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Life Satisfaction: Aging Female Informal Caregivers of Persons with Dementia

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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

LIFE SATISFACTION: AGING FEMALE INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA

by

Deborah A. Monson

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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

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DISSERTATION: Life Satisfaction: Aging Female Informal Caregivers of Persons with Dementia

DISSERTATION

COMMITTEE:

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Abstract

Purpose/Aims

The purpose of this study was to describe the relationship between aging female informal caregivers of persons with dementia (PWD) and care recipients' PWD demographic factors, aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

Background/Rationale

Older adults with dementia are living longer and the majority are receiving care by aging female informal caregivers. Dementia incrementally worsens over time impacting informal caregiver life satisfaction. Most studies have focused on negative aspects of informal caregiving. Therefore, this study investigated both positive and negative aspects of caregiving.

Conceptual Basis

The stress theory of Lazarus and Folkman (1984) delineates how people respond with attitude and behavior to situations that are stressful and Bandura (1977) emphasizes understanding the stress response and reaction to it can help a person realize and adapt to stress.

Method

The study purpose was achieved through a cross-sectional descriptive design. A convenience sample of aging female informal caregivers of PWD over age 56 (N = 35) were enrolled in the study. Six quantitative instruments were utilized: Scale of Positive and Negative Experience, Flourishing Scale, Caregiver Self-Assessment Questionnaire, and Satisfaction with Life Scale. Descriptive and inferential statistics were used to analyze the data.

Findings

In aging female informal caregivers of PWD, over half of the participants scored satisfied or higher in life satisfaction. Due to the study's small sample size, four models were tested using only two independent variables at a time to determine the variance in the dependent variable life satisfaction for each model. The independent variables accounting for the variance in life satisfaction within each of the four models were affect balance (62%), positive feelings (49%), sense of flourishing (47%), and negative feelings (62%); ($p < 0.001$).

Implications for Research

Future research is recommended. First, replicating this study in aging male informal caregivers of PWD would address a substantial gap in knowledge. Next, interventions aimed at increasing life satisfaction for aging informal caregivers of PWD would be crucial for those who are at-risk of diminished life satisfaction.

Keywords: caregiver, dementia, flourishing, life satisfaction, positive/negative experience

Dissertation

Dissertation, process bold -
Progressive search; bits of gold;
Phenomenon to behold.
Literature exploration
To examine a causation.

Relationship of cause inclined;
Linked to variables thus defined -
Statistics run. Are they aligned?
Are the findings corroboration
Of nursing practice ministration?

What a road to travel down;
At times provoking a meltdown.
But to this notion I would frown.
Maintaining forward motion
With professional devotion.

Dissertation now accomplished;
I am certainly astonished.
Now I must pay heartfelt homage
To colleagues, friends and family
Who encouraged me perpetually.

Deborah Monson

Dedication

I dedicate this dissertation to my 93-year-old mother Jane Hale who is also my best friend and who always promoting onward fortitude. And to my children Richard Flynn, Justin Monson, Hannah Monson and Benjamin Monson, and my daughter-in-law Tristen Flynn, and my grandchildren Matthew Smith, Kelly Flynn and McCoy Riddick who emboldened me to pursue my dreams and always contributed support along the way. And to my blessed friend Cookie Darling a spiritual advocate and provider of child entertainment. And to my good friend Lorraine Price who furnished enduring validation. And to my sister Marcia Buompensiero, a celebrated author, who inspired me to great heights with her demonstrated success! And to a tight knit group of women from Moms in Touch who stood by my side in prayer and friendship, especially to the hostess Judy Doyle. And to my best friend Sandy Brown who exudes vitality and unwavering determination and who propelled me beyond the tight spots.

Preface

Thank you to my dissertation chair Ann Mayo who guided me in this academic process and never wavered in the belief that I would accomplish this undertaking; and to the committee who kept me on track.

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Gratitude to my supervisor and scholastic peer Sofia Puerto who enthusiastically cheered me on and reinforced my ability to be professionally accomplished.

Table of Contents

Chapter One

Chapter Two

Chapter Three

Chapter Four

Chapter Five

List of Tables

Appendices

Figures

Chapter One

INTRODUCTION

This chapter covers the problem statement, the background of informal caregiving and dementia, theoretical perspective on stress theories, method, purpose and specific aims, research question, study conceptual framework, and significance of the study.

Problem Statement

Over 16 million American adult informal caregivers provide uncompensated care to persons with Alzheimer's disease and other forms of dementia (Alzheimer's Association, 2020) and the burden of care usually falls on the female spouse/partner (National Institute on Aging, 2015; Family Caregiver Alliance, 2020a). Female informal caregivers in the 50+ years of group comprise 61% of the informal caregiving force (National Alliance for Caregiving [NAC]/American Association of Retired Persons [AARP], 2020) and it is estimated 7 in100 informal caregivers is 75 or older (NAC/AARP, 2020). Considerable research indicates informal caregivers who provide care to persons with chronic or disabling conditions are themselves in jeopardy of health-related issues (NAC/AARP, 2020; Family Caregiving Alliance, 2006; Smith, et al., 2001; Houser & Gibson, 2008). As dementia progresses, assistance required by the care recipient increases considerably (Alzheimer's Association, 2020). An exponential increase in the number of aging female informal caregivers in the US is projected and so places this population at risk for an alteration in life satisfaction.

Background

Informal Caregiving and Dementia

An informal caregiver's experience is impacted in part by the extent to which he or she senses being in control of daily life encounters. Most people find a way to cope with the challenges of life; and providing care to a loved one with dementia is such a challenge. In the process of providing care what happens to the caregiver's experience of living and their perception of life satisfaction is important. This study is founded on the postulation that aging female informal caregivers of persons with dementia (PWD) face many challenges that will affect their life satisfaction. Other than continuing to live at home and receiving care from a spouse or other family member, options for care include paying a formal caregiver to provide service in the home or admitting the care recipient PWD to an extended care facility. However, remaining in the home environment keeps the family together foremost and is often the most cost-effective approach. Providing care to a spouse in the home environment is a privilege that comes with many challenges that affect daily life satisfaction in either a positive or negative manner (Broe, et al., 1999; Darling, et al., 2010; Kenneson & Bobo, 2010; Kruetzer et al., 2009; Wells, et al., 2005).

Informal Caregiving, Dementia and Life Satisfaction

The perception of an alteration in life satisfaction can especially be observed in the situation where the aging female informal caregiver is living with a spouse or partner suffering from the advancing stages of cognitive decline, as in the case of the dementia, and where the progression of this disease to death is inevitable (Alzheimer's Association, 2020; Clay, et al., 2008; Kaufman, et al., 2010; Kruithoff, et al., 2012; Thorpe, et al., 2009). Dementia diminishes the cognitive ability of the aging adult over a continuum of time as the disease progresses, and the person afflicted eventually requires round the clock care and monitoring. The effect of caring for a spouse or partner throughout the progressive stages of dementia cannot be completely understood by the informal caregiver at the time of initial diagnosis, and the response to the disease process varies from individual to individual. Care recipient anticipated and unanticipated consequences of the disease process place the aging female informal caregiver of PWD at risk for an alteration in life satisfaction. As the time demands increase for caregiving, aging female informal caregivers of PWD have a tendency to set aside or overlook their own needs, such as daily personal needs, medical appointments, prescription refills, preventive health care, and respite breaks (American Psychology Association, 2013; Borg & Hallberg, 2008; Kruetzer et al., 2009). Aging female informal caregivers of PWD have long-term needs of their own. What is the implication?

Life Expectancy and Provision of Care

Life expectancy in the future will continue to extend as the population embraces healthier lifestyles and advances in medicine. The number of existing extended care facilities is not adequate to serve the current population (Family Caregiver Alliance, 2020a; Centers for Disease Control, 2013), and therefore discovering ways to support aging female informal caregivers of PWD in the home environment is desirable. What provisions will be available in the future for persons unable to independently conduct the activities of daily living and who have no one to care for them in the home environment? The needs of aging female informal caregivers of PWD must be understood and addressed, and solutions discovered to ease the demands associated with providing long-term care in the home environment. Providing support for aging female informal caregivers of PWD to meet their own needs of daily living, medical and psychological issues will allow them to remain in the home to continue providing care to their loved one.

Providing long term care to a spouse/partner with dementia in the home environment is a stressful human experience. Routine and unpredictable stressors can be both positive and negative and are a daily occurrence for aging female informal caregivers of PWD in the home environment (American Psychology Association, 2013; National Alliance for Caregiving, 2015). The challenge of furnishing care for a person with dementia impacts all aspects of human functioning (emotional, physical, psychological, and spiritual) for the caregiver. No one theory describes life satisfaction. Therefore, two theories will be synthesized that support the research conceptual framework for this study. These two theories are coping theory and stress theory.

Theoretical Perspective

Theoretical Underpinning of Stress Theory

Since the introduction of General Adaptation Syndrome (GAS) by Selye in the 1930s, numerous studies on stress have been conducted, focusing primarily on the negative effects of stress to the human body. Modern day stress research can be credited to Lazarus who provides a comprehensive stress theory that has evolved overtime and delineates how people respond with attitude and behavior to situations that are stressful (Lazarus & Folkman, 1984). Understanding the stress response and reaction to it can help a person realize and adapt to stress, as in self-efficacy theory that suggests if people perceive themselves as possessing the necessary skills and abilities to generate positive outcomes it is more likely they will take this tack (Bandura, 1977).

Proactive Coping Strategies

Realizing and utilizing proactive coping strategies can assist persons to rely on internal and external resources that can help them conquer and rise above the challenges encountered on a daily (Folkman, 1997), while providing long term care to their loved one. Greenglas et al. (2005) support the concept of proactive approaches to stress; that is, anticipating what will occur and implementing strategies that will head off stressful events and negative reactions. Access to and maintaining a more positive outlook on life by the caregiver may reduce the ill effects of stress on their body (Borg & Hallberg, 2008; Manne et al., 1999). Older persons are tuned into what is best for them and given the option they will refrain from participating in disconsolate interactions or settings (Carstensen & Mikels, 2005; Carstensen et al., 2000).

Over the course of time, studies have not included a balance in examining life satisfaction of the older adult caregiver. Measuring positive and negative experiences, flourishing, caregiver stress, and life satisfaction is needed to provide insight into how aging female informal caregivers can develop and nourish a positive disposition when enduring ongoing demanding and often formidable circumstances that wax and wane during the lived caregiving experience.

Method

The study purpose was achieved through a cross-sectional descriptive design. Specifically, the relationship was described between aging female informal caregivers of persons with dementia (PWD) demographics, care recipients PWD demographics, aging female caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

A convenience sample of aging female informal caregivers of PWD (spouse, partner, or other family member) age 56 and older were enrolled in the study.

Purpose of Study

The purpose of this study was to describe the relationship between aging female informal caregivers of persons with dementia (PWD) and care recipients' PWD demographic factors, aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

Specific Aims

Study Aim 1

Describe select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample.

Study Aim 2

Describe the relationship between select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample.

Study Aim 3

Determine the amount of variance in aging female informal caregivers' life satisfaction accounted for by select demographics, social support factors, positive and negative feelings, flourishing, and stress.

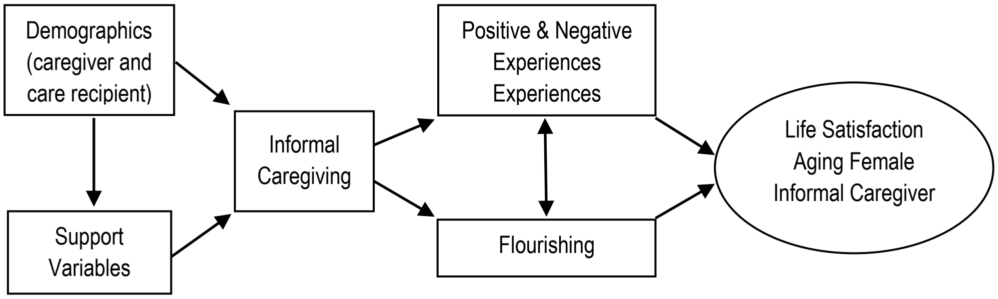
Research Question

What is the relationship between aging female informal caregivers of PWD and care recipients' PWD demographics, aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction?

Study Conceptual Framework

The conceptual framework was based on the premise that aging female informal caregivers of PWD and care recipients PWD demographics, aging female informal caregivers of PWD support factors, positive and negative experiences, and a sense of flourishing may affect life satisfaction. The aging female informal caregiver of PWD engages in activities of daily living with the dementia care recipient, and the activities of daily living are affected by the dementia process that includes progressive declining cognition and unpredictable behavior. The act of caring around- the-clock on a daily basis for the care recipient PWD who is unable to independently care for themselves in turn contributes to perceived positive and negative experiences, a sense of flourishing, and caregiver stress which ultimately influences aging female informal caregiver of PWD life satisfaction.

Figure 1. Study Research Conceptual Framework.



This study proposes the idea that aging female informal caregivers of PWD and care recipients' PWD demographics, aging female informal caregivers of PWD support variables, positive and negative feelings, a sense of flourishing, and stress contributes to aging female informal caregivers of PWD perception of life satisfaction. For nearly 15.5 million informal caregivers providing care to individuals with dementia, the disease is acknowledged as a 'family disease' because it affects everyone in the family (Alzheimer's Association, 2020). Aging female informal caregivers of PWD can become increasingly overwhelmed and sense that their life is monopolized as the care recipient's disease progresses and they are faced with a multitude of challenges including but not limited to the following: staggering emotions; fatigue and exhaustion; solitude and aloneness; monetary and employment obstacles (U.S. Department of Health and Human Services, 2020; Aging Care, 2016). Often over the course of providing care to the dementia care recipient, the informal caregiver neglects their personal well-being, and healthcare providers need to be on the frontline providing assessment, education, and support.

Progressive declining physical and/or mental health is a heavy price to pay for the informal caregiver of a person with dementia (Bullock, 2004; Schulz & Cook, 2011). To promote routine assessment of informal caregiver needs, the Physicians Quality Reporting Initiative now mandates that healthcare providers use standardized informal caregiver assessment instruments across the span of care recipient treatment (Alzheimer's Association, 2020; Centers for Disease Control, 2019) to assess informal caregivers of PWD each time they accompany the care recipient to a healthcare encounter. Regular administration of assessment instruments will allow the healthcare provider to identify needs, provide an opportunity for education and stimulate collaboration in making appropriate referrals that will benefit aging female informal caregivers of PWD as well as simultaneously benefiting the care recipient PWD (Amindazeh et al., 2005; Centers for Medicare, 2020). Along with adopting this approach to informal caregiver assessment, the Centers for Medicare and Medicaid Services have initiated a negatively imposed financial fine to healthcare providers for not complying with the initiative regulation (Centers for Medicare, 2020). Identifying and suggesting resources to manage the physical and emotional needs of both the care recipient PWD and the aging female informal caregiver of PWD are critical to promote the most desirable daily outcome.

Increasing numbers of aging female informal caregivers of PWD entice researchers to explore their daily lived experience. The contributions of this research to nursing science, health and social science, and health policy is that it will gain insight into the life satisfaction of aging female informal caregivers of PWD and will give a clue to the quality of the daily lived experience. Knowledge of an individual's perspective on life satisfaction may provide a mirror that reflects what makes people happy in stressful situations. Understanding positive functioning will lay the foundation to construct interventions to encourage individuals to flourish in the face of adversity. Promoting positive life satisfaction requires threads and fibers that are nourishing, in order to weave a cloth of resilience.

Significance of Study

Aging female informal caregivers of PWD experience an alteration in life satisfaction that is influenced by the caregiving process. Providing long term care to a care recipient PWD in the home environment is a stressful event that affects the daily lived experience. Positive and negative experiences and a sense of flourishing have an impact on the perception of life satisfaction. Overall life satisfaction arises from a prescribed set of expectations from within an individual that is compared and weighed against the lived life experience; thus, it is driven by beliefs within and expectations without. An individual will place a value judgment on life satisfaction according to self-generated assumptions and perceptions. Satisfaction with one's life is associated with intimate and supportive family, friends, enjoyment of employment, and a sense of meaning and importance in life.

Ongoing identification of effective informal caregiver assessment instruments, coupled with their consistent use, allows for identification of aging female informal caregiver of PWD problems and ultimately referral to a medical provider for routine or acute examination, it can stimulate educational conversations on respite care services and support groups available in the area. Effective interventions will positively support the informal caregiver role (National Alliance for Caregiving, 2020). Providing aging female informal caregivers of PWD with initial and ongoing education and referring them to support resources is critical in promoting life satisfaction and to aid them in maintaining a stable home environment for themselves and to achieve the most positive outcomes for the care recipient PWD.

Chapter Two

LITERATURE REVIEW

Introduction

Some informal caregivers experience and focus on the strain and despair of providing around-the-clock care to their loved one with a debilitating disease process; while others present a resilient nature that embraces a bright and positive outlook on life regardless of the burdensome circumstances. What brings about the dichotomous responses between different individuals who experience a similar challenging situation? In passing, it appears to be an emphasis on the positive rather than the negative. This research study describes how caregiving affects aging female informal caregivers of persons with dementia (PWD) perceptions of social support factors, positive and negative experiences, a sense of flourishing, and life satisfaction. An informal caregiver, for the purpose of this study, is one who provides uncompensated care (National Alliance for Caregiving, 2020).

Dementia

In this section, the topics of dementia, Alzheimer’s disease (AD), Alzheimer’s disease and related dementias (ADRD), and dementia stages are presented. While many caregiving studies do not define dementia or identify dementia subtypes of the PWD, understanding dementia and the subtypes assists in understanding the possible range of life satisfaction caregivers’ experience.

Dementia is not a disease in and of itself. Dementia is a syndrome that represents a decline in mental ability as a result of brain disease or brain injury (Jack et al., 2016).

Dementia is characterized by a cluster of symptoms affecting memory, thinking and social abilities severely enough to interfere with daily functioning (Alzheimer's Association, 2020). The World Health Organization (2016) reports that 47.5 million people worldwide have some form of dementia and nearly 8 million new cases present every year. Centers for Disease Control (2019) reported that an estimated 2 million people in the United States suffer from severe dementia and another 1 to 5 million people experience mild to moderate dementia. Five to eight percent of people over the age of 65 have some form of dementia and that beginning at the age of 65, the risk of developing dementia doubles every five years (Centers for Disease Control, 2019).

Alzheimer's Disease

According to the Alzheimer's Association (2020), Alzheimer's disease is the most common form of dementia and accounts for an estimated 60 percent to 80 percent of all cases. Although the greatest known risk factor for developing AD is increasing age, AD is not a normal part of aging. Alzheimer's disease brain change pathology is the progressive accumulation of protein plaques and tangles that cause changes inside and outside brain neurons. These changes ultimately lead to damage and death of neurons.

Prevalence

The Alzheimer's Association (2020) reports that in the United States nearly 6 million people have Alzheimer's disease (AD), and of these an estimated 5.8 million people are age 65 and older. One in ten people age 65 and older has AD. Approximately 200,000 persons under the age of 65 have what is termed younger-onset AD but this only accounts for approximately 5% of the disease. It is estimated that as Americans continue to age, the number of people age 65 and older with AD may nearly triple by 2050. Issues and complications emerge and advance as the disease progresses. There is no preventive or curative treatment for AD and available treatment options can only minimize a few symptoms.

Impairment

The Alzheimer's Association (2020) report indicates that Alzheimer's disease early impairment and symptom characteristics include difficulty remembering recent conversations, names or events, apathy, and depression. Later impairment and symptom characteristics include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing, and walking.

Alzheimer's Disease Related Dementias (ADRD)

While AD is the most common form of dementia (Alzheimer's Association, 2020; Kasper et al., 2014) other subtypes of neurodegenerative dementias known as Alzheimer's Disease Related Dementias exist. ADRD includes vascular dementia, dementia with Lewy bodies (DLB), frontotemporal lobar degeneration (FTLD), Parkinson's disease (PD) dementia, Creutzfeldt-Jakob disease (CLD), normal pressure hydrocephalus, Huntington's disease, Wernicke-Korsakoff Syndrome, and mixed dementia multifactorial dementia/ (Alzheimer's Association, 2020). Continued growth in the 85+ year population places a growing number of individuals at risk for developing ADRD (Alzheimer's Association, 2020). In this section, the related dementia disorders will be described and defined.

Vascular Dementia (VD)

The Alzheimer's Association (2020) informs that VD (also known as multi-infarct or post-stroke dementia) is less frequently diagnosed as a sole cause of dementia and only accounts for about 10 percent of dementia cases. However, in older individuals with dementia about 50 percent have pathologic evidence of VD (infarcts). The most common cause of VD is blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the person's cognition and physical functioning will be affected. In most circumstances, the infarcts coexist with AD pathology. Initial characteristics include impaired judgment or impaired ability to make decisions, plan or organize, as opposed to the memory loss often associated with the initial symptoms of AD. In addition to changes in cognition, people with VD can have challenges with motor function, especially slow gait, and poor balance.

Dementia with Lewy Bodies (DLB)

According to the Alzheimer's Association (2020), persons with DLB have some of the symptoms common in AD, but initial or early symptoms usually include sleep disturbances, well-formed visual hallucinations and slowness, gait imbalance or other parkinsonian movement features. These symptoms, as well as early visuospatial impairment, may occur in the absence of significant memory impairment. Brain change pathology is caused by abnormal clumps of the protein that cause damage to the brain cortex. Dementia can be solely caused by brain changes, but very often DLB coexists with AD or VD pathology.

Parkinson's Disease (PD) Dementia

The Alzheimer's Association (2020) indicates PD dementia is characterized by problems with movement (slowness, rigidity, tremor, and changes in gait) that is similar to progressive dementia of AD and DLB. The incidence of PD dementia is about one-tenth that of AD. Approximately one million Americans are diagnosed with PD dementia and an estimated four percent of people with PD dementia are diagnosed before the age of 50. PD dementia progresses with age (Parkinson's Disease Foundation, 2016). PD dementia is caused by the same pathology as DLB. The only difference between the two dementias is DLB presents before the PD motor symptoms appear and PD dementia presents after the PD dementia motor symptoms have appeared. Brain change pathology is caused by clumps that are likely to initiate in the substantia nigra deep in the brain. These clumps are thought to cause degeneration of the nerve cells that produce dopamine (Alzheimer's Association, 2020).

