Helping Patients with Compulsive Hoarding

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Abstract

- **Objective:** To review the application of cognitive behavioral therapy (CBT) for the treatment of compulsive hoarding.
- **Methods:** Presentation of treatment model with a case example.
- **Results:** Compulsive hoarding is a serious and disabling condition that increases in severity with age. CBT for compulsive hoarding includes components of motivational interviewing, problem solving, organizational skill building, cognitive restructuring, and exposure to discarding and acquiring. Through repeated exposures to discarding and acquiring, habitation occurs and urges to save and obtain items decrease. Directions for future research include combining medication and behaviorally focused or enhanced treatments for compulsive hoarding.
- **Conclusion:** CBT for compulsive hoarding may be useful. Patients will need to continue utilizing the skills learned in treatment for the rest of their lives.

Compulsive hoarding is a serious and disabling condition that increases in severity with age. Frost and Hartl [1] originally characterized hoarding as the acquisition of and inability to discard items even though they appear (to others) to have no value. Hoarding was later described as “compulsive hoarding syndrome” when hoarding and saving is the patient’s most prominent and distressing symptom dimension along with other associated symptoms such as indecisiveness, perfectionism, procrastination, difficulty organizing tasks, and avoidance [2–5]. Compulsive hoarding is driven by obsessional fears of losing important items that the patient believes might be needed at a later time as well as extreme emotional attachments to possessions. Recently, the DSM-V work group, refining the criteria put forth by Frost and Hartl, proposed the following criteria for compulsive hoarding [6]:

1. Persistent difficulty discarding or parting with personal possessions, even those of useless or limited value, due to strong urges to save items, distress, and/or indecision associated with discarding
2. Symptoms result in accumulation of a large number of possessions that fill up and clutter active living areas of the home, workplace or other surroundings and prevent normal use of space
3. Symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

Compulsive hoarding is associated with considerable disability across a broad array of domains including social, family, and occupational functioning. Greater severity of hoarding predicts more significant work impairment, and 38% of hoarders report annual incomes below the U.S. poverty line [7]. The degree of work impairment associated with hoarding may be greater than that associated with other disorders, including other anxiety, mood, and substance abuse disorders [2,7]. Compulsive hoarding is also associated with a broad range of severe and chronic medical conditions as well as higher rates of mental health care utilization. Severe cases of compulsive hoarding can lead to eviction or the removal of child or elder family members from the home. Compulsive hoarding in older adults may have dangerous additional consequences including increased fall risk, fire hazard, food contamination, social isolation, and medication mismanagement [8,9]. Victimization rates are also higher in patients with hoarding compared with obsessive-compulsive disorder (OCD) patients [10]. Altogether, compulsive hoarding is a large public health burden contributing to significant work impairment, poor physical health, and involvement of social services [7].

Clinically significant compulsive hoarding is not uncommon, with prevalence estimates ranging from 3% to 5% [11–13]. Hoarding and saving behaviors have been observed in several neuropsychiatric disorders, including schizophrenia, dementia, autism, and mental retardation, but the disorder is most commonly linked to OCD [5]. Several lines of evidence suggest, however, that compulsive hoarding is clinically distinct from OCD [2–4,14–17].

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In age-of-onset studies, hoarding symptoms were initially found in childhood or adolescence [3,18–21]. The course of compulsive hoarding tends to be progressive, with severe levels of hoarding starting in the mid-thirties, and increasing symptom severity and prevalence with age [13,19]. In a sample of elderly hoarders, all of the subjects reported increasing hoarding severity with each decade of life with no reports of late-onset hoarding [19]. Marx and colleagues [22] found 25% of elderly community residents and 15% of nursing home residents report clinically significant symptoms of compulsive hoarding. Unfortunately, there is a chronic nature to this disorder with no studies reporting spontaneous remission or improvement without treatment.

**CASE STUDY**

**Initial Presentation**

Joe, age 60, presents to treatment after seeing a research study flyer at his local library. Over the course of the enrollment interview, it becomes apparent that Joe has struggled with compulsive hoarding symptoms since childhood. This is the first time Joe has sought treatment for compulsive hoarding.

