



Easing dementia caregiver burden, addressing interpersonal violence

Caring for aggressive patients with dementia can lead to exhaustion, fear, and burnout. These strategies can help improve the welfare of both caregivers and patients.

Abu Baker Sheikh, MD;
Nismat Javed, MBBS;
Zainab Ijaz, MD;
Katarina Leyba, MD;
Eileen Barrett, MD;
Angela Dunn, DO

University of New Mexico Health Sciences Center, Albuquerque (Drs. Sheikh, Leyba, and Dunn); Shifa College of Medicine, Islamabad, Pakistan (Dr. Javed); William Beaumont Hospital, Royal Oak, MI (Dr. Ijaz); University of New Mexico Hospital, Albuquerque (Dr. Barrett); Veterans Affairs Clinics, Albuquerque (Dr. Dunn)

absheikh@salud.unm.edu

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PRACTICE RECOMMENDATIONS

› *Screen caregivers and family members of patients with dementia for signs of interpersonal violence.* **(C)**

› *Counsel caregivers early on that behavior changes in patients with dementia are likely and may be unpredictable.* **(C)**

› *Discuss safety strategies for the caregiver, including when it is appropriate to alter routines such as bedtimes and meals.* **(C)**

Strength of recommendation (SOR)

- (A)** Good-quality patient-oriented evidence
- (B)** Inconsistent or limited-quality patient-oriented evidence
- (C)** Consensus, usual practice, opinion, disease-oriented evidence, case series

The number of people with dementia globally is expected to reach 74.7 million by 2030 and 131.5 million by 2050.¹ Because dementia is progressive, many patients will exhibit severe symptoms termed *behavioral crises*. Deteriorating interpersonal conduct and escalating antisocial acts result in an acquired sociopathy.² Increasing cognitive impairment causes these patients to misunderstand intimate care and perceive it as a threat, often resulting in outbursts of violence against their caregivers.³

Available studies (TABLE⁴⁻¹⁷) make evident the incidence of interpersonal violence experienced by caregivers secondary to aggressive acts by patients with dementia. This violence ranges from verbal abuse, including racial slurs, to physical abuse—sometimes resulting in significant physical injury. Aggressive behavior by patients with dementia, resulting in violence towards their caregivers or partners, stems from progressive cognitive decline, which can make optimal care difficult. Such episodes may also impair the psychological and physical well-being of caregivers, increasing their risk of depression, anxiety, and even post-traumatic stress disorder (PTSD).¹⁸ The extent of the impact is also determined by the interpretation of the abuse by the caregivers themselves. One study suggested that the perception of aggressive or violent behavior as “normal” by a caregiver reduced the overall negative effect of the interactions.⁷

Our review emphasizes the unintended burden that can fall to caregivers of patients with dementia. We also address the role of primary care providers (PCPs) in identifying these instances of violence and intervening appropriately by providing safety strategies, education, resources, and support.

CASE ▶

A 67-year-old man with a medical history of PTSD with depression, type 2 diabetes, alcohol use disorder/dependence, hy-

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Caregivers may refuse support due to personal beliefs or values, accessibility or affordability issues, or in deference to the patient's wishes.

pertension, and obstructive sleep apnea was brought to his PCP by his wife. She said he had recently been unable to keep appointment times, pay bills, or take his usual medications, venlafaxine and bupropion. She also said his PTSD symptoms had worsened. He was sleeping 12 to 14 hours per day and was increasingly irritable. The patient denied any concerns or changes in his behavior.

The PCP administered a Saint Louis University Mental Status (SLUMS) examination to screen for cognitive impairment.¹⁹ The patient scored 14/30 (less than 20 is indicative of dementia). He was unable to complete a simple math problem, recall any items from a list of 5, count in reverse, draw a clock correctly, or recall a full story. Throughout the exam, the patient demonstrated minimal effort and was often only able to complete a task after further prompting by the examiner.

