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Anxiety and Stigma in Dementia: A Threat to Aging in Place

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Synopsis

The number of Americans with dementia is expected to increase as the population ages. Developing dementia is feared by many older adults and may result in anxiety in persons with dementia (PwD). 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 paper begins by describing dementia-related anxiety. Next, based on research by the authors and others, the association between stigma and anxiety is examined. The paper concludes with recommendations for assessment and treatment of anxiety and stigma in persons with dementia that will better allow them to age in place.

Keywords

Late life anxiety; stigma; early stage dementia; older adults; aging in place

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Approximately 5.2 million Americans, or 10 percent of people over the age of 65, have dementia, with individuals over the age of 85 years having the highest prevalence rate at 50 percent.^{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 (PwD). 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 paper begins by describing dementia-related anxiety. Next, based on research by the authors and others, the association between stigma and anxiety is examined. The paper 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, persons with dementia (PwD) often exhibit behavioral and psychological symptoms (BPSD) that are disruptive to caregivers, and others in the environment.⁶ Though they may fluctuate, behavioral symptoms appear in almost all PwD sometime over the course of the dementia, regardless of etiology.⁷ Anxiety and other BPSD 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 PwD.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 (e.g., hyperactivity, aggressive behavior, anxiety) found that these three 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 PwD in a variety of settings¹² with caregivers reporting rates of 19.5% with clinically significant anxiety and 22.5% with subclinical anxiety. About half of PwD report occasional anxiety.¹³ A pilot study found that 20% of PwD who lived in dementia-specific assisted living and 100% of those who lived traditional assisted living reported one or more symptoms of anxiety.¹⁴

Symptoms and related outcomes (See Table 1)

Anxiety is commonly exhibited through fearfulness, worries, irritability, paranoia, motor restlessness, suspiciousness, or day and night disturbances.^{15,16} Anxiety related symptoms

may also serve as an indicator of more challenging behaviors that could lead to unnecessary medication or harm to PwD or others in the surrounding areas.¹⁷ Other adverse outcomes associated with anxiety in dementia include greater functional impairment,¹⁸ lower self-concept,¹⁹ and attachment insecurity.²⁰ Type of dementia, disease severity and gender may also be factors as persons with Lewy Body dementia demonstrate more anxiety symptoms than those with Alzheimer's disease¹³ and anxiety occurs more frequently in males and persons with less severe dementia.¹⁵ Importantly, anxiety symptoms reduce the quality of life of PwD as well their caregivers.^{21,22} Further, anxiety can compromise the ability to age in place in that physical or social environments in the community may become too much for the person with dementia to manage. Concerns regarding rejection from others due to the stigmatizing aspects of dementia can increase isolation as well. This may lead to avoidance of situations where the environment is unfamiliar or where large groups of people will be present.²³ As a result, some activities that were once enjoyable to PwD may become stressful.

Association with other behaviors

Anxiety has also been associated with behaviors such as wandering, sexual misconduct, hallucinations, verbal threats, physical abuse,²⁴ with a higher likelihood of anxiety with each additional behavior exhibited. Similarly, excessive worry and anxiety in persons with mild, moderate, or severe Alzheimer's disease was significantly associated with restlessness, irritability, muscle tension, and respiratory symptoms.¹⁶

Causes

Anxiety, as well as other BPSD, may appear not only because of neurological changes in the brain but also as a result of the person with dementia's inability to effectively express their feelings, experiences, and personality.²³ For example, the ability to verbally communicate with others and comprehend what is being said in large groups may affect persons even in the early stages of dementia, leading to feelings of distress,²³ and expressive limitations may also lead to high levels of anxiety about everyday experiences such as change or environmental factors.²² Dementia related anxiety may also be exacerbated by physical and emotional stimulation, physical illness, or situations where the physical or social environment becomes overwhelming. Situations including noisy chaotic environments, frustration with inability to identify objects, or inability to communicate needs effectively (e.g., cannot identify or say the word of a wanted item) may lead to anxiety as the person with dementia's abilities to manage stress decrease.²⁵ Dementia related anxiety may also influence outcomes on exams and negatively impact performances.²⁶

Sometimes specific triggers may lead to anxiety related symptoms in PwD such as fatigue; changes in routine, caregiver, or environment; expectation to complete tasks beyond their abilities; over or under stimulation in the environment; feelings of loss; illness; pain; discomfort; or being unsure of their surroundings and the expectations of others.^{25,27} As a result of these triggers, PwD may exhibit distressing behaviors in order to communicate their needs. It is important for caregivers (both formal and informal) to learn anxiety-related triggers to prevent escalation of undesired behaviors in times of stress.²⁸

