1 Advanced hoarding

1.1. Collecting vs. Hoarding

- Collecting might be motivated by existential anxieties – the collection, an extension of our identity, lives on, even though we do not
- One psychoanalytical explanation for collecting is that unloved children learn to seek comfort in accumulating belongings
- More recently, evolutionary theorists suggested that a collection was a way to attract potential mates by signalling an ability to accumulate resources
- The endowment effect – describes our tendency to value things more once we own them
- The concept of contagion – some collectors are attracted to celebrity belongings because these objects are seen as being infused with the essence of the person who owned them (more about this in a moment).

The fuzzy boundaries between hoarding and collecting

- A collection excludes things; a hoard is omnivorous
- Hoards are hidden behind closed doors while collections are often on display.

1.2. At what point does a collection become a hoard, a collector a hoarder?

'A passion for collecting is a healthy outlet and an activity that keeps people connected to the world around them. But it can become a deadly enterprise when it crosses the line into hoarding' (Professor Randy Frost – Professor of Psychology)

At what point is the problem identified to be as a result of a disorder?

'A persistent difficulty discarding or parting with possessions regardless of their actual value'?

- Even if discarding is taking place, the continuation of collecting will still be a potential issue
- The collector/hoarder does not perceive there to be a problem
- To what extent is the availability of space a determinant as to whether the collection has become a hoard?

2 Latest or relevant research into Hoarding

2.1. Mataix, Pertusa and Snowden (2011) Is Hoarding genetic?, Journal of clinical psychology

Their research found that 'Hoarding runs in families'.

- 50-85% of hoarders report first degree relative who is a "packrat"
- 26-54% report family members with OCD
- Heritability of hoarding is 71%
- In a study of >5,000 twins, genetic factors accounted for 50% of variance, along with nonshared environmental factors, error
- Genetic studies suggest hoarding ≠ OCD.

2.2. Ayers, C.R et al (2018) Age at onset and clinical features of late life compulsive hoarding. Int J Geriatric Psychiatry 25: 142-149

- Hoarding symptoms typically started early, and always before age 30
- Hoarding severity increased with age
- ~50% had other psychiatric disorders, but only 16% had OCD
- Compulsive hoarding was grossly under detected and untreated (only 2/13 received any support or treatment for hoarding).

2.3. Lavigne et al (2016) Diogenes syndrome and Hoarding disorder: Same or different? L'Encephale, vol 42, 5, pg 421-425

- The Diogenes syndrome was first described in 1966 but was officially named for the ancient Greek philosopher in 1975 by Clark
- Its frequency is around five for 100,000 persons.

The diagnostic requires one major criteria*

The inability to ask for medical or social help.

Also, one of three minor criteria:

- A pathological relationship to the body, which leads to somatic illness
- A pathological relationship to the society, which leads to a progressive exclusion from it
- Finally, a pathological link with objects.

This last criterion is very interesting because it is closely related to the Hoarding syndrome: indeed, patients with Syllogamania, as also named, have a tendency to hoard every object they find. At the end, their homes are full of useless objects, and some living places can be unusable because they are cluttered and congested.

This last point is similar to the definition given in the DSM-5 for the hoarding disorder which describes a persistent difficulty parting with possessions; distress associated with discarding possessions; and accumulations that congest and clutter active living areas.

The hoarding disorder was first part of the obsessive and compulsive disorders, but it has progressively appeared that it could be individualized with its own prevalence of 2.3% to 14% lifetime. Genetical studies have shown that at least 50% of patients suffering from excessive hoarding had a relative with a dimension of hoarding.

2.3.1. Relationships between Hoarding disorder and the Diogenes syndrome

- A person with hoarding, and a poor insight, could be very isolated, and could persist in a lack of calling for help, because of not being aware of his pathology
- Thus, it could be diagnosed as a hoarding syndrome with a poor insight, or as a Diogenes syndrome, with the first major criterion (lack of calling for help) and one of the three minor criteria, the Syllogomania, or hoarding.

