Title

Personalizing Care for the Caregivers: An Exploration of Factors Contributing to the Experiences and Outcomes of Family Caregivers of Persons with Dementia

Author

Binford, Sasha Sage

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Personalizing Care for the Caregivers: An Exploration of Factors Contributing to the Experiences and Outcomes of Family Caregivers of Persons with Dementia

by
Sasha Sage Binford

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Approved:

DocuSigned by:
Dr. Heather Leutwyler — Dr. Heather Leutwyler
012039073579437...
Chair

DocuSigned by:
Margaret I Wallhagen — Margaret I Wallhagen
DocuSigned by: [illegible]742C...
Elena Flowers — Elena Flowers
DocuSigned by: [illegible]4DF...
Bob Levenson — Bob Levenson
DocuSigned by: [illegible]460...
Jennifer Merrilees — Jennifer Merrilees
CB3D314EF05642D...
Committee Members

Dedications and Acknowledgements

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Abstract

Personalizing Care for the Caregivers:
An Exploration of Factors Contributing to the Experiences and Outcomes of Family Caregivers of Persons with Dementia

Sasha Sage Binford

Family caregivers of persons with dementia are at increased risk for adverse health outcomes than their peers not in a caregiving role. Persistent heterogeneity in the literature focused on outcomes in this population complicates efforts at identifying who is at greatest risk and for what outcomes as well as avenues for personalizing their care. The purpose of this dissertation was to explore factors contributing to the experiences and health outcomes of family caregivers (FCG) of persons with dementia (PWD). The overarching goal of this dissertation was to move the science as well as clinical practice forward in providing individualized care to our family caregivers of persons with dementia. This dissertation sought to achieve this goal through triangulating data from both quantitative and qualitative sources.

A systematic review of the literature was conducted with a meta-analysis of the included studies' findings related to assessing personality traits (PT) as predictors of outcomes in the FCG of PWD. A quantitative secondary analysis was then conducted based on a self-report measure of PT in a sample of FCG of PWD. A novel approach using latent profile analysis was employed in this study for purposes of exploring how group membership into classes of PT profiles was associated with health outcomes in this population of FCG. The qualitative aspect explored theory development around a sub-group of FCG using a grounded theory approach to guide interviews and participant observations with 15 spouses of persons with an early-age of onset dementia (EOD) syndrome.

The systematic review with meta-analysis evaluated the strength of the current evidence supporting the assessment of PT (as defined by the Five Factor Model of Personality) of the

FCG of PWD as significant predictors of these caregivers' health outcomes, explaining some of the persistent heterogeneity observed. Only the dimensions of Neuroticism and Extraversion showed the greatest utility as reliable predictors through this review process, however. The meta-analyses of these data from the systematic review revealed statistically significant associations between Neuroticism and burden (pooled-*r* = .304), Neuroticism and depression (pooled-*r* = .593), and Extraversion and burden (pooled-*r* = -.233).

The quantitative study revealed a statistically significant difference between class membership and life satisfaction. Two classes (i.e., profiles) were identified through methods of latent class analysis that best fit the data. Membership in the "Higher Resilience" (HR) class was associated with higher self-reported measures of "global cognitive judgement" of personal satisfaction with life than membership in the "Lower Resilience" (LR) class. Membership in the HR class was also associated with higher self-reported measures of bodily pain and role limitation due to emotional problems as assessed by the SF-36 health-related quality of life (HRQoL) instrument. No significant differences between the HR and LR classes were identified in participant or patient characteristics or in the FCG outcomes of perceived burden, distress, depression, anxiety level, or the HRQoL subscales of physical role limitations.

The qualitative data revealed an underlying psychosocial process of a step-wise progression in role identity in spouses of persons with an EOD syndrome. A shift was described in how the well-spouse self-identified in the situation from that of "spouse" to that of "caregiver". These "step-downs" in the transition were interpreted as representing "moments of significance" in the PWEOD's continuous decline that held special meaning to the respective well-spouse and challenged them to take action in order to resolve resulting incongruencies to what it meant to them to be a spouse. The conditions of the situation (i.e., changes in the marital partnership and the interpersonal relationship between the dyads) carried unique aspects for this sub-group of FCG primarily due to the relatively young life stage at which this has occurred and the repercussions on their family and social life as well as financially.

Inter-individual factors (i.e., personality traits) as well as understandings of the unique situations of sub-groups of caregivers (i.e., spouses of PWEOD) are factors which contribute significantly to the experiences as well as to health outcomes of FCG of PWD. They are critical factors to consider in the development of tailored interventions aimed at improving the health outcomes of this population of FCG.

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Introduction

Statement of Interest

My interest in family caregivers (FCG), defined as relatives, partners, friends, or neighbors, who provide care and support to persons with Alzheimer's disease and related dementias (hereafter referred to as: persons with dementia (PWD)) began during my graduate training as an advanced practice nurse. During this time, I took an elective course designed to pair health professional students with patients who had a dementia syndrome in the mild stage with the goal of the patients "teaching" the students about what it is like for them living with dementia. The 9-month relationship that formed between me and a patient with an atypical form of Alzheimer's disease provided me a unique opportunity to hear about this individual's challenges as well as her growing concerns for her partner who was her primary family caregiver.

Subsequently, through my work at a tertiary memory care center while conducting interviews with the study partners of our patient-participants – most of whom were the FCG – I began to collect anecdotal evidence illustrating the challenging situations these FCG were in and the negative toll that was being reported by them. It became clear to me that even when the general situation was described in similar terms, the responses/reactions of the FCG were not the same – there appeared to be variability in the effects similar situations had on the different FCG. I also began to observe that there appeared to be different "types" of caregivers that described similar thought patterns or actions whether in a similar situation or not.

The current framework which typically gets employed for delivering care to these FCG is based on evidence from studies primarily focused on more "typical" FCG of patients with an older-age, Alzheimer's-type dementia syndrome. This "one-size-fits-all" approach risks overlooking specific needs that different FCG may be encountering and at different stages of the illness as well as at different life stages (1). I concluded that we need novel approaches to better understand who is at greatest risk and for what outcomes so that, as providers, we can tailor our interventions that best address a FCG's unique situation.

Background and Significance

Alzheimer’s disease and related dementias (ADRD) are a life-limiting diseases that involve persistent and progressive impairments in cognitive functioning which eventually lead to full dependency in activities of daily living (2). Over 5 million Americans have some type of ADRD and this number is expected to increase to over 13 million by 2050 (3, 4), posing a major public health crisis with total US costs of $277 billion reported in 2017 (5). In addition to significant financial burdens in the form of missed work hours and/or unpaid direct care (with economic value estimates of $232.1 billion in 2017 (4)), the situation of informally (i.e., not professionally; often a family-like member) caregiving for a person with dementia (PWD) presents with multiple physical and emotional stressors (i.e., demands from challenging care needs and/or difficult behaviors in the PWD), placing the family caregiver (FCG) at high risk for adverse mental and/or physical health outcomes (1, 6-10). PWD are understood to be high-need/high-cost patients and their FCG often face unique and cumbersome duties over extended periods of time while possibly lacking knowledge of the underlying disease process and skills for effectively managing the symptoms as the PWD continues to decline (10). These conditions can lead to risks for maladaptive coping behaviors and negative health outcomes for both the FCG as well as the PWD (8, 11).

Statement of the Problem

It has been established that FCG of PWD are at greater risk for adverse physical and mental health outcomes and poorer health-related quality of life (HRQoL) than age-related peers not in a FCG role and have been identified as “invisible second patients” (6, 8, 11-14). In addition, compared to FCG of persons with other diseases (e.g., cancer), FCG of PWD report higher levels of perceived burden as well as depressive and anxiety symptoms which place them at greater risk for increased morbidity and mortality (8, 11). While an extensive body of literature has documented the risk for adverse health outcomes in this population of FCG of PWD, it has been demonstrated that not all of these FCG are at the same magnitude of risk or at risk for the same outcomes even given similar caregiving conditions (1, 6, 11, 15-17).

Studies reporting on risk factors that might explain some of the heterogeneity seen in the health outcomes (e.g., higher perceived burden levels, worse depressive and anxiety symptoms, and poorer HRQoL) of FCG of PWD have focused on various FCG and/or care-recipient (i.e., PWD) characteristics (e.g., age, gender/sex, socio-economic status, kin relationship, pre-morbid relationship quality, duration of care, social support, functional level, and health status), with variable findings across studies (8, 18-21). More recently, differences in FCG appraisals, self-efficacy and/or coping styles have received attention as potential mediators or moderators between caregiving-related stressors and caregivers' perceived burden and subjective health (16, 17, 22-26), again, with variable findings, while motivation and finding meaning/purpose in caregiving has received less attention in the literature (17, 27-32).

The persistent heterogeneity in the literature has presented challenges in reliably predicting which FCG is at greatest risk and for which outcomes, impeding efforts at personalizing care (1, 7-9, 25, 26). In addition, the multitude of factors associated with outcomes reported on in the literature illustrates the complexity of the relationships and high variability in experience among FCG of PWD, highlighting that this broader population of FCG is not homogeneous and there is need for studies focusing on the inter-individual factors as well as sub-group factors of FCG of PWD. For example, younger FCG have long been recognized as being at risk for higher levels of burden than older FCG (33), while spousal FCG are reported to be four times as likely to experience new-onset depression than other family member caregivers of PWD (8, 11, 34).

These sub-group factors such as the life-stage the FCG is at and the relationship type are known to independently contribute to outcomes (35). To better understand the individual factors of caregivers within a subgroup of family CG, such as spouses of a person with an early-age of onset dementia (EOD; defined as age of symptom onset <65 years), a broader conceptualization of their shared but unique situation must be investigated. However, no published study focusing on the meanings these FCG of persons with EOD (PWEOD) make of their situation with the goal of theory development has been identified in the literature.

Purpose and Specific Aims

To help address these gaps in the literature related to factors contributing to the experiences and outcomes of family caregivers of persons with dementia, this dissertation employed a novel exploration (e.g., mixture modeling) into the inter-individual contributions to outcomes in FCG of PWD as well as a preliminary theory development around the situation of being the spouse of a PWEOD (e.g., qualitative interviews and analyses). While a true mixed-methods approach could not be achieved through this work, by incorporating parallel (i.e., quantitative and qualitative) studies, the enriched benefits of triangulation add new perspectives on and understanding of the overarching phenomenon of interest (36-38). These parallel methods of investigation offer avenues for tailoring interventions to meet the specific needs of individual FCG of PWD. Therefore, the purpose of this dissertation was to explore novel avenues of predicting which FCG is at risk and for what outcome as well as exploring the unique experiences of a sub-group of FCG (i.e., spouses of PWEOD) in the form of meaning-making and actions taken in their situation. The overarching research question that has shaped this dissertation work is: *how to move towards personalizing care for our invisible second patients?* (i.e., FCG).

For the quantitative study, a secondary data analysis employed latent profile analysis (LPA) as a novel approach to uncovering important contributors to the variability in outcomes and symptom experiences of FCG of PWD, specifically how their membership within a particular personality trait (PT) risk profile/class was associated with their characteristic and outcome variables. The objective was to better characterize who is at greatest risk and for what outcomes based on a PT risk profile. Institutional Review Board (IRB) approval was granted for this study by the UCSF Human Research Protection Committee on Human Research, **IRB# 18-25515**.

The qualitative study utilized a grounded theory methodology to specifically investigate the language-based meanings spousal/partner-FCG ascribe to their role in the situation of being the spouse/partner of a PWEOD, and the actions employed as coping mechanisms with the goal of providing the basis for development of explanatory theory illustrating the shared, basic, psychosocial processes underlying their situation. Institutional Review Board (IRB) approval was granted for this study by the UCSF Human Research Protection Committee on Human Research, **IRB# 17-22488**.

The **Specific Aims** for this dissertation were to:

Aim 1: *Explore the relationships between personality trait (PT) risk profile variables of family caregivers (FCG) of persons with dementia (PWD) and the FCG characteristic/outcome variables.*

Sub-Aim 1A: *Identify, using mixture modeling, latent classes of FCG of PWD with distinct PT (risk) profiles based on the Five Factor Model (FFM) of personality traits.*

Sub-Aim 1B: *Characterize the differences in FCG/PWD demographic and clinical characteristics between the latent classes.*

Sub-Aim 1C: *Evaluate the differences between the latent classes on the associations between class membership and FCG outcome variables of perceived burden, distress, anxiety and depressive symptoms, life satisfaction, and HRQoL.*

Aim 2: *Investigate qualitatively the underlying psychosocial processes at play in the situation of being a spouse of a person with an early-age of onset dementia (PWEOD).*

Sub-Aim 2A: *Describe the ways that these FCG define the situation in which they find themselves.*

Sub-Aim 2B: *Describe the actions these FCG take to manage their lives in the context of perceived challenges related to their spouses' gradual cognitive, emotional and functional decline.*

Sub-Aim 2C: *Develop theory framing the underlying psychosocial processes which illustrate the shared experiences of this caregiver population's problematic situation.*

Overview of Papers

The dissertation is organized into three parts. The first paper presents a review of the literature focused on assessing the relationship between FCG's PT and their health outcomes. This review was conducted systematically and included a meta-analysis. Paper two presents findings of the quantitative, secondary data analysis. This paper explored the utility of employing mixture modeling (i.e., latent profile analysis) to evaluate FCG PT profiles as predictors of their health outcomes. The third, and final, paper presents the key findings from the grounded theory study with the development of theory framing the shared experiences of being the spouse of a PWEOD. The final paper is followed by a synthesis of the findings as well as implications for nursing research and clinical practice.

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Paper 1

Measuring Personality Traits as Predictors of Health Outcomes in Family Caregivers of Persons with Dementia;

A Systematic Review with Meta-Analysis

Sasha Sage Binford

Abstract

Background: Family caregivers of persons with dementia are known to be at risk for adverse health outcomes. However, heterogeneity in the literature on predictors of those outcomes persists. Identifying which family caregiver is at greatest risk or at risk for what outcome remains elusive. **Objective:** To evaluate the evidence for assessing personality traits as defined by the Five Factor Model as strong predictors of health outcomes in family caregivers of persons with dementia. **Design:** A systematic review of the literature with meta-analyses of the data relevant to investigating the associations between personality traits and health outcomes in the family caregivers of persons with dementia. **Results:** Seven articles were systematically identified through databases which met the inclusion criteria for review. Neuroticism and Extraversion were the personality dimensions most commonly assessed across studies and were found to be significantly associated with health outcomes across five of the seven included studies. The meta-analyses of data from five of the seven articles included in the systematic review revealed statistically significant associations between Neuroticism and burden (pooled-*r* = .304), Neuroticism and depression (pooled-*r* = .593), and Extraversion and burden (pooled-*r* = -.233). **Conclusions:** The personality dimensions of Neuroticism and Extraversion showed the greatest utility as reliable and modestly robust predictors through this review process.

Measuring Personality Traits as Predictors of Health Outcomes in Family Caregivers of Persons with Dementia;
A Systematic Review with Meta-Analysis

Introduction

While an extensive body of literature has documented an increased risk for adverse health outcomes in the family caregivers (FCG) of persons with dementia (PWD), it has been identified that not all FCG are at the same magnitude of risk or at risk for the same outcomes (1, 2). Identifying who is at greatest risk and for what outcome remains elusive. The multitude of associated factors (e.g., age, gender, socio-economic status, relationship to PWD, PWD's diagnosis, PWD's cognitive status, PWD's illness severity, and/or behavioral and psychological symptoms of dementia (BPSD) in the PWD) reported on in the literature illustrates the complex, multi-factorial pathways potentially contributing to the variability in health outcomes and the need for investigations focused on the inter-individual differences among FCG that contribute to outcome variability.

The Five Factor Theory of Personality poses that personality traits (PT) are innate aspects of humans representing basic tendencies that are relatively stable over time and context (3-6). The five personality dimensions (i.e., factors; Neuroticism, Extraversion, Openness to Experience, Agreeableness, Conscientiousness) within the Five Factor Model (FFM) can be understood as underlying processes influencing an individual's appraisal, self-efficacy and/or coping style, which have been shown to have significant associations with outcomes (3). There is a limited but growing body of research investigating the PT of caregivers of PWD as predictors of their health outcomes, however, there is no known systematic review on the subject to date. The purpose of this systematic review with meta-analysis was to evaluate the strength of the current evidence supporting the assessments PT (as defined by the

FFM) of the FCG of PWD as significant predictors of these caregivers' health outcomes, explaining some of the persistent heterogeneity observed.

Methods for Systematic Review (SR)

SR Protocol

This systematic review was conducted and reported according to the **Preferred Reporting Items for Systematic Reviews and Meta-analyses: the PRISMA statement** (2009) (7). A deviation from protocol was that only a single investigator (SB) reviewed the search results. This systematic review has not been registered at this time.

SR Eligibility/Exclusion Criteria

Types of studies. The targeted study designs included in this search were cohort studies and cross-sectional studies published in peer-reviewed journals. The search dates ranged from January 1, 1990 to January 12, 2019. The length of time was chosen due to the limited numbers of studies on this population of interest published in the past 29 years. Additionally, the earlier years reflect an era that encompassed a high degree of debate on the concept of personality across populations. Included studies were limited to English language only.

Studies were excluded if caregiver PT were not defined or measured with a validated instrument. Because the primary aim of this review was to describe the association between FCG PT and health outcomes, randomized controlled trials were not included. Multiple articles based on a single study were excluded except for the first published paper that directly met the inclusion criteria.

Types of participants. The study samples included FCG of PWD living in the community. Search terms used for inclusion included: family caregiver; spouse; unpaid caregiver; care provider; care partner; patients with; neurodegenerative illness/disease; Alzheimer's-like; community dwelling; living at home. Relationship to care-recipient was specified as nonprofessional/non-paid caregiver. Age of FCG included was adults age 18 years or older. Female or male genders or studies where gender was not reported were included. Length of caregiving had no limits. Types of dementia syndromes included were: Alzheimer's disease (AD); vascular dementia; Lewy Body disease (LBD) and/or Parkinson's disease dementia (PDD); frontotemporal lobar dementia (FTLD); progressive supranuclear palsy (PSP); corticobasal degeneration/syndrome (CBD/S); Creutzfeldt-Jakob disease (CJD); and, unspecified dementia due to a neurodegenerative process.

Studies were excluded from the review if they included caregivers who were professional/paid, care-recipients with dementia who were institutionalized, or if the dementia diagnosis was memory/cognitive impairment other than due to a dementia/neurodegenerative process. Studies were excluded if FCG PT were not defined or measured with a valid instrument.

Types of outcomes. The primary outcomes of this review were objective and/or subjective FCG health status (including mental or physical symptoms). Alternative search terms included: self-reported health; health status; perceived health; negative/poor health; mental and/or physical health; burden; quality of life; stress; depression.

SR Information Sources

Three electronic databases were searched for this systematic review: MEDLINE (PubMed), PsycINFO, and Embase. Searches were conducted beginning January 24, 2017 with date of last search January 12, 2019. Google Scholar (www.scholar.google.com) was also utilized, and references were checked for relevant publications (i.e., snowball method).

SR Search Strategy

The initial search strategy was narrowly focused using specific terms relevant to this systematic review ("personality traits caregiver dementia"; "personality trait caregiver health";

“personality AND trait AND caregiver AND dementia”; “personality traits health dementia caregivers”). An additional search included an option for results to be displayed with abstract, suggested MeSH (or equivalent) terms, and highlighted search terms when available. See details of search strategies in **Appendix 2.A**.

SR Study Selection

Each of the identified articles from the database search was added to the primary reviewer’s (SB) general Endnote X8 library. From there, duplicates were removed using both the program’s automatic tool and a manual search through the library. The remaining articles in Endnote were screened, only adding those articles that addressed the purpose/foci of this systematic review based on the titles and abstracts to a separate library in Endnote for further consideration. The full text of these selected articles was then read to identify if they were eligible for inclusion in this review based on whether they met the inclusion criteria. The decision-making criteria for this process are shown in **Appendix 2.B**.

SR Data Collection Process

Articles were downloaded as PDFs directly from the respective database. A digital copy of older, non-digitized articles, or articles without free access were requested through the UCSF Library. No direct contact with a publisher(s) or investigator(s) was necessary for more information or permission for access. Non-duplicate articles identified through Google Scholar (n=1) were accessed through PubMed.

SR Data Items

Data extraction was performed after acquiring the full text articles (see **Appendix 2.C** for data extraction checklist). The identified articles were assessed in relation to the inclusion/ exclusion criteria and investigation of the variables of interest for this review: caregiver personality, defined as “trait”; FCG health status, defined as subjective or objective physical and/or mental health, caregiver burden, quality of life and/or general health. Alternate terminology for dependent variables or for operational definitions included: affect, anxiety, depression, distress, self-efficacy, strain, stress. Studies were considered even if other variables not of interest were investigated in addition to those of interest, but those variables are not reported in this systematic review.

SR Quality Appraisal

Quality assessments of the considered articles were performed using the Joanna Briggs Institute Critical Appraisal Checklist (Joanna Briggs Institute, 2017) (see **Appendix 2.D** for the Checklist for Cross-Sectional Studies). The instruments utilized for measuring PT and health outcomes were critiqued, including the reporting of their respective psychometric properties. The overall study designs and statistical analyses were examined for their appropriateness based on the aims(s) of the respective studies.

Risk of bias (RoB) was assessed at the study level using the Cochrane Risk of Bias Tool (Cochrane, 2016). In assessing RoB in the individual studies, focus was on: selection bias, controlling for confounders, attrition bias, and reporting bias. The methods and results sections were assessed for discrepancies, such as selective reporting or not accounting for missing data in the analyses.

Results for Systematic Review (SR)

SR Study Selection

Seven articles met the inclusion, ranging in publication date from 1994 to 2017. The flow-diagram (**Appendix 2.E**) illustrates the study selection process for obtaining the included articles for this systematic review (n = 7). The searches revealed a total of 880 articles, 480 through the utilized databases and 400 through searching “other” sources (Google Scholar and the reference lists of relevant studies). There were 434 duplicates of the 880 identified articles, which were removed through Endnote. The remaining 446 articles (including n=1 from Google Scholar) were screened by the primary reviewer in Endnote for relevance to this review based on the titles and abstracts, resulting in removal of 427 articles due to not meeting the purpose/foci of this review or the inclusion criteria: 197 did not measure PT(s) in the caregivers as the independent variable; five investigated the outcomes in the care-recipient; 173 did not include any of the dependent variables of interest with or without PT(s); in four, the caregivers were paid/professional; fourteen focused on caregivers of individuals with other medical conditions; six focused on institutionalized patients; one measured a “trait” concept other than personality defined by the FFM; twenty-seven were in a language other than English. The remaining nineteen articles were assessed by the primary reviewer for their eligibility by reading through the full text, with twelve excluded for not meeting inclusion criteria: five articles reported on different results of the same study; two were intervention studies; and five investigated samples with institutionalized care-recipients. A total of n = 7 articles were identified for inclusion in this review.

SR Study Characteristics

Six of the seven studies included in this review were cross-sectional, and one (8) was longitudinal with two time-points. Studies were conducted in five different countries: Canada (8), Portugal (9), South Korea (10), Spain (11) and the United States of America (US) (12-14). The three studies from the US each reported a theoretical framework (i.e., stress process models) underlying the respective research questions, however, the other four did not. The respective aims of the seven studies all focused on the influence, relationship, effects, or association of PT as defined by the Five Factor Model (15) and health outcomes of the FCG of a PWD. **Table 2.1** lists the seven included studies and their respective characteristics.

