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Teaching Case Studies: Managing Aberrant Behavior In Patients With Dementia

Visual Hallucinations and Paranoid Delusions

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Abstract

Visual well-formed hallucinations, fluctuations in the level of cognition, and alertness and extrapyramidal signs are core features of dementia with Lewy bodies. Some patients realize that what they are seeing or hearing are just hallucinations and learn to accept them. Others, however, experience these hallucinations as quite real and cannot be dissuaded from the firm belief that they are. In fact, efforts to dissuade them often serve only to confirm the often associated paranoid delusions and this may lead to a catastrophic ending. Hence, it is best not to contradict the patient. Instead, attempts should be made to distract the patient and change the focus of her or his attention. In this case scenario, we present a 68-year-old man who has been diagnosed with dementia with Lewy bodies. He lives with his daughter. He has visual hallucinations and paranoid delusions that worsen at night: He thinks there are people outside the house plotting to kill him. We discuss what went wrong in the patient/caregiver interaction and how the catastrophic ending could have been avoided or averted.

Keywords

Alzheimer’s/dementia, caregiving and management, cognition, confusional states

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Objectives

At the end of the scenario readers will appreciate the following:

1. Visual, well-formed hallucinations are core features of dementia with Lewy bodies (DLB). Patients also can have paranoid delusions.
2. It is best not to contradict a patient who has hallucinations and is delusional. To the patient, these are real.
3. If rationalizing with the patient is not successful the first-time round, further rationalizing should be avoided.
4. It may be helpful to play along with the patient until such a time that she or he can be distracted.
5. Disabling accessible guns at home may be a better strategy than hiding them.

Case Presentation

Characters

- Edwin, 68 years old, has DLB. His wife died about a year ago.
- Rosa is Edwin’s daughter. She is a widow and lives with her father.
- Rosa and her father are planning to visit her son, Raymond, and his family the following day, about 150 miles away.

Scenario

It is about 9:00 p.m., Edwin and his daughter Rosa have spent the past hour watching the news and commentaries on TV. Rosa stands up and tells Edwin that it is time to go to bed, reminding him that the following day they will be driving to visit Raymond and his family and that it will take them about 3 hr to get there.

Rosa is thinking about the long day they have ahead and the chores she still has to do to make ready for the

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trip. She notices that her father is anxious and agitated. He utters in a very hesitant voice:

Rosa, I saw and heard them outside my bedroom window. I heard them say that they are going to kill me. I don’t want to go to bed . . . and I don’t want to go to my room.

He is trembling, shaking and looks afraid.

Rosa first tries to reassure him that they are safe and secure, that nobody is outside the house and nobody is trying to kill him. They live in a safe, gated community; no outsider can get on the premises. Edwin is not convinced. Rosa then offers to go to her dad’s bedroom and check the window. Edwin refuses, “Please, don’t leave me alone. I saw them. They’re coming. I know. Please don’t go.”

Rosa tries to explain that the trees outside, the rain falling, the wind rustling the leaves, and the moon shining through the clouds are playing tricks on him and making him believe there are people with bad intentions outside. But Edwin does not accept it. “I saw them and heard them. They have evil intentions. They want to kill me.” Again Rosa tries to convince him, but to no avail.

Rosa again and again tells her dad that he is just imagining things. She reminds him they live in a very secure gated community and have nothing to worry about. But Edwin refuses to accept this. Rosa then reminds him that the doctor they saw a few weeks ago said that he may have hallucinations and that they should not worry about it. “Rosa! I’m telling you, I could see and hear them as clearly as I see and hear you now. They want to kill me!” Rosa tries to reassure him but he is not dissuaded. Edwin grows increasingly agitated. Rosa is tired and still has chores to do before going to bed; she is losing both patience and strength. Edwin lies down on the sofa and states that he will spend the night there.

