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Therapist and patient perspectives on cognitive-behavioral therapy for older adults with hoarding disorder: A collective case study

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Abstract

Utilizing a qualitative approach, the current study explored therapist and patient perspectives on a specialized cognitive-behavioral therapy (CBT) protocol for clinically significant hoarding in older adult patients. Data were derived from the following sources: (1) therapist observation; (2) CBT consultant observation; (3) clinical treatment notes; (4) participant feedback, including a focus group; and (5) participant in-session notes and completed homework assignments. Our findings showed that the value of homework, treatment session compliance, and deficits in executive functioning (prospective memory, planning, problem solving, and cognitive flexibility) were common themes among participants as viewed by the therapist. Patients reported that exposure exercises and the therapeutic relationship were the most helpful aspects of their treatment, while cognitive strategies had limited success. Our results suggest that treatment for hoarding in older adults may be improved by focusing on exposure therapy elements, remediating executive function deficits, providing simplified homework assignments, and decreasing the emphasis or modifying cognitive restructuring techniques.

Keywords

older adults; qualitative approach; exposure exercise; provider perspectives; executive function

Introduction

Although there is limited research on hoarding in elderly individuals, evidence suggests that it is more prevalent in older than in younger adults (e.g., Samuels et al., 2008). Marx and Cohen-Mansfield (2003) found that 25% of elderly community-dwelling day care residents

and 15% of nursing home residents displayed hoarding symptoms. Given the chronic and progressive nature of hoarding (e.g., Ayers, Saxena, Golshan, & Wetherell, 2010; Grisham, Frost, Steketee, & Hood, 2006), it is important to examine potential treatments later in life. Thus, the current investigation explored therapist and patient perspectives on a cognitive-behavioral therapy (CBT) protocol for hoarding in an older adult sample.

The DSM-5 workgroup for hoarding disorder proposes that this disorder is characterized by persistent difficulty discarding possessions combined with strong urges to acquire and save a large quantity of these possessions, regardless of item use or value (Mataix-Cols et al., 2010). The proposed criterion also noted that the clutter volume impairs the use of the home and potentially other important areas of functioning. Finally, these individuals must exhibit distress or impairment from the clutter to meet criteria.

Numerous studies have documented that hoarding symptoms emerge in mid to late childhood (Ayers et al., 2010; Frost & Gross, 1993; Grisham et al., 2006; Samuels et al., 2002; Seedat & Stein, 2002; Wheaton, Timpano, Lasalle-Ricci, & Murphy, 2008) and that symptom severity increases with each decade of life (Ayers et al., 2010). Interestingly, elderly patients often report a mid-life event as the trigger of their hoarding behavior (Ayers et al., 2010); however, research suggests that this timeline is inaccurate. Therefore, hoarding appears to be a chronic illness that begins early in life and may be exacerbated by age.

Hoarding is detrimental for any age group; however, the behavior results in particularly serious consequences for older individuals. For example, hoarding increases the risk of falls, fire hazards, food contamination, social isolation, and medication mismanagement (e.g., Ayers et al., 2010; Frost & Gross, 1993; Kim, Steketee, & Frost, 2001), and older adults may be less resilient to these hazards. According to service providers, 64% of elderly hoarders experience difficulty with self-care, and 81% are at physical health risks created from their hoarding behavior (Kim et al., 2001).

Despite these health concerns, the research in this area has been mostly limited to a few case studies or reports (e.g., Hogstel, 1993; Marx & Cohen-Mansfield, 2003; Rosenthal, Stelian, Wagner, & Berkman, 1999; Stein, Laszlo, Marais, Seedat, & Potocnik, 1997; Turner, Steketee, & Nauth, 2010). However, a recent project was carefully conducted using open label investigation with older adults (Ayers, Wetherell, Golshan, & Saxena, 2011). In this study, 12 older adult hoarding patients (seven women and five men; mean age 73.66 years) completed a manualized CBT protocol (Steketee & Frost, 2007) for hoarding. The exclusion criteria were (1) moderate to severe cognitive deficits, as indicated by scores below 23 on the Folstein Mini Mental State Exam (M. Folstein, S.E. Folstein, & McHugh, 1975); (2) not meeting criteria on the Hoarding Rating Scale (Tolin, Frost, & Steketee, 2010); (3) active substance use disorders; (4) psychotic disorders, in addition to bipolar I or II disorder; (5) concurrent participation in other forms of psychotherapy; and (6) changes in psychotropic medication either 12 weeks prior to or during the treatment. Assessments were completed at four time points: pretreatment, mid-treatment, posttreatment, and 6-month follow-up. Patients underwent 26 sessions of individual psychotherapy with a licensed clinical psychologist who specialized in hoarding. Each office session was 60 min in duration, and the therapy continued on average for 17 weeks. Treatment occurred twice weekly for first 20

