

Rethinking Psychosis in Dementia: An Analysis of Antecedents and Explanations

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Abstract

An in-depth analysis of qualitative data regarding antecedents, consequences, and descriptions of delusions of persons with dementia (PwD) provided by family caregivers is presented. Three broad classifications of reasons given behind types of delusions are included, namely environmental factors, personal factors, and dementia, with dementia being the most prominent factor. We observed an overlap between known cognitive symptoms of dementia and the characteristics of the reported “delusions” in dementia. It therefore appears that what is often classified as a delusion of a seemingly psychotic nature is in fact the PwD's disorientation combined with an attempt to fill in gaps caused by cognitive deficiencies.

Keywords

dementia, aging, psychosis, caregivers

Introduction

Delusions are defined as fixed beliefs that are not amenable to change when confronted with conflicting evidence Diagnostic and Statistical Manual of Mental Disorders (*DSM-5*)¹. Although delusions are considered a symptom of dementia, there is a wide range of reported prevalence, varying from 12% to 76% of persons with dementia (PwD).²⁻⁶ These rates varied by type of dementia, stage of the disease, and varying definitions across studies.³⁻⁹ Delusions which have been described in dementia include the following types: “one's house is not one's home” delusion, delusions of theft, delusions of abandonment, delusions of danger, delusions of misidentification, delusions of infidelity, and nonparanoid delusions.¹⁰ Previous studies indicated delusions of theft as the most common, followed by “one's house is not one's home” delusion and delusions of suspicion.¹¹

Understanding the etiology of delusions in PwD is limited and preliminary.^{2,11} This is partly because delusions are difficult to study since they represent internal rather than observable phenomena. Past explanations for delusions in dementia^{7,12,13} can generally be subsumed under 3 categories: delusions may evolve from brain damage caused by dementia, they may result from the person's response to the environment, and they may reflect an unrelated disorder.¹¹ A preliminary study,¹¹ investigating the meaning of delusions in nursing home residents with dementia, suggests that “delusions” in PwD often did not fit the formal definition of a delusion. Many of these “delusions” changed when presented with evidence, while others were based on reality. The aims of the current study are two-fold. First, we aim to examine the etiology of delusions within dementia by analyzing family members' perceptions of the reasons, content, and antecedents of delusions in

a sample of community-dwelling PwD. Thus, we hope to elucidate the context in which specific types of delusions arise. Furthermore, we aim to clarify whether the delusions encountered fit the definition of a delusion as outlined in the *DSM-5* or whether there is an alternative way to classify them within the symptoms of dementia.

Methods

Participants

Participants were family caregivers (52 women and 15 men) of 67 community-dwelling older persons aged 65 and over with a diagnosis of dementia. Relatives were 41 children of the PwD (33 daughters and 8 sons), 23 spouses, 2 daughters-in-law, and 1 sister. Fifty-seven of them had daily contact with the PwD, and 10 saw them often but not on a daily basis. Interviewees were recruited from 15 adult day centers, 8 support groups for caregivers of PwD, and an online advertisement. Inclusion criteria were the PwD not having a known acute or unstable medical

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condition and having at least minimal levels of verbal communication. The article included only PwD who had experienced psychotic symptoms as assessed by the Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) assessment¹⁴ or the Neuropsychiatric Inventory (NPI)¹⁵; consent to participate in the study was obtained from a responsible relative.

Assessments

Participants were asked to complete several assessment questionnaires regarding the PwD:

1. Behavioral Pathology in Alzheimer's Disease Rating Scale¹⁴: Each type of delusion ("people are stealing things," "one's house is not one's home," "spouse as imposter," abandonment, infidelity, paranoia, or other delusions) and/or hallucination (visual, auditory, olfactory, haptic, and other) experienced over the month prior to the interview is rated on a 4-point scale of severity (0 = "symptom not present" to 3 = "severe presentation of the symptom including violent action"). Multiple studies verified the reliability and validity of the BEHAVE-AD.¹⁶⁻²⁰ Cronbach α for internal consistency was .79 for the 67 participants of the current article. In addition, we have examined the inter-rater reliability using conjoint interviews for 23 participants and found full agreement for the delusion questions (ie, inter-rater agreement of 100% and κ value of 1.)
2. Neuropsychiatric Inventory¹⁵: Each type of delusion or hallucination experienced over the month prior to the interview is marked as either occurring or not present. The reliability and the validity of the NPI have been documented in past studies.^{17,21,22} In 22 conjoint interviews, we found an agreement rate of 86.3% with a κ of .68 for the delusions. Cronbach α for internal consistency was .88 for the participants of this article ($n = 67$).
3. Etiological Assessment of Psychotic Symptoms in Dementia (EAPSID): The EAPSID assessment tool developed for this study provides a functional analysis of the psychotic symptoms assessed by the NPI or the BEHAVE-AD. It evaluates psychosis in dementia from an etiological perspective, based on the nomenclature described by Cohen-Mansfield¹³ through a functional analysis. It includes queries regarding the different types of delusions and hallucinations. Each category includes open-ended items (eg, "please describe the content of the delusion") and close-ended items (eg, "where does the delusion occur"; occurrence frequency). The open-ended responses on the EAPSID provided the qualitative data for the study.
4. Functional status was assessed using the activities of daily living (ADL) and instrumental ADL (IADL) questionnaires, both based on the Older Americans' Resources and Services²³; the scores range between 0 and 14 for the ADL and 0 and 16 for the IADL, with a higher score indicating higher function.

5. The Mini-Mental State Examination (MMSE)²⁴ was administered to the PwD unless administered up to 3 months prior to the interview. Among the participants who were reported to experience delusions, there were 12 for whom we could not administer the MMSE because of either participant or caregiver refusal. In those cases, we extrapolated the MMSE score on the basis of the Brief Cognitive Rating Scale.²⁵

Procedure

This study was approved by the ethical committee of Tel Aviv University and the Helsinki committees of the Shoham Medical Center and the Sourasky Medical Center. Two independent translators translated the assessments into Hebrew, and a third translator revised the assessments into a final version after consultation with the researchers. The assessments were then administered to family caregivers of the PwD. When either the NPI or the BEHAVE-AD indicated the presence of a delusion, the EAPSID was administered to inquire about the circumstances surrounding the delusions and the explanations for them.

Analytic Approach

This study pertains specifically to the meaning of the delusions for the persons experiencing them, based on the data provided by family caregivers. Data analysis involved an in-depth examination of all the information caregivers provided regarding antecedents, consequences, descriptions, and explanations for the delusions. We compiled a list of all emerging explanations and clustered them into groups within each type of delusion, based on their similarity and overlap. These groupings were then further refined resulting in the identification of the main thematic categories. All questionnaires were then recoded according to this list of themes and subthemes. The rigor and transferability of data interpretation were ensured by having 2 of the authors (J.C.-M. and R.C.) first develop the coding scheme independently and only then applying multiple iterations of the coding scheme and discussions until agreement was reached.

In order to enhance the qualitative data, we provide descriptive data regarding demographic variables as well as cognitive, functional, and medical status for each delusion type. We combined the abandonment ($n = 2$), danger ($n = 4$), and infidelity ($n = 5$) categories into a category of threat, because these 3 represent beliefs of direct threat to the PwD themselves rather than to their belongings.

Results

Sample Characteristics

The PwD had a mean age of 81.2 (standard deviation [SD] = 7.6), and 64.2% were women. Close to half (43.3%) were born in Europe and around a quarter were born in North Africa or the Middle East (not including Israel, 28.4%) or in Israel (22.4%).

Table 1. Distribution of Explanations for Delusions by Main Categories (n).*

General Explanation Category	Number of delusions Specific Explanation of Delusion Subcategory	Type of Delusion					Total
		Home	Theft	Threat	Misidentification	Other	
		36	22	11	13	22	104
The environment	The delusion was grounded in reality	7	6	1	0	1	15
	Significant environmental change	10	2	1	1	0	14
	Caregiver's behavior	0	1	1	0	0	2
	Unmet needs	6	0	3	0	4	13
The person	Personality of the PwD	1	3	0	0	2	6
	Past experiences	7	5	2	2	6	22
	Negative feelings	6	4	4	3	4	21
Dementia	Memory problems causing the person not to find belongings	0	9	0	0	0	9
	Superiority of distant past over the recent past	1	0	1	5	1	8
	Disorientation	16	1	2	6	13	38
Total		54	31	15	17	31	148

*Some delusions have multiple explanations.

