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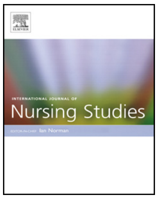

Review

Family caregivers of patients with frontotemporal dementia: An integrative review

Billy A. Caceres, Mayu O. Frank, Jin Jun [*], Melissa T. Martelly, Tina Sadarangani, Paloma Cesar de Sales

New York University, College of Nursing, 433 First Avenue, 6th Floor, New York, NY 10010, United States

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ABSTRACT

Objectives: The purpose of this integrative review is to: (1) identify the characteristics of family caregivers of patients with frontotemporal dementia, (2) explore the impact of providing care on family caregivers' health and well-being, and (3) identify coping strategies used by family caregivers.

Background: Frontotemporal dementia is thought to be the second most common form of dementia after Alzheimer's disease. Family caregivers of patients with frontotemporal dementia face unique challenges due to its early onset, behavioral symptoms, and slow progression of decline. However, there is a dearth of research evaluating the health and wellbeing of family caregivers of patients with frontotemporal dementia.

Design and data sources: An integrative review was conducted using the Whittemore and Knafl methodology. An electronic search of the literature was conducted using four electronic databases: PubMed, Embase, CINAHL, and Web of Science. The Crowe Critical Appraisal tool was used to evaluate the quality of the selected articles.

Results: Findings of 11 articles informed this integrative review. Family caregivers of patients with frontotemporal dementia identify behavioral disturbances as most troubling. Spouses and female caregivers experience greater caregiver burden, distress, increased rates of depression, as well as decreased sleep related to behavior disturbances. Though less explored, providing care to those with behavioral disturbances may also impact caregiver physical health. Additionally, female caregivers are most likely to employ coping strategies, most commonly, adaptation and reframing. Effective interventions to reduce family caregiver burden are poorly understood but family caregivers suggest education and internet-based support groups are most helpful.

Conclusions: Family caregivers of patients with frontotemporal dementia experience significant distress, which impacts their health and wellbeing. It is important for healthcare providers who care for patients with frontotemporal dementia to recognize the unique needs of family caregivers. Future research should focus on examining interventions and strategies to reduce caregiver burden.

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[*] Corresponding author. Tel.: +1 267 497 7300.
E-mail address: jj1528@nyu.edu (J. Jun).

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What is already known about the topic?

- Frontotemporal dementia is now one of the most common types of dementia in persons younger than 60 years of age.
- Increasingly, informal family caregivers take the responsibilities of providing care for these patients.
- Although it is already known that family caregivers generally experience physical and psychological stress and burden, not much is known about the experience family caregivers of patients with frontotemporal dementia.

What this paper adds

- This review demonstrates the unique needs of family caregivers of patients with frontotemporal dementia.
- Family caregivers of patients with frontotemporal dementia experience high levels of emotional and psychological difficulties.
- Healthcare providers need to be aware that these family caregivers experience significant caregiver burden and require tailored education and support.
- The use of patient-and-family centered care approach needs to be incorporated in the management of these patients.

1. Introduction

Frontotemporal dementia, once considered a rare neurodegenerative disorder, is now the most common type of dementia in persons younger than 60 years of age and represents 20% of all dementia diagnoses (University of California San Francisco [UCSF], 2012). Globally, the prevalence of frontotemporal dementia is estimated to affect 15–22 per 100,000 people (Johnson et al., 2005; Rascovsky et al., 2011). The frontotemporal dementia spectrum is comprised of four syndromes: (1) behavior variant frontotemporal dementia, (2) semantic dementia, (3) progressive non-fluent aphasia, and (4) frontotemporal dementia with motor neuron disease. Frontotemporal dementia is believed to affect men and women equally and possess a hereditary component (Onyike and Diehl-Schmid, 2013). Similar to individuals with Alzheimer's disease and other dementia subtypes, patients with frontotemporal dementia experience cognitive and functional decline and can live anywhere from 3 to 14 years post-diagnosis (Onyike and Diehl-Schmid, 2013). However, frontotemporal dementia differs from other forms of dementia, by occurring earlier in life with a mean age of onset between 52 and 56 years. Moreover, memory loss is not the primary feature of frontotemporal dementia (Shnall, 2009). On the contrary, frontotemporal dementia is characterized primarily by impaired judgment, erratic behavior, loss of executive function, mood swings, and changes in personality stemming from atrophic changes in the frontal lobe of the brain (UCSF, 2012).

Caring for patients with frontotemporal dementia is complicated by the slow progressive decline and behavioral changes that are hallmarks of the disease process. Family caregivers of patients with frontotemporal dementia face the unique, and often cumbersome, task of managing social awkwardness and disinhibition in their loved ones (Merrilees and Ketelle, 2010). Diminished and sometimes inappropriate emotions, apathy, lack of self-awareness and difficulty with communication can negatively impact the quality of relationships between patients with frontotemporal dementia and their caregivers (UCSF, 2012).

Caregiver burden refers to the physical, financial, and emotional strain experienced by informal caregivers of people who are ill (Dunkin and Anderson-Hanley, 1998). Caregivers experience worse overall physical health and more psychological stress, including anxiety and depression, than age-matched controls (Dunkin and Anderson-Hanley, 1998). Controlling behavioral symptoms has been found to be more taxing on caregivers than managing cognitive decline, particularly in early onset dementias (Kaiser and Panegyres, 2007; Rascovsky et al., 2011; Riedijk et al., 2006). Caregivers of patients with frontotemporal dementia experience higher levels of stress, burden, and physical decline than those who care for persons with Alzheimer's disease (Kaiser and Panegyres, 2007; Rascovsky et al., 2011; Riedijk et al., 2006). Diminished insight makes patients with frontotemporal dementia appear "self-centered" and emotionally blunt (Wong and Wallhagen, 2012). Patients with frontotemporal dementia may exhibit apathy and lack of regard for the emotional needs of others, which is a major cause of caregiver stress, especially among spousal caregivers (Shnall, 2009).

As healthcare costs continue to soar and the global population ages, caregivers are becoming increasingly responsible for patient care (Lynch and Lobo, 2012). The last decade has witnessed an unprecedented shift toward patient-and-family centered care (Institute for Patient and Family Centered Care, 2010). In 2007, the estimated economic value of caregivers' unpaid contributions was at least $375 billion (Family Caregiving Alliance, 2014). Caregivers play a vital role in the care of patients who suffer from cognitive impairment. Patient-and-family centered care encourages collaborative relationships between healthcare delivery centers, patients, and their caregivers in order to foster better health outcomes and mutually beneficial partnerships for all parties involved (Institute for Patient and Family Centered Care, 2010). However, the frustrations of caring for patients with frontotemporal dementia often create undue stress for caregivers. Caregivers are rarely prepared with the necessary support, education and resources to confront caregiver burden (Ryan and Sawin, 2009). Caregiver burden negatively affects informal caregivers' perceived ability to fulfill the caregiving role, and consequently limits the success of patient-and-family centered care initiatives.

The aims of this integrative review are to: (1) identify the characteristics of family caregivers of patients with frontotemporal dementia, (2) explore the impact of caregiving on family caregivers' health and well-being, (3) identify strategies used to reduce caregiver strain and (4) add to the dearth of literature evaluating the experience of family caregivers of patients with frontotemporal dementia. The findings of this integrative review are intended to assist healthcare providers in developing