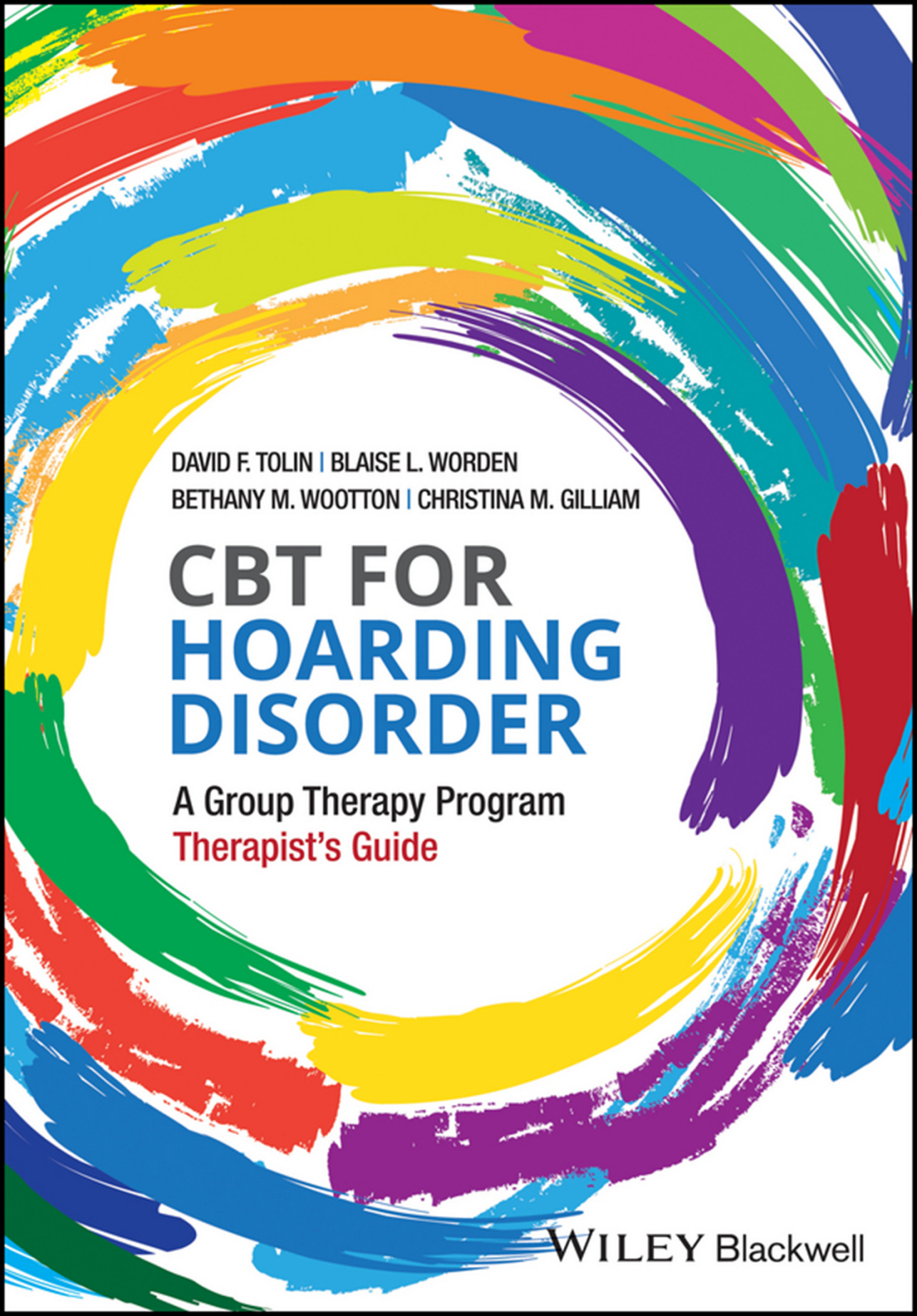




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CBT FOR HOARDING DISORDER

A Group Therapy Program
Therapist's Guide

WILEY Blackwell

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David F. Tolin

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Part I

Introductory Information
for Clinicians

What is Hoarding Disorder?

