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Too Many Choices Confuse Patients With Dementia

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Too Many Choices Confuse Patients With Dementia

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Abstract

Choices are often difficult to make by patients with Alzheimer Dementia. They often become acutely confused when faced with too many options because they are not able to retain in their working memory enough information about the various individual choices available. In this case study, we describe how an essentially simple benign task (choosing a dress to wear) can rapidly escalate and result in a catastrophic outcome. We examine what went wrong in the patient/caregiver interaction and how that potentially catastrophic situation could have been avoided or defused.

Keywords

Alzheimer's/Dementia, aberrant behavior, confusion, choices

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Introduction to the Series of Case Studies

Alzheimer Dementia and most other types of dementias are not rapidly fatal diseases: Patients often survive many years after the diagnosis is made. During this time, their mental functions deteriorate and their personality often changes. This can be distressing and unnerving to family, friends, and caregivers who often are at a loss: They simply do not know how to handle their loved one anymore.

Caretakers have to be constantly vigilant, 24 hours a day, 7 days a week, 52 weeks a year. They may not be able to take a break. As such, they become apprehensive, restless, mentally and physically exhausted, and prone to developing a number of diseases. The toll of dementia on the patient's caregivers is often quite significant and frequently overlooked.

Patients with dementia appear unpredictable and may exhibit aberrant behaviors. Caregivers often state that they do not know when a catastrophic reaction will unexpectedly erupt. They find themselves caught up in the confusion, unable to change course and catastrophic outcome. They feel powerless and often guilty.

It is our contention that many of these "aberrant" or "unpredictable" behaviors are, indeed, predictable, can be anticipated, avoided, averted, and defused. These "aberrant behaviors" are part of the disease process. This

is the reason why throughout the texts we refer to the "patient" as opposed to the "person" with dementia: We wish to emphasize that these aberrant behaviors are due to the underlying disease process, not different from, for instance, cough and fever being manifestations of pneumonia. The patient with pneumonia cannot help but develop fever and cough; similarly, aberrant behaviors are manifestations of the underlying dementia and not due to the patient being uncooperative or obnoxious.

In this series, based on real patients, we explore how some "aberrant behaviors" develop and may have a catastrophic outcome. The objectives of each case study are outlined at the beginning of the manuscript and are followed by a scenario depicting how a situation is generated, develops, escalates, and reaches its climax, often with a catastrophic ending. The scenario is followed by a step by step analysis of what went wrong in the caregiver/patient interaction and how the catastrophic outcome could have been avoided or defused.

This is followed by a case discussion where more information is given about the particular aberrant

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behavior, type of dementia in the specific case presented, or some other relevant feature(s). In the section "Summary," tangible advice is included on how to avoid that particular behavior from developing, escalating, and erupting. Finally, a list of references, recommended reading, and resources is included at the end of the case study.

It is hoped that clinicians will find these case studies helpful and use this material to counsel and/or give to caregivers who seek their help with similar issues. The authors will appreciate any feedback readers may have as well as any recommendations about particular behaviors to discuss in future case studies.

Objectives

At the end of this case presentation, readers will appreciate the following:

1. Patients with dementia should not feel they are being told what to do, they should be asked.
2. Choices could be significant stressors to patients with dementia.
3. Time limitation is a major stressor while caring for patients with dementia.
4. "Gentle" reminders are useful but have to be done in a nonthreatening manner.

Case Presentation

Characters

- Martha is a 70-year-old widow, retired high school mathematics teacher. About a year ago, she has been diagnosed with early Probable Alzheimer Dementia. Her husband died about 6 months ago, and since then, although physically independent, she has been living with her daughter Doris because she did not want to live on her own, could not maintain her house, and was not able to manage her financial affairs. Her late husband had to take over preparing the tax returns and controlling the household budget because she no longer wanted to continue doing them.
- Doris works full-time as a primary school teacher.

Martha helps Doris with several house chores. They have a good mutually supportive relationship. Doris also is a widow. She has two grown up children and three grandchildren who are quite supportive and visit regularly.

Scenario

It is Sunday morning. They just finished the breakfast Martha had prepared as had become customary since she moved with her daughter. It was a good breakfast they both enjoyed. They were both quite relaxed, happy

to be together, and especially that it was Sunday and Doris did not have to go to work.

Doris's plan is that they go to Church. She tells Martha to go to her room and get dressed as they have to leave in about 30 min. Martha is not enthusiastic but does as she is told.

