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Analysis of Caregiver Perceptions of "Hallucinations" in People With Dementia in Institutional Settings

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Abstract

This study investigated the meanings and etiologies of hallucinations in persons with dementia. Participants were 74 nursing home residents aged ≥65 diagnosed with dementia. Most of the reported visual and auditory hallucinations involved talking to persons who are not present, a phenomenon described as either a visual or auditory hallucination, or both. All participants who were reported to experience a hallucination had poor vision. Current results suggest that *hallucination* was a term staff caregivers used for the phenomena they could not easily explain, demonstrating their lack of understanding of the resident and/or the phenomena they termed hallucination. The classification of hallucinations into subtypes may not be meaningful, and most visual and auditory hallucinations were not associated with negative affect. Some hallucinations occurred out of boredom, which exacerbated the sensory deprivation experienced by these persons, thereby increasing the likelihood of hallucinations.

Keywords

hallucinations, dementia, old age, etiology, vision loss

Introduction

A hallucination (visual, auditory, or otherwise) refers to a sensory experience that occurs in the absence of actual sensory stimulation,[1-3] for example, seeing something that is not there. Studies reporting the prevalence of hallucinations in dementia have yielded a wide range of results,[4] possibly due to the various definitions of hallucinations the different informants used across studies[5] and to the heterogeneity of the populations studied. Visual hallucinations are much more common than, and are often followed by,[6] auditory ones, while tactile, gustatory, and olfactory hallucinations are rare.[4]

The etiology of hallucinations in dementia has been reported in several studies (eg[2,3,7]). Vision loss is the most common etiology,[5,8,9] possibly leading to misidentifying objects (eg[10,11]). Moreover, the perceptual deficits in low-vision syndrome may increase confusion, especially in unfamiliar settings such as a nursing home. Furthermore, "sensory deprivation," referring to the absence of the stimulation of sensory areas by external objects, can result in people experiencing hallucinations.[12,13] Insufficient lighting, which has been linked to hallucinations,[8] can similarly lead to misinterpretation of the visual environment. Following a similar notion, deafness appears to be the most consistent factor associated with auditory hallucinations and a decrease in auditory hallucination symptoms was observed with the use of a hearing aid,[14] although concomitant neurological or psychiatric disease has been reported in a large number of cases.[15]

Research concerning the onset of hallucinations and their prevalence in the various stages of dementia is inconclusive. In a study of residents of adult day care centers, Cohen-Mansfield et al[5] reported hallucinations to occur in very late stages of the disease, specifically, in stages 6 and 7 of the Brief Cognitive Rating Scale (BCRS).[16] Similarly, more hallucinations were reported among those with more advanced dementia.[17-19] In contrast, Burns et al[20] found that neither visual nor auditory hallucinations were related to the severity of dementia.

Given the limited research regarding the phenomena termed hallucination, this article aims to describe the hallucinations experienced by older persons with dementia and their context of occurrence and to elucidate their etiology as reported by their formal caregivers.

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Methods

Participants

Seventy-four resident-specific interviews were conducted with staff caregivers of nursing home residents aged 65 and above from 9 nursing homes in Israel. The nursing home residents had a diagnosis of dementia, had resided in the facility for at least 2 months, did not have a known acute or unstable medical condition or a known history of depression, and had at least minimal levels of verbal communication. Consent was obtained from a responsible family member.[21,22] There was 1 informant for each resident.

The staff caregivers worked in a variety of roles, including facility managers (31%), head nurses (13.5%), certified nurses (14.9%), nurses (20.3%), nurses aids (14.9%), and occupational aids (5%). About a quarter of the staff caregivers in the study had been working with the resident on whom they reported for between 1 and 2 years, and 28% had been working with him or her for over 2 years; 22% had been caregiving for less than 6 months, and 23% for 6 to 12 months. Circa three fourths (74%) of the caregivers were female. Some caregivers were interviewed multiple times about multiple residents. Characteristics of the residents are presented in Table 1.

