HOARDING: What is it & How to Help

CATHERINE CHATER, MSC, OT REG ONT

www.vha.ca
When I see this….

HOW DO I FEEL? WHAT AM I THINKING?

• “Hoarders are gross!!”
• “Every time I watch this show I clean my entire room.”
• “Poor thing she needs help”
• “OMG! this is disgusting!”
• “This woman is simply … lazy”
• “Easy. Hire a dump truck and haul it all to the dump.”
When I see this....

HOW DO I FEEL? WHAT AM I THINKING?

Health workers report:
• frustration, irritation, hopelessness, helplessness
• debating/arguing with client
• relief when client is no-show or a desire to transfer.

PRS correlates with working alliance (but not hoarding symptom severity!)

Recognize Hoarding Disorder = Chronic, complex, diminished insight, limited Tx adherence

Patient Rejection Scale (PRS)
To what extent did your client:
• show insight into the nature of her/his problems with hoarding?”
• display poor problem-solving skills?
• have difficulty answering questions about hoarding or other problems appropriately?” (providing too much info, irrelevant info, etc.)

Today’s Objectives

HERE’S WHERE WE ARE GOING

By the end of this workshop:

1. **Describe what is Hoarding Disorder**
   *(Why is it chronic/complex and with low insight/treatment)*

2. **Name two main types of approach to treating Hoarding Disorder (HD)**
   *(What can be done to help)*

3. **List a strategy (or more!) to optimize your support of clients who have HD**
   *(What you can do to help)*
Hoarding Disorder

THE NEW SCIENCE OF AN OLD DISORDER

Sherlock Holmes, according to Dr. Watson:

“Our chambers were always full of chemicals and criminal relics, which had a way of wandering into unlikely positions, and of turning up in the butter-dish, or even less desirable places….

He had a horror of destroying documents…Thus month after month his papers accumulated, until every corner of the room was stacked with bundles of manuscripts …”

~Sir Arthur Conan Doyle, 1893

What is Hoarding Disorder?

RECENTLY INCLUDED IN THE DSM-V

Hoarding ≠ OCD

- Raise awareness
- Reduce stigma
- Develop services
- Research
- Treatment guidelines

[Mataix-Cols & de la Cruz, 2014; Diagnosis of Hoarding Disorder, in The Oxford Handbook of Hoarding and Acquiring]
What is Hoarding Disorder?

**DSM-V CRITERIA**

1. **Difficulty Discarding**
   - Even objects of seemingly limited value
   - Due to strong urges to save items and/or distress with discarding

2. **Excess Clutter**
   - Rooms cannot be used for their intended function
   - Uncluttered by 3rd party

3. **Significant Distress, Impaired Functioning and/or Safety Risk**


Creating More Independence
Hoarder Disorder: Excessive Acquisition

DSM-V SPECIFIER

88%

Excess Acquisition*
*past or current EA; 526 self ID hoarders; 369-HD)

- Buying
- Acquiring
- Stealing

Avoidance of garage sales, dollar stores, shopping malls, etc.

Insight

Insight into presence or seriousness of problem is often limited.

- Refusal of treatment
- High treatment drop-out


Studies suggest hoarding is more frequent than first thought:

~ 5 % of POPULATION

Schizophrenia – 1%
OCD – 2.3%

[Iervolino et al 2009; Mueller et al 2009; Timpano et al 2011]

Hoarding Comorbidity

LIKELY TO HAVE ANOTHER MENTAL HEALTH CONDITION(S)

- Depression ~50%
- Generalized Anxiety Disorder ~25%
- Personality Disorder ~70%
- Alcohol Dependence ~50% (lifetime)
- ADHD ~20-30%
- Substance Abuse ~20%

Hoarding Comorbidity

LIKELY TO HAVE ANOTHER PHYSICAL HEALTH CONDITION(S)

HD vs. non-HD:

90% have 1+ medical condition
(vs. 44% without HD-seniors)

- Hypertension 61%
- Stroke 11%
- Sleep apnea 22%
- Seizures 11%

Less likely to receive regular care from primary provider.

Cross Cultural Experiences of Hoarding

HOARDING IS NOT A NORTH AMERICAN CONCERN

North America, Italy, Spain, Germany, England, Australia, Iran, Brazil...

Hoarding beliefs in China centered on themes of usefulness and wastefulness compared to more heterogeneous themes in the West...

Understanding Hoarding Disorder

OBJECTIVE 1: DESCRIBE WHAT IS HOARDING DISORDER

Why does hoarding occur?
Cognitive-Behavioural Model of Hoarding
FROST & HARTL, 1996

Vulnerability Factors
- Genetics
- Early Experiences
- Traumatic Life Events
- Family History

Beliefs about Possessions
- Emotional Attachment: personal significance
- Instrumental: waste, responsibility, opportunity
- Perception of poor memory

Emotional States
- Negative Feelings (avoided): anxiety, sadness, guilt, grief
- Positive Feelings (sought after): joy, pleasure, pride

Information Processing Problems
- Attention
- Memory
- Executive Functioning

Difficulty Discarding. Excessive Acquisition.

---CLUTTER---
Why Hoarding?

AN AREA OF ACTIVE RESEARCH

• 4x more common if excessively physically disciplined in childhood
• 4xs more common if break-in during childhood
• 3xs as common with parent with psychiatric symptoms
• More likely to recall lack of warmth in early environment
• 3xs more common in people over 55
  Average age of onset: 13

Associated with Trauma

CLUTTER MAY SERVE A PROTECTIVE FUNCTION

People who hoard report experiencing high levels of stressful & traumatic life events.