In her bedroom, Martha begins pulling dresses from her closet but cannot decide which one to wear. Each time she looks at a dress, she cannot remember what the previous dresses looked like. She becomes confused and agitated.

Calling several times, Doris reminds her mother that time is slipping away. This only compounds Martha's confusion, frustration, and agitation.

With only a few minutes left before the planned departure time, Doris marches into Martha's bedroom and sees that her mother is not dressed. She is sitting on the bed crying surrounded by dresses. Doris is irritated, upset, and angry. She cannot understand why her mother is not dressed ready to go to Church. They are going to be late for Church.

The scene escalates with harsh words exchanged. In desperation, Martha says "I hate you. I wish I were dead." To which Doris immediately replies without thinking, "Me too. We'd all be better off."

The scene ends with Martha crying and Doris angry and distraught over the words that have been spoken: a catastrophic outcome.

Case Analysis

Turning Points/Triggers That Led to This Aberrant Behavior

Doris told her mother they were going to Church. She did not ask her. Martha may not have wanted to go to Church. Many patients with dementia, especially Alzheimer Dementia, prefer to avoid social gatherings or any activity during which they are likely to interact with other people. They are often unable to remember the names of people they know and not able to recognize people they should know. These interactions are often stressful because as far as the patient with dementia is concerned she will be meeting strangers who seem to know her, but she has no idea who they are. Avoiding social gatherings is often one of the earlier manifestations of Alzheimer Dementia, often before the memory impairment becomes obvious.

Could it have been avoided? As much as possible, patients with dementia should be involved, or at least should feel involved, in the decision-making process. This will make them feel relevant, secure, and needed. Besides, had Martha been asked if she wanted to go to Church, chances are high she would have chosen to stay home and the entire situation would have been avoided.

Apart from the option of not going to Church, Doris may have offered her mother, should she prefer to stay at home, the option of doing some other house chore such as house gardening, folding the clean laundry that has just been washed, or some other activity to make her mother feel responsible and needed. While caring for patients with dementia, it is always useful to have a series of “jobs” that need to be done. These can be used to distract the patient and at the same time make the patient feel needed and relevant.

Doris told her mother to get dressed. She has given Martha an “order.” Patients with Alzheimer Dementia often have paranoid delusions. They may misinterpret the actions of others. Martha is annoyed. She feels Doris is ordering her and she does not like to be told what to do.

There is also another aspect to this situation: Daughter telling Mother what to do may go against their established relationship patterns. When these roles are reversed, Mother becomes the dependent person who is being told what she will do and when she will do it. For the new relationship pattern to be successful, Daughter must be very careful to make sure Mother feels important and relevant, is part of the decision process, and does not feel “ordered” about.

Could it have been avoided? It is better to ask rather than tell or order. “Mother shall I pick a dress for you?” might have averted the entire situation. Or, if she had sensed her mother’s hesitation, she might have realized she was ordering and quickly rephrased her request.

Martha could not decide on a dress to wear. Patients with dementia often become confused when offered too many choices. Their memory for recent events is poor and their attention span short. Therefore, having to make decisions, even apparently simple ones, can be frustrating and difficult.

For Martha, every time she saw a dress it is as if she saw it for the first time. This led to her frustration and helplessness. The only option left for her was to sit down on the bed and cry, very much like children who may cry because they are afraid and need help or attention and not because they are in pain.

Martha needed help to choose a dress. Patients with Alzheimer Dementia are often insecure and afraid: They know that “something” is wrong, but they do not understand it. They are apprehensive and need reassurance.

Could it have been avoided? It is often better to give only limited choices. So, instead of asking Martha to get dressed, which includes selecting one from several dresses in her wardrobe, Doris could have left only two dresses on the bed and asked her mother to choose one of these. Alternatively, if Doris knew from previous experience that her mother would find it difficult to even pick one of two dresses, she could have left only one dress on the bed and asked her mother to put on that dress.

Alternatively, Doris could have taken her mother’s hand, shown her a few dresses, and encouraged Martha to select the dress she thought most appropriate. “How about this blue dress?” There would have been no decision to be made, and as a bonus, Martha would have felt important and involved.

