COMPULSIVE HOARDING: Description, Epidemiology, Impact

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Howard County
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Outline

- What is hoarding?
- What is its epidemiology?
- What are its health impacts?
- What are its social impacts?
What is compulsive hoarding?
Case Presentation

The participant is a 65 year old, widowed white female under treatment for severe hoarding behavior and poor social relationships. Her hoarding began when she was about 20 years old, although she recalls excessive collecting as a teenager. When walking, she constantly collects discarded objects, such as soda cans, newspapers, and paper bags, which she says that she “may need sometime.” Her home is extremely cluttered, with objects scattered everywhere in a disorganized fashion; there are piles of clothes, bags, and boxes in all rooms, which she negotiates by making trails to walk through or by jumping over.
She said that she tries to throw things away but that she “just can’t decide what to get rid of.” About 6 months ago, she became unable to live in her 6-room house due to the clutter, and she rented an apartment elsewhere. She reports intrusive need for symmetry, constantly rearranging things, and counting objects. She admits to being extremely isolated socially, with few friends or acquaintances, none of whom she will allow into her home. She expressed feelings of shame and embarrassment for the extreme clutter in her home and her excessive accumulation, which she said was “overwhelming my life.”
Compulsive hoarding

- Difficulty discarding possessions
  - Strong urges to save; distress, indecision about discarding
  - even if things appear useless or of limited value

- Living spaces so cluttered that precludes activities

- Significant distress and impairment

- Not due to general medical condition

- Not restricted to symptoms of another mental disorder
  - e.g., cognitive deficits in dementia
Objects hoarded

<table>
<thead>
<tr>
<th>Possessions hoarded</th>
<th>% of N=58</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newspapers and magazines</td>
<td>89%</td>
</tr>
<tr>
<td>Other paper rubbish</td>
<td>87%</td>
</tr>
<tr>
<td>Containers</td>
<td>87%</td>
</tr>
<tr>
<td>Bottles</td>
<td>80%</td>
</tr>
<tr>
<td>Food and food garbage</td>
<td>76%</td>
</tr>
<tr>
<td>Others’ rubbish</td>
<td>48%</td>
</tr>
<tr>
<td>Animals</td>
<td>32%</td>
</tr>
</tbody>
</table>

Frost, Steketee, Williams (2000)
Clutter

Living room

Kitchen
Bedroom
Features

Reasons for saving

- “might be useful in future”
- “can’t decide what to keep and what to throw away”
- “feelings of security”
- “sentimental value”

Reactions to intervention

- very anxious when attempting to discard
- extremely upset if someone else discards
- intervention only if forced
- poor response to treatment
Characteristics

- socially isolated
- disorganized
- difficulty making decisions
- procrastination and avoidance
- poor insight

- social phobia, depression, generalized anxiety

*Note: Varies among cases*
Epidemiology
Epidemiology

- PREVALENCE
  - How frequent in the population?

- DESCRIPTIVE
  - How related to demographics (age, gender, SES)

- ANALYTIC
  - What are risk factors?
# Baltimore studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Years</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baltimore ECA Study</td>
<td>1981-1982</td>
<td>3,481</td>
</tr>
<tr>
<td>Baltimore ECA Follow-up</td>
<td>1993-1996</td>
<td>1,920</td>
</tr>
<tr>
<td>Hopkins Personality Study</td>
<td>1997-1999</td>
<td>742</td>
</tr>
</tbody>
</table>
Hoarding assessment in HEPS

- Do you find it almost impossible to throw out worn-out or useless things?
- Is that true even if they don’t have any sentimental value?
  - Give me some examples.
- Is this a problem for you or others?
  - Tell me about it.
- Rating
  - 0 (absent); 1 (accentuated); 2 (pathological)
Male respondent (49 years old)

“My room is like a bomb hit it. I’ve got books and papers, stuff in the corner there. I don’t want to throw nothing away. Old suits in my closet, I know I’ll never wear again in my life. Old beat up tennis shoes, think I’ll find a use for them. I never throw a book away. I like to keep articles, the whole paper; it starts building up on me in a hurry. Newspapers knee-high. I keep a whole drawer full of rubber bands; don’t know why, but I do. Lots of junk.”
Prevalence in Baltimore


Sample: 27 / 735

Population: 27 / 735

27 / 735
## Population prevalence

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK twins</td>
<td>5,022 twins</td>
<td>2.3%</td>
</tr>
<tr>
<td>German population</td>
<td>2,307</td>
<td>4.6%</td>
</tr>
<tr>
<td>Eastern Baltimore (HEPS)</td>
<td>742</td>
<td>3.7% (unweighted)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.3% (weighted)</td>
</tr>
</tbody>
</table>
Prevalence of hoarding

Age *

<table>
<thead>
<tr>
<th>34-44</th>
<th>45-54</th>
<th>55+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>5.0</td>
</tr>
</tbody>
</table>

Sex *

<table>
<thead>
<tr>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.0</td>
<td>5.0</td>
</tr>
</tbody>
</table>
Prevalence of hoarding

Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
</tbody>
</table>

Education

<table>
<thead>
<tr>
<th>Education</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not HS</td>
<td>3</td>
</tr>
<tr>
<td>HS Grad</td>
<td>4</td>
</tr>
<tr>
<td>Post HS</td>
<td>5</td>
</tr>
</tbody>
</table>
Demographics

Marital status

<table>
<thead>
<tr>
<th>Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mar</td>
<td>3</td>
</tr>
<tr>
<td>Sep/Div</td>
<td>3</td>
</tr>
<tr>
<td>Not Mar</td>
<td>5</td>
</tr>
<tr>
<td>Wid</td>
<td>6</td>
</tr>
</tbody>
</table>

