

ΑΝΑΣΚΟΠΙΚΗ ΕΡΓΑΣΙΑ

COMPULSIVE HOARDING SYNDROME: CLINICAL ASPECTS AND THERAPEUTIC IMPLICATIONS FOR NURSING PRACTICE IN COMMUNITY

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DOI: 10.5281/zenodo.3631122

Cite as: Zartaloudi, Afroditi. (2020). *Compulsive hoarding syndrome: clinical aspects and therapeutic implications for nursing practice in community*. *Perioperative Nursing (GORNA)*, E-ISSN:2241-3634, 8(3), 180–192. <http://doi.org/10.5281/zenodo.3631122>

Abstract

The aim of the present study was to provide an overview of the compulsive hoarding syndrome, including manifestations of the problem, comorbidity and diagnostic issues, treatment approaches, epidemiology, course, and demographic features of compulsive hoarding. **Material and Method:** A literature review was conducted on both Greek and English languages, through Pubmed, Scopus, Science Direct and Google Scholar databases, using the key-words: "compulsive hoarding", "treatment" "community". **Results:** Compulsive hoarding is a disabling psychological disorder characterized by acquisition, clutter, excessive collection of items, and inability to discard. Associated with increased risk of injury due to the severe clutter and unsanitary conditions, social isolation and disorganization, compulsive hoarding can be devastating for individuals, family members, and communities. Treatment may be affected by the accuracy of the community nurse's understanding of this complex disorder and educating individual hoarders, family and community members and other health care professionals as the effects of hoarding often extend outside the home. **Conclusions:** Compulsive hoarding is a serious public health problem that poses significant health and safety risks for individuals, families, and communities and has a profound effect on public health in terms of poor physical health, occupational impairment, and health care service involvement. Community health nurses play a unique role in the identification and care of hoarders.

Key words: Compulsive hoarding, treatment, community

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REVIEW ARTICLE

ΣΥΝΔΡΟΜΟ ΑΠΟΘΗΣΑΥΡΙΣΗΣ: ΚΛΙΝΙΚΕΣ ΚΑΙ ΘΕΡΑΠΕΥΤΙΚΕΣ ΠΡΟΣΕΓΓΙΣΕΙΣ ΓΙΑ ΤΗ ΝΟΣΗΛΕΥΤΙΚΗ ΠΡΑΚΤΙΚΗ ΣΤΗΝ ΚΟΙΝΟΤΗΤΑ

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Περίληψη

Σκοπός της παρούσας ανασκόπησης ήταν η διερεύνηση των βιβλιογραφικών δεδομένων αναφορικά με τα συμπτώματα, τη συννοσηρότητα, τα διαγνωστικά προβλήματα, τις θεραπευτικές προσεγγίσεις, την επιδημιολογία, την πορεία και τα δημογραφικά χαρακτηριστικά του Συνδρόμου Αποθησαύρισης. **Υλικό και μέθοδος:** Πραγματοποιήθηκε βιβλιογραφική ανασκόπηση άρθρων στην ελληνική και αγγλική γλώσσα συναφών με το θέμα στις ηλεκτρονικές βάσεις δεδομένων Pubmed, Scopus, Science Direct και Google Scholar, χρησιμοποιώντας ως λέξεις – κλειδιά: «Σύνδρομο Αποθησαύρισης», «θεραπεία», «κοινότητα». **Αποτελέσματα:** Το Σύνδρομο Αποθησαύρισης είναι μια εκπτώτικη ψυχιατρική διαταραχή, που χαρακτηρίζεται από συσσώρευση, ακατάστατους και βρώμικους χώρους διαβίωσης, υπερβολική συλλογή αντικειμένων και αδυναμία απόρριψης. Η συσχέτιση του συνδρόμου με αυξημένο κίνδυνο τραυματισμού εξαιτίας της σοβαρής ακαταστασίας και των ανθυγιεινών συνθηκών κάτω από τις οποίες διαβιώνει το άτομο, της κοινωνικής απομόνωσης μπορεί να αποβεί καταστροφική για το άτομο, την οικογένειά του και την κοινότητα. Η θεραπευτική προσέγγιση μπορεί να επηρεαστεί από το βαθμό που ο κοινοτικός(-ή) νοσηλευτής(-τρια) κατανοεί αυτή την πολύπλοκη διαταραχή και εκπαιδεύει τον πάσχοντα, την οικογένεια, την κοινότητα και τους άλλους επαγγελματίες υγείας, καθώς οι επιπτώσεις της ασθένειας συχνά εκτείνονται και γίνονται αντιληπτές και έξω από το σπίτι του πάσχοντα. **Συμπεράσματα:** Το Σύνδρομο Αποθησαύρισης αποτελεί σοβαρό πρόβλημα δημόσιας υγείας που δημιουργεί σημαντικούς κινδύνους για την υγεία και την ασφάλεια των ατόμων, των οικογενειών και της κοινότητας, λόγω της σημαντικής επίδρασης που ασκεί στην επιδείνωση της σωματικής υγείας του πάσχοντα, στη διατάραξη της επαγγελματικής του κατάστασης και στη χρήση των υπηρεσιών υγείας. Οι κοινοτικοί νοσηλευτές διαδραματίζουν έναν μοναδικό ρόλο στην ταυτοποίηση και τη φροντίδα των πασχόντων.

