked to see what they felt were positive aspects of caregiving without any influence from the researcher. During the interview it was mentioned that caregiving can be challenging at times, but also very rewarding, and asked what they believe are some of the positive aspects of being the caregiver for your wife? Other research studies have focused on this topic as it can sometimes buffer the negative effects of caregiving (Andrén, & Elmståhl, 2005; Cohen, Colantonio & Vernich, 2002; Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbè & Caron, 2006; Sanders, 2005; Siripoulos, Brown & Wright, 1999).

Caregiving activities was asked to determine the type of involvement in caregiving for each participant. The question asked was what are some activities that you help your wife with? Other researchers have focused on this topic as it provides more insight into each caregiving experience (Andrén, & Elmståhl, 2005; Cahill, 2000; Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbè & Caron, 2006).

Impact and support as a caregiver was asked to determine if each participant had any help in the caregiving experience as well as what types of methods they used to handle/manage caregiving. The question asked was: is there anything that you find helpful in managing the
challenges of caregiving? The prompts for this question include what do you do to relieve stress?, how do you manage the caregiving tasks? and do you receive any informal help such as family members, friends, etc?. What types of formal services used was also asked. Other researchers have also focused on this topic as it provides insight into each participant’s take on their caregiving role and how they handle it (Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbè & Caron, 2006; Calasanti & King, 2007; Kinney & Stephens, 1989; Kramer, 1997; Liew, Luo, Ng, Chionh, Goh & Yap, 2010; McFarland & Sanders, 1999; Raschick & Ingersoll-Dayton, 2004; Russell, 2001; Shim, Barroso, Gilliss & Davis, 2013; Siripoulos, Brown & Wright, 1999).

The demographics that were obtained included the age of husband, age of wife, length of marriage, length of time providing care/when wife was diagnosed and residency of wife. These were asked to know more details about each participant and to determine if there were themes based on ages or length of time caregiving, etc. Other researchers have also asked these questions because it provides more insight into the specifics of each participant (Ducharme, Lévesque, Lachance, Zarit, Vézina, Gangbè & Caron, 2006; Kramer, 2000; Liew, Luo, Ng, Chionh, Goh & Yap, 2010; Shim, Barroso, Gilliss & Davis, 2013).

Gain in Alzheimer’s care INstrument

The Gain in Alzheimer’s care INstrument (GAIN) (Yap, Luo, Ng, Chionh, Lim, & Goh, 2010) was recently developed based on a study about common positive aspects of caregiving for a person with Alzheimer’s with a sample size of 238. The instrument includes 10 positive statements about caregiving for a person with Alzheimer’s with participants responding on a 5-point likert scale (0= disagree a lot, 1= disagree a little, 2= neither agree or disagree, 3= agree a little or 4= agree a lot). Scoring is done by adding up the responses to all ten statements. With ten
questions, the highest possible score is a 40. The lowest possible score is a 0. The higher a caregiver scores, the more positive aspects they find through caregiving for a person with Alzheimer’s disease (Yap et al., 2010). The reported internal consistency of the Gain in Alzheimer’s care INstrument is 0.89. The test-retest reliability is 0.70. The GAIN correlates strongly with positive aspects of caregiving ($r = 0.68$, $df = 236$, $p < 0.0001$) based on other caregiving instruments (Yap et al., 2010). Based on a literature review, only one other study has used this instrument (Lin, Fee & Wu, 2012).

**Data Analysis**

All of the interviews were voice recorded to maintain a better record of the rich detail communicated by the husband during the interviews that cannot be remembered through memory and notes alone (Frattaroli, 2012). Each interview was audio recorded then saved electronically on a computer using a filename based on the code assigned to each participant. Back up files were saved on a USB stick with their assigned codes. As each interview was listened to, each response was transcribed as it related to the identified theme based on the definition of terms and review of literature.

Themes were identified based on the definition of terms and review of literature. When listening, if something the husbands said fit one of these themes, their responses were typed out in that theme file on the computer with each husband code attached to their statements. The statements from all of the husbands for each theme were put into the same file and analyzed for similarities.

Upon completion of listening to each interview, notes were taken focusing on the demeanor and feel of the interview. The analysis technique used was thematic, the goal was to identify common ideas, it did not require verbatim transcripts (Halcomb & Davidson, 2006).
Although the interviews were not transcribed, inter-rater reliability was checked to determine accuracy. After reviewing the themes, the researcher and advisor listened to a randomly chosen interview. Upon completion of listening to the interview, the researcher and advisor compared transcriptions of the experts based on the themes they heard. There were several instances of disagreement upon initial code, but discrepancies were discussed and an agreement was reached on all instances.

For the Gain in Alzheimer’s Care INstrument, data was entered using Excel and following the scoring protocol as established by Yap and colleagues (2010). As per instructions, the scores of each participant’s Likert Scale responses were added up to get a total score and compared statistically to calculate the average and standard deviation. The highest possible score was 40 and the lowest possible score was 0. The higher the score, the more positive aspects found. The positive aspects of care that were found were then compared to the statements in the Gain in Alzheimer’s Care INstrument to determine similarities and differences in the results.

Summary

This study’s design is a mixed method, allowing results to be found from different angles. Husband participants included in this research are husbands who are currently caregiving for their wives who have dementia and they were recruited from the Northwest Ohio Alzheimer’s Association and the Wood County Committee On Aging in Bowling Green, Ohio through flyers and support groups. The Human Subjects Review Board approved this study and data collection lasted nine weeks and included a semi-structured interview guide with open-ended questions to collect data.

The five main questions of the interview included information about relationship with wife, change in relationship, positive aspects of caregiving and caregiving activities. The Gain in
Alzheimer’s Care INstrument was used, which included ten positive statements about caregiving and then demographics were asked. These questions all helped to analyze the positive aspects of caregiving. Interviews were recorded and coded.
CHAPTER IV: FINDINGS

The interviews brought many findings. This chapter will describe the sample, husbands responses to questions about their relationship with their wives, reasons they provided care, changes in their relationship, what they believe to be the positive aspects of caring for their wives, caregiving tasks they assist with, and the impact of caregiving as well as the support they receive. The results of the Gain in Alzheimer’s Care INstrument are stated as well as the relation between the Positive Aspects of Caregiving and Gain in Alzheimer’s Care INstrument.

Sample

Eleven husbands were contacted. Ten responded and were interviewed. The other one never responded to subsequent inquiries. After initial phone contact, which started on May 1st and ended on July 1st, an interview time was set up. The average length of time between contact and interview date was 4.4 days. Range was from 1-11 days. Interviews took place at a place of the husbands’ choice. Three occurred in their homes, two at the Alzheimer’s Association, two at Clare Bridge Place, a long–term care community, two at their offices and one at a coffee shop. For two of the interviews, the wives were present. The average interview lasted 55.3 minutes with a range of 21 minutes to 72 minutes. The husbands in this study were all very similar in the fact that all wanted to share their stories with a complete stranger. That in itself is a strength.

