Hoarding: What it is, Individual and Public Consequences, and a Team Approach to Effective Interventions

Gail Steketee, PhD MassHousing Conference December 12, 2007



Collaborators

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Hoarding Team Projects

- Cognitive and Behavioral Treatment (NIMH)
- Psychopathology of Compulsive Hoarding (NIMH)
- Neural Mechanisms of Compulsive Hoarding (fMRI) (NIMH)
- Web-based Treatment of Hoarding (OCF)
- Neuropsychological Functioning in Compulsive Hoarding (NIMH)
- Community Response: Hoarding Task Forces in the US (Farnsworth)
- Merrimack Valley HUD Project on Treatment of Elders
- Group Treatment for Hoarding

What is Compulsive Hoarding?

- The acquisition of, and failure to discard, a large number of possessions
- Living spaces that are sufficiently cluttered as to preclude their intended use
- Significant distress or impairment caused by the clutter

Compulsive Acquiring

- Compulsive Buying
 - Retail/discount -
 - E-bay
 - Home shopping network -
- Compulsive Acquisition of Free Things
 - Advertising flyers/handouts
 - Give-aways
 - Trash dumpster diving
- Stealing/Kleptomania

Saving and Difficulty Discarding

- Reasons for saving
 - Sentimental "This helps me remember.
 This represents my life. It's part of me."
 - Instrumental "I might need this. I could fix this. Somebody could use this. Think of the potential!"
 - Intrinsic "Isn't this beautiful?"

Disorganization

- Condition of the home
 - Clutter
 - Mixture of important and unimportant items
- Behavior
 - Fear of putting things out of sight
 - Indecisiveness Churning
 - Categorization problems

Animal Hoarding

- Accumulation of a large number of animals, more than the typical pet owner, not for sale or breeding.
- Failure to provide an adequate living environment for the animals, as indicated by overcrowded or unsanitary living conditions, inadequate veterinary care, inadequate nutrition, or evidence of unhealthy condition of animals.
- Reluctance to place animals for adoption or into the care of others.

Co-morbid Problems

- Depression (57%)
- Social Phobia (29%)
- Generalized Anxiety Disorder (28%)
- Obsessive Compulsive Disorder (17%)
- Personality Features
 - Anxious/avoidant, dependent, paranoia/odd
- Attention Deficit Disorder
- Dementia

Epidemiology

- True prevalence not known
 - Guestimate = 1-2% of adults
- As a "subtype" of OCD...
 - 1-2% of the population has OCD
 - 25% of OCD patients have hoarding
 - = 1.5 million people in the US
 - Huge underestimate since most people who hoard don't have OCD

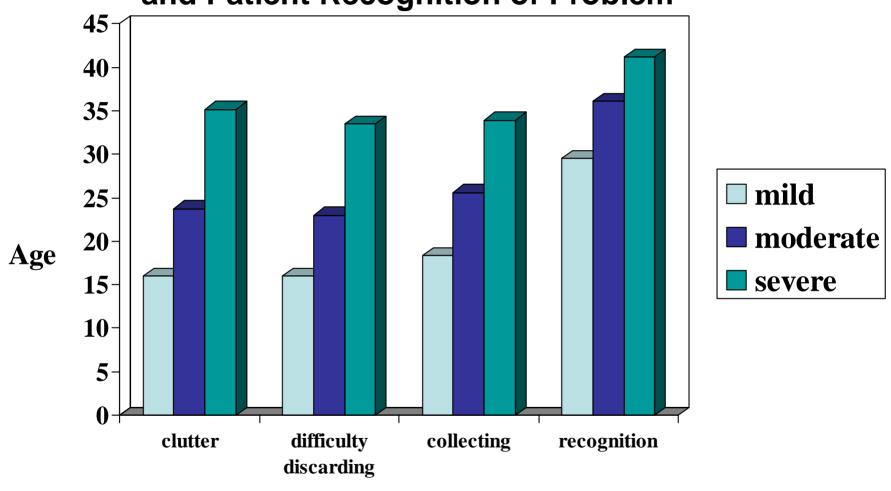
Demographics & Features

- Education: ranges widely
- Marital Status: tend to be single,
 - low marriage rate, high divorce rate
- Average age = 50
- Tend to live alone
- Family history of hoarding is common
- Squalid conditions uncommon among treatment seekers