TRAUMATIC EVENTS
- Interpersonal violence (75%)

STRESSFUL LIFE EVENTS
- Loss or damage to possessions (61%)
- Loss or change in relationship (divorce, marital separation, death of close family member) (90%)

Samuels et al. (2008); Grisham et al. 2006; Tolin et al. 2010
People who hoard DO NOT tend to report material deprivation.

I GREW UP IN THE DEPRESSION

Scarcity as a Risk Factor?

[Landau et al, Stressful Life Events & Material Deprivation in Compulsive Hoarding. 2011]
Genetics

Genes can contribute to development of hoarding.

Hoarding runs in families

- 50-85% report close relative is a “packrat”
- Twin studies suggest genetic factors account for ~50% of variance

[Saxena et al, 2008; Mathews et al 2001; Zhang et al 2002; Samuels et al 2007]
What things are hoarded?
Common Household Items

WIDE RANGE OF CATEGORIES + MORE OF THEM

Top 10:
1. Clothes
2. Books
3. Mementos/ souvenirs
4. Cards, letters
5. Bills, statements
6. Sentimental objects
7. Records, tapes
8. Knick knacks
9. Stationary
10. Recipes

Inside the Mind of Someone who Hoards

Why are these things hoarded?
Get out your KEYS please!

Why do you keep what you do on your key chain?
People who hoard typically keep things for the **same reasons** that most people do.
Why Things are Kept

EMOTIONAL ATTACHMENT, POTENTIALLY USEFUL

Sentimental
(Emotional attachment)

Intrinsic
(Evoke pleasure)

Instrumental
(Have potential use)

[Farby, 1978; Kellet et al, 2010; Pertrusa et al 2010]
Accumulating possessions can range from adaptive to excessive

Organization Skills

1. Attention:
2. Memory
3. Categorization
4. Decision-making

Neurocognitive impairments key factor in the onset and maintenance of hoarding.

[Gilliam & Tolin, 2010]
Assess Decision-Making

OBSERVE DISCARD DECISIONS; DETAILS, PERFECTIONISM

**Sorting:** Longer to decide, more anxiety, activation of regions in brain associated with emotional regulation. Effect greater with own papers.

Iowa Gambling Task
No impairment observed: complex decision-making.

Global indecisiveness likely not specific feature of HD.

Tolin, Kiehl, Worhunsky, Book, & Maltby, 2009; Tolin et al., 2012
Difficulty staying on task during session, easily distracted, tangential, overly-inclusive speaking style

- Robust relationship between ADHD and hoarding
  - ~28% meet ADHD criteria
- Self-report high levels of inattentiveness
- Research inconsistent: possible impaired visual attention

[Tolin & Villavincencia, 2010; Frost et al 2011; Moody et al, 2014]
Memory

MEMORY CONFIDENCE AND IMPAIRMENT

Worry about forgetting information, events, relationships → rely on objects to serve as memory aid.

Items not put away into storage.

Brief Visual Memory Test: Research Inconsistent: possible visuospatial memory impairment

Categorization

UNDER INCLUSIVE

Hoarding: longer, more piles, distressing

[Grishma et al 2010; Wincze et al 2007; Luchia et al 2007]
Cognitive-Behavioural Model of Hoarding

FROST & HARTL, 1996

Vulnerability Factors
- Genetics
- Early Experiences
- Traumatic Life Events
- Family History

Beliefs about Possessions
- Attachment
- Usefulness
- Intrinsic (Perception of poor memory)

Emotional States
- Negative Feelings (avoided)
- Positive Feelings (sought after)

Information Processing Problems
- Attention
- Memory
- Executive Functioning

Difficulty Discarding. Excessive Acquisition.

---CLUTTER---
Treatment of Hoarding Disorder

What can be done to help?
Avoid Focusing on the Clutter

THE PERSON IS THE KEY

“I want to know how to help my client with their hoarding problem”

Tell me how to get them to clear out the clutter!

100 ...... 75 ....... 50 ....... 25 ...... 0

%True?
What does help?

TWO TYPES OF SERVICES

Cognitive Behavioural Therapy  Harm Reduction

Which service will remove the clutter & prevent it from returning?
Cognitive Behavioural Therapy for HD

TEACHING SKILLS, EMOTIONAL REGULATION

1. Adjust thinking patterns
2. Organization Skills
3. Sorting/discard training
4. Exposure to non-acquiring

Motivation Strategies

Home HealthCare
Creating More Independence
Cognitive Behavioural Therapy for HD

TEACHING SKILLS, EMOTIONAL REGULATION

Goals of CBT:
1. Reduce frequency of hoarding behaviours
2. Teach skills to re-appraise need to hold onto or acquire belongings
3. Improve ability to regulate emotions

Treat symptoms to reduce impairment
CBT Treatment for Hoarding Disorder

LINKING YOUR CLIENTS TO SERVICE

CBT-trained therapists
- Outpatient mental health clinics
- Sunnybrook: Dx & group CBT

Guided bibliotherapy
- Delivery by non-clinicians
- Outcomes comparable
- Web Search: Facilitator’s Guide


[Image of CBT book covers]
CBT Effectiveness

TREATMENT RESULTS

Moderate Treatment Effects

Treatment completers:

• Most change with Difficulty Discarding

• Better outcomes with Women, Younger age, Greater number of CBT sessions

Room for Improvement

• Costly
• Can take ~1 year to complete
• Few clinicians are trained

Tolin, Frost, Steketee, Muroff. CBT for Hoarding Disorder: a Meta-Analysis Depression & Anxiety 32: 158-166
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CBT Effectiveness – Clinical Significance

CLINICALLY SIGNIFICANT CHANGE LESS ROBUST

With 13-35 CBT sessions by trained facilitator; in home & clinic:

Tolin, Frost, Steketee, Muroff. CBT for Hoarding Disorder: a Meta-Analysis Depression & Anxiety 32: 158-166
CBT Effectiveness – DIFFICULTY DISCARDING

CLINICALLY SIGNIFICANT CHANGE LESS ROBUST

# post treatment scores fit with general population, not hoarding population:

Symptomatic

Tolin, Frost, Steketee, Muroff. CBT for Hoarding Disorder: a Meta-Analysis Depression & Anxiety 32: 158-166
CBT Effectiveness - **CLUTTER**

**CLINICALLY SIGNIFICANT CHANGE LESS ROBUST**

# post treatment scores fit with general population, not hoarding population:

*In-home sessions improve clutter, discarding, impairment outcomes*

- To be effective, more time and intervention may be required than is typically provided with CBT.