Measures

The Neuropsychiatric Inventory: Nursing Home version (NPI-NH)[1]. Seven types of hallucinations (eg, hearing voices, seeing things that are not present) are marked as occurring or not present.

Etiological Assessment of Psychotic Symptoms in Dementia (EAPSID). The EAPSID is an assessment tool developed for this study, which evaluates psychosis in dementia from an etiological perspective, based on the nomenclature described by Cohen-Mansfield.[23] The EAPSID inquires about the etiology of psychosis in dementia through a functional analysis. It includes queries regarding the different types of hallucinations (eg, olfactory, sensory) and delusions (eg, theft, abandonment). Each such category includes open-ended items (eg, describe a specific situation in which the hallucination occurred; describe the content of the hallucination) and close-ended items (eg, where does the hallucination occur; frequency of occurrence). The questionnaire was administered to the staff caregivers (eg, nursing home assistants). The open-ended responses on the EAPSID provided the qualitative data for the study.

The Mini-Mental State Examination (MMSE)[24]. The MMSE was administered to residents unless available from a concurrent assessment in the chart. The MMSE score ranges from 0 (*severe cognitive impairment*) to 30 (*normal cognitive functioning*).

Procedure

The Ethical Committee of Tel Aviv University approved the study. We approached 16 nursing homes to participate in the study, 7 refused. The participating nursing homes combined had over 400 residents. Due to confidentiality issues, first contact concerning consent was made by the nursing home to the family of the person with dementia. Written consents were obtained from the closest family members of 77 residents after a complete description of the study. One person from this group died before the interview; 2 consents were obtained after the end of the study.

The NPI-NH and the EAPSID assessments were translated into Hebrew by 2 independent translators and a third translator examined discrepancies and revised the assessments into a final version after consultation with the researchers. This article only includes the sections of the questionnaires which assess hallucinations. The sections relating to delusions are reported elsewhere.[25]

The assessments were administered by research assistants to nursing home staff caregivers such as registered nurses, practical nurses, nurse aids, occupational workers, and nursing home administrators who had extensive knowledge of the resident. The NPI-NH was administered first and then the EAPSID.

Analytic Approach

The analytic approach involved in-depth analysis using the following principles of grounded theory methodology[26]: (1) data were collected and analyzed without a preconceived framework in mind; (2) the researchers aimed to develop theories and ideas based on the data which were grounded in localized accounts and experiences. Conclusions developed were not rigid, in order to accommodate any future contradictory data; (3) conclusions were developed first through broad concepts and then examined in more specific categories to represent the data; (4) the researchers aimed to develop a general analytical framework with relevance extending beyond the research setting; and (5) the process of data analysis was kept as open and transparent as possible. A list of all emerging themes across all transcripts was compiled, and these were clustered into groups within each type of hallucination on the basis of similarity and overlap. These groupings were further refined, resulting in the identification of the main themes. All transcripts were then recoded according to this list of themes and subthemes. Rigor and transferability of data interpretation were ensured by having several researchers develop the coding scheme and finalize it through multiple iterations. We then reanalyzed each response with regard to the coding theme, with another researcher reviewing the coding and topics of disagreement until mutual agreement was reached. Finally, the examples used in the manuscript were re-reviewed by all authors.

This study pertains specifically to the meaning of the hallucinations for the persons experiencing them, within the data available through staff caregivers.

