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Testing a modified model of stress process for understanding quality of life among informal caregivers and assessing their formal service use

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Testing a Modified Model of Stress Process for Understanding Quality of Life among Informal Caregivers and Assessing their Formal Service Use

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Abstract

Informal caregivers provide timely care to family members who are disabled or have a chronic condition that requires close monitoring or constant assistance. To provide adequate support to informal caregivers, there is a need to assess ways to improve their quality of life (QOL) and understand how formal services can be improved. This dissertation strives to extend the knowledge available for policy makers by examining the factors that can be targeted by policy makers to improve QOL of informal caregivers as well as the factors that enable the use of formal services provided to support informal caregivers.

The psychometric properties of the QOL instrument should be established before assessing QOL in informal caregivers. First, we assessed the psychometric properties of the World Health Organization's Quality of Life – Brief (WHOQOL-BREF) in the sample of informal caregivers. The WHOQOL-BREF was found to be psychometrically sound for use in assessment of QOL among informal caregivers with good internal consistency reliability, convergent and discriminant validity and known-groups validity. Overall, the results provide basis for the use of WHOQOL-BREF for the assessment of QOL in informal caregivers. Secondly, we explored the role of personality in influencing psychosocial factors and QOL of informal caregivers and whether its influence differs between two groups of informal caregivers. We found that only specific personality traits were associated with coping measures and QOL where they also differed in their effect at different levels of the personality trait. However, the

effect of personality was different when compared between the two groups of informal caregivers. This resulted in two different models unique to the informal caregivers of the two groups. Lastly, we explored the factors that were associated with the use of each of the formal services that included paid help, respite care and training sessions in a national sample of caregivers to get generalizable results. Paid help, respite care and training sessions, all had some unique factors that predicted their use that shows that each service should be treated separately. These factors can serve as starting points for practitioners and policy makers extending the use of these formal services.

Dedication

This dissertation is dedicated to my *mom, dad, sister* and late *grandmother* for their love and support.

List of Abbreviations

AARP	American Association of Retired Persons
ADL	Activities of Daily living
ALS	Amyotrophic Lateral Sclerosis
BS	Bootstrap
CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
CI	Confidence Interval
HRQOL	Health-related quality of life
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune deficiency syndrome
IADL	Instrumental activities of daily living
LLC	Limited Liability Company
LLCI	Lower Limit of Confidence Interval
NAC	National Alliance of Caregiving
QOL	Quality of Life
ULCI	Upper limit of Confidence Interval
RMSEA	Root mean square error of approximation
SE	Standard error
SEM	Structural equation modeling
SRMR	Standardized root mean square residual
TLI	Tucker Lewis Index
US	United States
WHOQOL-BREF	World Health Organization Quality of Life Brief
WLSMV	Weighted least square estimator

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Chapter 1

Background and Literature Review

Individuals with neurological, psychological, or physiological conditions, who have functional limitations, often need daily assistance with tasks such as taking medications, transportation, housekeeping, coordinating physician visits, or managing financial matters. In such cases, adult children, parents or spouses of the disabled individual are well-positioned to provide efficient and inexpensive care compared to paid care providers or keeping individuals in a care setting like a day care, residential, or long-term care facility. Informal caregivers hence form an essential component of the healthcare system that helps in reducing the economic costs of healthcare in the United States (US). Acknowledging their contribution to healthcare, researchers have undertaken studies to understand the stress that accompanies caregiving duties, how informal caregivers react to such stressors, and what impact the stressors have on informal caregiver's health and quality of life (QOL). However, not enough is known about how factors interplay and result in differences in informal caregivers' health and QOL.

This chapter will provide a background in the current state of caregiving, and the factors that influence caregiver health and QOL. The first section will describe the prevalence of informal caregiving in the US, demographic make-up of informal caregivers, and the role of the informal caregivers in reducing burden on care recipients. The second section will describe the impact of caregiving on health, the stressors that affect informal caregivers' ability to provide care, how informal caregivers react to them, and define their health or QOL. The third section

will describe the available resources for informal caregivers designed to improve their ability to provide care, reduce their burden, and improve their health. The fourth section will describe information presented in the second section with the help of several caregiving models that have been validated. The fifth section will describe personality and how it potentially influences caregiver health and QOL. The sixth and seventh section will enlist the need for the current study, objectives and specific aims.

A. Background on informal caregiving

Informal Caregiving

An unpaid caregiver or an informal caregiver is an individual such as spouse, partner, family member, or friend who assists with daily living activities and medical tasks. The responsibilities of informal caregivers include help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include getting in and out of bed and chairs, getting dressed, getting to and from toilet, bathing and showering, feeding, and dealing with diapers. IADLs include helping with transportation, grocery or other shopping, housework, preparing meals, managing finances, giving medications, pills or injections, and arranging outside services. Other than ADLs and IADLs, informal caregivers also communicate with different providers and professionals on behalf of the care recipients, keenly monitor recipient's condition, and act as an advocate for the care recipient with care providers, community services or government agencies.[1] Informal caregivers often perform tasks that are typically performed by nurses, called medical/nursing tasks, such as giving injections, tube feedings, or undertaking catheter and colostomy care.[1]

Prevalence of Informal Caregiving

Informal caregivers can be individuals caring for a spouse with a limitation, parents caring for their young children with chronic illness, parents caring for adult children with chronic conditions, or children caring for their elderly parents. The National Alliance of Caregiving (NAC) and the AARP Public Policy Institute collected data on 1,248 caregivers, ages 18 or older, in 2014 to study the landscape of unpaid family caregiving or informal caregiving in the United States (US). According to the report published in 2015, an estimated 43.5 million adults in the US provided unpaid care to an adult or a child in the prior 12 months.[2] The caregiving prevalence according to race and ethnicity was highest among Hispanics at 21%, followed by African-Americans at 20.3%, Asian-Americans at 19.7% and Caucasians at 16.9%.[2]

Demographic Characteristics of Informal Caregivers

Relatively few population-based studies exist that characterize the demographics of informal caregivers. The NAC study found that three in five informal caregivers (60%) taking care of adults or children with disability were female.[2] Among a sub-sample of those only caring for older family members, 43.4% were found to be male caregivers.[2] Nearly half (48%) of informal caregivers fall between the ages of 18 and 49 years while 34% were 65 years and above. Informal caregivers who provide care for more hours per week (21 hours or more) tend to be older than those caregivers providing care for less hours per week (less than 21 hours).[2] The average age of spousal caregivers was found to be 62.3 years. As far as the relationship between informal caregivers and care recipient is concerned, most of the informal caregivers take care of a relative (85%), while just 15% take care for a friend or neighbor. Among the relatives, 42% take care of a parent, while 12% take care of a spouse. According to race and ethnicity, 62% of

informal caregivers were Caucasians, 13% were African-Americans, 17% were Hispanics, and 6% were Asian-Americans.[2]

The number of informal caregivers that have a high school education or less (36%) was more than the number of caregivers that have a college degree (34%).[2] Most informal caregivers were married or living with their partner (65%), while 19% of informal caregivers were single. Sixty percent of informal caregivers had some kind of employment either full-time or part-time. About 53% of informal caregivers had at least $50,000 in household income.[2] The average duration of informal caregiving was 4 years. A quarter of informal caregivers provide care for more than 5 years, while 30% provide care for less than a year.[2]

Role of informal caregivers

Informal caregivers invest many hours in providing care to recipients with an average of 24.4 hours a week. About 23% of caregivers provide care for 41 hours or more each week, and 31% provide care between 9 and 40 hours per week.[2] Informal caregivers also spend 13 hours per month researching about care services or information on diseases, coordinating physician visits, or managing finances.[3] Informal caregivers of patients with Alzheimer's or dementia and patients with mental health condition mostly manage finances and arrange for outside services.[2]

About 60% of caregivers help with at least one ADLs with the most common being getting in and out of beds and chairs.[2] Informal caregivers who spend more time in caregiving often find themselves performing each ADL.[2] However, 10% of the caregivers performing just one ADL find it difficult to help with the ADL, while 48% of those performing 6 ADLs report difficulty with providing care. The most common IADLs that the informal caregivers helped with were transportation (78%), grocery or other shopping (76%) and housework (72%).[2] About 57% of informal caregivers said that they assist with medical/nursing tasks.[2] However, 42% of

these informal caregivers indicated that they were performing the medical/nursing tasks without any preparation.[2]

Economic value of informal caregiving

The AARP evaluated the economic value of the services provided by informal caregivers. Over the last decade, the estimated economic value of caregiving has increased from $375 billion in 2007, to $450 billion in 2009, and to $470 billion in 2013.[4] Importantly, the 2013 figure exceeded the value of paid home care and total Medicaid spending for the same year.[4] However, it must be noted that the estimate is conservative in the sense that it does not take into account physical, emotional and financial costs of care to caregivers. The biggest cost savings were found through care provided to patients with Alzheimer's disease or dementia, where the economic value was estimated to be $217.7 billion in 2014 or $43,000 per person per year.[5] Arno et al. calculated the amount of money needed to substitute informal care with formal alternatives and found that the value of caregiving is equivalent to 18% of total US healthcare expenditures.[6] While it is not currently counted as a part of healthcare expenditures, if it was, the US healthcare expenditures would surpass $1 trillion.[6]

B. Impact of informal caregiving

The impact of informal caregiving varies across caregivers. The NAC survey found that 48% of the informal caregivers perceived their health to be excellent or very good, 35% responded their health as good, and 17% said it was fair or poor.[2] The percentage of informal caregivers describing their health as fair or poor was greater than the percentage of general adult population who described the same (17% vs 10%).[7] The following sections will discuss the impact of caregiving on indicators such as depression, taking time off from work or reduction in immune response to more complex indicators such as caregiving burden and QOL.

Impact on caregiver health

Several studies and meta-analyses have documented psychological implications of caregiving stress among informal caregivers.[8-12] Previous studies have shown that caregivers are subjected to increased risk of psychological distress, depression, anxiety, and cognitive problems when compared to non-caregivers.[8,10,11] A review of 33 articles in caregiving by Schulz et al. (1990), found that caregivers had above average levels of psychological symptoms such as depression, anxiety, hostility, and paranoia.[11] Another review, looking at the well-being effects of caring for patients with dementia found that caregivers experience a higher levels of depressive symptoms.[10] Cooper et al. (2007) found in a systematic review involving studies among caregivers for patients with dementia that dementia care was associated with higher levels of caregiver anxiety.[13] Overall, depression and distress were the most commonly reported by studies that assessed caregiver health.

A number of caregiving-related stressors such as care recipients' behavior problems, level of physical and cognitive impairment, duration of caregiving and amount of caregiving were shown to be associated with depression among caregivers. [8] In a meta-analysis by Pinquart et al., integrating the findings on 228 studies showed that the relationship of caregiving stressors with burden and depressed mood differed according to sample characteristics.[8] For example, stressors like the amount of care provided and care receiver's physical impairments affected burden and depression more among caregivers of non-demented frail older adults compared to caregivers of patients with dementia.[8] In spouse caregivers compared to adult children caregivers, physical impairments and behavioral problems were associated with higher burden.[8]

In addition to the above caregiving-related stressors, studies also reported other types of stressors. Savage and Bailey, in their analysis of impact of caring on caregiver's mental health by

factors found that mental health outcomes among caregiver's were associated with the amount of emotional bonding between caregiver and care recipient.[14] A closer relationship between caregiver and care recipient resulted in positive mental health for the caregiver. Also, the negative association of mental impairment among care recipients with caregiver's mental health was enhanced by lack of social support and financial restrictions. Caregiver gender was also found to a play a role in caregiver's psychological health. Women report higher levels of depression, anxiety and lower levels of well-being compared to men over a two years of caring.[15,16] Pinquart and Sorensen, explain that the gender differences can be partly explained by the fact that women tend to provide longer and more intense care and that, after accounting for these factors, the remaining differences were insignificant.[17]

A number of longitudinal studies have examined the long-term impact of providing care to care recipients. Bookwala, found that caregivers suffer more over time, with increasing psychological burden and decreasing well-being.[15] Contrary to this, Hirst found that intense caregiving, that is, providing more than 20 hours of care, was associated with highest levels of distress at the time when caregiving began as well as after the caregiving spell ended.[18] The conclusion that can be drawn from the two longitudinal studies is that duration of caregiving and amount of caregiving both are important stressors in influencing caregiver distress and burden.

Physical health of caregivers was also directly or indirectly impacted as shown by higher levels of stress hormones, immune dysregulation, higher levels of chronic conditions, poor self-rated health, poor sleep quality and exacerbation of pre-existing conditions among caregivers compared to non-caregivers.[19,20] In a meta-analysis of articles on physical health published between 1986 and 2006, Pinquart and Sorensen found that poor physical health among informal caregivers is more likely to be related to the caregiver's poor mental health status than to

physical overload.[9] The association between informal caregiving and physical health outcomes is explained by Pinquart and Sorensen using three reasons: (i) the demanding nature of caregiving might cause musculoskeletal injuries and other chronic illnesses; (ii) caregivers are not able to give enough time to healthy lifestyle behaviors; and (iii) stress related to caregiving is likely to exacerbate physical conditions like hypertension and cardiovascular disease.[9] Other factors that contribute to caregiver's poor physical health include caregiver's age and gender, care recipient's behavior problems, cognitive impairment, functional disabilities, duration and amount of care provided, vigilance demands and co-residence of patient and caregiver.[19] However, the association between informal caregiving and physical health should be interpreted with caution because most studies are cross-sectional and thus do not account for endogeneity (e.g., Socio-economic status, shared health habits between caregiver and care-recipient) and pre-existing conditions.[21]

Impact on Quality of Life

The majority of research in informal caregiving focusses on only health effects and burden of care.[22-25] Only few studies among caregivers evaluated QOL which offers a broader perspective in terms of impact of caregiving on physical, psychological, social and financial well-being.[26,27] QOL has the ability to measure both positively and negatively valued aspects of life, and accounts for a broad range of human experiences that encompasses health, level of activity, spirituality, social support, satisfaction with personal accomplishments, resources and overall well-being.[28] It is multi-dimensional compared to health-related quality of life (HRQOL), which restricts itself to health. Thus, looking at health effects and caregiver burden instead of QOL does not offer a comprehensive picture of the struggles faced by caregivers.[29,30]

The few studies that have used QOL to measure the impact of caregiving in different chronic conditions found that informal caregiving is associated with lower QOL values on mental health, social functioning and economic well-being compared to non-caregivers.[31-33] Lower scores on QOL are partially explained by disease duration, perceived burden and patient therapeutic characteristics such as presence of dementia or Parkinson's.[34-37] However, there is considerable variation in the experience of burden and QOL, even if the caregivers are similar in clinical aspects or in intensity of caregiving. The reason given by researchers for such observation is that there is difference in the perception of stress by individuals due to mediating factors like coping behavior and self-efficacy.[38-41]

C. Resources used by informal caregivers

Informal caregivers have to manage time between providing care to their loved ones, self-recreation and meeting family or friends. Half of informal caregivers do not have help from other unpaid caregivers or family members.[2] Recently, a number of professional health and human services have been made available to supplement the care provided by informal caregivers. These services range from respite and day care programs, help from support groups, training for care provision, and professional caregivers.[42] A number of studies have looked at factors that affect service use among informal caregivers of individuals with specific disease conditions.[43-51] The major factors found to be predictive of service utilization were caregiver/care recipient relationship, rural/urban location, availability of transportation, medical insurance, caregiver knowledge of services, caregiver health problems and availability of secondary informal caregiver at home.[43,44,48,52-57] Among the informal caregivers who utilize services, they report the use of an average of 3.2 health services such as home health aide, inpatient service, outpatient service, mental health service, nursing home, or emergency room service and 3.7

human services such as day care, support group, financial assistance, homemaker, or in-home respite to assist them with caregiving.[58] The average number of service use was low because the definitions of health and human services were broad and all inclusive.

Despite the availability of such services, the use has been low. Toseland et al. found that the use of day care was 15.5%, support group was 12.2% and educational material was 12.2% among caregivers.[58] A previous study reported that informal caregivers lacked knowledge on the availability of services.[58] However, a high number of informal caregivers in the study indicated a need for at least one additional service and most of them agreed that such services will reduce the likelihood of institutionalization of the care recipient.[58] One limitation was that most of the studies were done in sample of caregivers providing care to individuals with specific disease condition mostly neurological conditions. A nationally representative sample of caregivers will help in understanding of factors that predict service use from a more generalizable point of view.

D. Theoretical models in caregiving

A multitude of theoretical frameworks of caregiving have been conceptualized and tested to explain the differences observed in health outcomes among caregivers.[23,59-61] The very first model was the Transactional Stress Theory developed by Lazarus and Folkman.[62] According to this model, the outcome experienced by the caregiver after being exposed to caregiving stress is mediated through caregiver's appraisal of the resources and coping strategy implemented. The specific stressors to which caregivers are subjected can be functional dependency of care recipient, severity of the condition, or care recipient's behavior problems.[62] These stressors trigger a cognitive appraisal process where the caregiver perceives stress as being taxing, in turn employing a coping behavior.

Coping involves minimizing, avoiding, tolerating, and accepting stressful situation.[63] Coping depends on what the person actually thinks or does in specific stressor situation. An individual can cope in various ways depending on how the stressful situation unfolds. The coping efforts have been defined by Lazarus and Folkman as being either problem-based or emotion-based.[59] Problem-based coping refers to adapting behavior as showed by the caregiver that directly alters or resolves the stressful situation.[10] Emotion-focused coping refers to managing and regulating one's emotional reactions to uncontrollable stressful situation.[10] Mechanisms like using problem-solving, social support and seeking information, fall under problem-based coping while emotional release, falls under emotion-based coping.[38] Based on the coping strategy implemented, caregivers experience different outcomes.

Previous studies utilizing the Transactional Stress Theory have evaluated different health outcomes such as caregiver's depression, life-satisfaction, and self-reported health.[38,41,64] This theory has also helped to establish that caregivers that undertake problem-based coping are likely to be less depressed.[65] Similarly, caregivers who view performing caregiving tasks as satisfying or portray self-efficacy in carrying out caregiving have lower levels of distress.[66] While, caregivers who show avoidant-evasive and regressive coping styles or have lesser emotional and social support report higher levels of depression, burden, and lower life-satisfaction. Caregiver's subjective appraisal of patients' problems and their self-efficacy in managing problems better predicted their relationship with depression while social support better predicted caregiver's life satisfaction than depression.[63] Similarly, coping responses better predicted relationship with self-reported health. A study testing the mediation analysis of stress-coping-outcome reported that only some aspects of emotion-based coping like "wishfulness" and intrapsychic strategies

mediate the relationship between stressor and well-being while instrumental strategies under problem-focused coping only predicted one part of outcome (positive effect).[65]

In the Stress-Process model developed by Pearlin et al., caregiver outcomes were tested against socioeconomic characteristics of caregivers, primary stressors, and secondary stressors with coping and social support intervening at multiple points along the stress process.[23] Primary stressors were linked directly to care recipient and disease severity while secondary stressors arise from the demands of the caregiving role. This model has had the greatest influence on the theoretical understanding of the process of caregiver outcomes.[67-69] Studies that have utilized these models have found that coping and social support play their part in the manifestation of caregiver burden by intervening at different points along the stress process, thereby playing a mediating role.[70]

These theoretical frameworks have improved the understanding of outcomes among informal caregivers providing care to care-recipients with chronic disabling conditions. In particular, they have established that self-efficacy, caregiver-recipient relationship, social support, and coping play an important role in caregiver outcomes. However, these models do not emphasize the role of the subjective characteristics of the caregiver in caregiver outcomes.[71] Caregiver's self-perception, mastery, and personality have been explored as potential factors that can impact caregiver behavior and outcomes.[71] However, most of the research has concentrated on exploration of caregiver personality as a potential factor in explanation of overall caregiver health, but not in the possibility of personality interacting with stress appraisal and coping. A certain type of personality, for example neuroticism, under high perceived stress may adopt emotion-based coping while extraversion, under high perceive stress may adopt problem-based

coping. Similarly, neurotic individual adopting problem-based coping may have adverse outcomes which needs to be further explored.

E. Personality

Personality and health outcomes

Research has shown that different personalities differ in their tendencies to appraise stressful events as problematic and threatening. In a study conducted by Vollrath, personality was found to play a defining role in stress appraisal.[72] Neurotic individuals were found to be vulnerable to appraise events as more stressful compared to individuals with other traits. On the contrary, conscientiousness is associated with appraising stress as manageable, because conscientious individuals tend to plan ahead for predictable stressors. Agreeableness is associated with assessment of events as less stressful due to proclivity of agreeable people to have low interpersonal conflict and low social stress. [72] Extraversion and openness perceive events as challenges rather than threats and therefore show positive stress appraisal. Individuals who were high on neuroticism and low on conscientiousness assessed stress negatively while individuals showing low neuroticism and high conscientiousness assessed stress positively i.e., as less threatening.[72]

Certain studies also explored the relationship between personality and outcomes. In a study done by Tew et al. it was found that conscientiousness was associated with benefits in the psychological domain of quality of life, openness predicted benefits in the environment domain, and neuroticism was associated with reduction in the psychological domain.[73] A number of other studies established that neuroticism was associated with negative mental and physical health among caregivers of patients with dementia, Alzheimer's disease and multiple functional impairments.[74,75,76] A couple of studies conducted with spouse caregivers, one among caregivers

of patients with lung cancer and the other among caregivers of patients with dementia, found that neuroticism was directly associated with greater depressive symptoms.[77,78] Lockenhoff et al. also found physical and mental health to be positively associated with extraversion, conscientiousness, agreeableness and openness.[76] Melo et al. found that agreeableness was found to decrease the burden on caregivers of patients with dementia.[79]

Personality and coping

Meta-analyses suggest that the relation between personality and coping is modest.[80] Individuals high on neuroticism are less likely to engage in problem-focused coping while relying more on emotion-focused coping such as escape-avoidance, self-blame, seeking emotional support and wishful thinking and antagonistic means of coping such as hostile reactions and catharsis.[80] Individuals high on extraversion engage in problem-focused coping and in adaptive forms of emotion-focused coping such as positive thinking and support seeking.[80] Openness was found to be unrelated with coping behavior in a study done by Hooker et al. while another study found that open individuals were more likely to engage in positive thinking, self-adaptation, sedation and emotional expression.[81,82] Individuals high on agreeableness are more likely to be involved in problem-focused coping such as seeking support and less likely to be involved in emotion-focused coping such as self-blame, avoidance and wishful thinking while individuals high on conscientiousness tend to use more problem-focused coping such as active coping, problem solving, planning and restraint coping and less of emotion-focused coping.[82]

The individual and independent association of personality with stress appraisal, coping and health outcomes, opens a potential question of what role personality of caregiver can play within the stress process model. This possibility has not been explored previously despite some evidence presented outside the caregiving literature. David el al. in a study involving community

residing nominally healthy men found that neuroticism and openness moderated the relationship between stress appraisals of a bothersome event (includes perceived uncontrollability and perceived severity) and coping strategy use.[83] Similarly, Lee-Baggley et al. in a sample of couples living in a stepfamily found that personality moderated the relationship between perceived stressors of marital conflict or child misbehavior and coping strategy use.[84] Bolger and Zuckerman explored the possibility of personality traits interacting with coping strategies for interpersonal conflicts in affecting health and psychological outcomes among introductory psychology students.[85] They found that the highly neurotic individuals who engaged in self-controlling and escape-avoidance coping strategy were predicted to have depression.[85] Such evidence can be used as a basis to explore the role of personality within the stress-coping-outcome framework. This will help in gaining a more complete picture of the interrelationship of factors in explaining caregiver outcomes, especially QOL.

F. Need for study

Previous studies have assessed QOL and the impact of caregiver-related, care-recipient related, and psychosocial factors on informal caregivers of individuals with specific disease conditions. None of the previous studies have assessed QOL among informal caregivers caring for only older individuals or young children. To assess QOL among informal caregivers caring for only older individuals or young children, it would be interesting to see if both set of caregivers differ in the interpretation of questions assessing their QOL. Further, in order to obtain evidence for the use of a QOL instrument to measure QOL in informal caregivers caring for only older individuals or young children, it is necessary to assess its psychometric properties. Also, evidence of psychometric properties are needed to ensure the broad application of a

generic instrument such as World Health Organization's Quality of Life Brief (WHOQOL-BREF) across different caregiver populations.

In order to explain the inherent difference in the expression of QOL among informal caregivers, previous studies have used the stress-coping-outcome framework. However, personality has been found to have an independent association with stress appraisal, coping and, health outcomes. With the recent establishment and validation of stress-process models in assessing caregiver outcomes, there is a need to explore the role that the personality traits of caregivers can play within the stress process model. Specifically, there is a need to understand if caregivers of certain personality traits choose specific coping strategies under stressful situations and if the type of coping strategy they choose decides their QOL. This will contribute to our understanding of the impact that personality has on QOL among informal caregivers. Health policy educators could use this information to understand what personality type is prone to low QOL and develop educational materials for caregivers that is tailored to individual personality needs. There is also a need to understand if the personality effects differ with respect to caregiver's care for child or adult care-recipient, so the educational materials can be tailored accordingly. With health policy stressing the importance on understanding of outcomes among informal caregivers, assessing the role of personality will add to existing knowledge.

To help with the process of caregiving, informal caregivers have access to services like respite and day care programs, community support groups, training for care provision, and professional caregivers. However, the use of such services is low. It is important to understand the factors that influence of use of such services among a nationally representative caregiver population. Till now, patient-specific and caregiver-specific factors have been explored separately and in specific groups such caregivers of patients with dementia. There is a need to

assess factors that influence service use in generic caregiver sample and the relative contribution of patient-specific and caregiver-specific factors in utilization of services. It will give a general idea of what factors are important that can be improved upon to increase the uptake of caregiver services.

G. Specific aims and objectives

1. To examine the factor structure and measurement invariance of the WHOQOL-BREF among informal caregivers of individuals with neurological conditions
    a. Assess the reliability of WHOQOL-BREF.
    b. Assess the factor structure for WHOQOL-BREF.
    c. Assess the evidence for measurement invariance in the WHOQOL-BREF among informal caregivers, specifically focusing on type of care-recipient, age and chronic condition burden.
2. To investigate the role of personality in the stress-process model with QOL as the outcome among informal caregivers
    a. The compare the model among informal caregivers of patients with Alzheimer's disease with the model among informal caregivers of patients with Autism-spectrum disorder.
    b. To test the hypothesized model in informal caregivers of patients with Alzheimer's disease.
    c. To test the hypothesized model in informal caregivers of patients with Autism-spectrum disorder.

3. To assess patient and caregiver-specific factors that predict the use of health and human services
    a. Identify the predictors of respite service use by informal caregivers.
    b. Identify the predictors of training service use by informal caregivers.
    c. Identify the predictors of professional help by informal caregivers.