Path analyses were conducted in all six of the cross-sectional studies to examine the direct and indirect relationships between one or more of the PT and one or more health outcome. Three (12-14) of those studies utilizing path analysis included a personal characteristic measure (assessed in the caregiver) as a potential mediator: 1. Gallant and Connell, 2003 (12), hypothesized the mediating role for health behaviors; 2. Hooker, et al., 1998 (13), investigated social support as a potential mediating factor; and, 3. Lockenhoff, et al., 2011 (14), examined the mediating effect(s) of self-efficacy. While important considerations, these personal characteristics of the FCG were not included in this review since the focus for this review was on health outcomes (i.e., burden, depression, etc.). All of the included studies analyzed and reported the direct associations between PT and the respective health outcomes variables.

The largest variation between the seven study sample characteristics (**Table 2.2**) was in sample size which ranged from 33 to 536. More than 50% of the FCG in each study sample were female. FCG age ranged from 44.3 to 79.5 years across the seven studies. The relationship of FCG to care-recipient was primarily either a spouse or an adult child; five of the seven studies included “other” FCG relationship type without specifications. FCG education level ranged across studies from 0-4 years to college (not reported in one study (8)). Across the five studies (8-10, 12, 13) that reported length of caregiving, the time range was less than one year to 8.9 years, with both of these bounds (i.e., <1-8.9 years) reported within a single study (10) and the other four reporting within that range. Not all studies reported on the type of dementia diagnosis in the care-recipients; Alzheimer’s dementia was the most common diagnosis when reported. Refer to **Tables 2.1** and **2.2** for study characteristics.

SR Study Results

Statistically significant results were reported in all seven studies for the correlations between at least one PT measured and one health outcome variable assessed in the FCG. See

Table 2.3 for summary of results from the respective included studies. Seventeen different health outcome operational definitions were reported across the seven studies, which were organized into nine common health outcome categories based on the primary investigator's (SB) clinical expertise (**Table 2.4**). In this format, the health outcome categories that were measured in at least two of the included studies were: depression, five studies (9-13), with either the Center for Epidemiological Studies Depression Index (CES-D) or Beck Depression Inventory (BDI) utilized; caregiver burden, four studies (8-11), with each utilizing the Zarit Burden Inventory instrument; state anxiety, two studies (11, 13), with each using the State-Trait Anxiety Inventory (STAI); and, Health-Related Quality of Life (HRQoL), two studies (10, 14), with each using the Short Form Health Survey (SF-36). None of the seventeen health outcomes variables were measured across all seven studies.

All seven studies assessed PT within the Five-Factor Model (FFM) construct, with all but one (10) using a version of the Neuroticism-Extraversion-Openness Personality Inventory (NEO-PI) instrument (16). Three (9, 10, 14) of the seven studies reported on all five of the personality factors, with one study (13) including an additional construct outside of the FFM (i.e., dispositional optimism). Neuroticism was the only trait measured in all seven studies, and Extraversion was measured in all but two studies (12, 13). See **Table 2.5** for PT and health outcomes measured in the respective included studies.

The FCG health outcomes categories reported across studies with two or more statistically significant correlations with the respective PT measured (see **Table 2.3** for the correlation coefficients for each respective study) were between: *Burden* and: Neuroticism (positive), Extraversion (negative), Agreeableness (negative); *Strain* and: Neuroticism (positive), Agreeableness (negative); *Depression* and: Neuroticism (positive), Extraversion (negative), Openness (negative), Agreeableness (negative), Conscientiousness (negative); *HRQoL* and: Neuroticism (negative), Extraversion (positive), Openness (positive), Agreeableness (positive), Conscientiousness (positive); and, *General Health* and: Neuroticism (negative), Extraversion (positive). Only Depression and HRQoL health outcomes had statistically significant associations with each of the five PT reported across the included studies. **Table 2.6** provides a summary of the correlation coefficients (i.e., *r*) for the relationships between PT dimensions and caregiver health outcomes investigated across two or more studies.

In summary, this review identified from the respective results of the included seven studies that the PT Neuroticism and Extraversion were most often investigated and significantly associated with FCG health outcomes across five of the seven studies. Neuroticism was moderately correlated with eight of the nine health outcomes categories measured across the studies. Extraversion was mildly to moderately correlated with four of the nine health outcomes categories measured across the studies. Burden, anxiety, depression and HRQoL were the health outcomes categories measured most commonly across the included studies and had the greatest frequency of statically significant results for associations with the PT measured in the respective studies.

SR Quality Results

Quality analyses revealed relatively small sample sizes in two studies; Gonzalez-Abraldes, et al., (2013) (11) recruited 33 participants, and Hooker, et al., (1998) (13) recruited 88 participants. Recruitment for the study by Gonzalez-Albraldes, et al., was conducted through mailing questionnaire packets to identified relatives of dementia “sufferers” with a 36.7% (41 out of 109) response rate, of which 8 did not meet the inclusion criteria. A response bias may have been introduced from this method, representing those members of the population with a greater motivation to participate, or time to complete and mail back the questionnaires. Incentives to respond were not reported. The responding participants in this study ranged in age from 35 to 82 years (mean 57.5, standard deviation 11.3). Only the Neuroticism and Extraversion dimensions of the FFM PT were assessed in relation to 5 health outcomes variables examined in this study. Based on the sample size and number of outcomes, the study may have been underpowered. Psychometric properties were not reported on for any of the instruments utilized in this study. The investigators controlled for care-recipient characteristics, such as disease severity and functional status.

Hooker, et al., reported recruitment from “a variety of sources” without details of the protocol that resulted in a sample of 88 and 95.5% reported race/ethnicity as “Caucasian.” The lack of racial/ethnic heterogeneity in this sample could limit the generalizability of the results. Only the Neuroticism factor of the FFM was reported, with the addition of a personality concept outside of the FFM. This study may have been underpowered due to the small sample size and large number (i.e., seven) of health outcomes being tested. Cronbach’s alpha was reported for six out of the seven measures, with all but one (affect) above .70. No care-recipient characteristics were included in the analyses as potential confounders.

Gallant and Connell, 2003 (12), investigated only the Neuroticism factor with two health outcomes variables. Their sample size was large (N = 233) but lacked racial/ethnic heterogeneity with 91% reporting as “White.” A response bias may have been introduced with 355 self-report surveys mailed out and 233 responding (66%). Cronbach’s alpha was reported for two of the three instruments, each above .70. No care-recipient characteristics were included as potential confounders in this study, including disease severity.

Kim, et al., 2017 (10), reported utilizing the Korean short-form version of the Big-Five Inventory (BFI) instrument, which may not have captured the full range of the complex structure of the original instrument. All five factors were assessed, however, and analyzed for their respective association with three different health outcomes in this study with a large sample size (N = 476). Cronbach’s alpha was reported on for all three of the instruments utilized in this study with each above .70. This study did not include care-recipient characteristics such as disease severity or functional status.

The study by Lockenhoff, et al., (2011) (14), had a lack of racial/ethnic heterogeneity (98% “White”), but reported recruitment methods from broader national regions (Ohio, New York

State, West Virginia) and recruited a large sample size (N = 536). This study was a secondary analysis of a randomized, controlled trial conducted between 1998 to 2002, with a 41.8% attrition rate. This secondary study reported a 78.2% (536 out of 685) response rate. The authors provided explanations for the loss in recruitment as well as reporting on their intent-to-treat analyses for missing data. Cronbach's alpha was only reported on for one (adaptation of Pearlin et al., caregiver strain, $\alpha = .89$) of the three instruments utilized in this study, with one instrument (i.e., SF-36) cited (17) for its psychometric properties and evidence for validity from samples outside this study. These investigators did control for care-recipient characteristics, such as disease severity.

Melo, et al., 2011 (9) recruited from a single clinic, utilizing a convenience sample strategy. The sample size was relatively small (N = 105), with all five factors assessed for their respective associations with three different health outcomes variables. The interviews/ assessments were conducted in-person and a desire to please may have biased the responses from participants. Care-recipient (i.e., PWD) characteristics were considered in the analyses, such as disease severity and the Behavioral and Psychological Symptoms of Dementia instrument.

The study by Reis, et al., 1994 (8) was the only one in this review with a longitudinal study design, and reported an attrition rate of 26% (157 out of 213) at the 2-year follow-up, with explanations for participant loss. The authors investigated only two of the five factors (i.e., Neuroticism and Extraversion) with two health outcomes variables. Limited psychometric properties were reported on for this study's sample, with test-retest reliability (initial and final assessments) provided for each of the outcomes measured (Cronbach's $\alpha = .53$ and $\alpha = .60$, respectively, $p < .05$). Care-recipient characteristics were included in the analyses.

Four of the seven included studies did not investigate the FFM of PT comprehensively, and all studies utilized self-report measures for all variables investigated, which carries a risk for reporting bias. There was variability in recruitment procedures and assessment methods (mailing versus in-person) across the seven studies. Two (11, 18) of the seven studies had small samples sizes, and may have been underpowered. Six out of the seven study designs were cross-sectional with one (8) being a longitudinal study. Therefore, temporal or causal relationships could not be reported. The statistical analyses across studies were appropriate for the respective study aims, all measuring the associations of PT with various health outcomes in the caregivers of individuals with dementia. No selective reporting was detected in any of the seven studies. All seven of these studies had limitations but showed good quality in their respective study designs, methods and reporting.

Methods for Meta-Analysis (MA)

MA Eligibility/Exclusion Criteria

To be included in the meta-analysis, a study needed to have reported the correlation coefficient (i.e., *r*) for the respective PT-health outcome association investigated. For the respective PT-health outcomes meta-analyses, we set the minimum for included studies at three to maximize power given so few available studies.

MA Information Sources

The studies included in this systematic review were the only source of data for the meta-analysis.

MA Data Analyses

Data were analyzed using Stata version 15.1 (StataCorp, College Station, TX). Data (i.e., the correlation coefficients) were translated into Fisher's *z*-transformed scores (i.e., Z-scores) with corresponding 95% confidence interval (CI) utilizing the online calculator source from DB Wilson (https://campbellcollaboration.org/escalc/html/EffectSizeCalculator-R2.php) and then back-translated to the pooled-*r* statistic using an online statistics calculator (http://onlinestatbook.com/2/calculators/r_to_z.html). Pooling estimates of the respective Z-scores was conducted using the “metan” command in Stata with statistical significance determined by the 95% CI (i.e., not significant if zero in the CI). The more conservative random effects model was utilized with the goal of estimating the “true” effects from the sample of included studies which were assumed to be relatively heterogeneous based on the results of the systematic review process. Heterogeneity among the sample of studies (i.e., whether the studies measured the same thing or not) was assessed with the Q statistic *p*-value (i.e., evidence for heterogeneity if $p < .05$) and the degree of heterogeneity with the I-squared (I^2) value (i.e., variation (%) in effect size attributable to heterogeneity). Given the relatively small number ($n = 5$) of included studies, we decided *a priori* to use the Begg’s test (i.e., an adjusted rank correlation) for small-study effects to assess for evidence of publication bias (i.e., $p < .05$). No stratification or sub-group analyses were investigated in this meta-analysis due to the small number of available studies.

Results for Meta-Analysis (MA)

MA Study Selection

All but one (9) of the seven studies from the systematic review reported the correlation coefficients (i.e., *r*) in their respective results (see **Table 2.3**). Of these remaining six studies, five (8, 10-13) contributed to meeting the minimum (i.e., three) for the various PT-health outcomes analyses (see **Table 2.7**).

MA Study Characteristics

The five studies included in the meta-analysis consists of: three studies (8, 10, 11) investigating the relationship between Neuroticism and Burden; four (10-13) investigating the relationship between Neuroticism and depression; and, three (8, 10, 11) investigating the relationship between Extraversion and burden. See **Table 2.7** for the respective study analyses included in the meta-analyses.

MA Study Results

For the relationship between Neuroticism and the outcome of burden (see **Table 2.8** for MA results), the pooled effect size (pooled-*z* = .314; back-translated pooled-*r* = .304) was statically significant (i.e., zero was not included in the 95% CI). This small sample (*n* = 3) was found to be "highly" heterogeneous (i.e., Q-statistic *p* = .003; I^2 = 82.7%), though the forest plot (see **Figure 2.1**) illustrates that each of the studies were same direction (i.e., above the significance line of zero). There was no evidence found for publication bias (*p* = .117).

For the relationship between Neuroticism and the outcome of depression (see **Table 2.8** for MA results), the pooled effect size (pooled-*z* = .683; back-translated pooled-*r* = .593) was statically significant (i.e., zero was not included in the 95% CI). This small sample (*n* = 4) was found to be "highly" heterogeneous (i.e., Q-statistic *p* = .000; I^2 = 95.7%), though the forest plot (see **Figure 2.2**) illustrates that each of the studies were same direction (i.e., above the significance line of zero). There was no evidence found for publication bias (*p* = .497).

For the relationship between Extraversion and the outcome of burden (see **Table 2.8** for MA results), the pooled effect size (pooled-*z* = -.314; back-translated pooled-*r* = -.233) was statically significant (i.e., zero was not included in the 95% CI). This small sample (*n* = 3) was found to be "highly" heterogeneous (i.e., Q-statistic *p* = .004; I^2 = 81.7%), though the forest plot (see **Figure 2.3**) illustrates that each of the studies were same direction (i.e., below the significance line of zero). There was no evidence found for publication bias (*p* = .117).

Discussion

Summary of Evidence

To our knowledge, this is the first systematic review examining the published studies which have investigated relationships of PT (as defined by the FFM) with health outcomes in the FCG of PWD. The goal of this systematic review with meta-analysis was to evaluate the utility (i.e., pooled strength) of measuring PT as statistically significantly predictors of health outcomes in this population. Seven articles were identified in the literature relevant to this focus, with all seven measuring PT within the same framework (i.e., the FFM) and utilizing the same or a similar instrument (i.e., NEO-PI or a comparable version). Nine categories of health outcomes were organized from the seventeen different operational definitions reported for health outcomes across the studies: affect, anxiety, burden, strain, depression, distress, HRQoL, general health, and stress. In each of the seven included studies, statistically significant correlations were reported between some dimension of PT measured (i.e., Neuroticism, Extraversion, Openness to Experience, Agreeableness, and/or Conscientiousness) and a respective health outcome measured. See **Table 2.6** for a summary of the statistically significantly associations reported for PT and the respective health outcome category.

Of the seven studies included in this systematic review, data from five of those met inclusion criteria for the meta-analyses (see **Table 2.7**). The major findings from these meta-analyses suggest that there is an overall: 1) mild-moderate, positive association between Neuroticism and burden (pooled-*r* = .304) interpreted as: higher levels of Neuroticism increase the risk for burden in the FCG of PWD; 2) moderately-strong, positive association between Neuroticism and depression (pooled-*r* = .593) interpreted as: higher levels of Neuroticism increase the risk for depression in the FCG of PWD; and, 3) mild-moderate, negative association between Extraversion and burden (pooled-*r* = -.233) interpreted as: higher levels of Extraversion decrease the risk for burden in the FCG of PWD. See **Table 2.8** for a summary of the results from these meta-analyses.

The additional findings from the systematic review suggest other potentially important (i.e., statistically significant) associations between PT and health outcomes which could not be further investigated in the meta-analyses due to too few (<3 studies) data. Additional, *ad hoc*, descriptive interpretations made of these published statistically significant results indicate that higher levels of: 1) Neuroticism moderately increases state anxiety (*r* = .44, .46); 2) Neuroticism moderately decreases mental HRQoL (*r* = -.25, -.44); 3) Neuroticism mildly decreases physical HRQoL (*r* = -.17, -.17); 4) Neuroticism moderately increases perceived stress (*r* = .53, .61); 5) Extraversion mildly decreases depression (*r* = -.13, -.20); 6) Extraversion mildly increases mental HRQoL (*r* = .11, .19); and, 7) Extraversion mildly increases physical HRQoL (*r* = .13, .14). See **Table 2.6** for a summary of PT-outcome relationships (i.e., *r*) reported across two or more studies included in this review.

Overall, across the seven studies included in this review (see **Table 2.5**): Neuroticism was shown to be significantly correlated with each of the nine categories of health outcomes in at least one study; Extraversion with burden, depression, HRQoL, and general health; Openness to Experience with depression and PCS HRQoL; Agreeableness with burden, strain, depression, and MCS HRQoL. Conscientiousness with depression and HRQoL. In summary, utilization of these PT measures in the context of family caregiving for PWD is supported for providing both knowledge generation and moderate predictive value in identifying who is at greatest risk and for which health outcome(s) and for tailoring interventions to the individual FCG accordingly.

Conclusion

In conclusion, the findings of this systematic review illustrate that each of the five PT dimensions within the FFM measured in FCG of PWD are statistically significant predictors of at least one aspect of a FCG health outcome investigated in the literature when measured with the NEO-PI instrument (or a validated, reliable alternate version). However, only the specific health outcomes of burden and depression could be meta-analyzed for a pooled effect size with Neuroticism and/or Extraversion. Each of these analyses provided statistically significant evidence of a mild-moderate association between: 1) Neuroticism and burden; 2) Neuroticism and depression; and, 3) Extraversion and burden. These results suggest that the dimensions of Neuroticism and Extraversion are relatively good predictors for the specific health outcomes of burden and/or depression in caregivers of PWD.

A gap identified in this review process is for comprehensive studies implementing all five dimensions of PT and each category of the most relevant health outcome variables in this population (i.e., perceived stress/distress, anxiety, burden, depression, general health and QoL). With only three of the seven studies included in this review reporting on associations of all five PT dimensions, the utility of assessing each of the individual factors with health outcomes cannot be fully analyzed here. In addition, the sheer number (i.e., seventeen) of health outcomes operational definitions investigated across these included studies presented challenges in assessing which health outcome would be most strongly associated with PT in FCG of PWD. The wide variation in variables investigated across studies suggests that the relationships between PT and health outcomes is complex and requires more comprehensive investigations to fully understand, including assessing the influence of personal characteristics (i.e., other innate aspects such as genotypes, emotion regulation, social determinants, self-efficacy, coping abilities, health behaviors) as mediators/moderators on the strength of these associations in addition to evaluating the role of PT in outcome predictions using longitudinal designs.

Investigating the single PT dimensions may only be telling a part of the complex story of the relationships between PT and health outcomes, however. An additional gap identified in the literature was an absence of investigations employing mixture modeling (e.g., latent profile analysis (LPA)) to explore classes of PT in the population of FCG of PWD. LPA can complement the single-variable approach which, by itself, risks limiting the scope of investigation by overlooking the reality that traits do not exist in isolation (i.e., dimensions of the FFM have been shown to co-vary some (19)). This approach to investigating PT could conceptualize personality as a profile of an interrelated system of several traits and may help identify previously unobserved patterns of personality in this population which could then be evaluated for differences on a wide range of characteristics.

Implications/Future Research

The implications of the findings of this systematic review are of limited support for the utilization of assessing FCG PT using the NEO-PI (or other FFM instrument) in predicting who may be of greatest risk and for a what health outcomes based on one-to-one relationships with the individual PT dimensions. A research goal moving forward is to investigate the associations between membership in PT *profiles* of a sample of FCG of PWD, encompassing all five of the dimensions in the FFM of personality in a LPA class, and key health outcomes variables. With this comprehensive approach, important relationships may be illuminated which better characterize who is at greatest risk and for what outcomes in this caregiver population.

Strengths/Limitations

A strength of this study is in the systematic examination of the literature on the principle dimensions of PT and health outcomes investigated in the population of FCG of PWD. The range in dates for these studies (1994 to 2019) may exemplify a “test-of-time” for associations between PT and health outcomes in this population of caregivers, as significant correlations have been investigated and identified for over two decades. While a limitation could be identified from having only a single reviewer (SB), the more significant limitation is in the relatively small number of studies published and available for review and analysis. An additional limitation is the variation of health outcome definitions that were subsequently categorized by the primary investigator (SB), though highly informed through extensive knowledge of the literature as well as expertise clinical practice. The heterogeneity in type of health outcomes measured across the studies presented challenges to systematically assessing their associations with PT in this review. Although the final analyses ultimately could collectively include only the outcomes of burden and depression, this categorization process may have introduced some reviewer bias to the review process.

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Appendix 2.A

Search Strategy

MEDLINE (PubMed) (sorted by “best match”)

1. personality trait caregiver dementia = 38
2. personality trait caregiver health = 37
3. **((("Personality"[Mesh] or "personality trait" or "personality traits")) AND ("Dementia"[Mesh] or dementia)) AND (("Caregivers"[Mesh] or Caregiver*) and (informal or spouse or family))** Sort by: **Relevance;** = 325

PsycINFO

1. SU.EXACT("Caregivers") AND SU.EXACT("Dementia") AND SU.EXACT("Personality Traits") = 25

Embase

1. personality AND trait AND caregiver AND dementia = 11
2. 'caregiver'/exp OR 'caregiver' AND ('dementia'/exp OR 'dementia') AND ('personality'/exp OR 'personality' OR 'personality traits') AND ('health'/exp OR health) AND ('outcomes'/exp OR outcomes) = 130

Google Scholar

1. personality traits health dementia caregivers = 400

Appendix 2.B

Decision-Making Criteria for Article Inclusion

Abstract and Title Screening Form

1. Is article published in English? Exclude if not English.
2. Does the article report on independent variable of interest? Exclude if personality trait(s) not measured.
3. Does article report on outcome variable(s) of interest? Exclude if not health-related.

Full-Text Eligibility Form

1. Are the study participants defined as informal caregivers or other acceptable terminology? Exclude if not “informal”.
2. Are the care-recipients defined as diagnosed with a type of dementia not due to a reversible cause? Exclude if not dementia diagnosis.
3. Does the care-recipient live in the community? Exclude if not community-dwelling (institutionalized).
4. Is study design cohort study or cross-sectional? Exclude if an intervention study, RCT, case report, or systematic review/meta-analysis.