Characteristics of the sample are identified in Table 1 below. The average age of the husbands was 77.8 (range was from 64-91). The average age of the wives was 76 (range was from 60-87). The average length of the marriage was 43.4 (range was 7-62). The average length of caregiving was 7.45 years (range was from 1-15 years). Currently the wife was residing at home for six of the couples and the other four were residing in a long-term care facility. All husbands resided in their own homes. When asked questions during the interview guide,
husbands answered based on their current situation of home care or long-term care, but were also asked about when they were still caring at home.

Table 1

<table>
<thead>
<tr>
<th>Code Number</th>
<th>Age of Husband</th>
<th>Age of Wife</th>
<th>Length of Marriage (in years)</th>
<th>Length of Caregiving (in years)</th>
<th>Residence of Wife</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>84</td>
<td>84</td>
<td>58</td>
<td>5.5</td>
<td>Home</td>
</tr>
<tr>
<td>2</td>
<td>64</td>
<td>60</td>
<td>40</td>
<td>11</td>
<td>Home</td>
</tr>
<tr>
<td>3</td>
<td>76</td>
<td>74</td>
<td>54</td>
<td>10</td>
<td>Long-term care</td>
</tr>
<tr>
<td>4</td>
<td>91</td>
<td>87</td>
<td>61</td>
<td>15</td>
<td>Home</td>
</tr>
<tr>
<td>5</td>
<td>84</td>
<td>84</td>
<td>61</td>
<td>3</td>
<td>Home</td>
</tr>
<tr>
<td>6</td>
<td>83</td>
<td>84</td>
<td>61</td>
<td>6.5</td>
<td>Long-term care</td>
</tr>
<tr>
<td>7</td>
<td>78</td>
<td>76</td>
<td>17</td>
<td>7</td>
<td>Home</td>
</tr>
<tr>
<td>8</td>
<td>73</td>
<td>62</td>
<td>7</td>
<td>1</td>
<td>Home</td>
</tr>
<tr>
<td>9</td>
<td>80</td>
<td>80</td>
<td>62</td>
<td>9</td>
<td>Long-term care</td>
</tr>
<tr>
<td>10</td>
<td>65</td>
<td>69</td>
<td>13</td>
<td>6.5</td>
<td>Long-term care</td>
</tr>
<tr>
<td>Mean</td>
<td>77.8</td>
<td>76</td>
<td>43.4</td>
<td>4.45</td>
<td></td>
</tr>
</tbody>
</table>

** Relationship with Wife **

Relationship with wife was asked to identify length of marriage, characteristics of relationship and decision to provide care. As shown above in Table 1, the average length of marriage was 43.4 years with a range of 7-62 years. All of the husbands reminisced with fondness about how they met their wives and talked in detail about their first dates. When asked about the characteristics of the relationship, six of the participants noted an affectionate and loving relationship that was consistent with earlier years of marriage, two indicated a change in the relationship, and one noted that prior to dementia, the marriage ‘wasn’t that bad’. The most common theme focused on the affection between the couple. For instance:

_When I go visit her we hold hands, in fact, she won’t let go of it. When I say goodbye she puckers up for a kiss. [Code 6]_

Another participant stated this about the affection:

_We have always gotten along very well, we still hug and kiss and things like that. We_
have a very solid relationship and she still tells me she loves me. [Code 7]

The two husbands who indicated a change are discussed in the next section on relationship changes. For the husband who said it ‘wasn’t that bad,’ it shows more of the context of his relationship with his wife and it not being very good prior to caregiving with the affects of the dementia.

**Reasons for Providing Care**

When asked about their reasons for providing care, it was taken two ways: 1. What were the specifics as to why she needed a caregiver? And why they chose to be her caregiver? The most common reasons for wives needing a caregiver were the signs of dementia and other health related problems that the wives have, such as not being able to drive or having epilepsy. Two stated behaviors related to dementia such as memory loss, not being able to cook, and getting lost as reasons for providing care. As far as why they chose to be her caregiver, one husband stated he decided to be her caregiver because he thought he could provide better care than someone else. Two husbands said there really were no other options or they could not afford anyone else. Two more husbands said they never even thought about it, it was just something they figured they needed to do and three husbands stated that they cared for their wives because they are married and they took a vow. For example:

*Being a caregiver is part of being married. I took a vow when I got married, in sickness and in health, ‘til death do us part.* [Code 2]

Husbands were convinced that the wives would do the same for them, especially since they were married. For instance:

*I love her and I promised I’d take care of her. It could have been the other way around.* [Code 7]
Relationship Changes

Changes in the relationship was asked in order to determine the impact of caregiving and husband’s attitudes towards caregiving. All ten participants indicated a change in the relationship with their wife. These changes ranged from less communication to being very angry with a lot of fighting. Five of the participants stated that there is less communication with their wives. For example:

*I can’t talk to her anymore, there is no communication.* [Code 9]

The other five did not address if communication was less. Additionally, five of the ten husbands indicated a different connection as a relationship change. For example:

*The connection is different. I am not a husband anymore, I am a caregiver. I make all the decisions. I was married before and now I don’t feel like I’m married anymore. I have a wife that I have to take care of, all of the things that a wife does and that you do with your wife we don’t do anymore.* [Code 4]

Different connection meant that they connect in a different way other than husband and wife. The husbands are caregivers now and the wives rely on them for everything. For two of the husbands who indicated a change, the change was good. In the context of caregiving, one of the husbands did not know that his changes within the relationship were dementia related until post diagnosis. Diagnosis provided a greater understanding of the relationship. The husband who did not know the changes in the relationship were due to the dementia said:

*Originally, she was very nasty so it was very tough, but it’s better now that she has been diagnosed and is on medication. We were about to sign the divorce papers because of her behavior, but then we found out it was the dementia and we get along way better now.* [Code 8]

The other participant who stated positive changes, but did know changes were due to the dementia said:

*Before she was very angry and we were at each other’s throats. She told me she hated me. Now she is much more subdued. We still have a loving relationship and I have the*
best relationship with her as I possibly can with her living in long-term care. [Code 10]

**Positive Aspects of Caregiving**

The qualitative thematic findings were based on response to open-ended questions. All ten husbands stated at least one positive aspect of caregiving. Eight of the ten husbands found more than one positive aspect of caregiving. Husbands were specifically asked to state what they believed were the positive aspects of caregiving. Positive Aspects of Care are listed in Table 2 below and include growing closer to the care recipient, increasing the patience level and positive changes within the caregiver like being a stronger, more resilient person. Positive Aspects of Care was asked to see what they believed were positive aspects of caregiving without any influence from the researcher. The top three PAC, stated by half or more of the participants were still being able to do things with her and spend time with her:

*We like to read, do things locally like go to the library museum of art, gardening.* [Code 8]

knowing she is getting proper and personalized care:

*It’s individualized care, obviously no one will ever know her better than I do.* [Code 2]

and the wife still knowing who he is:

*It’s very difficult to tell how much she knows. I think she knows me, I’m not certain all the time, I don’t think she knows our son. I think she might know our daughter because she sees her more often.* [Code 6]

Six of the ten husbands stated positive aspects immediately. Another two husbands initially said they could not think of any positive aspects, but after a few moments they both came up with something positive. The final two husbands said they could not think of anything, but each mentioned one thing during the course of their interviews that could be considered a positive aspect. It is important to note that these two husbands who could not find anything positive were the only two husbands whose wives were combative and violent.
Three to four of the participants stated that her happiness is his happiness, they have a
good relationship, they still have positive moments together and he still gets to keep her involved
in his life and their children’s lives. One or two of the participants stated that he gets to hold her
hand and show her affection, gets to hear her remember things, it has brought them closer, he is
able to give back to others what he has learned, he has a gain in knowledge about dementia, she
is still here and they are still companions, he is more patient now and he realized how lucky he is
to be alive. The husband who stated how lucky he is to be alive had already watched his first
wife die of cancer.