Onset and Course of Symptoms

- Saving begins in childhood, onset age 13
- Little evidence for history of material deprivation
- Hoarding may be precipitated by loss
- Chronic or worsening course
- Insight fluctuates
- Severity range from mild to life-threatening

Mean Age of Onset of Hoarding Symptoms and Patient Recognition of Problem



Symptom type

Mass. Health Dept. Study

Frost, Steketee & Williams, 2000

- 88 (28%) health officers serving 1.8 million residents
- 64% had at least 1 hoarding complaint in past 5 yrs.
- 471 cases recorded (48% new, 57% repeat cases)
- Sources of referral: Complaints by neighbors (52%), fire/police (47%), social service (19%), workers (16%)
- Problems: sanitation (88%), fire hazard (67%), odor (53%), odd behavior (38%), 3 deaths due to house fire
- Animal hoarders posed more serious risk to community

Mass. Health Dept. Study

Frost, Steketee & Williams, 2000

- Cost of clean up was \$16,000 in one case, repeated 1 year later
- Repeat visits to home: median = 3, range = 0 to 13
- 79% involved another agency; 47% 2 or more agencies
- 32% of cases were cooperative in cleanup; 28% agreed but did little;
- 40% refused to cooperate and had involuntary cleanout; nearly half of these had building condemned or eviction
- Few animal hoarders cooperated (6.3%)

Hoarding Complications in Elderly Clients

(Steketee, Frost, & Kim, 2001)

62 cases identified by case workers

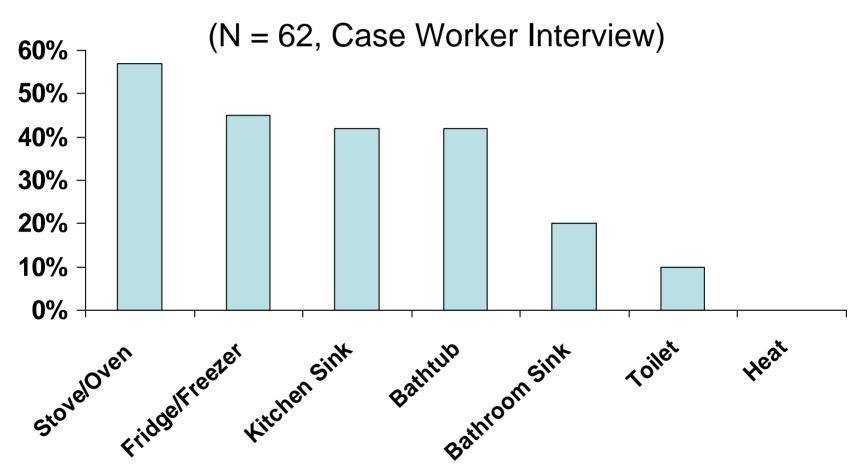
– Medical problems 27%

- Unsanitary conditions 32%

Risk of falling39%

Fire hazard 45%

Elderly Hoarders: Percentage of Appliances not Useable



Steketee et al., Health Soc Wk 2001; 26:176-184

Effects on Family & Community

- Family
 - Conflict
 - Isolation
- Community
 - Fire/Safety
 - Health
 - Infestation
 - Strain on agency resources

Problems Identified in Case Studies of Hoarding

- Treatment refusal
- Treatment dropout
- Lack of cooperation in treatment
- Absence of resistance to hoarding behavior
- Poor insight

Pharmacotherapy

- Hoarding predicts negative outcome of serotonergic medications in OCD
- Hoarding and non-hoarding OCD patients respond similarly to paroxetine
 - (The bad news: neither group improved much– 28% vs 32% responder rate)

