

Anxiety and Stigma in Dementia

A Threat to Aging in Place

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KEYWORDS

• Late-life anxiety • Stigma • Early-stage dementia • Older adults • Aging in place

KEY POINTS

- Behavioral and psychological symptoms (BPSDs), such as anxiety, appear in almost all persons with dementia (PwDs) sometime over the course of the illness.
- BPSDs are discomforting to the person with dementia; diminish his or her quality of life; and increase the risk for institutionalization, morbidity and mortality, more costly hospitalizations, and greater caregiver distress.
- Anxiety manifests through fearfulness, worries, restlessness, and irritability, as well as physical symptoms, such as racing heart and poor sleep.
- Anxiety is related to a number of adverse outcomes, such as depression, functional impairment, decreased self-concept, and insecurity, and can compromise the ability to age in place.
- Anxiety is related to stigma in persons with early-stage dementia.
- Stigma is a prominent concern among PwDs, resulting in shame, social isolation, and decreased quality of life.
- Assessment of stigma, anxiety, and associated depression is crucial in PwD.
- The Stigma Impact Scale, Rating of Anxiety in Dementia, and Cornell Scale for Depression in Dementia are tools recommended to measure these concepts, respectively.

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Funding Sources: National Institute of Nursing Research, National Institutes of Health grant R03 NR010582-02 to Dr S. Burgener, PI.

R.J. Riley's dissertation research, University of Iowa, 2012 (3552027), was supported by a grant from the National Institute of Nursing Research, National Institutes of Health, grant R03 NR010582-02.

Conflict of Interest: None.

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Nurs Clin N Am 49 (2014) 213–231

<http://dx.doi.org/10.1016/j.cnur.2014.02.008>

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- A number of interventions are available to treat anxiety in PwDs, including caregiver and health care professionals' educational programs, and pharmacotherapy and psychosocial interventions, such as modified cognitive behavioral therapy for PwDs.
- The stigma of dementia can be addressed by public and provider education, and in-home services.
- Older adults with dementia who transition between care settings and who live alone are particularly vulnerable to losing their ability to age in place.

Approximately 5.2 million Americans, or 10% of people older than 65, have dementia, with individuals older than 85 having the highest prevalence rate at 50%.^{1,2} This number will likely continue to grow as the population ages,³ and may be unsettling, as dementia is feared by many,^{4,5} resulting in anxiety in persons with dementia (PwDs). This article focuses on anxiety, one of the least understood symptoms associated with dementia in community-dwelling older adults, the stigma of dementia, and the relationship between anxiety and stigma in dementia. When undetected and untreated, anxiety and associated stigma can adversely affect quality of life and the ability to age in place. The article begins by describing dementia-related anxiety. Next, based on research by the authors and others, the association between stigma and anxiety is examined. The article concludes with recommendations for assessment and treatment of anxiety and stigma in persons with dementia that will better allow them to age in place.

DEMENTIA-RELATED ANXIETY

Cognitive deficits have traditionally been the focus of treatment for persons diagnosed with dementia; however, PwD often exhibit behavioral and psychological symptoms (BPSD) that are disruptive to caregivers, and others in the environment.⁶ Although they may fluctuate, behavioral symptoms appear in almost all PwDs sometime over the course of the dementia, regardless of etiology.⁷ Anxiety and other BPSDs are important to consider, as they result in personal discomfort, diminished quality of life, premature institutionalization, increased morbidity and mortality, greater caregiver distress, increased emergency room visits and hospitalizations, and increased cost of care.⁸

Definition

There is a debate about the definition of anxiety related to dementia, as some symptoms of anxiety and dementia overlap.⁹ Moreover, symptoms of anxiety, depression, and agitation also have similarities, causing further confusion about the definition of anxiety in PwDs.⁹ However, a review of studies examining the difference between these constructs found more evidence supporting a distinct difference between anxiety and agitation.⁹ Similarly, an earlier study examining behavioral syndromes in dementia (eg, hyperactivity, aggressive behavior, anxiety) found that these 3 syndromes were unique and should not be lumped under the construct of agitation.¹⁰ Thus, the literature suggests that anxiety symptoms in dementia are identifiable, measurable, and treatable.¹¹

Prevalence

Anxiety frequently occurs in PwDs in a variety of settings,¹² with caregivers reporting rates of 19.5% with clinically significant anxiety and 22.5% with subclinical anxiety.

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