Appendix 2.C

Data Extraction Checklist Sheet

Checklist of Items to Consider in Data Extraction

1. **Source**
   - ☐ Date of Extraction:
   - ☐ Author(s):
   - ☐ Article title:
   - ☐ Source of journal:
2. **Eligibility**
   - ☐ Inclusion criteria:
   - ☐ Reason for exclusion:
   - ☐ Recruitment procedures:
3. **Methods**
   - ☐ Study design:
   - ☐ Total study duration:
   - ☐ Specific theoretical model:
   - ☐ Study purpose:
   - ☐ Bias:
4. **Participants**
   - ☐ Total number (N):
   - ☐ Setting:
   - ☐ Age:
   - ☐ Sex:
   - ☐ Country:
   - ☐ Co-morbidity:
   - ☐ Socio-demographics
   - ☐ Race/ethnicity
5. **Measure of health outcomes**
   - ☐ Dependent variable(s):
   - ☐ Independent variable(s):
   - ☐ Mediators/Moderators:
   - ☐ Other covariates:
   - ☐ Statistical tests:
   - ☐ Does technique adjust for confounding?
   - ☐ Was attrition dealt with?
6. **Measurements**
   - ☐ For scales, upper and lower limits, and whether high or low score is good:
   - ☐ Measurement derived from (cite if existing tool):
   - ☐ Validation of tool and how?
7. **Results**
   - ☐ Sample size:
   - ☐ Missing participants:
   - ☐ Key results with estimate of effect (CIs; *p* value):
8. **Miscellaneous**
   - ☐ Funding source:
   - ☐ Correspondence required:
   - ☐ Miscellaneous comments by the review author:

Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.handbook.cochrane.org. Retrieved 01/10/18; modified 02/26/18

Appendix 2.D

Quality Appraisal Checklist

THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer_____________________________________Date___________________________

Author ______________________________________Year_________Record Number______

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
2. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were objective, standard criteria used for measurement of the condition?	☐	☐	☐	☐
5. Were confounding factors identified?	☐	☐	☐	☐
6. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix 2.E

Study Selection Flow Diagram

PRISMA 2009 Flow Diagra

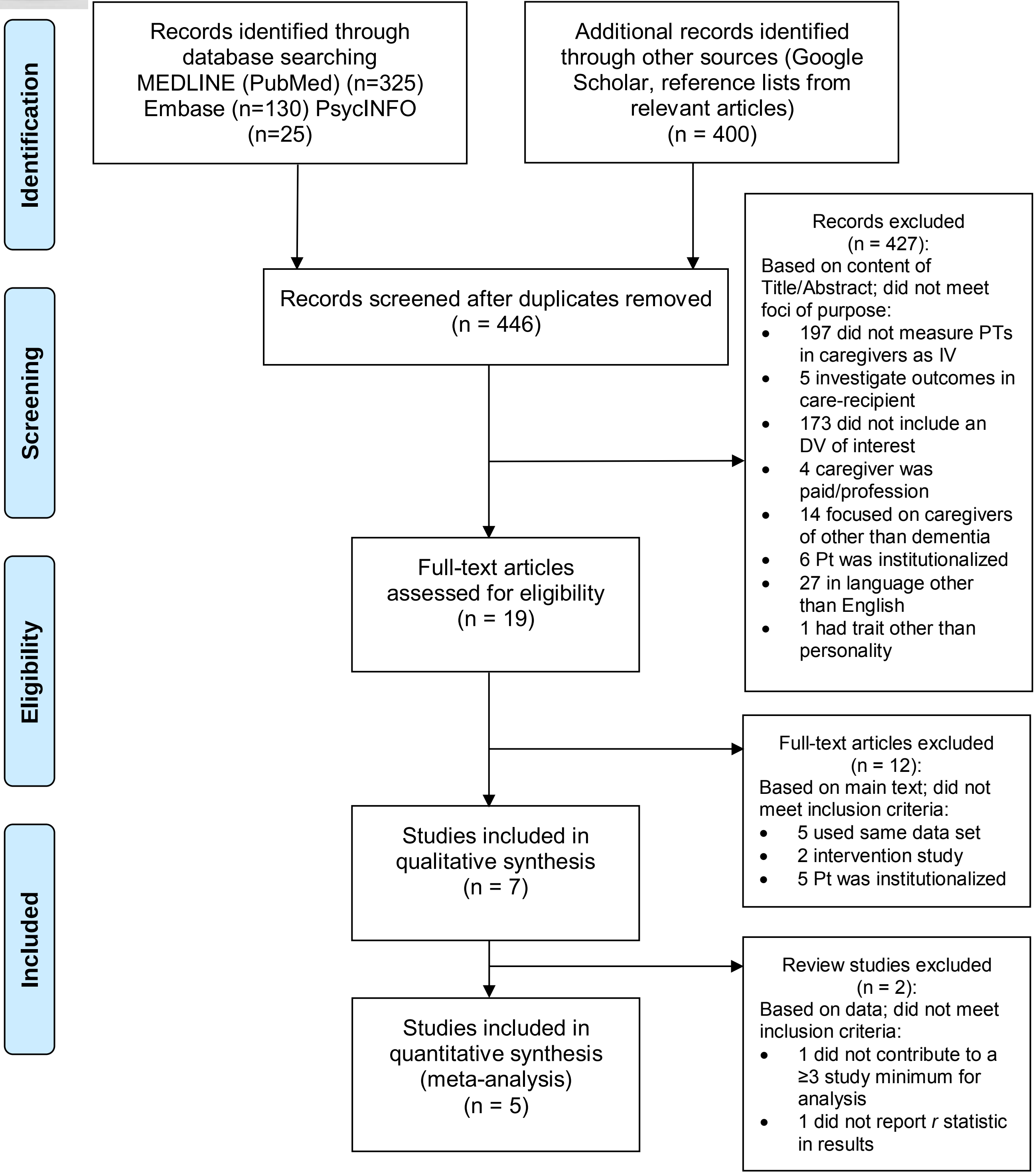


Table 2.1 Study design characteristics of included studies in systematic review.

Study	1st Author, Year, Country	Aim(s) of Study	Study Design	Theoretical Framework
1(12)	Gallant, 2003 USA	To examine the role of health behaviors as a potential mediator of the relationship between neuroticism and depressive symptoms among older adult spouse caregivers.	Cross-Sectional	Caregiver Stress Process
2(11)	Gonzalez-Abraldes, 2013 Spain	1) To analyze the influence that 2 personality traits (neuroticism and extraversion) have on dementia caregiver self-rated burden. 2) To examine the possible relationship between caregiver personality and psychological morbidity (depression and anxiety).	Cross-Sectional	N/R
3(13)	Hooker, 1998 USA	To examine the direct and indirect effects of personality on mental and physical health of spouse caregivers.	Cross-Sectional	Cognitive Appraisal Process
4(10)	Kim, 2017 South Korea	To examine the difference between mental and physical HRQoL in terms of mediating effects of caregiver burden and depression on the link with personality traits.	Cross-Sectional	N/R
5(14)	Lockenhoff, 2011 USA	To examine the relation between personality traits and caregivers' subjective mental and physical health.	Cross-Sectional	Caregiver Stress Process
6(9)	Melo, 2011 Portugal	To examine the influences personality has on caregiver's depression, burden and distress related to BPSD.	Cross-Sectional	N/R
7(8)	Reis, 1994 Canada	To test predictions specifying the influence of caregiver personality traits on negative outcomes of caregiving, health complaints and burden.	Longitudinal Observation	N/R

N/R, not reported; HRQoL, health-related quality of life; BPSD, behavioral and psychiatric symptoms in dementia

Table 2.2 Sample characteristics of included studies in systematic review.

Study	Sample Size (N)	Mean Age years(SD)	Gender (%)	Relationship (%)	Education Years Mean(SD)/%	Mean Length of Caregiving years(SD)	Type of Dementia in Care-Recipient (%)
1(12)	N=233	68 (range: 30-92)	Female (53)	Spouse (100)	≥High School (87.5) College Degree (33)	≤4(55%)	"Dementia" NOS
2(11)	N=33	57.5(11.3)	Female (84.8)	Child (63.6) Spouse (27.3) Other (9.1)	0-4 (18.2) 5-8 (3.0) 9-12 (48.5) College (30.3)	N/R	Mild "dementia" (9.1) Moderate "dementia" (51.5) Severe "dementia" (39.4)
3(13)	N=88	70.2(9.5)	Female (59.1)	Spouse (100)	13.3(3.6)	4.4(3.7)	AD
4(10)	N=476	57.4(13.1)	Female (67.7)	Spouse (37.9) Daughter-in-law (17.1) Son (15.2) Daughter (27.3) Other (2.5)	Illiterate (2.5) Primary School (9.4) Middle School (12.7) High School (35.8) College (39.6)	4.3(4.6)	AD (N/R) Subcortical VaD (N/R)
5(14)	N=536	62.9(13.7)	Female (72)	Spouse (42) Unspecified (58)	14(N/R)	N/R	AD (100)
6(9)	N=105	67.0(12.5)	Female (68.6)	Spouse (75.2) Child (16.2) Other (8.6)	7.9(4.6)	4.2(3.2)	AD (61) FTD (17.1) DLB (6.7) VaD (6.7) Other (10.7)
7(8)	N=157	63.10(14.04)	Female (68.1)	Spouse (60.1) Child (27.7) Other (12.2)	N/R	3.23(N/R)	Progressive "dementia" disorder

N/R, not reported; AD, Alzheimer's disease; FTD, frontotemporal dementia; DLB, dementia with Lewy bodies; VaD, vascular dementia; NOS, not otherwise specified

Table 2.3 Summary of included studies for systematic review.

Study	FFM Personality Factor Measured	Personality Trait Assessment Instrument	Outcome Measure (See Table 4)	Results	Limitations/ Biases
1(12)	FFM: Neuroticism	NEO Five-Factor Inventory (NEO-FFI)	*F*, *Q*	Neuroticism had a direct positive correlation with: (*F*) Depression (**$r=.76$**, $p<.001$), and (*Q*) Stress (**$r=.53$**; $p<.001$)	Cross-sectional design; Homogenous sample (91% White); Response bias via mailed self-report surveys (233/355 = 66%)
2(11)	FFM: Neuroticism, Extraversion	NEO Five-Factor Inventory (NEO-FFI)	*B*, *C*, *D*, *G*, *O*	Neuroticism had a positive correlation with: (*B*) State Anxiety (**$r=.46$**, $p<.01$), (*C*) Trait Anxiety (**$r=.67$**, $p<.01$), (*D*) Burden (**$r=.60$**, $p<.01$), (*G*) Depression (**$r=.68$**, $p<.01$); and a negative correlation with: (*O*) Self-Rated Health (**$r=-.46$**, $p<.01$); Extraversion had a positive correlation with: (*O*) Self-Rated Health (**$r=.35$**, $p<.05$); and a negative correlation with: (*B*) State Anxiety ($r=-.15$), (*C*) Trait Anxiety ($r=-.33$), (*D*) Burden (**$r=-.46$**, $p<.01$), (*G*) Depression ($r=-.13$)	Cross-sectional design; Small sample size Self-report questionnaires
3(13)	FFM: Neuroticism	NEO Five-Factor Inventory (NEO-FFI)	*A*, *B*, *F*, *K*, *L*, *M*, *P*	Neuroticism had a direct positive correlation with: (*A*) Affect (**$r=-.43$**; $p<.05$), (*B*) State Anxiety (**$r=.44$**; $p<.01$), (*F*) Depression (**$r=.55$**; $p<.01$), (*P*) Perceived Stress (**$r=.61$**; $p<.01$); and a direct negative correlation with: (*K*) Health Perceptions (**$r=-.29$**; $p<.05$); (*L*) General Health (**$r=-.30$**; $p<.05$)	Cross-sectional design Small sample size Large number of variables tested Homogeneous sample (95.5% Caucasian) Self-report questionnaires
4(10)	Big Five: Extraversion, Agreeableness, Conscientiousness, Neuroticism, Openness	Big Five Inventory-Korean Version (BFI-K)	*D*, *G*, *I*, *J*	Neuroticism had a positive correlation with: (*D*) Burden (**$r=.12$**, $p<.01$), (*G*) Depression (**$r=.32$**, $p<.01$); and a negative correlation with: (*I*) Mental HRQoL (**$r=-.25$**, $p<.01$), (*J*) Physical HRQoL (**$r=-.17$**, $p<.01$); Extraversion had a positive correlation with: (*I*) Mental HRQoL (**$r=.19$**, $p<.01$), (*J*) Physical HRQoL (**$r=.14$**, $p<.01$); and a negative correlation with: (*D*) Burden ($r=-.08$), (*G*) Depression (**$r=-.20$**, $p<.01$); Openness had a positive correlation with: (*I*) Mental HRQoL ($r=.04$), (*J*) Physical HRQoL ($r=.08$); and a negative correlation with: (*D*) Burden ($r=-.02$), (*G*) Depression (**$r=-.13$**, $p<.01$);	Cross-sectional design BFI-K-10 was a short version of personality scale may not capture the full range of complex structure of personality variables as much as the original instrument. Self-report questionnaires

				Agreeableness had a positive correlation with: (*D*) Burden (r=.00), (*I*) Mental HRQoL (r=.02), (*J*) Physical HRQoL (r=.02); and a negative correlation with: (*G*) Depression (**r=-.17**, p<.01); Conscientiousness had a positive correlation with: (*D*) Burden (r=.05); and a negative correlation with: (*G*) Depression (**r=-.11**, p<.05), (*I*) Mental HRQoL (r=-.02), (*J*) Physical HRQoL (r=-.02)	
5(14)	Five-Factor Structure: Neuroticism, Extraversion, Openness to Experience, Agreeableness, Conscientiousness	NEO Personality Inventory Revised (NEO-PI-R)	*E, I, J*	Neuroticism had a direct positive correlation with: (*E*) Caregiver Strain (**r=.30**, p<.01); and a direct negative correlation with: (*I*) MCS (**r=-.44**, p<.01), (*J*) PCS (**r=-.17**, p<.01); Extraversion had a direct positive correlation with: (*I*) MCS (**r=.11**, p<.05), (*J*) PCS (**r=.13**, p<.01); and a direct negative correlation with: (*E*) Caregiver Strain (r=-.04); Openness had a direct positive correlation with: (*E*) Caregiver Strain (r=.05), (*I*) MCS (r=.03), (*J*) PCS (**r=.14**, p<.01); Agreeableness had a direct positive correlation with: (*I*) MCS (**r=.13**, p<.01); and a direct negative correlation with: (*E*) Caregiver Strain (**r=-.10**, p<.05), (*J*) PCS (r=.06); Conscientiousness had a direct positive correlation with: (*E*) Caregiver Strain (r=.02), (*I*) MCS (**r=.16**, p<.01), (*J*) PCS (**r=.18**, p<.01)	Cross-sectional design; Exclusive focus on subjective health ratings; Does not reflect the racial/ethnic diversity of the U.S.; Participant response bias
6(9)	FFM: Neuroticism, Extraversion, Openness to Experience, Agreeableness, Conscientiousness	NEO Five-Factor Inventory (NEO-FFI)	*D, F, H*	Neuroticism directly increased: (*D*) Caregiver Burden (**β=.42**, p<.001), (*F*) Depression (**β=.63**, p<.001); Extraversion directly decreased: (*D*) Caregiver Burden (**β=-.18**, p=.04), (*F*) Depression (**β=-.24**, p<.001); Openness had no significant direct correlation with any health outcome variable; Agreeableness directly decreased: (*D*) Caregiver Burden (**β=-.20**, p=.03); Conscientiousness had no significant direct correlation with any health outcome variable; *No dimension of personality directly correlated with caregiver (H) Distress related to BPSD*	Cross-sectional design; Small sample size; Convenience sampling
7(8)	FFM: Neuroticism-Adjustment Facets, Extraversion-Introversion Facets	NEO Personality Inventory (NEO-PI)	*D, N*	Neuroticism had a positive correlation with: (*D*) Burden (**r=.29**, p<.05), and a negative correlation with: (*N*) General Health (**r=-.47**, p<.05); Extraversion had a positive correlation with: (*N*) General Health (**r=.25**, p<.05); and a negative correlation with (*D*) Burden (**r=-.15**, p<.05)	Attrition rate of 26% at 2-year follow-up

FFM, Five-Factor Model; NEO, Neuroticism, Extraversion, Openness; PCS, physical component summary; MCS, mental component summary; BPSD, behavior and psychiatric symptoms in dementia; *A-Q*, corresponds to type of health outcome variable investigated in study (specified in **Table 4**)

Table 2.4 Definition of health outcomes measured across included studies, grouped by category.

	Type of Health Outcome	Definition/Instrument
A	**Affect Category**	Positive and negative affect/Bradburn Affect Balance Scale (ABS)
	“Anxiety” Category	
B	*Anxiety, State*	State (situational and transient) anxiety level/State-Trait Anxiety Inventory (STAI)
C	*Anxiety, Trait*	Trait (dispositional and stable) anxiety level/State-Trait Anxiety Inventory (STAI)
D	**Burden Category**	Perceived burden; psychological health, well-being, social and family life, finances, degree of control over one’s life/Zarit Burden Inventory (ZBI)
E	**Caregiver Strain Category**	The negative psychological consequences of caring for an individual with mental or physical impairments/Adaptation from Pearlin et al. measurement model of caregiver stress process
	“Depression” Category	
F	*Depression/Mental Health*	Overall level of depression experienced in the past week/Center for Epidemiological Studies Depression Index (CES-D)
G	*Depression/Mental Health*	Existence and severity of depressive symptoms/Beck Depression Inventory (BDI)
H	**Distress Category**	Emotional and psychological distress/Neuropsychiatric Inventory Distress (NPI-D)
	“Health-Related Quality of Life” Category	
I	*Mental Component Summary (MCS) Health-Related Quality of Life (HRQoL)*	Social functioning, role-emotional, mental health /Short Form Health Survey (SF-36)
J	*Physical Component Summary (PCS) Health-Related Quality of Life (HRQoL)*	Physical functioning, role-physical, bodily pain, general health /Short Form Health Survey (SF-36)
	“General Health” Category	
K	*Health Perceptions*	Current health/Subscale of the Health Perceptions Questionnaire (HPQ)
L	*General Health*	Self-report questions predictive of morbidity and mortality/Health Index
M	*Chronic Conditions*	Number of chronic health conditions diagnosed by a doctor/Multilevel Assessment Instrument (MAI)
N	*Physical and Psychological Health*	Self-report physical and psychological health complaints/General Health Questionnaire (GHQ)
O	*Self-Rated Health*	Self-report rating of health/Single question with 5 possible responses (Likert scale)
	“Stress” Category	
P	*Perceived Stress*	Perceived chronic stress deriving from ongoing circumstances/Perceived Stress Scale (PSS)
Q	*Stress*	Perceived stress/the Social and Emotional Burden subscales of the Caregiver Burden inventory

Table 2.5 Summary of health outcomes measured (Table 4) in the respective included study with statistically significant associations (starred)

Study	**PT**	***Affect*** ***A***	***State Anxiety*** ***B***	***Trait Anxiety*** ***C***	***Burden*** ***D***	***Strain*** ***E***	***Depression*** ***F,G***		***Distress*** ***H***	***HRQoL*** ***I,J***		***General Health*** ***K,L,M,N,O***					***Stress*** ***P,Q***	
1(12)	N	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	***	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	***
2(11)	N E	(N/R)	** *N/S*	** *N/S*	** **	(N/R)	(N/R)	** *N/S*	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	** *	(N/R)	(N/R)
3(13)	N	*	**	(N/R)	(N/R)	(N/R)	**	(N/R)	(N/R)	(N/R)	(N/R)	*	*	*N/S*	(N/R)	(N/R)	**	(N/R)
4(10)	N E O A C	(N/R)	(N/R)	(N/R)	** *N/S* *N/S* *N/S* *N/S*	(N/R)	(N/R)	** ** ** ** *	(N/R)	** ** *N/S* *N/S* *N/S*	** ** *N/S* *N/S* *N/S*	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)
5(14)	N E O A C	(N/R)	(N/R)	(N/R)	(N/R)	** *N/S* *N/S* * *N/S*	(N/R)	(N/R)	(N/R)	** * *N/S* ** **	** ** ** *N/S* **	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)
6(9)	N E O A C	(N/R)	(N/R)	(N/R)	*** * *N/S* * *N/S*	(N/R)	*** *** *N/S* *N/S* *N/S*	(N/R)	*N/S* *N/S* *N/S* *N/S* *N/S*	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)
7(8)	N E	(N/R)	(N/R)	(N/R)	* *	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	(N/R)	* *	(N/R)	(N/R)	(N/R)

PT, personality trait dimension investigated; N, Neuroticism; E, Extraversion; O, Openness to Experience; A, Agreeableness; C, Conscientious; *A-Q*, Type(s) of health outcome measured (see Table 4); N/R, measure not reported in study; *N/S*, measured but not statistically significant in study

***p-value < .05 **p-value < .01 ***p-value < .001**

Table 2.6 Summary of ≥2 studies contributing to direct correlations (*r*) between personality trait dimensions, using the FFM, with the respective health outcome categories across included studies.

PT	**Anxiety – State (B)**	**Burden (D)**	**Depression (F,G)**	**HRQoL – MCS (I)**	**HRQoL – PCS (J)**	**Stress (P,Q)**
N	**.44****(13), **.46****(11)	**.12****(10), **.29***(8), **.60****(11)	**.32****(10), **.55****(13), **.68****(11), **.76*****(12)	**-.25****(10), **-.44****(14)	**-.17****(10), **-.17****(14)	**.53*****(12), **.61****(13)
E	[-.15(11)]	**-.08**(10), **-.15***(8), **-.46****(11)	**-.13**(11), **-.20****(10)	**.11***(14), **.19****(10)	**.13****(14), **.14****(10)	N/R
O	N/R	[-.02(10)]	[-.13**(10)]	[.04(10)]	[.08(10)]	N/R
A	N/R	[.00(10)]	[-.17**(10)]	[.02(10)]	[.02(10)]	N/R
C	N/R	[.05(10)]	[-.11*(10)]	[-.02(10)]	[-.02(10)]	N/R

PT, personality trait; N, Neuroticism; E, Extraversion; HRQoL, health-related quality of life; MCS, mental component summary; PCS, physical component summary; (B-Q), label for category of health outcome (see Table 4);[], only measured in one study; N/R, measure not reported; #, correlation coefficient reported between respective PT dimension and health outcome with statistical significance at *$p < .05$, ** $p < .01$, *** $p < .001$

Table 2.7 Studies from systematic review included in meta-analysis (*n*=5).

Study	**Author, Year, Country**	**Sample Size (N)**	**PT Dimension(s) Included in Analysis**	**Caregiver Health Outcome(s) Included in Analysis**
1(12)	Gallant, 2003 USA	N=233	Neuroticism	Depression
2(11)	Gonzalez-Abraldes, 2013 Spain	N=33	Neuroticism, Extraversion	Burden, Depression
3(13)	Hooker, 1998 USA	N=88	Neuroticism	Depression
4(10)	Kim, 2017 South Korea	N=476	Neuroticism, Extraversion	Burden, Depression
7(8)	Reis, 1994 Canada	N=157	Neuroticism, Extraversion	Burden

Table 2.8 Results from Meta-Analyses.

PT	**Burden**	**Depression**
Neuroticism	Pooled-z = .341 (.074, .553)* **Pooled-r = .30*** Q = 11.56 (df = 2) p = .003 I^2 = 82.7% Begg's test Pr > $\|z\|$ = .117	Pooled-z = .683 (.298, 1.068)* **Pooled-r = .59*** Q = 69.79 (df = 3) p = .000 I^2 = 95.7% Begg's test Pr > $\|z\|$ = .497
Extraversion	Pooled-z = -.237 (-.471, -.004)* **Pooled-r = -.23*** Q = 10.91 (df = 2) p = .004 I^2 = 81.7% Begg's test Pr > $\|z\|$ = .117	N/A

PT, personality trait dimension; N/A, not analyzed; ***,** statistical significance determined with a 95% confidence interval (not significant if zero in interval).

Figure 2.1 Forest plot from Meta-Analysis of the relationship between Neuroticism and Burden.