Diagnosing Hoarding Disorder

Hoarding Disorder (HD) was first afforded diagnostic status in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5; American Psychiatric Association, 2013). The DSM-5 diagnostic criteria for HD include:

1. Difficulty discarding or parting with possessions due to strong urges to save items and/or distress associated with discarding.
2. Clutter that precludes activities for which living spaces were designed.
3. Significant distress or impairment in functioning caused by the hoarding.

Prior to the publication of the DSM-5, hoarding behaviors were informally considered to be a syndrome or subtype of obsessive-compulsive disorder (OCD). However, as evidence mounted about the differences between hoarding and OCD (Pertusa et al., 2010), it became increasingly clear that hoarding represented a unique syndrome that had not been adequately categorized. Epidemiological research has suggested that the prevalence rate of HD is between 2 and 5% (Frost, Steketee, & Williams, 2000; Iervolino et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008), making HD a very common condition.

Understanding the Symptoms of Hoarding Disorder

Difficulty discarding. The hallmark symptom of HD is reluctance to discard personal possessions, including objects that non-hoarding individuals might consider to be worthless or having little intrinsic value. Although the reasons for saving objects tend to be similar to those described by non-hoarding individuals (Frost & Gross, 1993), for individuals with HD these beliefs are more intense and rigid, and applied to a greater number of possessions. Attempts to discard usually cause substantial emotional distress, and therefore are frequently avoided.

Excessive clutter. Excessive clutter is the most visible feature of compulsive hoarding. Unlike normatively “messy” or disorganized individuals, those with HD commonly describe significant difficulty using the living spaces of their homes due to clutter. For example, individuals with HD often have clutter that may cover beds, chairs, or tables, rendering them unusable. In severe cases, the clutter prohibits movement through the house or access to certain parts of the home.

Excessive acquiring. Although acquiring is not a DSM-5 diagnostic criterion for HD, research suggests that most individuals with HD do engage in excessive acquiring (Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009). Excessive acquisition can include compulsive buying, collection of free items, inheritance of items, and rarely, stealing. Many report spending many hours each week searching for and acquiring objects (e.g., excessive shopping, rummaging through trash bins). Individuals with HD therefore may also present with distress related to overspending or debt as a result of compulsive shopping behaviors.

Understanding Hoarding-Related Impairment

Health risks. Clutter can lead to substantial personal impairment or injury, and has the potential for fatal consequences. Clutter’s interference with basic home functions such as cooking, cleaning, moving through the house, and even sleeping can make hoarding dangerous, increasing the likelihood of fire, falling, poor sanitation, and pest infestation (Steketee, Frost, & Kim, 2001).

Clutter poses a major fire risk both to those who live in the home and to neighbors. A study analyzing residential fires over a 10-year period indicated that hoarding accounted for 24% of all preventable fire fatalities (Harris, 2010). Blocked egress, such as doors and windows, may prevent individuals from escaping home fires, and can prevent emergency personnel from entering the home when needed.

Elderly individuals in particular may be injured by falling objects or even trapped by collapse of clutter or other structural elements of the home. Health

risks to children who live in the home may include the presence of mold, contributing to respiratory difficulties such as asthma. Children or elderly may become ill from keeping and ingesting expired food. Plumbing or heating may be inoperable; or other repairs may be needed but avoided due to concern about others entering the home.

Due to the potential for harm, clutter may lead to protective removal of children or elderly from the home (Tolin, Frost, Steketee, Gray, & Fitch, 2008). Involvement of government agencies, such as child or elderly protective services, fire marshals, police, or public health departments, is not uncommon. Clutter may also lead to threats of eviction by housing authorities.

Psychological impact. Individuals with HD are likely to be particularly susceptible to isolation. Embarrassed by their clutter or avoidant of criticism, many individuals with HD avoid inviting friends, family, or repair workers to their homes, contributing to social isolation (Rasmussen, Steketee, Tolin, Frost, & Brown, 2014).

HD may also increase rates of intrafamilial conflict and rejection of the hoarding individual. Family members may be upset by excessive time spent on acquiring or in response to financial debt related to compulsive buying. Family members may become frustrated with the patient's reluctance or inability to change. In one large survey (Tolin, Frost, Steketee, & Fitch, 2008) of family members of hoarding individuals, scores on a measure of rejection of hoarding individuals were higher than family rejection scores for clients with schizophrenia, especially if the hoarding individual was perceived as having little insight into their problem.