Insight and anxiety

Persons in the early stages of dementia are those most likely to want to age in place, to have insight into their abilities and to have higher rates of generalized anxiety disorder²⁹ and anxiety symptoms.^{30,31} Specifically, they are better able to understand their diagnosis,³² know there is no cure, and experience fears about how the disease will progress.^{25,33} They also anticipate their cognitive decline and worry about future losses, dependency on others, and the reactions of others to their diagnosis.³⁴ Others fear losing their intellectual abilities,³⁴ and embarrassing themselves because of cognitive decline, such as forgetting who people are, or not being able to follow conversations.²⁹ All of these result in a perception of a lack of contribution to society.³⁴

Feelings of insecurity and fear about the future may lead PwD to become suspicious of the motives of others, fearing financial abuse or exploitation due to their memory loss.²³ As a result of their awareness of cognitive losses and feelings of insecurity, some PwD may overcompensate with hypervigilance and misinterpret environmental stimuli as dangerous.²⁷ Unfortunately, there is some truth to their suspicions, as PwD are more vulnerable to exploitation than other populations.^{23,35}

Relationship between Stigma and Anxiety in Persons with Early Stage Dementia

Stigma is a complex individual experience in which manifestation of diseases and social environments interact and in so doing affect personal identity and sense of self.³⁶ The degree to which a condition such as dementia is considered stigmatizing depends upon a variety of factors: whether the person is thought to be responsible for their condition; the impact of the illness on others; and changes in ability and appearance associated with the condition.³⁷ Negative social meaning is linked to the person through a labeling process and the person with dementia may internalize these meanings. Thus, stigma is potentially powerful because of the emotional responses created by the stigmatizing process.³⁸

In 2006, the Alzheimer's Association launched an initiative that involved an advisory group of people with early-stage Alzheimer's to bring first-hand experiential knowledge and serve as spokespersons, advocates and advisors to the Association. This group participated in a series of Voices of Alzheimer town hall meetings that provided the first nationwide forum for discussion about living with Alzheimer's disease by people experiencing it. Those who attended the nationwide Voices of Alzheimer's town hall meetings reported the stigma of dementia as a prominent concern.³⁴ Some of these concerns resulted from the negative stereotypes and societal attitudes expressed toward PwD²⁶ and reinforced in the media,³⁹ which can influence how individuals feel about themselves when diagnosed with dementia.²⁶ Others stem from behavioral symptoms that often elicit negative responses from others⁴⁴ and result in negative labeling of PwD.³⁹ When people hear the word "dementia", they often have preconceived ideas and misconceptions of what the diagnosis represents.³⁴ As noted, individuals in the early stages of dementia are often aware of their deficits and consequently, many experience symptoms of anxiety,^{12,40} worrying about how others might respond to their diagnosis³⁴ or about embarrassing themselves.²⁹ Others experience shame surrounding their diagnosis and therefore, may deny the diagnosis exists,⁴¹ keep it a secret, or withdraw from social situations completely,²³ leading to social isolation, overdependence

on family, and decreased quality of life. Thus, societal labels and attitudes impact how PwD view themselves⁴⁵ and may influence their comfort with continuing to live in the community.

Similarly, the potential negative impact of stigma on persons with dementia was documented in a recent World Alzheimer Report.⁴² The report noted that stigma can prevent affected individuals from acknowledging their symptoms and seeking the help they need to enjoy the highest quality of life possible, which typically includes aging in place.⁴² Stigma can create situations where even well-intentioned individuals and organizations become unhelpful, for example, by emphasizing the negative aspects of dementia and its symptoms and losses rather than supporting retained abilities in persons with dementia.

In a small study, people who had been diagnosed with Alzheimer's disease in the early stages (n=22) were asked to name their diagnosis. Most participants were unable to admit they had Alzheimer's disease and identified several consequences that resulted from the diagnosis, including frustration and anger, self-blame, embarrassment, feeling cut off others, feeling useless, depression, feelings of loss, and feeling one would rather be dead.⁴¹ These consequences may be indicative of the stigma of dementia and consequently influence PwD's quality of life.⁴³

Research Findings on Anxiety and Stigma in Dementia

As part of a larger, longitudinal, multi-site (Illinois, Iowa and North Carolina) study on Stigma in Persons with Dementia and their Caregivers, led by Dr. Sandy Burgener, the authors explored the relationship between perceived stigma and level of anxiety in 43 PwD in the early stages of dementia.⁴⁶ Stigma was conceptualized as the stigmatizing responses of others including labeling behavior (e.g., not allowing PwD to complete simple tasks once aware of their diagnosis), negative social interpretations (e.g., beliefs that PwD lack independence or societal contribution³⁹); and suboptimal health care (e.g., PwD is not taken seriously by their physician.³⁴). In addition, stigma included perceived stigma in PwD that results from interactions with the external environment (e.g., social rejection, internalized shame, isolation⁴⁷). This study demonstrated a significant positive relationship between perceived stigma of dementia and anxiety levels ($r=.35, p = .022$). That is, as perceived stigma increased in persons with early stage dementia, anxiety levels also increased. Social support, demographic variables, stage of disease, or mental ability did not mediate the relationship between perceived stigma and anxiety.

