

Hoarding and Hoarding Behaviors: Definitions and Best Practices

Keith Brown, Ph.D.

Hoarding Connection of Cuyahoga County

Cuyahoga County Bed Bug Task Force

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Session Objectives

- Understand the definition of hoarding.
- Identify types of hoarding situations.
- Identify tools used to identify Hoarding levels
- Understand current best practices.

Definitions

Hoarding is a complex disorder that is made up of three connected problems:

- 1) collecting too many items
- 2) difficulty getting rid of items
- 3) problems with organization

These problems can lead to significant amounts of clutter which can severely limit the use of living spaces, pose safety and/or health risks, and result in significant distress and/or impairment in day-to-day living. (International OCD Foundation)









Hoarding Causes

Hoarding Components Frost and Hartl (1996)

- Acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value.
- Living spaces that are sufficiently cluttered so to preclude activities for which those spaces were designed.
- Significant distress or impairment in functioning caused by the hoarding.



Hoarding - Diagnosis

- DSM-IV (Fourth Edition) – diagnosed as 304.1, Obsessive Compulsive-Personality Disorder
- “Individuals with this disorder may be unable to discard worn-out or worthless objects, even when they have no sentimental value (Criterion 5).”, page 673.
- DSM-V – (May 2013)
- (Pertusa 2008), “In most individuals, compulsive hoarding appears to be a syndrome separate from OCD, which is associated with substantial levels of disability and isolation.”
- (Saxena 2008) — “Compulsive hoarding is part of a discrete clinical syndrome that includes difficulty discarding, urges to save, excessive acquisition, indecisiveness, perfectionism, procrastination, disorganization, and avoidance.”

Hoarding - Diagnosis

Contrast between OCD and Hoarding

OCD

- Symptoms are recognized, unwanted, intrusive and cause significant distress to the person.
- 83% of people with significant hoarding problems do not have OCD (Frost et al, 2006)

Hoarding

- No distress to the individual, only distress at having to give up objects.
- Biological differences (University of California 2004)

General Personality Traits of Persons Who Hoard

- Give emotional meaning to every item in their possession
- Feel safer with things than with people
- Compulsively acquire items.
- Experience intense anxiety when confronted with the need to discard items.
- Perfectionistic
- Generally disorganized and can't stay on task very long.
- Have high level of resistance to requests/demands – internal or external.





Hoarding Incidence and Prevalence

Estimates range from 2% to 4%

- San Francisco Hoarding Task Force – 2%-4%
(Annual cost estimates of \$2.01 million)
- 5% Samuels (2008)

Rates of Mental Illness in the US (NIMH)

- Anxiety Disorders – 18.1%
- Mood Disorders – 9.5%
- Bipolar Disorder – 2.6%
- Schizophrenia – 1.1%

Hoarding - Characteristics

Steketee (2001) found that elderly hoarders:

- Were female, unmarried, and lived alone
- Extensive clutter was associated with significant impairment, interfering with basic hygiene and posing a serious physical threat to the hoarder.
- Lack of insight and resistance to change led to ineffective treatment.
- Never married status was associated with more severe hoarding, greater impairment and worse outcomes.
- Few hoarding clients showed deficits in cognitive functioning, indicating that hoarding was not a function of dementia.

Hoarding - Characteristics

Ayers (2010) found that:

- Onset of hoarding symptoms was initially reported as being in mid-life but actually found to be in childhood or adolescence
- Compulsive hoarding severity increased with each decade of life.
- Comorbid mood and anxiety disorders were common, but only 16% met criteria for OCD if hoarding symptoms were not counted toward the diagnosis.
- The vast majority of clients had never received treatment for hoarding.
- Older adults with compulsive hoarding were usually socially impaired and living alone.

Hoarding - Characteristics

Terms of Note

- Anosognosia /ano-sog-no-sia/ (an-o"so-no´zhah) is a condition in which a person who suffers [disability](#) seems unaware of the existence of his or her disability. Unlike denial, which is a defense mechanism, anosognosia is rooted in physiology (for example, damage to the frontal or parietal lobe due to illness and disease). This may include unawareness of quite dramatic impairments, such as [blindness](#) or [paralysis](#). (Wikipedia, online.)
- “Syllogomania (Sylloge is Greek for “collection”) is widely regarded as one marker of self-neglect amount the elderly, along with poor personal hygiene and squalid living conditions.” Stuff, the Compulsive Hoarding and the Meaning of Things, Randy O. Frost & Gail Steketee, Houghton Mifflin Harcourt Publishing Company, 2010, page 177.

Hoarding – Animal Hoarders

Animal hoarding is more than just having a large number of animals, although numbers do need to be taken into account. The published definition of an animal hoarder (Patronek 1999) is someone who:

Accumulates a large number of animals, and

- Fails to provide minimal standards of nutrition, sanitation, and veterinary care, and
- Fails to act on the deteriorating condition of the animals (including disease, starvation and death) or the environment (severe overcrowding and extremely unsanitary conditions), and
- Fails to act on the negative effect of the collection on their own health and well-being and that of other household members.