Λέξεις-Κλειδιά: Σύνδρομο Αποθησαύρισης, θεραπεία, κοινότητα

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Introduction

Hoarding is defined as the acquisition of and inability to discard items even though they appear (to others) to have no value. According to Valente¹, compulsive hoarding is a serious public health hazard that poses significant health and safety risks for individuals, families, and communities. For example, extreme clutter can lead to unsanitary conditions, increasing risk of falls, fires, and respiratory ailments related to mold/bacteria growth. Individuals who experience hoarding difficulties are known to be impaired in several areas of everyday functioning such as cooking, washing up, paying bills, and performing well at work.² In addition, compulsive hoarding has a profound effect on public health in terms of poor physical health, occupational impairment, and health care service involvement.³ Community health nurses play a unique role in the identification of hoarders. Most health care providers do not see their patients in their home environments and may remain unaware of the true nature and seriousness of the problem.¹

Material and Method:

A literature review was conducted on both Greek and English languages, through Pubmed, Scopus, Science Direct and Google Scholar databases, using the key-words: "compulsive hoarding", "treatment" "community".

Definition and severity of compulsive hoarding syndrome

Collecting and saving are widespread human behaviors and, as such, can range from normal and

adaptive to excessive or pathological.⁴ However, compulsive hoarding is a term more commonly used to describe excessive collectivism. An amplified interest in the study of hoarding behavior has, over the past two decades, produced a series of increasingly-explicit definitions of what was originally termed "compulsive hoarding behavior." The first of these definitions, produced by Frost and Hartl⁵ stipulated that compulsive hoarding consists of three criteria: (a) The acquisition of and failure to discard a large number of possessions that seem to be useless or of limited value. (b) Living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed. (c) Significant distress or impairment in functioning caused by hoarding. In addition to the core symptoms of excessive acquisition, compulsive hoarding is also associated with disorganization, indecisiveness, procrastination, perfectionism, and avoidance.⁶

Compulsive hoarding is listed as one of the eight criteria of obsessive-compulsive personality disorder in the Diagnostic and Statistical Manual of Mental Health Disorders-IV.⁷ It has also been described as a symptom of obsessive-compulsive disorder [OCD]. However, several research studies have suggested that it is often independent from other disorders, thus giving consideration to the possibility of being listed as a stand-alone, new diagnosis in the Diagnostic and Statistical Manual of Mental Disorders-V[DSM-V].⁸ (see Table 1)