Taking Edwin by the arm and pulling him up, Rosa tells him that he is being silly and implores him to go to his room. Edwin is upset. He now thinks that his daughter is in cahoots with the murderers outside his window. “My own daughter, my own flesh and blood. Get away from me before I hurt you! I’ll take care of the people outside myself. I’ll kill them all, same as I did many times in Nam!” He opens the drawer where he used to keep his gun and rummages through the drawer but cannot find the gun. He demands that Rosa tell him what she has done with the gun. Rosa tries to explain that the doctor told her to hide it so that he does not injure himself.

Edwin is angry now; he curses the doctors and yells about them “meddling in other peoples’ affairs.” He picks up the car keys and announces that he is going to the gun fair, about 30 miles away, to get a gun; he says he may even get two or three guns. “I don’t even have to wait for security clearance. I’ll pay cash and buy the guns.” He pulls a few 100 dollar bills from another drawer and storms out of the house. Rosa tries to physically stop him, but he pushes her away; she falls on the ground, injured, and cannot get up. Edwin drives off.

Case Analysis

Turning Points—What Went Wrong? Could It Have Been Avoided, Averted, or Defused?

Rosa cavalierly dismisses her dad’s fears. Rosa just tells her dad that he is imagining things and that nobody is outside the house trying to kill him, but does not verify it. In other words, she contradicts him without first ensuring she is correct and that her dad is having hallucinations and is delusional. Edwin may therefore feel that his daughter does not really believe him: if she had, she would have made attempts to find out whether the threat is real or imaginary.

Edwin firmly believes that there are people outside the house planning to kill him. He categorically states that he saw them. Trying to convince him of the contrary is likely to be a difficult almost impossible task especially after the first few attempts at trying to convince him were not successful. The more his daughter tries to convince him that he is hallucinating and has delusions, the more entrenched Edwin tends to become in his belief that they are real. In other words, it does not help to repeatedly try to convince the patient of these hallucinations and delusions, especially if the patient is agitated and anxious.

It would have been more convincing to Edwin that he is hallucinating had his daughter attempted to find out if anybody was outside the house. Instead, she just tells him that these are hallucinations and reminds him of their encounter with his doctor who warned him about having them. Contradicting her dad creates conflict between patient and caregiver.

Could it have been averted/avoided?

Rather than repeatedly trying to convince him that he is having hallucinations and delusions, his daughter should have tried to distract him and get him to refocus his attention on some other object or activity. However, for this strategy to be successful, the caregiver should not persist in trying to convince the patient that he is hallucinating because with each failed attempt it becomes more and more difficult to convince the patient that he is hallucinating and having delusions.

Edwin would have been much more likely to accept that he is hallucinating had his daughter entertained, or pretended to entertain his hallucinations, albeit temporarily. For example, she might have taken the following steps:

a. Peered through the windows to see if someone was outside the house.

b. Switched on the lights outside the house to have a better view of the immediate surroundings of the house.

c. Thoroughly and convincingly checked and demonstrated to her father, that the windows and doors are properly closed and the security system is armed.
d. Once reassured, she could have gone outside, with or without her dad, to further convince him that no one is lurking outside. On the way out, she could have picked up a disabled gun to further demonstrate to her dad that she believes him.
e. Told her dad that she is going to phone the police, ask him to accompany her, making sure he is hearing her “talk” to the police, while in fact only pretending to do so.

After using such strategies, she may then try to distract her father. For instance, as they go through the kitchen she may offer him a drink or his favorite food. Similarly, as they go through a bedroom she may ask him to check an electric outlet or drawer that does not close properly. This has the added advantage of Edwin’s feeling needed and may distract him from his original delusions.

Rosa, therefore, needed to distract her dad or get him to focus on a different issue very early in the evening as soon as she became aware of the hallucinations. She may, for instance, have asked his help to load the car, or put out the clothes he will be taking with him on their forthcoming trip.

**Rosa tries to argue with her dad, providing rational explanations to his hallucinations and delusions.** The more Rosa tries to argue with her dad and convince him that he is hallucinating the more likely is her dad to get entrenched into his hallucinations and delusions, especially as he is anxious, apprehensive, and agitated. Given his condition it is very difficult for him, especially at this stage, to make the correct associations and be convinced that the voices he heard were the wind rustling through the leaves of the trees and that the shadows he saw were the moonlit surroundings of the house and the cloudy sky.