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Chapter 2

Factor structure and measurement invariance of the WHOQOL BREF among caregivers of patients with Alzheimer's disease or Autism-spectrum disorder

Introduction

Informal caregiving, and caregivers, play an integral role in assisting people with chronic and long-term illnesses. Spouses, parents, and children undertake the role of caregiving for their family members who are chronically ill, disabled or aging, more often than professional caregivers in the US.[1-3] In the process of assuming this role, caregivers are exposed to primary (e.g., cognitive or behavioral depreciation of family member, activity of daily living) and secondary stressors (e.g., family and job conflicts, economic problems) that can have an adverse effect on their own health.[4] A large body of evidence has shown that informal caregivers are at increased risk of depression.[5-8] In fact, the rates at which informal caregivers report depression are two to three times higher than the general population.[9,10] Moreover, informal caregivers report emotional and cognitive problems at a higher level compared to non-caregivers.[11-13] Caregiving also takes a toll on caregivers' physical health. Research has shown that they suffer from reduced antibody response, poor sleep quality, and increased risk of hypertension and hyperlipidemia.[7,14-16] Finally, informal caregivers also face social and work difficulties with less time to spend with friends, to fulfill other family obligations, or to focus on work commitments.[17,18]

Previous studies have examined specific outcomes of caregiving such as depression, mental health, social impact and work difficulties. However, few studies have looked at the effects of caregiving in terms of a broader concept such as caregivers' quality of life (QOL). QOL is an all-inclusive subjective concept incorporating diverse aspects of health like physical functioning, psychological well-being, level of activity, as well as non-health-related components such as social interaction, satisfaction with personal accomplishment, life situations and spirituality.[19] Thus, an individual's QOL is defined by not only health but also economic, environmental, political, social, and spiritual factors. Health-related quality of life (HRQOL), in comparison, is a subset of QOL which focuses mainly on an individual's health.[20] Previous studies that evaluated the HRQOL in caregivers of patients with cancer, amyotrophic lateral sclerosis (ALS), otitis media, Alzheimer's disease, and dementia, found that HRQOL of caregivers was low compared to non-caregivers, and decreased according to caregiver burden and severity of a patient's condition.[21-26] Assessing the impact of caregiving in terms of QOL will give a better understanding of caregiving's effect on both health and non-health-related components of well-being.

Only a few studies have measured QOL of caregivers and found that QOL is associated with caregiver burden, quality of caregiver-care-recipient relationship, coping skills, depression, and self-efficacy.[27-29] The instruments used by these studies to measure QOL were disease-specific measures for Alzheimer's and cancer. Disease-specific QOL measures are only applicable to caregivers of patients with that particular disease which restricts comparisons between caregivers. Generic QOL measure assesses QOL without any influence of patient characteristics and facilitates comparisons between caregivers that enables generalization of results to the whole caregiver sample. In order to evaluate QOL in a sample of informal

caregivers of patients with different conditions, a generic measure such as the World Health Organization Quality of Life – Brief (WHOQOL-BREF) would be helpful.

The WHOQOL-BREF is an instrument developed by the WHO specifically to measure QOL.[30] The instrument takes into account how satisfied or bothered people are by important aspects of their life. It is an abbreviated 26-item version of the WHOQOL-100, and like the WHOQOL-100, it has been cross-culturally validated in 19 different languages in 23 countries.[30-33] The WHOQOL-BREF is an appropriate instrument to measure QOL as it covers a very broad range of facets relevant to the assessment of QOL. The facets were identified by 15 culturally-diverse field centers all over the world through focus group meetings involving health professionals, patients and well subjects.[31] A final list of 24 facets were identified by field testing and were included in WHOQOL-100 and WHOQOL-BREF. The WHOQOL-BREF captures information on four domains of QOL: Physical health, psychological health, social relationships, and environment. It contains one item from each of the 24 facets of QOL plus two items on overall QOL and general health. Skevington et al. psychometrically validated WHOQOL-BREF by fielding it in 24 field centers representing 23 countries.[30] The Cronbach's alpha was more than 0.7 for 3 of 4 domains demonstrating that the brief version of the instrument had high reliability, and the instrument showed good discriminant and construct validity.[32]

Since its validation in the general population across 23 countries, it has also been validated in older adults, and among patients with conditions such as arthritis, spinal cord injury, autism, schizophrenia, type 2 diabetes, pregnancy, dementia, sickle-cell disease, depression, and HIV/AIDS.[34-43] The results of these past studies suggest that the WHOQOL-BREF has good psychometric properties. The overall internal consistency reliability for WHOQOL-BREF

(range: 0.84-0.88) and for each domain i.e., physical (range: 0.73-0.87), psychological (range: 0.65-0.84), social (range: 0.54-0.68) and environmental (range: 0.72-0.84) was good. The studies also showed that the convergent, discriminant and known-groups validity were good while construct validity was acceptable. Previous studies also showed that a four-factor hierarchical model where second-order factor (QOL) influences first-order factors (physical, health, psychological health, social relationships and environment) is the best fitting model compared to a one-factor model.[30,33,44]

The psychometric properties of the WHOQOL-BREF amongst caregivers in the US has not been established. A previous study established the psychometric properties of this instrument among caregivers of patients with autism in Jordon.[45] They found no evidence supporting an alternative to the original 4-factor model, although some of the items were redistributed to different domains.[45] Moreover, the assumption of measurement invariance has not been tested previously with respect to key predictors of QOL like caregiver's age, presence of chronic condition and condition of caregiver's spouse or child. It is essential to establish that the items comprising the QOL measure operate equivalently across different caregiver subgroups. In other words, caregivers of patients with any kind of chronic condition, disability, or age-related ailment should assign the same meaning to questionnaire items. The primary objective of this study is to establish factor structure and internal consistency reliability for the WHOQOL-BREF among caregivers of patients with Alzheimer's disease and Autism-spectrum disorder in the US. The secondary objective is to examine whether the psychometric properties of the items comprising the WHOQOL-BREF vary between caregivers of patients with Alzheimer's disease and Autism-spectrum disorder in the US and within each group of caregivers by age and chronic condition burden.

Methods

A. Study Design and Sample

The current study had a prospective, cross-sectional design wherein data were collected using an online survey. The study protocol was reviewed and approved by the University of Mississippi Institutional Review Board. The survey was distributed to a national purposive sample of informal caregivers of patients with Alzheimer's disease or Autism-spectrum disorder in the United States. We concentrated on caregivers of patients with conditions that primarily affect mental well-being because according to a systematic review these caregivers are subjected to more adverse health effects when compared to those caregivers providing support to individuals with more physical limitations.[5,14] The sample was obtained from Rare Patient Voice LLC., Towson, MA, a market research vendor company, which maintains panels of patients and caregivers with various conditions. The company recruits caregivers from disease-specific conferences and patient advocacy group meetings across the US.

The participants of the study were adults (≥ 18 years of age) who self-identified as informal caregivers to patients with either Alzheimer's disease or Autism-spectrum disorder. In the Autism-spectrum disorder group, caregivers had to provide care to a patient who is less than 18 years of age to be eligible. This criteria was included to get two distinct sample of patients in the terms of age in addition to disease condition. There were no other inclusion criteria. Based on analytical requirements, an a priori sample size of 400 caregivers, with 200 representing caregivers of patients with Alzheimer's disease and 200 representing caregivers of patients with Autism-spectrum disorder, was considered adequate to meet study objectives.[46]

B. Study Methodology

A cover letter explaining the purpose of the study, eligibility criteria, and contact information of the principal investigator was emailed to all eligible caregivers on the panel. Within the letter assurances were given on the confidentially of responses and a unique ID was assigned to each responder. This unique ID was used to identify the respondent during analysis. A URL link to the survey programmed in Qualtrics (Qualtrics Inc, Provo, UT) was included in the email. The survey link was open for a 2-month period starting from 6/25/2018 to 8/25/2018 and reminders were sent bi-weekly. All responders were provided with an honorarium for completing the survey.

C. Study Measures

World Health Organization Quality of Life – Brief (WHOQOL-BREF): As mentioned previously the WHOQOL-BREF items are classified into four domains: physical health (seven items), psychological health (six items), social relationships (three items) and environment (eight items). The 24-items representing each facet of QOL are measured using a five-point response format ranging from 'Not at all' to 'Completely'. For the calculation of the raw scores, three items were reversed coded in the questionnaire. The raw scores for each domain was calculated by adding the scores of the item in each domain. The raw scores was transformed to 0-100 using the algorithm provided by the WHOQOL-BREF group. A lower score on this instrument indicates lower perceived QOL. The WHOQOL-BREF contains additional two items capturing overall QOL and general health which are not included in scoring.

Demographic and caregiving information: Information was collected on the following socio-demographic and caregiving characteristics: (1) age, (2) race/ethnicity, (3) sex of the caregiver,

(4) marital status, (5) occupational status, (6) education status, (7) relationship to care recipient, (8) year caregiving started, and (9) number of hours per week spent in caregiving.

D. Statistical Analysis

Sample description: Descriptive statistics were calculated in the form of frequencies and percentages for categorical variables, and means and standard deviations for the continuous variables.

Item-level analysis: The item-response pattern was presented as frequency and percentage of each response. If the response to any item was missing, it was treated as a separate category and frequency and percentage was reported for it along with other responses.

Missing data handling and analysis: If more than 20% of data was missing for assessment on the WHOQOL-BREF, that individual was not included in final analysis. Where a response to an item was missing, the mean of other items in the domain was substituted. Where responses to more than two items were missing from a domain, the domain score was not calculated. For confirmatory factor analysis, which was used to assess the factorial validity of the WHOQOL-BREF, the sample with all available responses was used.[47]

Factorial validity: The factor structure of the WHOQOL-BREF instrument was evaluated using confirmatory factor analysis (CFA) using responses from both caregivers of patients with Alzheimer's disease and Autism-spectrum disorder. CFA is a structural equation modeling technique used to assess the fit of a theoretically-based model. The most commonly tested models for WHOQOL-BREF are a one-factor model, four-factor model and second-order factor model (i.e., a four-factor model with a second-order global QOL factor). These three models

were tested using CFA in the current study. The one-factor model forced all the items on the WHOQOL-BREF to load on a single latent factor (QOL). The four-factor model had specific items loading on four factors namely physical health, psychological health, social relationships and environment. All four factors were allowed to intercorrelate. The second-order model was based on the approach adopted by Skevington et al. where items were specified to load onto four first-order factors (physical health, psychological health, social relationships and environment) and those four first-order factors were specified to load onto a single latent QOL factor (Figure 1.1).[30]

Because the items on the WHOQOL-BREF scale are measured on an ordinal scale, a robust weighted least squares estimator (WLSMV) for categorical indicators was used. There are various fit indices to determine a model's fit.[46,48] The most common are Tucker Lewis Index (TLI), Comparative Fit Index (CFI), root mean square error of approximation (RMSEA) and standardized root mean square residual (SRMR). The criteria suggested for good fit of the model are TLI>0.95, CFI>0.95, RMSEA<0.06 and SRMR≤0.08.[49,50] (Hu and Bentler, 1999) Model fit was assessed using χ^2 statistic, TLI, CFI, RMSEA and SRMR. All CFA models was estimated using Mplus version 8 (Muthen & Muthen, Los Angeles, CA).

Convergent validity: The fundamental property of convergent validity is that items which indicate a particular latent construct should correlate strongly with each other or share a high proportion of variance compared to items from other latent construct.[51] The convergent validity among item measures was assessed using factor loadings and item-total correlations. Factor loadings give the amount of variance in a particular item that can be explained by the latent construct. Standardized factor loadings of 0.5 or higher was indicative of good convergent

validity. Item-total correlations computes the Pearson's correlation between score on an individual item with the total score remaining items of the latent construct. If the correlations were high, it indicates that items in the same latent construct correlate strongly to each other. It is hypothesized that there was strong correlation of items belonging to a latent construct to the corrected score on latent construct itself.

Discriminant validity: The fundamental property of discriminant validity is that items which make up a latent construct should correlate poorly with other latent constructs.[51] Thus, when correlation of latent factors is fixed to 1, there would be significant changes to the fit of the model compared to the established four-factor model. Discriminant validity was evaluated by comparing the fit of the four factor model with the fit of a model where the correlation between 2 latent factors is fixed to 1. The change in fit was evaluated by using DIFFTEST option in MPlus and a significant change was suggestive of discriminant validity.

Known-groups validity: Known-groups validity evaluates whether two groups that are on different severity level or with different conditions are able to be differentiated by latent construct. It was hypothesized that caregivers with no chronic condition would differ on QOL compared to caregivers with any chronic condition. The idea behind using the presence of chronic condition as a measure to test known-groups validity was that chronic condition affects the daily activities and well-being of an individual that will be reflected in the measurement of QOL if the instrument has known-groups validity. The difference was evaluated using an independent t-test between caregivers with no chronic condition and caregivers with any chronic condition.

Reliability: The internal consistency reliability was assessed using Cronbach's alpha for the overall scale and each domains of WHOQOL-BREF. A Cronbach's $\alpha \geq 0.70$ was suggestive of adequate internal consistency reliability, with values ≥ 0.80 considered preferable.

Measurement invariance analysis: Multi-group CFA was used for testing the assumption of measurement invariance across the informal caregivers responding to the survey grouped according to condition of the care recipient (Alzheimer's disease vs Autism-spectrum disorder). Additionally, measurement invariance was conducted within caregivers of patients with Alzheimer's and caregivers of patients with Autism between different age groups (identified according to median split) and whether or not they had a chronic condition. As mentioned earlier, robust weighted least squares estimator (WLSMV) was use together with the delta parameterization in MPLUS.[52] The testing of measurement invariance of the WHOQOL-BREF was carried out using a series of tests and nested model as outlined by Millsap and Yun-Tein.[53] The series of nested models imposed successive restrictions on model parameters in multiple-groups CFA. The first step was to test invariance of the factor structure called configural invariance, which involves conducting the CFA separately in each group. If the covariance matrices did not differ significantly between groups, step 2 was carried out. Step 2 involved undertaking step 1 + testing invariance of the factor loadings. This test is often referred to as the test of metric invariance or weak factorial invariance.[54] The final step involved step 2 + testing invariance of the thresholds. This test has been alternatively termed as scalar invariance or strong factorial invariance.[54] If there was no significant difference in comparing each step, the scale would pass the test of measurement invariance.

Statistically significant differences in model fit between nested models were assessed using the DIFFTEST option in Mplus 8 (Muthen & Muthen, Los Angeles, CA). However, chi-

square is known to be overly sensitive to minor violations in the model and to be severely affected by sample size. Therefore, a ΔCFI of larger than .01 was used to indicate serious reduction in fit.[55] If the fit, after adding each restrictive constraint to the model, is found to be significantly worse than the previous less constrained model, then further invariance testing was stopped and an inspection of the modification indices was conducted. Starting from the largest modification index, problematic constraints was removed at each level of invariance testing until the model fit is found not to be worse as compared to the previous model with fewer constraints on model parameters. Thus in cases where full invariance does not hold, an examination of partial measurement invariance was conducted. Further testing by placing more restrictive parameter constraints will only continue if at least one indicator (besides the marker indicator) was found to be invariant across patient sub-groups.[54]

Results

Sample breakdown and demographic characteristics: The panel used for the study had 1,239 caregivers that included 798 caregivers of patients with Alzheimer's and 441 caregivers of patients with Autism. There were 13 caregivers who opted out of the study. A total of 574 caregivers responded to the survey giving a response rate of 46.8%. Out of the 574 who responded, 457 had a response on WHOQOL-BREF, among them 234 (51.2%) were caregivers of patients with Alzheimer's and 223 (48.8%) were caregivers of patients with Autism. Table 1.1 shows the distribution of the caregivers according to each characteristic. Most of the caregivers were parents (45.3%) of the patients or son/daughter of the patients (25.2%). A large proportion of the caregivers were females (90.8%), Caucasians (79%), married (52.5%), had some college degree (29.3%), employed (32.4%) and lived in a suburban area (40.3%) (Table1). The mean age of the caregivers was 38.8(±10.2) years and they spent an average of 70.6(±49.2) hours per week

in caregiving (Table 1.2). More than half of the caregivers did not have any chronic condition (53.4%).

Item and domain distribution: Table 1.3 shows the response distribution for each item of the WHOQOL-BREF among all caregivers. The domain score was transformed to the scale of 4-20. The mean scores for physical, psychological, environmental and social domains were 13.6(±3.26), 13.11(±3.44), 13.82(±2.8), and 12.20(±4.04) respectively.

Factorial validity: Three models were tested that included one-factor model, four-factor model and second-order factor model to assess the factorial validity of the WHOQOL-BREF among caregivers of patients with Alzheimer's disease or Autism. Table 1.4 gives the fit indices for the three models. The one-factor model where all items loaded onto a single latent QOL factor had a poor fit (Chi-square [df] = 1844.32[252]; CFI = 0.871; TLI=0.858; RMSEA [90% CI] = 0.118[0.113-0.123]; SRMR=0.066). The second-order factor model based on the approach used by Skevington et al. had a mediocre fit (Chi-square [df] = 1376.37[248]; CFI = 0.908; TLI=0.898; RMSEA [90% CI] = 0.1[0.095-0.105]; SRMR=0.056). The four-factor model based on the approach by Theuns et al. also had a mediocre fit but the fit was similar to the higher-order model but with lesser restrictions (Chi-square [df] = 1371.56[246]; CFI = 0.909; TLI=0.897; RMSEA [90% CI] = 0.1[0.095-0.105]; SRMR=0.056).

Convergent validity: Table 1.5 depicts the standardized factor loadings for each of the items of WHOQOL-BREF in the four-factor model. All factor loadings were greater than 0.5 except item 3 and 4 on the physical domain. Nonetheless, all factor loadings were significant at $\alpha = 0.05$. Table 1.6 gives the item-total correlations between the items and the individual domains. The correlations between all domains and their corresponding items were more than 0.6 and

statistically significant. The factor loadings and item-total correlations suggest that the convergent validity for the items that devised the four domains was good among caregivers.

Discriminant validity: To evaluate discriminant validity, the fit of the four factor model was compared to the fit of the model where the correlation between two of the four factors was fixed to 1. Correlation of each combination of factors were fixed to 1, one at a time and then compared to the four-factor model. The results of each comparison of model fit are depicted in Table 1.7. Each of the comparisons yielded a significant difference in chi-square value. This shows that the items that devised the domains had good discriminant validity, suggesting that the four domains of the WHOQOL-BREF assess different constructs.

Known-groups validity: The independent t-test showed that the difference in each of the domain scores between caregivers had at least one chronic medical condition and caregivers who had no chronic medical condition was significant (Table 1.8). The effect size of the difference was calculated by using Cohen's d. The effect size for physical domain was large, suggesting that the two groups differ by 0.84 standard deviations. The effect size for psychological domain was medium, such that the two groups differed by 0.56 standard deviations. The effect sizes were smallest for social and environmental domains, where the two groups differed by 0.43 and 0.49 standard deviations, respectively. This shows that the WHOQOL-BREF scale was able to discriminate between caregivers with differing conditions.

Internal consistency reliability: The internal consistency reliability for the four domains of the WHOQOL-BREF among caregivers was good. The Cronbach's alpha for all four domains were above 0.7 and ranged from 0.88-0.76 as depicted in Table 1.9.

Floor and ceiling effects: Assessing the distribution of domain scores in the study sample showed that less than 20% of caregivers received the lowest or the highest possible score on all four domains. This suggests absence of any floor or ceiling effects.

Measurement invariance: The test of measurement invariance was carried across the caregivers grouped according to condition of the care recipient (Alzheimer's disease vs Autism-spectrum disorder). The assumption was that caregivers from each group who were at the same level or had the same score on all four latent domains will have similar response pattern on the items. The assessment ensures that sub-group membership does not influence the measurement of the QOL domain and the differences in the QOL between the subgroups are true reflection of the QOL measurement. Other than care-recipient condition, two additional tests of measurement invariance were conducted within the two groups of caregivers according to age and caregiver chronic condition, the results of which are depicted in Table 1.10.

Care-recipient condition: The test of configural invariance (i.e., invariance of factor structure) was conducted to assess if there was difference in the covariance matrices of the four-factor model in the two groups. The fit indices were acceptable ($\chi^2(492) = 1551.16$, RMSEA = 0.09, CFI = 0.91) suggesting that the covariance matrices were identical in the two groups. The test of equal factor loadings i.e., metric invariance was not significant as evident from the minimal change in the model fit: $\chi^2(512) = 1525.75$ ($\Delta\chi^2(20)=21.16$), RMSEA = 0.09, CFI = 0.91 (ΔCFI=0.003). This implies that all factor loadings, except for those that were fixed to one for identification purposes (items 3, 5, 8, and 20), are invariant across both groups. The test of equal item thresholds or scalar invariance was significant as indicated by a substantive decrease in the fit of the model: $\chi^2(579) = 1529.63$ ($\Delta\chi^2(67)=89.25$), RMSEA = 0.085, CFI = 0.923 (ΔCFI=0.006). In order to identify the specific non-invariant thresholds, model with a single

threshold held equal across the groups while all other thresholds are allowed to vary was compared with a base model where all thresholds were allowed to vary. This test was carried out consecutively for each of the item threshold to identify the specific items that were non-invariant. Table 1.11 gives the Δ-indices from the comparison of the two models. A Bonferroni correction was applied to account for multiple testing and the critical value was set at 0.002. Out of all the items, only item 24 was found to show threshold non-invariance.

By age within two groups of caregivers: Two sub-groups were created based on median splits across age. For caregivers of patients with Autism disease, the median split at 36 years of age divided the subsample into two groups i.e., caregivers between 18 to 35 years of age and caregivers greater than 36 years of age. For caregivers of patients with Alzheimer's disease, the median split at 38 years of age divided the subsample into two groups (caregivers between 18 to 38 years of age and caregivers greater than 38 years of age). All three invariance tests of equal form, equal factor loadings and equal indicator intercepts were insignificant for two age groups among caregivers of patients with Autism disease as shown by the insignificant differences in χ^2 values. The results indicates that the observed values of WHOQOL-BREF are invariant across the age groups for caregivers of Autism disease, and therefore any observed differences were "true differences" and not systematic measurement artifacts.

The configural invariance test between the two age groups among caregivers of patients with Alzheimer's disease was insignificant as suggested by comparable fit indices in two groups ($\chi^2(492) = 1068.38$, RMSEA = 0.1, CFI = 0.912). However, the metric and scalar invariance was significant as indicated by a substantive reduction in model fit ($\Delta\chi^2(20)=40.45$, ΔCFI<0.0005 for metric and $\Delta\chi^2(67)=112.10$, ΔCFI=0.002 for metric). The results indicates that the observed

values of WHOQOL-BREF are non-invariant across the age groups for caregivers of Alzheimer's disease, and therefore systematic measurement artifacts may exist.

By presence or absence of chronic condition within two groups of caregivers: Two sub-groups were created based on whether the caregiver had at least one chronic condition or none within caregivers of patients with Autism and Alzheimer's disease. All three invariance tests of equal form, equal factor loadings and equal indicator intercepts were insignificant for two sub-groups among caregivers of patients with Autism disease as shown by the insignificant differences in χ^2 values. The results indicate that the observed values of WHOQOL-BREF are invariant across the chronic condition sub-groups for caregivers of Autism disease, and therefore any observed differences were "true differences" and not systematic measurement artifacts.

The configural invariance test between the two chronic condition sub-groups among caregivers of patients with Alzheimer's disease was insignificant as suggested by comparable fit indices in two groups ($\chi^2(492) = 1081.50$, RMSEA = 0.104, CFI = 0.906). The metric invariance test was also non-significant as indicated by a minimal reduction in model fit: $\chi^2(512) = 1084.82$ ($\Delta\chi^2(20)=28.35$), RMSEA = 0.1, CFI = 0.908 (ΔCFI=0.002). However, the scalar invariance test was significant as indicated by substantive reduction in model fit: $\chi^2(577) = 1140.61$ ($\Delta\chi^2(65)=119.93$), RMSEA = 0.094, CFI = 0.910 (ΔCFI=0.002). The results indicates that the observed values of WHOQOL-BREF are non-invariant across the chronic condition sub-groups for caregivers of Alzheimer's disease because of systematic difference in weight given to response categories for specific items.

Discussion

Informal caregivers play an important role in improving the well-being of the society. As a result, the health and well-being of the informal caregivers themselves becomes a vital

consideration for healthcare practitioners. It is imperative to capture the well-being of the caregivers from a global perspective using QOL. To facilitate accurate and meaningful measurement of QOL, a psychometrically sound instrument that depicts the impact of caregiving on each aspect of caregiver well-being such as physical health, mental health, social well-being and environmental effects is needed. The instrument should not only assess QOL accurately and extensively, but also needs to be measure QOL without any influence of differences in caregiver and patient characteristics. Therefore, as an antecedent to the use of an instrument in understanding QOL in caregivers, the psychometric validation of that instrument in caregiver population needs to be performed. The current study assessed the psychometric properties of WHOQOL-BREF in a sample of informal caregivers and the instruments performance on measurement invariance in terms of care recipient's disease state, age and presence of chronic condition.

Three different models were tested to examine the factorial validity of the WHOQOL-BREF. The model fit indices revealed that the four-factor model had the best fit although the quality of the fit was mediocre. The results of the model fit are consistent with those of the previous studies that tested the factorial validity of WHOQOL-BREF in diverse study samples that included patients hospitalized with trauma, patients with spinal-cord injury, students, and the general population.[30,44,56,57] These studies concluded that the evidence supports the use of the four-factor model. The four-factor model is favored above the second-order factor model even though they had similar model fits because the number of terms that are freely estimated in the four-factor model are less (i.e., the four-factor model is parsimonious). In order to improve the mediocre fit of the four-factor model, certain modifications (for example, adding cross-loadings) to the model can be done based on modification indices. However, such modifications were not

made in previous studies because all 24 items of the WHOQOL-BREF are designed to measure an exclusive domain, which would make cross-loadings difficult to interpret.

Further evidence for four-factor model was provided by tests of convergent and discriminant validity. The pattern of standardized loadings for each item was more than 0.5, however, two items, 'medication' and 'pain' had relatively lower factor loadings. This suggests that the physical domain was not able to fully capture information with items on medication and pain. The item on medication has been shown to have low factor loading in previous studies on trauma patients and in general population.[28,51] The item on pain might have poor factor loadings in informal caregivers as responsibilities related to caregiving may increase their pain threshold. All other items had a standardized loading of greater than 0.5 indicating good convergent validity. We found evidence of discriminant validity for WHOQOL-BREF, suggesting that the four domains were distinct in their definition. Although the correlations among domains were high, they were significantly less than 1 or perfect correlation. Further evidence of convergent and discriminant validity was provided by the strong correlations between items loading on the same domain and weak correlations between items that were loading on two separate domains.

The WHOQOL-BREF was able to discriminate between the QOL of those informal caregivers who had at least one chronic condition and informal caregivers who had no chronic conditions. The chronic condition burden was taken as a proxy for severity of caregiver condition. The difference between the two groups was discernible by scores on physical domain and to a moderate extent, by scores on psychological domain. A difference was also found in scores on social and environmental domain, but the effect size of differentiation was small. The reason for this finding is attributed to the physical and metal effects of a chronic condition like progression of disease and being more prone to mental disorder. This is exemplified in a study

among patients with chronic condition in Netherlands where patients having chronic conditions had poor physical health and more mentally distressed compared to a random community sample.[58]

The mean score on each domain were lower than the average in general population but similar to those in sick population except for the social domain as reported by Skevington et al[51]. The lower score in social domain is indicative of the restrictions that informal caregivers have to face in terms of socializing. The internal consistency reliability of the four domains were good and better as compared to those in the previous studies.[30,44,56,57] High internal consistency reliability indicates that WHOQOL-BREF is sensitive in capturing the variation in QOL among a sample of informal caregivers.

Assessment of measurement invariance between informal caregivers providing care for different sub-groups of patients showed that the thresholds for item 24 'access to health services' was non-invariant across subgroups. This finding might be due to the difference in demographic constitution of the sub-group of informal caregivers providing care to patients with Autism or Alzheimer's disease. Informal caregivers of patients with Autism were younger, and with lower chronic condition burden as compared to informal caregivers of patients with Alzheimer's disease. Previous studies have shown that satisfaction with access to health is subjective where individuals that fall into the young adults and adult categories or those with lower disease burden have less experience with access to health service and are generally more satisfied with it compared to the elderly.[59,60] This may be reflected in the current sample where younger informal caregivers might express more satisfaction with health services compared to older caregivers, but show similar interpretation or response pattern on other items in the questionnaire at same level of latent construct. Even if there was evidence of measurement non-invariance, meaningful

comparisons can be done, when the proportions of items that are non-invariant is small.[61] Overall, the findings of the study suggest that items of the WHOQOL-BREF are interpreted equivalently across the subgroup of informal caregivers providing care to patients with two different conditions. This finding is of key importance as it will allow planned comparisons of QOL between sub-groups of informal caregivers providing care to patients with different chronic conditions.