weeks followed by once per week for 6 weeks. The CBT protocol included assessment (2–3 sessions), case formulation (2 sessions), motivational interviewing (throughout the treatment), skills training (2–3 sessions), cognitive restructuring (major focus after initial sessions and then throughout the treatment, 15–20 sessions in total), imagined and direct exposure to acquiring and discarding (major focus after initial sessions, 15–20 sessions), and relapse prevention (final 2 sessions). Approximately 75% of the sessions (19–20 sessions) occurred in the therapist’s office, while the remaining 25% (6–7 sessions) occurred in the patient’s home (75–90-min sessions). Home visits occurred roughly every 4–5 sessions. An independent rater reviewed two randomly selected tapes for adherence to the treatment manual and therapist competency. The therapist received a 96% rating. Although the results from this study showed statistically significant changes in the severity of hoarding symptoms and depression, only three of 12 patients were classified as treatment responders (35% reduction in hoarding severity measures and rated as minimally improved or better) at posttreatment. Moreover, their treatment success was not maintained according to average Clinical Global Impression (CGI) scores (Guy, 1976), which indicated ‘no change’ posttreatment or at a 6-month follow-up. In addition, clinician improvement ratings, anxiety, disability, and clutter ratings were not statistically significant at posttreatment and follow-up. In fact, two participants were rated as ‘minimally worse’ on the CGI and showed an increase in hoarding symptom severity measures immediately posttreatment and at their 6-month follow-up evaluations.

Given disappointing outcomes and the impairment caused by hoarding, qualitative information on issues affecting treatment may be useful for future research to better understand and treat late-life hoarding. The current article, a companion project to Ayers et al. (2011), presents factors affecting treatment outcome, such as perspectives from the therapist, treatment consultant, and patients. In addition, we discuss the clinical implications for working with older adults with hoarding disorder.

Qualitative method

Qualitative analysis, for cases in a large open-label trial, illuminates the complex interplay of multiple mechanisms involved in treatment delivery and response among people with psychological disorders. As such, the current project utilized case studies, a methodology that describes and analyzes phenomena situated in a specific context. A case study includes the process of inquiry itself, as well as the results from that inquiry for each sample (Stake, 1995). Hence, in using this method, value is placed on experiential knowledge of the case and the influences of multiple contexts. Moreover, the development of the study requires special attention to the research such as contextualization of knowledge, triangulation (convergence of data from multiple sources), and researcher activities (Stake, 1995; Yin, 2003). In a collective case study, multiple cases are examined simultaneously. This methodology is used when a broader understanding of a condition, phenomenon, or population is needed (Stake, 1995).

The current article examined the specific and unique factors within collective case studies that contributed to and detracted from treatment effectiveness. To achieve this goal, we used multiple methods of data triangulation. Furthermore, data were derived from the following

five sources in order to limit bias and ensure a comprehensive understanding: (1) clinician observation; (2) CBT consultant observation; (3) clinical treatment notes; (4) participant feedback after each session and at the end of treatment, including a focus group; and (5) participant in-session notes and completed homework assignments (Yin, 2003). In addition to data triangulation, clinician and consultant self-reflection and consultation were used to minimize the impact of biases (Maxwell, 2005). This was achieved through a mentor facilitated debriefing for both the consultant and therapist. Data were analyzed from the above sources via review of written content (patient feedback ratings, ongoing therapist/consultant notes, and focus group notes) and interviews (ongoing consultant/therapist meetings, mentor debriefing, and patient verbal feedback from focus group).

Consistent with the case study methodology, the data were interpreted directly and were also aggregated. For direct interpretation, each individual instance was analyzed separately. Then, the instance or event was synthesized with other analyzed events until a class of events was formed (Stake, 1995). Within-case themes emerged into two broad categories: patient perspectives and therapist perspectives. In addition, several themes from the therapist perspective were taken into consideration, given the influence on treatment processes (Table 1). To be included within the therapist perspectives category, at least three sources of support had to contribute to the data (Maxwell, 2005). Similarly, a minimum of three participants had to discuss helpful and unhelpful aspects of therapy to be included in the patient perspectives category (Table 1). Deidentified cases are presented to illustrate these common themes across the 12 cases.

