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Psychiatry and Addictions Case Conference

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HOARDING DISORDER: AN OVERVIEW

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SPEAKER DISCLOSURES

✓ No relevant conflicts of interest to disclose

PLANNER DISCLOSURES

The following series planners have no relevant conflicts of interest to disclose; other disclosures have been mitigated.

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QUICK INFO ABOUT ME

- Clinical Director and Director of the Anxiety Center at EBTCS
  - EBTCS is an outpatient specialty clinic: child anxiety/OCD, adult anxiety/OCD, eating disorders (lifespan) and DBT (adolescent and adult)
- I specialize in treating adults with anxiety, obsessive-compulsive, and trauma-related disorders; primary orientation is CBT/behavior therapy
- Been working with clients with hoarding for 15-20 years
  - Consultant to the OCD and Hoarding Support Group in Seattle
  - Training faculty with the International OCD Foundation (IOCDF)
  - Therapist for several episodes of the TV show Hoarding: Buried Alive on TLC

OBJECTIVES

- Identify the key components of compulsive hoarding and acquiring
- Describe common characteristics of people who hoard
- Describe current state of the treatment literature for hoarding
- Understand common obstacles to treatment

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Quick history

- Prior to DSM-V, hoarding was classified as a subtype of OCD
  - There was no “hoarding” diagnosis or formal diagnostic criteria
  - Made assessment of hoarding symptoms difficult
  - Led to significant “lags” in the treatment development research
- Hoarding became its own disorder in DSM-V (2013) in response to a number of important research findings
  - Hoarding is as common or more common than OCD
  - Most people who hoard do not meet criteria for other types of OCD
  - Treatments for OCD were ineffective for hoarding

DSM-V

- DSM-V criteria for Hoarding Disorder include:
  - 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 them.
  - 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 spaces are uncluttered, it is only because of interventions of third parties (e.g., family members, cleaners, authorities).

DSM-V

- DSM-V criteria (continued):
  - Specify if: *With Excessive Acquisition:* If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.
  - Specify level of insight: Good/fair, poor, or absent/delusional beliefs
  - 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).
  - The hoarding is not attributable to another medical condition or better explained by the symptoms of another mental disorder.

Benefits of the “new” diagnosis

- Greater awareness and recognition of the problem
- Increased accuracy of diagnosis
- Increased funding for treatment research
- Improved training for mental health professionals
- Greater differentiation between hoarding and OCD behaviors

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What do we know about people who hoard?

- Hoarding was previously believed to be an uncommon problem; initial estimates were that between 1-2% of people hoard
  - Updated studies found that hoarding is perhaps more prevalent than previously believed, with estimates ranging between 1.5 - 6% (Timpano et al., 2011); a more recent meta-analysis indicated 2.5% (Postlethwaite et al., 2019)

- Gender differences in prevalence rates have generally not been observed and that was confirmed by a more recent meta-analysis (Postlethwaite et al., 2019)

- Some studies have found no age differences in prevalence of hoarding behaviors, but several suggest that symptoms may be more prevalent and severe in older adults as compared younger adults (Cath et al, 2017; Reid et al., 2011; Samuels et al., 2008)
  - More recent meta-analysis (Zaboski et al., 2019) found a mean age of onset of 16.9 years of age with possible bimodal distribution of onset of symptoms and clinically impairing symptoms

What do we know about people who hoard?

- An internet-based study of 751 adults with self-reported hoarding symptoms examined the course of hoarding symptoms over time (Tolin et al., 2010)
  - Focused on severity of hoarding symptoms over the lifespan, as well as the incidence of stressful life events
  - 70% reported the onset of hoarding behaviors prior to age 21
    - Later onset was rare (less 4% with onset over age 40)
  - Symptoms generally did not become moderate to severe until mid-life (ages 40-70)
  - Nearly 75% reported a chronic course of their symptoms

  - Rates of reported stressful life events were high
    - 75% reported a history of interpersonal violence (vs. 32% of women in the general population)
    - Interpersonal violence and disruption in interpersonal relationships were associated with periods of symptom onset and increased severity
    - This relationship was strongest for those with symptom onset over age 16

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What do we know about people who hoard?