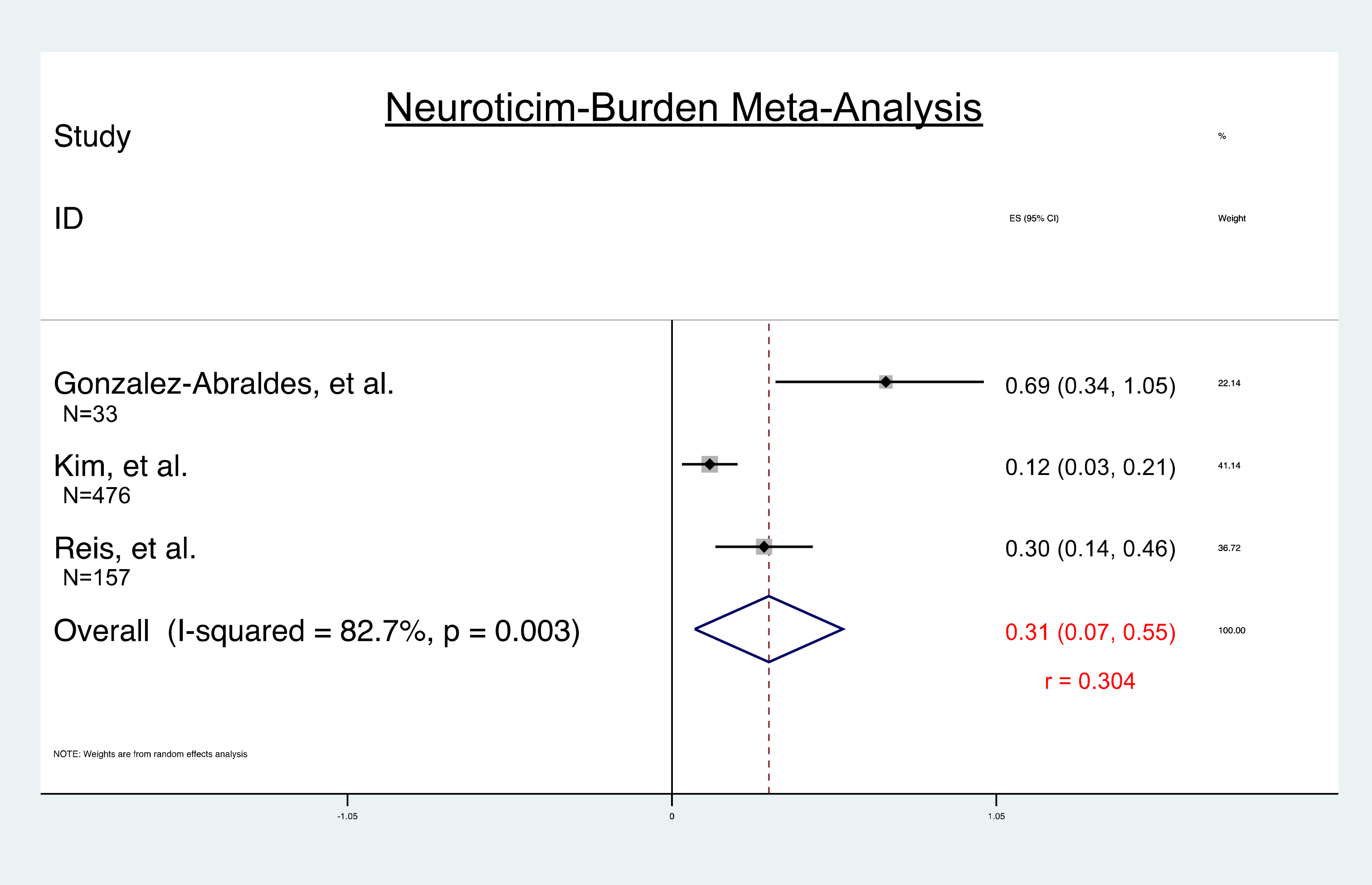


Figure 2.2 Forest plot from Meta-Analysis of the relationship between Neuroticism and Depression.

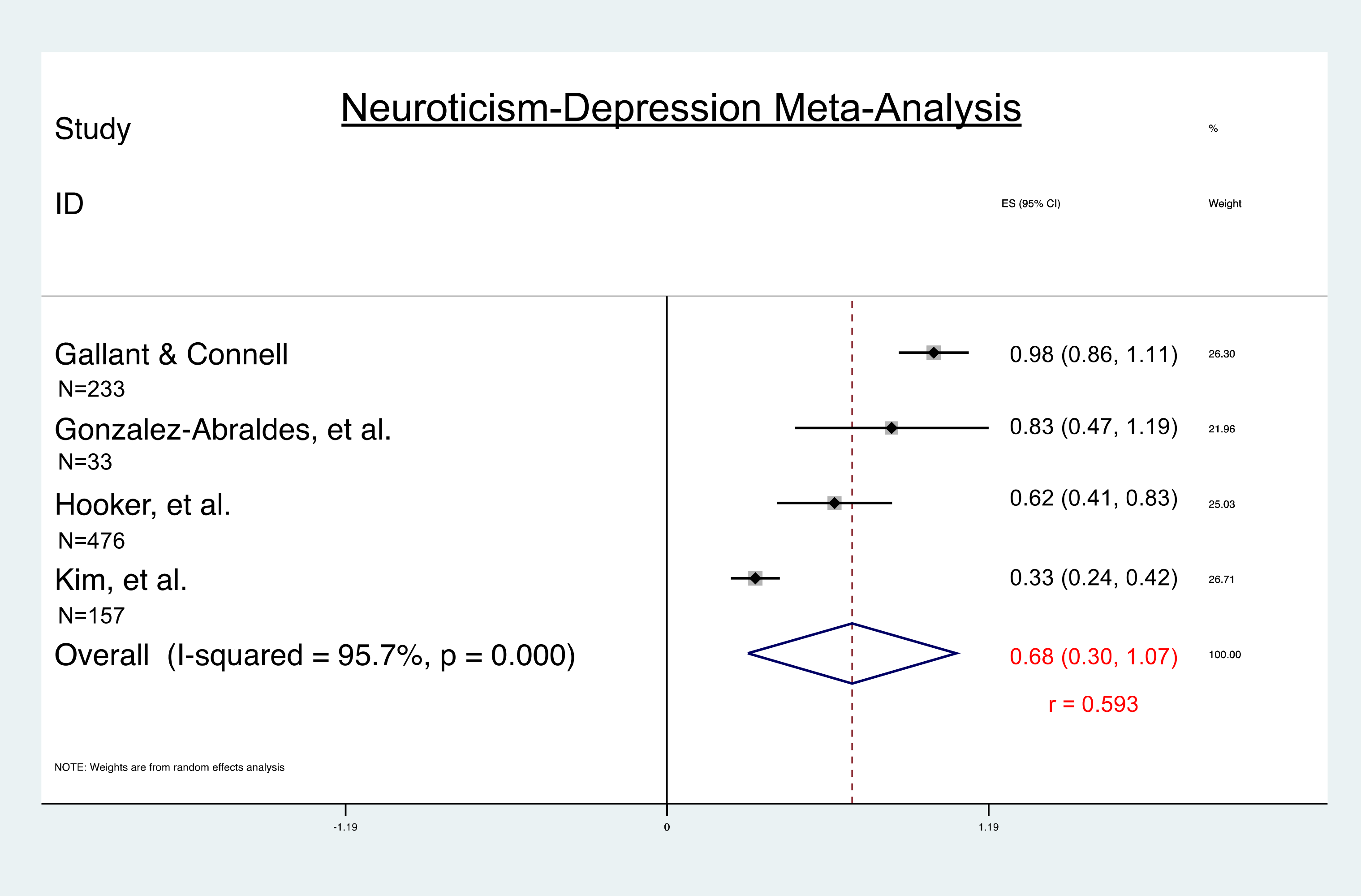
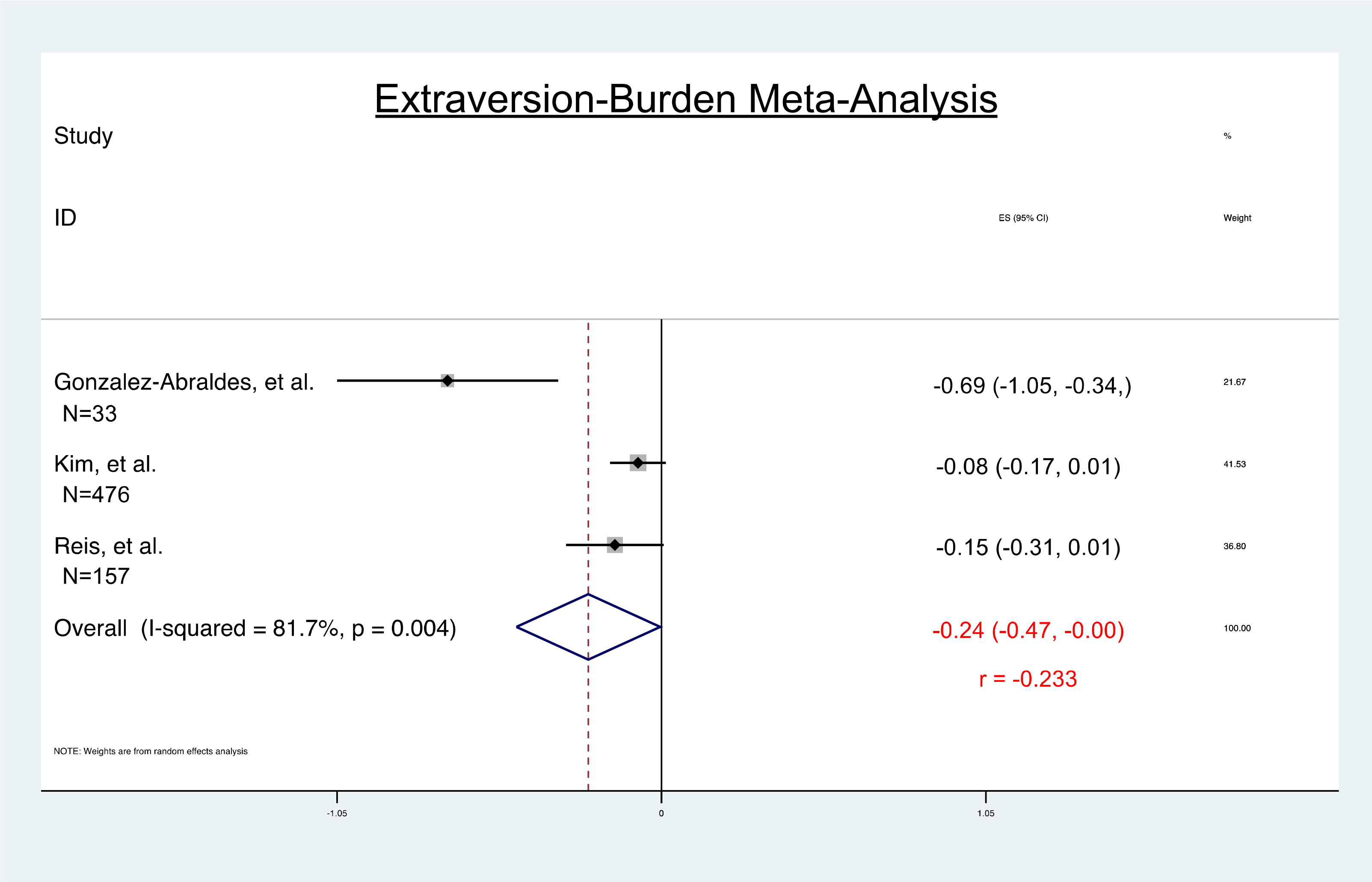


Figure 2.3 Forest plot from Meta-Analysis of the relationship between Extraversion and Burden.



Paper 2

Associations of personality profiles with perceived burden, distress, depression, anxiety, life satisfaction and health-related quality of life in family caregivers of persons with dementia

Sasha Sage Binford

Abstract

Background: While an extensive body of literature has documented the risk for adverse health outcomes in the family caregivers of persons with dementia, it has been demonstrated that not all of these caregivers are at the same magnitude of risk or at risk for the same outcomes. However, persistent heterogeneity in the literature complicates identifying who is at greatest risk and for which outcomes remains elusive. **Objective:** To explore a novel approach to characterizing who among this caregiving population is at greatest risk and for what outcomes based on a personality trait profile. **Design:** Secondary data analysis of the differences between personality trait profiles on health outcomes in a sample of 147 family caregivers of persons with dementia. **Methods**: Latent profile analysis was conducted on the mean responses of a self-report personality trait measure (BFI-10) based on the Five Factor Model of personality. **Results:** A two-class solution for latent classes of personality traits was identified as the best fit of the data. Statistically significant differences were observed between the two personality trait profiles ("Higher Resistance" and "Lower Resistance") on caregiver satisfaction with life (SWLS) as well as the health-related quality of life measures (SF-36) of bodily pain and role limitations due to physical health. **Conclusions:** Though the results of this study did not complement previous trait-based, variable-centered approaches to examining associations between personality traits and outcomes in this population as would be expected, important relationships were uncovered. Such risk profiles can be useful in evaluating for differences on a wide range of characteristics. Future research should further explore these approaches with larger samples of caregivers of persons with dementia and more comprehensive instruments.

Associations of personality profiles with perceived burden, distress, depression, anxiety, life satisfaction and health-related quality of life in family caregivers of persons with dementia

Introduction

The most widely adopted structure for measuring personality traits (PT) is the Five Factor Model (FFM) which describes recurrent patterns of thought and behavior (1-4). The "Big Five" personality dimensions of the FFM (i.e., Neuroticism, Extraversion, Openness to Experience, Agreeableness, Conscientiousness) (1-4) have been validated across cultures and are argued to approximate a universal structure of personality with hierarchical organization. These five dimensions (i.e., factors) each run along a respective continuum and cut across dichotomous distinctions (i.e., has vs. does not have) made by traditional personality theories, revealing the pervasive influences PT have on the psychosocial functioning of the individual (1-4). PT assessments using the FFM measure how much of a respective trait a person has and have been identified as important inter-individual factors that influence numerous important health experiences, including perceived stress, burden, coping, anxiety and depressive symptoms, health behaviors and quality of life.

It has been established that the family caregivers (FCG) (i.e., family members or close friends not in a paid/profession role) of persons with dementia (PWD) are at increased risk for adverse health outcomes compared with their peers who are not in a caregiving role (5-10). FCG tend to report higher levels of burden, increased occurrence of depression, and lower quality of life (5, 6). Numerous personal and/or care-recipient (i.e., PWD) characteristics (e.g., age, gender, socio-economic status, relationship to PWD, PWD's diagnosis, PWD's cognitive status, PWD's illness severity, and/or behavioral and psychiatric symptoms of dementia (BPSD) in the PWD) have been explored as potential predictors (5, 11-15) of these health experiences and outcomes. However, heterogeneity in the relationships between these characteristics and their impact on FCG persists, and not all FCG of PWD are at the same risk for adverse outcomes even with similar caregiving circumstances (6, 9, 12, 16). Identification of which FCG is at greatest risk and for which outcome remains elusive (5, 11-15).

Personality has emerged as an established factor known to influence a caregivers' experiences (17). Several studies (18-27) focused on the inter-individual factors of personality traits to help explain some of the variability in outcomes for FCG of PWD. These studies suggest that higher reported levels of Neuroticism are associated with low to high increased risk for higher levels of perceived burden and depression (18-20, 22, 23, 27). For example, among FCG living in the home with PWD in Montreal, Canada (N = 157), higher Neuroticism scores were mildly associated with increased burden ($r = .29$; $p < .05$) (27), and among spouse caregivers of PWD in Michigan, USA (N = 233), higher Neuroticism scores were strongly associated with higher depression levels ($r = .76$; $p < .001$) (22).

In addition, these studies have reported that higher levels of Extraversion are associated with low to moderate decreased risk for perceived burden and depression levels (18-20). For example, among FCG living in the home with PWD in Portugal (N = 105), higher Extraversion scores were mildly associated with lower burden ($ß = -.18$; $p < .05$) and depression ($ß = -.24$; $p < .05$) scores (19). While not consistently included in these published studies, additional dimensions of the FFM (i.e., Openness to Experience, Agreeableness, and Conscientiousness) have each been found to mildly influence various caregiver outcomes, including general health and health-related quality of life (18, 19, 21).

A limitation of these trait-based study designs is in the reliance on the individual PT dimensions as self-contained variables. It has been shown, however, that the five PT dimensions within the FFM do co-vary, suggesting that the FFM may be better utilized when considering the interactions of its dimensions within a profile thus accounting for the contribution of all five dimensions and their respective facets (i.e., sub-scales which detail dimension characteristics) (1-4). No studies were identified which utilized a method of combining traits in this population of caregivers rather than investigating the single traits (i.e., dimensions) independently.

Latent profile analysis (LPA) is an empirically driven method which generates previously unobserved, discrete groups or classes (i.e., "profiles") of people based on the normal distribution of the observed (continuous) data (e.g., the 5 dimension mean scores of the Big Five Inventory) (28). This analytic approach can be complementary to trait-based, variable-centered approaches to examining associations with PT (29-31). Previous studies utilizing LPA to assess for associations with PT profiles (in illnesses other than dementia and/or in otherwise generally healthy adults) have identified three latent classes from their respective data with significant differences among the classes on various measures (31-33). Such risk profiles can be useful in evaluating for differences on a wide range of characteristics (28, 29), including demographic and/or clinical characteristics as well as health experiences/outcomes of FCG of PWD such as burden, distress, depressive and anxiety symptoms, life satisfaction and health-related quality of life (HRQoL). However, no known study has previously employed LPA in this population of FCG of PWD to investigate risk associated with membership within an uncovered PT class/profile.

The purpose of the present study was to explore the utilization of LPA in determining whether interactions among FFM personality dimensions can be used to organize a sample of FCG of PWD into groups with similar trait profiles. Once profile groups are defined, the goal of this study was to examine each class in relation to demographic and clinical characteristics that were chosen based on empirical and theoretical considerations to assess for group differences among the profile classes. Therefore, the aims of this study were to identify if there were significant differences in group membership on: 1) FCG demographic characteristics (age, gender, race, education level, employment status, annual income, marital status, relation to PWD and length of marriage when applicable, if living with PWD, and how often PWD is seen; 2) PWD demographic and clinical characteristics of age, gender, race, diagnosis, global cognition, severity of cognitive and physical impairment, and presence of behavioral and psychiatric symptoms of dementia (BPSD); and, 3) FCG outcomes of perceived burden, distress related to BPSD in PWD, depressive and anxiety symptoms, life satisfaction and HRQoL.

Methods

Patients, settings, and procedures

This analysis utilized data from two separate but related, ongoing studies: 1) a descriptive study which evaluates the FCG of PWD (Levenson Lab at the University of California, Berkeley); and 2) a descriptive, longitudinal study which evaluates the patients with a dementia syndrome of a neurodegenerative type which the FCG were caring for (Miller at the University of California, San Francisco, Memory and Aging Center). The present analysis included data from participants from the Levenson FCG study who self-identified as a caregiver of a PWD who also reported on their personality traits (N = 147). The PWD data from the longitudinal (Miller) study which matched closest in timing (within one year) to collection of the corresponding caregiver data from the respective labs were selected for analysis. The cross-sectional analysis presented here is based on data collected between 5/2013-5/2018. This study was approved by the Institutional Review Board at the University of California, San Francisco.

Instruments

The Big Five Inventory, short version 10 (BFI-10), is a 10-item instrument which measures personality traits as defined by the Five Factor Model (i.e., Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness). Each of the five dimensions (i.e., traits) was evaluated using two self-rated items utilizing a 5-point Likert scale (i.e., 1 = disagree strongly, 2 = disagree a little, 3 = neither agree or disagree, 4 = agree a little, 5 = agree strongly), with five of the ten total items requiring reverse-scoring. Higher scores indicate higher levels of each personality dimension. The validity and reliability of the BFI-10 were demonstrated in studies of personality in multiple samples of university students (ranging from N = 75 to N = 726) (34). In our study, the Cronbach's alphas for the BFI-10 were as follows: 0.47 for Neuroticism, 0.57 for Extraversion, 0.41 for Openness to Experience, 0.34 for Agreeableness, and 0.46 for Conscientiousness.

The level of perceived burden experienced by the FCG was measured with the short version of the Zarit Burden Interview (ZBI) (35). This 12-item instrument assesses the level FCG report currently feeling that caring for their PWD affects their health, social life, emotional welfare and other factors using a 4-point Likert scale (i.e., 0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, 4 = nearly always).

Caregiver distress as related to the psychiatric symptomatology of the PWD was collected with the "Distress" scale of the Neuropsychiatric Inventory (NPI) (see below). The total caregiver distress score is obtained by totaling the reported level on each of the applicable (i.e., present in the PWD) instrument domains (up to twelve) using the 5-point "distress" scale of the NPI.

The Center for Epidemiological Studies–Depression scale (CES-D) consists of 20 items selected to represent the major symptoms in the clinical syndrome of depression (36). Total scores can range from 0 to 60, with scores of ≥16 indicating the need for individuals to seek clinical evaluation for major depression. The CES-D has four subscale scores (i.e., depressive affect, somatic, interpersonal problems, positive affect). The CES-D has well established validity and reliability (37).

Anxiety level in the FCG was measured with the Beck Anxiety Inventory (BAI), a 21-item instrument assessing for common symptoms of anxiety within the past month (38). The scoring uses a 4-point Likert scale (i.e., 0 = not at all, 1 = mildly, 2 = moderately, 3 = severely) with a total anxiety score calculated by finding the sum of the 21 items.

The Satisfaction with Life Scale (SWLS) measures global life satisfaction (39). This 5-item instrument assesses the degree of life satisfaction using a Likert scale (i.e., 1 = strongly disagree, 2 = disagree, 3 = slightly disagree, 4 = neither agree or disagree, 5 = slightly agree, 6 = agree, 7 = strongly agree) with a total score obtained by summing the score for each of the five items.

To measure health-related quality of life (HRQoL) in the FCG, the RAND 36-Item Health Survey (SF-36) was used (www.rand.org). While the instrument was designed to assess eight health concepts, only the subscales of physical functioning, role limitations due to physical health, role limitations due to personal/emotional problems and bodily pain were collected and available for analysis.

Assessments for data utilized in this study on the PWD were obtained using the following instruments:

Global cognition was measured with the 30-point Mini-Mental State Exam (MMSE) (40), a screening instrument for the purpose of assessing cognitive impairment.

Severity of cognitive impairment was measured using the Clinical Dementia Rating (CDR) instrument which is a dementia staging instrument (i.e., 0 = normal, 0.5 = very mild dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) assessing six domains (i.e., memory, judgment and problem solving, community affairs, home and hobbies, and personal care) of cognitive and functional performance (Morris, 1993).

Functional status related to the PWD’s level of dependence with instrumental activities of daily living was measured with the 10-item Functional Activities Questionnaire (FAQ) (41).

Functional status related to the PWD’s level of independence with activities of daily living was measured with the 10-item Barthel Index (42).

The neuropsychiatric symptomatology (i.e., behavioral and psychiatric symptoms of dementia (BPSD)) in the PWD was measured with the Neuropsychiatric Inventory (NPI) via informant interview (43). This 12-domain instrument assesses the symptomatology of the PWD over the past month (at time of reporting) from the primary caregiver's perspective and includes a 4-point "frequency" scale, a 3-point "severity" scale and a 5-point "distress" scale which measures how distressing a respective symptom is for the caregiver themselves. The NPI total score is obtained by multiplying the frequency and severity points from domains reported as present in the PWD then adding up the products from each applicable domain.

Data Analysis

Data were analyzed using Stata version 15.1 (StataCorp, College Station, TX) and Mplus Version 8.1 (30, 44-47). Descriptive statistics and frequency distributions were calculated for participant and PWD demographic and clinical characteristics. Latent profile analysis (LPA) was used to identify previously unidentified groups of respondents (latent classes) based on the mean scores of the five BFI scales. Linear regression, Pearson Chi-squared tests of independence, and Kendall's tau coefficients were employed to test differences among the resulting latent personality profile groups in demographic, clinical, and symptom characteristics. Estimation for linear regression was carried out with the nonparametric bootstrap when the outcome was not normally distributed (48). All significance tests were two-sided with an alpha of .05.

Unconditional LPA was employed to identify PT profiles of mean scores on the BFI-10 dimensions that characterized previously unobserved subgroups (latent classes) of this sample of FCG of PWD. Estimation was carried out with full information maximum likelihood (FIML) with standard errors and a Chi-square test that are robust to non-normality and non-independence of observations. Model fit was evaluated to identify the solution that best defined the observed latent class structure based on the Bayesian Information Criterion (BIC), the Vuong-Lo-Mendell-Rubin (VLMR) likelihood ratio test for the K versus K-1 model, entropy, and latent class percentages that were large enough to be reliable (i.e., likely to replicate in new samples: 15%

or about 22 caregivers) (30, 44-47). The BIC is a descriptive fit index wherein comparatively smaller values indicate better model fit. Mixture models such as LPA are known to produce solutions at local maxima. Therefore, our models were fit with from 800 to 1600 random starts. This approach ensured that the estimated model was replicated many times and not due to a local maximum. Estimation was conducted with Mplus Version 8.1 (30, 44-47).

Results

Sample

The total sample (N) of FCG of PWD included in this study's analyses was 147. The mean age was 62.1 years old (SD = 10.5), with 61.2% of the FCG reporting as female, 77.4% as white (non-Hispanic) as their race, 42.1% as retired, and 28.3% as working full-time. 87.7% of the caregivers identified as the spouse/partner of their PWD.

