

Hoarding Behavior in Three Different Types of Dementia Cases

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SUMMARY

Introduction: Hoarding behaviour, which is generally defined as collecting and keeping unnecessary, cheap objects or things that can not be used, is more common in elderly than young people. The of hoarding behaviour in dementia was reported as 22%. In this paper, three different types of dementia cases are presented in order to emphasize the clinical awareness for hoarding disorder, which is common in the elderly, especially those with dementia.

Cases: The first case is a patient with a diagnosis of frontotemporal dementia who was collecting old things before the appearance of changes like verbal and physical agitation. The second one is a patient who was admitted with complaints of forgetting, diagnosed as having Alzheimer's Disease and presented with paper hoarding behavior in his clinical follow-up. The last patient was presented with visual hallucinations, forgetting, collecting old things and depressive symptoms. He received a diagnosis of Lewy body dementia.

Discussion: It is prominent that all three different dementia cases hoarding behavior at early stages of dementia. It should be kept in mind that hoarding behavior which begins at late life might be a sign of dementia or it might appear in the dementia process.

Keywords: Hoarding, dementia, elderly

INTRODUCTION

Compulsive hoarding is generally defined as collecting and keeping unnecessary, cheap objects or things which can not be used (Frost et al. 1995). This condition is also called "sylogomania" (Clark et al. 1975). Recent epidemiological studies reported the prevalence of clinically significant compulsive hoarding as 2-5% in adults (Iervolino et al. 2009, Samuels et al. 2008). Compulsive hoarding leads to a restricted home and living space, plus it can also be considered a public health problem because it reduces the quality of life of both the patient and relatives. In addition, this disorder impairs daily functions and causes environmental threats (fire and risk of falling) as well as serious health problems (infections, insect bites, etc.) (Frost et al. 2000). Health issues are especially

serious in the elderly population and lead to significant caregiver burden (Frost et al. 2000).

Compulsive hoarding, which was historically associated with Obsessive Compulsive Disorder (OCD), has recently been suggested to be a separate entity and diagnosis (Fontenelle et al. 2004, Grisham et al. 2005). Hoarding disorder is categorized as a separate diagnosis under the title of "Obsessive Compulsive and Related Disorders" Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in DSM-5, which was published in 2013. DSM-5 suggests excluding other psychiatric and medical diseases, including neurocognitive disorders, for this diagnosis. It emphasizes that the onset of hoarding behavior is insidious and late in degenerative disorders like frontotemporal dementia or Alzheimer's disease. Furthermore,

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such patients are reported to display disinhibition and a lack of personal and domestic hygiene in addition to their hoarding behavior (American Psychiatric Association 2013).

Approximately one third of patients with OCD show compulsive hoarding (Hartl et al. 2005). Compulsive hoarding is also related to many psychiatric disorders, such as schizophrenia (Luchins et al. 1992), depression (Frost et al. 2011), anorexia nervosa (Frankenburg 1984), attention deficit and hyperactivity disorder (Hartl et al. 2005), and dementia (Hwang et al. 1997, Hwang et al. 1998). Compulsive hoarding, which usually presents alongside social withdrawal in elderly people, is also known as Diogenes Syndrome. Dementia was reported in some of the cases with Diogenes Syndrome (Zuliani et al. 2013).

Although compulsive hoarding behavior is more common in the elderly, comprehensive clinical studies have not been conducted yet. In one study, compulsive hoarding behavior was reported as 15% in nursing homes and 25% in the general population (Marx and Cohen-Mansfield 2003). When elderly subjects with or without compulsive hoarding behavior have been compared, no difference in terms of sociodemographic (age, education level, sex) or clinical (dementia, cognitive impairment, or other diseases) features have been found. However, their functioning status, other agitation behaviors and psychotic symptoms were different (Marx and Cohen-Mansfield 2003).

Two studies conducted with dementia patients reported the prevalence of hoarding behavior as 36% (Hwang et al. 1997) and 22.6% (Hwang et al. 1998). The studies found that hoarding behavior can be seen in different types of dementia and that symptoms like repetitive behavior, hyperphagia, and stealing were common (Hwang et al. 1998).