These results were congruent with the Voices of Alzheimer's town hall meetings discussed earlier³⁴ where PwD indicated the stigma of dementia had a negative impact on their quality of life. They also support other research showing that PwD in the early stages tend to have awareness of the negative perceptions society holds about dementia²³ and may have internalized these negative societal attitudes, thus worrying about how others might respond to their diagnosis.³⁴ Findings from this study also support the need to develop and test interventions that have the potential to decrease perceived stigma and in turn reduce symptoms of anxiety in PwD.

Case Study—Part 1

Mrs. Bernice Stasi is a 78 year old widowed white female who currently lives alone in a 2 bedroom apartment in a small Midwestern college town. Once very active in her church circle, bridge club and an avid golfer, she seldom leaves her apartment these days, refusing all invitations from friends, family and organizations she used to belong to because she “doesn’t want people to know she is losing her mind.” Approximately 3 years ago, she was diagnosed with probable Mild Cognitive Impairment by her primary care practitioner, Dr. Townsend. Her current Mini-Mental Status Exam score is 22. Bernice’s only child, a son Tom, who teaches at the local college, lives nearby. He and his wife have assumed responsibility for most of Bernice’s needs, including grocery shopping, housekeeping and financial management of her affairs. Lately he has threatened to put Bernice in the memory care unit of a local nursing facility as she calls her son at work several times a day “just to be sure everyone is OK”. The thought of being forced to live in a memory care unit with “those zombies” terrifies Bernice, and if anything escalates her insecurity and need to call people for reassurance. For some time after her diagnosis, Bernice refused to speak to or see Dr. Townsend because she blamed him for giving her the diagnosis and “great shame” of dementia. But more recently she has begun calling the doctor’s office several times per week to complain about her “fluttery” hear, trouble falling asleep and feeling “shaky” when she walks around her apartment.” Tom notes that his mother was “always a Nervous Nelly” but identifies recent increases in “nastiness”, confusion and losing things, all of which lead him to believe she needs to be institutionalized, “for her own good” and “our sanity.”

Clinical Implications for Healthcare Professionals

In general, non-pharmacologic interventions are preferred in the treatment of most late life anxiety, as older adults experience changes in pharmacokinetics that may lead to medication toxicity, and many are taking an array of medications for other conditions that increase risk of drug interactions. The first step in any treatment plan, however, is assessment. The following section recommends three instruments that nurses can use to assess depression (which frequently accompanies anxiety), anxiety and stigma in persons with dementia. By establishing baseline levels, monitoring changes over time and intervening early when any of these conditions become problematic, nurses can play an important role in helping community-dwelling older adults with dementia age in place.

Assessment—For older adults-- those with and without dementia--- depression often accompanies anxiety, and both conditions can be debilitating, reducing overall health, quality of life and ability to age in place. It is important for nurses to know the signs of anxiety and depression and to assess their older patients with dementia for both, making referrals to primary health providers and/or mental health professionals as indicated. One informant-rated instrument commonly used to assess for depression in dementia is the Cornell Scale for Depression in Dementia (CSDD), available from the cited reference.⁴⁸ The CSDD⁴⁸ is a validated severity tool that assesses for signs and symptoms of major depression in patients with and without dementia. Because some persons with dementia lack insight, have trouble articulating symptoms or otherwise provide unreliable self-reports, the preferred method of administration is to first interview an informant (someone who knows

and has frequent contact with the patient) and then to interview and observe the patient. Symptoms from the patient interview can often be filled out after direct observation of the patient, but should be supplemented by the patient's self-report. In the case of discrepancies in ratings between the informant and the patient interviews, it is recommended to re-interview both the informant and the patient in an effort to resolve the discrepancy. The final score, however, represents the rater's clinical impression on the presence or absence of each symptom, rather than the responses of the informant or the patient. Severity ratings of mild versus severe are made based on the symptom's: a) degree of intensity or distress, b) pervasiveness (i.e., presence throughout the day), and c) persistence (i.e., number of days present in the last week). The CSDD is validated to rate depressive symptomology over the entire range of cognitive impairment.⁴⁸

Each item is ranked for severity on a scale of 0–2 (0 = absent, 1 = mild or intermittent, 2 = severe). The items scores are added. Scores above 10 indicate a probable major depression. Scores below 6 as a rule are associated with absence of significant depressive symptoms. A score of 11 or greater should prompt further evaluation of the patient for depression.

