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Family Caregivers of Persons with Frontotemporal Dementia:  
Factors Associated with Caregiver Mental and Physical Health

by

Cindy C. Wong

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

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of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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by

Cindy C. Wong, RN, PhD

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Family Caregivers of Persons with Frontotemporal Dementia:  
Factors Associated with Caregiver Mental and Physical Health

Cindy C. Wong, RN, PhD

Abstract

Individuals with the behavioral variant of frontotemporal dementia (bvFTD) commonly manifest a wide range of different behavioral problems and neuropsychiatric symptoms (Snowden et al., 2001). Therefore, providing informal support to someone with bvFTD could be particularly stressful. It is important to acknowledge the well-being and contributions of bvFTD family caregiver. Currently, however, there is a paucity of research on the unique experiences of FTD family caregivers.

The purpose of this dissertation is to identify factors associated with the mental and physical health of FTD family caregivers. This dissertation will be presented as three publishable papers which are based on findings from a cross-sectional, correlational study on family caregivers of persons with FTD (with behavioral problems). Participants completed a set of questionnaires, which were submitted anonymously by standard mail. Data on 61 family caregivers were collected and analyzed.

The first paper focuses on the relationship between coping and caregiver health. This paper examines the coping strategies used by caregivers in response to patient neuropsychiatric symptoms and/or behavioral problems. Emotion-focused coping was positively associated with caregiver mental health, and problem-focused coping was positively associated with caregiver physical health.

The second paper focuses on the relationship between perceived control and caregiver health. There was not a statistically significantly correlation between perceived

control and caregiver physical health. However, there was a strong, positive association between perceived control and caregiver mental health, suggesting that caregivers with greater perceived control tend to report better mental health.

The third paper focuses on the relationship between the severity of patient symptoms and/or behavioral problems and caregiver health. There was not a statistically significant relationship between caregiver physical health and patient symptoms. However, patient symptom severity was negatively associated with caregiver mental health. Caregiver emotional distress from patient symptoms/behavioral problems was negatively associated with caregiver mental health.

These findings reinforce the importance of examining the self-perceptions and unique needs of FTD family caregivers. The critical role of dementia family caregivers and the demands that they experience cannot be overlooked. Future qualitative studies on FTD family caregivers would be invaluable in providing a more in-depth understanding of their caregiving experiences.

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## Table of Contents

Chapter 1. Introduction.....	1
Chapter 2. Examining the Relationship between Coping and Caregiver Physical and Mental Health.....	18
Chapter 3. The Relationship between Perceived Control and Caregiver Mental and Physical Health.....	55
Chapter 4. The Relationship between Patient Symptom Severity and Caregiver Physical and Mental Health.....	79
Chapter 5. Summary and Conclusions.....	109

## List of Tables

Chapter 2. Examining the Relationship between Coping and Caregiver Health	
Table 1. Emotion-Focused, Problem-Focused, and Dysfunctional Coping Strategies.....	26
Table 2. Caregiver and Patient Categorical Demographic Variables.....	31
Table 3. Caregiver and Patient Quantitative Variables.....	32
Table 4. Means and Standard Deviations for Brief COPE Scale.....	33
Table 5. Correlations between Coping and Caregiver Health Variables.....	35
Table 6. Summary of Multiple Regression Analyses.....	37
Chapter 3. The Relationship between Perceived Control and Caregiver Health	
Table 1. Caregiver and Patient Demographic Variables.....	65
Table 2. Correlations between Perceived Control and Other Variables.....	67
Table 3. Means and Standard Deviations for Self-Report Measures.....	67
Chapter 4. The Relationship between Patient Symptom Severity and Caregiver Health	
Table 1. Additional Neuropsychiatric Symptoms.....	87
Table 2. Demographic Characteristics, Neuropsychiatric Inventory Questionnaire (NPI-Q), and Caregiver Health.....	89

Table 3. Means and Standard Deviations for NPI-Q and Additional Neuropsychiatric Symptoms.....	90
Table 4. Correlations between Self-report Measures: NPI-Q, Additional Neuropsychiatric Symptoms, and Caregiver Health.....	93

**List of Figures**

Chapter 2. Examining the Relationship between Coping and Caregiver Health	
Figure 1. Mean Scores for Individual Coping Strategies.....	34
Chapter 4. The Relationship between Patient Symptom Severity and Caregiver Health	
Figure 1. Frequency of Neuropsychiatric Symptoms from NPI-Q.....	91
Figure 2. Frequency of Additional Neuropsychiatric Symptoms.....	92

# **Chapter 1**

## Introduction

## **Introduction**

Family caregivers are individuals who participate in the care of a relative or loved one usually without pay (Family Caregiver Alliance, 2005). They manage a wide range of responsibilities to provide emotional support and assistance to patients with daily activities such as showering and dressing, coordinating appointments, managing medications, and/or preparing meals. About 44 million Americans 18 years of age and older provide such unpaid support and assistance to community-dwelling older adults with disabilities (National Alliance for Caregiving & AARP, 2004). The value of this unpaid help is estimated to be at least \$306 billion annually (National Family Caregivers Association & Family Caregiver Alliance, 2006). The terms *family caregiver* and *informal caregiver* are often used interchangeably; however, the former will be used throughout this dissertation for consistency. It is important for healthcare providers to acknowledge the needs and contributions of family caregivers. This becomes especially salient given that many family caregivers experience worse health as a result of their caregiving role (Barrow & Harrison, 2005; Lee, Corlditz, Berkman, & Kawachi, 2005; Thompson, 2004).

### **Dementia Caregiving**

Worldwide, approximately 25 million people were reported to be affected with dementia in 2000, with 114 million cases projected by 2050 (Wimo, Winblad, Agüero-Torres, & Strauss, 2003). Symptoms of dementia may include wandering or pacing, resisting care, screaming, depression and psychosis and may present a number of challenges for family caregivers (Buhr & White, 2006). Dementia onset has been found

to be associated with an increased risk of hospitalization among care recipients 65 years of age or older (Phelan et al., 2012), and the behavioral and psychological symptoms of dementia have been shown to be risk factors for nursing home placement of care recipients (Steele, Rovner, Chase, & Folstein, 1990).

Dementia family caregivers perform a critical function in providing care for older adults with dementia at home; however, the behavioral and psychological symptoms of dementia have been found to predict caregiver psychological distress, depression and burden of care (Black & Almeida, 2004). It is important to understand factors affecting the health and well-being of dementia caregivers so targeted interventions can be initiated before the development of physical and mental health problems, such as depression. Dementia is a very broad and heterogeneous entity; therefore, it is important to consider how various types of dementia, which present differently, impact the experiences and emotional well-being of family caregivers.

### **Family Caregivers of Persons with Frontotemporal Dementia**

Frontotemporal dementia (FTD) is a group of syndromes that are manifested due to pathology in the frontotemporal lobes of the brain (Neary et al., 1998). FTD syndromes can be categorized into progressive aphasia or behavioral disturbances (Grossman, 2002). Three common syndromes of FTD include behavioral variant of FTD (bvFTD), semantic dementia (SD), and progressive nonfluent aphasia (PFNA; Hodges & Miller, 2001; Mohandas & Rajmahan, 2009). Patients with bvFTD usually present with a wide range of behavioral problems and neuropsychiatric symptoms, including social avoidance and awkwardness, personal neglect, overeating, wandering, and an unusual

preference for sweet foods or carbohydrates (Snowden et al., 2001). SD is characterized by an impaired ability to understand written and spoken words or recognize familiar objects and faces (Neary et al., 1998; Tolnay & Probst, 2001). PNFA is a disorder of language expression and non-fluent, effortful spontaneous speech, characterized by word retrieval difficulties, reading and writing problems, and grammatical errors (Neary et al., 1998).

Providing care for someone with FTD could be particularly stressful and distressing for the family caregiver. Bristow and colleagues (2008) studied the psychological and physiological impact of caring for a partner with FTD (FTD caregivers = 25, non-caregivers = 36) and found that FTD caregivers reported poorer mental health ( $t_{57} = 3.32, p = 0.002$ ), more perceived stress over the preceding month ( $t_{57} = 2.74, p = 0.008$ ), and significantly greater daily stress ( $t_{38.23} = 2.77, p = 0.008$ ); counter to the authors' expectations, however, there were no statistically significant differences between caregivers and non-caregivers in satisfaction with emotional support ( $t_{56} = 0.73, p > .05$ ), satisfaction with practical support ( $t_{37.91} = 1.62, p > .05$ ), and levels of mucosal immunity ( $t_{44} = 0.22, p > .05$ ; Bristow, Cook, Erzinclioglu, & Hodges, 2008). Nevertheless, these results suggest that caring for someone with FTD may contribute to increased caregiver stress and psychological distress and highlight the importance of focusing on strategies to prevent or reduce the negative consequences of caring for someone with FTD.

In an international survey to understand the needs of FTD caregivers, 52% of respondents reported that the most troubling aspect of FTD caregiving was "Not knowing

that it was a dementia or some other kind of neurological impairment” (p. 755), and 43% of the respondents reported “difficulty in acquiring a diagnosis” (p. 755) as a concern (Chow, Pio, & Rockwood, 2011; *N* = 78). Furthermore, more than 40% of respondents had difficulty in getting a correct patient diagnosis, and 27% of respondents reported that the most unexpected aspect of FTD caregiving was the fact that dementia may also affect younger individuals (Chow, Pio, & Rockwood, 2011; *N* = 64). In spite of these findings, additional data is needed to understand determinants of positive or negative mental and physical health outcomes among families providing care to someone with FTD.

It is important to understand factors associated with the mental and physical health of FTD family caregivers in order to promote caregiver health and alleviate caregiver emotional distress. Therefore, this dissertation research will focus on various factors related to the mental and physical health of families providing care for someone with FTD with behavioral problems. These specific factors include caregiver coping strategies, perceived control, and patient neuropsychiatric symptoms and/or behavioral problems.

In the next section, the theoretical underpinnings of this dissertation research will be presented. An introduction to the Family Life Course Development Framework will be provided, followed by a description of one of its theoretical variants, the life course theory. Pertinent background information about the life course theory will be discussed, including its five principles as described by Elder (1999).

## **Theoretical Framework**

### **Family Life Course Development Framework**

The life course has been defined as a “multilevel phenomenon, ranging from structured pathways through social institutions and organizations to the social trajectories of individuals and their developmental pathways” (Elder, 1994, p. 5). The family life course development framework focuses on the systematic changes that families experience as they progress through various life events and stages, including the constantly changing social roles and membership structure of a family over time (White & Klein, 2008). In addition, this general theoretical framework is concerned with family factors affecting an individual’s ontogenetic (or physiologic) development, in addition to family and individual changes within a larger framework of birth cohort, historical period, and individual age factors (White & Klein, 2008).

Three theoretical approaches to the family life course development framework have been described: individual life span, family development, and life course theory (White & Klein, 2008). The life span development theory is from the field of psychology, and the life course theory is a sociological approach. The next section will focus on the life course theory, which could be viewed as one variant of the life course development framework. The life course theory will be integrated with the life course development framework to provide a contextualize approach to studying FTD family caregivers.

### **The Life Course Theory**

The life course theory focuses on the historical events a person experiences and how earlier events influence outcomes later in life, such as a divorce (White & Klein,



2008). The life course perspective allows one to study families and individuals over time within a single generation and across the historical contexts of repeated generations (Elder, 1977; Elder, Johnson, & Crosnoe, 2003). Therefore, this theoretical perspective involves a dynamic, contextual approach to studying how families change over time (Bengtson & Allen, 1993).

The decisions and actions of FTD family caregivers, for instance, cannot be fully understood by focusing exclusively on a specific *life stage*, which is an interval of time with a distinct structure and pattern of interactions between family members that may be qualitatively different from other time periods (White & Klein, 2008). *Transitions* represent shifts from one life stage to another life stage (White & Klein, 2008). A *family life course* is composed of all of the events and stages (time periods between events) experienced by families and refers to the notion that current life stages are affected by the past (White & Klein, 2008). The *normative age-graded* life course refers to the expected changes in the psychological and biological aspects of aging individuals, as well as the typical changes in social roles, tasks, and settings (Elder, 1999). *Non-normative* influences are unexpected events which occur out of synchrony, and *normative history-graded* influences are socio-historical events occurring within a larger social context (Rankin, 2000). This theoretical approach suggests that the evaluation of one's life course and significant non-normative and normative history-graded influences (e.g., World War) is necessary to fully appreciate the experiences of FTD family caregivers.

The life course perspective has been used in previous caregiving studies (e.g., Moen, Robison, & Dempster-McClain, 1995). For instance, Ward-Griffin et al. (2007)

conducted an interpretive descriptive study, guided by feminist and life-course perspectives, to better understand the caregiving and care-receiving experiences of adult daughters and their mothers with cognitive impairment ( $N = 15$ ). Using a life-course perspective highlights the evolving social interactions between these daughters and mothers and assumes that the meaning of caregiving and care receiving is based on a lifetime of experiences (Ward-Griffin et al., 2007). Results from this study revealed four dynamic types of mother-daughter relationships: custodial, combative, cooperative, and cohesive (Ward-Griffin et al., 2007). Custodial and cooperative mother-daughter relationships are primarily concerned with the provision and receipt of various caregiving tasks, whereas cohesive and combative relationships are more emotion-focused (Ward-Griffin et al., 2007). This study also found that certain contextual factors, such as expectations of caregiving and levels of support, shaped the development of these mother-daughter relationships (Ward-Griffin et al., 2007).

### **Human Development and Aging as Life-Long Processes**

Elder (1999) describes five principles of the life course theory to provide guidance for future research in aging. The first principle states that “human development and aging are life-long processes” (Elder, 1999, p. 7). This principle highlights the importance of examining early influences, actions, and behavioral patterns throughout an individual’s life course.

The life course view also acknowledges “that timing and sequencing norms are affected by and change with historical period, the age of the individual experiencing events, and the norms carried by the birth cohort” (White & Klein, 2008, p. 140). Also,

“age variations in expectations and options that impinge on decision making and the course of events give shape to life stages, transitions, and turning points” (Elder, 1977, p. 282). FTD family caregivers experience different course of events and have different expectations and opportunities as they grow older, which all influence their behaviors and the choices they make.

### **Principle of Historical Place and Time**

The principle of historical place and time underscores the importance of appreciating the socio-historical context of an individual’s upbringings. “The life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime” (Elder, 1999, p. 13). Consequently, it is imperative to acknowledge how environmental factors (e.g., neighborhood characteristics) and significant historical events (e.g., Vietnam War, Civil Rights Movement) may impact the caregiving experiences and health and well-being of FTD family caregivers.

### **The Timing Principle**

The timing principle asserts “The developmental antecedents and consequences of life transitions, events, and behavior patterns vary according to their timing in a person’s life” (Elder, 1999, p. 9). For instance, depression could be linked to low income and unemployment in young and middle aged FTD family caregivers who may still be juggling multiple caregiving roles, but impaired physical health may be a prominent predictor of depression among older retired caregivers. In fact, the “timing of an event may be as important for life experience as whether the event occurs at all” because age-related differences in expectations, course of events, and opportunities that influence

decision-making help shape an individual's life course (Elder, 1977, p. 282). Hence, the impact of significant socio-historical events (e.g., The Great Depression) may vary depending on where individuals were situated in their life course during that particular event (Elder, 1977).

### **The Principle of Linked Lives**

The principle of linked lives postulates “Lives are lived interdependently and social-historical influences are expressed through this network of shared relationships” (Elder, 1999, p.10). The life course theory acknowledges that caregivers are typically embedded within social relationships across the life span (Elder, 1994). In addition, social support, norms, and expectations are transmitted through the interactions and relationships that FTD family caregivers develop with other individuals.

### **Human Agency**

The principle of human agency assumes “Individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstances” (Elder, 1999, p. 15), suggesting that FTD family caregivers may have some degree of control over their life course through the decisions they make and actions they take. However, careful and meticulous planning and competence may still produce little or insignificant changes in one's life course if the present and future are disrupted by unexpected events and socio-cultural changes.

### **Summary of Life Course Theory**

Overall, the life course theory acknowledges the multidimensional and interdependent nature of an individual's life course (since progression through life stages

involves relationships with other people and multiple roles), appreciates influential socio-historical events throughout one's lifetime, and provides insight as to how individuals change and grow over time (Elder, 1977). When studying the experiences of FTD family caregivers, it is particularly important to examine how the caregivers' age, expectations, opportunities, and relationship to the patient influences the caregivers' behaviors and health outcomes. FTD usually affects younger individuals between 45 to 65 years of age (Mohandas & Rajmohan, 2009; Weder et al., 2007), so spousal caregivers of people with FTD may be required to provide care at an earlier time in their life than caregivers of persons with late-onset Alzheimer's disease (AD). In addition, many spousal caregivers providing care for someone with FTD may still be in the workforce and raising young adult children at home. Consequently, the caregiving experiences of FTD family caregivers may differ from caregivers of persons with late-onset dementia (e.g., AD) due to differences in age, family and work roles and responsibilities, and prior life experiences. The life course theory underscores the importance of examining how caregiver age, previous life experiences, and contextual and situational factors influence the health and well-being of FTD family caregivers.

## **Dissertation Aims**

The goal of this dissertation is to identify factors associated with the mental and physical health of FTD family caregivers. This dissertation will be divided into five chapters.