Age has been assessed as one of the predictors of QOL among informal caregivers in previous studies.[62-64] Assessment of age-related differences in QOL among informal caregivers using the WHOQOL-BREF requires establishment of measurement invariance across age groups. The current study found that measurement invariance holds across age groups among informal caregivers of patients with Autism disorder. Therefore, whatever difference in QOL found across age groups can be attributed as true difference and not measurement artifacts.

Measurement invariance was not found across age groups among informal caregivers of patients with Alzheimer's disease with both metric and scalar assessment being non-invariant. Thus, informal caregivers at the same level of latent construct show considerable difference in endorsing questionnaire items as age increases. However, there was not enough evidence of measurement non-invariance in terms of change in CFI. Further evidence needs to be evaluated for this discrete behavior. This result warrants cautious approach in using WHOQOL-BREF to examine differences in QOL across age groups among informal caregivers of patients with Alzheimer's disease.

The study also assessed measurement invariance of WHOQOL-BREF with respect to chronic condition burden among both sub-groups of informal caregivers. The results of the current study suggest that the assumption of measurement invariance holds among those who

have at least one chronic condition and those who have no chronic condition in informal caregivers of patients with Autism disorder. Therefore, between groups comparison of QOL according to chronic condition burden is informative. In other groups of caregivers of patients with Alzheimer's disease, the assumption was scalar invariance did not hold between those who have at least one chronic condition and those who have no chronic condition. Such partial invariance is acceptable if the number of non-invariant items are small and configural invariance is held.[61] Thus, meaningful comparisons of QOL between informal caregivers with different chronic condition burden can be conducted among caregivers providing care to patients with Alzheimer's disease. Further assessment is needed to find the number of items that are non-invariant.

The study findings should be viewed in light of some limitations. Firstly, all responses were self-reported by informal caregivers and they were likely not verified against clinical records or cross-checking with family members. Not all forms of validity and reliability were tested such as predictive validity and test-retest reliability due to cross-sectional natural of the study. Measurement invariance with respect to time could not be tested for the same reason. Although the study sampled from the largest representative population of informal caregivers, including caregivers of patients with Alzheimer's disease or Autism disorder, generalization to caregivers of patients with other conditions should be made with caution. Also to recruit the caregiver sample, convenience sampling was employed which may not give an adequate representation of the caregiver population in the US. Model fit indices used to test the model fit are a product of maximum likelihood estimation and therefore its use with WLSMV should be made with caution. Nonetheless, this study gives concrete evidence of suitability of the use of the WHOQOL-BREF in informal caregivers as a way to capture QOL. This is also the first study to

test the psychometrics and measurement invariance of the WHOQOL-BREF in caregiver sample in the US.

Conclusion

The WHOQOL-BREF is a psychometrically sound instrument for use in capturing QOL among informal caregivers in the US. The four-factor structure is the best model to assess QOL in terms of constructs that define QOL. The four-factor model showed good convergent and discriminant validity among informal caregivers. Known-groups of caregivers that were expected to differ in their QOL were appropriately distinguished by the WHOQOL-BREF. The instrument was also sensitive to capturing variation in the QOL. Lastly, the instrument was able to capture true difference in QOL according the condition of the care-recipient, age of caregiver and chronic condition burden, however, caution should be exercised in certain sub-groups.

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Appendix

Tables

Table 1. 1: Demographic characteristics of the sample responding to the WHOQOL-BREF (N=457)

Characteristic	N/Mean	Percent/±SD
Relation to the patient		
Spouse	26	5.7%
Parent	207	45.3%
Son/Daughter	115	25.2%
Grandparent	11	2.4%
Sibling	8	1.8%
Friend	38	8.3%
Other	52	11.4%
Caregiver sex		
Male	42	9.2%
Female	415	90.8%
Patient sex		
Male	227	49.7%
Female	202	44.2%
No response	28	6.2%
Race of the caregiver		
Caucasian	361	79%
African American	47	10.3%
American Indian	6	1.3%
Asian	5	1.1%
Native Hawaiian	1	0.2%
Other	12	2.6%
No response	25	5.5%
Ethnicity of the caregiver		
Hispanic	43	9.4%
Non-Hispanic	380	83.2%

No response	34	7.4%
Marital status of the caregiver		
Married	240	52.5%
Widowed	5	1.1%
Divorced	52	11.4%
Separated	23	5%
Never Married	56	12.3%
Not married. Living with a partner	57	12.5%
No response	24	5.3%
Education level of the caregiver		
Less than high school	10	2.2%
High school graduate	92	20.1%
Some college	134	29.3%
2 year degree	82	19%
4 year degree	69	16%
Professional degree	19	4.4%
Master's degree	25	5.8%
Doctoral degree	1	0.2%
No response	25	5.5%
Occupation of the caregiver		
Employed/Self-employed full time	148	32.4%
Employed part time	73	16%
Unemployed, looking for work	28	6.1%
Unemployed, not looking for work	12	2.6%
Retired	31	6.8%
Student	10	2.2%
Home-make	116	25.4%
Other	26	3.5%
No response	23	5%
Residential area of the caregiver		
Urban	111	24.3%
Suburban	184	40.3%
Rural	138	30.2%
No response	24	5.3%
Does the caregiver has any chronic condition?		
Yes	190	41.6%

No	244	53.4%
No response	23	5%
Condition of the patient		
Alzheimer's	234	51.2%
Autism	223	48.8%
Age of the caregiver	38.8	±10.2

Table 1. 2: Caregiver-specific information

	Minimum	**Maximum**	**Mean**	**Std. Deviation**	**Median**
Age	19	82	38.84	10.16	37
Number of hours per week spent on caregiving	3	168	70.66	49.22	50
No. of Years since started with caregiving	0	30	6.54	4.67	5

Table 1. 3: Response distribution for each item of the WHOQOL-BREF

Item	**Response 1**	**Response 2**	**Response 3**	**Response 4**	**Response 5**
Q1 How would you rate your quality of life?	10(2.2%)	59(12.9%)	102(22.3%)	218(47.6%)	69(15.1%)
Q2 How satisfied are you with your health?	21(4.6%)	114(24.8%)	91(19.8%)	185(40.3%)	48(10.5%)
Q3 To what extent do you feel that physical pain prevents you from doing what you need to do?	22(4.8%)	54(11.8%)	111(24.2%)	172(37.5%)	100(21.8%)
Q4 How much do you need any medical treatment to function in your daily life?	14(3.1%)	48(10.5%)	96(20.9%)	154(33.6%)	147(32%)
Q5 How much do you enjoy life?	20(4.4%)	85(18.5%)	140(30.5%)	153(33.3%)	61(13.3%)
Q6 To what extent do you feel your life to be meaningful?	13(2.8%)	64(13.9%)	119(25.9%)	158(34.4%)	105(22.9%)
Q7 How well are you able to concentrate?	22(4.8%)	76(16.6%)	167(36.4%)	142(30.9%)	52(11.3%)
Q8 How safe do you feel in your daily life?	2(0.4%)	29(6.3%)	102(22.2%)	192(41.8%)	134(29.2%)
Q9 How healthy is your physical environment?	6(1.3%)	28(6.1%)	120(26.1%)	207(45.1%)	98(21.4%)

Q10 Do you have enough energy for everyday life?	58(12.6%)	87(19%)	126(27.5%)	150(32.7%)	38(8.3%)
Q11 Are you able to accept your bodily appearance?	60(13.1%)	80(17.4%)	127(27.7%)	144(31.4%)	48(10.5%)
Q12 Have you enough money to meet your needs?	79(17.2%)	119(25.9%)	97(21.1%)	125(27.2%)	39(8.5%)
Q13 How available to you is the information that you need in your day-to-day life?	10(2.2%)	56(12.2%)	138(30.1%)	189(41.2%)	66(14.4%)
Q14 To what extent do you have the opportunity for leisure activities?	86(18.7%)	164(35.7%)	116(25.3%)	74(16.1%)	19(4.1%)
Q15 How well are you able to get around?	5(1.1%)	25(5.4%)	72(15.7%)	191(41.6%)	16(36.2%)
Q16 How satisfied are you with your sleep?	85(18.5%)	149(32.5%)	98(21.4%)	94(20.5%)	33(7.2%)
Q17 How satisfied are you with your ability to perform your daily living activities?	21(4.6%)	88(19.2%)	104(22.7%)	183(39.9%)	63(13.7%)
Q18 How satisfied are you with your capacity for work?	43(9.4%)	89(19.4%)	102(22.2%)	161(35.1%)	64(13.9%)
Q19 How satisfied are you with yourself?	28(6.1%)	87(19%)	116(25.3%)	179(39%)	49(10.7%)
Q20 How satisfied are you with your personal relationships?	38(8.3%)	86(18.7%)	96(20.9%)	180(39.2%)	59(12.9%)
Q21 How satisfied are you with your sex life?	111(24.2%)	80(17.4%)	111(24.2%)	112(24.4%)	45(9.8%)
Q22 How satisfied are you with the support you get from your friends?	57(12.4%)	90(19.6%)	111(24.2%)	156(34%)	45(9.8%)
Q23 How satisfied are you with the conditions of your living place?	21(4.6%)	56(12.2%)	88(19.2%)	201(43.8%)	93(20.3%)
Q24 How satisfied are you with your access to health services?	27(5.9%)	53(11.5%)	95(20.7%)	198(43.1%)	86(18.7%)
Q25 How satisfied are you with your transport?	21(4.6%)	33(7.2%)	64(13.9%)	216(47.1%)	125(27.2%)
Q26 How often do you have negative feelings such as blue mood, despair, anxiety, depression?	40(8.7%)	94(20.5%)	139(30.3%)	157(34.2%)	29(6.3%)

Table 1. 4: Fit statistics for each proposed model of WHOQOL-BREF

Fit Statistics	4-factor	1-factor	Higher-order
Chi-square (df)	1371.56(246)	1844.31(252)	1376.37(248)
CFI	0.909	0.871	0.908
TLI	0.897	0.858	0.898
RMSEA (90% CI)	0.1 (0.095-0.105)	0.118(0.113-0.123)	0.1(0.095-0.105)
SRMR	0.056	0.066	0.056

Table 1. 5: Factor loadings for each item and correlations between domains in the 4-factor model

Items	Estimate	SE
Physical domain		
Q3 To what extent do you feel that physical pain prevents you from doing what you need to do?	0.461	0.039
Q4 How much do you need any medical treatment to function in your daily life?	0.494	0.037
Q10 Do you have enough energy for everyday life?	0.849	0.019
Q15 How well are you able to get around?	0.716	0.029
Q16 How satisfied are you with your sleep?	0.755	0.025
Q17 How satisfied are you with your ability to perform your daily living activities?	0.894	0.014
Q18 How satisfied are you with your capacity for work?	0.759	0.024
Psychological domain		
Q5 How much do you enjoy life?	0.851	0.016
Q6 To what extent do you feel your life to be meaningful?	0.806	0.018
Q7 How well are you able to concentrate?	0.748	0.022
Q11 Are you able to accept your bodily appearance?	0.738	0.023
Q19 How satisfied are you with yourself?	0.877	0.014
Q26 How often do you have negative feelings such as blue mood, despair, anxiety, depression?	0.734	0.023
Social domain		
Q20 How satisfied are you with your personal relationships?	0.908	0.018
Q21 How satisfied are you with your sex life?	0.737	0.026
Q22 How satisfied are you with the support you get from your friends?	0.663	0.032
Environmental domain		
Q8 How safe do you feel in your daily life?	0.724	0.027
Q9 How healthy is your physical environment?	0.721	0.028
Q12 Have you enough money to meet your needs?	0.691	0.028
Q13 How available to you is the information that you need in your day-to-day life?	0.734	0.026
Q14 To what extent do you have the opportunity for leisure activities?	0.742	0.027
Q23 How satisfied are you with the conditions of your living place?	0.598	0.033
Q24 How satisfied are you with your access to health services?	0.630	0.030

Q25 How satisfied are you with your transport?	0.527	0.034

Correlations between domains		
Physical With Psychological	0.842	0.017
Physical with social	0.696	0.031
Psychological with social	0.830	0.021
Psychological with environmental	0.803	0.022
Environmental with physical	0.830	0.019
Environmental with social	0.755	0.028

Table 1. 6: Correlation between items of WHOQOL-BREF and individual domains

Item	**PHY**	**PSYH**	**SOC**	**ENV**
QID3	0.635	0.265	0.2	0.238
QID4	0.631	0.301	0.244	0.294
QID5	0.585	0.837	0.562	0.602
QID6	0.5	0.819	0.538	0.573
QID7	0.613	0.709	0.46	0.545
QID8	0.508	0.559	0.386	0.664
QID9	0.467	0.559	0.411	0.681
QID10	0.755	0.677	0.474	0.598
QID11	0.503	0.785	0.503	0.547
QID12	0.459	0.504	0.405	0.738
QID13	0.498	0.532	0.427	0.736
QID14	0.51	0.585	0.521	0.658
QID15	0.725	0.452	0.333	0.526
QID16	0.68	0.588	0.532	0.537
QID17	0.825	0.706	0.522	0.593
QID18	0.763	0.537	0.427	0.524
QID19	0.629	0.85	0.666	0.615
QID20	0.545	0.688	0.845	0.61
QID21	0.436	0.546	0.855	0.456
QID22	0.392	0.48	0.779	0.453
QID23	0.362	0.424	0.42	0.64
QID24	0.444	0.411	0.419	0.667
QID25	0.344	0.338	0.291	0.618
QID26	0.555	0.76	0.547	0.546

Table 1. 7: Discriminant validity of WHOQOL-BREF

Model[a] (correlation fixed to 1)	Chi-square value	DF difference	P-value
Physical with psychological	100.89	1	<0.001
Physical with social	102.56	1	<0.001
Physical with environmental	96.96	1	<0.001
Psychological with environmental	93.08	1	<0.001
Psychological with social	68.96	1	<0.001
Social with environmental	81.6	1	<0.001

[a]Model was compared to base model with no restriction on correlation between domains i.e. correlations were freely estimated

Table 1. 8: **Known-groups validity WHOQOL-BREF**

	No chronic condition	Has chronic condition	P-value	Cohen's D
Physical domain	14.69(2.88)	12.26(2.94)	<0.001	0.84
Psychological domain	13.97(3.49)	12.11(3.08)	<0.001	0.56
Social domain	13.03(3.88)	11.32(4.02)	<0.001	0.43
Environmental domain	14.46(2.75)	13.12(2.70)	<0.001	0.49

Table 1. 9: **Reliability analysis of WHOQOL-BREF**

	Mean (±SD)	No. of items	Cronbach's alpha
Entire scale	80.27(±16.79)	24	0.937
Physical domain	13.60(±3.16)	7	0.842
Psychological domain	13.11(±3.44)	6	0.882
Social domain	12.20(±4.04)	3	0.769
Environmental domain	13.82(±2.80)	8	0.830

Table 1. 10: Results from Measurement invariance testing of WHOQOL-BREF

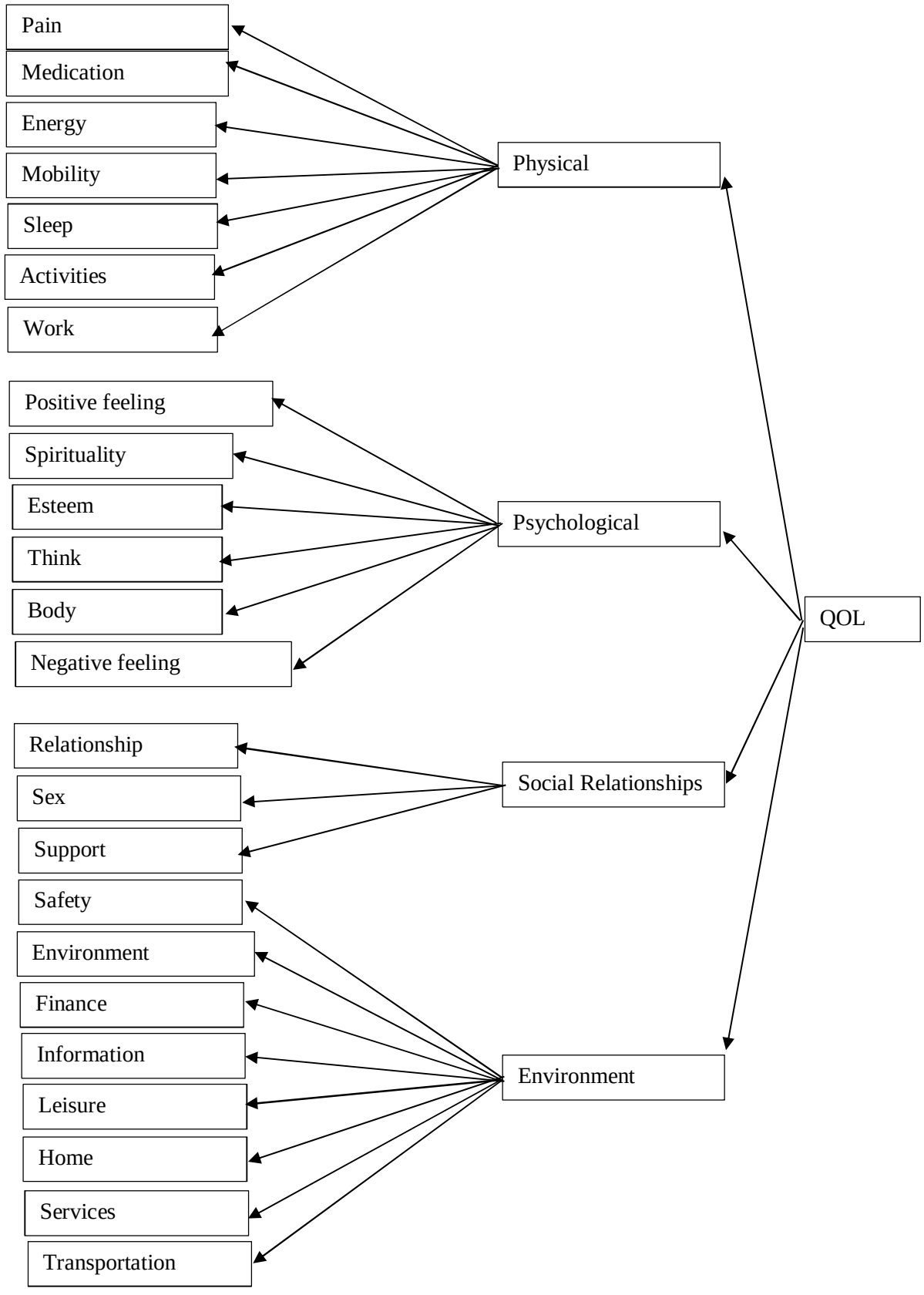
By disease state of the patient (Autism vs Alzheimer's)								
	Chi-square	df	chi square difference	df difference	RMSEA	SRMR	CFI	TLI
Configural invariance	1551.16*	492			0.097	0.063	0.914	0.903
Metric invariance	1525.75*	512	21.16	20	0.093	0.063	0.917	0.911
Scalar invariance	1529.63*	579	89.25*	67	0.085	0.064	0.923	0.926
Caregivers of patients with Autism by age category[a] of the caregiver								
	Chi-square	df	chi square difference	df difference	RMSEA	SRMR	CFI	TLI
Configural invariance	859.05*	492			0.082	0.072	0.932	0.924
Metric invariance	861.38*	512	20.71	20	0.078	0.073	0.936	0.931
Scalar invariance	902.23*	577	72.65	65	0.071	0.074	0.94	0.943
Caregivers of patients with Alzheimer's by age category of the caregiver								
	Chi-square	df	chi square difference	df difference	RMSEA	SRMR	CFI	TLI
Configural invariance	1068.38*	492			0.1	0.076	0.912	0.901
Metric invariance	1084.92*	512	40.45*	20	0.098	0.077	0.912	0.905
Scalar invariance	1142.57*	579	112.1*	67	0.092	0.079	0.914	0.918
Caregivers of patients with Autism by chronic condition status of the caregiver								
	Chi-square	df	chi square difference	df difference	RMSEA	SRMR	CFI	TLI
Configural invariance	829.9*	492			0.08	0.073	0.942	0.935
Metric invariance	843.29*	512	27.74	20	0.078	0.074	0.944	0.939
Scalar invariance	887.88*	577	72.89	65	0.071	0.075	0.947	0.949
Caregivers of patients with Alzheimer's by chronic condition status of the caregiver								
	Chi-square	df	chi square difference	df difference	RMSEA	SRMR	CFI	TLI
Configural invariance	1081.50*	492			0.104	0.082	0.906	0.894
Metric invariance	1084.82*	512	28.35	20	0.1	0.082	0.908	0.901
Scalar invariance	1140.61*	577	119.93*	65	0.094	0.085	0.91	0.914

[a]Age categories were created by identifying the median and splitting groups on either side of the median, *significant at p-value of 0.05

Table 1. 11: **Thresholds, fit parameters, and drop in model fit resulting from equating thresholds for each consecutive WHOQOL-BREF item**

Threshold			**Model fit and caused fit deterioration in partial metric invariance test**				
Item	Autism	Alzheimer's	CFI	ΔCFI	$\Delta\chi^2$	df	P-value
Q3	-1.663/-0.968/-0.164/0.788	-1.663/-0.968/-0.305/0.779	0.944	0.000	1.465	2	0.481
Q4	-1.871/-1.126/-0.386/0.562	-1.871/-1.076/-0.419/0.373	0.944	0.000	2.657	3	0.447
Q5	-1.705/-0.739/0.118/1.170	-1.705/-0.739/0.043/1.057	0.943	0.001	1.069	2	0.586
Q6	-1.903/-0.935/-0.107/0.773	-1.903/-0.985/-0.260/0.709	0.943	0.001	2.190	3	0.534
Q7	-1.660/-0.804/0.350/1.400	-1.660/-0.779/0.054/1.076	0.944	0.000	9.624	3	0.022
Q8	-1.491/-0.549/0.523	-1.491/-0.549/0.577	0.944	0.000	0.187	1	0.665
Q9	-1.443/-0.386/0.773	-1.443/-0.454/0.823	0.944	0.000	0.561	2	0.755
Q10	-1.137/-0.423/0.338/1.463	-1.137/-0.539/0.129/1.316	0.943	0.001	4.521	3	0.211
Q11	-1.119/-0.460/0.326/1.316	-1.119/-0.552/0.107/1.198	0.943	0.001	4.296	3	0.321
Q12	-0.938/0.051/0.485/1.463	-0.938/-0.293/0.260/1.291	0.944	0.000	7.774	3	0.051
Q13	-2.013/-0.935/-0.017/1.065	-2.013/-1.221/-0.260/1.057	0.944	0.000	7.518	3	0.057
Q14	-0.892/0.267/0.918/1.861	-0.892/-0.032/0.765/1.633	0.944	0.000	8.054	3	0.045
Q15	-1.508/-0.819/0.498	-1.508/-0.709/0.227	0.944	0.000	5.483	2	0.065
Q16	-0.893/0.051/0.643/1.569	-0.893/0.000/0.552/1.369	0.943	0.001	2.149	3	0.542
Q17	-1.684/-0.699/-0.006/1.239	-1.684/-0.722/-0.172/0.985	0.943	0.001	4.680	3	0.197
Q18	-1.316/-0.549/0.118/1.126	-1.316/-00.546/-0.064/1.038	0.943	0.001	2.826	3	0.419
Q19	-1.543/-0.589/0.051/1.343	-1.543/-0.750/-0.021/1.156	0.943	0.001	3.334	3	0.343
Q20	-1.383/-0.608/0.051/1.126	-1.383/-0.608/-0.140/1.156	0.944	0.000	2.620	2	0.269
Q21	-0.697/-0.164/0.485/1.371	-0.697/-0.249/0.350/1.244	0.943	0.001	2.477	3	0.479
Q22	-1.144/-0.338/0.279/1.239	-1.144/-0.589/0.043/1.369	0.944	0.000	8.006	3	0.046
Q23	-1.860/-0.935/-0.338/0.868	-1.680/-0.985/-0.373/0.808	0.943	0.001	0.782	3	0.854
Q24	-1.557/-0.773/-0.084/0.953	-1.557/-1.115/-0.515/0.839	0.944	0.000	17.190	3	<0.001
Q25	-1.685/-1.105/-0.536/0.804	-1.685/-1.267/-0.765/0.443	0.944	0.000	11.054	3	0.011
Q26	-1.350/-0.472/0.423/1.697	-1.350/-0.615/0.075/1.397	0.944	0.000	11.293	3	0.010

Figure 1. 1: Second order four-factor model of the WHOQOL-BREF



Chapter 3

Testing a modified model of stress-process for understanding quality of life among informal caregivers of patients with Alzheimer's disease and patients with Autism-spectrum disorder

Introduction

Importance of caregiving: Spouses, adult children or parents of individuals suffering from chronic disabling diseases or conditions of older age form a critical source of help with daily activities of living for these individuals. Most assume the role of informal caregivers, easing the needs for care and potentially saving the costs of long-term services and support given to these individuals. In the United States (US), an estimated 43.5 million adults provided informal caregiving to an adult or a child in 2014.[1] The costs saved as a result of care provided by informal caregivers was estimated to be between $257 and $389 billion making them an integral part of the US healthcare cost savings.[2-5]

The health and well-being of the informal caregiver remains vital, and research into understanding and improving the health of this population is necessary particularly as their numbers are expected to increase in the future. The aging of the boomer generation is estimated to cause a rapid growth in the number of elderly with functional deficits from 22 million in 2005 to 38 million by 2030.[6] The rates of chronic conditions and disability in children is estimated to increase in the same duration. The major contributing factors are medical advances ensuring survival of high-risk infants, i.e., those born prematurely or with low birth-weight, increase in

diagnosis rates of conditions affecting children and increased awareness of childhood disabilities enabling its reporting.[7]

Stress related to caregiving: Once assuming the role, informal caregivers are often under the strain of completing important caregiving tasks.[8] Informal caregivers have to carry out caregiving tasks like activities of daily living (ADL) that includes helping the care-recipient with toileting, bathing or dressing and instrumental activities of daily living (IADL) such as transportation, grocery shopping or household chores. Providing care often restricts them from carrying out activities that benefit their own personal life, social life or even employment.[9,10] For example, informal caregivers have to take leave from work or cut working-hours to take care of their loved ones. Some informal caregivers even have to deal with difficult behavioral problems of the care recipient, such as verbal or physical aggression and confusion.[11] Therefore, the stress associated with caregiving can put informal caregivers at a substantial risk of financial, physical and psychological hardship.

The stress related to caregiving has been measured objectively and subjectively. Objective stressors of caregiving include behavioral problems and functional dependencies of the care recipient. Functional dependency has been measured in terms of number of ADLs or IADLs the caregiver has to perform, while behavioral problems have been measured clinically in terms of memory loss or dementia symptoms experienced by care recipient. Subjective stress appraisal includes personal significance of stressors, severity of condition or susceptibility to stressors and is generally measured using perceived stress instruments.