As noted above, given the adverse outcomes associated with anxiety and stigma in persons with dementia, it is also essential that nurses are able to identify and monitor both conditions in order to intervene in a timely manner, help to prevent institutionalization and maximize the PwD's ability to age in place. Two reliable, valid and easy to administer instruments nurses can use for this purpose are the Stigma Impact Scale (SIS) and the Rating Anxiety in Dementia (RAID).

Stigma Impact Scale—Perceived stigma can be measured using the Stigma Impact Scale (SIS), developed and tested by Fife and Wright⁴⁹ and adapted for use with PwD by Burgener and Berger.⁵⁰ The SIS is grounded in Modified Labeling Theory (MLT)⁵¹ and is divided into four categories (Social Rejection, Financial Insecurity, Internalized Shame, Social Isolation). Social rejection measures feelings of being discriminated by others in society (e.g. “I feel I have been treated with less respect than usual by others”). Financial insecurity focuses on financial problems individuals might experience as a result of their memory loss (e.g. “I have experienced financial hardship that has affected how I feel about myself”). Internalized shame explores how much social rejection and financial issues impacted individuals' feelings about themselves and how they interacted with others (e.g. “I feel I need to keep my impairment a secret”). Social isolation addresses feelings of loneliness, inequality, and uselessness (e.g. “I feel less competent than I did before my memory loss”). The SIS yields a total score ranging from 0 to 96, with higher scores indicating higher perceived stigma.

Anxiety Level—The 18-item Rating Anxiety in Dementia (RAID) scale can be used to measure anxiety levels of persons with dementia. The RAID is based on the total score of items 1 to 18.⁵² The total score ranges from 0 to 54 and a score of 11 or more indicates significant clinical anxiety.⁵² This scale was specifically designed to assess anxiety in persons with dementia⁵² using caregiver or clinician-based observations of behaviors over a two week period. Items on the RAID can also be reliably and validly answered by PwD in the early stages of dementia. The RAID is divided into six sub-groups (e.g. worry,

apprehension and vigilance, motor tension, autonomic hyperactivity, phobias, and panic attacks; 52). Each question is rated as absent, mild or intermittent, moderate, and severe. The worry category measures the level of worry about various things (e.g. worry about physical health; worry about cognitive performance (failing memory, getting lost when goes out, not able to follow conversation); worry over insignificant matters. Apprehension and vigilance measures things such as sleep disturbances, autonomic arousal, irritability, and outbursts (e.g. frightened and anxious; exaggerated startle response; short tempered). Motor tension (e.g. trembling, headaches, body aches, restlessness, fatigability) is examined because the concepts of anxiety and motor tension seemed to be related.⁵³ Autonomic hyperactivity symptoms (e.g. palpitations, dry mouth, shortness of breath, dizziness, sweating) are often reported by PwD and are related to anxiety. Phobias are also reported in people over the age of 65, and this section of the tool addresses specific fears (e.g., fears that were excessive, that did not make, and caused people to avoid crowds, small rooms, heights, etc.). The section on panic attacks discusses the severity of symptoms of panic and asks PwD to describe their symptoms (e.g. feelings of anxiety or dread that were so strong that they thought they were going to die or have a heart attack).

In addition to assessing for anxiety, depression and stigma nurses may also wish to examine other stresses and changes in the life of a person with dementia that often accompany aging, such as poor mental and physical health and losses, that are associated with anxiety. For example, fear of falling, expenses associated with treatment for dementia and medications, being victimized, being dependent on others, being left alone, and death, can all increase anxiety in this population. Nurses should also consider alcohol or substance abuse issues, which may hide the symptoms of anxiety or make them worse. Investigating recent stressful events, such as the death of a loved one or pet is also warranted. Finally, nurses should inquire if PwD have been treated before for an anxiety and if so, ask about previous treatment, including medication and psychosocial therapies. If the PwD received medication to help manage anxiety, nurses should try to determine what drug(s) was used, dosage, side effects, and whether pharmacological treatment was helpful. If the PwD attended therapy sessions for anxiety the nurse should ask the person or an informed caregiver to describe the type of therapy, how many sessions, and whether it was helpful.

Treatment

Nurses and other health care professionals can play an important role in the treatment of anxiety and stigma, and are often involved in the evaluation of cognitive concerns. Therefore, it is important for them to be familiar with the behavioral and psychological symptoms of dementia--BPSD⁵⁴ and to have an understanding of the progression of the disease.⁵⁵ This may help to guide treatment and to manage BPSD (including anxiety) which often worsen as the disease progresses.⁵⁶ Treatment options can include medication, therapy, stress reduction, coping skills, and family/caregiver or other social support, some of which are briefly discussed in the following section. Nurses may directly intervene with PwD and their caregivers or refer those they evaluate as being affected by anxiety and or stigma to mental health specialists such as those in local Community Mental Health Centers or in the private sector.