Frontotemporal lobar degeneration (FTLD)

The Alzheimer's Association (2020) informs that FTLD includes dementias such as behavioral-variant FTLD, primary progressive aphasia, frontotemporal dementia, corticobasal degeneration and progressive supranuclear palsy. Early symptoms commonly include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Dissimilar to AD, memory impairment does not occur in the early stages of disease. No specific brain change pathology is associated with all cases of FTLD; each has its own unique pathology. Symptoms develop at a younger age for persons with this type of dementia. About 60 percent of people with FTLD are ages 45 to

60. FTLD accounts for about 10 percent of dementia cases (Alzheimer’s Association, 2020).

Creutzfeldt-Jakob Disease (CJD)

Centers for Disease Control (2019) describe CJD as a human prion neurodegenerative disease disorder that is rapidly progressing and always fatal. It occurs worldwide with an annual estimated incidence reported to be about one case per million population. It is characterized by rapidly impaired memory and coordination and causes behavior changes. Brain change pathology results from misfolded prion protein that causes a cascade effect throughout the brain leading to malfunctions (Alzheimer’s Association, 2020).

Huntington’s Disease Dementia

The Alzheimer’s Association (2020) describes Huntington’s disease as being characterized by abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression, and other mood changes. It occurs in approximately one in every 10,000 persons—nearly 30,000 in the United States. Juvenile Huntington’s disease occurs in approximately 16 percent of all cases. It progresses without remission over 10 to 25 years (Swierzewski, 2015). Brain change pathology occurs from a gene defect that causes abnormalities in a brain protein that, over time, lead to worsening symptoms (Alzheimer’s Association, 2020).

Mixed Dementia/Multifactorial Dementia

The Alzheimer’s Association (2020) indicates that mixed dementia/ multifactorial dementia is when evidence of more than one dementia subtype is present concurrently.

Mixed dementia/multifactorial dementia is most commonly a combination of AD with VD, followed by AD with DLB, and AD with VD and DLB. VD with DLB is occurs less frequently. The tendency of having mixed dementia increases with age and is greatest in the oldest-old, age 85 and older.

Dementia Stages

Dementia is categorized into three stages that are early-stage, middle-stage, and late-stage. In the early stage of dementia, the care recipient functions independently, and the diagnosis is classified as possible. In the middle-stage to late-stage, care recipient cognitive function continues to decline, and the diagnosis is classified as probable (Kasper et al., 2014). As dementia progresses, physical function deteriorates and as cognitive decline advances, the ability to function independently also declines and around-the-clock care becomes necessary to keep the care recipient as free from harm as possible (Alzheimer’s Association, 2020). Persons with AD disease exhibit a variety of alterations in their personage and demeanor exhibited as impairment or abnormal behavior.

Impairment related to dementia includes, but is not limited to, communication challenges, poor sleeping habits, poor nutritional habits, declining personal hygiene, memory loss, confusion, and wandering (Alzheimer's Association, 2020; Kasper, et al., 2014). Behaviors related to dementia include, but are not limited to, states of agitation, anxiousness or aggression, hallucinations, false ideas, and loss of inhibition.

The individual with dementia experiences an evolution of ongoing symptoms that pose a challenge to the informal caregiver on a minute-by-minute basis. Constant adjustability and awareness are necessary on the part of the informal caregiver

(Alzheimer’s Association, 2020). Therefore, the impact of imminent disease progression places the informal caregiver at potential risk for an alteration in perceived life satisfaction as they face such challenges as psychological and physical strain, numerous healthcare provider encounters, needed support from family, friends, and community resources, and unanticipated legal and financial issues.

Informal Caregiving

Informal caregiving is generally provided by members of the family such as parents, spouses, adult children, or other relatives (U.S. Department of Health and Human Services, 2020). Informal caregivers deliver 80% of the long-term care in the United States (U.S. Department of Health and Human Services, 2020) and within this group 30% are aged 65 years and older (Alzheimer’s Association, 2020; U.S. Department of Health and Human Services, 2020). The highest percentage of informal caregivers in the home environment is females (Baumann et al., 2012; Darling et al., 2010; Kenneson & Bobo, 2010; Kruetzer, et al., 2009; Wakefield et al., 2012). In addition, 59% of informal caregivers maintain employment outside the home and over 50% of female informal caregivers have arranged work hour adaptations to navigate the demands of caregiving in the home (U.S. Department of Health and Human Services, 2020). Adults are living longer in this present day and a greater percentage of women outlive men. In the United States in 1910, the life expectancy was 48.4 years for men and 51.8 years (Centers for Disease Control and Prevention, 2013) for women. In 2018, the average life expectancy was 76.2 years for men and 81.2 years for women (Centers for Disease Control and Prevention, 2018). The impact of women having a greater life expectancy than men is that they remain in the role of primary or sole aging female informal caregiver in the home environment.

Informal Caregivers

The informal caregiver, according to Family Caregiver Alliance (2020b), is defined as any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary informal caregivers and live with, or separately from, the care recipient. The care provided is usually uncompensated. In the United States, approximately nearly 48 million informal caregivers (slightly over 19% of the population) provide uncompensated care to adults (aged 18+) with a disability or illness (National Alliance for Caregiving, 2020).

Informal Caregiver Challenges

Challenges that place informal caregivers at risk include direct out-of-pocket expenses, economic uncertainty related to alterations in employment patterns (Houser & Gibson, 2008), depression, anxiety (Broe et al., 1999; Darling et al., 2010; Kaye et al., 2003; Kenneson & Bobo, 2010; Ostwald et al., 2009; Thorpe et al., 2009; Wakefield et al., 2012;), sleep deprivation (Borg & Hallberg, 2006; Kruetzer et al., 2009), excessive alcohol consumption (Kruetzer et al., 2009), inadequate time to socialize and decreased social support (Borg & Hallberg, 2006; Clay et al., 2008; Kaufman et al., 2010; Kaye et al., 2003; Kenneson & Bobo, 2010), impoverished health (Borg & Hallberg, 2006; Ostwald et al., 2009), decreased marital satisfaction (Ostwald et al., 2009), and overall diminished quality of life (Baumann et al., 2012; Kaufman et al., 2010).

Research on informal caregivers has often employed various stress and coping models (Greenglas et al., 2005; Lazarus & Folkman, 1984; Perlin et al., 1990) and indicates that informal caregiver appraisal (perception and translation) of their daily lived experience, that expresses itself as positive and negative feelings, is a crucial factor in adjusting to stressful situations. In particular, a person's appraisal of their daily lived experience has a substantial connection with stress, and routinely predicts an assortment of emotional and physical consequences (Athay, 2012; Borg & Hallberg, 2006; Broe et al., 1999; Darling et al., 2010; Kaye et al., 2003; Kruetzer et al., 2009; Wells et al., 2005).

Earlier research on aging informal caregivers focused on stress and negative outcomes while recent research has begun to examine aging informal caregivers from a positive or neutral position (Folkman & Greer, 2000; Kruithof et al., 2012; Ostwald et al., 2010). Although limited, this progressive field of research robustly indicates that many aging informal caregivers report positive perspectives related to their caregiving role such as self-satisfaction, happiness and joy (Baumann et al., 2012; Clay et al., 2008; Folkman & Greer, 2000; Kenneson & Bobo, 2010; Kruithof et al., 2012; Mayo, et al., 2020; Ostwald et al., 2009). Moreover, these studies suggest that positive perspectives affiliated with the informal caregiving experience may contribute to the development of interventions for aging female informal caregivers of PWD that will lead to increasing positive informal caregiving circumstances.

Informal Caregivers of Persons with Dementia

In this section, the topics of informal caregivers of persons with dementia (PWD) stress, stress and co-morbidities, physical symptoms, psychological symptoms, depression, finances, legalities, positive aspects of caregiving, supportive aspects of caring, and supportive resources in caregiving are presented.

Stress

Alzheimer's Association (2020) reports that in 2015 nearly 16 million informal caregivers of PWD provided 17 billion hours of unpaid care to the care recipient PWD. Approximately two-thirds are female informal caregivers, and 34 percent are age 65 or older. Informal caregivers of PWD face a variety of challenges associated with caregiving (Alzheimer's Association, 2020; U.S. Department of Health and Human Services, 2020). Approximately 25-29% of all care recipients PWD 50 years or older with cognitive impairment are provided care by informal caregivers (National Alliance for Caregiving, 2020). Alzheimer's Association (2020) estimates that in 2019 there were 16 million informal caregivers providing 18.6 billion hours of care at a value of $244 billion dollars. Informal caregivers of PWD average age was 48 years old. In addition, 18% of children 8 to 18 years old provide unpaid care for a care recipient PWD. The vast majority (87%) of care recipients PWD are cared for at home by family informal caregivers. Informal caregivers of PWD assisted care recipients PWD who are their parent or parent-in-law (57%), grandparents (11%), or spouses (6%). And 10% of family informal caregivers of PWD are doing so long distance (Alzheimer's Association, 2020). Kasper et al. (2014) reported that mean hours of informal caregiving provided each month was substantially different depending on care recipient PWD disease status.

Wisniewski et al. (2003) report that aging female informal caregivers of PWD (average age of 62) are equally distributed as either spouse or children. The informal caregivers of PWD provided care for an average of eight hours daily over an 18-month period and over that time they had a decline in health and a 25% increased need for healthcare services (Wisniewski et al., 2003). In addition, Wisniewski et al. reported that 41% of informal caregivers of PWD were at risk for clinical depression. Amindazeh et al. (2015) reported that a vast majority of informal caregivers of PWD goals were concentrated on care recipient PWD needs and slightly less than 10% were aimed at their own needs. In addition, they reported that slightly over 40% of informal caregivers of PWD received assistance from outside entities that was less than sufficient, and they desired an increase in publicly funded personal and/or home support services, and a need for more assistance from family and friends. Informal caregivers of PWD rated their caregiving experiences negative 20% to 25% of the time; and, that those ratings were influenced by fatigue at the end of the day, having more responsibility than they could handle, and not having personal time (Kasper et al., 2014). The informal caregiver of PWD faces daily uncertainty due to the unpredictable symptoms exhibited by the care recipient PWD as intellectual functioning declines (Alzheimer's Association, 2020, Mayo et al., 2020). Much of the research on informal caregivers reveals a variety of consequences linked to the caregiving experience, such as uncertainty, sense of loneliness, and complexities of frustration (Mayo et al., 2020). Schulz et al. (2003) reported that active interventions that stressed engagement of informal caregivers of PWD are beneficial in reducing depression and maintaining health. Informal caregivers of PWD declining physical and psychological health places the individual at risk.

The population of aging female informal caregivers of PWD chosen for this study exemplifies an under researched, at risk group. In the case of dementia, the disease has a gradual onset that progressively worsens with the passage of time and places increasing stress on the aging female informal caregiver of PWD. Furthermore, informal caregivers of PWD face many unexpected situations as the care recipient PWD disease process proceeds. The anticipated extension of life expectancy for the adult population places aging female informal caregiver of PWD along with their care recipient PWD at potential risk if interventions to increase life satisfaction are not considered.

Stress and Co-morbidities

Informal caregiving, stress, and co-morbidities have been examined in a variety of contexts. For example, female family informal caregivers of persons with cancer, primarily age 64 and older, find that the demand of caregiving and disrupted schedules negatively impacts their physical and psychological health, reduces social interactions, and increases financial strain (Chen et al., 2009; National Cancer Institute, 2016). Financial challenges are often a consequence of informal caregivers needing to readjust their customary home and/or work schedule to accommodate care recipient appointments. Smith et al. (2001) recruited mostly female informal caregivers age 50 and reported that female spouse and adult children caregivers of PWD participated in outside-of-home work ranging from part to full time; and of these, 40% indicated that the caregiving they provided mandated adjustment to their outside-of-home work schedule. This was similar to findings of Chen et al. (2009) and National Cancer Institute (2016). While all three studies examined informal caregivers, there were some differences between the studies.

For example, National Cancer Institute (2016) identified that social roles and relationships between informal caregivers and care recipients that existed prior to diagnosis and treatment had an impact on the social interaction over the course of diagnosis, treatment, and remission states. While Chen et al. (2009) discovered that informal caregivers' perceived unhappiness was driven by the lack of social support.

While all three studies examined factors that affected informal caregivers there were some differences between the studies. For example, National Cancer Institute (2016) conducted a literature review to document the support needs of informal caregivers across the age spectrum of cancer care recipients, while Chen et al. (2009) used a cross-sectional correlational design study to look at the support needs of patients with oral cancer and burden to their informal caregivers. The work of National Cancer, Chen et al. and Smith et al. provided a broad understanding of challenges faced by informal caregivers of cancer patients and may be generalizable beyond the study sample. Yet Chen et al. only investigated the care recipients and their informal caregivers during the postoperative phase and not the disease stage or the recovery stage. All three studies examined spouse informal caregivers and therefore contribute to our understanding of aging female informal caregivers of PWD, an important population of caregivers.

Tallman et al. (2012) recruited care recipients age 46-89 and their family informal caregivers and reported needs that were sorted into themes that were sensitive and effective communication about advanced illness, timely access to coordinated medical care, respect for and honoring care decisions, psychological, social and spiritual needs, and caregiver support. Many needs of the care recipient and informal caregivers were reported to be met during hospitalization but not following discharge, similar to the findings of National Cancer Institute (2016) and Chen et al. (2009). The Tallman et al. study also identified that the post-discharge needs identified were understanding normal vs. abnormal symptoms, point-of-contact for medical vs. nonmedical inquiries, accessing and communicating with medical providers shortly after discharge, training for in-home caregiving, and addressing healthcare needs for family caregivers. In addition, Tallman et al. reported that the needs of the patient and family informal caregivers evolved as the of care recipient's disease progressed, which is also in alignment with the findings of National Cancer Institute (2016) and Chen et al. (2009).

In the Tallman et al. (2012) study a rich understanding was gained as study participants were observed over time. The researchers described participants' personal experiences and identified trends and common attributes shared by the family informal caregivers. Also, informal caregiver behaviors and needs were observed for change over time. This study contributes to our understanding of aging female informal caregivers of PWD. However, there may be potential study bias due to convenience sampling, and unknown influences associated with presence of an interviewer and videographer observer. Due to the small sample size and convenience sampling, the knowledge gained might not be generalizable to aging female informal caregivers of PWD.

In another group of studies, Bullock (2004) Joling et al. (2015), Millenaar et al. (2015), Schulz & Cook (2011), and Schultz & Martire (2004) reported that informal caregivers of PWD experienced higher levels of physical and psychological symptoms, and depression that resulted in escalated use of health care services. While all five studies examined physical and psychological symptoms, depression and use of healthcare services, there were some differences between the studies. For example, Millenaar et al. (2015) examined informal caregivers for care recipients with young onset dementia (YOD) and late onset dementia (LOD). Joling et al. (2015) examined predictors of societal costs in female spousal informal caregivers of PWD. Schulz & Cook (2011) examined the declining health in informal caregivers of PWD. Schultz & Martire (2004) examined the prevalence, health effects and support strategies of informal caregivers of PWD, and Bullock (2004) conducted a literature search on AD, caregiving time, and behavioral symptoms but did not specify gender or age range.

Physical Symptoms

Millenaar et al. (2015) reported informal caregivers in both the YOD and LOD groups reported lower health-related quality of life. Schulz & Cook (2011) reported informal caregivers of PWD health declined over time, while use of medical services (emergency room and healthcare provider) increased over the same period of time. Informal caregivers of PWD whose health status was poor or fair at baseline sought more medical services as care recipient health status declined and caregiving needs increased. Bullock (2004) reported informal caregivers of PWD frequently reported one or more co-morbidities. And reducing or keeping in check care recipient disturbing behaviors minimized the physical and psychological toll it took on informal caregivers of PWD over time.

Psychological Symptoms

Millenaar et al. (2015) reported informal caregivers in both the YOD and LOD groups reported decreased feelings of competence. Joling et al. (2015) indicated poor health of informal caregivers of PWD was a predictor of later onset of depression and/or anxiety. Informal caregivers of PWD reported greater stress than informal caregivers of persons with conditions other than dementia (Schultz & Martire, 2004).

Depression

Informal caregivers of PWD, compared with other caregiver groups, more frequently gave up their vacations and hobbies, spent less time with other family members, and experienced increased work-related hardships that increased feelings of isolation and depression (Schultz & Martire, 2004). Joling et al. (2015) reported that baseline assessment of spousal informal caregivers of PWD sub-threshold depressive symptoms are predictors of later onset of depression and/or anxiety and it did not contribute to characteristics of the care recipient PWD, length of time the spousal informal caregiver of PWD had been providing care nor was it associated with caregiver social support. Female informal caregivers of PWD reported more elevated levels of depression and anxiety symptoms and reduced levels of life satisfaction compared with their male informal caregivers of PWD counterparts (Schulz & Martire, 2004).

All five studies inform the knowledge on physical and psychological symptoms, and depression. While there were differences between these studies, it is important to note that they all supported the same general notion that informal caregivers of PWD experience negative health outcomes and use more health care services as the result of caring for the care recipient PWD. Although there were differences between the studies, the works provided broad information on informal caregivers of PWD physical symptoms, psychological symptoms and depression and therefore contribute to our understanding of aging female informal caregivers of PWD.

Finances

Several AD support organizations report that Medicare, Medicaid and private insurance carriers do not cover all costs for care of the care recipient PWD, placing a great financial hardship on the both the informal caregiver of PWD and the care recipient PWD (Alzheimer's Association, 2020). Over 60% of care recipient PWD financial costs are not covered by insurance (Alzheimer's Association, 2020). Alzheimer's Association (2020) reports another factor contributing to financial stress is that respite care is often not covered by insurance. Informal caregivers of PWD often expressed a quandary at who to contact to inquire about qualifying for low-income housing assistance and information on free or low-cost public transportation (U.S. Department of Health and Human Services, 2020). This provides valuable insight into the financial challenges faced by many aging female informal caregivers of PWD.

Legalities

Informal caregivers of PWD often express a desire for information on power of attorney, power of attorney for health care, living will, standard will, living trust, guardianship/ conservatorship, and assistance in completing documents (Alzheimer's Association, 2020). Initiating legal documents makes the wishes of the care recipient PWD clear and allows the informal caregiver of PWD to direct care that will ultimately have either a positive or negative impact on household finances (de Boer et al., 2009). De Boer et al. reported that early dementia diagnosis was desired to enable the care recipient PWD an opportunity to initiate an advance directive before their cognition declines to the point at which time they were no longer able to create the document. A challenge exists for the informal caregiver of PWD regarding when to initiate the advance directive because in the early stages of disease the care recipient PWD seems to be alert, functioning and interacting with their surroundings, capable of expressing hopes and desires, although many times are identified as being incompetent. Informal caregivers of PWD should be informed by the care provider that Advance Directives and Power of Attorney documents should be completed as soon as possible following the care recipient diagnosis of dementia (Alzheimer’s Association, 2016)

These three studies bring to light the value of early-stage disease diagnosis for the care recipient PWD and the importance of offering education to both the informal caregiver of the PWD and the care recipient PWD on legal, financial, and long-term care planning. Providing early education to the care recipient PWD and informal caregiver of PWD will provide them with an opportunity to collaboratively make decisions about the future regarding the variety of legal offerings available and direction on how to access legal entities. Future research is necessary to understand the barriers to completing legal documents and identify how healthcare providers can provide education that will positively impact the decision for the informal caregiver of PWD and care recipients PWD to complete legal documents earlier in the disease process.

Positive Aspects of Caregiving

While much of the literature reports on caregiver burdens associated with informal caregivers of PWD and a focus on negative perception, several studies reported on informal caregivers of PWD focus on positive perception of caring. The informal caregiver of PWD when provided support and resources may have a positive perception of caring. Four studies reported positive aspects of caring and recruited participants age 50 and older and those were Amindzadeh et al. (2005), Goy et al. (2010) Kasper, et al. (2014) who recruited primarily female informal caregivers of PWD, and Smith et al. (2001) who recruited aging informal caregivers. Positive aspects of aging informal caregiving will be discussed as perception of caregiving, comprehending patient needs, caring for self, respite care and skilled training.

Perception of Caregiving

Kasper et al. (2014) reported 86% of informal caregivers of PWD expressed considerable life satisfaction knowing the care recipient PWD was well cared for as a result of their caregiving. Slightly over half indicated informal caregiving of PWD gave them a closer relationship with the care recipient PWD as they faced the arduous tasks of caregiving. Over two-thirds of informal caregivers of PWD indicated overall gains from the caregiving experience (Kasper et al.).

Comprehending Patient Needs

Amindazeh et al. (2005) reported informal caregivers of PWD positively valued a better understanding of care recipient PWD illness inclusive of assessment, diagnosis of the dementia, prognosis, and what to expect regarding the progressive stages of dementia.

They also reported informal caregivers of PWD wanted to know how to better manage care for the care recipient PWD inclusive of general information, advice, assistance with problem solving and decision support, and treatment or resolution of health problems. And they reported informal caregivers of PWD were interested in how to maintain patient functional independence and safety. In addition, they reported that informal caregivers of PWD desired information on how to increase care recipient PWD quality of life and wellness, how to acquire help in caring, and how to resolve service delivery issues. Smith et al. (2001) reported aging informal caregivers desired information on housing assistance, advice on how to acquire used or new durable medical equipment (such as, hospital bed, toilet riser, tub shower seat), and how to identify community organizations and/or independent contractors to perform home modifications (such as, ramps, knobs removed from stove, locks added to doors, and door chimes signaling egress and ingress).

Caring for Self

Informal caregivers of PWD positively appreciated direction on how to gain access to participate in individual and group counseling to acquire coping skills, learn how to express feelings, learn how to take better care of themselves, and how to have time for self with a demanding caregiver schedule (Amindazeh et al., 2005; Goy et al., 2010). Other appreciated commodities included receiving positive support from family or friends, church and/or spiritual activities, and maintaining a strong faith (Smith et al., 2001).

Respite Care and Skills Training

Informal caregivers of PWD positively valued support services that included structured skills training, day care programs, respite care, and individual and group counseling in order to gain caregiving and coping skills, discover a variety of community support options, and spend some quality time away from the care recipient PWD (Amindazeh et al., 2005; Goy et al., 2010). Informal caregivers of PWD also expressed interest about information on global positioning system devices for the patient that was prone to wandering.

It is of interest that researchers utilized dissimilar methodology; yet all found similar results. Amindazeh et al. (2005) utilized a 6-month longitudinal qualitative-quantitative study and recruited participants from one outpatient comprehensive geriatric assessment program in a teaching facility, in Ottawa, Canada. Goy et al. (2010) utilized a systematic evidence review study. While the Smith et al. (2001) study was similar to the other two studies, it was different in that it was a small sample qualitative cross-sectional study that utilized semi-structured interviews of informal caregiver participants who were recruited from rural Midwestern and Southeastern United States. All four studies may provide insight into aging female informal caregivers of PWD and positive aspects that help them meet the challenges of caregiving as dementia progresses.