In our country, Altunöz et al. (2012) used the Cohen-Mansfield Agitation Inventory in patients with dementia and showed that hoarding, together with negativism, was a separate dimension of agitation.

In this paper, three different types of dementia cases are presented in order to emphasize the clinical awareness for hoarding disorder, which is common in the elderly, especially those with dementia.

Case 1: İB, 74 year-old, male, illiterate, retired worker. He was admitted to the Geriatric Psychiatry outpatient clinic with bizarre behavior which started 4 years prior, such as irritability, nervousness, quarrelling with his wife, swearing at children, verbally abusing women, and singing in the mosque. His relatives reported that a few years ago the patient hoarded old carpets, newspapers, pencils, lighters, and expired bus cards. He couldn't explain why he hoarded those things and because of the hoarding, there was no room in his home. Psychiatric examination revealed poor thought

content, affective blunting, and loss of insight. Diffuse cerebral cortical atrophy was present in the Cranial Computerized Tomography and hypometabolism in the bilateral frontal and temporal lobes was observed in Cranial Positron Emission Tomography. The neuropsychological tests showed impairment in frontal functions (see Table-1) and the patient received a diagnosis of frontotemporal dementia according to the Neary Diagnostic Criteria (1998). Olanzapine 5 mg/day and Escitalopram 10 mg/day were prescribed for behavioral disorders and insomnia during the follow-up. Olanzapine was changed to Risperidone 1-2 mg/day due to lack of efficiency, after which all agitation behaviors, including hoarding, decreased. This treatment continued for approximately a year, but Risperidone was later tapered and eliminated due to bradykinesia, replaced by Quetiapine 25 mg/day.

Case 2: NB, 66 year-old, male, high school graduate, retired government employee. He was admitted to the Geriatric Psychiatry outpatient clinic with complaints of forgetting what he spoke and where he placed belongings, all starting three years prior. His psychiatric examination and neuropsychological tests revealed significant short term memory and attention deficits, as well as apraxia, language, and executive disorders (Table-1). Cranial Magnetic Resonance Imaging (MRI) showed global cortical atrophy. According to National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) diagnostic criteria (1984), the patient received a diagnosis of dementia due to Alzheimer's disease. After one year, the symptoms of leaving his house and hoarding paper (he had a closet full of old newspapers and papers) both appeared. The patient, who was followed for four years, was first given Rivastigmine patch 5-10cm²/day and Escitalopram 10mg/day. One year after that, Memantine 20mg/day was added because of rapid decline in his Mini Mental State Examination (MMSE) scores. Two years before he was admitted, he had urinary incontinence and he occasionally had behavioral disorders like committing violence against his wife and running out of his house. Quetiapine 25-50mg/day was added to his treatment. His hoarding behavior declined and his last MMSE score was recorded as 4/30.

Case 3: CFT, 81 year-old, male, high school graduate, retired government employee. He was admitted to the Geriatric Psychiatry outpatient clinic with his daughter and he had complaints of a lack of appetite, drowsiness, amnesia, depressed mood, and seeing insects. For several months, he had been forgetting where he put his belongings, wandering around at night, having nightmares, and acting as if he were dreaming. His forgetfulness began about one and a half years prior to admission and increased slowly, but he had become more irritable and sleepless for the last few months. The patient's daughter shared that her father was talking about women walking around, and the more recently he was seeing

insects and washing the house with cologne. Additionally, he was collecting plastic bottles, flowerpots, and dishes on the balcony and for this reason, the balcony was inaccessible. His psychiatric examination and neuropsychological evaluation revealed depressive mood, short term memory and attention deficits (Table-1), visual hallucinations, and REM (Rapid Eye Movement) sleep disorder. Cranial MRI showed bilateral temporoparietal atrophy. The patient received a diagnosis of Lewy body dementia (McKeith et al. 2005) and he was given Rivastigmine patch 5-10cm²/day, Escitalopram 10-15mg/day, and melatonin 3mg/day. Upon follow-up, his agitation behaviors were exacerbated and he was prescribed Quetiapine 50-150mg/day, however he did not improve. He died of pulmonary infection a year ago.