**History**

Joe reports that as a child he would keep excessive possessions in his room and throughout several areas of his home. He kept these items in the event that he may need them later. Joe's mother also had a habit of acquiring free items and had filled their garage with possessions. Joe noted a pattern of finding free items and keeping them throughout his young adult life. When he was 24, Joe married Betty and subsequently had 2 children. Joe worked as a mechanic and Betty as a secretary. Joe prided himself on reusing parts in his auto shop. Betty often complained about Joe's “mess” and need to pick up free items. They often resolved this by Joe keeping all of his “stuff” in the garage and Betty was free to keep the house in order. When Betty was 45, she was diagnosed with breast cancer and died 1 year later. After her death, Joe spent most of his time in his home and the rooms slowly started to fill with items. Now, the home is in great disrepair. Approximately 85% of his 4-bedroom home is filled with clutter. Joe pays rent for 1 large storage unit which is also filled. The clutter has greatly impaired his activities of daily living and instrumental activities of daily living. Due to clutter, Joe is unable to prepare food, use his stove, eat at a table, and sleep in his bed. He currently sleeps in his living room as his bedrooms are unusable. Additionally, Joe has great difficulty using his sink and finding important papers. Joe acknowledges that medical personnel would have severe difficulty coming into his home if necessary. Joe's acquisitions surround a theme of informational gathering. He currently collects paper and newspapers. He also spends a significant amount of time (> 3 hrs per day) video and audio taping informational shows. Joe has obsessional thoughts related to the need to know and to keep information in the event he may need it someday. He reports anxiety about the amount of money he spends per month on video/audio equipment and his storage unit as he is on a limited, fixed income.

• What aspects are important to cover in the clinical evaluation of the patient with compulsive hoarding symptoms?

**Clinical Assessment**

During the initial interview, it is critical to maintain a non-judgmental stance, as in many cases of compulsive hoarding, this may be the first time the patient has sought treatment. Symptom severity is best assessed through combining information gathered at the clinical interview, home visit, family or caregiver reports, and self-report instruments. The clinician should directly ask about the intensity of urges to save and difficulty discarding. Gathering information on the amount and type of clutter in each area of the home as well as outside storage units will be useful for deciding where to start the discarding work. It is also necessary to examine the patient’s beliefs about possessions as these will be challenged using cognitive restructuring throughout the treatment process. Often, hoarding-related beliefs about the importance of possessions are related to sentimental attachments, utility/usefulness, or intrinsic beauty. Further, it is essential to understand the frequency and amount of acquisitions. The “incoming flood” must be stopped before patients are able to make gains in discarding possessions.

A careful evaluation of motivation for treatment and insight into the problem will also be useful as these are directly related to treatment outcome. Inquiring how the clutter has impacted other life domains, such as financial, legal, work or family relationships will assist with developing motivation for treatment as well as treatment planning. Finally, a health hazards and risk assessment is necessary, particularly when working with older adults due to potential limitations in physical abilities.

A variety of measures have been used to assess the severity of compulsive hoarding. Hoarding-specific questionnaires include the Hoarding Rating Scale (HRS) [23], a 5-item questionnaire that can be used as a screening tool to determine if further evaluation is warranted. The Savings Inventory-Revised (SI-R) [24] is a 23-item self-report measure that has demonstrated decent reliability and validity and assesses hoarding severity. Subtests of the SI-R include excessive clutter, excessive acquisition, and ability to discard. The UCLA Hoarding Severity Scale (UHSS) [25] is a 10-item,
Clinician: Tell me about some of the reasons you save.
Joe: If I can find a use for it or if it has some good information, then why throw it out?
Clinician: So if you can find a use for it, then you believe there is no reason to throw it out. What kinds of items are you saving?
Joe: I have a lot of auto parts — basically from my old job as a mechanic and auto shop owner. I tend to keep papers too. I tape a lot of talk radio so I have lots of tapes in my home.
Clinician: How much are you accumulating per week?
Joe: The biggest thing is the tapes. I tape for hours every day so I need to go buy a 50 pack of tapes at least once a week. The auto parts come to me from old friends — they will just drop things off at my door. The papers just tend to pile up.

Clinician: What are effective interventions for compulsive hoarding?