Supportive Resources in Caregiving

Supportive resources identified in studies have been reported to increase informal caregivers of PWD perception of positive experiences associated with the daily lived experience of caregiving. Supportive resources for informal caregivers of PWD gleaned from literature review are organized into eight categories and will be presented, as follows: disease process and healthcare providers; care recipient PWD physical demands; community resources; psychosocial behaviors; family/friends and daily routine; financial assistance and legal aid; psychological and physical strain; and positive aspects of caregiving.

Disease Process and Healthcare Providers

Aging female informal caregivers of PWD will benefit from receiving information on the disease process and interaction on their level with healthcare providers, and examples include understanding symptoms and receiving communication in lay person terminology and not medical jargon (see Table 1).

Table 1

Disease Process and Healthcare Providers

Easy access to their healthcare providers along with ongoing communication [1, 6]
Early diagnosis [8, 10]
Understanding normal vs. abnormal symptoms and how to respond [1, 6]
Communication in lay person terminology and not medical jargon [1, 5, 8]
Receiving information from healthcare providers at a reduced speed and not experiencing a rushed atmosphere during the healthcare encounter [8]
How healthcare providers interact with the caregiver and care recipient [1, 8, 11]
Sensitive and effective communication regarding information on the disease and its trajectory [1, 6, 8, 11, 12]
Treatment options including respite care [2, 5, 6, 7]
Care management inclusive of information, advice, problem solving, and decision support [1, 6]
Skills training [1, 2, 3, 4, 5, 7, 8]
Timely access to coordinated healthcare without the need for the caregiver to be overly assertive or aggressive when telephoning to speak with a healthcare provider or when scheduling appointments [1, 10, 8]
Receiving test results in a timely manner [6]
Dignity and acceptance regarding care decisions and not feeling pressured into selecting options [1]
Respect for the patient, as well as the informal caregiver [1, 7]

Global positioning system devices the wandering care recipient or boundary alarms [7]

Medication therapy [4, 5, 6, 9]

Point of contact for medical vs. non-medical emergencies [1]

Alternative living arrangements [12]

Note: This table addresses issues faced by the caregiver in relationship to the ADRD care recipient disease process and encounters with healthcare providers.
[1]Tallman et al., 2012; [2]Kasper et al., 2014; [3]Millenaar et al., 2015; [4]Joling et al., 2015; [5]Schultz & Martire, 2004; [6]Amindazeh et al., 2015; [7]Goy et al., 2010; [8]Smith et al., 2001; [9]Houser & Gibson, 2008; [10]Alzheimer's Association National Plan, 2014; [11]Riedel, et al. 2016; [12]Bejjani et al., 2015

Care Recipients' Person with Dementia Physical Demand Characteristics

Care recipients' person with dementia exhibit different characteristics as the dementia disease process presents and progresses, and examples include stages of the disease, functional ability, and side effects of treatment (see Table 2).

Table 2

Care Recipients' Person with Dementia Physical Demand Characteristics

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Stage of the disease [1, 2, 4, 5, 6, 7, 9, 10, 11, 12]

Symptoms [1, 2, 4, 5, 6, 9, 10, 11, 12]

Functional ability (ADL/IADL) [1, 2, 3, 5, 9, 10, 11, 12]

Energy level [1, 2, 3]

Side effects of treatment [1, 2, 5, 12]

Travel to and attending appointments [1, 2, 9, 13, 18]

Procedures and hospitalization [1, 2]

Hours of care provided per month [3, 4, 8, 9, 12, 14]

Note: This table lists care recipient physical demand characteristics that challenge caregivers. Caregivers are required to adjust their customary schedule to accommodate the needs of the care recipient.
[1]Family Caregiver Alliance, 2020d; [2]Chen et al., 2009; [3]Kasper et al., 2014; [4]Bullock, 2004; [5]Amindazeh et al., 2005; [6]Tallman et al., 2012; [7]deBoer et al., 2009; [8]Millenaar et al., 2015; [9]Schultz & Martire, 2004; [10]Joling et al., 2015; [11]Schulz & Cook, 2011; [12]Smith et al., 2001; [13]Talllman et al., 2012; [14]Houser & Gibson, 2008

Community Resources

Aging female informal caregivers of PWD are interested in referral to community resources, and examples include social support groups, day care programs, nutritional support, and palliative care (see Table 3).

Table 3

Community Resources

Initial and ongoing information on a variety of neighborhood offerings [1]
Community resources and how and when to access those resources [1, 3, 4, 7, 8, 11]
Transition management programs and case management [9, 10]
Paratransit [7]
Social support groups [1, 5, 7]
In-home support services [1]
Day care programs [2, 5, 7]
Palliative care [6]
Nutritional programs [7]

Note: This table identifies community resources desired for the care recipient that will lessen demands on the caregiver.
[1]Amindazeh et al., 2005; [2]Joling et al., 2015; [3]deBoer et al., 2009; [4]Kasper et al., 2014; [5]Smith et al., 2001; [6]Tallman et al., 2012; [7]Family, 2020b; [8]Schultz & Martire, 2004; [9]Goy et al., 2010; [10]Houser & Gibson, 2008; [11]Bejjani et al., 2015

Psychosocial Resources

Aging female informal caregivers of PWD may prosper from access to psychosocial resources, and examples how to reduce stress, how to deal with personal psychological challenges, and techniques on self-forgiveness (see Table 4).

Table 4

Psychological Resources

Techniques on how to deal with their personal psychological and social challenges [2, 4, 7]
How to reduce stress when interacting with the health care community and insurance carriers [7, 10, 11]
Individual and group counseling or support groups [1, 3, 4, 5, 6, 7]
Talking with family/friend to release emotions [1, 4]
Communication and behavior management skills [1, 5, 8]
Techniques on self-forgiveness [8]
Laughter [8]
Spirituality and faith [4, 6, 7]
Church [6]
Spirituality – not only being questioned about their spirituality but being encouraged to seek spiritual counsel and support from their personal clergy [1, 4, 6, 7]
Exercise [3, 7, 8]
Hobbies [1, 8]
Vacation [1, 5]
Personal time [5, 8]
Social roles and relationships between caregiver and care recipient that existed prior to the diagnosis and treatment [1, 2, 9]

Note: This table addresses psychological resources desired by the caregiver that strengthen and refresh their psychological stamina and build their emotional endurance bank in order to deal with the day-to-day challenges associated with providing care.
[1]Schultz & Martire, 2004; [2]Amindazeh et al., 2005; [3]Goy et al., 2010; [4]Tallman et al., 2012; [5]Kasper et al., 2014; [6]Smith et al., 2001; [7]Family, 2020b; [8]Family Caregiver Alliance, 2020d; [9]Ostwald et al., 2009; [10]Darling et al., 2010; [11]Chen et al., 2009

Family/Friends and Daily Routine

Aging female informal caregivers of PWD appreciate social support in their daily routine, and examples include help with the care recipient PWD and household chores, avoiding disruption in the daily schedule, and learning to accept help when offered (see Table 5).

Table 5

Family/Friends and Daily Routine

Assistance and interaction with family/friends [1, 2, 3, 4, 5, 6, 7, 8, 9, 16]
Help in caring for the patient [4, 6, 8, 9, 17]
Organizing family care [18]
Disrupted schedules [1, 2, 3, 4, 8]
Assistance transporting the care recipient to and from healthcare provider appointments [10]
Help with household chores [1, 2]
Learning to accept help when offered [8, 17]
Social interaction and/or talking about caregiving [1, 2, 11, 12, 13, 14, 15, 17]
Work schedule [1, 2, 5, 8, 9, 10]

Note: This table identifies items that caregivers find supportive and assists with their daily routine.
[1]National Cancer Institute, 2016; [2]Chen et al., 2009; [3]Kasper et al., 2014; [4]Joling et al., 2015; [5]Schultz & Martire, 2004; [6]Amindazeh et al., 2005; [7]Goy et al., 2010; [8]Smith et al., 2001; [9]Tallman et al., 2012; [10]Houser & Gibson, 2008; [11]Borg & Hallberg, 2006; [12]Clay et al., 2008; [13]Kaufman et al., 2010; [14]Kaye, 2003; [15]Kenneson & Bobo, 2010; [16]Family Caregiver Alliance, 2020b, [17]Mayo et al., 2020; [18]Bejjani et al., 2015

Financial Assistance and Legal Aid

Aging female informal caregivers of PWD are faced with financial challenges and also wish to receive information on legal aid, and include understanding insurance coverage (such as co-pays, deductibles and out-of-pocket expenses), how to acquire durable medical equipment, and understanding types of advance directives (see Table 6).

Table 6

Finances and Legal Aid

Out-of-pocket expenses [1, 2, 6, 7, 15, 17]
Insurance carriers do not cover all costs for dementia care [1, 2, 6, 9, 14, 15]
Durable medical equipment [6]
Household modifications [6]

Available money and managing finances [1, 3, 6, 8, 9, 14, 15, 16]

Respite care is often not covered by insurance [10, 14, 15, 17]

Low-income housing assistance [6, 12]

Free or low-cost public transportation [11]

Advance directive assistance (power of attorney, power of attorney for health care, living will, standard will, living trust) [4, 6, 10, 11, 12, 13, 14, 17]

Guardianship/conservatorship [4, 6, 10, 11, 13, 14]

Assistance in completing documents 6, [10, 11, 13]

Caregiver work-related hardships [5, 6]

Income and quality of daily tasks [17]

Note: This table lists financial and legal issues that impact caregiving households. [1]National Cancer Institute, 2016; [2]Chen et al., 2009; [3]Kasper et al., 2014; [4]de Boer et al., 2009; [5]Schultz & Martire, 2004; [6]Smith et al., 2001; [7]Houser & Gibson, 2008; [8]Bullock, 2004; [9]Fiscal, 2003; [10]Alzheimer's Association National Plan, 2013; [11]Alzheimer's Association, 2016; [12]Family Caregiver Alliance, 2020b; [13]deBoer et al., 2009; [14]Tallman et al., 2012; [15]Houser & Gibson, 2008, [16]Mayo et al., 2020; [17]Bejjani et al., 2015

Psychological and Physical Strain

Aging female informal caregivers of PWD encounter unwanted situations that provoke psychological and physical strain that requires relief, and examples include caregiver and care recipient PWD co-morbidities, care recipient PWD disturbing behaviors, and caregiver abuse of the care recipient PWD (see Table 7).

Table 7

Psychological and Physical Strain

Caregiver and care recipient co-morbidities resulting in increased healthcare visits and increased financial burden [1, 2, 3, 6, 7, 8, 10, 18, 21, 26, 28]

Caregiver learning how to better take care of self [1, 5, 9, 11, 25, 27]

Care recipient experiencing early placement in a long-term care facility [3, 10]

Caregiver and care recipient treatment for clinical depression and anxiety [1, 4, 6, 7, 8, 9,10, 12, 13, 14, 15, 16, 18, 19, 20, 21, 22, 23, 24, 25, 27]

Female caregiver high risk depression [29]

Caregiver abuse of the care recipient [10]

Care recipient abuse of caregiver [10]

Care recipient disturbing behaviors [7, 10, 26]

Caregiver social and spiritual needs [1, 2, 3]

Fatigue at end of day [1, 5, 10]

Sleep deprivation [1, 15, 19, 20, 22, 23, 27]

Caregiver primarily focused on care recipient needs and denying their own needs [5, 11, 25, 27]

As caregiver physical and psychological strain increased and support decreased, abusive behavior toward the care recipient escalated [4, 10]

Caregivers with unmet needs reported higher levels of depression/stress [29, 30, 31, 32, 35]

Caregiver depression has been shown to be influenced by several factors including female gender depression [30. 31. 32]

Health of caregiver and functional status [33, 34]

Note: This table addresses caregiving issues and situations that impact the caregiver and influence the manner in which the caregiver relates to and interacts with the care recipient. [1]Family Caregiver Alliance, 2020d; 2Chen et al., 2006; [3]Tallman et al., 2012; [4]Beach et al., 2005; [5]Kasper et al., 2014; [6]Millenaar et al., 2015; [7]Joling et al., 2015; [8]Schulz & Cook, 2011; [9]Schultz & Martire, 2004; [10]Bullock, 2004; [11]Amindazeh et al., 2005; [12]Darling et al., 2010; [13]Kenneson & Bobo, 2010; [14]Broe et al., 1999; [15]Ostwald et al., 2009; [16]Thorpe et al., 2009; [17]Wakefield et al., 2012; [18]Kaye et al., 2003; [19]Borg & Hallberg, 2006; [20]Kruetzer et al., 2009; [21] National Institute of Neurological Disorders and Stroke, 2013; [22]Alzheimer's Association, 2016; [23]Kasper, et al., 2014; [24]Wisniewski et al., 2003; [25]Family Caregiver Alliance, 2020b; [26]Smith et al., 2001; [27]Goy et al., 2010; [28]Houser & Gibson, 2008; [29]Bejjani et al., 2015; [30]Chien et al., 2011; [31]Huang et al., 2015; [32]Shoemaker et al., 2010; [33]Butterworth et al., 2020; [34]Cucciare et al., 2010; [35]Riedel, et al. 2016

Positive Aspects of Caregiving

Aging female informal caregivers of PWD report positive aspects of caregiving, and examples include recognition of personal strength, increased solidity of the relationship between themselves and the care recipient PWD, and support from family/friends (see Table 8).

Table 8

Positive Aspects of Caregiving

Recognition of personal strength in the face of adversity [1, 3, 6, 8]
Elevated sense of worth [1, 6, 8]
Increased solidity of the relationship between themselves and the care recipient [1, 3, 8]
Acknowledgment of personal growth [1]
Care recipient well cared for as a result of caregiver actions [3, 5]
Support from family/friends [1, 2, 4, 7, 9]

Note: This table lists experiences that result in a positive experience for the caregiver. [1]Family Caregiver Alliance, 2020d; [2]Chen et al., 2006; [3]Kasper et al., 2014; [4]Smith et al., 2001; [5]Tallman et al., 2012; [6]Amindazeh et al., 2005; [7]Smith et al., 2001; [8]Mayo et al., 2020; [9]Jones et al., 2019

Strong evidence exists for the thirty-nine references cited in Table 1 – Table 8. Seven are evidence from systematic reviews of relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs. One is evidence obtained from at least one well-designed RCT. Five are evidence from well-designed case-control and cohort studies. Five are evidence from systematic reviews of descriptive and qualitative studies. Fourteen are evidence from a single descriptive or qualitative study.

Positive and Negative Feelings in Caregiving

In this section, the topics of positive and negative feelings in caregiving, positive and negative feelings in other populations, positive and negative feelings and life satisfaction, and positive and negative feelings in aging female informal caregivers of persons with dementia are presented. As discussed above, there are aspects of caregiving that are perceived as a negative burden and others that have a more positive component. Positive and negative feelings are typically both measured in research.

Positive and negative feelings in caregiving refer to emotions experienced by informal caregivers (related to what one has been doing and experiencing) (Diener et al., 2010). Specifically, positive feelings in caregiving refer to feelings that reflect positive states of interest, positive engagement, and physical pleasure. On the other hand, negative feelings in caregiving refer to feelings that reflect negative states of interest, flow, negative engagement, and physical displeasure. Positive psychology is an area of study for which the focal point is on well-being and optimal functioning that assists an individual to look beyond negative feelings and stress in order to examine their feelings and strengths that may contribute to a sense of flourishing and life satisfaction (Duckworth et al., 2005; Diener, 2000; Diener et al., 2010). Positive affect mirrors positive feelings while negative affect resounds with negative feelings (Telef, 2015).

Positive and Negative Feelings in Other Populations

Research has been conducted in populations of blue-collar and white-collar workers, undergraduate and graduate university students, and informal caregivers of HIV positive care recipients. On the whole, all studies have demonstrated that positive and negative feelings are associated with measures of happiness and life satisfaction (Bastian et al., 2012; Carstensen et al., 2000; Folkman, 1997; Silva & Caetano, 2013; Neuser, 2010; Telef, 2015).

Positive and Negative Feelings and Life Satisfaction

Bastian et al. (2012) and Telef (2015) reported that positive and negative feelings are associated with life satisfaction. And overall positive feelings are associated with increased life satisfaction and negative feelings are associated with decreased life satisfaction. The Carstensen et al. (2000) study recruited participants 18 and older and reported age is unrelated to frequency of positive feelings and that frequency of negative feelings decline until approximately age 60. After age 60 positive feelings are longer lasting but negative feelings are less stable. In addition, experiences that only infrequently ignited high intensity positive feelings did not sustain long-term happiness (Carstensen et al., 2000; Folkman, 1997; Silva & Caetano, 2013; Telef, 2015).

Positive and Negative Feelings in Informal Caregivers of Persons with Dementia

Both positive and negative feelings incorporate the whole feeling realm (holistic approach) and are reflected in life satisfaction. Assisting the aging female informal caregiver of PWD to examine their positive and negative feelings may help them to elevate their perception of pleasure, promote engagement, bolster their positive perspective on life in general, and elevate life satisfaction (Diener, 2000; Diener et al., 2010; Duckworth et al., 2005). Therefore, it is important to research aging female informal caregivers of PWD to explore and/or measure caregiver positive and negative feelings. Instruments have been developed and are available to measure both positive and negative feelings within the same measure. Promoting positive feelings may be helpful to aging female informal caregivers of PWD. However, no studies have examined positive feelings among aging female informal caregivers of PWD to establish a baseline understanding. Future research might focus on designing interventions to promote the positive feelings while attending to negative feelings.

Flourishing

In this section, flourishing, flourishing and positive and negative feelings, flourishing in other populations, and flourishing of aging female informal caregivers of PWD are presented.

Flourishing is defined as experiencing major aspects of social psychological functioning such as “relatedness, optimism, self-acceptance, feeling competent, having support and rewarding relationships, contributing to the happiness of others, and being respected by others” (Diener et al., 2010, p. 144). Flourishing describes psychological resources and strengths that encompass psychological well-being, social well-being, and social-psychological prosperity.

Flourishing and Positive and Negative Feelings

A sense of flourishing and positive and negative feelings goes hand-in-hand. A sense of flourishing has its roots grounded in positive psychology and is a notion that grows out of an individual’s measure of positive and negative feelings that are associated with relationships, social support, personal health, self-esteem, purpose and other life experiences (Diener & Biswas-Diener, 2009; Diener et el., 2009; Duckworth et al., 2005; Edwall & Yngve, 2015). Feelings are associated with, and often precede, a sense of flourishing (Fosha, 2009).

A sense of flourishing has the foundational psychological pillars of emotional, psychological and social well-being, as well as affirmative associations with others, awareness of positive and negative feelings, capacity to respond positively, self-determination and self-acceptance. Conversely, a sense of flourishing is negatively associated with self-judgment, reclusiveness, and over-identification that often tend to magnify discomfort and hardship (Satici et al., 2013). An individual’s perception of a sense of flourishing and life satisfaction is positively associated with an awareness of positive feelings (Goy, 2006).

Flourishing in Other Populations

Research on the topic of flourishing has been conducted in a variety of different populations including Canadians, undergraduate university and college students, and law firm employees. Interestingly, these studies used different instruments to measure flourishing; however, reported results were similar.

Mongrain & Anselmo-Matthews (2012) recruited Canadian participants age 18 and older (over 75% female) to examine positive psychology exercises and a sense of flourishing. Study results revealed that positive psychology exercises had an impact on a sense of flourishing. Three other studies of university students in Turkey, Canada and Sweden found some similar results (Akin & Akin, 2015; Edwall & Yngve, 2015; Satici et al., 2013). Smit (2015) recruited participants from a law firm in South Africa to examine flourishing at work in order to explore a link between subjective well-being and productivity.

Study results indicated that a sense of flourishing was associated with health and happiness and contrarily linked to isolation. In addition, workers who exhibited a strong sense of flourishing and good health had higher attendance at work and were more positively engaged in the workplace than their counterparts. Weaknesses of the study included no operational definition for “flourishing”, small sample size, and the fact that gender and age were not taken into consideration for analysis.

While each of these studies used different instruments to measure flourishing many reported results were similar; namely that an orientation to a life of meaning, pleasure and engagement, mindfulness, and employing positive psychological exercises are positively associated with flourishing. Finally, while these studies contribute to our understanding of flourishing in university students and one study to workers in a law firm, they do not contribute to our understanding of flourishing in aging female informal caregivers of PWD.

Flourishing of Aging Female Informal Caregivers of Persons with Dementia

Only one study could be located in the literature on flourishing and informal caregivers of PWD. Sabat (2011) conducted a qualitative, longitudinal convenience sample case study of one aging female spouse informal caregiver of PWD (married 60 years) to examine flourishing. At the outset of the study, using e-mail communications as an intervention, the aging female informal caregiver of PWD reported feelings of helplessness, sadness, low self-esteem, stress, and frustration at the care recipient PWD condition. Over time, the intervention demonstrated to be useful and supportive and the aging female informal caregiver of PWD began to develop and express a sense of flourishing and happiness.

This study provides a beginning insight into flourishing of the aging female informal caregiver of PWD. No other studies were discovered that addressed flourishing of aging female informal caregivers of PWD. Further research is necessary to understand flourishing and the aging female informal caregiver of PWD population.

Life Satisfaction

In this section, the topics of life satisfaction, life satisfaction state of the science, factors negatively and positively associate with life satisfaction, and life satisfaction study limitations are presented.

Life satisfaction is defined as “global cognitive judgment of satisfaction with one’s life” (Diener, 2000, p. 34). Duckworth et al. (2005) define well-being as an aggregate of presence of positive feelings, absence of negative feelings, and a personal judgment of life satisfaction; with a sense of well-being and the perception of life satisfaction being synonymous terminology. Lyumbomirsky et al. (2005) declare that, “happy persons are those who experience frequent positive emotions, such as joy, interest and pride, and infrequent (though not absent) negative emotions, such as sadness, anxiety and anger” (p.215). A strong sense of life satisfaction is influenced by positive affect, an outgrowth of positive feelings. A negative affect is an outgrowth of negative feelings (Fosha, 2009; Diener et al., 1985; Diener, 2000; Diener et al., 2009; Lyumbomirsky & Lepper, 1999). The perception of positive life satisfaction has an enlarging effect on positive feelings and a diminishing effect on pain and negative feelings (Duckworth et al., 2005). Positive feelings are highly associated with a strong sense of flourishing which in turn drives life satisfaction in a positive direction (Lyumbomirsky et al., 2005).