Doris called a number of times to remind Martha that time is running out. Given the short attention span and easy distractibility of patients with dementia, especially Alzheimer Dementia, reminders are important to ensure they keep to the assigned task. Multiple reminders, however, can have a negative effect and backfire especially if they sound more like alarm warnings. They also are often of little help as the patient frequently does not have a concept of time: whether it is in five or 25 min that they are due to leave does not make much of a difference. The only thing they are conscious about is that they need to make a decision quickly, but cannot. They are cognitively paralyzed and cannot decide. They may panic. Feeling rushed increases the level of stress and worsens the patient’s confusion. Doris’s repeatedly calling her mother to remind her of the deadline was irritating and further impaired her ability to think clearly and handle the situation. Her only recourse was to become frustrated, sit on the bed, and cry.

Could it have been avoided? Patients with dementia have a short attention span, are easily distracted, and have an impaired memory especially for recent events. Frequent, focused follow-up reminders of the task at hand are needed and, in fact, necessary. They, however, should be offered in a nonthreatening, nonstressful manner that should not sound like orders being issued. Doris could have gone to Martha’s room to ensure that she had found a dress and was putting it on well before the deadline was so close.

A compliment about the way her mother looked would have gone a long way to reassure her mother and might have avoided some of the stress and anxiety associated with the activity. Also, depending on their relationship, a gentle touch or hug could have reassured Martha that she is loved.

Doris lost her calm when she found her mother sitting on the bed crying surrounded by dresses. It is difficult, sometimes virtually impossible, to remain calm given the emotions involved. If, however, the caregiver cannot remain calm, the patient with dementia senses this and becomes agitated and irritable. The patience of caregivers can be sorely tested, but it is truly a necessity to avoid catastrophic endings.

Could it have been avoided? To remain calm is easier said than done. Planning to avoid time-sensitive situations may help. Alternative backup plans are necessary. Caregiver support groups or one-on-one meetings with a professional can be helpful.

Doris also could have defused the situation by sitting close to her mother on the bed, putting her arm round her shoulders, and giving her a hug. A different, less rushed time to go to Church could have been selected.

Persons with dementia often feel insecure, lonely, and rejected. It is, therefore, important to keep reassuring them that they are loved. A gentle touch and the occasional hug are comforting. Given the person's poor memory, these statements and gestures of affection have to be repeated frequently.

Case Discussion

The Diagnostic Clinical Features of Alzheimer Dementia

The diagnostic clinical features that must be present for a clinical diagnosis of Probable Alzheimer Dementia to be made include the following:

1. A deterioration in cognitive functions, from a higher previously established level.
2. The deterioration in cognitive functions is interfering with the patient's ability to conduct daily activities.
3. There are no underlying medical conditions, major psychiatric disorders, or medication intake that may explain these findings.
4. Evidence of other cognitive deficits, such as anomia, apraxia, and agnosia.
5. Impaired judgment.
6. Lack of insight.
7. An insidious onset and gradual progress.

Martha meets these requirements and therefore satisfies the clinical diagnosis of Probable Alzheimer Dementia. At present, the final diagnosis of Alzheimer Dementia can only be made by microscopic examination of brain tissue. This, however, is likely to change given the progress made in imaging brain studies such as functional magnetic resonance imaging (fMRI):

- She was a high school mathematics teacher. She therefore was functioning at a much higher level than at present. As such, therefore, there has been deterioration in her cognitive functions.
- This deterioration is interfering with her daily activities: She could not find a dress to wear even though several dresses were in front of her, hanging in her wardrobe. Furthermore, she could not survive on her own after the death of her husband and has to rely on her daughter to handle her financial affairs.
- There is no evidence of any acute medical disease, major psychiatric disorder, or intake of medication (prescribed, over-the-counter, or recreational) that may be responsible for the impaired cognitive functions.

- The onset is insidious. The disease manifested itself insidiously several years ago when Martha could not/did not want to continue preparing the tax returns and controlling the household budget. Her husband had to take over these activities.

Causes of Dementia

Although Alzheimer Dementia is the most frequent cause of dementia, it is not the only cause. Several other diseases may present with dementia. These will be discussed in subsequent cases. This article is confined to Alzheimer Dementia as a cause of dementia.

The Main Features of Alzheimer Dementia Include the Four "A's"

1. Amnesia: Memory impairment

The memory impairment seen in patients with Alzheimer Dementia is global, affecting both trivial as well as important issues. This is a major differentiating feature between the memory impairment seen in patients with Alzheimer Dementia and those with benign forgetfulness or mild cognitive impairment (MCI). Whereas patients with benign forgetfulness tend to forget only trivial nonimportant things, or what they consider trivial, patients with dementia—except in the very early stages—tend to forget the important as well as the trivial.