Household Income ($)

<table>
<thead>
<tr>
<th>Income</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;50,000</td>
<td>1</td>
</tr>
<tr>
<td>20-50,000</td>
<td>5</td>
</tr>
<tr>
<td>&lt;20,000</td>
<td>6</td>
</tr>
</tbody>
</table>
Demographics

Employed

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

Lives alone

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>
Possible causes
Possible causes

- Psychological
- Response to adversity
- Brain structure and/or function
- Genetics
- Interactions among these
Axis I Disorders (OCGS)

Social phobia

Generalized anxiety disorder

%
<table>
<thead>
<tr>
<th>Personality disorder traits (HEPS)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Number of traits</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paranoid</td>
<td>1.60 **</td>
</tr>
<tr>
<td>Schizotypal</td>
<td>1.49 ***</td>
</tr>
<tr>
<td>Avoidant</td>
<td>1.66 ***</td>
</tr>
<tr>
<td>Obsessive-compulsive</td>
<td>1.76 ***</td>
</tr>
</tbody>
</table>
Childhood adversities (HEPS)

Death of parent

Parental sep/divorce
Childhood adversities

Psychiatric symptoms, father *

Psychiatric symptoms, mother *

Depression, mania, or heavy drinking
Childhood adversities

Excessive physical discipline *

Insecurity from home breakins *

<table>
<thead>
<tr>
<th>%</th>
<th>CH+</th>
<th>CH-</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>30</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>40</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>60</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
# Childhood adversities

<table>
<thead>
<tr>
<th>Adversity</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents separated or divorced</td>
<td>2.1</td>
</tr>
<tr>
<td>Death of parent</td>
<td>2.3</td>
</tr>
<tr>
<td>Psychiatric symptoms, father *</td>
<td>2.7</td>
</tr>
<tr>
<td>Psychiatric symptoms, mother *</td>
<td>2.7</td>
</tr>
<tr>
<td>Insecurity from home break-ins *</td>
<td>3.9</td>
</tr>
<tr>
<td>Excessive physical discipline *</td>
<td>4.2</td>
</tr>
</tbody>
</table>
Hoard in brain disorders

- Physical trauma to brain
  - Stroke
  - Traumatic injury

- Dementia
  - Frontotemporal dementia

- Mental retardation
  - Prader-Willi syndrome

- Autism

- Schizophrenia

*Most hoarding cases do not have these.*
Information processing deficits

- Decision-making
- Categorization
- Organization
- Memory

(Frost & Hartl, 1996)
Prevalence of hoarding, by indecision (OCGAS)
Lower cerebral glucose metabolism in dorsal anterior cingulate gyrus
12 hoarding vs 33 nonhoarding OCD; PET; (p<0.001)
Anterior cingulate

- motivation
- executive control
- focused attention
- assigning emotional valence to stimuli

- problem solving
- detecting errors
- selecting responses
- decision-making
Executive functions in CHFS

BRIEF Scale

T-score

Initiate  WorkMem  PlanOrg  TaskMon  OrgMat  MetaIndex

CH+ (N=70)

CH- (N=13)
Familial aggregation in CHFS

CHFS Study
- 70 CH+ cases
- 356 first-degree relatives
- 13 CH- controls
- 91 first-degree relatives

Familiality (% of relatives)
Hoarding pedigrees (OCGS)

Pedigree 246

Pedigree 262
Families with 2+ hoarding relatives
Health impacts
Health hazards

- injury from falling
- fire hazard
- contamination from rotting food
- allergies from dust pollen
- animal waste
- vermin infestation
- inability to use rooms (eating, sleeping, bathing)
- hazards to individual, family, neighborhood
Health impacts

- Tolin et al., 2008 (*Psychiatry Research* 160:200-211)
- 864 self-identified hoarding individuals who responded to internet request and completed main questionnaires
  - ~94% female;
  - mean age ~49 years old (range, 21-83)
- 665 family informants of hoarding individuals
- Compared to National Comorbidity Survey
Chronic medical conditions

BMI

Chronic conditions

[Graph showing BMI distribution among Hoard+, Hoard+/-, and Informants]

[Graph showing prevalence of chronic conditions among Hoard+ and Hoard+/- groups]

Conditions: Hypertension, Arthritis, Stomach, Diabetes, Heart
Psych work impairment days

Psychiatric work impairment days in past month

NCS
Mental health treatment

Mental health treatment in past 12 months

- Hoard+
- Hoard+/-
- NCS
Social impacts

- Restricted focus
- Financial burden
- Social isolation
- Threat of eviction
- Strained family relationships
- Impact on family members
- Threat to neighbors
- Burden on social agencies
Burden on family members

- 665 family informants; internet survey
- Findings
  - Unhappy childhood
  - Difficult having people over to house
  - Strained relationship with parents
  - Embarrassed about home
  - Rejection of hoarding relative

Tolin et al., 2008
Conclusions from epidemiology

- Hoarding is a serious disorder
- Prevalence in community is 4-5%
- Demographic correlates (age, sex, income)
- Psychology: anxiety disorders, personality
- Biology: Neuroimaging, neurocognitive, and genetic findings
- Environment: childhood adversities
- Adverse health and social impacts
- Need for more research to elucidate causes
A lot we still don’t understand

- What causes hoarding?
- How best to treat it?
- How to respond in the community?
- How to prevent it?
Collaboration essential

To go from this …… To this !