During the interviews, five of the ten husbands stated that they try to stay as positive as
they can. One participant stated:

*I’m doing my duty and taking care of her and making her happy. When she smiles, I smile
and when she’s cheerful, I’m cheerful.* [Code 2]

Another participant stated positive changes within himself:

*I used to be a very controlling person with no patience, now I am more patient.* [Code 6]

During the interview process, all ten husbands indicated that caregiving is difficult and
sometimes positives are hard to find, however, all of them mentioned at least one thing that can
be considered a positive aspect about caregiving for their wives. Shown below in Table 2. One
husband even noted:

*When the diagnosis strikes, you wonder, why me? But you can’t dwell on it.* [Code 3]

These positive aspects of caregiving help this husband not to dwell on the diagnosis.
Table 2

Positive Aspects of Caregiving (N=10)

<table>
<thead>
<tr>
<th>Positive Aspects</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Still being able to do things with her and spend</td>
<td>7</td>
</tr>
<tr>
<td>time with her</td>
<td></td>
</tr>
<tr>
<td>Knowing she is getting proper and personalized care</td>
<td>5</td>
</tr>
<tr>
<td>She still knows who he is</td>
<td>5</td>
</tr>
<tr>
<td>Her happiness is his happiness</td>
<td>4</td>
</tr>
<tr>
<td>They have a good relationship</td>
<td>3</td>
</tr>
<tr>
<td>They still have positive moments together</td>
<td>3</td>
</tr>
<tr>
<td>Getting to keep her involved in his life and their</td>
<td>3</td>
</tr>
<tr>
<td>children’s lives</td>
<td></td>
</tr>
<tr>
<td>He gets to hold her hand and show her affection</td>
<td>2</td>
</tr>
<tr>
<td>Hearing her remember things</td>
<td>2</td>
</tr>
<tr>
<td>It has brought them closer</td>
<td>1</td>
</tr>
<tr>
<td>He is able to give back to others what he has learned</td>
<td>1</td>
</tr>
<tr>
<td>Gain in knowledge about dementia</td>
<td>1</td>
</tr>
<tr>
<td>She is still here</td>
<td>1</td>
</tr>
<tr>
<td>They are still companions</td>
<td>1</td>
</tr>
<tr>
<td>He is more patient now</td>
<td>1</td>
</tr>
<tr>
<td>He realized how lucky he is to be healthy</td>
<td>1</td>
</tr>
</tbody>
</table>

Not only did husbands mention these positive things throughout their interview, they also agreed with many positive aspects of caregiving for their wives during the Gain in Alzheimer’s Care INstrument discussed later.

**Caregiving Activities**

Caregiving activities were asked to determine the type of involvement in caregiving for each participant. Husband participants were also asked to state what caregiving activities they help their wife with. Only one husband stated that his wife did not really need help with any caregiving tasks, but he acknowledged that she needed help to pack for when they go on vacation. Four of the ten wives live in long-term care. The husbands of these wives stated that they did everything that needed to be done for them before they moved into long-term care. The remaining five husbands do everything that needs to be done which can include feeding, showering, toileting, yard work, house work, cooking, helping her get ready in the morning, assistance with medication, driving and finances. Table 3 presents all caregiving activities that
husbands are currently doing and those that they did before moving wives into long-term care.

An example of one husband who is currently doing everything said:

*I do everything that needs to be done, including showers. I tell her what to wash, I help her wash her back, I do the laundry, cooking, clean the house, mow the law, plant the flowers, grocery shopping, whatever has to be done, I do it.* [Code 1]

Another example:

*I do it all. Just about everything now. The driving, dressing her, bathing her, feed her, help her in the bathroom, housework, mow the lawn, cook and clean.* [Code 2]

Table 3

Caregiving Activities (N=10)

<table>
<thead>
<tr>
<th>Task</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cooking</td>
<td>9</td>
</tr>
<tr>
<td>Housework (including cleaning and laundry)</td>
<td>8</td>
</tr>
<tr>
<td>Driving</td>
<td>7</td>
</tr>
<tr>
<td>Yard work</td>
<td>5</td>
</tr>
<tr>
<td>Shower/Bath</td>
<td>5</td>
</tr>
<tr>
<td>Yard work</td>
<td>5</td>
</tr>
<tr>
<td>Helps her get ready in the morning</td>
<td>5</td>
</tr>
<tr>
<td>Bathroom</td>
<td>5</td>
</tr>
<tr>
<td>Medication</td>
<td>5</td>
</tr>
<tr>
<td>Helps her walk</td>
<td>3</td>
</tr>
<tr>
<td>Grocery Shopping</td>
<td>2</td>
</tr>
<tr>
<td>Reads to her</td>
<td>2</td>
</tr>
<tr>
<td>Finances</td>
<td>2</td>
</tr>
<tr>
<td>Packs when leaving for vacation</td>
<td>1</td>
</tr>
<tr>
<td>Schedules her appointments/takes her to them</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* The tasks include those that the husbands mentioned they are currently doing as well as what those whose wives live in long-term care did for them when they cared for them at home. It is possible that more husbands do these tasks, but they did not specifically state it. Frequency represents how many husbands stated assisting in each task. Husbands could assist in more than one task.