We administered the following tests to each patient: MMSE (Güngen et al. 2002), Clock Drawing Test (CDT) (Can et al. 2010), Informant Questionnaire for Cognitive Decline in the Elderly (IQ-CODE) (Özel-Kızıl et al. 2010), Functional Activities Questionnaire (FAQ) (Selekler et al. 2004), Cohen-Mansfield Agitation Inventory (CMAI) (Özel-Kızıl et al. 2012), Cornell Scale for Depression in Dementia (CSDD) (Amuk et al. 2003), and the Trail Making Test (TMT) (Cangöz et al. 2007). Table-1 shows the test scores and evaluations according to the cut-off points of each scale. The cut-off point for MMSE is suggested as 24/25. The cut-off score of the CDT was three out of five. The cut-off score for the Turkish version of the ICODE was 3.4. The CMAI is a Likert-type scale consisting of 29 items, scored between 1-never and 7-several times in an hour, and the CMAI evaluates the frequency of various agitation symptoms. The 23rd and 24th items of the scale are about hiding objects and hoarding objects, respectively, and they are both related to hoarding behavior. A CSDD total score of 8 or above reflects depression. The TMT consists of two forms, A and

B. In TMT-A subjects are asked to connect written numbers from 1-25. In TMT-B subjects are asked to connect alternating numbers and Turkish letters from “1-13” and “A-İ”. For both forms, administration duration in seconds is taken into consideration.

DISCUSSION

Three different types of dementia cases with hoarding behavior were presented in this paper. In the first case, hoarding behavior appeared before other symptoms of frontotemporal dementia, whereas in the other two cases it appeared after dementia had progressed. All neuropsychological assessments showed that frontal functions were affected and depressive symptoms were present in all cases.

In the previous literature, hoarding has been reported in different types of dementia cases, especially in Alzheimer’s disease. (Hwang et al. 1998, Rabinowitz et al. 2005, Nakaaki et al. 2007). In a frontotemporal dementia case reported by Nakaaki et al. (2007), garbage hoarding appeared about three years before the other symptoms, which include excessively consuming sweets, gambling, and abnormal sexual behavior. It was also noted that dementia cases with hoarding behavior had hyperphagia, stealing, and repetitive behavior. However, our cases did not present such behavior.

Hoarding is considered to be an agitation behavior in cases with dementia (Cohen-Mansfield et al. 1996). The CMAI total score and the scores of the items about hoarding behavior of all three patients were high. Factor analytic studies in dementia patients also revealed that the “hiding objects” (item 23) and “hoarding objects” (item 24) items of the CMAI comprised a separate factor and were observed in similar frequencies (about 20-30%) in every stage of dementia (Cohen-Mansfield et al. 1989, Suh 2004, Rabinowitz et al. 2005, Majic et al. 2012). Suh (2004) found that object hiding and hoarding behavior were more common in Alzheimer’s disease than in vascular dementia (38% vs 15%). Therefore, researchers concluded that hoarding in dementia had more specific psychopathological mechanisms (Majic et al. 2012, Zuidema et al. 2007).

Patients with compulsive hoarding presented lower performances in neuropsychological tests measuring attention (Grisham et al. 2007), visual memory (Hartl et al. 2004), executive functions like decision making (Lawrence et al. 2006, Nakaaki et al. 2007), and categorizing (Luchian et al. 2007, Wincze et al. 2007, Grisham et al. 2010). Additionally, hoarding presenting alongside changes in personality and impaired social functioning was defined in cases with traumatic brain injury and associated with the medial prefrontal and orbitofrontal cortex (Volle et al. 2002, Anderson et al. 2005). In another study, compulsive behaviors were related to bilateral