Table 1. Characteristics of Participants With Hallucinations by Type of Hallucination and Overall[a]

	Hallucinations								
	Overall—no hallucinations	Visual	Auditory	Tactile (touch)	Gustatory (taste)	All hallucinations	No delusions or hallucinations	All hallucinations vs no delusions or hallucinations $t_{(df)}$ or $\chi^2_{(df)}$	Total sample M (SD)/ %
	M (SD)/%								
N	64	3	4	4	1	10	36		74
Female	77.8	33.3	50	75	1	70	75	$\chi^2_{(1)} = 0.10$	77
Age (years)	85.14 (6.30)	87.0 (6.56)	87.0 (7.62)	85.25 (7.37)	88	87.8 (6.07)	84.67 (7.16)	$t_{(44)} = 1.26$	85.45 (6.28)
Married	20.3	0	0	25	0	10	22.2	$\chi^2_{(1)} = 0.74$	18.9
Education (years)	11.00 (5.21)	6.67 (6.11)	10 (2.83)	6 (8.49)	–	5.60 (5.37)	11.76 (5.17)	$t_{(20)} = 2.33$[b]	10.40 (5.44)
# Living children	2.23 (1.16)	1.33 (1.16)	1.75 (0.96)	2.5 (1.0)	1	1.80 (1.135)	2.14 (1.22)	$t_{(44)} = 0.79$	2.18 (1.16)
Length of nursing home stay	2.67 (4.03)	3.67 (2.52)	2.50 (3.70)	2.5 (1.0)	4	3.30 (2.41)	3.26 (4.6)	$t_{(43)} = 0.03$	2.76 (3.83)
# Medical diag	6.50 (2.89)	7.00 (4.58)	7.00 (3.16)	9.0 (1.83)	10	7.30 (2.87)	6.03 (2.97)	$t_{(44)} = 0.07$	6.61 (2.89)
Cognitive function: MMSE	9.71 (6.77)	8.00 (8.49)	6.50 (5.45)	5.0 (6.63)	3	4.11 (4.40)	9.56 (7.46)	$t_{(41)} = 2.08$[b]	8.99 (6.76)
Vision problems	60.9	100	100	100	1	100	50	$\chi^2_{(1)} = 8.21$[c]	66.2
Hearing problems	32.8	33.3	25	25	1	40	19.4	$\chi^2_{(1)} = 1.82$	33.8

[a] Numbers may not add up because of overlaps, that is, some persons manifested more than 1 hallucination.
[b] $P < .05$.
[c] $P < .01$.

Results

Description of Hallucinations

Ten residents were reported to experience hallucinations, including visual (P1, P2, and P3), auditory (P1, P4, P5, and P6), tactile (P1, P7, P8, and P9), and gustatory (P10). One person (P1) had visual, auditory, and tactile. The demographic, health, and functional characteristics of residents with and without hallucinations are presented in Table 1. Because a specific phenomenon, such as talking to someone who is not present, is interpreted as a delusion by some and as a hallucination by others, we compared participants with hallucinations to those with neither delusions nor hallucinations. Residents with reported hallucinations had significantly fewer years of education, were significantly more cognitively impaired, and had significantly more vision problems than those without hallucinations or delusions. While persons manifesting hallucinations were more than twice as likely to have hearing problems compared to those without delusions or hallucinations, the difference was not statistically significant.

Visual hallucinations. Three residents were described as experiencing visual hallucinations. P1 is an 80-year-old male with an MMSE score of 14 and poor vision. The visual hallucination involves an auditory hallucination as well. It is described as him talking to people who are not present, while looking as if he is holding a cell phone. He seems to be asking for permission from an authority figure, and he is worried about the permission. The symptoms occur at nonconsistent places, several times throughout a day–night period, but especially in the afternoons. P2 is a 93-year-old man with poor hearing and vision. In his visual hallucinations, he talks to someone who is not present. The hallucinations are vague. It looks like he feels comfortable with the hallucinations. P3 is an 88-year-old widow, with an MMSE of 2 and poor vision. The visual hallucinations were described as occurrences in which she waves her hands, as if to remove or catch something with her hands. They occur less than once a week in no consistent time or place. The staff caregivers and other residents ignore her when the hallucination is manifested.