- In a large-scale epidemiological study, the prevalence of hoarding was not related to education level, living arrangements (living alone or with someone), or race/ethnicity (White vs. non-White) (Samuels et al. 2008).

- However, the prevalence of hoarding was significantly related to income level; individuals in the lowest income level (<$20K/yr) were 4 times more likely to have hoarding than those in the highest income level (>$49K/yr). This was true even after controlling for all other variables associated with income.

- It is not currently known whether financial problems lead to hoarding behaviors, or whether hoarding behaviors lead to financial problems.

What do we know about people who hoard?

- Very little quality research has been conducted examining co-morbid mental health problems among people who hoard

- Research with a sample of 217 people who met proposed DSM-V criteria for hoarding found the following rates of co-occurring mental health problems (Frost, Steketee, & Tolin, 2011):
  - Major depressive disorder - 50.7%
  - Generalized anxiety disorder - 24.4%
  - Social phobia - 23.5%
  - Obsessive compulsive disorder - 18%
  - ADHD, Inattentive Type - 27.8%
  - ADHD, Hyperactive-Impulsive Type - 13.7%
  - Obsessive compulsive personality disorder* - 18.4%

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Components of Hoarding: Acquiring behaviors

- Many people who hoard have problems with acquiring more things than they need or can use
- Items can be acquired in various way
  - Buying – sale items, “good deals,” yard sales, “special” items, internet shopping
  - Picking up free items – side of road, dumpsters/trash, pamphlets, OfferUp/NextDoor
  - Stealing (small percentage of cases)
- Some people who hoard may acquire multiples of items to be sure that one will be available when needed
- Very difficult for individuals to walk away from desired items due to worries that they will regret it later
- Acquiring is usually associated with positive feelings in the moment (i.e., joy, satisfaction of getting a “good deal”), but can lead to negative feelings afterward (i.e., guilt, shame)

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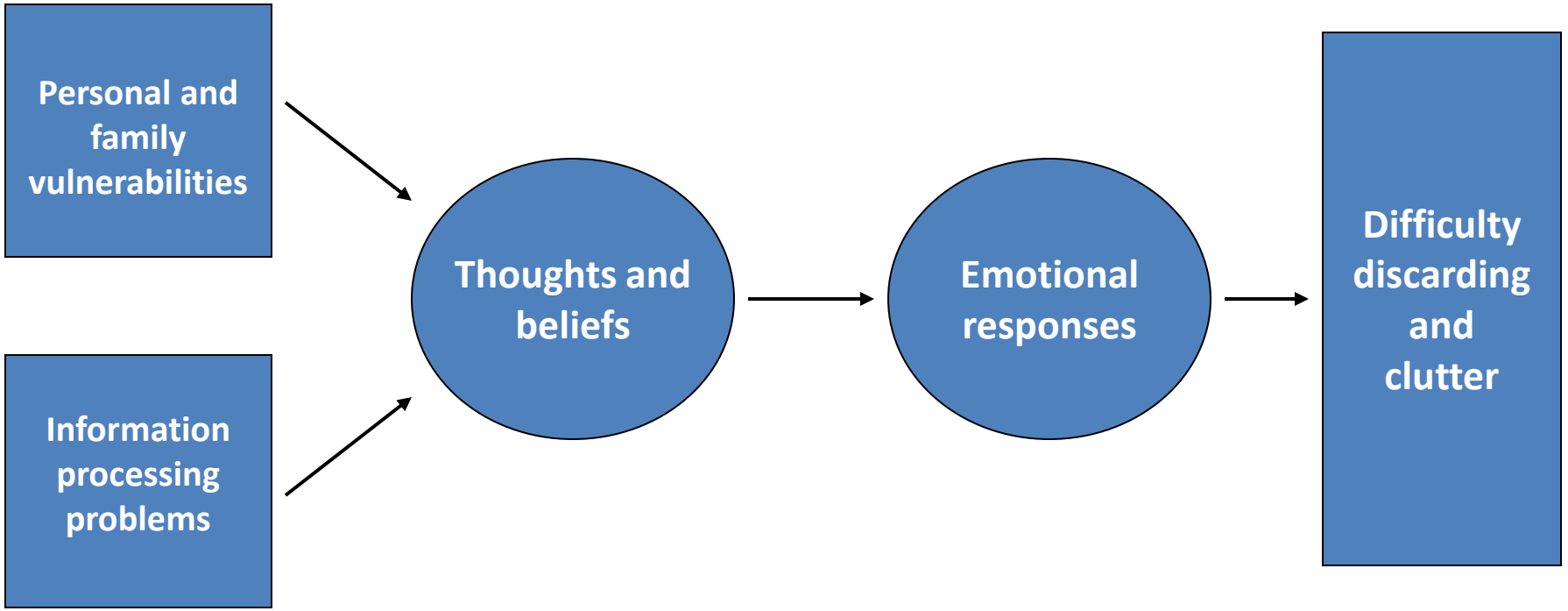
Components of Hoarding: Saving behaviors