Many individuals with HD describe impaired work and role functioning. Individuals who self-identified as having HD reported missing more work due to psychiatric reasons than individuals with depression, anxiety disorders, or substance use (Tolin, Frost, Steketee, Gray, et al., 2008).

Hoarding may also have a negative psychological impact on children who are raised in the hoarding environment. In the Tolin, Frost, Steketee, and Fitch (2008) survey, children who identified as having grown up in the home of a parent with HD described lower satisfaction with their childhood than individuals who did not grow up in the cluttered home. Specifically, children raised in the hoarding home reported embarrassment of the home and avoidance of having peers in the home, along with increased conflict within the home.

Financial cost to society. In addition to the health risks, HD also presents a high financial cost to society. Individuals with HD tend to be high utilizers of services, including medical, mental health, and social welfare services. In one study (Frost, Steketee, & Williams, 2000) approximately 64% of surveyed public health officials reported receiving at least one complaint of hoarding during a five-year period. The majority (88%) of the cases concerned unsanitary conditions. The City of San Francisco conservatively estimated that HD costs service providers and landlords in that city \$6.4 million per year (San Francisco Task Force on Compulsive

Hoarding, 2009). The Melbourne Fire Department study found that the average cost of firefighting hoarding-related fires was eight times greater than that of hoarding-unrelated fires (Harris, 2010).

Understanding Comorbidity in Hoarding

Management of hoarding cases tends to be complicated by a high presence of co-occurring mental health and medical concerns. As many as 92% of individuals with HD meet criteria for co-occurring psychiatric conditions (Frost, Steketee, & Tolin, 2011). As noted previously, the link between hoarding and OCD is not as strong as previously thought, although a significant minority (approximately 18%) of HD clients will also meet diagnostic criteria for OCD (Frost, Steketee, et al., 2011). Depression and anxiety are highly common among those with HD, with Major Depressive Disorder (53%), Social Anxiety Disorder (24%), and Generalized Anxiety Disorder (24%) among the most common co-occurring diagnoses in treatment-seeking HD clients (Frost, Steketee, et al., 2011).

Hoarding is also associated with relatively high rates of personality disorders and maladaptive personality traits. Although excessive saving of potentially low-value items is a criteria for the diagnosis of Obsessive-Compulsive Personality Disorder (OCPD), most HD clients do not meet criteria for OCPD when the hoarding criterion is removed (Frost, Steketee, et al., 2011). However, Dependent, Avoidant, Paranoid, and Schizotypal Personality Disorders appear fairly common in hoarding samples (Frost, Steketee, Williams, & Warren, 2000; Samuels et al., 2008).

Research increasingly suggests a link between hoarding and Attention-Deficit/Hyperactivity Disorder (ADHD), or a similar symptom profile. Hoarding clients often report significant problems with attention and executive function that resemble those seen in people with ADHD. Individuals with hoarding symptoms commonly obtain high scores on self-report ADHD measures, and in one study, 20% of HD clients, compared to 4% of OCD clients and 3% of community controls, met full DSM-IV-TR diagnostic criteria for ADHD (Frost, Steketee, et al., 2011). These data comport with those of a study of OCD clients, in which those with hoarding symptoms had a risk of ADHD almost 10 times higher than those without hoarding (Sheppard et al., 2010). Studies of neuropsychological performance in hoarding clients have yielded mixed results, although individuals with HD appear to have more specific deficits in the areas of problem solving, organization, and sustained attention (Woody, Kellman-McFarlane, & Welsted, 2014).

It is important to be aware that hoarding *behaviors* such as saving, excessive acquiring, or disorganization may be present in a variety of disorders beyond HD. Hoarding behavior has been noted in clients with OCD (Matsunaga, Hayashida, Kiriike, Nagata, & Stein, 2010) and schizophrenia (Luchins, Goldman, Lieb, & Hanrahan, 1992), as well as after certain neurological insults such as damage to

prefrontal and orbitofrontal cortex (Eslinger & Damasio, 1985; Volle, Beato, Levy, & Dubois, 2002) and dementia (Hwang, Tsai, Yang, Liu, & Lirng, 1998). Therefore, in cases of severe clutter and saving behavior, it is important to consider whether alternative diagnoses may better explain the hoarding problem. At this point, this manual has not been tested with individuals without a formal diagnosis of HD.

