Hoarding Disorder
A new mental disorder in DSM-5

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Disclosures

- Financial: None
- Advisor to DSM-5 Anxiety and OCD Spectrum Workgroup
Collecting: a widespread human activity

- Up to 70% of children own a collection (Evans et al 1997)
- 30% of British adults have a collection at any given time (Pearce, 1998)
- Success of collector-based media, e.g. BBC’s Bargain Hunt and Antiques Roadshow (33rd season!)
- Regarded as normative and benign
- Like all human behaviours, it can range from normal to 'excessive' or 'pathological' (i.e., hoarding)

(Compulsive) Hoarding

- 1) The acquisition of, and failure to discard large numbers of possessions that appear (to others) to be useless or of limited value
- 2) Living or other spaces sufficiently cluttered so as to preclude activities for which those spaces were designed
- 3) Significant distress or impairment in functioning caused by the hoarding or clutter

Frost & Hartl, 1996
Most commonly hoarded items

- Old clothes
- Magazines
- CDs/Video tapes
- Letters
- Pens
- Old notes
- Bills
- Newspapers
- Receipts
- Cardboard boxes
- Beads
- Wool/fabric
- Pins
- Clothing rags
- Old medication
- Old food (canned)
- Body products (nails, hair, feces...) *
- Used nappies *
- Rotten food *
- Animals

* In the context of OCD only
(Pertusa et al, 2008)

Reasons given for hoarding

- Perceived need for the items (intrinsic value)
  - ‘I may need it some day’

- Emotional attachment to possessions (emotional value)
  - ‘I feel safe around my possessions’

- Identification with possessions
  - ‘I feel the object is part of me’
Substantial disability

- Substantial social (C.H.A.O.S.) and occupational impairment (Steketee & Frost, 2003)
- Health risks from infestations, falls, fires etc (Steketee & Frost, 2003)
- High family and economic burden; high service utilisation (Tolin et al 2008a)
- 8-12% evicted or threatened with eviction (Tolin et al 2008b)
- Six (8%) of 78 homeless people admitted that hoarding problems had contributed to them being homeless (unpublished data)

Tragic hoarding news

**Collector killed by his own hoard**

A “compulsive” collector who hoarded tonnes of rubbish probably died when some of the items fell on him at his home, an inquest has heard.

John Jones’ house in Aberystwyth was so full that he built a network of tunnels so he could move around in it.

Four tonnes of rubbish was removed from the 62-year-old’s bedroom where police carried his body out through a window, the inquest was told.

Ceredigion coroner Peter Bruntion recorded a verdict of accidental death.

The inquest in Aberystwyth was told Mr Jones, a widower who weighed 25 stone and had mobility problems, had collected rubbish for more than 20 years.

His garden and sheds at his home were packed full of rubbish, along with several garages which he had rented from Ceredigion Council.
Hoardings as a symptom

- Has been described in:
  - Dementia - mainly frontal type
  - Brain lesions
  - Autism & learning disabilities
  - Genetic disorders (e.g. Prader-Willi)
  - Eating disorders (mainly food)
  - Obsessive-Compulsive Disorder (15-40%; severe in 5%)
  - Obsessive Compulsive Personality Disorder (1 of 8 criteria)

- But in most cases hoarding cannot be explained by another medical or psychiatric disorder

In most cases, hoarding is independent from OCD

- In an epidemiology study of hoarding, none of the identified hoarders met criteria for OCD (Samuels et al, 2008).
- Hoarding can be attributed to OCD only a minority of severe hoarders (Pertusa et al 2008)
- Frost et al (2011). Of 217 severe hoarders:
  - MDD = 51%
  - GAD = 24.4%
  - Social phobia = 23.5%
  - ADHD (inattentive) = 28%
  - OCD = 18%

- Hoarding is highly comorbid with mood and anxiety disorders but in most cases, hoarding symptoms cannot be explained by those comorbidities
Hoarding in DSM-IV-TR

- Only listed as one of the 8 criteria for OCPD. In the differential diagnosis section it states: “(...) OCD should be considered especially when hoarding is extreme (...). When criteria for both disorders are met, both diagnoses should be recorded (p. 728)”