A computed tomography scan of the head revealed no signs of hemorrhage or damage. Thyroid-stimulating hormone levels and vitamin B12 levels were normal. A rapid plasma reagin test result was negative. The patient was given a diagnosis of Alzheimer disease. Donepezil was added to the patient's medications, starting at 5 mg and then increased to 10 mg. His wife began to assist him with his tasks of daily living. His mood improved, and his wife noted he began to remember his appointments and take his medications with assistance.

However, the patient's irritability continued to escalate. He grew paranoid and accused his wife of mismanaging their money. This pattern steadily worsened over the course of 6 months. The situation escalated until one day the patient's wife called a mental health hotline reporting that her husband was holding her hostage and threatening to kill her with a gun. He told her, "I can do something to you, and they won't even find a fingernail. It doesn't have to be with a gun either." She was counseled to try to stay calm to avoid aggravating the situation and to go to a safe place and stay there until help arrived.

His memory had worsened to the point that he could not recall any events from the previous 2 years. He was paranoid about anyone entering his home and would not allow his deteriorating roof to be repaired or his

yard to be maintained. He did not shower for weeks at a time. He slept holding a rifle and accused his wife of embezzlement.

The patient was evaluated by another specialist, who assessed his SLUMS score to be 18/30. He increased the patient's donepezil dose, initiated a bupropion taper, and added sertraline to the regimen. The PCP spoke to the patient's wife regarding options for her safety including leaving the home, hiding firearms, and calling the police in cases of interpersonal violence. The wife said she did not want to pursue these options. She expressed worry that he might be harmed if he was uncooperative with the police and said there was no one except her to take care of him.

Caregivers struggle to care for their loved ones

Instances of personal violence lead to shock, astonishment, heartbreak, and fear. Anticipation of a recurrence of violence causes many partners and caregivers to feel exhausted, because there is minimal hope for any chance of improvement. There are a few exceptions, however, as our case will show. In addition to emotional exhaustion, there is also a never-ending sense of self-doubt, leading many caregivers to question their ability to handle their family member.^{20,21} Over time, this leads to caregiver burnout, leaving them unable to understand their family member's aggression. The sudden loss of caregiver control in dealing with the patient may also result in the family member exhibiting behavioral changes reflecting emotional trauma. For caregivers who do not live with the patient, they may choose to make fewer or shorter visits—or not visit at all—because they fear being abused.^{7,22}

Caregivers of patients with dementia often feel helpless and powerless once abrupt and drastic changes in personality lead to some form of interpersonal violence. Additionally, caregivers with a poor health status are more likely to have lower physical function and experience greater caregiving stress overall.²³ Other factors increasing stress are longer years of caregiving and the severity of a patient's dementia and functional impairment.²³

TABLE

Dementia and aggression: A look at the literature

We conducted searches on PubMed, CINAHL, and EMBASE using the terms “dementia,” “aggression,” “violence,” “caregivers,” “agitation,” and “behavioural problems.” In all, we found 399 studies from 1990 to 2021. We excluded systematic reviews and meta-analyses as well as non-English language studies. The 14 studies summarized here focused on patients with dementia and their caregivers’ experiences with any form of violence or aggression. All included studies examined the experiences of either formal caregivers (eg, nurses, home health aides, paid family caregivers, and nursing home staff) or informal caregivers, such as family members.⁴⁻¹⁷