Table-1. Neuropsychological Assessments of the Cases

Neuropsychological tests	Frontotemporal dementia case (case 1)	Alzheimer’s disease case (case 2)	Lewy body dementia case (case 3)
MMSE score	24/30 (+)	9/30 (+)	18/30 (+)
CDT score	2/5 (+)	0/5 (+)	2/5 (+)
CSDD score	9 (+)	10 (+)	10 (+)
FAQ score	13/30 (+)	23/30 (+)	18/30 (+)
IQCODE score	3,3 (-)	4,3 (+)	4,5 (+)
CMAI score	69 item 23:6/7 item 24:6/7	106 item 23:6/7 item 24:6/7	47 item 23:5/7 item 24:5/7
TMT-A total duration	+ (332 sec)	+ (>300sec)	(119sec)
TMT-B total duration	+ (>300sec)	+ (>300sec)	+ (305sec)

+ : scores above or below the cut-off or norm values and refers to abnormal neuropsychological test performance

- : refers to normal neuropsychological test performance.

globus pallidus, left putamen, and left temporal lobe atrophy in patients with frontotemporal dementia (Perry et al. 2012).

The results of these studies suggest that hoarding in dementia is associated with impaired frontal lobe functions. Although the three presented cases had different types of dementia, their frontal functions (evaluated by the CDT and the TMT) were impaired. Therefore, hoarding, like other behavioral/neuropsychiatric symptoms, is a mutual symptom related to frontal lobe dysfunction which can be observed in different types of dementia.

Wang et al. (2012) studied the clinical features and underlying causes of hoarding in dementia patients with Alzheimer's disease. They reported that these behaviors were associated with dementia symptoms, premorbid personality traits, and re-experiencing past economic crisis. The patients in our cases did not present hoarding behavior or obsessions before the onset of dementia.

For the treatment of hoarding in dementia patients, serotonergic and antipsychotic medicine (Mendez and Shapira 2008 Suh et al. 2006, Rabinowitz et al. 2007), as well as behavioral methods (Baker et al. 2011), have been suggested.

As a result, dementia should be considered for the differential diagnosis, especially in elderly-onset hoarding behavior. Furthermore, hoarding can emerge during the follow-up of patients with a dementia diagnosis and should be inquired about during clinical evaluation. Hoarding, which appears due to disinhibition and is classified among agitation behaviors in dementia, may have different causes. In every case, appropriate management, especially behavioral interventions, should be applied in order to decrease caregiver burden.