Sometimes old people living for many years have a tendency to hoard. Progressively, some of them had a congested and cluttered home, and a few were living in squalor, a description very close to the Diogenes syndrome

- They call for a dimensional model, based on two dimensions: hoarding and squalor
- Hoarding disorder is the major expression of the first dimension, and Diogenes syndrome the major expression of the second
- Both of them could be a different expression of one central aetiology.

2.4. Nordsletten and Mataix-Cols (2012) Hoarding versus collecting: where does pathology diverge from play?

- Considerably less attention has been paid to addressing the suitability of the proposed criteria for effectively differentiating pathological hoarding from normative collecting behaviour
- This is crucial in order to avoid false positives or the over pathologisation of this widespread human activity
- Collecting behaviour mirrors many of the core features of hoarding (eg, the acquisition of and emotional attachment to a potentially large number of objects), is highly prevalent and is generally considered a normative form of object amassment; as such, it represents a valid population with which to explore the diagnostic boundaries of Hoarding Disorder.

- For a minority of 'extreme' collectors, a diagnosis may potentially be adequate.

2.5. Mueller, A. and De Zwaan, M. (2010) An overview of empirical findings with regard to compulsive hoarding. Psychiatric, Prax. 37(4): 167-74

- Neuropsychological studies and neuroimaging indicate dysfunction of the anterior cingulated cortex and other ventral and medial prefrontal cortical areas
- Brain-imaging studies of people with Hoarding Disorder reveal abnormal activation in areas of the brain known to process:

  Error monitoring

  Weighing the value of things

  Assessing risks

  Unpleasant feelings

  Emotional decisions.
- These studies pinpoint brain circuit activity suspected of underlying the lack of self-insight, indecisiveness, and inflated desirability of objects.

2.6. Frost, R. Patronek, G. and Rosenfield,E. (2011) Comparison of object and animal hoarding. Depression and Anxiety, May 2013

- This article discussed the similarities and differences between object and animal hoarding
- People who hoard animals appear to meet the basic diagnostic criteria for hoarding disorder
- Their homes are cluttered, disorganized, and dysfunctional
- They have great difficulty relinquishing animals to people who can more adequately care for them, and they form intense attachments (urges to save) that result in significant impairment
- However, they differ from people who hoard objects in several ways
- They conclude by stating that some Animal Hoarders may meet the criteria for Hoarding Disorder, some may not. They call for further research into animal hoarding, and possible changes to the criteria in the future.

2.7. Ivanov et al (2018) Enhancing group cognitive-behavioural therapy for hoarding disorder with between-session Internet-based clinician support: A feasibility study. J Clin Psychol. 2018 Jul;74(7)

- In this research they combined CBT with in between session Internet net support (therapist could skype and interact with the client)

- This additional contact (weekly or twice per week) produced a reduction in the 'Saving inventory-revised, better treatment attendance, and better outcomes over three months
- Between-session motivational support from the therapist was most frequently mentioned as the main strength of the system.

3 Hoarding background information

3.1. Hoarding and mental health

Around 75% of individuals who have HD have a co-occurring mental health condition.

The most common co-occurring disorders are:

- Major depressive disorder
- Social anxiety disorder/social phobia
- Generalized anxiety disorder
- Around 20% of people with HD also have OCD.

3.2. Hoarding origins?

Hoarding symptoms begin to appear early in life and continue through the entire lifespan, increasing in severity with each passing decade – if untreated.

- Ages 11-15: symptoms may first emerge
- By the mid-20's: symptoms begin interfering with everyday functioning
- By the mid-30's: individuals demonstrate clinically significant impairment and are likely to meet full criteria for a diagnosis of HD
- Hoarding symptoms appear to be almost three times more common in older adults (ages 55-94 years).

3.2.1. Increased challenges with older adults include:

- Older adults tend to have more collected items
- Increased risk of severe injury related to a fall or topple hazard
- Tend to have more risk of diminished physical and mental capacity (disease, dementia)
- Multiple medications/multiple medical providers
- Combined issues possibly indicating self-neglect

- Tend to have more losses (less support)
- Not familiar/comfortable with psychiatric treatment.
- Limited/fixed income.

3.3. Squalor

- Squalor is a situation of extreme filth, decay, deterioration of objects and or structure
- Often includes infestation of bugs or creatures seeking shelter
- Mould and mildew usually present
- When the living space is consumed with a high level of items, people with hoarding disorder - by necessity - carve out areas for themselves – often referred to as: a nest – a cocoon – command central – bunker - home base.

