

What are effective interventions for hoarding?



What you need to know

- Little research exists on the efficacy of interventions specifically designed to treat hoarding disorder, but a number of approaches are demonstrating successful outcomes.
- Many jurisdictions have formed community hoarding taskforces made up of professionals from a broad range of disciplines and are showing particularly promising results.
- A form of cognitive behavioural therapy designed specifically to treat hoarding has proven effective, and adapted versions are being tested for use with specific populations, in groups, in home settings, and via the web, as well as for use with other forms of treatment.
- Approaches must take into account that many individuals who hoard are resistant to assessment and treatment.
- The complex nature of hoarding disorder calls for dynamic treatment approaches, with the precise services required being determined on a case-by-case basis.

What's the problem?

Hoarding is not a new phenomenon; however, it has only recently been classified as a distinct mental disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V, 2013). Hoarding disorder (HD) is characterized by the excessive accumulation of items and a refusal to discard these items, resulting in significant impairment.¹ Recent estimates suggest that 2% to 5% of the adult population engage in some type of hoarding behaviour,^{1,2} which can create hazardous living conditions for individuals and communities.³

With awareness of hoarding on the rise, the prevalence of self-reporting and referrals from service providers is also increasing.^{3,4} As a result, health practitioners and researchers are focusing on how to treat and remedy



the often debilitating symptoms. Attempts have been made to help individuals using various types of interventions, with varying results.

It can be challenging to isolate which interventions are most effective. For this reason, a Local Health Integration Network in Ontario reached out to EENet to identify what the research says are the most effective clinical and community-based approaches. The purpose of this evidence review is to inform the development of municipal hoarding intervention guidelines.

What did we do?

We conducted a search of academic literature in March 2016 using the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, In Process Medline, PsycINFO, and the Cochrane Database of Systematic Reviews.

For our review of evidence on clinical interventions, we included all relevant peer-reviewed systematic reviews and meta-analyses focused on hoarding or HD published in English after 2010.

Due to the limited number of publications on community interventions for hoarding, our exploration of evidence on this topic was expanded to include single studies (e.g., case examples), as well as grey literature identified via a Google search, published after 2005.

Our review excluded the following types of publications:

- Those focused on symptoms, causation, diagnosis, disease classification, or prevalence of hoarding (i.e., those not focused on intervention, treatment, or management of hoarding);
- Those not specifically focused on hoarding (e.g., studies focused more generally on obsessive compulsive behavior);
- Those exclusively focused on interventions for specific populations (e.g. children, seniors, or people with dementia);
- Those focused only on the hoarding of specific items (e.g. animals or medication).

What did we find?

Following a review of titles and abstracts, we found a total of 24 articles to be relevant; 14 on community interventions and 10 on clinical interventions. The following section outlines the findings from each of these areas of research.



Community-based Interventions

While hoarding is a complex disorder that requires dynamic interventions, the literature is clear on what a successful intervention does not look like. Evidence indicates that one-time forced removal of clutter, or “clean sweeps”, may exacerbate and perpetuate hoarding⁵ because they don’t address the underlying causes.^{4,6} However, home clean-out remains the most commonly sought form of help, especially for non-extreme cases.⁷

Although mental health treatments such as cognitive behavioural therapy are highly recommended, they are used in fewer than 20% of cases.⁷ Ultimately, the best evidence-informed approach is to use a collaborative, multi-disciplinary, community hoarding taskforce that includes mental health support.⁸ This appears to be true for all populations, including older adults and individuals who resist help.^{5,8,9}

The first hoarding taskforce was formed in Virginia in 1999, and there are now at least 85 across Canada, the United States, and Australia.¹⁰ Such multifaceted, multi-organizational approaches, designed to address the unique circumstances of each case, are considered the most promising practice for communities to deal with hoarding.^{3,5,6,8,11} In 2013, Singh and Jones suggested that almost half of hoarding interventions without community taskforce involvement had no signs of improvement and 15% resulted in worsening of hoarding. The 8% of cases that did improve slightly tended to relapse back to baseline.⁹

How effective hoarding taskforces work

The literature suggests several key steps for successful community hoarding taskforces to take when dealing with hoarding.¹² They include:¹²

- Initial referral or case consultation;
- Home visit and development of assessment goals;
- Creation of an action plan through a joint agency case conference;
- Implementation of chosen intervention(s);
- Implementation of a support system and follow-up process;
- Case closure.