**Impact and Support**

Impact on husbands was not specifically asked, but was analyzed during the interviews to see how the husbands perceive caregiving. Responses from other open-ended questions provided a vision for how the husbands are handling caregiving. Support was asked to determine if each participant had help in caring for their wives and if so, what type of help. Some caregivers go it alone while others have friends and family help or seek professional help with their care.
Impact

Caregiving can have a vast impact on a caregiver, while others may handle it very well. Husbands perceive and handle caregiving in many different ways. For four of the husbands, caregiving for their wives eventually got to be too much and they had to place them in long-term care. Seven out of ten of the husbands stated that the caregiving is working out “well” right now. One husband specifically stated that he felt he has dealt with caregiving pretty well because it is part of his job as a husband:

*I don’t mind having to take care of her. It is part of my job as a husband.* [Code 9]

Other husbands stated that they made adjustments in order to adapt to their wife’s decline. For instance:

*She is very cautious of different colored flooring, so I painted the vents the same color as the carpet and now we don’t have that problem anymore.* [Code 2]

Other husbands had a very difficult time mentally with the stress of caregiving for their wives and needed to take some time to care for themselves. For example:

*I admitted myself into the hospital for eight days because of the stress.* [Code 3]

Another husband expressed the affect caregiving had on his work life. For instance:

*This affected my job, I had to step down at work and it cost us a lot of money.* [Code 10]

The husbands also talked about how caregiving impacted their emotions and feelings. Four of the ten husbands expressed their worry for the future and who will take care of their wives if something happened to them. One example:

*I worry about the future and who would take care of her if something happens to me.* [Code 10]

Five of the ten husbands stated that it is stressful and sad to see their wives in this condition, they
feel sorry for them. One participant stated:

_She handled moving into the long-term care facility better than I did. I couldn’t go in to see her at first. It was just too tough emotionally._ [Code 6]

It is known that caregiving can be very difficult and many of the husbands expressed that. For example:

_It’s not the life we envisioned originally, but it’s the one we have._ [Code 2]

_I am locked in and there’s no way to get out. It’s hell._ [Code 5]

_It’s not something you want to do; it’s something you have to do._ [Code 9]

Since there can be an immense impact in caregiving, husbands were asked what they do to relieve stress. Three of the ten husbands stated that they take breaks or walk away for stress relief. One of the ten husbands uses sarcasm while another uses humor. One of the ten husbands counts on his “faith in the Lord.” Six of the ten husbands use physical activity and exercise and five stay busy to relieve stress. Two self-medicate or drink alcohol.

**Support**

Since caregiving can be so demanding, the husbands in this study chose to take advantage of the help that is available. They enlist the help of others such as family and friends, known as informal support or professionals, known as formal support.

**Informal.** Participants were asked if they receive any informal help from family and friends. Responses indicated all husbands received some kind of informal support. Eighty percent of husbands received a lot of support from children and their children’s spouses as well as friends. Some husbands get help from neighbors and siblings. Although mostly everyone had whatever help they needed when they needed it, two of the eight husbands said their children help a little bit, but not often. For instance:

_Two of my children live too far away, but my son comes to help every once in a while._
[Code 9]

**Formal.** Participants were also asked to indicate what formal support they used.

Responses include adult day care, in home health aid, caregiving classes from the Alzheimer’s Association, Hospice classes, any informational meetings offered, Hospice, support groups, and Benjamin Rose Institute classes. Other responses from open-ended questions indicated many husbands go to church often, use long-term care, meals on wheels and even specialist doctors. See Table 4 below.

<table>
<thead>
<tr>
<th>Formal Support</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church</td>
<td>5</td>
</tr>
<tr>
<td>Support Groups</td>
<td>5</td>
</tr>
<tr>
<td>Alzheimer’s Association</td>
<td>5</td>
</tr>
<tr>
<td>Long-Term Care</td>
<td>4</td>
</tr>
<tr>
<td>Specialist Doctors</td>
<td>4</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td>3</td>
</tr>
<tr>
<td>In Home Health Aid</td>
<td>3</td>
</tr>
<tr>
<td>Hospice</td>
<td>3</td>
</tr>
<tr>
<td>Benjamin Rose Institute Classes</td>
<td>2</td>
</tr>
<tr>
<td>Respite</td>
<td>1</td>
</tr>
<tr>
<td>Caregiving Classes/ Meetings</td>
<td>1</td>
</tr>
<tr>
<td>Meals On Wheels</td>
<td>1</td>
</tr>
</tbody>
</table>

**Gain in Alzheimer’s Care INstrument**

This quantitative instrument is very complementary to the qualitative section. However, the GAIN is not an appropriate tool by itself. Overall, the result of the Gain in Alzheimer’s Care INstrument showed that there are many gains in caregiving. The mean Gain in Alzheimer’s Care INstrument (GAIN) score for the sample was 32.5 ($SD=4.78$) and the range was 26-38. The standard deviation for each item in the GAIN ranged from .48 to 1.24, which is very low. Table 5 shows how many participants responded to each statement based on a Likert scale. The majority of the caregivers “agreed a little” or “agreed a lot” with each GAIN statements. The two
statements that scores were the highest for were “increased my knowledge and skills in dementia care and more” and “given me deeper insights into the meaning of my life and my life’s perspective” with mean scores of 3.6 and 3.7 respectively. The item with the lowest score was for “helped me bond my family closer” with a mean score of 2.8. Many of the husbands stated that their families were already very close while another husband stated that it tore his family apart.

<table>
<thead>
<tr>
<th>GAIN</th>
<th>Providing care to my wife has...</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: increased my patience and understanding</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td></td>
<td>3.4</td>
<td>1.08</td>
<td></td>
</tr>
<tr>
<td>2: made me stronger and resilient</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>3.2</td>
<td>1.03</td>
<td></td>
</tr>
<tr>
<td>3: increased my self-awareness</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>3.5</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td>4: increased my knowledge and skills in dementia</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>7</td>
<td>3.7</td>
<td>0.48</td>
<td></td>
</tr>
<tr>
<td>5: grow closer to wife</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>3.2</td>
<td>1.03</td>
<td></td>
</tr>
<tr>
<td>6: helped me bond my family closer</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2.8</td>
<td>1.03</td>
<td></td>
</tr>
<tr>
<td>7: enabled me to better relate to others</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>6</td>
<td>2</td>
<td>3.0</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>8: given me deeper insights into the meaning of life</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>6</td>
<td>3.2</td>
<td>0.52</td>
<td></td>
</tr>
<tr>
<td>9: helped me grow spiritually</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>3.1</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>10: sparked off altruistic goals in me</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>3.4</td>
<td>1.25</td>
<td></td>
</tr>
</tbody>
</table>

Note. 0 = Disagree A Lot, 1 = Disagree A Little, 2 = Neither Agree or Disagree, 3 = Agree A Little, 4 = Agree A Lot

Positive Aspects of Caregiving & Gain in Alzheimer’s Care INstrument

It was necessary to include both qualitative and quantitative methods in this research. The Gain in Alzheimer’s care INstrument is directly associated with the research question and allowed the participants to classify whether or not they have experienced those things. Prior in the interview when asked what they felt the positive aspects were for caregiving, they might not
have been able to think of any immediately. This instrument allows them the opportunity to acknowledge other positive aspects and say how much each of these positive aspects is associated with their caregiving.

Although not all of the husbands could come up with a positive aspect of caregiving when specifically asked, every participant answered “agree a little” or “agree a lot” to at least six of the ten statements of the Gain in Alzheimer’s Care INstrument (GAIN). The two husbands who said they could not find any positives answered “agree a little” or “agree a lot” to six and eight statements. The top three most common PAC throughout the interview were not really related to any item in the GAIN. Other statements that were stated throughout the interview, but not related to statements in the GAIN include her happiness is his happiness, they have a good relationship, they still have positive moments together, they get to keep her involved in their lives and their children’s lives, they get to hold her hand and show her affection and hear her remember things. All of these were stated by at least two participants, but not even mentioned in the GAIN.