Characteristically, the memory impairment seen in Alzheimer Dementia affects primarily short-term memory and is compounded by a short attention span. Patients are able to remember events that occurred several years ago but are not able to remember events that occurred only a few days, hours, or even minutes previously. This can be a cause of friction between patient and caregivers, especially in the early stage of Alzheimer Dementia when the patient appears to be otherwise "normal" and caregivers may think the patient is uncooperative or obnoxious.

Impaired memory for recent events could be responsible for the patient forgetting to relay messages such as that the patient's grandchildren need to be picked from school at a different time or that a doctor's appointment has been rescheduled. This often causes frustration among caregivers who may feel that the patient does not care or could not be bothered. The truth is actually that given the underlying pathology, the patient is just not able to remember.

Impaired memory for recent events, combined with a short attention span, could have significant implications as may occur when the patient attempts to cook a meal. The patient may switch the stove on, but—given the short attention span, easy distractibility, and impaired memory for recent events—gets distracted from the original task of cooking and leaves the stove on unattended and inadvertently starts a fire.

Memory aids are not very useful to patients with impaired memory for recent events as they often forget to check them. So the patient may be given a list of items to purchase

at the store but may forget that he has the list in his pocket and as a result fails to buy the right items or buys the wrong items. Similarly, the patient may be given a list of chores to be done but forgets to check the list he was handed. This could lead to serious problems if the patient is given time-sensitive tasks such as picking up grandchildren from school, taking them to their ball game, or even helping them with homework.

2. Anomia: Word-finding difficulties

Patients with Alzheimer Dementia often are unable to name objects. For instance, when shown a wristwatch, they may recognize it as such and know what it is used for, but cannot recall the word "wristwatch." Instead of using that word, they may use a sentence to describe the shown object, such as "this is the time keeper, it tells you the time of the day. You attach it to your wrist." Anomia often manifests itself in a flowery, flamboyant, and interesting speech: The patient often uses sentences instead of single words, while referring to a simple object.

Anomia tends to affect first objects that the patient does not see frequently or is not familiar with: A lawyer may not remember the word "stethoscope" but remembers the word "gavel," whereas a health care professional may not readily recall the word "gavel" but may immediately recall the word "stethoscope."

Anomia also may be responsible for not being able to remember the names of people who should be well known to the patient. The patient indeed recognizes these people, knows who they are but cannot remember their names. This is often a source of embarrassment, irritation, and frustration to patient, caregivers, relatives, and also friends. Often relatives, especially children and spouse, get upset about the patient not remembering their names and sometimes accuse the patient of not really caring enough to remember their names, or even not liking/loving them.

A comment often made is "We've been married for over 50 years and she does not recognize me, she does not know I am her husband. She can't even remember my name." Relatives should understand that the anomia is an integral part of Alzheimer Dementia in a way similar to fever being an integral part of pneumonia. The patient cannot help it: It is part of the illness.

3. Agnosia: Difficulties recognizing objects

Agnosia is the inability to recognize objects. Unlike anomia where the patient recognizes the object but is unable to find the correct word for this particular object, patients with agnosia do not recognize the object. For instance, a patient may see a knife but not recognize it as such, thinks it is a spoon, tries to scoop the soup with the knife, and gets frustrated at being unable to feed himself.

Agnosia could have serious implications if the patient is not able to recognize that certain items are not edible and may therefore try to eat them, including soil, flowers, grass, or even pets' food. The patient also may not recognize that

food has become rotten. Most people recognize that food is rotten, given its appearance, color, texture, smell, and even taste. Whereas a person with normal cognitive functions will not eat rotten food, a patient with Alzheimer Dementia may not recognize the food is now rotten and may eat it.

Similarly, patients with agnosia may not be able to take their medication as recommended, even though the various tablets have been placed in clearly defined, well-marked spots in the pill boxes by their caregivers. In addition to the patients forgetting to take their medication, they may be unable to recognize which tablet or pill should be taken and when it should be taken. This may lead to serious problems as the patients may not take medications appropriately or may overdose.

Agnosia also may be responsible for the patient not recognizing that the clothes she is wearing are dirty, need to be washed, and that she should not wear them. Similarly, agnosia may be responsible for the patient not wanting to shower. Trying to convince the patient that she needs to shower is a wasted effort that often backfires and generates ill feelings: because there is no way of convincing the patient that she needs to have a shower. This issue will be discussed in a future case study.

