

The high cost of

hoard



hoarding disorder

By Kathryn Murphy, DNSc, NP

The popular reality TV show *Hoarding: Buried Alive* has brought hoarding disorder and its effects to the public's attention. Compulsive hoarding is a pattern of thoughts (obsessions) about the perceived danger of discarding items and repetitive behaviors (compulsions) of collecting things. One in 20 people experience compulsive hoarding, with severity ranging from mild to life-threatening.¹ According to the American Psychiatric Association, the onset of symptoms is usually between ages 11 and 15, becoming problematic in the individual's 20s, and progressively increasing in severity with advancing age. With the U.S. population of people age 65 or older expected to increase to 36% by 2020, compulsive hoarding is an important issue facing communities today. The nurse is central in both identifying and treating problems associated with hoarding disorder.

Hoarding disorder defined

The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (DSM-5)* includes a new diagnostic category for hoarding disorder.² In the past,

hoarding behaviors were included in the obsessive-compulsive disorder (OCD) category, but research has demonstrated that hoarding is a distinct disorder that requires distinct treatment. By creating a separate diagnosis, the hope is that more research and development into specific treatment of hoarding behaviors will occur.

The *DSM-5* diagnostic criteria for hoarding disorder start with persistent difficulties discarding or parting with possessions, regardless of their value. These behaviors result in an accumulation of possessions that clutter the active living areas of the home, workplace, yard, or vehicles, preventing normal use of the space. Other diagnostic criteria include:

- severe distress that occurs when any attempt is made to throw away items
- indecision about what to keep or discard
- suspicions of other people touching the items
- obsessive thoughts of running out of an item or needing it in the future
- checking the trash for accidentally discarded items
- functional impairment, such as loss of living space, social isolation, dysfunctional relationships,

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financial problems, and health hazards.

In addition, for a diagnosis of hoarding disorder, these symptoms can't be attributed to any medical condition, such as brain injury, or another mental illness, such as OCD or delusions from psychosis. (See *Table 1*.)

What causes these behaviors?

Brain imaging of individuals with hoarding disorder shows a pattern of changes. These individuals have less activity in the cingulate gyrus—the part of the brain that communicates with the limbic, or emotional, center and the neocortex, or thinking center.³ If activity is reduced in the neocortex, a person can have difficulty with attention, problem solving, and decision making. And when the communication between the neocortex and limbic system is compromised, more emotional meaning is assigned to stimuli. This means that an individual with hoarding disorder can have trouble with both the emotional and cognitive aspects of stimuli.

Other studies have looked at the neuropsychological testing of compulsive hoarders who didn't exhibit any criteria for OCD. These studies also found brain hypoactivity, with

slow decision making and difficulty with attention and spatial tasks, contributing to difficulty staying focused, organizing, and developing strategies for categorizing and sorting that are necessary for decreasing accumulation.⁴ Making decisions about items, sorting them, and discarding them becomes unpleasant and insurmountable for the individual with hoarding disorder.

What drives the behavior of people with hoarding disorder? The behavior of an individual with OCD is driven by reducing anxiety. However, the behaviors of the compulsive hoarder are driven by intrusive thoughts about not having an item that may be deemed valuable and not being able to discard items.⁴ Individuals with OCD are aware of the irrationality of their thoughts or behaviors, but individuals with hoarding disorder lack this insight and don't see their behaviors as a problem.

Facing the consequences

Hoarding disorder causes social and economic burdens on the community, as well as environmental hazards and health risks. There's a high rate of divorce in compulsive hoarders; family members may

experience frustration at and anxiety about their loved one's hoarding. People with this disorder miss more days of work and use mental health services five times more than the general population. In addition, individuals with hoarding disorder also demonstrate increased medical comorbidities, such as stroke, gastric ulcers, diabetes, and heart disease.⁵ Compulsive hoarders often fail to seek medical care because of embarrassment about or denial of the disorder.