Life Satisfaction State of the Science

Life satisfaction is related to emotions, pleasure, meaning, engagement, mental and physical health, self-esteem, and optimism (Bastian et al., 2014; Biswas-Diener & Diener, 2001; Lyumbomirsky et al. 2005; Peterson et al., 2005). In the studies of Bastian et al. (2014, Lyumbomirsky et al. (2005) and Peterson et al. (2005), it was reported that persons who experienced positive emotions also experienced increased life satisfaction and those who experienced negative emotions also experienced decreased life satisfaction. Persons who reported feeling low in pleasure, engagement and meaning also reported themselves low on life satisfaction. Mental and physical health symptoms are reported less frequently among people who report high levels of life satisfaction. Life satisfaction was positively associated with self-esteem and optimism as well as a more positive mindset toward others. People with higher life satisfaction have a propensity to be more socially engaged and exhibit higher energy levels.

Factors Negatively Associated with Life Satisfaction

Three studies compared life satisfaction among informal caregivers and non-caregivers. Overall, life satisfaction was lower among informal caregivers and decreases with advancing age (Borg & Hallberg, 2008; Broe et al., 1999; Clay et al., 2008). Specifically, informal caregivers who were unemployed, with poor health and limited social resources had significantly lower life satisfaction.

Six studies examined life satisfaction and brain injury (Baumann et al., 2012; Ergh et al., 2003; Kershner-Rice, 2011; Kruithof et al., 2012; Ostwald et al., 2009; Wells et al. 2005). Ergh et al. (2003) indicated that informal caregivers age 24-79 and primarily female reported that negative life satisfaction was associated with care recipient neurobehavioral disturbances. Other factors associated with low life satisfaction include low social support and care recipient progressive cognitive dysfunction. Informal spouse caregivers age 50 and older of persons post stroke indicated that lower life satisfaction was related to poorer health and greater stress (Ostwald et al., 2009). Baumann et al. (2012) reported that life satisfaction was lower among informal caregivers with low-level education and higher among those who were employed in the community.

Two studies examined life satisfaction and primarily female informal caregivers. Darling et al. (2010) recruited informal caregivers of persons with AIDS, age 19-65 and examined life satisfaction and stress. They reported that life satisfaction was most strongly associated with perception of stress. Specifically, female informal caregivers divulged greater levels of stress had lower life satisfaction. Wakefield et al. (2012) recruited informal caregiver participants age 18 years and older (mean age 59) and primarily females from the Veteran Health Administration to examine life satisfaction and chronic illness. They reported that informal caregiver negative life satisfaction was associated with care recipient poor health, older age, and depression.

Another study examined life satisfaction of both male and female informal caregivers. Waldron-Perrine et al. (2009) conducted a study of informal caregiver participants age 20-81 (mean age 51), slightly more males than females and three-quarters spouses who were recruited through a neurology clinic to examine life satisfaction and multiple sclerosis. Waldron et al. reported that informal caregiver unsureness of illness, severity of illness, neuropsychological functioning, low income, and low social support are all associated with negative life satisfaction.

These twelve studies indicated that lower life satisfaction among informal caregivers was associated with being unemployed, having poor health, low-level education and limited social resources. Lower life satisfaction was associated with stress, low income, low social support, and concomitant external employment. In addition, lower life satisfaction was associated with care recipient poor health, severity of illness, older age and depression, neuropsychological functioning/disturbances, and progressive cognitive dysfunction. It is important to know what issues informal caregivers identify to be negatively associated with life satisfaction in order to develop a plan to address such issues and/or develop interventions to improve life satisfaction for aging female informal caregivers of PWD.

Factors Positively Associated with Life Satisfaction

Wells et al. (2005) reported that informal caregivers age 23-84 and primarily spouses indicated that positive life satisfaction was associated with effective coping skills, greater income and among those who were employed in the community (Baumann et al., 2012). There was also some evidence that life satisfaction may be related to gender and ethnicity as female informal caregivers reported higher levels of life satisfaction compared to men (Borg & Hallberg, 2008). The Clay et al. (2008) study recruited African American informal caregivers of PWD (mean age 55.7) and reported that life satisfaction was significantly greater and constant over time for African American caregivers compared to Caucasian caregivers.

Darling et al. (2010) reported informal caregivers and AIDS care recipients who had higher levels of historical family functioning reported higher levels of life satisfaction. The Wakefield et al. (2012) study indicated that positive life satisfaction was associated with use of counseling, prayer, use of paid help, seeking advice from family/friends, and exercise. And that assisting the care recipient with equipment and administering medication was associated with higher life satisfaction.

In these studies, informal caregiver life satisfaction was positively associated with employment, higher income, female gender, ethnicity, counseling, prayer, paid help, advice from family and friends, exercise, and pre-existing higher levels of historical family functioning. It is important to know what items informal caregivers report to be positively associated with life satisfaction in order to facilitate existing life satisfaction or develop a plan to address the items and elevate life satisfaction.

Life Satisfaction Study Limitations

Studies reported above have a number of limitations making generalizability to aging female informal caregivers of PWD difficult. The primary limitation with the studies above is that only one sample included aging female informal caregivers of PWD. Other study limitations include age discrepancies such as all informal caregivers being over 75 (Broe et al., 1999), and uneven sampling issues (caregivers 30% and non-caregivers 70%) (Borg & Hallberg, 2008).

Life Satisfaction in Informal Caregivers of PWD

In this section, the topic of life satisfaction and informal caregivers of PWD will be presented. However, only three studies on life satisfaction and informal caregivers were located in the literature.

The first study, conducted by Kaufman et al. (2010) recruited informal caregivers of PWD from rural areas of Alabama, ages 23-82 years (mean age 52), females 85%, spouses 60%, White 52%, and African American 48% to examine caregiver burden, social support and life satisfaction. Findings revealed that informal caregivers of PWD life satisfaction was positively associated with moderate to high levels of social support. In particular, high life satisfaction was strongly associated with levels of social support in the form of someone to talk to or with whom to socialize and receive positive affirmation. The study included over primarily female informal caregivers, which may contribute to our understanding of life satisfaction and aging female informal caregivers of PWD.

The second study, conducted by Perren et al. (2006) was a retrospective study of informal caregivers of PWD, mean age 68.4, female 63%, and primarily spouses of care recipients PWD. Recruitment was conducted in a Zurich, Germany memory clinic and area physician referrals. This study examined informal caregivers of PWD life satisfaction, subjective well-being, and adaptation to change. Findings revealed that life satisfaction was negatively associated with care recipient behavioral problems, cognitive and functional impairment and was further impacted by a more rapid rate of change in these areas. Female spouse informal caregivers of PWD life satisfaction decreased over time as care recipient behavioral problems and cognitive and functional impairments increased linearly over time. They also identified that care recipient PWD behavioral problems were the strongest predictor for poor informal caregivers of PWD well-being and life satisfaction. Psycho-educational interventions positively affected informal caregivers of PWD well-being and life satisfaction. In addition, informal caregivers of PWD from the psycho-educational intervention group were more inclined to seek respite care than those of the control group, which also elevated life satisfaction.

Finally, the third study conducted by Thorpe et al. (2009) was a retrospective study of a sample drawn from the Veteran Health Administration national data base of female informal spouse caregivers of PWD (mean age 68) to examine the role of caregiver life satisfaction and barriers to outpatient care. Findings revealed that female informal caregivers of PWD life satisfaction was negatively associated with the care recipient PWD receiving outpatient care and other health services. Informal caregiver diminished life satisfaction reduced the occurrence of them assuring that the care recipient PWD received timely routine care from both primary care and mental health care services. African American informal caregivers of PWD were less likely to schedule the care recipient PWD for outpatient mental health services. Increased informal caregivers of PWD life satisfaction was positively associated with the care recipient PWD being scheduled for an outpatient healthcare appointment and attending that appointment. And informal caregivers of PWD life satisfaction was positively associated with receiving help from family and friends. In addition, care recipients PWD living with their informal caregiver had a higher likelihood of being scheduled for a specialty care appointment.

These three studies reveal that life satisfaction of informal caregivers of PWD was negatively associated with care recipient PWD behavioral problems and cognitive and functional impairment and further impacted by a more rapid rate of change. Life satisfaction of informal caregivers of PWD was positively associated with moderate to high levels of social support, receiving positive affirmation, psycho-educational interventions, respite care, and receiving help from family and friends.

Summary

The review of the literature indicates that our comprehension of informal caregiving has exponentially increased over the past twenty to thirty years; yet ongoing research is critical to uncover a more global understanding of the female informal caregiver of PWD. Due to the increasing demands placed on the female informal caregiver of PWD, as stages of dementia progresses, the daily lived caregiving experience often causes increasing stress that ultimately impacts life satisfaction.

The daily perceived life satisfaction of the female informal caregiver of PWD can easily be affected by the taciturn and unpredictable behavior of the care recipient. The precise stimulators of stress for the female informal caregiver of PWD is not appreciated to the full extent. Research routinely reveals that the informal caregiving role is extraordinarily stressful for caregivers of individuals with dementia. Informal caregiver strains of financial and ethical boundaries that can provoke a sense of being overwhelmed. It is extrapolated from this literature review that positive feelings play a primary role in developing a personal sense of flourishing and overall life satisfaction, while negative feelings may have the opposing effect.

The basic phenomenon of interest for this study is life satisfaction of the aging female informal caregiver of PWD. The literature review indicates that life satisfaction has been investigated in the young adult to elderly population of both genders (primarily of women), across a variety of ethnicities, and in different disease populations (e.g., brain injury). However, only a few studies have examined life satisfaction in dementia caregiving. Most of the life satisfaction studies were conducted with age and population groups that are different from the aging female informal caregiver of PWD but are nonetheless relevant. A few of the studies looked at aging adult informal caregivers. Assessment of life satisfaction needs to be initiated and maintained as a long-term goal for the aging female informal caregiver of PWD during each clinical encounter attended with the care recipient. Assessment is necessary in order to initiate referrals for appropriate interventions aimed at maintaining a healthy approach to caregiving that would likely increase positive outcomes for the care recipient. Life satisfaction among the aging female informal caregiver of PWD is sparse leading to a gap in the literature.

Chapter Three

RESEARCH METHODS

Introduction

This chapter presents the research question, specific aims, operational definitions, design, sampling plan, inclusion criteria, recruitment procedure, sample, sample size calculation and variables, setting and recruitment plan, data collection plan, instruments, power analysis ad effect size, data analysis, protection of human subjects, study limitations, and summary.

Study Research Question

What is the relationship between aging female informal caregivers of PWD and care recipients' PWD demographics, and secondly, aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction?

Specific Aims

Study Aim 1

Describe select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample.

Study Aim 2

Describe the relationship between select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample.

Study Aim 3

Determine the amount of variance in aging female informal caregivers' life satisfaction accounted for by select demographics, social support factors, positive and negative feelings, flourishing, and stress.

Operational Definitions

For the purpose of this study, operational definitions are provided.

Aging Female Informal Caregivers of PWD Demographic Characteristics

Demographic characteristics for aging female informal caregivers of PWD that was collected include age, race/ethnicity, rural/urban, highest level of education, location of residence, socioeconomic status, income, employment status, religion, marital status, language, mobility, and personal medical challenges.

Care Recipients' PWD Demographic Characteristics

As reported by the aging female informal caregivers of PWD, demographic characteristics of care recipients PWD was collected and include age, race/ethnicity, rural/urban, highest level of education, location of residence, socioeconomic status, income, employment status, religion, marital status, language, mobility, and personal medical challenges.

Care Recipients' PWD Clinical Factor (Dementia Subtype)

The care recipients PWD dementia subtype information was collected from the aging female informal caregiver PWD. Subtypes include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, Parkinson's disease dementia, frontotemporal lobar degeneration, Creutzfeldt-Jakob disease or mixed dementia/multifactorial dementia.

Social Support Factors

Social support factors are defined as hours of additional help from others, (family, friends, or neighbors); the presence of in the home professional respite care; and access to community programs.

Positive and Negative Feelings

Positive and negative feelings is defined as emotions experienced by the informal caregiver (related to what one has been doing and experiencing) not just those positive and negative feelings for a certain specific situation, and are based on the amount of time the feelings were experienced during the past four weeks (Diener et al., 2010). The range of positive and negative experiences include specific feelings and also reflects other states such as interest, flow, positive engagement, and physical pleasure (Diener & Biswas-Diener, 2009).

Sense of Flourishing

A sense of flourishing is defined as experiencing major aspects of social psychological functioning such as “having supportive and rewarding relationships, contributing to the happiness of others, being respected by others, having a purposeful and meaningful life, being engaged and interested in one’s activities, having self-respect and optimism, and feeling competent and capable in activities that are important [to one’s self]” (Diener et al., 2010, p. 144-145). Flourishing links social well-being, psychological well-being, and social-psychological prosperity.

Caregiver Stress

Caregiver stress is defined as frequent encounters during caregiving that disrupt the thought process, provoke feelings and emotions, disrupt sleep, and exacerbate physical symptoms that have an impact on the daily living experience.

Life Satisfaction

Life satisfaction is defined as “global cognitive judgment of satisfaction with one’s life” (Diener, 2000, p. 34). Life satisfaction stems from a judgment process of the individual (Diener et al., 1985). It comes to light that a person constructs a standard, which they realize as appropriate for themselves, and analyze the aspects of their life to that standard. Thus, this is a subjective judgment, rather than a judgment based on some “externally imposed” standard (Diener et al., 1985, p. 71). Life satisfaction is an evolving accumulation of an individual’s general life perspective, inclusive of cultural orientation, and life occurrences (Diener et al., 2013). Items on this measure reflect general life satisfaction rather than satisfaction with particular areas of life (Diener et al., 1985).

Design

The study purpose was achieved through a cross-sectional descriptive design. Specifically, the relationship was described between aging female informal caregivers of PWD demographics, care recipients PWD demographics, social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

Sampling Plan

This is a pilot study. A convenience sample of aging female informal caregivers of PWD (spouse, partner, or other family member) age 56 and older were enrolled in this study. The rationale for this method of sampling in this study is that homogenous sampling lessens variation allowing for a more focused inquiry.

Inclusion Criteria

The inclusion criteria encompass aging female informal caregivers (relative, partner, or friend) age 56 and older, providing uncompensated care in a home environment to a person with dementia, and possessing verbal/written literacy in English. Participants were included who resided permanently in the area and temporarily in the area, but whose primary residence was elsewhere in United States.

Sample Size Calculation and Variables

Sample size calculation was conducted utilizing 31 variables. One dependent variable is selected which is satisfaction with life (see Table 9). Thirty independent variables are selected that include general demographic variables (see Table 10), support variables (see Table 11), positive and negative feelings variables (see Table 12), flourishing variables (see Table 13); and variables from the caregiver self-assessment questionnaire (see Table 14).

Table 9

Dependent Variables – Satisfaction with Life Scale

In most ways my life is close to my ideal
Conditions of my life are excellent
Satisfied with my life
So far, I have gotten the important things I want in life
If I could live my life over, I would change almost nothing

Table 10

Independent Variables - General Demographics

Aging Female Informal Caregiver of PWD Demographics	Care Recipient PWD Demographics
Age	Age
Race/ethnicity	Race/ethnicity
Level of education	Level of education
Location of residence	Location of residence
Socioeconomic status	Socioeconomic status
Income	Income
Employment status	Employment status
Religion	Religion
Marital status	Marital status
Language	Language
Mobility	Mobility
Personal medical challenges	

Table 11

Independent Variables – Support

Additional help from others (family, friends, neighbors

Hours of additional help from others

In-home professional respite care

Table 12

Independent Variables – Positive and Negative Feelings Scale

Positive Feelings	Negative Feelings
Positive	Negative
Good	Bad
Pleasant	Unpleasant
Happy	Sad

Joyful	Afraid
Contented	Angry

Table 13

I lead a purposeful and meaningful life
My social relationships are supportive and rewarding
I am engaged and interested in my daily activities
I actively contribute to the happiness and wellbeing of others
I am competent and capable in the activities that are important to me
I am a good person and live a good life
I am optimistic about my future
People respect me

Table 14

Difficulty making decisions
Crying spells
Feeling overwhelmed
Rating of level of stress
Feeling couldn’t leave relative alone
Feeling loss of privacy/personal time
Found relative’s living situation inconvenient or barrier to care
Trouble keeping mind on task
Feeling useful and needed
Feeling lonely
Upset relative has changed so much
Feeling satisfied with support family has given
Feeling edgy/irritable
Sleep disturbances
Back pain

Feeling ill (headache, stomach problems, common cold)
Rating of their perception of their current health in comparison to their health 1 year ago
Feeling strained between work and family responsibilities

Power Analysis and Effect Size. A minimal sample size of 190 participants was needed for the study when considering a multiple regression Statistics Calculators (Statistics, 2015). Anticipated effect size (f2): The anticipated effect size is 0.15. By convention, effect sizes of 0.02, 0.15, and 0.35 are considered small, medium, and large, respectively. Desired statistical power level: The desired statistical power level is ≥ 0.8. By convention, this value should be greater than equal to 0.80. Number of variables: The total number of variables in the model is 31. Due to time constraints, this is a pilot study with 35 participants recruited. Probability level: The desired probability level is ≤ 0.05. Also known as the p-value, alpha level, or type I error rate. By convention, this value should be less than or equal to 0.05 to claim statistical significance.

Setting & Recruitment Plan

Participants recruited were aging female informal caregivers of PWD who accompanied the care recipient PWD to an appointment at a geriatric clinic or who were present at senior community venues located in southern California. A recruitment flyer (see Appendix A) was posted nearby at the study sites inviting aging female informal caregivers of PWD to participate in the study.

Data Collection Plan

Data collection was initiated with potential participants by the researcher who was on site in a health care clinic or at a senior community venue. The health care clinic had a caseload of approximately 840 patients per month and approximately 60 of those were older adults with dementia (36-40 scheduled face-to-face healthcare provider appointments per month; 8-10 scheduled pharmacy appointments per week; and 2 walk-in appointments per day 4 days per week). The senior community venues had approximately 12-50 persons present.

Instruments

Six quantitative instruments that were suitable for administration by the researcher were utilized as follows: demographics, support factors, *Scale of Positive and Negative Experience*, *Flourishing Scale*, *Caregiver Self-Assessment Questionnaire*, and the *Satisfaction with Life Scale.* The dementia subtype information was solicited in the form of a question during collection of demographic information.

Aging Female Informal Caregivers of PWD Demographics

In order to characterize the sample and explore other associations of life satisfaction, participant demographics were collected using an instrument designed by the investigator. Information was obtained on aging female informal caregivers of PWD age, gender, ethnicity, rural/urban, education level, relational status (example: married, domestic partner), employment status, household income, living situation, level of independence, type of residence, mobility challenges, and medical issues (see Appendix B).

Care Recipients' PWD Demographics and Dementia Subtype

In order to characterize the sample and explore other associations of life satisfaction, care recipient demographics were collected from the caregiver using an instrument designed by the investigator. Information was obtained on the care recipient age, gender, ethnicity, education level, household income, living situation, level of independence, type of residence, mobility challenges, onset of dementia, and dementia subtype (see Appendix C).

Social Support Factors

Social support factors, as defined by the investigator, is the receipt of help from others (family, friends, or neighbors), the presence of in-home professional respite care, and access to community programs (see Appendix B).

Scale of Positive and Negative Experience

The *Scale of Positive and Negative Experience (SPANE)* instrument was developed by Diener et al. (2010. At the time SPANE was developed, another scale, the Positive and Negative Affect Schedule (PANAS), had been frequently used by researchers. However, the PANAS scale items were "all high arousal feelings, and many were not considered emotions or feelings" Diener et al. (2010, p. 145). The SPANE was developed to "reflect all levels of arousal for both positive and negative feelings" (Diener et al. (2010, p. 145). It has been used to study college and university students, youth with mental health issues, and informal caregivers of persons with traumatic brain injury (TBI) among young adult to middle age populations and within many cultures. The SPANE has been translated into six languages. When administered the participants are instructed to think about what they have been doing and experiencing during the previous four weeks.

The SPANE instrument includes 12 items with six items designed to measure positive feelings and six items to measure negative feelings in order to derive an overall affect balance score. The SPANE instrument is subdivided into two subscales – the positive experiences and the negative experiences subscales: SPANE P (positive feelings) and SPANE N (negative feelings). SPANE P includes three general items (positive, good, pleasant) and three more specific items (happy, joyful, contented). SPANE N includes three general items (negative, bad, unpleasant) and three more specific items (sad, afraid, angry) (Diener et al., 2009; Diener et al., 2010) (see Table 15).

Table 15

Components of Feelings and Indicator Items from the Scale of Positive and Negative Experience Instrument

Positive Feelings (SPANE P) indicator items	Negative Feelings (SPANE N) indicator items
Positive	Negative
Good	Bad
Pleasant	Unpleasant
Happy	Sad
Joyful	Afraid
Contented	Angry

The SPANE instrument measurement scale items are rated on a 1-5 rating scale: 5 – Very Often or Always; 4 - Often; 3 - Sometimes; 2 - Rarely; 1 – Very Rarely or Never (Diener et al., 2009).

The measure can be used to derive an overall affect balance score but can also be divided into positive and negative subscales. To score the overall Affect Balance (SPANE-B), the sum of the negative feelings score, ranging from 1 to 5, is summed and subtracted from the sum of the positive feelings score, ranging from 1 to 5, and the resultant difference score can range from 5 to 35. Scores of 31-35 indicate extremely satisfied; 26-30 Satisfied; 21-25 Slightly satisfied; 20 Neutral; 15-19 Slightly dissatisfied; 10-14 Dissatisfied; 5-9 Extremely dissatisfied (Diener et al., 2009; Diener et al., 2010). Therefore, the resultant difference score can vary from -24 (unhappiest possible) to 24 (highest affect balance possible). A respondent with a very high score of 24 reports that she or he rarely or never experiences any of the negative feelings, and very often or always has all of the positive feelings. To score the Positive Feelings (SPANE-P) subscale, sum the items, ranging from 1 to 5, for the six items: positive, good, pleasant, happy, joyful, and contented. The calculated score for the positive feeling subscale can vary from 6 (lowest possible) to 30 (highest positive feelings score). To score the Negative Feelings (SPANE-N) subscale, sum the items, ranging from 1 to 5, for the six items: negative, bad, unpleasant, sad, afraid, and angry. The calculated score for the negative feeling subscale can vary from 6 (lowest possible) to 30 (highest negative feelings score).

The reliability and sensitivity of the Scale of Positive and Negative Experience instrument has been established. Additionally, it has been demonstrated that the instrument produces valid data. The total affect balance score (twelve items) has high reliability ($\alpha = .89$) and moderately high temporal stability ($\alpha = .68$) (Diener et al., 2010). The two positive and negative subscales have high reliability ($\alpha = .81 - .87$) and temporal stabilities are moderately high (α = .61 - .62). The negative and positive scales are correlated at *r* = -.60 (N = 682, p<.001). The SPANE instrument performed well in terms of reliability and convergent validity with other measures of emotion, well-being, happiness, and life satisfaction (Diener et al., 2010).