According to the proposed ICD-11 diagnostic guidelines, the essential features of hoarding disorder include: (1) excessive accumulation of and attachment to possessions, regardless of their actual

value; (2) repetitive urges or behaviours related to buying, stealing or amassing items; and (3) difficulty discarding items due to a perceived need to save items and distress associated with discarding them. The proposed ICD-11 diagnostic guidelines also indicate that significant distress or functional impairment is also a required feature of the disorder, to distinguish hoarding from collecting. Inclusion of the requirement for difficulty discarding items, alongside excessive acquisition, is consistent with recent evidence that both belong to a one-dimensional hoarding phenotype.⁹ The diagnostic requirement that excessive acquisition and failure to discard items in hoarding disorder result in cluttered living spaces whose use or safety are compromised is intended to differentiate clinically significant hoarding from normal accumulation of items and collecting. One assumption that is made in this definition is that clinically significant hoarding cannot occur in the absence of clutter. However, the extent to which clutter may be present and/or interfere with usual activities may vary (e.g., depending on resources and available space), and various possibilities were considered for setting a reasonable threshold for the diagnosis. A field trial of the DSM-5 criterion that requires “key” living spaces to be sufficiently cluttered so as to preclude activities for which those spaces were designed¹⁰, which is similar to earlier definitions of hoarding⁵, was considered too strict because it resulted in not assigning the diagnosis to individuals who were significantly distressed and impaired and

met all other diagnostic criteria for hoarding disorder, yet still managed to somehow use some of their “key” living spaces.¹¹

Onset and course of hoarding disorder

Hoarding is considered chronic and progressive, with high rates of prevalence in middle and late adulthood.^{12,13} Hoarding symptoms often develop during childhood or adolescence, and become clinically significant during middle age.^{14,15} The mean age at onset of compulsive hoarding symptoms is 12 to 13 years.^{16,17} Symptoms generally worsen from mild during the teenage years to moderate when patients are in their 20s to severe when they are in their 30s.¹⁵ Because children do not have the means to acquire multiple items, acquisition tends to have a later onset within the disorder. Having the means to acquire and accumulate objects as a child may be substantially restricted; therefore, it may take a decade or more for symptoms to become clinically significant. In such cases, progression of hoarding symptoms may be slow. In other cases, hoarding may have a sudden onset in adulthood, such as after a traumatic life event or brain injury.^{15,17} People who report late onset of hoarding associate the behavior with a stressful or traumatic life event.^{13,15} Hoarding may also begin following a brain injury. Within the last decade, research has shown the onset of hoarding behaviors in people with damage to the orbitofrontal cortex.¹² In addition, pathogenesis studies have also begun to establish that hoarding may have specific neurotransmission pathways¹⁸ or genetic markers.¹⁹

Importantly, a large proportion of individuals who hoard report having at least one first-degree relative who experiences hoarding problems.^{4,16,20} In a sample of individuals with OCD, Samuels and colleagues¹⁶ reported that probands of individuals with hoarding symptoms were four times more likely to experience hoarding symptoms than probands of individuals who did not report hoarding symptoms. Genetic factors and unshared environmental factors may explain this familial connection. In a large sample of female twins, genetic factors accounted for approximately 50% of the variance in compulsive hoarding, while shared environmental factors encountered by twins growing up in the same household did not substantially contribute to the other half.²¹

Comorbidity associated with compulsive hoarding

Hoarding is found in multiple comorbidities, such as schizophrenia, social phobia, organic mental disorders, eating disorders, depression, and dementia.^{3,4,11,16,22} Hoarding traits are also found in 30% of people diagnosed with OCD.²³ In children, hoarding characteristics are seen in children with attention deficit hyperactivity, autism, anorexia nervosa, and Prader-Willi syndrome.¹⁷ Hoarders also appear more likely to experience an alcohol-use disorder at some point in their lives. A community study has found that the prevalence of co-occurring disorders differs for men and women. In men, hoarding is associated with generalized anxiety disorder and tics, while among women, hoarding is associated with social phobia, post-traumatic stress disorder, body dysmorphic disorder, nail biting, and skin

picking.¹⁹ As previously mentioned, compulsive hoarding is associated with social phobia and depression. Findings of isolation and limited social networks among elders who hoard support this association.²⁴ Samuels et al¹⁶ also suggest a high frequency of depression in people who suffer from compulsive hoarding.

