HOARDING

JEWISH FAMILY AND CHILDREN'S SERVICE OF GREATER PHILADELPHIA

COURTNEY OWEN, LCSW

LEARNING OBJECTIVES

- Participants will be able to identify behaviors of individuals with hoarding disorder and understand the criteria based on the DSM5.
- Participants will review a case study and the impact of EBPs, including CBT and HR.
- Participants will learn 2-3 intervention techniques they can use when in the homes of those who hoard to help them learn to discard items, reduce acquiring items, and decrease distress related.

HISTORY OF HOARDING

- 1908: Freud links hoarding to the anal stage of development due to the loss of control and the desire to gain back the control in the form of "possessions".
- 1912: Fixations at the Anal stage → Anal Personality → OCPD (DSM-III)
- 1966: The term "compulsive hoarding" was first mentioned to describe collecting in the article by Bolman & Katz, "*Hamburger Hoarding: A case of symbolic cannibalism resembling Whitico psychosis*."

http://cdn.theatlantic.com/static/mt/assets/science/Hamburger_Hoarding__A_Case_of_Symbolic_Cannibalism.4.pdf

- 1987: Research article on compulsive hoarding by D Greenberg was published.
- 1990s: Major empirical studies and research began. Primarily by Randy O Frost, Gail Steketee, David F Tolin, and Tamara L Hartl.
- 1996: Definition of compulsive hoarding, used today, was developed by Randy O Frost & Tamara L Hartl.
- 2013: Hoarding Disorder became a new diagnosis in the DSM-5.

A FEW FACTS ABOUT HOARDING

- 2-6% of the population suffer from Hoarding Disorder- making it one of the most prevalent.
- The 5% rate is 2x the rate of OCD & 4x the rate of bipolar and schizophrenia.
- 92% of individuals diagnosed with Hoarding Disorder also have another co-occurring disorder.
- 15% of hoarder have insight and acknowledge their behavior as irrational.
- 50% of hoarders grow up in a hoarded home.
- Without intervention the rate of recidivism is nearly **100%**.

PREHISTORIC HOARDER

MYTHS ABOUT HOARDING

1. "DISORGANIZED, LAZY, UNMOTIVATED, UNSANITARY"
   - HD IS A DIAGNOSIS, RATHER THAN AN UNFAIR STIGMA
   - WHAT PEOPLE REALY NEED IS COMPASSION
2. "CAN'T STOP HOARDING"
   - INTERVENTIONS CAN BE SUCCESSFUL, IT IS A LONG PROCESS
3. "THOSE WHO HOARD ARE COLLECTORS"
   - HOARDING AND COLLECTING ARE 2 DIFFERENT THINGS

HOARDING DEFINED BY DSM-5:

- The DSM-5 categorizes hoarding disorder (300.3) as:
  - Persistent difficulty discarding or parting with possessions, regardless of their actual value.
  - This difficulty is due to a perceived need to save the items and to distress associated with discarding the items.
  - The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered it is only because of the interventions of third parties (e.g., family members, cleaners, authorities)
  - The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).

HOARDING DEFINED BY DSM-5:

- The hoarding is not attributable to another medical condition.
- The hoarding is not better explained by the symptoms of another mental disorder.

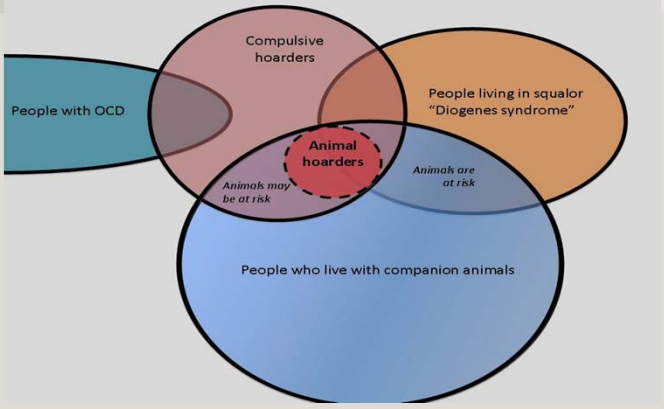
Specify if:

- *Excessive Acquitision: Do they continue to acquire items they don't have space or need for?*
- *Level of Insight: Good, Fair, Poor, Absent/Delusional*

WHO IS HOARDING?