Convergence of the Satisfaction with Life Scale instrument with SPANE-P is moderate (r =.58, N = 686); with the SPANE-N (r = -.46, N = 682); and the SPANE-B (r =.57, N = 681) (Diener et al., 2010). Silva & Caetano (2013) discovered the SPANE scale showed high correlations with other measures of happiness (Satisfaction with Life Scale; Subjective Happiness Scale; Fordyce's single item of happiness, and single item satisfaction with quality of life), ranging from 0.46 to 0.59. The SPANE P and SPANE N subscales also showed moderate to strong correlations with the other measures with *r* values varying between 0.44 to 0.61, and -0.36 to -0.42, respectively. Furthermore, and consistent with the nature of the measured construct (that reflects a pleasant emotional experience), the scales showed significant correlations in the expected direction with the SPANE subscales (i.e., negative correlations with the low pleasurable scale, and positive correlations with the high pleasurable scale).

In summary, the Scale of Positive and Negative Experience is a short 12-item instrument that can measure a full range of emotions and feelings, from a good or bad perspective, that an informal caregiver may be experiencing. It is appropriate to administer to aging female informal caregivers, and it complements the Flourishing Scale instrument to provide greater insight into the state of aging female informal caregiver well-being.

Flourishing Scale

The Flourishing Scale (FS) instrument was developed by Diener and Biswas-Diener (2009) and was established taking into account preceding humanistic psychology theories that evolved out of the concept of universal human needs and effective functioning that defined well-being as comprised of feelings of engagement, interest, pleasure, meaning, purpose, optimism, and human need (Maslow, 1954; Ryan & Deci, 2000; Ryff & Singer, 2002; Seligman, 2002). The FS instrument measures particularly common universal human psychological longings, bringing these together with theories of well-being (Diener et al., 2010).

Early on, it was called the Psychological Well-being Scale and consisting of twelve-item, the instrument was later reduced to an eight-item instrument (Diener & Biswas-Diener, 2009). It is a brief summary measure of psychological functioning, designed to complement other measures of subjective wellbeing, while incorporating items to measure the integral components of various popular theories of well-being (Diener et al., 2010). It was initially used to study college and university students in varying locales, but since its creation it has been used across different age groups and within many cultures. The Flourishing scale instrument has been translated into sixteen languages.

The FS instrument includes eight items that are a summary measure of the respondent's self-perceived psychological resources and strengths (Diener & Biswas-Diener, 2009) (see Table 16).

Table 16

Components of Flourishing and Indicator Items from the Flourishing Scale Instrument

Components of flourishing	Flourishing Scale indicator items
Purpose/meaning/satisfying life	I lead a purposeful and meaningful life
Positive relationships/supportive relationships	My social relationships are supportive and rewarding
Engagement/positive functioning (engagement)	I am engaged and interested in my daily activities
Social contributions/positive functioning (meaning and purpose)	I actively contribute to the happiness and wellbeing of others
Competence/positive functioning (competence)	I am competent and capable in the activities that are important to me
Self-respect/resilience and self-esteem (Self-esteem)	I am a good person and live a good life
Optimism/resilience and self-esteem (optimism)	I am optimistic about my future
Social relationships/trust and belonging	People respect me

The FS instrument measurement scale items are rated on a 1-7 rating scale: 7 - Strongly agree; 6 – Agree; 5 - Slightly agree; 4 - Neither agree nor disagree; 3 - Slightly disagree; 2 - Disagree; 1 - Strongly disagree.

To score the FS instrument, eight items ranging from 1-7 are summed to provide a single psychological well-being score (Diener et al., 2009). The possible range of scores is from 8 (lowest possible) to 56 (highest possible). A high score represents a person with many psychological resources and strengths. High scores signify that respondents view themselves in positive terms in important areas of functioning. Although the scale does not separately provide measures of facets of well-being, it does yield an overall view of positive functioning across diverse domains that are widely believed to be important (Diener et al., 2009; Diener & Biswas-Diener, 2009).

The reliability and validity of the FS instrument has been established. Numerous studies thus far verify the reliability, the invariant one-factor structure of the FS instrument in a variety of populations across the world, and its ability to generate valid data (Diener et al., 2010; Hone et al., 2014; Khodarahimi, 2013; Silva & Caetano, 2013). Internal reliability is strong (α = .87), with a temporal stability (α = .71) (Diener et al., 2009; Diener & Biswas-Diener, 2009). Construct validity in terms of convergence of the Flourishing Scale instrument with Satisfaction with Life Scale instrument has been established (.62, N = 680) (Diener et al., 2010).

The Flourishing Scale instrument performed well with high convergence with similar instrument scales. It correlated strongly with the summed scores for other psychological well-being instrument scales, at .78 and .73. Therefore, the Flourishing Scale instrument yields a good measurement of overall self-reported psychological well-being (Diener et al., 2010, p. 152-153). Satici et al. (2013) demonstrated that there are significant correlations between flourishing and self-compassion. Correlations between flourishing and self-compassion were statistically significant. Self-kindness, common humanity, and mindfulness relayed positively to flourishing. On the other hand, self-judgment, isolation, and over identification with loneliness and submissive behaviors were found negatively associated with flourishing.

Silva & Caetano (2013) examined convergent validity by correlating the Flourishing Scale and the Scale of Positive and Negative Experiences with measures of happiness and well-being (Satisfaction with Life Scale; Subjective Happiness Scale; Fordyce’s single item of happiness, and single item satisfaction with quality of life). Their findings revealed substantial correlations ranging from 0.48 to 0.58 between the FS and other happiness measures. The FS shows a high correlation with the Subjective Happiness Scale. Silva & Caetano also analyzed the intercorrelations between the FS and SPANE and the FS showed a high correlation with the SPANE (r = 0.58) and with its subscales (SPANE P: *r* = 0.58; SPANE N: *r* = -0.42).

In summary, the Flourishing Scale is a short 8-item instrument that can identify prominent aspects of sociological and psychological functioning from the perspective of the informal caregiver, which goes hand-in-hand with the Scale of Positive and Negative Experience instrument to enhance the overall picture of aging female informal caregiver well-being.

Caregiver Self-Assessment Questionnaire (CSAQ)

The CSAQ (see Appendix D) was originally developed and tested by the American Medical Association (2009). The CSAQ instrument was normed on a small national sample of family caregivers (n=60). The questionnaire serves as a guide for the informal caregiver and healthcare provider to look at personal behavior and health risk and serves two purposes: 1) it gives informal caregivers insight into their own behavior and potential health risks and 2) it is intended to healthcare providers in assessing the stress-levels of informal caregivers. The CSAQ instrument is administered at the time the informal caregiver attends a healthcare visit with the care recipient (American Medical Association, 2009). The questionnaire can assist informal caregivers look at their personal behavior and health risks. The CSAQ can aid the informal caregiver and their healthcare provider to arrive at decisions that may benefit both the informal caregiver and the care recipient.

The CSAQ instrument includes eighteen items that measure the caregiver's self-perception of their own well-being (see Table 17).

Table 17

Components of Caregiver Self-Assessment and Indicator Items from the Caregiver Self-Assessment Questionnaire Instrument

Components of Caregiver Self-Assessment	Caregiver Self-Assessment indicator items
Emotional well-being (absence of negative feelings)	Difficulty making decisions
Emotional well-being (absence of negative feelings)	Crying spells
Emotional well-being (positive feelings)	Feeling overwhelmed
Emotional well-being (positive feelings)	Rating of level of stress
Positive functioning (autonomy)	Feeling couldn't leave relative alone
Positive functioning (autonomy)	Feeling loss of privacy/personal time
Positive functioning (autonomy)	Found relative's living situation inconvenient or barrier to care
Positive functioning (engagement)	Trouble keeping mind on task
Positive functioning (meaning and purpose)	Feeling useful and needed
Positive functioning (engagement)	Feeling lonely
Supportive relationships	Upset relative has changed so much
Supportive relationships	Feeling satisfied with support family has given
Vitality	Feeling edgy/irritable
Vitality	Sleep disturbances
Vitality	Back pain
Vitality	Feeling ill (headache, stomach problems, common cold)
Vitality	Rating of their perception of their current health in comparison to their health 1 year ago
Well-being at work	Feeling strained between work and family responsibilities

To score the CSAQ instrument, sum the items, for only the “Yes” responses, for items #1-16, and sum the items, ranging from 1-10, for items #17 and #18. Items #5 and #15 are reverse scored.

Interpretation of the scores is as follows. If the participant responds “Yes” to either or both questions #4 and #11; If the total “Yes” scores = 10 or more; If the score on question #17 is 6 or higher; If the score on question #18 is 6 or higher, it suggests that the caregiver may be highly stressed, and follow-up is recommended such as discussing community resources with a healthcare provider or a social worker (American, 2009; Epstein-Lubow et al., 2010). The simple scoring system allows the informal caregiver to score their results independently and to determine whether or not they are highly stressed; although, the healthcare provider can score the CSAQ instrument for or along with the informal caregiver. For the purposes of this study, only the participants will be completing the instrument.

The reliability of the CSAQ instrument and its ability to generate valid data is established. During the development of the CSAQ instrument scale, research indicated a reliability coefficient alpha of .78 (Epstein-Lubow et al., 2010) and specific items were noted to be predictive of caregiver stress (Epstein-Lubow, 2010; American, 2009). Ongoing research reports that the CSAQ instrument shows a high internal consistency (Chronbach alpha = .82) (Epstein-Lubow, 2010).

The CSAQ instrument also may be a valid instrument for assessing caregiver depression according to Epstein-Lubow et al. (2010) who examined scores on the CSAQ instrument from a sample group of 106 family caregivers and discovered it correlated highly (Pearson $r = .807$, $p < .001$) with their scores from several reliable caregiver depression instruments: Center for Epidemiological Studies Depression Scale (CES-D); Perceived Stress Scale, 4-item version (PSS4); and the Rapid Screen for Caregiver Burden (RSCB). Epstein (2010) concluded that the CSAQ instrument may also be valid for assessing caregiver depression as indicated by the correlates between the CSAQ instrument (items # 1-16), the Center for Epidemiologic Studies Depression Scale (CES-D) instrument, the Perceived Stress Scale instrument and the Rapid Screen for Caregiver Burden instrument. The CES-D instrument and the CSAQ instrument were highly correlated (Pearson $r = .807$, $p<.001$). Furthermore, the CSAQ instrument's level of sensitivity to predict significant depressive symptoms is 0.98, with a specificity of 0.52.

In summary, the Caregiver Self-Assessment Scale is a brief 18-item instrument that may be self-administered or administered by a healthcare provider. While not being a purpose of this proposed study, the CSAQ can aid the healthcare provider to determine personal behavior and health risk that may be concealed, and assist the healthcare provider in recommending preventive services for personal behavior(s) and health risk(s) identified for the aging female informal caregiver who is an at-risk population. Moreover, it may enhance communication between the healthcare provider and the aging female informal caregiver and therefore promote a healthcare provider-informal caregiver health partnership (American, 2009). The CSAQ instrument and scoring forms were initially available free of charge from the American Medical Association website but are now distributed at no cost by the National Caregivers Library. As an additional education piece, listed on the second page of the CSAQ Instrument scoring sheet are several telephone numbers and websites for caregiver resources, including the Eldercare Locator (American, 2009; Epstein-Lubow et al., 2010).

Satisfaction with Life Scale (SWLS)

The SWLS instrument was developed by Diener, Emmons, Larsen and Griffin (1985) and “intended as a brief assessment of an individual’s general sense of satisfaction with their life as a whole (Pavot & Diener, 2008, p. 138). The study dependent variable life satisfaction is defined as “global cognitive judgment of satisfaction with one’s life” (Diener, 2000, p. 34) and by design, items on this measure resonate with general life satisfaction rather than satisfaction with particular areas of life (Diener et al., 1985). Development of the original SWLS instrument began with 48 items designed to mirror life satisfaction and well-being. The original instrument’s, factor analysis identified ten items with high loadings (.60 or above) on one common factor interpreted as global evaluations of a person’s life (Pavot & Diener, 2008). Following eradication of redundancies, the number of items was reduced to five items, with minimal effect on the alpha reliability of the scale.

The SWLS instrument has been used across a considerable period of time to study persons across the population spectrum from pre-school youth to the elderly, including but not limited to college students from a variety of higher learning institutions around the world, youth with mental health issues, nurses and health workers, older French-Canadian adults, active and contemplative religious women, printing trade workers, military wives and nurses, doctoral students, male prison inmates, Veteran Affairs hospital in-patients, Dutch medical out-patients, abused women, clinical clients of psychological private practice, informal caregivers of persons with TBI, older adult caregivers, and a specially designed SWLS instrument for the pre-school population (Kerschner-Rice, 2011; Pavot & Diener, 1993). The SWLS instrument has been translated into thirty-three languages (Diener, 2009).

This SWLS instrument includes five items that measure positive and negative feelings. The items reflect general life satisfaction rather than satisfaction with particular areas of life (Diener et al., 1985) (see Table 18).

Table 18

Components of Satisfaction with Life and Indicator Items from the Satisfaction with Life Scale Instrument

Components of satisfaction with life	Satisfaction with life indicator items
Satisfying life	In most ways my life is close to my ideal
Satisfying life	Conditions of my life are excellent
Satisfying life	Satisfied with my life
Satisfying life	So far, I have gotten the important things I want in life
Satisfying life	If I could live my life over, I would change almost nothing

The SWLS instrument measurement scale items are all worded in a positive direction (Pavot & Diener, 2008) and are rated on a 1-7 rating scale: 7 - Strongly agree; 6 - Agree; 5 - Slightly agree; 4 - Neither agree nor disagree; 3 - Slightly disagree; 2 - Disagree; 1 - Strongly disagree (Diener, 2009).

To score the SWLS instrument, the items, ranging from 1 to 7, are summed across all five items. The possible range of scores is from 5 (lowest possible) to 35 (highest possible) (Diener, 2009), with a score of 20 representing the neutral point on the scale (Pavot & Diener, 2008). Scores between 5 and 9 indicate that the respondent is extremely dissatisfied with life, whereas scores ranging between 31 and 35 indicate that the respondent is extremely satisfied with life. Scores between 21 and 25 represent slightly satisfied, and scores from 15 to 19 are interpreted as falling in the slightly dissatisfied range.

The reliability of the Satisfaction with Life Scale instrument is established, and it is determined that instrument produces valid data. A succession of reliability and validation studies completed by Diener et al. (1985) established that the SWLS instrument scale is a multi-item measure of global life satisfaction, showing good internal consistency and reliability, with content appropriate for a wide range of populations and age groups around the world. The SWLS instrument has shown strong internal reliability and moderate temporal stability (Pavot & Diener, 1993) with a coefficient alpha of .87 for the scale and a 2-month test-retest stability coefficient of .82 (Diener et al., 1985). Over time other investigators have also reported both good internal consistency and temporal reliability for the SWLS instrument scale. The concept of life satisfaction when measured by differing scales and by a variety of entities with questions in multiple time periods over years have demonstrated an overall correlation with the SWLS of r = .94 (Diener et al., 1985; Diener et al., 2013; Pavot & Diener, 1993).

Duckworth et al. (2005) concluded that traditional “symptom checklists” were a less than beneficial instrument since they address symptoms or complaints and do not capture and bring to the forefront “potential resources, strengths, or supports that may be successful in building successful interventions” (p. 636), These authors strongly support the use of brief item well-being scales such as the Satisfaction with Life Scale. They have demonstrated that the five-item Satisfaction with Life Scale (Diener et al., 1985), the four-item Subjective Happiness Scale (Lyubomirsky & Lepper, 1999, as cited in Duckworth et al., 2005), and the two-item Fordyce Happiness Measures (Fordyce, 1988, as cited in Duckworth et al., 2005) correlate highly with one another ($r \approx 0.8$).

In summary, the Satisfaction with Life Scale is a short 5-item instrument to measure global cognitive judgments of life satisfaction, that is easy to administer, culturally sensitive, and the aging female informal caregiver can complete the items in a minimal amount of time. Aging female informal caregiver life satisfaction is impacted by multiple introspective and interpersonal feelings and emotions; therefore, a well-rounded insight of aging female informal caregiver life satisfaction may be enhanced when viewing the results of the Satisfaction with Life Scale along with the Scale of Positive and Negative Experience, the Flourishing Scale, and the Caregiver Self-Assessment Questionnaire.

Study Instruments Synopsis

Study instruments synopsis of variable measure, author/year, alpha, range of ratings, and number of items is provided below (see Table 19). Permission was granted to use the following instruments Scale of Positive and Negative Experience, flourishing Scale, and Satisfaction with Life Scale. The Caregiver Self-Assessment Questionnaire was available in the public domain.

Table 19

Study Instruments

Instrument Name	Variable Measure	Author/Year	Alpha	Range of Ratings	# Items
Scale of Positive and Negative Experience (SPANE)	feelings	Diener, E., Wirtz, D., Tov, W., Kim-Pierto, C., Choi, D., Oishi, S., & Biswas-Diener, R. (2009).	.87	1-5	12
Flourishing Scale	well-being	Diener, E., Wirtz, D., Tov, W., Kim-Pierto, C., Oishi, S., & Biswas-Diener, R. (2009).	.87	1-7	8
Caregiver Self-Assessment Questionnaire	stress	Epstein-Lubow, et al., 2010, American Medical Association (2009).	.7804	yes/no and 1-10	18
Satisfaction with Life Scale (SWLS)	life satisfaction	Diener, E., Emmons, R.A.., Larsen, R.J., & Griffin, S. (1985).	.87	1-7	5

Data Analysis

A variety of statistical procedures were conducted to address each study aim: descriptive statistics (frequencies, percentages, means and standard deviation), Spearman's rho correlation analysis, Mann Whitney Test and Independent t-test, and multiple linear regression. Note that separate models were constructed using fewer independent variables due to the study's small sample size.

Protection of Human Subjects

Participant anonymity was protected, and the study data will remain confidential. Results were only reported in aggregate form. No personally identifiable information was reported, including outlier information such as age, >/=90 as an age for all >/=90 years old, or gender, that might identify a participant or small group of participants. A handout was provided to the participant that describes the purpose of study, identification of researcher; sponsoring institution; how participants were selected; purpose of the research; benefits of participating; level and type of participation involvement; risk to the participant; confidentiality; assurance that the participant could withdraw at any time; and names of persons to contact if questions arise (see Appendix E).

Anonymity of the participants was preserved by using non-identifier codes. Surveys are kept in a locked cabinet in a secure area separate from a code book (also locked in a secure location) for a period of five years and data will be kept on a password protected computer for a period of seven years.

An institutional review board (IRB) application was submitted to the University of San Diego IRB and to the VA Loma Linda Healthcare System IRB for determination of level of study oversight. Both IRBs approved the application (see Appendix F).

Study Limitations

Threats to validity may include response bias, conceptual meaning bias, cross-cultural issues, selection bias, and random error. To reduce study bias and other issues, caregivers were encouraged to take their time in completing the instrument items and to answer the instruments to best of their ability. Caregivers were provided assurance that their responses provided will remain anonymous and responses will in no way impact the way they were perceived by the investigator.

The small sample size may not be representative of the entire population. A small sample size also affects the reliability of the study because it leads to a higher variability, which may lead to bias.

Summary

In summary, the study purpose was achieved through a cross-sectional descriptive design. A convenience sample of aging female informal caregivers of PWD age 56 and older (N = 35) providing care in a home environment to a person with dementia were enrolled in the study. Six quantitative instruments (demographics, support factors, Scale of Positive and Negative Experience, Flourishing Scale, Caregiver Self-Assessment Questionnaire, and the Satisfaction with Life Scale) were utilized to describe the relationship between aging female informal caregivers of persons with dementia (PWD) and care recipient demographics, aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction. Variables examined were one dependent variable life satisfaction and 31 independent variables. A minimal sample size of 190 participants was needed for the study when considering a multiple regression but due to time constraints, this was a pilot study with 35 participants recruited. Participants were recruited who accompanied the care recipient PWD to an appointment at a geriatric clinic or who were present at senior community venues located in southern California.

To analyze the data, a variety of descriptive (frequencies, percentages, means and standard deviation) and inferential (Spearman’s rho correlation analysis, Mann Whitney Test, Independent t-test, and multiple linear regression) statistics were used to address each study aim. Separate models were constructed using fewer independent variables due to the study’s small sample size. Participant anonymity was protected, and results were only reported in aggregate form. Regarding study limitations, threats to validity may include response bias, conceptual meaning bias, cross-cultural issues, selection bias, and random error. And small sample size may not be representative of the entire population.

Chapter Four

RESULTS

Thirty-five (35) aging female informal caregivers of person with dementia participants (PWD) completed the de-identified instruments and there was no participant attrition from the study. The cross-sectional descriptive design study examined if relationships existed between independent variables (aging female informal caregivers demographics (PWD) and care recipients PWD demographics, aging female informal caregivers' demographics (PWD) social support factors, positive and negative feelings, a sense of flourishing, and stress and the dependent variable life satisfaction. Each of the variables were individually examined and compared to determine if a relationship to life satisfaction existed. Statistical analyses were performed using IBM SPSS Statistics (Version 26; IBM Corporation 1989, 2019.). Alpha was set at 0.05 significance level.

Study Research Question

What is the relationship between aging female informal caregivers of PWD and care recipients' PWD demographics, aging female informal caregivers of PWD, social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction?

Study Aim 1

Describe select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample. To address study aim #1, descriptive statistics including frequencies, percentages, means and standard deviations (SD) were utilized.

Caregiver Sociodemographic and Characteristic Findings

Aging Female Caregivers of PWD Characteristics

Aging female informal caregivers of PWD sociodemographic revealed that the mean age of the caregiver was 65.0 (SD = 8.0) years, 69% were currently married, 57% primarily white race, 71% listed English as their primary language. In all, they had mean 16.23 (SD = 2.94) years of schooling, 31% had a total household income $100,000 to $149,999, 49% were employed full-time outside the home, 91% were able to live independently, and 6% required some assistance with basic activities (see Table 20).

