Family Caregivers of Individuals with Frontotemporal Dementia
Examining the Relationship Between Coping and Caregiver Physical and Mental Health

ABSTRACT
To identify strategies to assist family caregivers of individuals with frontotemporal dementia (FTD) in dealing with their caregiving demands, nurses must understand these family members’ unique needs and how they currently deal with their demands. The purpose of this study was to examine the relationship between coping and caregiver physical and mental health among FTD family caregivers. Participants were primary caregivers of individuals with FTD (with behavioral symptoms) living at home (N = 61). A small positive association was noted between problem-focused coping and caregiver physical health (r = 0.29, p < 0.05), and a small but nonsignificant positive correlation was noted between emotion-focused coping and caregiver mental health (r = 0.21, p = 0.10). However, multiple regression analysis showed that emotion-focused coping (β = 0.46, p < 0.05) 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 behavioral symptoms manifested by individuals with FTD. [Journal of Gerontological Nursing, xx(xx), xx-xx.]

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

The direct cost of caring for an individual with FTD has been reported to be $4,924 per year (Rojas et al., 2011), and comparative studies of family caregivers of individuals with FTD and AD 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). Providing care for someone with a behavioral variant of frontotemporal dementia (bvFTD) can be particularly challenging and overwhelming because such patients usually have a broad range of behavioral and neuropsychiatric symptoms, such as social awkwardness, personal neglect, and an unusual preference for sweet foods and carbohydrates (Snowden et al., 2001).

Negative outcomes caused by caregiving for someone with bvFTD could potentially 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 individuals with bvFTD in dealing with the demands they experience, nurses must understand the family members’ 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 nurses, and assist in the development of targeted nursing 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 (1984, 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. Emotion-focused coping is primarily cognitive and directed at decreasing emotional distress, and problem-focused coping strategies aim to manage problems that cause distress (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 symptoms are common in individuals with bvFTD, this study focused on the coping strategies that family caregivers use in response to various behavioral and neuropsychiatric symptoms manifested by individuals with FTD.

STUDY PURPOSE

The purpose of this study was to examine the relationship between the coping strategies used by family caregivers in response to behavioral symptoms exhibited by individuals with FTD and the caregivers’ physical and mental health. Our hypotheses were: (a) problem-focused coping will be associated with more positive caregiver physical and mental health, (b) emotion-focused coping will be associated with more positive caregiver physical and mental health, and (c) dysfunctional coping will be associated with more negative caregiver physical and mental health.

METHOD

Recruitment and Sample

Potential participants were recruited between June 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 of the Association for Frontotemporal Degeneration (AFTD, http://www.theaftd.org), which is a nonprofit organization whose mission includes promoting FTD research and providing support to individuals with FTD and their family caregivers. 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 (C.C.W.) contact information. Potential participants were also recruited from FTD caregiver support groups in Portland, Oregon, and San Francisco, California.

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

Eighty questionnaire packets were sent out to potential participants who expressed interest in participating in the study; 63 questionnaire packets were returned by standard mail (79% response rate). Two questionnaire packets were excluded from the data analyses because they arrived after the study enrollment period. Thus, data on 61 caregivers were collected and analyzed.

Procedures and Ethical Considerations

The family caregivers accepted into the study completed a set of questionnaires that elicited their observations of the care recipient, their own general physical and mental health, coping strategies, their relationship with the care recipient, and their experiences as a caregiver of someone with FTD with behavioral symptoms. Interested and eligible family caregivers received hard copy versions of the questionnaires by standard mail or from the co-principal investigator (C.C.W.) during an FTD caregiver support group meeting. All measures were self-administered, and participants completed the questionnaires on their own time in a convenient location. Upon receipt of the questionnaires, participants had the option of receiving a $5 gift card to a supermarket in appreciation of their
efforts. The questionnaires, which took approximately 30 minutes to complete, were submitted anonymously by standard mail.