Chapter 1 provides an introduction to family caregiving and presents some background information about individuals with frontotemporal dementia (FTD) and their family caregivers. In addition, the theoretical underpinnings of this dissertation research are described.

Chapter 2 presents the findings of a cross-sectional, correlational research study to examine the relationship between coping and the mental and physical health of FTD family caregivers. This study also examines gender differences in coping and different coping strategies used by caregivers in response to patient neuropsychiatric symptoms and/or behavioral problems.

Chapter 3 focuses on the relationship between perceived control and the mental and physical health of FTD family caregivers. Moreover, this study examines the impact of perceived control on caregiver mental health above and beyond the influence of patient symptom severity, caregiver age, and caregiver gender.

Chapter 4 presents the findings on the relationship between the severity of neuropsychiatric symptoms and/or behavioral problems in FTD patients and the health of their family caregivers. This chapter also describes the frequency of different symptoms/behavioral problems exhibited by patients with FTD and the relationship

between caregiver emotional distress from patient symptoms and/or behavioral problems and caregiver mental and physical health.

Chapter 5 summarizes the findings that are presented in this dissertation. This chapter provides a discussion of the clinical, theoretical, and policy implications of this research on FTD family caregivers. Recommendations for future FTD caregiving research are also discussed.

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## **Chapter 2**

Family Caregivers of Persons with Frontotemporal Dementia:

Examining the Relationship Between Coping and

Caregiver Physical and Mental Health

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## Abstract

The purpose of this cross-sectional study was to examine the relationship between the different coping strategies used by family caregivers of persons with frontotemporal dementia (FTD) and caregiver physical and mental health. Participants were primary caregivers of persons with FTD (with behavioral problems) living at home ( $N = 61$ ). There was a small positive association between problem-focused coping and caregiver physical health ( $r = .29, p < .05$ ) and a small but nonsignificant positive correlation between emotion-focused coping and caregiver mental health ( $r = .21, p = .10$ ). However, multiple regression analysis showed that emotion-focused coping ( $\beta = 0.46, p < .05$ ) made a statistically significant, unique contribution to caregiver mental health and explained approximately 14% of its variance. These findings support the potential value of emotion-focused coping strategies when dealing with patient behavioral problems and neuropsychiatric symptoms. Further study of FTD caregivers is needed to examine the longitudinal effect of individual coping strategies.

Keywords: dementia caregiving, coping, caregiver health, frontotemporal dementia

## **Background**

Frontotemporal dementia (FTD) encompasses a heterogeneous group of progressive neurodegenerative syndromes that usually affect individuals between 45 and 65 years of age (Mohandas & Rajmohan, 2009; Weder, Aziz, Wilkins, & Tampi, 2007). At present, FTD is the third most common type of degenerative dementia, following Alzheimer's disease and dementia with Lewy bodies (Mohandas & Rajmohan, 2009). Unlike Alzheimer's disease, whose hallmark is memory problems, FTD presents with these common, early symptoms: social awkwardness, loss of executive function, passivity, and disinhibition (Lindau et al., 2000).

Providing care for someone with behavioral variant of frontotemporal dementia (bvFTD) can be particularly challenging and overwhelming because such patients usually present with a broad range of behavioral and neuropsychiatric symptoms, such as social avoidance and awkwardness, personal neglect, overeating, wandering, and an unusual preference for sweet foods and carbohydrates (Snowden et al., 2001). The direct cost of caring for a person with FTD has been reported to be \$4,924 per year (Rojas et al., 2011), and comparative studies of family caregivers of persons with FTD and Alzheimer's disease suggest that the former experience greater burden and distress (Boutoleau-Bretonnière, Vercelletto, Volteau, Renou, & Lamy, 2008; De Vugt et al., 2006; Riedijk et al., 2006).

Negative outcomes caused by caregiving for someone with FTD could be minimized by using effective coping strategies. However, previous studies of caregiving have not focused on the coping strategies that FTD family caregivers use to alleviate their

distress. To identify specific strategies to assist family caregivers of persons with FTD in dealing with the demands they experience, researchers must understand their perceptions, unique needs, and how they currently deal with their demands. Further, a comprehensive understanding of the association between coping strategies and the physical and mental health of such family caregivers could inform theory, increase collaboration among researchers and clinicians, and assist in the development of targeted caregiver interventions focusing on effective coping strategies in different caregiving situations.

### **Theoretical Conceptualization of Coping**

The transactional theory of stress and coping, developed by Lazarus and Folkman (Lazarus & Folkman, 1984; Lazarus, 1991), postulates a dynamic and bidirectional relationship between an individual and his or her environment. *Cognitive appraisal* and *coping* are conceptualized as mediators of the stressful person-environment relationship (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Folkman, 1984). Thus, determining whether a person-environment relationship is stressful depends on how an individual appraises his or her situation. If the individual appraises the person-environment transaction as exceeding available resources, he or she may use coping strategies (i.e., cognitive and behavioral efforts) to manage or minimize the demands (Folkman et al., 1986). Assessing coping responses entails an examination of what individuals think and do in a given situation and what changes occur in these thoughts and actions as an encounter unfolds.

## **Coping Strategies**

Coping strategies have been defined as environmentally-attuned efforts that depend on available resources for meeting various caregiving demands (Livneh & Martz, 2007). Emotion-focused coping is primarily cognitive and directed at decreasing emotional distress (e.g., distancing oneself, positive reappraisal, and accepting responsibility for one's actions; Lazarus & Folkman, 1984). Problem-focused coping strategies aim to manage problems that cause distress (e.g., rational and deliberate efforts to solve problems and assertive interpersonal efforts to change a situation; Lazarus & Folkman, 1984). The effectiveness of coping strategies varies depending on the specific stressor, the type of caregiving situation, and individual cultural values and beliefs of what is deemed "functional" and "dysfunctional" coping (Lazarus & Folkman, 1984). Because severe behavioral problems are common in persons with bvFTD, this study focused on the coping strategies that their family caregivers use in response to patient behavioral and neuropsychiatric symptoms.

### **Purpose of Study and Hypotheses**

The purpose of this study was to examine the relationship between the coping strategies used by FTD family caregivers in response to patient behavioral and neuropsychiatric symptoms and the caregivers' physical and mental health. Our hypotheses were the following:

1. Problem-focused coping will be associated with more positive caregiver physical and mental health.
2. Emotion-focused coping will be associated with more positive caregiver



physical and mental health.

3. Dysfunctional coping will be associated with more negative caregiver physical and mental health.

## **Methods**

### **Recruitment and Sample**

Potential participants were recruited between June 2011 and November 2011 by means of convenience and snowball sampling. During the recruitment period, information on the study was included in the newsletters and on the website (<http://www.theaftd.org/>) of the Association for Frontotemporal Degeneration. Snowball sampling was used to recruit additional individuals: Initial participants referred other FTD family caregivers to the study by providing them with the Co-Principal Investigator's contact information (CW). Potential participants were also recruited from FTD Caregiver Support Groups in Portland, Oregon, and San Francisco.

Participants were primary family caregivers of a person diagnosed with FTD and exhibiting behavioral problems. To be included in the study, a caregiver had (a) to identify themselves as *the* family member who is primarily responsible for the patient's care; (b) to live with the patient; (c) to have provided care to the patient for at least 6 months; (d) to receive no financial compensation for caregiving; (e) to speak, read, and understand English; and (f) to be 18 years of age or older. If more than one caregiver was involved in the patient's care, the family caregiver providing most of the care was selected. The eligibility criterion for patients was a diagnosis of FTD with behavioral problems, as reported by his or her caregiver.

Data on 61 caregivers were collected and analyzed. Six caregivers who expressed interest in the study were deemed ineligible to participate and to complete the study questionnaires because they were providing care to someone in a nursing home or other institution. Eight other caregivers who expressed interest in the study were deemed ineligible to participate and to complete the study questionnaires because their patient had died prior to enrollment.

### **Procedures and Ethical Considerations**

The family caregivers accepted into the study completed a set of questionnaires that elicited their observations of the patient, their own general physical and mental health, coping strategies, their relationship with the patient, and their experiences as a caregiver of someone with FTD. On receipt of the questionnaires, participants had the option of receiving a Safeway gift card (\$5.00) in appreciation of their efforts. Participants completed the questionnaires on their own time in a convenient location. The questionnaires, which took roughly 30 min to complete, were submitted anonymously by standard mail.

The University of California, San Francisco's Committee on Human Research approved this study of human subjects. In an introductory letter, participants were notified that consent would be implied if they completed and submitted the survey. However, all participants were given an informed consent document that provided detailed information on this study, such as the study's purpose, procedures, and risks.

## Measures

**Coping strategies.** The Brief COPE Scale, a 28-item self-report questionnaire that measures 14 conceptually different coping reactions, was used to assess the participants' coping reactions (Carver, 1997). The scale's instructions were modified for this study to ensure that caregivers reported the coping strategies that they use in response to patient neuropsychiatric and/or behavioral symptoms. Response options range from 0 (*"I haven't been doing this at all"*) to 4 (*"I've been doing this a lot"*). Two items correspond to each coping strategy. Total scores for the Brief COPE range from 0 to 112; scores for each coping strategy range from 0 to 8.

Cooper, Katona, and Livingston (2008) examined the psychometric properties of the Brief COPE Scale and its emotion-focused, problem-focused, and dysfunctional subscales in a sample of dementia caregivers ( $N = 125$ ). They found good internal consistencies for the emotion-focused, problem-focused, and dysfunctional subscales,  $\alpha = .72$ ,  $\alpha = .84$ , and  $\alpha = .75$  respectively. Test-retest reliability (over a year) has been shown for the emotion-focused ( $r = .58$ ), problem-focused ( $r = .72$ ), and dysfunctional coping ( $r = .68$ ) subscales among caregivers in whom burden scores did not change significantly ( $p < .001$ ; Cooper et al., 2008). Furthermore, an exploratory factor analysis yielded a factor structure that was consistent with the full COPE (Carver, 1997), and evidence of concurrent and convergent validity has been shown in regression analyses (Cooper et al., 2008). In this sample, Cronbach alphas were  $\alpha = .80$  for emotion-focused,  $\alpha = .66$  for problem-focused, and  $\alpha = .62$  for dysfunctional coping strategies.

Table 1

*Emotion-Focused, Problem-Focused, and Dysfunctional Coping Strategies*

Coping Strategy	Definition
<b>Emotion-focused coping</b>	
Emotional support	Getting sympathy, moral support, or understanding from others.
Religion	Trying to seek comfort through religion or spiritual beliefs. This may include using prayer or meditation to find comfort.
Positive refraining	Trying to see the situation in a different light to make it more positive. This includes looking for something positive in a stressful situation.
Humor	Making jokes or fun of a situation.
Acceptance	Accepting the reality of a stressful situation and learning to live with it.
<b>Problem-focused coping</b>	
Active coping	Taking steps to remove the stressor or decrease its effects, such as initiating direct action to solve a problem.
Planning	Considering how to cope with a particular stressor, such as devising action strategies and deciding how best to handle a problem.
Instrumental support	Seeking advice, information, or assistance from others.
<b>Dysfunctional coping</b>	
Self-distraction	Attempting to keep one's mind off of a stressful situation by turning to work or other activities.
Denial	Refusing to believe the reality of a situation.
Venting	Focusing on whatever distress someone is experiencing and ventilating those feelings.
Substance use	Using alcohol and/or other drugs to seek comfort.
Behavioral disengagement	"Reducing one's effort to deal with the stressor, even giving up the attempt to attain goals with which the stressor is interfering" (Carver et al., 1989, p. 269).

*Note.* Adapted from: "Assessing coping strategies: A theoretically based approach," by C. S. Carver, M. F. Scheier, and J. K. Weintraub, 1989, *Journal of Personality and Social Psychology*, 56, 267-283.

Table 1 describes the 14 coping strategies assessed in the Brief COPE. In this study, coping strategies were categorized into the three coping subtypes suggested by

Cooper et al. (2008). Emotion-focused coping strategies are aimed at reducing the emotional distress associated with a situation (Carver, Scheier, & Weintraub, 1989). The emotion-focused subscale includes acceptance, emotional support, humor, positive reframing, and religion. Problem-focused coping strategies are aimed at problem solving or doing something to change the source of stress (Carver et al., 1989). Problem-focused coping strategies include active coping, instrumental support, and planning. The dysfunctional subscale includes coping strategies that are believed to exacerbate caregiver distress (Carver et al., 1989). Dysfunctional coping strategies include behavioral disengagement, denial, self-distraction, self-blame, substance use, and venting.

**Caregiver relationship satisfaction.** The Couples Satisfaction Index (CSI-4; Funk & Rogge, 2007) was used to assess the caregivers' level of satisfaction with their relationship to the patient. The CSI-4 is a 4-item measure that is designed to assess relationship satisfaction between couples (Funk & Rogge, 2007). As appropriate, the word *partner* was replaced with *care recipient* to make this measure applicable to nonspousal caregivers. Total possible scores range from 0 to 21; higher scores indicate better relationship satisfaction. Principal component analysis and item response theory were applied to a larger pool of items to develop the CSI-4 scales (Funk & Rogge, 2007). The CSI-4 has shown excellent internal consistency ( $\alpha = .94$ ) in addition to higher precision of measurement (less noise) and greater power for detecting differences in levels of satisfaction when compared with other well-validated, relationship satisfaction measures (Funk & Rogge, 2007). Furthermore, the CSI-4 has shown strong construct and

convergent validity with existing measures of relationship satisfaction (Funk & Rogge, 2007).

**Patient neuropsychiatric symptoms.** The Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer et al., 1998; Kaufer et al., 2000) was used to assess 12 neuropsychiatric disturbances common in patients with dementia: aberrant motor behavior, agitation, anxiety, apathy, appetite and eating disorders, delusions, disinhibition, dysphoria/depression, euphoria, hallucinations, irritability, and night-time behavior disturbances. The NPI-Q was cross-validated and adapted to the standard NPI (Cummings et al., 1994; Cummings, 1997) to provide a quantitative measure of patient symptom severity and caregiver distress in relation to specific neuropsychiatric disturbances (Kaufer et al., 1998). The total symptom severity score ranges between 0 and 36; higher scores reflect greater severity of patient neuropsychiatric symptoms. The total caregiver distress score ranges between 0 and 60; higher scores reflect greater caregiver distress in relation to patient symptoms. The reliability and validity of this measure has been previously established in two studies (Kaufer et al., 1998, 2000).

**Caregiver and patient demographic characteristics.** The collected demographic characteristics of caregivers and patients included age, gender, race/ethnicity, and primary language. Also collected was information about the caregivers' relationship to the patient (e.g., spouse versus children); income (total household income before taxes in 2010); the number of years the caregiver has known the patient; and the number of years the caregiver has been providing care to the patient.

**Caregiver physical and mental health.** The physical and mental health component scores from the 12-Item Short-Form Health Survey (SF-12) were used to assess the caregivers' physical and mental health status (Ware, Kosinski, & Keller, 1996). The SF-12 was derived from the 36-Item Short-Form Health Survey, which is a generic health measure that is applicable to a variety of settings (Ware & Gandek, 1998; Ware & Sherbourne, 1992). The reliability estimates for the physical and mental component scores on the SF-36 usually exceeded .90; evidence of validity for the physical and mental health components has been previously established (Ware, Kosinski, & Keller, 1994). The SF-12 can be self-administered or given by a trained interviewer in person or by telephone. Test-retest (2-week) correlations for the 12-item Physical Component Summary (PCS) and Mental Component Summary (MCS) were found to be .89 and .76, respectively, in the general U.S. population ( $N = 232$ ; Ware, Kosinski, & Keller, 1996). Furthermore, the SF-12's two summary scales (physical health and mental health), originally developed from the SF 36, have been shown to have good accuracy and less respondent burden (Jenkinson & Layte, 1997).

### **Data Analysis**

SPSS version 19.0 was used for all data analyses. For the quantitative variables of interest, means were used to assess central tendency, and standard deviations were used to assess dispersion. Frequencies and percentages were calculated to assess and to describe categorical data. To assess the magnitude and direction of the relationships between the quantitative variables of interest (e.g., different coping subtypes and caregiver physical and mental health), Pearson's correlation coefficients were conducted.

To determine whether a statistically significant difference existed between male and female caregivers in their use of emotion-focused, problem-focused, and dysfunctional coping strategies, *t*-tests were conducted. Findings from *t*-tests were consistent with results from the Mann-Whitney *U* Test.

Bivariate relationships were initially explored, followed by three, separate, standard, multiple linear regression tests to determine whether a statistically significant association existed between coping and caregiver physical and mental health, after controlling for variables such as caregiver relationship satisfaction (as measured by the CSI) and demographic characteristics. For the first multiple regression (MR 1), the dependent variable was caregiver mental health (as measured by the MCS) and the independent variables entered into the model were caregiver gender, emotion-focused coping, caregiver relationship satisfaction, and caregiver age. For the second multiple regression (MR 2), the dependent variable was caregiver physical health (as measured by the PCS), and the independent variables entered into the model were problem-focused coping, caregiver relationship satisfaction, caregiver gender, and caregiver age. For the third multiple regression (MR 3), the dependent variable was caregiver mental health, and the independent variables included dysfunctional, problem-focused, and emotion-focused coping in addition to caregiver gender and age. Alpha was set at .05 for all analyses (two-tailed).