- Thus hoarding can potentially be a symptom of OCD, despite not being mentioned in the OCD section

- This is exclusive to DSM-IV (as no mention of this appears in previous editions)

- Confusing, as clinicians struggle to decide when a diagnosis of OCD is appropriate, particularly when no other OCD symptoms are present

- PS. Hoarding not mentioned in ICD-10

'Something of value'
(from the DSM-IV-TR casebook)

- For the past month Mr. Wolfe has been living in the basement of his apartment building, eating in restaurants, and using a health club for showers. His own apartment is so full of newspapers, magazines, and books that he is no longer able to get in the door, but he cannot bring himself to get rid of any of his 'stuff'.

- Mr. Wolfe began collecting baseball cards and then books and magazines when he was 12. Eventually, however, his apartment became so cluttered that his parents threw out much of his collection. He retrieved it from the garbage, and from that point on his 'collecting' became a focus of conflict with family and employers.

- Mr. Wolfe does not go out of his way to obtain things, but once he has a newspaper, book, or magazine, he cannot throw it away because 'there might be something of value written in it.' The thought of throwing things out makes him extremely anxious, and, in the end, he simply cannot do it.

- After his divorce, 10 years ago, he moved some of his collection into his own apartment and rented storage space for the rest. Gradually his new apartment filled up with newspapers, magazines, and books, and it became a struggle just to get in the front door and make his way to his bed. Finally, last month, he injured his shoulder trying to push things aside and then abandoned the apartment for a cot in the basement of the building. He understands that his inability to throw things out is irrational, but the thought of starting to do it makes him intolerably anxious.
Why do we need the new disorder?

- Highly prevalent (2-5% of the population) (e.g. Samuels et al, 2008; Iervolino et al 2009; Timpano et al 2011)
- Causes significant distress and impairment to the sufferer, family members and society at large (economic burden)
- Current diagnostic categories leave out the majority of sufferers
- Fits the DSM-5 definition of ‘mental disorder’ (Stein et al 2010)
- Advantages of creating the new disorder outweigh the potential harms (e.g. pathologising normal behaviour)

Mataix-Cols et al, 2010

The birth of a new disorder

- The DSM-5 Obsessive Compulsive Spectrum sub-workgroup is currently proposing the creation of a new diagnostic category named ‘Hoarding Disorder’ (Mataix-Cols et al 2010)
- To be classified in the new ‘OCD Spectrum’ chapter (Phillips et al 2010)
- Provisional diagnostic criteria: [www.dsm5.org/ProposedRevisions](http://www.dsm5.org/ProposedRevisions)
- Based on Frost and Hartl’s 1996 definition
- ICD-11 (due 2015) likely to follow suit
Provisional diagnostic criteria

A. Persistent difficulty discarding or parting with personal possessions, regardless of their actual value.
B. The difficulty is due to a strong urges to save items and/or distress associated with discarding.
C. The symptoms result in the accumulation of a large number of possessions that fill up and clutter active living areas of the home or workplace to the extent that their intended use is no longer possible. If all living areas are uncluttered it is only because of the interventions of third parties (e.g. family members, cleaners, authorities).
D. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning (including maintaining a safe environment for self and others).
E. The hoarding symptoms are not due to a general medical condition (e.g. brain injury, cerebrovascular disease).
F. The hoarding symptoms are not restricted to the symptoms of another mental disorder (e.g. hoarding due to obsessions in Obsessive Compulsive Disorder, decreased energy in Major Depressive Disorder, delusions in Schizophrenia or another Psychotic Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder, food storing in Prader-Willi Syndrome).

Mataix-Colis et al, 2010
Specifiers

1 - Specify if:

With Excessive Acquisition: If symptoms are accompanied by excessive collecting or buying or stealing of items that are not needed or for which there is no available space.

2 - Specify whether hoarding beliefs and behaviors are currently characterized by:

Good or fair insight: Recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are problematic.

Poor insight: Mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.

Absent (delusional) insight: Completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.