Although these are logical arguments, a patient with dementia is unable to make the required deductions and be convinced that his hallucinations are not factual. Edwin’s judgment is impaired. He is not in a position to understand the seemingly convoluted argument his daughter is making. To accept this argument, he would have to be able to detach himself from his beliefs and recognize the rationality of the argument. Given that he has dementia and therefore an impaired judgment, he cannot do this.

**Could it have been avoided?** Arguments should be avoided. It is very difficult, almost impossible, to convince a patient with dementia of logical arguments because the patient is unable to draw the expected conclusions. In addition to the poor memory and the short attention span, patients with dementia have an impaired judgment.

Rosa would have been much better off is she had played along until such a time an opportunity arises to distract her dad from his hallucinations.

**Rosa tells her dad she hid the gun.** This was a major turning point. By telling him outright that she has hid the gun and that this was done on the instructions of his doctor, she immediately sets herself up against her dad. Edwin feels he can no longer trust his daughter. This may further fuel his delusions that there are people trying to kill him. He may feel that his daughter is part of the plot.

**Could it have been avoided?** Rosa should not have admitted to having hid the gun. She could have pleaded ignorance to its whereabouts and even offered to help search for it. In fact, she could have used this as a ploy to redirect his attention from his delusions to searching for the gun and in the process, at the right time, distract him by getting him involved in some other activity.

Alternatively, rather than hiding the gun, she may have had the gun disabled thus rendering it harmless, while reassuring her dad that he has a gun and could defend himself. Gun ownership is such an entrenched principle in many people that they feel threatened without ready access to a gun. Some of the issues related to gun ownership are discussed in another case study.

**Rosa disagrees with her dad spending the night on the couch. She physically tries to get him off the couch.** Rosa does not recognize the intensity of her father’s delusions. He is convinced that people are trying to kill him and that spending the night in his room increases their chances of succeeding, so he decided to spend the night on the couch.

**Could it have been averted?** There probably is no good reason why Edwin could not spend the night on the couch. If, however, the couch is too uncomfortable to spend the whole night, Rosa could have offered to exchange bedrooms: He could spend the night in her bedroom and she would spend the night in his bedroom or, if available, she could have offered him to spend the night in the spare bedroom.

**Rosa could have reassured her dad that she loves him.** Throughout this encounter, there is very little show of love and affection. Understandably, Rosa has many chores to complete before driving to her son’s house the following day and is pressed for time. She is feeling overwhelmed by all that she needs to accomplish and is anxious. She nevertheless needs to consider her dad’s apprehension and possible anxiety about the following day’s trip to his grandson; these indeed may have colored his interaction with his daughter.

**Could it have been avoided?** Patients with dementia including DLB need to be constantly reassured that they are loved and cherished. Caregivers must appreciate that these patients do not really understand what is going on: They know their cognitive functions are not as good as they used to be and find it difficult to adjust to
any change in situation or circumstances. In addition to showing signs of affection, Rosa could have reassured her father that she loves him and would never let anything bad happen to him.

**Rosa could have considered alternate plans.** Given Edwin’s state and Rosa’s own exhaustion and anxiety, it may have been optimal to postpone the trip. Perhaps an additional day, or longer, to complete the trip preparations and increase the likelihood of a good night’s sleep for Edwin would have eased the tension this night and positioned them both for a more enjoyable trip.

**Could it have been avoided?** Caregivers need to recognize that, in general, plans that include a person with dementia have to be tentative. Much like those who struggle with chronic illness, who can never be sure when they will have a severe flare up or will be feeling unwell, dementia patients have to be allowed much leeway with any expectation about their participation in plans or events. This can be very frustrating for the caregiver, perhaps Rosa only had the weekend to make the trip and postponing it even one day would not have been possible. Even so, exercising the greatest flexibility possible and always allowing for a Plan B is the optimal mode for making plans that include a patient with dementia.