## Results

### Caregiver and Patient Demographic Characteristics

Table 2

*Caregiver and Patient Categorical Demographic Variables*

Variables	Caregiver (N = 61)	Patient (N = 61)
Gender, n (%)		
Female	48 (78.7)	20 (32.8)
Male	13 (21.3)	41 (67.2)
Primary language, n (%)		
English	60 (98.34)	60 (98.4%)
Spanish	1 (1.6)	1 (1.6%)
Race/ethnicity, n (%)		
Caucasian/White	57 (93.4)	58 (95.1)
African American/Black	1 (1.6)	1 (1.6)
Hispanic	1 (1.6)	1(1.6)
Chinese	2 (3.7)	1(1.6)
Relationship to patient, n (%)		
Spouse (or equivalent)	55 (90.2)	
Daughter	4 (6.6)	
Other	2 (3.3)	
Total household income (n = 60), n (%)		
< \$20,000	2 (3.3)	
\$20,000-35,000	7 (11.5)	
\$35,000-50,000	8 (13.1)	
\$50,000-75,000	14 (23)	
> \$75,000	22 (36.1)	
Decline to state	7 (11.5)	

*Note:* N = 61 unless otherwise specified.

Table 3

*Caregiver and Patient Quantitative Variables:**Demographic Variables, NPI-Q, PCS, MCS, and CSI (N = 61)*

Variables	Mean (SD)	Range
<b>Caregiver</b>		
Age	61.85 (10.83)	35-90
Number of years caregiver has known patient	39.39 (13.83)	4-70
Duration of caregiving, years	5.96 (8.03)	1-47
NPI-Q distress (0-60, <i>n</i> = 58)	15.36 (8.52)	0-35
SF 12: Physical component score	51.49 (11.22)	18.62-64.85
SF 12: Mental component score	42.49 (10.96)	23.29-66.14
CSI (0-21, <i>n</i> = 60)	9.31 (5.02)	0-19
<b>Patient</b>		
Age	65.79 (9.35)	38-88
Number of years since diagnosis	4.45 (2.49)	1-12
NPI-Q severity (0-36, <i>n</i> = 59)	12.31 (6.14)	0-27

*Note.* *N* = 61 unless otherwise specified. NPI-Q = Neuropsychiatric Inventory Questionnaire; PCS = Physical Component Summary from SF-12; MCS = Mental Component Summary from SF-12; CSI = Couples Satisfaction Index; NPI-Q distress = total caregiver distress score on NPI-Q; NPI-Q severity = total symptom severity score on NPI-Q.

Tables 2 and 3 present the demographic characteristics of the sample. The caregivers' average age was 62 (range: 35-90). Most of the caregivers were women (78.7%), spouses (90.2%), Caucasian/White (93.4%), and married/partnered (95.1%). On average, the caregivers had known their patients for 39 years and had been providing care for about 6 years.

The patients' average age was 66 (range: 38-88). The average number of years since patients were first diagnosed with FTD was 4 years. Most of the patients were male (67.2%) and Caucasian/White (95.1%).

## Coping Strategies

Table 4

*Means and Standard Deviations for the Brief COPE Scale*

Coping Strategy	Mean ( <i>SD</i> )	Range
Emotion-focused coping strategies (0-40)	25.82 (5.83)	12-40
Acceptance (0-8)	6.80 (1.29)	2-8
Emotional support (0-8)	6.08 (1.61)	2-8
Humor (0-8)	3.54 (1.56)	2-8
Positive reframing (0-8)	4.72 (1.85)	2-8
Religion ((0-8, <i>n</i> = 59)	4.58 (2.25)	2-8
Problem-focused coping strategies (0-24)	18.85 (2.99)	14-24
Active coping (0-8)	6.48 (1.36)	3-8
Instrumental support (0-8)	6.07 (1.55)	2-8
Planning (0-8)	6.31 (1.32)	3-8
Dysfunctional coping strategies (0-48)	21.93 (4.18)	13-32
Behavioral disengagement (0-8)	2.52 (0.83)	2-5
Denial (0-8)	2.77 (1.16)	2-7
Self-distraction (0-8)	5.66 (1.59)	2-8
Self-blame (0-8)	3.26 (1.42)	2-7
Substance use (0-8, <i>n</i> = 60)	2.85 (1.29)	2-6
Venting (0-8)	4.85 (1.76)	2-8

*Note.* *N* = 61 unless otherwise specified.

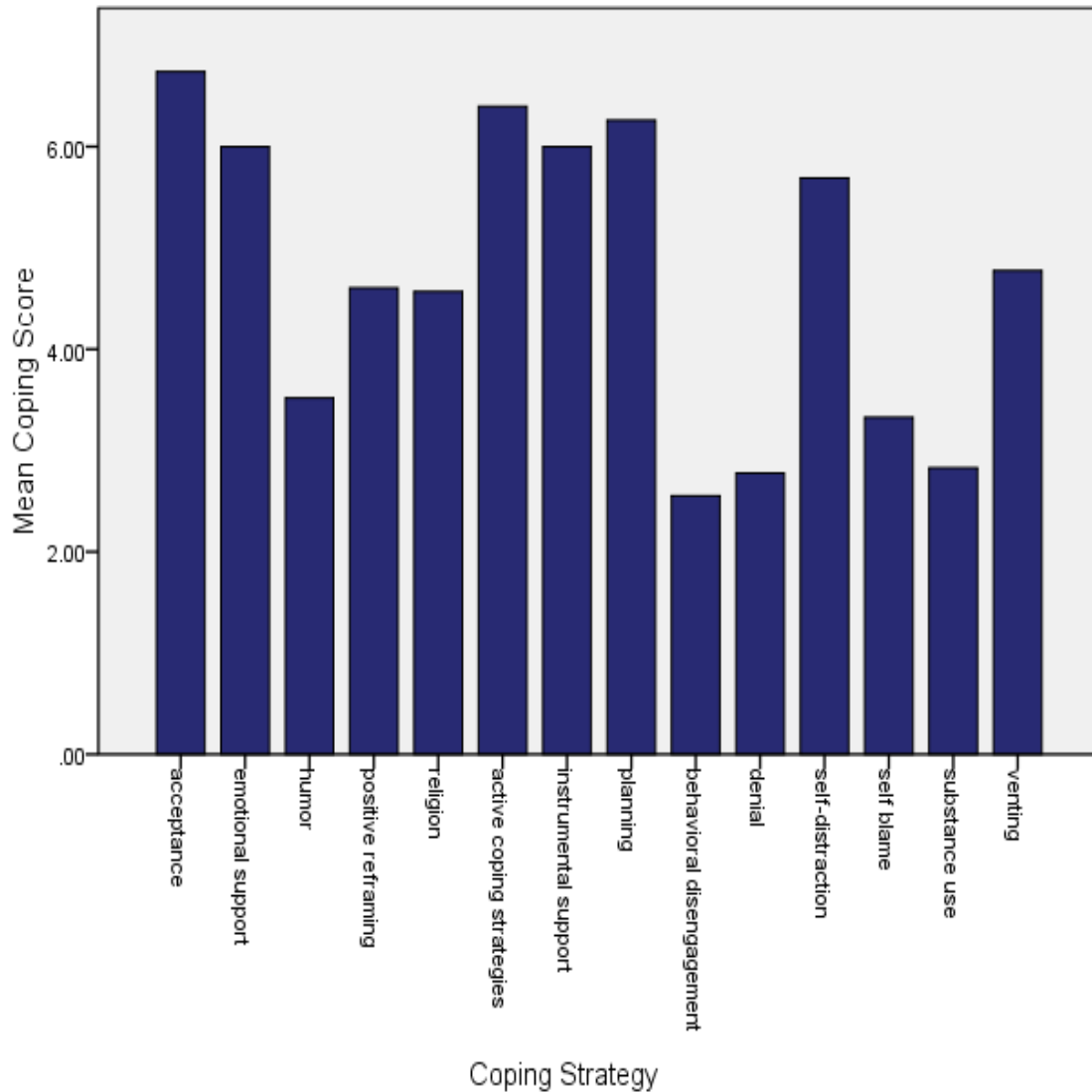


Figure 1. Mean scores for individual coping strategies ( $N = 61$ )

Table 4 presents the mean scores for each coping subtype (emotion-focused, problem-focused, and dysfunctional coping) and strategy. Figure 1 depicts the mean scores for each coping strategy. On average, the caregivers most often used “acceptance” [ $M(SD) = 6.80(1.29)$ ], “active coping strategy” [ $M(SD) = 6.48(1.36)$ ], and “planning” [ $M(SD) = 6.31(1.32)$ ] when dealing with patient neuropsychiatric symptoms and/or

behavioral problems. Coping strategies used the least, on average, included “behavioral disengagement” [ $M(SD) = 2.52(0.83)$ ] and “denial” [ $M(SD) = 2.77(1.16)$ ].

### Correlations Between Quantitative Caregiver Variables

Table 5

*Correlations Between Coping and Caregiver Health Variables (N = 61)*

Measure	Emotion-focused coping	Problem-focused coping	Dysfunctional coping	MCS	PCS
Emotion-focused coping	1	0.48*	0.32*	0.21	-0.08
Problem-focused coping		1	0.06	0.01	0.29*
Dysfunctional coping			1	-0.18	0.02
MCS				1	-0.26*
PCS					1

*Note.* MCS = Mental Component Summary from the SF-12; PCS = Physical Component Summary from the SF-12.

\* $p < 0.05$

Table 5 presents Pearson’s correlation coefficients between the different coping subtypes (emotion-focused, problem-focused, and dysfunctional coping) and caregiver physical health (as measured by the PCS) and mental health (as measured by the MCS). A small, statistically significant negative correlation was found between dysfunctional-focused coping and caregiver age ( $r = -.27, p < .05$ ) and between dysfunctional coping and caregiver relationship satisfaction ( $r = -.35, p < .05$ ). Dysfunctional-focused coping

was not significantly correlated with the PCS, the MCS, and NPI-Q severity scores ( $p > .05$  for all).

Emotion-focused coping had a small, positive but nonstatistically significant correlation with the MCS ( $r = .21, p = .10$ ). In addition, emotion-focused coping was not significantly correlated with the PCS ( $r = -.08, p = .54$ ), NPI-Q severity scores ( $r = .21, p = .116$ ) or caregiver age ( $r = -.20, p = .12$ ). However, a positive and small statistically significant relationship was noted between emotion-focused coping and the CSI scores ( $r = .26, p = .04$ ).

Problem-focused coping was not significantly related to the MCS, caregiver age, NPI-Q severity scores, and the CSI scores ( $p > .05$  for all analyses). However, a statistically significant positive association was observed between problem-focused coping and the PCS ( $r = .289, p = .02$ ).

To examine potential predictors of caregiver physical and mental health, regression analyses were conducted. The selection of predictors was based on preliminary analyses of the associations between the quantitative variables of interest and the study's purpose. For all multiple regression tests, preliminary analyses were conducted to ensure no violation of the assumptions of linearity, normality, multicollinearity, and homoscedasticity. Regression analyses that violated these assumptions were not analyzed and reported.

## Predictors of Caregiver Mental and Physical Health

Table 6

*Summary of Multiple Regression to Examine Predictors of MCS and PCS (N = 61)*

Predictor	MR 1			MR 2			MR 3		
	<i>B (SE)</i>	$\beta$	Model summary	<i>B (SE)</i>	$\beta$	Model summary	<i>B (SE)</i>	$\beta$	Model summary
Emotion-focused coping	0.66 (0.21)	.35*					0.87 (0.23)	0.46*	
Problem-focused coping				1.21 (0.46)	0.32*		-0.40 (0.43)	-0.11	
Dysfunctional coping							-0.38 (0.29)	-0.15	
Caregiver age	0.60 (0.11)	0.59*		-0.18 (0.13)	-0.17		0.58 (0.11)	0.57*	
Caregiver gender	-2.54 (3.02)	-0.10		-4.99 (3.41)	-0.18		-2.79 (2.86)	-0.11	
CSI	0.19 (0.24)	0.09		-0.78 (0.27)	-0.35*				
$R^2$			0.43			0.24			0.45
<i>F</i> for change in $R^2$			10.44*			4.45*			8.96*

*Note:* MCS = Mental Component Summary from SF 12; PCS = Physical Component Summary from SF 12; MR = multiple regression. CSI = Couples Satisfaction Index. MCS was the dependent variable for MRs 1 and 3. PCS was the dependent variable for MR 2.

\* $p < .05$

Table 6 presents the results of three, standard, multiple regression tests. In the first multiple regression (MR 1), we examined the ability of emotion-focused coping to predict caregiver mental health (as measured by the MCS) beyond the influence of caregiver age, gender, and relationship satisfaction (as measured by the CSI). Approximately 43% of the variance was explained by the model with 4 independent variables; the entire model was statistically significant [ $R^2 = .43$ ,  $F(4, 55) = 10.44$ ,

$p < .05$ ]. Emotion-focused coping ( $\beta = 0.35, p < .05$ ) and caregiver age ( $\beta = 0.59, p < .05$ ) both made statistically significant unique contributions to the MCS. Emotion-focused coping uniquely explained approximately 9.7% of the variance found in the MCS, and caregiver age uniquely explained about 32% of the variance in the MCS. The unique variance explained by the CSI was only about 0.7% ( $\beta = 0.09, p = .43$ ). Of note, emotion-focused coping was not significantly correlated with the MCS by itself ( $r = .21, p = .10$ ), but when added in this model, it made a unique statistically significant contribution to the MCS.

In the second multiple regression test (MR 2), we examined the ability of problem-focused coping to uniquely explain caregiver physical health (as measured by the PCS) beyond the influence of caregiver relationship satisfaction (as measured by the CSI), age, and gender. Approximately 24% of the variance was explained by the model with 4 independent variables, and the entire model was statistically significant [ $R^2 = .24, F(4, 55) = 4.45, p < .05$ ]. Problem-focused coping ( $\beta = 0.32, p < .05$ ) and the CSI ( $\beta = -0.35, p < .05$ ) were the only predictors that made a statistically significant unique contribution to the PCS. Problem-focused coping uniquely explained about 9.54% of the variance in the PCS; the CSI uniquely explained about 11.16% of the variance in the PCS.

For the third multiple regression (MR 3), all three coping subtypes (emotion-focused, problem-focused, and dysfunctional coping) and caregiver age and gender were entered into the model as predictors of the MCS. Approximately 45% of the variance was



explained by the model with 5 independent variables; the entire model was statistically significant [ $R^2 = .45$ ,  $F(5, 55) = 8.96$ ,  $p < .05$ ]. Only emotion-focused coping ( $\beta = 0.46$ ,  $p < .05$ ) and caregiver age ( $\beta = 0.57$ ,  $p < .05$ ), however, made statistically significant unique contributions to the MCS. Caregiver age uniquely explained about 30% of the variance in the MCS, and emotion-focused coping uniquely explained about 14% of the variance. Problem-focused coping ( $\beta = -0.11$ ,  $p = .36$ ) and dysfunctional coping ( $\beta = -0.15$ ,  $p = .19$ ) did not make a statistically significant unique contribution to the MCS. Problem-focused coping only explained about 0.86% of the variance in the MCS, while dysfunctional coping uniquely explained approximately 1.8% of the variance.

#### *Gender Differences in Coping*

Statistically significant differences were noted between male ( $n = 13$ ) and female ( $n = 48$ ) caregivers in the use of emotion-focused coping strategies, ( $t(df) = -2.75(59)$ ,  $p = .01$ , 95% CI [-8.22, -1.30]) and problem-focused coping ( $t(df) = -2.69(36.36)$ ,  $p = .01$ , 95% CI [-3.10, -0.43]). However, no statistically significant gender differences were observed in the use of dysfunctional coping strategies ( $t(df) = -1.36(59)$ ,  $p = .18$ , 95% CI [-4.36, -0.83]). On average, women used more emotion-focused coping [women  $M(SD) = 26.84(5.81)$ , men  $M(SD) = 22.08(4.31)$ ], problem-focused coping [women  $M(SD) = 19.23(3.16)$ , men  $M(SD) = 17.46(1.71)$ ], and dysfunctional coping [women  $M(SD) = 22.30(4.25)$ , men  $M(SD) = 20.54(1.04)$ ].

### **Discussion**

The purpose of this study was to examine the relationship between coping and caregiver physical and mental health in families providing care at home for someone with

FTD and behavioral problems. We hypothesized that caregivers who use more problem-focused and emotion-focused coping strategies would report better physical and mental health and that caregivers who use more dysfunctional coping strategies would report poorer physical and mental health. Overall, only two hypotheses were supported:

(1) Problem-focused coping will be associated with more positive caregiver physical health, and (2) Emotion-focused coping will be associated with more positive caregiver mental health.

The finding that problem-solving coping strategies were associated with better reported physical health conflicts with the findings of McConaghy and Caltabiano (2005), who reported no statistically significant relationship between practical forms of coping (e.g., planning, seeking instrumental support) and the caregivers' physical health. However, they did find a moderate, negative association between practical forms of coping and caregiver burden ( $r = -.43, p < .01$ ). Thus, caregivers who used more practical forms of coping had a tendency to report less burden (McConaghy & Caltabiano, 2005). Almgberg, Grafström, and Winblad (1997) conducted a qualitative study of primary dementia family caregivers to compare those who experienced "burnout" ( $n = 17$ ) with those who did not ( $n = 29$ ) and to investigate how dementia family caregivers coped with major strain. The researchers found that caregivers who did not experience burnout used more problem-focused coping strategies, while individuals who experienced burnout used more emotion-focused coping (Almgberg et al., 1997). In the current study, caregivers who used more problem-focused coping strategies tended to report more positive physical health. This could be due to the fact that problem-focused coping strategies,

such as receiving help and advice from others (instrumental support), may decrease caregivers' burden and feelings of burnout and enable caregivers to spend more time on their own physical health needs. Furthermore, persons who report improved physical health may be better able to implement problem-focused coping strategies.