- Difficulties with getting rid of possessions is the hallmark of hoarding
- Individuals describe that getting rid of objects can feel like they are losing a part of themselves
- Discarding items can lead to intense feelings of anxiety, sadness, loss, regret, and other negative emotions
- Attempts by others to get rid of items often leads to feelings of anger and increased conflict with the person who hoards

Components of Hoarding: Clutter/disorganization

- (**Excessive acquiring**) + (Saving behaviors) + (Time) = **CLUTTER!**
- Clutter prevents areas of the home from being used as intended; living spaces may be quite limited
- Living conditions may be poor due to the clutter
  - Lack of access to stove, water sources, etc.
  - Appliances may break and cannot be fixed (e.g., heat, air conditioning)
  - Trash may pile up and create unsanitary conditions
- Many people who hoard have significant problems with functions that are essential to maintaining an organized home:
  - Attention/concentration
  - Memory
  - Decision making
  - Ability to categorize objects/information
  - Ability to create and maintain systems of organization (i.e., filing systems)

Conceptual model of hoarding (CBT)



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Treatment

- Treatment research on hoarding did not begin until the early to mid- 1990's and is lagging about 10-15 years behind research on OCD
- Early attempts at treating hoarding in therapy used treatments that were developed for OCD (e.g., ERP), as hoarding was considered a subtype of OCD
- This approach led to poor outcomes for people who hoard (even though it works very well for people with OCD)
- As a result, a new treatment approach was developed that has been studied for the last 15 years
- The treatment is a type of cognitive behavioral therapy that addresses the different factors that maintain hoarding behaviors

Treatment – therapy

- Treatment includes interventions that target:
  - Thought patterns and beliefs that lead to acquiring and saving behaviors
    - Cognitive therapy strategies that help people recognize unhelpful thought patterns and replace them with thoughts that are more accurate and helpful
  - Acquiring behaviors
    - Exposure therapy strategies that help the person learn how to confront triggers for acquiring and then “walk away” without acquiring
  - Saving behaviors
    - Exposure therapy strategies that help the person learn how to sort items into meaningful categories and then discard items that are not needed
  - Clutter/disorganization
    - Problem solving and organizational skills that help the person learn how to create and maintain systems of organization for items that do need to be kept

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Treatment - therapy

- Treatment is generally conducted both in the office and in the client's home
- Can be helpful to have an additional "coach" or professional organizer for the individual to work with between sessions
- Very active and hands on treatment
- Treatment is designed to be a minimum of 26 sessions, but often can take much longer depending on the client's motivation and the severity of the problem
- Large scale "clean outs" don't tend to be effective in the long-term unless the individual has learned the skills for how to reduce acquiring, make decisions about discarding items, and how to keep an organized home

Clean outs

- Large scale clean outs tend to be more effective when:
  - Motivation and readiness to change is high
  - Getting a “jump start” would be helpful for the individual
  - There is a lot of trash or recyclables to be removed from the home
  - The individual has made a lot of progress in therapy and is ready and able to get rid of a lot of items in a short amount of time
  - There is a team of people who can help and can follow rules created by the individual
  - They are a part of a broader treatment plan that addresses the other components of hoarding

- Professional cleaning/hauling companies can be helpful under certain circumstances
  - Dangerous or hazardous materials need to be removed
  - Large amounts of trash/recyclables need to be removed
  - Large quantity of heavy items need to be removed
  - A lot of items need to be removed in a short amount of time