A more general approach to management of anxiety is for nurses to help caregivers establish a routine and to repetitive daily tasks as this helps preserve cognitive functioning,^{41,57} reduces agitation,⁵⁸ and provides PwD with feelings of independence and self-esteem, therefore, increasing their quality of life. Although the structure of daily tasks could become monotonous to family caregivers, it is likely that the management of distressing symptoms such as anxiety outweighs the boredom associated with this approach. Nurses can also provide support in a number of other ways by: helping the PwD acknowledge worries and address any fears that can be handled such as talking about their responses to loss of abilities, or episodes of confusion/disorientation; encouraging them to express feelings and to talk with family members, friends or spiritual counselors about such things as social isolation or fatigue; adopting stress management techniques, including meditation, prayer, and deep breathing exercises; and avoiding things that may aggravate anxiety symptoms such as large group situations, caffeinated beverages and chocolate, nicotine, over-the-counter cold medications and some herbal supplements, or reporting the anxiety-producing side effects of prescription medications. It is best to speak in a calm and reassuring tone of voice and to remain positive when talking to the person with dementia, and to encourage participation in activities, exercise and pleasant events.

Educating Health Care Professionals—Interdisciplinary teams would also benefit from education about BPSD, including anxiety, and possible ways to intervene when behavioral and psychological symptoms of dementia worsen. They should also be informed about potential triggers that escalate BPSD, for example that PwD often become frustrated when they are unable to effectively communicate their needs,²² so that symptoms may be decreased or prevented.^{25,27} BPSD are often points of stress with caregivers (both formal and informal) and may lead to premature institutionalization (17), thus threatening the ability to age in place.

Caregiver Education and Support—Behavioral expressions such as anxiety can be stressful for caregivers and lead to premature institutionalization. Educational programs and dementia support groups can increase caregivers' knowledge of dementia, improve the ability of caregivers to cope, help them to feel less isolated in their experiences, and teach them to recognize behavioral symptoms. Programs that also identify mental health resources in the community for treatment of anxiety may allow PwD to continue to live in their own homes and to better adapt to changing needs and conditions.

Anxiety Interventions for PwD

Pharmacological Interventions: Medication will not cure anxiety disorders but may keep anxiety symptoms sufficiently under control to allow the person with dementia to age in place. Although anxiety does respond to judicious use of medication, side effects are a key consideration in any geriatric prescribing, with all psychotropic medications in general, and benzodiazepines, in particular. The types of medications primarily used to treat anxiety disorders are antidepressants, anti-anxiety drugs, and beta-blockers.

With antidepressants, symptoms usually start to resolve after 4–6 weeks, so it is important for the nurse to make sure the PwD is giving them adequate time to work. Antidepressants

include selective serotonin reuptake inhibitors (SSRIs), such as Citalopram, Sertraline, Paroxetine and Fluvoxamine, which have been found to improve anxiety, mood and fear in this population, serotonin and norepinephrine reuptake inhibitors (SNRIs), tricyclics, and monoamine oxidase inhibitors (MAOIs).⁵⁹

Anxiolytics, or anti-anxiety drugs, are sometimes prescribed when a short-term medication is needed. Benzodiazepines can be effective but should be prescribed only for short periods of time because of the risk of memory impairment, unsteadiness, and falls. Some older adults experience withdrawal symptoms if they stop taking them abruptly and there is a remote chance of addiction when taken regularly for a long time. Nurses may administer Lorazepam (short acting, no active metabolites, available in tablet and liquid forms, average dose=1.5–2.5mg) or Oxazepam. Chronic anxiety is sometimes treated with Trazadone or Buspirone. Trazadone can be effective in treating sundowning behaviors (late day agitation/confusion) as well if given in the late afternoon it is often the drug of choice. Beta blockers such as Propanolol have also been used with some success as they can help relieve anxiety by preventing the physical symptoms that go along with certain anxiety disorders.⁵⁹

Psychosocial Interventions—Therapy or psychotherapy involves talking with a trained mental health professional in an effort to discover what may be causing the anxiety and how to better deal with its symptoms. Importantly, Medicare now reimburses for psychotherapy for persons with dementia.

Cognitive Behavioral Therapy (CBT): In cognitive-behavioral therapy, therapists help people change the thinking patterns that contribute to their fears and the ways they react to anxiety-provoking situations. A therapist can teach new coping and relaxation skills and help resolve problems that cause anxiety. Approaches include desensitizing the PwD to situations that trigger anxious feelings, deep breathing and other relaxation techniques to relieve anxiety. Often modifications to standard CBT are needed to assist persons with dementia, as described below.