Validation of the criteria

- DSM-5 Survey (Mataix-Cols et al 2011)
- London Field Trial (Mataix-Cols et al submitted)
- DSM-5 Field Trials (ongoing)
DSM-5 Survey: Hoarding Disorder

- Aims:
  - To test the sensitivity and specificity of the proposed diagnostic criteria for Hoarding Disorder
  - To examine the perceived usefulness and acceptability of the criteria among professionals
  - Using a clinical vignette methodology

Participants: 2 samples

- OCD and hoarding experts
  - Total sample = 500
  - Undeliverable emails = 80
  - Total sent = 510
  - Completed surveys = 211 (41.4%)

- APA members
  - Total sample = 500
  - Undeliverable emails = 17
  - Total sent = 483
  - Completed surveys = 45 (9.9%)
Procedure

- Online survey: http://www.surveygizmo.com

- 8 clinical vignettes:
  - 4 Hoarding Disorder cases (including a comorbid HD + OCD case)
  - 4 not meeting criteria: 1 brain damage, 1 OCD, 1 Schizophrenia, 1 No dx (subclinical case)

Mataix-Cols et al, 2011 (Psychological Medicine)

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Ms. SB is a widowed 51-year-old woman. She reports that she has experienced difficulty discarding items for as long as she can remember, although she did not regard this behavior as problematic in the past. In recent years, she has noticed that her three-bedroom flat has started to become increasingly cluttered. Despite her efforts to clear the clutter, she feels unable to discard most common items (especially paperwork) because she thinks they might be useful in the future. She also reports being sentimentally attached to her possessions –which serve as a reminder of happier times when she was married. She has managed to keep her kitchen and bathroom relatively uncluttered, but her living room is cluttered to the extent that she can no longer sit on the sofa and only has one chair on which to sit. She has not been able to watch TV for several years as it is currently buried under piles of old newspapers and magazines. Her hoarding behavior has a major impact on her social life (she has not been able to invite anyone to her home for 2 years because of embarrassment). She does not report any psychiatric symptoms other than high anxiety when facing the prospect of discarding her possessions. When asked about how she feels about her behavior, she describes her symptoms as being mainly egosyntonic (i.e., they are not unwanted), but she decided to seek help once the clutter started to interfere with her life.
Ms. SB is a widowed 51-year-old woman. She reports that she has experienced difficulty discarding items for as long as she can remember, although she did not regard this behavior as problematic in the past. In recent years, she has noticed that her three-bedroom flat has started to become increasingly cluttered. Despite her efforts to clear the clutter, she feels unable to discard most common items (especially paperwork) because she thinks they might be useful in the future. She also reports being sentimentally attached to her possessions—which serve as a reminder of happier times when she was married. She has managed to keep her kitchen and bathroom relatively uncluttered, but her living room is cluttered to the extent that she can no longer sit on the sofa and only has one chair on which to sit. She has not been able to watch TV for several years as it is currently buried under piles of old newspapers and magazines. Her hoarding behavior has a major impact on her social life (she has not been able to invite anyone to her home for years because of embarrassment). She does not report any psychiatric symptoms other than high anxiety when facing the prospect of discarding her possessions. When asked about how she feels about her behavior, she describes her symptoms as being mainly egosyntonic (i.e., they are not unwanted), but she decided to seek help once the clutter started to interfere with her life.

In your clinical judgment, which of the following diagnoses are present in the clinical case above?
Please select one or two options from the list below:

- Dementia / Organic Brain Disorder
- Hoarding Disorder
- Obsessive-Compulsive Disorder
- Obsessive-Compulsive Personality Disorder
- Schizophrenia
- I don’t think this patient warrants any diagnosis
- Other mental disorder (please specify): ____________________

Now, please select which of the individual criteria for Hoarding Disorder are met:

- A. Persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions.
- B. This difficulty is due to strong urges to save items and/or distress associated with discarding.
- C. The symptoms result in the accumulation of a large number of possessions that fill up and clutter active living areas of the home or workplace to the extent that their intended use is no longer possible. If all living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).
- D. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
- E. The hoarding symptoms are not due to a general medical condition (e.g., brain injury, cerebrovascular disease).
- F. The hoarding symptoms are not restricted to the symptoms of another mental disorder.
### SENSITIVITY