Impact of stress on health and quality of life (QOL): Research shows that the stress of caregiving is related to poor health outcomes including poor mental health, physical health and quality of life.[12-15] Informal caregivers experience direct and indirect physical health consequences like higher level of stress hormones and poorer sleep quality.[16-18] Informal caregivers also report higher levels of stress/distress, depression, emotional problems, and cognitive problems compared to non-caregivers.[19,20] Caregiving not only affects caregiver health, but also influences social, environmental and economic well-being.[12-15] Previous studies that measured health-related quality of life (HRQOL) found it to be strongly associated with objective and subjective stress.[21-23] However, the extent of impact on health and QOL experienced by informal caregivers differs by individual caregivers and research efforts have been directed in understanding these differences in health outcomes.

Individual differences in health outcomes of informal caregivers have been explained by factors like stress appraisals, coping responses, social support, self-efficacy, burden and relationship between caregiver-care recipients.[24,25] These psycho-social factors have been found to interplay between the pathway of stresses of caregiving and health outcomes. For example, informal caregivers who have benign appraisal of caregiving stressors, have greater social support or better coping responses such as problem-focused coping rather than emotion-focused coping were found to have lesser burden.[26] As a result, researchers have developed and tested some stress-process models to explain the subjective variation in stress and provide a better understanding of poor health outcomes.

Theoretical models defining caregiver outcomes: The stress-process model tests the direct and indirect relationships between an array of factors that influence health outcomes of the informal

caregivers. The Transactional Stress Theory developed by Lazarus and Folkman tested that health outcomes experienced by informal caregivers depend on stressors such as care recipient's behavioral problems, functional dependency of the care recipient and severity of condition and are mediated through informal caregiver's appraisal of resources and coping strategy implemented.[27] Perlin, Mullan, Semple and Skaff derived a model that added background or contextual factors (e.g., socioeconomic status, gender and age of care recipient) as antecedent factors in the pathway of stressors (e.g., behavioral problems, functional dependency), the mediators of stress (e.g., coping and social support), and the outcome of stress (e.g., mental and physical health, quality of life).[28] Both these models made a helpful contribution in understanding the differences in the experience of health outcomes between informal caregivers, however recent findings regarding the influence of intrinsic factors of informal caregivers demand exploring other caregiver-related factors.

The stress-process models of Pearlin's and Lazarus and Folkman's emphasize that stress originates when the care recipient condition demands additional care which obstructs caregivers' daily objectives, thus producing stress due to exogenous factors. However, individual informal caregivers may subjectively differ in perceiving these situations as stressful depending on endogenous factors such as personal resources and characteristics as well as informal caregiver relation with care recipient. Moreover, literature strongly suggests that inherent characteristics of informal caregivers may make them vulnerable to select certain coping strategies or preclude them towards certain health outcomes.[29] The importance of personal characteristics is not reflected in the caregiving model and therefore should be further explored to give an integrated picture of the influence of factors on health outcomes.

Previously, few researchers have explored the influence of personality, a major inherent characteristic of an individual, because personality was equated to coping. Both personality and coping were considered to be traits of an individual.[30] Only after testing of the Transactional Stress Theory was coping considered as behavioral in nature in specific situations which made it distinguishable from personality.[27] Personality is considered as trait that typifies the disposition of individuals which can influence their appraisals and choice of coping behavior.[31-33] Personality has been explored in several studies as a characteristic of individual informal caregiver that can potentially influence caregiver outcomes.[34,35] Therefore, personality can play a defining role in influencing health outcomes of informal caregivers and thus should be further investigated.

In caregiving research, a considerable number of studies have documented the association between personality and poor mental and physical health.[34,36-39] For example, neuroticism has been found to be associated with poor mental health, depression and poor physical health in spouses of cancer patients, Alzheimer's and Parkinson's patients and patients with cardiovascular disease.[34,40-42] Similar associations were also found in informal caregivers of patients with dementia and in parents of patients with chronic mental disability.[39,43] Lower levels of extraversion in caregivers of patients with cancer was associated with higher levels of depression and poor mental and physical health.[40] Hooker et al. found that higher levels of conscientiousness was associated with fewer chronic health conditions among caregivers of patients with Alzheimer's disease.[34] Studies evaluating openness and agreeableness did not find any association with physical health but these studies lacked power due to small sample sizes.[43] The evidence provided by these studies suggest that personality plays a role in caregiver outcomes, however, its influence of QOL is understudied. Moreover, personality may predispose

caregivers to select specific coping strategies that can in turn define outcomes for caregivers which needs further investigation.

Knowledge about the influence of personality on caregiver outcomes will assist both clinicians and healthcare policymakers understand the health of caregivers, develop appropriate interventions like caregiver education and social support improving overall health of informal caregivers. Moreover, the influence of personality on health outcomes may differ if care recipient is a child as compared to if care recipient is spouse or a parent which warrants further exploration. The current study explored the influence of personality in the stress-outcome process of informal caregivers of a spouse or parent using a theory-driven approach and compared the model in informal caregivers of adults and informal caregivers of children.

Conceptual Framework

Using Lazarus and Folkman's Transactional Stress Theory as a base framework, we built a model that tests the influence of personality on the health outcome of caregivers. The Transactional Stress Theory contains four components: the stressors that include objective stressors like behavioral problems and functional dependency of care recipient, stress appraisal that include personal significance of stressors, severity of condition or susceptibility to stressors, coping behaviors, and the outcome of stress that include mental and physical health or quality of life.[27] This model has been previously validated in caregivers of adults with Alzheimer's disease, dementia and multiple sclerosis.[26,44,45]

Some modifications were made to the original Lazarus and Folkman model according to evidence found in recent studies. Previous caregiving studies in parent and spouse caregivers found that there were no direct relationships between objective stressors and subjective stress appraisal.[24,46-48] Also, except behavioral stressors, the association of objective stressors with

mental and psychological health was low.[49-51] Therefore, only stress appraisal was kept in the model instead of keeping both objective stressors and stress appraisal. Such modifications to the original model have been made previously with a study of caregivers with Alzheimer's disease.[34] The base model consisted of three components: stress appraisal, coping behavior and outcome of stress. Previous studies have shown that the effect of caregiver perceived stress on caregiver outcomes is mediated through the coping behavior adopted.[25,52,53] Based on previous studies, we hypothesized that the effect of appraised stress on caregiver QOL would be mediated through coping behavior.

Informal caregiver's perceived stress was included as a construct that represents stress appraisal. Perceived stress assesses the informal caregiver's stress as a global indicator rather than pertaining to caregiving situations. Studies have consistently reported a positive association between informal caregiver's perceived stress and poor physical or mental health outcome.[12,34] The differences in the impact of perceived stress on caregiver health in individual informal caregivers have been explained by the type of coping behavior that would be adopted. [25,52,53] There are two types of coping strategies: Adaptive coping and maladaptive coping. Adaptive coping involves active attempts to manage the situation of caregiving or associated emotions by decreasing the stressor through problem-focused coping or positive thinking, while maladaptive coping involves avoiding or distancing oneself from stressor and related feelings.[27] The type of coping behavior adopted itself has been found to be strongly associated with caregiver health.[24,54-56] The general consensus from these studies was that the use of maladaptive and regressive coping styles among caregivers is associated with lower well-being and greater depression compared to positive reappraisal and problem-focused efforts.

Caregiver quality of life (QOL) is the outcome to be assessed in the model. QOL offers a comprehensive perspective on the person's health and well-being. According to the World Health Organization, QOL is defined as "an individual's perception on their position in life in context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns".[57] The coping strategy adopted by informal caregivers contributed to scores on a HRQOL instrument.[58,59] Greater use of maladaptive coping was found to be associated with lower mental HRQOL. However, HRQOL is only a subset of a more comprehensive QOL construct and therefore, evaluating the influence of caregiving factors on overall QOL will be useful and informative.

Personality has been found to be associated with all components of the basic model - i.e., perceived stress, coping strategies and QOL. Delongis et al. found that a person can have different interpretations of a stressful situation depending on personality traits where people according to their dispositional characteristics assign different meaning to the stressor.[60] For example, individuals with high neuroticism are likely to appraise situations as stressful compared to individuals with low neuroticism. Hooker et al. found that among spouse caregivers of individuals who had Alzheimer's disease or related dementia, caregivers with high neuroticism scores had higher perceived stress.[34] However, the influence of other dimensions of Big 5 personality traits - i.e., extraversion, conscientiousness, openness and agreeableness on perceived stress has not been established.

Similarly, personality has been found to play a role in the type of coping behavior that is adopted by the caregiver.[43,61] Caregivers who show high neuroticism and agreeableness were found to engage in maladaptive coping strategies while caregivers that show high extraversion

and conscientiousness were found to engage in adaptive coping strategies in a sample of caregivers of patients with Alzheimer's disease.[43]

The independent relationships between personality and perceived stress, personality and coping behaviors and perceived stress and coping behavior gives a basis for exploring the moderating effect of personality on the relationship between perceived stress and coping behavior. Research outside caregiving has tested and validated the moderating effect of personality on the relationship between perceived stress and coping. For example, David et al. in a study involving community-residing, nominally-healthy men found that neuroticism and openness moderated the relationship between stress appraisals of a bothersome event and coping strategy use.[62] Similarly, Lee-Baggley et al. in a sample of couples living in a stepfamily found that personality moderated the relationship between perceived stressors of marital conflict or child misbehavior and coping strategy use.[63] Therefore, we hypothesized that personality will moderate the relationship between perceived stress and coping strategy use in a sample of caregivers.

Finally, the association between personality and poor outcomes has also been established. Studies in personality have contributed to the consensus that certain personality characteristics can affect health in general.[64,65] In caregiving research, a considerable number of studies have documented the association between personality and poor mental and physical health.[34,36-39] Neuroticism has been found to be associated with poor mental health, depression and poor physical health in spouses of patients having a range of conditions as well as in parents of patients with chronic mental disability.[34,39-43] Lower levels of extraversion in caregivers of patients with cancer was associated with higher levels of depression and poor mental and physical health.[40] Higher levels of conscientiousness was associated with fewer chronic health

conditions among caregivers of patients with Alzheimer's disease.[34] Studies evaluating QOL among caregivers of Parkinson's disease found that neuroticism was associated with reduced QOL while conscientiousness enhanced psychological QOL and openness predicted benefits in environmental domain of QOL.[41,66] As previously discussed, type of coping behavior adopted was associated with QOL of caregivers. Based on these findings we hypothesized that a specific personality trait may moderate the influence of coping strategy adopted on the QOL of the caregiver. Research outside caregiving has tested and validated the moderating effect of personality on relationship between coping strategy adopted and health outcomes. Bolger and Zuckerman explored the possibility of personality traits interacting with coping strategies for interpersonal conflicts in affecting health and psychological outcomes among introductory psychology students.[67] They found that the highly neurotic individuals who engaged in self-controlling and escape-avoidance coping strategy were predicted to have depression.[67]

Based on prior research as well as the Transactional Stress Theory, the present study aimed to test the following hypotheses:

A) Informal caregivers with high perceived stress will have low scores on QOL. The relationship will be mediated by whether they engage in adaptive coping or maladaptive coping.
B) Informal caregivers high on neuroticism or agreeableness will be highly susceptible to engage in maladaptive coping under high perceived stress.
C) Informal caregivers high on extraversion, conscientiousness and openness will be highly susceptible to engage in adaptive coping under high perceived stress.
D) Informal caregivers high on neuroticism or agreeableness will be have poor QOL. This relationship will be stronger if they engage in adaptive coping.

E) Informal caregivers high on extraversion, conscientiousness and openness will be have poor QOL, specifically in the social relationships and environment domains. This relationship will be stronger if they engage in maladaptive coping.

Finally, we hypothesized that these relationships may differ depending on whether the informal caregiver is looking after an adult or a child. Therefore, we tested the theoretical framework in informal caregivers of patients with Alzheimer's disease and in informal caregivers of patients with Autism-spectrum disorder.

Methods

A. Study Design

The study had a prospective, cross-sectional design where data was collected by means of an internet-based survey. The survey was distributed to a national convenience sample of informal caregivers of patients with Alzheimer's disease or Autism-spectrum disorder in the United States using Qualtrics survey software program (Qualtrics Inc, Provo, UT). The study protocol (Protocol# 18x-255) was reviewed and approved by the University of Mississippi Institutional Review Board.

B. Study Sample

For the purpose of the study, the caregiver groups selected were informal caregivers of patients with Alzheimer's disease and informal caregivers of patients with Autism-spectrum disorders. These groups were selected in order to have a group that was specifically providing care to older people and another group that was specifically providing care to children. We selected informal caregivers of patients with Alzheimer's disease because the incidence of this condition is higher in older populations and previous research showed that the health of these

caregivers is worst affected compared to caregivers of other neurological conditions.[39,68,69] We selected informal caregivers of patients with Autism-spectrum disorders because these caregivers experience a greater degree of burden compared to caregivers of children with other developmental disorders or mental health conditions.[70]

All participants of the study were adults (≥ 18 years of age) as informal caregivers to patients with either Alzheimer's disease or Autism-spectrum disorders. Outside of being an informal caregiver for a patient with Alzheimer's disease there are no other inclusion criteria for that group of participants. In the Autism-spectrum disorders group, caregivers must provide care to a patient that is less than 18 years to be eligible. For the study, a national convenience sample was obtained from Rare Patient Voice LLC, Towson, Maryland, a market research vendor company, which maintains panels of patients and caregivers in various conditions. The company recruits caregivers from disease-specific conferences and patient advocacy group meetings across the US. An a priori sample size of 200 caregivers each of patients with Alzheimer's disease and caregivers of patients with Autism-spectrum disorders was considered adequate for the study because of use of structural equation modeling for statistical analysis.[71]

C. Data Collection

Informal caregivers on the panel were sent an email that included a cover letter explaining the purpose of the study, eligibility criteria, contact information and survey link. Assurance was given on confidentially of responses and a unique ID was assigned to all responders. A URL link to the survey programmed in Qualtrics (Qualtrics Inc, Provo, UT) was included in the email. The survey included all measurement instruments pertinent to the study including perceived stress, coping behavior, personality, QOL and sociodemographic

information. The survey link was open for participants for a 3-month period starting from the date of first email. Reminders were sent bi-weekly to secure maximum responders to survey. All respondents were provided with an honorarium of $10 for participating in the study.

D. Study Measures

World Health Organization Quality of Life – Brief (WHOQOL-BREF): WHOQOL-BREF is a brief version of WHOQOL-100 which was developed and validated across 23 countries.[72] WHOQOL-BREF has 26-items which includes one item from each 24 facets of QOL, one item on overall QOL and one item on general health.[73] The 24-items representing each facet of QOL are measured using a five-point response format ranging from 'Very Dissatisfied' to 'Very Satisfied'. The items are classified into four domains: physical health (seven items), psychological health (six items), social relationships (three items) and environment (eight items). Three items are reversed coded in the questionnaire. The raw scores for each domain were calculated by adding the scores of the item in each domain. The raw scores were transformed to 0-40 using the algorithm provided by the WHOQOL-BREF group.[74] A low score on this instrument indicates poor QOL. The internal consistency reliability of the instrument measured by Cronbach's alpha was found to be more than 0.70. For respondents with missing data on more than 20% of items, the overall score of QOL was not calculated.

Perceived stress scale: Overall stress levels of the informal caregiver was calculated by the Perceived Stress Scale (PSS) which is a 14-item instrument. It is designed to evaluate the degree of stress as perceived by the individual while facing specific life situations.[75] Specifically it asks subjects how often they have had particular thoughts or feelings during the past month. It has been successfully used to measure perceived stress in caregivers in the past.[34,39] Sample items from this scale include, "In the last month, how often have you been able to control the way you

spend your time?" and "In the last month, how often have you felt that you are effectively coping with important changes in your life?" It uses a five-point response format ranging from "Almost never" to "Very often". Scores were obtained by reverse scoring 7 positive-worded items and taking the score of negatively-worded items as it is. Scores on PSS range from 0 to 56 with higher score indicating more perceived stress. Past studies have found the internal consistency reliability as measured with Cronbach's alpha to be good (0.84-0.87).[76,77] Cohen et al. (1983) found the test-retest reliability of PSS to be 0.85.[75] Predictive validity of PSS has been tested on its ability to predict physical and mental health outcomes.[75] Perceived stress with measures specific to caregiving were not considered because we are interested in understanding how global trait of personality influences the relationship between perceived stress and coping measures.

Brief Coping Orientation to Problem Experience (Brief COPE): The coping behaviors used by informal caregivers as a result of caregiving stress was determined using the Brief Coping Orientation to Problem Experience (Brief COPE) measure.[78] This 28–item instrument is used to capture two broad coping strategies: adaptive coping and maladaptive coping. Adaptive coping is measured by 16-items where each 2 items represent active coping, planning, positive reframing, acceptance, humor, religion, use of emotional support and use of instrumental support.[79] Maladaptive coping is measured by 12-items where each 2 items represent self-distraction, denial, venting, substance abuse, behavioral disengagement, and self-blame.[79] Each item is measured on a four-point response format ranging from "I haven't been doing this at all" to "I have been doing this a lot". Item scores were summed to determine total score on adaptive and maladaptive coping, with higher scores indicating frequent use of coping behaviors. The internal consistency reliability of the scales was found to be between 0.50 and 0.90.[78]

Big Five Inventory - 44: Personality traits were measured using the abbreviated version of Big Five Inventory (BFI) personality inventory.[80,81] The BFI-44 is a 44-item instrument where the items measure each of the five broad personality domains: neuroticism, extraversion, conscientiousness, agreeableness and openness. It uses a 5-point Likert response format ranging from 'strongly agree' to 'strongly disagree'. It provides total scores for each specific personality domains. It has strong psychometric properties with Cronbach's alpha of 0.82 for Neuroticism, 0.78 for Extraversion, 0.85 for Conscientiousness, 0.71 for Agreeableness and 0.56 for Openness.[82] The Neuroticism scale assesses an individual's proneness to experience negative affect. The Extraversion scale assesses individual's propensity to seek out social interactions and activities. The Openness scale assesses the degree to which an individual seeks out new experiences and enjoys exploring the unfamiliar. The Agreeableness scale assesses the individual's degree to think tactfully and behave in a way that is characterized as friendly, considerate and generous. The Conscientiousness scale assesses the degree to which an individual is persistent, organized and goal-oriented. It has been previously used in research involving spouses and family members of chronically ill patients.[34,36,37,39,43] It has good psychometric properties and corresponds well with the longer version i.e., BFI.[82]

Demographic and caregiving information: Information was collected on following socio-demographic and caregiving characteristics: (1) age, (2) race/ethnicity, (3) sex of the caregiver, (4) sex of the care recipient, (5) marital status, (6) occupational status, (7) education status, (8) relationship to care recipient, (9) year caregiving started, and (10) number of hours per week spent in caregiving.

E. Statistical Analyses

All variables and scales used in the study were summarized using descriptive statistics. Means and standard deviations were reported for continuous variables and scales. Frequencies and proportions were reported for categorical variables. Differences in group means for continuous variables were analyzed using independent t-test and differences in group proportions for categorical variables were analyzed using chi-square tests with a priori alpha as 0.05. Internal consistency reliability was calculated for all scales using Cronbach's alpha. A Cronbach's alpha of ≥ 0.70 is indicative to good internal consistency reliability.

Structural equation modeling (SEM) was used to test the hypothesized theoretical model. This model tested the mediating role of coping behavior in the perceived stress and QOL relationship. Further analyses looked at the moderating effect of different types of personality - i.e., neuroticism, conscientiousness, extraversion, openness and agreeableness on the perceived stress and coping relationship as well as the coping and QOL relationship. The additive moderated mediation approach as suggested by Hayes (2017) was employed to assess relationships in the hypothesized paths (see Figure 1).[83] Perceived stress was used as a global scale where total scores were used in the analysis (i.e., each participant's responses were averaged across all 14 items). Global QOL was used as a latent factor derived from the scores on four individual domains (i.e., domain scores served as indicators of a latent variable similar to the approach used by Lanfredi et al.[84] and Johansen et al.[85]). In addition, individual subscale scores measuring psychological health, physical health, social and environmental domains were used as separate dependent variables in the SEM analysis to assess whether the tested effects differed across the multiple QOL domains. Coping as measured by Brief COPE had scores for adaptive coping and maladaptive coping obtained by summing individual items that represented the two constructs. Individual scores for neuroticism, conscientiousness, extraversion, openness

and agreeableness were calculated by summing the score on individual items that represented the five constructs from BFI and used in the analysis. To test the moderating effect of personality, interaction terms were created for adaptive coping, maladaptive coping and perceived stress with neuroticism, conscientiousness, extraversion, openness and agreeableness. The absolute skewness and kurtosis indices was assessed to test the assumption of multivariate normality and linearity, respectively.[71]

The mediation and final model was assessed for both groups - i.e., caregivers of patients with Alzheimer's disease and caregivers of patients with Autism-spectrum disorder separately. Model fit was assessed using the following five fit indices: the χ^2 statistic, the root mean square error of approximation (RMSEA), the Tucker Lewis Index (TLI), comparative fit index (CFI), and standardized root mean square residual (SRMR). The criteria suggested for a good fitting model are RMSEA<0.06, TLI>0.95, CFI>0.95 and SRMR≤0.08.[86] All non-significant paths were eliminated and parameters were added to arrive at the best-fitting model based on the underlying theory in addition to the standardized residuals and modification indices. Additionally, multi-group testing was carried out to see if the parallel multiple mediator model differed between the two caregiver groups. All analyses were carried out in Mplus version 8 (Muthen & Muthen, Los Angeles, CA).

Results

Sample breakdown and demographic characteristics: The panel used for the study had 1,239 caregivers that included 798 caregivers of patients with Alzheimer's and 441 caregivers of patients with Autism. There were 13 eligible caregivers who opted out of the study. A total of 574 caregivers responded to the survey giving a response rate of 46.8%. Out of the 574 who

responded, 434 had complete response on all the measures, among them 222 (51.2%) were caregivers of patients with Alzheimer's and 212 (48.8%) were caregivers of patients with Autism. Table 2.1 shows the distribution of the caregivers according to each characteristic by the condition of the care-recipient for whom they caregiver provided care. Most of the caregivers were either a son or a daughter of the patients (51.8%) in the Alzheimer's group, while in the Autism group most caregivers were parents (88.7%).

A large proportion of the caregivers in both groups were females, Caucasians, fell in the middle age (31-45 years), were married, had some college education employed, stayed in the south and stayed in a suburban area (Table 2.1). More than half of the caregivers did not have any chronic condition and around two-thirds had used some formal service for caregiving. The Chronbach's alpha of WHOQOL-BREF was 0.93, PSS was 0.83, maladaptive coping domain was 0.72, adaptive coping domain was 0.81, neuroticism was 0.87, extraversion was 0.81, agreeableness was 0.79, conscientiousness was 0.82, and openness was 0.74.

The results of the first hypothesis, where parallel mediation was tested, and the corresponding difference is indirect effects between the two groups is given in Table 2.2. Five separate parallel mediation models were run for each group, one where the outcome variable of global QOL was measured as a latent variable with the scores from each of the four domains of the WHOQOL-BREF serving as indicators and the other four with each of the domains of the WHOQOL-BREF acting as an outcome (Results in Table 2.3, 2.4, 2.5, 2.6).

While assessing global QOL as an outcome, the indirect effect from perceived stress to Maladaptive coping to global QOL was significant showing mediation (estimate=-0.039, bootstrap [BS] 95% confidence interval [CI] = -0.073 to -0.012) for the Autism group while the

indirect effect from perceived stress to adaptive coping to global QOL was significant showing mediation (estimate=-0.015, BS 95% CI = -0.036 to -0.002) for the Alzheimer's group. However, the indirect effect from perceived stress to adaptive coping to global QOL was not significant for the Autism group (estimate=-0.003, BS 95% CI = -0.013 to 0.001) and the indirect effect from perceived stress to maladaptive coping to global QOL was not significant for the Alzheimer's group (estimate=-0.013, BS 95% CI = -0.035 to 0.006). The direct effect from perceived stress to global QOL remained significant for both groups (estimate=-0.212, BS 95% CI = -0.256 to -0.170 for the Autism group and estimate=-0.159, BS 95% CI = -0.197 to -0.117 for the Alzheimer's group).

Based on these results, there are differences in significance for each indirect effects between both groups. Difference testing (see bottom of Table 2.3) showed that the difference for both of these indirect effects i.e., the indirect effect from perceived stress to adaptive coping to global QOL and the indirect effect from perceived stress to maladaptive coping to global QOL between the two caregiver groups was not significant. Since there was some evidence of difference in significance for each indirect effect between two groups further assessment of moderated mediation was conducted separately among the two caregiver groups.

Individual parallel mediation models with each of the domains of QOL as the main outcome showed similar results as that for global QOL in Autism and Alzheimer caregiver groups in difference testing where none of the differences in indirect effects were significant. For the assessment of parallel mediation, of note were the models with the psychological domain and the social domain as outcome variables. For the psychological domain, the indirect effect of perceived stress to adaptive coping to psychological effects (estimate=-0.028, BS 95% CI = -0.057 to -0.010) was significant for the Alzheimer caregiver group and the indirect effect of

perceived stress to maladaptive coping to psychological effects (estimate=-0.041, BS 95% CI = -0.084 to -0.001) was significant for the Autism caregiver group. For the social domain, both the indirect effects of perceived stress to adaptive coping to social effects (estimate=-0.043, BS 95% CI = -0.080 to -0.018) and perceived stress to maladaptive coping to social effects (estimate=-0.057, BS 95% CI = -0.099 to -0.023) were significant for the Alzheimer caregiver group. For the Autism caregiver group, the indirect effect from perceived stress to maladaptive coping to social effects was significant (estimate=-0.078, BS 95% CI = -0.136 to -0.030).

Moderating role of personality traits for caregivers of Autism disease patients: The results of the assessment of whether each of the personality traits moderated the four paths, which are, perceived stress to adaptive coping, perceived stress to maladaptive coping, adaptive coping to global QOL, and maladaptive coping to global QOL, are depicted in Table 2.7. Of the five personality traits, only neuroticism and conscientiousness moderated some paths for caregivers of patients with Autism-spectrum disorder. Neuroticism moderated the path between perceived stress and adaptive coping i.e., the effect of perceived stress on adaptive coping differed based on the levels of neuroticism. For caregivers that had a score for neuroticism 1 standard deviation (SD) above the mean, perceived stress was associated with low uptake of adaptive coping measure (estimate=-0.609, BS 95% CI = -0.858 to -0.369). Neuroticism also moderated the path between maladaptive coping and QOL that shows the effect of maladaptive coping on QOL differed based on the levels of neuroticism. For caregivers that had a score for neuroticism 1 SD above the mean, maladaptive coping was associated with worse QOL (estimate=-0.068, BS 95% CI = -0.131 to -0.001).

Conscientiousness moderated the path between perceived stress and adaptive coping and the path between perceived stress and maladaptive coping. For caregivers that had a score for

conscientiousness 1 SD below the mean, perceived stress was associated with low uptake of adaptive coping measure (estimate=-0.456, BS 95% CI = -0.711 to -0.197). For caregivers that had a score for conscientiousness 1 SD above the mean, adaptive coping was associated with better QOL (estimate=0.043, BS 95% CI = 0.009 to 0.085). Other personality traits did not have any moderating effect of all paths. The final model with the moderating effects of personality for caregivers of Autism-spectrum disorder is depicted in Figure 2.