3.4. Animal hoarding

- Animal Hoarding was first described in 1982, and formally defined in 1999
- Animal hoarding used to be described as “animal collectors”
- An animal hoarder is someone who had accumulated animals and who fails to provide minimum standards of nutrition, sanitation, and veterinary care
- A person can have just a few animals and meet the standard of ‘animal hoarder’
- Likewise, they can have a substantial number of animals, but not be animal hoarders because of good care.
- Animal hoarders fail to act on the deteriorating condition of the animals (including disease, starvation and death), and the environment (severe overcrowding, and extreme unsanitary conditions
- They also do not have insight into the negative effects on their own health and well-being, and that of other family members
- Air quality is a concern in animal hoarding situations. It is not uncommon for first responders to require respiratory protection during removal of the animals
- Ammonia is a known irritant of the eyes and upper respiratory tract. In the US the Occupational Safety and Health Administration (OSHA) sets a limit of 50 ppm (parts per million) for safe air quality
- Like with hoarding disorder of inanimate objects, animal hoarding situations also have close to 100% relapse rate without on-going monitoring and oversite
- Those who hoard animals have the fixed belief they are truly helping the animals, regardless of the state of care, health or even death of the animals in the home.

3.5. General hoarding information

Types and characteristics of hoarding

BIBLIOMANIA: Books and written information – such as newspapers, magazines and articles, and to include DVDs and videos, and data hoarding. It could present with the storage of data collection equipment such as computers, electronic storage devices or paper. A need to store copies of emails, and other information in an electronic format.

Fear and anxiety: compulsive hoarding may have started as a learnt behaviour or following a significant event such as bereavement.

- The person who is hoarding experiences comfort in buying or saving things which may relieve the anxiety and fear they feel.
- Any attempt to discard the hoarded items can induce feelings varying from mild anxiety to a panic attack with sweats and palpitations.

Long-term behaviour pattern: possibly developed over many years where comfort is attained by buying, and a value attributed to the item through the process of purchasing, then experiencing anxiety at the idea of merely throwing away such item.

Excessive attachment to possessions: people who hoard may hold an inappropriate emotional attachment to items.

Indecisiveness: people who hoard may struggle with the decision to discard items that are no longer necessary, including rubbish. This can cause a distraction from the real issue by deflecting and raising other concerns, eg, pest control.

Unrelenting standards: people who hoard will often find faults with others, require others to perform to excellence while struggling to organise themselves and complete daily living tasks.

Socially isolated: people who hoard will typically alienate family and friends and may be embarrassed to have visitors. They may refuse home visits from professionals and not engage well with any agency.

Large number of pets: people who hoard may have a large number of animals that can be a source of complaints by neighbours due to insanitary conditions that the large number of animals creates.

Churning: hoarding behaviour can involve moving items from one part of the property to another, without ever discarding them.

Self-care: a person who hoards may appear unkempt and dishevelled, due to lack of bathroom or washing facilities in their home. However, some people who hoard will use public facilities in order to maintain their personal hygiene and appearance.

Insight? A person who hoards may see nothing wrong with their behaviour and the impact it has on them and others.

Forced "clean out" is the last resort: ie, when possessions are a fire/health hazard (vermin, rodents, toxins, or risk of falls).

POOR outcome long-term

- Consider risk management approach if possible
- Slow gradual steps to establish trust, working relationship
- Gradual reduction of risk.

4 Hoarding disorder (May 2013 – DSM-V) Diagnostic Criteria 300.3

- Manifest features are acquisition, saving and chronic disorganization
- Not a character flaw caused by laziness, lack of standards, or lack of responsibility
- Large percentage of those with HD are competent and able to make their own decisions.

4.1. All six criteria must be met

1. Persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions.
2. This difficulty is due to strong urges to save items and/or distress associated with discarding
3. 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 become uncluttered, it is only because of the interventions of third parties (ie,: family members, staff, etc.).
4. The symptoms cause clinically significant distress of impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
5. The hoarding symptoms are not due to a general medical condition (eg, brain injury, cerebrovascular disease).
6. The hoarding symptoms are not restricted to the symptoms of another mental disorder (eg, 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).