Tolin, Frost, Steketee, Muroff. CBT for Hoarding Disorder: a Meta-Analysis Depression & Anxiety 32: 158-166
Harm Reduction – Reduce Safety Risks

FIRE … EVICTION … INFESTATIONS …. UNSANITARY CONDITIONS …
Harm Reduction focuses on organizing & discarding only that which is necessary to maintain the person in their home with improved safety & comfort.

Harm Reduction for Hoarding Disorder

DECREASE CONSEQUENCES OF HIGH RISK BEHAVIORS

Does not require the individual stops hoarding.

Goals of Harm Reduction:
• Improve safety of client
• Move possessions to reduce hazards
• Support to organize
• Decluttering/cleaning of high risk spaces

Harm Reduction – Clutter Impact

REALISTIC OUTCOMES
Type of Intervention ➔ Stage of Recovery

“Help – I want to change this”

“**I don’t have a hoarding problem**”

Harm Reduction

SAFETY RISKS

Cognitive Behavioural Therapy

FEW RISKS

[Prochaska & DiClemente, 1982; Miller & Resnick, 2013]
Assessing Readiness / Stage of Recovery

ASKING THE RIGHT QUESTION

Yes  Is the client ready?  No

What **type of service** will most support positive change?
What are they ready for?
Assessment: What type of service will help?

THE ANSWER TELLS YOU HOW BEST TO PLAN

Readiness Spectrum

Action……….Preparation……..Contemplation……..Pre-Contemplation

Strategies overlap – in home visits, Ax/plan
Not static – expect change, Ax ongoing
Hoardings Assessment

WHAT TO ASSESS & DOCUMENT

Client Demographics:
- Age, gender, marital status, address, number of occupants in the home...

WHAT TO ASSESS & DOCUMENT

Medical Status:
- Diagnosis, comorbidities, past medical history, surgeries, medications...

WHAT TO ASSESS & DOCUMENT

Hoarding History:
- Time of onset, circumstances of onset, family history, client's perspective of etiology...

WHAT TO ASSESS & DOCUMENT

Status of the Home:
- Volume of clutter, usability of rooms, content of clutter, structural issues...

WHAT TO ASSESS & DOCUMENT

Treatment History:
- Type(s) of treatment modalities, success, nature of therapeutic alliance...

WHAT TO ASSESS & DOCUMENT

Goals of Client:
- Motivation to change, reasons for addressing hoarding, desired outcomes (client, referral source, others)...

WHAT TO ASSESS & DOCUMENT

Support Network:
- Family relationships, health professionals, medical care...

WHAT TO ASSESS & DOCUMENT

Acquisition Habits:
- Volume/frequency of acquisition, types of objects, financial circumstances, locations of acquisition...

WHAT TO ASSESS & DOCUMENT

...
Assessment = What do I need to know to best help?

PARETO PRINCIPLE …. FOR HOARDING

The 80:20 Rule

Look for indicators in the person and their environment that are most likely to be changeable and positively impact the situation.
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

**Key Indicators:**

1. Safety & Eviction Risks
2. Good Insight & Motivation
3. Cognitive Functioning
4. Client Goals

**Plan**

Modifiers

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CBT Skills Teaching

Harm Reduction

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YHA Home HealthCare

Creating More Independence
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

**KEY INDICATORS:**

1. Safety & Eviction Risks

To Develop Plan:

- **Assess:** what are the key safety concerns in this situation?
How to assess and intervene in situations of risk:

 ✓ STEP 1: Protect Yourself
 ✓ STEP 2: Safety Assessment
 ✓ STEP 3: Prioritize service goals
 ✓ STEP 4: Provide hands-on support
How to assess and intervene in situations of risk:

- **STEP 1: Protect Yourself**
- **STEP 2: Safety Assessment**
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- **STEP 4: Provide hands-on support**
Safety Risks – how can I assist?

YOUR SAFETY IS IMPORTANT TOO!

✔ **STEP 1: Protect Yourself**

**HOW?**

- Place personal belongings in garbage bag & seal
- Protective equipment: gloves, boots, gown, mask
- Avoid sitting
- Locate exits/paths
- Bring alcohol-based handrub
- Wear PPE if required
Safety Risks: Assessment & Plan

HARM REDUCTION IN ACTION

How to assess and intervene in situations of risk:

- **STEP 1:** Protect Yourself
- **STEP 2:** Safety Assessment
- **STEP 3:** Prioritize service goals
- **STEP 4:** Provide hands-on support

- Clutter Image Rating Scale
- Health & Safety Checklist
- HOMES
- Environmental Cleanliness & Clutter Scale
- Home Environment Index
Safety Assessment

FIRE RISK: VOLUME OF CLUTTER

Fires are Larger in Homes with Hoarding

Financial loss (av.)
- Non-hoarding home = $12 500
- Hoarding home = $100 000

Fires Contained to Room of Origin (av.)
- Non-hoarding home = 90%
- Hoarding home = 40%

https://www.youtube.com/watch?v=qy1h-vbmd78

[Harris, 2012. Household Hoarding and Residential Fires]
Clutter Image Rating Scale (CIR)
FROST, STEKETEE & RENAUD, 2008

