

CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

The Experiences of Informal Caregivers Assisting Individuals with Dementia

A graduate project submitted in partial fulfillment of the requirements

For the degree of Master of Social Work

By

Nicholas Malenka in collaboration with Anthony Born

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The graduate project of Nicholas Malenka is approved:

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Dr. Allen Lipscomb

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Date

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Dr. Eli Bartle

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Date

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Dr. Jodi Brown, Chair

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Date

California State University, Northridge

## Dedication

Dedicated to the ones I love.

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## Abstract

### The Experiences of Informal Caregivers Assisting Individuals with Dementia

By

Nicholas Malenka

Master of Social Work

**Purpose:** The purpose of this study was to qualitatively explore the experiences of informal caregivers of Individuals With Dementia (IWD) in caring for their loved ones.

**Focus of inquiry:** What are the experiences of Informal Caregivers who assist IWD?

**Methods:** A phenomenological study method was utilized with a snowball sampling recruitment method. The study was conducted through the formal interviewing of ten informal caregivers. The data from these interviews was analyzed and compared to

current literature. **Results:** The results yielded the following recurring themes: daughters as caregivers, time burden, caregiver responsibility, caregiver burden, the protective factor of family and friends, and the protective factor of the Christian Church.

**Discussion:** This study demonstrates how the role of caregiving shapes the participant's lives. While Informal caregivers of IWD face a variety of difficulties while caring for their loved ones, protective factors were found to play a critical role in alleviating some of the adverse effects of caregiver burden. Resources such as ADS and caregiver support groups were found to be beneficial but underutilized. The implications of this study suggest that future research on informal caregivers of IWD should focus on the enhancement of protective factors for this population.

## **Introduction**

This study intends to explore the experiences of informal caregivers assisting individuals with dementia (IWD). Informal caregivers encounter high levels of care-related stressors daily (Mosquera, Vergara, Larrañaga, Machón & Río, 2016; Zarit Kim, Femia, Almeida, & Klein, 2014). The chronic stress exposure to caregivers of IWD is associated with physical health decline, psychiatric morbidity and poor quality of life, which in turn is a major reason for the institutionalization of IWD (Mosquera, et al., 2016; Zarit et al., 2014). This study examines the experience of caregiver stress on 10 individual informal caregivers over the course of two months. This includes the physical and emotional health effects surrounding these experiences as well as the overall quality of life of informal caregivers.

Caregiver burden has been defined as a negative reaction to the impact of providing care on caregivers' social, occupational and personal roles (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014). A caregiver is any person who cares for a needy person in his or her direct environment on a regular or full time basis (Schoenmakers, Buntinx, & Delepeleire, 2010). Formal care constitutes care provided in institutions by providers who are trained and paid for what they do while informal care constitutes care provided outside of institutions by providers who are untrained and unpaid (Bittman, Fast, Fisher, & Thomson, 2004). An informal caregiver is related (family, friends, neighbors, etc.) to the person receiving care and is not a professional caregiver. 8.9 million informal caregivers provide care to someone aged 50+ with dementia (AARP, 2011). Informal caregivers assisting individuals with dementia (IWD) encounter high levels of care-related stressors on a daily basis. It is well-established that the symptoms of dementia, such as behavioral dysfunction which include apathy, depression, hostility, anger, and aggression, are an influential source of caregiver burden and stress, which in turn is a major

reason for the institutionalization of IWD (Mosquera, et al., 2016; Zarit et al., 2014). There is also evidence that chronic stress exposure in caregivers of IWD is associated with physical health decline, psychiatric morbidity and poor quality of life (Mosquera, et al., 2016; Zarit et al., 2014). This study will produce preliminary data on the individual experiences of informal caregivers that will potentially contribute to future research in providing services for this population. The major cause of the psychosocial and physical burden to the caregiver lies in the intrusive character of dementia. Not only does the disease have an invasive effect on the IWD, but also when a member of the family environment begins to develop symptoms of dementia, role, patterns and relationships in the IWD's home environment are turned upside down and rearranged (AARP, 2011).