Table 20

Aging Female Informal Caregivers of PWD Characteristics and Level of Independence Challenges (N=35)

Variables	*Mean (SD)* or N (%)
Age (range 56-84 years)	65.0 (8.43)
Marital Status	
Currently Married	24 (68.6%)
Widowed	2 (5.7%)
Divorced	4 (11.4%)
Never Married	3 (8.6%)
Living as Married	1 (2.9%)
Other	1 (2.9%)
Primary Language	
English	25 (71.4%)
Spanish	8 (22.9)
Mandarin	1 (2.9%)
Other	1 (2.9%)
Primary Race	
White	20 (57.1%)
Hispanic/Latino	8 (22.9%)
Asian (includes Vietnamese)	4 (11.4%)
Black or African American	3 (8.6%)
Hispanic or Latino ethnicity	

Yes	8 (22.9%)
No	27 (77.1%)
If yes, Hispanic/Latino ethnicity	
South American	4 (44.4%)
Puerto Rican	2 (22.2%)
Central American	2 (22.2%)
Other	1 (11.1%)
Years of Schooling	16.23 (2.94)
Total Household Income	
< $25,000	4 (11.4%)
$25,000 to $34,999	2 (5.7%)
$35,000 to $49,999	4 (11.4%)
$50,000 to $74,999	3 (8.6%)
$75,000 to $99,999	5 (14.3%)
$100,000 to $149,999	11 (31.4%)
$150,000 or >	6 (17.1%)
Occupational Status	
Full-time outside the home	17 (48.6%)
Full-time in the home	4 (11.4%)
Part-time outside the home	5 (14.3%)
Part-time in the home	1 (2.9%)
Retired	8 (22.8%)
Level of Independence	
Able to live independently	32 (91.4%)
Requires some assistance with basic activities	2 (5.7%)
Requires some assistance with complex activities	1 (2.9%)

Aging Female Informal Caregivers of PWD Residence and Living Situation

Aging female informal caregivers of PWD resided permanently in the area and temporarily in the area, but whose primary residence was elsewhere in United States (see Table 21). As for aging female informal caregivers of PWD living situation, 94% lived in a single-family residence (house/apt/condo), 69% lived with a spouse or partner, and 57% lived in an urban area (see Table 22).

Table 21

Aging Female Informal Caregivers of Persons with Dementia Primary Residence (N = 35)

Zip Code (first 3 digits)	N (%)
117 [New York]	1 (2.9%)
275 [North Carolina]	1 (2.9%)
864 [Arizona]	2 (5.7%)
913 [Thousand Oaks, Ventura County]	1 (2.9%)
917 [Rancho Cucamonga, San Bernardino County]	2 (5.7%)
920 [San Diego, San Diego County]	1 (2.9%)
922 [Indio, Riverside County]	3 (8.6%)
923 [San Bernardino, San Bernardino County]	18 (51.4%)
925 [Riverside, Riverside County]	2 (5.7%)
945 [Oakland, Alameda County]	1 (2.9%)
970 [Portland OR]	1 (2.9%)
971 [Portland OR]	1 (2.9%)
992 [Spokane WA]	1 (2.9%)

Table 22

Aging Female Informal Caregivers of Persons with Dementia Residence and Living Situation (N=35)

Variables	N (%)
Type of Residence	
Single family residence (house/apt/condo)	33 (94.2%)
Retirement community	1 (2.9%)
Assisted living/boarding home/adult family home	1 (2.9%)
Living Situation	
Lives alone	1 (2.9%)
Lives with spouse or partner	24 (68.6%)
Lives with relative or friend	9 (25.7%)
Lives with group	1 (2.9%)
Lives in Rural or Urban Area	
Rural	15 (42.9%)
Urban	20 (57.1%)

Aging Female Informal Caregivers of PWD Support and Challenges

With regards to aging female informal caregivers of PWD support and challenges, 69 % were without mobility challenges. Regarding support, they had mean 3.31 (SD = 2.94) family members/others on whom they could call on for help, of those persons on whom they were able to rely on most for help 60% were located nearby in Inland Empire, additional help from others (family/friends) was mean 8.91 (SD = 12.95) hours per week, they were able to discuss private matters with mean 3.34 (SD = 2.61) persons, 46% had family/others (including care recipient with dementia) relied on the caregiver for help, and they had mean 2.20 (SD = 1.94) memberships in community/church/volunteer organizations. The caregiver provided care to the person with dementia for mean 6.77 (SD = 5.40) years, 94% had never received home professional respite care, 77% had never been asked about their caregiving needs when attending medical appointment with person with dementia, 69% had never been offered information on community resources and how to access those resources, 91% had never participated in dementia support group, and 91% had never participated in dementia caregiver skills training (see Table 23).

Table 23

Aging Female Informal Caregivers of Persons with Dementia Support and Challenges (N=35)

Variables	Mean (SD) or N (%)
Has Mobility Challenges	
Yes	11 (31.4%)
No	24 (68.5%)
Number Family Members/Others with Whom Can Call on for Help	3.31 (2.94)
Of those persons above on Whom Most Rely on for Help were Located nearby in Inland Empire	
Yes	21 (60.0%)
No	14 (40.0%)
Additional Help from Others (Family/Friends) Hours per Week	8.91 (12.95)

Number of People with Whom Can Discuss Private Matters	3.34 (2.61)
Number of Family/Others Who Rely on You (Caregiver) for Help (including care recipient with dementia)	
1	16 (45.7%)
2	10 (28.6%)
3	4 (11.4%)
4	2 (5.7%)
5	1 (2.9%
9	1 (2.9%)
12	1 (2.9%)
Number of Memberships in Community/Church/ Volunteer Organizations	2.20 (1.94)
Number of Years as Caregiver of Person with Dementia	6.77 (5.40)
Has Home Professional Respite Care	
Yes	2 (5.7%)
No	33 (94.3%)
When Attending Medical Appointment with Person with Dementia, Care Provider Asks About Caregiving Needs	
Yes	8 (22.9%)
No	27 (77.1%)
Has Been Offered Information on Community Resources and How to Access those Resources	
Yes	11 (31.4%)
No	24 (68.6%)
Participates in Dementia Support Group	
Yes	3 (8.6%)
No	32 (91.4%)
Has Been Offered Dementia Caregiver Skills Training	
Yes	4 (11.4%)
No	31 (88.6%)
Has Participated in Dementia Caregiver Skills Training	
Yes	3 (8.6%)
No	32 (91.4%)

Care Recipients' Sociodemographic and Characteristic Findings

Care Recipients' PWD Sociodemographic and Characteristics

Care recipients PWD sociodemographic and characteristics revealed that a total of 35 care recipient males (*N*=19) and females (*N*=16) were in the study. The average age of the care recipient was mean 79.74 (SD = 10.98) years, 54% were male, 54% were currently married, 66% listed English as the primary language, and 53% identified primarily as white. In all, they had mean 13.31 (SD = 5.01) years of schooling, and 57% had a total household income < $25,000 (see Table 24).

Table 24

Care Recipients' Person with Dementia Sociodemographic and Characteristics (N = 35)

Variables	Mean (SD) or N (%)
Age	79.74 (10.98)
Range 51-96 years	80.0 (11.0)
Gender	
Male	19 (54.3%)
Female	16 (45.7%)
Marital Status	
Currently Married	19 (54.3%)
Widowed	11 (31.4%)
Divorced	1 (2.9%)
Never Married	3 (8.6%)
Living as Married	1 (2.9%)
Primary Language	
English	23 (65.7%)
Spanish	7 (20%)
Mandarin	1 (2.9%)
Other	4 (11.4%)
Primary race or ethnicity	
White	18 (52.9%)
Black or African American	3 (8.8%)
American Indian/Alaska Native	1 (2.9%)
Asian (includes Vietnamese)	5 (14.7%)
Hispanic/Latino	6 (17.6%)
Other	1 (2.9%)
Hispanic or Latino ethnicity	
Yes	7 (20%)
No	28 (80%)
If yes, Hispanic/Latino ethnicity	
Puerto Rican	2 (28.6%)
Central American	1 (14.3%)
South American	3 (42.9%)
Columbian	1 (14.3%)
Years of Schooling	13.31 (5.01)

Total Household Income	
< $25,000	20 (57.1%)
$25,000 to $34,999	3 (8.6%)
$35,000 to $49,999	4 (11.4%)
$50,000 to $74,999	3 (8.6%)
$75,000 to $99,999	3 (8.6%)
$100,000 to $149,999	1 (2.9%)
$150,000 or >	1 (2.9%)

Care Recipients' PWD Residence and Living Situation

Care recipients' PWD receiving care from aging female informal caregivers of PWD were included who resided permanently in the area and temporarily in the area, but whose primary residence was elsewhere in United States (see Table 25). As for care recipient PWD residence and living situation, 94% lived in a single-family residence (house/apt/condo), 63% lived with a spouse or partner, 34% required some assistance with complex activities and 34% were completely dependent (see Table 26).

Table 25

Care Recipients' Person with Dementia Primary Residence (N = 35)

Zip Code (first 3 digits)	N (%)
117 [New York]	1 (2.9%)
275 [North Carolina]	1 (2.9%)
853 [Glendale, Arizona]	1 (2.9%)
864 [Kingman, Arizona]	2 (5.7%)
913 [Thousand Oaks, Ventura County]	1 (2.9%)
917 [Rancho Cucamonga, San Bernardino County]	1 (2.9%)
920 [San Diego, San Diego County]	2 (5.7%)
922 [Indio, Riverside County]	3 (8.6%)
923 [San Bernardino, San Bernardino County]	1 (2.9%)
925 [Riverside, Riverside County]	2 (5.7%)

927 [Santa Ana, Orange County]	1 (2.9%)
945 [Oakland, Alameda County]	1 (2.9%)
971 [Portland OR]	1 (2.9%)
992 [Spokane WA]	1 (2.9%)

Table 26

Care Recipients' Person with Dementia Residence and Living Situation (N = 35)

Variables	N (%)
Type of Residence	
Single family residence (house/apt/condo)	33 (94.2%)
Retirement community	2 (5.7%)
Living Situation	
Lives alone	3 (8.6%)
Lives with spouse or partner	22 (62.9%)
Lives with relative or friend	10 (29%)
Level of Independence	
Able to Live Independently	3 (8.6%)
Requires Some Assistance with Complex Activities	12 (34.3%)
Requires some Assistance with Basic Activities	8 (22.9%)
Completely Dependent	12 (34.3%)

Care Recipients' PWD Support and Challenges

With regards to care recipients' PWD support and challenges, 31% were diagnosed with Alzheimer's disease, with onset of dementia mean 7.83 (SD = 6.30) years, 74% were with mobility challenges, had memberships in community/church/ volunteer organizations mean 2.20 (SD = 1.94), and 97% had never participated in a dementia support group (see Table 27).

Table 27

Care Recipients' Person with Dementia Support and Challenges (N = 35)

Variables	Mean (SD) or N (%)
Type of Dementia	
Alzheimer's Disease	11 (31.4%)
Unknown	9 (25.7%)
Vascular Dementia	5 (14.3%)
Parkinson's Disease Dementia	4 (11.4%)
Mixed Dementia	3 (8.6%)
Dementia with Lewy Bodies	2 (5.7%)
Frontotemporal Lobar Degeneration	1 (2.9%)
Onset of Dementia in Years	7.83 (6.30)
Has Mobility Challenges	
Yes	26 (74.3%)
No	9 (25.7%)
Number Memberships in Community/Church/Volunteer Organizations	2.20 (1.94)
Participates in Dementia Support Group	
Yes	1 (2.9%)
No	34 (97.1%)

Caregiver Self-Assessment Questionnaire Findings

Regarding aging female informal caregivers of PWD Caregiver Self-Assessment Questionnaire scores characteristics (prevalence and severity of caregiver stress levels), 86% were with overall high stress. In all, mean 0.74 (SD = 0.44) felt that they couldn't leave their relative alone, mean 0.63 (SD = 0.49) felt completely overwhelmed, mean 0.69 (SD = 0.47) were upset that their relative had changed so much from his/her former self, mean 0.69 (SD = 0.47) felt a loss of privacy and/or personal time, mean 0.66 (SD = 0.48) were edgy or irritable, mean 0.60 (SD = 0.50) were with disturbed sleep because of caring for their relative, mean 0.57 (SD = 0.50) felt strained between work and family responsibilities, and mean 0.57 (SD = 0.50) were with back pain. While mean 0.43 (SD = 0.50) had trouble keeping their mind on what they were doing, mean 0.26 (SD = 0.44) had difficulty making decisions, mean 0.06 (SD = 0.24) did not feel useful or needed, mean 0.37 (SD = 0.49) felt lonely, mean 0.49 SD = (0.51) had crying spells, mean 0.43 (SD = 0.50) felt ill (headaches, stomach problems or common cold), mean 0.40 (SD = 0.50) were not satisfied with the support given by family, and mean 0.49 (SD = 0.51) found their relative's living situation to be inconvenient or a barrier to care (see Table 28).

Table 28

Aging Female Informal Caregiver of Persons with Dementia Self-Assessment Questionnaire Scores Characteristics (N of Items = 18) (N = 35)

Variables	Mean (SD) or N (%)
Had trouble keeping my mind on what I was doing	15 (49.2%)
Felt that I couldn't leave my relative alone	26 (74.3%)
Had difficulty making decisions	9 (29.7%)
Felt completely overwhelmed	22 (62.9%)
Felt useful and needed	33 (94.3%)
Felt lonely	13 (37.1%)
Been upset that my relative has changes so much from his/her former self	24 (68.6%)
Felt a loss of privacy and/or personal time	24 (68.6%)
Been edgy or irritable	23 (65.7%)
Had sleep disturbed because of caring for my relative	21 (60.0%)
Had a crying spell(s)	17 (48.6%)
Felt strained between work and family responsibilities	20 (57.1%)
Had back pain	20 (57.1%)
Felt ill (*headaches, stomach problems or common cold*)	15 (49.2%)
Been satisfied with the support my family has given me	21 (60.0%)
Found my relative's living situation to be inconvenient or a barrier to care	17 (48.6%)
Total Satisfaction Score	8.06 (3.24)
On a scale of 1-10, with 1 being "not stressful" to 10 being "extremely stressful," rate your current level of stress	6.80 (2.35)
On a scale of 1-10, with 1 being "very healthy" to 10 being "very ill," rate your current health compared to what it was this time last year	5.49 (3.07)
Overall Stress Score	
Low	5 (14.3%)
High	30 (85.7%)

Caregiver Medical Challenges and Personal Needs Findings

An open-ended question was included in two instruments. The Caregiver Demographic Profile Questionnaire asked the caregiver to list any medial or personal challenges. The Caregiver Self-Assessment Questionnaire invited comment or feedback. A variety of medical challenges and personal needs emerged (see Table 29).

Table 29

Aging Female Informal Caregivers of Persons with Dementia Reported Medical Challenges and Personal Needs (N = 35)

Medical Challenges	N Reported
Asthma	4
Allergies	1
Chronic Bronchitis	1
Shortness of Breath	1
Coronary Artery Disease	1
Hypertension	4
High resting heart rate and require sleep monitor alert when rate elevates; and spouse frequent angry outbursts cause heart rate to elevate	1
Vertigo	1
Diabetes	1
Hypothyroidism	1
Parathyroidism	1
Depression	7
Difficulty getting up from the floor helping fallen spouse	1
Fibromyalgia	3
Systemic Exertional Intolerance Disease (SEID)	1
Chronic Fatigue	3
Difficulty or Disturbed Sleep	20
Migraine Headache	1
Frequent Frustration	6
Frequent Crying	17
Lumbar Fusion	1
Chronic Back Pain	21
Total Knee Replacement	1
Osteoarthritis	6
Rheumatoid Arthritis	1
Gait Unsteady	2
Requires Walker to Ambulate	1
Lower extremity pain and decreased standing endurance	1

Unilateral Upper Extremity loss of function	1
Vertigo	1
Irritable Bowel Syndrome	1
Ulcerative Colitis	1
Increased periods of illness and not feeling well	15

Personal Challenges	N Reported
Unable to Drive	1
Care Recipient Frequent Arguing	2
Recent divorce and many money challenges	1
Stress level increases with holidays	1
Stress from not getting work done	1
Sad over loss of interaction with spouse	1
Lonely from loss of relationship with spouse when seeing other couples together	1
Very difficult being the caregiver to person I love; person I knew is no longer there	1
Life has become so hard	1
Some days my body shuts down and I can’t do any more	1
Difficult to lift, bath and tend to spouse due to my small stature	
Desperately need help but no one available	1
Keep asking doctor for months how to get covered help when spouse was at worse but not informed of possible covered home help until just after spouse passed away	1
Experience with the first doctor was very impersonal and detached. The second doctor was more personal, and the genuine concern was a help as my partner deteriorated	1
When I get sick there is no one to help me or my spouse	1
Have to pay out-of-pocket for a care provider when I need to be away for an appointment or away for a few days	2
No community resources ever offered for my spouse, but I was referred to Braille Institute for my low vision that gave me challenges in caregiving	1
Received training on how to manage spouse stomach tube, but was never offered dementia training of any sort	1
Can’t plan ahead to do anything	1
Occasionally I question why the caregiver responsibility falls on me, but I try to put this out of my head	1
Religion and Christian beliefs had a big impact on my approach and accepting this situation with my spouse with positiveness	1
Some of restrictions place a burden on me, but having others that can assist me makes it bearable	1

Caregiver Flourishing Scale Findings

Aging Female Informal Caregivers of PWD Flourishing Scale with Subcategories

Regarding aging female informal caregivers of PWD Flourishing Scale scores with subcategories (prevalence and severity of sense of flourishing) and overall Flourishing Scale scores, mean 49.97 (SD = 6.12) were with an overall sense of flourishing. In all, mean 6.60 (SD = 0.60) felt they lead a purposeful and meaningful life, mean 6.57 (SD = 0.61) felt they actively contributed to the happiness and well-being of others, mean 6.51 (SD = 0.74) felt they were competent and capable in the activities that were important to them, mean 6.46 (0.95) felt they were a good person and lived a good life, and mean 6.29 (0.93) felt they were respected by people. While mean 5.83 (SD = 1.60) felt their social relationships were supportive and rewarding, mean 5.97 (SD = 1.64) were engaged in their daily activities, and mean 5.74 (SD = 1.29) were optimistic about their future (see Table 30 and Table 31).

Table 30

Aging Female Informal Caregivers of Persons with Dementia Flourishing Scale with Subcategories (N of Items = 8) (N = 35)

Variables	N (%)
I lead a purposeful and meaningful life	
Slightly agree	2 (5.7%)
Agree	10 (28.6%)
Strongly agree	23 (65.7%)
My social relationships are supportive and rewarding	
Strongly disagree	1 (2.9%)
Disagree	2 (5.7%)
Neither agree nor disagree	3 (8.6%)
Slightly agree	3 (8.6%)
Agree	10 (28.6%)
Strongly agree	16 (45.7%)
I am engaged and interested in my daily activities	
Strongly disagree	2 (5.7%)

Disagree	1 (2.9%)
Neither agree nor disagree	1 (2.9%)
Slightly agree	3 (8.6%)
Agree	10 (28.6%)
Strongly agree	18 (51.4%)
I actively contribute to the happiness and well-being of others	
Slightly agree	2 (5.7%)
Agree	11 (31.4%)
Strongly agree	22 (62.9%)
I am competent and capable in the activities that are important to me	
Neither agree nor disagree	1 (2.9%)
Slightly agree	2 (5.7%)
Agree	10 (28.6%)
Strongly agree	22 (62.9%)
I am a good person and live a good life	
Disagree	1 (2.9%)
Slightly agree	1 (2.9%)
Agree	12 (34.3%)
Strongly agree	21 (60.0%)
I am optimistic about my future	
Disagree	1 (2.9%)
Slightly disagree	2 (5.7%)
Neither agree nor disagree	2 (5.7%)
Slightly agree	6 (17.1%)
Agree	13 (37.1%)
Strongly agree	11 (31.4%)
People respect me	
Slightly disagree	1 (2.9%)
Neither agree nor disagree	1 (2.9%)
Slightly agree	2 (5.7%)
Agree	14 (40.0%)
Strongly agree	17 (48.5%)

Note: Chronbach's Alpha = 0.840

Table 31

Aging Female Informal Caregivers of Persons with Dementia Overall Flourishing Scale Scores (N of Items = 8) (N = 35)

Variables	Mean (SD)
I lead a purposeful and meaningful life	6.60 (0.60)
My social relationships are supportive and rewarding	5.83 (1.60)
I am engaged and interested in my daily activities	5.97 (1.64)
I actively contribute to the happiness and well-being of others	6.57 (0.61)

I am competent and capable in the activities that are important to me	6.51 (0.74)
I am a good person and live a good life	6.46 (0.95)
I am optimistic about my future	5.74 (1.29)
People respect me	6.29 (0.93)
Flourishing Score Sum	49.97 (6.12)

Note: Chronbach's Alpha = 0.840

Caregiver Scale of Positive and Negative Experience Findings

Regarding aging female informal caregivers of PWD Scale of Positive and Negative Experience scores (prevalence and severity of positive and negative experience), positive experiences, less than half often felt positive (49%), good (48%), happy (43%), joyful (40%), and contented (37%). As for caregiver negative experiences, more than half sometimes felt negative (60%), and sad (57%); while less than half sometimes felt bad (42%), unpleasant (46%), angry (23%), and less than half very rarely or never felt afraid (37%). Regarding overall affect mean 6.37 (SD = 10.15) (see Table 32).

Table 32

Aging Female Informal Caregivers of Persons with Dementia Scale of Positive and Negative Experience Scores (N of Items = 12) (N = 35)

Variables	Mean (SD) or N (%)
Q1 Positive	3.80 (0.99)
Q3 Good	3.89 (0.83)
Q5 Pleasant	3.91 (0.89)
Q7 Happy	3.83 (0.98)
Q10 Joyful	3.74 (1.07)
Q12 Contented	3.71 (0.96)
Calculated Positive Feelings Score	22.89 (4.83)
Q2 Negative_Reversed	3.03 (1.01)
Q4 Bad_Reversed	3.31 (1.13)
Q6 Unpleasant_Reversed	3.37 (1.14)
Q8 Sad_Reversed	3.09 (1.07)
Q9 Afraid_Reversed	3.54 (1.38)
Q11 Angry_Reversed	3.14 (1.19)
Calculated Negative Feelings Score	16.51 (5.85)
SPANE Score Average	3.53 (0.85)
Calculated Overall Affect Balance Score	6.37 (10.15)

Affect Balance	
Unhappiest - always unhappy (- 24)	0 (0.0%)
Very often unhappy (-23 to - 16)	0 (0.0%)
Often unhappy (- 15 to -6)	5 (14.3%)
Sometimes happy (-5 to 4)	9 (25.7%)
Often happy (6 to 14)	12 (34.3%)
Very often happy (15 to 23)	9 (25.7%)
Highest - always happy/never experiences negative feelings (24)	0 (0.0%)

Note: Chronbach's Alpha = 0.947

Caregiver Satisfaction with Life Scale Findings

Regarding aging female informal caregivers of PWD Satisfaction with Life Scale scores (prevalence and severity of life satisfaction), mean 25.09 (SD = 7.47) were with an overall satisfaction with life score. Less than half agreed that their life was in most ways close to their ideal (34%), agreed that the conditions of their life were excellent (29%) while others slightly agreed (29%), agreed that they were satisfied with their life (37%), agreed that so far they have gotten the important things they wanted in life (45%), and if they could live their life over, they would change almost nothing (26%) (see Table 33).