In our work on hoarding, we’ve found that people have very different ideas about what it means to have a cluttered home. For some, a small pile of things in the corner of an otherwise well-ordered room constitutes serious clutter. For others, it’s when the narrow pathways make it hard to get through a room does the clutter register. To make sure we get an accurate sense of a clutter problem, we created a series of pictures of rooms in various stages of clutter – from completely clutter-free to very severely cluttered. People can just pick out the picture in each sequence comes closest to the clutter in their own living room, kitchen, and bedroom. This requires some degree of judgment because no two homes look exactly alike, and clutter can be higher in some parts of the room than others. Still, this rating works pretty well as a measure of clutter. In general, clutter that reaches the level of picture #4 or higher impairs enough on people’s lives that we would encourage them to get help for their hoarding problem. These pictures are published in our treatment manual (Compulsive Hoarding and Acquiring: Therapist Guide, Oxford University Press) and in our self-help book (Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding, Oxford University Press).

To use: select picture that most closely matches home conditions. Average out the total volume within the room.
Assessment: Clutter Volume

CLUTTER IMAGE RATING SCALE: FROST, STEKETEE & RENAUD, 2008

Clutter Image Rating: Bedroom
Please select the photo that most accurately reflects the amount of clutter in your room.

1  2  3
4  5  6
7  8  9

http://www.science.smith.edu/departments/PSYCH/rfrost/Hoarding_Images.htm
Clutter Image Rating Scale

Bedroom

4
Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.

1  2  3

4  5  6

7  8  9

[Frost, Steketee, Tolin, Renaud, 2008]
Clutter Image Rating Scale

KITCHEN

6
Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
9.
Clutter Image Rating Scale

LIVING ROOM

8
Typical Fire Safety Concerns with Hoarding:

- A large volume of things which can burn
- Blocked exits & hallways
- Combustibles:
  - near sources of heat (i.e. stove, radiator, exposed lightbulbs),
  - open flames (i.e. candles, lighted cigarettes),
  - on top of extension cords/electrical outlets
- Unsafe cooking/heating practices because utilities or appliances are not working or inaccessible.
Fire services can inspect a home and enforce fire code.

- For example:
  “the tenant shall not allow any activity or permit any condition to exist in the leased premises that may create fire or health hazard”

Breach of fire code can result in inspection orders, fines, court proceedings.
Personal Health Information Disclosure
WITHOUT CLIENT CONSENT

There is no legal duty to inform
• Moral/ethical & professional role

EXCEPT

Children – must be reported to CAS
Example of physical neglect: child’s need for food, clothing, shelter, cleanliness not adequately met
HOMES
BRATIOTIS, 2009

- Assesses squalor conditions
- Can be used to quantify risk for service personnel.

To use: Rate degree of each item 0-3
- Accessibility
- Accumulation of refuse/garbage
- Accumulation of belongings
- Cleanliness
- Bathroom/toilet
- Kitchen/food
- Odour
- Vermin
- Sleeping area
- Structural conditions/maintenance

Positive scores identify areas for goal setting.
Is self-report accurate?

SOMETIMES...

Limited insight common: does not consistently = under-reporting:

Clutter Image Rating Scale:

Person with HD = Indep. Rater ≤ Family

Home Environment Index:

Person with HD < Family

Safety Risks – how can I assist?

HARM REDUCTION IN ACTION

✔ STEP 1: Protect Yourself
✔ STEP 2: Safety Assessment
✔ STEP 3: Prioritize service goals
✔ STEP 4: Provide hands-on support

WHY?
1. Assess level of risk
2. Educate your client about risks
3. Document any concerns
4. Assists to prioritize goals & service
Practice: Assess this Situation

HOARDING BURIED ALIVE: GOURMET KITCHEN

http://www.tlc.com/tv-shows/hoarding-buried-alive/videos/gourmet-kitchen/
Safety Risks: Assessment & Plan

HARM REDUCTION IN ACTION

How to assess and intervene in situations of risk:

✓ STEP 1: Protect Yourself
✓ STEP 2: Safety Assessment
✓ **STEP 3: Prioritize service goals**
✓ STEP 4: Provide hands-on support
Setting Realistic Service Goals
HARM REDUCTION IN ACTION

• You can’t control outcome:
  – Respond to the client, not responsible for the clutter
• See success in small changes:
  – Manage your own expectations for change
• Connect with the goals of the client:
  – “For the PSW to keep coming, here’s what would need to change for them to continue visits”
• Teach skills & support; don’t take away the problem
• Support clients to understand choice consequences:
  “If you keep these newspapers in the hall, what do you think the landlord will do when she inspects the apartment next week?”
1. The client will not fall again in the home.

2. The client & their support team will clear a 75 cm wide path on the stairs. The client will have access to a local handyman service to install handrails & add lighting in the stairwell.

3. The client will stop acquiring new things.

4. The client & their support team will discard all food that is rotten or beyond its expiration date.

Realistic SERVICE Goals: HARM REDUCTION IN ACTION

Tip for Success: write your goals out in a plan for client and all helpers! ‘MOU’

Work on the things that are within your control to influence. You can respond but you are not responsible
Manage Expectations

Hoarder Disorder:
Chronic, Complex,
Clutter slow to change

“We cleared things out just last year and prevented her from being evicted ... now things are right back to where it was!”
Manage Expectations

Realistic goals

- Clients are learning to sort, make decisions, and manage feelings associated with discarding.
- Collaborative work with hoarding clients can move at a glacial pace.
- Organizing and de-cluttering can take a year or even longer.