The cost of caring for IWD is both monetarily and psychologically taxing. Partners, relatives and friends who take care of IWD experience emotional, physical, and financial stress and caregiving demands often leads to the institutionalization of the IWD (Mosquera, et al., 2016; Zarit et al., 2014; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Lost income and benefits over a caregiver's lifetime are estimated to range from a total of \$283,716 for men to \$324,044 for women, or an average of \$303,880.30 (AARP, 2011). Even as informal caregivers pay an emotional, physical, and financial price to care for their loved ones, their efforts as informal case managers, record keepers, paramedics, and patient advocates play an invaluable role in providing quality home care to IWD while saving the public from the high cost of formal institutionalized care which AARP valued at \$350 billion in 2006 (Bookman and Harrington, 2007; Span, 2009).

## **Literature Review**

According to the article, *The Caregiver Stress Process and Health Outcomes*, the authors

examined the effects of both objective and subjective caregiving stressors on three dimensions of caregiver health through a comprehensive interview about their current care situation (Son, Erno, Shea, Femia & Zarit, 2007). The 234 participant's responses were measured according to the care receiver's behavior problems, the objective stressor, and the caregivers' feelings of overload, and the subjective stressor (Son et al., 2007).

In a study of informal caregivers' experiences, Rodger, Neill and Nugent (2015), found that there were four main themes, which emerged from the unstructured interview of informal caregivers who were recruited from an outpatient clinic that provides informal caregiver support. Unlike the previous quantitative study outlined above, Rodger, Neill and Nugent (2015) utilized a qualitative design where the data analyzed was in a narrative form which captured the thoughts and feelings of the participants. The four recurring themes were; time is not your own (there is no time for the caregiver's personal needs), duty of care (the bond between the caregiver and recipient is strong), burden of caring (the physical and psychological effects of caring for IWD), and the need for support for informal caregivers (support from family, friends and mental health professionals).

In a study, which examines the day to day experiences of informal caregivers who utilize adult day services (ADS) as respite from their duties, Zarit, Kim, Femia, Almeida and Klein (2014), interviewed participants over eight consecutive days to compare the caregiver experiences on care days to respite days. The study found that "*care-related stressors decreased on ADS days, whereas non-care stressors and positive events increased*" (p.576) and that the "*increases in non-care stressors and positive events on ADS days were mainly due to positive and stressful experiences at work*" (p.577) stating that caregivers report their work lives to be enjoyable (Zarit et al., 2014). The evidence that ADS use can be associated with temporary relief

of care-related stressors is encouraging and suggests that it could play a critical role in efforts to assist caregivers and to prevent a downward spiral of emotional and physical health (Zarit et al., 2014).

In a two-year study by Bookman and Harrington (2007), that took place in the Northeastern United States from 2003 to 2005, the researchers observed “*a geriatric care team and a palliative care team*” across “*a variety of health care facilities*” (p. 1012). Tracking a research population of family caregivers that was “*...economically and racially diverse*” Bookman and Harrington (2007), suggest that the professional care teams struggled “*...with some difficulty—to coordinate their work across a cumbersome and uncoordinated health care system*” (p. 1012). The study indicates “*weaknesses in the present geriatric health care system*” while family caregivers functioned “*...as geriatric case managers, medical record keepers, paramedics, and patient advocates to fill dangerous gaps in a system that is uncoordinated, fragmented, bureaucratic, and often depersonalized*” (Bookman & Harrington, 2007, p. 1005). The study suggests “*the experiences of family caregivers must be central to the creation of new policies and a more coordinated system that uses the complex work of family caregivers by providing the training and support that they need*” (Bookman & Harrington, 2007, p. 1005). The implications of this study highlight the importance of informal caregivers as they pick up the slack within the healthcare system while simultaneously serving their family members.

In a study utilizing comparative analysis, Youngmee and Schulz (2008), took sample populations of family caregivers and compared data for caregivers of “*...persons with cancer, dementia, diabetes, or frail elderly from a nationally representative sample of 606*” (p. 483). A diverse population was recruited based on each caregiver’s self-report of caring for an individual with either dementia, diabetes, or frail elder (p. 487). Variables measured, included:

sociodemographic information of the caregiver and relationship to care recipient, the illness as described by the caregiver, duration of caregiving, the types of caregiving provided to the recipient, and the types of strain experienced by the caregiver (Youngmee & Schulz, 2008, p. 487-490). Results of the study as it relates to caregivers of IWD showed a “...*similarity of cancer caregiving to dementia caregiving*” in terms of the higher stress-related difficulties faced by the family caregiver(s) (Youngmee & Schulz, 2008, p. 498). Youngmee and Schulz (2008), found that both cancer and dementia caregivers: “*provided assistance for similar numbers of ADLs and IADLs*” (p. 498-499). The implications of this study, “...*support the stress-coping perspective, indicating that younger age, male gender, and higher education were personal resources to handle the caregiving demands*” (Youngmee & Schulz, 2008, p. 499). It also emphasizes a “*support model of illness appraisal and coping*” that highlight “*associations between disease-specific conditions by different caregiver groups and the caregiving outcomes*” (Youngmee & Schulz, 2008, p. 499).

Overall, the general research focusing on informal caregivers who work with IWD, suggests that their function is crucial not just to the IWD, but to the overall health care system as indicated in the study by Bookman and Harrington (2007). Bookman and Harrington (2007) suggest that informal caregivers take on the daily responsibilities that health care professionals do not. The focus and underlying issue of much of the research demonstrated that stressors among informal caregivers are an ongoing issue, especially among those working with IWD (Youngmee & Schulz, 2008; Son et al., 2007). There were also implications pointing towards respite in the form of adult day services (ADS) as a form of relief from stressors for caregivers (Zarit et al., 2014). The research tended to highlight recurring themes of caregiver stressors as they relate to negative outcomes for informal caregiver health and relief in the form of respite.

With the world population of older adults, age 60 and over, expected to reach 2 billion by the year 2050 (World Health Organization, 2014) and the responsibility of their daily care falling on friends and family members, continued research on how to provide additional supports for the informal caregiver is vital.

**Aims and objectives.**

This study intends to explore the experiences of informal caregivers assisting IWD, looking particularly at the experience of caregiver stress; physical and emotional health effects surrounding these experiences; and the overall quality of life of the caregivers.

**Research Question**

What are the experiences of Informal Caregivers who assist IWD?

## **Method**

### **Participants.**

The sample population of participants in this study was recruited from a diverse group of 10 to 15 informal caregivers of Individuals with Dementia (IWD). An inclusion criterion was stipulated that the sample population would have cared for an IWD for a minimum of one consecutive year of informal caregiver service. However, if the participant population lacked at least 10 individuals upon finishing the recruitment process, the researchers would change the criteria to consist of participants who had at least six months of consistent and continuing informal caregiving experience. Each participant was the primary caregiver for the IWD in his or her private home on a daily basis. The sample population was recruited from a diverse age cohort consisting of early to late adulthood (18 and up), male and female genders, varying socioeconomic statuses and ethnicities, including marital status. The Phenomenology theory was utilized and the fieldwork was conducted through the snowball sampling method to aid in the recruitment of participants. The snowball sampling method entailed recruitment via word-of-mouth from one participant to another. The first individual was reached through acquaintance via word of mouth of the researchers. No incentives were offered to the individuals and no direct benefits were expected during or as a result of this study.

### **Reflexivity Statement.**

Both researchers have family members who are experiencing the effects of Dementia and are acquainted with the informal caregivers who take on the majority of responsibility for their care. Both researchers recognize a need for caregivers in general and the tremendous effort required in taking on this role.

A phenomenological model was utilized to gain insight into the experiences of informal caregivers of IWD. Utilizing the phenomenological model as described by Creswell (2007), the researchers maintained a self-awareness of biases and refrained from pre-judgements of the experiences of informal caregivers. It was important for the researchers to distance themselves from the participants by remaining objective observers of the phenomena being studied. The researchers maintained an understanding that the participants were themselves the sole experts of their own experiences in informal caregiving. Following Creswell's explanation (2007), Researchers refrained from interjecting their "...own interpretation based on the cultural, social, gender, class, and personal politics" they may have brought into the study to the best of their ability (p. 179).