Approximately, half (52.2%) were married, with the majority of the remainder (41.8%) being widowed. The average MMSE score was 10.6 (SD = 5.5, range 0-26), and for ADL and IADL, the scores were 7.8 (3.9) and 2.0 (2.9), respectively.

Reasons for the Delusions and Their Meanings

The distribution of the categories of explanations by type of delusion is presented in Table 1 and described below.

The Environment. This general category of explanations includes 4 subtypes of explanations: delusion grounded in reality, delusion resulting from significant environmental change, delusion triggered by the caregiver's behavior, and finally, unmet needs of the PwD.

Delusion grounded in reality. This subcategory includes cases when the explanation described real events that could explain the belief. For example, Ms A demonstrated her "house is not home" delusion when she asked her son to pack her belongings because she wanted to go back home. When asked about the last change in residency, her son explained that for the previous 2 years she had been living at his home. This change of residence could explain her sense of not being at home. In another example, Ms B's delusion of theft involved her saying that someone took her blouses that were usually placed on a specific chair. Indeed, when her daughter described this delusion, she mentioned that the cleaner put them in a different place. When Ms B was shown the blouses, she was glad to have found them. Although the daughter did not provide this as an explanation for the delusion, the researchers categorized it as such since the blouses were indeed taken.

Significant environmental change. This subcategory includes changes in the home, routine, or locations, all pertaining mostly

to the "house is not one's home" delusion. Examples of each type are provided below.

Changes in home or routine: Mr C asked about the house they lived in—"did we sell it?"; "do other people live there?" His daughter explained that her mother (Mr C's wife) was greatly affected by her own deteriorating health, and thus, he perceived her as a different person. Since Mr C did not recognize her as his wife, he thought their residence was not his home. His daughter mentioned that the delusion might reflect a longing for the previous home routine. Similarly, Ms D, experiencing the "house is not home" delusion, asked her daughter when they would return home. When shown her own pictures and carpet, she said that they were hers but that the house belonged to the paid caregiver. The presence of a paid caregiver significantly altered the nature of the house, making it feel different from home. A similar trigger for Mr E was the introduction of a hospital bed and medical equipment into his home. When lying in bed, he would ask: "Are we going home?"; "Will we remain a long time at the hospital?"

Changing locations: Ms F would wander around her house, saying it was not her home, and asking to go back home. Her daughter said these behaviors usually occurred after Ms F returned home from an outing and thus the change in location was the main explanation for the delusion.

Caregiver's behavior. This explanation, referring to the demeanor of the caregiver when interacting with the PwD, was used for "theft" and "threat" delusions. For example, in explaining Ms G's belief that her caregiver had stolen her money, her daughter explained that the caregiver had been unkind to her mother and that this could underlie her delusion.

Unmet needs. This subcategory refers to needs that are not addressed by the environment, including need for social interactions and activities. It was the explanation given for “house is not a home,” theft, and “other” delusions.

Need for social interactions: This category includes the need for social contact and love. Mr G talked to his reflection in the mirror, which he referred to as a close friend. This was thought to meet a need for social contact. Similarly, Ms H’s daughter explained that her mother’s belief that the figures on television were people present in the room, and her interactions with them stemmed from loneliness.

Lack of activities: When Ms J was at her home, she said she wanted to go back home. Her daughter explained this as resulting from boredom.

The person. This category includes the following subcategories of explanations: personality of PwD, past experiences, and negative feelings. These are demonstrated in the following examples.

Personality. This explanation was used for “house is not home,” theft, and “other” delusions. Suspiciousness was the most common personality trait described. For example, Ms K’s daughter attributed Ms K’s belief that someone had taken her bracelets, to a lifelong personality trait of suspiciousness. Similarly, Ms L’s son attributed her “house is not home” delusion to a need for attention, which, according to him, had always been a part of her life (including fake suicide attempts) but worsened with the onset of dementia.

Past experiences. This subcategory includes longing for the past and reliving past experiences and roles.

Longing for the past: Mr M mistook his wife for his mother and sister. His wife attributed this to his missing these past family connections; his mother and one of his sisters had died, and his other sister lived abroad. Given that in dementia long-term memory is often better preserved than more recent memory, some participants perceived the people around them as those from their distant past for whom they longed.

