The meanings of delusions in dementia: A preliminary study

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ABSTRACT

One of the common symptoms of dementia is delusions. Due to a biological conceptualization of the behaviors represented as delusions, these are classified as psychotic symptoms. This is a qualitative and quantitative study aiming to describe the delusions experienced by older persons with dementia and the context of occurrence, and to elucidate their etiology. Participants were 74 nursing home residents aged 65 and over, diagnosed with dementia, from nine nursing homes in Israel. Participants with delusions were found to have significantly more difficulties in performing ADLs, and poorer vision and hearing. Based on assessment using the BEHAVE-AD, six categories of delusions were examined: 1. One's house is not one's home, 2. Theft, 3. Danger, 4. Abandonment, 5. Misidentification, and 6. Other non-paranoid. Common themes appeared across delusions including reality, disorientation, re-experience of past events, loneliness and insecurity, boredom, and trigger. Current results suggest that delusions may not represent psychotic symptoms for most participants, because they sometimes represented reality, or were neither firm nor incontrovertible. Thus, utilizing the term *delusion* relegates the person's behavior to the domain of severe psychiatric phenomena and precludes understanding its true meaning.

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1. Introduction

DSM-IV (American Psychiatric Association, 2000) defines a delusion as a false belief, based on incorrect inference about an external reality, that is firmly sustained despite what almost everyone believes and despite evidence constituting incontrovertible and obvious proof to the contrary. Types of delusions associated with dementia include the '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 non-paranoid delusions (Fischer et al., 2004).

Study limitations and inconsistencies in the definitions and classifications of delusions in dementia have led to inconclusive results regarding the frequency of experiencing delusions in dementia, and its prevalence over time. Past research reveals that 10%–73% of individuals with Alzheimer's Disease (AD) suffer from delusions (Wragg and Jeste, 1989; Wilson et al., 2000; Scarmeas et al., 2005; Fernandez et al., 2010). While rates of subtypes of delusions among persons with dementia vary across studies, most studies found delusions of theft to be most common, followed by the delusion that 'one's house is not one's home,' and delusions of suspicion (see Table 1) (Reisberg et al., 1987; Burns et al., 1990; Deutsch et al., 1991; Khandelwal et al., 1992; Rubin, 1992; Migliorelli et al., 1995; Gormley et al., 1998; Shaji et al., 2009).

Various types of explanations have been proposed concerning the etiology of delusions in dementia (Cummings and Victoroff, 1990; Ballard and Oyebode, 1995; Rao and Lyketsos, 1998; Cohen-Mansfield, 2003). Essentially, these reflect three categories: (1) Delusions may evolve from brain damage, caused by dementia; (2) Delusions may evolve from the person's response to the environment, which is restricted by the impairments caused by dementia; and (3) Delusions may reflect a separate disorder unrelated to dementia.

Prior research was confined to describing the prevalence of delusions in dementia and their subtypes using a variety of assessments, or to correlating delusions to demographic and medical data. Yet, previous studies focused on a biological conceptualization of the behaviors represented as delusions and thus failed to examine the potential influence of psychosocial and environmental factors on the presentation of delusional symptoms in this population. Thus, this study aims to describe the delusions experienced by older persons with dementia and the context of occurrence, and to elucidate their etiology.

2. Methods

2.1. Participants

Participants were 74 nursing home residents aged 65 and over, from nine nursing homes in Israel, who had a diagnosis of dementia in the medical chart, resided in the

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Table 1
Prevalence of specific delusions across studies.

Source	Dementia status	Sample size	Sample type	Overall delusions (%)	Paranoid (general) (%)	Theft (%)	'One's house is not one's home' (%)	Suspiciousness (%)	Abandonment (%)
Burns et al. (1990)	AD	178	OS, IS, CS	15.7	*	9 [a]	*	5.6 [a]	*
Cohen-Mansfield et al. this study	Dementia	74	IS	46	*	22 [a]	7 [a]	*	5 [a]
Deutsch et al. (1991)	Prob. AD	181	CS	41[a]	29.8 [a]	*	14.4 [a]	*	*
Gormley et al. (1998)	Prob. AD	70	CS, OS, IS	34.3[a]	*	4.3 [a]	*	7.1[a]	*
Khandelwal et al. (1992)	Dementia	30	CS	48	*	27 [a]	10[a]	33 [a]	10[a]
Migliorelli et al. (1995)	Prob. AD	103	OS	20	*	14.6 [a]	5.8 [a]	*	6-8 [a]
Reisberg et al. (1987)	AD	57	OS	*	12 [a]	28 [a]	12 [a]	12 [a]	12 [a]
Rubin (1992)	AD	110	IS	*	31 [a]	26 [a]	*	9 [a]	*
Shaji et al. (2009)	DAT	40	OS, PH	53	*	30 [a]	35[a]	5 [a]	5 [a]

* Not available for this study.
Note: numbers may not add up because of overlaps, i.e., some persons manifested more than one delusion.
CS – Community Sample, IS – Institutional Sample, OS – Outpatient Sample, PH- Psychiatric Hospital
Prob – probable, AD – Alzheimer's Disease, DAT – Dementia of Alzheimer's Type.
[a] out of total sample.