Table 33

Aging Female Informal Caregivers of Persons with Dementia Satisfaction with Life Satisfaction Scores (N of Items = 5) (N = 35)

Variables	Mean (SD) or N (%)
In most ways my life is close to my ideal	4.83 (1.77)
The conditions of my life are excellent	4.66 (1.85)
I am satisfied with my life	5.23 (2.02)
So far, I have gotten the important things I want in life	5.57 (1.44)
If I could live my life over, I would change almost nothing	4.80 (1.88)
Calculated Satisfaction with Life Score	25.09 (7.47)
Satisfaction Score Sum CAT	
Extremely dissatisfied (5 - 9)	1 (2.9%)
Dissatisfied (10 - 14)	4 (11.4%)
Slightly dissatisfied (15 - 19)	2 (5.7%)
Neutral (20)	1 (2.9%)
Slightly satisfied (21 - 25)	7 (20.0%)

Satisfied (26 - 30)	11 (31.4%)
Extremely satisfied (31 -35)	9 (25.7%)

Note: Chronbach's Alpha = 0.887

Study Aim 2

Describe the relationship between select aging female informal caregivers of PWD and care recipients' demographic factors, social support factors, positive and negative feelings, flourishing, stress, and life satisfaction in the study sample.

Hypothesis 1

A null hypothesis and alternative hypothesis were proposed.

$H1_0$.

There is no relationship between aging female informal caregivers of PWD and care recipients PWD demographic factors, and aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction in the study population.

$H1_A$.

There is a relationship between aging female informal caregivers of PWD and care recipients PWD demographic factors, and aging female informal caregivers of PWD social support factors, positive and negative feelings, a sense of flourishing, stress, and life satisfaction in the study population.

In order to assess hypothesis 1, a Spearman's rho correlation (see Table 34 and Table 35) was conducted to examine if a relationship exists between variables.

Study Aim 2 Findings

From these findings, it can be concluded that for the aging female informal caregivers of PWD there was a strong positive correlation between life satisfaction and positive feelings (r = 0.65, p = <0.001), affect balance (r = 0.78, p = <0.001), sense of flourishing (r= 0.66. p = <0.001), and strong negative correlation for negative feelings (r = -0,78, p = <0.001), weak negative correlation for aging female informal caregivers of PWD age (r = -0.28, p = <0.105) and number of family/others to help (r = -0.20, p = <0.240). There was a strong positive correlation between positive feelings and affect balance (r = 0.92, p = <0.001) and medium correlation for aging female informal caregivers of PWD sense of flourishing (r = 0.55, p = <0.001). There was a strong negative correlation between negative feelings and affect balance (r = -0.93, p = <0.001), moderate negative correlation for sense of flourishing (r = -0.48, p = <0.003), weak positive correlation for aging female informal caregivers of PWD age (r = 0.20, p = < 0.248), and number of years aging female informal caregivers of PWD (r = 0.27. p = <0.118). There was a strong positive correlation between affect balance and sense of flourishing (r = 0.54, p = <0.001), weak negative correlation for aging female informal caregivers of PWD age (r = -0.14, p = <0.410) and number years as caregiver (r = -0.17, p = < 0.340). There was a weak negative correlation between aging female informal caregivers of PWD age and sense of flourishing (r = -0.35, p = <0.041), age care recipient PWD (r = -0.12, p = < 0.477), and weak positive correlation for number years as caregiver (r = 0.12, p = <0.508). There was a weak negative correlation between aging female informal caregivers of PWD years schooling (r = -0.36, p = < 0.033), weak positive correlation for number family members/others to help (r = 0.15, p = <0.397) and age care recipient PWD (r = 0.12, p = <0.508). There was a weak positive correlation between number family members/others to help and positive feelings (r = 0.16, p = <0.347), informal caregiver years of schooling (r = 0.15, p = <0.397), weak negative correlation for sense of flourishing (r = -0.17, p = <0.319) and age care recipient PWD (r = -0.11, p = <0.522). There was a weak positive correlation between number of years as aging female informal caregiver of PWD (r = 0.13, p = <0.461 and weak negative correlation for age care recipient PWD (r = -0.15, p = <0.403). There was a weak positive correlation between sense of flourishing and care recipient PWD age (r = 0.10, p = < 0.574).

From these findings, it can be concluded that for the aging female informal caregivers of PWD there was a strong positive relationship between life satisfaction and positive feelings (r = 0.65), overall affect balance (r = 0.78), sense of flourishing (r= 0.66), and a strong negative relationship for negative feelings (r = -0,78). For the aging female informal caregiver of PWD, age, years of schooling, number of family members/other to help, number of years as caregiver, and age of the care recipient PWD had a less significant relationship with life satisfaction (see Table 34 and Table 35).

Table 34

Matrix of Correlations (N = 35)

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
(1) Caregiver Age	1.00										
(2) Caregiver Years of Schooling	-0.06	1.00									
(3) Number of Years as Caregiver	0.12	-0.36*	1.00								
(4) Care Recipient Age	-0.12	0.12	-0.15	1.00							
(5) Number Family Members/ Others to Help	0.06	0.15	0.05	-0.11	1.00						

(6) Positive Feelings Score	-0.05	-0.05	-0.04	-0.05	0.016	1.00					
(7) Negative Feelings Score	0.20	-0.06	0.27	0.01	0.02	-0.73**	1.00				
(8) Overall Affect Balance Score	-0.14	0.01	-0.17	-0.02	0.06	0.92**	-0.93**	1.00			
(9) Flourishing Score	-0.35*	-0.10	0.13	0.10	-0.17	0.55**	-0.49**	0.54**	1.00		
(10) Overall Stress Score	-0.19	-0.08	0.19	0.07	-0.07	-0.37*	0.51**	-0.45**	-0.07	1.00	
(11) Life Satisfaction Score	-0.28	0.09	-0.02	0.05	-0.20	0.65**	-0.78**	0.78**	0.66**	-0.19	1.00

Note: ** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the $p < 0.05$ level (2-tailed)

Table 35

Correlations (N = 35)

Dependent Variable	Life Satisfaction Spearman Correlation Coefficient
Positive Feeling	0.65**
Negative Feeling	-0.78**
Overall Affect Balance	0.78**
Sense of Flourishing	0.66**
Age Caregiver	-0.28
Years of Schooling CG	0.09
Number of family members/others to help	-0.20
Number of years as caregiver of person with dementia (PWD)	-0.02
Age care recipient PWD	0.05

Note: ** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the $p < 0.05$ level (2-tailed)

In order to assess hypothesis 1, a Mann Whitney Test and Independent t-test (see Table 36) was conducted to examine if a relationship exists between variables.

From these findings, it can be concluded that for aging female informal caregivers of PWD there was a relationship between select variables and life satisfaction. It was significantly higher for primary race non-white (Median = 30.0) than that of white (Median = 24.5), $p = 0.039 < 0.05$, occupation status full-time/part-time outside the home (Median = 29.0) than that of full-time, part-time in the home and retired (Median = 23.0), p = 0.016 < 0.05, marital status others (28.8 ±3.1) than that of married (23.6 ± 8.2), p = 0.010 < 0.05, and no mobility challenges (28.2 ± 4.8) than that of mobility challenges (18.4 ± 8.1), p = 0.002 < 0.05. There was not a strong relationship between being offered information on community resources and living in a rural or urban area (see Table 36).

Table 36

Relationship Between Select Demographic Variables and Life Satisfaction Score for Aging Female Informal Caregivers of Persons with Dementia (N = 35)

Variables		Median (range) or mean ± SD	P-value
Primary Race	White	24.5 (09.0 - 33.0)	0.039*
	non-White	30.0 (11.0 - 35.0)	
Occupation Status	Full-time / Part-time outside home	29.0 (11.0 - 35.0)	0.016*
	Full-time, Part-time home	23.0 (09.0 - 33.0)	
Marital Status	Married	23.6 ± 8.2	0.010**
	Others	28.8 ±3.1	
Income	Less than $75,000	23.5 ± 8.0	0.354*
	$75,000 or higher	26.0 ± 7.2	
Mobility Challenges	Yes	18.4 ± 8.1	0.002*
	No	28.2 ± 4.8	
Offered Info on community resources	Yes	27.5 ± 6.8	0.209
	No	24.0 ± 7.6	
Do you live in a rural or urban area	Rural	24.0 ± 7.6	0.467
	Urban	25.9 ± 7.4	

Note: * Mann Whitney Test
** Independent *t*-test

The null hypothesis was rejected, and the alternative hypothesis was accepted. In other words, there is a relationship between select aging female informal caregivers of PWD and care recipients PWD demographic factors, social support factors, positive and negative feelings, a sense of flourishing, stress, and informal caregiving in the study population.

Study Aim 3

Determine the amount of variance in aging female informal caregivers’ life satisfaction accounted for by select demographics, social support factors, positive and negative feelings, flourishing, and stress.

Hypothesis 2.

A null hypothesis and alternative hypothesis were proposed.

$H2_0$.

There is no amount of variance in aging female informal caregivers of PWD life satisfaction accounted for by select aging female informal caregivers of PWD and care recipients PWD demographics, aging female informal caregivers of PWD social support, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

$H2_A$.

There is an amount of variance in aging female informal caregivers of PWD life satisfaction accounted for by select aging female informal caregivers of PWD and care recipients PWD demographics, aging female informal caregivers of PWD social support, positive and negative feelings, a sense of flourishing, stress, and life satisfaction.

In order to assess hypothesis 2, for the aging female informal caregiver of PWD, a multiple linear regression was conducted with overall affect balance, age of the caregiver, positive feelings, negative feelings, and sense of flourishing predicting current life satisfaction. Multiple linear regression was used to examine how much of a variance in the current life satisfaction could be explained by the predictor variables: overall affect balance, age of the caregiver, positive feelings, negative feelings, and sense of flourishing. Note that separate models were constructed using fewer independent variables due to the study's small sample size.

Study Aim 3 Findings

From these findings**,** it can be concluded that the results of the regression were significant for aging female informal caregivers of PWD. In Model #1, the independent variable positive feelings accounted for 49% of the variance of life satisfaction (see Table 37). In Model #2, the independent variable negative feelings accounted for 62% of the variance of life satisfaction (see Table 38). In Model #3, the independent variable of overall affect balance accounted for 62% of the variance of life satisfaction (see Table 39). And finally, in Model #4, the independent variable sense of flourishing accounted for 47% of the variance of life satisfaction (see Table 40). The age of aging female informal caregivers of PWD did not account for variance of life satisfaction in any of the four models.

Table 37

Model #1 Multiple Linear Regression with Positive Feelings and Age of Aging Female Informal Caregivers of Persons with Dementia (N= 35)

Independent Variables	Coefficients		95.0% Confidence Interval		P-value	Partial R-square
	B	Std. Error	Lower Bound	Upper Bound		
Positive Feelings	1.081	0.189	0.696	1.466	<0.001	0.49
Age Caregiver	-0.135	0.108	-0.356	0.086	0.222	0.02

Note: Dependent Variable Life Satisfaction
Adj. R-squared = 0.484

Table 38

Model #2 Multiple Linear Regression with Negative Feelings and Age of Aging Female Informal Caregivers of Persons with Dementia (N= 35)

Independent Variables	Coefficients		95.0% Confidence Interval		P-value	Partial R-square
	B	Std. Error	Lower Bound	Upper Bound		
Negative Feelings	-1.021	0.134	-1.294	-0.748	<0.001	0.62
Age Caregiver	-0.049	0.093	-0.239	0.140	0.601	0.00

Note: Dependent Variable Life Satisfaction
Adj. R-squared = 0.637

Table 39

Model #3 Multiple Linear Regression with Overall Affect Balance and Age of Aging Female Informal Caregivers of Persons with Dementia (N= 35)

Independent Variables	Coefficients		95.0% Confidence Interval		P-value	Partial R-square
	B	Std. Error	Lower Bound	Upper Bound		
Overall Affect Balance	0.583	0.077	0.426	0.741	<0.001	0.62
Age Caregiver	-0.082	0.093	-0.271	0.107	0.383	0.01

Note: Dependent Variable Life Satisfaction
Adj. R-squared = 0.663

Table 40

Model #4 Multiple Linear Regression with Sense of Flourishing and Age of Aging Female Informal Caregivers of Persons with Dementia (N= 35)

Independent Variables	Coefficients		95.0% Confidence Interval		P-value	Partial R-square
	B	Std. Error	Lower Bound	Upper Bound		
Sense of Flourishing	0.875	0.158	0.553	1.197	<0.001	0.47
Age Caregiver	0.013	0.115	-0.221	0.246	0.913	0.00

Note: Dependent Variable Life Satisfaction
Adj. R-squared = 0.478

The null hypothesis was rejected, and the alternative hypothesis was accepted. In other words, there is an amount of variance in aging female informal caregivers of PWD life satisfaction accounted for by positive and negative feelings, overall affect balance, and a sense of flourishing.

Summary

In summary, aging female informal caregivers of PWD sociodemographic revealed that the mean age of the caregiver was 65 years, slightly over two-thirds were currently married, slightly over half primarily white race, and nearly three-quarters English language. In all, they had approximately 16 years of schooling, slightly less than one-third had a total household income $100,000 to $149,999, nearly half were employed full-time outside the home, majority were able to live independently, and very few required some assistance with basic activities. They resided permanently in the area and temporarily in the area, but whose primary residence was elsewhere in United States. As living situation, majority lived in a single-family residence (house/apt/condo), slightly above two-thirds lived with a spouse or partner, and slightly over half lived in an urban area.

With regards to aging female informal caregivers of PWD support and challenges, slightly above two-thirds were without mobility challenges. Regarding support, they had on average 3 family members/others on whom they could call on for help, of those persons on whom they were able to rely on most for help nearly two-thirds were located nearby in Inland Empire, additional help from others (family/friends) was on average nine hours per week, they were able to discuss private matters with on average three persons, nearly half family/others (including care recipient with dementia) relied on the caregiver for help, and they had on average two memberships in community/ church/ volunteer organizations. The caregiver provided care to the person with dementia for approximately seven years, majority had never received home professional respite care, slightly over three-quarters had never been asked about their caregiving needs when attending medical appointment with person with dementia, slightly over two-thirds had never been offered information on community resources and how to access those resources, majority had never participated in dementia support group, and majority had never participated in dementia caregiver skills training

In aging female informal caregivers of PWD, over half of the participants scored satisfied or higher in life satisfaction. Due to the study's small sample size, four models were tested using only two independent variables at a time to determine the variance in the dependent variable for each model, life satisfaction. The independent variables accounting for the variance in life satisfaction within each of the four models were affect balance (62%), positive feelings (49%), sense of flourishing (47%), and negative feelings (62%); ($p < 0.001$).

Chapter Five

DISCUSSION

This chapter presents study findings as related to other published results. It also with present a discussion on opportunities to maintain or elevate life satisfaction.

Factors Related to Life Satisfaction

The current study demonstrates factors related to life satisfaction among aging female informal caregivers of persons with dementia (PWD). The independent variables positive and negative feelings, overall affect balance, and sense of flourishing accounted for variance of life satisfaction. Specifically, relationships demonstrate that as positive feelings, overall affect balance and sense of flourishing increase, life satisfaction increases; and that as negative feelings increase, current life satisfaction decreases. Several other studies support the current study's conclusions that positive and negative feelings, overall affect balance, and sense of flourishing are associated with life satisfaction. For example, Bastian et al. (2014) found that aging female informal caregivers of PWD positive and negatives feeling are intimately associated with life satisfaction. In addition, experiencing pleasure and engagement is a predictor of positive affect and a high sense of flourishing (Edwall & Yngve, 2015). Mayo et al. (2020) reported that informal caregivers of PWD experienced positive feelings associated with daily life; this was often associated with knowledge that they were assisting the care recipient PWD and accomplishing new tasks.

Aging Female Informal Caregivers of Persons with Dementia Socialization

In the current study, slightly over two-thirds of aging female informal caregivers of PWD were currently married, nearly half were employed full-time outside the home, some had family members or others on whom they could call on for help, memberships in community/ church/ volunteer organizations, and persons with whom they could discuss private matters, and nearly half had social relationships that were supportive and rewarding. These factors contributed in varying degrees to their life satisfaction. It has been demonstrated in other studies that persons with higher life satisfaction often have more positive social interactions, reap the benefits of more social support, and enjoy greater marital contentment compared to those with lesser life satisfaction (Diener & Seligman, 2002; Pavot & Diener, 2008). Life satisfaction increased when informal caregivers engaged in desired positive activities and socialization (Lyubomirsky & Layous, 2013). Socializing is associated with increased in life satisfaction for informal caregivers of persons with Duchene-Becker muscular dystrophy (Kenneson & Bobo, 2010) and informal caregivers of PWD (Kaufmann et al., 2010).

Aging Female Informal Caregivers of Person with Dementia Feelings, Flourishing and Challenges

In the current study, aging female informal caregivers of PWD negative feelings, negative overall affect balance and negative sense of flourishing were associated with lower life satisfaction. In addition, lower life satisfaction was associated with employment challenges, sleep disturbance, health co-morbidities, increasing amounts of time providing care, lack of others to talk to, and lack of social support. This is consistent with the findings of several other studies. Spouse informal caregivers of stroke survivors reported that increasing caregiving tasks were associated with decreasing life satisfaction (Kruithof et al., 2012). Borg & Halberg (2006) reported that informal caregiver lower life satisfaction was associated with lack of employment, sleep disturbance, health co-morbidities, higher amount of time providing care, lack of social resources and inability to speak with other informal caregivers in a similar situation.

Aging Female Informal Caregivers of Persons with Dementia Stress

In the current study, the majority of aging female informal caregivers of PWD had overall high stress that was associated with lower life satisfaction which is similar to results reported in other studies. Female informal caregivers of persons with AIDS report that increasing stress was associated with an alteration in life satisfaction (Darling et al. 2010). Informal caregivers of persons with chronic illness reported that many increasing tasks, lack of support and depressive symptoms was associated with increasing stress (Wakefield et al., 2012). Mayo et al. (2020) discovered that aging informal caregivers of PWD had mild to extreme frustration regarding concerns about the future and were exhausted from the caregiving experience. Informal caregivers of PWD reported high levels of physical and emotional stress (Millenaar, et al., 2015) and high levels of emotional exhaustion along with a modicum of depersonalization and a sense of reduced personal accomplishment (Truzzi, et al., 2012).

Aging Female Informal Caregivers of Persons with Dementia Respite Care

It is known that informal caregivers of PWD experience increased life satisfaction when they receive in-home or institutional respite care or day care services (Goy et al., 2010). However, in the current study, the great majority of aging female informal caregivers of PWD did not receive home respite care, and this contributed to lower life satisfaction; they wished that they had been offered this service. But this finding is consistent with findings of previous research. For example, Mayo et al. (2020) reported that some informal caregivers of PWD were not knowledgeable of palliative care which may have provided them with respite care.

Aging Female Informal Caregivers of Persons with Dementia Depression

In the current study, unmet caregiver needs resulted in high overall stress as reported by 86% of participants and seven participants directly reported depression, this is similar to reports from a number of other studies (Butterworth et al., 2010; Schoenmakers et al., 2010; Chien et al., 2011; Bejjani et al., 2015; Huang et al., 2015). In an open-ended question, aging female informal caregivers of PWD reported medical challenges that contributed to psychological strain, as follows: chronic back pain (N = 21); difficulty or disturbed sleep (N = 20); frequent crying (N = 17) increased periods of illness and not feeling well (N = 15); frequent frustration (N = 6); and osteoarthritis (N = 6), this is in alignment with other studies (Bejjani et al., 2015; Chien et al., 2011; Huang et al., 2015; Shoemaker et al., 2010; Butterworth et al., 2020; Cucciare et al., 2010; Riedel, et al. 2016; Family 2020b; Family 2020d).

The great majority did not participate in a dementia support group; most wished they had been offered an opportunity for individual or group support, which is emphasized in other studies (Smith et al., 2001; Amindazeh et al., 2005; Tallman et al., 2012; Family 2020b; Family 2020d). Informal caregivers desired to participate in some form of counseling (Chien et al., 2011; Wakefield et al., 2012; Tallman et al., 2012; Family 2020b; Family 2020d) and informal caregivers of PWD experienced decreased depression when participating in a combination of individualized counseling and group support (Goy et al., 2010).

Aging Female Informal Caregivers of Persons with Dementia Needs

In the current study, the majority of aging female informal caregivers of PWD were never asked about their caregiver needs when attending a medical appointment with the person with dementia, nor were they offered information on community resources and how to access those resources, and the vast majority were not offered dementia caregiver skills training. Most importantly a lack of such inquiry and offerings was associated with lower life satisfaction. This is consistent with findings of previous studies. A wide range of emotions are experienced by informal caregivers of PWD and clinicians should take advantage of opportunities to discuss with aging female informal caregivers of PWD available services (Mayo et al., 2020). In this study, there was not a strong relationship between being offered versus not being offered information on community resources. Perhaps if the aging female informal of PWD had been referred to appropriate resources and taken full advantage of desired resources, this may have had an impact on higher life satisfaction.

Informal caregivers of persons with advanced illness indicated a desire from the clinician for understandable information about the care recipient’s condition, access to care, ability to make choices, and support across the psychological, social and spiritual realms (Tallman et al., 2012). Informal caregivers of persons with chronic illness wanted more information from the clinician on the care recipient's medication and expressed a need for in-home caregiving assistance. In addition, lower life satisfaction was associated with lack of social support (Wakefield et al., 2012). Mayo et al. (2020) reported that informal caregivers of PWD had worries about dementia symptoms (severity and progression) and that this was concerning when anticipating future care.

Previous studies also reported that higher life satisfaction was linked to overall health and living longer (Dahlrup et al., 2015; Siahpush et al., 2008) and promoted maximum functioning (Diener, 2012). As in the current study, higher levels of life satisfaction have been associated with decreased informal caregiver strain and health risk and greater interaction with family and friends (Baumann & Bucki, 2013; Dahlrup et al., 2015). Informal caregivers of PWD benefited from ongoing telephone contact over a 4-month period that resulted in a better understanding of dementia, increased self-confidence, made life easier, and helped with the caregiving process (Gitlin et al., 2010).