What Causes Hoarding Disorder?

Our treatment model is based on the idea that the most effective interventions are those that target the active *mechanisms* of the problem – that is, the reasons *why* the person engages in the behavior.

Etiology: Why Did These Symptoms Begin?

Research points to certain etiologic factors that might help explain why hoarding occurs in the first place. One such factor is a history of traumatic or stressful life events. Individuals with HD report a high frequency of lifetime traumatic events (Cromer, Schmidt, & Murphy, 2007; Hartl, Duffany, Allen, Steketee, & Frost, 2005; Tolin, Meunier, Frost, & Steketee, 2010), and in many cases, these stressful life events coincide with the onset or worsening of hoarding symptoms. Some have suggested that hoarding behaviors develop, in part, as a means of strengthening one's sense of safety following a trauma or a chaotic childhood environment (Cromer et al., 2007; Samuels et al., 2008). We note, however, that hoarding is often present in individuals without any reported history of trauma, and most individuals with trauma histories do not engage in hoarding behaviors. Trauma, therefore, seems to have limited explanatory power in our estimation.

Hoarding symptoms appear to have a strong familial component, suggesting influences of both modeling (learning by observing) and genetics. HD likely has a high heritability rate; in one study of rates of HD in twins raised in the same residence, genetic factors were estimated to account for 49% of the variance in diagnostic (HD vs. no HD) status (Iervolino et al., 2009). Most individuals with HD describe at least one first-degree relative as a “packrat” (Winsberg, Cassic, & Koran, 1999), and family members of individuals who hoard are likely to report indecisiveness (Frost, Tolin, Steketee, & Oh, 2011; Samuels, Shugart, et al., 2007), suggesting that decision-making problems might be an inherited vulnerability factor. Many clients with HD report being taught or observing in their parent, from early in life, beliefs and behaviors associated with hoarding. For example, their parents would condemn “wasteful behavior,” or the individual would observe excessive acquiring behaviors by the parent. Additionally, certain genetic abnormalities have been identified in families with hoarding behavior (Samuels, Shugart, et al., 2007).

Maintenance: Why Do These Symptoms Persist?

One limitation of understanding HD according to the various etiological factors is that such a model does not provide us with clear, actionable targets for treatment. We cannot, for example, go back in time and undo traumatic or stressful life events, nor can we alter a person's genetics or family history. We therefore place greater emphasis on understanding *maintenance* mechanisms; that is, the ongoing processes that keep the behavior in place and cause them to recur day in and day out. Our CBT model explicitly aims to identify and interrupt the mechanisms that maintain hoarding behavior. Below, we will describe the maintenance mechanisms that are our targets for intervention.

Target 1: Problems of decision-making and other cognitive processes. We believe that HD is maintained in large part by a breakdown in the person's decision-making process. People with HD report high levels of indecisiveness (Frost, Tolin, et al., 2011; Samuels et al., 2002), and we suspect that much of the difficulty discarding seen in HD stems from the fact that sufferers cannot make effective and efficient decisions about their possessions. Indeed, in one of our studies, the degree of self-reported indecisiveness was negatively correlated with the number of possessions discarded during a task (Tolin, Stevens, et al., 2012). When a decision to discard a possession is successfully made, it is often a result of time-consuming and emotionally draining deliberation and doubt.

One possible contributor to the presence of decision-making deficits is impairment in basic cognitive processes such as attention, memory, and executive function. As discussed previously, clients with HD frequently report notable problems with sustained *attention*. These self-reports are corroborated by results of standardized tests of attentional capacity, in which hoarding is associated with diminished non-verbal attention, greater variability in reaction time, and poorer ability to detect target stimuli (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Tolin, Villavicencio, Umbach, & Kurtz, 2011).

Many hoarding individuals describe themselves as having poor *memory*, and report keeping certain possessions due to fears that they will forget relevant information or lose an important memory if they discard an object. Standardized tests of memory functioning have revealed that individuals with HD show impaired delayed recall (both verbal and visual), and use less effective visual recall strategies, than do healthy control participants (Hartl et al., 2004), although the degree of memory impairment is less pronounced than the degree of attentional impairment.