Edwin storms out of the house and intends to purchase a gun at the gun fair. Rosa was unable to restrain her father and prevent him from going to the gun fair to purchase a gun, where he would not have to go through the security screening process or waiting period. Given that he had sufficient cash with him, it is conceivable that he could have acquired a gun that very same evening.

**Could it have been avoided?** By the time Edwin leaves the house, it really is too late for Rosa to try and stop him: Climax has been reached and it is not possible to go back in time. Rosa nevertheless could contact the police to let it be known that her father, who has DLB, is on his way to purchase a gun. She could give the police all the relevant information such as the make and color of the car, the license plate number, and her father’s name and solicit their assistance in finding him.

It also is not recommended to have large sums of cash readily available at home. Had the cash not been available, Edwin would not be in a position to go to the gun fair and purchase a gun. Similarly, Edwin would not have been able to use a credit card or check to purchase the gun had the legal steps been taken to invalidate his use of credit cards or checks.

Although physical confrontation is not common among this patient population, it is possible that a violent scenario may arise as an outcome of hallucinations and paranoid delusions. If a patient seems liable to become violent, it is important that a caretaker makes sure to appear nonthreatening—do not stand too close, and maintain direct or lower eye level rather than towering over the patient. Be sure the patient does not have access to weapons, including makeshift weapons such as cutlery. Make sure to keep a clear exit route from the room that is not blocked by the patient. Patients suffering from dementia typically have very short attention spans, so distraction is an effective tactic to subvert a physical confrontation. If there is no other option and the patient is safe without access to weapons, the best option may be simply to leave the scene temporarily. While safety is always the primary concern, in some circumstances gentle physical touch may actually serve to reassure and calm the patient.

**Case Discussion**

1. **DLB—Diagnostic features**

Dementia with Lewy bodies is the second commonest type of dementia after Alzheimer’s disease.

The diagnosis of DLB is based on the following criteria (Budson & Solomon, 2016; Donaghy & McKeith, 2014; McKeith et al., 2005; National Institute of Health [NIH], 2013):

- **Central feature:** Decline in cognitive functions interfering with daily activities.
- **Core features:** Fluctuations in degree of alertness/attention and cognitive functions. Well-formed, detailed visual hallucinations. Parkinsonism: clinical features of Parkinson’s disease.
- **Suggestive features:** Rapid eye movement sleep behavioral disorders. Severe neuroleptic sensitivity. Low dopamine transporter uptake in basal ganglia (Single Photon Emission Computed Tomography or Positron Emission Tomography scans).

The main problem with DLB, however, is not so much with memory as it is with the patient’s ability to conduct complex mental activities such as multitasking, problem solving, reasoning, and analytical thinking.

2. **Parkinsonism—extrapyramidal signs**

Characteristic extrapyramidal signs (Parkinsonism) include (NIH, 2013; Sapira, 1990):

a. Fine tremors at rest. Unlike cerebellar tremors that are accentuated while carrying out voluntary activities (intention tremors), parkinsonian
tremors tend to stop or decrease in intensity when the patient voluntarily moves the affected arm. Characteristically the tremors stop when the patient is about to pick an object, but then start again once the task is completed. The tremors tend to be exaggerated if the patient is anxious or mentally stressed. They are absent while the patient is asleep. The wrist and fingers are kept in a flexed position and the hand tremors are often described as “pill-rolling tremors.” These tremors tend to start in one upper limb affecting mostly the fingers, hand, and wrist and then spread to the lower limb on the same side then the opposite side.

b. Increased muscle tone or rigidity. An early sign of increased muscle tone associated with Parkinsonism is the patient’s handwriting becoming cramped and smaller: “micrographia.” When both sides of the body are affected, the rigidity of the facial muscles causes the face to appear expressionless: “mask face.” Smiling, frowning, and changing facial expressions are rare. Furthermore, when the patient smiles, the smile develops slowly over a period of few seconds and then disappears also over a period of time. Patients tend to speak in a weak voice. When both sides are affected, the upper part of the body is flexed and the patient adopts a stooped posture. As this may cause the patient’s center of gravity to be slightly displaced forward, the patient appears to be trying to catch up with his center of gravity to prevent falling forward. The increased muscle tone also causes the patient to take short steps while walking “marche à petits pas,” and as the patient is often not able to lift the feet sufficiently to clear the floor, the patient appears to have a “shuffling gait.” Patients often have an impaired muscle coordination, balance problems, and may sustain repeated falls. The combination of increased muscle tone and tremors is referred to as “cog-wheel rigidity.” The combination of shuffling gait and tremors is described as a “festinating gait.”