The findings on emotion-focused coping and caregiver mental health are inconsistent with earlier studies of dementia caregiving. Emotion-focused coping strategies have been found to be associated with increased caregiver burden (Cooper et al., 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007); however, Van Den Wijngaart, Vernooij-Dassen, and Felling (2007) found no statistically significant association between emotion-focused coping and caregiver burden. Furthermore, Cooper and colleagues' (2008) longitudinal study found that using fewer emotion-focused coping strategies during initial assessment (Time 1) were associated with greater anxiety at follow-up a year later (Time 2). Knight, Silverstein, McCallum, and Fox (2000) compared levels of emotional distress across ethnic groups among dementia caregivers and found that African Americans ( $n = 41$ ) tended to use more emotion-focused coping than non-African American caregivers ( $n = 128$ ), which indirectly increased their levels of emotional distress. However, these findings may be biased because the African Americans in this study were significantly younger, more likely to be children than spouses, and reported poorer health than non-African Americans (Knight et al., 2000).

Nevertheless, the current study supports FTD caregivers' use of emotion-focused coping strategies when dealing with patient neuropsychiatric symptoms and/or behavioral

problems. According to the transactional theory of stress and coping (Lazarus & Folkman, 1984), emotion-focused coping is more likely to occur when an individual views a stressful condition as refractory to change or inevitable; problem-focused coping is more likely to occur when stressful conditions are appraised as amenable to change (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984, 1987). We were unable to compare the mean emotion-focused, problem-focused, and dysfunctional coping subscale scores because of differences in the range of possible scores for each coping subtype. However, when a person deals with a caregiving situation or stressor that is less amenable to change or perceived as being uncontrollable, emotion-focused coping strategies may be more beneficial for caregiver mental well-being.

Dysfunctional coping strategies, such as blaming oneself and denial, were negatively associated with caregiver mental health, but this relationship was not statistically significant. However, the internal consistency of the dysfunctional coping subscale was low ( $\alpha = .62$ ), and a statistically, significant positive relationship was noted between dysfunctional coping and emotion-focused coping ( $r = .32, p < .05$ ). This may be explained in part by the way in which the Brief COPE Scale classified coping strategies. In previous studies, several types of coping strategies, such as denial and self-distraction, have been categorized as emotion-focused rather than dysfunctional. On the other hand, Cooper and colleagues (2008), in using the Brief COPE Scale, found that dysfunctional coping was predicted by increased caregiver burden ( $\beta = 0.36, p < .001$ ).

Other studies have found support for the deleterious effects of using coping strategies defined as dysfunctional, such as denial and substance use. For instance,

*avoidant coping* (e.g., isolation and denial) has been found to be positively associated with caregiver depression (Mausbach et al., 2006). In addition, Wright, Lund, Caserta, and Pratt (1991) examined coping strategies that caregivers use to manage their daily responsibilities and found that use of *avoidance-evasive coping* (e.g., getting nervous, worrying, doing nothing, resigning, and pessimism) and *regressive coping* (e.g., putting tension on others, blaming others, smoking or chewing gum, drinking alcohol, getting mad or cursing) were associated with lower levels of life satisfaction and higher levels of caregiver burden ( $N = 597$ ). However, the participants in Wright et al.'s study were predominantly White (94%) women (73.5%) who were using supportive services. Thus, their findings may not be generalizable to ethnically diverse caregivers and individuals who are not receiving formal services. To further clarify the effect of coping strategies currently considered dysfunctional, additional studies on FTD caregivers are needed.

Also, statistically significant gender differences were found in the use of emotion-focused and problem-focused coping but not in the use of dysfunctional coping. On average, women used more coping strategies. These findings are consistent with prior studies that found that female caregivers of persons with dementia tend to use more emotion-focused coping strategies than male caregivers (Almberg et al., 1997; Van Den Wijngaart et al., 2007). However, McConaghy and Caltabiano (2005) found no significant differences between men and women on the use of emotional coping ( $z = -1.507$ ;  $U = 109.00$ ,  $p = .14$ ), but the sample size ( $N = 42$ ) may have been too small to detect statistically significant gender differences. In examining gender differences in specific coping strategies, Papastavrou et al. (2007) found statistically significant

differences between female and male caregivers in the strategies of “seeking social support” (men:  $M = 1.66$ , women:  $M = 1.98$ ,  $p < .05$ ) and “wishful thinking” (men:  $M = 1.66$ , women:  $M = 1.92$ ,  $p < .05$ ). However, there were far more women than men (48 versus 13) in the current study, and the internal consistency reliability for the problem-focused ( $\alpha = .69$ ) and dysfunctional coping ( $\alpha = .62$ ) subscales were relatively low. Nevertheless, these findings highlight the importance of obtaining additional data on male FTD family caregivers to assess their needs, determine whether different coping strategies may be more effective at alleviating their emotional distress, and explore the types of strategies they use when dealing with stressors that are perceived as inevitable and uncontrollable such as certain types of patient behavioral problems. Future studies should examine explanatory factors for the gender differences in coping among FTD caregivers, such as the effect of cultural values and perceived societal norms and expectations of gender roles and caregiving.

Of note, caregiver age was negatively associated with the use of dysfunctional coping strategies and positively associated with caregiver mental health. The poorer mental health reported by younger FTD caregivers in this study could be due to the fact that they may still be juggling work and other families responsibilities while trying to manage different behavioral problems common in patients with FTD. As a result, without adequate support and resources, younger caregivers may be vulnerable to increased caregiver burden and distress. Because caregiver age was positively associated with the number of years the caregivers have known their patients ( $r = .62$ ,  $p < .05$ ), this could ultimately affect their satisfaction and feelings of competency in the caregiving role and

overall caregiving experiences. These findings highlight the importance of focusing on the needs of not only older but also younger FTD caregivers and taking measures to ensure that they are getting the necessary support and resources.

Why a small, negative correlation between caregiver mental and physical health was found is unclear ( $r = -.26, p < .05$ ), but it could be attributable to the inherent nature of the sample. Participants who reported better mental health may be older and experiencing more physical health problems. Further study is needed to understand the factors that may be influencing the relationship between physical and mental health among FTD family caregivers.

### **Limitations and Strengths**

This study has a number of limitations. First, the internal consistency for two coping subscales were relatively low (problem-focused coping  $\alpha = .69$ , dysfunctional coping  $\alpha = .62$ ). Although the internal consistency for the emotion-focused coping subscale was good ( $\alpha = .80$ ), the results for problem-focused and dysfunctional coping should be interpreted with caution. Second, because this was an anonymous survey and the diagnosis of FTD was based on caregiver self-report, the criteria used for establishing a diagnosis of FTD was unknown. However, all participants were contacted through an association that specifically supports caregivers of persons with FTD. Third, most participants were Caucasian/White. Thus, the results may not be generalizable to culturally and ethnically diverse caregiver populations. Fourth, the sample size ( $N = 61$ ) was small. According to Hulley, Cummings, Browner, Grady, and Newman (2007), the sample size requirements when using the correlation coefficient ( $r$ ) for a medium effect

size ( $r = .30$ ; Cohen, 1988) would be 85 subjects ( $\beta = 0.20$ ,  $\alpha = .05$ , two-sided test).

According to Tabachnick and Fidell (2007), a sample size of 82 would be required to run a multiple regression with 4 independent variables [ $50+8(4) = 82$ ]. Although the sample size was small, we still found statistically significant relationships between coping and caregiver physical and mental health outcomes.

Despite its limitations, this study has a number of strengths. First, this is the first study to examine the coping strategies used by FTD family caregivers in response to patient neuropsychiatric symptoms and behavioral disturbances. Understanding that earlier dementia caregiving studies have not focused on the effect of coping strategies on this population of family caregivers, our study breaks new ground in focusing on the at-risk, understudied FTD caregiver population. Second, because the caregivers were recruited through the AFTD, a national organization, the participants represented caregivers from various locations throughout the United States and Canada. Third, our regression analyses showed that emotion-focused coping makes a statistically significant unique contribution to caregiver mental health and problem-focused coping makes a statistically significant unique contribution to caregiver physical health. These findings have important implications for clinicians and future research.

### **Clinical Implications**

Clinicians may use these findings as an incentive (a) to educate FTD family caregivers about emotion-focused coping strategies, (b) to encourage them to focus on their own emotions, and (c) to motivate them to experiment with strategies that could alleviate their emotional distress when dealing with situations or stressors perceived as



uncontrollable or not amendable to change. When coping with patient behavioral problems and neuropsychiatric symptoms (e.g., apathy, indifference, social awkwardness), caregivers may benefit by focusing on their own emotions and using coping strategies, such as accepting the reality of a situation, receiving emotional support from friends and relatives, or using humor to deal with the situation. Also, problem-focused coping strategies (e.g., planning and receiving instrumental support) may be useful in certain situations that warrant action on a specific problem to promote patient safety. For instance, to prevent a person with FTD from engaging in criminal behavior or making inappropriate jokes or comments, a caregiver could use problem-focused coping strategies, such as seeking help and advice from others about what to do (instrumental support), considering a strategy to solve the problem, and weighing the next steps to take (planning).

### **Future Research**

This study has implications for future research. Although we were unable to conduct an appropriate factor analysis due to the small sample size, future researchers should examine the reliability and validity of the Brief COPE Scale in a larger sample of FTD family caregivers. Future studies are also needed to assess the longitudinal effect of individual coping strategies on the health and well-being of FTD caregivers over time and to evaluate the effect of coping among culturally and ethnically diverse FTD caregivers. Furthermore, qualitative studies could be invaluable in developing an in-depth understanding of the unique experiences of FTD family caregivers and the coping process.

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The authors declare no conflicting interests with respect to authorship and/or the publication of this article.

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### **Chapter 3**

The Relationship Between Perceived Control and Caregiver

Mental and Physical Health in Family Caregivers of

Persons with Frontotemporal Dementia

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## Abstract

**Objective:** To examine the relationship between perceived control and caregiver mental and physical health in family caregivers of persons with frontotemporal dementia (FTD).

**Design:** Cross-sectional, correlational study.

**Setting:** FTD family caregivers were recruited throughout the United States and Canada using convenience and snowball sampling. Participants were family members providing care to someone with FTD who was living at home.

**Participants:** Sixty-one primary caregivers of persons with FTD (with behavioral problems).

**Measurements:** Self-report measures of caregivers' perceived control, health, relationship satisfaction, and demographic characteristics were collected and analyzed. Patient symptoms were measured by the Neuropsychiatric Inventory Questionnaire.

**Results:** A strong, statistically significant, positive correlation was found between perceived control and caregiver mental health ( $r = .63, p < 0.05$ ). No statistically significant correlation was found between perceived control and caregiver physical health ( $r = -.03, p = 0.81$ ). In a multiple regression analysis with caregiver mental health as the dependent variable, perceived control made a statistically significant, unique contribution to caregiver mental health ( $\beta = 0.498, p < 0.05$ ], accounting for roughly 22% of its variance.

**Conclusions:** Results suggest that caregivers with greater perceived control tend to report better mental health. This study highlights the importance of assessing the self-perceptions and unique needs of FTD family caregivers, particularly their perceived sense

of control. Additional studies of FTD caregiving are needed to explore strategies that can effectively increase caregiver perceived control and, in turn, improve caregiver mental health.

**Key Words:** Caregiver, caregiver health, frontotemporal dementia, perceived control

**Conflict of interest:** No disclosures to report.

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Approximately 25 million people were affected by dementia worldwide in 2000, and 63 million cases are projected by 2030 (1). Dementia is a syndrome of cognitive impairment which is progressive and leads to a decreased ability to perform activities of daily living (2-3). Because dementia alters how an individual acts, thinks, and feels, it may be associated with the development of psychological and behavioral disturbances (2-3).

Frontotemporal dementia (FTD) encompasses multiple heterogeneous and progressive neurodegenerative syndromes (4-5). Unlike Alzheimer's disease (AD), which typically causes problems with memory, FTD is more commonly associated with early symptoms of social awkwardness, loss of executive function, passivity, and disinhibition (6). The behavioral variant of FTD (bvFTD) usually presents with a broad range of behavioral and neuropsychiatric symptoms, such as social avoidance, personal neglect, overeating, wandering, and an unusual preference for sweet foods (7).

### **Family Caregivers of Persons with Dementia**

Sixty percent of family caregivers provide unpaid support and assistance to individuals with AD or other types of dementia (8). Family caregivers perform a critical function in providing care for individuals with dementia at home; however, the behavioral and psychological symptoms of dementia have been found to predict caregiver psychological distress, depression, and burden of care (9). Understanding the factors that affect the health and well-being of dementia caregivers is important so that targeted interventions can be initiated before mental and physical health problems develop. Because dementia is a very broad and heterogeneous entity, health care professionals

must consider how the varied types of dementia, which express themselves differently, affect the experiences and emotional well-being of family caregivers.

Providing care for someone with bvFTD can be particularly challenging and overwhelming because it is associated with a wide range of behavioral and neuropsychiatric symptoms (7). Prior research studies have shown that patient behavioral disturbances that are common in patients with bvFTD are strong contributors to caregiver burden and psychological distress (10-13). For instance, Davis and Tremont (2007) examined the impact of behavioral functioning in dementia patients on caregivers (N = 72) and found that behaviors related to disinhibition and executive dysfunction were predictors of caregiver burden (14). Because of the severe behavioral problems common in patients with bvFTD, understanding the different factors that may be associated with the health and well-being of their family caregivers is critically important.

### **Perceived Sense of Control**

One factor that may be associated with the health and well-being of FTD family caregivers is *perceived sense of control*. Perceived control has been “defined from within a person-environment framework as the perception that salient aspects of one’s life are manageable or being managed” (15, p. 569). A caregiver’s appraisal of his or her resources and demands “occurs from within the individual’s sociocultural context and includes past as well as present meanings” (15, p. 569). If a caregiver perceives that his or her caregiving demands exceed available resources, the person’s perceived sense of control would decrease (15). In Wallhagen and Brod’s (1997) study of the influence of perceived control among individuals with Parkinson’s disease (69 patients and

45 caregivers), they found that the patients' perceived control over their symptoms was significantly associated with patient well-being ( $r = .22$ ,  $p = 0.02$ ; 16). Furthermore, after controlling for disease severity, patient perceived control over symptoms was statistically significantly associated with better caregiver well-being ( $\beta = 0.33$ ,  $p = 0.03$ ) and less caregiver burden ( $\beta = -0.29$ ,  $p = 0.03$ ; 16).

The notion of perceived control has not been well-studied among families providing care to someone with dementia. The few published studies of perceived control do suggest, however, that perceived lack of control is associated with worse caregiver outcomes, such as increased caregiver strain and depression (17). For instance, Wallhagen (1993) investigated perceived control among 60 elderly caregivers and found that perceived control had a direct relationship with caregiver depression ( $\beta = -0.45$ ,  $p < 0.001$ ) and life satisfaction ( $\beta = 0.24$ ,  $p = 0.03$ ): Higher levels of perceived control were associated with lower levels of depression and greater life satisfaction (18).

Recent caregiving studies have not focused on the concept of perceived control in the context of caregiving for someone with a cognitive and/or behavioral problem. Wong and colleagues (2011) examined the concept of perceived control in a small sample of dementia family caregivers and found that bvFTD caregivers, on average, experienced lower levels of perceived control than AD caregivers ( $N = 53$ ; 19). However, this study did not explore the effect of perceived control on the experiences of family caregivers (19). Understanding the relationship between caregiver perceived control and the mental and physical health of FTD family caregivers could accelerate the development of caregiver interventions aimed at promoting caregiver health and subjective feelings of

well-being. Assisting FTD caregivers to develop effective strategies for gaining more control over their caregiving situation and managing patient behavioral problems could potentially mitigate the detrimental effects of FTD caregiving.

## **Objective and Hypotheses**

The objective of this cross-sectional, correlational study was to examine the relationship between caregiver perceived control and the mental and physical health of FTD family caregivers. The study's hypotheses were 1) Higher levels of perceived control will be associated with more positive caregiver mental health; and 2) Higher levels of perceived control will be associated with more positive caregiver physical health.

## **Methods**

Potential participants for this study were recruited between June 2011 and November 2011 by means of snowball and convenience sampling. Information about the study was presented at FTD Caregiver Support Group meetings in Portland, Oregon, and San Francisco and in Association for Frontotemporal Degeneration (AFTD) newsletters and on the association's website (<http://www.theaftd.org/>).

Participants were primary family caregivers of someone with FTD (with behavioral problems). The eligibility criteria for caregivers were 1) identifying oneself as the family member who is primarily responsible for the patient's care; 2) living with the patient; 3) providing care to the patient for at least 6 months; 4) receiving no financial compensation for caregiving; 5) being able to speak, read, and understand English; and 6) being 18 years of age or older. If more than one caregiver was involved in the patient's

care, the family caregiver providing most of the care was selected. The criterion for patient eligibility was a diagnosis of FTD with behavioral problems (based on caregiver report).