Author/study type	Aim/criteria	Findings
Skovdahl et al ⁴ Descriptive study	To study caregivers’ reflections about, and attitudes toward, behavioral and psychiatric symptoms of dementia Inclusion: Narrative interviews were carried out with 15 formal caregivers who had been permanently employed for at least 1 year and who had experienced aggressive behavior from 3 different units	Caregivers could not relate to the aggression of the patients and were having difficulties administering care owing to verbal violence experienced daily.
Kristiansen et al ⁵ Descriptive study	To describe the experience of job satisfaction among nursing staff working for people with dementia and behavioral disturbances Inclusion: All care staff were asked to participate. Participants included 19 women and 1 man.	Most caregivers experienced physical abuse at work. One person had evidence of physical injury.
Wharton et al ⁶ Descriptive study	To review home-based dementia caregiving and care-recipient violence Inclusion: NA	Home health care workers were 4 times more likely to experience assault if they had ≥ 1 patients with dementia
Ostaszkiwicz et al ⁷ Descriptive study	To describe nurses’ experiences of caring for people with dementia Inclusion: All nurses experienced in caring for residents with dementia and employed on 3 units	There was evidence of many incidences of physical abuse and verbal abuse—particularly racial slurs.
Kim et al ⁸ Descriptive study	To explore the experience of paid family-care workers managing the care of people with dementia in South Korea. Inclusion: Paid family-care workers who had been caring for a relative with dementia for at least 1 month were recruited to the study. Workers were required to have had formal education that included clinical placements and to possess the care worker’s license.	Paid family-care workers struggled to manage the behavioral and psychological symptoms of their care recipients. Workloads created physical, emotional, social, and financial burdens.
Band-Winterstein et al ⁹ Descriptive study	To differentiate between the experiences of 2 groups of women caring for a partner with dementia. They were coping with lifelong intimate partner violence and dementia-related violence or dementia-related violence only. Inclusion: 16 participants, all of whom were female spouses of men with dementia and coping with dementia-related aggression.	All 16 women had experienced some sort of violence. Participants encountering violence for the first time viewed it as a drastic abruption. Recalling positive memories provided caregivers with strength. Women reported exhaustion and fatigue from the episodes of violence. Two of the 16 participants considered admitting their partners to an institution because of the violence they faced.

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Interventions to reduce caregiver burden

Many studies have assessed the role of different interventions to reduce caregiver bur-

den, such as teaching them problem-solving skills, increasing their knowledge of dementia, recommending social resources, providing emotional support, changing caregiver

TABLE

Dementia and aggression: A look at the literature (*cont'd*)

Author/study type	Aim/criteria	Findings
Munkejord et al ¹⁰ Descriptive study	To examine the experiences of older women in Nordic culture caring for a spouse with cognitive decline. Inclusion: 11 older women, residents of Iceland or Norway, caring for a spouse with cognitive decline.	State of shock at the onset of symptoms. Sense of confinement. Hiding of household items (eg, knives) for safety. Development of exhaustion, psychosis, and "broken heart syndrome."
Seidel et al ¹¹ Descriptive study	To describe family caregivers' and professional caregivers' burden after hospitalization of patients with dementia. Inclusion: Family members who were the patient's main caregiver; and professional caregivers with major involvement in care of the person with dementia.	Highest burden in caregivers was due to perceived conflicts between their own needs and their responsibilities. Family caregivers perceived a higher burden than did professional caregivers. The burden due to aggressive and disoriented behavior, personal constraints, and social appreciation was more likely perceived by daughters-in-law. The burden due to care tasks was more likely perceived by spouses and life partners. Compared with professionals, family caregivers perceived a higher burden from the patient's cognitive impairment and aggressive and disoriented behavior.
Tang et al ¹² Survey	To describe experiences of caregivers of people with Alzheimer disease and related dementias on self-reported health, type of assistance provided, perceptions of how caregiving interferes with their lives, and perceived level of support. Inclusion: A sub-sample of adults who self-identified as providing regular care or assistance to a friend or family member with a chronic health condition or disability.	4.8% of the participants reported poor health status. Important health problems for caregivers included blood pressure (35.7%), depression (18.7%), chronic pain (16.9%), anxiety (15.2%), and insomnia/sleep disorder (14.3%).
Benbow et al ¹³ Descriptive study	To report instances of violence and to contribute to prevention of these instances. Inclusion: Reviews of the following cases were included: 1. Victim only, age > 60 y 2. Perpetrator/alleged perpetrator only, age > 60 y 3. Victim and perpetrator, age > 60 y.	In 7/30 cases, underlying mental illness of the perpetrator was determined to be a significant factor for violence. In 11/30 reviews, the victim was the perpetrator's caregiver.
Herron et al ¹⁴ Descriptive study	To determine how agitative or aggressive behaviors are perceived by the caregivers and to what extent social or environmental factors have a role. Inclusion: Purposive sample of caregivers was recruited for interviews between June 2016 and June 2017 in a largely rural region in southwestern Manitoba, Canada.	Verbal abuse was commonly experienced by most caregivers. Formal caregivers reported that scratching and pinching were common, probably as a result of their pulling away too quickly during personal care. Young male patients were more likely to exhibit forceful agitative behavior and had to be dealt with carefully. Caregivers also identified a lack of mental and emotional support services for themselves, which gradually changed their perception of the patients' actions.