<table>
<thead>
<tr>
<th>True Status</th>
<th>Test Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disorder (+)</td>
<td>True positives</td>
</tr>
<tr>
<td></td>
<td>False Negatives</td>
</tr>
<tr>
<td>No disorder (-)</td>
<td>False Positives</td>
</tr>
<tr>
<td></td>
<td>True Negatives</td>
</tr>
</tbody>
</table>

**True positives**

- Calculated as: True positives / (True positives + False negatives)

**False Negatives**

- Calculated as: False negatives / (True positives + False negatives)

### SPECIFICITY

<table>
<thead>
<tr>
<th>True Status</th>
<th>Test Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disorder (+)</td>
<td>True positives</td>
</tr>
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<td></td>
<td>False Negatives</td>
</tr>
<tr>
<td>No disorder (-)</td>
<td>False Positives</td>
</tr>
<tr>
<td></td>
<td>True Negatives</td>
</tr>
</tbody>
</table>

**True negatives**

- Calculated as: True negatives / (True negatives + False positives)

**False Positives**

- Calculated as: False positives / (True negatives + False positives)
## Results: Specificity/Sensitivity

<table>
<thead>
<tr>
<th></th>
<th>Experts (N = 211)</th>
<th>APA (N = 48)</th>
<th>HD Experts (N = 48)</th>
<th>Non-experts (N = 163)</th>
<th>Psychiat (N = 97)</th>
<th>Psychol (N = 88)</th>
<th>Other (N = 26)</th>
<th>Trainee (N = 26)</th>
<th>Non-trainee (N = 185)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity</td>
<td>0.85</td>
<td>0.74</td>
<td>0.87</td>
<td>0.84</td>
<td>0.79</td>
<td>0.91</td>
<td>0.87</td>
<td>0.89</td>
<td>0.84</td>
</tr>
<tr>
<td>Specificity</td>
<td>0.89</td>
<td>0.91</td>
<td>0.84</td>
<td>0.91</td>
<td>0.90</td>
<td>0.89</td>
<td>0.87</td>
<td>0.89</td>
<td>0.89</td>
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<tr>
<td>False positives</td>
<td>10.67%</td>
<td>8.87%</td>
<td>15.62%</td>
<td>9.2%</td>
<td>9.8%</td>
<td>11.07%</td>
<td>12.5%</td>
<td>10.55%</td>
<td>10.67%</td>
</tr>
<tr>
<td>False negatives</td>
<td>15.02%</td>
<td>25.5%</td>
<td>13.02%</td>
<td>15.62%</td>
<td>21.4%</td>
<td>8.8%</td>
<td>12.5%</td>
<td>10.57%</td>
<td>15.67%</td>
</tr>
</tbody>
</table>

Mataix-Cols et al, 2011 (Psychological Medicine)

## Results: Acceptability

How acceptable do you find the proposed criteria for Hoarding Disorder?

- Very acceptable
- Somewhat acceptable
- Not acceptable
- Not at all acceptable

**EXPERTS SAMPLE (N = 211)**

<table>
<thead>
<tr>
<th>Acceptability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very acceptable</td>
<td>60.50%</td>
</tr>
<tr>
<td>Somewhat acceptable</td>
<td>33.6%</td>
</tr>
<tr>
<td>Not acceptable</td>
<td>5.20%</td>
</tr>
<tr>
<td>Not at all acceptable</td>
<td>0.50%</td>
</tr>
</tbody>
</table>

**APA SAMPLE (N = 48)**

<table>
<thead>
<tr>
<th>Acceptability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very acceptable</td>
<td>50%</td>
</tr>
<tr>
<td>Somewhat acceptable</td>
<td>39.60%</td>
</tr>
<tr>
<td>Not acceptable</td>
<td>10.40%</td>
</tr>
<tr>
<td>Not at all acceptable</td>
<td>0%</td>
</tr>
</tbody>
</table>

Mataix-Cols et al, 2011 (Psychological Medicine)
Results: Acceptability

How acceptable do you think the proposed criteria will be for the patients?