Table 2.8 depicts the results from assessment of the effect of personality traits on the parallel mediation model. The significance of the indirect effect from perceived stress to maladaptive coping to QOL was unharmed at 1 SD above the mean of neuroticism when neuroticism was included as a moderator in the maladaptive coping to QOL path (estimate=-0.018, BS 95% CI = -0.044 to -0.002). The indirect effect from perceived stress to adaptive coping to QOL became significant at 1 SD above the mean score of conscientiousness when conscientiousness was included as a moderator in both the paths (estimate=-0.015, BS 95% CI = -0.044 to -0.002). Since none of the other personality traits showed moderation, they were included as control variables in the model. A post-hoc estimation of the main effects of the personality traits was conducted (Table 2.9). It was found that neuroticism (estimate=-1.088, BS 95% CI = -1.538 to -0.619), extraversion (estimate=0.847, BS 95% CI = 0.437 to1.227) and conscientiousness (estimate=0.583, BS 95% CI = 0.077 to 1.097) was directly associated with QOL. Retaining the significant paths, the final model for caregivers of patients with Autism-spectrum disorder looked as in Figure 2.2.

Moderating role of personality traits for caregivers of Alzheimer's disease patients: The results of the assessment whether each of the personality traits moderated the four paths, which are, perceived stress to adaptive coping, perceived stress to maladaptive coping, adaptive coping to

QOL and maladaptive coping to QOL, are depicted in Table 2.10. Out of the five personality traits, neuroticism, agreeableness and openness moderated some paths. Neuroticism moderated the path between perceived stress and maladaptive coping i.e. the effect of perceived stress on maladaptive coping differed based on the levels of neuroticism. For caregivers that had a score for neuroticism 1 SD below the mean, perceived stress was associated with high uptake of maladaptive coping measure (estimate=0.399, BS 95% CI = 0.250 to 0.538). The effect of this association reduced as the score on neuroticism increased. Agreeableness moderated the path between perceived stress and adaptive coping that shows the effect of perceived stress on adaptive coping differed based on the levels of agreeableness. For caregivers that had a score for agreeableness 1 SD above the mean, perceived stress was associated with higher adaptive coping measures (estimate=0.329, BS 95% CI = 0.014 to 0.633). Openness moderated the path between adaptive coping and QOL. For caregivers that had a score for openness of 1 SD below the mean, adaptive coping was associated with better QOL (estimate=0.062, BS 95% CI = 0.026 to 0.100). The final model with the moderating effects of personality for caregivers of Alzheimer's disease is depicted in Figure 2.3.

Table 2.11 depicts the results from assessment of the effect of personality traits on the parallel mediation model. The significance of the indirect effect from perceived stress to adaptive coping to global QOL became non-significant when agreeableness and openness were included as moderators in the path between perceived stress to adaptive coping and the path between adaptive coping to QOL, respectively. The indirect effect from perceived stress to maladaptive coping to QOL became significant at 1 SD above the mean score of neuroticism when neuroticism was included as a moderator in the path from perceived stress to maladaptive coping (estimate=-0.018, BS 95% CI = -0.049 to -0.001). As other personality traits did not show any

moderation effects, they were introduced as control variables in the model. A post-hoc estimation of the main effects of the personality traits was conducted. It was found that neuroticism (estimate=2.091, BS 95% CI = 0.964 to 3.163), agreeableness (estimate=-1.571, BS 95% CI = -2.967 to -0.195), openness (estimate=1.744, BS 95% CI = 0.217 to 3.175), and conscientiousness (estimate=-2.179, BS 95% CI = -3.636 to -0.807) was directly associated with maladaptive coping.

Discussion

The current study used a previously tested framework among informal caregivers to generate hypotheses of how the personality trait of the caregiver may play a role in caregiver's QOL. The Transactional Stress theory developed by Lazarus and Folkman was used as a basis for the framework and supported the finding that QOL among caregivers depend on perceived stress of caregiving and can be mediated through informal caregiver's coping strategy. As hypothesized, higher perceived stress was associated with worse QOL among both set of caregivers. The negative effect of perceived stress persisted on each of the four domains of QOL i.e., physical, psychological, social and environmental. This corroborates the findings in previous studies conducted in caregivers of patients with schizophrenia, cancer and Parkinson's disease which found lower QOL values on mental health, social functioning and economic well-being with caregivers compared to non-caregivers.[21-23]

Testing and comparing the parallel mediation model in the current study sample of informal caregivers for patients with Alzheimer's disease and those for Autism-spectrum disorder found that the direct and indirect effects persisted. However, there were specific differences between the two caregiver samples in the way indirect effect of perceived stress on QOL was expressed. For Autism caregivers, perceived stress was mediated through maladaptive

coping in expression of QOL and for caregivers of patients with Alzheimer's disease perceived stress was mediated through adaptive coping in expression of QOL.

This is the first study to test if the mediation persisted in two different groups of caregivers. It has been debated in the literature that since most research in mediation analysis conducts within-group analyses, it is important to conduct between-group analysis in mediation because correct interpretation is often context dependent.[87] The above finding demonstrates that the indirect effects of perceived stress-coping-QOL, although not significantly different, differed depending on the patients to whom the caregivers are providing care.

Among caregivers of patients with Autism-spectrum disorder, only neuroticism and conscientiousness showed some moderation in the model. For caregivers that had a higher score on neuroticism, perceived stress was associated with low uptake of adaptive coping measure and higher uptake of maladaptive coping was associated with worse QOL. The association of neuroticism with higher perceived stress and worse outcomes is well supported in literature. In a study conducted by Vollrath (2001), neurotic individuals were found to appraise events as more stressful compared to individuals with other traits.[88] Other studies have examined the effect of neuroticism on outcomes among caregivers providing care to patients with cancer or dementia and found that neuroticism was associated with a higher number of depressive symptoms.[37,89] Neuroticism also had a negative effect on physical health among caregivers of patients with dementia.[36] Finally, a meta-analyses shows that neuroticism was associated with high uptake of emotion-based coping and antagonistic means of coping.[90] By showing the moderation effect of neuroticism, the current study adds to the existing knowledge base that among individuals at higher level of neuroticism, perceived stress is associated with low uptake of adaptive coping.

Conscientiousness was other personality trait that showed evidence of moderation. For informal caregivers that had a low score for conscientiousness, perceived stress was associated with low uptake of adaptive coping measure which was in turn associated with worse QOL. Previous studies have shown the association of conscientiousness with stress, coping and outcome. Vollrath (2001) showed that individuals low on conscientiousness do not mange stress adequately.[88] Lockenhoff et al. (2011) in a study conducted in caregivers showed that conscientiousness was positively associated with mental and physical health.[38] In terms of coping mechanisms, individuals high on conscientiousness used more problem-focused coping such as problem solving and planning.[91] The finding in the current study ties to these individual findings by showing the moderating effect of conscientiousness on coping mechanisms adopted and on QOL.

In the assessment of moderated mediation, the introduction of other personality traits expect for neuroticism and conscientiousness as moderators in the analysis was found to remove the mediation effect previously found between perceived stress, maladaptive coping and QOL. The main effects of these personality trait on coping and QOL were explored and it was found neuroticism, extraversion and conscientiousness were associated with QOL of the informal caregivers, while agreeableness was associated with maladaptive coping mechanisms. This direct association of certain personality traits with coping and QOL might have affected the size of the effect of perceived stress on maladaptive coping and of maladaptive coping on QOL, in turn, affecting the mediation effect. The principles of model building suggest that in case of insignificant moderation effects, the model can be trimmed to include only the main effects of variables involved in moderation.[92]

Among caregivers of patients with Alzheimer's disease, neuroticism, agreeableness and openness showed some moderation in the model. For caregivers that had a higher score on neuroticism, perceived stress was associated with high uptake of maladaptive coping measure. The strength of this relationship improved as the score on neuroticism decreased. A previous meta-analyses showed that neuroticism was associated with high uptake of emotion-based coping and antagonistic means of coping which supports the current finding.[90] Also, neurotic individuals were found to appraise events as being more stressful compared to individuals with other traits. The current study extends our existing knowledge by confirming the moderation effect of neuroticism on the relationship between perceived stress and maladaptive coping.

Agreeableness and openness were other personality traits that showed evidence of moderation. For informal caregivers that had a high score on agreeableness, perceived stress was associated with high uptake of adaptive coping measures while for informal caregivers that had a low score on openness, adaptive coping was associated with better QOL. It has been established in previous studies that individuals high on openness perceive strenuous events as "challenges" and are more likely to engage in positive thinking and emotional expression.[91] This study adds to the current knowledge on openness, that for individuals low on openness score, uptake of adaptive coping measures is associated with better QOL. On the other hand, individuals high on agreeableness are shown to likely be more involved in problem-focused coping such as seeking support which is reflected in them being involved in adaptive coping measure under stress.[91] The finding in the current study corroborates these individual findings by showing the moderating effect of agreeableness on the path between perceived stress and adaptive coping and openness on path between coping mechanisms adopted and on QOL.

In the assessment of moderated mediation, the introduction of personality traits other than neuroticism, openness, and agreeableness as moderators in the analysis removed the mediation effect found between perceived stress, adaptive coping, and QOL among caregivers of patients with Alzheimer's disease. The main effects of personality trait on coping and QOL were explored and it was found neuroticism was associated with QOL of the informal caregivers, while conscientiousness, agreeableness and openness were associated with maladaptive coping mechanisms. This direct association of certain personality traits with maladaptive coping and QOL might have affected the size of the effect of perceived stress on adaptive coping and of adaptive coping on QOL, in turn, affecting the mediation effect.

The results of the current study demonstrate that personality traits play a role in the overall QOL of informal caregivers. However, the association of personality differs according to the patients to whom the caregivers are providing care. The practical implication of this result is that caregivers need individualized services according to their type of personality trait and condition of the patient to whom they provide care so that they can not only give great care to their patient, but also maintain their QOL. For example, caregivers in whom neuroticism dominates other personality traits, training efforts may involve motivating them to undertake adaptive coping measures as adaptive coping is associated with better QOL. Similar strategy can be applied for caregivers that score low on conscientiousness.

Currently, the number of informal caregivers in the US far exceed the number of paid resources available to help patients.[69] As the number patients with disabling chronic conditions are projected to increase, informal caregivers will play an even greater role in fulfilling the requirement for providing care to these patients. Therefore, it is important for the policy makers to provide enough support to the caregivers in order to keep their health intact and maintain the

availability of their services. In terms of theoretical implications, the Lazarus and Folkman's model of stress-appraisal-outcome worked in two groups of caregivers. However, the some relationships did not hold when personality traits were introduced in the model. Thus the theoretical model was critically reviewed and updated for the two caregiver groups. The updated framework provides a more comprehensive view of the multifactorial nature of caregiver QOL. This is the first study that compared a theoretical model in two groups of caregivers. Such comparisons of models in different groups could help in detailed understanding of outcomes. As such, the results from this study would be a great starting point in driving future research on QOL by looking at how personality affects psychosocial factors like self-efficacy and social support. However, as number of caregivers are bound to increase in the future, the implications of age on QOL and how it fits into the theoretical model should be further explored.

Some limitations should be considered while understanding the study results. A convenience sample of caregivers from a vendor company were used to get responses for the study survey. The sample of caregivers may not represent the national sample of caregivers and therefore, generalization of study results should be made with caution. Further contributing to the lack of generalization was the uneven distribution of the current sample of caregivers across the regions in the US. Since caregivers were given online surveys to fill, this study may suffer from non-response bias. Around 25% of the sample did not have complete responses on the online survey. Third, the segregation of the coping scale (Brief-COPE) into maladaptive coping and adaptive coping was based on previous research, but has not been backed by extensive factor analysis of the scale. Future research should consider establishing the two-factor structure of the Brief-COPE before calculating separate scores for maladaptive coping and adaptive coping.

Conclusion

The mediation between perceive stress – coping – QOL was found but the pathway was different in the two samples of caregivers. Personality played a role is the stress-coping-QOL framework showing moderating effect at different pathways in the framework. The final model was individualized for the two caregiver sub-samples.

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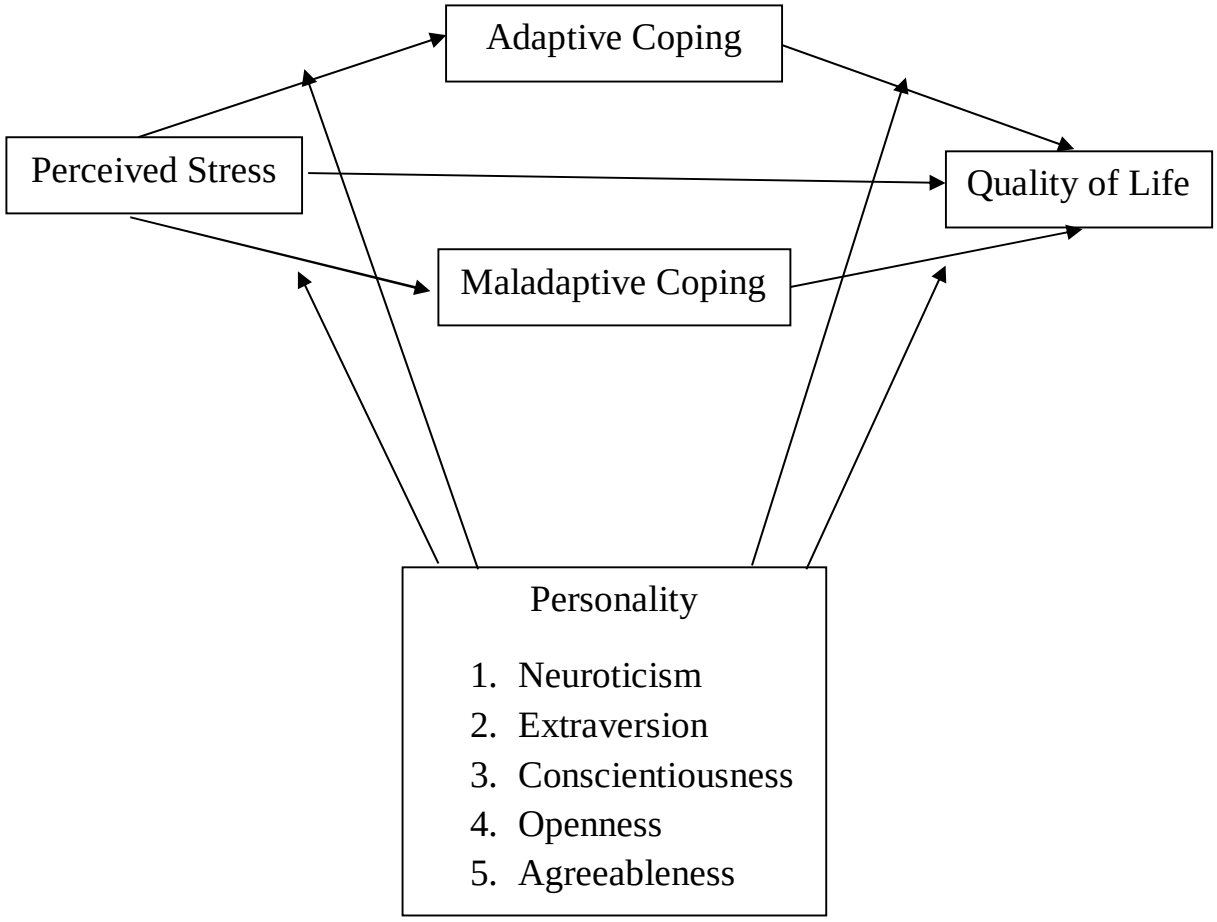
Appendix

Figure 2. 1: Hypothesized framework for the study



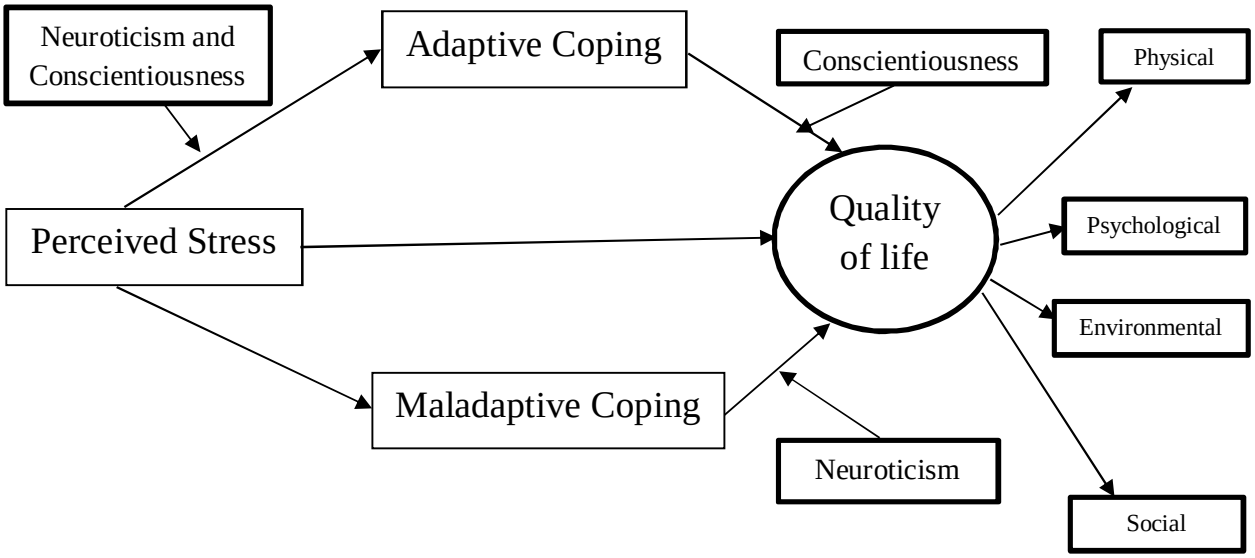


Figure 2. 2: Final model for Autism

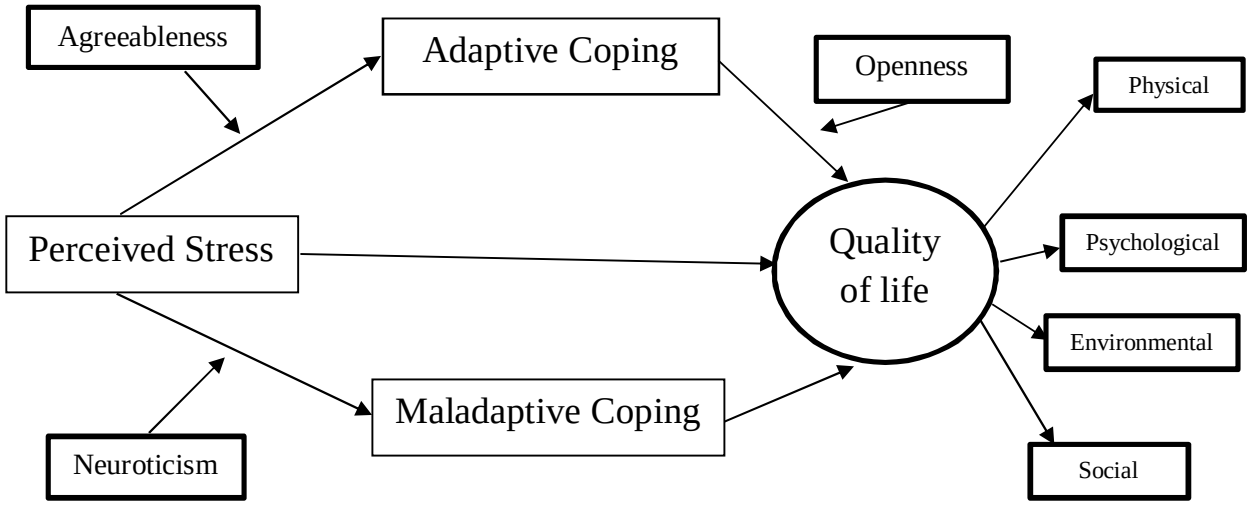


Figure 2. 3: Final model for Alzheimer's disease

Table 2. 1: **Demographic characteristics of the caregivers**

	Alzheimer's group (N=222)	Autism group (N=212)	Chi-square P value
Relation to the patient			<0.001
Spouse	24 (10.8%)	2 (0.9%)	
Parent	5 (2.3%)	188 (88.7%)	
Son/Daughter	115 (51.8%)	1 (0.5%)	
Grandparent	3 (1.4%)	4 (1.8%)	
Sibling	4 (1.8%)	4 (1.8%)	
Friend	28 (12.6%)	7 (3.3%)	
Other	43 (19.4%)	6 (2.8%)	
Age category of caregiver			
18-30	37 (16.7%)	32 (15.1%)	<0.001
31-45	119 (53.6%)	157 (74.0%)	
45 above	66 (29.7%)	23 (10.8%)	
Caregiver sex			0.750
Male	19 (8.6%)	20 (9.4%)	
Female	203 (91.4%)	192 (90.6%)	
Patient sex			<0.001
Male	85 (38.3%)	146 (68.9%)	
Female	137 (61.7%)	66 (31.1%)	
Race of the caregiver			
Caucasian	158 (71.2%)	172 (81.1%)	
African American	22 (9.9%)	21 (9.9%)	
Hispanic	33 (14.9%)	13 (6.1%)	
Other	9 (4.1%)	6 (2.8%)	
Ethnicity of the caregiver			0.003
Hispanic	33 (14.9%)	13 (6.1%)	
Non-Hispanic	189 (85.1%)	199 (93.9%)	
Marital status of the caregiver			0.453
Married	116 (52.3%)	124 (58.5%)	

Widowed/Divorced/Separated	43 (19.4%)	37 (17.5%)	
Never Married	63 (28.4%)	51 (24.1%)	
Education level of the caregiver			
Less than high school	5 (2.3%)	5 (2.4%)	0.567
High school graduate	51 (23.0%)	41 (19.3%)	
Some college	63 (28.4%)	72 (34.0%)	
2 year degree	47 (21.2%)	35 (16.5%)	
4 year degree	32 (14.4%)	38 (17.9%)	
Professional degree	10 (4.5%)	9 (4.2%)	
Master's degree	13 (5.8%)	12 (5.6%)	
Doctoral degree	1 (0.4%)	0 (0.0%)	
Occupation of the caregiver			0.305
Employed/Self-employed full time	77 (34.7%)	72 (33.9%)	
Employed part time	41 (18.5%)	32 (15.1%)	
Unemployed, looking for work	16 (7.2%)	12 (5.7%)	
Unemployed, not looking for work	8 (3.6%)	4 (1.9%)	
Retired	28 (12.6%)	3 (1.4%)	
Student	6 (2.7%)	4 (1.9%)	
Home-make	39 (17.6%)	76 (35.8%)	
Other	7 (3.2%)	9 (4.2%)	
Residential area of the caregiver			0.247
Urban	63 (28.4%)	48 (22.6%)	
Suburban	84 (37.8%)	100 (47.2%)	
Rural	75 (33.8%)	64 (30.2%)	
Region of the caregiver			<0.001
Northeast	30 (13.5%)	37 (17.5%)	
Midwest	19 (8.6%)	49 (23.1%)	
South	131 (59.0%)	88 (41.5%)	
West	34 (15.3%)	31 (14.6%)	
No response	8 (3.6%)	7 (3.3%)	
Does caregiver has any chronic condition?			0.231
Yes	91 (41.0%)	99 (46.7%)	
No	131 (59.0%)	113 (53.3%)	

Has caregiver used any Formal service?			0.748
Yes	155 (69.8%)	151 (71.2%)	
No	67 (31.2%)	61 (28.8%)	

Table 2. 2: **Estimates from individual model and from comparison of parallel mediation models between Autism and Alzheimer's caregivers for global quality of life as main outcome**

			Bootstrap 95% confidence intervals	
	Estimate	SE	ULCI	LLCI
Autism				
Perceived stress → Adaptive coping → Quality of life[a]	-0.003	0.003	-0.013	0.001
Perceived stress → Maladaptive coping → Quality of life[a]	-0.039	0.016	-0.073	-0.012
Total indirect effect	-0.042	0.016	-0.075	-0.014
Alzheimer's disease				
Perceived stress → Adaptive coping → Quality of life[a]	-0.015	0.008	-0.036	-0.002
Perceived stress → Maladaptive coping → Quality of life[a]	-0.013	0.010	-0.035	0.006
Total indirect effect	-0.029	0.015	-0.059	-0.001
Difference between each path of Autism and Alzheimer's disease model[b]				
Perceived stress → Adaptive coping → Quality of life[a]	0.012	0.009	-0.002	0.033
Perceived stress → Maladaptive coping → Quality of life[a]	-0.025	0.019	-0.066	0.008
Total indirect effect	-0.013	0.022	-0.058	0.028

a. Quality of life was measured as a latent variable with each of the four domain scores serving as indicators
b. Difference testing assessed if the path differed in magnitude between Autism and Alzheimer's disease model

Table 2. 3: **Estimates from individual model and from comparison of parallel mediation models between Autism and Alzheimer's caregivers for physical domain as main outcome**

			Bootstrap 95% confidence intervals	
	Estimate	SE	ULCI	LLCI
Autism				
Perceived stress → Adaptive coping → Physical domain	0.001	0.003	-0.004	0.009
Perceived stress → Maladaptive coping → Physical domain	-0.046	0.019	-0.085	-0.009
Total indirect effect	-0.045	0.020	-0.085	-0.006
Alzheimer's disease				
Perceived stress → Adaptive coping → Physical domain	0.009	0.011	-0.012	0.032
Perceived stress → Maladaptive coping → Physical domain	-0.002	0.013	-0.028	0.026
Total indirect effect	0.008	0.019	-0.032	0.045
Difference between each path of Autism and Alzheimer's disease model[a]				
Perceived stress → Adaptive coping → Physical domain	-0.009	0.012	-0.032	0.014
Perceived stress → Maladaptive coping → Physical domain	-0.044	0.023	-0.092	0.000
Total indirect effect	-0.053	0.028	-0.108	0.001

a. Difference testing assessed if the path differed in magnitude between Autism and Alzheimer's disease model

Table 2. 4: **Estimates from individual model and from comparison of parallel mediation models between Autism and Alzheimer's caregivers for psychological domain as main outcome**

			Bootstrap 95% confidence intervals	
	Estimate	SE	ULCI	LLCI
Autism				
Perceived stress → Adaptive coping → Psychological domain	-0.005	0.005	-0.018	0.001
Perceived stress → Maladaptive coping → Psychological domain	-0.041	0.021	-0.084	-0.001
Total indirect effect	-0.046	0.021	-0.089	-0.004
Alzheimer's disease				
Perceived stress → Adaptive coping → Psychological domain	-0.028	0.012	-0.057	-0.010
Perceived stress → Maladaptive coping → Psychological domain	-0.022	0.014	-0.050	0.006
Total indirect effect	-0.050	0.020	-0.089	-0.013
Difference between each path of Autism and Alzheimer's disease model[a]				
Perceived stress → Adaptive coping → Psychological domain	0.023	0.012	0.003	0.053
Perceived stress → Maladaptive coping → Psychological domain	-0.019	0.025	-0.073	0.028
Total indirect effect	0.004	0.029	-0.054	0.058

a. Difference testing assessed if the path differed in magnitude between Autism and Alzheimer's disease model

Table 2. 5: **Estimates from individual model and from comparison of parallel mediation models between Autism and Alzheimer's caregivers for environmental domain as main outcome**

			Bootstrap 95% confidence intervals	
	Estimate	SE	ULCI	LLCI
Autism				
Perceived stress → Adaptive coping → Environmental domain	-0.003	0.004	-0.015	0.001
Perceived stress → Maladaptive coping → Environmental domain	-0.029	0.020	-0.072	0.006
Total indirect effect	-0.032	0.020	-0.074	0.004
Alzheimer's				
Perceived stress → Adaptive coping → Environmental domain	-0.003	0.009	-0.024	0.013
Perceived stress → Maladaptive coping → Environmental domain	0.009	0.013	-0.016	0.037
Total indirect effect	0.006	0.019	-0.031	0.04
Difference between each path of Autism and Alzheimer's disease model[a]				
Perceived stress → Adaptive coping → Environmental domain	0.000	0.010	-0.017	0.022
Perceived stress → Maladaptive coping → Environmental domain	-0.038	0.024	-0.089	0.005
Total indirect effect	-0.038	0.027	-0.096	0.012

a. Difference testing assessed if the path differed in magnitude between Autism and Alzheimer's disease model