Effects of hoarding behavior on patients

A growing body of research suggests that hoarding is associated with a lower quality of life. Children who hoard tend to have failed friendships, due to stealing or not returning items, weight gain from eating food that is hoarded, increased allergies due to dust and mold, and increased injuries related to falls in cluttered environments.¹⁷ Adult hoarders tend to be Caucasian, overweight, and suffer from chronic medical conditions such as hypertension, autoimmune disease, fibromyalgia, or chronic fatigue syndrome.³ They report feelings of low self-esteem, isolation, and anxiety; tend to be single, have few friends; and are from low socioeconomic levels.^{13,25} Lower rates of marriage and higher rates of divorce have been reported for those who hoard^{23,24,26}, suggesting problems in domestic relationships. Those who are married or cohabitating tend to have a lower degree of hoarding severity.³ This is consistent with Fromm's²⁷ description of those with a "hoarding orientation" as withdrawn and remote from others and may relate to findings of greater social anxiety and schizotypy among compulsive hoarders.¹⁶ Additionally, hoarding appears to occur more frequently in the unemployed

and poor. Hoarding may at least contribute to financial insecurity.¹⁴ Five percent of the Web sample reported they had been fired because of hoarding, and on average, employed individuals reported seven psychiatric work impairment days per month.³ Isolation is also a common characteristic of people who hoard. Hoarding is associated with high rates of family frustration. Families often report that the behavior is more severe than the patient believes.²⁸ People who hoard have unusual emotional attachments to the items. They have limited social interaction and present with a detached manner in interpersonal relationships.²⁹ Family members who cohabit with hoarders report being embarrassed about the condition of their home, arguing about the clutter, and feeling rejection and hostility toward the hoarder.³

The main symptoms of hoarding include acquisition, clutter, or excessive collection of items, and inability to discard.¹⁵ The acquisition of goods can come from compulsive buying, picking through trash, collecting free items, or kleptomania.^{20,30} Failure to discard worthless or worn-out objects has been linked to beliefs about their instrumental and emotional value suggesting that possessions are imbued with importance far in excess of their true value. Compulsive hoarding is most commonly driven by obsessional fears of losing important items that the patient believes will be needed later or making the “wrong” decision about what to keep and what to discard. These fears cause substantial distress and lead to compulsions to acquire and save items to prepare for every imaginable

contingency. Hoarders also frequently have excessive emotional attachments to possessions and distorted beliefs about possessions’ importance, leading to excessive saving. The consequent clutter can cause significant social and occupational impairment.⁶

Clutter in the homes of people with hoarding problems is extremely disorganized; valuable objects (and sometimes money) are commonly mixed in with trash.⁵ In severe hoarding cases, clutter prevents the normal use of space to accomplish basic activities, such as cooking, cleaning, moving through the house, and even sleeping. Piles of items can block doorways and prevent people from performing tasks for which the room was intended (e.g., the person is unable to sleep in the bed due to too many items covering the bed).³ Interference with these functions can make hoarding a dangerous problem, putting people at risk for fire, falling (especially elderly people), poor sanitation, and health risks.²⁴ Rotting food, pet feces, dust, and mold can lead to health problems.³ Avoidance is prominent and includes behavioral avoidance of discarding items, putting things away, or cleaning, as well as cognitive avoidance of making decisions or even thinking about the clutter or its consequences. When a person tries to discard the items, it leads to distress.³¹

Patronek and Nathanson³² described animal hoarding as keeping an unmanageable number of animals while failing to provide them with basic care. Although not as widely discussed, animal hoarding is associated with increased risks and complications, including significantly less sanitary

conditions than cases not involving animals, as well as ethical implications that may involve cruelty to animals.⁴