Some research suggests that clients with HD perform more poorly than do control participants on standardized tests of *executive functions* such as planning and problem solving (Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Woody et al., 2014). The ability to categorize possessions – a key skill in maintaining organization – appears to be compromised in those with HD. When asked to sort their personal possessions, individuals with HD took longer, and created more

categories (with a smaller number of items per category), than did healthy controls or participants with OCD (Wincze, Steketee, & Frost, 2007). Similarly, our experience has been that HD clients often exhibit poor problem-solving abilities. Seemingly minor roadblocks, such as a scheduling conflict or inability to find space to sort, become insurmountable obstacles. This makes it very easy for progress to stall as the patient may have difficulty seeing that a goal can be accomplished via alternative routes, or that different options are available.

Target 2: Maladaptive beliefs about possessions and discarding. Individuals with HD commonly hold maladaptive, exaggerated beliefs about possessions and discarding. Many describe a heightened sense of *responsibility* for possessions (Frost, Hartl, Christian, & Williams, 1995) – for example, exaggerated beliefs that they are responsible for finding an appropriate “home” for an object. For many, simply imagining a potential use for a possession implies that it must be saved for that purpose, even if its use is unlikely. Clients with HD show particularly strong beliefs about the need to acquire and save objects because of a strong *aversion to wastefulness* and *fears of losing important information* (Frost, Steketee, Tolin, Sinopoli, & Ruby, 2015). Clients with HD may also exhibit an exaggerated *need to maintain control* over their possessions, which is often demonstrated by an aversion to others moving, sharing, or touching their possessions; such actions appear to be perceived as a threat to personal autonomy, or disruptive of visually-based organizational systems. *Perfectionism* beliefs may also inhibit discarding by rendering individuals fearful of making decisions due to concerns about making a mistake (e.g., discarding the wrong item).

Target 3: Difficulty with emotion regulation. The prospect of discarding generally evokes strong feelings in individuals with HD. Many report strong emotional attachments to items (e.g., an over-appreciation for the aesthetics or sentimental value of objects). In some cases, clients have reported feeling a greater sense of attachment to objects than to people. In some cases, that emotional attachment is expressed in terms of *anthropomorphization* (imbuing inanimate objects with human qualities such as thoughts and feelings), in which clients are excessively concerned about making sure that the possession “goes to a good home” and is unharmed. In other cases of emotional attachment, objects are associated with fond memories of people, places, or activities – so much so that the object becomes “fused” in the person’s mind with that person, place, or activity. In still other cases, possessions serve as a visual representation of the person’s desired identity – for example, a collection of books to define oneself as knowledgeable. Discarding possessions, therefore, is sometimes equated with losing a loved one, a symbol of an important time in the person’s life, or part of the person’s own identity. Relatedly, many clients with HD describe their emotional reaction toward discarding as sadness or grief, in addition to anxiety.

We propose that HD is characterized by poor *emotion regulation*. Though emotion regulation has been defined in various ways, we favor the model offered by Gratz and Roemer (2004), which suggests that people with poor emotion regulation

show (a) lack of awareness, understanding, and acceptance of emotions; (b) lack of access to adaptive strategies for modulating the intensity and/or duration of emotional responses; (c) an unwillingness to experience emotional distress as part of pursuing desired goals; and (d) the inability to engage in goal-directed behaviors when experiencing distress. The unwillingness to experience emotional distress (or *low emotional distress tolerance*) appears to be particularly important in HD. Individuals with HD often report exaggerated fears about the consequences of distress and low confidence in their ability to tolerate emotional distress. For example, they may worry that they “will never recover” if an important item is discarded, that they “will never stop thinking about the item” or that “the sadness [or other emotion arising when discarding] would be intolerable.” Research on college volunteers (Timpano, Buckner, Richey, Murphy, & Schmidt, 2009; Timpano, Shaw, Cougle, & Fitch, 2014) suggests that low self-reported distress tolerance is associated with hoarding behaviors. Hayes, Wilson, Gifford, Follette, and Strosahl (1996) use the term *experiential avoidance* to describe an unwillingness to experience strong, generally negative emotions, accompanied by efforts to avoid such distressing emotions. In HD, this can be seen in the avoidance of discarding because it is likely to cause a negative emotion, or acquiring an item in order to feel a more pleasant emotion (Wheaton, Abramowitz, Franklin, Berman, & Fabricant, 2011).