c. Paucity of associated movements such as crossing one’s legs, or shifting position when seated and swinging the arms while walking. Drooling of saliva. Because of the rigidity and bradykinesia of the swallowing muscles, the patient is not able to swallow all the saliva that is naturally produced and it may drool outside the mouth, giving the impression that the patient is producing a large amount of saliva.

d. Bradykinesia and akinesia: difficulties initiating movements. For instance when the patient, who is standing up, is asked to walk, he finds it difficult to initiate walking. His feet appear to be glued to the floor. The patient is seen trying to move his legs but is initially unable to do so immediately: It may take him a few seconds to set his legs in motion, during this period the tremors may become worse.

3. Dementia with Lewy bodies versus Parkinson’s disease dementia: The 1-year rule

If the dementia and extrapyramidal signs manifest themselves within 1 year of each other the diagnosis is likely to be dementia with Lewy bodies. On the contrary, if more than 1 year separate the onset of extrapyramidal signs from the onset of dementia, then the diagnosis is Parkinson dementia.

4. Hallucinations

Hallucinations are imagined perceptions in the absence of a stimulus. Unlike illusions that are due to an erroneous interpretation of stimuli, such as a coat being interpreted as a person and tinnitus as a voice, hallucinations occur without a stimulus. The patient may see another person in the absence of that person. In other words, the origin of hallucinations is entirely in the patient’s mind. It occurs in the absence of any peripheral stimulation: visual, auditory, or tactile.

Visual hallucinations may be formed, with the patients convinced they are seeing or hearing other people actually talking to them, or they may “see” animals without any stimulus generating this vision. Less frequently hallucinations may be unformed with the patients seeing flashes of light or different colors or hearing noises they cannot interpret.

Hallucinations can also be complex with the person seeing, hearing, and conversing with other people who are just not there. This can be quite unnerving to caregivers and loved ones.

Formed auditory hallucinations are also a sign of schizophrenia with patients hearing voices often ordering them to take some action.

5. Delusions

Delusions are false unsubstantiated beliefs, often strong beliefs, held despite firm evidence to the contrary. For instance, a patient with paranoid delusions may believe that his wife or other loved ones are stealing his money. It is of interest to note that the very first patient described by Dr. Alois Alzheimer in 1906 believed her husband was being unfaithful to her, even though there was no evidence to support this belief. Patients with delusions often feel rejected, unloved, or suspect infidelity. In this present case, Edwin is firmly convinced that people outside the house are planning to kill him.

Paranoid delusions make it difficult to manage patients as they often feel they are the victims of a conspiracy against them. Patients with delusions need to be constantly reassured that they are loved. Given the impaired short-term memory and short attention span, reassuring
gestures of love and affection have to be demonstrated at frequent intervals.

6. Illusions

An illusion is a misperception, a distorted perception of an object or a situation. For instance, the person may mistake a coat hanging on the wall as a person watching her. A scarf on the floor may be perceived as a snake. A fur coat may be perceived as an animal about to attack the person. Illusions tend to be short lived with the person quickly realizing that what she thought she saw or heard are in fact distorted perceptions.

Illusions tend to be more common in the evening and at night when illumination may be inadequate. They also may occur in the presence of glare. Cataracts, macular degeneration, glaucoma, errors of refraction, and even inappropriate or dirty lenses may interfere with visual acuity and lead to illusions. Tinnitus also may be the source of an illusion with the person interpreting the tinnitus as someone trying to converse with her.