- Very acceptable
- Somewhat acceptable
- Not to acceptable
- Not at all acceptable

<table>
<thead>
<tr>
<th>EXPERTS SAMPLE (N = 211)</th>
<th>APA SAMPLE (N = 48)</th>
</tr>
</thead>
<tbody>
<tr>
<td>very acceptable</td>
<td>54.10%</td>
</tr>
<tr>
<td>somewhat acceptable</td>
<td>44.60%</td>
</tr>
<tr>
<td>not acceptable</td>
<td>2.80%</td>
</tr>
<tr>
<td>not at all acceptable</td>
<td>0.50%</td>
</tr>
<tr>
<td>very acceptable</td>
<td>52.10%</td>
</tr>
<tr>
<td>somewhat acceptable</td>
<td>32.40%</td>
</tr>
<tr>
<td>not acceptable</td>
<td>10.40%</td>
</tr>
<tr>
<td>not at all acceptable</td>
<td>0%</td>
</tr>
</tbody>
</table>

Mataix-Cols et al, 2011 (Psychological Medicine)

London Field Trial: Aims

- Are the criteria able to discriminate between HD and other forms of hoarding (e.g. hoarding caused by other mental disorders) and between HD and normative collecting?

- Inter-rater reliability of the HD diagnosis and each of its individual criteria.

- Degree of acceptability, perceived stigma and usefulness of the new disorder among sufferers.
London Field Trial: Methods

- Participants:
  - 50 unselected participants with prominent hoarding behaviour (mainly recruited from a hoarding support group).
  - 20 unselected (self-defined) collectors (mainly recruited via email, KCL distribution list).
- Thorough assessment (including home visits in most cases)
- DSM-5 criteria
- 2 independent raters
- Best estimate diagnosis (gold standard)

London Field Trial: Results

- 29 (58%) met full criteria for HD
- 16 (32%) did not have sufficient clutter (Criterion C) and of those 12 still had clinically significant distress or interference ('sub-clinical')
- 5 (10%) hoarding attributable to OCD (did not meet criterion F)
- 20 (69%) of those meeting criteria also had other comorbid mental disorders but HD was sufficiently impairing on its own
### Sensitivity/specificity (all participants; n=70)

<table>
<thead>
<tr>
<th>Best estimate diagnosis</th>
<th>Specificity</th>
<th>Sensitivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>absent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Rater 1 | | | |
|----------| | | |
| present  | 29 | 0 | 1 | 1 |
| absent   | 0  | 41| |

| Rater 2 | | | |
|----------| | | |
| present  | 29 | 1 | 1 | .98 |
| absent   | 0  | 40| |

### Sensitivity/specificity (All hoarders; n=50)

<table>
<thead>
<tr>
<th>Best estimate diagnosis</th>
<th>Specificity</th>
<th>Sensitivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>absent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Rater 1 | | | |
|----------| | | |
| present  | 29 | 0 | 1 | 1 |
| absent   | 0  | 21| |

| Rater 2 | | | |
|----------| | | |
| present  | 29 | 1 | 1 | .95 |
| absent   | 0  | 20| |
### Sensitivity/specificity (HD, n=29 vs collectors, n=20)

<table>
<thead>
<tr>
<th></th>
<th>Best estimate diagnosis</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>present</td>
<td></td>
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<td>Rater 1</td>
<td>present</td>
<td>29</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>absent</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Rater 2</td>
<td>present</td>
<td>29</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>absent</td>
<td>0</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Specificity</th>
<th>Sensitivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rater 1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Rater 2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: not a single of the self-defined collectors met criteria for HD!