Latent Profile Analysis

Two groups (i.e., profiles) of FCG of PWD were identified based on their most likely latent class membership as derived from their estimated posterior probabilities. Fit indices for the 1- through 3-class solutions are shown in **Table 3.1**. The 2-class solution was selected as the best-fitting model because the BIC for that solution was lower than the BIC for both the 1- and 3-class solutions (46, 47, 49). Further, entropy was acceptable for the 2-class solution at .76 (≥.70; (50)), and the two respective profiles of the BFI-10 means for the 2-class solution made conceptual sense (46, 47). Labels for each of the two classes were chosen by the authors based on examination of the pattern of scores on the personality dimensions, and prior literature using latent class methods to identify classes of personality profiles using a validated personality trait measure (31-33, 51-53).

As summarized in **Table 3.2** and depicted in **Figure 3.1**, the largest proportion of FCG (78%; *n* = 114) was classified in the "Higher Resistance" (HR) class. This class had higher scores on three of the five dimensions (i.e., Extraversion, Agreeableness, and Conscientiousness) compared to the other group, which comprised 22% of the sample (*n* = 33) and was classified as the “Lower Resistance” (LR) class. Compared to the HR class, the LR class had higher scores on both Neuroticism and Openness to Experience. When comparing the empirical data means based on the groupings of the model, the differences between the two classes on mean BFI-10 scores for the dimensions of Neuroticism, Agreeableness and Conscientiousness were each statistically significant (at $p < .01$) (see **Table 3.3** and **Figure 3.2**).

Differences between the latent classes in caregiver characteristics and PWD clinical characteristics

No significant differences or associations between the two latent classes were found on FCG characteristics or in PWD clinical characteristics when examined with bootstrapped simple linear regression, Chi-squared tests of independence, and Kendall's tau-b, depending on the scale of the characteristic. (See **Tables 3.4** and **3.5**).

Differences between the latent classes in caregiver outcomes

FCG perceived burden, distress, depression (including four subscales of depression), anxiety level, life satisfaction, the health-related quality of life (HRQoL) principle component scale as well as the HRQoL bodily pain, physical role limitations and emotional role limitations subscales, were all tested to evaluate how the two latent classes differed. Differences were estimated with nonparametric bias-corrected bootstrapped confidence intervals due to non-normality of the score distributions. Three statistically significant differences were found. The LR class reported lower mean scores than the HR class on life satisfaction, and the HRQoL subscales of bodily pain and role limitation due to emotional/personal problems. (See **Table 3.6**).

Discussion

This is the first known study to utilize LPA to explore latent classes of FCG of PWD on the Big Five personality dimensions. We found a statistically significant difference between the two classes (i.e., “Higher Resistance” (HR) vs. “Lower Resistance” (LR)) on levels of life satisfaction (SWLS) and two subscales of the SF-36 HRQoL instrument. Membership in the HR class is associated with higher levels of life satisfaction but also higher levels of reported bodily pain and role limitation due to emotional problems. The HR class is defined particularly by higher levels of Conscientiousness and also lower levels of Neuroticism and higher levels of Agreeableness (see **Table 3.3** and **Figure 3.2**). Each of these three differences in personality dimensions among the two latent classes were statistically significant with Conscientiousness contributing the largest difference in mean scores among the five PT dimensions.

Conscientiousness is presumed to measure an individual’s level of “organization, persistence, control and motivation in goal directed behavior” (1-4). Some instrument versions measuring the Big Five also measure multiple facets (i.e., sub-scales) within the five primary dimensions. In these instruments, the Conscientiousness dimension includes sub-scales such as competency/efficiency, order/organization, dutifulness/carefulness, achievement striving, and deliberation (1-4). The SWLS is designed to measure “global cognitive judgments of one’s life satisfaction” (39) which may be influenced by the degree of organization and persistence an individual tends to employ in different situations and at different times. The subscales (i.e., self-discipline, achievement striving, competency) deemed to be most represented by the relevant Conscientiousness questions asked in the BFI-10 (i.e., I see myself as someone who: 3. … tends to be lazy (gets reverse scored); and, 8. … does a thorough job) indicate tendencies which may help support these caregivers scoring high on Conscientiousness in resisting the challenges presented in their caregiving situation. This profile high in Conscientiousness may, in addition, facilitate achieving a satisfactory level of quality of life while in the chronic situation of caring for a PWD. This may be due, in part, to tendencies for planning ahead and being selfdisciplined in their achievement striving. The mean SWLS total score (22.96 (SD = 7.31)) for the HR class suggests that on average these members score in the “Average” range (i.e., 20-24) on the SWLS. This range is categorized as being generally satisfied with most areas of their lives but with recognition that there are areas where they would like to see improvement (39).

While the LR class is defined, in part, by higher mean scores on the Neuroticism dimension, the mean scores for each of the five personality dimensions were above the median (i.e., 2.5) of the respective 0-5 scales across both classes. These two relatively high-scoring profiles suggest that the sample of FCG as a whole scored mild-to-moderately high on all five personality dimensions with Conscientiousness being the primary difference between the two latent classes. The pattern of the overall sample profile follows closely to that of the profile for the HR class (see **Figure 3.3**). The total sample’s mean (SD) scores for each of the five dimensions were: 2.66 (.82) for Neuroticism, 3.48 (.85) for Extraversion, 3.62 (.89) for Openness to Experience, 3.88 (.63) for Agreeableness, and 4.27 (.65) for Conscientiousness (see **Figure 3.3**).

Our HR class resembles Morgan, et al.’s (32) “Resilient” class. The authors reported on three latent classes in patients undergoing chemotherapy (N=1248) – defined as “Resilient”, “Normative” and “Distressed” – with their “Resilient” class scoring lowest on Neuroticism, and highest on the other four dimensions. In addition, our HR class is partially consistent with Merz & Roesch’s (33) “Well-adjusted” class with the lowest scores on Neuroticism and relatively higher scores on the other dimensions and most class means above the median (i.e., 2.5). The authors reported on a 3-class solution that best fit their data in a heterogeneous sample of college students from a large university (N = 371).

Although we did not explicitly predict any *a priori* hypotheses for associations between latent classes and caregiver outcomes, the analytical approach employed in this study (i.e., LPA) was expected to complement prior studies that used trait-based approaches to examine personality in relation to caregiver outcomes (29, 31-33). Our study, however, did not find any of th, previously observed differences between the two latent classes on highly prevalent caregiver outcomes such as perceived burden and depressive and/or anxiety symptoms. Neuroticism and Extraversion are the two dimensions most frequently investigated in this population of caregivers with statistically significant findings across studies of their respective relationships with outcomes such as perceived stress, role strain, perceived burden, anxiety and depressive symptoms and quality of life (18-27). While the LPA performed in this sample did not support previous findings for these dimensions, it should be noted that our sample size (N=147) was relatively small for conducting mixture modeling techniques, and we may not have been powered to reveal these types of associations in this manner.

An additional limitation of this study was in the instrument used to measure PT. The BFI-10 measures only two items per dimension, limiting the amount of data as well as relevant subscales measured by the instrument (1-4). In addition, the alphas for each of the Big Five dimensions as measured by the BFI-10 in this sample were below an “acceptable” level of item correlation (≥ .70) between items. The potentially high degree of variance explained by error in the measurements made from the BFI-10 limit the reliability of interpretations that can be made from their scores.

Despite these limitations, the present findings suggest that personality traits continue to be important considerations when evaluating the health outcomes of caregivers of PWD. The PT profile in the LR class may represent a combination of traits that, in this particular context, predisposes to relatively lower levels of life satisfaction. In contrast, the HR class showed a predisposition to relatively higher levels of life satisfaction but also higher levels of reported bodily pain and limitations due to personal/emotional problems. However, these findings should not be interpreted to suggest that the combination of traits illustrated in the HR class is inherently better. Future research should examine latent classes in larger samples of caregivers of PWD while also using a more robust instrument measuring the Big Five. Approaches such as LPA may be useful to researchers examining the relationship of personality with affect, coping, symptoms, health behaviors and quality of life in different caregiver populations. These approached may be well-suited in the clinical setting as well for purposes of better predicting which FCG may be at higher risk and for what outcomes to guide tailored interventions.

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Table 3.1 Latent profile solutions and fit indices for 1-, 2- and 3-class solutions.

Model	LL	AIC	BIC	Entropy	VLMR
1-Class	-836.976	1693.953	1723.857		
2-Class[a]	-820.764	1673.529	1721.375	0.759	χ^2 = 32.424[b]
3-Class	-806.905	1657.811	1723.600	0.682	χ^2 = 27.718[c]

Abbreviations: LL = log-likelihood; AIC = Akaike's Information Criterion; BIC = Bayesian Information Criterion; VLMR = Vuong-Lo-Mendell-Rubin likelihood ratio test for the K vs. K-1 model.

[a] The 2-class solution was selected because the BIC for that solution was lower than the BIC for the 1- and 3-class class solutions.

[b] Not significant at *p* = 0.054

[c] Not significant at *p* = 0.086

Table 3.2 Profile Means of the BFI LPA 2-Class Model (N = 147).

BFI Factor Dimension	Class 1 n = 33 (22%) Mean (SE)	Class 2 n = 114 (78%) Mean (SE)
Neuroticism	2.97 (0.15)	2.56 (0.09)
Extraversion	3.37 (0.17)	3.52 (0.09)
Openness to Experience	3.75 (0.19)	3.57 (0.09)
Agreeableness	3.61 (0.12)	3.97 (0.07)
Conscientiousness	3.41 (0.18)	4.56 (0.06)

Abbreviations: BFI = Big Five Factor; C1 = Class 1; C2 = Class 2; LR = lower resistance; HR = higher resistance; SD = standard deviation.

**Statistically significant difference in means between the two classes

1 >< 2 = direction of difference between classes

Table 3.3 Differences in empirical means of the five BFI personality dimensions between the personality classes (N = 147).

BFI Factor Dimension	**C1** **n = 33 (22%)** **Mean (SD)**	**C2** **n = 114 (78%)** **Mean (SD)**	**Test statistic and contrasts**
Neuroticism	3.03 (0.83)	2.55 (0.79)	*t* = 3.04; *p* = .003** 1 > 2
Extraversion	3.41 (0.84)	3.50 (0.85)	*t* = -.57; *p* = .57 1 < 2
Openness to Experience	3.83 (0.94)	3.55 (0.86)	*t* = 1.59; *p* = .12 1 > 2
Agreeableness	3.62 (0.70)	3.95 (0.59)	*t* = -2.73; *p* = .007** 1 < 2
Conscientiousness	3.30 (0.41)	4.55 (0.38)	*t* = -16.17; *p* < .0005** 1 < 2

Abbreviations: BFI = Big Five Inventory; C1 = Class 1; C2 = Class 2; SD = standard deviation.
**Statistically significant difference in means between the two classes.
1 >< 2 = direction of difference between classes

Table 3.4 Differences in caregiver characteristics between the personality latent classes (N = 147).

Characteristic	**C1 – LR** **Mean (SD)/*n* (%)**	**C2 – HR** **Mean (SD)/*n* (%)**	**Test statistic and contrasts**
Age (years)	62.21 (10.52)	62.06 (10.58)	-4.17 3.99†
Gender			$\chi^2 = 0.24$; $p = 0.63$
Female	14 (42)	43 (38)	Cramér's V = 0.04
Male	19 (58)	71 (62)	
Ethnicity/Race			$\chi^2 = 0.03$; $p = 0.86$
White/ Non-Hispanic	15 (79)	67 (77)	Cramér's V = 0.02
Other/Non-White	4 (21)	20 (23)	
Education (level)			Kendall's tau-b = -0.04;
Less than HS	0	0	$p = 0.63$
HS/GED	4 (12)	10 (9)	
2-year College	5 (15)	22 (20)	
4-year College	12 (36)	46 (41)	
Master's Degree	6 (18)	23 (20)	
PhD, MD, Other Professional Degree	6 (18)	12 (11)	
Employed			$\chi^2 = 1.69$; $p = 0.64$
Full-Time	8 (24)	33 (30)	Cramér's V = 0.11
Part-Time	4 (12)	20 (18)	
Retired	17 (52)	44 (39)	
Not/Other	4 (12)	15 (13)	
SES (annual income bracket)			Kendall's tau-b = 0.08; $p = 0.33$
< $20,000	4 (17)	12 (15)	
$20,000-$35,000	4 (17)	10 (12)	
$35,001-$50,000	2 (8)	9 (11)	
$50,001-$75,000	5 (21)	13 (16)	
$75,001-$100,000	4 (17)	9 (11)	
$100,001-$150,000	2 (8)	12 (15)	
> $150,001	3 (13)	18 (22)	
Marital Status			$\chi^2 = 0.49$; $p = 0.48$
Married/Partnered	32 (97)	106 (94)	Cramér's V = -0.06
Not Married/Partnered	1 (3)	7 (6)	
Relationship to PWD			$\chi^2 = 0.414$; $p = 0.52$
Spouse/Partner	30 (91)	98 (86.73)	Cramér's V = -0.05
Child/Other	3 (9)	15 (13)	
Length of Marriage to PWD (years)	34.47 (14.34)	34.31 (15.22)	-6.09 5.69†
Lives with PWD			$\chi^2 = 0.02$; $p = 0.97$
Yes	30 (91)	103 (92)	Cramér's V = 0.004
No	3 (9)	10 (9)	
Sees PWD			$\chi^2 = 0.19$; $p = 0.67$
≥ Daily	29 (90.62)	105 (93)	Cramér's V = 0.04
< Daily	3 (9.38)	8 (7)	

Abbreviations: C1 = Class 1; C2 = Class 2; LR = lower resistance; HR = higher resistance; F = female; SD = standard deviation; SES = socioeconomic status; PWD = person with dementia. †Significance tested with nonparametric bias corrected bootstrapped confidence interval (at 95%); if 0 is in the interval, it is not significant.

Table 3.5 Differences in clinical characteristics in PWD between the personality latent classes (N = 147).

Characteristic	**C1 – LR** **Mean (SD)/*n* (%)**	**C2 – HR** **Mean (SD)/*n* (%)**	**Test statistic and contrasts**
PWD Age (Years)	66.18 (7.54)	66.06 (9.35)	-2.96 3.08†
PWD Gender			$\chi^2 = 0.75$; $p = 0.39$
Female	17 (52)	65 (57)	Cramér's V = -0.07
Male	16 (49)	49 (43)	
PWD Race/Ethnicity			$\chi^2 = 0.09$; $p = 0.77$
White/Not-Hispanic	28 (85)	99 (87)	Cramér's V = -0.02
Other/Non-White	5 (15)	15 (13)	
Dx			$\chi^2 = 1.70$; $p = 0.64$
AD	5 (15)	26 (23)	Cramér's V = 0.11
bvFTD	6 (18)	26 (23)	
PPA	10 (30)	30 (26)	
Parkinsonism/Other	12 (36)	32 (28)	
Global Cognition Total	22.79 (6.72)	23.62 (5.71)	-3.52 1.49†
Cognitive Impairment Severity Total	4.15 (2.32)	4.41 (2.86)	-1.19 0.68†
Cognitive Impairment Severity Level			Kendall's tau-b =-0.04; $p = 0.59$
Not Impaired	2 (6)	10 (9)	
MCI	13 (40)	52 (46)	
Mild Dementia	17 (52)	41 (36)	
Moderate Dementia	1 (3)	11 (10)	
Severe Dementia	0	0	
Cognitive Functional Impairment Total	12.56 (7.60)	13.04 (8.05)	-3.51 2.43†
Physical Functional Impairment Total	93.94 (11.23)	93.21 (14.69)	-4.18 5.14†
BPSD Total	27.33 (19.79)	30.48 (23.55)	-11.14 5.06†

Abbreviations: C1 = Class 1; C2 = Class 2; LR = lower resistance; HR = higher resistance; SD = standard deviation; PWD = person with dementia; Dx = diagnosis; AD = Alzheimer's disease; bvFTD = behavioral frontotemporal dementia; PPA = primary progressive aphasia; RPD = rapid progressive dementia; MCI = mild cognitive impairment; BPSD = behavioral and psychiatric symptoms of dementia.

†Significance tested with nonparametric bias corrected bootstrapped confidence interval (at 95%); if 0 is in the interval, it is not significant.

Table 3.6 Differences in perceived burden, distress level related to BPSD in PWD, depression, anxiety, life satisfaction and HRQoL between the personality latent classes (N = 147).

Measure	**C1 – LR Mean (SD)**	**C2 – HR Mean (SD)**	**Test statistic and contrasts**
Perceived Burden Level	18.97 (8.43)	17.29 (9.96)	-1.87 5.56†
Distress Total	12.82 (9.02)	13.51 (9.21)	-4.18 2.87†
Depression Total	13.80 (8.26)	11.38 (8.22)	-0.65 5.81†
Depressive Affect Subscale	4.10 (3.42)	3.41 (3.43)	-0.61 2.12†
Somatic Subscale	4.97 (3.09)	3.96 (3.27)	-0.15 2.36†
Interpersonal Problems Subscale	0.47 (.82)	0.18 (.64)	-0.01 0.63†
Positive Affect Subscale	7.77 (3.02)	8.20 (2.88)	-1.58 0.78†
Anxiety Level	9.10 (8.48)	6.28 (6.66)	-0.25 6.05†
Life Satisfaction	20.23 (6.03)	22.96 (7.31)	**-5.20 -0.25†**** 1 < 2
HRQoL			
PCS	69.35 (36.35)	70.87 (38.11)	-17.16 12.80†
Pain Subscale	73.23 (18.99)	81.03 (20.62)	**-15.42 -0.62†**** 1 < 2
Role Limitation – Physical	15.23 (14.74)	12.49 (17.74)	-3.19 9.09†
Role Limitation – Emotional	66.67 (44.72)	84.10 (29.95)	**-34.10 -1.46†**** 1 < 2

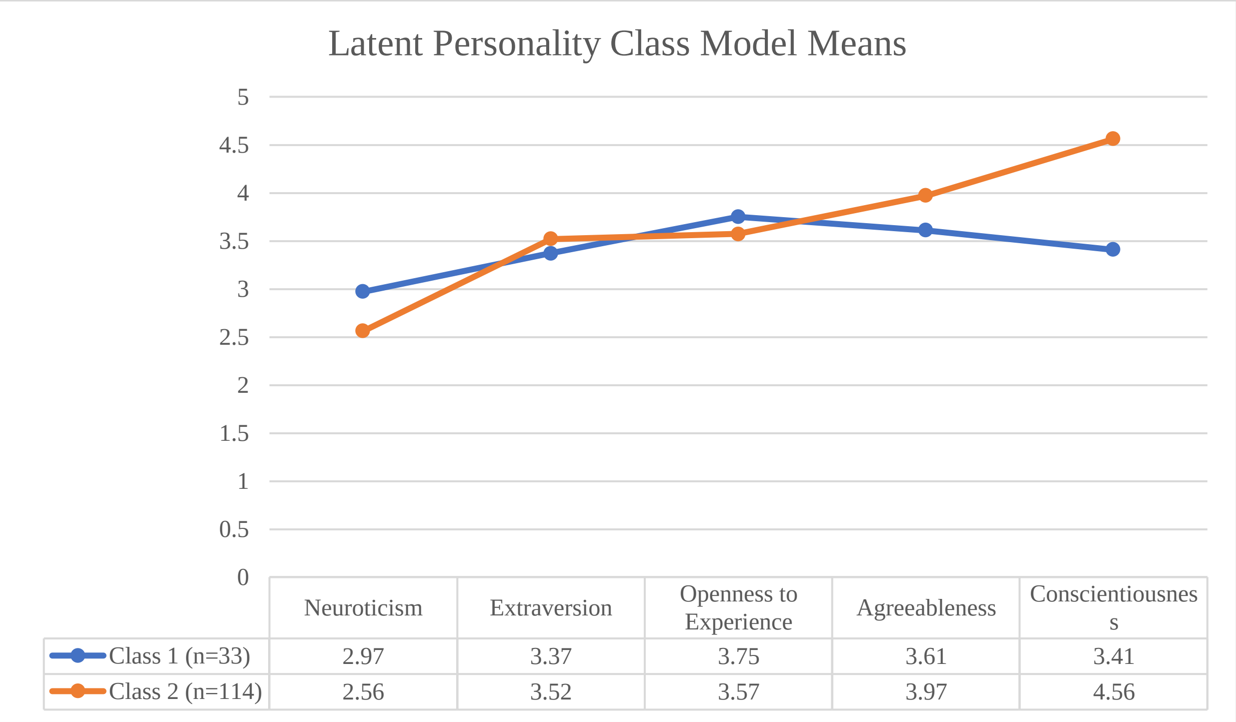
Abbreviations: C1 = Class 1; C2 = Class 2; LR = lower resistance; HR = higher resistance; SD = standard deviation; r/t = related to; BPSD = behavioral and psychiatric symptoms of dementia; PWD = person with dementia; HRQoL = health-related quality of life; PCS = physical health component summary.

†Significance tested with nonparametric bias corrected bootstrapped confidence interval (at 95%); if 0 is in the interval, it is not significant.

******Statistically significant difference between classes at 95% Confidence Interval

1 < 2 = direction of difference between classes

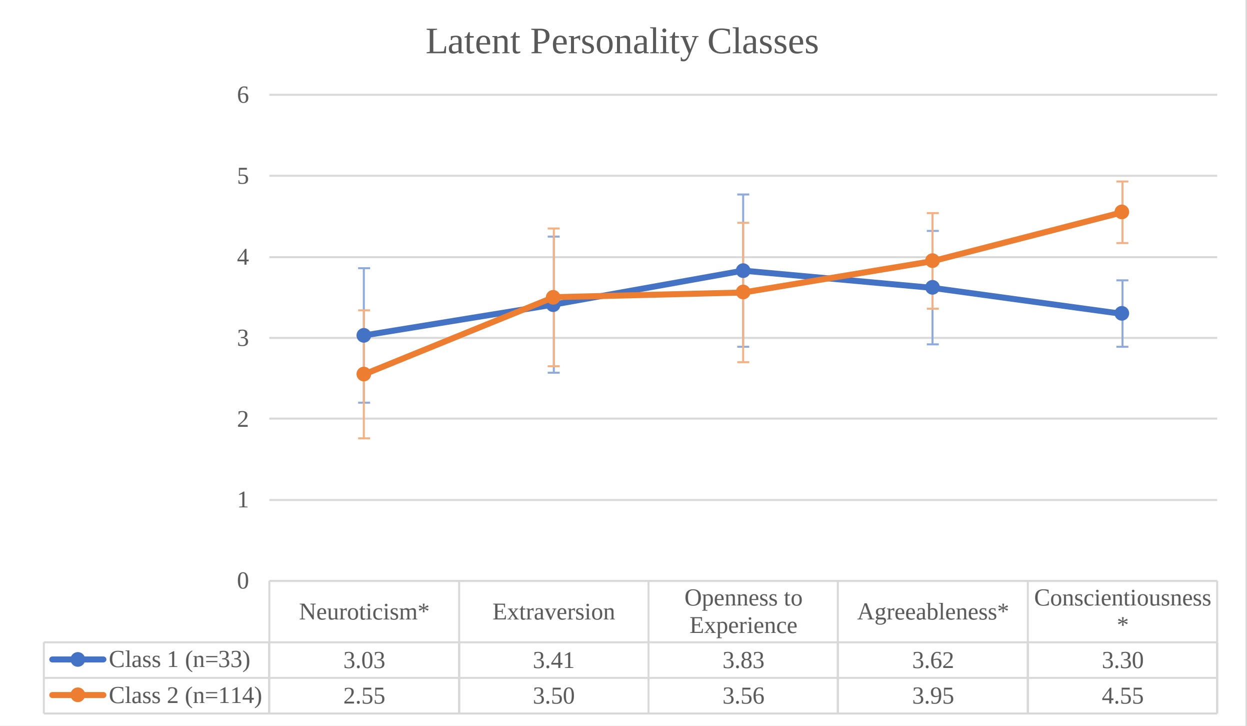
Figure 3.1 Graph of the LPA 2-Class Model (N = 147).