Effects of hoarding behavior on family members

Unlike many psychological conditions, hoarding behavior hits people where they live and thereby affects all who live with the person who hoards. In addition to the impact experienced directly by those who hoard, research has suggested that those caring for, or living with, a hoarding individual also experience repercussions of hoarding. Family members who live in a hoarding situation face the same health and safety risks as the person who hoards, including chronic headaches, respiratory problems, and poor nutrition, the risk of slip and fall injuries, and the way a highly cluttered home slows or prevents emergency medical personnel from responding to a person in need.²⁴

Tolin et al³ found higher rates of frustration among the family members of those who hoard compared to the families of those seeking OCD treatment. Frustrated family members contact hoarding experts approximately twice as often as does the individual with the problem.³³ Many family members are angry, resentful, and critical of the family member who hoards. Children typically have a strained relationship with the hoarding parent. Children often blame the parent for not only the condition of the home but also the effect the hoarding behavior had on them when growing up. Researchers reported that the level of rejection toward the person who hoards was comparable to the rejection among family members of clients

with schizophrenia.³³ In addition, many people who hoard appear to lack the interpersonal skills necessary to repair and maintain effective relationships with family members.²⁹ Spouses, children, siblings, and even parents of compulsive hoarders suffer from worrying about things that could go wrong in their loved one's home. Adult children of people who hoard, for example, fear they will receive a phone call in the middle of the night informing them that their mother's home has burned down with her trapped inside. They worry about falls, poisoning from expired foods, or eviction. However, in spite of the pleas from concerned family members, many people who hoard consistently refuse help for the problem. Limited recognition (insight) of the severity and impairment caused by hoarding behavior is a problem that is particularly troublesome for family members and service providers. Because people who hoard are unable to recognize the severity of the problem, they are often resistant to outside help.³⁴

Treatment approaches for compulsive hoarding

Treatment is complex, mirroring the complexity of the disorder itself. Research suggests that hoarding is not easy to treat and is often associated with poor outcomes following treatments such as medication, cognitive behavioral therapy (CBT), and exposure response therapy, that have been successful with non-hoarding OCD symptoms.⁴ Hoarding treatment begins with a thorough assessment of the patient's amount of clutter; beliefs about possessions; information-processing, decision-making and organizational skills; avoidance behaviors;

daily functioning; level of insight; motivation for treatment; social and occupational functioning; level of support from friends and family; and medication compliance. Before treatment begins, patients must provide baseline photographs of their cluttered areas. Treatment includes exposure and response prevention (ERP), excavation of saved material, decision-making training, and cognitive restructuring.³¹ Patients learn to conceptualize their hoarding in terms of problems with anxiety, avoidance, and information processing. Patients then gradually expose themselves to situations that cause them anxiety (e.g., being required to throw something away or make a decision about what to do with a specific object). With repeated practice, ERP extinguishes the fear of losing something important, thereby reducing the strength of the patient's urges to save. According to a cognitive behavioral model of compulsive hoarding, manifestations of hoarding (acquisition, saving, clutter) result from basic deficits or problems in (a) information processing, (b) beliefs about and attachments to possessions, and (c) emotional distress and avoidance behaviors that develop as a result.²⁴

CBT for compulsive hoarding is directed toward decreasing clutter, improving decision-making and organizational skills, and strengthening resistance to urges to save. Frost and Hartl⁵ developed a cognitive-behavioral model for the treatment of compulsive hoarding that has provided a framework for further understanding and treatment of compulsive hoarding. Higher scores on the hoarding symptom factor predict premature dropout and poor response to CBT.³⁵ Lack of insight and egosyntonic

nature of hoarding symptoms continue to pose several barriers such as poor compliance, treatment refusal, lack of cooperation, and poor treatment outcomes.^{23,36} Even during treatment, motivation levels among people with hoarding problems may be low. Christensen and Greist³⁷ also described passive resistance to treatment among hoarding clients who expressed an intention to work on their problem, but made little real effort to do so. Attempting to remove clutter, clean, and organize is often met with outrage and anger.³⁸ Removing clutter is only addressing the symptom of hoarding, not the problem. Tompkins³⁸ suggested that, in cases in which individuals persistently refuse treatment and continue to live in unsafe environments, applying the harm reduction (HR) approach may be most beneficial. The goal of the HR approach is to decrease adverse outcomes associated with high-risk behaviors without necessitating individuals stop their behavior.