The participating university’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 is a 28-item self-report questionnaire that was used to assess the participants’ coping strategies (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 neuropsychiatric and/or behavioral symptoms exhibited by care recipients with FTD. 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, Cronbach’s alpha coefficients = 0.72, 0.84, and 0.75, respectively. Test-retest reliability (over 1 year) has been shown for the emotion-focused (r = 0.58), problem-focused (r = 0.72), and dysfunctional coping (r = 0.68) subscales among caregivers in whom burden scores did not change significantly (p < 0.001; Cooper, Katona, & Livingston, 2008). Furthermore, an exploratory factor analysis yielded a factor structure that was consistent with the full COPE (Carver, 1997), and evidence of concurrent and con-
vergent validity has been shown in regression analyses (Cooper, Katona, & Livingston, 2008). In this sample, Cronbach’s alpha coefficients were 0.80 for emotion-focused, 0.66 for problem-focused, and 0.62 for dysfunctional coping strategies.

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, Katona, and Livingston (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 emotional support, religion, positive reframing, humor, and acceptance. 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, planning, and instrumental support. The dysfunctional subscale includes coping strategies that are believed to exacerbate caregiver distress (Carver et al., 1989). Dysfunctional coping strategies include self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame.

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 care recipient. 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 as perceived by the family caregiver.

Patient Neuropsychiatric Symptoms. The Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer et al., 1998, 2000) was used to assess 12 neuropsychiatric disturbances common in individuals 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 provides a quantitative measure of patient symptom severity and caregiver distress in relation to specific neuropsychiatric disturbances. 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). The intraclass correlation (ICC) between two raters of the NPI-Q was $r = 0.96$ ($p < 0.001$; Kaufer et al., 1998), and test-retest correlations between the total symptom and caregiver distress scores on the NPI-Q were 0.80 and 0.94 ($p < 0.0001$ for both; Kaufer et al., 2000).

Caregiver and Patient Demographic Characteristics. The collected demographic characteristics of

![Table 2](image)

**Table 2**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>61.85 (10.83)</td>
<td>35 to 90</td>
</tr>
<tr>
<td>NPI-Q (distress) (0 to 60, n = 58)</td>
<td>15.36 (8.52)</td>
<td>0 to 35</td>
</tr>
<tr>
<td>SF-12: Physical component score</td>
<td>51.49 (11.22)</td>
<td>18.62 to 64.85</td>
</tr>
<tr>
<td>SF-12: Mental component score</td>
<td>42.49 (10.96)</td>
<td>23.29 to 66.14</td>
</tr>
<tr>
<td>CSI (0 to 21, n = 60)</td>
<td>9.31 (5.02)</td>
<td>0 to 19</td>
</tr>
<tr>
<td>Care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>65.79 (9.35)</td>
<td>38 to 88</td>
</tr>
<tr>
<td>Number of years since diagnosis</td>
<td>4.45 (2.49)</td>
<td>1 to 12</td>
</tr>
<tr>
<td>NPI-Q (severity) (0 to 36, n = 59)</td>
<td>12.31 (6.14)</td>
<td>0 to 27</td>
</tr>
</tbody>
</table>

Note. NPI-Q = Neuropsychiatric Inventory Questionnaire (Kaufer et al., 1998, 2000), where higher scores reflect greater severity of patient neuropsychiatric symptoms; SF-12 = Short-Form Health Survey (Ware, Kosinski, & Keller, 1996), where higher scores indicate greater health; CSI = Couples Satisfaction Index (Funk & Rogge, 2007), where higher scores indicate better relationship satisfaction as perceived by the family caregiver.

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caregivers and care recipients included age, gender, and race/ethnicity. Also collected was information about the caregivers’ relationship to the care recipient (i.e., spouse versus children), the number of years the caregiver has known the care recipient, and the number of years the caregiver has been providing care to the care recipient.

**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 (SF-36), which is a generic health measure that is applicable to a variety of settings (Ware & Gandek, 1998; Ware & Sherbourne, 1992). Test-retest (2-week) correlations for the 12-item Physical Component Summary (PCS) and Mental Component Summary (MCS) were found to be 0.89 and 0.76, respectively, in the general U.S. population (N = 232; Ware et al., 1996). The stability of the SF-12 has been found to be good for both the PCS (ICC = 0.79) and the MCS (ICC = 0.79) among people with severe mental illness (N = 64; Salyers, Bosworth, Swanson, Lamb-Pagone, & Osher, 2000). Furthermore, the SF-12’s two summary scales (physical health and mental health) have been shown to have good accuracy and less respondent burden compared to the SF-36 (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 categorical data. To assess the magnitude and direction of the relationships between the quantitative variables of interest, Pearson’s correlation coefficients were conducted. To determine if there were statistically significant gender differences in the 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 tests.

