# Hallucinations Are Real to Patients With Dementia

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R. C. Hamdy, MD<sup>1</sup>, A. Kinser, PhD<sup>1</sup>, J. V. Lewis, MD<sup>1</sup>, R. Copeland, MD<sup>1</sup>, A. Depelteau, PhD<sup>1</sup>, T. Kendall-Wilson, RN<sup>1,2</sup>, and K. Whalen, BA<sup>1</sup>

### Abstract

In this case study, we present a patient with preexistent posttraumatic stress disorder and psychosis who has been recently diagnosed with Dementia with Lewy Bodies. He is experiencing vivid hallucinations. What went wrong between him and his wife as a result of these hallucinations is presented. Alternative actions that could have been used are suggested.

### Objectives

At the end of this case study, readers will know the following:

The characteristic clinical features of Dementia with Lewy Bodies (DLB). Patients experiencing hallucinations should not be contradicted, to them, these hallucinations are real. Easy distractibility and short attention span can be exploited to avert or defuse potentially catastrophic situations. Patients with dementia should not have access to loaded guns.

#### Keywords

Alzheimer's/dementia, hallucinations, Dementia with Lewy Bodies, catastrophy

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# **Case Presentation**

# Characters

- David is 71 years old, a retired Marine, known to have posttraumatic stress disorder and psychosis. He has been diagnosed as having Dementia with Lewy Bodies (DLB) about 1 year ago. He is physically independent and lives with his wife, Mary.
- Mary is David's wife for 40 years.

# Scenario

It is about 3:30 a.m., David is awake, anxious, and agitated. His wife, Mary, is sound asleep. David is going around the house, appearing to alternate between hiding and searching for something. He hides behind the couch, peeps above it, listens for noises, crawls to the window, and rises just sufficiently to take a quick furtive look.

David mutters, "I can't let them capture us. I must find them before they find us." He walks over to a cabinet and pulls out a handgun that he proceeds to load. He crouches on the floor behind the couch. There is a window beside the couch; he peers through it with a pair of binoculars. He puts them down and slowly gets up from his hiding spot. He draws his gun and walks toward the bedroom. He is looking around quickly to make sure no one has spotted him. He slowly opens the bedroom door and surveys the room. His wife is soundly asleep.

Very slowly he gets close and whispers in her ear, "Don't worry, Major, I've got everything under control. They will not capture us alive." Mary reaches for the bedside light, but David stops her: "Don't switch that light on, Major! The terrorists will know our position. They have us surrounded and we are outnumbered."

Mary, now fully awake, says, "You're crazy. There are no terrorists around here, and I'm not a major, I'm

#### **Corresponding Author:**

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<sup>&</sup>lt;sup>1</sup>East Tennessee State University, Johnson City, USA <sup>2</sup>Alzheimer's Tennessee, Inc., Knoxville, USA

R. C. Hamdy, Department of Geriatric Medicine, East Tennessee State University, Box 70429, Johnson City, TN 37601, USA. Email: Hamdy@mail.etsu.edu

your wife! You are imagining things again." David is agitated. He murmurs in Mary's ear, "Major, I told you I saw them: they're coming closer. They'll find us." Mary, now irritated, answers with, "For Heaven's sake Dave! Will you stop these stupid games? They are exhausting me." David gets more agitated, despite Mary's attempts to persuade him that they are safe and secure in their own home in the United States and that there are no terrorists, but to no avail. Mary now proceeds to ridicule David.

David says, "If the terrorists get inside this compound, I'll shoot you and then shoot myself." He shows Mary the gun and releases the safety. Mary says, "Put that gun away. You're imagining things. Nobody is after us!"

David tries to calm her by putting his hand on her arm. He squeezes her tight. Mary is now afraid and agitated. She shrieks, "Put that gun away before one of us gets hurt!" David puts his hand on her mouth. Whispering he says: "Don't be afraid Major. I will not let them behead us." Mary is now petrified, she sees that David is serious. She quickly gets out of the bed and starts to run away. David shoots and hits her, she falls to the ground. He then shoots himself fatally in the head: A catastrophic ending!

# **Case Analysis**

Turning points/triggers that led to this aberrant behavior include the following:

1. Mary did not acknowledge the hallucinations even though David has been hallucinating for quite some time and is past the stage of recognizing them as hallucinations. To him they are real.

In the early stages, patients with DLB are aware and not frightened by their hallucinations. Most of the time, they are fleeting and the patients quickly realize they are hallucinating. As the disease progresses, however, they believe that the hallucinations experienced are real. In some instances, they may be longer lasting, as in David's case. This is probably because of the combination of DLB, psychosis and posttraumatic stress disorder. The vividness of David's hallucinations and the length of time he was gripped by them intensified his anxiety and paranoia.