Those statements that were stated in GAIN, but not mentioned when asked what the PAC open ended were that it made them a stronger, more resilient person, increased their self-awareness, helped them bond their families closer, enabled them to better relate to older persons and persons with dementia, gave them deeper insights into the meaning of their life and helped them grow spiritually. The items that are in the GAIN that are related to the PAC mentioned throughout the interviews include that it has brought them closer, he is able to give back to others what he has learned, increased patience, and gain in knowledge about dementia. These items were only stated by one participant each throughout the interviews.
Summary

All husbands found one positive aspect of caregiving and eight of the ten found more than one positive aspect of caregiving. The sample of this study included ten husbands who were interviewed at the place of their choice with interviews lasting on average 55.3 minutes. The average age of the husbands was 77.8 and the average age of the wives was 76. Overall, husbands seemed to still have loving, affectionate relationships for the most part. The most common reason for providing care for their wives was because they were married and they took a vow.

Some changes were discussed with the most common change of less communication with their wives. All ten husbands found positive aspects of caregiving for their wives with dementia and some of these include having a good relationship, seeing her smile and still being able to spend time with her. Only one of the husbands stated that he did not really help his wife with any caregiving activities except packing for her to go on vacation. The rest of the husbands stated that they do what needs to be done which can include anything from driving to toileting assistance.

The majority of husbands stated that they were handling caregiving well right now and made adjustments as their wives caregiving needs intensified. Other husbands stated that caregiving had a negative impact on them including forcing them to step down from their job at work and for another husband, admitting himself into the hospital for stress. With the amount of stress caregiving can cause, all husbands use some sort of informal and/or formal support. The Gain in Alzheimer’s Care INstrument showed many gains in caregiving and had results very similar to that of the original study. Using both the qualitative interview guide and the quantitative GAIN proved to be very beneficial as they were complementary to each other. Each
method found different PAC that would not have been found without using both. Using both
methods allowed the researcher to look at what the husbands felt the positive aspects of
caregiving were from different angles and it allowed for a more holistic point of view.
CHAPTER V: DISCUSSION & CONCLUSIONS

Every husband was able to state at least one positive aspect of caregiving and eight of the ten were able to find more than one positive aspect of caregiving. The research question was what are the positive aspects of caregiving for a wife with dementia? The top three positive aspects of caregiving include still being able to do things with her and spend time with her, knowing she is getting proper and personalized care and their wives still knowing who he is. When asked, not every husband could come up with a positive aspect of caregiving, but mentioned something that could be considered a positive aspect somewhere else during the interview. All husbands acknowledge the level of difficulty in being a caregiver and most reminisced about their past relationships with fondness. In this chapter, findings will be linked with findings from the literature review about the main topics which include why husbands provide care for their wives with dementia, changes in the relationship, caregiving activities, the impact and burden of dementia caregiving as well as support that husbands receive. The implications, limitations and future directions of research will follow this linkage.

**Husband Caregivers**

On average, the husbands in this study were about five years older than the average husband caregiver. The average age of wives was not mentioned often in the literature, but in this study their average age was 76. In the literature review, the average age of caregiving husbands was about 72 years old (Baker et al., 2010; Cahill, 2000; Calasanti & King, 2007; Ducharme et al., 2006; Kramer, 1997; Kramer 2000; McLennon et al., 2011; Rose-Rego, Strauss & Smyth, 1998). In this study, the average age of the husband was 77.8. Although the husbands in this study were slightly older, it did not seem to have an affect on the findings. The difference in age did not seem that significant.
In this study, the range was 7-61 years. The length of marriage in the literature is 5-66 years (Baker et al., 2010; Kramer, 1997). Overall, the length of marriage was pretty similar to that in the literature. This sample is equally representative of those within the literature. The length of time in the caregiver role is important also. In this study, the length of time caregiving was 7.45 years with a range of 1–15 years. Again, these findings were very similar to the literature, which ranges from less than a year to 17 years (Cahill, 2000; Ducharme, 2006; Kramer, 1997; Kramer, 2000; McLennon et al., 2011; Shim, Barroso & Davis, 2011; Shim, Barroso, Gillis & Davis, 2013; Siriopoulos, Brown & Wright, 1999). Overall, this study was comprised of a representative sample that exists in the literature of white men with median socioeconomic status. This is due to the variety of ages, length of time married and length of time caregiving in this sample as well as the similarity in ages and length of marriages and length of time spent caregiving in the literature.

Reasons for Providing Care

The husbands in this study provided even more reasons why they provided care for their wives than found in the literature. The reasons husbands provided care to their wives tended to be relational, focusing on love. In this study, this reason resonated for three out of the ten participants. Three husbands cared for their wives because they were married, loved them, felt they would do the same for them and took a vow to take care of them, two husbands felt they did not have any other option or because they could not afford anyone else, two said they never thought about it and just felt it was something they needed to do, two felt their wives needed assistance with their dementia behaviors, and one husband said because he felt he could provide better care than someone else. These are the same reasons for providing care as found in Cahill (2000) and Mullin et al. (2011), whose husbands cared for their wives with dementia did so
because they loved them (35%), were married to them (27%) and felt a duty (7%). Another reason husbands cared for their wives were because they felt their care was best for their wives. Other husbands wanted to reciprocate the love and care their wives had shown them (Russell, 2011; Siriopoulos et al., 1999).

**Relationship Changes**

All of the husbands in this study stated changes in the relationship with their wife. Some changes were positive while others were neutral and one negative change. The positive changes resulted from the diagnosis and the realization that the negative changes in the relationship were due to the dementia and things changed for the better once medication was prescribed. Another positive change was the husband who stated they were previously at each other’s throats and now they have the best relationship that they can have with his wife living in long-term care.

The neutral changes were husbands stating that they had a different connection with their wife. These different connections involve being a caregiver now instead of a husband. The negative change came from one husband who said his wife hates him and all they do is fight. The most common change in the relationship was less communication with their wives. It was noted in the literature that as a person develops dementia, there becomes a lack in communication (Ducharme et al., 2006; Mullin et al., 2011; Peacock et al. 2010; Shim et al., 2011). Ducharme et al. (2006) also noted that almost half of the husbands in their study experienced moderate or great losses in exchanges with their wives. Ducharme et al. (2006) also found that the husband caregivers lost the practical things that their spouses used to do for them.

Another common theme within this study and in the literature was the husbands losing the practical things that their wife did for them, like cooking (Ducharme et al., 2006). On the other hand, Ducharme et al. (2006) also found that these same husbands felt like they lost the
chance to do things they had planned together like traveling. This was not mentioned in this study, which could be due to the fact that the husbands in this study all have quite the array of past experiences with their wives, many of which include traveling.

The relationship change of less communication in this study was spot on with the literature. Although behavior changes are common in those with dementia, it was not discussed as changes within the literature nor was a different connection mentioned in the literature.