Hoarding is a public health issue. Compulsive hoarding can lead to health and safety risks to the individual, family, and neighbors, creating a large cost for the community. In one study in Massachusetts, 42% of hoarders had blocked access to their refrigerator, stove, and bathroom, causing filthy or unsafe living conditions. Often, feces and urine were found in containers on the bed or in the house; dead animals were also found.⁶

People with hoarding disorder have clutter throughout their homes, with small, navigable trails or areas no longer navigable. Excessively cluttered bathrooms, kitchens, and bedrooms cause sanitation, hygiene, and food preparation problems. The weight of the items may also lead to structural damage to the house that can result in collapse. Large amounts of clutter also pose a fire hazard risk, especially when outlets are blocked or electrical appliances are being used with things piled on or in them.⁷ If there was a fire, the house of a compulsive hoarder would be difficult to leave in an emergency and difficult for firefighters to get in quickly.

Health risks may include injuries from falls or objects falling from piles and infestations of fleas, rats, mice, or bedbugs. The cluttered

Table 1: OCD or hoarding disorder?

	OCD	Hoarding disorder
Are obsessions present?	Yes	Yes, fear of losing something deemed valuable
Are compulsions present?	Yes	Yes
Is behavior motivated by anxiety?	Yes	No
Do medications work?	Yes	Not as well as with OCD
Does the patient understand that the behaviors aren't rational?	Yes	No

condition makes it difficult for extermination to occur, and a single heat treatment to remove bedbugs can cost up to \$1,000. Dust, mildew, and high ammonia levels from waste products can increase respiratory problems. The risk of parasites and food-related illness is also increased.

Individuals with hoarding disorder often spend most of their money on buying items, causing problems in meeting financial obligations such as rent, heat, and food. With the cluttered environment making it hard to cook in the kitchen, the added expense of take-out food can also limit the money available for other bills. People with hoarding disorder also have increased legal problems. They risk eviction or their homes being condemned for public safety reasons. Children may be removed from the home, and the individual with hoarding disorder may be charged with child neglect. People who hoard animals may be charged with animal cruelty, which is a felony charge in some states.

Community and family interventions

Some of the challenges in treating individuals with hoarding disorder include lack of resources, lack of counselors, and lack of identification and reporting. Now that hoarding disorder is included in the *DSM-5*, services for treatment can be billed independently. This includes any mental health services or exposure therapy that's performed by a community nurse. If the patient is over age 60, heavy chore services may be available. It's also possible for individuals with hoarding disorder to support each other in the home and with work.

There's no cure for hoarding disorder, but the nurse can help the

patient develop healthier behaviors and realize a better quality of life. Nurses can screen for compulsive hoarding behaviors and make referrals to community and mental health services. In fact, the Hoarding Rating Scale (HRS) and Clutter Image Rating Scale (CIRS) are screening tools that can be used to identify people at risk for this

Consistency is important, so the nurse establishes regularly scheduled meetings of about 1 to 2 hours duration. The nurse must clarify that his or her role is to help reach the goals set in the service agreement, not to be the person doing the heavy chores of cleaning up. If homemaking services, heavy chore services, supportive housing

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disorder. The HRS uses verbal cues, whereas the CIRS uses pictures to help screen for hoarding behaviors.⁸

Community interventions start at a referral meeting. Over the phone, the nurse gathers as much information as possible about the problem, the individual involved, and the condition of the home from the person making the referral. Next, the nurse schedules a meeting either in the individual's home or, for comfort level, at a neutral location. It's during this meeting that the nurse starts to build rapport with the hoarder; this relationship will be a long one and proceeding at the individual's own pace is important for successful outcomes. After the problem has been identified and the severity assessed, the nurse and the individual develop a service plan agreement that identifies the overall goal to maintain safety in the home. By making the service plan a formal agreement that both parties sign, it demonstrates commitment to the plan.

assistance, or mental health treatment is needed, the nurse can help the patient arrange for these services.

The nurse should review the safety of all people living in the household and the safety of the structure. The nurse can gain the insight of the compulsive hoarder regarding his or her disorder, his or her capacity both financially and emotionally to address the problems, and resources available for cleaning services or healthcare needs.

The nurse starts the actual exposure work, with the patient decluttering and dealing with emotions that arise during the tasks. A mental health professional may be part of the visits to better address the intrapsychic motives and reasons for the disorder and to avoid escalation in the patient.