Interventions
Interventions that are effective for OCD have been shown to be less effective among OCD patients who also have compulsive hoarding symptoms. Studies of medication treatments for patients with OCD have consistently found poorer responses in patients with compulsive hoarding symptoms [33–35]. An exception is a study by Saxena and colleagues [25] who found no differences between OCD patients with and without compulsive hoarding symptoms in response to paroxetine. Cognitive behavioral therapy (CBT) for OCD, consisting mainly of exposure with response prevention techniques, has also been less effective among OCD patients with compulsive hoarding symptoms [33,36,37], and OCD patients who endorse high levels of compulsive hoarding symptoms are more likely to dropout prematurely from CBT [37]. A multimodal treatment intervention that includes...
Psychosocial rehabilitation, CBT, and medication led to significant symptom improvements in hoarding OCD patients, though their improvement was comparatively less than that among non-hoarding OCD patients [4].

Recent studies utilizing a CBT protocol specifically developed for hoarding have provided some promising results [38,39]. Such protocols are based on a cognitive behavioral model of hoarding that holds that (1) information processing deficits, (2) maladaptive beliefs about, and emotional attachment to, possessions, and (3) emotional distress and avoidance contribute to the excessive acquisition, difficulty discarding, and clutter that characterize compulsive hoarding disorder [40]. The treatment consists of multiple components including motivational interviewing to increase insight and motivation to change, problem solving, decision making and organizational skill building to target cognitive processes, cognitive restructuring techniques to address maladaptive beliefs about possessions, and exposure to target negative emotions associated with discarding and resisting acquiring. The treatment includes home visits and the duration of treatment may vary from 6 to 12 months. In a small open-label trial of specialized CBT for hoarding, 50% of treatment completers were rated as “much improved” or “very much improved” on the Clinician Global Impression (CGI) scale at post-treatment [38]. Other symptom severity ratings were not as strong (28% and 31% improvement on the SI-R and CIR, respectively). In a controlled trial of 36 hoarders, participants demonstrated a 27% decrease on self-reported hoarding severity and 26% improvement on the CGI [39]. These studies provide some initial support for the efficacy of this specialized CBT for hoarding, at least in middle-aged samples (mean participant ages were 45 and 54, respectively). However, it should be noted that treatment gains would not be considered clinically significant according to OCD improvement criteria (35% improvement; [41,42]). A recent investigation using the same CBT protocol found less support for it efficacy in a geriatric sample (all over age 65), with only 25% of completers considered responders post-treatment (Ayers et al, unpublished data). The authors concluded that treatment of compulsive hoarding in older adults may be enhanced by focusing on behavioral (namely, exposure) techniques and incorporating techniques to foster cognitive rehabilitation.

- What are components of the CBT treatment?

Psychoeducation is a critical component to the initial session. This is followed by some brief motivational interviewing to get a sense of and foster internal motivation. Clinicians should be aware that for some patients, it may not be the right time for treatment. If the patient is not internally motivated to work on their hoarding symptoms or there are current life stressors, this could hinder the treatment process. Asking the patient to identify the costs and benefits as well as their reasons for initiating treatment is important.

Particular cognitive rehabilitation strategies aimed at remediating executive functioning weaknesses include modules that target problem solving, prospective memory, and cognitive flexibility. Starting with cognitive remediation will “prime” participants to better utilize hoarding-specific intervention skills and increase homework compliance. Concrete and practical assignments for daily scheduling, setting priorities, problem solving, and time management are critical for many hoarding patients.

Ample time must be devoted to treatment rationale for exposure therapy. The basic premise of exposure therapy is universal to the treatment of all anxiety disorders—through repeated exposure, a patient will habituate to the anxiety-provoking trigger. A hierarchy should be established for the patient’s living space such that rooms are ranked from least to most difficult. Difficulty is based on subjective patient reports; however, usually rooms are ranked according to volume of clutter and distress associated with possessions in the room.

Typically, treatment would start with limit setting on incoming clutter and the exposure treatment would be focused on discarding. In a small number of cases where there is extreme acquisition behavior, the exposure targets acquisitions first then moves to discarding. Patients are instructed to take a small box from a predetermined sorting path and systemically proceed around that living space. Rules are established for the sorting exercises, which typically include the therapist not being allowed to touch or make choices about items, the items must be put away or discarded immediately after the exercise is complete, and once a choice to discard has been made, the patient cannot change his mind. It is helpful to write out these mutually agreed-upon rules and post them in an obvious location. Decisions about how items will be discarded (eg, recycled, discarded) are made before initiating the exposure to discarding exercises. Exposures begin by asking the patient to rate his level of distress on a scale from 0 to 10, 10 being the highest level of distress. The ratings are also known as “SUDs” (subjective units of distress). Then the patient will pick up an item in the box and decide whether to keep or discard the item. Each decision is made quickly and patients cannot change their mind about their discard decisions. Additionally, patients are asked to verbalize their decision making process for later review and thought challenging exercises. Exposure work makes up the majority of therapy time, approximately 75%. In younger adults, exposure is paired with more cognitive therapy techniques to challenge beliefs about possessions [41]. Unfortunately, we believe cognitive therapy techniques

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have limited utility with older adults [42 and Ayers et al, unpublished data].