The overall sample consisted of 12 subjects over the age of 65 (seven women and five men; mean age 73.66 years; age range 66–87 years), with hoarding as their most severe or prominent psychiatric condition. This cohort included 10 Caucasian subjects and two Hispanic subjects (refer to Ayers et al., 2011, for full description of subjects). The focus group consisted of six patients (two males/four females, two treatment responders/four nonresponders, mean age 70), who were part of the original subject pool. Five patients from the original study could not attend due to illness and one died. A licensed clinical psychologist (White female) with specialty training in geropsychology and hoarding delivered the treatment and ran the focus group.

Therapist perspective

Homework and treatment session compliance—Homework compliance is an important factor in the success of hoarding treatment (Ayers et al., 2011; Tolin, Frost, & Steketee, 2007). As such, patients were asked to complete homework on a daily basis, which was then rated and reviewed at the beginning of each session. Overall, homework compliance was poor. That is, three of 12 subjects did not attempt to do their homework, and nine of 12 subjects attempted but did not complete their homework. There were three subjects among the nine who attempted to do their homework and who attained 51–75% homework completion and were treatment responders. Although patients showed the ability to complete similar practice assignments in session, all struggled to complete the assignments at home. Regardless of the compliance rate, all patients were markedly better at completing discarding tasks and reducing their acquisition activity than completing the

cognitive strategies homework assignments (e.g., examining evidence for and against beliefs and taking another perspective). Below is an example of a typical session regarding homework:

Ralph came into session looking anxious. He explained that he hadn't looked at his advantages and disadvantages worksheet until last night and once he did, he couldn't understand or remember what was required of him and had a hard time filling out the homework form. Ralph told his therapist that he really wanted to be in treatment but just couldn't complete the assignment.

The collected homework showed that patients attempted few of the assigned cognitive therapy techniques. When asked about the failure to complete the assignments, patients reported feelings of guilt, sadness, and/or embarrassment for their lack of homework. For example, one participant would often telephone the therapist prior to his therapy session to 'admit that (he) did not do the homework'. Patient explanations for uncompleted homework assignments included forgetfulness, level of difficulty, or other competing demands. These results suggest that simplified, concrete homework may produce higher compliance rates.

Three patients showed poor compliance with treatment session structure, content, and activities; however, motivation and long-standing maladaptive personality features may have contributed to these problems. Poor compliance included the refusal to complete exposure or cognitive therapy exercises, completing exposure exercises rapidly without listening to instructions, and neglecting to bring appropriate materials. The most problematic behavior was refusal to comply with the session agenda. For example, the three previously noted patients preferred to use session time to 'vent', rather than participate in the structured treatment. In addition, their distress was generally displayed by feelings of anger or resentment toward family and friends, regardless of whether the issues were related to hoarding. In these incidences, addressing avoidance behaviors, psychoeducation about CBT treatment, and problem-solving skills were useful for redirection and guidance in solving patient complaints. Below is an example of redirection when a patient has difficulty adhering to session structure.

Ruth believed that the more she discussed how her family had abandoned her, she would get to the 'root of the matter', which would subsequently help her hoarding. She actively resisted treatment exercises and would often end up recounting memories of the past where she believed she was treated poorly. Gently asking how this strategy was working for her allowed Ruth to decide if she wanted to try a different approach. Additionally, the therapist continuously reiterated the rationale for exposure and used examples where exposure principles had worked previously in Ruth's own life. After several sessions, Ruth reported she was ready to try exposure therapy.

Skill deficits—Mid-life hoarders struggle with multiple areas of executive functioning deficits, including the acquisition of new information, retention of newly acquired information, attention, response inhibition, decision making, categorization, organization of information, and planning (e.g., Bechara, A.R. Damasio, H. Damasio, & Anderson, 1994; Grisham, Brown, Savage, Steketee, & Barlow, 2007; Grisham, Norberg, Williams, Certoma,

& Kadib, 2010; Hartl et al., 2004; Wincze, Steketee, & Frost, 2007). Grisham et al. (2010) claim that executive functioning deficits contribute to organizational and decision-making difficulties observed in hoarding patients. This is especially concerning since we already expect an increase in neurocognitive deficits among older adults with hoarding behaviors.

Deficits in specific skills may have contributed to homework and treatment session noncompliance. A majority of patients (10 patients) noted one or more cognitive problem (e.g., prospective memory, planning, problem solving, and cognitive flexibility) during the pretreatment evaluation and throughout the treatment sessions. Moreover, the therapist observed deficits in all subjects throughout the treatment period. It was apparent to both the therapist and the consultants that these skill deficits hindered patients' abilities to complete homework and instrumental activities of daily living, such as paying bills and taking medications.