Bivariate relationships were initially explored, followed by two, 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 age, gender, and race/ethnicity.

**TABLE 3**

MEANS AND STANDARD DEVIATIONS FOR THE BRIEF COPE SCALE$^a$ (N = 61)

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

$^a$ Brief COPE Scale (Carver, 1997), where higher scores indicate using the strategy a lot.
as caregiver relationship satisfaction (as measured by the CSI) and demographic characteristics. The selection of independent variables was based on preliminary analyses of the associations between the quantitative variables of interest and the study’s purpose. For the 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. 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.

The sample size requirements when using the correlation coefficient ($r$) for a medium effect size would be 85 participants ($\beta = 0.20$, Cronbach’s coefficient alpha $= 0.05$; Hulley, Cummings, Browner, Grady, & Newman, 2007). A medium effect size was selected because a moderate association has been found between patient neuropsychiatric symptoms and caregiver burden in previous dementia caregiving studies (Davis & Tremont, 2007; Knutson, Zamboni, Tierney, & Grafman, 2008). Furthermore, according to Tabachnick and Fidell (2005) a sample of 82 would be required to run a multiple regression with four independent variables. Due to the potential for missing data, however, the target sample size was 95 participants. For all analyses, the alpha value was set at 0.05 (two tailed).

## RESULTS

### Demographic Characteristics

Table 2 presents the demographic characteristics of the sample. Most of the caregivers were women (78.7%), spouses (90.2%), Caucasian/White (93.4%), and married/partnered (95.1%). Most of the care recipients were men (67.2%) and Caucasian/White (95.1%). There were 4 daughter caregivers (6.6%) and 2 caregivers (3.3%) who reported another type of relationship to the care recipient. On average, the caregivers had known their care recipient for 39 years ($SD = 13.83$, range = 4 to 70 years) and had been providing care for approximately 6 years ($SD = 8.03$, range = 1 to 47 years).

### Coping Strategies

Table 3 presents the mean scores for each coping subtype (emotion-focused, problem-focused, and dysfunctional coping) and strategy. On average, the caregivers most often used acceptance (mean = 6.80, $SD = 1.29$), active coping (mean = 6.48, $SD = 1.36$), and planning (mean = 6.31, $SD = 1.32$) when dealing with care recipient behavioral symptoms. Coping strategies used the least, on average, included behavioral disengagement (mean = 2.52, $SD = 0.83$) and denial (mean = 2.77, $SD = 1.16$).

### Correlations Between Quantitative Caregiver Variables

Table 4 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 coping and caregiver age ($r = -0.27, p < 0.05$) and between dysfunctional coping and caregiver relationship satisfaction ($r = -0.35, p < 0.05$). Dysfunc-

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### Table 4

#### CORRELATIONS BETWEEN COPING AND CAREGIVER HEALTH VARIABLES ($N = 61$)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Emotion-Focused Coping</th>
<th>Problem-Focused Coping</th>
<th>Dysfunctional Coping</th>
<th>MCS</th>
<th>PCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused coping</td>
<td>1</td>
<td>0.48*</td>
<td>0.32*</td>
<td>0.21</td>
<td>-0.08</td>
</tr>
<tr>
<td>Problem-focused coping</td>
<td></td>
<td>1</td>
<td>0.06</td>
<td>0.01</td>
<td>0.29*</td>
</tr>
<tr>
<td>Dysfunctional coping</td>
<td></td>
<td></td>
<td>1</td>
<td>-0.18</td>
<td>0.02</td>
</tr>
<tr>
<td>MCS</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>PCS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Note. MCS = Mental Component Summary from the 12-Item Short-Form Health Survey (SF-12); PCS = Physical Component Summary from the SF-12.

*p* $< 0.05.$
tional coping was not significantly correlated with the PCS, the MCS, and NPI-Q severity scores ($p > 0.05$ for all).