Reliving past experiences: This explanation was given for instances of delusions of theft and threat. Mr M claimed that his newspaper was stolen and that people stole from the residents’ bags at the daycare center. He told his wife: “everyone steals there, at the daycare center. They even stole my walker,” yet when shown the missing items, he changed his mind. His wife associated the delusion with 3 past burglaries at their own home. In an example of a delusion of threat, Mr N’s wife interpreted his delusion of being persecuted by Nazis to him reliving his holocaust traumas.

Past roles: Ms O’s belief that she had no money and thus had to work was explained by her past role as the main income earner at home. Similarly, Mr P wanted to get dressed and go to work each morning, telling his wife that people were waiting for him at work. This delusion was explained as

continuing his past habit of getting ready for work every morning.

Negative feelings. This subcategory refers to feelings, such as anger, discomfort, envy, and fear. Envy, for instance, was the explanation given for the delusion of infidelity experienced by Ms Q. Ms Q was afraid her husband would abandon her when he partook in social activities. She waited for him near the door, and when he came back, she would ask him many questions regarding the social activity. One of her husband’s explanations for the delusion was that they used to go dancing together until she had a cerebrovascular accident (CVA). After the CVA, she continued to come but joined him only occasionally. The rest of the time, he danced with other women (with her approval), and sometimes it made her envious. In another example, Mr R’s wife attributed his delusion of theft to fear. Specifically, she explained his accusing a bank teller of stealing their money to his having heard a news story about another bank teller who had indeed stolen many customers’ money.

Dementia. This category includes 3 subcategories of explanations pertaining to known symptoms of dementia: memory problems, superiority of episodic memory for the distant past over the recent past, and disorientation.

Memory problems causing the person not to find belongings. This explanation was used only in delusions of theft. Had the PwD found their belongings, they would not have believed them stolen. Stealing is thus the explanation provided by the PwD for the item being missing. For example, Mr T could not find his watch and complained that someone had taken it. However, when shown the watch, he accepted the fact that it was not stolen and said: “Great, it is here. Everything is fine.”

Superiority of distant past over recent past.

Considering childhood home as home: Mr U’s delusion involved him telling his migrant caregiver that he was not at his home and asking to go there. His daughter explained this as a wish to return to his childhood home.

Considering people as someone else from their past based on their age: This refers to cases where the PwD misidentified persons in the present environment to be persons from their past based on their age. In delusions of infidelity, Ms E mistook her son to be her deceased husband and accused him of being unfaithful and planning to leave her.

Disorientation. This subcategory includes disorientation to time, place, and person, as well as other disorientation. These forms of disorientation are common symptoms of dementia. Additionally, common conditions such as fatigue or vision problems can contribute to disorientation.

Disorientation to time: Ms V thought her deceased parents were alive but did not know where they were, requesting money to search for them.

Disorientation to place was common in the “house is not home” delusion, as in the case of Mr X. He used to ask his wife and son to bring him back home or to show him the way home. He perceived his home to be a hotel with his wife as the hotel owner.

Disorientation to person: Mr Y was at the theatre with his wife, and when she wanted to go home, he told her he was waiting for his wife and thus could not come with her. His wife explained this by his general problems recognizing things, with fatigue contributing to his disorientation to person. Similarly, when Ms Z mistook her nephews for other people, her daughter attributed this to her poor vision. In delusions of misidentification, disorientation to person was sometimes exacerbated by similarity in names or appearance. For instance, Mr C mistook his grandson for his (deceased) son, which, according to his daughter, was due to the resemblance of the grandson to his (deceased) father. Other disorientation. This explanation applies to cases where the PwD believed television to be reality or objects to be something they resemble in shape. For example, Ms H communicated with people on television, considering them to be real. Mr AB told his wife that a package he was holding was dangerous and they should throw it away. When his wife opened it, she found a few paintbrushes wrapped in paper, which he had considered to be a weapon.

Discussion

This study involved an analysis of relative caregivers’ explanations for seemingly psychotic symptoms experienced by PwD. It also includes a summary of a functional analysis applied to clarify the conditions under which the psychotic symptoms occurred in this population. The first aim of the study was to analyze the explanations given for different types of delusions. The explanations encountered were categorized into 3 broad categories: the environment, the person, and the dementia. Dementia was the most commonly used category, but instances of the other categories were common. The type of explanation tended to relate to the type of psychotic symptom. For example, the 2 cases of delusion of abandonment were explained by the need for social contact. Significant environmental changes were a common explanation for the “house is not home” delusion, and theft delusions were often explained as resulting from dementia-induced memory deficits, which interfered with PwD finding their possessions.