### **Research Design.**

Over the course of eight weeks, this qualitative study explored the experiences of informal caregivers through a single formal interview conducted by the researchers. The researchers looked for underlying themes and patterns that suggested an impact on the quality of life of the informal caregiver of IWD. Through analysis of the formal interview process, patterns concerning the impact on the financial, physical, and emotional wellbeing of participants were evaluated

### **Procedure.**

The interaction with participants occurred informally via phone call or email to briefly explain the research study and set up the formal interview date and time. Upon meeting in-person for the first time, an in-depth explanation of the study took place, including an explanation and signing of the consent form as well as answering the participant's questions or concerns. The interview then took place. No new procedures were investigated in this study and deception was

not used. The researchers reviewed the consent form and established the participant's understanding of his/her rights stated on the consent form, prior to obtaining the signature. If the participant had signed the consent form and verbally agreed, the researchers began the formal interview process.

The researchers met with the participant population individually at the individual's place of residence or a discreet location of their choice for their convenience. The interview process consisted of open-ended questions that intended to probe the experience that participants have with their IWD. The questions featured open ended wording to allow for informal conversation to take place between researcher and participant, subsequently allowing for increased data collection. The interviews were digitally recorded and transcribed within 24 hours of having taken place. Each individual participant's transcription was subsequently printed and read by the participant to ensure accuracy of the data that was collected. Following the completion of the recorded interview, the researchers transcribed the recording into written word and had the participant view the notes for clarification of accuracy and permission to move forward with the study. The researchers began collecting data on February 1, 2016. Interviews took place through March 2017 and were scheduled according to the convenience of the participants. The interview process was a minimum of 30 minutes to a maximum of 60 minutes to allow for the interview guide approach to take place.

Upon completion of the data collection process and transcription of all interviews, the researchers analyzed the data. The researchers looked for trends and patterns within the data as it related to the participant's status as caretakers of IWD.

## Results

Participant	Age	Race	Religion	Health Status	Relationship to Loved One
Participant 1	58	African American	Christian	good	Daughter
Participant 2	57	Hispanic	Christian	good	Niece
Participant 3	39	Caucasian	Christian	improvable	Sister
Participant 4	58	Caucasian	Christian	good	Daughter
Participant 5	58	Caucasian	Jewish	good	Daughter
Participant 6	35	Caucasian	Christian	good	Daughter
Participant 7	59	Caucasian	Christian	good	Daughter
Participant 8	67	Caucasian	Christian	good	Husband
Participant 9	57	Caucasian	Christian	good	Daughter
Participant 10	59	Caucasian	Christian	improvable	Daughter

There were five underlying themes found as a result of data analysis: daughters as caregivers, time burden, caregiver responsibility, caregiver burden, the protective factor of family and friends, and the protective factor of the Christian Church. The themes are examined below and explained in detail.

### Daughters As Informal Caregivers

Upon the completion of the interview process with all ten participants, the majority of informal caregivers were found to be daughters of the IWD. In all, seven of the ten participants were daughters of their loved ones being cared for. The personal narrative surrounding the reasoning for each daughter's involvement as the informal caregiver for their loved one with IWD was found to be varied and different for each individual. When deciding what to do with her father upon learning of his diagnosis of Dementia, participant 4 reasoned that it simply made “logical” sense for her to become the informal caregiver:

*We decided that this would be a good time to actually sell his house and convince him to move in with me and my family. Since I wasn't working anymore, it became the logical choice...and we were happy to take him here... so that's what we did.*

Similarly, participant 6 found that it was the right choice for her and family:

*Um, but ... I, I feel as if this was the best decision for me, and for the family, and um, it's taking me the right direction in my life. But it's, you know, I cannot get back the time that I've spent with my parents right now, and um, even though it doesn't feel joyful and it doesn't feel as if, you know, we're having fun all the time, you know you really just have to find those moments and cherish the time that you're spending, even if it's just, you know, driving them back and forth.*

Participant 6 found that while her caring for her father was the right decision for her family, she admitted that it is not “joyful” and is not “fun all the time.” In the case of Participant 9, she felt forced into the situation of being the informal caregiver of her mother:

*So that's no fun. And you know, all my friends are like, why do you do it? What else am I supposed to do? She won't go in a home, the only way I can get her forcibly into a home, is that, somebody has to declare her nuts.*

Unlike Participants 4 and 6, participant 9 felt as though she had no choice and was forced into her role as an informal caregiver due to her mother's unwillingness to go into a supported living situation. The daughters whom were interviewed had varying feelings regarding their current roles as informal caregivers. Yet, an underlying sense of duty and responsibility for their loved ones appeared to take precedent during the interviews. As Participant 4 noted when asked about any sacrifices she had to make to care for her father, “Well...no. I don't consider it a sacrifice. People are always saying: "Oh my god, I can't believe you have to do that." But, he's my dad so I didn't think twice about it.” The sense of reluctant duty could also be found in Participant 9's statement, “What else am I supposed to do?”