#### Could it have been avoided?

It is important to appreciate that if the patients do not quickly realize they are hallucinating it is preferable not to repeatedly contradict them. This only increases their level of frustration and anxiety and triggers or worsens their paranoid delusions. They should neither be patronized nor ridiculed but reassured. These hallucinations are real to them. In David's case, therefore, it probably would have been best not to disagree with him or try repeatedly to convince him that he was imagining things. He was afraid, agitated, had developed a plan, and was likely to execute it. Reassuring him and exploiting his need to feel important and needed would likely have calmed him.

Some approaches Mary could have adopted include the following:

- "Oh Dear! Who are these people? What do they want?" This would have given her some time to assess the situation and develop a strategy to defuse it.
- "I'm so afraid. Please don't go. You are so brave! Please stay with me. Tell me more about your plan."
- "I'm so relieved! Thanks for taking care of me. You are so good. I'm glad we are on the same team. Why don't you rest for a while? Here give me the gun and try get some sleep."
- "I'm sure our boys will come soon. Let's huddle together and not make any noise until our boys are here. You must be exhausted. Why don't you lie down? I am rested. I'll keep watch. Here, give me the gun."
- "I always knew I could count on you. Thank you. What would you like me to do? I've got some of the apple pie you like, shall I go get it? You must be quite hungry."
- "Have you checked the attic and basement? Let's go check them, give me the gun, I'll cover you."
- "How about taking shifts. I'll take the first shift while you rest. You must be exhausted. Here, give me the gun and get some sleep. Tomorrow is going to be a very busy day."

Once David is reassured, attempts could be made to take the gun from him, or, better still, have him hand over the gun.

2. Mary tried to argue with David.

Arguments should be avoided with patients who have dementia. It is just not possible to successfully argue with a patient who has dementia as the patient is not able to understand the point made, store it in his memory, associate it with past experiences and fund of knowledge to come up with an adequate response to the argument made. Furthermore, as David is anxious and afraid, he probably is not in a position to even listen to any argument that his wife may make. Arguing in that case is likely to be futile and counterproductive as it may trigger paranoid delusions which may have dire consequences as he is carrying a loaded gun.

Could it have been avoided?

Given that David is so agitated and afraid, his wife's first task is to try reassure him. Contradicting him and trying to convince him of his hallucinations is not likely to succeed and in fact could be counterproductive. Therefore, instead of arguing with David, Mary should first agree with him, try to reassure him, calm him and very quickly try to distract him. She could have adopted a variety of strategies, including the following:

- "I think my gun is in the room next door. Let's go and get it."
- "Why don't we try phoning our boys? Let me get my cell phone" or "The landline was working about an hour ago; let's go and find out if is still functional."
- "I think the window in the bedroom is open. Let's go close it."
- "Let's take another walk around the house just to make sure all the windows and doors are bolted."

On the way to her destination, she could have tried to distract David, by telling him, for instance, that she's baked his favorite dessert and guide him to the kitchen or that she has some other task for him, such as changing a lightbulb or any other activity. Chances are high that David would have accepted the invitation and gotten distracted from his hallucinations. By seeking his help, Mary affirms that he is needed.

3. Mary ran away.

Fortunately, the gunshot wound Mary sustained was not fatal. She lived to tell the story. Unfortunately, David fatally shot himself. His death was the ultimate result of an event stemming from the hallucinations that often accompany DLB. It is important not to run away from a potentially hazardous situation without being sure running is the safest alternative. It rarely is. Running away offers a target that may be difficult for a former Marine to miss.

Could it have been avoided?

Mary should not have run away. She could have used other methods, outlined above, to defuse the situation and relieve David of the gun.

4. If a gun needs to be in a house where a person with dementia lives, it should not be easily accessible and the ammunition should be kept separate. This is especially true if the patient has DLB because of the vivid hallucinations often experienced and the patient's fluctuating degree of cognitive impairment. Many patients with other types of dementia are also likely to misuse a readily available gun, because of their cognitive impairment.

If a gun is to be kept in the house, it should be locked away with the key not easily accessible. The ammunition should be kept separately, in a locked drawer also with the key not readily accessible. Alternatively gun locks could be installed or the gun may be disabled.

## **Case Discussion**

#### Prevalence of DLB

After Alzheimer's disease, DLB is the second most common type of dementia in older adults. It usually manifests itself between the ages of 60 and 80 years (Hanagasi, Bilgic, & Emre, 2014, 2016) and accounts for up to 20% of autopsy documented dementia cases (Budson & Solomon, 2016). When compared with Alzheimer's disease, it tends to have a more rapid rate of deterioration, with more patients needing earlier nursing home placement and dying. Time from diagnosis to nursing home placement is 2 to 6 years and to death is 3 to 8 years (Budson & Solomon, 2016).

#### The Clinical Diagnosis of DLB

The clinical diagnosis as per guidelines established by the fourth consensus report of the Dementia With Lewy Bodies Consortium in 2017 (McKeith, 2017) is based on the following:

1. Essential feature:

As mentioned in Case 1 of this series, the sine qua non features of dementia are first, a deterioration in the level of cognitive functioning from a previously higher level of functioning. Second, the deterioration is of such magnitude that it interferes with the daily activities of the patient. Both features must be present when the patient is lucid, alert and not delirious, and in the absence of acute underlying pathologies such as pneumonia, urinary tract infection, or acute heart failure that may interfere with cognitive functions.

