

Hoarding



Hoarding is a mental health disorder characterized by difficulties with discarding possessions, yielding cluttered and chaotic home environments that can pose significant safety concerns, impairment to functioning, and distress for those who live in and encounter these situations. Understanding the condition and the strategies available to support individuals who hoard are important skills for the home care provider and are described here in the context of one community organization's response via the development of a Community Clutter and Hoarding Toolkit.

in the Home

Introduction

Hoarding is neither a new mental health condition, nor an uncommon one: recent prevalence estimates suggest that about 5% of the adult population engages in hoarding behavior (Samuels et al., 2008). In the last decade, popular television shows, elevated media coverage, and the exponential growth in hoarding research have significantly increased public and professional awareness of this phenomenon (Pertusa et al., 2010; Snowden & Halliday, 2004). Understanding this disorder and the specific strategies available to home healthcare providers to improve safety conditions in cluttered environments can be invaluable to healthcare workers and the people they support (Chater & Levitt, 2009).

Hoarding is characterized by a marked difficulty with discarding objects of seemingly limited value, leading to cluttered homes, safety concerns, distress, and impaired functioning (Frost & Hartl, 1996). Most people who hoard engage in the disproportionate acquisition of possessions, typified by excessive shopping, “bargain hunting,” or collecting of trash and other giveaway items that do not have a practical place to be stored or used (Frost et al., 2009). This imbalance between acquisition and discarding results in the accumulation of excess clutter. Clutter is typically composed of common household items such as papers, books, clothes, food, and furniture, which are spread about the home in disorganized piles that blend important and useful possessions with trash, disused, and unlike items. Spaces within the home of someone

A Toolkit for the Home Healthcare Provider

who hoards are frequently inaccessible and unusable—the shower, for example, may be filled with stacked clothes, the bed so covered with belongings that occupants must sleep in a chair, or a broken freezer inoperable as it cannot be accessed by the repair technician. It is

estimated that in about half of the homes of people who hoard, the sink, tub, stovetop, or refrigerator is unusable, and that 1 in 10 homes do not have a working toilet (Frost et al., 2000).

The functional and social implications of hoarding are significant (Tolin, Frost, Steketee, & Fitch, 2008; Tolin, Frost, Steketee, Gray, & Fitch, 2008). Hoarding behaviors and excessive clutter are also frequently described as a source of significant distress and frustration for family members of people who hoard, leading to levels of rejection comparable to that measured among family members of people with schizophrenia (Tolin, Frost, Steketee, & Fitch, 2008; Tolin, Frost, Steketee, Gray, & Fitch, 2008).

Excess clutter can seriously compromise health and safety. Fires, floods, falls, unhygienic conditions, mold, infestations, and unmanaged garbage create significant risks for the home’s occupants as well as other units or dwellings in the immediate locale (Frost, Steketee, & Williams 2000; Frost, Steketee, Williams, & Warren, 2000; Lucini et al., 2009; Steketee et al., 2001). Eviction and other court proceedings may result in homelessness, expensive fines, or an unwanted move into a long-term-care facility (Frost, Steketee, & Williams 2000; Frost, Steketee, Williams, & Warren, 2000; Tolin, Frost, Steketee, & Fitch,

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2008; Tolin, Frost, Steketee, Gray, & Fitch, 2008). The serious nature of health, safety, and functional impairment characteristic of people who hoard highlights the need for community health providers to have knowledge and the tools to respond effectively to situations of excess clutter (Valente, 2009).

This article describes the experiences of clients and health providers who encounter hoarding in their community practice, reviewing specific strategies for intervening through a skill development and harm reduction framework. This approach will be described within the context of a hoarding program and toolkit that was developed by one community-based, nonprofit health service agency (referred to herein as “the organization”).