Eligible and interested caregivers completed a set of questionnaires on their own time. The questionnaires took about 30 min to complete and were submitted anonymously by standard mail. Upon receipt of the questionnaires, participants had the option of receiving a \$5 Safeway gift card.

Human subjects approval was obtained from the University of California, San Francisco's Committee on Human Research. In an introductory letter, participants were notified that implied consent would be assumed if a caregiver completed and submitted the survey. All participants were provided with a copy of an informed consent document, which provided additional information about the study's purpose, procedures, and risks and benefits.

Of the caregivers who contacted the research investigator and expressed interest in participating, six were deemed ineligible because they were providing care for someone who was residing in a nursing home or another type of institution, and eight were ineligible because their patient was already deceased during the study enrollment period. Data for 61 caregivers were collected and analyzed.

## **Measures**

### **Perceived Control**

The 15-item version of the Perceived Control Questionnaire (PCQ-15) was used to assess the caregivers' perceived sense of control (15, 20). Respondents rate each item



on a 4-point scale that best describes the degree to which they agree or disagree with each statement (15). The total score ranges from 15-60; higher scores reflect greater levels of perceived control (15). The PCQ-15 achieved an internal consistency reliability ( $\alpha$ ) of .94 and has been found to be significantly related to social and physical functioning, emotional and physical role involvement, mental health, vitality, and general health perception in a small sample of African Americans with type 2 diabetes (N = 23; 15).

### **Caregiver Mental and Physical Health**

The mental and physical health component scores from the 12-Item Short-Form Health Survey (SF-12) were used to assess the caregivers' mental and physical health (21). The SF-12 was derived from the 36-Item Short-Form Health Survey, which is a generic measure of health that can be used in a variety of settings (22-23). The SF-12 can be self-administered or given by a trained interviewer in-person or by telephone (23). Test-retest (2-week) correlations of .76 and .89 have been found for the Mental Component Summary (MCS) and Physical Component Summary (PCS) in the general U.S. population (N = 232; 21). Furthermore, the SF-12, originally developed from the SF-36, has been shown to produce two summary scales (mental and physical health) with great accuracy and less respondent burden (24).

### **Couples Satisfaction Index**

The 4-item Couples Satisfaction Index (CSI-4; 25) was used to assess the caregivers' level of satisfaction with their relationship to the patient. The CSI was derived through use of principal component analysis and item response theory applied to a larger pool of items (25). The CSI-4 has shown excellent internal consistency ( $\alpha = .94$ )

in addition to higher precision of measurement (less noise) and greater power for detecting differences in levels of satisfaction than other well-validated relationship satisfaction measures (25). Furthermore, the CSI has shown strong construct and convergent validity with existing measures of relationship satisfaction (25). To make this measure applicable to nonspousal caregivers, items 2 and 3 were modified by replacing the word *partner* with *care recipient*. Total possible scores range from 0-21; higher scores indicate better relationship satisfaction.

### **Patient Neuropsychiatric Symptoms**

The Neuropsychiatric Inventory Questionnaire (NPI-Q; 26-27) was used to assess 12 neuropsychiatric disturbances common in dementia patients: aberrant motor behavior, agitation, anxiety, apathy, appetite and eating disorders, delusions, disinhibition, dysphoria/depression, euphoria, hallucinations, irritability, and night-time behavior disturbances. The NPI-Q has been cross-validated with the standard NPI (28-29) to provide a quantitative measure of patient symptom severity and caregiver distress in relation to specific neuropsychiatric disturbances (26). The total patient symptom severity score ranges between 0-36; higher scores reflect greater severity of patient neuropsychiatric symptoms. The total caregiver distress score ranges between 0-60; higher scores reflect greater caregiver distress in relation to patient neuropsychiatric symptoms. The reliability and validity of this measure has been established previously (26-27).

## Caregiver and Patient Demographic Characteristics

Information about caregiver and patient age, gender, and race/ethnicity were collected to assess the demographic characteristics of the sample. Caregivers were also asked about their relationship to the patient (i.e., spouse, child, or sibling), marital status (i.e., single, married, or widowed), the number of years they had known the patient, the number of years they had been providing care to that patient, and additional paid and unpaid sources of support.

### Data Analysis

We used SPSS version 19.0 to conduct all analyses. To assess the magnitude and direction of the relationships between the quantitative variables of interest, we used Pearson's correlation coefficient tests. In addition, we conducted a standard multiple linear regression test to determine whether an association existed between perceived control and caregiver mental health, above and beyond the influence of the severity of patient symptoms (NPI-Q Severity) and caregiver age and gender. Alpha was set at 0.05 for all analyses.

## Results

### Caregiver and Patient Demographic Characteristics

**Table 1**  
Caregiver and Patient Demographic Variables

<b>Variable</b>	<b>Caregiver (n = 61)</b>	<b>Patient (n = 61)</b>
Gender, % female	78.7	32.8
Relationship to patient, % spouse	90.2	
Mean (SD) age in years	61.85 (10.83)	65.79 (9.35)
Race, % Caucasian/White	93.4	95.1
Mean (SD) number of years since diagnosis		4.45 (2.49)

*Note:* SD: standard deviation.

Table 1 presents the demographic characteristics of the sample. The average age of the caregivers was 62 (range: 35-90). Most were women (78.7%), spouses (90.2%), Caucasian/White (93.4%), and married or partnered (95.1%). The average number of years the caregivers had known their patient was 39 years, and the average number of years the caregivers had been providing care was about 6 years. About half (52.5%) of the caregivers were providing care at home without some type of paid support; 43% were receiving paid support for 1-2 days a week. Almost half (47.5%) of the caregivers were not receiving unpaid support from friends or relatives; about 44% were receiving unpaid support 1-2 days per week.

The average age for patients was 66 years of age (range: 38-88). The average number of years since the patient was first diagnosed with FTD was 4.45 years (SD = 2.49). The majority of the patients were male (67.2%) and Caucasian/White (95.1%).

## Correlations Between PCQ Scores and Caregiver Variables

**Table 2**  
Correlations Between Perceived Control and Other Caregiver Variables (N = 61)

Measure/Variable	1	2	3	4	5
1. PCQ-15	1				
2. NPI-Q Distress	-.33*	1			
3. MCS	.63*	-.40*	1		
4. PCS	-.03	-.07	-.26*	1	
5. Caregiver Age	.34*	-.24	.55*	-.23	1

*Notes:* PCQ-15: Perceived Control Questionnaire. NPI-Q Distress: total caregiver distress score on Neuropsychiatric Inventory Questionnaire. MCS: mental component score from SF-12. PCS: physical component score from SF-12. \*p < 0.05

**Table 3**  
Means and Standard Deviations for Self-Report Measures

Measure	Mean (SD)	Range
<b>Caregiver</b>		
PCQ-15	44.68 (7.94)	22-59
NPI-Q Distress	15.36 (8.52)	0-35
PCS	51.49 (11.22)	18.62-64.85
MCS	42.49 (10.96)	23.29-66.14
CSI (0-21)	9.31 (5.02)	0-19
<b>Patient</b>		
NPI-Q Severity	12.31 (6.14)	0-27

*Notes:* SD: standard deviation. PCQ-15: Perceived Control Questionnaire. NPI-Q Distress: total caregiver distress score on Neuropsychiatric Inventory Questionnaire. NPI-Q Severity: total patient symptom severity score on Neuropsychiatric Inventory Questionnaire. MCS: mental component score from SF 12. PCS: physical component score from SF 12. CSI: Couples Satisfaction Index.

Table 2 presents the correlations among the PCQ scores, NPI-Distress scores, MCS scores, PCS scores, and caregivers' age. Table 3 presents the means and standard deviations for these measures, in addition to the patient NPI Severity scores. We found a small, statistically significant positive correlation between the PCQ scores and caregiver age ( $r = .34, p < 0.05$ ). We also found a weak, positive correlation between the PCQ scores and the number of years the caregivers had known their patient ( $r = .21, p = 0.12$ ) and the number of years the caregivers had been providing care ( $r = .17, p = 0.21$ ), but these correlations were not statistically significant. On the other hand, we observed a small, statistically significant negative correlation between the PCQ and NPI Distress scores ( $r = -.33, p < 0.05$ ). Also, we found a small, statistically significant positive correlation between the PCQ and CSI scores ( $r = .32, p < 0.05$ ).

We also used Pearson's correlations to explore the relationship between the PCQ scores and caregiver health variables. We did not find a statistically significant correlation between the PCQ and PCS scores ( $r = -.03, p = 0.81$ ). However, we did observe a strong, statistically significant positive correlation between the PCQ and MCS scores ( $r = .63, p < 0.05$ ), suggesting that the greater the caregivers' perceived sense of control the better the caregivers' mental health.

### **Multiple Regression Analysis**

We used standard multiple regression to examine the association between the PCQ scores and the MCS scores, above and beyond the influence of the NPI-Q Severity scores (as a measure of patient symptom severity) and caregiver age and gender.

Preliminary analyses were conducted to ensure no violation of the assumptions of

linearity, normality, multicollinearity, and homoscedasticity. Roughly 53% of the variance was explained by the model with four independent variables, and the entire model was statistically significant [ $R^2 = .53$ ,  $F(4, 52) = 14.82$ ,  $p < 0.05$ ]. PCQ score ( $\beta = 0.498$ ,  $p < 0.05$ ) and caregiver age ( $\beta = 0.358$ ,  $p < 0.05$ ) were the only independent variables that made a statistically significant unique contribution to the MCS scores. Caregiver age uniquely explained roughly 10% of the variance in the MCS scores, and the PCQ scores uniquely accounted for roughly 22% of the variance in the MCS scores.

## **Discussion**

The purpose of this study was to examine the relationship between perceived control and the mental and physical health of FTD family caregivers. We found no statistically significant relationship between perceived control and caregiver physical health; however, we did observe a strong, statistically significant positive relationship between the caregivers' perceived sense of control and caregiver mental health. Only this study's first hypothesis (the relationship between perceived control and caregiver mental health) was supported: Caregivers who reported higher levels of perceived control had a tendency to report better mental health. Furthermore, in a regression analysis, perceived control made a statistically significant unique contribution to caregiver mental health and accounted for roughly 22% of the variability in caregiver mental health.

Our study's results, which are consistent with those of previous investigations, support the important contribution of perceived control on health and mental well-being (30). For instance, Infurna and colleagues' (2011) secondary data analysis examined the longitudinal effect of perceived control on health and found that levels of perceived

control predict changes in health over time in old age (65 years of age and older; n = 1,238) but not in midlife (25-64 years of age; n = 2,364). These findings reinforce the important role of perceived control for health and successful aging in older adults (31). Bailis and colleagues (2001) studied how perceived control functions in relation to behavioral and sociodemographic determinants of health using data from the National Population Health Survey of Canada (1995; N = 11,110) and found that perceived control mediates the influence of socioeconomic status (SES) on self-rated health. Individuals with high-SES (more education, greater income, and current employment) reported less mental distress and fewer depressive symptoms, and these variations in health were related to the tendency of high-SES subjects to have greater perceived control over life events (32). However, because both studies operationalized perceived control differently and used a mastery measure to assess perceived control (31-32), comparability with the current study is questionable.

Nevertheless, our findings highlight the importance of focusing on FTD caregivers' perceived sense of control to promote their mental well-being. In this study, perceived control was positively associated with caregiver mental health; the greater perceived control the caregivers experienced, the better their self-reported mental health. Furthermore, we found a statistically significant negative correlation between the caregivers' level of distress from patient neuropsychiatric symptoms and perceived control: The greater perceived control the caregivers experienced, the less emotional distress they felt from patient neuropsychiatric symptoms. These findings are consistent with Wallhagen's (1998) person-environment interaction model of control, which



conceptualizes sense of control as an outcome of the interplay between an individual and his or her own environment and the appraised balance between one's available resources and perceived demands (33). If FTD caregivers perceive that their caregiving demands exceed their necessary resources, they may feel that they cannot effectively manage their caregiving responsibilities. Thus, they report low levels of perceived control.

Consequently, caregivers with low perceived control of their current situation may be vulnerable to increased emotional distress and worse mental health outcomes.

Conversely, if FTD caregivers believe that they have the resources (e.g., support from friends or relatives, money, and education about FTD) to manage their patient's behavioral problems and other caregiving demands, their mental health and emotional well-being would likely improve because they would experience a greater sense of control over their current situation. Because of the severe behavioral disturbances common in patients with bvFTD, providing care for someone with the disease can be overwhelming and stressful and precipitate feelings of lack of control without adequate support and resources. Thus, clinicians should assess FTD caregivers' perceived sense of control and help them to develop strategies for gaining more control over their life.

Of note, we found a statistically significant, positive relationship between caregiver age and perceived control, suggesting the caregivers' level of perceived control increased with increasing caregiver age. The positive relationship between caregiver age and perceived control could be attributable to the fact that younger FTD caregivers in this study may be managing greater caregiving demands, other family responsibilities, and more work obligations with less support and experience. Nevertheless, further study is

needed to better understand why perceived control increases with age in families providing care to someone with behavioral problems.

This study has several limitations. First, because ours was an anonymous survey and the diagnosis of FTD was based on caregiver self-report, the criteria used for establishing a diagnosis of FTD was unknown. Second, because most of the participants were spouses and Caucasian/White, the results may not be generalizable to nonspousal caregivers from socioculturally and ethnically diverse backgrounds. Third, in using a cross-sectional study design, we were unable to evaluate the effects of caregiver perceived control over time or make causal inferences about the relationship between perceived control and caregiver health outcomes. Fourth, our sample size ( $N = 61$ ) was small. According to Hulley and colleagues (2007), the sample size requirements when using the correlation coefficient ( $r$ ) for a medium effect size should be 85 subjects ( $\beta = 0.20$ ,  $\alpha = .05$ , two-sided test; 34). Although our sample size was small, we still found a statistically significant relationship between perceived control and caregiver mental health.

## **Conclusion**

Despite its limitations, our study does have potential implications for clinical practice and future research. Findings from this study highlight the importance of assessing the self-perceptions and unique needs of FTD family caregivers, particularly their own perceived sense of control. Clinicians could instruct family caregivers of persons with FTD about different strategies for increasing their perceived sense of control while managing patient-related stressors, such as behavioral disturbances or personality

changes. Potential strategies could include learning more about FTD, acquiring strategies for managing different behavioral problems common in FTD, and seeking additional paid and unpaid sources of support. Additional studies of FTD caregiving are needed to determine the effectiveness of strategies aimed at increasing caregiver perceived control and improving caregiver mental well-being, to improve our understanding of the longitudinal effect of perceived control on caregiver mental/psychological well-being over time, and to assess the psychometric properties of the PCQ in a larger sample of FTD family caregivers.

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## **Chapter 4**

Family Caregivers of Persons with Frontotemporal Dementia:

The Relationship Between Patient Symptom Severity and

Caregiver Physical and Mental Health

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## Key Words

Behavioral symptoms • Caregiver • Frontotemporal dementia • Neuropsychiatric inventory

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## Abstract

**Aim:** The primary aim of this study was to examine the relationship between the severity of neuropsychiatric symptoms and/or behavioral problems in persons with frontotemporal dementia (FTD) and caregiver physical and mental health. **Methods:** Sixty-one FTD family caregivers participated in a postal survey. Self-report measures of caregiver health, relationship satisfaction, and patient neuropsychiatric symptoms were collected.

**Results:** Apathy/indifference was the most frequently reported (84%) and most distressing symptom for family caregivers. Patient symptom severity was negatively associated with caregiver mental health ( $r = -.26, p < 0.05$ ). In addition a medium, negative relationship was found between caregiver distress from patient symptoms and caregiver mental health ( $r = -.40, p < 0.05$ ). Caregiver physical health was not statistically significantly related to the severity of patient symptoms. **Conclusion:** This study supports a negative relationship between caregiver mental health and the severity of patient neuropsychiatric symptoms and/or behavioral problems. Further study is required to understand other factors that may be influencing this relationship.

## **Introduction**

Frontotemporal dementia (FTD) is a common cause of early-onset dementia, the prevalence of which has been reported to be 81 per 100,000 [1]. It occurs in 5-15% of individuals with dementia and frequently affects younger individuals between the ages of 45 and 65 [2-3]. Social awkwardness and behavioral changes, such as apathy and disinhibition, are common initial symptoms of FTD [2, 4]. Patients with the behavioral variant type of FTD (bvFTD) usually present with a broad range of behavioral and neuropsychiatric symptoms, such as social avoidance, personal neglect, overeating, wandering, and an unusual preference for sweet foods and carbohydrates [5]. Because individuals with bvFTD usually exhibit severe and unusual behavioral disturbances, family caregivers can find it particularly challenging and overwhelming to provide care for someone with this form of dementia.

Prior research studies have shown that the behavioral disturbances common in patients with bvFTD are strong contributors to caregiver burden and psychological distress [6-8]. For instance, in their study of the impact of behavioral functioning in dementia on caregiver burden ( $n = 72$ ), Davis and Tremont (2007) found that behaviors related to disinhibition and executive dysfunction were predictors of caregiver burden ( $t = 2.09, \beta = 0.36, p < 0.01$ ) [9]. Mourik and colleagues (2004) studied which behavioral symptoms occur together in clusters ( $n = 63$ ) and found these two clusters: (1) mood (comprising anxiety and depression) and (2) agitation/psychosis (comprising agitation, delusions, hallucinations, and irritability) [10]. The researchers also investigated the relationship between behavioral clusters and caregiver distress ( $n = 63$ ) [10]. After

controlling for confounding variables, they found caregiver distress to be strongly related to agitation/psychosis ( $b = 0.56$ ,  $p < 0.0001$ ), followed by mood ( $b = 0.27$ ,  $p < 0.001$ ) [10].