Once a case of hoarding comes to light, the first step is to make an objective assessment to decide if an intervention is necessary.⁹ Once a taskforce or individual service provider has been granted access to a hoarding site, one of several tools may be used to assess the severity of the situation:²

- the Hoarding Rating Scale (HRS);



- the Clutter Image Rating Scale (CIR);
- the Saving Inventory-Revised (SIR);
- the Service Utilization Questionnaire (SUQ).

According to Chater, Shaw, and McKay the individual assessing the situation should follow four steps:²

- Ensuring one's personal safety;
- Assessing the safety of the site;
- Identifying the service goals;
- Convening a team to handle the specific case.

A critical element of the intervention is building trust between the taskforce members (especially mental health service providers) and the client.⁹ This can be done using a motivational approach that focuses on harm reduction (rather than solely symptom reduction), promoting safety, minimizing loneliness, empowering the individual, and providing education.⁸ It is also helpful to take the time to build a therapeutic alliance and use a strengths-based, incremental approach to assessment, followed by positive reinforcement for each small gain that is made. There are also potential benefits to working with peer support workers and family members, as well as using legal aid or tenancy tribunals to avoid eviction, if necessary.⁶ Better results can also be achieved by adapting the approach to the individual's specific circumstances and needs, and by intervening well before the point of crisis.²

2. Taskforce composition

Although the literature does not suggest a specific type of taskforce approach or exactly who should be on a taskforce, possibly owing to the dynamic nature of the condition, certain services or organizations should be involved.^{2,3,5,8,9} The general recommendation is that taskforce composition be based on the needs of the individual hoarder.^{3,8,9} The most notable services included in community taskforces are: fire services, environmental safety/protection, public health, housing, mental health, ambulance services, nursing, professional cleaning and organizing, social workers, psychologists, general practitioners, landlords, senior services, and animal control.^{2,3,6,8,9,11}

Typically, it is recommended that one agency be selected as the central coordinating unit or the single point of entry into the network of supports. A services roadmap is then established, along with common guidelines, protocols, and training material that all collaborating agencies can use.^{13,14} Several case studies



highlight the central role of social workers or community nurses as care coordinators, system navigators, and patient advocates.^{6,11,13}

While membership on most taskforces is voluntary, participant organizations report a positive impact, including cost savings, from collaboration. The taskforces accomplish this by meeting regularly to discuss cases and by educating members on both how to intervene and new research developments. By doing so, taskforces report being able to make an impact, despite not having formal power to create or influence policy.

Although the community taskforce is reported to be the best solution to hoarding, several barriers to taskforce implementation have been identified. These include: insufficient funding (related to lack of policies regarding hoarding or hoarding taskforces),^{3,9} the time required for non-mandated work,³ and a shortage of mental health providers with specific training.^{8,9}

3. Approaches for resistant individuals

It is estimated that half of hoarders do not recognize their hoarding behaviour as being problematic¹⁵ and many individuals with HD are unwilling to accept help. *No Room to Spare*, a report outlining Ottawa's community response to hoarding, provides three suggestions for consideration in these instances:¹³

- Initiation or continuation of ordinance (law or by-law) enforcement;
- Emergency placement under guardianship;
- Mental health assessment.

Snowden and Halliday¹² offer more detailed recommendations to address this situation. The Partnership Against Homelessness in New South Wales, Australia, published a succinct set of guidelines based on Snowden and Halliday's recommendations, illustrating different referral pathways for those who have cognitive or decision-making capacity and those who lack it.¹⁶ For those with capacity, they suggest that case managers work to persuade the individual to accept help, but if the attempt fails, an environmental risk assessment should be requested from the police, fire brigade, or animal control services.^{12,16} For individuals determined to have limited capacity, especially where not intervening could lead to high-risk outcomes, the authors suggest coordinating a medical and psychiatric assessment, followed by application for a guardian to be appointed to make decisions about health and accommodation, in partnership with the designated case manager on the taskforce. The authors also suggest appointing a financial manager to make decisions about access to property and clean-up.^{12,16}



Clinical Interventions

With regard to clinical approaches for managing hoarding, the type of intervention that has been most thoroughly researched and is considered to be most effective is cognitive behaviour therapy (CBT). However, some medication-based approaches and some novel approaches that can be used in the home or in group settings are proving to be promising practices. Each of these is explored below.