### **Time Burden**

A lack of time for any activities outside of the caregiving role was also a theme noted throughout the conducted interviews. As participant 1 noted when asked about sacrifices she had to make to care for her mother:

*Uh, well yeah, yeah, w-if I-if-if I s-if I have to mention a sacrifice, and I don't mean that in a, um, in kinda like in a rhetorical manner is that, um, I'm limited to what I can do or*

*what I h-h-the time o-away. So, either I take her with me or I don't go. And then, um, just bein bound to home. Which, I mean it wasn't-it hasn't been really a-a big thing, but, um, yeah I-I jus wanna came back from Africa.*

Participant 1 found that her status as an informal caregiver to her mother “limited” her to activities done with her mother and subsequently often kept her confined to her home. Her trip to Africa was identified as the only period of time that included a full day and night where she was away from her mother in over a year. When answering the same question, participant 8 gave a similar example:

*Just a thing of... not being able to go where I wanted to go anytime. And not that I did it a lot but I knew I could. A lot of times that gives you a free feeling or something. Knowing that you could... and now I can't because she needs me for her pills and that sort of thing.*

Participant 7 described the frustration she felt in an emotional statement explaining the lack of time for outside activities away from her loved one:

*Yes, my whole life is a sacrifice. No. Yes, because when I'm going out to dinner next Friday, and I got to find somebody to sit with her. Right now, the two people that I've already contacted can't. This is going to present a problem to me until ... Yeah, I have to make sacrifices. I sacrificed. I'm not going out to dinner with my husband. Because I sacrifice a lot. If I wanted to disappear, I couldn't, because she calls me 100 times a day, you know what I mean? Yeah, yeah, I sacrifice going out, or being with friends and as much as I would like to, or going out with my husband for dinner, or picking up and going away for the weekend. You just can't do it anymore.*

Participant 7’s statement demonstrated the theme of time burden as a lack of time for any outside activity away from their role as a caregiver. The emotional burden of time committed to their loved ones was highlighted throughout the interviews. The effects extended into the caregiver’s social life which will be explored in a later theme.

### **Daily Caregiver Responsibility**

The daily responsibilities of caregivers were found to be similar across the interviewed participants. Daily responsibilities for loved ones were described as a regular routine and focused

on basic needs. Meal preparation was viewed as a primary function for each caregiver.

Assistance with hygiene was often required as well to varying degrees depending on the need of the participant's loved one. Participant 4's experience primarily focused on reminders when describing caring for her father, "*You do have to prod him to brush his teeth and help him along to bed.*" In the case of Participant 1, her experiences were more involved:

*She can pretty much still dress herself. She doesn't remember to brush her teeth or anything like that so I have to someone has to do that. And then she cannot be in the shower alone. So, s-s-you have to do-have that.*

Medication regulation was also viewed as a necessary function for the participants to perform on a daily basis to maintain a safe and consistent medicating of their loved ones. As participant 2 stated:

*I give her her medication for the morning and night in a little box. So we just give her a little box for the morning and we take it away. Then we give her the medication for the night.*

Participant 1 explained a similar scenario regarding medication in his daily routine:

*Or some place to eat, she can do that but there's nothing to do for her then it gets-it progress and then she has to be medicated and then put down to bed so.*

Participants also viewed scheduling as a means to prepare for the next day and for appointments as a necessity. Participant 7 referred specifically to a chalkboard on which she writes her mother's daily schedule to help assist her with her routine. She explained, "*I have to tell her, 'Today...' I have a chalkboard in her room, 'Monday, you clean your dentures.', you know what I mean?'*" Participant 7's example represented the outlier in terms of using scheduling directly with her mother. The majority of participants utilized scheduling strictly for the management of their loved one's routines and appointments. The participants' daily caregiver responsibilities centered on a routine. In the interviews, the routine consistently involved the

responsibilities of hygiene, meal preparation, scheduling, and medication regulation.