Study Implications for Clinicians

This study makes clinician-based recommendations that will benefit the aging female informal caregiver of PWD and the care recipient PWD. The following are not without worthiness when considering the Centers for Medicare and Medicaid Services (CMS) Quality Payment Program Merit-based Incentive Payment System (MIPS) program. This program uses incentive payments to reward high-value, high-quality Medicare clinicians with payment increases - while at the same time reducing payments to those clinicians who are not meeting performance standards (Centers for Medicare, 2020). The incentive payment percent is reassessed each year. Of many MIPS requirements, one is specific to the PWD and their caregiver who accompanies them to their appointment, detailed as follows:

> To document and report communication and coordination of dementia education and support of caregivers for patients with dementia. The clinician must report the percentage of patients with dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes and were referred to additional resources for support in the last 12 months. In 2020, under the Medicare Access and Children's Health Insurance Program Reauthorization Act of 2015, the clinician is eligible to receive an announced disbursement of up to 9% Alternative Payment Model Incentive Payment (CMS, 2020, item 98 & 99).

First, aging female informal female caregivers of PWD may likely experience an elevation in life satisfaction when the clinician engages with them when they accompany the care recipient PWD to their appointment. This engagement should include providing to them initial and ongoing education on dementia disease management and health behavior changes and making referrals to additional resources. Interaction with the aging female informal caregivers of PWD may be accomplished through telephone assistance or face-to-face clinical practice. Initial and ongoing evaluation and assessment can be obtained during discussion and by administering instruments such as the Satisfaction with Life Scale, Flourishing Scale, Scale of Positive and Negative Experience and the Caregiver Self-Assessment Questionnaire and tracking changes over time. Initial and ongoing assessment of aging female informal caregivers of PWD will allow discussion that informs preventive strategies and the offering of potentially advantageous interventions. In addition, teaching positive approaches to managing daily stressors may be helpful.

Next, clinicians must participate in facilitating development of and referral to local programs. These may include local caregiver support groups. Caregiver support group interventions should be providing caregivers with practical strategies that target higher life satisfaction and happiness. For example, psychology exercises that have demonstrated to have a positive long-term effect on happiness (Mongrain & Anselmo-Matthews, 2012) may contribute to higher life satisfaction for aging female informal caregivers of PWD. Prover et al. (2013) conducted a longitudinal study, with most participants being female, that focused on building character strengths such as how to ask for and express gratitude for help, optimizing hope, and expressing curiosity about resources that might reduce their daily stressors and amplify their happiness and life satisfaction. Prover et al. reported that engaging in purposeful character strength activities were predictive of higher happiness and higher life satisfaction, and lower depression. Group activities that provide tools to build character strengths is one example of how to increase life satisfaction in aging female informal caregivers of PWD. Such caregiver groups should be at the top of the listed of recommended groups.

Moreover, it is critical for clinicians to be familiar with other existing resources and make referrals as appropriate. Additional resources refer to local, county, state, and national offerings, of which there are many. Five resources for consideration are offered here for consideration.

Clinician Resources and Referral Opportunities

Family Caregiver Alliance National Center on Caregiving

The Family Caregiver Alliance National Center on Caregiving through the local Aging and Disability office of Family Caregiver Support Program provides a wide variety of information and suggestions encompassing assistance, care management, individual counseling, support groups, caregiver training, respite care, and limited supplemental services, such as transportation and home modifications (Family Caregiver Alliance, 2020c; Family Caregiver Alliance, 2020d).

National Caregivers Library

The National Caregivers Library (2020) provides a wealth of information of challenges currently faced by caregivers. Topics readily available are categorized, as follows: caregiving basics; caring for yourself; checklists and forms; disabilities; diseases; emotional issues, employer resources; end-of-life issues; faith-based resources; home care housing issues; legal matters; long-distance care; money matters; other research; real estate; state advance directives; transportation popular articles; quick tools; and highlighted topics such as consumer protection, difficult caregiving decisions, elder abuse and many more. In addition, they have a speaker who can be scheduled to attend gatherings and to engage in conversations on how aging and caregiving affects families, businesses, churches, and institutions.

State Alzheimer's Associations

The State Alzheimer's Associations provide information in easily accessible categories. Alzheimer's and dementia education (dementia types, stages, facts and figures, how it is diagnosed, ten signs of approaching memory loss, research and progress, and treatments). Help and support (community resource finder, brain health, caregiving, and community). They also have a feature for chapter location, news, and a list of Alzheimer's events (Alzheimer's Association, 2020). The State of California Senior Gateway also offers information & resources (State of California, 2020).

California Department of Aging

The California Department of Aging addresses many issues on Alzheimer's and dementia/ including topics such as family caregiver services, food and nutrition, health promotion, information, assistance and referral, nutrition and exercise, and senior employment training. In addition, they provide Medicare counseling, health insurance counseling, and have an advocacy program to assist in understanding rights and care options (California Department of Aging, 2020).

San Bernardino County of Aging and Adult Services

The San Bernardino County of Aging and Adult Services provides information on an elderly nutrition program, early service grocery hours, and other nutrition services. In addition, they have an age wise program offering information on behavioral health services and counseling resources. They educate on family caregiver support, in-home support services, senior employment programs, and provide information on emergency disaster preparedness, scam, and fraud alerts. They maintain a list of senior centers, senior community services, and cooling centers to provide relief when the temperatures soar (San Bernardino County, 2020)**.**

Implications for Future Research

Three study implications for future research are recommended. Replicate this study in the aging male informal caregivers of PWD population to understand their life satisfaction. Conduct a retrospective chart review to examine clinician and nurse documentation recorded during care recipient PWD appointments to determine if the needs of aging female informal caregivers of PWD are assessed and if appropriate referral is initiated. Conduct a pretest-posttest study to examine aging male and female caregivers of PWD life satisfaction assessment at baseline before appropriate referral is offered; once the desired referral service is accepted and utilized for a period of time, measure life satisfaction again.

Study Limitations

Four limitations restrict the generalizability of the current study findings. These include the study sample size, number of variables, sampling, and recruitment approach. Methodologically, this was a pilot study that resulted in a small sample of 35 participants. Initially, sample size calculation was completed using the criteria required for 31 study variables; one dependent and 30 independent variables; therefore, a minimal sample size of 190 participants would have been desirable. Due to the study timeline a smaller number of participants were recruited. Replicating this study in male informal caregivers would allow for diversity across both genders and greater generalizabilty.

Strength of Study

Of the female participants, 20 were Caucasian, eight Hispanic/ Latino, four Asian and three Black or African American which was a diverse sample for a small sample size. Dementia is a public health crisis in the US and around the world and the work of caregivers is very important, so consideration of diversity is important for research. An additional strength of this study was that it examined this topic from a unique angle, incorporating positive aspects of caregiving, not just focusing on the negative aspects, as so many studies do.

Future Research

Future research suggestions include conducting an interventional study, replicating the study in male informal caregivers, and determining the degree of compliance with the Centers for Medicare and Medicaid Services (CMS) Quality Payment Program Merit-based Incentive Payment System (MIPS) program. First, implementing an interventional study designed to improve life satisfaction could incorporate a mixed methods design documenting initial assessment of aging caregiver needs via discussion and instrument administration, making appropriate resource referrals based on that assessment (intervention), and finally measuring the degree the intervention altered life satisfaction. Second, replicating the study in aging male informal caregivers in order to understand their life satisfaction would be an important next step. And, finally conducting a retrospective chart review of care recipients' to collect data on aging informal caregivers to determine if clinicians/nurses are documenting encounters with caregivers at the time of the appointment for the care recipient and making appropriate referrals would help in our understanding of the effect of Centers for Medicare and Medicaid Services (CMS) Quality Payment Program Merit-based Incentive Payment System (MIPS) program.

Summary

In summary, more positive feelings, fewer negative feelings, a more positive affect balance, and higher flourishing contributed to overall better life satisfaction for aging female informal caregivers of PWD. This finding is substantiated by other reported studies. Aging female informal caregivers of PWD face many challenges in their daily lived experience. Aging female informal caregivers of PWD have needs that are often not voiced and are therefore not met. Or when they are brought to the forefront and expressed, the aging female informal caregiver of PWD is confounded with how to get those needs met and does not know who to turn to seek assistance. All clinicians must conduct initial and ongoing assessment of caregiver needs. Clinicians must take the opportunity at every care recipient encounter to inquire of the needs of the caregiver so that strategies can be recommended to maintain or elevate life satisfaction. For example, it is essential for clinicians to be aware of available resources and make referrals as appropriate in order to maintain or elevate the life satisfaction of aging female informal caregivers of PWD.

Conclusion

In conclusion, the current study suggests that for aging female informal caregivers of PWD positive and negative feelings, overall affect balance and a sense of flourishing influenced life satisfaction. Initial and ongoing assessment of life satisfaction for aging female informal caregivers of PWD is important. Furthermore, interventions aimed at increasing life satisfaction for aging female informal caregivers of PWD are crucial for those who are at-risk as a result of their caregiving experience.

As a society, everyone, particularly nurses have an obligation to provide support and a variety of easily accessible strategies to aging female informal caregivers of PWD who carry the burden of providing long-term care to persons with dementia, in an attempt to maintain or increase their sense of life satisfaction. Older adults will continue to live longer lives. Persons with dementia are living to older age. Caring for these PWD places the aging female informal caregiver of PWD at-risk for a low level of life satisfaction. The need for consistent and readily available support and interventions are necessary in order to bolster life satisfaction. Moreover, it is essential that health care professionals take the opportunity to inquire of the needs of aging female informal caregivers of PWD at every care recipient PWD medical appointment and clinical encounter.

Appendix A

Recruitment Flyer

Participants are needed in a Research Study:

Life Satisfaction: Aging Female Informal Caregivers of Persons with Dementia

I am seeking aging female family caregivers over the age of 56 years who are providing care in the home environment to a spouse, partner or other family member who has Alzheimer's disease or a related dementia. I am a nursing doctoral student at the University of San Diego conducting a study to look at how aging female family caregivers experience life satisfaction. Participation involves filling out 5 questionnaires that will take about an hour. Your interest and desire to participate in this study is greatly appreciated. Please contact Deborah Monson

Appendix B

Demographic Profile Questionnaire
Caregiver

Code number_________

Instructions: I will read the instructions to you and write down your responses. You can decline to answer any question and that all information provided will be kept secure and remain anonymous.

1. Age __ __ __

2. Gender 1. M 2. F

3. Hispanic or Latino ethnicity 1.Yes 0. No 99. Unknown

4. If yes, reported ethnicity

   1. Mexican/Chicano/Mexican-American 2. Puerto Rican 3. Cuban

   4. Dominican 5. Central American 6. South American

   50. Other *(specify)* ____________________ 99. Unknown

5. Primary race or ethnicity

   1. White 2. Black or African American 3. American Indian/Alaska Native

   4. Native Hawaiian or other Pacific Islander 5. Asian (includes Vietnamese)

   6. Hispanic/Latino 50. Other *(specify)* _______________________

   99. Unknown

6. Additional race or ethnicity reported

   1. White 2. Black or African American 3. American Indian/Alaska Native

   4. Native Hawaiian or other Pacific Islander 5. Asian (includes Vietnamese)

   6. Hispanic/Latino 50. Other *(specify)* _______________________

   88. None reported 99. Unknown

7. Primary language

1. English	2. Spanish	3. Mandarin
4. Cantonese	5. Japanese	6. Russian
7. Vietnamese	8. Other	99. Unknown
10. Other ____________________		

8. How many years of schooling have you received? __ __ (enter exact number of years)

    Key for higher categories:
    High school (GED)= 12 years
    Bachelors = 16 years
    Masters = 18 years
    Doctorate = 20 years
    Unknown = 99

9. What was your total household income before taxes during the past 12 months?
    1. Less than $25,000
    2. $25,000 to $34,999
    3. $35,000 to $49,999
    4. $50,000 to $74,999
    5. $75,000 to $99,999
    6. $100,000 to $149,999
    7. $150,000 or more

10. Do you live in a rural (low population density) or urban (high population density) area?
    1. Rural
    2. Urban

11. Living situation

    1. Lives alone
    2. Lives with spouse or partner
    3. Lives with relative or friend
    4. Lives with group
    5. Other *(specify, for example, independent living/assisted living):* ___________________

    99. Unknown

12. Level of independence

    1. Able to live independently
    2. Requires some assistance with complex activities
    3. Requires some assistance with basic activities
    4. Completely dependent

    99. Unknown

13. Type of residence

    1. Single family residence *(house/apt/condo)*
    2. Retirement community
    3. Assisted living/boarding home/adult family home
    4. Skilled nursing facility/nursing home
    5. Other *(specify):* __________________________ 99. Unknown

14. Primary residence zip code *(first 3 digits)* ___ ___ ___

15. Marital status

    1. Currently married

2. Widowed
3. Divorced
4. Separated
5. Never married
6. Living as married
7. Other *(specify)* ________________________
99. Unknown

16. Occupational status

1. Full-time outside the home
2. Full time in the home
3. Part-time outside the home
4. Part-time in the home
5. Retired
99. Unknown

17. Do you have mobility challenges?

1.Yes 0.No

18. List any personal medical challenges that you feel comfortable sharing:
____
____
____
____

19. Number of family members/others with whom you can call on for help _ _

20. Is the person upon whom you most rely located in the Inland Empire (San Bernardino County or Riverside County)?

1.Yes 0. No 99. Unknown

21. Do you have additional help from others (family, friends, or neighbors). How many hours each week? _ _
22. Number of family members/others with whom can discuss private matters (a confidant) _ _
23. Number of family members/others who *rely on you* for help (including the care recipient with dementia) _ _
24. Number of memberships you have in community/church/volunteer organizations _ _
25. How many years have you been a caregiver of a person with dementia? _ _
26. Do you have in the home professional respite care?

    1.Yes 0.No

27. When you attend the medical appointment with the person with dementia, does the provider ask you about caregiving needs?

    1.Yes 0.No

28. Have you been offered information on community resources and how and when to access those resources?

    1.Yes 0.No

29. Do you participate in a dementia support group?

    1.Yes 0.No

30. Have you been offered dementia caregiver skills training?

    1.Yes 0.No

31. Have you participated in dementia caregiver skills training?

    1.Yes 0.No

Appendix C

Demographic Profile Questionnaire
Care Recipient

Code number_________

Instructions: This questionnaire is read to the caregiver. “I will read the instructions to you and write down your responses. You can decline to answer any question and that all information provided will be kept secure and remain anonymous.”

1. Age __ __ __

2. Gender 1. M 2. F

3. Hispanic or Latino ethnicity 1.Yes 0. No 99. Unknown

4. If yes, reported ethnicity

    1. Mexican/Chicano/Mexican-American 2. Puerto Rican 3. Cuban

    4. Dominican 5. Central American 6. South American

    50. Other *(specify)* ____________________ 99. Unknown

5. Primary race or ethnicity

    1. White 2. Black or African American 3. American Indian/Alaska Native

    4. Native Hawaiian or other Pacific Islander 5. Asian (includes Vietnamese)

    6. Hispanic/Latino 50. Other *(specify)* _______________________

    99. Unknown

6. Additional race or ethnicity reported

    1. White 2. Black or African American 3. American Indian/Alaska Native

    4. Native Hawaiian or other Pacific Islander 5. Asian (includes Vietnamese)

    6. Hispanic/Latino 50. Other *(specify)* _______________________

    88. None reported 99. Unknown

7. Primary language

    1. English
    2. Spanish
    3. Mandarin
    4. Cantonese
    5. Japanese
    6. Russian
    7. Vietnamese
    8. Other
    99. Unknown
    10. Other ____________________

8. How many years of schooling have you received? __ __ (enter exact number of years)

Key for higher categories:
High school (GED)= 12 years
Bachelors = 16 years
Masters = 18 years
Doctorate = 20 years
Unknown = 99

9. What was your total household income before taxes during the past 12 months?

    1. Less than $25,000
    2. $25,000 to $34,999
    3. $35,000 to $49,999
    4. $50,000 to $74,999
    5. $75,000 to $99,999
    6. $100,000 to $149,999
    7. $150,000 or more

10. Living situation

    6. Lives alone
    7. Lives with spouse or partner
    8. Lives with relative or friend

    9. Lives with group
    10. Other *(specify, for example, independent living/assisted living):* _________________
    99. Unknown

11. Level of independence
    5. Able to live independently
    6. Requires some assistance with complex activities
    7. Requires some assistance with basic activities
    8. Completely dependent
    99. Unknown

12. Type of residence
    6. Single family residence *(house/apt/condo)*
    7. Retirement community
    8. Assisted living/boarding home/adult family home
    9. Skilled nursing facility/nursing home
    10. Other *(specify):* _______________________ 99. Unknown

13. Primary residence zip code *(first 3 digits)* ___ ___ ___

14. Marital status
    8. Currently married
    9. Widowed
    10. Divorced
    11. Separated
    12. Never married

13. Living as married

14. Other *(specify)* ________________________

99. Unknown

15. Do you have mobility challenges?

1.Yes 0.No

16. List any personal medical challenges that you feel comfortable sharing:

____

____

____

____

17. Number of memberships you have in community/church/volunteer organizations _ _

18. Do you participate in a dementia support group?

1.Yes 0.No

19. Onset of dementia symptoms began how many years ago? _ _

20. With what type of dementia have you been diagnosed?

1. Alzheimer's disease
2. vascular dementia
3. dementia with Lewy bodies,
4. Parkinson's disease dementia
5. frontotemporal lobar degeneration
6. Creutzfeldt-Jakob Disease
7. mixed dementia
8. Unknown

Appendix D

Caregiver Self-Assessment Questionnaire

How are you?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

1. Had trouble keeping my mind on what I was doing ....☐Yes ☐No
2. Felt that I couldn't leave my relative alone...............................☐Yes ☐No
3. Had difficulty making decisions ....☐Yes ☐No
4. Felt completely overwhelmed.......☐Yes ☐No
5. Felt useful and needed ....☐Yes ☐No
6. Felt lonely ....☐Yes ☐No
7. Been upset that my relative has changed so much from his/her former self...................................☐Yes ☐No
8. Felt a loss of privacy and/or personal time ....☐Yes ☐No
9. Been edgy or irritable ....☐Yes ☐No
10. Had sleep disturbed because of caring for my relative ....☐Yes ☐No
11. Had a crying spell(s) ....☐Yes ☐No
12. Felt strained between work and family responsibilities...........☐Yes ☐No
13. Had back pain ....☐Yes ☐No
14. Felt ill *(headaches, stomach problems or common cold)* ....☐Yes ☐No
15. Been satisfied with the support my family has given me ....☐Yes ☐No
16. Found my relative's living situation to be inconvenient or a barrier to care ....☐Yes ☐No
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _______
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _______

Comments: ____

____

____

Caregiver Self-Assessment Questionnaire Scoring Guidelines

1. Reverse score questions 5 and 15. *(For example, a "No" response should be counted as "Yes"*
   and a "Yes" response should be counted as "No")
2. Total the number of "yes" responses.

To Interpret the Score:

Chances are that the caregiver is experiencing a high degree of distress:

- If the answer is "Yes" to either or both Questions 4 and 11; or

- If the total "Yes" score = 10 or more; or

If the score on Question 17 is 6 or higher; or

- If the score on Question 18 is 6 or higher.

Next steps:

- Consider seeing a doctor for a check-up.
- Consider having some relief from caregiving (Discuss with the doctor or a social worker the resources available in the community).
- Consider joining a support group

Valuable Resources for Caregivers:

Eldercare Locator: *(a national directory of community services)*
1-800- 677-1116
www.aoa.gov/elderpage/locator.html

Family Caregiver Alliance
1-415- 434-3388
www.caregiver.org
Medicaid Hotline Baltimore, MD
1-800-638-6833

National Alliance for Caregiving
1-301-718-8444
www.caregiving.org

National Family Caregivers Association
1-800 896-3650
www.nfcacares.org

National Information Center for Children and Youth with Disabilities
1-800-695-0285
www.nichcy.org

For additional instruments for caregiving or aging, visit www.CaregiversLibrary.org

Retrieved from http://www.caregiverslibrary.org/portals/0/caringforyourselfcaregiverself

assessmentquestionaire.pdf

Appendix E

Research Participants Consent Form

University of San Diego
Institutional Review Board

Research Participant Consent Form

For the research study entitled:
Life Satisfaction: Aging Female Informal Caregivers of Persons with Dementia

I. Purpose of the research study

Deborah Ann Monson is a Doctor of Philosophy student in the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a research study she is conducting. The purpose of this research study is to examine various aspects of caregiving among woman who are caring for family members or friends who have dementia.

II. What you will be asked to do

If you decide to be in this study, you will be asked to:
Complete five questionnaires that ask you about: 1) your background such as age marital status, and education; 2) similar questions about the background of the person you care for; 3) amount of time you spend caregiving; 4) what type of support you have to help you with caregiving; and 5) any types of feelings you might have about caregiving.

Your participation in this study will take a total of 30 minutes.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day:
San Bernardino County Crisis Services:
West Valley Region 909-485-1517; East Valley Region 909-421-9233; High Desert Region 760-956-2345; Morongo Basin 760-499-4429

IV. Benefits

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be in knowing that you helped researchers better understand providing care for people with dementia.

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher’s office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

You will receive no compensation for your participation in the study.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you’re entitled to, like your health care, or your employment or grades. **You can withdraw from this study at any time without penalty.**

VIII. Contact Information

If you have any questions about this research, you may contact either:

1) Deborah Ann Monson

2) Ann M. Mayo, Dissertation Chair

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant Date

Name of Participant (**Printed**)

Signature of Investigator Date

Appendix F

University of San Diego Committee on the Protection of Human Subjects

IRB-2019-291 - Initial: Initial - Exempt
1 message

irb@sandiego.edu <irb@sandiego.edu> Mon, Mar 11, 2019 at 5:31 PM
To: amayo@sandiego.edu, dmonson-11@sandiego.edu

Mar 11, 2019 2:31 PM PDT

Deborah Monson
Hahn School of Nursing & Health Science

Re: Exempt - Initial - IRB-2019-291, Life Satisfaction: Aging Female Informal Caregivers of Persons with Dementia

Dear Deborah Monson:

The Institutional Review Board has rendered the decision below for IRB-2019-291, Life Satisfaction: Aging Female

Informal Caregivers of Persons with Dementia.

Decision: Exempt

Selected Category:

Findings: None

Research Notes:

Internal Notes:

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited or exempt review at any time.

Sincerely,

[redacted]
Administrator, Institutional Review Board
Office of the Vice President and Provost
Hughes Administration Center, Room 214
5998 Alcalá Park, San Diego, CA 92110-2492
Phone (619) 260-4553 • Fax (619) 260-2210 • www.sandiego.edu

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