Assessment

- Hoarding interview
- Functional assessment (chain analyses)
- Clutter Image Rating Scale
- Saving Inventory – Revised
- Saving Cognitions Inventory

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Common obstacles to treatment

- Poor insight into the problem
- Low motivation to change
- Resistant to perceived control by others
- Patterns of family conflict related to the hoarding
- History of negative experiences when others have tried to help
- Treatment takes longer than for many other mental health problems
- Difficult to maintain progress over the long-term

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Insight and motivation

- Insight is poor or absent for many people who hoard
- Limited insight is a primary obstacle to working on hoarding behaviors
  - If someone does not perceive a problem, why would he/she want to change?
- In response to limited insight and poor motivation, families and agencies often push harder for change
  - Reasoning, trying to convince the person, arguing, threatening, etc.
- This approach tends to make people *LESS* willing or likely to change
- A different approach (harm reduction) is needed with these individuals
- Process is very slow and requires significant patience!

Harm reduction approach

- Tompkins and Hartl (*Digging Out*; 2009) outline a harm reduction approach for families of people who hoard and have refused help/refuse to change
- Goal of this approach is not to stop hoarding behaviors, but to limit the harm that the behaviors can cause the individual (and others)
- Steps of a harm reduction approach include:
  - Assessing harm potential
  - Assembling a harm reduction team
  - Creating a harm reduction plan
    - Identifying harm reduction targets/goals
    - Creating a harm reduction contract
    - Plan for ongoing monitoring and follow-up
  - Problem-solving contract failures if/when they occur

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Harm reduction approach

- The attitude or “spirit” of a harm reduction approach is critical
- Emphasis is on building common ground and reversing patterns of unhelpful conflict about the hoarding behaviors
- This is accomplished by:
  - Letting go of past conflicts and beliefs about what will be helpful
  - Understanding the problem from the person with hoarding’s perspective
  - Working on forgiveness for past negative interactions
  - Practicing active listening skills
  - Empathizing with the individual’s experiences
  - Focusing on areas of agreement
  - Partnering with the individual
  - Being assertive and setting limits

Therapy models

- Cognitive behavioral therapy (CBT)
  - Individual therapy
  - Group therapy with professional leader
  - Group therapy with peer leader
  - Adaptations for older adults
- Acceptance and Commitment Therapy (ACT)
- Compassion Focused Therapy (CFT)

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Meta-analysis - CBT

- Rodgers, McDonald, & Wootton (2021) conducted a meta-analysis of CBT treatment studies for hoarding
  - Analysis included 16 studies and 505 participants
  - Sample: 72% female; average of 56 years of age; all from Northern hemisphere countries
  - Studies: 4 were controlled; 4 had follow-up data (between 3-6 months); 4 were individual treatment (vs. group)

- Results for hoarding symptoms
  - Pre- to post-treatment effect size: 1.11 (large)
  - Pre- to follow-up effect size: 1.25 (large)
  - The only moderator of outcomes was percentage of women in the study sample – samples with more women had better outcomes
  - The following did not moderate outcome: type of study, length of treatment, home visits, therapist level of training, age

Meta-analysis - Medication

- Brakoulias, Eslick, & Starsevic (2015) conducted a meta-analysis of medication studies for hoarding
  - Analysis included 7 studies and 92 participants
  - Studies: 1 RCT, 3 open trials, 3 case series; each study examined a different medication; 3 were augmentation studies of an SSRI
  - Medications included: Zoloft, Paxil, Effexor, and Ritalin (primary); Seroquel, Naltrexone, and Minocycline (all augmenting an SSRI)

- Results
  - Treatment response occurred in 37-76% of participants (> than 25% or 30% reduction in symptoms depending on the measure)
  - Zoloft, Paxil, and Effexor showed effectiveness
  - Limited to no evidence for the other medications
  - None of the studies had replications
  - Only 1 study was an RCT (Naltrexone) and it did not have positive findings

Medication – next steps

- One study published after the meta-analysis examined the effectiveness of atomoxetine for treating hoarding symptoms (Grassi et al., 2016)
  - Medication is approved for treating child and adult ADHD; was hypothesized that it could be helpful given attentional problems that have been found in people with hoarding disorder
  - Open trial with 12 participants (11 completers); received 12 weeks of the medication and could not have any other medication changes or any CBT during the trial
    - 6 participants were considered full responders, 3 were partial responders, and 2 were non-responders
    - At the group level, reductions in both hoarding symptoms and attentional symptoms were significant
    - Changes in attentional symptoms were not correlated with changes in hoarding symptoms