Defining Features?
1. Accumulation of clutter
2. Unable to use living space
3. Distress with letting go

Most People who Hoard also Experience?
4. Cognitive difficulties
5. Traumatic Life Events
6. Runs in Families
7. Limited Insight
8. Excessive acquisition

Types of Intervention that Help?
9. Harm Reduction
10. Cognitive Behavioural Therapy
VHA Home HealthCare (VHA)—a not-for-profit charity—has provided care since 1925. With over 1,800 staff and service providers VHA offers home and community services that support Ontarians’ independence including: **homemaking, nursing, personal support and rehabilitation services.**

VHA is:

- Accredited with **Exemplary Standing** by Accreditation Canada
- An RNAO **Best Practice Spotlight Organization** candidate and;
- A founding member agency of **United Way Toronto.**

[www.vha.ca](http://www.vha.ca)
Today’s Objectives

HERE’S WHERE WE ARE GOING

By the end of this workshop:

1. Describe what is Hoarding Disorder
   (Why is it chronic/complex and with low insight/treatment)

2. Name two main types of approach to treating Hoarding Disorder (HD)
   (What can be done to help)

3. List a strategy (or more!) to optimize your support of clients who have HD
   (What you can do to help)
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

**KEY INDICATORS:**

To Develop Plan:
- **Assess:** what are the key safety concerns in this situation?

1. Safety & Eviction Risks

Safety & Eviction

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VHA Home HealthCare
Creating More Independence
How to assess and intervene in situations of risk:

- **STEP 1:** Protect Yourself
- **STEP 2:** Safety Assessment
- **STEP 3:** Prioritize service goals
- **STEP 4:** Provide hands-on support
Safety Risks: Strategies for Success

HARM REDUCTION IN ACTION

How to help in situations of risk:

- STEP 1: Protect Yourself
- STEP 2: Safety Assessment
- STEP 3: Prioritize service goals
- STEP 4: Provide hands-on support
Harm Reduction - Reduce Safety Risks

STRATEGIES WITHOUT FOCUS ON DISCARDING
Hands-on, in-home

A DIFFICULT HOLE TO FILL: TIME, COST INTENSIVE

Assess Support Options:
- What could be funded?
- What type of physical support needed to lift, move etc.?
- What type of supports does the client already have?

- Creativity Needed - Volunteers, PSWs, Mental health workers, organizers; Coached Friends, family, community groups (FAM training)
Harm Reduction – Clutter Impact

REALISTIC OUTCOMES
Hands-on Support in the Home
Sorting with the 3-S Technique

Set-Up:
Pick a place to start & gather materials

Sort:
Decide if the item is Keep or Out: create categories

Store:
Put things away immediately
Where would you start?

SAFETY ... EVICTION ... MOTIVATION ... FUNCTION
Hands-on Support in the Home
Sorting with the 3-S Technique

**Set-Up:**
Pick a place to start & gather materials

**Sort:**
Decide if the item is **Keep** or **Out**:
create categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoes</td>
<td>Front hall closet</td>
</tr>
<tr>
<td>Cosmetics</td>
<td>Bathroom cupboard</td>
</tr>
<tr>
<td>dry food/cans</td>
<td>Pantry</td>
</tr>
<tr>
<td>books</td>
<td>Bookcase</td>
</tr>
<tr>
<td>recipes</td>
<td>Kitchen shelf</td>
</tr>
</tbody>
</table>
Hands-on Sorting Assistance:

ESTABLISH GROUND RULES WITH CLIENT

- Only touch things with client’s **permission**
- The **client makes** all final decisions
- Support client to **stay focused**
- Have client **speak aloud thoughts** as they sort
- **Be encouraging**: recognize small gains
- Support with decision-making: questions
  - Have you used this in the past year?
  - Could you get this some other way if you really needed it?
  - Would letting this go help with the clutter?
  - Is this really important, or does it just seem that way because you’re looking at it now?
Hands-on Support in the Home
Sorting with the 3-S Technique

Store:

Out:
Where could these go?

LOOK UP POSSIBLE LOCAL DONATION
Hands On Assistance

WHAT DO YOU NOTICE THE COACH DOING?

A&E Hoarders Buried Alive; Mar 9 2011; Order out of Chaos

http://www.youtube.com/watch?v=XiafdkzpbeE
Empty Your Purse/Bag Please!

What is this like for you?
What about Extreme Cleanouts?

NOT GENERALLY EFFECTIVE FOR HOARDING

Does not address behaviours that create clutter.
Not all Clutter is Hoarding Disorder

HOARDING AS A SYMPTOM FOR OTHER DISORDERS

Dementias
Acquired Brain Injury
Diogenes
Parkinsons

Huntingtons
Prader Willie Syndrome
Autism Spectrum Disorders
Frailty, Depression, Vision…

Petrusa et al 2011; Frost et al 2011;
Assessment of Hoarding Disorder

In the field:
Select a specific pile, ask which objects could be discarded right now.

Clinical Ax: SI-R, HRS, SIDH, UHSS
What about Extreme Cleanouts?

NOT GENERALLY EFFECTIVE FOR HOARDING, EXCEPT...

**Optimize**: collaborate with Client, respect the home’s contents, set up keep boxes/areas, consider appointing surrogate decision-maker, use clear garbage bags

Collaborative, client-driven removal once discard skills well integrated.

Safety risks far outweigh risks of cleanout
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

**KEY INDICATORS:**

1. Safety & Eviction Risks

To Develop Plan:

- **Assess:** what are the key safety concerns in this situation?

Safety & Eviction
Eviction
Eviction – How can I assist?