Cognitive Behavioural Therapy

Improvements have been seen both with CBT interventions for hoarding as a symptom of obsessive-compulsive disorder (OCD) and for CBT interventions designed specifically for hoarding as a distinct category in the DSM-V.¹

a) CBT for hoarding as a symptom of OCD

Exposure and Ritual Prevention (EX/RP) has been used since the 1960s to treat individuals with OCD who have hoarding symptoms.¹ About 50% of individuals with OCD who hoard do not improve with EX/RP,¹⁷ but those who do improve have significant reduction in symptoms over the short and long term.¹ However, individuals with OCD who hoard have high treatment dropout rates and poor treatment outcomes compared to people with OCD who don't hoard.¹⁰

b) CBT for hoarding disorder

Based on a protocol developed by Gail Steketee and Randy O. Frost, CBT for HD that involves exposure, cognitive restructuring, and motivational interviewing¹ is considered to be the most promising clinical approach.¹⁸ All studies of this approach show a decrease in the severity of HD symptoms,¹⁹ although the improvement is not always statistically significant and many effect sizes are modest.¹ HD-specific CBT contributes to the strongest improvement in ability to discard items, but less improvement in clutter and in the practice of acquiring items.¹⁹ Notably, better clinical outcomes have been found for women, younger people, those who have a greater number of home visits from service providers or peer support workers, and people who attend a greater number of CBT sessions.¹⁹ For children and youth with HD, case studies have shown adapted, family-based CBT to be effective, although no clinical trials have been done.¹⁰

Treatment gains are largely maintained following treatment with HD-specific CBT, but patients typically continue to experience some degree of hoarding behaviour and impairment. Scores after treatment usually remain closer to the HD range than the normal range.¹⁹ As is true with CBT for hoarding as a symptom of OCD, treatment refusal and non-compliance significantly influence outcomes and the duration of those outcomes.¹⁰ There are better outcomes when individuals participate in peer-facilitated support groups and in-home assistance from people who are not counselors.¹⁰ Group CBT also shows positive outcomes. It is slightly less effective than individual treatment, but more cost-effective.¹⁰



2. Pharmacotherapy

A large proportion of individuals with HD have responded well to medication (37-76%),²⁰ and antidepressants seem to be as effective as CBT-based treatment.¹⁵

The following medications have been effective:

- Selective serotonin reuptake inhibitors, such as paroxetine (Paxil) and sertraline (Zoloft);²⁰
- Serotonin and norepinephrine reuptake inhibitors, such as extended-release venlafaxine (Effexor XR).²⁰

More research is needed on the use of medication,²¹ as well as on the combination of medication and counseling or CBT⁵ and on the use of stimulant medications such as methylphenidate (i.e., Ritalin and other medications used for attention deficit hyperactivity disorder).^{21,22}

3. Novel Approaches

The following approaches show promise, either combined with CBT or as alternatives when CBT is not an option:

- Home-based webcam interventions;¹⁸
- Web-based CBT group intervention;¹⁸
- Book-based self-help groups;¹⁸
- Experiential, visual methods (e.g., use of photography and video to stimulate motivation to change and facilitate organization).²³

For older adults, CBT combined with cognitive rehabilitation strategies that target memory, organization, problem solving, and cognitive flexibility have been shown to double treatment response rates in comparison to CBT alone.¹⁸

What are the limitations of this review?

Only 24 studies met our inclusion criteria. The findings are limited by the parameters of our methods, including the research question and the timeframe of the search strategy. As a result, this rapid review may not present a comprehensive view of knowledge on this topic.

Although hoarding has been studied for several decades, little research exists on the efficacy of interventions to treat hoarding.¹⁵ Also, most research is limited with respect to the number of participants, ethnic and



cultural diversity, and study replication,¹⁵ with the majority of research having been conducted on highly-educated, Caucasian women.¹⁰

The research is also limited because of a lack of consistent outcome measures. Many studies use the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS), which does not specifically measure hoarding severity.¹⁵ Additionally, research has not sufficiently explored several moderators of treatment outcomes. For example, studies have not investigated how treatment of various commonly concurrent mental health conditions may impact hoarding behaviour.¹⁹

As is true in the literature on clinical interventions, much of the literature on the outcomes of community-based interventions is from qualitative case studies with anecdotal evidence rather than quantitative data.⁶ Future longitudinal studies will need to illustrate explicit action plans.

What are the conclusions?

Hoarding is recognized as a growing concern among all age groups, but particularly in older adults who choose to live independently.⁸ Increased awareness and research may bring more effective interventions to treat the disorder. Although no single treatment exists, consensus has emerged that using a community-based taskforce approach that includes the provision of mental health support and hoarding-specific CBT appears to have the most success.

Instances of hoarding must be assessed on a case-by-case basis to determine the severity of the situation, the willingness and capacity of the individual to receive help, and the composition of the taskforce or the services required to intervene successfully. The complex nature of the disorder calls for a dynamic approach to treatment, and warrants further study. Doing so will help us better understand the underlying issues of individuals who hoard and to help improve their treatment outcomes.



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