### **Caregiver Burden**

In addition to time burden, other trends were found that contributed to the overall theme of caregiver burden. A loved one's Sundown Syndrome was a trend that was shown to contribute to emotional distress and thus the overall burden of five of the ten interviewed caregivers. As participant 1 explained when discussing Sundown Syndrome:

*So, um, bout 12:30, 1:00 she has a lot of delusionary stuff so I couldn't take her. So I had to find somebody to watch her. So that kind of stuff, you know, kinda keeps me from havin an extensive life outside.*

Participant 1's experience of the burden associated with Sundown Syndrome was further exemplified by Participant 9 when she stated, "*The Dementia and the Sundowners is really the worst part of it.*"

The distress caused by the day-to-day behavioral issues surrounding IWD's was shown to have a significant impact on the interviewed caregivers emotional state. This was made particularly clear when participants referred to their loved one's current mental state. When asked about things that bother her most about caring for her loved one, participant 3 stated that:

*Uh... And I feel, my heart breaks for my sister. It does, because I don't know how much of her is there and how much of her isn't, and I, I don't know if it feels like she's trapped in her own body.*

Participant 7 also expressed the feeling of emotional distress around the declining health of loved ones when she stated: "*I miss my Mom. I miss her. I'm going to start to cry now. I miss the woman she was, I miss having her to talk to about things.*" This tendency to reminisce about their loved ones' prior to the onset of Dementia came up at various points throughout the interviews.

### **Family and Friends as A Protective Factor**

While several protective factors were identified throughout the interview process, two

key themes stood out. One key theme was the support of family and friends.

Throughout the interview process, the support of family and friends was commonly identified as an important protective factor for informal caregivers. Family members and friends were found to provide emotional support. When asked about whom she turned to when she needed support, participant 4 responded:

*Well...I mean, I talk to my husband because he can understand the most, since he lives here, (laughs). But...I also don't want to complain or vent too much to him because he is nice enough to agree to open our home to my dad. Plus, my group of close girlfriends makes for a safe place to vent. They can just sort of support you, verbally.*

While participant 4 could turn to her husband for support, she also found that her “girlfriends” could be supportive as well. This emotional support was found to provide a way for the caregivers to share their experiences of caring for their loved ones. As participant 5 explained:

*I have my sister, my husband...and I know a few other people who are similarly situated...so sometimes I'll talk to them and...we trade experiences.*

Other participants identified family and friends as an outlet to vent their frustrations about their experiences in caregiving. Participant 9 described this experience when visiting her friend, “*Sometimes I just go over there and scream.*” Either friends or family were also singled out as the primary persons that the caregiver would turn to for support as in the case of participant 6, who divorced her husband. When asked about who she turned to for support, participant 6 responded:

*That's a good question, I mean obviously going through the separation and now, you know, divorce, I mean I've lost my husband who was my, you know, whole support, but I have um, you know I'm back in my home town, so I have my, my close friends that I went to school with, grew up together, um, and also we have, I have a great network of friends that we all went to college together that are still up here.*

In the case of participant 6, when she could no longer turn to a family member, she found that her friends were accessible in her hometown.

## **The Church As A Protective Factor**

The second underlying protective factor found throughout the interviews was the support participants found from within their respective Churches. As nine of the ten the participants identified as Christian, supports found within the Christian faith were found to be important to participants. When asked about who she turned to for support, Participant 1 referred specifically to the fellow members of her Church when she stated:

*The people in my, um, immediate circle, which is my brothers and sisters in-in-in the fellowship.*

While participant 6 recognized her friends as an important support in her life, she also stated that “...also my church is really important, so, I find comfort in that also”. Beyond the supports within the Church, an outlier was found in participant 8 when he stated:

*I'm in an Evangelical quartet, usually just the weekends, because it's so difficult, the base singer's wife would come over. She came over and spent the night one time, I remember we were out and going to be very late coming back. And...she stayed the night with my wife. They had a good time because she's light and airy and knows the situation.*

Here, the bonds he formed within his Evangelical quartet allowed Participant 8 to receive direct support in the caregiving of his loved one.