- **Age**: Hoarding behavior may begin as early as adolescence around age 13 (mild), behaviors progress to a moderate problem in the 20s-30s, and to a severe problem in the 40s-50s. Late onset is rare (after 40yo) and usually is correlated with a traumatic event. Hoarding symptoms have been shown to increase each decade.
- **Race/Ethnicity**
- **Gender**: Reports of gender differences have been mixed.
- **Income**: In one study 54.4% of participants report financial difficulty and 37.9% report receiving less than the poverty level in 2005. However, income level varies and resources are an important factor.
- **Other Contributing Factors**: Significant loss, experience of a traumatic event, family history of hoarding, domestic violence, and memory issues were also reported in the analysis of MBHP's study.
- **IMPORTANT: there is not a "typical" description of a person who hoards. Hoarders are from all backgrounds, ages, socioeconomic status, gender, ethnicity & race.**

SQUALOR? NOT ALWAYS..



* A study by MBHP's analysis of the HI/TPP shows that squalor occurs in 33% of Hoarding cases (total of 175 participants).
* Squalor and Hoarding are not mutually exclusive.

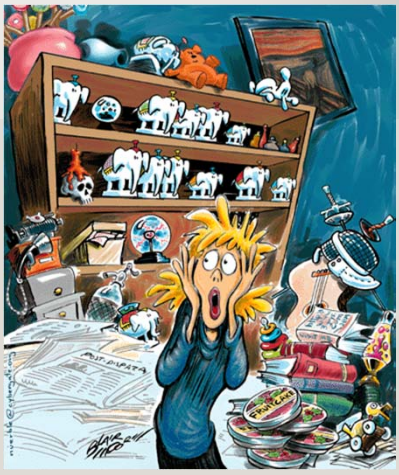
"Diogenes syndrome (DS) is characterized by severe self-neglect, domestic squalor, social withdrawal, syllogomania, and refusal of help that may be precipitated by stressful events."

WARNING SIGNS

- Difficulty discarding items, regardless of value
- Excessive attachment to items
- Inability to use spaces for intended purposes due to clutter
- Acquiring unneeded items (free and/or purchased items)
- Difficulty managing daily activities/decision-making
- Difficulty organizing
- Isolation or limited social interaction
- Shame or embarrassment
- Excessive bargain shopping
- Feeling overwhelmed by amount of items
- Hesitancy to allow "outsiders" in their home

ITEMS HOARDED

- Paper (mail, newspapers, etc.)
- Books
- Clothes
- Containers (boxes, paper & plastic bags, etc.)
- Garbage/Rotten Food (less common)
- Animals (Even less common)



A STORY…MARTHA

The story of Martha is a common one, yet one that has many complexities.