	Neuroticism	Extraversion	Openness to Experience	Agreeableness	Conscientiousness
Class 1 (n=33)	2.97	3.37	3.75	3.61	3.41
Class 2 (n=114)	2.56	3.52	3.57	3.97	4.56

Abbreviations: BFI = Big Five Inventory; LPA = latent profile analysis; SE = standard error.

Figure 3.2 Graph of the empirical personality profile means data (N = 147).



	Neuroticism*	Extraversion	Openness to Experience	Agreeableness*	Conscientiousness *
Class 1 (n=33)	3.03	3.41	3.83	3.62	3.30
Class 2 (n=114)	2.55	3.50	3.56	3.95	4.55

* = statistically significant difference in means on dimensions between classes at *p* < .01

Qualitative Descriptions of Empirical Class Profiles:

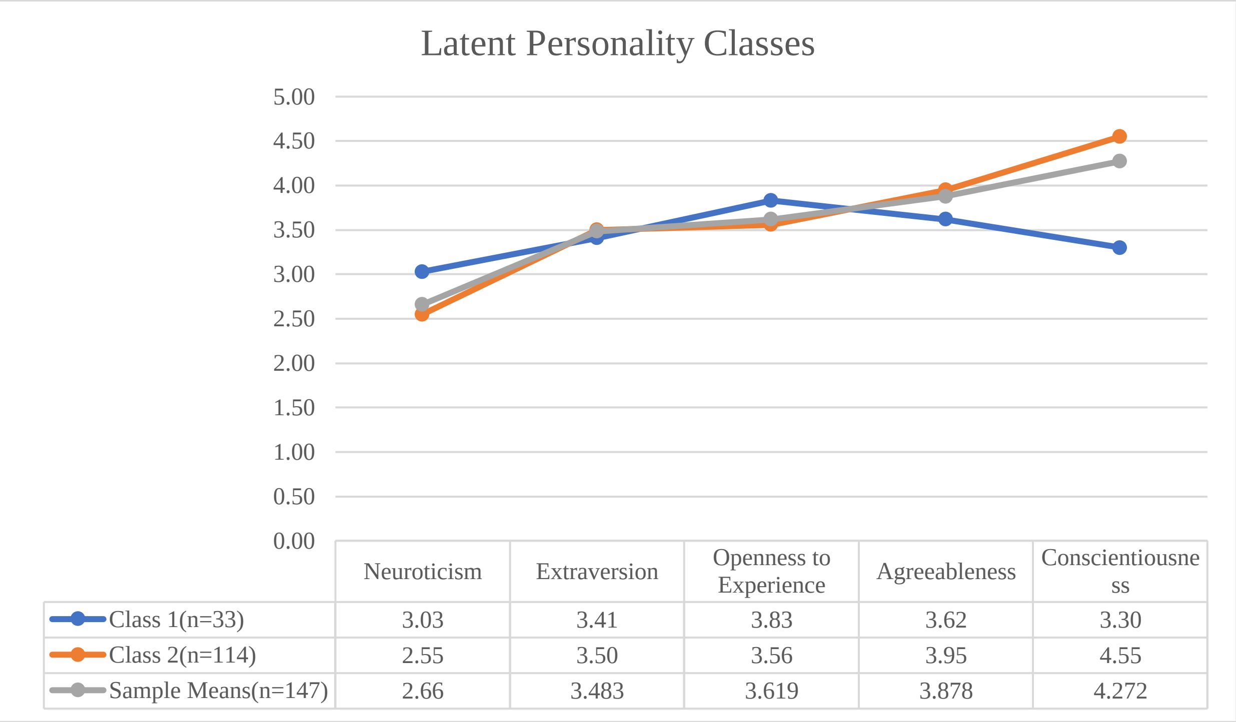
<u>Class 1: Lower Resistance</u>

- Higher on:
  - Neuroticism*
  - Openness to Experience
- Lower on:
  - Conscientiousness*
  - Agreeableness*
  - Extraversion

<u>Class 2: Higher Resistance</u>

- Higher on:
  - Conscientiousness*
  - Agreeableness*
  - Extraversion
- Lower on:
  - Neuroticism*
  - Openness to Experience

Figure 3.3 Graph of the LPA class and total sample means (N = 147).



	Neuroticism	Extraversion	Openness to Experience	Agreeableness	Conscientiousness
Class 1(n=33)	3.03	3.41	3.83	3.62	3.30
Class 2(n=114)	2.55	3.50	3.56	3.95	4.55
Sample Means(n=147)	2.66	3.483	3.619	3.878	4.272

Paper 3

Role Identity Transition: A Theoretical Framework Around Being the Spouse of a Person with Early-Age Onset Dementia

Sasha Sage Binford

Sasha S. Binford, PhDc, AGCNS-BC[1,2], Karen Schumacher, PhD[1],
Margaret Wallhagen, PhD[1], GNP-BC, Heather C. Leutwyler, PhD, FNP, CNS[1]

1. University of California, San Francisco, School of Nursing
2. University of California, San Francisco, Memory and Aging Center

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Abstract

Purpose: The purpose of this study is to explore the meanings caregivers of spouses with early-age onset dementia (EOD; defined as age of symptom onset before 65 years) ascribe to their role in their unique situation, and actions employed as coping mechanisms to provide the basis for development of theory illustrating the shared, basic, psychosocial processes underlying their situation of being a spouse of a person with EOD. **Background**: The informal caregivers of persons with EOD are most frequently the affected individuals' spouse and are reported to experience greater levels of distress and burden and lower quality of life than those caring for older individuals with a more typical Alzheimer's-type dementia. These caregivers face unique challenges related to the unexpected nature of disease onset at this life stage and atypical symptoms more prevalent in this patient population, and report feeling less prepared for the role than spouses of late-onset dementia (defined as age of symptom onset at/after 65 years). These factors can have potentially devastating repercussions on socio-professional, financial, and psychological dimensions of family life for these EOD caregivers. A "one-size-fits-all" approach to supporting these caregivers continues to be employed which risks overlooking specific needs stemming from this caregiver population's unique situation and contributing to adverse outcomes. However, there is no known study exploring the meanings made of the shared situation of this caregiver population with attention on development of a theoretical framework to guide relevant studies investigating interventions specific to this caregiver population. **Methods**: Semi-structured interviews and participant observations were conducted with five participants. Qualitative data were collected and analyzed with grounded theory methodology. **Results**: Each of the participants had made or was in the process of making an identity transition: how they view their role in their respective dynamic is becoming more and more caregiver-like towards an eventual, complete shift to that of a caregiver. The distinction was made across all five participants between identifying as a spouse versus as a caregiver of their person with EOD – they do not see themselves as a combination of both (i.e., a "spousal

caregiver”). This process appears to take on a step-wise fashion, with incremental shifts in identity reflecting challenges to the notion held of what it means to be a “spouse” (defined by each participant as a “partner”). These shifts occur as means of coping with the incongruencies presented by their person with EOD’s inabilities to meaningfully contribute to family needs (e.g., generating an income, managing financial responsibilities, providing dependent care, as well as attending to emotional aspects of the relationship). The “step-downs” represent particular moments in the otherwise continuous decline of the person with EOD which carry special meanings for the respective participant, causing them significant distress and requiring them to take action. **Implications**: These results support prior research highlighting the unique experiences of these caregivers at this life stage while providing a framework for understanding psychosocial dimensions unique to this caregiver population. The results inform the design of future tailored interventions for spouses of persons with EOD.

Role Identity Transition: A Theoretical Framework Around Being the Spouse of a Person with Early-Age Onset Dementia

Introduction

Background/Significance

Studies with a focus on persons with an early-age of onset dementia (EOD; defined as an age of symptom onset younger than 65 years) have indicated that the primary caregivers are more frequently the person with EOD's (PWEOD) spouse (also: "partner/companion/significant other") (1). These younger, spouse-caregivers are reported to experience greater levels of stress and burden and lower quality of life than those – including their peers – caring for older individuals with the more common, typical (i.e., memory-predominant) Alzheimer's dementia (2-8). Spouse-caregivers for persons with PWEOD face unique challenges related to the unexpected nature of the disease onset at this life stage and the atypical symptoms more prevalent in this patient population (e.g., dysexecutive, disinhibition, apathy), and report feeling less prepared for the role than spouses of late-onset dementia (LOD; defined as an age of symptom onset at or older than 65 years) (8-11). These factors can have potentially devastating repercussions on the socio-professional, financial, and psychological dimensions of family life for these EOD caregivers (12).

Clinical experience suggests that spouse-caregivers of PWEOD report regularly about the challenges they are confronted with in their home/family situations, including early changes in the marital dynamics, managing difficult behaviors, the impact on their employment and earning status, and the concerning effects on dependent children still in the home. The framework currently employed for delivering care to spouse-caregivers of PWEOD is primarily based on evidence from studies focused on more "typical" caregivers of older-age persons with Alzheimer's-type dementia. This "one-size-fits-all" approach does not account for specific needs of the PWEOD spouse-caregivers' unique situation and may contribute to their negative outcomes (13). We need more comprehensive avenues for understanding the psychosocial dimensions unique to this population to better inform designing tailored interventions that best address their situation.

In addition, there were many assumptions carried over within the above-stated work interactions, both with the dyads but also with colleagues in the same setting. For example, it is not uncommon in practice to refer to the spouses of our patients with dementia as “caregivers” even at the onset of a diagnosis when a respective patient may still be relatively independent in their Activities of Daily Living (ADLs); an assumption is made that these spouses self-identify as such which may overlook the significance of the meaning that identity (i.e., of “caregiver”) may carry to the individual.

Investigating the meanings these caregivers ascribe to their role in their situation of being the spouse of a PWEOD, and the actions employed as coping mechanisms can provide the basis for development of theory illustrating the shared, basic, psychosocial processes underlying their situation. The resulting tailored framework could guide relevant studies investigating interventions specific to uncovered (mal)adaptive mechanisms *these* caregivers use to cope with the circumstances around their role as a spouse-caregiver for a PWEOD at their relatively young age. While previous studies have reported on the experiences of the spouses of PWD, meanings for this specific population of spouses of PW*EOD* have not been reported on in the literature.

A process of adjustment was interpreted by Robinson, Clare and Evans (14) in their qualitative study of spousal dyads in which one partner had received a dementia diagnosis within the prior two years of investigation. The authors described a broad theme of “*attempting to make sense of their situation in the early stages of a dementia diagnosis*” and illustrated changes in the caregivers’ roles and identities while managing grief associated with real and anticipated loss. Shim, Barroso and Davis’s (15) comparative qualitative analysis identified three distinct groups of spousal caregivers based on how they described their experience – *negative,* *ambivalent, or positive*. The authors concluded that these different perspectives influence caregivers' varying abilities to accept the changes in their spouse and adapt their role in accordance to their spouse's growing needs.

In their qualitative systematic review, Evans and Lee (16) aimed to understand the impact of dementia on marriage and interpreted a process of *transition* and *loss*. The authors described these caregivers' role transition as being related to the cyclic interplay of change and loss, as each brings about the other: change leads to loss, and loss leads to change. Pozzebon, Douglas and Ames (17) synthesized the qualitative research exploring the experiences of the spouses of PWD with a focus on the influential cognitive-behavioral aspects. The authors identified the central theme of "*loss of partner*" with four synthesized subthemes: "*acknowledging change; being in crisis; adapting and adjusting; accepting and moving forward*" (pp. 546).

None of the above studies were specific to spouses of a PW*EOD*, however, and the respective findings may not be understood as generalizable processes applicable to understanding the unique situation of EOD spouse-caregivers at the life stage that they are affected.

Two qualitative studies which reported on key aspects specifically related to the impact on and perspectives of the family caregivers of individuals with *EOD* have described themes around issues of: "*diagnostic problems, impact of caregiving, relationship changes and lack of resources*" (18); and, "*acceptance, perception of the relationship, role adaptation, availability of appropriate services, social support, awareness in the person with dementia and acceptance of help*" (19). In their systematic review of the qualitative literature, Cabote, Branble & McCann (20) explored the experiences of family caregivers caring for a relative with EOD, and reported five themes: "*dementia damage, grief for loss of relationship, changes in family roles, positive and negative impacts of family caregiving, and transition to formal care*". While these studies touched on important aspects specifically related to the experiences of caregiving for persons with *EOD*, the participants were not exclusively the *spouses/partners* of the PWEOD.

Ducharme et al., (21) documented the lived experience of *spouse* caregivers in EOD and identified themes specific to: "*difficulty managing behavioral and psychiatric symptoms, long quest for diagnosis, nondisclosure to others and denial of diagnosis, grief for loss of spouse and midlife projects, difficulty juggling unexpected role and daily life responsibilities, and difficulty planning for future*".

The themes that emerged in the above qualitative studies remained limited to narrow categories of experience and did not articulate a unifying shared problematic situation, nor did they provide any construction of an overarching framework illustrating the basic social processes at play in the specific situation of caregiving for a spouse with EOD. To move the science forward in identifying who in the caregiver population of spouses of PWEOD is at greatest risk for adverse health outcomes and how to best intervene, an understanding of the basic, shared psychosocial processes involved in this population's unique problematic situation is needed. There is no known study exploring the *meanings* made of the shared situation of this caregiver population with attention on development of a theoretical framework through exploring the interactions and processes that take place within the EOD spouse-caregiver situation.

Purpose, Specific Aims of the Study, and Research Question

The purpose of this study was to understand the underlying psychosocial processes at play in the situation of being a spouse of a PWEOD with the goal of investigating the shared basic social problems from the participants' perspectives. The aims of this study were to: (1) describe the ways that spouse-caregivers of PWEOD define the situation in which they find themselves; (2) describe the actions spouse-caregivers of PWEOD take to manage their lives in the context of perceived challenges related to their spouses' gradual cognitive, emotional and functional decline; and, (3) develop theory framing the psychosocial process(es) that illustrates the shared experiences of the problematic situation for this population of spouse-caregivers of PWEOD. An assumption was made that the participants share a problematic situation, which they may or may not know on a conscious level (22). Their own understandings of the problem needed to be revealed so that the developed theory would reflect what the participants do to resolve it (22).

A concern for this investigation was in determining how the conditional features (i.e., situational elements) of the social environment situate the direction and form of the identified psychosocial processes through their influence on the meanings made of and subsequent actions taken in response to their problematic situation (23). The ultimate goal of this study was to generate a framework of understanding around these processes that are specific for this caregiver population of spouses of PWEOD to inform future researchers but also current practitioners, particularly the nurses, who work with the caregiver-care-recipient EOD dyads in more effectively helping them manage *their* situation, and, ultimately, to help reduce the risk for adverse outcomes related to caregiving for a spouse with EOD.

Methods

Methodology

This study employed the methods of Grounded Theory (GT) described by Strauss and Corbin (24, 25). GT aims to understand human experience with a focus on the social contexts of human action and interaction, meaning, and interpretation of meaning, with emphasis on developing explanatory theory (24-26). Context in GT is understood as having a function "to facilitate, to hinder, and to influence human goals and social psychological processes" (27). In the context of caregiving for a spouse diagnosed with EOD, the methodology of GT enabled a focus on the Symbolic Interactionist (SI) principle of starting with the meanings in the interactions I am studying (28, 29). SI is a micro-level theory which focuses on the relationships between individuals within a social context outlined by the basic assumptions that: 1) humans interact with things based on meanings ascribed to those things; 2) the ascribed meaning of things comes from the interactions with others and society; and, 3) the meanings of things are interpreted by a person when dealing with things in specific circumstances (i.e., contexts) (29). SI guided the approach to this inquiry through one-on-one conversations with a sample of individuals from this EOD spousal-caregiver population to study the language and actions reflective of their meaning-making.

It has been argued within the SI framework that all knowledge is situated knowledge; just as social actors interpret and make sense of what is "real," so too do the researchers who study them (28). Inevitably, sensitizing concepts would be carried into this study from this researcher's clinical work, reading, and educational/research experience, as well as from explicit theories that might be useful if checked against the systematically gathered data, in union with theories emerging directly from analysis of these data (22). While this researcher's presence and personal experiences could not be removed from the process, work was made towards cultivating theoretical sensitivity through utilizing reflexive memos to capture preconceived notions and also by engaging in constant comparison with the data which allowed for the emergence of theory that is truly grounded in those data (26).

Participants

Participants were identified and recruited through a memory care center in the Bay Area of California based on the study inclusion criteria of: *a self-reported spouse/partner/significant other of a person with a confirmed diagnosis of an EOD (defined as symptom onset younger than 65 years; e.g., early-age onset Alzheimer's disease, frontotemporal dementia, parkinsonism), who is English-speaking, and has email access*. A study modification was approved to include the option of conducting interviews through an online videoconferencing application (Zoom: https://zoom.us) to enable an expanded range of recruitment outside of the geographically accessible area of this researcher.

An exact determination of the size of the sample for a GT study could not be established *a priori*; the units of analysis are not predetermined in GT and cannot be known until more data are in hand (22). Therefore, only an initial sampling for data collection using the inclusion criteria and resulting participant pool described above could be planned in advance, with a goal for a minimum sample size set at ten. As data collection proceeded, and concepts identified, the process of theoretical sampling (24-26) was employed, in which this researcher engaged in ongoing data analysis to identify emerging themes or leads in the data, which then were followed up by choosing new research participants and/or interview questions to gather specific data until data saturation was met.

Eighty-four potential participants met the study criteria and were sent an email invitation to participate. Thirty-six (43%) responded to the email invite with: six (14%) refusing to participate due to time constraints; seven (19%) stating they would “maybe” participate at a later date but were then lost to follow-up; and seven (19%) agreeing to participate but then did not follow-through with scheduling an interview for unknown reasons. Sixteen (45%) interviews were scheduled with: one not showing up at the scheduled time; and fifteen (42%) completed by the end of the study. See **Table 4.1** for participant characteristics.

Data Collection and Analysis

The University of California, San Francisco’s Institutional Review Board approval was obtained for this study. Verbal consent following a joint review of the consent form was deemed sufficient with a copy of the form, including the IRB’s contact information, provided to each participant prior to beginning with the interview.

Semi-structured interviews with participant observations were the primary methods of data collection, with an interview guide created to facilitate this process (see **Appendix 4.A** for examples of interview questions). The kinds of questions considered at the beginning stage of the data collection process generally asked: “*What all is going on here?”* with follow-up questions and prompts to get richer, more detailed descriptions of their situation, using caution not to “lead” the participants into providing answers that may have been expected. As hunches developed about what was going on in the data, exploratory analyses were conducted around various circumstances under which an event does or does not happen, which meant asking more specific questions and seeking out informants that met more specific or different criteria. Participation included at least one in-depth interview lasting 1-1.5 hours with the option for up to three interviews if new questions arose in interviews with later participants. Each interview was audio-recorded with knowledge of and permission by the participants.

The participant’s home was the preferred setting for data collection in accessible locations, though left up to each respective participant to decide what they were comfortable with or what worked best for the situation. A potential strength in utilizing GT methodology is that research takes place in naturalistic settings (27) enabling the researcher to study human behavior within its social context. In addition, to catch process, this researcher took the role of an acting unit of study under the assumption that knowledge is embodied and situated (29). Blumer, as cited by Pawluch & Neiterman (28), urged “firsthand and deep acquaintance with the sphere of life under study”; he advised researchers “to become intimately familiar with the groups they were studying and to continuously test and modify the images they were forming” – those fundamental processes that play themselves out in the social situations under study. For participants outside of the geographical area of study or for those who preferred to even if accessible (n=10), the option to “meet” through a videoconferencing application was provided. This still enabled the observation of human behavior within its context. Only one interview needed to be conducted with audio-only due to technological limitations.

The audio-recorded interviews were transcribed word-for-word by the primary investigator (SB) and/or a professional transcriptionist into a word-processing document. After formatting the transcriptions, line-by-line (hand) coding was employed by SB to break the data down into identifiable descriptions and actions on the part of the interviewee (i.e., open codes).

The constant comparative process (24-26) was, then, the primary mode of analysis in this study for construction of theory through comparing codes-to-codes, codes-to-categories and categories-to-categories, and continued until the point of “saturation” was reached – where new data only confirm or reinforce the budding theory without adding new insights or ideas (22).

Strategies employed to ensure the quality and rigor of this study were guided by the eight “Big-Tent” criteria for excellent qualitative research outlined by Tracy (30).

A Situational Analysis (SA) exercise was explored utilizing Clarke’s (23) Social Worlds/Arenas Map (see **Figure 4.1**). In both SI and SA, all knowledge is situated knowledge, and situation was the unit of analysis in this study with attention to discourse.

Findings

The Situation

The initial findings following fifteen completed interviews (see **Table 4.1** for participant characteristics) revealed the primary shared situation for these participants as: *dynamic challenges to their role identity*. It was evidenced that the situation of being a spouse of a PWEOD was uniquely problematic primarily due to the disruptive conditions formed out of the consequential changes of the progressive decline in the PWEOD *at this relatively younger life stage*.

> *“… it was so shocking when you don’t expect someone in their 50’ to have dementia and Alzheimer’s ... the loss of what he [*will have*] lost out on ... then the loss for my kids.”*
>
> *“You hear the news and it’s hard to fathom. He’s 51 and he’s diagnosed with this and it’s like, ‘are you sure, how could you know?’ And you just kind of question the whole thing.”*
>
> *“It’s devastated our lives – my life … it’s horrible. Financially devastating, emotionally very painful … and [*I’m*] telling people my husband has dementia at 53 … ‘Are you nuts, lady?!’ … I’ve learned not to say dementia because [*other people*] can’t process that.”*

> *“… it’s horrible. You know, and it’s horrible to have it happen so young. First, you know, is disbelief, like, ‘how could this be happening? You know, really happening?’ And then it’s … ‘sh**, what do I do?’ Yeah … and to do it so young … I mean, this was really our time. And I think, all those* [coming] *years without him … but, I try not to think about it.”*
>
> *“It was very hard for me when she was first diagnosed because that was, ‘What?! You’re not going to be there? What does that mean?’ I’ve had to go on my own little journeys and discoveries of what, rediscoveries of who I am.”*

The conditions within this situation of being the souse of a PWEOD include inappropriate behaviors, direct personal care needs, financial strains, as well as other family/social strains. These conditions continually challenge each of the participants’ respective role identity within their situation. These challenges over time shifted them towards a change in identity from that of “spouse” to that of “caregiver” in order to resolve and adapt to the incongruencies the conditions presented to the evolving meanings they made of their situation.

Through the SA mapping, (see **Figure 4.1**) a highly complex situation was illustrated with multiple Worlds intersecting within and across the Arena of *Early-Age of Onset Dementia*. The spouse, as a direct member and/or an incidental actor within many of these worlds, constructs meanings in order to navigate through the ambiguity of it and make sense of their own situation within it. From a perspective outside of the situation, but within both the Provider and Research Worlds, this researcher brought to this inquiry the assumption that the spouses of our EOD patients self-identify as “caregiver” at the onset of the early signs and symptoms recognizable of a dementia illness. A distinction between the two descriptors (“spouse” vs. “caregiver”) was made, however, with each participant clarifying that they did not immediately identify as a “caregiver” but still as a “spouse”.