The effectiveness of cognitive behavioral therapy (CBT) as a treatment for anxiety in persons with dementia has been examined.^{60–62} CBT skills such as diaphragmatic breathing and coping statements were implemented in two case studies conducted by Kraus and colleagues (61). Skills were simplified in order to address comprehension, learning, memory and application issues that may arise when working with PwD. In order to enhance learning and ensure understanding, PwD were encouraged to repeat information learned back to the provider. Spaced retrieval was also used whereby the PwD were asked to correctly recall information over systematically increasing intervals over time (e.g., recall after 10 seconds, 20 seconds, 40 seconds, 60 seconds, and so on).⁶³ Telephone contact between sessions encouraged skill usage and answered questions. Sessions were also shortened to thirty to forty minutes due to fatigue in PwD. Caregivers were present during sessions and were encouraged to learn CBT skills, so they could remind PwD to use the skills in their daily life. The two participants in this case study demonstrated reductions in anxiety after CBT was implemented, indicating that a modified approach to the skills might be helpful to PwD in the early stages. However, due to the small sample and non-rigorous methodology, it is difficult to draw valid conclusions.

Peaceful Mind is a type of CBT designed specifically for anxiety in PwD.⁶² There are five different modules discussed in Peaceful Mind, including self-awareness, breathing, calming thoughts, increasing activity and sleep skills. Select behavioral rather than cognitive skills are emphasized, and only one skill is introduced at a time. Much of each session focuses on repetition and practice of skills, with visual cues and spaced retrieval techniques implemented in order to improve memory. After six months of treatment, most family members reported a decrease in anxiety on the Neuropsychiatric Inventory-Anxiety (86% at three months) with mixed results on other measures of anxiety.

CBT, implemented with appropriate modifications, seems to be helpful to persons who have early stage dementia and who experience symptoms of anxiety. These studies provide hope that CBT might be a useful treatment for PwD with anxiety. However, further randomized controlled trials with much larger samples are needed in order to determine effectiveness with this population.

Interventions for Stigma—It is important for nurses and other health care professionals to be aware of perceived stigma and how this might influence persons with dementia's willingness to seek treatment and talk about their challenges. It is crucial to understand that PwD, particularly in the early stages of the disease, are capable of making decisions about their lives and such things as where they want to live.^{25,32} Indeed, PwD are often open to learning new methods of coping as these may ease disturbing symptoms such as anxiety.⁶⁴

An overall theme that arose from the Voices of Alzheimer's town hall meetings were the issues of grief and loss. PwD expressed concern that they would no longer be able to contribute to society,³⁴ and, that as the disease progresses, they might be forced to give up long term careers. This in turn could lead to feelings of sadness, loss, and shame and a perception that they are no longer able to complete the tasks that were once second nature. Other participants in the town hall meetings noted that they lost relationships or were treated differently by their social circle.³⁴ Loss of relationships or status in the community may also have a negative effect on PwD and lead to symptoms of depression or anxiety. Because some PwD worry about burdening a spouse or family member with their concerns, individual counseling might provide helpful support in times of distress. As noted above, nurses can make these referrals while at the same time encouraging PwD to talk about feelings of sadness and loss and explore positive coping methods.

In the Voices of Alzheimer's town hall meetings³⁴ discussed earlier, persons who had early stage dementia also discussed how the stigma of the disease affected their quality of life. They became socially isolated and felt disappointed with the lack of resources (e.g., support and educational groups) available to them in the early stages of dementia. Thus providing education and support services for this population is another area where nurses can effectively contribute.

Public Education about Dementia—Nurses and other health care professionals may provide group, individual, or community based programs that educate others about dementia and debunk stereotypes of PwD as “the living dead” that can lead to their dehumanization.⁶⁵ It is important to provide accurate education to the public, as well as persons with dementia

and their caregivers, about symptoms of dementia in order to address misperceptions about the disease.⁶⁶ Educational programs should also emphasize that PwD in the early stages of the disease can often maintain a relatively normal life and continue to have joy and individuality.⁶⁶ Moreover, studies over the last decade support continuing insight and decisional capacity into the later disease stages as well. As a result of education about dementia, the public may begin to better understand the disease, respond more appropriately to PwD, and be more accepting of them in their neighborhood or apartment building.⁴ Increased understanding of dementia may result in decreased stigma associated with the disease and improved quality of life among PwD.