In analyzing the delusions, a basic paradox becomes evident, namely that there is an overlap between the known cognitive symptoms of dementia and the characteristics of the accepted “delusions” in dementia. Specifically, disorientation to place, person, and time are hallmark symptoms of dementia and appear in many screening assessments for dementia. It appears that what is often classified as a delusion could be an attempt of the PwD to compensate for dementia-related deficits.

From this perspective, the “house is not home” belief is a clear case of disorientation to place, often accompanied by requests to go home. Misidentification is a case of disorientation to person, together with an effort to fill the missing gap of who the person is. The delusion of theft involves not finding an object due to memory deficits. When the person cannot find the object, she/he assumes it was stolen, attributing the stealing to a person in their environment. The “delusion” is clearly explained by the cognitive symptom and by the gap it raises in the persons’ interaction with the environment. The filling of the gap is based on additional processes. One common underlying influence is the process of retaining long-term memory, while forgetting more recently acquired memories. Therefore, identifying home or people in the current environment often seems to be based on the age of present company in relation to the age of those from the PwD’s past or what was home for the PwD in the past. Other environmental cues are also used by the PwD to explain their current situation, such that use of a hospital bed indicates that the place is a hospital. Past experiences of danger/theft may also resurge at times of uncertainty regarding the present reality.

The theft delusion is an example where “delusions” in dementia do not meet the classic definition of a delusion, since the belief is often reversible. When PwD are shown the missing object, they usually accept it and do not insist on the idea of theft, meaning the “delusion” was not a groundless fixed idea, but rather resulted from a need to explain the world compromised by cognitive deficits.

The distinction between the characterization of a mistaken belief as a “delusion” as opposed to a cognitive deficit and the subsequent attempt to adapt to it by explaining the missing knowledge is important for several reasons. First, when family members encounter the filling in of missing information to handle the disorientation, they need to understand that this is a natural adaptive response to the cognitive deficits, rather than a new psychotic phenomenon. This has implications for treatment, as there is no indication for use of antipsychotic medication. It might be more useful to apply creative nonpharmacological patient-centered interventions such as preliminary explanations, environmental manipulation, validation techniques, and social involvement. Second, the categories of explanations identified in this article can assist caregivers in understanding the mistaken filling in of missing information or the reality as experienced by the PwD. Our proposed categories of explanations can be used as a guide for determining the antecedent of a delusion, whether it is a recent unremembered change of circumstances, environmental change, personality tendencies, or past experiences. Third, some of the categories point to needs of the PwD, especially those pertaining to need for social activities and a sense of control, thus informing therapeutic decisions. As such, we suggest that such delusions in PwD be referred to as “explained disorientations.”

This analysis has some consistencies and some inconsistencies with prior explanations of delusions, which understood them as resulting from brain damage, environmental circumstances, and unrelated disorders. We have shown that while the

“delusions” result from the cognitive symptoms of dementia, they are not a result of an independent “brain damage,” but rather of the memory loss, especially loss of recent memory. They do respond to the environment in multiple ways, such as the change in location of residence, change in placement of familiar objects, or change in persons in the house, all aggravated by the loss of recent memory. Personality traits and separate disorders, such as post traumatic stress disorder (PTSD), also sometimes affect delusions. Yet, the “delusion” is not the other disorder, but rather the impact of memory loss on the response to the disorder. In all these ways, “delusions” in dementia are not a psychotic symptom, but rather a by-product of memory loss, thus deserving a different label.

The results point to the necessity of expanding the assessment of “delusions” among PwD. Assessments which describe the content of “delusions” or “explained disorientations” need to be supplemented by both caregivers’ explanations and direct questioning, which specifically targets the explanation categories identified in this article, such as recent changes in the environment, or the needs of the PwD. Future research needs to validate these findings and refine the categories of ways in which PwD compensate for cognitive deficits. Although we had no delusion without an explanation, the explanations were sometimes incomplete. For example, while the disorientation explained the mistaken belief, it did not necessarily explain the specific interpretation given by the PwD. Future assessment targeted to this question may further reveal the reasons that a PwD holds one interpretation of a dementia-induced disorientation over another.

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