Treatment – medication

- Currently no FDA approved medications for hoarding disorder
- Medication is frequently used to treat co-morbid symptoms that might interfere with behavioral treatment
  - Anxiety
  - Depression
  - ADHD

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Resources

- International Obsessive Compulsive Disorder Foundation (IOCDF)
  - Hoarding Center (online): https://hoarding.iocdf.org/
- OCD and Hoarding Support Group of Seattle
  - Free hoarding support group: www.ocdseattle.org
- Books
  - *Buried in Treasures* (2014) by Tolin, Frost, and Steketee
  - *Compulsive Hoarding and Acquiring: Workbook* (2014) by Steketee and Frost
  - *Stuff* (2011) by Steketee and Frost
  - *Digging Out* (2009) by Tompkins and Hartl
  - *The Hoarder In You* (2011) by Zasio

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APPENDIX – TREATMENT STUDIES

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Treatment – individual therapy

- Steketee et al. (2010)
  - Randomized wait list controlled trial
  - 46 individuals with hoarding disorder were randomly assigned to 12 week wait list or CBT treatment (26 session treatment protocol)
  - All participants received the treatment over time (36 completed)
  - At 12 weeks, those in treatment were significantly improved as compared to those on the wait list
  - After 26 sessions, participants showed significant improvements from baseline
  - 71% were rated by therapists as improved
  - However, only 41% were rated as clinically significantly improved
- Results suggest that the treatment has promise, but that most clients will need more than 26 sessions to attain clinically significant results

Treatment – group CBT

- Tolin et al. (2019) examined the efficacy of a group-based CBT intervention for hoarding
  - 87 adults were randomized to immediate CBT group or waitlist; waitlist participants received the intervention later
  - 16 weekly, 90-minute sessions emphasizing sorting and discarding (protocol on next slide)
  - Drop out and removal for non-compliance was an issue
    - 5 people dropped from the waitlist and never got CBT
    - Of those who were randomized to CBT or who were slated to get it after the waitlist period, 11 dropped out (4 before starting; 7 during treatment) and 13 were removed for noncompliance
    - Of the 78 people who started CBT, 26% either dropped out or were removed from the study

Table 1
Outline of Group Cognitive–Behavioral Therapy for Hoarding Disorder

Session	Session theme	Major group procedures
1	Group introduction	Introduction, group rules, and psychoeducation about hoarding disorder
2	Mechanisms of hoarding	Review of pretreatment photos Psychoeducation about mechanisms of hoarding Goal setting
3	Decision-making and problem-solving	Discussion of scheduling time to sort and discard Discussion about organizational strategies Sorting and discarding practice
4	Decision-making and problem-solving	Guidelines for reducing acquiring Use of virtual store to identify reasons for acquiring Problem-solving training Sorting and discarding practice
5	Emotion regulation	Psychoeducation about emotions Practice identifying emotions with virtual store and items from home
6	Emotion regulation	Psychoeducation about distress tolerance Practice using distress tolerance skills with virtual store and items from home
7	Cognitive restructuring	Psychoeducation about unhelpful thoughts Practice identifying unhelpful thoughts using items from home
8	Cognitive restructuring	Practice using challenging questions for discarding with items from home
9	Motivational enhancement	Psychoeducation about motivation Identification of goals and values Practice sorting and discarding while reviewing personal goals and values
10	Motivational enhancement	Visualization of decluttered spaces Practice sorting and discarding while reviewing personal goals and values
11	Combination	Troubleshooting barriers Sorting and discarding practice
12	Combination	Troubleshooting barriers Sorting and discarding practice
13	Combination	Troubleshooting barriers Sorting and discarding practice
14	Combination	Troubleshooting barriers Sorting and discarding practice
15	Relapse prevention	Review of progress and skills learned Inventorying and challenging negative thoughts about progress Sorting and discarding practice
16	Relapse prevention	Review of posttreatment home photos Skills for maintaining motivation Additional questions End-of-class celebration