Table 2. 6: **Estimates from individual model and from comparison of parallel mediation models between Autism and Alzheimer's caregivers for social domain as main outcome**

			Bootstrap 95% confidence intervals	
	Estimate	SE	ULCI	LLCI
Autism				
Perceived stress → Adaptive coping → Social domain	-0.004	0.005	-0.021	0.001
Perceived stress → Maladaptive coping → Social domain	-0.078	0.026	-0.136	-0.030
Total indirect effect	-0.082	0.027	-0.140	-0.031
Alzheimer's disease				
Perceived stress → Adaptive coping → Social domain	-0.043	0.026	-0.080	-0.018
Perceived stress → Maladaptive coping → Social domain	-0.057	0.019	-0.099	-0.023
Total indirect effect	-0.100	0.027	-0.157	-0.049
Difference between each path of Autism and Alzheimer's disease model[a]				
Perceived stress → Adaptive coping → Social domain	0.039	0.017	0.011	0.077
Perceived stress → Maladaptive coping → Social domain	-0.021	0.033	-0.089	0.040
Total indirect effect	0.018	0.038	-0.059	0.090

a. Difference testing assessed if the path differed in magnitude between Autism and Alzheimer's disease model

Table 2. 7: Moderation of each path by personality trait for Autism caregivers

	Adaptive coping								**Maladaptive coping**							
	Perceived stress → Adaptive coping				Adaptive coping → Quality of life				Perceived stress → Maladaptive coping				Maladaptive coping → Quality of life			
	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI
Neuroticism					0.006	0.007	-0.016	0.049	0.268	0.067	0.131	0.397				
1 SD below mean	-0.140	0.154	-0.433	0.177									0.030	0.036	-0.038	0.104
Mean	-0.374	0.117	-0.589	-0.125									-0.019	0.028	-0.071	0.037
1 SD above mean	-0.609	0.125	-0.858	-0.369									-0.068	0.033	-0.131	-0.001
Conscientiousness									0.268	0.067	0.131	0.397	-0.019	0.029	-0.073	0.040
1 SD below mean	-0.456	0.129	-0.711	-0.197	-0.004	0.023	-0.048	0.041								
Mean	-0.403	0.119	-0.617	-0.150	0.020	0.016	-0.011	0.051								
1 SD above mean	-0.351	0.148	-0.628	-0.044	0.043	0.019	0.009	0.085								
Extraversion	-0.413	0.118	-0.624	-0.171	0.025	0.016	-0.006	0.057	0.268	0.067	0.131	0.397	-0.022	0.029	-0.076	0.037
Agreeableness	-0.413	0.118	-0.624	-0.171	0.025	0.016	-0.006	0.057	0.268	0.067	0.131	0.397	-0.022	0.029	-0.076	0.037
Openness	-0.413	0.118	-0.624	-0.171	0.025	0.016	-0.006	0.057	0.268	0.067	0.131	0.397	-0.022	0.029	-0.076	0.037

a. If conditional effect are not provided for a personality trait (i.e. effect at different levels [mean, one SD above and one SD below] of the personality trait), then there was no evidence that the personality trait moderated the relationship

Table 2. 8: Direct and Indirect effects by personality trait for Autism caregivers

	Indirect effects								**Direct effects**			
	Perceived stress → adaptive coping → Quality of life				Perceived stress → maladaptive coping → Quality of life				**Perceived stress → Quality of life**			
	Effect	BootSE	BootLLCI	BootULCI	Effect	BootSE	BootLLCI	BootULCI	Effect	BootSE	BootLLCI	BootULCI
Neuroticism									-0.151	0.027	-0.206	-0.101
1 SD below mean	-0.002	0.004	-0.019	0.002	0.008	0.010	-0.009	0.033				
Mean	-0.006	0.007	-0.023	0.005	-0.005	0.008	-0.022	0.009				
1 SD above mean	-0.010	0.010	-0.032	0.009	-0.018	0.010	-0.044	-0.002				
Conscientiousness					-0.005	0.008	-0.022	0.010	-0.151	0.027	-0.210	-0.101
1 SD below mean	0.002	0.011	-0.019	0.024								
Mean	-0.008	0.007	-0.026	0.003								
1 SD above mean	-0.015	0.010	-0.044	-0.002								
Extraversion	-0.010	0.007	-0.029	0.001	-0.006	0.008	-0.024	0.009	-0.145	0.027	-0.203	-0.095
Agreeableness	-0.010	0.007	-0.029	0.001	-0.006	0.008	-0.024	0.009	-0.145	0.027	-0.203	-0.095
Openness	-0.010	0.007	-0.029	0.001	-0.006	0.008	-0.024	0.009	-0.145	0.027	-0.203	-0.095

a. If conditional effect are not provided for a personality trait (i.e. effect at different levels [mean, one SD above and one SD below] of the personality trait), then there was no evidence that the personality trait moderated the relationship

Table 2. 9: **Relationships between personality traits and coping mechanisms and QOL**

	Caregivers of patients with Alzheimer's disease			
	Effect	SE	LLCI	ULCI
Neuroticism → QOL	**-1.269**	**0.218**	**-1.709**	**-0.844**
Extraversion → QOL	0.220	0.220	-0.220	0.634
Conscientiousness → QOL	0.333	0.257	-0.164	0.839
Agreeableness → QOL	0.247	0.281	-0.326	0.789
Openness → QOL	-0.209	0.291	-0.801	0.355
Neuroticism → Adaptive coping	-0.384	0.945	-2.283	1.412
Extraversion → Adaptive coping	1.257	1.040	-0.827	3.257
Conscientiousness → Adaptive coping	-0.858	1.247	-3.281	1.684
Agreeableness → Adaptive coping	2.193	1.331	-0.357	4.849
Openness → Adaptive coping	2.282	1.164	-0.090	4.516
Neuroticism → Maladaptive coping	**2.091**	**0.557**	**0.964**	**3.163**
Extraversion → Maladaptive coping	-0.190	0.681	-1.547	1.116
Conscientiousness → Maladaptive coping	**-2.179**	**0.718**	**-3.636**	**-0.807**
Agreeableness → Maladaptive coping	**-1.571**	**0.703**	**-2.967**	**-0.195**
Openness → Maladaptive coping	**1.744**	**0.744**	**0.217**	**3.175**
	Caregivers of patients with Autism-spectrum disorder			
Neuroticism → QOL	**-1.088**	**0.232**	**-1.538**	**-0.619**
Extraversion → QOL	**0.847**	**0.201**	**0.437**	**1.227**
Conscientiousness → QOL	**0.583**	**0.260**	**0.077**	**1.097**
Agreeableness → QOL	0.165	0.298	-0.446	0.719

Openness → QOL	0.217	0.309	-0.368	0.851
Neuroticism → Adaptive coping	0.294	1.020	-1.704	2.316
Extraversion → Adaptive coping	**2.153**	**1.067**	**0.089**	**4.286**
Conscientiousness → Adaptive coping	1.379	1.218	-1.026	3.773
Agreeableness → Adaptive coping	1.087	1.354	-1.560	3.752
Openness → Adaptive coping	2.903	1.470	-0.030	5.792
Neuroticism → Maladaptive coping	**1.633**	**0.545**	**0.517**	**2.649**
Extraversion → Maladaptive coping	-0.519	0.573	-1.665	0.572
Conscientiousness → Maladaptive coping	-0.232	0.621	-1.503	0.956
Agreeableness → Maladaptive coping	**-2.275**	**0.738**	**-3.703**	**-0.820**
Openness → Maladaptive coping	0.975	0.832	-0.617	2.650

[a]All associations were controlled for demographic variables, length of caregiving, and intensity of caregiving

Table 2. 10: Moderation of each path by personality trait for Alzheimer's caregivers

	Adaptive coping								**Maladaptive coping**							
	Perceived stress → Adaptive coping				Adaptive coping → Quality of life				Perceived stress → Maladaptive coping				Maladaptive coping → Quality of life			
	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI	Effect	SE	LLCI	ULCI
Neuroticism	0.078	0.125	-0.169	0.318	0.018	0.017	-0.016	0.051					-0.061	0.034	-0.128	0.004
1 SD below mean									0.399	0.073	0.250	0.538				
Mean									0.341	0.073	0.196	0.479				
1 SD above mean									0.291	0.087	0.125	0.462				
Extraversion	0.078	0.125	-0.169	0.318	0.018	0.017	-0.016	0.051	0.367	0.072	0.221	0.502	-0.061	0.034	-0.128	0.004
Conscientiousness	0.078	0.125	-0.169	0.318	0.018	0.017	-0.016	0.051	0.367	0.072	0.221	0.502	-0.061	0.034	-0.128	0.004
Agreeableness					0.018	0.017	-0.016	0.051	0.367	0.072	0.221	0.502	-0.061	0.034	-0.128	0.004
1 SD below mean	-0.203	0.157	-0.492	0.106												
Mean	0.100	0.122	-0.136	0.342												
1 SD above mean	0.329	0.158	0.014	0.633												
Openness	0.078	0.125	-0.169	0.318					0.367	0.072	0.221	0.502	-0.055	0.032	-0.121	0.005
1 SD below mean					0.062	0.019	0.026	0.100								
Mean					0.026	0.016	-0.005	0.059								
1 SD above mean					-0.024	0.024	-0.073	0.020								

a. If conditional effect are not provided for a personality trait (i.e. effect at different levels [mean, one SD above and one SD below] of the personality trait), then there was no evidence that the personality trait moderated the relationship

Table 2. 11: Direct and Indirect effects by personality trait for Alzheimer's caregivers

	Indirect effects								**Direct effects**			
	Perceived stress →adaptive coping → Quality of life				Perceived stress → maladaptive coping → Quality of life				**Perceived stress → Quality of life**			
	Effect	BootSE	BootLLCI	BootULCI	Effect	BootSE	BootLLCI	BootULCI				
Neuroticism	0.001	0.003	-0.002	0.013					-0.126	0.031	-0.188	-0.066
1 SD below mean					-0.024	0.015	-0.059	0.000				
Mean					-0.021	0.013	-0.052	0.000				
1 SD above mean					-0.018	0.012	-0.049	-0.001				
Extraversion	0.001	0.003	-0.002	0.013	-0.022	0.014	-0.055	0.000	-0.126	0.031	-0.188	-0.066
Conscientiousness	0.001	0.003	-0.002	0.013	-0.022	0.014	-0.055	0.000	-0.126	0.031	-0.188	-0.066
Agreeableness					-0.022	0.014	-0.055	0.000	-0.126	0.031	-0.188	-0.066
1 SD below mean	-0.004	0.006	-0.021	0.003								
Mean	0.002	0.003	-0.002	0.014								
1 SD above mean	0.006	0.007	-0.004	0.025								
Openness					-0.020	0.013	-0.052	0.000	-0.122	0.031	-0.182	-0.060
1 SD below mean	0.005	0.008	-0.010	0.023								
Mean	0.002	0.004	-0.003	0.015								
1 SD above mean	-0.002	0.004	-0.019	0.003								

a. If conditional effect are not provided for a personality trait (i.e. effect at different levels [mean, one SD above and one SD below] of the personality trait), then there was no evidence that the personality trait moderated the relationship

Chapter 4

Patient and caregiver factors predicting the use of formal caregiver services

Introduction

The contribution of informal caregivers to the healthcare system in the United States is substantial. Informal caregivers provide timely care to family members with a chronic disability or condition requiring assistance. In the process, they help avoid adverse events, decrease the need for institutionalization of the family member and save healthcare costs. The value of services provided by informal caregivers amounted to $470 billion in 2013, up from $375 billion in 2007.[1,2] As the percentage of population 65 years and older grows from 40 million to 55 million by 2020, the proportion of individuals diagnosed with chronic diseases and disabilities will increase, ultimately increasing the need for assistance at home.[3] As the prevalence of people with chronic diseases and disabilities increases, the current workforce in the formal care system may fail to keep up with the increased needs.[4] As a result, family members will play a more vital role than ever in reducing the burden of caregiving.

The number of American adults assuming the role of informal caregiver is substantial. According to 2015 estimates, 43.5 million adults were informal caregivers either to an adult or a child in the past 12 months.[5] This represents roughly 13.9% of the adult US population caring for another adult and 2.7% of the adult US population caring for a child.[5] Most informal caregivers are Caucasians, however, the rate of caregiving is highest amongst Hispanics, followed by African Americans and Caucasians.[5] About 75% of all informal caregivers are females who spend 50% more time in caregiving roles than males.[6] The caregiving responsibilities for adults

older than 50 years of age are primarily carried out by adult children or spouses, while grandparents typically take the responsibility of caring for a child with special needs.[7] The two adult conditions that informal caregivers regularly report providing care for are old age and Alzheimer's disease.[5] These differ from conditions among children, where informal caregivers report providing care to children with activity limitations or developmental problems such as attention deficit hyperactivity disorder, asthma, cerebral palsy, autism spectrum disorder, and cystic fibrosis.[3]

Informal caregivers help with a range of general activities termed as instrumental activities of daily living (IADL). The common IADLs are transportation, housework, grocery shopping, and preparing meals.[8] Other than IADLs, 56% of informal caregivers provide assistance with personal needs of the care recipient termed as activities of daily living (ADL).[5,9] The common ADLs performed by informal caregivers are helping care recipient get in and out of bed, dress, and bathe.[8] Informal caregivers of children also spend some time in monitoring the child's condition, ensuring that other people, especially school teachers, know how to deal with the child, advocating on his or her behalf to schools or providers, and giving medications on top of performing IADLs and ADLs.[9]

The responsibilities of caregiving often fall unexpectedly on family members. After assuming the role, informal caregivers invest many hours of care to recipients. About 23% of caregivers provide 41 hours of care or more each week, and 31% provide care between 9 and 40 hours per week.[5] as such, performing caregiving activities often puts the informal caregivers under increased stress managing time between providing care to loved ones, work commitments, and meeting family or friends.[10,11] The duties that come with caregiving have shown to affect mental and physical health of the informal caregiver.[12-14] Informal caregivers reportedly

experienced direct and indirect physical health consequences like higher level of stress hormones and poorer sleep quality.[15-17] Informal caregivers also report higher levels of stress/distress, depression, emotional problems, and cognitive problems compared to non-caregivers.[18,19] In a national survey of informal caregivers, 17% reported their health to be 'fair' or 'poor' while only 10% of the general adult population reported the same.[20] About 60% of informal caregivers report being employed at the time of caregiving, and struggling to divide time and resources between work and caring for family member.[5] However, roughly 18% of informal caregivers reported experiencing financial strain as a result of increased spending on care recipients and reduced income due to less hours at work.[5] Fifty-three percent of informal caregivers also reported getting less time to meet family and friends and 89.2% reported having less leisure time.[21,22]

The burden associated with caregiving can often result in the need for supplementary services for informal caregivers. In a study conducted among informal caregivers of patients with dementia, 85% caregivers had unmet needs for resource referrals to communities such as Alzheimer's Association and caregiver education on topics such as availability of community–based services, skills required by caregivers, and disease conditions affecting the care-recipient.[23] In response to the growing needs of informal caregivers, policy makers have been instituting home and community-based programs to relieve the burden on informal caregivers.[24] These programs include support groups, adult day care or respite services, training for care provision, and financial support for the care recipient. Among informal caregivers who utilized services, there was a positive effect on both caregivers and care-recipients. Informal caregivers reported that care recipients' use of community service was beneficial to them in terms of achieving higher life satisfaction, and less restricted social activities.[25] Caregivers of elderly patients using

respite care reported having fewer behavioral and memory problems with care recipient.[26] Montgomery and Borgatta reported in two separate studies that objective and subjective burden reduced significantly after respite service use.[27,28]

The general consensus of studies assessing the use of formal services is that the utilization of these services is low among informal caregivers.[29-34] It was found that only 15.5% of caregivers used day care, 12.2% used support groups and another 12.2% used educational services.[35] Studies focusing on the factors that predict service use by informal caregivers of elderly people or patients with Alzheimer's or Dementia found they faced barriers such as lack of access, lack of transportation and no coverage which stopped them from using such services.[29,36-43] Caregiver-specific factors such as burden and their perception of health also defined their use of these services.[19,39,43] However, these studies were restricted to small localized populations or to restrictive groups of caregivers such as caregivers of patients with Alzheimer's or dementia or caregivers of community-dwelling patients in a large city. Therefore, it would be useful to assess if the same factors defined the use of formal services in a national sample of informal caregivers. Therefore, the objective of this study was to identify factors related to patients and caregivers that predict the use of formal services, specifically support groups, respite care, and caregiver training by informal caregivers in a nationally representative sample of caregivers.

Methods

Study Design and Data Source

A retrospective study was conducted using data from the National Study of Caregiving (NSOC) 2015, a publicly available dataset. Caregivers were identified for the study from NSOC who responded to interviews conducted as a supplement to Round 5 of the National Health and

Aging Trends Study (NHATS). The NHATS gathers information in person from a nationally representative sample of Medicare beneficiaries 65 years of age and above. To identify the sample for survey, the NHATS utilizes a three-stage sample design where 95 primary sampling units (PSUs) which consist of individual counties or groups of counties are first selected. Next 655 secondary sampling units (SSUs) among the identified PSUs, which consist of ZIP codes or ZIP code fragments are selected. In the third stage beneficiaries aged 65 and older are sampled from the identified SSUs. The Medicare beneficiaries are drawn from the Medicare enrollment file such that there is oversampling of people at older ages and those of African American descent.

At the end of round 1, each Medicare beneficiary who participated in NHATS was asked to provide contact information for up to 5 family members or non-paid unrelated helpers who assisted with self-care, mobility, or household activities. These family members or non-paid unrelated helpers were eligible for the NSOC where they were subjected to a 30-minute telephone interview asking questions about caregiving activities, duration and intensity of help, effect on caregivers of providing assistance, support services used by caregivers and basic demographic information. The caregivers can be linked with their care recipient in NHATS using identifiers in the data. Out of the 5,212 eligible caregivers, interviews were conducted with 2,204 caregivers.

Questions on the NSOC interview were divided into nine sections: (1) care activities, (2) duration of care, (3) aspects of caregiving, (4) support environment, (5) participation, (6) health and well-being, (7) household composition and demographics, (8) employment and caregiving, and (9) health insurance and income. Questions on care activities cover the ways a caregiver provided help to the sampled person (SP) from the Medicare file in terms of household chores,

personal care and mobility. Questions on duration of care elicit days and hours spent by the caregiver providing care to SP in last month. Questions on aspects of caregiving focused on positive and negative views of the caregiver's relationship with SP and the experience of being a caregiver. Questions on support environment focused on availability of friends and family members to help with care and other resources of support.

Participation questions asked about whether the caregivers participated in activities like visiting family and friends, attending religious services, doing volunteer work or working for pay. Health questions asked the caregivers whether they had ever been diagnosed with a list of common chronic conditions, whether they experienced particular impairments and symptoms, and finally their height and weight. Well-being questions screened the caregivers on depression and anxiety, positive and negative effect, self-actualization and self-efficacy. Household composition and demographics section included questions on marital status, number of children, household size, education, age and spouse/partner education. The employment and caregiving section asked questions about current occupation, hours worked in last week, reason for absence from work, number of days work missed to help SP, and how caregiving affects work. Lastly, the health insurance and income section asked questions about health insurance coverage and total income for individuals.

Study Sample

The study sample comprised of all caregiver participants who responded to the measures that were used in the present study and also had a direct relationship with the SP - i.e., was a spouse or a child of the SP. Relationship to the caregiver was identified by looking at the 'c1relatnshp' variable in the NSOC file. All caregivers should be living with or caring for the SP during the time duration covered by questions on interview in NSOC.

Study Measures

Dependent variables: The use of formal services offered to caregivers were used as the dependent variables in the subsequent analysis. The NSOC included four questions related to formal service use: paid help, support group, respite care and training. Caregivers answered 'Yes' or 'No' to the following four questions, "In the last year, have you helped SP find a paid helper to do household chores or personal care?"; "In the last year, have you gone to a support group for people who give care?"; "In the last year, have you used any service that took care of SP so that you could take some time away?"; "In the last year, have you received any training to help you take care of SP?" Responses the all four questions were used as separate outcome variables for statistical analysis.

Independent variables: Patient-related factors and caregiver-related factors were used as predictor variables in the analysis. A number of questions that captured patient factors were asked in the NHATS. Items that have been used in prior research were selected from this set of measures. SP's presence of dementia, number of chronic conditions, and physical capacity were assessed as a part of patient-related factors. The presence of dementia was identified by responses on the AD8 instrument. The AD8 is a validated instrument that distinguishes individuals with very mild dementia from those without dementia.[44] The responses on the AD8 items were scored 1='Yes' and 0='No' where the total score ranged from 0-8 with higher scores indicating dementia/Alzheimer's. A cut-off score of 2 and above on AD8 is used to indicate dementia/Alzheimer's.[44]

Each SP is also asked whether he/she has ever been told by a doctor that he/she has selected chronic condition such as heart disease, high blood pressure, arthritis, osteoporosis, diabetes or type of cancer. If the SP indicates the presence of any chronic condition it was

flagged as 1 and the total was summed to get number of chronic conditions. Physical capacity was measured by asking the SP about their ability to perform 12 activities in the last month. A total score is obtained from the responses where lower scores indicated restricted physical capacity.[45]

Caregiver-related factors that can potentially influence formal service use were level of care activities, duration of caregiving, intensity of help, informal support, social participation, physical, emotional and financial difficulties, mood and perceived health. A number of questions that captured caregiver-related factors were asked in the NSOC. Items that have been used in prior research were selected from this set of measures. The caregivers were asked about their level of care activities with regards to helping with (1) chores, (2) shopping, (3) personal care and (4) getting around home. The responses for these questions ranged from 1 = every day to 5 = never. Lower scores indicate higher level of involvement in helping with daily activities. A score of 12 and below was considered as high level of care activities.[46] The intensity of caregiving was measured in terms of hours of care per month.

The duration of caregiving was measured in terms of whether the caregiver has been helping the SP for a year or longer. Financial, emotional and physical difficulty were measured using responses to the questions: "How difficult is helping SP financially?, emotionally?, and physically?" Responses to these questions ranged from 'A little difficult' or 'Very difficult'. Participants with a score of 1 or more were characterized as experiencing difficulty.[47] Informal support was measured by response to three questions which are: (1) "Do you have friends or family that you talk to about important things in your life", (2) "Do you have friends or family that help you with your daily activities, such as running errands, or helping with things around

the house?" and (3) "Do you have friends or family that help you care for SP?" The responses to these questions can be either 1 = "yes" or 0 = "No" which was summed.[46]

Restriction on social participation was assessed using responses to the questions: In the last month, did helping SP keep you from visiting friends and family?, attending religious services?, participating in club meetings or group activities?, and going out for enjoyment? Caregivers were categorized according to those who reported no restrictions and those who reported any restrictions.[47] General health status was assessed by the response to the question, "Would you say that in general, your health is excellent, very good, good, fair or poor?" which ranged from "Excellent" to "Poor". The subjective feeling of mood was assessed using four questions which has a 4-level response from 1= not at all to 4 = nearly every day and asks whether caregiver (1) had little pleasure in doing things?, (2) felt down, depressed or hopeless?, (3) felt nervous, anxious or on edge?, and (4) been unable to stop worrying? Responses were dichotomized into having no mood disorder and having mood disorder.[46]

Caregiver background characteristics were included in the analysis. Background characteristics include caregiver's age, sex (0=male, 1=female), marital status (0=not married including living with partner, never married, divorced/separated/widowed, 1=married), education (0=high school or less, 1=some college or mare), number of children under age 18, race (0=Caucasian, 1=African American, 2=Asian, 3=Others), work status (0= yes, 1=no), health insurance (0=Government, 1=Private, 2=None) and income (0=less than 100% poverty line, 1=between 100-200% poverty line, 2=between 200-400% poverty line, 3=above 400% poverty line).

Statistical analyses

All analyses were conducted in Statistical Analysis System (SAS) version 9.4 (SAS Institute Inc., Cary, NC). The unit of analysis was individual caregiver. Descriptive statistics were performed on socio-demographic variables to characterize the study population. Differences in scale scores between formal service users and non-users was assessed by an independent t-test. Differences in proportions between formal service users and non-users of categorical variable was assessed by chi-square test. Survey weights were used to adjust all analyses to account for differential probabilities of selection of caregivers for interviews and to reduce potential bias from differential nonresponse. Non-response to specific items on the questionnaire was handled using multiple imputation. Three separate multivariable logistic regression models using PROC SURVEYLOGISTIC with a sub-setting domain statement was run with respite service use, support service use and training use as the dependent variables. Significant predictors were identified using an a priori alpha level of 0.05. Variance estimates were computed with stratum and cluster variables using Taylor series linearization.

Results

There were 1,462 caregivers who responded to the questionnaire in 2015. After applying the exclusion criteria, 1,450 caregivers were included in the study sample. Complete responses were available for 1220 caregivers. Table 3.1 gives the distribution across demographic characteristics of caregivers overall and by the formal services used. The majority of caregivers were female, Caucasian, fell in the age group range of 45-65 years, were married or living with a partner, had some college degree, and fell in the income category of $0-14,600. Most of the caregivers were related to patients as either their spouse or child. Most of caregivers had a public insurance and had 2 or more chronic conditions.

The use of formal service among caregivers who participated in the survey was very low. Out of 1220 caregivers, 275 (22.5%) caregivers got some paid help, 199 (16.3%) caregivers used respite care, 95 (7.8%) caregivers underwent some caregiver training, and only 39 (3.2%) attended some support groups. The numbers were then extrapolated to national estimates using survey weights. At a national level, 11.6 million caregivers were identified, out of which 2.2 million (19.6%) caregivers got paid help, 1.5 million (13.2%) caregivers used respite care, 807,661 (6.9%) caregivers took training sessions and 305,263 (2.6%) caregivers attended some support group.

The estimates for all the factors predicting use of each of the formal services was derived through logistic regression analysis are given in Table 3.2. Analysis to identify factors predicting use of support groups could not be carried out because of very few people using the service. The factors that predicted if caregivers ever used any formal service were working status (Odds ratio[OR] = 0.442, 95% confidence interval [CI] = 0.232 to 0.841), staying with the patient (OR=0.397, 95% CI = 0.192 to 0.821), the patient not having Alzheimer's (OR=0.453, 95% CI = 0.276 to 0.743), the caregiver having a social activity (OR=0.677, 95% CI = 0.507 to 0.905), and a decreasing number of people in the same household (OR=0.640, 95% CI = 0.469 to 0.875). These findings suggest that factors predicting the use of any formal service were more caregiver-related like having a social activity and having a job than patient-related like patient having Alzheimer's disease. The probability of use of formal services was low among caregivers who were working or have a job and who were not living with the patient. Similarly, as the amount of social activity for the caregiver decreased and as the number of people in the same household increased, the probability of using a formal service decreased. Lastly, the probability of caregiver using formal service increased when the patient had Alzheimer's disease.

The factors that predicted if caregivers utilized paid help were chronic condition burden of caregiver (OR=0.786, 95% CI = 0.506 to 0.819), having emotional difficulty (OR=1.786, 95% CI = 1.182 to 2.697), not having informal support (OR=0.780, 95% CI = 0.634 to 0.960), caregiver having social activity (OR=0.760, 95% CI = 0.609 to 0.949), improved quality of relationship (OR=0.867, 95% CI = 0.780 to 0.964), reduced mobility of the patient (OR=1.138, 95% CI = 1.016 to 1.274), and decreasing number of people in the same household (OR=0.772, 95% CI = 0.646 to 0.922). Again the factors predicting the use of paid help were more caregiver-related than patient-related. Caregivers with higher chronic condition burden and emotional difficulty had higher probability of use of paid help. In terms of inter-personal factors, as quality of relationship with the patient becomes worse, as social activity decreases and as informal support decreases, the probability of caregiver using paid help decreases. Lastly, mobility is the only patient-related factor that predicted the use of paid help with increasing mobility problems being a trigger for more caregivers using paid help.