Hoarding: How it Happens

The onset of hoarding symptoms typically occurs in early adolescence and follows a chronic and progressive course, yielding excess clutter and impairment by mid-to-late life (Frost & Gross, 1993; Grisham et al., 2006; Tolin et al., 2010; Winsberg et al., 1999). The appearance and severity of hoarding behaviors have been linked to the occurrence of traumatic and stressful life events both in childhood and across the lifespan (Grisham et al., 2006; Hartl et al., 2005; Samuels et al., 2008; Tolin et al., 2010). For example, individuals with hoarding behaviors are more likely to report a history of childhood break-ins, excessive physical discipline, or a parent with psychiatric illness (Samuels et al., 2008). The phenomenological research of Kellet et al. (2010) similarly concluded that people who hoard often understand their own behavior in terms of

a reaction to childhood adversity, including the experience of learned emotional suppression in the face of authoritarianism and rejecting parenting styles and other abusive experiences. In adults, rates of interpersonal violence and the stressful experience of having a belonging taken by force are reported at disproportionately high rates and furthermore noted to trigger periods of symptom intensification (Cromer et al., 2007; Samuels et al., 2008; Tolin et al., 2010).

Exploring themes of emotional deprivation and loss can assist in the development of personalized case formulations (Box 1) and allow client and clinician alike to understand the emotional purpose clutter represents (Landau et al., 2011). This lays the foundation for clients to develop the skills to process their emotions as emotions, and relate to objects as the physical items that they are.

When asked about why objects are acquired and saved, people who hoard typically cite the same reasons that nonhoarders will describe for keeping their possessions, albeit with significantly greater intensity and broader application (Frost & Gross, 1993; Kellet et al., 2010; Pertusa et al., 2008). Furby (1978) first described this in terms of the ways in which people perceive value in their possessions: sentimental, instrumental, and intrinsically motivated attachments.

Sentimental Hoarding and Emotional Attachment

Sentimental hoarding arises with objects that are held onto as representations of the connection to important people, events, and places, evoking the memories and associated emotions. Kellet and colleagues describe sentimental hoarding in terms of “object–affect fusion” whereby an individual’s emotional association with an object is no longer an experience owned within the individuals themselves, but perceived as *being* the object (Kellet, 2006; Kellet & Knight, 2003). In this context, the task of intervention becomes one of supporting clients to uncouple their emotional experience from the object—that is, to keep (or process) the affect without keeping the item itself (Figure 1).

Strong emotional attachment to possessions is a consistent theme among people who hoard (Kellet et al., 2010). Although this is often reflected as a process of sentimental attachment, it can also be experienced as an exaggerated

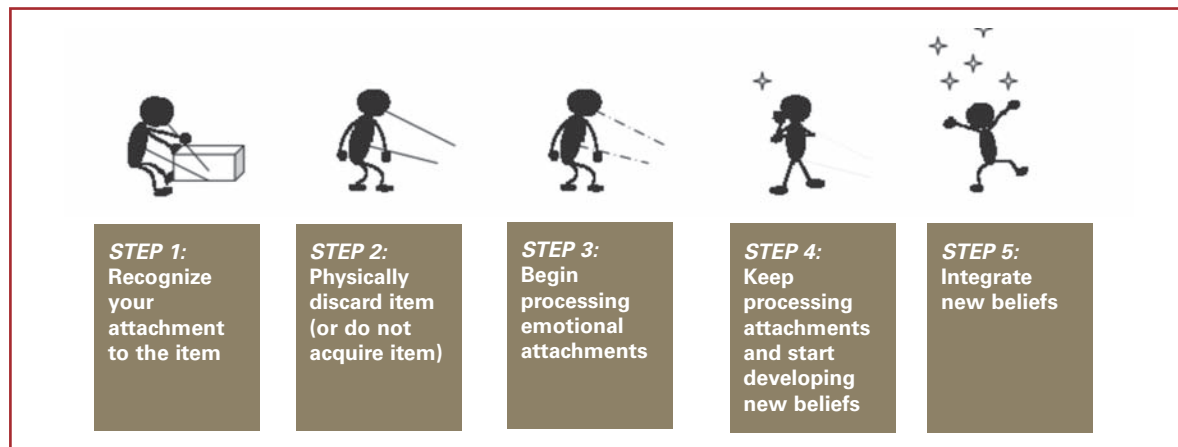
Box 1. Hoarding Case Formulation

Ask your client about his or her theory of why he or she hoards:

When did you notice that this started for you?
Why do you think it started? Were there any particular triggers? What was it like for you growing up? What are some of the things that you find particularly difficult to discard? Why is it so hard for you to let these items go?

Source: Kellet et al., 2010.

Figure 1. Task of the intervention: Letting go of emotional attachments.