Conversely, in their 2-year longitudinal study, Riedijk and colleagues (2008) found that caregiver emotional burden caused by patient neuropsychiatric symptoms significantly decreased ( $n = 63$ ;  $p < 0.01$ ) from baseline ( $M[SD] = 9.4[6.8]$ ) to 24 months ( $M[SD] = 6.4[4.9]$ ; 11). Overall, caregiver burden also decreased significantly ( $p < 0.01$ ) during the 2 years (baseline  $M[SD] = 5.6[2.6]$ ; 24 month  $M[SD] = 4.2[2.8]$ ; 11).

However, selective drop-out is a potential limitation because 10 dyads, who dropped out for unknown reasons, had higher scores on patient neuropsychiatric disturbance and subsequent caregiver burden [11]. Nevertheless, these findings support the hypothesis that the negative affect of patient neuropsychiatric symptoms on family caregivers may decrease over time as caregivers become more accustomed to their role and develop better strategies for managing patient neuropsychiatric and/or behavioral symptoms.

Despite these findings, few research studies have been conducted on the impact of patient symptoms on the physical and mental health of FTD family caregivers. The vast majority of adults (78%) in the United States who receive long-term care at home get that care from family caregivers; unfortunately, many family caregivers experience deteriorating health as a result of their efforts [12-14]. Furthermore, family caregivers of persons with dementia have reported more physical and mental health problems than non-dementia caregivers as a result of caregiving [15-16]. This finding underscores the importance of focusing on factors that affect the health and well-being of FTD family

caregivers. Clarifying the relationship between patient behavioral problems and the health of FTD family caregivers could spur future research on effective strategies for managing unusual behavioral problems common in patients with FTD. Also, if health care professionals are to develop a fuller appreciation of the experiences of FTD family caregivers, they must understand the different types of patient neuropsychiatric symptoms and behavioral problems that these family caregivers routinely manage.

The primary aim of this descriptive, correlational study was to examine the relationship between the severity of neuropsychiatric symptoms and/or behavioral problems in FTD patients and the physical and mental health of their family caregivers. The study's secondary aims were 1) to describe the frequency of neuropsychiatric symptoms and/or behavioral problems in patients with FTD and their emotional impact on family caregivers; and 2) to assess the relationship between caregiver emotional distress from patient neuropsychiatric symptoms and/or behavioral problems and caregiver physical and mental health.

This study is unique in specifically assessing the distinctive symptoms more commonly manifested in bvFTD (e.g., social avoidance, criminal behavior such as shoplifting, and perseverative/obsessive behaviors) when examining the relationship patient symptom severity and caregiver health outcomes.

## **Methods**

### *Participants*

Family caregivers of FTD patients were recruited by convenience and snowball sampling between June 2011 and November 2011. Potential participants were recruited

from FTD Caregiver Support Group meetings in Portland, Oregon, and San Francisco. Information on the study was also included in the newsletters and on the website (<http://www.theaftd.org/>) of the Association for Frontotemporal Degeneration (AFTD). Participants were primary family caregivers of someone with FTD who were living with the patient, receiving no financial compensation for caregiving, and 18 years of age or older. If more than one caregiver was involved in a patient's care, the family caregiver providing most of the care was selected. The criterion for patient eligibility was a diagnosis of FTD (with behavioral problems), based on caregiver report.

Interested and eligible family caregivers completed a set of questionnaires that took roughly 30 min to complete. Upon receipt of the questionnaires, participants had the option of receiving a \$5 Safeway gift card as an acknowledgement of their time. Completed questionnaires were returned anonymously by standard mail.

Human subjects approval was obtained from the University of California, San Francisco's Committee on Human Research. In an introductory letter, participants were notified that consent would be implied if the caregiver completed and submitted the survey. All participants were provided with an informed consent document, which provided additional information on the study such as the study's purpose, procedures, risks and benefits.

Data from 61 caregivers were collected and analyzed. The demographic characteristics of the caregivers and patients included age, gender, and race/ethnicity. Caregivers were also asked about their relationship to the patient (e.g., spouse, child, or sibling), their marital status (e.g., single, married, or partnered), the number of years they

had known the patient, the number of years they had been providing care to the patient, and additional paid and unpaid sources of support.

### *Instruments*

#### Caregiver Physical and Mental Health

The participants' physical and mental health status was assessed by the physical and mental health component scores from the 12-Item Short-Form Health Survey (SF-12) [17]. The SF-12, which was derived from the 36-Item Short-Form Health Survey, is a generic measure of health that can be used in different settings [18-19]. The SF-12 can be self-administered or given in person by a trained interviewer [17]. Test-retest (2-week) correlations for the Physical Component Summary (PCS) and the Mental Component Summary (MCS) have been found to be .89 and .76, respectively, in the general U.S. population (n = 232) [17]. Furthermore, the SF-12 has been shown to produce two summary scales (physical health and mental health), originally developed from the SF-36, which offer good accuracy and decreased respondent burden [20].

#### Patient Neuropsychiatric Symptoms

The Neuropsychiatric Inventory Questionnaire (NPI-Q) [21-22] was used to assess 12 neuropsychiatric disturbances common in dementia patients: aberrant motor behavior, agitation, anxiety, apathy, appetite and eating disorders, delusions, disinhibition, dysphoria/depression, euphoria, hallucinations, irritability, and night-time behavior disturbances. The NPI-Q was cross-validated with the standard NPI [23-24] to provide a quantitative measure of patient symptom severity and caregiver distress in relation to different neuropsychiatric disturbances [21]. The total symptom severity score

ranges between 0-36; higher scores reflect greater severity of patient neuropsychiatric symptoms. The total caregiver distress score ranges between 0-60; higher scores reflect greater caregiver distress in relation to patient neuropsychiatric symptoms. The reliability and validity of this measure has been previously established [21-22].

Because the NPI-Q does not assess some symptoms that are common in patients with bvFTD, we developed and included eight additional NPI-Q items to assess these symptoms/behavioral disturbances: loss of insight, social inappropriateness, social avoidance, criminal behavior, hypersexuality, hyposexuality, preference for sweets, and perseverations/obsessions. The study investigator (CW) verified these items with family caregivers at a FTD caregiver support group meeting in San Francisco. For these eight additional NPI-Q items, each question corresponded to a symptom/behavioral problem (refer to Table 1). Participants were first asked to respond *Yes* (present) or *No* (absent) to each question. If caregivers answered *No*, they proceeded to the next question. If they answered *Yes*, they rated the severity of symptoms in the previous month on a 3-point scale. Participants were then asked to rate the amount of emotional distress caused by each neuropsychiatric symptom on a 6-point scale. The total symptom severity score for the eight additional NPI-Q items ranges between 0-24; higher scores reflect greater severity of patient neuropsychiatric symptoms. The total caregiver distress score ranges between 0-40; higher scores reflect greater caregiver distress in relation to patient neuropsychiatric symptoms.



**Table 1.** Additional NPI-Q Items

- 
1. **Loss of Insight:** During the past month, was the patient unaware of any problems and/or changes in his/her behavior?
  2. **Social Inappropriateness:** During the past month, did the patient say and/or do things that are socially unacceptable? This may include being rude or acting childish.
  3. **Social Avoidance:** During the past month, did the patient seem socially disengaged and/or avoided social situations and interactions with others?
  4. **Criminal Behavior:** During the past month, was the patient involved in any type of criminal behavior, such as traffic violations, shoplifting, and public indecency?
  5. **Hypersexuality:** During the past month, has the patient's sexual behavior been unusually excessive? This may include making sexual remarks, touching others inappropriately, and undressing more frequently.
  6. **Hyposexuality:** During the past month, has the patient's sexual behavior been unusually diminished or absent? This may include difficulty achieving sexual arousal and/or an inability to achieve an orgasm.
  7. **Preference for Sweets:** During the previous month, has the patient been consuming excessive quantities of sweets, such as candies and pastries?
  8. **Perseverations/Obsessions:** During the past month, has the patient been repeating actions and/or remarks?
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NPI-Q = Neuropsychiatric Inventory Questionnaire.

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#### *Data Analysis*

We used SPSS version 19.0 to conduct all data analyses. For the quantitative variables of interest, mean scores were calculated to assess central tendency along with their standard deviations as a measure of dispersion. To assess the magnitude and direction of the linear relationships between the quantitative variables of interest, Pearson's correlation coefficient tests were conducted.

After examining bivariate relationships, two, separate, standard multiple linear regression tests were conducted to determine whether patient symptom severity and caregiver distress from patient symptoms made statistically significant unique contributions to caregiver mental health above and beyond the influence of other important variables (e.g., caregiver age). For the first multiple regression (MR 1), the dependent variable was caregiver mental health and the independent variables entered into the model were the NPI-Q Severity scores (total patient symptom severity score from the NPI-Q), caregiver age, the number of years caregivers had known their patient, and the number of years they had been providing care for that person. For the second multiple regression (MR 2), the dependent variable was still caregiver mental health, but the independent variables entered into the model were the NPI-Q Distress scores (total caregiver distress score from the NPI-Q), caregiver age, the number of years caregivers had known their patient, and the number of years they had been providing care to that person. Alpha was set at 0.05 for all data analyses.

## Results

### *Caregiver and Patient Demographic Characteristics*

**Table 2.** Caregiver and Patient Demographic Characteristics, NPI-Q, MCS, and PCS

	Caregiver (n = 61)	Patient (n = 61)
Gender, <i>n</i> (%)		
Female	48 (78.7)	20 (32.8)
Male	13 (21.3)	41 (67.2)
Mean age, years	61.85 (10.83)	65.79 (9.35)
Relationship to patient, <i>n</i> (%)		
Spouse (or equivalent)	55 (90.2)	
Daughter	4 (6.6)	
Other	2 (3.3)	
Race/ethnicity, <i>n</i> (%)		
Caucasian/White	57 (93.4)	58 (95.1)
African American/Black	1 (1.6)	1 (1.6)
Hispanic	1 (1.6)	1(1.6)
Chinese	2 (3.7)	1(1.6)
Duration caregiver has known patient, years	39.39 (13.83)	
Duration of caregiving, years	5.96 (8.03)	
Number of years since diagnosis		4.45 (2.49)
NPI-Q Severity (0-36, <i>n</i> = 59)		12.31 (6.14)
NPI-Q Distress (0-60, <i>n</i> = 58)	15.36 (8.52)	
SF-12: Physical Component Score	51.49 (11.22)	
SF-12: Mental Component Score	42.49 (10.96)	
Results presented as means with standard deviations in parenthesis unless otherwise specified. N = 61 unless otherwise specified. NPI-Q = Neuropsychiatric Inventory Questionnaire. NPI-Q Distress = total caregiver distress score on the NPI-Q. NPI-Q Severity = total patient symptom severity score on the NPI-Q. MCS = mental component score from the SF-12. PCS = physical component score from the SF-12.		

Table 2 presents the demographic characteristics of the sample. Caregivers had an average age of 62 (range: 35-90), and most were women (78.7%), Caucasian/White (93.4%), and married or partnered (95.1%). Caregivers had known their patient for an average of 39 years and had been providing care for an average of 6 years. About half (52.5%) of the caregivers were not receiving any type of paid support at home; 43% were

receiving some type of paid support 1-2 days per week. Almost half (47.5%) of the caregivers were receiving no unpaid support from friends or relatives; about 44% of the caregivers were receiving unpaid support 1-2 days a week.

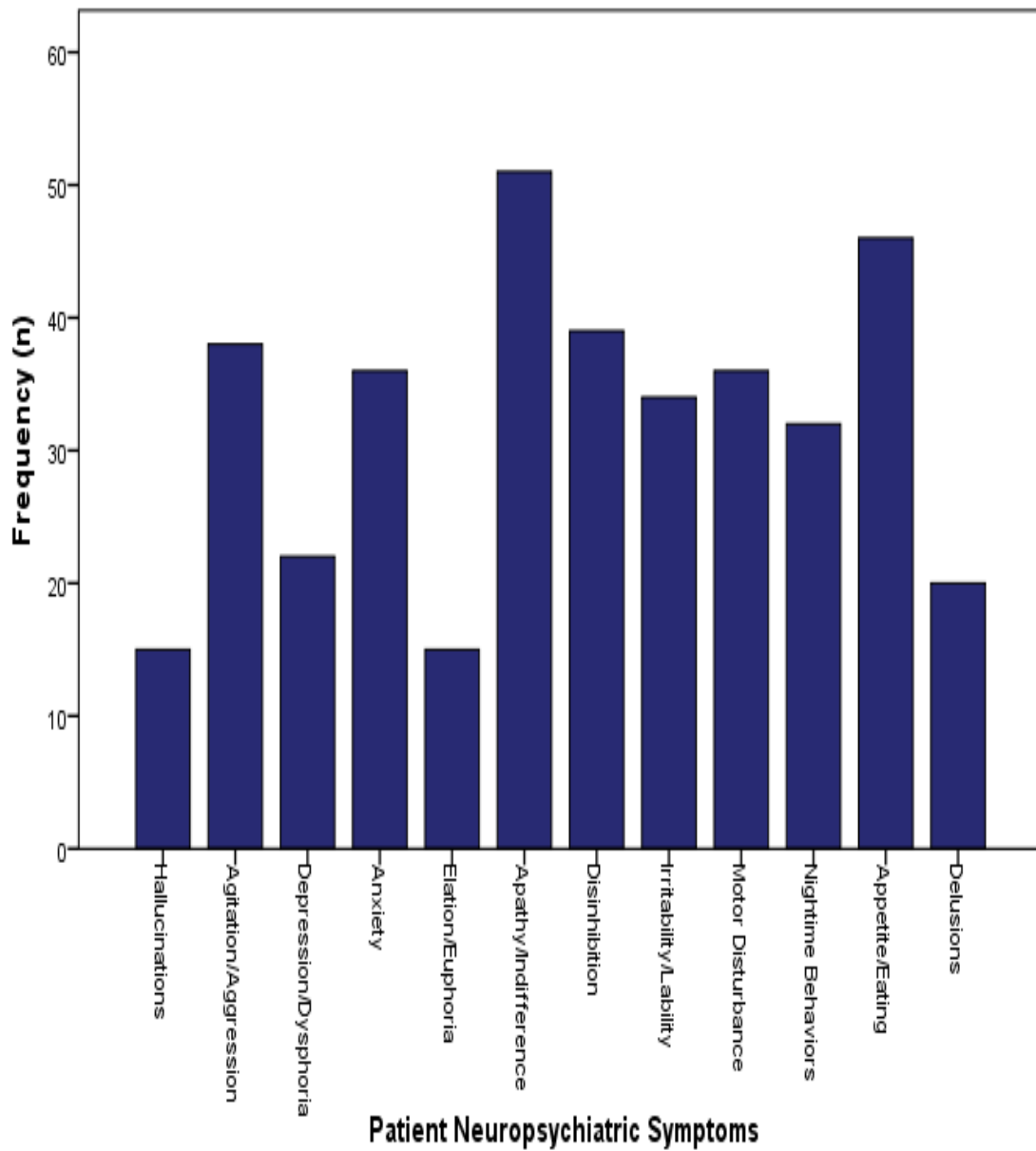
The average age of the patients was 66 years (range: 38-88), and the average number of years since FTD diagnosis was about 4 (SD = 2.49). Most patients were men (67.2%) and Caucasian/White (95.1%).