Emotion-focused coping had a small, positive but nonstatistically significant correlation with the MCS ($r = 0.21$, $p = 0.10$). In addition, emotion-focused coping was not significantly correlated with the PCS ($r = -0.08$, $p = 0.54$), NPI-Q severity scores ($r = 0.21$, $p = 0.116$), or caregiver age ($r = -0.20$, $p = 0.12$). However, a positive and small statistically significant relationship was noted between emotion-focused coping and the CSI scores ($r = 0.26$, $p = 0.04$).

Problem-focused coping was not significantly related to the MCS, the caregivers’ age, NPI-Q severity scores, and the CSI scores ($p > 0.05$ for all analyses). However, a statistically significant positive association was noted between problem-focused coping and the PCS ($r = 0.289$, $p = 0.02$). To further examine the relationship between coping and caregiver physical and mental health after controlling for other variables, two regression analyses were conducted.

### Multiple Regression Analyses

Table 5 presents the results of two, standard, multiple regression tests. In the first multiple regression (MR 1), we examined the relationship between emotion-focused coping and caregiver mental health above after controlling for caregiver age, gender, and relationship satisfaction. Approximately 43% of the variance was explained by the model with four independent variables; the entire model was statistically significant, $R^2 = 0.43$, $F(4, 55) = 10.44$, $p < 0.05$. Emotion-focused coping ($b = 0.35$, $p < 0.05$) and caregiver age ($b = 0.59$, $p < 0.05$) 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 approximately 32% of the variance in the MCS. The unique variance explained by the CSI was only approximately 0.7% ($b = 0.09$, $p = 0.43$). Of note, emotion-focused coping was not significantly correlated with the MCS by itself ($r = 0.21$, $p = 0.10$), 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 beyond the influence of caregiver relationship satisfaction, age, and gender. Approximately 24% of the variance was explained by the model with four independent variables, and the entire model was statistically significant, $R^2 = 0.24$, $F(4, 55) = 4.45$, $p < 0.05$. Problem-focused coping ($b = 0.32$, $p < 0.05$) and the CSI ($b = -0.35$, $p < 0.05$) were the only independent variables that made a statistically significant unique contribution to the PCS. Problem-focused coping uniquely explained approximately 9.54% of the variance in the PCS; the CSI uniquely explained approximately 11.16% of the variance in the PCS.

### 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, $t(df) = -2.75(59)$, $p = 0.01$, 95% confidence interval (CI) $[-8.22,$
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, Katona, Orrell, & Livingston, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007) among family caregivers of individuals with AD; however, Van Den Wijngaart, Vernooij-Dassen, and Felling (2007) found no statistically significant association between emotion-focused coping and caregiver burden among spousal caregivers of non-institutionalized people with dementia (N = 95). More research is needed to better understand the relationship between emotion-focused coping and caregiver burden among FTD family caregivers.

Nevertheless, the current study supports FTD caregivers’ use of emotion-focused coping strategies when dealing with different neuropsychiatric symptoms manifested by those with FTD. 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 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). When a person deals with a caregiving situation or stressor that is 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. Likewise, previous studies found support for the deleterious effects of using coping strategies defined as dysfunctional, such as denial and substance use. For instance, avoid-

**KEYPOINTS**


1. This study examined the relationship between coping and caregiver physical and mental health among family caregivers of individuals with frontotemporal dementia (FTD).

2. Participants completed a set of questionnaires about their coping strategies, health, observations of the care recipient, and experiences as a caregiver of someone with FTD (N = 61).

3. The results support the potential value of emotion-focused coping strategies when dealing with behavioral symptoms manifested by individuals with FTD.

\[-1.30\] and problem-focused coping, \(t(df) = 2.69(36.36), p = 0.01, 95\% \text{ CI } [–3.10, –0.43]. \) However, no statistically significant gender differences were observed in the use of dysfunctional coping strategies, \(t(df) = 1.36(59), p = 0.18, 95\% \text{ CI } [–4.36, –0.83]. \) On average, women used more emotion-focused coping (women: mean = 26.84, \(SD = 5.81\); men: mean = 22.08, \(SD = 4.31\)), problem-focused coping (women: mean = 19.23, \(SD = 3.16\); men: mean = 17.46, \(SD = 1.71\)), and dysfunctional coping (women: 22.30, \(SD = 4.25\); men: mean = 20.54, \(SD = 1.04\)).