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TABLE

Dementia and aggression: A look at the literature (*cont'd*)

Author/study type	Aim/criteria	Findings
Herron et al ¹⁵ Descriptive study	To report partners' response, interpretation, and explanation of the aggressive behaviors of patients with dementia. Inclusion: Interviews were conducted with people who identified as having formerly (in the past 1-5 years) been a partner caring for someone with dementia.	Caregivers understood the triggers of violent behavior and developed coping mechanisms. Some caregivers gave patients time and space until the initial trigger had passed. Having a formal caregiver at home in the presence of a family caregiver created confusion; some caregivers resorted to managing the patient on their own. Caregivers felt there was limited support and time provided by hospital staff, which was likely due to staff's inadequate training in managing patients with dementia.
Spencer et al ¹⁶ Descriptive study	To illustrate the defensive strategies used by the caregivers in the face of violence and to evaluate these strategies as potential causes for long-term harmful behaviors. Inclusion: Pre-diary interviews of caregivers from a large Canadian city.	Common strategies included flight (leaving the relationship) and resistance (hospitalizing or institutionalizing the family member). Caregivers also tried ways to contain the threat. One caregiver divorced her husband but did not report him for stalking her; this was one way of acting as if the caregiver was still responsible for the patient. Because of previous experiences with former spouses, a caregiver chose not to leave the relationship and bore the patient's controlling tendencies. One caregiver acted indifferently to the entire situation, as if she were trying to save her emotional energy.
Skovdahl et al ¹⁷ Descriptive study	To obtain insight into the reasoning of the caregivers who had reported problems when dealing with older people with dementia and aggressiveness. Inclusion: 9 caregivers from 2 different nursing homes participated in the video recording.	Caregivers expressed feelings of vulnerability. Routines gave the caregivers a sense of control and structure.

NA, not available.

perceptions of the care situation, introducing coping strategies, relying on strengths and experiences in caregiving, help-seeking, and engaging in activity programs.²⁴⁻²⁸ For Hispanic caregivers, a structured and self-paced online telenovela format has been effective in improving care and relieving caregiver stress.²⁹ Online positive emotion regulators helped in significantly improving quality of life and physical health in the caregivers.³⁰ In this last intervention, caregivers had 6 online sessions with a facilitator who taught them emotional regulation skills that included: noticing positive events, capitalizing on them, and feeling gratitude; practicing

mindfulness; doing a positive reappraisal; acknowledging personal strengths and setting attainable goals; and performing acts of kindness. Empowerment programs have also shown significant improvement in the well-being of caregivers.³¹

■ Caregivers may reject support. Hindrances to caregivers accepting support can include personal factors (eg, attitude, beliefs, values), service-related issues (eg, accessibility, affordability), and relational factors (preferences of the patient).³² In the case of patients with dementia who had a higher functional status, caregivers tend to reject any form of support.³² PCPs, of course, are

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optimally suited to care for entire families, often having known their patients and family members for years.