*Patient Neuropsychiatric Symptoms and Behavioral Problems*

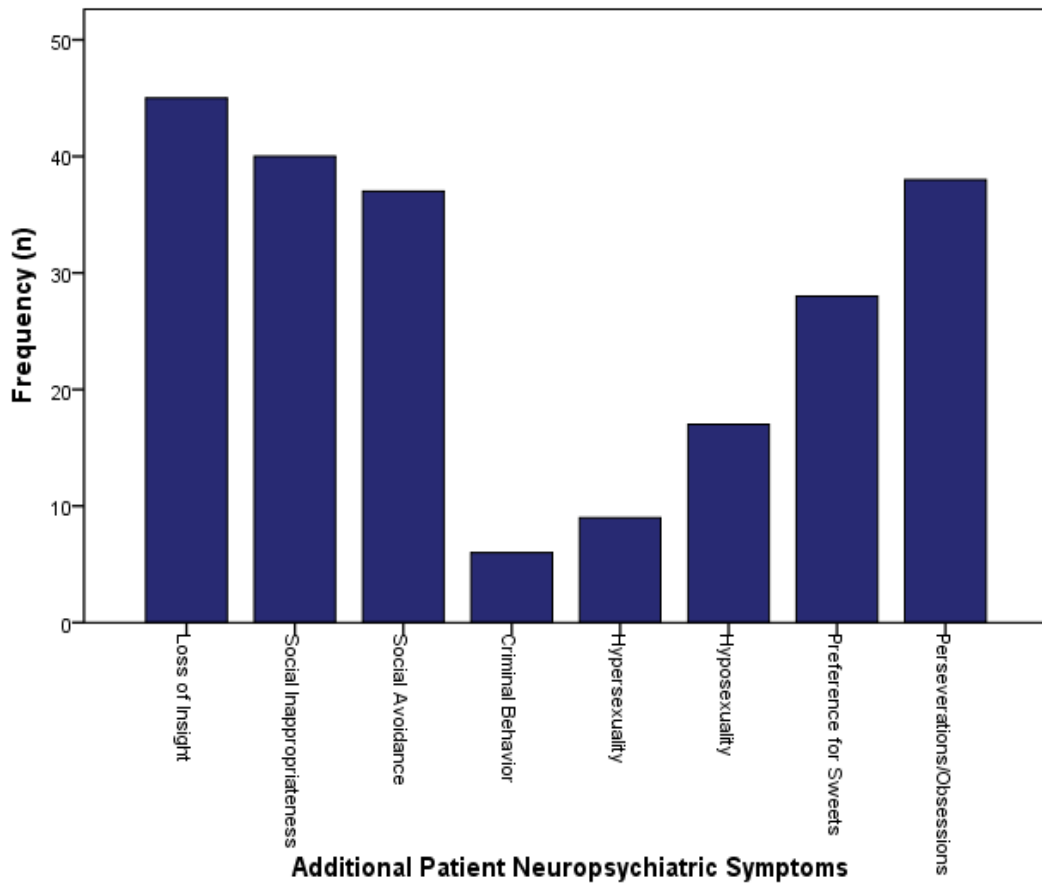
**Table 3.** Means and Standard Deviations for the NPI-Q and Additional Neuropsychiatric Symptoms

Symptom	Frequency (%)	Patient symptom severity mean $\pm$ SD (median)	Caregiver distress mean $\pm$ SD (median)
<b>NPI-Q</b>			
Delusions	20 (32.8)	0.54 $\pm$ 0.89 (0)	0.69 $\pm$ 1.23 (0)
Hallucinations	15 (24.6)	0.41 $\pm$ 0.82 (0)	0.43 $\pm$ 0.94 (0)
Agitation/aggression	38 (62.3)	1.08 $\pm$ 1.04 (1)	1.57 $\pm$ 1.54 (1)
Depression/dysphoria	22 (36.1)	0.61 $\pm$ 0.88 (0)	0.77 $\pm$ 1.28 (0)
Anxiety	36 (59)	1.05 $\pm$ 1.06 (1)	1.48 $\pm$ 1.52 (1)
Elation/euphoria	15 (24.6)	0.49 $\pm$ 0.94 (0)	0.46 $\pm$ 1.09 (0)
Apathy/indifference	51 (83.6)	1.82 $\pm$ 1.03 (2)	2.17 $\pm$ 1.53 (2)
Disinhibition	39 (63.9)	1.31 $\pm$ 1.15 (1)	1.62 $\pm$ 1.65 (1)
Irritability	34 (55.7)	1.03 $\pm$ 1.08 (1)	1.38 $\pm$ 1.56 (1)
Motor disturbance	36 (59)	1.18 $\pm$ 1.13 (1)	1.38 $\pm$ 1.50 (1)
Nighttime behaviors	32 (52.5)	1.07 $\pm$ 1.16 (1)	1.23 $\pm$ 1.41 (0.5)
Appetite/eating problems	46 (75.4)	1.56 $\pm$ 1.15 (2)	1.65 $\pm$ 1.55 (1)
<b>Additional NPI-Q Items</b>			
Loss of insight	46 (75.4)	1.18 $\pm$ 0.92 (1)	1.82 $\pm$ 1.46 (2)
Social inappropriateness	41 (67.2)	1.02 $\pm$ 0.90 (1)	1.41 $\pm$ 1.41 (1)
Social avoidance	37 (60.7)	0.98 $\pm$ 0.96 (1)	1.30 $\pm$ 1.35 (1)
Criminal behavior	6 (9.8)	0.20 $\pm$ 0.68 (0)	0.31 $\pm$ 1.07 (0)
Hypersexuality	9 (14.8)	0.30 $\pm$ 0.78 (0)	0.43 $\pm$ 1.15 (0)
Hyposexuality	17 (27.9)	0.39 $\pm$ 0.76 (0)	0.49 $\pm$ 1.15 (0)
Preference for sweets	28 (45.9)	0.74 $\pm$ 0.98 (0)	0.85 $\pm$ 1.30 (0)
Perseverations/obsessions	39 (63.9)	1.02 $\pm$ 0.98 (1)	1.34 $\pm$ 1.53 (1)

NPI-Q = Neuropsychiatric Inventory Questionnaire.



**Fig. 1.** Frequency of each neuropsychiatric symptom from the NPI-Q



**Fig. 2.** Frequency of eight additional neuropsychiatric symptoms

Table 3 presents the frequency, means, and standard deviations of each neuropsychiatric symptom on the NPI-Q and the eight additional neuropsychiatric symptoms. Figures 1 and 2 illustrate the number (frequency) of patients who exhibited each neuropsychiatric symptom. Eighty-four percent of patients exhibited some degree of apathy/indifference. Other common neuropsychiatric symptoms included loss of insight (75%), appetite/eating problems (75%), social inappropriateness (67%), perseverations/obsessions (64%), and disinhibition (64%). Caregivers were most distressed when their patient exhibited apathy/indifference ( $M[SD] = 2.17[1.53]$ ) and loss

of insight ( $M[SD] = 1.82[1.46]$ ). Less commonly reported symptoms included elation/euphoria (25%), hallucinations (25%), hypersexuality (15%), and criminal behavior (10%).

*Correlations Between Patient Neuropsychiatric Symptoms and Caregiver Health*

**Table 4.** Correlations between self-report measures: NPI-Q, Additional NPI-Q Items, MCS, and PCS

Measure	1	2	3	4	5	6
1. NPI-Q Severity	1					
2. NPI-Q Distress	.86 *	1				
3. Additional NPI-Q Severity	.71 *	.67 *	1			
4. Additional NPI-Q Distress	.58 *	.66 *	.86 *	1		
5. MCS	-.26 *	-.40*	-.34 *	-.36*	1	
6. PCS	-.06	-.07	.02	-.01	-.26*	1

NPI-Q = Neuropsychiatric Inventory Questionnaire. NPI-Q Severity = total patient symptom severity score on the NPI-Q. NPI-Q Distress = total caregiver distress score on the NPI-Q. Additional NPI-Q Severity = total patient symptom severity score on the additional NPI-Q items. Additional NPI-Q Distress = total caregiver distress score on the additional NPI-Q items. MCS = mental component score from the SF-12. PCS = physical component score from the SF-12.

\* $p < .05$

Table 4 presents the correlations between the NPI-Q Severity scores, NPI-Q Distress scores, Additional NPI-Q Severity scores (total symptom severity score for eight additional neuropsychiatric symptoms), Additional NPI-Q Distress scores (total caregiver distress score from eight additional neuropsychiatric symptoms), MCS scores (as a measure of caregiver mental health), and PCS scores (as a measure of caregiver physical health). As expected, moderate-to-strong, statistically significant positive relationships were observed between the NPI-Q Severity scores, NPI-Q distress scores, Additional NPI-Q Severity scores, and Additional NPI-Q Distress scores ( $p > 0.05$  for all). The NPI-Q Severity scores had a small, statistically significant negative association with the MCS scores ( $r = -.26, p < 0.05$ ). Also, a small, statistically significant negative relationship was found between the Additional NPI-Q Severity scores and the MCS scores ( $r = -.34, p < 0.05$ ) and between the Additional NPI-Q Distress scores and the MCS scores ( $r = -.36, p < 0.05$ ). A medium negative relationship was noted between the NPI-Q Distress scores and the MCS scores ( $r = -.40, p < 0.05$ ). The severity of patient symptoms (as measured by the NPI-Q and Additional NPI-Q Severity scores) and caregiver distress from patient symptoms (as measured by the NPI-Q Distress and Additional NPI-Q Distress scores) was not statistically significantly related to the PCS scores ( $p > 0.05$  for all).

Standard regression analyses were subsequently conducted to determine whether the NPI-Q Severity scores and the NPI-Distress scores both made statistically significant unique contributions to caregiver mental health above and beyond the influence of other potentially influential variables. The selection of predictors was based on preliminary



analyses of the associations between the quantitative variables of interest and the study's aims. Preliminary analyses were also conducted to ensure no violation of the assumptions of linearity, normality, multicollinearity, and homoscedasticity. Multiple regression analyses that violated these assumptions were not reported. Although the maximum Mahalanobis distance value of 25.52 for MR 1 and 26.6 for MR 2 suggests the presence of outliers, the maximum Cook's distance value for both analyses was less than 1, indicating that no outliers are having an undue influence on the results of the models [27].

### *Multiple Regression Analyses*

MR 1 was conducted to assess the association between the NPI-Q Severity scores and the MCS scores beyond the influence of caregiver age, the number of years a caregiver had known the patient, and the number of years he or she had been providing care for the patient. Approximately 34.5% of the variance was explained by the model with 4 independent variables, and the entire model was statistically significant ( $R^2 = 0.35$ ,  $F [4, 54] = 7.11$ ,  $p < 0.05$ ). Only caregiver age made a statistically significant unique contribution to the MCS scores ( $B[SE] = 0.40[0.15]$ ,  $\beta = 0.40$ ,  $p < 0.05$ ) and explained approximately 9% of the variability in the MCS scores. The NPI-Q Severity scores did not make a statistically significant contribution to the MCS scores ( $B[SE] = -0.24[0.21]$ ,  $\beta = -0.14$ ,  $p = 0.25$ ) and only explained about 1.6% of the unique variance in the MCS scores. The number of years a caregiver had known the patient ( $B[SE] = 0.12[0.11]$ ,  $\beta = 0.16$ ,  $p = 0.28$ ) and the number of years the caregiver had been providing care to the patient ( $B[SE] = 0.16[0.15]$ ,  $\beta = 0.12$ ,  $p = 0.30$ ) did not make a statistically significant unique contribution to the MCS scores.

MR 2 was conducted to determine whether the NPI-Q Distress scores made a statistically significant unique contribution to the MCS scores above and beyond the influence of caregiver age and how long a caregiver had known and had been providing care for the patient. About 42.3% of the variance was explained by the model with 4 independent variables, and the entire model was statistically significant ( $R^2 = 0.43$ ,  $F [4, 53] = 9.72$ ,  $p < 0.05$ ). The NPI-Q Distress scores made a statistically significant unique contribution to the MCS scores ( $B[SE] = -0.41[0.14]$ ,  $\beta = -0.32$ ,  $p < 0.05$ ) and explained approximately 9.5% of the variability in the MCS scores. Caregiver age also made a statistically significant unique contribution to the MCS scores ( $B[SE] = 0.34[0.14]$ ,  $\beta = 0.34$ ,  $p < 0.05$ ) and explained approximately 6.6% of the variability in the MCS scores. The number of years a caregiver had known the patient ( $B[SE] = 0.15[0.11]$ ,  $\beta = 0.19$ ,  $p = 0.17$ ) and the number of years the caregiver had provided care to the patient ( $B[SE] = 0.17[0.15]$ ,  $\beta = 0.13$ ,  $p = 0.24$ ) did not make statistically significant unique contributions to the MCS scores.

## **Discussion**

The purpose of this study was to describe the frequency of neuropsychiatric symptoms and/or behavioral problems exhibited by patients with FTD and the emotional impact of these symptoms on family caregivers. This study also examined the relationship between caregiver health and patient symptom severity in addition to caregiver emotional distress from patient symptoms and behaviors. The most frequently reported patient symptoms included apathy/indifference (84%), loss of insight (75%), appetite/eating problems (75%), and social inappropriateness (67%). Caregivers reported

the greatest emotional distress from patient apathy/indifference and loss of insight. Even so, their average score still only registered as “mildly distressed.”

It is unclear why the participants, on average, were only mildly distressed by patient apathy/indifference and minimally-to-mildly distressed by patient agitation/aggression, appetite and eating problems, disinhibition, and loss of insight. Perhaps many of these caregivers were participating in support groups or belonged to an association that supports caregivers of persons with FTD. If so, these individuals may have had greater social support networks than other caregivers who did not have such support. In fact, more than 40% of the caregivers were receiving some type of paid support at least 1-2 days a week (e.g., paid formal caregiver) and unpaid support at least 1-2 days a week from friends, relatives, or neighbors. Thus, a number of the family caregivers in this study may have learned to effectively manage patient behaviors to minimize their negative emotional impact.

An inverse relationship was observed between the severity of patient symptoms and caregiver mental health, suggesting that the caregivers’ mental health improved as the severity of patient neuropsychiatric symptoms and/or behavioral disturbances decreased. In addition, caregiver emotional distress from patient neuropsychiatric symptoms and/or behavioral problems was negatively associated with caregiver mental health. No statistically significant relationship was detected between the severity of patient symptoms (in addition to caregiver distress from patient symptoms) and caregiver physical health.

However, in a multiple regression analysis, patient symptom severity did not make a statistically significant unique contribution to caregiver mental health after controlling for variables such as caregiver age and duration of caregiving. Consequently, other situational and demographic factors must be considered when examining the relationship between patient symptom severity and caregiver mental health. Results suggest that the negative effect of patient symptom severity on family caregivers may be mitigated by other personal and environmental factors, such as the caregivers' previous caregiving experiences and available resources. Future research is needed to identify potential variables that mediate or moderate the relationship between the severity of patient neuropsychiatric symptom and caregiver health and well-being.

Conversely, caregiver distress from patient symptoms did make a statistically significant unique contribution to caregiver mental health above and beyond the influence of the caregivers' age and how long they had known and been providing care to their patient. This finding suggests that the caregivers' personal experiences and perceived emotional distress from patient symptoms and/or behaviors may be more important and influential to caregiver mental health than merely the severity of their patient's symptoms or behavioral problems. Despite the severity of a patient's neuropsychiatric symptoms and/or behavioral problems, caregiver mental health may not be as affected or jeopardized if caregivers do not perceive these symptoms and/or behaviors to be particularly distressing and unmanageable.

These findings are consistent with those of previous studies that examined the affect of patient behavioral problems on the experiences of FTD family caregivers. For

instance, De Vugt et al. (2006) compared caregiver emotional distress from patient behavioral symptoms between Alzheimer's disease and FTD caregivers and found that apathy was the most common behavioral symptom and occurred more often among FTD patients (89%). In addition, the most distressing symptom for FTD caregivers was apathy (mean = 2.4; SD = 1.6) followed by disinhibition (mean = 2.0; SD = 1.7) [25]. In Mourik et al.'s (2004) study, apathy was noted in 95% of patients, with a mean composite score of 8.9 (SD = 3.3) [10]. Similarly, the current study also found that apathy was the most frequently reported patient symptom and the most distressing symptom for caregivers, on average. When a patient becomes indifferent and is no longer interested in matters of concern to a caregiver, the caregiver may feel distressed by the perceived lack of an emotional connection to the patient.

Knutson et al. (2008) found that caregiver burden was moderately correlated with patient behavioral disturbances among caregivers of patients with FTD ( $r = .45$ ;  $p = 0.01$ ; one-tailed), which shows that greater patient behavioral disturbances/neuropsychiatric symptoms are associated with an increase in caregiver burden [6]. In a stepwise multiple regression analysis, Knutson et al. (2008) also found that patient behavioral disturbances/neuropsychiatric symptoms, assessed by the NPI, explained 16% of the variability in caregiver burden scores ( $F [1, 24] = 5.68$ ,  $p = .03$ ; 6). Davis et al. (2007) found that patient behavioral problems were predictive of caregiver burden after controlling for caregiver depression and patient activities of daily living scores (as a measure of patient functional independence) ( $R^2 = 0.10$ ,  $F [1, 69] = 8.7$ , two-tailed,  $p < 0.01$ ; 9). In the current study, the severity of patient symptoms was negatively

correlated with caregiver mental health by itself; but in a multiple regression analysis, the severity of patient neuropsychiatric symptoms did not make a statistically significant unique contribution to caregiver mental health with three other independent variables. This finding reinforces the importance of considering other factors that could buffer the negative effect of patient behavioral problems on caregiver mental health, such as the caregiver's coping strategies, availability of social support, and perceived knowledge and ability to manage the severe behavioral problems common in patients with bvFTD.

Of note, caregiver age was positively correlated with caregiver mental health ( $r = .55, p < 0.05$ ). However, caregiver age was negatively associated with the severity of patient neuropsychiatric symptoms ( $r = -.29, p < 0.05$ ) and positively associated with the number of years a caregiver had known the patient ( $r = .62, p < 0.05$ ), which could partially explain the better mental health status noted among older FTD family caregivers in this study. These findings underscore the importance of focusing on the needs of not only older but also younger FTD caregivers and ensuring that they get the proper support and resources that they need to deal with the severe behavioral disturbances common in patients with bvFTD, such as disinhibition, obsessive behaviors, and social inappropriateness.

We are unsure why there was a statistically significant negative relationship between caregiver mental and physical health; the explanation could be the mere characteristics and nature of the sample. Caregivers in this study who reported better mental health may also be experiencing more physical health problems due to older age or other unknown reasons. Further study is needed to investigate potential mediators and

moderators influencing the relationship between caregiver physical and mental health in this population.