**Positive Aspects of Caregiving**

Every single husband found one positive aspect of caregiving and eight of the ten found more than one positive aspect. At least half of the participants stated that they were still able to do things with her and spend time with her, are glad to know that she is getting proper and personalized care and are happy that she still knows who he is. Three to four of the participants stated that her happiness is his happiness, that they still have positive moments together and they get to keep her involved in his life and their children’s lives. One or two of the participants stated that he gets to hold her hand and show her affection, hear her remember things, it has brought them closer, gain in knowledge about dementia, ability to give back to others what he has learned, she is still there, they are still companions, he is more patient and realized how lucky he is to be healthy.

There are positive aspects of caregiving. Many were found in this study and they are listed above. The goal of this study was met because positive aspects were found and there is a list. Sometimes husbands have to reach for them, but they do exist. Any assumptions made about what husband was going to find the most positive aspects were far from the correct. Each husband was unique and each needed the time they were given to open up about caregiving and share their life. Each husband was able to find a positive aspect. Although the sample was small,
every husband being able to find a positive aspect is pretty significant.

**Caregiving Activities**

The types of caregiving activities husbands help with were asked to determine the type of involvement in caregiving for each participant. By looking at the responses to types of formal services used, seven out of the ten husbands delegated at least part of their caregiving activities to others at some time. One husband uses respite care while four husbands have delegated all of their tasks to long-term care and three have brought in in-home health aids for assistance. On occasion, husbands receive informal help with their wives from friends and family. The husbands who are caregiving for their wives at home do everything that needs to be done and the husbands whose wives are in long-term care stated that they did everything that needed to be done when their wives lived at home. Some husbands did not specifically mention every task they assisted with and simply said “everything.” When prodded to elaborate, they stated a few things ranging everywhere from bathroom assistance to housework and yard work. There does not seem to be any limit to what the husbands will do for their wives, just like those in the literature. The findings in this study are very similar to those found in the literature in this way as well as in the way the husbands eventually decide to delegate tasks in a managerial way. Husbands in this study delegated certain tasks to in home health aids as well as friends and family on occasion while four have delegated all of the tasks to long-term care. There did not seem to be any link between husbands who used different types of support and how many positive aspects they found.

Husbands help wives with any and all activities from yard work to bathroom assistance (Cahill, 2000; Ducharme et al., 2006). Doing any and all activities for wives was also stated by five of the six husbands whose wives are living at home with them. The four husbands whose
wives are living in long-term care also stated that when their wives lived at home, they did any and all types of caregiving activities. The literature states that some husbands approach caregiving in a managerial way by delegating tasks to others and that some looked at it as an extension of their job (Calasanti & King, 2007; McFarland & Sanders, 1999; Raschick et al., 2004). This is another similarity found in this study with husbands eventually delegating difficult self-care tasks to long-term care and in home health aids. In the literature it was mentioned that when dealing with wives and trying to complete tasks, some husbands used force, restraint and intimidation (Calasanti & King, 2007). Unlike the literature, none of the husbands in this study mentioned using force, restraint or intimidation.

**Caregiving: Impact and Support**

Caregiving can bring about a very large impact on a caregiver’s life. Many times for husbands, the caregiver role is unexpected and they can be unprepared for it. Some husbands decide that they do not need to ask for help while others get assistance from friends and family as well as professionals.

**Impact and Burden**

Similar to current research, husbands in this study who continued caring for their wives within the community appraised their wives’ memory and behavior problems as well as activities of daily living as less stressful over time (Kramer, 2000). In this study at least 80% of the men mentioned making changes in their lives to adapt to the changes their wives were going through, which is similar to the research. Husbands seemed to get used to the tasks at hand and looked at the tasks as just something they needed to do. Russell (2001) stated that men are very adaptable and resilient. This was the case in this study.

In order to relieve stress, husbands in this study mentioned staying busy. Husbands also
used breaks in caregiving, held onto the memories and used humor as coping strategies as well as utilizing assistance from formal and informal support, which is like findings in the research (Calasanti & King, 2007; Siriopoulos et al., 1999). Although the husbands in this study may have coped in these ways, they did not mention focusing on the task at hand and doing what needs to be done a well as trying not to let the disease affect the continuance of their life (Calasanti & King, 2007). Other ways husbands coped involved self–medicating or drinking alcohol, breaks from caregiving and using formal and informal support. This was similar to the research (Calasanti & King, 2007; McFarland & Sanders, 1999). In the literature, husbands stated journaling to keep track of their wives personal care needs as a way to stay in control (McFarland & Sanders, 1999) and this was not mentioned in this study.

Husbands in this study acknowledged the burden that caregiving placed upon them and the stresses that come along with it, which is also very common in the literature. Overall, this sample was very representative in the impact and burden area. These husbands, like those in the literature, have many of the same impacts and burdens and cope with them in very similar ways.

Support

Informal support can be help from friends and family. Similar to current research, all husbands had friends and family that were always available to help if they needed, but none of them did much instrumentally (Ducharme et al., 2006). Husbands in this study would go out to eat with family and friends as well as allow family and friends to give them a break, which is a common way to use them as support (Siriopoulos et al., 1999). Husbands also received most of the help from their daughters or daughter–in–laws, which is definitely similar to current research (Cahill, 2000). However, in this study, it was also common for sons to assist informally.

Formal support is assistance from professionals. Husbands in this study felt they needed
formal support and used support groups, church and the Alzheimer’s Association the most followed by specialist doctors and long-term care. Adult day care and in home health aids were also somewhat common with three out of the ten husbands using each. Husbands feeling like they need support and the common types of support used are similar to the literature (Cahill, 2000; Ducharme et al., 2006; Siriopoulos et al., 1999). Unlike the literature, one of the most common types of formal support was church, which was not mentioned in the literature. Men in McFarland and Sanders (1999) study said that they felt that using resources was an admittance of weakness, but none of the husbands in this study gave that impression unless it was using long-term care as a last resort if they could not care for their wives anymore.

**Gain in Alzheimer’s Care INstrument**

The mean Gain in Alzheimer’s Care INstrument (GAIN) score for the sample was 32.5 (SD=4.78) and the range was 26-38. Yap and colleagues had a mean GAIN score of 30.5 (SD=6.5). Therefore, it seems that the results of this study and the original study are very similar, but it is important to note sample size difference. This study had 10 participants while Yap and colleagues (2010) had 238. Liew et al. (2010) had an average score of 30 (SD= 6.6, range= 7-40). The Gain in Alzheimer’s Care INstrument is very individualized and focuses heavily on the benefit for the individual caregiver. It does not take into account any other possible benefits and this is a limitation of this instrument.

**Positive Aspects of Caregiving & Gain in Alzheimer’s Care INstrument**

It was necessary to include both qualitative and quantitative methods in this research. The Gain in Alzheimer’s care INstrument is directly associated with the research question and allowed the participants to classify whether or not they have experienced those things. Since not all of the husbands could come up with a positive aspect of caregiving when specifically asked,
without the GAIN, it would have given the impression that there were no positive aspects of caregiving according to them. The two husbands who said they could not find any positives answered “agree a little” or “agree a lot” to six and eight statements and every participant answered “agree a little” or “agree a lot” to at least six of the ten statements of the Gain in Alzheimer’s Care INstrument. However, the top three most common PAC throughout the interview were not really related to any item in the GAIN. The items that were in the GAIN that were related to the PAC mentioned throughout the interviews were only stated by one participant each throughout the interviews.