These practical tips can help

Based on our review of the literature, we recommend offering the following supports to caregivers:

- Counsel caregivers early on in a patient’s dementia that behavior changes are likely and may be unpredictable. Explain that dementia can involve changes to personality and behavior as well as memory difficulties.^{33,34}
- Describe resources for support, such as day programs for senior adults, insurance coverage for caregiver respite programs, and the Alzheimer’s Association (www.alz.org/). Encourage caregivers to seek general medical and mental health care for themselves. Caregivers should have opportunities and support to discuss their experiences and to be appropriately trained for the challenge of caring for a family member with dementia.³⁵
- Encourage disclosure about abrupt changes in the patient’s behavior. This invites families to discuss issues with you and may make them more comfortable with such conversations.
- Involve ancillary services (eg, social worker) to plan for a higher level of care well in advance of it becoming necessary.
- Discuss safety strategies for the caregiver, including when it is appropriate to alter a patient’s set routines such as bedtimes and mealtimes.^{33,34}
- Discuss when and how to involve law enforcement, if necessary.^{33,34} Emphasize the importance of removing firearms from the home as a safety measure. Although federal laws do not explicitly prohibit possession of arms by patients with neurologic damage, a few states mention “organic brain syndrome” or “dementia” as conditions prohibiting use or possession of firearms.³⁶
- Suggest, as feasible, nonpharmacologic aids for the patient such as mas-

sage therapy, animal-assisted therapy, personalized interventions, music therapy, and light therapy.³⁷ Prescribe medications to the patient to aid in behavior modification when appropriate.

- Screen caregivers and family members for signs of interpersonal violence. Take notice of changes in caregiver behavior or irregularity in attending follow-up appointments.

CASE ▶

Over the next month, the patient’s symptoms further deteriorated. His PCP recommended hospitalization, but the patient and his wife declined. Magnetic resonance imaging of the patient’s brain revealed severe confluent and patchy regions of white matter and T2 signal hyperintensity, consistent with chronic microvascular ischemic disease. An old, small, left parietal lobe infarct was also noted.

One month later, the patient presented to the emergency department. His symptoms were largely unchanged, but his wife indicated that she could no longer live at home due to burnout. The patient’s medications were adjusted, but he was not admitted for inpatient care. His wife said they needed help at home, but the patient opposed the idea any time that it was mentioned.

A few weeks later, the patient presented for outpatient follow-up. He was delusional, believing that the government was compelling citizens to take sertraline in order to harm their mental health. He had also begun viewing online pornography in front of his wife and attempting to remove all of his money from the bank. He was prescribed aripiprazole 15 mg, and his symptoms began to improve. Soon after, however, he threatened to kill his grandson, then took all his Lasix pills (a 7-day supply) simultaneously. The patient denied that this was a suicide attempt.

Over the course of the next month, the patient began to report hearing voices. A neuropsychological evaluation confirmed a diagnosis of dementia with psychiatric symptoms due to neurologic injury. The patient was referred to a geriatric psychiatrist and continued to be managed medically. He was assigned a multidisciplinary team comprising palliative care, social work, and care manage-

ment to assist in his care and provide support to the family. His behavior improved.

At the time of this publication, the patient's irritability and paranoia had subsided and he had made no further threats to his family. He has allowed a home health aide into the house and has agreed to have his roof repaired. His wife still lives with him and assists him with activities of daily living.

Interprofessional teams are key

Caregiver burnout increases the risk of patient neglect or abuse, as individuals who have been the targets of aggressive behavior are more likely to leave demented patients unattended.^{8,16,23} Although tools are available to screen caregivers for depression and burnout, an important step forward would be to develop an interprofessional team to aid in identifying and closely following high-risk patient-caregiver groups. This continual and varied assessment of psychosocial stressors could help prevent the development of violent interactions. These teams would allow integration with the primary health care system by frequent and effective shared communication of knowledge, development of goals, and shared decision-making.³⁸ Setting expectations, providing support, and discussing safety strategies can improve the health and welfare of caregivers and patients with dementia alike.

JFP

CORRESPONDENCE

Abu Baker Sheikh, MD, MSC 10-5550, 1 University of New Mexico, Albuquerque, NM 87131; absheikh@salud.unm.edu.

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➤ An important step forward would be to develop an interprofessional team to aid in identifying and closely following high-risk patient-caregiver groups.

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