The factors that predicted if caregivers used respite care services were income of the caregiver (OR=0.381, 95% CI = 0.185 to 0.785), having emotional difficulty (OR=1.680, 95% CI = 1.044 to 2.707), staying with the patient (OR=0.482, 95% CI = 0.286 to 0.812), not having informal support (OR=0.776, 95% CI = 0.618 to 0.975), caregiver having social activity (OR=0.770, 95% CI = 0.605 to 0.981), reduced mobility of the patient (OR=1.165, 95% CI = 1.048 to 1.294), and decreasing number of people in the same household (OR=0.773, 95% CI = 0.638 to 0.936). Caregiver-related factors that predicted the use of respite care were income, and emotional difficulty with caregivers in higher income category, and those with emotional difficulty having higher probability of using respite services. In terms of inter-personal factors, not staying with the patient, low informal support and social participation is associated with low

use of respite care by caregivers. Mobility was the only patient-related factor that was associated with respite care use with caregivers having higher probability of using respite care with higher mobility problems. A household factor that predicted respite care use was the number of people in the household staying with the patient with higher number of people in household reducing the probability of using respite care by caregiver.

The factors that predicted if caregivers undertake training sessions were level of care given by the caregiver (OR=0.909, 95% CI = 0.835 to 0.990), number of hours per week that caregivers spent in caregiving (OR=1.009, 95% CI = 1.000 to 1.018), caregiver having social activity (OR=0.631, 95% CI = 0.454 to 0.878), and improved quality of relationship (OR=0.773, 95% CI = 0.624 to 0.956). Compared to other formal service use, the factors predicting caregiver's use of training sessions were more related to activity of caregiving such as level of care provided to patient and intensity of caregiving. Higher level of care and longer hours of caregiving per week was associated with higher probability of undertaking training sessions. Inter-personal factors like lower quality of relationship with the patient and lower social participation was associated with lower use of training sessions.

Discussion

A number of community-based programs such as adult day care or respite care, training for care provision, and support groups have been instituted for informal caregivers. The purpose of these services is to provide support to caregivers, improving their quality of life and keep them motivated in their daily provision of care. The use of such services still remains low among caregivers as reported by studies that assessed service uptake among caregivers of patients with specific disease at a local level.[29,30,32-34] This study adds to the knowledge base of service uptake by providing national level estimates of each kind of service use by informal caregivers and

giving a deeper understanding of the factors that trigger the use of such services among a national sample of informal caregivers. Awareness, access and coverage of these services are some of the reasons well documented in the literature for low use of these services by previous literature.[38,48] As efforts to improve awareness and availability of these services are at its peak, this study strives to answer a critical question that will follow for providers and policy makers which is to understand the caregiver-specific and patient specific factors that explain the use of each of the services that are currently offered to informal caregivers.

The current study found that in a national sample of informal caregivers, the use of formal services was still low. Among the services that were available for informal caregivers, a larger share utilized paid help (19.6%), followed by respite care use (13.2%) and caregiver training sessions (6.9%). The use of support groups was very low, 2.6% in this national sample. The predictors of each of the formal service use were more caregiver-specific such as caregiver's emotional difficulty, chronic condition burden, caregiver's income, level of care provided and intensity of care and also inter-personal related such as social participation, informal support for the caregiver, quality of relationship with the care-recipient compared to patient-specific factors. Moreover, the factor which was associated with a particular service use differed according to the type of service suggesting that there are some distinguishing factors that predict the use of each service.

The low use of formal services by caregivers have been reported by a number of studies. The national estimates for respite care use found in this study was similar to what was reported in the previous study which recruited caregivers from the New York State Alzheimer's disease registry.[35] However, the estimates for training sessions and support groups were way below those reported in the previous study.[35] The reason for this discrepancy may be that the previous study

was conducted is New York State where the services are more accessible and therefore estimates of service use tend to be higher compared to states comprised of more rural areas where services are not readily available causing awareness and accessibility problems among caregivers. Li and Blaser found that underuse of community services is more pervasive in rural areas.[49] The most frequently used services by family caregivers in rural areas were visiting nurses and homemakers while the use of support groups was lowest as shown by a study done among caregivers of patients with dementia living in rural southeastern US.[50]

The factors associated with using a formal service differed from that assessing the use of specific formal services. Results from predictors of ever using a service suggest that caregivers who work or are on job have lower probability of using a service. The finding is understandable as some of the services like support groups and training sessions are provided during working hours which makes attending these services impossible for working caregivers. Weekend or after business hours services may help improve the uptake of these services among caregivers with a job. Other critical factors for caregivers to ever use a service were caregiver living in the same household as patient and patient having Alzheimer's disease. The former finding suggests that living with the patient might be making the caregiver aware of their need for better provision of care to care-recipient leading use of services. The latter finding is not unusual as the number of caregivers providing care to patients with Alzheimer's disease is the largest and studies have shown that the burden of caregiving on these caregivers is huge.[51,52] A number of training sessions and support groups have targeted caregivers of patients with Alzheimer's disease and should continue to do so in the future.

A number of caregiver-specific and inter-personal factors were explored in this study to see its association with the use of each of the formal service which has not been done in previous

studies. Factors that predicted each of the service use including paid help, training sessions and respite care was caregiver involvement in social activity such as visiting a friend or a family, attending religious services or going for a club meeting. The result suggests that participating in social activity may have raised awareness among informal caregivers about the availability of formal services which might have led to the use of services. Low informal support was found to be associated with low use of paid help and respite care. This result is contrary to the finding that when there is no informal support, caregivers may tend to use support services.[53] A possible explanation may be distrust of paid help or respite care by informal caregivers with lack of informal support. Besides these factors, quality of relationship with patient explained caregiver use of paid help and training sessions. Past studies have highlighted the importance of close relationship between caregiver and care-recipient in providing good care to care-recipient.[54-56] This association may be extrapolated to caregiver putting extra effort in finding paid help or attending training sessions. Other caregiver-specific factors identified in the study were similar to findings for a typical utilization of healthcare services study. Paid help was used more by caregivers with high chronic condition burden and emotional difficulties whereby the factors reiterate caregiver's inability of providing appropriate care. Respite care was used by caregivers with lower income as individuals falling in Medicaid are provided free access to such services. Training sessions were utilized by caregivers involved in a number of activities of care and spent long hours in those activities showing that these caregivers may probably like to learn more efficient ways of providing care. Future studies may further explore the specific reasons for such findings.

The only patient-related factor that predicted the use of paid help and respite care use was mobility problems. Patients with mobility problems require assistance with daily activities of

living and instrumental activities of living.[57] As a result of continuous care requirement for these patient, caregivers may foresee the requirement of help when they are doing other household chores, running an errand or attending their job, leading them getting paid help or putting them in respite care. Similar finding has been shown in studies of wheel-chair bound patients where their tendency to get paid help is high.[58] Lastly, a finding of low importance is the tendency of caregiver using paid help or respite care when the number of people in the household are small showing the lower availability of people to distribute the burden of care.

The study results should be considered in light of some limitations. The NSOC included caregivers of only patients that were Medicare eligible and those assisted with at least one task pertaining to mobility, self-care, household activities, transportation or medical care. Therefore, the national estimates are restricted to this sub-sample and does not provide a whole picture for all caregivers in the US. The chronic condition burden among caregivers as well as patients was gathered through responses to questions on disease condition which is susceptible to recall bias. The strength of the study resides in the use of a rigorous method i.e. multiple imputation for handling non-response bias in addition to accounting for complex survey design for all analyses. In addition, survey weighting allowed to generate national estimates for all descriptive analyses.

The current study provides added granularity to the factors and barriers to the use of each of the formal services. Previous studies have identified access, knowledge and costs of the service as the major barriers for the use of these services.[38,48] While these barriers remain of utmost importance, this study highlights certain need-based factors that are caregiver, patient and inter-personal specific that can be tended to as policy makers try to address barriers to care. The findings of association of participation in social activity with higher service use points at different avenues to target for awareness of these formal services. Future marketing efforts for

formal service may target religious service or club meeting to raise awareness of availability of such services among informal caregivers. The findings also highlight the differences in factors that predict the use of each of the service and give directions to policy makers to improve services offered to caregivers. For example, trainings provided to caregivers may include sessions on efficient managing of care as one of the factor associated with use of training sessions was intensity of care. Further research needs to be done to understand how the results of this study can be used to develop targeted efforts to improve use of each of the formal service.

Conclusion

At the national level, the use of formal services were low, with caregivers mostly using paid help and rarely using support groups. The study results shed light on the fact that use of each of the formal services is associated with some unique factors that shows that each service should be treated separately. Caregiver-related and interpersonal factors explained the majority of the use of each of the formal services showing their importance when planning future directions to improve service use.

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Appendix

Table 3. 1: Demographic characteristics of caregivers according to formal service use status

Characteristic	Total (N=1220)		Formal service use status							
			Support Group (N=39)		Respite care (N=199)		Training (N=95)		Paid help (N=275)	
	N (%)	Weighted Frequency	N (%)	Weighted Frequency	N (%)	Weighted Frequency	N (%)	Weighted Frequency	N (%)	Weighted Frequency
Gender of caregiver										
Male	373 (30.6%)	4,247,603	12 (30.7%)	47,184	52 (26.1%)	428,577	24 (25.3%)	264,730	94 (34.2%)	796,238
Female	843 (69.1%)	7,330,806	27 (69.2%)	258,079	147 (73.8%)	1,107,047	71 (74.7%)	542,931	181 (65.8%)	1,488,388
Refused	4 (0.3%)	39,885	0 (0%)	0	0 (0%)	0	0 (0%)	0	0 (0.0%)	0
Race of caregiver										
Caucasian	694 (56.9%)	7,601,130	18 (46.2%)	198,802	116 (58.3%)	955,878	33 (34.7%)	357,135	157 (57.1%)	1,474,294
African American	345 (28.3%)	1,432,773	17 (43.6%)	46,509	54 (27.1%)	204,680	43 (45.3%)	176,678	76 (27.6%)	276,877
Hispanic	65 (5.3%)	1,055,985	2 (5.1%)	52,580	12 (6.0%)	190,104	6 (6.3%)	113,700	17 (6.2%)	297,623
Other	116 (9.5%)	1,528,406	2 (5.1%)	7,371	17 (8.5%)	184,962	13 (13.7%)	160,148	25 (9.1%)	235,833
Relationship with patient										

Spouse	355 (29.1%)	3,530,118	10 (25.6%)	60,865	39 (19.6%)	300,017	26 (27.4%)	313,444	64 (23.3%)	599,339
Children/Stepchildren	568 (46.6%)	4,834,610	19 (48.7%)	146,252	120 (60.3%)	846,746	47 (49.5%)	343,042	156 (56.7%)	1,173,471
In-laws	58 (4.8%)	538,294	0 (0%)	0	12 (6.0%)	79,574	3 (3.1%)	18,444	18 (6.6%)	126,205
Sibling/grandkids	150 (12.3%)	1,654,173	5 (12.8%)	32,334	18 (9.1%)	195,624	14 (14.7%)	102,811	32 (11.6%)	332,135
Other relationship/Friend/ No relationship	89 (7.3%)	1,061,098	5 (12.8%)	65,811	10 (5.0%)	113,663	5 (5.3%)	29,920	5 (1.8%)	53,478
Marital status of caregiver										
Married/living with partner	752 (61.6%)	7,631,278	22 (56.4%)	128,566	128 (64.3%)	1,034,297	50 (52.6%)	521,673	180 (65.5%)	1,593,376
Separated/Widowed /Divorced/Never married	463 (37.9%)	3,959,857	17 (43.5%)	176,697	70 (35.2%)	491,351	44 (46.3%)	276,012	93 (33.8%)	676,460
Refused	5 (0.4%)	27,159	0 (0%)	0	1 (0.5%)	9,976	1 (1.1%)	9,976	2 (0.7%)	14,791
Education of caregiver										
High school or less	485 (39.8%)	4,795,598	15 (38.5%)	172,055	49 (24.6%)	382,200	30 (31.6%)	293,136	82 (29.8%)	784,918
Some college or more	722 (59.2%)	6,754,531	24 (61.5%)	133,208	148 (74.4%)	1,137,665	62 (65.3%)	495,359	189 (68.7%)	1,474,492
Refused	13 (1.1%)	68,165	0 (0%)	0	2 (1.0%)	15,759	3 (3.2%)	19,166	4 (1.5%)	25,216
Income Category of caregiver										
$0-$14,600	509 (18.4%)	4,827,081	14 (35.9%)	70,934	60 (30.2%)	464,980	40 (42.1%)	407,281	87 (31.6%)	752,159

$14,601-30,000	148 (12.1%)	1,461,178	10 (25.6%)	90,406	17 (8.5%)	130,182	15 (15.8%)	127,327	33 (12.0%)	325,318
$30,001-60,000	160 (13.1%)	1,490,600	4 (10.2%)	22,666	25 (12.6%)	167,889	11 (11.6%)	87,279	29 (10.6%)	241,099
Above $60,000	178 (14.6%)	1,863,958	3 (7.7%)	13,365	53 (26.6%)	478,020	14 (14.7%)	113,448	65 (23.6%)	522,504
Refused	225 (18.4%)	1,975,477	8 (20.5%)	107,891	44 (22.1%)	294,553	15 (15.8%)	72,327	61 (22.2%)	443,547

Table 3. 2: Pooled parameter estimates from regression analyses of multiple imputed data

	Ever used service			**Paid help**			**Respite care**			**Training**		
Parameter	Odds Ratio	95% Confidence Limits		Odds Ratio	95% Confidence Limits		Odds Ratio	95% Confidence Limits		Odds Ratio	95% Confidence Limits	
Intercept	40.813	1.354	1230.284	15.534	0.919	262.434	60.886	1.644	2252.960	14.600	0.172	1241.406
Relationship with patient	0.778	0.169	3.579	5.529	1.203	25.406	1.114	0.331	3.747	1.614	0.452	5.778
Condition category	0.780	0.414	1.473	0.786	0.506	0.819	0.868	0.445	1.692	0.510	0.195	1.338
Marital status of caregiver	1.487	0.736	3.010	1.108	0.641	1.916	1.004	0.433	2.333	0.993	0.419	2.354
Race of caregiver	0.608	0.169	2.186	1.204	0.415	3.494	0.891	0.276	2.881	0.397	0.101	1.565

Sex of caregiver	1.160	0.698	1.927	1.408	0.838	2.363	1.041	0.635	1.706	1.012	0.535	1.917
Education level of caregiver	0.694	0.408	1.182	0.955	0.586	1.557	0.556	0.320	0.967	0.722	0.362	1.436
Income category of caregiver	1.267	0.379	4.238	0.517	0.217	1.234	0.381	0.185	0.785	0.624	0.177	2.201
Age category of caregiver	0.817	0.415	1.610	1.261	0.645	2.465	0.855	0.402	1.818	2.098	0.891	4.938
Financial difficulty	1.912	0.992	3.684	1.107	0.676	1.815	1.994	1.096	3.629	0.445	0.194	1.021
Emotional difficulty	2.026	0.984	4.170	1.786	1.182	2.697	1.680	1.044	2.707	1.317	0.683	2.537
Physical difficulty	0.842	0.470	1.508	1.162	0.718	1.879	0.723	0.347	1.502	0.883	0.349	2.234
Working status	0.442	0.232	0.841	1.127	0.686	1.853	0.965	0.554	1.680	1.404	0.662	2.977
Sex of patient	0.685	0.347	1.354	1.100	0.718	1.685	1.613	0.908	2.863	1.809	0.948	3.452
Staying with patient	0.397	0.192	0.821	0.933	0.546	1.595	0.482	0.286	0.812	1.043	0.524	2.077

Census division	0.829	0.370	1.853	0.546	0.098	3.034	1.050	0.510	2.162	0.196	0.071	0.540
Patient age category	1.459	0.660	3.228	1.224	0.566	2.649	0.961	0.438	2.106	0.806	0.317	2.048
Patient has Alzheimer's disease	0.453	0.276	0.743	0.884	0.580	1.349	0.530	0.278	1.011	1.870	0.808	4.332
Health status of the caregiver	0.590	0.116	3.001	0.666	0.220	2.016	1.603	0.519	4.958	0.569	0.128	2.540
Health status of the patient	1.324	0.550	3.190	1.368	0.689	2.716	0.790	0.356	1.754	1.950	0.703	5.403
Number of chronic conditions in patient	0.984	0.799	1.210	0.982	0.849	1.137	0.991	0.834	1.178	1.004	0.816	1.235
Level of care	0.944	0.881	1.011	0.957	0.902	1.015	0.947	0.896	1.001	0.909	0.835	0.990
Intensity of care	1.003	0.996	1.010	0.998	0.993	1.004	0.995	0.987	1.004	1.009	1.000	1.018
Years since started caregiving	0.971	0.934	1.009	1.009	0.991	1.028	1.001	0.979	1.023	0.967	0.922	1.012

Quality of relationship with patient	0.984	0.861	1.124	0.867	0.780	0.964	1.085	0.956	1.234	0.773	0.624	0.956
Informal support	0.922	0.688	1.236	0.780	0.634	0.960	0.776	0.618	0.975	0.867	0.634	1.185
Social participation	0.677	0.507	0.905	0.760	0.609	0.949	0.770	0.605	0.981	0.631	0.454	0.878
Mobility of patient	0.964	0.818	1.137	1.138	1.016	1.274	1.165	1.048	1.294	1.053	0.892	1.242
Number of people in household	0.640	0.469	0.875	0.772	0.646	0.922	0.773	0.638	0.936	0.855	0.678	1.077

Chapter 5

Dissertation Summary and Future Research

Summary

Informal caregivers provide timely care to family members who are disabled or have a chronic condition that requires close monitoring or constant assistance. The constant care provided by the informal caregiver helps in improving patients' condition, decreasing the chances of any adverse events and saving substantial healthcare costs.[1] In order to sustain these savings in healthcare costs, attention needs to be given to the health and QOL of the informal caregivers to ensure they are not adversely affected. QOL of informal caregiver might improve with efforts from the healthcare environment to provide appropriate services and support. In the past few years, policy makers have been trying to extend the understanding of factors that affect caregiver health and QOL.[2-9] These factors can be targeted in the services provided to caregivers with the hope of maintaining caregiver QOL. The health of the informal caregiver and their readiness to provide care is of utmost importance as formal workforce that provides care to patients is unable to keep pace with the increase in chronic condition prevalence.[10] This dissertation strives to extend the knowledge available for policy makers by focusing on two important questions. A) What are the factors that can be targeted by policy makers to prevent QOL of informal caregivers from degrading? and b) What are the factors that enable the use of formal services provided to support informal caregivers?

Study 1

Before assessing QOL in informal caregivers, a key consideration is the use of an appropriate instrument to capture QOL. The instrument must show good reliability and validity in measuring all aspects of QOL such as physical health, mental health, social well-being and environmental effects. Additionally, the instrument should be able to measure QOL without any influence of caregiver characteristics or patient characteristics. Therefore, the psychometric properties of the QOL instrument must be established before its use for assessment of QOL in a specific population i.e., informal caregivers.[11] The WHOQOL-BREF has not been used previously for the assessment of caregiver's QOL. Therefore, its psychometric properties in the informal caregiver population must be established. The study provided evidence for WHOQOL-BREF being psychometrically sound for use in assessment of QOL among informal caregivers. Assessing the construct validity of the WHOQOL-BREF showed that the four factor structure was the best model to capture QOL. Additionally, the instrument showed good convergent validity, discriminant validity and internal consistency reliability. Informal caregivers that differed on their health status were able to be distinguished in terms of QOL with the WHOQOL-BREF. Lastly, the instrument was able to capture the true differences in QOL according specific care-recipient and caregiver characteristics such as the condition of the care-recipient, age of caregiver and caregiver's chronic condition burden. Overall, the results provide basis for the use of WHOQOL-BREF for the assessment of QOL in informal caregivers.

Study 2

Previous studies have explored the effect of patient's severity of disease and psychosocial factors like stress appraisal, coping, self-efficacy and informal support on caregiver outcomes.[12,13] While these factors are important for policy makers to target for improvising

services for caregivers, intrinsic factors of the caregivers present a starting point for providing individualized care. Personality being the major intrinsic factor have been found to directly affect caregiver outcomes.[14] This study explores the role of personality in influencing psychosocial factors and QOL of informal caregivers and whether its influence differs between two types of informal caregivers. A theory-driven approach was adapted to guide the complexity in the influence of factors on caregiver's QOL. Hypotheses were generated based on previous findings and were tested in two separate samples of informal caregivers: those caring for patients with Alzheimer's disease and those caring for patients with Autism-spectrum disorder. The study found that for both the groups the effect of perceived stress on QOL was mediated through coping but the mediator type i.e., adaptive coping or maladaptive coping, differed in the two groups. In terms for effects of personality traits, only specific traits moderated the hypothesized paths within the two groups. Neuroticism and conscientiousness moderated some paths in the hypothesized model in Autism caregiver group while neuroticism, agreeableness and openness moderated some paths in the hypothesized model in Alzheimer's caregiver group. This resulted in two different models unique to the informal caregivers of the two groups. Knowledge about how personality plays a role in different caregiver groups will help policy makers provide targeted interventions and the caregivers to reflect and better manage their care. The services developed by policy makers can incorporate the study findings to provide individualized trainings to informal caregivers, thus ensuring better health of caregiver and the care-recipient.

Study 3

A precursor to providing individualized services to informal caregivers is to understand the factors that trigger the informal caregivers to utilize the services offered. Currently, formal services that are available for informal caregivers are paid help, respite care or day care, training

sessions and support groups. These services have been shown to have positive effect on the caregiver.[15-17] Finding the caregiver and care-recipient specific factors that act as a barrier or help the caregiver utilize a formal service will extend policy makers understanding and help in further improvement of services provided to caregivers. A national sample of caregivers were used to identify the factors, where weights were applied to get generalizable results. Paid help, respite care and training sessions, all had some unique factors that predicted their use that shows that each service should be treated separately. Most of the factors were caregiver-specific as opposed to patient-specific. These factors can serve as starting points to tackle while extending the use of these formal services.

Overall, the dissertation has made some useful additions to the literature available on informal caregivers. Establishing the psychometrics properties of the WHOQOL-BREF in informal caregivers will help future studies to use the instrument for the evaluation of QOL among informal caregivers. The instrument's invariance in assessing QOL among caregivers providing care to different set of patients will help future studies carry out QOL comparisons between caregivers providing care to patients having two different conditions. Personality was found to play an important role in the QOL of caregivers giving a basis for its use in targeted trainings for informal caregivers. Finally, caregiver-specific factors that predicted the use of each of the formal service can be used for better service management for caregivers.

Future directions

The findings from the dissertation study can be used to support future research on informal caregivers.

Study 1

Future studies can evaluate modifications that can be done to improve the fit of the four factor model of the WHOQOL-BREF. Also, longitudinal studies can be undertaken to assess test-retest reliability, predictive validity and whether invariance holds across time.

Study 2

Future studies can assess how personality and its association with psychosocial factors and QOL can be integrated into practice that will help support the informal caregivers in the longer run. Specifically, studies can look at how policy makers can utilize the results of the study to modify existing service offered to caregivers. Studies can also utilize a random sample of caregivers to understand the role of personality in QOL.

Study 3

Future studies can examine the utility of caregiver-related factors in improving availability of services offered to informal caregivers by policy makers and practitioners.

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Appendices

Appendix A

Cover letter from study conductors

Testing a Modified Model of Stress Process for Understanding Quality of Life among Informal Caregivers and Assessing their Formal Service Use

Dear Sir/Madam,

We are conducting a study to gather information about the experiences of caregivers' to assess various aspects of caregivers' quality of life. In particular, we are going to be collecting information on stress related to caregiving, the personality traits of the caregivers, and coping mechanisms adopted by caregivers. This study is a part of my Ph.D. dissertation project, and is being conducted in collaboration with researchers from the University of Mississippi – School of Pharmacy. **Your survey response will help us understand differences in the quality of life among informal caregivers.**

In particular, we are looking for **adult informal caregivers (18 years of age and older) caring for patients with Alzheimer's disease or caring for patients below 18 years of age with Autism-spectrum disorder.** The survey should take no longer than 25 minutes to complete. No identifiable information will be asked in the survey. Upon completion of the survey, you will be emailed a $10 gift card as a token of appreciation for your participation and an executive summary of the final study findings. To receive your electronic gift card and an executive summary kindly provide a current e-mail address upon completion of the survey. Your e-mail address will not be linked with your response or used for any other purpose.

This study has been reviewed by The University of Mississippi's Institutional Review Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or irb@olemiss.edu.

Please follow the link below to start the survey:

By clicking the survey link above you agree that you have read and understand the above information. By completing the survey, you consent to participate in the study.

We thank you for your time in advance and appreciate your contribution to this research. If you have any questions or need more information about the study, please contact Nilesh Gangan.

Sincerely,

Nilesh Gangan, MS	Meagen Rosenthal, Ph.D.	John Bentley, Ph.D.
Ph.D. Candidate	Assistant Professor	Department Chair
Pharmacy Administration	Pharmacy Administration	Pharmacy Administration
The University of Mississippi	The University of Mississippi	The University of Mississippi
School of Pharmacy	School of Pharmacy	School of Pharmacy

Appendix B

Cover letter from third party

Dear Sir/Madam,

Thanks for being a member of Rare Patient Voice. We have an opportunity for you to take part in a '**Caregiver quality of life and support service use' study.** This study is a part of a Ph.D. dissertation project, and is being conducted by researchers at the University of Mississippi – School of Pharmacy. Our project number for this study is **UMS_2201**.

In particular, we are looking for **adult primary informal caregivers (18 years of age and older) caring for patients with Alzheimer's disease or caring for patients below 18 years of age with Autism-spectrum disorder.**

Project Details:

- **Online survey is 20-25 minutes long | $10 Reward**

Things to Note:

- Only primary informal caregiver, i.e., the individual who is most often available to support or assist the care-recipient is invited
- This is a unique link, please do not pass along for a 2nd use
- Survey is Mobile Friendly
- If you have any questions or need more information about the study, please contact Nilesh Gangan.
- This study has been reviewed by The University of Mississippi's Institutional Review Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or irb@olemiss.edu.

If you are interested in this study, please click the link below to start the survey. By clicking the survey link below you agree that you have understood the above information and give your consent to participate in the study.

Thanks as always for your participation! Please be aware that by entering this information you are not guaranteed that you will be selected to participate. As always, we do not share any of your contact information without your permission.

Not interested in this study? (Click link below so we do not send you reminders for this study)

Best Regards,

Wes Michel

Appendix C

Survey

Instructions: This survey has 5 sections from A to E. Please go through each question carefully and choose the best possible answer

Section A: General information

General Instructions: For each of the following questions please answer or check the most appropriate response.

Q1 Are you above 18 years of age?

- o Yes (1)
- o No (2) If No Is Selected, ➡ GO TO THANK YOU PAGE

Q2 What is your current age? _____ years

Q3 What is your biological sex?:

- o Male
- o Female
- o Prefer not to answer

Q4 Which of the following best describes your race or ethnicity?

- o White/Caucasian
- o African American/Black
- o American Indian/Alaska Native
- o Asian
- o Hispanic
- o Native Hawaiian/Other Pacific Islander
- o Other (please specify)

Q5 Which of the following describes your current marital status?