Eleven of the patients showed deficits in prospective memory (ability to remember to do things in the future) and planning. Five patients attempted to use a calendar to organize their schedules; however, they used them in ineffective ways. For example, one patient wrote down his activities in the calendar at the end of the day to serve as a daily 'record', three patients carried the calendar but never used it, and one patient spent a significant amount of time preparing a printout calendar on the computer. The remaining seven patients did not display any organizational method for a daily schedule. Not surprisingly, organizing and completing future tasks were problematic for all patients. Items that needed to be completed were often mixed with lower priority items. For instance, paying overdue electric bills were given the same priority as buying and planting new flowers. Furthermore, four patients often overwhelmed themselves by attempting unmanageable amounts of tasks per day, while another four did not attempt to complete any tasks or assignments at all. The inability to organize and prioritize items was frustrating for many patients:

Sally noted increased frustration that she wasn't ever able to get anything done. She pulled out one of her many to do lists which itemized approximately 15 tasks of varied importance. She planned to spend the weekend working on these tasks and only completed one less important task. Sally felt stuck and unable to move forward with her exposure exercises until she was able to accomplish some very important jobs on her list. In fact, she did not complete any of her exposure homework because she felt pressure to complete her list.

Planning ahead was difficult for all participants. For example, two patients would often telephone at their appointment time to report that they were just leaving their home to come to session. It was apparent that patients had little idea about the timing of necessary routines (e.g., grooming, dressing, eating, gathering homework, and driving to session). Approximately half of the patients (seven) expressed frustration that they were frequently late to meetings or appointments. To improve these skills and decrease patient frustration, future sessions should increase daily structure and planning techniques.

Patients also struggled with problem-solving skills and cognitive flexibility. Ten patients reached an impasse when they encountered a life problem for which a decision and action were needed. Some struggles were directly related to their hoarding behaviors (e.g., mice

living in the clutter and disrepair in the home), whereas others were independent of the disorder (e.g., conflict with church group member and how to learn about their insurance benefits). Patients lacked the ability to brainstorm alternative solutions without assistance and would often get stuck in a rigid thought process. In addition, all patients showed difficulty in tasks requiring cognitive flexibility and were unable to shift their beliefs or behaviors, even when presented with evidence showing that their methods were not working. For example, eight participants had a specific, and ineffective, method for dealing with incoming mail. Despite this problem, they were not able to accurately evaluate the outcomes of their choices or to shift their thoughts and actions to more appropriate, beneficial options for mail organization. These cognitive impairments suggest there is a greater need for specific skill deficit modules in future research with older adult patients who display hoarding behaviors. Below is a typical example of how poor problem solving shows up in real life.

John knew he needed to pay his overdue water bill and was at risk of having his water turned off. He didn't have the money to pay the bill entirely. He felt like his only option was to save enough money to pay the bill entirely. After a session of brainstorming possible solutions, John selected the option of calling the water company and asked to be placed on a payment plan. To his surprise, he was able to set up a payment plan. He noted that it helped to think of different ways of dealing with his situation because he was thinking there was only one way to handle it.

Patient perspective

Helpful aspects of treatment—According to the feedback obtained at the end of individual sessions and throughout therapy, combined with that from the focus group, the direct exposure exercises were the most helpful component of treatment. Although there may have been initial hesitation to complete the exposure assignments, 10 patients noted a sense of accomplishment and three patients were surprised that they were able to tolerate their decision to remove items. In fact, one participant even reported that she was 'shocked' that she did not 'fall apart' during a challenging exposure exercise on her exposure hierarchy. As noted below, patients were often surprised by their own capabilities.

Leda noted some anxiety and resistance about completing her first in-session exposure exercise. She failed to bring in a box of items for the exposure activities on the first day she was supposed to start exposure. Despite assurance from her therapist that she would not be forced to throw something away, she believed that somehow she would be forced to do something that would be distressing. Leda needed additional time to discuss the treatment rules and exposure rationale. After doing so, she felt ready to bring in a box of items next session. When Leda brought a box of items to her next session, she quickly got into the exposure exercise and noticed that despite her anxiety, she was able to stay with the exercise and make choices about her items. At the end of the exercise, she felt surprised that she was able to make difficult choices.

Overall, nine patients appreciated the concrete and simplistic nature of exposure therapy. In addition, all focus group patients noted that the combination of office and home-based

exposure exercises was very helpful. Home visits were reported as being particularly useful for goal setting, planning, and generalization of exposure exercises (10 patients).