Traditional Cognitive-Behavior Therapy

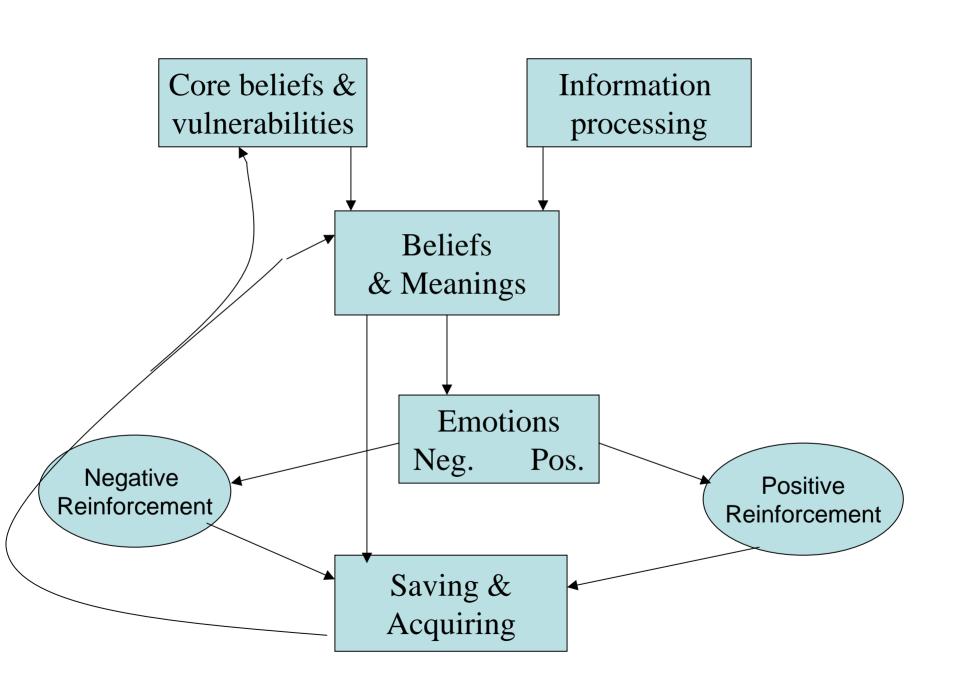
- Hoarding is less responsive than OCD to traditional CBT
 - 31% vs. 59% rate of clinically significant change for therapist-directed exposure and response prevention
 - 25% vs. 48% response rate for computerassisted self-directed exposure and response prevention

Combination Therapy

- Not particularly helpful
 - response rate to paroxetine + ERP is18% for hoarding vs. 67% for OCD
 - response rate to multiple meds + CBT in partial hospitalization program is 45% for hoarding vs. 63% for OCD

Roles and Stages of Intervention

- Understanding the hoarding problem in context
- Assessing severity and change
- Addressing motivational problems
- Deciding who can intervene
- Engaging in CBT for hoarding symptoms
- Community resources and pressures



Core Beliefs & Vulnerabilities

- Self-worth
- Lovability
- Vulnerability
- Helplessness

- Family History
 - Parental values
 - Parental behaviors
- Losses
- Mood
- Co-morbidity
- Physical constraints
 - Health, Time, Space

Biological underpinnings: Genetics

- Hoarding and indecisiveness more common among family members of people who hoard
- Specific genetic abnormalities have been found
 - L/L genotype of COMT Val158Met polymorphism
 - Chromosome 14

Information Processing Problems

- Attention
- Categorization
- Memory
- Perception
- Association
- Decision-making

Beliefs and Meanings of Possessions

- Beauty/aesthetics
- Memory
- Utility/opportunity
- Opportunity/ uniqueness
- Sentimental
- Comfort
- Safety

- Identity/potential identity
- Control
- Mistakes
- Responsibility/waste
- Completeness
- Validation of worth
- Socialization

Strong Emotions

- Positive Emotions
 - Pleasure
 - Excitement
 - Pride
 - Relief
 - Joy
 - Fondness
 - Satisfaction

- Negative Emotions
 - Grief/loss
 - Anxiety
 - Sadness
 - Guilt
 - Anger
 - Frustration
 - Confusion

Reinforcement Processes

- Immediate positive emotions reinforce acquiring and saving
- Immediate negative emotions lead to avoidance
- Avoidance prevents testing of beliefs
- Avoidance prevents alternative beliefs

Measuring Severity: Clutter Image Rating

- Select the picture that is closest to the clutter in your living room, kitchen, bedroom.
- Pictures ranked from 1-9
- Rate the following rooms:
 - Living Room
 - Kitchen
 - Bedroom
 - Dining Room
 - Hallway
 - Garage
 - Car
 - Other

Activities of Daily Living

- To what extent does clutter prevent...
 - Preparing food
 - Using refrigerator
 - Using stove, etc.
- Living Conditions
 - Rotten food
 - Insects
 - Feces, etc.
- Safety issues
 - Fire hazard
 - Blocked egress, etc.