-Lives alone

-Family home

-Older adult, Physical health is declining

-Socially isolated, no support system, or family support

-Afraid of being removed from home

-Lack of insight

-Many safety concerns & infestations

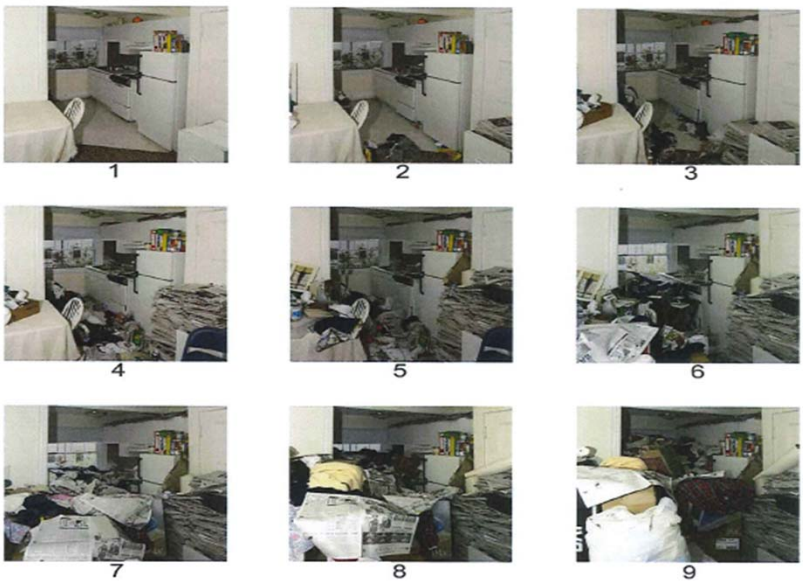
-Home needs many repairs

-Squalor is present

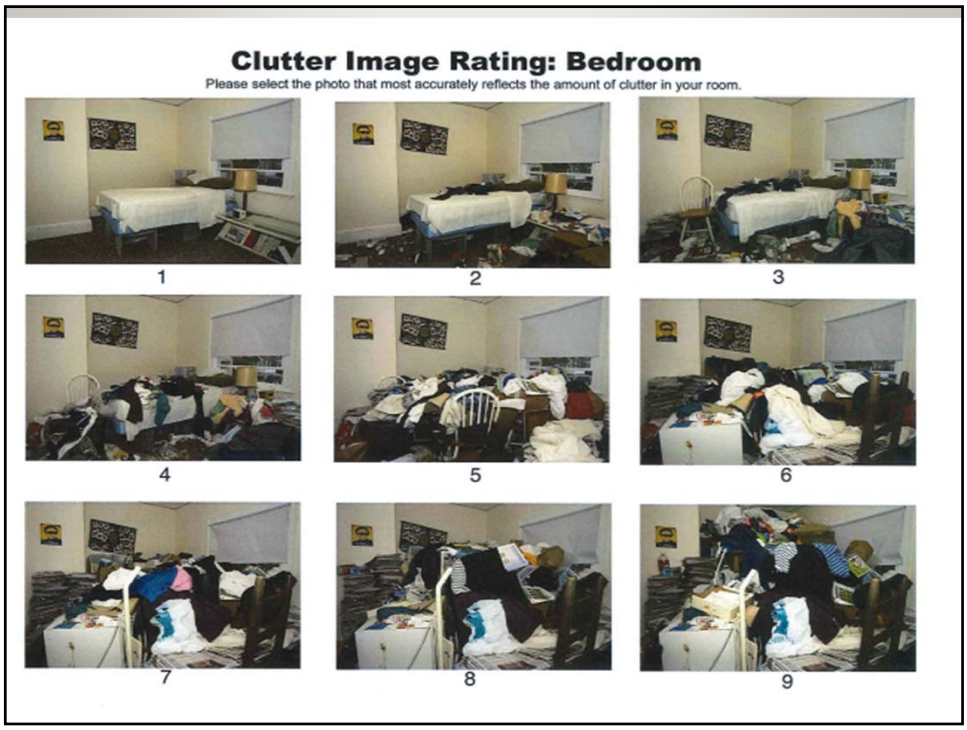
-Basic needs not being met (shower, toilet, food, etc.)

Clutter Image Rating Scale: Kitchen

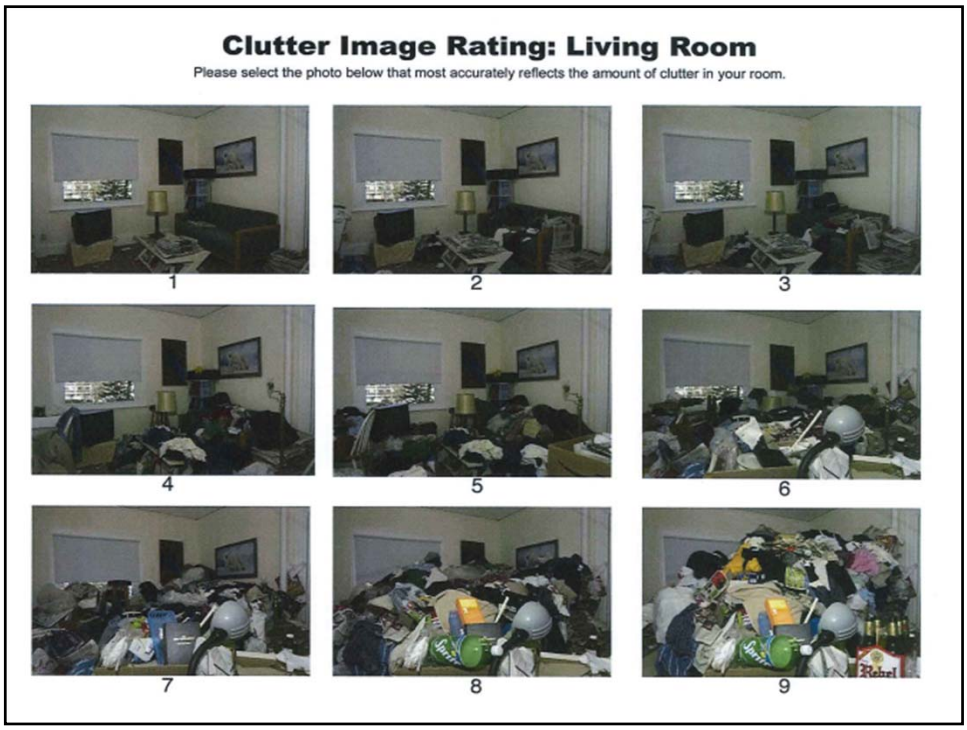
Please select the photo below that most accurately reflects the amount of clutter in your room.