Agnosia also may be responsible for the patient not recognizing that, for instance, the weather is cold: She may see the snow but is unable to recognize that the presence of snow implies cold weather and therefore that she should put on some warm clothes before going out. As a result, she may try to go outside the house for a walk inappropriately dressed.

Agnosia may also be responsible for the patient not recognizing an obvious hoax and falling victim to predators in society. This is probably also due to the impaired judgment that prevails in patients with Alzheimer Dementia and will be discussed in a separate case study.

4. Apraxia: Inability to carry out physical tasks requiring dexterity in the absence of muscle weakness or paralysis

Patients who have apraxia are not able to carry out voluntary physical activities that require dexterity such as, for instance, buttoning and unbuttoning a shirt. This relatively simple benign task requires the rapid transmission of impulses from the sensory receptors in the fingers to the brain: first to the sensory cortex (where the sensations are felt), then to the sensory association area (where the various impulses received are analyzed and interpreted), then to the motor association area (where plans are developed to take some appropriate action such as moving the fingers of one hand in such a way as to introduce the button attached to one side of the shirt through the buttonhole of the other side of the shirt), then to the primary motor area (where the plans developed in the motor association area are translated into definite movements of the hands and fingers). These impulses are then transmitted from the brain to the hands and fingers so that the appropriate action is taken to button or unbutton the shirt. Throughout this exercise, sensory

impulses generated in the fingers are sent to the brain to coordinate and fine tune the activity of the various muscles involved in buttoning a shirt. It is sobering that this apparently simple task involves so many steps carried out within fractions of a second.

Because patients with Alzheimer's disease are not able to process all these nervous impulses in a timely manner, they are not able to coordinate the contraction and relaxation of various muscles involved in various activities, even though there is no definite muscle weakness or paralysis. Patients with Alzheimer Dementia are not able to process the brain information from the periphery (fingers) to the brain and back to the periphery in a timely manner. This often interferes with their ability to conduct appropriately their activities of daily living such as getting dressed and undressed, brushing their teeth, and washing their hair.

It is important for caregivers to recognize and accept these limitations: Patients with Alzheimer Dementia are not being difficult, uncooperative, or obstinate; they are just not able to carry on their daily activities because of the limitations imposed by their underlying disease.

5. Impaired judgment

In addition to the four "A's" mentioned above, the patient's judgment is often impaired early in the disease process often before the characteristic features are fully manifest. It may be advisable to seek legal help while the patient is still able to make rational decisions and also give a trusted person Power of Attorney (PoA), including durable PoA. These issues will be discussed in subsequent cases.

6. Lack of insight

Except for the very early stages of Alzheimer Dementia, patients usually have little or no insight into their impaired memory and other declines in cognitive functions. They do not recognize that their memory has deteriorated and often accuse other people of hiding various objects they have been unable to find. This lack of insight often feeds the patient's paranoia.

Symptoms Preceding Memory Impairment in Patients With Alzheimer's Disease

Although medical help is usually not sought and the diagnosis of Alzheimer Dementia not made until the patient starts to develop the typical impairment in memory, several symptoms manifest themselves months or even years before the clinical diagnosis of Alzheimer's disease is made. These include social withdrawal, paranoid delusions, language difficulties, difficulties learning new skills, and depression sometimes with suicidal ideation.

In the early stages of the disease, patients know that their cognitive functions are deteriorating and are no longer able to continue with their daily activities, especially their professional responsibilities. These early signs of dementia will be discussed in subsequent cases.

Summary

While caring for patients with dementia,

1. Patients should not feel they are told what to do; they should be asked and feel they are involved in the decision-making process.
2. The need to make choices can be a significant stressor.
3. Time limitation can be a major problem for the caregiver. Ample time should be allowed, and alternate plans made in case the deadline is not met.
4. Reminders are useful but have to be done in a gentle nonthreatening manner.
5. Patients need to be constantly reassured that they are loved, and relatives/caregivers should be encouraged to repeatedly make affectionate remarks and gestures.
6. Caregivers should understand the reasons for their loved ones' aberrant behavior.
7. Caregivers should try to remain calm at all times, regardless of the circumstances.
8. Health care providers should be able to explain to caregivers the various mechanisms underlying these apparently aberrant behaviors and how they can be avoided or averted.
9. Education and support for the caregiver are essential to avoid aberrant behaviors from developing, escalating, and having a catastrophic ending.

Authors' Note

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