How can we motivate people to change?

Dealing with limited insight and ambivalence

Principles and Techniques of MI

- Articulate ambivalence
- Reinforce change talk & action
 By...
- Expressing empathy
- Developing discrepancy
- Rolling with resistance
- Supporting self-efficacy

Multi-method Treatment of Hoarding

- Assessment and case formulation
- Motivational enhancement
- Skills training organizing, problem solving
- Practicing discarding (exposure)
- Challenging thoughts and beliefs
- Restricting acquiring
- Preventing relapse

Treatment Format

- Individual and/or group
- Office and in-home sessions
- Acquiring locations
- Family consultation
- Assistance from a coach
- Cleanouts with trained staff if needed

Establish Personal Goals and Values

- Ask about personal values
 - What does the client care most about
 - Family, friends, honesty, achievements, etc.
- Identify personal goals
 - What does the client most want to do in the remainder of his/her life?
 - List these goals
- Refer back to goals and values to clarify ambivalence and reduce indecision

Establish Treatment Rules

- Therapist may not touch possessions
- All decisions made by the client
- O.H.I.O. (or at most twice)
- Establish categories first, then sort
- Proceed systematically

Skills Training

- Problem solving
- Decision making
- Categorizing
- Organizing
- Managing ADHD
- Maintaining the system

Gradual Exposures to Sorting/Discarding

- Imagine discarding
- Behavioral experiments
- Practice with clinician
- Practice when alone
- Practice in office and at home
- Homework assignments

Gradual Exposures for Compulsive Acquiring

- Non-shopping Excursions
 - Drive-by non-shopping
 - Walk-through non-shopping
 - Browsing and picking non-shopping

Establishing Personal Rules for Saving and Acquiring

- I must have
 - an immediate use for it
 - time to deal with it appropriately
 - money to afford it comfortably
 - space to put it

— . . .

Cognitive Treatment

- Identify problematic beliefs during sorting and acquiring practice
- Socratic questioning to examine beliefs and consider alternatives

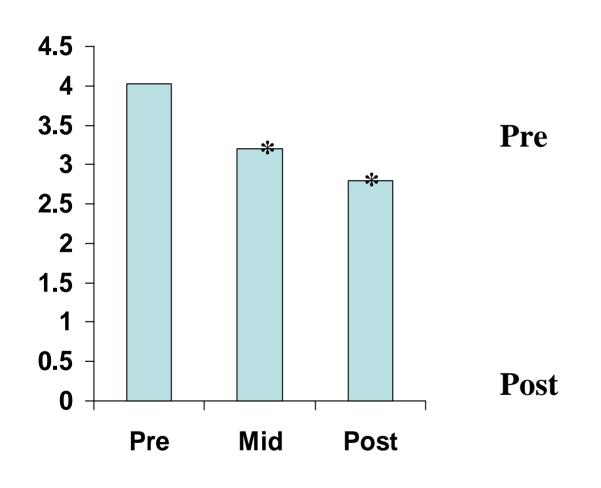
Socratic Questioning: Thinking it Through

- What's the probability of the negative outcome you fear?
- How catastrophic would this be?
- How well could you cope with not having this?
- How much distress would you feel?
- How long would the distress last?
- Can you tolerate with feeling?