HARM REDUCTION IN ACTION

- STEP 1: Be informed
- STEP 2: Educate client & Advocate
- STEP 3: Prioritize goals
- STEP 4: Provide hands-on support
Eviction – How can I assist?

✅ **STEP 1: Be informed**

**KNOW THE LEGISLATION**
- Residential Tenancy Act
- Ontario Human Rights Code
- Legal Aid
- Property standards
Residential Tenancies Act

EVICTION NOTICES ISSUED FOR HOARDING

Notice to Terminate a Tenancy Early

- willfully or negligently **damaged** the rental unit or the complex

- substantially interfered with the **reasonable enjoyment** of the landlord or another tenant.

- The tenant of the rental unit has seriously impaired the safety of another person.

Legislation permits enforcement of decluttering
Residential Tenancies Act

EVICATION NOTICES ISSUED FOR HOARDING

N5: Notice to Terminate a Tenancy Early

- willfully or negligently **damaged** the rental unit or the complex
- substantially interfered with the **reasonable enjoyment** of the landlord or another tenant.

At least 20 days notice.
Opportunity to correct within 7 days.
Tenant can void the notice if first N5 in 6 months.

Legislation permits enforcement of decluttering
Residential Tenancies Act

EVICTION NOTICES ISSUED FOR HOARDING

N7: 10-day Notice to Terminate Tenancy Early

- The tenant of the rental unit has seriously impaired the safety of another person.
- The tenant has willfully damaged the rental unit or the residential complex.
- The tenant has substantially interfered with landlords reasonable enjoyment of the rental unit, or your lawful rights, privileges or interests.

(<3 units, landlord residing in residence)
L2: Application to Terminate Tenancy & Evict Tenant

The landlord can apply to the Landlord and Tenant Board:

- Unaddressed N5
- Second N5 in 6 months
- N7

Board issues Notice of Hearing
Part B

Details About the Reasons for this Notice

The landlord must provide details about the events that led to giving you this notice, including information about the dates and times these events occurred.

On February 9th, 2011 the landlord met with the tenant in the rental unit to discuss the problem with bed bugs and unit condition. They review procedures to prepare for treatment that would take place on February 13th, 2011 and the tenant agreed to follow the instructions provided.

On February 13th, 2011, at 1:45 pm the landlord inspected the unit with a pest control technician who attended to treat for bed bugs. They found that it was in an unsanitary state with bed bugs throughout. Furthermore the Tenant has failed to prepare the unit or improve the condition from the February 9th inspection. The state of the unit made it impossible to treat for bed bugs. The landlord is informed by its pest control agent that this infestation is spreading from this unit to other units. Despite the offer of assistance from the Landlord, and the offer of assistance from community resources such as Homemakers, the Tenant will not accept such assistance nor will he rectify the unsanitary condition of the unit and prepare it for treatment.

There is debris, garbage, clothing, papers, items that appear to have been brought in from the street scattered throughout the unit covering 80% of the floor area. This notice may be voided if the tenant corrects the behaviour set out in this notice by correcting the above which includes, but is not limited to sorting and removing debris from the unit, bagging clothing as per the provided instruction sheet, removing all food-stuffs from the floor, throwing our old newspapers, reducing the quantity of items so that there is space to spray in all rooms in the unit including surrounding all furniture and baseboards, and correcting the condition so that the pest control company is able, in its expert opinion, to treat the unit for bed bugs.

The pest control company charged the landlord $100 as a flat-rate cancellation charge for the wasted visit and another visit will be required.

As part of the voiding of this notice, the landlord is also seeking reimbursement of the $100 cost they incurred that was wasted due to the tenant’s failure to prepare for unit treatment.
Landlords must work with tenant in "shared responsibilities of accommodation."

**DUTY TO ACCOMMODATE:**
Ex: contact community supports, provide organization and clutter removal services, short-term tolerance of moderate health & safety concerns, tolerating a degree of unkemptness.

- To the point of “undue hardship.”
- The greater the resources of the landlord, the more involved the accommodation measures must be.

Human Rights Commission policy guideline on Human Rights in Rental Housing:

[www.ohrc.on.ca](http://www.ohrc.on.ca)

Outcomes via OLTB are inconsistent.

- SOL-07404-10 (2010). Evict based on substantial interference of reasonable enjoyment of landlords and other tenants.
  - Large volume preventing access to stove, heating unit, oven; Unsanitary, odorous
  - Landlord linked to ACTT, issued warnings: tenant declined Tx but agreed to attend hospital pgm.

Outcome: unit to be cleaned to landlords satisfaction within 30 days & not evicted.
Ontario Landlord Tenant Board

DUTY TO ACCOMMODATE VS. HEALTH, SAFETY, UNDUE HARDSHIP

• TSL-07237-10 (2010). Evict based on accumulation of combustible material creating fire hazard that seriously impairs the safety of other persons.
  – Landlord granted a delay to allow for decluttering, but proceeded with eviction upon relapse.

Outcome: tenant required to reduce clutter in apartment within 30 days to the point where unit is not a fire hazard.

Common Eviction Concerns:
- Fire risks
- Infestations
- Odor, cleanliness
- Damage to structure, appliances
- Landlord/maintenance access to exits, appliances, heating
- Pets unmanaged
- Rent not paid

Common Bylaw Infractions (Rural):

Fines can be imposed on property owners who are in violation of bylaws. Inspectors are dispatched in response to complaints.

Bylaws cover:
Yards, structural safety, exists, garbage, doors, infestations, cleanliness/sanitary conditions, plumbing, appliances
Eviction – How can I assist?