Target 4: Saving as avoidance. From the discussion above, it is not hard to understand why an individual with HD would want to avoid discarding; the process is cognitively demanding and stirs up strong negative feelings that the person then has difficulty tolerating. Put simply, the very idea of discarding can be overwhelming. As is the case with many forms of avoidance, however, avoidance of discarding serves to maintain the problem. In HD, the avoidance is theorized to allow maladaptive beliefs to persist (e.g., if the person believes they could never recover after discarding a possession, avoidance prevents that belief from being disconfirmed), contribute to excessive negative emotion (discarding seems more threatening the more the person avoids it), and, of course, allows for the buildup of excessive clutter.

Target 5: Acquisition as impulsivity. Clients with HD often identify acquiring as one of their most enjoyable activities, elaborating that acquiring elicits various positive emotions (“exciting”) and cognitions (“I feel thrifty and smart”). In these instances, acquisition behaviors are positively reinforced appetitive behaviors. This difficulty exerting control over one’s impulses and urges (sometimes termed *poor self-control*) appears high among individuals with hoarding behaviors (Frost et al., 2009; Timpano & Schmidt, 2013) as well as among those with compulsive buying (Billieux, Rochat, Rebetz, & Van der Linden, 2008). Indeed, some studies have found a correlation between hoarding behavior and impulse control disorders (Frost, Meagher, & Riskind, 2001; Frost, Steketee, et al., 2011).

Target 6: Poor problem recognition and motivation. Some individuals who hoard display a striking lack of awareness of the severity of their behavior, sometimes denying the problem and/or resisting intervention attempts. Others may defensively rationalize their acquiring and saving (Frost, Tolin, & Maltby, 2010; Samuels et al., 2002; Tolin, Fitch, Frost, & Steketee, 2010). Research reports indicate that many individuals with HD do not consider their behavior unreasonable (Samuels et al., 2002), and that recognition of a problem with hoarding typically does not occur until at least a decade after onset (Grisham, Frost, Steketee, Kim, & Hood, 2006). In a large survey of family members of hoarding individuals, the family members described their relatives with HD on average as having fair to poor insight, with more than half described as having “poor insight” or “lacks insight/delusional” (Tolin, Frost, Steketee, & Fitch, 2008). We have found that many HD clients can verbalize the problem and consequences, but when faced with discarding, show strong beliefs resistant to disconfirming evidence, which are sometimes near-delusional in intensity.

Relatedly, clients show variable motivation to change their behavior. Among residents reported to health departments due to unsanitary housing conditions from hoarding, less than one third were willing to cooperate with health officials to improve the condition of their home (Frost, Steketee, & Williams, 2000). Treatment-interfering behaviors, such as poor attendance and noncompliance, are common (Christensen & Greist, 2001), even among individuals who seek treatment willingly. Many clients attend treatment only at the behest of others, and may passively resist the intervention.

Perhaps not surprisingly, this limited insight and motivation, coupled with a high rate of treatment-interfering behavior, can lead to frustration on the part of clinicians and social service personnel. When we surveyed professionals about their work with both hoarding and non-hoarding clients, we found that they reported that the working alliance was weaker for the hoarding clients, and that they were more likely to harbor negative attitudes about their hoarding clients than other patients. (Tolin et al., 2012).

Target 7: Poor organizational skills. When one visits the home of someone with HD, one is immediately struck not only by the sheer volume of clutter, but also by the disorganized manner in which the possessions are typically stored. Food items might be in the living room; clothing might be in the bathroom; or auto parts might be in the kitchen. This disorganization may be due, in part, to the executive functioning (e.g., categorization) deficits described above. Potentially because of difficulty deciding on the relative importance of items and where they should be stored, items of varying importance may be placed together. It is not uncommon for participants in our treatment groups to find uncashed checks or other important documents (e.g., a birth certificate or mortgage bill) in a pile of newspapers or other less important paperwork/items. Such disorganization complicates efforts to intervene: Clients are often reluctant to discard a