Treatment

Joe needed to prevent the incoming clutter by setting some limits on his taping. He agreed that the goal would be to tape 2 shows per night with an ultimate goal of not taping by the third week. He developed a hierarchy of rooms for his discarding exposures listing the kitchen as the easiest room to start followed by the hallway, living room, front bedroom, back bedroom, bathroom, office, and storage unit. He decided he would start in the kitchen to the immediate right by the entrance way and proceed systemically around the room until it was complete. Given that it was unlikely he could donate much of the items, he decided he would only have 2 choices—keep or discard. He made himself a small area to sort in the kitchen for his at home practice. He then brought in a small box to the office to sort. He initially reported high SUDs ratings when starting the exposure but there was a drastic decrease between sorting sessions. He built momentum and was quickly able to proceed around the kitchen over the course of 15 sessions. His next area proved to be more difficult as it contained tapes that he believed he might need in the future. Joe noted difficulty grasping traditional cognitive therapy techniques. He was able to challenge himself by selecting 3 questions to ask every time he was leaning towards keeping the tape: (1) Could I find this information somewhere else? (2) Did I know that I had this item? (3) What is the likelihood that someone else will be interested in this information in the future? While other cognitive techniques were attempted with Joe, the questions about possessions proved to be the most useful for him.

Clinician: Now let’s start with your discarding exposure. What is your SUDS now?
Joe: I’m at a 5. Ok. I really think this tape is good, there is no label on it but it looks new and it might be a good show.

Clinician: Now try a couple of those questions you picked out.
Joe: Well, could I find this information elsewhere? I don’t know what is on the tape but the answer is “yes,” probably could look it up online. Did I know I had this item? The answer is “no” because I don’t even know what it is. Ok, I think I could discard this item.

Clinician: SUDS rating?
Joe: 4. I’m doing OK with this.

Clinician: Note that you SUDs have changed a lot between exposure sessions. When we first started exposures, you tended to have SUDs ratings in the 8 to 10 range. Now you tend to start at a 5 and decrease much more quickly during the exercise. Most importantly, you can tolerate distress associated with discarding.

- What if a patient resists doing exposures or does not complete the homework?

Most patients who present to treatment are able to complete the in-session exercises with little difficulty. There are several reasons for participants not completing the at-home exposures, including poor motivation, poor insight, or skill deficits. Some patients with hoarding have little internal motivation to work on their hoarding problem—saving items and not having to throw them out helps avoid distress. When poorly motivated patients present to treatment, it is often external factors such as pressure from family members, code enforcement violations, or an impending event where people will need to be brought into the home. It is critical to spend time at the beginning of treatment for the patient to develop motivation if it is not already present through motivational interviewing. Thus, clinicians who work with compulsive hoarding patients should be adequately trained in motivational interviewing. Insight is another factor that can be problematic for treatment adherence. Realistically, those with poor insight will not independently seek treatment. If they seek treatment, it is again likely due to an external pressure. Spending more time on psychoeducation, reality testing, and motivational interviewing may be helpful in these cases. If a participant does not show gains in treatment compliance, it may not be the best time for psychotherapy.

Often problems in completing exposure practice reflect executive functioning deficits rather than lack of motivation or insight. Patients with hoarding have difficulty with abstract reasoning, planning, problem solving, and cognitive flexibility, which may impact their ability to translate in-office techniques to the home environment. It may be beneficial to have the patient participate in cognitive remediation to improve these deficits before starting exposure treatment. Cognitive rehabilitation techniques can assist with homework compliance. For example, behaviors the patient engages in consistently can be paired with the completion homework (eg, a favorite TV show or taking medication could be paired with discarding exposures). Another strategy that has proven useful is “can’t miss reminders” where patients leave something out or put up a sign that will assist them in remembering to complete their task.

- What role does family play in treatment?