4.2. Obsessive compulsive disorder hoarding

Around 20% of people with HD also have Obsessive Compulsive Disorder (OCD)

- In some cases, a person may appear to have HD, when really, they have OCD

- This can occur when the apparent hoarding behaviours are the result of OCD symptoms.

Examples:

- Contamination obsessions may prevent someone from touching things that have fallen to the floor
- A person who feels they must check, and re-check documents may ignore piles of papers to avoid their checking rituals
- Non-religious or moral scrupulosity obsessions may enhance a person's hypersensitivity regarding feelings of guilt around issues of waste or phobias of being wasteful.

4.3. OCD – based hoarding

Here are some other differences between saving and clutter due to OCD and HD:

- In OCD, the individual does not get any pleasure from saving things and the resulting clutter, which they find to be unwanted and highly distressing
- Individuals with OCD are much less interested in the items they save. They have few sentimental attachments or beliefs about the value/worth of the items themselves
- Excessive acquisition of items is rare among those with OCD based saving and clutter
- Saving and clutter due to OCD is treated by using the same treatments methods used for other types of OCD (exposure with response prevention (ERP) and/or medication (antidepressants)
- Excessive anxiety about others moving or touching possessions
- Inability to complete necessary activities due to clutter (cooking, paying bills, etc.)
- Inability to use areas of home as intended; lack of working utilities/appliances
- Inability to work because of the clutter
- The distress or impairment caused by hoarding can be seen in a variety of ways.

5 Practical aspects of working with hoarders

Important interpersonal aspects

- Utilize curious questioning (Cultural Humility)
- Use Empathic Statements
- Statements of Concern

- Focus on relationship building instead of clutter reduction
- Initially identify issues of safety/imminent risk
- Develop a collaborative “plan of attack”.

Action words

- Tell me about…
- Show me…

Curious questioning

- I wonder if…
- Help me understand…

Empathic statements

- It sounds like you are feeling (worried about, frustrated, etc.)…
- I can understand (how hard this is, that you are feeling sad, etc.)…

Statements of concern

- I worry that …
- I am concerned because …

6 Treatment and therapies?

Treatment with Cognitive Behavioural Therapy (CBT) and Motivational Interviewing (MI) Evidence supports benefits of CBT and MI – 70% or more of those who hoard show improvement after 26 CBT sessions, which can take a year or more. CBT with exposure therapy, MI, and harm reduction, are often used in conjunction with one another.

6.1. CBT Treatment

- Type of therapy that challenges negative thoughts
- Works on changing beliefs about the self and the world
- Based on the premise that your thought and beliefs affect your behaviour, as well as conscious or unconscious emotions
- Identifying Core Beliefs: deeply ingrained beliefs, possibly formed early in childhood, that we have about different areas of life

- They serve as “filters” though which we process information
- We all have different life experiences, so our filters are unique to us
- This is why two people can experience the same event differently
- Finding the core value through Downward Arrow Interviewing
- Aaron Beck developed the downward arrow technique to get through automatic/obsessive thoughts to the persons’ core beliefs.

6.2. An in-home session discussing piles and piles of yogurt containers

- **W**: “What would be so bad if you got rid of those yogurt containers?”
- **C**: “I need them. They can be very useful”
- **W**: “What would be so bad if you didn’t have the containers?”
- **C**: “I wouldn’t know what to put things in, like leftover food.”
- **W**: “What would happen if you couldn’t store food in the containers?”
- **C**: “It would spoil.”
- **W**: “What would happen if your food spoiled?”
- **C**: “That would be wasteful.” This is the Core Belief that is driving the saving It’s painful for all of us to confront our core beliefs.

As the discussion unfolds, the worker talks about whether the client was worried that she was a wasteful person, or that her behaviour was wasteful.

- Build up from least to most feared situation (hierarchy)
- Start with small area of focus
- Help client learn to tolerate and manage anxiety
- Anxiety will dissipate, the body cannot remain anxious forever
- Frequent exposure is necessary to develop a new skill set
- Schedule consistent appointments for exposure work.