Auditory hallucinations. Four residents were reported to have auditory hallucinations (P1, P4, P5, and P6). For the first, P1, the auditory hallucination is accompanied by the visual hallucinations described above. In these conversations, he acts as if he hears a voice and is seeking approval. The other 3 are described as follows: P4 is an 81-year-old widow with an MMSE score of 5 and is blind in 1 eye. The auditory hallucination is manifested when she hears noises and suspects that people enter her vicinity; and when she talks to her daughter who is not present, usually asking her questions. The hallucination takes place a few times a day—during morning or evening care, or in the activity room while she rests or walks. P5 is a 95-year-old female divorcee with an MMSE score of 6 and visual deficits. The auditory hallucination takes place once or twice a day while she is sitting on a chair alone in the dining room, not engaged in activities (the dining room is where staff caregivers leave her when there are no activities). She hears voices that excite her and looks for their origin. The television is usually on. She does not tell anyone about the hallucination. P6 is a 92-year-old widower who has an MMSE score of 1, has hearing problems, and is blind. In his auditory hallucinations, he hears his daughter's voice and talks with her though the content is not clear. This happens once or twice a week when he is in the dining room, which has a window and while the television is on, and sometimes an intercom and telephone messages are heard. He feels comfortable during the hallucination and has no specific emotional responses. The staff caregivers react by explaining to him that he is wrong. The informant said it may occur because he is getting ready for his daughter's visit; the informant assumes that had they not told him about the upcoming visit, the hallucination would have not occurred.

Tactile hallucinations. Four residents were reported to have tactile hallucinations. P1, who was also reported to have visual and auditory hallucinations, was reported to say that things crawl on his skin. P7 is an 84-year-old married woman who has an MMSE score of 0 and visual problems. Her tactile hallucination is manifested in hand movements, in which she tends to scratch herself, shout, and cry. It has persisted for 3 years. Medical examinations revealed no problem with her skin. The hallucination occurs several times a week at no consistent time or place. P8 is an 80-year-old divorcee with an MMSE of 6 and vision problems. The tactile hallucination is expressed by her complaining that something crawls over her skin. It happens several times a week at no consistent time or place. The staff caregivers explain to her that she is wrong; other residents ignore her. P9 is a 95-year-old widow who has an MMSE score of 0 and both auditory and vision problems. Her tactile hallucination is expressed in her thinking that the body lotion spread on her body after a shower is water. This hallucination has persisted for 3 years; it occurs once or twice a day after taking a shower, when the lotion is spread on her body either in the shower or in her room after being dressed. The staff caregivers' reaction is to explain to her that she is wrong.

Gustatory hallucination. One resident, P10, was reported to have hallucinations of taste. She is an 87-year-old widow with an MMSE of 3 and with poor hearing and vision. The hallucination of taste is an aftertaste or salty taste which occurs several times a day during meals in the dining room.

Analysis of Hallucinations

The overarching theme that seems to emerge from the descriptions of the hallucinations is that behaviors that are not easily explained or complaints that are not understood are labeled as hallucinations by staff caregivers. This is most evident in the tactile and taste hallucinations. If the person feels like something is crawling on them, and no medical problem is detected, that is considered a hallucination. Similarly, an aftertaste that is

not explained by the food is considered a hallucination. A hand position that looks like someone is holding a cell phone or moving something (P3) are similarly considered a hallucination, as is talking to people who are not present. The main underlying themes are described as follows:

Talking to persons who are not present. Most of the visual and auditory hallucinations (P1, P2, P4, and P6) involved talking to a person who was not present, a phenomenon sometimes described as a visual hallucination, at other times as auditory, or as both. Two residents (P4 and P6) were talking to their daughters, whereas in the other cases, it was unclear who they were talking to. In some cases (P4 and P5), the person with the auditory hallucination heard sounds and was looking for their origin. To what extent such behavior represents a coping mechanism for loneliness is difficult to ascertain. In terms of visiting, P1 had children and grandchildren visit several times a week; P4's daughter comes to visit her on an almost daily basis, P2 has sons who visit him 3 times a week, P6's 2 children visit once a week. While all receive family visits, it is unknown to what extent they feel lonely in the nursing home.