Each participant had made or were in the process of making a transition towards identifying their role in the respective dynamic as being more and more caregiver-like, with an eventual complete shift for some to that of caregiver. There appears to be a self-imposed threshold over which each participant had or would eventually fully identify themselves as caregiver for the PWEOD. Working definitions of what it means “*to be a spouse,*” …

> *“We entered into this as a relationship that’s a partnership for life.”*
>
> *“She was really my partner. We didn’t agree on everything, but we worked together.”*
>
> *“… someone you’re really sharing your life with, … partnering through your life.”*

… versus, what it means “*to be a caregiver,*” …

> *“… to be the person to make all the decisions for this person.”*
>
> *“… it’s really being there 24/7 and making sure he doesn’t hurt himself …”*
>
> *“… if you’re caregiver, you need to acknowledge that you no longer have a partner who can share life with you, and that’s quite painful.”*

… were described in each interview, with similar language explaining how each saw their “role” as a spouse stemming from an initial “partnership” between them and their respective spouse with EOD. This partnership, however, actively undergoes an assault from multiple fronts; the natural progression of the dementia illness leads to a decline in the affected individual’s cognition, functional level and emotion awareness/regulation. These changes, in turn, have direct and indirect consequences on the “healthy” spouse, challenging their notions of what it means to be a spouse in these conditions and at this life stage both requiring action to resolve.

> *“It was definitely a partnership… so, yeah, I am alone. I’m doing everything alone. You know, it feels terrible. It’s more responsibility.”*
>
> *“Our roles are changing … when you first get married, you talk about sharing responsibilities … you really get into different modes, and you have roles. I’m assuming both roles in many ways and eventually I am going to be the sole provider of the family and that weighs heavily … that’s a big impact.”*

The Conditions

The conditions these participants described as the primary dimensions (or, drivers) of their experience were: (1) the balancing of and carrying out established roles in the sharing of responsibilities at this life-stage; and, (2) the reciprocity and appropriateness of the interpersonal dynamics within the family (see **Figure 4.2**). Over time, the well spouses change how they self-identify in order to try and meet the growing demands of their role in this situation out of necessity. The consequences of these conditions for the well spouse, then, become: (1) an increase in their load to carry within the marriage; and, (2) a decrease in the quality and/or type of the interpersonal/family relationship.

> *"… they begin failing very gradually in their roles … you gradually, and with a lot of pain, start realizing that you can no longer count on that person for anything, that you have to take over every single role – every single thing."*
>
> *"… I didn't sign up for this kind of thing. I'm uncomfortable with that. So my whole role is changing, I guess not only in terms of a husband-wife relationship… but my whole kind of role view of myself is having to change … this is not who I think I am."*

While the situational elements of culture, family, career and resources all influence how these participants define their situation, it is through the actions and interactions they described of their respective attempts at navigating safely through these new conditions that brought to the surface their own search for what this situation means for them and who they are in it. The Home Environment was most salient to these attempts at reconciling their changing role with their identity in the situation of being a spouse with an individual with EOD. The home was where most of the interviews were conducted and researcher observations made. The home was interpreted as symbolizing for these participants the initial melding of their respective individual lives into a partnership – which is actively dissolving over time. The home was defined as a mutual space where compromises get made, responsibilities shared, and roles established for the respective dyads. The home is also where some of the most significant changes for the spouses get realized; in each interview, changes in the home environment (e.g., remodeling or making additions, relocating/moving, repurposing space) were identified which occurred over time as part of accommodating their respective situation and/or re-defining themselves within it.

> *“[*PWEOD*] and I had a conversation the other night about making a decision about possibly moving out of our community. And [*PWEOD*] was like, ‘yeah, well, right now we’re okay but maybe* [in] *five years’ … I was like, ‘yeah, but it might be five months’ … there is no bus service or any public transportation near us … I’m concerned about getting places … and it’s like maybe we really need that … maybe we really need some infrastructure.”*

> *“… it was so painful being home … I just worked and worked and worked … one night I just flat out said ‘I’ll buy you a brand new house if you let me live here with the kids’ because she had been complaining about noise and this … and so we actually moved her out* [to her own place as she could still take care of herself independently at the time].*”*

> *“… he did all the stuff in the house … I’m doing everything alone* [now]*; if something breaks in the house … of course [I] could call someone, but to recognize that I would have to call someone … when we did this addition [so I could work from home and be here for him],* [the workers] *would talk to him but he didn’t get anything and I had to say to the contractor, ‘it’s me, it’s not him’ … I’m in charge of the house. I had to learn how to do all these things.”*

> *“We’ve done a lot of, around the house, um, to be able to make what we think the future holds a little bit easier.”*

> *“… we have given [PWEOD] as comfortable a life as we could imagine … with* [a] *spreadsheet, we sort of sat down to make decisions about what we’re gonna do first, second, third [*to identify and stay ahead of the symptoms/care needs*] … cause the big one was remodeling the house [*to accommodate providing her care in the home*]. But for the first time in our marriage, I made choices about the kinds of things I want to have inside the home … my domain was always outside while hers was inside … but I haven’t brought her over here to see what I’ve done … it’s very different than what she would have done.”*

The Process

The conditions of the situation (i.e., changes in the marital partnership and interpersonal relationship between the dyads) were not illustrated anywhere in the data as necessarily taking on a linear form from the perspectives of the participants themselves but were required in order for process to occur. Though they described understanding the illness in terms of a generally gradual progression, they also acknowledged the typically subtle nature of the changes which enabled them to adapt along with them without much day-to-day notice or requirement of significant change. The conditions of their situation were interpreted to initially take on a more-or-less amorphous presence which was constant but without clear demarcations. It was not until a particular kind of change, constellation of changes, or their recognition of either that they expressed being aware of a shift in their role which had been building but just not noticed at the time for what it was. These "moments of significance" carried particular meanings for the respective participant which captured their attention in different ways, requiring them to act.

> *"We'd be cooking together [*which had been a long-standing tradition for this dyad*], and [this time] I had to sit with him and show him how to cut the apple in a certain way… I asked him to take the bagels out of the microwave which we do every single day and he could not identify the microwave."*
>
> *"… you don't expect your husband not to be able to figure out how to put his shirt on, because he puts three shirts on … or if I rearrange those sock drawers one more time … because he's putting three socks on one foot and one on the other."*
>
> *"[*A friend*] went out in the ocean with him and he couldn't even bait his hook and I'm like, 'I can bait a hook and I'm not that good at it'"*
>
> *"… yeah, the falling. At one point, I had the firefighters come to the house three times a day, yeah. And that costs you, because they start charging after a while … that is kind of expensive … so that and the bathroom problems, you know … it just, yeah, that was the deal breaker."*
>
> *"… he was having some behavioral issues where he wasn't acting like a parent, he was acting more like a sibling to my daughter who was like in eighth grade."*

The conditions have exerted a unique toll for each participant and challenged each to renegotiate what the terms were of their meanings for what being a spouse means to them in their situation. Each described trying to find ways to reconcile their identity as a spouse while enmeshed in the realization of this change or constellation of changes which had produced a particularly significant meaning for them. These were interpreted as "markers" indicating a threshold of incongruency in their being able to identify as spouse given the necessary changes in their role within particular changes in the condition. Not all participants appeared challenged by the same types or degree of changes, and the changes themselves appeared to not hold the same meaning as other changes, or for other participants in a similar situation. A shared, underlying psychosocial process of changing how each sees themselves in relation to the changes emerged, however.

> *"… the marriage was over long before diagnosis … it was certainly when she was abusive to the children. Her behaviors towards the kids and me were a betrayal of our marriage. I no longer saw her as my wife."*
>
> *"He's so affectionate… but he's, like… too affectionate. And I love to be, you know, kissed and cuddled and all that stuff, but, you know, but the relationship changes too… you know, it's not just a little kiss, it's a big kiss… it's just, it feels like 'blach!' … I see him both as my husband and love of my life and as a child."*
>
> *"… if he was acting out or having a lot of acting out behavior, it would definitely change things."*

A step-wise progression (see **Figure 4.3**) in changing identity from a spouse to caregiver was interpreted as an underlying psychosocial process at play for these participants within these amorphous conditions of their shared situation. Any give "step down" represents the interpretation of these "moments of significance" for the respective participant but does not imply that they follow any particular sequence or time-course; for some participants the process was illustrated as having happened over a relatively short course and for others it had or was still occurring over many years. The types of conditions which elicited a significant meaning was most likely to involve a "breach" of the relationship as defined by the respective participant.

> *"… maybe further down the road I can identify as caregiver, but I'm just the spouse doing what spouses do … that's what you do in a relationship … you take care of the other person, but to the point of being a caregiver? … that has other implications to me."*

> *“I’ve seen that happen with step-by-step progressing … needing more and more help socially with relationships and talking to people, making decisions about finances … all that stuff has progressed to the point where I’m doing more and more of that.”*

> *“It’s definitely been more gradual because I can really think about it [when] we got the diagnosis this is dementia it changed the relationship but I wouldn’t say to caregiver at that time … [now] I’ve already transitioned in thinking not really as a spouse … I’m more of a caregiver than a spouse.”*

> *“… and at one point I realized that we were no longer husband and wife, and there is not such a thing anymore … people identify differently depending on where they are … but it’s hard to say you are a caregiver … it’s very hard. No one wants that job description.”*

> *“He was a partner to me … and a good spouse … I’m caregiver now and he’s not really there in his mind … he’s just gone … right now, I don’t visualize myself as a spouse, because he’s not there … I mean, I am totally just caring for him.”*

Discussion

This study’s aims were to explore the meanings ascribed by the spouses (also, partners/significant others) of PWEOD of their shared situation. The goal of this investigation was development of theory describing the basic, underlying psychosocial processes at play in the situation of this spouse-caregivers population. While previous studies (17, 21) have explored and described themes from the lived experience of dementia caregivers, a theory that encompasses these experiences while also illustrating the underlying process of transition in identity goes beyond describing experience and provides a framework for systematically understanding the situation and tailoring interventions.

The home environment was salient in the situation of the participants in this current study and, within the conditions of the situation of consequences due to the decline of the affected individual, an underlying process of transition in identity was brought to the surface: from that of spouse to that of caregiver. The home broadly symbolized the union and, subsequent, dissolution of the dyad’s marital relationship and was the primary stage where action was identified in their situation. Within this situation, the traditional roles established by the respective dyad as part of their marriage/partnership were directly challenged due to the decline in the PWEOD's changes (i.e., cognitive, motoric, behavioral and/or emotional) as well as indirectly through consequences of those changes (i.e., strains or repercussions on the social and psychological dimensions of family life at this life stage). This theoretical finding of role transition as an underlying psychosocial process complements those described in prior studies with a focus on identity change in caregivers, while expanding on the concepts related to what constitutes the conditions of change.

Montgomery and Kosloski (31) synthesized the literature supporting their caregiver identity theory (32, 33), and described older-age, informal/family caregiving in general as a process of changing identity. The authors emphasized the "transformation of an existing role relationship" (pp. 47) rather than a new role just added to a repertoire of social roles. The implications of this perspective were argued that it: (1) contributes to the recognized heterogeneity and dynamic relationship of caregiver experiences/outcomes, and (2) requires that effective interventions from the medical perspective begin by assessing their unique situations. The authors suggested that, specific to *spousal* caregivers of PWD, the process of change in role identity is slow and insidious and comes about in ambiguous steps in response to changes in the care-recipient's needs over time which the authors stressed as "tasks" related to the caregiving role. The meanings, the authors argued, that a spousal caregiver assigns to the tasks related to the care needs and the distress this causes them is what determines the progressive shifts in role identity for the caregiver.

While a step-wise transition similar to Montgomery and Kosloski's (31) "phases of accommodation" in the changing identity of a caregiver was identified as an underlying social process in this current study, an important distinction that emerged out of these data is the expansion of the conditions which the role identity changes respond to and represent in this study "moments of significance". Caregiver identity theory (31-33) emphasizes task-related demands – "changing activity patterns, changes in the health of the care recipient" (pp. 48), etc.,

– as the primary drivers for role changes. Their model, however, does not fully account for the impact of personality changes and/or other behavioral symptoms or dysexecutive features more commonly present in EOD syndromes, especially early in the disease process. These symptoms were reported by the participants in this current study as significant challenges to their notion of what being a spouse meant. For some, these conditions initiated their transition towards caregiver prior to an official diagnosis even being made or traditional caregiving-related tasks needing to be performed.

Savundranayagam and Montgomery (34) later investigated in their quantitative study whether role discrepancies mediated the relationships between illness-related stressors and burden and argued that the level of distress experienced is partially determined by the level of discrepancy felt by the caregiver in terms of the internalized norms associated with their role as a spouse performing certain caregiving duties. The reports provided by the participants in the current study offer arguments in support of caregiver burden and distress levels related to role discrepancies presented by the PWD’s behavioral changes independent of any resulting caregiving “duties” deemed outside of internalized norms. This is an area that warrants further investigation through qualitative as well as quantitative research.

In their comparative descriptive study, Ducharme et al., (1) working within a framework of role transition, reported a general problematic situation of lack of preparedness among family caregivers of PWD, and argued for early assessment of caregiver needs within the process of identity change. Findings from the current study support assessment of caregiver needs though emphasize the need to reassess over time as their needs may change in response to where they are individually in the process of transition of their identity within their situation. The participants in this study highlighted the need for providers to work with them early on in helping identify what they need in terms of education but also in preparing them with the expected behavioral and care-need changes in the affected spouse. Each participant described having different levels of readiness for information and at different stages of the transition. The concept of “moments of significance” illustrated in the step-wise transition developed out of this current study (see **Figure 4.3**) may provide a basis for investigating particular changes in the conditions presented by the PWEOD that carry more significance for one spouse-caregiver but not another. When explored further, these may offer healthcare providers insight into how to tailor inventions aimed at reducing the distress associated with anticipated discrepancies, including directing spouse-caregivers to/providing them with the appropriate anticipatory guidance, resources, or through facilitating a change in the spouse-caregiver’s own behavior and/or their re-appraisal of the situation.

While the findings from the above studies did not directly account for the unique situation of being the *spouse of an individual with an EOD*, they are corroborated by the general findings from this current study which provide support for the generalizability of the concepts underlying this theory of transition in identity in caregivers of PWEOD. For spouses at a younger age, however, other unique aspects not necessarily captured in these previous studies include the impact of the changes at this life-stage. The financial as well as psychosocial effects of a dementia illness on those family caregivers still in their planning and preparing phase for a retired future together may be different than for those already in their retirement stage and no longer dependent on an active income as well as responsible for the demands from other family needs. The need to work while also providing care may be more of a reflection of the life-stage these early-age onset dyads are at in their situation than for later-age onset dyads.

These younger dyads may still have dependent children in the home and the “healthy” parent may need to weigh the children’s developmental needs with the competing needs of their spouse’s, and even of themselves, while taking on the role of sole parent and provider when previously a shared responsibility. In addition, inappropriate behaviors exhibited by the PWEOD may present psychological and/or physical risks to the children and warrant early changes in the home environment (e.g., institutional placement of the PWEOD) as illustrated in the reporting of some of the participants in this study. These findings provide evidence of a need for the providers caring for patients with EOD to assess these broader psychosocial factors more commonly present in the situation of EOD and provide referrals to the appropriate social services.

Conclusion

Theoretical frameworks can outline a situation's conditions and the related consequences that enable predictability. Through exploring the meanings, actions and interactions of a sample of spouses of persons with EOD, it was possible to bring to light an underlying, shared psychosocial process among these participants illustrating the conditions of their situation. The "moments of significance" represented in this study's theoretical process of identity change may represent sub-conditions where a respective spouse-caregiver is particularly vulnerable to the effects of the consequential changes in conditions over time. Understanding of the situation through this theoretical framework may help better guide providers in tailoring interventions in this population through a collaborative care-planning process that incorporates identifying potential individual "triggers" from these illness-related changes and helping to better prepare the individual spouses for expected changes before they arise.

Next steps include future research studies investigating these "moments of significance" in greater depth to bring clarity to whether they represent periods of vulnerability for the spouse-caregiver and if that information has predictive value for identifying who may at greater risk for adverse outcomes and where to focus intervening within these conditions of their unique situation. In addition, future research should incorporate a focus on the decision-making processes involved in these "moments of significance" in relation to successful transitions for both the well spouse and the affected PWEOD.

Limitations of this study include the small number of participant interviews available to draw data from and continue to compare findings with, ensuring "saturation." However, through constant comparison with the data, the major concepts emerging from the data began to culminate after approximately five interviews which enabled exploring these further through the subsequent ten interviews which resulted in a saturation of the data through their continual support by these additional data. The participant sample was fairly homogeneous with regards to their reported ethnicity and annual household income, biasing these findings to members of this population who may have more access to resources in their situation and enable them to volunteer time to research. To help address this potential bias, this researcher sought out participants from outside of the geographical area through theoretical sampling to test the findings against. This enabled more diversity in income and access to services.

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Appendix 4.A

Semi-Structured Interview Guide

1. Tell me what it has been like for you having a spouse/partner with [*EOD*].
2. Describe aspects of your life that have changed due to [*X*]'s condition – [*Possibly to accommodate [X]'s immediate needs and/or for those anticipated in the future*].
3. How would you describe your role in relation to [*X*]'s needs at this time?
4. What words would you use to describe what being a *spouse* means to you?
5. What words would you use to describe what being a *caregiver* means to you?
6. To what extent do you consider yourself a *caregiver* for [*X*]?
7. Tell me what you remember about the day when [*X*] was given this diagnosis.
8. Could you walk me through your experiences leading up to [*X*]'s diagnosis?
9. In what ways would you say your identity (how you see yourself in relation to your situation) has changed to accept the new/additional responsibilities brought on by this disease?
10. Is there anything else I should know about what it means to you to provide care for a spouse with [*EOD*] that I didn't ask?
11. What thoughts would you want to convey to someone at the beginning stages of their experience being spouse of an individual with [*EOD*]?

Figure 4.1 Situation Analysis Social Worlds/Arenas Map

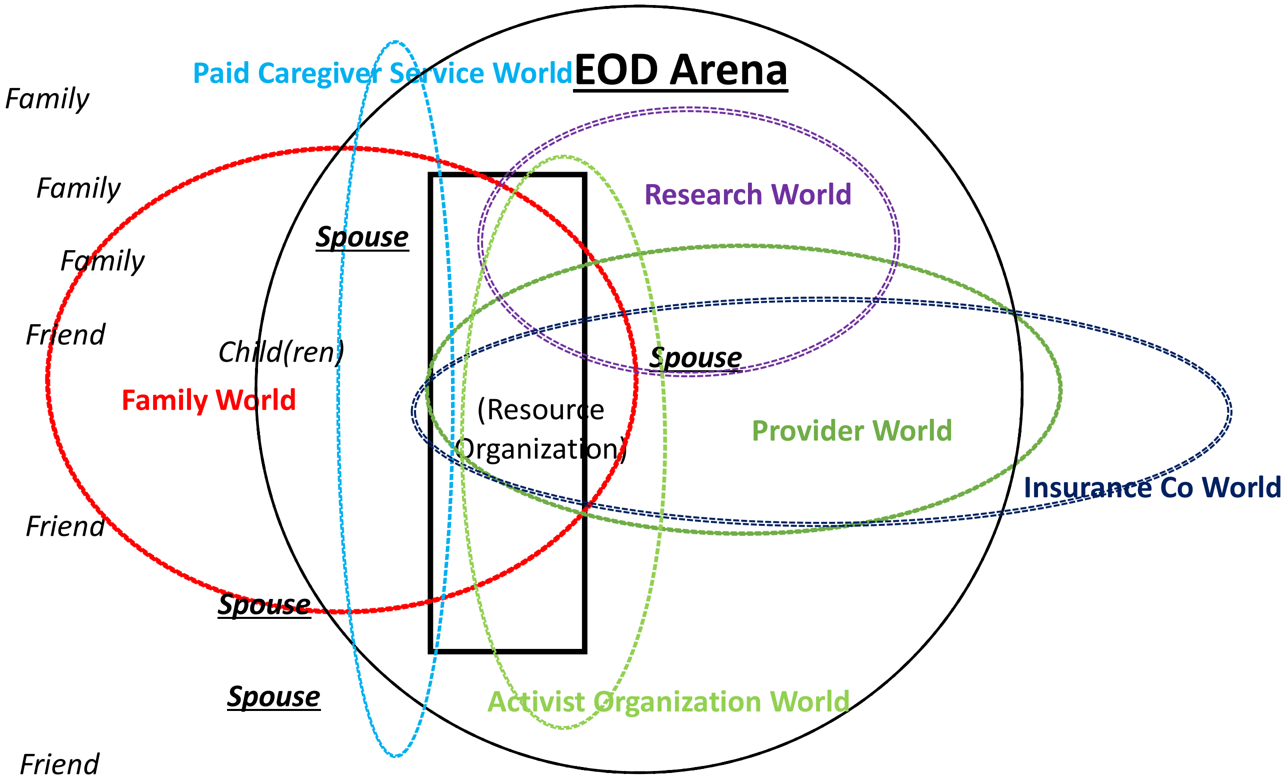

Figure 4.2 The situation of being the spouse of a PWEOD in the amorphous conditions of change due to the PWEOD's decline

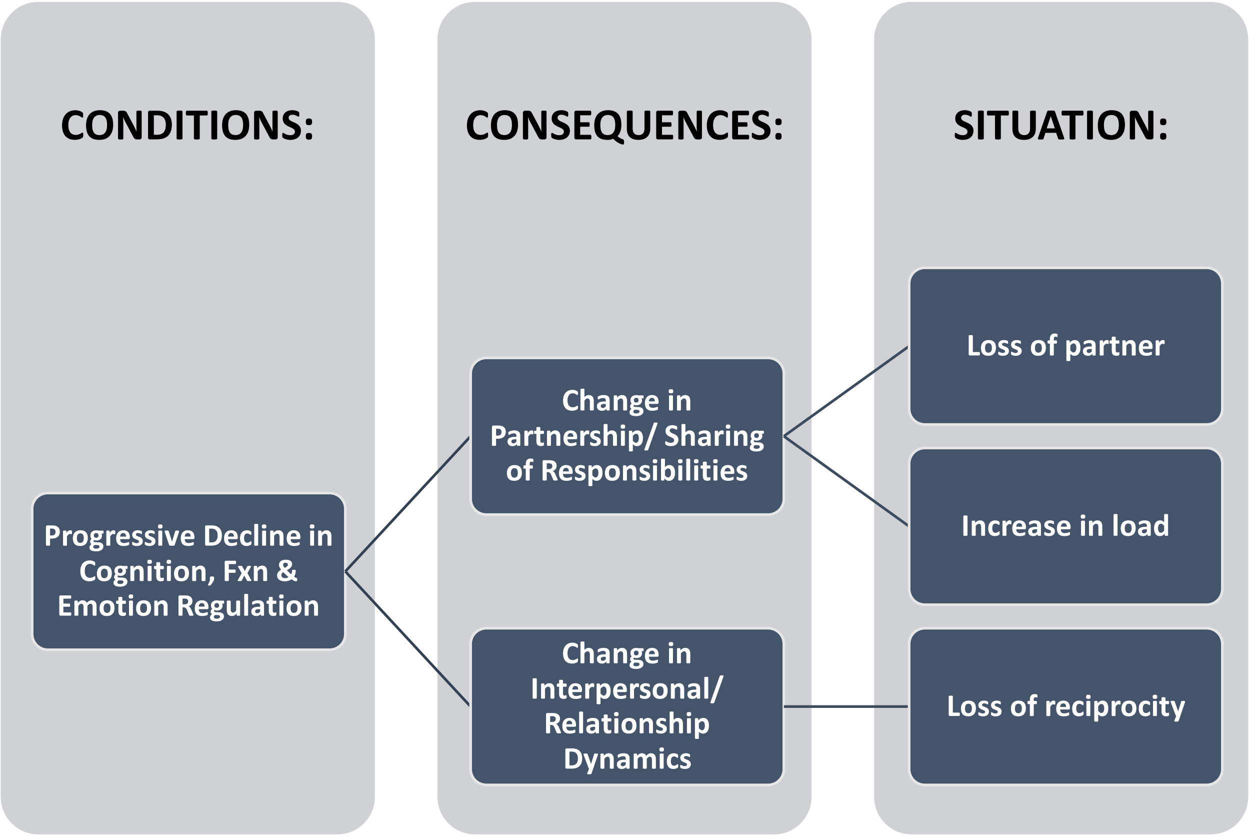

Figure 4.3 A step-wise process of role identity change within the amorphous conditions of the situation triggered by moments of significance

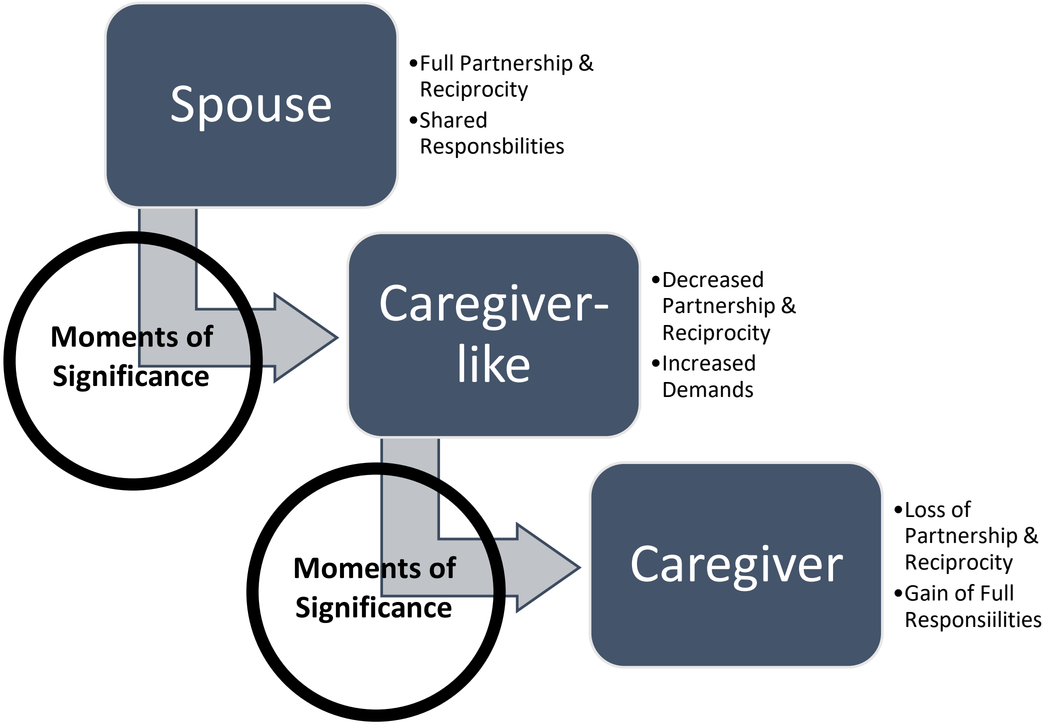

Table 4.1 Participant Characteristics

Gender	Age (years) Median(Range)	Ethnicity	SES/ Annual Income	Employment Status	Education	Relationship	PWD Dx
F(10); M(5)	57(46-68)	White/ Non-Hispanic(14); Asian(1)	$25,001-75,000(3); $75,001-100,000(3); $100,001-120,000(2); >$120,000(5)	F/T(6); P/T(4); Retired(4)	Some College(2); Bachelor Degree(2); Graduate Degree(10)	Spouse(15)	AD(6); CBD(1); PSP(1); bvFTD(4); svPPA(3)

SES, socioeconomic status; F, female; M, male; F/T, full-time; P/T, part-time; PWD, person with dementia; Dx, diagnosis; AD, Alzheimer’s disease; CBD, corticobasal degeneration; PSP, progressive supranuclear palsy; FTD, behavioral variant frontotemporal dementia; svPPA, semantic variant primary progressive aphasia.