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Treatment – group CBT

- Tolin et al. (2019) cont.
  - CBT was superior to waitlist with 42% of participants in CBT meeting the criteria for clinically significant change on the Saving Inventory – Revised (SI-R) as compared to 8% of waitlist participants
  - Between group effect size for the SI-R was 1.59 (large)
  - 83.3% of participants in CBT were rated as much improved or very much improved as compared to 11.1% on the waitlist
  - Changes in hoarding related cognitions were found to be a significant mediator of outcomes (supporting the theoretical model)
  - One of the few RCTs for hoarding, but no active control condition

New directions – peer facilitators

- Mathews et al. (2018) conducted a large RCT comparing psychologist-led group CBT for hoarding with peer-facilitated group therapy for hoarding
  - Psychologist-led groups were 16 sessions over 20 weeks, included two 30 min home sessions and participants were assigned clutter buddies
  - Peer-facilitated groups were 15 sessions over 20 weeks, with no home sessions, and no assigned clutter buddies
    - Peer facilitators were individuals with lived experience with hoarding disorder
  - 323 participants were randomized to treatment; 269 attended at least one session and 231 (71%) completed treatment
  - No difference in drop out rates, but session attendance was higher in the psychologist led groups (73.3% vs. 57.7%)

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New directions – peer facilitators

- Mathews et al. (2018) cont.
  - Both groups improved in hoarding symptoms (between 25-27% reductions on the SI-R) and functional impairment (between 10-12% reductions on the ADL-H) and the differences were not significant between the groups, suggesting that they worked equally well
    - Higher rates of homework completion predicted outcome in both groups
  - Follow-up data were collected more than 3 months post-treatment (average was 14.4 months later)
    - There were no differences between groups at any time point and gains on the SI-R were maintained at follow-up; though gains decreased with longer follow-up interval

New directions – CFT

- Chou et al. (2020) sought to evaluate the efficacy of a compassion focused therapy (CFT) group for hoarding
  - Participants were individuals who had participated in a psychologist-led CBT group in the prior Mathews et al. (2018) study, but who remained symptomatic for hoarding over a year later (score > 41 on the SI-R, clinical cut-off score)
  - Participants were assigned to either the CFT group, or another round of the CBT group; assignment was not random (sequential)
  - The CFT group consisted of 16 weekly, 2 hour sessions; the CBT group consisted of 15 weekly, 2 hour sessions (intro session was dropped, and no home visits in this study)
  - All participants in both groups were told they would be removed if they missed more than 3 sessions

New directions – CFT

Table 1. Treatment aims and techniques of group CFT and CBT

	CFT	CBT
Psychoeducation and case formulation	• An evolutionary model for hoarding • Understanding the distinction between different motivational systems: their associated emotions, thinking patterns, and behaviours	• A biopsychosocial model for hoarding • Understanding the relationships between thoughts, behaviours, and emotions
Motivation and goal setting	• Identify sources of suffering • Compassion-focused imagery	• Clutter and non-clutter imagery
Awareness enhancement	• Mindfulness training: recognizing feelings and bodily sensations under different states of mind • Chair work: enacting inner dialogue between different parts (e.g., anxious vs. angry; critical vs. compassionate) of the self	• Functional analysis • Familiarizing and training to recognize hoarding-related beliefs
Symptom intervention and wellness improvement	• Soothing skills training • Compassionate mind training: giving and receiving compassion, imagery of a compassionate other and the compassionate self • Compassion-focused exposure • Compassion letter writing • Compassionate buddy	• Cognitive restructuring • Rules and questions for acquiring and saving • Exposure • Pleasure activity planning • Information-processing skill training (i.e., decision-making, sorting, and organizing) • Planning and problem solving • De-clutter buddy

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New directions – CFT

- Chou et al. (2020) cont.
  - 17 participants were enrolled in the CFT group (13 completed) and 19 were enrolled in the CBT group (7 completed)
  - Among the CFT completers, 77% were treatment responders and 62% had a clinically significant reduction in hoarding symptoms; among the CBT completers, 23% were treatment responders and 29% had a clinically significant reduction in hoarding symptoms
  - 100% of CFT completers rated the treatment as positive or extremely positive