Mental health professionals may use family intervention, medications, and cognitive behavioral therapy to treat hoarding disorder.

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When a family is interested in an intervention for their loved one's hoarding behaviors, they first meet with a therapist to learn about the disorder and treatment options. The family members must be cohesive and agreeable to the intervention because the individual who hoards can't be helped if the family fears the consequences of the intervention. Sometimes, the therapist will have the family stage a practice intervention before it actually occurs.

Next, the family members arrange to talk as a unit to their loved one about the effect of the clutter on their lives and what help is available. Each of the family members explains in a nonjudgmental way why he or she is concerned. It's a critical element for all family members to communicate clearly that the treatment is mandatory. The hope is that when the individual with hoarding disorder faces a cohesive group of people who are concerned for him or her, it will be hard to hide and minimize the problem. The intervention is just the first step; both the hoarder and his or her family members must commit to ongoing therapy to address the issues that surround the behaviors and learn how to handle future issues that may arise during the process.

Therapy and medications

Considered a first-line treatment, cognitive behavioral therapy is effective in treating hoarding disorder. In this therapy, the goal is to change a person's automatic thoughts that occur spontaneously and lead to dysfunctional thinking. According to this type of therapy, psychological pain stems from what the person thinks an event means rather than what actually happens. In hoarding disorder, cognitive behavioral therapy focuses on excessive acquisition, difficulty discarding possessions, disorganization, and clutter.

The therapist can first help the patient identify his or her beliefs and attachments to an item. Then an exploration into the feelings about getting rid of possessions occurs. Finally, a strategy for organization and decision making about removal of the clutter is taught. After treatment begins, the change is slow, with relapse twice as high due to the difficulty that the compulsive hoarder may have in understanding or accepting the disorder. Because the belongings are often viewed as an extension of the individual, many patients will resist the change or procrastinate.

Group treatment can be an important part of recovery for the compulsive hoarder. Shame

and isolation can be decreased by participating in group therapy. By listening to each other's stories, group members can increase motivation and instill hope. The Internet can be another helpful resource in supporting interventions for compulsive hoarders. (See *Table 2*.) Virtual self-help groups provide hope and advice for dealing with clutter or shame. Web-based cameras can allow family members who live far away to monitor a relapse into hoarding behaviors. Also, virtual face-to-face therapy can be done through sites such as Skype.

Selective serotonin reuptake inhibitors (SSRIs) are effective in treating the symptoms of OCD. However, these medications aren't as effective in treating people with hoarding disorder. Yet, the individual with hoarding disorder may have coexisting anxiety disorder or depression that can benefit from treatment with SSRI medications. Also, treatment of depression and anxiety can increase the success of engaging the compulsive hoarder in treatment for the disorder. Tricyclic antidepressants (TCAs) may also be prescribed to help with anxiety or depression. (See *Table 3*.)

As with any psychiatric medication, it's important for the nurse to thoroughly explain the actions and adverse reactions in appropriate language to the patient and family. Awareness of cultural differences is also valuable when initiating psychotropic treatment. In the assessment history, the nurse should determine any genetic or dietary influences on metabolism related to the patient's particular culture. If English isn't the patient's primary language, the nurse must take steps to ensure that the patient understands when obtaining consent. Enlisting the support of translators is advantageous,

Table 2: Online resources

- **American Psychiatric Association:** <http://www.psychiatry.org/hoarding-disorder>
- **Anxiety and Depression Association of America:** <http://www.adaa.org/understanding-anxiety/obsessive-compulsive-disorder-ocd/hoarding-basics>
- **Columbia University Medical Center:** <http://www.columbiapsychiatry.org/hoarding/>
- **International OCD Foundation:** <http://www.ocfoundation.org/hoarding/>
- **Mayo Clinic:** <http://www.mayoclinic.com/health/hoarding/DS00966>
- **University of California, San Diego:** http://psychiatry.ucsd.edu/OCD_hoarding.html

with joint signing of the consent form by the practitioner and translator. These extra steps aid in compliance.