Persons with dementia have reported losing friends⁶⁶ because of a lack of understanding of the disease (e.g., public is fearful they might “catch” dementia) and this negatively impacted their social and psychological well-being.⁴³ As a result, both persons with dementia,⁴³ as well as those with mental illness⁶⁸ emphasized the importance of public education to reduce stigma. Some expressed a desire to become involved in public education as a means of contributing and found this experience to be empowering.^{34,68} The National Alzheimer’s Association Early Stage Advisory Group⁶⁹ provided guidelines (See Table 2) to persons with dementia to assist them in overcoming the stigma of dementia:

Individuals who feel stigmatized might benefit from joining together and forming groups that reject the stigma of mental illness and dementia.⁷⁰ This idea supports the expressed need of PwD’s to connect with others who have been through similar situations³⁴ and would provide opportunities to learn more effective ways of coping.⁷⁰ The opportunity to be in a group that educates society about dementia or participates in research could instill feelings of worth and expand support systems, both of which are valuable to PwD (34).

Stereotypes about dementia are formed over a lifetime of negative experiences and contribute to perceived stigma.²⁶ After frequent exposure to these stereotypes, children form beliefs and values about what it means to have dementia. When they become older adults, they have internalized the stereotypes,²⁶ leading to feelings of shame and embarrassment about symptoms of dementia.⁴³ Thus it would be beneficial for nurses and other health care professionals to develop educational programs about dementia for children that would help them to better understand the different stages of dementia, how to interact with individuals who have dementia (as many might have grandparents who have the disease), and hopefully, decrease the stigma surrounding the disease. Resources such as “What’s Happening to Grandpa?” by Maria Shriver are readily available and often helpful when working with children.⁷¹

Educating Health Care Professionals/ Providers

As noted earlier, nurses often work as consultants to interdisciplinary teams (e.g., physicians, other nurses, certified nursing assistants, social workers, physical therapists, occupational therapists, and others) in the healthcare field.⁷² Interdisciplinary team members who work with persons with dementia would benefit from education about the stigma of dementia and how this might inhibit PwD’s willingness to share symptoms with others. As previously discussed, persons with dementia will sometimes deny their diagnosis and avoid medical care because they are uncertain about treatment options that could help them to age

in place, and are unaware of medications⁶⁶ or other interventions that could help control troubling symptoms such as anxiety. Specifically, the literature documents that the diagnosis of dementia creates feelings of anxiety about losing control and worries about how the disease will progress.⁶⁶ Sometimes, the fear of a dementia diagnosis is so strong that when PwD (and their families) finally seek medical assistance, symptoms have become so serious (that the person can no longer remain in the community).

Table 3 lists 10 general recommendations to help overcome the stigma of dementia as set forth by the National Alzheimer's Association Early Stage Advisory Group.⁶⁹ Although much more research on the effectiveness of specific interventions to ameliorate the stigma of dementia is required, the above recommendations provide nurses and other healthcare professionals with suggestions for helpful strategies.

Case Study: Part 2

Dr. Townsend contacted the visiting nurse, Ms. Carson, who had previously worked with Mrs. Stasi and her family during her late husband's illness. He asked that they work together to address Bernice's anxiety behaviors that accompanied her early stage dementia, and the debilitating stigma she was experiencing that contributed to her social isolation, feelings of shame and embarrassment and that put her at risk for institutionalization. Together Dr. Townsend and Ms. Carson, in cooperation with Mrs. Stasi who "agreed to do anything not to be sent to that 'hell hole'" (memory care center), developed a plan that began with referral of Bernice to a psychologist, Dr. Bertram, at the local Community Mental Health Center who specialized in the treatment of anxiety. The 10-week treatment sessions focused on helping Bernice to better recognize her anxiety symptoms and related behaviors.⁷³ Dr. Bertram asked Bernice to complete a symptom and behavior log weekly and to bring the log to the next session. This enabled them both to monitor and discuss her levels of anxiety, activities or thoughts that prompted anxious feelings, and how she dealt with feeling anxious. By discussing the log and monitoring her feelings and behavior, Bernice began to develop some insight into how her calling negatively affected not only her own life, but also that of Tom and his family. Concurrently Dr. Bertram helped Bernice to acquire some basic skills to help manage her anxiety such as deep breathing and problem-solving.⁷³

Next Ms. Carson convened a family meeting to educate Tom, his wife and Bernice about dementia, stigma and the anxiety behaviors that commonly accompany the disorder. She referred Tom to a local early-stage dementia support group for caregivers and provided reading materials about dementia and its associated symptoms. Tom agreed to wait 6 months before revisiting the issue of moving his mother out of her apartment. Ms. Carson made a contract with Bernice to attend congregate meals at the local Senior Center two to three times per week and while there to participate in an exercise class to help ease her tensions. She communicated these plans to Dr. Townsend, who expressed his own frustration with Bernice's behaviors, but agreed to keep her on as a patient and see how her behaviors progressed. At the interim 12 week evaluation point, Bernice reported she "worried less", did not feel "judged" by people at the Senior Center, many of whom she characterized as "worse off than me". The phone calling behavior steadily decreased as Bernice felt more

confident and in control and at the 6 month point, Tom and his wife agreed they would support Bernice's desire to stay in her apartment and age in place.