Lack of stimulation/boredom. Some hallucinations could be related to inactivity and boredom. In particular, 2 were described to occur in the dining room, when there were no activities. P5 hears people entering and is looking for them, and P6 hears his daughter's voice and talks to her. Additionally, P4, when inactive, hears voices and suspects that people enter the room. Three residents were reported as not having full command of Hebrew (P3, P6, and P9), the language most used in the nursing facilities.

Trigger. While most hallucinations were described as not having consistent circumstances or triggers, some of the hallucinations seemed to be triggered by other events. For P6, it was the announcement that his daughter is coming to visit that caused him to start talking to her. Given his vision and hearing deficits and his poor MMSE score (1 of 30), it is possible that this behavior represents a misunderstanding that she had already arrived. For P9, the trigger was the sensation of the lotion that made her feel as if she was being washed with water again.

Vision/sensory deprivation. All residents who were reported to experience a hallucination had poor vision and some of them (P2 and P6) also had poor hearing.

Discussion

The results provide a more thorough examination of staff caregivers' interpretation of the meanings of hallucinations, which have received scant prior research attention. Our results suggest the following main conclusions:

Hallucination was the term staff caregivers used for phenomena they could not explain. It did not involve the older person providing any detailed account of an unexplainable sensory experience; rather, it represented the staff caregivers' lack of understanding of the resident. In general, the staff caregivers did not seem to have much knowledge or understanding of hallucinations and could not describe the circumstances of the hallucinations' occurrences or their significance to the older persons. This probably stems from a combination of 2 factors: The residents under study were mostly in the advanced stages of dementia and probably could not clearly express their sensations and experiences; and the nursing home staff caregivers often do not have the skills to observe such circumstances and neither are they trained to do so nor do they have the time to do so. These factors should be taken into account when involving staff caregivers in both formal and informal assessments of persons with dementia, and the assessments' results should be interpreted with caution. A better nomenclature may be useful to improve the staff caregivers' understanding of residents and thus to promote improved quality of care.

The classification of hallucinations into subtypes of auditory and visual may not be meaningful as ''talking to persons who are not present'' was defined on separate occasions as both visual (P2) and auditory hallucinations (P4 and P6).

Most of the visual and auditory hallucinations reported were not associated with negative affect or behavior, though a few were associated with discomfort. In contrast, tactile and taste hallucinations involved discomfort, such as scratching, unpleasant sensation (eg, water on skin or taste of salt), for which staff caregivers did not find a physiological explanation. This suggests that many of the former may not require treatment, whereas the latter require additional investigation and possible intervention.

The hallucinations reported by staff caregivers were the result of observing a behavior or a patient complaint; hallucinations which do not elicit a response (such as hearing pleasant music) and/or which are not negative (eg, pleasant tactile hallucinations) may not be brought to the attention of the staff because they are neither observable nor require intervention. This indicates a potential response bias.

Some of the hallucinations occurred when there were no activities. Boredom and lack of activities may exacerbate the sensory deprivation and therefore increase the likelihood of hallucination. Residents who do not speak the majority language well (P3, P6, and P9 in our study) may suffer from isolation and a lack of interaction with others due to this language barrier and may therefore be at higher risk of experiencing hallucinations. Appropriate activities may be useful in preventing such hallucinations.

In agreement with prior research,[5,8,9] this study found that persons experiencing hallucinations have sensory losses, suggesting that some of the behaviors that are interpreted as hallucinations may actually be outcomes of neurologic stimulations due to sensory deprivation. Our results showed that while all participants were known to have poor vision and 4 of whom had poor hearing, this is probably an underestimate of their actual sensory loss; the majority was not tested for either hearing or vision impairments during their nursing home stay. All 3 participants who manifested visual hallucinations had poor

vision and 2 did not have eye examinations in the years prior to the interview, whereas the third was prescribed glasses but did not use them. Caregivers should check the timing of eye tests and the use of assistive devices to accommodate sensory deficits when evaluating patients for potential hallucinatory behaviors or when planning interventions or preventions.