6.3. Motivational interviewing

Using Motivational Interviewing/motivational techniques:

- The best strategy is to begin with the client’s concern
- Don’t assume that the hoarded environment is what they see as the problem

- They may say “How do I get (my daughter/landlord, that social worker, etc.) to leave me alone.”
- Identifying what their motivational goal is, can lead to contracting steps required to meet that goal
- Motivation to change depends on two things:

  Importance of the change

  Confidence that they can change.

7 Harm reduction approach

It’s an approach to managing severe hoarding to decrease the harmful consequences of hoarding, especially when the person consistently refuses help or treatment, and continues to engage in the behaviour or activities that place their health and safety (or that of others) at immediate risk.

7.1. Reduction principles

- Recognize that the person may make the decision not to allow harm reduction interventions, by exerting their right to autonomy
- It’s not necessary that the individual stop all hoarding behaviour – just make environment habitable - “good enough”
- Change is slow (reasonable adjustments
- The person with Hoarding Disorder is an essential part of the harm reduction/care plan team.

7.2. Three Goals: SAFETY-HEALTH-COMFORT

SAFETY

- Move flammable materials away from heat sources
- Clearing 3-foot walkways of potential trip hazards
- Clearing enough room around doors and windows for exit in an emergency, and for staff or fire brigade/ambulance.

HEALTH

- Clear access to the bathroom and washing facilities
- Make sure appliances are functional: (refrigerator/toilet/shower/oven/laundry)
- Ensure proper food storage

- Address appropriate trash and waste disposal
- Eliminate pest infestations.

COMFORT

- Addressing heating and cooling problems in the room
- Ensure proper ventilation
- Designate and clear appropriate places to sit, sleep and socialize.

8 Legislation relevant to hoarding behaviours

8.1. Mental capacity

When working with people with hoarding behaviour it is important to remember that capacity is assumed unless it has been formally assessed otherwise by a person qualified to make that decision. The Mental Capacity Act (MCA) 2005 provides a statutory framework for people who lack the capacity to make decisions by themselves.

The Act has five statutory principles and these are legal requirements of the Act:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.
4. An act done, or decision made, under this act for, or on behalf of, a person who lacks capacity must be done, or made in the person's best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The core principles of the MCA 2005 clearly identify that professionals should always start from an assumption of capacity. Doubts about a person's capacity may arise because of: their behaviour, circumstances or concerns raised by a third party.

When a person's hoarding behaviour poses a serious risk to their health and safety, professional intervention will be required. With the exception of statutory requirements, the intervention or action proposed must be a proportional response.

Although the person may be considered to have mental health issues this does not mean that they have issues with capacity.

Capacity can fluctuate and when someone's capacity is being assessed, there is a two stage test which in brief is as follows:

- Does the person have an impairment of the mind or brain or is there some sort of disturbance affecting the way their mind or brain works (whether the impairment or disturbance is temporary or permanent)
- If so, does the impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

Consequently, a person can have mental capacity to carry out certain acts or make certain decisions but lack capacity for others.

9 Tools to use with Hoarders

9.1. Subjective units of distress scale

Before discussing the process of organising and de-cluttering it is important to explain the concept of SUDS, since this is central to the conduct of any exposure procedure. It's a good way to measure anxiety and stress.

Try to get used to rating their anxiety or discomfort on a scale of 0 – 100. Imagine you have a "fear thermometer" to measure your anxiety according to the following scale. Notice how your level of anxiety changes over time and in different situations.

SUDS: The Fear Thermometer



100	Highest anxiety/distress that you have ever felt
90	Extremely anxious/distressed
80	Very anxious/distressed, unable to concentrate
70	Quite anxious/distressed, interfering with performance
60	
50	Moderate anxiety/distress, uncomfortable but can continue to perform
40	
30	Mild anxiety/distress, no interference on performance
20	Minimal anxiety/distress
10	Alert and awake, concentrating well
0	Totally relaxed

The SUDS is simply a means of rating the severity of current distress (or anxiety), thereby allowing you to monitor changes over time, for example, following the teaching of an anxiety management strategy or during exposure to a feared stimulus.