KITCHEN


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


BEDROOM #2
This Photo by Unknown author is licensed under CC BY-NC-ND.


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

LIVING ROOM

Activities of Daily Living for Hoarding (ADL-H)

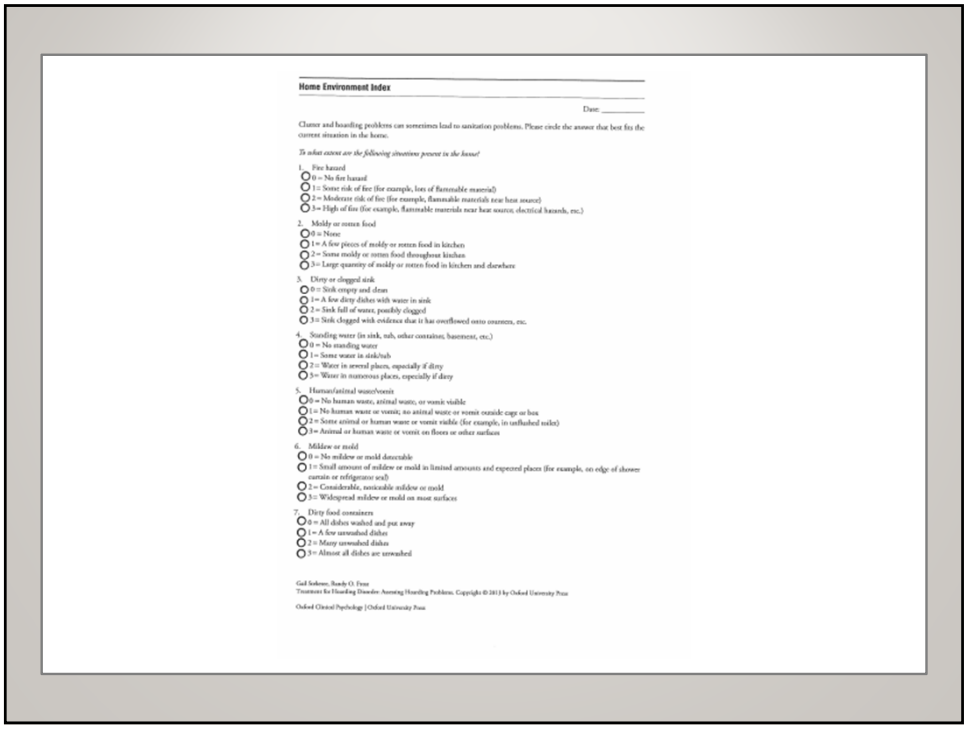
Date: _____

Sometimes clutter in the home can prevent you from doing ordinary activities. For each of the following activities, please circle the number that best represents the degree of difficulty you experience in doing this activity because of the clutter or hoarding problems. If you have difficulty with the activity for other reasons (for example, unable to bend or move quickly due to physical problems), do not include this in your rating. Instead, rate only how much difficulty you would have **due to hoarding**. If the activity is not relevant to your situation (for example, you don't have laundry facilities or animals), circle Not Applicable (NA).