Source: Chater and Levitt (2009).

relationship with inanimate objects to the point where items are perceived to have emotional states (anthropomorphizing), viewing possessions as so enmeshed within one's identity that they are extension of self, or as cues that signal a safe environment to the individual who hoards (Frost & Steketee, 1998).

Intrinsic Hoarding and Collections

Intrinsic objects are those that do not have a practical use or sentimental meaning but are perceived as aesthetically appealing, special, or possessing unique craftsmanship (Cherrier & Ponner, 2010; Furby, 1978; Kyrios et al., 2004). As it is common for people who hoard to attend to the aesthetic features of an object that most nonhoarders would not consider as noteworthy (e.g., the ink color of newspaper type or the texture of a water bottle) and attribute unique qualities to their objects (Grisham et al., 2010; Wincze et al., 2007), the volume and diversity of objects saved for their perceived intrinsic value can be almost limitless for people who hoard. Intervention for intrinsic hoarding involves assisting clients to reevaluate internalized criteria for assessing an object's true uniqueness and value.

Instrumental Hoarding: "Just in Case"

Objects that serve a clear functional purpose, such as a pair of shoes or toothbrush, hold practical value in either the present or possible future, such as a raincoat. Excess acquisition of these types of objects, termed instrumental

hoarding (Furby, 1978), is often motivated by an exaggerated sense of responsibility to respond to unspecified future needs (Frost & Gross, 1993; Frost & Hartl, 1996; Frost et al., 1995), resulting in the voluminous accumulation of possessions "just in case they are needed someday for something." Newspapers, flyers, documents, and magazines are common examples of items hoarded to avoid anticipatory anxiety associated with discarding information that is perceived to hold critical importance for some later date (Nezioglu et al., 2004). Supporting clients to reevaluate their thinking about the actual versus the imagined importance of information (or other instrumental items) and to gain new perspective on the realistic consequences of not having a needed item can be useful strategies to overcome barriers to discarding possessions (Box 2).

Organizational Skills

Challenges with sorting and organization for individuals who hoard not only derive from emotional attachments and impractical beliefs about instrumental, intrinsic, and sentimental objects but also appear to be shaped by informational processing deficits (Frost & Gross, 1993; Frost & Hartl, 1996). Standardized testing and self-report measures suggest that many individuals who hoard experience substantial problems with attention and frequently exhibit symptoms consistent with attention-deficit hyperactivity disorder (Grisham et al., 2007; Tolin, 2011a; Tolin & Villavicencio, 2011). Memory impairment involving delayed verbal and visual recall is

Box 2. Questions to Help Sort Possessions

- Could you get this some other way if you really needed it?
- Would letting go of this help with your clutter problem?
- Is this really valuable or does it seem that way because you're looking at it now?
- Have you used it in the past year?
- Do you have a plan to use it within the next 6 months?
- Do you really need this? Could you get by without it? What's the worst thing that could happen if you let it go and needed it later?
- Does it need fixing? Do you have the energy to fix it?
- Would letting this go help you with your clutter problem?

Sources: Chater & Levitt, 2009; Grisham et al., 2007; Tolin, 2011a, 2011b.

furthermore documented to affect some individuals who hoard (Hartl et al., 2004), although the high levels of self-reported memory problems also reflect subjective overestimation of the importance in remembering information and a perceived lack of confidence in memory abilities (Frost & Hartl, 1996; Tolin, 2011b). The abilities to categorize is also noted to be compromised in people who hoard, who appear to treat each object as so unique that sorting is slowed and results in unnecessarily specific categories when fewer would suffice (Grisham et al., 2010; Wincze et al., 2007). Indecisiveness compounds difficulties with organization for many people who hoard and may be a core feature of this disorder (Frost & Gross, 1993; Pertusa et al., 2010; Samuels et al., 2002). Correspondingly, training in organizing, decision-making, and effective categorization skills is an important component of hoarding interventions and has been included in several toolkit skill development worksheets (Box 3).

Hoarding: The Home Service Provider Experience

Even seasoned community health professionals can experience strong reactions when entering the home of someone who hoards, and frequently describe feelings of anxiety in light of the serious

and pernicious safety concerns (Bratiotis et al., 2011; Tolin, 2011b; Toronto Hoarding Coalition, personal communication, November 17, 2010). Compounding the concerns about the cluttered and chaotic conditions of the home, clinicians routinely report frustration when working with people who hoard, and can feel challenged by the slow rate of progress, high treatment drop-out rate, and limited client engagement characteristic of the therapeutic process (Frost et al., 2010; Tolin, 2011b).