**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 exhibiting behavioral symptoms. 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: Problem-focused coping will be associated with more positive caregiver physical health, and emotion-focused coping will be associated with more positive caregiver mental health.

The findings on the relationship between problem-solving coping strategies and caregiver 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 (\(r = –0.43, p < 0.01\)); thus, caregivers who used more practical forms of coping had a tendency to report less burden (McConaghy & Caltabiano, 2005). Our findings that caregivers who used more problem-focused coping strategies tended to report more positive physical health 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. On the other hand, persons who report improved physical health may be better able to implement problem-focused coping strategies.

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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, Katona, Orrell, & Livingston, 2008; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007) among family caregivers of individuals with AD; however, Van Den Wijngaart, Vernooij-Dassen, and Felling (2007) found no statistically significant association between emotion-focused coping and caregiver burden among spousal caregivers of non-institutionalized people with dementia (N = 95). More research is needed to better understand the relationship between emotion-focused coping and caregiver burden among FTD family caregivers.

Nevertheless, the current study supports FTD caregivers’ use of emotion-focused coping strategies when dealing with different neuropsychiatric symptoms manifested by those with FTD. 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 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). When a person deals with a caregiving situation or stressor that is 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. Likewise, previous studies found support for the deleterious effects of using coping strategies defined as dysfunctional, such as denial and substance use. For instance, avoid-
ant coping (e.g., isolation, denial) has been found to be positively associated with caregiver depression (Mausbach et al., 2006). Cooper, Katona, and Livingston (2008) and Cooper, Katona, Orrell, et al. (2008), in using the Brief COPE Scale, found that dysfunctional coping was predicted by increased caregiver burden ($\beta = 0.36, p < 0.001$). To further clarify the effect of coping strategies currently considered dysfunctional, however, additional coping research studies on FTD family 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 usually find that female dementia caregivers tend to use more emotion-focused coping strategies than male caregivers (e.g., Van Den Wijngaart et al., 2007). McConaghy and Caltabiano (2005) found no significant differences between men and women on the use of emotional coping ($z = -1.507; U = 109.00, p = 0.14$), 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: mean $= 1.66$; women: mean $= 1.98, p < 0.05$) and wishful thinking (men: mean $= 1.66$, women: mean $= 1.92, p < 0.05$). Future research 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.

Why a small, negative correlation between caregiver mental and physical health ($r = -0.26, p < 0.05$) was found is unclear, 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 was relatively low (Cronbach’s alpha coefficients: problem-focused coping = 0.69, dysfunctional coping = 0.62). Although the internal consistency for the emotion-focused coping subscale was good (Cronbach’s alpha coefficient = 0.80), the results for problem-focused and dysfunctional coping should be interpreted with caution. Future research is needed to examine the psychometric properties of the Brief COPE Scale in a larger sample of FTD caregivers. 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, recruitment was based on membership to an association that specifically supports FTD caregivers or participation in an FTD caregiver support group affiliated with a Memory and Aging Center that offers comprehensive and interdisciplinary evaluations for the diagnosis and treatment of FTD patients. Third, the sample was small ($N = 61$); nonetheless, we still found statistically significant relationships between coping and caregiver physical and mental health outcomes. Fourth, most participants were Caucasian/White. Therefore, the results may not be generalizable to culturally and ethnically diverse caregiver populations.

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 behavioral symptoms manifested in individuals with FTD. 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 and problem-focused coping made statistically significant unique contributions to caregiver health after controlling for variables such as caregiver relationship satisfaction, gender, and age. These findings have important implications for nurses and future research.

**NURSING IMPLICATIONS AND CONCLUSION**

It is important for nurses to acknowledge the needs and contributions of family caregivers and be aware of different strategies that could positively or negatively impact the mental and physical health of FTD caregivers. Nurses may use these findings as an incentive to: (a) educate FTD family caregivers about various emotion-focused coping strategies, (b) encourage them to focus on their own emotions, and (c) motivate them to experiment with strategies that could alleviate their emotional distress when dealing with situations perceived as not amendable to change. When managing different behavioral symptoms common in bvFTD, family caregivers of individuals with FTD 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 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 experimental studies on FTD caregivers are needed to validate these findings and assist in the identification of effective strategies for managing common behavioral symptoms manifested in persons with FTD.

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