Synthesis

While it is known that family caregivers (FCG) of persons with dementia (PWD) are at risk for adverse health outcomes, identifying which FCG is at greatest risk and for which outcome remains elusive. In an attempt to address some of these gaps in the literature, the purpose of this dissertation was to explore factors contributing to the experiences and outcomes of FCG of PWD through employing novel methods (i.e., latent profile analysis and Grounded Theory). This dissertation achieved this through triangulating data from both quantitative and qualitative sources and descriptively analyzing risk associated with health outcomes in this FCG population as well as qualitatively analyzing the meanings a sub-group of FCG of PWD make of their situation.

The purpose of this final section is to synthesize the dissertation results. First, the study results will be summarized, followed by a reflection on theoretical concepts that guided this dissertation. Next, key themes identified across the studies will be presented. Then, the limitations will be discussed, followed by implications for clinical practice, and will conclude with directions for future research.

Summary of Study Results

While not achievable through a “true” mixed-methods approach, these data provided important insights in parallel to my overarching inquiry of “*how can we best care for our family caregivers?*”. Through the first, quantitative study, I began with a systematic review of the literature on the utility of assessing innate personality traits (PT) as predictors of health outcomes in FCG of a PWD. A meta-analysis of these data was conducted as well. This was followed with an exploratory analysis of how group membership into classes of PT *profiles* (uncovered through latent profile analysis) was associated with health outcomes in this population of FCG. In the final, qualitative paper I explored theory development around the psychosocial processes underlying the shared situation of being the spouse/partner/significant other of a person with an early-age of onset dementia (EOD; defined as an age of symptom onset younger than 65 years) syndrome. Through semi-structured interviews and observations, the meanings made and actions taken by these FCG were analyzed through deductive and inductive processes to help better understand their unique situation.

Summary of Literature Review

There is a limited but growing body of research investigating the PT of FCG of PWD as predictors of their health outcomes. However, no known systematic literature review or meta-analysis had been published evaluating the utility of measuring PT as predictors of health outcomes in FCG of PWD.

In the systematic review of the literature conducted for this dissertation, all five of the PT dimensions (i.e., Neuroticism, Extraversion, Openness to Experience, Agreeableness, Conscientiousness) within the FFM in FCG of PWD were found to be statistically significant predictors of health outcomes when using the NEO-PI instrument (or a validated, reliable version, such as the Big Five Inventory), but only for the specific outcome variables of depression and health-related quality of life (HRQoL). The review identified that the PT dimensions of Neuroticism and Extraversion were most often investigated and significantly associated with FCG health outcomes across five of the seven included studies. Burden, anxiety, depression and HRQoL were the health outcome categories measured most commonly across the included studies and had the greatest frequency of statically significant results for associations with the respective PT measured in the respective study. The meta-analysis revealed statistically significant associations between: 1) Neuroticism and burden (pooled-r = .304); 2) Neuroticism and depression (pooled-r = .593); and, 3) Extraversion and burden (pooled-r = -.233).

An important gap identified in this review process was for comprehensive studies evaluating each of the five factors (i.e., dimensions) of personality and each category of the most relevant health outcome variables (e.g., perceived burden, depressive/anxiety symptoms, HRQoL). In addition, investigating single PT factor variables may only tell a part of the complex story of the associations between PT and health outcomes. An additional gap in the literature identified was an absence of mixture modeling approaches such latent profile analysis of the PT in the population of FCG of PWD.

Summary of the Secondary Data Analysis

Latent profile analysis (LPA) is a type of mixture modeling which generates previously unobserved, discrete “classes” (i.e., “profiles”) from the normal distribution of the observed data (1). This analytic approach to investigating PT can complement the single-variable (i.e., individual dimension of PT) approach which, by itself, risks limiting the scope of investigation by overlooking the reality that traits do not exist in isolation and collinearity exists among the FFM traits (2-4).

In this dissertation, LPA was employed as a novel approach to conceptualizing PT as an interrelated system of several traits based on the mean responses to the 10-item version of the Big Five Inventory instrument. This methodological approach (i.e., LPA) helped identify previously unobserved patterns of personality in this population of FCG. Two latent classes (i.e., “Higher Resistance” and “Lower Resistance”) were identified which best fit the data. The “Higher Resistance” (HR) class is defined by lower levels of Neuroticism, higher levels of Agreeableness, and, in particular, higher levels of Conscientiousness. The “Lower Resistance” (LR) class, then, is defined, by higher mean scores on the Neuroticism dimension and lower mean scores on Agreeableness and Conscientiousness.

These two classes were then employed as a single, dichotomous variable representing composite profiles of PT and evaluated for differences on a wide range of characteristics and the health outcomes of caregiver perceived burden, distress as related to PWD neuropsychiatric symptoms, depression (and four subscales of depression), anxiety level, life satisfaction, and the health-related quality of life (HRQoL) principle component scale as well as the HRQoL bodily pain, physical role limitations and emotional role limitations subscales. Membership in the HR class was associated with higher self-reported measures in “global cognitive judgement” of personal satisfaction with life than membership in the LR class. Membership in the HR class was also associated with higher self-reported measures of bodily pain and role limitation due to emotional problems as assessed by the SF-36 HRQoL instrument.

No significant differences between the HR and LR classes were identified in participant or patient characteristics or in the FCG outcomes of perceived burden, distress, depression, anxiety level, or the HRQoL subscales of physical role limitations. This finding was unexpected as mixture modeling techniques are expected to compliment single-variable approaches, and these data did not support previous findings of statistically significant association between each of the five PT dimensions and the prevailing health outcomes investigated in this population of FCG (i.e., perceived burden, distress, depression, anxiety level, or HRQoL).

Summary of the Grounded Theory Study

The initial goal of the qualitative study for this dissertation was to investigate the shared basic psychosocial problems of being the spouse of a person with an early-age of onset dementia syndrome from the participants’ perspectives (5) through the overarching research questions: 1) *what is it like (i.e., what meanings are made) for the participant being the spouse of an individual with an early-age of onset dementia (*EOD*)?; and, 2) how do they cope with the changes brought on by the disease process at this life stage?* Their own understandings of the problem needed to be revealed so that the developed theory would reflect what the participants do to resolve it (5) and guide future research as well as practice focused on caring for this sub-group of FCG of PWD. To address these aims, Grounded Theory (GT) methodology was employed in order to understand this sub-group of FCGs’ experiences (i.e., the meanings they made of their situation and actions employed within it).

An underlying psychosocial process was identified in this sample of spouse-caregivers and interpreted as a “transition in role identity”. The theoretical framework around the identified step-wise fashion this transition takes over the course of caregiving for a spouse with an EOD suggests there are “moments of significance” for the respective well-spouses which represent to them significant declines in their PWEOD and may be understood as periods of vulnerability for these spouse-caregivers. In addition, these “moments of significance” extend beyond caregiving-related “tasks” (e.g., bathing, dressing, toileting, feeding) and include behavioral changes as well as which can be understood as incongruencies to the meanings these spouse-caregivers apply to their role as a “spouse”.

Theoretical Concepts

This dissertation was guided by theoretically underpinnings around appraisal processes, primarily from well-established stress-process theories as well as trait theory. Key concepts from symptom management models (e.g., symptom experience) (6, 7) and life-course perspectives (e.g., transitions, trajectory, agency) (8-10) were identified to be relevant and applicable though not systematically.

Stress Process

A central task of stress research is to explain why individuals exposed to similar conditions deemed as stressful do not necessarily experience the same outcomes (11). Stress process theories address the sources of stress (i.e., demands) specific to a situation such as caregiving for a PWD. These theories can be applied to this population of FCG in order to more comprehensively assess why all FCG of PWD are not at the same magnitude of risk or at risk for the same outcomes even given a similar situation.

It has been argued that the situation of caregiving for a PWD is inherently “stressful” and one of the most challenging aspects for FCG of PWD is effectively managing the behavioral and psychological symptoms of dementia (BPSD), which can be understood as the outward expression of unmet needs (12-16). The impact that BPSD and other dementia-related symptoms or care-needs have on a FCG may vary, however, depending on the dynamic nature of their respective process for making sense of these potential stressors as threats (17-19).

A basic principle assumed in stress theories is that a stressful event does not automatically provoke feeling "stress"; there is a differentiation made between the occurrence of a source of potential stress (i.e., a stressor) and a person's appraisal (i.e., meaning-making response to the stressor) of the event (20). In addition to the individual meanings ascribed to a potentially stressful event, personal characteristics (e.g., self-efficacy, coping style) are important dimensions taken into consideration within stress process theories (11, 20-24).

The prevailing models most frequently incorporated in research investigating the health outcomes of FCG of PWD have been Pearlin's Stress Process model (11, 21, 22) and Folkman and Lazarus' Stress and Coping Model (20, 23). When employed by themselves, these models are limited in scope and utility, however, primarily due to presenting an incomplete framework constructed from a single discipline's perspective (e.g., sociology and psychology, respectively). The heterogeneity in health outcomes observed in this population of FCG caring for a PWD may be better explained by variations in the respective model's different dimensions of a stress process at different phases when blended into a single, psychosocial stress process model (see **Figure 5.1**). For example, even given a sociological/environmental situation with similar stressors, differences in individual appraisals, personal resources/characteristics (e.g., self-efficacy, past experiences), and/or coping styles could result in differences in the effect of the stressors on an individual's health and well-being (e.g., perceived burden, anxiety/depressive symptoms, HRQoL), with each potentially influenced by other inter-individual factors (e.g., personality traits).

Utilizing this blended psychosocial theoretical stress process framework (see **Figure 5.1**) also offered the investigations of this dissertation improved utility for disentangling the dimensions of the stress process with particular attention on the situational meaning-making (i.e., appraisal) with consideration of the individual’s non-modifiable characteristics (e.g., personality traits) as strong, stable predictors of health outcomes (e.g., well-being, perceived burden level, depressive/anxiety symptoms, HRQoL).

Trait Theory

Given the dynamic (i.e., context-dependent) nature of personal characteristics (e.g., self-efficacy, coping style) and the prolonged, changing situation of caregiving for an PWD, these factors may be less reliable as predictors of outcomes over time than would more stable traits (e.g., personality traits). Personality traits (PT) are factors which have been identified as significantly influencing FCG risk for adverse health outcomes (17, 25-35). Measuring PT, as defined by the Five-Factor Model (FFM) (36), may provide a robust avenue for explaining some of the inter-individual variance in health outcomes in this population of FCG of PWD. Trait Theory poses that PT are innate aspects of humans representing basic tendencies that are relatively stable over time and context, and can be understood as influencing an individual’s appraisal (i.e., the meaning one makes of a stressor as it relates to their safety or well-being), self-efficacy (i.e., the perception or belief about one’s own capacity for successfully responding to the demands of the situation) and/or coping mechanism (i.e., response to the demands of the situation in attempts to manage them) independent of time and/or context, which have been shown to moderate health outcomes (17, 25). These factors (i.e., appraisal, self-efficacy, coping style), in turn, are understood to be integral in the downstream processes leading to health outcomes (e.g., perceived levels of stress and burden, depressive/anxiety symptoms, and health status/quality of life).

Themes

The overarching focus of this dissertation work was in exploring factors which contribute to the experiences of and help explain the variance in outcomes for family caregivers of persons with dementia. Through triangulating data from different sources and methodological approaches, major themes around inter-individual factors as well as sub-group factors were uncovered in this work.

Inter-Individual Factors

While heterogeneity persists in the literature focused on outcomes of family caregivers of persons with dementia, inter-individual factors, such as personality traits, are emerging as strong predictors of those outcomes which can help explain some of the observed variance. The results from this dissertation's systematic review support the utility of assessing the personality trait dimensions of Neuroticism and Extraversion as single-variable, inter-individual factors moderately predictive of outcomes in this population of caregivers.

The findings around "moments of significance" in this dissertation's qualitative study help frame important inter-individual factors related to potential "triggers". These personal "triggers" may be identifiable so as to anticipate them for a particular situation and appropriately intervene before becoming problematic for the respective individual.

Sub-Group Factors

This dissertation's secondary data analysis uncovered two sub-groups in a sample of family caregivers of persons with dementia in the form of latent personality trait profiles. The results from exploring differences between these two latent classes highlighted a novel association between membership within a profile and level of satisfaction with life.

The grounded theory approach in this dissertation's qualitative study enabled an exploration of a sub-group of family caregivers of persons with dementia (i.e., spouses of persons with an early-age of onset dementia syndrome). The resulting theoretical framework around role identity transition in these family caregivers provide novel insights into their unique situation and can help identify factors related to their outcomes.

Limitations

One limitation identified early on in the dissertation was a dearth of research on personality traits as predictors of health outcomes in the family caregivers of persons with dementia. However, this gap built an even stronger case for studying these inter-individual factors of outcomes in this population of caregivers. Due to the limited data, the literature included in the systematic review and the results from the meta-analyses could not provide support for the utility of assessing each of the five personality trait dimensions as defined by the Five Factor Model of personality in this caregiver population.

Limitations in conducting the secondary data analysis related to the sample and the instrument used to measure personality traits. The overall sample was a group biased towards those family caregivers caring for a higher functioning portion of the population of persons with dementia who were eligible to enroll and participate in the parent study focused on the dyads. It may be that samples of family caregivers caring for persons with dementia with milder illness severity will report less adversity in their current situation. Longitudinal studies are needed. Studies exploring latent classes with samples of family caregivers caring for person with dementia with higher severity of illness are also needed. Another limitation in this study was the sample size (N=147) itself which was relatively small for mixture modeling, and a latent profile analysis may uncover classes differently with more data. In addition, to better analyze data through mixture modeling, utilizing a longer, more comprehensive version of a validated and reliable personality trait instrument may yield more robust results.

For the grounded theory study, one potentially limiting factor was a fairly homogeneous sample with regards to their reported ethnicity and annual household income, biasing these findings to members of this family caregiver population who may have more access to resources in their situation and enable them to volunteer time to research. To help address this potential bias, participants from outside of the geographical area were sought out via theoretical sampling to interpret the findings against and better ensure rigor.

Implications

Nursing Practice

An overarching goal for this dissertation work was to contribute to the identification of potentially clinically-feasible means for tailoring care aimed at family caregivers of persons with dementia. Measuring the personality traits of Neuroticism and Extraversion in this caregiver population may offer moderate utility in predicting who is at greater risk for the outcomes of burden or depression. This may offer an avenue for intervening proactively with those who are identified as at risk. An additional avenue for tailoring care based on personality traits is through the evaluation of personality trait profiles. This approach encompasses each of the five dimensions of personality as defined by the Five Factor Model of personality and may prove to be useful for better predicting who is at greatest risk and for what outcomes based on an individual's membership within a particular group. This, in turn, may assist health care providers with more efficient and effective allocation of resources by helping clinicians identify where they should focus their interventions given a particular personality trait profile.

The clinical implications of this dissertation also include tailoring interventions and care plans to meet the unique needs of sub-groups of family caregivers of persons with dementia. The theoretical framework developed around the situation of being the spouse of a person with an early-age of onset dementia can provide insights into where nurses should focus care. Understanding the unique repercussions on social and family life due to the onset of illness at this life-stage can provide useful context for providing valuable anticipatory guidance and in exploring with individuals in this sub-group of family caregivers potential “triggers” for them which may hold particular significance and lead to greater distress in their role identity transition. Tailored interventions, such as cognitive behavioral therapy, may then be useful in facilitating a re-appraisal of the meanings these identified triggers are given by the family caregiver with the goal of lessoning their impact downstream.

In addition, this re-appraisal process may be strongly influenced by the individual's PT profile (37), and also a key element in the stress process as it represents the individual's control mechanism for adjusting their emotional response (and subsequent coping mechanism employed to try and manage the situation) to meet the current situational needs (37, 38). Assessing for personality traits as individual dimensions or as a profile can assist nursing practice in identifying who may be at greater risk for adverse outcomes such as depression or poor HRQoL and intervene more precisely.

Future Research

In general, more comprehensive studies are needed on sub-groups of family caregivers of persons with dementia, including (sub-)group-level factors (e.g., atypical dementia syndromes, age of onset), inter-individual factors, biological (e.g., genotype) factors, as well as temporal factors (e.g., "stage" of illness). Latent class analysis may provide some utility in a larger sample with a more robust instrument to refine the influence a personality trait profile may have in risk for downstream outcomes. In addition, the "moments of significance" identified in the qualitative study warrant further investigations to help better define and, potentially, categorize those events (i.e., "triggers") for development of screening instruments and tailoring interventions in a more targeted fashion.

Ultimately, however, a "true" mixed-methods approach is needed for assessing the relationships between the instruments currently employed to measure the experience and outcomes of family caregivers of persons with dementia quantitatively and the qualitative meanings they ascribe to their situation. This type of investigation could offer important value in more precisely predicting risks associated with downstream health outcomes in this population of family caregivers.

Conclusion

It is clear that family caregivers of persons with dementia are at risk for adverse health outcomes from the multiple, chronic stressors inherent in their situation. Identifying who within this population of caregivers is at greatest risk and for what outcomes remains a challenge, however. Work needs to be done in order to tailor interventions that meet individual needs with the goal of achieving optimal levels of mental and physical health. The inter-individual factors of personality traits as well as sub-group factors such as relationship type and life stage at which the illness occurs are all critical factors which warrant consideration when promoting better health outcomes for this family caregiver population.

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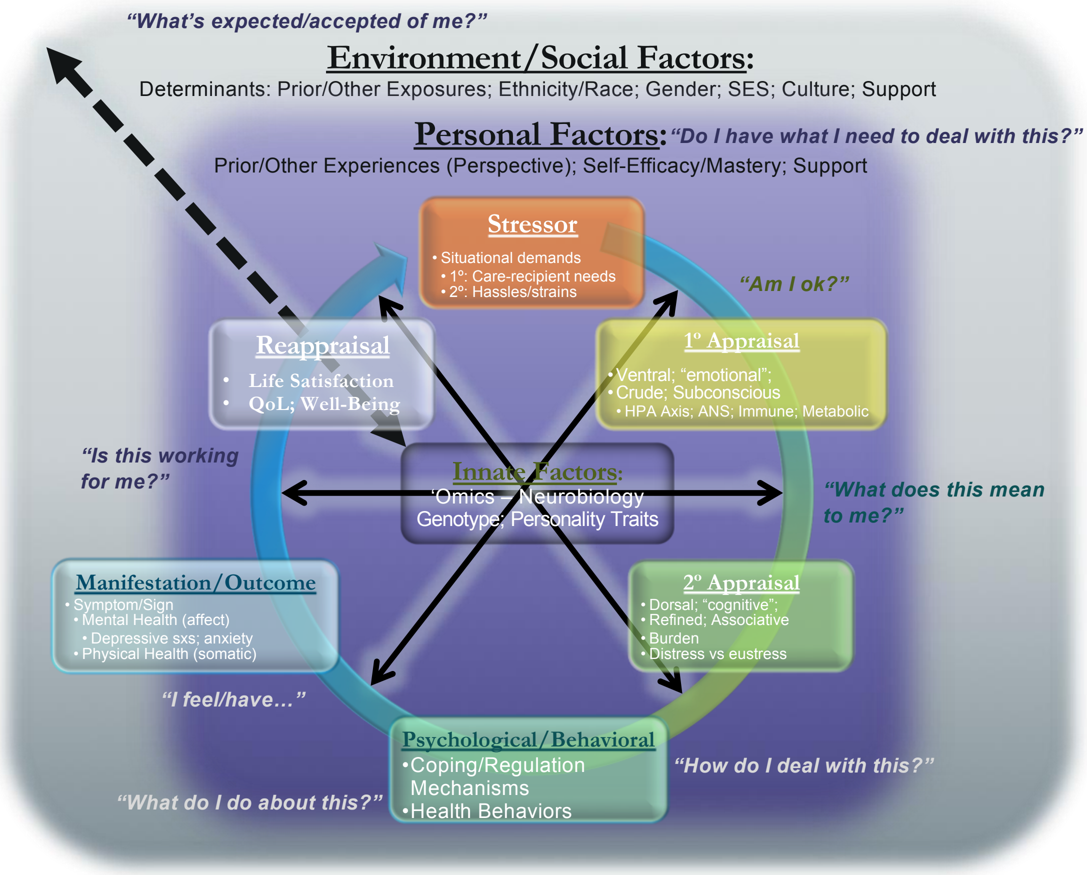
Figure 5.1 Blended PsychoSocial Stress Process Theoretical Model



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