- **STEP 1:** Be informed
- **STEP 2:** Educate client & Advocate

**Options & consequences:**

- Do nothing – eviction likely
- Appeal eviction (legal support)
- Identify specific reasons for eviction and/or key safety risks: address these/ negotiate with landlord
Involve early in process (before N5 or N7)

Assist client with Landlord & Tenant Board
  – Duty to Accommodate: adjournment, interim orders; mediated agreements

Adjudicators typically seek change in clutter conditions over a period of a few months.
Advocate for your Client

WORK WITH LANDLORD FOR ACCOMMODATION

1. Establish the existence, seriousness & impact of a disability:
   
   • obtain diagnosis
   • impact symptoms have on maintaining environment

2. Support / arrange efforts for intervention:
   
   • Tenant to demonstrate they are an active part of the accommodation

3. Educate the landlord about their need for accommodation

- OCfoundation.org Hoarding Fact Sheet
- DSM-5 Criteria

Eviction – How can I assist?

- **STEP 1:** Be informed
- **STEP 2:** Educate Client
- **STEP 3:** Prioritize goals
  - Identify & address specific reasons for eviction
    - Clearout kitchen → keep all flammables 30cm from stove; do not store items in oven
    - Declutter living room → clear 1m pathway to back exit, remove items within 1m of radiators.
Eviction – How can I assist?

✓ STEP 1: Be informed
✓ STEP 2: Educate client & Advocate
✓ STEP 3: Prioritize goals
✓ STEP 4: Provide hands-on support
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

KEY INDICATORS:

1. Safety & Eviction Risks
2. Good Insight & Motivation
3. Cognitive Functioning
4. Client Goals

Modifiers:
- Anticipate occurrence
- Assess by observation as you implement plan
Refine Implementation Plan

Prioritized Service Goals/Plan
(Safety & Eviction Prevention)

+ Limited Insight & Motivation
  - Refine plan to include motivational strategies
  - Reduce pace & expectations around goals
Addressing Insight & Motivation

OBSERVE BEHAVIOUR THROUGHOUT PLAN IMPLEMENTATION

Limited Insight:
1. Anasognosia
2. Over-valued beliefs
3. Defensiveness (reactance)

Motivation:
Readiness Ruler – specific goals
Motivation

READINESS RULER

Importance – Confidence Ruler

How important is it to keep all flammables 30cm from stove?

<table>
<thead>
<tr>
<th>Not At All Convinced</th>
<th>Totally Convinced</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

How confident are you that you can remove all items within 1m of radiators?

<table>
<thead>
<tr>
<th>Not At All Confident</th>
<th>Totally Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

Why “4”? Why not “6”?
What would it take to move from a “5” to an “8”?

<table>
<thead>
<tr>
<th>Importance/Confidence Score</th>
<th>Stage of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 on either</td>
<td>Pre-Contemplation</td>
</tr>
<tr>
<td>3-7 on either or both</td>
<td>Contemplation</td>
</tr>
<tr>
<td>&lt; 7 on either</td>
<td>Not motivated to change</td>
</tr>
<tr>
<td>8-10 on Conviction</td>
<td>Determination</td>
</tr>
<tr>
<td>9-10 on Confidence</td>
<td>Action or Maintenance</td>
</tr>
</tbody>
</table>
What is meant by “Limited Insight”

Anasognosia:
1. Not knowing there is a problem
   - Lacking awareness of problem severity
   - Indifference to consequences of hoarding
   - More likely to interact with community providers than outpatient clinics

Blue black is white gold ??

AVOID TEMPTATION TO DEBATE

Build discrepancy to support client to draw their own conclusions (where life is vs. where would like to be)

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
What is meant by “Limited Insight”

ANASOGNOSIA |

Client: My landlord treats me like a child. He just comes by and judges me, threatens me!
Therapist: Meetings with him have been pretty upsetting, eh?
Client: Yeah, they are.
Therapist: What do you think would make him treat you differently?
Client: If he drops the eviction and just leaves me alone!
Therapist: And if he drops it, things will go back to normal?
Client: Yes, and I can get on my with life. I’ve had to put things aside to deal with all this. It’s a distraction, and unneeded one!
Therapist: From the sounds of it, he’s not likely to drop it, eh?
Client: No.

Build discrepancy to support client to draw their own conclusions (where life is vs. where would like to be)

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
Meet Rick ...

HOUSING INSTABILITY

https://www.youtube.com/watch?v=olKtz189oCk
What is meant by “Limited Insight”

ANASOGNOSIA | OVER-VALUED IDEATION | DEFENSIVENESS

Over-Valued Beliefs

2. Thoughts about possessions so tightly held can appear delusional
   • Range from mild to extreme
   • Sentimental/Instrumental/Intrinsic

Example: Aunt’s 300+ Cookbooks = identity as a good cook/mother, dream of having grandchildren over for holiday dinners, connection to deceased aunt.

AVOID (1) PRESENTING RATIONAL ARGUMENTS OR (2) TELLING CLIENT TO DISCARD TO DECLUTTER.

Support client to test beliefs with Behavioural Experiments

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
Addressing Over-valued Beliefs

BEHAVIOURAL EXPERIMENTS

Over-Valued Beliefs

Support client to test beliefs with Behavioural Experiments

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
“Defensiveness”

3. Perception that personal will is being imposed upon
   - Presents as argumentativeness, frustration (client/therapist)
   - Therapeutic reactance: motivation to restore personal freedom perceived to have been threatened/lost
   - Maintaining control over possessions

Avoid presenting reasons to declutter; or issuing directives

Demonstrate to client they are in control.

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
What is meant by “Limited Insight”

DEFENSIVENESS

“Defensiveness”

All sorting decisions are theirs, ask permission to touch things, set goal to create living space (vs. declutter), provide choices (do this or that now?), let go of personal agenda for change

Demonstrate to client they are in control.