Interventions to Promote Aging in Place in Persons with Dementia Experiencing Anxiety

Strategies that foster early detection and treatment of behavioral and psychological symptoms associated with dementia are essential to enhancing aging in place. One such program, emphasizing care coordination and person-centered approaches is the Maximizing Independence at Home (MIND) out of Johns Hopkins University. In this program, a dementia care coordinator comes into the home to address a variety of care issues before the community dwelling person with dementia spirals out of control and may need to be relocated. The coordinator maintains contact once a month or more often as needed, assesses and refers for unmet needs and physical or mental health problems, such as anxiety. Importantly, there is access to an interdisciplinary team including a psychiatric nurse and geropsychiatrist. The project demonstrated the people were able to age in place without sacrificing the quality of life.⁷⁴

Finally, The Aging in Place project sponsored by the University of Missouri-Columbia, has produced positive outcomes, decreased costs and facilitated the development and evaluation of technology, though not limited to persons with dementia. The head of the project, Dr. Marilyn Rantz, was named an American Academy of Nursing Edge Runner for the program, which relies on RN Care Coordination, health promotion, and early illness recognition through Sinclair Home Care.⁷⁵ The goal of the project is to provide high quality services at home, thus allowing people to age in place, and avoid or delay hospitalizations. Sinclair Home Care provides community-based care based on individual choice and autonomy. Services maximize each older adult's mental, physical and psychosocial strengths. Costs of the program have never approached the average cost of nursing home care.⁷⁵

Special Considerations for Aging in Place: Transitional Care and "Live Alones"

Persons with dementia tend to move back and forth between settings (e.g., home, hospital, nursing home).⁷⁶ Transitions between levels of care are an important consideration for nurses in all these settings as well as ensuring that PwD have access to high quality behavioral health services. This is especially critical for persons with dementia who may be temporarily residing in an institutional setting to assure that they are able to return to their preferred home and neighborhood. As the process of transitioning across settings can, in itself, produce anxiety in persons with dementia, care should be taken to minimize the number and types of setting transitions. Another high-risk group is the more than 800,000 people in the US with dementia who live alone.⁷⁷ About half these "Live Alones" have no identifiable caregiver, and are perhaps most vulnerable to being unable to continue to age in place safely, comfortably regardless of age, income or ability level.

Conclusion

Both anxiety and dementia-related stigma are common among persons with dementia, especially in the early stages of the disease. Research by the authors and others has demonstrated a relationship between anxiety and stigma in this population. Nurses can play

an important role in the assessment and treatment of these under-studied and under-treated conditions in persons with dementia through psychosocial and pharmacological interventions, educational programs and support for health care professionals and caregivers of persons with dementia. These efforts can improve quality of life for persons with dementia and promote their desired ability to age in place.

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Key Points

- Behavioral and psychological symptoms (BPSD), such as anxiety appear in almost all persons with dementia (PwD) sometime over the course of the illness.
- BPSD are discomforting to the person with dementia and diminish their quality of life as well as increasing 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 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 persons with dementia 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.
- A number of interventions are available to treat anxiety in persons with dementia including caregiver and health care professionals' educational programs, and pharmacotherapy and psychosocial interventions such as modified cognitive behavioral therapy for PwD.
- 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.

Table 1**SYMPTOMS OF ANXIETY**

- Excessive worry or fear
- Refusing to do routine activities or being overly preoccupied with routine
- Avoiding social situations
- Overly concerned about safety
- Racing heart, shallow breathing, trembling, nausea, sweating
- Poor sleep
- Muscle tension, feeling weak and shaky
- Hoarding/collecting
- Depression
- Self-medication with alcohol or other central nervous system depressants

Table 2**GUIDELINES FOR PERSONS WITH DEMENTIA TO COMBAT STIGMA**

1	Be open and direct
2	Communicate the facts
3	Seek support and stay connected
4	Don't be discouraged
5	Be part of the solution

National Alzheimer's Association Early Stage Advisory Group 2012⁶⁹

Table 3**RECOMMENDATIONS TO OVERCOME STIGMA OF DEMENTIA**

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1	Educate the public
2	Reduce isolation of the person with dementia
3	Give people with dementia a voice
4	Recognize the rights of persons with dementia and their caregivers
5	Involve persons with dementia in their local communities
6	Support and educate informal and formal caregivers
7	Improve the quality of care at home and in care homes
8	Improve dementia training of primary care providers
9	Call on governments to create national dementia plans (done in the US)
10	Increase research into how to address stigma in persons with dementia.
-

National Alzheimer's Association Early Stage Advisory Group 2012⁶⁹