Implications for nursing practice

Although treatment approaches vary, it appears that there is consistency in regards to the need for a multidisciplinary approach to treatment in order to eliminate individual and family burden of this challenging population. Community health nurses are often the first to identify hoarding cases. In addition, nurses represent the largest components of the health care work force and, as such, have significant opportunities to create environments to that ensure good and safety health.³⁹⁻⁴¹ Seeing clients in their homes allows community health nurses the opportunity to identify hoarding cases,

conduct an initial health and safety assessment, and link hoarders to treatment and resources (e.g., adult and child health and social services, fire and police departments, local services).³⁴ Treatment may be affected by the accuracy of the community nurse's understanding of this complex disorder. Recognizing the various biological, psychological, and environmental aspects of hoarding disorder will help nurses better understand how and why people hoard. The behaviors of hoarders are manifestations of an illness, rather than personality flaws or malicious behaviors.³ With the appropriate educational background, nurses contribute directly and decisively to detect hoarding cases, prevent and reduce harm to these patients, educate their clients about available treatment and resources and promote understanding within the community. Knowledge allows nurses to develop interventions aimed at controlling or reducing the adverse effects of the disease. A deeper understanding of the nature and clinical and therapeutic characteristics are essential for the effective planning of nursing actions for these clients. Educating individual hoarders, family and community members, and other health care professionals will be needed as the effects of hoarding often extend outside the home. An important goal of comprehensive hoarding disease management should be to sensitize all health care professionals involved to the need and the means to detect and treat this chronic and disabling mental disorder because of its devastating effects on individuals, family members, communities and public health in terms of poor physical

health, occupational impairment, and health care service involvement.

Conclusion

A review of the literature indicates that compulsive hoarding is a growing environmental and social concern. Associated with increased risk of injury due to the severe clutter and unsanitary conditions, risk of homelessness, social isolation and disorganization, compulsive hoarding can be a serious public health hazard that poses significant health and safety risks for all members involved. Because people who hoard are characterized by limited insight of the severity and impairment caused by hoarding behavior, as well as disorganization, indecisiveness and avoidance, they are often resistant to outside help. As trusted professionals, nurses may be the first and only outsiders that hoarders allow into their homes. The detection and treatment of their psychological, as well as their social and physical needs would improve quality of life and well-being of these patients and their families. The deeper knowledge regarding the true nature of this disorder, the many factors that contribute to the complexity of compulsive hoarding, and the existing resources available within one's community could be beneficial for a better care planning and for the development of an appropriate strategy for a high-quality care provided from the multidisciplinary health team working with compulsive hoarders. Despite the increased research on compulsive hoarding in recent years, several avenues still require exploration.

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Table 1 Diagnostic criteria for Hoarding Disorder in DSM-5.

Criterion	Content
A	Persistent difficulty discarding or parting with personal possessions, regardless of their actual value
B	The difficulty is due to strong urges to save items and/or distress associated with discarding.
C	The symptoms result in the accumulation of a large number of possessions that fill up and clutter active living areas of the home or workplace to the extent that their intended use is no longer possible. If all living space is uncluttered, it is only because of the interventions of third parties (e.g. family members, cleaners, authorities).
D	The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning (including maintaining a safe environment for self and others).
E	The hoarding symptoms are not due to a general medical condition (e.g. brain injury, cerebrovascular disease)
F	The hoarding symptoms are not restricted to the symptoms of another mental disorder (e.g. hoarding due to obsessions in Obsessive Compulsive Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder, food storing in Prader–Willi Syndrome)

Specifier	Content
Acquisition	Specify if with excessive acquisition: If symptoms are accompanied by excessive collecting, or buying, or stealing of items that are not needed or for which there is no available space
Insight	Specify whether hoarding beliefs and behaviors are currently characterized by: Good or fair insight: Recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic. Poor insight: Mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary. Absent insight (delusional): Completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.