Using a Coach

- Family member, friend, chore/home health aide, hired assistant
- Teach coaches about hoarding and various manifestations of symptoms
- Meet as a team therapist, client, coach
- Decide on the coach's role

Open Trial: Clutter Image Rating

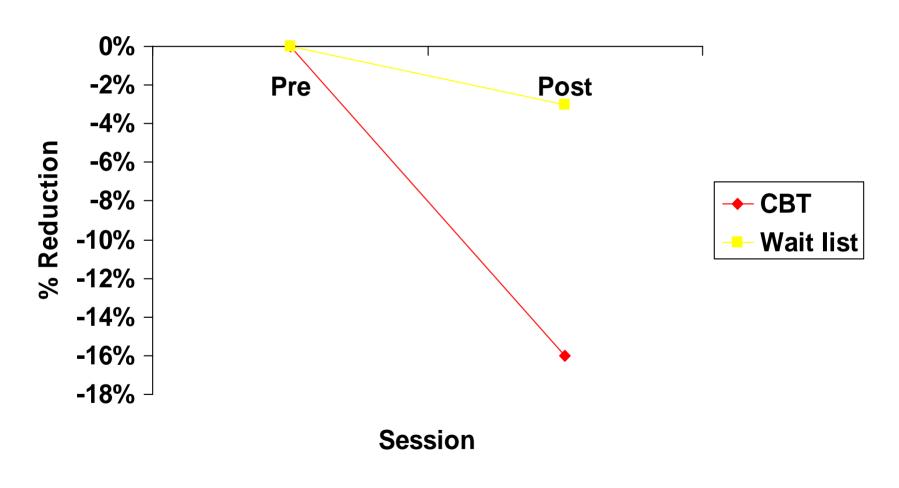






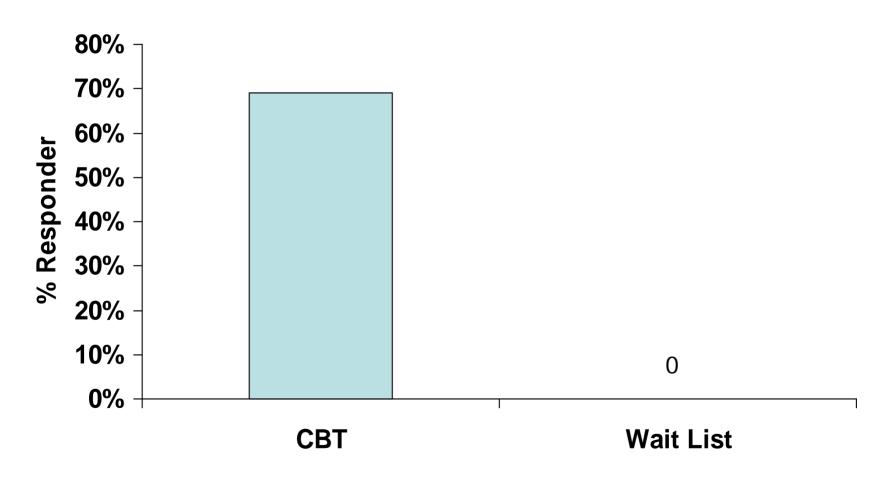
Tolin, Frost, & Steketee (in press), Behav Res Ther