Individuals with bvFTD often present with a wide range of behavioral disturbances that are not typically seen in patients with Alzheimer's disease, such as personality changes, social awkwardness, and social inappropriateness [5]. Thus, acknowledging these behavioral problems and the emotional impact that they have on FTD family caregivers is very important. As expected, there were moderate-to-large, positive correlations between the NPI-Q scores and scores for the eight additional NPI-Q items in assessing both the severity of patient neuropsychiatric symptoms and caregiver distress from patient neuropsychiatric symptoms and/or behavioral problems. All of the neuropsychiatric symptoms and/or behavioral disturbances from the additional NPI-Q items (loss of insight, social inappropriateness, social avoidance, criminal behavior, hypersexuality, hyposexuality, preference for sweets, and perseverations/obsessions) were seen in the patients. Seventy-five percent of patients showed some degree of loss of insight, and more than half of the patients exhibited social inappropriateness (67%), perseverative/obsessive behaviors (64%), and social avoidance (61%). These findings underscore the potential value of incorporating the eight additional NPI-Q items into the NPI-Q when assessing patient behavioral problems and caregiver distress from patient neuropsychiatric symptoms and/or behavioral disturbances in FTD.

This study has a number of limitations that warrant consideration. First, because this was a cross-sectional study, we were unable to determine whether specific patient neuropsychiatric symptoms and/or behavioral problems predict changes in caregiver

physical and mental health outcomes over time. Second, the criteria used for establishing a diagnosis of FTD was unknown because our survey was anonymous and the diagnosis of FTD was based on caregiver self-report. However, the participants were contacted through an association that specifically supports caregivers of persons with FTD. Third, the sample size ( $n = 61$ ) was relatively small. According to Hulley and colleagues (2007), the sample size requirements when using the correlation coefficient ( $r$ ) for a medium effect size would be 85 subjects ( $\beta = 0.20$ ,  $\alpha = 0.05$ , two-sided test) [26]; and, according to Tabachnick and Fidell (2007) a sample size of 82 would be required to run a multiple regression with 4 independent variables ( $50 + 8[4] = 82; 27$ ). Although our sample size was relatively small, we still found statistically significant relationships between some of the quantitative variables of interest (e.g., the relationship between the severity of patient neuropsychiatric symptoms and caregiver mental health).

Despite its limitations, the current study is innovative: It focused on an understudied, at-risk population of family caregivers of persons with FTD and examined the relationship between patient neuropsychiatric symptoms and/or behavioral disturbances and caregiver health. Previous studies of dementia caregiving have not focused on the effect of patient neuropsychiatric symptoms and/or behavioral disturbances on the physical and mental health of FTD family caregivers. This study also examined additional neuropsychiatric symptoms and/or behavioral disturbances not assessed by the NPI-Q but commonly seen in patients with bvFTD, such as loss of insight, hyposexuality, and preference for sweet foods (e.g., pastries or candies). Furthermore, because the caregivers were recruited through the AFTD, a national



organization, participants included caregivers living in various locations throughout the United States and Canada.

This study's findings have important implications for clinicians and future research. They enlighten clinicians about the different neuropsychiatric symptoms and/or behavioral problems that family caregivers of persons with FTD deal with and enable them to help such caregivers anticipate these behavioral problems before they occur. The negative relationship that was found between the severity of patient neuropsychiatric symptoms and/or behavioral problems and caregiver mental health reinforces how important it is for clinicians to educate FTD family caregivers about strategies that can help them manage the severe behavioral problems common in bvFTD patients, thereby promoting caregiver mental health and well-being. When clinicians design caregiver interventions, this study's findings can help them focus on behavioral problems, such as apathy/indifference and loss of insight, which can be particularly distressing for family caregivers. Future caregiving studies are needed to assess the psychometric properties of the NPI-Q with the eight additional NPI-Q items in a larger sample of FTD family caregivers and to examine the effectiveness of different symptom management strategies that family caregivers can use to effectively manage the behavioral problems that are commonly seen in patients with bvFTD. Additional longitudinal studies are also needed to understand the effect of specific patient neuropsychiatric symptoms and/or behavioral problems on the health and well-being of FTD family caregivers over time.

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## **Chapter 5**

### Summary and Conclusions

Frontotemporal dementia (FTD) is a frequent cause of early-onset dementia, with a reported prevalence of 15 per 100,000 people among individuals 45 to 64 years of age (Ratnavalli et al., 2002). Individuals with behavioral variant of FTD (bvFTD) may show changes in personality and behavior, such as loss of insight, aggression, and disinhibition (Chan et al., 2011), or may become apathetic and have a tendency to neglect their personal hygiene (Kirshner, 2010). Off-label use of medications has been used to manage patient behavioral problems, but there are no disease-modifying agents specifically developed to treat FTD. Rather, treatment is based on the management of any associated difficult behaviors along with providing ongoing support to the family caregiver (Chan et al., 2011).

Family caregivers play a critical role in providing care for individuals with FTD at home, but there is a paucity of research on their health and well-being. Given the increasing number of people diagnosed with dementia (Wimo et al., 2003), it is imperative for researchers and clinicians to focus on the unique experiences of families providing care to someone with FTD so appropriate care management can be tailored to their specific needs. The goal of this dissertation was to understand factors associated with the mental and physical health of family caregivers of persons with FTD.

This dissertation presents the findings from a cross-sectional, descriptive study focusing on the experiences of primary family caregivers providing unpaid support and assistance to someone with FTD (with behavioral problems) at home. Chapter 2 examined the relationship between coping strategies used in response to patient neuropsychiatric symptoms and/or behavioral problems and caregiver mental and



physical health. Emotion-focused coping was associated with better subjective caregiver mental health and problem-focused coping was related to more positive subjective caregiver physical health. These findings support the potential value of using emotion-focused coping strategies, such as getting emotional support from others or humor, when dealing with neuropsychiatric symptoms and/or behavioral problems in FTD. Chapter 3 provides evidence that greater perceived control experienced by FTD family caregivers is associated with more positive caregiver mental health. Chapter 4 describes the frequency of different neuropsychiatric symptoms and/or behavioral problems in FTD and provides evidence of the negative affect of caregiver distress from patient neuropsychiatric symptoms on FTD caregivers' mental health. In addition, the severity of patient neuropsychiatric symptoms was negatively associated with caregiver mental health. These findings underscore the importance of focusing on the perceived demands experienced by family caregivers and ensuring they are getting the necessary support and resources they need to effectively manage patient behavioral disturbances.

Overall, findings from this study are consistent with previous caregiving research providing evidence of the negative impact of behavioral problems in FTD on family caregivers. Previous research on family caregivers of persons with dementia have shown that behavioral disturbances common in patients with bvFTD are strong contributors to caregiver psychological distress and burden (Baumgarten et al., 1992; Clyburn, Stones, Hadjistavropoulos, Tuokko, 2000; Pinquart & Sorensen, 2003). Patient behavioral disturbances associated with dysfunction in the frontal system of the brain (e.g., executive dysfunction, disinhibition, and apathy) have also been shown to be a predictor

of caregiver burden (Davis & Tremont, 2007; Rymer et al., 2002). De Vugt et al. (2006) compared caregiver distress from patient behavioral problems between AD ( $n = 47$ ) and FTD ( $n = 27$ ) family caregivers and found that FTD family caregivers perceived caregiving as more distressing ( $t = 3.4, p < .05$ ).

Results from this dissertation study also contribute to the caregiving literature on coping, which support an association between coping and the health and well-being of dementia family caregivers. For instance, the use of problem-focused coping strategies, such as planning and seeking instrumental support, has been negatively associated with caregiver burden (Di Mattei et al., 2008; McConaghy & Caltabiano, 2005). On the other hand, Cooper et al. (2008) found a statistically significant positive relationship between problem-focused coping and caregiver burden ( $r = 0.46, p < 0.001$ ). In this dissertation study, problem-focused coping was positively associated with caregiver physical health, which provides support for FTD caregivers' use of coping strategies focusing on managing problems that cause distress when dealing with patient behavioral disturbances.

Previous dementia caregiving studies have found support for the deleterious effects of using emotion-focused coping strategies on the mental health of family caregivers (Butt et al., 2002; Knight et al., 2000). For instance, the use of emotion-focused coping strategies have been found to be associated with increased caregiver burden (Cooper et al., 2008; Papastavrou et al., 2007). Mausbach and colleagues (2006) tested a meditational model of the associations between patient problem behaviors, escape-avoidance coping, and depressive symptoms in AD caregivers ( $N = 99$ ). Findings from the study by Mausbach and colleagues (2006) confirmed that escape-avoidance

coping significantly mediated the relationship between patient behavioral problems and caregiver depression. Despite these previous findings, the current study provides support for FTD caregivers' use of emotion-focused coping strategies when dealing with stressors or situations perceived as not amenable to change, such as certain types of patient neuropsychiatric symptoms and/or behavioral problems. The next section will focus on the pertinent implications of this dissertation for clinicians, policy, theory, and future research in FTD family caregiving.

### **Clinical Implications**

The findings from this dissertation have a number of important implications for clinicians. Clinicians may use these findings to inform FTD family caregivers about different emotion-focused coping strategies when managing patient neuropsychiatric symptoms and/or behavioral problems and encourage these caregivers to focus on their own emotions when dealing with a stressful situation perceived as not amenable to change. In addition, caregiver support groups could be tailored to provide opportunities for family caregivers to express their feelings about providing care for a family member with behavioral problems, receive the necessary emotional support, and share past caregiving experiences of effectively coping with similar problems. Clinicians may also raise awareness about various problem-focused coping strategies, such as seeking instrumental support from others and problem-solving, when FTD caregivers are confronted with a particular situation which necessitates a need to take action and focus on the problem at hand in order to promote patient safety and well-being.

This dissertation also underscores the importance of assessing the perceived control of FTD family caregivers. Clinicians should not overlook the self-perceptions and perceived demands and resources of FTD caregivers in order to understand their unique needs and help them gain the necessary tools to continue providing safe care at home. In addition, findings from this research could serve as an impetus for the development of caregiver education programs focusing on different strategies FTD family caregivers may utilize in an effort to increase their perceived control, such as becoming more informed about FTD and seeking additional sources of social support.

Furthermore, this dissertation could help clinicians gain a better appreciation about the different neuropsychiatric symptoms and/or behavioral problems dealt by FTD family caregivers and the impact of these symptoms/behaviors on caregivers. The inverse relationship that was found between patient symptom severity and caregiver mental health highlights the importance of clinicians to educate FTD family caregivers about effective strategies for managing problematic symptoms/behaviors common in bvFTD. The findings from this dissertation may also assist in the development of future caregiver interventions by helping clinicians focus on the management of specific behavioral problems, such as apathy and loss of insight, which may be particularly distressing for FTD family caregivers.

### **Policy Implications**

This dissertation underscores the importance of raising public awareness about issues related to FTD family caregiving. Policy implications include promoting the development and utilization of community-based caregiver support programs

(e.g., coping skills training, education about dementia care, and in-home nursing care) targeted towards better meeting the specific needs of FTD family caregivers. A significant legislative accomplishment for family caregivers is the passage of the National Family Caregiver Support Program, funded through the federal Older Americans Act, which provides various services to family caregivers, such as respite care and counseling (<http://www.agingcarefl.org/caregiver/NationalSupport>). However, FTD family caregiver may benefit from services tailored more towards their specific needs, such as education and support for managing some of the severe behavioral problems common in bvFTD. Additional funding sources are also needed in FTD caregiving research to gain a better understanding about specific resources that will enhance the caregiving experiences of FTD family caregivers.

### **Theoretical Implications**

In Chapter 1, the life course theory was proposed to provide a contextualized approach towards studying the unique experiences of FTD family caregivers (Elder, 1977, 1999). The life course view acknowledges “that timing and sequencing norms are affected by and change with historical period, the age of the individual experiencing events, and the norms carried by the birth cohort” (White & Klein, 2008, p. 140). Moreover, “age variations in expectations and options that impinge on decision making and the course of events give shape to life stages, transitions, and turning points” (Elder, 1977, p. 282). Hence, FTD family caregivers experience a different course of events and have different expectations, norms, and opportunities as they grow older, which all influence the choices they make and their caregiving experiences. In addition, the

emotional, psychological and physical impact of providing continuous care for someone with FTD and behavioral problems may vary depending on the caregiver's age and other background factors.

Findings from this dissertation study contribute to the life course theoretical perspective by highlighting the important health impact of caregiver age and situational factors on FTD family caregivers. The strong, positive association between perceived control and caregiver mental health underscores the importance of examining the perceived demands of FTD family caregivers and ensuring they are receiving the resources and support they need to continue providing care at home. Given the cross-sectional nature of this study, we were unable to examine how previous socio-historical events influence the health and well-being of FTD family caregivers over time; however, we were able to examine the influence of caregiver age among FTD family caregivers. Interestingly, caregiver age had an inverse relationship with the use of dysfunctional coping strategies and severity of patient neuropsychiatric symptoms. Caregiver age was positively associated with caregiver mental health and perceived control, suggesting that as caregiver age increased caregiver mental health improved and the caregivers' experienced greater perceived control. In addition, caregiver age made a statistically significant unique impact on caregiver mental health even after controlling for variables such as caregiver gender, duration of caregiving, and patient symptom severity. Despite the largely positive outcomes associated with increased caregiver age, additional data is needed to understand other circumstantial and contextual factors that could be

moderating and/or mediating the relationship between caregiver age and mental health among FTD family caregivers.

It is also important to acknowledge potential normative and non-normative influences affecting life course progression in FTD family caregivers. Normative age-graded influences are linked to caregiver age and pertain to the expected changes in the biological, emotional, psychological and social aspects of an individual as he or she ages. These influences encompass physical and emotional maturation during childhood as well as typical changes in social roles as one grows older, such as family and work roles and responsibilities. Examples of age-graded normative influences include beginning formal education, graduation, marriage, retirement from work, and biological determinants such as puberty and menopause. Non-normative influences include unexpected events that significantly impact the lives of FTD caregivers, such as a major personal injury or illness. A prominent non-normative influence experienced by the caregivers in this study was being faced with the challenges and difficulties of caring for a loved one with FTD at an earlier time in one's life course than otherwise expected. Due to the intense nature of caregiving for someone with FTD, these family caregivers may need to make major changes in other aspects of their life to continue providing safe and effective care at home.

Furthermore, it is important to appreciate the impact of cohort effects or social changes over the 20<sup>th</sup> and 21st century on FTD family caregivers. Because most of the participants were middle-aged, these caregivers were likely affected by the feminist movement in the 1960s, rapidly changing demographics of western society, advances in

technology, and evolving family and gender roles. The philosophy of postmodernism, along with the growing feminist interest, ultimately gave shape to the development of feminist epistemology (White & Klein, 2008). The concept of *feminism* has been attributed to the following: a concern with political or personal action; the struggle for equality; respecting the individual; and an awareness of oppression that may be experienced by women (Allan, 1993). Feminist postmodernists believe that different ethnic groups, socioeconomic classes and genders have varying views of the world, so it is misleading to have a singular description of the world (Godfrey-Smith, 2003). As a result, an increasing number of men have assumed the role of the family caregiver, and more women have been entering the workforce while managing multiple caregiving roles. In fact, over half of family caregivers are the primary breadwinners of the household (55%) and employed full or part time (44%), and 26% of family caregivers have children under 18 years old who are living with them (Alzheimer's Association, 2011). Although there is greater recognition and acceptance of men serving as family caregivers, additional research is needed on the peculiar experiences of male FTD family caregivers to identify the services and strategies that could better meet their needs.

### **Implications for Future Research**

Given the cross-sectional design of this study, one cannot infer the causal effects of different variables on caregiver health outcomes or examine the effects of caregiver coping responses over time. Therefore, future longitudinal research studies with repeated measures and/or hierarchical linear modeling would be ideal to evaluate the effect of different coping strategies on the health and well-being of FTD family caregivers over



time and examine the longitudinal impact of patient neuropsychiatric symptoms and/or behavioral disturbances on family caregivers. Caregiver physiological measures, such as markers of immune function and stress, would also be interesting and potentially useful to investigate in future longitudinal research on FTD caregivers.

Caregiver intervention research has been found to achieve clinically significant outcomes in improving caregiver depression and delaying institutionalization of patients (Schulz et al., 2002). However, there are currently no published randomized controlled trials designed to alleviate caregiver burden and distress among FTD family caregivers. Future experimental studies on FTD family caregivers are needed to assist in the identification of effective coping strategies and strategies for managing common behavioral problems manifested in persons with bvFTD.

Future qualitative studies are also needed to provide an in-depth understanding of the caregiving experiences of FTD family caregivers, which cannot be captured through quantitative research methods. A qualitative approach to studying FTD family caregiving could improve our understanding about how FTD family caregivers make sense of their caregiving experiences and life world in their own environment (Holloway & Wheeler, 2002). Kumamoto et al. (2004) conducted case reports on two FTD patients and their family caregivers and provides a clear description about the specific behavioral problems of the FTD patients; however, the article provides limited information about how behavioral disturbances affect the family caregivers or how social and psychological factors may influence the effects of these behaviors. More qualitative studies are needed

to further explore the caregiving experiences of FTD caregivers in the home and assist the public in better understanding factors contributing to their mental well-being.

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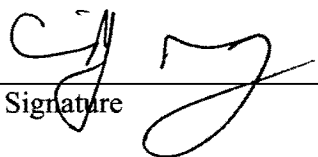
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