The patient–therapist relationship was also cited as an important component of therapy. Patients verbally identified ‘*encouragement, kindness, and support*’ of the study therapist as a useful component to their treatment (10 patients). Moreover, the relationship between patient and therapist was viewed as a critical element for completing the treatment sessions. All patients displayed a strong trust of the therapist, as shown by symptom disclosure and home visits. The nonjudgmental nature of the therapist likely assisted with this level of trust. For three patients, the study therapist was the first person to enter their home in over 10 years:

Jose had little social contact and support. He noted great sadness at the end of treatment due to the loss of frequent supportive contact with the therapist. ‘You’re the only one who knows (about my hoarding problems) and who I can talk with about this – it’s like losing a relative’.

Unhelpful aspects of treatment—All 12 patients indicated that the provided cognitive tools and strategies were too abstract and difficult to generalize or link to their hoarding problems. During one session, a patient remarked, ‘I don’t understand why you’re having me do this Need versus Want worksheet. You’ve explained it to me, but it doesn’t help with my clutter’. Not only was it difficult for patients to understand the cognitive elements during treatment, it was also problematic for them to recall the techniques at the end of treatment (12-month posttreatment focus group). These issues are demonstrated by Chuck:

Chuck noted that when he tried to use the Thought Record (tool used to identify and challenge problematic thinking), he struggled to identify his thoughts and record them in real time. After careful explanation by the therapist and several examples done together during three sessions, Chuck was able to identify a few of his thoughts and compare them to a list of cognitive distortions. The therapist then assisted Chuck with identifying more helpful alternative beliefs. Though Chuck was able to use the tool in session with the support of the study therapist, he was not able to apply this technique at home or in real time.

Ten subjects in particular displayed difficulty with cognitive techniques throughout the course of treatment. These individuals were unable to identify their thoughts as related to their clutter and struggled with abstract cognitive concepts, such as taking another perspective, visual imagery, and downward arrow (tool used to identify core beliefs). Those patients who were able to grasp the cognitive concepts in session were unable to consistently implement the strategy in a novel situation at home. Eight patients reported that indirect exposure (imagery) was much less useful than direct exposure. Finally, participants also failed to remember case formulations (detailed descriptions of factors contributing to hoarding) toward the end of treatment and at 6-month follow-up (10 patients). Consequently, these were considered to have limited utility or necessitate modification.

Conclusions

From the therapist's perspective, the two most salient themes affecting treatment outcome were homework and treatment session compliance, in addition to patient skill deficits (prospective memory, planning, problem solving, and cognitive flexibility). In comparison, patients reported that direct exposure exercises, the therapeutic relationship, and home visits were the most helpful aspects of treatment. In general, the therapist and patients agreed on the advantages and disadvantages of treatment techniques.

Patients noted that cognitive strategies and case formulation work were not incredibly helpful, which suggests that cognitive-behavioral treatment needs to be modified for this population. Given the importance of homework compliance, concrete and simplified assignments may be more appropriate. In addition, we recommend providing motivational interviewing and psycho-education about hoarding during the early stages of therapy as outlined in the study by Steketee and Frost (2007).

As skill deficits may contribute to difficulties with in-session treatment and homework completion, it is important to address and reduce the deficits in prospective memory, planning, problem solving, and cognitive flexibility. One may achieve this by implementing modified problem-solving therapy or specific modules from traditional cognitive rehabilitation that focus on executive functioning. Importantly, we recommend using direct exposures for a majority of the treatment session, as these exercises were evaluated as the most helpful aspect of treatment. The increased time for behavioral interventions could be taken from that time traditionally given to cognitive therapy methods. Finally, the patient-therapist relationship is important to treatment success. It is critical that the therapist maintains a nonjudgmental attitude and continuously offers support and encouragement throughout treatment.

There are some limitations of our study. First, given the small sample size, future research using more subjects is needed to replicate and validate our findings. Second, qualitative treatment consultant, patient, and therapist biases may have impacted our results, although we attempted to mitigate biases through the use of multiple data sources. Despite these limitations, the exploration of patient and therapist perspectives on therapy is an important step toward finding the most effective treatment for this serious condition. The impact of these themes on treatment outcome in other hoarding subgroups warrants further study.

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Table 1

Factors influencing treatment processes and outcomes for older adults with hoarding disorder.

Therapist perspective	Patient perspective
Patient preexisting skill deficits: prospective memory, planning, problem solving, and cognitive flexibility*	Exposure therapy techniques (helpful)
Homework and treatment session compliance *	Home visits (helpful)
Strength of patient–therapist relationship	Relationship with therapist (helpful)
Long-standing maladaptive personality features	Cognitive therapy techniques (unhelpful)
Motivation for treatment	Case formulation (unhelpful)

* Note: Most evidence for direct impact on treatment.