Waitlist Controlled Trial: Saving Inventory-Revised



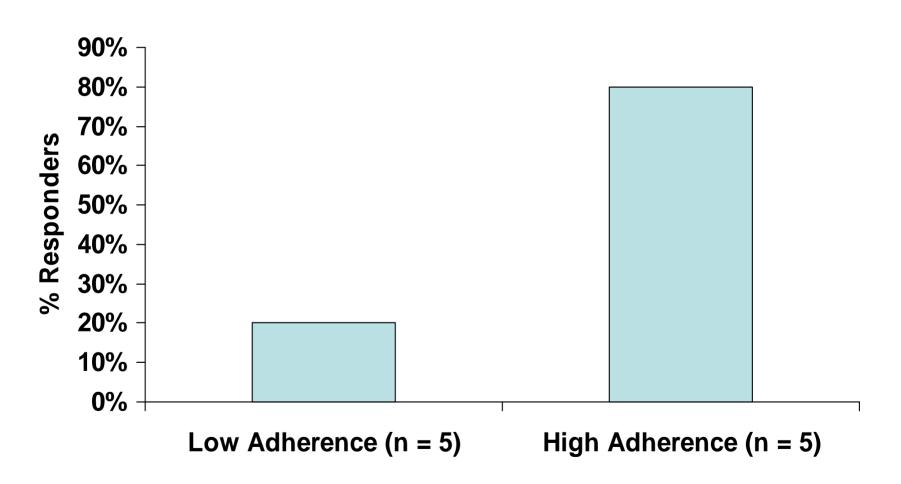
Frost et al. (2007), submitted

Controlled Trial: Treatment Responders

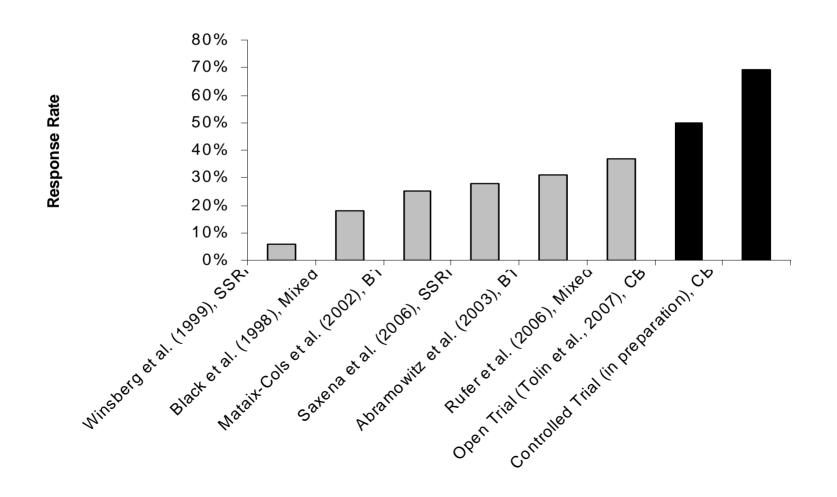


"Much Improved" or "Very Much Improved"; Frost et al. (2007),

Open Trial: High vs. Low Homework Adherence (Median Split)



Specialized CBT improves upon other treatments for hoarding



Cooperation with Authorities

- Task Force Model
- Official Pressure
- Forced Intervention

Task Force Members

- Public Health
- Social Services (Elder Services)
- Housing Authority
- Mental Health Services
- Courts
- Public Safety (fire, police)
- Volunteers

Task Force Case Protocol

- Evaluating threat
- Determining legal directives
- Developing a case plan
- Implementing the plan
- Evaluating outcomes & modifying the plan
- Continued monitoring

Applying Official Pressure

- Specify infractions, objectives and time line for correcting problems
- Identify resources for assistance
- Determine who will monitor outcomes
- Clarify the consequences of noncompliance

Specify Objectives & Timeline

- Negotiate with client
- Specify expectations and consequences
 - Clear stove-top by
 - Remove perishable foodstuffs by
 - Clear kitchen table by
- Emphasize saving everything possible

Identify Resources for Assistance

- Family members and friends
- Trained volunteers
- Paraprofessionals
- Professional organizers
- Mental health professionals
- Self-help groups
- Service personnel
- Other

Creating Common Goals

- Reframe the goals by emphasizing dysfunction and personal goals
- Good cop/bad cop strategy
 - How can we help you meet the court order?
 - How can we keep the housing authority off your back?
 - How can we satisfy your family concerns, as well as your own needs?
- Creative alternatives
 - Make money by selling items
 - Help others by giving away

Monitoring and Consequences of Noncompliance

- Scheduled visits by official monitor(s): fire inspector, housing authority, etc.
 - Difficulty identifying officials with authority in private homes
- Re-negotiation of contract
- Forced intervention
- Eviction

Forced Intervention

- Gradual Clearing Model
- One Room Clean-out Model
- Total Clean-out Model
- Assisted Living
- Monitoring

Comments

- Specialized CBT for hoarding works moderately well to reduce symptoms of hoarding
- Therapist can be a trained MH professional and/or para-professional
- Limited outcome data, especially for elderly clients and for long-term outcome
- Best coordination of community services is not yet established
- Best practices requires more work on all sides