## Discussion

This study explored the experiences of informal caregivers assisting individuals with Dementia and demonstrates how the role of caregiving shapes the participant's lives. The majority of the reviewed literature focused on the chronic stress, physical and psychological decline, lost income and poor quality of life of the caregivers of IWD (AARP, 2011; Mosquera, et al., 2016; Zarit et al., 2014). This study found key themes of the participant's experiences in caregiving to include: daughters as caregivers, lack of time, the multiple roles the caregiver fills on a daily basis, caregiver burdens and protective factor. Some similarities were found between the reviewed literature and this study, with the exception of an outlier.

The theme of daughters being the majority of caregivers interviewed showed little consistency between the reasoning that participants found for taking on this role. The exception here was a feeling of responsibility for the well-being of their loved one and their respective families. Review of the literature found no comparison for the specific demographic of daughters as informal caregivers. Further inquiry into this possible trend would serve to identify or disprove this as a consistent theme among informal caregivers.

This study reinforced the theme of "*Time is not your own*", with a number of participants reporting a lack of time to perform tasks outside of their role as a caregiver (Rodger, Neill, & Nugent, 2015, p. 282). This lack of time limited the caregiver's ability to participate in healthy coping activities such as vacationing or socializing. There were also implications pointing towards respite in the form of adult day services (ADS) as a form of relief from stressors for caregivers (Zarit et al. 2014). However, it was not found to be a theme as only two of the ten participants utilized ADS. The literature found that, "*care-related stressors decreased on ADS days...*", demonstrating the importance of ADS as a resource for informal caregivers (Zarit et al.,

2014, p. 576). Being that only two participants utilized these services, may suggest that informal caregivers would benefit from an increase in ADS. Further research on the rate of informal caregivers utilizing ADS is needed.

Participants were found to unilaterally take on multiple responsibilities in their role as informal caregiver. Responsibilities such as medication regulation, food preparation and scheduling were found to subsequently decrease the amount of time outside of the caregiver role. In Bookman and Harrington (2007), the multiple responsibilities taken on by informal caregivers were found to relieve the cost of public health care for IWD. That is to suggest that informal caregivers take on the bulk of the caring for their loved one's and provides another reason for increased supports. Further literature review suggested that healthcare providers of IWD's should take into consideration the role that the Informal Caregiver plays and aide in referring them to appropriate resources (Rodger, Neill, & Nugent, 2015).

The study found that the intrusive nature of Dementia including the loss of depth of the former caregiver/IWD relationship, the introduction of behavior issues that often presented as Sundown Syndrome, and the continuous deterioration of the IWD's condition added a particularly burdensome aspect to the caregiver's experience. These findings and those of the literature were found to align (Mosquera, et al., 2016; Zarit et al., 2014). The results of this caregiver burden are shown to yield negative consequences for caregiver mental and physical health (Mosquera, et al. 2016; Zarit et al., 2014). These findings imply the need for further research about the effectiveness of caregiver peer support groups and other mental health counseling services.

Friends and family as a protective factor were found to be the underlying source of support for the participants. Participants were found to utilize their friends and family as a way to

share their experiences in caregiving, thus working to help alleviate the burden of caregiving. Findings by Rodger, Neill, and Nugent (2015), suggest that “*internal supports*” such as family and friends were one form of support. While friends and family were commonly referenced throughout the interviews, “*external supports*” “...*provided by professionals in the community*” were seldom brought up during the interviews as a support that was currently being used (Rodger, Neill, & Nugent, 2015, p. 283). The exceptions were found in the interviews of participants 1 and 2 who were actively utilizing Adult Day Services (ADS) as a support to help care for their loved ones. Given the significant impact of ADS on relieving stressors related to caregiving, the participants of this study were found to be underutilizing these services (Zarit et al., 2014). In addition to ADS, participants 1 and 2 utilized social supports in the form of caregiver support groups. Findings by Vann (2013) suggest that those who care for a loved one with Alzheimer’s disease be recommended for a support group by their doctor. The literature findings demonstrated external supports such as ADS and social supports such as caregiver support groups may be beneficial in relieving the burden of caregiving. This suggests that eight of the ten participants were not utilizing available resources beyond their underlying support from friends and family.

The Christian Church was found to be the second underlying protective factor among the participants. Nine out of the ten participants identified themselves as Christians with three specifically referring to Church or Church-related groups as important supports in their caregiving experiences. Findings by Do Hoon Kim (2016), demonstrated that “*religiosity reduce(s) support burden and depressive symptoms among caregivers of Dementia patients as a potential protective factor*” (p. 607). Participants who participated in the Church reported social support in the caring of their loved ones among their peers. In support of the themes of friends,

family, and Christianity as protective factors against the effects of caregiver burden, participant 9, who had little in the way of social supports as protective factors, reported to be experiencing the highest level of emotional distress out of all of the participants interviewed.