However, there were so many statements including her happiness is his happiness, they have a good relationship, they still have positive moments together, they get to keep her involved in their lives and their children’s lives, they get to hold her hand and show her affection and hear her remember things that were mentioned throughout the interviews, but not related to GAIN. These were all mentioned by two participants each, but not even mentioned in GAIN.

This suggests that even though they may not have all listed positive aspects when asked, they all believed that there are multiple positive aspects of caregiving. If GAIN was not used, there would not be a way to determine what the husbands felt were positive aspects of caregiving for their wives. However, if only GAIN was used, it would have limited what the husbands believed were positive aspects of caregiving and it would have influenced their thoughts on the topic. Asking them what they believed were the positive aspects initially, provided a starting point to see how they expanded on their original thinking and it gave them the opportunity to come to the realization that there are positive aspects of caregiving. Using the Gain in Alzheimer’s Care INstrument also contributed to the literature on this instrument since it is very new and their findings were supported. Both the qualitative interview guide and the quantitative
Gain in Alzheimer’s Care INstrument were necessary and very complementary to each other. With the GAIN being so individualized and all of the statements focusing heavily on the benefits for the individual, it did not allow for any relational gains that were mentioned throughout the interviews such as being able to see their wives happy and it making them happy as well.

The statement in the GAIN that had the lowest score was that it helped them bond their family closer. It only had an average score of 2.8, which really is not even that low. The reason many husbands stated as scoring this statement so low was because they felt they were already very close.

**Implications**

These findings imply that there are many positive aspects of caregiving for a wife with dementia, even though the negative aspects are what are focused on more in the literature. This study could alter the way people think about caregiving and encourage them to focus on the positive aspects of caregiving. The theoretical framework of PAC (Positive Aspects of Caregiving) links up perfectly with the strengths-based perspective in this study. It is effective because its acknowledgement of the tough aspects, but reminds husbands that there is room to change and grow in situations. In order to have the best experience caregiving, focus on the strengths of the caregiver and care receiver and think of all of the positive aspects along the way while growing and changing. This study supports the theoretical framework of PAC and also the strengths based-perspective.

This study answers the question of what are the positive aspects of caregiving. It answers the question with many reasons and the fact that every single husband could find at least one positive aspect of caregiving implies that every caregiver should be able to find at least one positive aspect about caregiving. Focusing on the positive aspects is so important in caregiving.
This study is so very important because it finally gives voice to the husbands who are caregiving for their wives with dementia. Husbands are caregivers too so it is important to let their voice be heard. This study adds to the caregiving literature in that aspect.

Another implication of this study is that more support groups just for men should be created because they seem to get the most benefit from those. They feel like they did not fit in at women’s groups and found far more benefit from mens only where they were able to let their guard down around other men.

**Limitations**

As any study, this one has limitations. First, the sample size of this study with ten participants does not allow for generalizations. It does allow for speculation for husband caregivers that many positive aspects of caregiving do exist and that the three most common are still being able to do things with her and spend time with her, knowing she is getting proper and personalized care and his wife still knowing who he is.

Secondly, some researchers have found a link between level of education and likelihood to find positive aspects of caregiving. Researchers have also found links with number of hours spent caregiving per week and positive aspects of caregiving. Level of education and number of hours spent caregiving per week was not asked and therefore this link could not be verified. Another limitation is whether or not similar findings are relevant to same-sex couples. All of the participants were white heterosexual males and findings cannot be generalized to other races, ethnicities or same-sex couples. The majority of the husbands coming from a support group means that this is not exactly a representative sample for that reason as well.

Another possible limitation is the newness of the Gain in Alzheimer’s Care INstrument. With this being only the second study to use this instrument, there is limited reliability and
validity information available. The husband who could not be reached is a limitation as the reason for not wanting to participate is unknown.

**Future Directions**

In the future, other studies may include a higher number of husbands and also wife caregivers of husbands with dementia for comparison. Same-sex couples need to be examined as well as couples of other socio-economic statuses, races and ethnicities. It may also be interesting to determine if there is a difference of opinion on positive aspects based on whether or not the wife is in long-term care and for how long. Later, the researcher would like to examine positive aspects based upon the length of time spent caregiving per week and level of education. More mixed method and quantitative data need to be done on positive aspects of caregiving. More mixed methods will allow the results to be all encompassing while the quantitative data alone will reach more participants. It would also be interesting to integrate gender literature into the men versus women caregiving role.

In the future, it may be necessary to improve the Gain in Alzheimer’s Care INstrument and add questions that are relational. Perhaps adding the three most common positive aspects of caregiving from this study, which include: still being able to do things with her and spend time with her, knowing she is getting proper and personalized care and the care recipient still knowing who their caregiver. This would help the GAIN to be more inclusive with its results.
REFERENCES


Recruiting Script:

Hi, my name is Mackenzie Hiemstra. I am a graduate student in gerontology at Bowling Green State University. I am currently inviting husbands who are caregivers for their wives with dementia to talk with me about the positive aspects of caregiving for their wives and complete a short 10-item survey.

Do you have any questions? 
If yes, then answer questions. 
If no, proceed with script.

Would you be interested in participating? 

If someone says yes, then I will give him the sign up sheet to record his information and let him know that I will be in contact with him very soon. If he chooses not to sign the sheet, I will ask him to contact me through the information on the flyer.

If someone says no, I will thank them for their time and tell them that there are no consequences for not participating.

If someone does not respond or says they are not sure, I will remind them that my contact information is on the flyer and to please contact me if they would like to participate.

I will be sure to pass out a flyer to each individual in case they would prefer to contact me confidentially.
Are you a husband who is caregiving for your wife who has dementia?

This is an invitation for you to participate in a study focusing on the positive aspects of caregiving. The interview would last about an hour at your convenience.

Interested in participating?
Please contact
Mackenzie Hiemstra
BGSU gerontology graduate student
419-357-5321
mackenh@bgsu.edu
APPENDIX C: PHONE SCRIPT

Voices of Husbands: Positive Aspects of Caregiving for Wives with Dementia

PHONE SCRIPT: Interest and Screening

The PI will call the husbands in response to a call or signing of their name on the sign up sheet indicating that they are interested.

Research Description

Good morning (afternoon, evening), Mr. _____________.
This is Mackenzie Hiemstra from the study about positive aspects of caring for a wife with dementia. You expressed interest during the support group (or sign up sheet, phone call, email). Is this a good time to discuss it?
If yes, proceed with script.
If no, When would be a better time for me to call you? ____________________
    Thank you for your time, I’ll try calling you at that time.

My research is about finding the positive aspects of caregiving for husbands who are caring for their wives with dementia. I know that there is a large amount of caregiver burden and negativity surrounding caregiving and I would like to learn about the other side of it. Being a part of my study will involve meeting at a time and place of your convenience for about an hour. I will interview you about your caregiving experience and ask you ten questions from a survey.