Activities affected by clutter or hoarding problem	Can do it easily	Can do it with a little difficulty	Can do it with moderate difficulty	Can do it with great difficulty	Unable to do	Not Applicable
1. Prepare food	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
2. Use refrigerator	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
3. Use stove	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
4. Use kitchen sink	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
5. Eat at table	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
6. Move around inside the house	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
7. Exit home quickly	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
8. Use stairs	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
9. Use bath/shower	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
10. Use bathroom sink	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
11. Answer door quickly	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
12. Sit in sofa/chair	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
13. Sleep in bed	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
14. Do laundry	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA
15. Find important things (such as bills, tax forms, etc.)	○ 1	○ 2	○ 3	○ 4	○ 5	○ NA

Gail Steketee, Randy O. Frost
Treatment for Hoarding Disorder: Assessing Hoarding Problems. Copyright © 2013 by Oxford University Press

Oxford Clinical Psychology | Oxford University Press



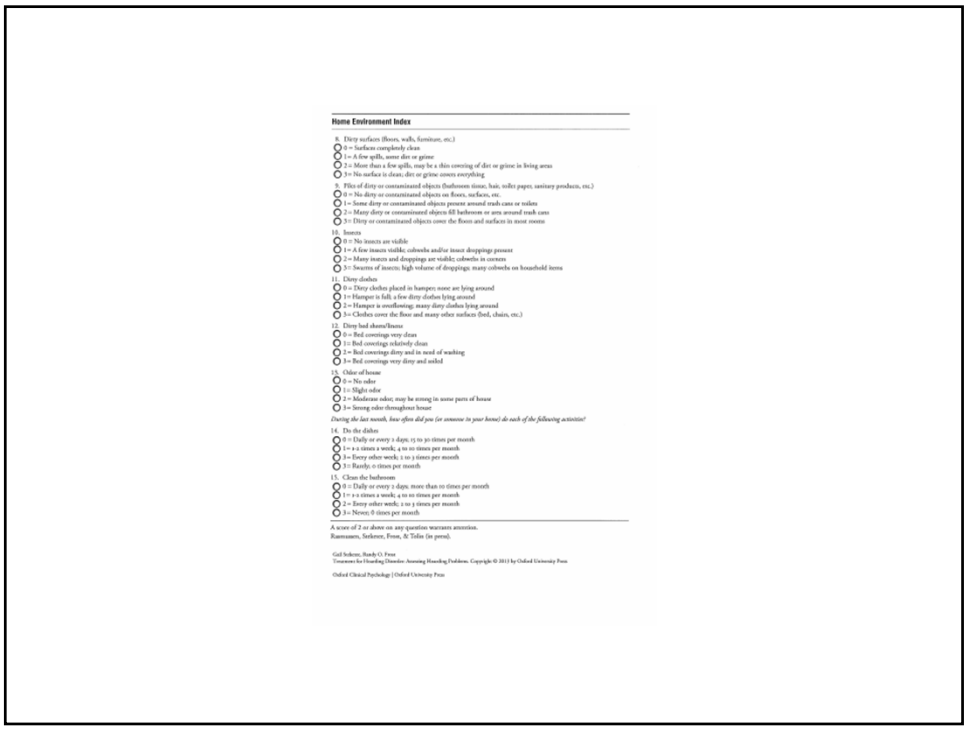
Home Environment Index

Date: _____

Clutter and hoarding problems can sometimes lead to sanitation problems. Please circle the answer that best fits the current situation in the home.

To what extent are the following situations present in the house?

1. Fire hazard
   - 0 = No fire hazard
   - 1 = Some risk of fire (for example, lots of flammable material)
   - 2 = Moderate risk of fire (for example, flammable materials near heat source)
   - 3 = High of fire (for example, flammable materials near heat source, electrical hazards, etc.)
2. Moldy or rotten food
   - 0 = None
   - 1 = A few pieces of moldy or rotten food in kitchen
   - 2 = Some moldy or rotten food throughout kitchen
   - 3 = Large quantity of moldy or rotten food in kitchen and elsewhere
3. Dirty or clogged sink
   - 0 = Sink empty and clean
   - 1 = A few dirty dishes with water in sink
   - 2 = Sink full of water, possibly clogged
   - 3 = Sink clogged with evidence that it has overflowed onto counters, etc.
4. Standing water (in sink, tub, other container, basement, etc.)
   - 0 = No standing water
   - 1 = Some water in sink/tub
   - 2 = Water in several places, especially if dirty
   - 3 = Water in numerous places, especially if dirty
5. Human/animal waste/vomit
   - 0 = No human waste, animal waste, or vomit visible
   - 1 = No human waste or vomit; no animal waste or vomit outside cage or box
   - 2 = Some animal or human waste or vomit visible (for example, in unflushed toilet)
   - 3 = Animal or human waste or vomit on floors or other surfaces
6. Mildew or mold
   - 0 = No mildew or mold detectable
   - 1 = Small amount of mildew or mold in limited amounts and expected places (for example, on edge of shower curtain or refrigerator seal)
   - 2 = Considerable, noticeable mildew or mold
   - 3 = Widespread mildew or mold on most surfaces
7. Dirty food containers
   - 0 = All dishes washed and put away
   - 1 = A few unwashed dishes
   - 2 = Many unwashed dishes
   - 3 = Almost all dishes are unwashed