### **Limitations**

The study's potential limitations were identified, in part as a result of a focus on the Phenomenological method. Were a mixed method format to be utilized, the interviews could have included a survey in addition to the formal interview portion of the study. This would allow for increased data collection regarding their levels of stress and emotional response towards their experiences as informal caregivers. A small sample size may have limited the data collected from the participants. A sample size of ten participants may have limited the variety of participants in terms of demographics and possibly further identifying patterns in the data collected. In utilizing the Snowball recruitment method, the focus on recruiting participants was done via word of mouth. The Snowball recruitment method may have limited the potential for a more demographically diverse participant population were a more decisive method utilized. The questionnaire format was based on specific questions and did not allow for dialogue between the participant and researcher. An open format interview may have allowed for a more open discussion and therefore increased the amount of data collected.

## **Conclusion**

The phenomenological study of the experiences of informal caregivers assisting individuals with Dementia revealed the complexity of the informal caregivers' lives due to the many roles they take on while caring for their loved ones. The participants' responses to the interview indicated not only a sense of responsibility towards their loved one's health, but also a positive experience overall while caring for their loved ones. The identified protective factors of friends and family as well as the Christian Church demonstrated not only the importance of these factors but also a lack of additional protective factors by the majority of the participants. Resources such as ADS and caregiver support groups were found to be beneficial but underutilized. The implications of this study suggest that future research on informal caregivers of IWD should focus on the enhancement of protective factors for this population.

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## **Appendix A**

### **Interview Questions**

1. Tell me about your relationship with (your loved one).
2. How did you learn that they were suffering from Dementia?
3. At what point did you realize (your loved one) needed fulltime care?
4. Did you have to change anything in your life to care for (your loved one)?
5. Have you had to make any sacrifices to care for (your loved one)?
6. Describe the events of a typical day/week.
7. Is there anything you would change about your typical day/week?
8. What are some of the things you enjoy about caring for (your loved one)?
9. What are some things that bother you about caring for (your loved one)?
10. What do you do for fun or to unwind?
11. How is your health? (specific)
12. You spend a lot of time and energy caring for (your loved one), who do you turn to when you need support?
13. Has caring for (your loved one) affected you financially in any way?
14. Do you have any advice for someone who is at the beginning of his or her journey to becoming the caregiver of a loved one?

## Appendix B: Addendum

### ADDENDUM – The Experiences of Informal Caregivers Assisting Individuals with Dementia

The Experiences of Informal Caregivers Assisting Individuals with Dementia is a joint graduate project between Nicholas Malenka and Anthony Born. This document will explain the division of responsibilities between the two parties.

Student Name #1 is responsible for all the following tasks/document sections:

- Conducted 5 Interviews
- Transcribed 5 Transcriptions
- Conducted Coding and Thematic Analysis

Student Name #2 is responsible for all the following tasks/document sections:

- Conducted 5 Interviews
- Transcribed 5 Transcriptions
- Conducted Coding and Thematic Analysis

Both parties shared responsibilities for the following tasks/document sections:

- 5 Interviews
- 5 Transcriptions
- Coding and Thematic Analysis

**\*Any additional information can be included in a separate document attached to this Addendum page**

Nicholas Malenka	03/29/2017	Anthony Born	03/29/2017
<hr/> <b>Student Name #1</b>	<hr/> Date	<hr/> <b>Student Name #2</b>	<hr/> Date
106215692		100192961	
<hr/> <b>Student ID</b>		<hr/> <b>Student ID</b>	
Jodi L. Brown		Eli E. Bartle	
<hr/> <b>Committee Chair</b>	<hr/> Date	<hr/> <b>Graduate Coordinator</b>	<hr/> Date
Eli E. Bartle		Eli E. Bartle	
<hr/> <b>Committee Member</b>	<hr/> Date	<hr/> <b>Department Chair</b>	<hr/> Date
Allen E. Lipscomb			
<hr/> <b>Committee Member</b>	<hr/> Date		