Individuals who hoard commonly resist attempts at intervention, a phenomenon that is likely associated with the “ego-syntonic” nature of the disorder—that is, hoarding behaviors are largely in keeping with an individual’s worldview (Pertusa et al., 2010; Steketee & Frost, 2003). This means that the drive to acquire or retain each belonging typically has an accompanying rationale (“I could use it; it reminds me of someone I love; throwing this out would be wasteful,” etc.) that is fully believable to the individual (Black et al., 1998; Frost et al., 2000) and accounts for the pleasurable feelings experienced when acquiring or admiring belongings and the distress that accompanies discarding. Studies consistently

Box 3. How to Organize: Setup, Sort, Store Possessions

1. Setup
 - Pick a place to start.
 - Prepare the things needed to organize the items.
2. Sort
 - Decide whether the item is “keep” or discard.
 - Place item into one of these groups (use OHIO rule: “only handle it once”).
 - Create categories for “keep” and discard (trash, recycle, sell, giveaway).
3. Store
 - Take out trash and recycling immediately.
 - Put away kept items immediately.
 - Arrange for pick up or your giveaway items right away.

Sources: Chater & Levitt, 2009; Frost & Steketee, 1998.

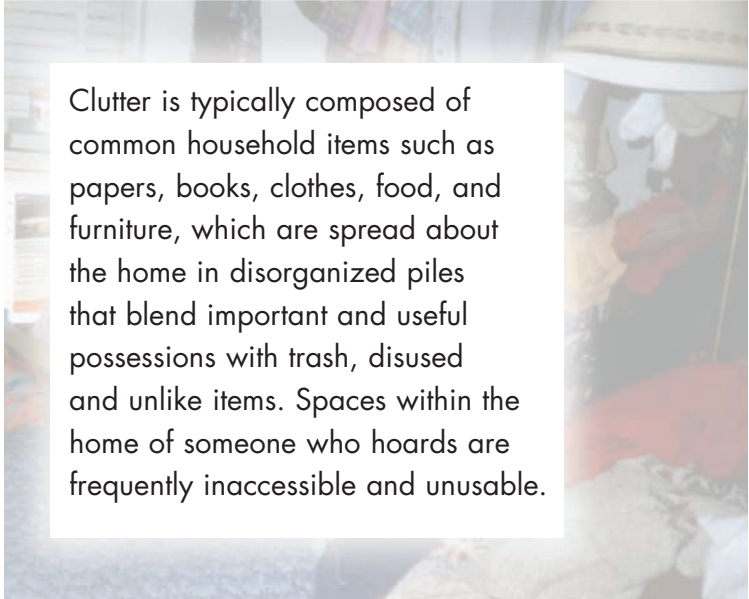
report low levels of insight into the severity of hoarding behaviors by the individual who hoards (De Berardis et al., 2005; Frost et al., 1996; Ravi Kishore et al., 2004; Samuels et al., 2007; Tolin et al., 2001), even if these behaviors create cluttered conditions that are distressing (ego-dystonic) to the individual, impair functioning, and/or cause substantial stress for family members and other caregivers (Kellet, 2007). This highlights the importance of assessing an individual's insight and readiness for change and to tailor intervention strategies accordingly. Accordingly, the worksheets within the toolkit were organized by their utility for clients at differing stages of change, and emphasis is placed on selecting "the right tool for the job at hand" pending client insight, motivation, and interest in addressing their hoarding behaviors.

Cognitive Behavioral Therapy

Best-practice hoarding treatment includes techniques adopted from motivational interviewing (Miller & Rollnick, 2002) to address this ambivalence around change and to promote client engagement in the therapeutic process (Steketee & Frost, 1997; Tolin et al., 2010). This type of tailored program of cognitive behavioral therapy (CBT) also incorporates elements of organizational skills training, exposure, and cognitive restructuring of hoarding-related beliefs (Steketee & Frost, 2007; Tolin et al., 2010). Using this approach, positive changes across the three dimensions of hoarding—acquisition, discarding, and clutter volume—have been empirically documented, although gains were measured and required approximately 7 to 12 months to effect (Tolin et al., 2010). Worksheets to challenge distorted cognitions and to develop graded exposure activities were included within the toolkit for use by clinicians seeking to support clients in cognitive restructuring and habituation to the anxiety of discarding or nonacquiring.