### Inter-rater reliability (kappa)

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rater 1 vs Rater 2</th>
<th>p-value</th>
<th>Rater 1 vs BED</th>
<th>p-value</th>
<th>Rater 2 vs BED</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>.97</td>
<td>&lt;.001*</td>
<td>1</td>
<td>&lt;.001*</td>
<td>.97</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Criterion A</td>
<td>.79</td>
<td>&lt;.001*</td>
<td>1</td>
<td>&lt;.001*</td>
<td>.79</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Criterion B</td>
<td>.80</td>
<td>&lt;.001*</td>
<td>.92</td>
<td>&lt;.001*</td>
<td>.86</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Criterion C</td>
<td>.94</td>
<td>&lt;.001*</td>
<td>1</td>
<td>&lt;.001*</td>
<td>.94</td>
<td>&lt;.001*</td>
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<tr>
<td>Criterion D</td>
<td>.68</td>
<td>&lt;.001*</td>
<td>.97</td>
<td>&lt;.001*</td>
<td>.71</td>
<td>&lt;.001*</td>
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<tr>
<td>Criterion E</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Criterion F</td>
<td>1</td>
<td>&lt;.001*</td>
<td>.90</td>
<td>&lt;.001*</td>
<td>.90</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>
Excessive acquisition specifier

- Both specifiers were assessed independently for both raters.
  - Rater 1: all 29 individuals with HD endorsed this specifier
  - Rater 2: 28 (97%) endorsed it
- Obtainment of free items (both raters, N=27, 93.1%)
- Excessive buying (Rater 1: N=22, 75.9%; Rater 2: N=18, 62.1%; Kappa=.68, p <.001).
- Stealing (both raters, N=2, 6.9%).

Insight specifier

<table>
<thead>
<tr>
<th></th>
<th>Rater 1</th>
<th>Rater 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/fair insight</td>
<td>N=25 (86.2%)</td>
<td>N=26 (89.7%)</td>
</tr>
<tr>
<td>Poor insight</td>
<td>N=3 (10.3%)</td>
<td>N=2 (6.9%)</td>
</tr>
<tr>
<td>Absent (delusional)</td>
<td>N=1 (3.4%)</td>
<td>N=1 (3.4%)</td>
</tr>
</tbody>
</table>

- Good inter-rater agreement (ICC=.66, 95% CI=.38–.83).
- Degree of insight on an ordinal scale (good/fair, poor, absent/delusional) poorly correlated with the BABS (Rater 1: Spearman rho=-.34, p=.08; Rater 2: Spearman rho=-.24, p=.21).
If Drs were to agree on creating a new diagnosis called hoarding disorder, how acceptable would you find this?

Perceived acceptability

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Do you think this diagnosis would be useful for the development of more specific treatments for this condition?

Perceived usefulness
Would you find it **stigmatizing** to receive such a label?

- **Not at all stigmatizing**: 8
- **Not too stigmatizing**: 9
- **Somewhat stigmatizing**: 8
- **Very stigmatizing**: 4

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Is criterion C too strict?

- 16 individuals were ‘sub-clinical’; of those, 12 had substantial distress and interference but their use of space was not TOTALLY impossible (did not endorse C).
- Are some of those false negatives?
- Subclinical cases were less severe but their scores were still within the clinical range
- Subclinical cases more likely to be in a relationship, be highly educated and live in larger properties (protective factors?)
Refinement of the criteria

- Several minor wording changes
- Criterion B: Change word ‘urge’ to ‘perceived need to save’
- Criterion C: “The symptoms result in the accumulation of a large number of possessions that congest and clutter active living areas of the home to the extent that their intended use is no longer possible, or substantially impaired....
- The latter should improve the balance between false positives and false negatives

Summary and Conclusions

- Preliminary data show that the proposed criteria are valid and highly reliable.
- The criteria are written conservatively and appear unlikely to over-pathologise normal behaviour. In fact, the wording may be too strict and lead to false negatives.
- The proposed criteria are deemed acceptable/useful by professionals and sufferers alike.
- The ongoing field trial may provide further information.
- The criteria require testing in pediatric samples and in other cultures.
What happens next?

- DSM-5 Scientific Review Committee has approved the inclusion of the new disorder – scored very high
- Text has been written and is currently being reviewed by the various committees (developmental, life span, gender, cultural, race and ethnicity)
- Feedback generally enthusiastic
- As far as I know, all is on track for publication in 2013!

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