REFERENCES

- Altunöz U, Özel Kızıl ET, Kırıcı S et al (2014) Demans Hastalarında Cohen Mansfield Ajitasyon Envanteri ile Değerlendirilen Ajitasyon Boyutlarının Araştırılması. *Türk Psikiyatri Derg* 25 (baskıda, doi: 10.5080/u7628).
- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, Arlington, VA, American Psychiatric Association p. 247-51.
- Amuk T, Karadağ F, Oğuzhanoğlu N et al (2003) Reliability and validity of the Cornell Scale for Depression in Dementia in an elderly Turkish population. *Türk Psikiyatri Derg* 14:263-71.
- Anderson SW, Damasio H, Damasio AR (2005) A neural basis for collecting behavior in humans. *Brain* 128:201-12.
- Baker JC, LeBlanc LA, Raetz PB et al (2011) Assessment and treatment of hoarding in an individual with dementia. *Behav Ther* 42:135-42.
- Can SS, Özel-Kızıl ET, Varlı M et al (2010) Psychometric Properties of the Turkish Versions of Three Different Clock Drawing Tests in Patients with Dementia. *Archives of Neuropsychiatry* 47: 91-5.
- Cangöz B, Karakoç E, Selekler K (2007) İz Sürme Testi'nin 50 yaş ve üzeri Türk yetişkin ve yaşlı örneklemindeki norm belirleme ve geçerlik-güvenirlilik çalışmaları. *Turkish Journal of Geriatrics* 10: 73-82.
- Clark AN, Mankikar GD, Gray I (1975) Diogenes syndrome. A clinical study of gross neglect in old age. *Lancet* 15;1:366-8.
- Cohen-Mansfield J, Marx MS, Rosenthal AS (1989) A description of agitation in a nursing home. *J Gerontol* 44:77-84.
- Cohen-Mansfield J (1996) Conceptualization of agitation: results based on the Cohen-Mansfield Agitation Inventory and the Agitation Behavior Mapping Instrument. *Int Psychogeriatr* 8:309-15.
- Güngen C, Ertan T, Eker E, Yaşar R, Engin F (2002) Standardize Mini Mental Test'in Türk Toplumunda Hafif Demans Tanısında Geçerlik ve Güvenilirliği. *Türk Psikiyatri Derg* 13: 273-81.
- Fontenelle LF, Mendlowicz MV, Soares ID et al (2004) Patients with obsessive-compulsive disorder and hoarding symptoms: a distinctive clinical subtype? *Compr Psychiatry* 45: 375-83.
- Frankenburg FR (1984) Hoarding in anorexia nervosa. *Brit J Med Psychol* 57: 57-60.
- Frost RO, Hartl TL, Christian R et al (1995) The value of possessions in compulsive hoarding: Patterns of use and attachment. *Behav Res Ther* 33: 897-902.
- Frost RO, Steketee G, Williams L (2000) Hoarding: A community health problem. *Health and Social Care in the Community* 8: 229-34.
- Frost RO, Steketee G, Tolin DF (2011) Comorbidity in hoarding disorder. *Depress Anxiety* 3;28: 876-84.
- Grisham JR, Brown TA, Liverant GI et al (2005) The distinctiveness of compulsive hoarding from obsessive-compulsive disorder. *J Anxiety Disord* 19:767-79.
- Grisham JR, Brown TA, Savage CR et al (2007) Neuropsychological impairment associated with compulsive hoarding. *Behav Res and Ther* 45: 1471e1483.
- Grisham JR, Norberg MM, Williams AD et al (2010) Categorization and cognitive deficits in compulsive hoarding. *Behav Res and Ther*, 48, 866-72.
- Güngen C, Ertan T, Eker E et al (2002) Standardize Mini Mental Test'in Türk Toplumunda Hafif Demans Tanısında Geçerlik ve Güvenilirliği. *Türk Psikiyatri Derg* 13: 273-81.
- Hartl T, Frost RO, Allen GJ et al (2004) Actual and perceived memory deficits in individuals with compulsive hoarding. *Depress. Anxiety* 20: 59-69.
- Hartl TL, Duffany SR, Allen GJ et al (2005) Relationships among compulsive hoarding, trauma, and attention-deficit/hyperactivity disorder. *Behav Res Ther* 43: 269-76.
- Hwang JP, Yang CH, Tsai SJ et al (1997) Behavioral disturbances in psychiatric inpatients with dementia of the Alzheimer's type in Taiwan. *Int J Geriatr Psych* 12: 902-6.
- Hwang JP, Tsai SJ, Yang CH et al (1998) Hoarding behavior in dementia: A preliminary report. *Am J Geriatr Psychiat* 6:285-9.
- Iervolino AC, Perroud N, Fullana MA et al (2009) Prevalence and heritability of compulsive hoarding: a twin study. *Am J Psychiatry* 166:1156-61.
- Lawrence NS, Wooderson S, Mataix-Cols D et al (2006) Decision making and set shifting impairments are associated with distinct symptom dimensions in obsessive-compulsive disorder. *Neuropsychology* 20:409-19.
- Luchian SA, McNally RJ, Hooley JM et al (2007) Cognitive aspects of nonclinical obsessive compulsive hoarding. *Behav Res and Ther* 45,1657-62.
- Luchins DJ, Goldman MB, Lieb M et al (1992) Repetitive behaviors in chronically institutionalized schizophrenic patients. *Schizophr Res* 8:119-23.
- Majić T, Pluta JB, Mell T et al (2012) Correlates of agitation and depression in nursing home residents with dementia. *Int Psychogeriatr* 24:1779-89.
- Marx MS, Cohen-Mansfield J (2003) Hoarding behavior in the elderly: a comparison between community-dwelling persons and nursing home residents. *Int Psychogeriatr* 15:289-306.
- McKeith I, Dickson D, Lowe J et al (2005) Dementia with Lewy bodies: diagnosis and management: Third report of the DLB Consortium. *Neurology* 65:1863-72.
- McKhann G, Drachman D, Folstein M et al (1984) Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology* 34:939-44.
- Mendez MF, Shapira JS (2008) The spectrum of recurrent thoughts and behaviors in frontotemporal dementia. *CNS Spectr* 13:202-8.
- Nakaaki S1, Murata Y, Sato J et al (2007) Impairment of decision-making cognition in a case of frontotemporal lobar degeneration (FTLD) presenting