Illusions are often aggravated by reduced visual or auditory acuity that further impairs the patients’ ability to clearly see the surroundings or hear people talking to them. They are also aggravated by agnosia when the person is unable to recognize objects or people. The person, for instance, may think that the chaplain dressed in black is the “reaper” coming to claim their lives or that a technician in a white uniform is an “angel.”

Illusions are usually short lived but may be quite vivid and interfere with the patient’s daily activities. The patient, for instance, may refuse to go to a poorly lit toilet because she thinks the towel on the floor is a rat.

7. Pareidolias

Pareidolias are complex visual illusions generated by looking at ambiguous forms and perceiving them as meaningful objects. Pareidolias are not hallucinations because they are triggered by an actual stimulus. They nevertheless reflect the patient’s susceptibility to develop visual hallucinations. They are the basis of a test (pareidolias test) designed to help in the diagnosis of dementia with Lewy bodies. This test has been shown to have a sensitivity of 100% and specificity of 88% to diagnose dementia with Lewy bodies. Compared to patients with Alzheimer’s disease and normal controls, patients with DLB saw significantly more meaningful illusory images (pareidolias) and the number of pareidolias correlated with the severity of the visual hallucinations. Finally, medications enhancing cholinergic activity were shown to reduce the number of pareidolias (Uchiyama et al., 2012).

8. Sleep disorders in dementia with Lewy bodies

Rapid eye movement behavioral disorders (RBD) have already been discussed in the case study: “Hallucinations are real to patients with dementia.” RBD may appear several years before the onset of dementia. Patients with DLB often sleep 2 or more hours during the day and complain of difficulties falling asleep and maintaining sleep at night: They may wake up early in the morning.

9. Behavioral and mood symptoms

Patients with DLB are susceptible to several behavioral and mood changes including depression, apathy, anxiety, irritability, and agitation.

10. Neuroleptic sensitivity: The neuroleptic malignant syndrome (NMS)

Patients with DLB may develop the NMS, a severe, life threatening condition, developing within days or sometimes weeks of initiating treatment with neuroleptics or antipsychotic medication including the typical antipsychotics (such as haloperidol and droperidol), phenothiazines (such as chlorpromazine and promethazine), and to a lesser extent the atypical antipsychotics (such as clozapine, olanzapine, risperidone, and quetiapine and ziprasidone; Berman, 2011; Straw, Keck, & Caroff, 2007). NMS may also occur in patients with Parkinson’s disease when the dose of dopaminergic medication, such as levodopa, is abruptly reduced. NMS also has been reported following the administration of medications with anti-dopaminergic activity such as metoclopramide (Friedman, Weinrauch, & D’Elia, 1987).

Patients present with agitation, acute confusion, altered levels of consciousness, excessive sweating, tachycardia, muscle rigidity, cramps, tremors, an increased body temperature, and unstable blood pressure. NMS is a medical emergency. Complications of NMS include rhabdomyolysis, hyperkalemia, renal failure, and seizures. Mortality can be as high as 10%.

11. Sundowning

All of these issues may be exacerbated at nighttime. Many dementia patients’ circadian rhythms become distorted, leading to confusion in the hours preceding and immediately following the sunset. Therefore, hallucinations and delusion may present more commonly at nighttime than during the day. This phenomenon is discussed in greater detail in another case study in this series.

Summary

1. Hallucinations and delusions are real to patients with dementia especially dementia with Lewy bodies and are further aggravated by the patient’s often impaired judgment.
2. Once the second or third attempt fails to convince the patients that they have hallucinations and/or delusions caregivers should not
persevere. Instead they should try to redirect and refocus the patient’s attention in a direction different from their hallucinations and delusions.

3. Arguments should be avoided with patients who have any type of dementia, especially is the patient is anxious and agitated.

4. Guns and large amounts of cash should not be readily accessible to patients with dementia. Guns can be disabled if it is essential for the patient to have access to them.

5. Patients with dementia with Lewy bodies are susceptible to developing the NMS, a serious potentially fatal reaction to the administration antipsychotic medication, particularly the atypical ones and phenothiazine.

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