Some hallucinations seem to provide interactions with loved ones. This has been termed "comfort phenomenon,"[27] which may represent a positive coping mechanism; staff caregivers may need to find ways to accommodate its related behaviors. Such behaviors may or may not represent hallucinations. One literary reference to such behavior can be found in *Suite Française* by Irene Nemirovsky.[28] On page 282 Madame Angellier, whose son is a soldier captured as a prisoner of war, talks to her young son, ". . . You can lay your little head on Mama's lap." The author then explains, "It was neither delirium nor the first signs of madness; never had she been more totally lucid and aware of herself. It was deliberate play-acting, the only thing that brought her some solace, in the same way as morphine or wine . . . she could relive the past . . .. Treasured memories resurfaced." In this case, the behavior, while not hallucinatory, represented a coping mechanism for an extreme sense of loneliness. The extent to which loneliness is the underlying cause for most cases of talking to a person not present, the extent to which it involves true hallucinations whether auditory or visual, and the extent to which such phenomenon relieves the loneliness, all need to be explored in future research. From a practical standpoint, if hallucinations co-occur with isolation and loneliness, staff caregivers should interpret these hallucinations and delusions as signs of possible loneliness in the resident and intervene accordingly.

In contrast with Mosimann et al's research,[29] which relied largely on self-reports and included participants with a mean MMSE score of 19, we used a population with an MMSE range of 0 to 6, excluding 2 participants (1 with a score of 14 and 1 for whom the MMSE score was unavailable). For participants with this level of cognitive impairment, self-report is not viable and informant-based interviews are needed, as they comprise the most reliable method for the study of such complex phenomena.[30] Thus, the results of our study are based on the informants' reports, in this case, those of staff caregivers. In order to validate that the caregivers did indeed consider those to be hallucinations, all reported hallucinations were rated as such on the NPI-NH and then further described on the EAPSID.

It is unclear from the data whether staff naturally interpreted inexplicable behavior as hallucinations because it was a plausible explanation, or rather, when confronted with the questionnaire, attributed the bizarre behavior to hallucinations because they were limited to the choices given on the questionnaire. This needs to be explored in future research. Furthermore, given the reliance on staff caregivers for accurate assessment of persons with dementia, there is a need to educate caregivers on the nature and causes of hallucinations and delusions. This will allow not only for better assessment of the resident but also for increased sensitivity to true hallucinations versus inexplicable behavior which may require other assessment to determine their nature. Such understanding can improve the quality of services provided to persons with dementia and promote a deeper understanding by the caregiver of the resident's needs.

The current state of affairs raises serious questions that relate to the well-being of the residents. Are the sensations of being crawled on by something truly a result of dementia-related brain stimulation and therefore an illusion, or do they reflect some real physical sensation? In either case, what can alleviate them? Could the aftertaste experienced by 1 resident have something to do with poor mouth hygiene or with the quality of the food or its correspondence with the person's tastes or habits? Can proper evaluation by staff caregivers identify triggers to these discomforting hallucinations and prevent them from occurring? Are the measures used to evaluate persons with dementia actually valid, given that clinicians and researchers often need to rely on staff caregivers who are the only ones truly acquainted with the persons with dementia and their living experiences yet they may not fully understand hallucinatory and delusion phenomena? Are the results from these commonly used measures being interpreted with this in mind? These are crucial questions for understanding hallucinations and maximizing quality of life for persons with dementia and should form the basis for nonpharmacologic interventions for hallucinations. They call for staff education on how to better understand hallucinations and how to relate to residents having them. For instance, interventions aimed at decreasing residents' sense of loneliness and boredom may reduce the incidents of visual and auditory hallucinations, in which they either interact with others or experience the arrival of others; alternatively, interventions need to optimize accommodation of residents' hallucinations when those hallucinations are pleasant or comforting. Findings also call for future research to further enhance the understanding of the phenomena labeled as hallucinations.

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