facility for at least 2 months, did not have a known acute or unstable medical condition, had at least minimal levels of verbal communication, and for whom consent was obtained from a responsible family member (Cohen-Mansfield et al., 1998). Participant characteristics are presented in Table 2. In terms of diagnoses, all participants had a diagnosis of dementia, 70% had cardiovascular diagnoses, 61% digestive diseases, 41% genitourinary, 32% neurological and 30% had skeletomuscular diagnoses. There were high levels of medications, with half the sample receiving cardiovascular medication, half receiving gastrointestinal medication, 47% receiving antidepressant medication, and another close to a third receiving sedative/hypnotics. About a third were taking antihypertensive, 30% diuretics, and 13.5% were taking antipsychotic medication.

2.2. Assessments

2.2.1. Behavioral pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Reisberg et al., 1996)

Each type of delusion or hallucination is rated on a 4-point scale of severity. The reliability and validity of the BEHAVE-AD has been reported in multiple studies (Auer et al., 1996; Cohen-Mansfield and Golander, 2011; Monteiro et al., 1998, 2001; Patterson et al., 1990; Sclan et al., 1996). In addition, we have examined the inter-rater reliability using conjoint interviews for 23 participants, and found a full agreement for the delusions questions (i.e., inter-rater agreement of 100% and kappa value of 1.)

2.2.2. Neuropsychiatric inventory: Nursing Home Version (NPI-NH; Cummings et al., 1994)

Each type of delusion or hallucination is marked as either occurring or not present. The reliability and the validity of the NPI have been documented (Wood et al., 2000; Lange et al., 2004; Cohen-Mansfield and Golander, 2011). In 22 conjoint interviews we found an agreement rate of 86.3% with a kappa of 0.68 for the delusions.

2.2.3. 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 (2003). The EAPSID inquires about the etiology of psychosis in dementia through a functional analysis. It includes queries regarding the different types of delusion (e.g., theft, abandonment) and hallucinations (e.g., olfactory, sensory). Each such category includes open-ended items (e.g., describe a specific situation in which the delusion occurred; describe the content of the delusion) and close-ended items (e.g., where does the delusion occur; frequency of occurrence). The questionnaire was administered to the formal caregivers (e.g., nursing home assistants). The open-ended responses on the EAPSID provided the qualitative data for the study.

2.2.4. Functional status

Functional status was assessed using an Activities of Daily Living questionnaire (ADL) based on the Older Americans' Resources and Services (OARS; Center for the Study of Aging and Human Development, 1975).

2.2.5. The Mini Mental State Examination

The Mini Mental State Examination (MMSE; Folstein et al., 1975) was administered to participants unless available from a recent administration in the chart.

2.2.6. Trauma

Trauma was assessed by asking the formal caregivers as well as relatives whether the participants had experienced different types of past trauma, specifically, regarding experience of the Holocaust, terrorist attacks, sexual abuse, car accident, or other trauma.

2.3. Procedure

The Ethical Committee of Tel Aviv University approved this study. We approached 16 nursing homes to participate in the study, and seven refused. Due to confidentiality issues, nursing home staff members selected residents with dementia, who had at least some ability to communicate (on the assumption that without any ability to communicate, delusions could not be detected) and approached the responsible party for permission to be contacted by the research team. Consents were obtained from the closest family members of 74 residents.

The assessments described earlier were translated into Hebrew by two independent translators, and a third translator examined discrepancies and revised the assessments into a final version after consulting the researchers. The assessments were then administered to nursing home staff members such as registered nurses, practical nurses, nurse aids, occupational workers and nursing home administrators, who had extensive knowledge of, and (95% of whom) had daily contact with, the participant. Ninety-seven percent of the informants' reports were rated as highly reliable by the research assistants. The other 3% sometimes had difficulty understanding the questions. The assessments included many close-ended questions, which were entered directly into a computer via data entry software, and some open-ended items, which were transcribed in real time. The NPI-NH and the BEHAVE-AD were administered to all informants (with one exception, for whom only the NPI-NH was administered) in random order. The EAPSID was administered to those who reported delusions on the BEHAVE-AD and the NPI.

2.4. Analytic approach

2.4.1. Qualitative approach

The analytic approach involved in-depth analysis using the following principles of grounded theory methodology (Strauss and Corbin, 1998): 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 to 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 delusion on the basis of similarity and overlap. These groupings were then further refined resulting in the identification of the main themes. All transcripts were then recoded according to this list of themes and sub-themes. 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 a mutual agreement is reached. Finally, the examples used in the manuscript have been re-reviewed by all authors.

2.4.2. Quantitative approach

In order to enhance the qualitative data, we provide descriptive data regarding demographic variables, cognitive, functional, and medical status, and trauma, for each delusion subtype. In addition, we compare those who presented symptoms of delusions to those who did not on the same demographic, cognitive, functional, medical and trauma variables via t-tests for continuous and ordinal variables and via chi-square tests for nominal variables.

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