Intervention – Best Practices

Enforced Harm Reduction Model (Orange County, CA)

Goals:

- To ensure that the property complies with community accepted standards of health, fire safety and sanitation.
- To provide respectful support to hoarders to manage their disorder
- To keep first responders and service providers safe
- To provide support to those who intervene

This model relies on a team of housing enforcement and social, health and mental health services personnel to work with the person who hoards. The goal is long term management of the situation, not house beautiful. The Cuyahoga County Hoarding Connection recommends a goal of achieving Level III or lower on the National Study Group on Chronic Disorganization (NSGCD) Clutter Hoarding Scale.

Intervention – Best Practices

Enforced Harm Reduction Depends on:

- Reasonable, clearly written housing codes and regulations that address the accumulation of debris inside a private residence
- Collaboration among a team of stakeholders who are willing and able to work outside of their “silos” to effect change with the individual who hoards and within their own systems as well.

Team Members may include:

- Housing safety inspectors who have the willingness and ability to enforce codes if necessary
- A helper/supporter who can establish an unconditional relationship with the person who hoards
- The consumer to the degree that he/she is able to participate
- The Housing Court of the city of residence
- Legal Aid (to protect consumer rights)

Intervention – Best Practices

Team Members (continued)

- Mental Health professional
- If over 60, Adult Protective Services

What Works:

- Working as part of an intervention team
- Understanding that the person who hoards will require long term, periodic intervention
- Listening without judgment: being planned and steady
- Skill Building (Cognitive Behavioral Therapy)
- Real Consequences
- Being prepared – knowing available community resources

Intervention – Best Practices

What Doesn't Work:

- Trying to intervene alone
- Expecting that a one-time clean out will solve the problem
- Being dramatic, or distracted or criticizing or nagging
- Total clean-out unless necessary to protect health, safety and sanitation; surprise clean-out
- Exaggerating consequences
- Treating only the symptoms



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Hoarding - Tools

- NSGCD Hoarding Scale – provides a 5-level identification system (National Study Group on Chronic Disorganization)
 - Level 1 being not problematic to level 5 being most problematic
- Hoarding Clutter Image Rating Scale (OCD Foundation)
http://www.ocfoundation.org/hoarding/assessment_tools.aspx

Hoarding Data Collection

- Data Collection form (on hoardingconnectioncc.org)
- Data Collection instruction form (on hoardingconnectioncc.org)
- Disclaimer (on confidentiality)

Hoarding & Confidentiality

New national health information privacy standards have been issued by the U.S. Department of Health and Human Services (DHHS), pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The new regulations provide protection for the privacy of certain individually identifiable health data, referred to as protected health information (PHI). **Balancing the protection of individual health information with the need to protect public health, the Privacy Rule expressly permits disclosures without individual authorization to public health authorities authorized by law to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability, including but not limited to public health surveillance, investigation, and intervention.**

Hoarding & Confidentiality

Public health practice often requires the acquisition, use, and exchange of PHI to perform public health activities (e.g., public health surveillance, program evaluation, terrorism preparedness, outbreak investigations, direct health services, and public health research). Such information enable public health authorities to implement mandated activities (e.g., identifying, monitoring, and responding to death, disease, and disability among populations) and accomplish public health objectives. Public health authorities have a long history of respecting the confidentiality of PHI, and the majority of states as well as the federal government have laws that govern the use of, and serve to protect, identifiable information collected by public health authorities.

The purpose of this report is to help public health agencies and other understand and interpret their responsibilities under the Privacy Rule. Elsewhere, comprehensive DHHS guidance is located at the HIPAA website of the Office for Civil Rights (<http://www.hhs.gov/ocr/hippa/>).

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- Orange County California Hoarding Task Force. Retrieved from: <http://www.ochealthinfo.com/behavioral/amhs/hoarding.htm>

Suggested Readings

Stuff: Compulsive Hoarding And The Meaning of Things, by Randy O. Frost and Gail Steketee, Houghton Mifflin Harcourt, Boston, 2010.

Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding . David F. Tolin, Randy O. Frost, Gail Steketee. Oxford; New York: Oxford University Press, 2007

Digging Out: helping your loved one manage clutter, hoarding & compulsive acquiring. Michael A. Tompkins & Tamara L. Hartl. Oakland, CA: New Harbinger Publications, Inc., 2009

Overcoming Compulsive Hoarding. Why You Save & How You Can Stop. Neziroglu, Fugen; Bubirk, Jerome, and Yaryura-Tobias, Jose A. Oakland, CA:New Harbinger Publications, Inc. 2004

Ghostly Men: The Strange but True Story of the Collyer Brothers and My Uncle Arthur, New York's Greatest Hoarders (An Urban Historical). Lidz, Franz, Bloomsbury, USA, 2008

Questions?

Find out more online at

www.hoardingconnectioncc.org