Frost, Tolin, Maltby (2010). Cog Behav Practice, 17: 404-413
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PLAN

REFINERS

CBT Skills Teaching

Harm Reduction

VHA Home HealthCare
Creating More Independence
Organization Skills

1. Attention
2. Memory (visual)
3. Categorization
4. Decision-making:

Neurocognitive impairments key factor in the onset and maintenance of hoarding.

Hoarding

Randy Frost: Classic Profile of the Hoarder

Randy Frost, Ph.D. Professor of Psychology, Smith College
Refine Implementation Plan

Prioritized Service Goals/Plan
(Safety & Eviction Prevention)

+ Impaired Cognitive Functioning
  • Refine plan to include organizational supports
  • Reduce pace & expectations around goals
Assess Decision-Making

OBSERVE DISCARD DECISIONS; DETAILS, PERFECTIONISM

**Sorting:** Longer to decide, more anxiety, activation of regions in brain associated with emotional regulation. Effect greater with own papers.

_Iowa Gambling Task_
No impairment observed: complex decision-making.

Global indecisiveness likely not specific feature of HD.

Tolin, Kiehl, Worhunsky, Book, & Maltby, 2009; Tolin et al., 2012
Cognitive re-appraisal may not be the most effective ingredient in CBT for HD; neural regions required for re-interpretation may be impaired.

Distancing via thought listing: describe aloud thoughts about discarding with no effort to modify them.
Strategies for Decision Making: Practice

TOLERATING THE DISTRESS OF DISCARDING OR MAKING DECISIONS

**Letting Go**

**STEP 1:** Recognize your attachment to the item

**STEP 2:** Physically discard item (or do not acquire item)

**STEP 3:** Begin processing emotional attachments

**STEP 4:** Keep processing attachments and start developing new beliefs

**STEP 5:** Integrate new beliefs
Categorization

UNDER-INCLUSIVE GROUPING

Hoarding: longer, more piles, distressing

Clinically significant visual categorization impairment observed:
Delis-Kaplan Executive Function System – sorting test

Luchian et al., 2007; Wincze et al., 2007; NOT Grisham et al., 2010
Assess Memory Beliefs

MEMORY CONFIDENCE AND IMPAIRMENT

Worry about forgetting information, events, relationships:
→ rely on objects to serve as memory aids

- **Strategies for Memory Confidence:**
  - Let's try putting this into the drawer, I’ll write it down & we can see if next week you remember what we put there?
  - List of contents
  - Clear plastic bags, bins

**Brief Visual Memory Test:**
Research Inconsistent: possible visuospatial memory impairment

Assess Attention

DIFFICULTY WITH SUSTAINED ATTENTION

- Robust relationship between ADHD and hoarding: ~28% meet ADHD criteria
- **Self-report** high levels of inattentiveness
- Research suggests possible visual attention impairment

**Observe Client:**
Difficulty staying on task during session, easily distracted, tangential, overly-inclusive speaking style

**Strategies: Redirect & Focus:**
“How about we finish this bag of shoes before moving on...”

“Margaret, let me interrupt you here... I only have a limited time to help and I really want to see you succeed with your organizing... do you want to store these shoes in the closet or front hall?...”

Tolin & Villavincencia, 2010; Frost et al 2011; Moody et al, 2014
Assessment = Where is my Client (today)?

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**PLAN**

**REFINERS**
Assessment - Functional Goals

LINK SERVICE GOALS TO CLIENT’S GOALS

Client’s values, dreams and goals. What drives motivation to for a livable space?

ADL-H measure impairment in key functional domains.

[Frost et al 2013]
Acceptability of Hoarding Services

PERCEPTION THAT TREATMENT IS AGREEABLE, PALATABLE OR SATISFACTORY

More acceptable if:

- personalized
- being held accountable (goals, home visits)
- belief that treatment works

Tip for Success: personalize your plan!

Tip for Success: leverage the visitor effect!

Tip for Success: advertise successes!

Innovators!

More acceptable options needed.

Rodriguez et al, 2016, JOCRD, 11: 1-8]
Assessment = Where is my Client (today)?

THE ANSWER TELLS YOU HOW BEST TO HELP

**Key Indicators:**

1. Safety & Eviction Risks
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Plan

Modifiers

CBT Skills Teaching

Harm Reduction
Today’s Objectives

HERE’S WHERE WE ARE GOING

By the end of this workshop:

1. **Describe what is Hoarding Disorder**
   (Why is it chronic/complex and with low insight/treatment)

2. **Name two main types of approach to treating Hoarding Disorder (HD)**
   (What can be done to help)

3. **List a strategy (or more!) to optimize your support of clients who have HD**
   (What you can do to help)
Types of Modifiers that help you to personalize the client’s safety plan?

1. Insight & Motivation
2. Cognitive Functioning
3. Client’s goals

Harm Reduction Strategies?

4. Reduce risk without reducing clutter volume
5. Hands on sorting assistance (set-up, sort, store)
6. Organizational skills teaching (focus, decision-making, categorization, memory)
7. Eviction-prevention advocacy

Types of Interventions to help with Insight Barriers?

8. Build Discrepancy
9. Behavioural Experiments
10. Client is in control
VHA Home HealthCare (VHA)—a not-for-profit charity—has provided care since 1925. With over 1,800 staff and service providers VHA offers home and community services that support Ontarians’ independence including: homemaker, nursing, personal support and rehabilitation services.

VHA is:

• Accredited with Exemplary Standing by Accreditation Canada
• An RNAO Best Practice Spotlight Organization candidate and;
• A founding member agency of United Way Toronto.

www.vha.ca