The nurse's role

Nurses are key in the identification of patients with hoarding disorder. (See *Table 4*.) When a person seeks treatment for a medical problem, the nurse can listen to the patient's and family's concern about the living environment. The nurse can observe if the patient is collecting things during his or her hospital stay, such as medicine cups, silverware, or trays. Does the patient have trouble throwing out items while hospitalized? Part of the nursing assessment can include questions about collections that the patient may have, any difficulty he or she has discarding items from the collection, trouble organizing the collection, or hard feelings when someone else touches items from the collection. Nurses can talk to family members to get an additional view on the behaviors.

To be successful, the nurse needs to build trust with a caring attitude and nonjudgmental approach that demonstrates respect for the patient. The nurse should encourage the patient to talk about the effects of the hoarding behaviors. To provide this open communication, the nurse must first examine his or her own feelings about compulsive hoarding. Empathy with the patient involves trying to understand the attachment that he or she has to the belongings. Instead of confronting the patient with hoarding behaviors, the nurse can help him or her identify the feelings attached to the behaviors and the reasons why giving them up can be hard.

The nurse can discuss the consequences of the hoarding behaviors, such as eviction, loss of valuable relationships, and safety hazards.

Table 3: Medications used to treat hoarding disorder

Class	Medications	Adverse reactions
SSRIs	<ul style="list-style-type: none"> • Escitalopram • Fluoxetine • Paroxetine • Sertraline 	<ul style="list-style-type: none"> • General: sexual dysfunction, gastrointestinal upset, sedation, and restlessness • Discontinuation problems: nausea, headache, dizziness, and flu-like symptoms • Serotonin syndrome: confusion, hallucinations, agitation, BP changes, nausea/vomiting, and seizures
TCAs	<ul style="list-style-type: none"> • Amitriptyline • Imipramine • Nortriptyline • Desipramine • Clomipramine 	<ul style="list-style-type: none"> • Dry mouth and eyes • Constipation • Weight gain • Sedation • Cardiac dysrhythmias

Table 4: Nursing interventions

- Build trust with the patient and be nonjudgmental.
- Assess the patient's hoarding behaviors.
- Instruct the patient about stress reduction techniques.
- Teach the patient about the possible consequences or risks of hoarding behaviors.
- Help the patient set small, realistic goals to remove clutter.
- Educate the patient's family members about hoarding disorder and to expect slow change and possible relapse.

He or she can talk about the benefits of changing the behaviors, such as reuniting with loved ones and increased living space. The nurse can help the patient identify ways that he or she can improve home safety, such as removing clutter from hallways, stoves, and heat sources. Because discussion about hoarding behaviors may cause anxiety, teaching the patient relaxation techniques can be valuable.

It's important for the nurse to engage in adequate self-care because working with this disorder can be difficult. Nurses should practice safety in the patient's home

by bringing a cellphone and alerting others where and when their visits will be. Nurses can use a fanny pack for supplies to avoid needing to put them down in the environment. After the visit, nurses should change clothing and wash the clothes worn in the patient's home to decrease the risk of infestation in their own homes. It's beneficial for nurses to have plastic bags for their shoes and wet wipes when they visit the patient's home. Fire prevention services, the board of health, or building inspection services should be included to assist if the home is deemed unsafe. It's

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also important to teach both the patient and his or her family about any safety hazards that are present. Creating a support group of other professionals treating this population so that feelings of frustration can be shared may be beneficial.

After the patient with hoarding disorder is in treatment, it's important for the nurse to continue to encourage and coach behaviors toward health. Recognizing the patient's need for control and emotional attachment to the items is paramount. Also, because the hoarding behaviors developed and grew over time, so will the progress to health. Nurses must recognize that the patient's progress will be slow and keep hope alive if he or she relapses.

A difficult diagnosis

Compulsive hoarding is a difficult disorder with complicated nursing

care involving different agencies and care teams. Hoarding disorder may also elicit emotional responses in nurses. It's important for nurse managers in a variety of settings to understand this disorder and its safety consequences to better assist their staff members. Because hoarding disorder not only affects the patient but also the community, the nurse manager is in a prime position to plan for the needs of both. **NM**

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