- with pathologic gambling and hoarding as the initial symptoms. *Cogn Behav Neurol* 20:121-5.
- Nearly D, Snowden JS, Gustafson L et al (1998) Frontotemporal lobar degeneration: a consensus on clinical diagnostic criteria. *Neurology* 51:1546-54.
- Ozel-Kizil ET, Bastug G, Sakarya D et al (2012) Cohen-Mansfield Ajitasyon Envanteri'nin Türkçe Uyarlamasının Psikometrik Özellikleri. *Turkish Journal of Geriatrics* 15:24-29.
- Ozel-Kizil ET, Turan ED, Yilmaz E, et al (2010) Discriminant validity and reliability of the Turkish version of Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE-T). *Arch Clin Neuropsych* 25: 139-45.
- Perry DC, Whitwell JL, Boeve BF et al (2012) Voxel-based morphometry in patients with obsessive-compulsive behaviors in behavioral variant frontotemporal dementia. *Eur J Neurol* 19:911-7.
- Rabinowitz J, Davidson M, De Deyn PP et al (2005) Factor analysis of the Cohen-Mansfield Agitation Inventory in three large samples of nursing home patients with dementia and behavioral disturbance. *Am J Geriatr Psychiatry* 13: 991-8.
- Rabinowitz J, Katz I, De Deyn PP et al (2007) Treating behavioral and psychological symptoms in patients with psychosis of Alzheimer's disease using risperidone. *Int Psychogeriatr* 19:227-40.
- Samuels JF, Bienvenu OJ, Grados MA et al (2008) Prevalence and correlates of hoarding behavior in a community-based sample. *Behav Res Ther* 46:836-44.
- Selekler K, Cangöz B, Karakoç E (2004) Norm determination and adaptation study of Functional Activities Questionnaire on 50+ Turkish elderly. *Turkish Journal of Neurology* 10: 102-07.
- Suh GH (2004) Agitated behaviors among institutionalized elderly with dementia: validation of the Korean version of the Cohen-Mansfield Agitation Inventory. *Int J Geriatr Psychiatry* 19: 378-85.
- Suh GH, Greenspan AJ, Choi SK (2006) Comparative efficacy of risperidone versus haloperidol on behavioral and psychological symptoms of dementia. *Int J Geriatr Psychiatry* 21:654-60.
- Volle E, Beato R, Levy R et al (2002) Forced collectionism after orbitofrontal damage. *Neurology* 58: 488-90.
- Wang JJ, Feldt K, Cheng WY (2012) Characteristics and underlying meaning of hoarding behavior in elders with Alzheimer's dementia: caregivers' perspective. *J Nurs Res* 20:189-96.
- Wincze JP, Steketee G, Frost RO (2007) Categorization in compulsive hoarding. *Behav Res Ther* 45:63-72.
- Zuidema SU, de Jonghe JF, Verhey FR et al (2007) Agitation in Dutch institutionalized patients with dementia: factor analysis of the Dutch version of the Cohen-Mansfield Agitation Inventory. *Dementia and Geriatric Cognitive Disorders* 23:35-41.
- Zuliani G, Soavi C, Dainese A et al (2013) Diogenes syndrome or isolated syillogomania? Four heterogeneous clinical cases *Aging Clin Exp Res* 25:473-8.