Often patients with hoarding are socially isolated and may have little contact with their family. People with hoarding are
often embarrassed by their clutter, which limits friendships, or have become estranged from their family due to conflict over their clutter. If family is available, the relationship may be strained. On the other hand, some families enable the person with hoarding by giving the patient items. Family members may also keep the place livable so that the person with hoarding does not suffer all the consequences of the disorder. In either case, bringing family members in at the beginning of treatment is helpful.

There are several ways family members can be incorporated into treatment. Psychoeducation is critical as many family members believe that the hoarder was “doing it on purpose” or it is controllable. If family members are enabling by purchasing possessions or colluding with avoidance on the part of the hoarder, education about family accommodations for hoarding is necessary. Setting parameters about accepted and expected behaviors in the home can be useful and help to keep the person on track. Sometimes family members may act as coaches or support people while the patient is completing exposure exercises sorting; however, this may not be advisable if there is family tension surrounding the hoarding. The best way for family members to be involved—whether it is to help move large items or to simply praise the person for their hard work—varies depending on the family. The family member may also need individual therapy to examine how their behaviors are contributing to the problem.

In Joe’s case, his family is not available for in-person treatment. His relationship with his children is strained due to the clutter. A conference call was arranged involving the family to review psychoeducation on compulsive hoarding. Joe’s daughter was accepting of this and appreciated the call. She was given further resources for additional reading and support. In the end, she valued the open discussion about her father’s hoarding as she felt it was not adequately addressed over the years. Another unanticipated outcome included an invitation by Joe to his daughter to visit once he had made progress.

It is possible to treat patients without home visits, but home visits have been found to be useful for both clinicians and patients. It allows a clinician to view the severity of hoarding, health risks, and safety hazards. These visits also provide an opportunity for the clinician to show a patient how to collect a box of items to bring into session, plan a starting place in a chosen room, and develop a hierarchy. Most importantly it provides an opportunity for the patient to transfer techniques learned in the office to the home setting, which can be the most difficult part of therapy. Patients may experience anxiety during the first visit because they often view the therapist as potentially judging them or forcing them to throw out items. It is crucial that the therapist does not display judgment, regardless of the severity of the home, and clearly explains the purpose of the home visit.

• Are home visits a necessary part of treatment?

Physicians can ask patients simple questions when they suspect hoarding problems. These questions may include: Do you have difficulty throwing things out? and Is your home so cluttered with items that it has created problems for you? If the answer is yes to either question, the physician should know of appropriate area referrals. Several major cities across the country have hoarding task forces that provide education and referrals to the community. Further, the International OCD Foundation recently developed a hoarding center (www.ocfoundation.org/hoarding/) that contains extensive resources and information for patients, families, and health care providers.

Physicians should also be aware that the person with hoarding may have difficulty complying with complex medical regimens and may need additional structured support for compliance. There may be risks in the home that directly impact health. In the case of Joe, he had significant allergies and COPD, which were exacerbated by the condition of his home. He also struggled to organize his medications and take them properly. A nurse from his primary care office was contacted and was able to provide greater structured support of his medical regimes. Further, the least cluttered room in the house was identified for sleeping in order to decrease respiratory distress.

Further Course

In the middle of treatment, it became apparent that Joe began struggling with his at home exposures once he hit a more heavily cluttered area in his hierarchy. He would sort the items but then not remove the discarded items from his home, thus, not fully completing the exercise and resulting in several discard piles around his home. Fortunately, this was discovered upon a home visit where Joe was able to practice several “complete” exposures.

Over the course of 26 sessions, Joe reported a 30% improvement in his urges to save and difficulty discarding. He demonstrated understanding that his new sorting behaviors would become a “lifestyle” for him. He still was not completely finished with the kitchen but had visibly made
progress. Most importantly, Joe experienced significantly less distress when making choices about his possessions.

Summary

The first step to working with patients with hoarding is a careful and thorough assessment using a mixture of clinical interview and clinician-administered and self-report assessments. If possible, a home visit will assist in examining the nature and severity of hoarding in the home. The next phase in treatment includes psychoeducation and motivational interviewing. Cognitive rehabilitation of poor problem solving, planning, and prospective memory may be necessary. Exposure therapy is the bulk of the treatment, where the patient will practice making discarding choices about their possessions in a hierarchical manner. Cognitive therapy may be useful, although for a limited number of patients. Treatment expectations should be carefully laid out as patients will need to continue utilizing the skills learned in treatment for the rest of their lives.

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References


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