- o Never married
- o Married
- o Divorced
- o Separated
- o Widowed
- o Not married, living with partner

Q6 What is the highest level of education you have completed?

- Less than high school
- High school/GED
- Some college
- 2 year college degree
- 4 year college degree
- Professional degree
- Master's degree
- Doctoral degree

Q7 Which of the following best describes your main occupation?

- Employed/Self-employed full time
- Employed part-time
- Retired
- Home-maker
- Student
- Seeking work
- Other (please specify)

Q8 Please indicate the region of the country in which you reside

- Northeast
- Midwest
- South
- West

Q9 Which of the following best describes the area you reside in?

- Urban
- Suburban
- Rural

Q10 Have you been suffering from any chronic condition in the past 6 month?

- Yes
- No

Q11 Which of the following best describes your relationship with the care-recipient?

- Spouse
- Parent
- Sibling
- Grandparent
- Son/Daughter
- Friend
- Other (please specify)

Q12 The biological sex of your care-recipient is:

- o Male
- o Female

Q13 In what year did you start caregiving for current care-recipient? _____

Q14 Approximately how many hours do you spend in caregiving in a week? _____ Hours

Q15 In the last year, have you used any of these formal services (Check all that apply)

- o Respite care/day care
- o Caregiver training/educational sessions to help take care of care-recipient
- o Support groups for caregivers in the community
- o Other (please specify)

Section B: Quality of life (WHOQOL-BREF – The WHO Group 1998)

Instructions: This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please read each question, assess your feelings, and select the option on the scale that gives the best answer for you for each question.

1. How would you rate your quality of life?

    - o Very poor
    - o Poor
    - o Neither poor nor good
    - o Good
    - o Very Good

2. How satisfied are you with your health?

    - o Very dissatisfied
    - o Dissatisfied
    - o Neither satisfied nor dissatisfied
    - o Satisfied
    - o Very satisfied

The following questions ask about how much you have experienced certain things in the last two weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

- o Not at all
- o A little
- o A moderate amount
- o Very much
- o An extreme amount

4. How much do you need any medical treatment to function in your daily life?

    - o Not at all
    - o A little
    - o A moderate amount
    - o Very much
    - o An extreme amount

5. How much do you enjoy life?

    - o Not at all
    - o A little
    - o A moderate amount
    - o Very much
    - o An extreme amount

6. To what extent do you feel your life to be meaningful?

    - o Not at all
    - o A little
    - o A moderate amount
    - o Very much
    - o An extreme amount

7. How well are you able to concentrate?

    - o Not at all
    - o Slightly
    - o A moderate amount
    - o Very much
    - o Extremely

8. How safe do you feel in your daily life?

    - o Not at all

- Slightly
- A moderate amount
- Very much
- Extremely

9. How healthy is your physical environment?

- Not at all
- Slightly
- A moderate amount
- Very much
- Extremely

10. Do you have enough energy for everyday life?

- Not at all
- A little
- Moderately
- Mostly
- Completely

11. Are you able to accept your bodily appearance?

- Not at all
- A little
- Moderately
- Mostly
- Completely

12. Have you enough money to meet your needs?

- Not at all
- A little
- Moderately
- Mostly
- Completely

13. How available to you is the information that you need in your day-to-day life?

- Not at all
- A little
- Moderately
- Mostly
- Completely

14. To what extent do you have the opportunity for leisure activities?

- o Not at all
- o A little
- o Moderately
- o Mostly
- o Completely

15. How well are you able to get around?

- o Very poor
- o Poor
- o Neither poor nor well
- o Well
- o Very well

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

16. How satisfied are you with your sleep?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

17. How satisfied are you with your ability to perform your daily living activities?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

18. How satisfied are you with your capacity for work?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

19. How satisfied are you with yourself?

- o Very dissatisfied

- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

20. How satisfied are you with your personal relationships?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

21. How satisfied are you with your sex life?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

22. How satisfied are you with the support you get from your friends?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

23. How satisfied are you with the conditions of your living place?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

24. How satisfied are you with your access to health services?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

25. How satisfied are you with your mode of transportation?

- o Very dissatisfied
- o Dissatisfied
- o Neither satisfied nor dissatisfied
- o Satisfied
- o Very satisfied

The follow question refers to how often you have felt or experienced certain things in the last two weeks.

26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

    - o Never
    - o Seldom
    - o Quite often
    - o Very often
    - o Always

Section C: Personality

The Big Five Inventory (BFI) - John, O. P., & Srivastava, S. (1999)

Here are a number of characteristics that may or may not apply to you. For example, do you agree that you are someone who likes to spend time with others? Please indicate the extent to which you agree or disagree with that statement.

I see Myself as Someone Who...	Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
Is talkative	O	O	O	O	O
Tends to find fault with others	O	O	O	O	O
Does a thorough job	O	O	O	O	O
Is depressed, blue	O	O	O	O	O
Is original, comes up with new ideas	O	O	O	O	O
Is reserved	O	O	O	O	O
Is helpful and unselfish with others	O	O	O	O	O
Can be somewhat careless	O	O	O	O	O
Is relaxed, handles stress well	O	O	O	O	O
Is curious about many different things	O	O	O	O	O
Is full of energy	O	O	O	O	O
Starts quarrels with others	O	O	O	O	O

Is a reliable worker	O	O	O	O	O
Can be tense	O	O	O	O	O
Is ingenious, a deep thinker	O	O	O	O	O
Generates a lot of enthusiasm	O	O	O	O	O
Has a forgiving nature	O	O	O	O	O
Tends to be disorganized	O	O	O	O	O
Worries a lot	O	O	O	O	O
Has an active imagination	O	O	O	O	O
Tends to be quiet	O	O	O	O	O
Is generally trusting	O	O	O	O	O
Tends to be lazy	O	O	O	O	O
Is emotionally stable, not easily upset	O	O	O	O	O
Is inventive	O	O	O	O	O
Has an assertive personality	O	O	O	O	O
Can be cold and aloof	O	O	O	O	O

Perseveres until the task is finished	O	O	O	O	O
Can be moody	O	O	O	O	O
Values artistic, aesthetic experiences	O	O	O	O	O
Is sometimes shy, inhibited	O	O	O	O	O
Is considerate and kind to almost everyone	O	O	O	O	O
Does things efficiently	O	O	O	O	O
Remains calm in tense situations	O	O	O	O	O
Prefers work that is routine	O	O	O	O	O
Is outgoing, sociable	O	O	O	O	O
Is sometimes rude to others	O	O	O	O	O
Makes plans and follows through with them	O	O	O	O	O
Gets nervous easily	O	O	O	O	O
Likes to reflect, play with ideas	O	O	O	O	O

Has few artistic interests	O	O	O	O	O
Likes to cooperate with others	O	O	O	O	O
Is easily distracted	O	O	O	O	O
Is sophisticated in art, music, or literature	O	O	O	O	O

Section D: Perceived stress (Perceived Stress Scale - Cohen S, Kamarck T, Mermelstein R, 1983)

Q1 In the last month, how often have you been upset because of something that happened unexpectedly?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q2 In the last month, how often have you felt that you were unable to control important things in your life?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q3 In the last month, how often have you felt nervous and “stressed”?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q4 In the last month, how often have you dealt successfully with irritating life hassles?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q5 In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q6 In the last month, how often have you felt confident about your ability to handle your personal problems?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q7 In the last month, how often have you felt that things were going your way?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q8 In the last month, how often have you found that you could not cope with all the things that you had to do?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q9 In the last month, how often have you been able to control irritations in your life?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q10 In the last month, how often have you felt that you were on top of things?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q11 In the last month, how often have you been angered because of things that happened that were outside of your control?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q12 In the last month, how often have you found yourself thinking about things that you have to accomplish?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q13 In the last month, how often have you been able to control the way you spend your time?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Q14 In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

- o Never
- o Almost never
- o Sometimes
- o Fairly often
- o Very often

Section E: Coping strategies (Brief COPE - Carver CS, 1997)

These items deal with ways you've been coping with the stress in your life since you assumed the responsibility of caregiving. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Q1 I've been turning to work or other activities to take my mind off things.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q2 I've been concentrating my efforts on doing something about the situation I'm in.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q3 I've been saying to myself "this isn't real.".

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q4 I've been getting emotional support from others.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q5 I've been giving up trying to deal with it.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q6 I've been taking action to try to make the situation better.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q7 I've been refusing to believe that it has happened.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q8 I've been saying things to let my unpleasant feelings escape.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount
- o I've been doing this a lot

Q9 I’ve been getting help and advice from other people.

- o I haven't been doing this at all
- o I've been doing this a little bit
- o I've been doing this a medium amount

- I've been doing this a lot

Q10 I've been trying to see it in a different light, to make it seem more positive.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q11 I’ve been criticizing myself.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q12 I've been trying to come up with a strategy about what to do.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q13 I've been getting comfort and understanding from someone.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q14 I've been giving up the attempt to cope.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q15 I've been looking for something good in what is happening.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q16 I've been making jokes about it.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q17 I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q18 I've been accepting the reality of the fact that it has happened.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q19 I've been expressing my negative feelings.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q20 I've been trying to find comfort in my religion or spiritual beliefs.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount

- I've been doing this a lot

Q21 I’ve been trying to get advice or help from other people about what to do.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q22 I've been learning to live with it.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q23 I've been thinking hard about what steps to take.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q24 I’ve been blaming myself for things that happened.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q25 I've been praying or meditating.

- I haven't been doing this at all
- I've been doing this a little bit
- I've been doing this a medium amount
- I've been doing this a lot

Q26 I've been making fun of the situation.

- I haven't been doing this at all
- I've been doing this a little bit

- o I've been doing this a medium amount
- o I've been doing this a lot

Did someone help you to fill out this form?

- o Yes
- o No

Vita

Nilesh Gangan

PERSONAL INFORMATION:

Work Address: Faser Hall Room 128, School of Pharmacy
University of Mississippi
PO Box 1848
University, Mississippi 38677

EDUCATION:

The University of Mississippi (August 2014 - Present)
Doctoral Candidate, Department of Pharmacy Administration (Track: Health Economics and Outcomes Research)
CGPA: 3.9
Relevant coursework: Pharmacoepidemiology, Pharmacoeconomics, Primary data techniques, Secondary data techniques, General linear models, Multivariate data analysis, Longitudinal Data Analysis, Mediation and moderation, Econometrics, Drug development and marketing, Marketing theory, Health economics

University of Toledo
Master of Science (MS) in Health Outcomes and Socio-economic Sciences (August 2011 – Dec 2013)
CGPA: 3.85
Relevant Coursework: Research Methods, Marketing System, Pharmacoeconomics, Biostatistics, Public Health Epidemiology, Econometrics, Analysis of Pharmaceutical Environment, Methods of Survey Research, Introduction to Healthcare Environment

University of Mumbai (August 2006 – May 2010)
Bachelor of Pharmacy (B. Pharm), India

KEY SKILLS:

- Around 5 years of research experience in the field of health outcomes.
- Proficient in Secondary Data Techniques including retrospective analysis of survey databases, electronic health records and administrative claims data

- Possesses a working knowledge of statistical software packages like SPSS, SAS, STATA, and R.
- Proficient in using validation techniques like psychometrics and measurement invariance for patient-reported outcomes (PRO) instruments.
- Experience in using advanced methods for reducing effects of confounding like propensity score matching and inverse probability of treatment weights.

- Experience in economic modeling using TreeAge Pro and Microsoft Excel.
- Well versed in conceptualizing study designs and using advanced statistical techniques.
- Experience in Primary Data Techniques including qualitative interview, cognitive debriefing and content analysis.
- Skilled in conducting systematic reviews and literature searches using online databases.
- Possesses a working knowledge of creating survey in Qualtrics.
- Possesses a good experience in vendor management during internship.

DATABASES:

- **Claims databases**: Mississippi Medicaid, 5% Medicare sample, National Medicaid, Optum, Truven Health MarketScan
- **Public databases:** Medicare Current Beneficiaries Survey (MCBS), Medical Expenditure Panel Survey (MEPS), National Ambulatory Medical Care Survey (NAMCS), Behavioral Risk Factor Surveillance System (BRFSS) and National Health and Trends Survey (NHATS)

WORK EXPERIENCE:

Researcher, Healthcore, Inc., Anthem - **(April 2019 - Present)**

- Design protocols for clients from Pharmaceutical companies in the area of Health economics and outcomes research
- Help in data analysis and interpretation of results using the Healthcore integrated dataset.

Research Analyst, Center for Pharmaceutical Marketing and Management (CPMM), University of Mississippi – **(January 2015 – December 2018)**

- Worked in the Mississippi Medicaid Drug Utilization Review (MS-DUR) initiative as a part of my research assistantship (RA)
- Responsibilities include undertaking ad-hoc MS Medicaid Drug Utilization Review projects that look into patient profiling, treatment patterns, resource utilization, exceptions monitoring, adherence and quality measures using MS Medicaid data.
- Create monthly or quarterly reports for Mississippi Medicaid on medication adherence, resource utilization to help influence policy decisions and provide monthly reports to physicians on patient's performance on quality measures.
- Project highlights:
    - Medication adherence initiative – Built a SAS macro to monthly identify Mississippi Medicaid beneficiaries with COPD or Asthma who are not adherent to controller medications.
    - Opioid use quality measure initiative –
        - Developed a SAS macro to monthly identify Mississippi Medicaid beneficiaries not diagnosed with cancer that take high morphine equivalent dose of opioids for consecutive 30 days and generate a letter to alert the physician.
        - Developed a SAS macro to monthly identify Mississippi Medicaid beneficiaries not diagnosed with cancer that take opioids who are provider shopping and generate a letter to alert the physician.
    - High cost beneficiaries monitoring – Prepared a SAS code to identify beneficiaries with high cost spending for Mississippi Medicaid and predict their spending in the coming year using a risk adjustment model.
    - Mississippi Medicaid performance on HEDIS measures – Developed a SAS macro to calculate the use of multiple concurrent antipsychotic drugs in children.

Graduate Intern (Neuroscience HEOR team), AbbVie, Mettawa, Illinois – **(June 2016 – August 2016)**

- Initiated new studies and worked on ongoing projects to support Duodopa® (Product for Parkinson's disease).
- Attended protocol review meetings to discuss study design and statistical techniques.
- Collaborated with cross-functional teams to understand market strategies and access problems.
- Project highlights:
    - Assessment of treatment in patients with Parkinson's disease
        - Developed a study protocol and statistical analysis plan to improve understanding of treatments in patients with Parkinson's disease.
        - Used Truven Health Market Scan data to assess treatment patterns and adherence to oral therapies.
        - Analyzed the impact of non-adherence to oral therapies on healthcare resource utilization and costs among patients with Advanced Parkinson's disease.
    - Pipeline product market assessment
        - Assisted in generating Real World Evidence using MarketScan commercial claims for understanding market feasibility of a pipeline product.
    - Assessment of caregiver outcomes for patients with Parkinson's disease
        - Assisted in developing a study protocol and statistical analysis plan for understanding the impact of Parkinson's disease symptoms on caregiver-reported outcomes.
        - Co-ordinated with a vendor to ensure completion of statistical analysis.

HEOR Intern, EPI-Q, Inc., Oak Brook, Illinois – **(June 2015 – August 2015)**

- Identified important patient outcomes to be assessed in patients with atrial fibrillation that can be included in an analyzer tool and tested it using electronic healthcare records (EHR).
- Created an interface in MS Excel that would use population level data to give detailed information on epidemiology of a condition.
- Reviewed manuscripts for peer-reviewed journals.

Graduate Teaching Assistant, Pharmacy Management and Methods course, University of Mississippi – **(August 2014 - December 2014)**

- Created a question bank for quizzes and exams.
- Graded all the exams and quizzes.
- Responsible for conducting major announcements and exam review sessions.

Research Assistant, University of Toledo – **(June 2013 to July 2014)**

- Student Investigator on a grant titled "Impact of cardiovascular complications among Type 2 Diabetes patients on healthcare costs, quality of life and mortality" funded by Bristol Myers Squibb (BMS).
- Student Investigator on a grant titled "Comparison of Healthcare Resource Use and Costs in Patients with Type 2 Diabetes Mellitus after Treatment Initiation with Saxagliptin or Sitagliptin" funded by AstraZeneca.
- Developed decision tree model, proposed analysis plans and analyzed claims database (Optum Insights Inc.)
- Conducted training workshops on secondary research and SAS.

Graduate Assistant, College of Pharmaceutical Sciences, University of Toledo **– (August 2011 to May 2013)**

- Proposed study design and analyzed data using large healthcare databases (MCBS, MEPS, NAMCS) using SAS, Stata.
- Assisted in preparing proposals, manuscripts and conducting Qualitative research.

Sales Executive, Blue Cross laboratories Ltd., Mumbai **– (July 2010 to July 2011)**

- Promoted companies' products to physicians and surgeons working in hospitals.
- Conducted free blood sugar and blood pressure check-up in physician's office.
- Conducted CME's for healthcare providers.

RESEARCH EXPERIENCE:

PhD Dissertation topic: "Testing a Modified Model of Stress-Process for understanding Quality of Life among Caregivers and assessing Formal Service Use"

- Assessing psychometric properties and measurement invariance for responses on WHO-QOL BREF among caregivers of patients with Alzheimer's and caregivers of patients with Autism-spectrum disorder.
- Assessing the role of personality in influencing quality of life among caregivers of patients with Alzheimer's and caregivers of patients with Autism-spectrum disorder using moderated mediation analysis.
- Understanding the predictors of formal service use among caregivers of elderly patients with chronic health conditions and its relation to caregiver burden and quality of life.

Master's Thesis: "Identifying factors predicting Primary Medication Non-adherence and its impact on Health services utilization among beneficiaries with Cardiovascular Disease"

- Examined predictors of Primary medication non-adherence behavior in elderly patients newly-diagnosed with cardiovascular disease using Medicare Current Beneficiaries Survey (MCBS) data.
- Propensity score matched groups of adherent and non-adherent patients were compared to assess difference in health service utilization.

Projects:

- **Comparative effectiveness of Coronary Artery Bypass Grafting (CABG) and Percutaneous Coronary Intervention (PCI) in Medicare beneficiaries in terms of costs and Resource Use.**
    - Analyzed national 5% Medicare administrative claims data to compare economic outcomes and resource utilization between the two procedures using generalized linear models.
- **Comparative effectiveness of Coronary Artery Bypass Grafting (CABG) and Percutaneous Coronary Intervention (PCI) in Medicare beneficiaries with End-Stage Renal Disease or Chronic Kidney disease.**
    - Analyzed national 5% Medicare administrative claims data to compare clinical and economic outcomes between a propensity-matched samples undergoing the two procedures.
    - Assessed time to all-cause mortality and time to cardiovascular mortality between the two samples undergoing CABG or PCI.
- **Testing of Pharmacy quality measures in opioid use among Mississippi Medicaid population.**

- Examined the daily Morphine equivalent dosage for beneficiaries on opioid therapy and whether it falls above the level recommended by PQA.
- Assessed the relationship between high morphine equivalent dose and odds of an adverse event such as opioid overdose or mortality.

- **Systematic Review of prevalence, costs, productivity and mortality associated with cardiovascular complications in Type 2 diabetes patients.**

  - This project was a part of a grant funded by Bristol Myers Squibb.
  - Generated search strategy for article search on library databases and created a data inventory for all finalized articles.
  - Made biweekly reports to communicate with BMS team about the progress of the project.
  - Co-authored the manuscript.

- **Comparative effectiveness of Treatment Initiation with Saxagliptin or Sitagliptin in Patients with Type 2 Diabetes Mellitus.**

  - This project was a part of a grant funded by AstraZeneca.
  - Analyzed administrative claims data obtained from Optum Insights to compare healthcare resource use and costs in a propensity score matched patients using Saxagliptin or Sitagliptin.

- **Cost-utility analysis in Hepatitis C Virus Genotype 3 infection: Comparing the new 12-week regimen with other standard therapies.**

  - Designed a Markov simulation model in TreeAge Pro to compare new approved daclatasvir and sofosbuvir combination therapy with other standard therapies for patients with Hepatitis C Genotype 3 infection.

- **Association of HRQoL with HIV testing behavior in a national sample of adult population.**

  - Analyzed BRFSS data to understand the association of HRQoL with HIV testing behavior.

- **Understanding the decision making of student pharmacists for choosing a school of pharmacy.**

  - Conducted qualitative interviews of pharmacy students to understand their decision-making behind choosing school of pharmacy and analyzed it using content analysis.

Publications:

- Vaidya V, Hufstader-Gabriel M, **Gangan N**, Shah S, Bechtol R. Utilization of smoking-cessation pharmacotherapy among chronic obstructive pulmonary disease (COPD) and lung cancer patients. *Current medical research and opinion*. June 2014, 30(6) 1043-1050.
- Vaidya V, Hufstader-Gabriel M, **Gangan N**, Borse M. Characteristics of Prescription and Non-prescription sleep medication users in the United States. *Population Health Management*. December 2014, 17(6): 345-350
- Vaidya V, **Gangan N**, Sheehan J. Impact of Cardiovascular Complications among Patients with Type 2 Diabetes Mellitus: A Systematic Review. *Expert Review of Pharmacoeconomics and Outcomes Research*. May 2015, 15(3) 487-497.

- Vaidya, V, **Gangan, N**, Comerota, A, & Lurie, F. Cost-Effectiveness Analysis of Initial Treatment Strategies for Nonembolic Acute Limb Ischemia Using Real-Word Data. *Annals of vascular surgery* 39 (2017): 276-283.
- **Gangan N**, Yang Y. Impact of Work Absences on Health Services Utilization and Costs among Employed Individuals with depression. *Journal of Occupational & Environmental Medicine*. March 2018 60(3): e139-e145.
- **Gangan N,** Shah R, Yang Y, Bentley JP, Banahan BF. Comparative-effectiveness of Coronary Artery Bypass Grafting (CABG) and Percutaneous Coronary Intervention (PCI) in Medicare beneficiaries in terms of costs and Resource Use**.** (Under review – *Value in Health*)

Podium Presentations:

- **Gangan N**, Vaidya V, Pinto SL, Amialchuk A. Identifying factors leading to Primary Medication Non-adherence and its impact on Health services utilization among beneficiaries with Cardiovascular Disease – Podium presentation at APhA Annual Meeting and Exposition 2014 held in Orlando, Florida.

Poster Presentations:

- **Gangan N**, Stover KR, Barber KE, Pittman E, Banahan BF III, Noble S. Assessing the trends in the use of fluoroquinolones before and after FDA notice of its restricted use in uncomplicated infections. Poster presentation at ISPOR 23rd Annual International Meeting 2018 held in Baltimore, MD. **(Recognized among top 10% of all posters presented at the conference)**
- Inguva S, **Gangan N**, Pittman E, Banahan BF, Noble S. Prescription Opioid Use Before and After An Overdose Event In Mississippi Medicaid. Poster presentation at ISPOR 23rd Annual International Meeting 2018 held in Baltimore, MD. **(Recognized among top 10% of all posters presented at the conference)**
- **Gangan N**, Pittman E, Banahan B III, Noble S. Risk Of Subsequent Migraine Events After Treating Migraine With Opioids Among Mississippi Division of Medicaid Beneficiaries. Poster presentation at ISPOR 23rd Annual International Meeting 2018 held in Baltimore, MD.
- **Gangan N**, Banahan BF, Kirby TR, Noble SL. **Relationship between Performance on the Medication Management for Asthma Quality Measure and Asthma Related Physician Office Visits and Emergency Department Visits – Implications for Quality Improvement Strategies.** Poster presentation at AMCP Nexus meeting 2017 held in Dallas, TX. **(Recognized as Gold medal abstract at the conference)**
- **Gangan N**, Banahan BF III. Relative Risk of Antipsychotic Use in Foster Children Beneficiaries Enrolled in the Mississippi Division of Medicaid (DOM). Poster presentation at ISPOR 22th Annual International Meeting 2017 held in Boston, MA.
- **Gangan N**, Pace P, Dibie C, Banahan BF, Kirby TR, Noble SL. Assessment of Hospitalizations Due to
  Overdose among Mississippi's Division of Medicaid (DOM) Beneficiaries with Opioid Prescriptions. Poster presentation at ISPOR 22th Annual International Meeting 2017 held in Boston, MA. **(Recognized among top 10% of all posters presented at the conference)**
- **Gangan N**, Banahan B. Comparing diagnosis-based and prescription-based comorbidity measures on ability to predict health service utilization and costs - Poster presentation at ISPOR 20th Annual International Meeting 2015 held in Philadelphia, PA.
- **Gangan N**, Yang Y. Health services utilization and costs among employed adults with depression - Poster presentation at ISPOR 20th Annual International Meeting 2015 held in Philadelphia, PA.
- Ramachandran S, **Gangan N**, Bhattacharya K, Shahpurwala Z, Banahan B. GLP-1 Agonist Product Case Study. Poster presentation at the 9th Annual PMRG Institute meeting, October 2015, Philadelphia, PA.

- Vaidya V, **Gangan N**, Sheehan J. Systematic Review of prevalence, costs, productivity and mortality associated with cardiovascular complications in Type 2 diabetes patients – Poster presentation at ISPOR 19th Annual International Meeting 2014 held in Montreal, Canada.
- **Gangan N**, Guduru R, Vaidya V. Factors and costs associated with prescription and non-prescription sleep medication use in the United States – Poster presentation at ISPOR 19th Annual International Meeting 2014 held in Montreal, Canada.
- **Gangan N**, Gangal N, Bechtol R, Vaidya V. Utilization of smoking-cessation agents in patients with Lung Cancer: An Exploratory Study - Poster presentation at ISPOR 18th Annual International Meeting 2013 held in New Orleans, Louisiana.
- Shah S, **Gangan N**, Bechtol R, Vaidya V. Smoking in Chronic Obstructive Pulmonary Disease (COPD) Patients: Socio-demographic factors associated with Smoking-cessation" - Poster presentation at ISPOR 18th Annual International Meeting 2013 held in New Orleans, Louisiana.
- **Gangan N**, Gangal N, Shah S, Pinto SL. Tools used to improve Medication Adherence: A Systematic Review – Poster presentation at ISPOR 18th Annual International Meeting 2013 held in New Orleans, Louisiana.

Manuscript Review:

Occasional reviewer for *Journal of clinical psychopharmacology*.

ADDITIONAL TRAINING:

October 2012 – January 2013: Successfully completed an online course titled 'Health in Numbers: Quantitative Methods in Clinical and Public Health Research' offered by Harvard School of Public Health

PROFESSIONAL AFFILIATIONS AND RESPONSIBILITIES:

- Initiated into Phi Kappa Phi honor society (2016)
- Initiated into Rho Chi honor society (2016)
- Member of Survey Evaluation Committee in International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Student Network (2016-2017)
- President of International Society for Pharmacoeconomics and Outcomes Research (ISPOR) University of Mississippi student chapter (2016-2017)
- Vice-President of International Society for Pharmacoeconomics and Outcomes Research (ISPOR) University of Mississippi student chapter (2015-2016)
- Secretary of International Society for Pharmacoeconomics and Outcomes Research (ISPOR) University of Toledo student chapter (2012-2013)
- Member of PMRG student chapter (2014-2016)
- Member of Indian Pharmaceutical Association-Students Forum (2007-2008)
- Registered Pharmacist: Maharashtra State Pharmacy Council

AWARDS:

- Phi Kappa Phi Scholarship
- University of Mississippi Dissertation Fellowship 2018
- MME Fellowship 2017 – 2nd student to win the award
- Gold medal abstract – AMCP Nexus 2017
- ISPOR Travel Grant recipient: Student travel grant for attending ISPOR 22th Annual International Meeting 2017 held in Boston, MA.