Home Environment Index

8. Dirty surfaces (floors, walls, furniture, etc.)
   - 0 = Surfaces completely clean
   - 1 = A few spills, some dirt or grime
   - 2 = More than a few spills, may be a thin covering of dirt or grime in living areas
   - 3 = No surface is clean; dirt or grime covers everything
9. Piles of dirty or contaminated objects (bathroom tissue, hair, toilet paper, sanitary products, etc.)
   - 0 = No dirty or contaminated objects on floors, surfaces, etc.
   - 1 = Some dirty or contaminated objects present around trash cans or toilets
   - 2 = Many dirty or contaminated objects fill bathroom or area around trash cans
   - 3 = Dirty or contaminated objects cover the floors and surfaces in most rooms
10. Insects
    - 0 = No insects are visible
    - 1 = A few insects visible; cobwebs and/or insect droppings present
    - 2 = Many insects and droppings are visible; cobwebs in corners
    - 3 = Swarms of insects; high volume of droppings; many cobwebs on household items
11. Dirty clothes
    - 0 = Dirty clothes placed in hamper; none are lying around
    - 1 = Hamper is full; a few dirty clothes lying around
    - 2 = Hamper is overflowing; many dirty clothes lying around
    - 3 = Clothes cover the floor and many other surfaces (bed, chairs, etc.)
12. Dirty bed sheets/linens
    - 0 = Bed coverings very clean
    - 1 = Bed coverings relatively clean
    - 2 = Bed coverings dirty and in need of washing
    - 3 = Bed coverings very dirty and soiled
13. Odor of house
    - 0 = No odor
    - 1 = Slight odor
    - 2 = Moderate odor; may be strong in some parts of house
    - 3 = Strong odor throughout house

During the last month, how often did you (or someone in your home) do each of the following activities?

14. Do the dishes
    - 0 = Daily or every 2 days; 15 to 30 times per month
    - 1 = 1-2 times a week; 4 to 10 times per month
    - 2 = Every other week; 2 to 3 times per month
    - 3 = Rarely; 0 times per month
15. Clean the bathroom
    - 0 = Daily or every 2 days; more than 10 times per month
    - 1 = 1-2 times a week; 4 to 10 times per month
    - 2 = Every other week; 2 to 3 times per month
    - 3 = Never; 0 times per month

A score of 2 or above on any question warrants attention.
Rasmussen, Steketee, Frost, & Tolin (in press).

IN THE HOME…NOW WHAT

- Tiered system
- Sorting session, what does it look like
- Building a relationship….so important