Deficits in attention, executive function, and visuoperceptual ability tend to be prominent early in the disease process. Judgment is also impaired. Memory impairment may not be evident in the early stages but usually manifests itself as the disease progresses.

- 2. Core clinical features:
- a. *Fluctuations* as manifested by changing levels of the following:
- Cognition: Cognitive dysfunction, disorganized thought process and speech.
- Attention: Various degrees of attention and inattention, including staring into space for long periods of time.
- Alertness: Daytime drowsiness/somnolence, daytime sleep episodes lasting at least 2 hr.

Characteristically, these fluctuations have a variable duration and may last from just a few minutes to a few hours leading caregivers to think that the patient is being uncooperative or obnoxious. They also may have a rapid almost sudden onset or may gradually develop over a period of minutes or hours. Given their unpredictability and their waxing and waning, fluctuations are most frustrating to relatives and caregivers.

b. Hallucinations: Usually hallucinations are complex visual, often animate, well-formed, and detailed, featuring people—sometimes deceased family members—children, or animals. They occur in about 80% of patients with DLB (McKeith, 2017), early in the disease process and are frequently under reported. In most instances, patients are aware of these hallucinations, tolerate them, and are not afraid. As the disease progresses, patients may not be able to distinguish hallucinations from reality (Budson & Solomon, 2016).

Hallucinations need to be differentiated from illusions and delusions. A hallucination is a sensory experience without any sensory stimulus to trigger it. An illusion is a misperception or misinterpretation of an actual sensory stimulus, for instance, a door slamming is interpreted as a gunshot. A delusion is a false belief held despite evidence to the contrary (Galik, 2016). Paranoid delusions tend to occur late in the course of the disease and include spousal infidelity, theft and intruders. Occasionally patients may believe that impostors have replaced their spouse or caregiver, the Capgras syndrome (Gomperts, 2016).

c. Extra-pyramidal signs: Extra-pyramidal signs are observed in about 85% of patients with DLB and include fine tremors at rest, increased muscle tone, and a paucity of involuntary movements such as swinging the arms while walking, crossing legs while sitting down, changing facial expressions, and looking around. These are the typical signs of Parkinson's disease. On the contrary, up to 25% of patients with autopsy documented DLB had no extrapyramidal clinical signs (Budson & Solomon, 2016).

The "one-year rule" is sometimes used to differentiate dementia complicating Parkinson's disease from dementia seen as part of DLB. When both the extrapyramidal signs and dementia occur within 1 year of each other, it is probable the patient has DLB. However, if the time lapse between dementia and Parkinson's disease is more than 1 year, then it is probable that the patient has dementia complicating Parkinson's disease: Parkinson's disease dementia. In this last instance, the time gap between Parkinson's disease and dementia is usually a number of years that could be as long as 20 or even more.

d. Rapid eye movement sleep Behavior Disorder (RBD):

RBD is a recurrent parasomnia resulting from the lack of the atonia that normally occurs while the person is dreaming (the Rapid Eye Movement [REM] phase of sleep). As a result, the patient enacts the dreams, especially dreams involving chasing or being chased, attacking or being attacked. RBD is often not noticed by the patient but reported by the bed partner. If the patient has no bed partner and in the absence of a plausible explanation, finding pillows or bedsheets on the floor is often an indirect evidence of RBD. Autopsy confirmed cases document that RBD occurs in 76% of patients with DLB as compared with 4% in non-DLB dementia (Ferman et al., 2011). RBD is rare in other neurodegenerative disorders. It usually manifests itself many years prior to the onset of DLB.

- 3. Supportive Clinical Features:
- a. Hypersomnia:

Usually manifested as excessive daytime sleepiness

b. Hyposmia:

Reduced ability to detect and identify various smells tends to occur earlier in DLB than in Alzheimer's disease.

c. Increased sensitivity to neuroleptic medications:

Neuroleptics can, irreversibly, trigger or aggravate Parkinson's disease and in patients with DLB also can increase mortality. Patients with DLB are particularly sensitive to neuroleptics and can develop the life-threatening neuroleptic malignant syndrome: high fever, confusion, muscle rigidity, excessive sweating, hypertension or hypotension, and tachycardia. Complications include rhabdomyolysis, hyperkalemia, kidney failure, and seizures. The prognosis of the malignant neuroleptic syndrome is such that it has been suggested patients and caregivers be told that the patient is allergic to haloperidol and other neuroleptics with significant D2 receptor antagonist activity (Gomperts, 2016).

#### Summary

- Patients with DLB who are experiencing hallucinations should not be contradicted. To them the hallucinations are real events.
- The easy distractibility and short attention span of patients with DLB can be exploited to avert or defuse potentially catastrophic situations.
- Patients with dementia should not have access to loaded guns.

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