To protect your privacy, you will be assigned a code number. All personal information will be associated with your code number, not your name. Confidentiality will be protected at all times.

Do you have any questions about what I’ve explained?
    If yes, answer questions.
    If no, proceed with script.

Screening Criteria

Next I’d like to ask you a few questions to determine if you are eligible to participate.
1. Are you a husband? (YES)
2. Does your wife have some form of dementia? (YES)
3. Are you CURRENTLY caring for your wife with dementia? (YES)

If the husband meets the criteria, then:
    Thank you. You are qualified for this research study. Are you still interested in participating? ________________

    Good, I am excited that you are willing to help me. Are you available some time within the next week to be interviewed? If this isn’t a good time, I can wait a week or so to schedule a meeting.
If yes, plan a date and time with a specific location of their choosing (suggesting a library or nearby coffee shop).

If no, O.K., let’s set up a day that I can call to reschedule.

*If the husband does not meet the criteria, then:*

Thank you. I am currently recruiting husbands who fit different criteria, so you are not eligible to participate in this current study. Thank you for your time.
APPENDIX D: INFORMED CONSENT FORM

Positive Aspects of Husbands Caregiving for Wives with Dementia: Voices of Husbands

Informed Consent

Hello. My name is Mackenzie Hiemstra, a graduate student in Gerontology. I attend Bowling Green State University. Gerontology is the study of older adults. My advisor is Dr. Laura Landry-Meyer. She is an Associate Professor in Human Development and Family Studies. I am studying caregiving of husbands for their wives with dementia. I am inviting you to participate in my research so I can learn more about caregiving. I want to learn about it from the view of husbands providing care for wives who have dementia.

The point of my research is to identify the positive parts of caregiving for a wife with dementia. There are no direct benefits to you as the participant.

An interview will occur at a place you choose. The interview will last about an hour. The interview contains questions about you, your wife and your experience caregiving. It will be recorded in order to report your answers accurately. If you choose not to be recorded, I will take notes to the best of my ability. Once I have asked all of the questions, the interview is over.

Your participation is completely voluntary. You are free to stop at any time. You may decide to skip questions or stop at any time without penalty. Your participation will not affect your relationship with Bowling Green State University. Your participation will also not affect your relationship with Bowling Green Senior Center or the Alzheimer’s Association.

The informed consent form will have a number on it. That number will serve as your ID. That ID number will be the only identification attached to the voice recording and any other files. The informed consent forms with your
name and ID number will be locked in a secure location. The voice data will be saved to the computer with only the ID number attached. The only people having access to the data are my advisor and myself. Your identity will remain completely CONFIDENTIAL.

There is a possible risk of emotional distress when discussing caring for your wife. I will provide you with resources from the Alzheimer’s Association or Wood County Committee on Aging. Also, I am ethically bound to report any situation in which you may harm yourself or someone else.

Do you have any questions? You can ask me now or use the contact information below:

Contact information: If you have any questions or worries about the research or interview, please feel free to contact me.

Mackenzie Hiemstra phone 419-357-5321
Email mackenh@bgsu.edu

You may also contact Dr. Laura Landry-Meyer, my advisor.
Phone: 419-372-7848
Email: landrym@bgsu.edu

If you have any questions about your rights as a participant in this research, You may contact the Chair, Human Subjects Review Board
Phone: 419-372-7716
Email: hsrb@bgsu.edu

Thank you for your time.

INFORMED CONSENT FORM

I have been informed of the purposes and procedures of this study.
I have been informed of the risks and benefits of this study.

BGSU HSRB - APPROVED FOR USE
INHRT ID # 337766
EFFECTIVE 03/24/2014
EXPIRES 03/23/2016
I have had the opportunity to have all my questions answered. I have been informed that participating is completely voluntary. By signing below and beginning the interview, I agree to participate in this research.

X _______________________________ Date: __/__/____
Signature
Hello. I am Mackenzie, a graduate student in gerontology at BGSU. I will be interviewing you today to learn more about the positive aspects of caregiving from the view of husbands providing care for wives who have dementia.

I will be asking you several questions about your caregiving experience. Answer as best you can and as honestly as possible. In order to accurately portray your responses, I would like to record our conversation.

Is it okay for me to record our conversation?

If no,

I understand your request. As we talk, I will be taking notes. Just because I may be busy writing I will still be listening. I want to make sure I get all of the information written down. After explaining, proceed.

If yes, proceed.

I look forward to hearing your story.

1. Let’s start by telling me about your relationship with your wife.
   Prompts: How long were you married?
   Tell me how you met?
   How/why did you decide to be her caregiver?

2. How has your relationship changed since you started providing care?
   Prompt: What are the biggest differences in your relationship pre and post dementia

3. Caregiving can be challenging at times, but also very rewarding. What do you feel are some of the positives of being the caregiver for your wife?

4. What are some activities that you help your wife with?

5. Is there anything that you find helpful in managing the challenges of caregiving?
   Prompt: What do you do to relieve stress?
   How do you manage the caregiving tasks?
Do you receive any informal help? Family members, friends, etc.?

GAIN Instrument
I am going to ask you to respond to 10 statements about the positive aspects of caregiving. Please respond using the Likert scale of 0 = disagree a lot, 1= disagree a little, 2= neither agree nor disagree, 4= agree a little and 5= agree a lot. I have a page listing the Likert Scale for your convenience in responding.
You can either use the words: disagree a lot, disagree a little, neither agree nor disagree, agree a little or agree a lot or the numbers 0-5.

Providing care to my wife has…
   a. helped to increase my patience and be a more understanding person
   b. made me a stronger and more resilient person
   c. increased my self-awareness, making me more aware of myself
   d. increased my knowledge and skills in dementia care and more
   e. helped me grow closer to my wife with dementia
   f. helped me bond my family closer
   g. enabled me to better relate to older persons and persons with dementia
   h. given me deeper insights into the meaning of my life and my life’s perspective
   i. helped me grow spiritually (e.g., closer to God and being able to look beyond the material world)
   j. sparked off altruistic goals in me (e.g., wanting more to help others and contribute to the welfare of others who may be going through similar difficulties)

I have a few other questions about you.
   - What year were you born? When was your wife born?
   - What year were you married?
   - How long have you been providing care? When was your wife diagnosed?
   - What is the residency of your wife (since diagnosis)? (at home, care facility, etc.)
   - Obviously you use (based on where I recruited them from) the Wood County Committee on Aging or Alzheimer’s Association support groups, are there any other services that you utilize? (adult day care, support groups, senior centers, etc.)

Is there anything else you would like me to know?
If yes, listen to them.
If no, thank you so much for your time.
I really appreciate you taking the time to help me with my research.
APPENDIX F: LIKERT SCALE RESPONSE SHEET

0  Disagree a Lot

1  Disagree a Little

2  Neither Agree or Disagree

3  Agree a Little

4  Agree a Lot