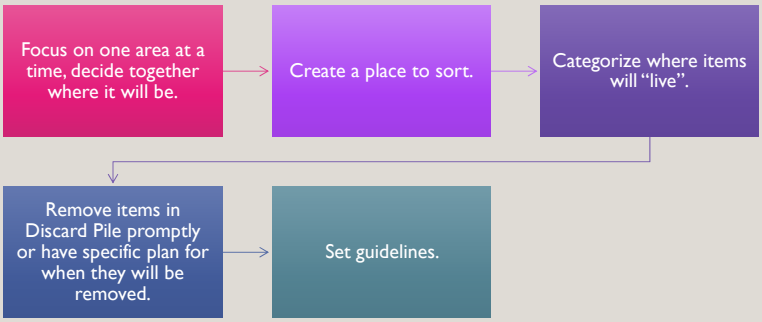
4 TIER SYSTEM

- ***Tier 1: Ensure client safety in accordance with Philadelphia safety and housing codes.***
- ***Tier 2: Support clients in reverting rooms in their homes to their intended function.***
- ***Tier 3: Establish organizational systems with clients.*** JFCS supports clients in establishing methods of organization, such as storage containers or filing cabinets, which can help them determine which belongings are essential. These practices contribute to reduced rates of recidivism and help clients maintain orderly and safe living spaces over the long term.
- ***Tier 4: Provide clients with after-care and continued care coordination to reduce recidivism.*** JFCS care managers continue to support clients who have successfully de-cluttered their homes and undergone therapy related to managing hoarding behaviors, in order to reduce the likelihood that hoarding tendencies will return, and to ensure that clients have ongoing support following their time in the program. When needed, JFCS connects clients with outside resources that can help monitor client success, like home health aides who previously may not have been able to enter the home.

SORTING SESSION

- Keep Pile
  - Over time items in this pile will reduce
- Maybe Pile
  - Must decide at end of session
- Discard Pile
  - Trash, Recycle, Donate, Give away
  - Don't remove from pile once decided (create back up plan so items don't return to Keep Pile).

TIPS FOR SORTING SESSIONS



DOS AND DON'TS

- **DO** utilize the same language and descriptors the client uses to describe their items or clutter, such as "collections", "things". These are items of value to the individual and we want to validate their feelings and beliefs.
- **DO** consider safety first rather than discarding items.
- **DO** identify strengths rather than barriers and utilize positive, encouraging language.
- **DON'T** use language that can be perceived as judgmental or negatively defines their possessions. ("trash", "junk", "mess", etc.). Be cautious of your non-verbal cues!
- **DON'T** engage in a power struggle regarding objects and be aware of suggestions to discard perceivably valuable items, even well intended suggestions may have a negative impact.
- **DON'T** touch personal possessions with permission.

TREATMENT OPTIONS

- **Cognitive Behavioral Therapy**-Developed by Steketee and Frost in 2007. A 26 week intervention model to reduce clutter and decrease acquisition of items.

- **Harm Reduction Model**-Developed by Michael A. Tompkins. An alternative to traditional interventions which may be challenging for individuals with hoarding behaviors who may be resistant to treatment.

TREATMENT INTERVENTIONS-CBT

Cognitive Behavioral Therapy Model for Hoarding (Steketee & Frost, 2007)

- This model presumes problems result due to:
  - Personal vulnerabilities (past experiences, comorbidity, negative mood, core beliefs, personality traits, info processing)
  - ⬇
  - Beliefs about possessions
  - ⬇
  - Positive and negative emotional responses
  - ⬇
  - Hoarding behaviors: acquiring, difficulty discarding, disorganized clutter.
- Hoarding behaviors are reinforced positively OR negatively.

Positive Reinforcement: Pleasure from acquiring or saving

Negative Reinforcement: Avoidance of a negative stimuli (or emotions)

MARTHA

- Personal Vulnerabilities
  - comorbidity, personal beliefs about herself/shame, past traumas-loss of parents/sentimentality, family history, personality traits-aesthetic
- Beliefs about Possessions/Thought process
  - sentiment of her items, connection she believed she had with them, perceived value of items
- +/- Emotional responses
  - Positive emotions-obtaining items for crafts, beautiful items, family heirlooms, memories
  - Negative emotions-distress with discarding, fear of losing memories or how would people perceive her (including parents)
- Hoarding Behaviors
  - Collecting arts and crafts, papers, items from parents, mail, food boxes, etc.
  - HOW IS SHE +/- REINFORCED TO MAINTAIN BEHAVIOR?

TREATMENT INTERVENTIONS-CBT

- Risks: Martha's story
  - Uncovering traumatic memories or unresolved grief
  - Mandated reporting
  - Squalor
- Benefits: Martha's success
  - After 26 weeks of treatment:
    - 37%-39% showed a reduction in hoarding symptoms
    - 71% were rated as "much" or "very much" improved by therapists
    - 81% were **self-**rated as "much" or "very much" improved
  - Individuals gain important skills
  - Interventions typically increase self-esteem, mood, & functioning
  - Improvements with Hoarding and clutter which:
    - May reduce risk of eviction
    - Reduce environmental & safety risks

TREATMENT INTERVENTIONS-HR

Harm Reduction for Hoarding

(Michael Tompkins, 2012)

- Hoarding is a unique disorder because it has a connection between the person, condition, and person's environment.
- Person who hoards is considered a significant member of the harm reduction team.
- Person does not need to stop acquiring items altogether.
- Person does not need to endure a full "clean-out" of all their possessions.
- The approach takes failure into account and is part of the harm reduction plan, it does not mean the approach is failing.
- People can hoard and make positive changes in their lives that allows them to live safely and independently.
- Assesses for harm potential based on four categories:

*Environmental Risk *Social Capacity*Physical Capacity*Psychological Capacity

MARTHA

- Martha has not left her home in over 5 years, lived in her home for entire life
- Martha is engaged, initial member of the team, over the course of 1 year had 33 people enter her home.
- Continued to acquire, purchases became more thoughtful, unable to leave home so delivery was important.
- SAFETY DAY
- Martha's goal was for her home to be "safe enough" to age in place.
- Back steps, built into intervention process. When expected it helps to protect Martha and Support Person.

TREATMENT INTERVENTIONS-HR

BENEFITS

- Increases involvement for those who are treatment resistant.
- Allows individual to live safely without the trauma of a full Clean Out.
- Allows for fluctuation in motivation.

CHALLENGES

- Comorbidity
- Other members of the hoarding contract are either too involved or not as involved as planned.
- Lack of contract adherence measures
- Burnout

Benefits & Challenges-Martha's Story

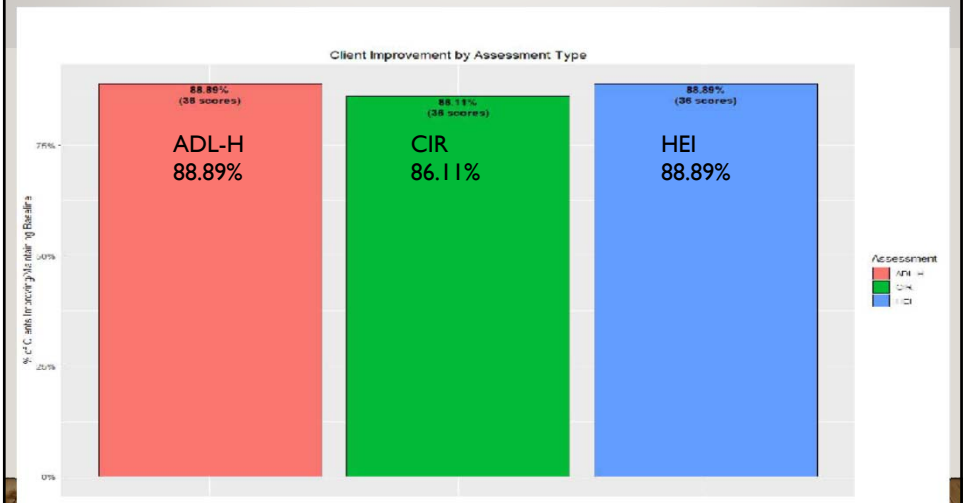
ALTERNATIVE TREATMENT INTERVENTIONS

- Exposure and Ritual Prevention (ERP) is typically utilized for individual with OCD-symptoms.
  - This treatment has shown to be ineffective in most cases.
- Support Groups
  - Some success when highly structured
  - *Buried In Treasures: Help for Compulsive Acquiring, Saving, and Hoarding* has created a structured guide to facilitate a group.
  - The Hoarding Project: Family member support groups
- Forced Clean-outs
  - Usually result in anger, hurt, trauma, and mistrust.
  - Should only be used when necessary for personal and environmental safety.
  - The individual should always be involved in the clean-out process.
- Medication:
  - No medication specific to hoarding disorders
  - Other medications may be prescribed for comorbid disorders such as: antidepressants, antipsychotics, anxiolytics, etc.

ASSESSMENT TOOLS

- Clutter Image Rating (CIR)
- Activities of Daily Living-Hoarding (ADL-H)
- Homes Environment Index (HEI)

HOARDING PROGRAM @ JFCS



36 scores over 2 years

- JFCS of Greater Philadelphia
- Hoarding Intervention Program

THANK YOU!!

- Courtney Owen, LCSW
- cowen@jfcsphilly.org
- 267-838-1462
- OR
- 1.866.JFCS.NOW