Harm Reduction

Situations in which clients cannot access specialized CBT services, or who are not expressing interest in help, and are facing imminent safety risk require clinicians to have additional strategies within their intervention toolkit. Techniques aimed at reducing the problematic effects of hoarding behaviors, if not necessarily the behavior itself, are a familiar aim of the harm reduction



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approach (Marlatt & Tatarsky, 2010) and can provide a useful framework for treating hoarding in the community. Harm reduction relieves the focus on discarding, which can otherwise create a significant barrier to therapeutic engagement if a client is not ready to set this goal or even consider it as a distant possibility (Tompkins & Hartl, 2009). Premature or overemphasis on the clearing out of a home, often effected as an "extreme clean," can create distrust, resentment, and resistance within the therapeutic relationship and actually exacerbate hoarding symptoms (Steketee et al., 2001), perhaps as it is experienced by the individual as a personal violation and significantly stressful event. Harm reduction, with its focus on organizing or discarding only that which is necessary to maintain the individuals in their home with a reasonable level of safety and comfort (Lorig, 2001; Tompkins, 2011), is the approach most frequently employed by the hoarding program clinicians when safety and eviction-prevention are the priorities.

Home Safety

The safety of an individual who hoards, and others in their immediate locale, can be significantly compromised in situations of extreme clutter (Frost, Steketee, & Williams 2000; Frost, Steketee, Williams, & Warren, 2000; Lucini et al., 2009). The organization employs a four-step approach to guide clinicians in their response to health and

safety concerns (Table 1), which promotes targeted care planning in keeping with the harm reduction and a self-management goal-setting framework more familiar to other chronic disease management programs (Chater & Levitt, 2009; Lorig, 2001).

Help, My Client Hoards! The Community Clutter and Hoarding Toolkit

The organization serves over 60,000 clients each year within a defined public home care system. The development of the toolkit was catalyzed by the frequency with which the organization's frontline healthcare providers encountered safety concerns with hoarding, often within the

context of referrals for nonhoarding healthcare needs. These home care workers were faced with the challenge of recognizing the significance of the safety issues, without ready access to the knowledge or tools to effectively intervene, and within a time-limited service model of managed care in public home care. Concerned healthcare practitioners were repeatedly asking: "How do I help with little time and without in-depth expertise in hoarding or even mental health?"

This community organization responded by assembling a team of clinicians to review best-practice literature and translate this knowledge into a tool that service providers from varied backgrounds could readily apply in their community practices. The resultant "Community Clutter

TABLE 1. Home Safety Risks: How Do I Assist?

STEP 1: Safeguard yourself

- Take only essential items with you.
- Place personal belongings into a plastic bag, seal it, and leave it near the door, to be picked up when exiting the home. Consider bringing a change of clothes in more severe circumstances.
- Avoid wearing loose fitting clothing, open-toed shoes, or shoes with deep treads that could hold pests or unsanitary debris. Consider using protective equipment (gloves, boots, gown, mask) in more concerning environments while weighing the impact this may have on the therapeutic alliance.
- Avoid sitting, particularly on soft-covered furniture.
- Do not lift, carry, or walk into areas you do not feel comfortable accessing.
- Be aware of your exits and paths. Avoid areas where piles can easily topple.

STEP 2: Safety assessment

- Identify specific risks in the environment: falls, access to emergency services, fire hazards, infestations, unsanitary conditions, elderly dependents, children, or pets in the home adversely affected by clutter.
- Educate your client about these risks; discuss potential consequences and options to address.
- Document your concerns and discussion with your client.

STEP 3: Prioritize service goals

- Use data from safety assessment to prioritize goals: address most critical issues first.
- Apply a harm reduction approach (Tompkins, 2011).
- Incorporate self-management principles.

STEP 4: Assemble a team

- Coordinate service with local health authorities as appropriate: fire department, public health, senior services, mental health workers, and so on.
- Consider issues of health information privacy and duty to report.
- Draw on natural support networks: adult children, friends, church associates, extended family for hands-on assistance, emotional support, and/or financial support.

Source: Chater, Shaw, & McKay.

Box 4. Mr. Lennard: A Case Study With Small Gains Toward a Safer Home

Mr. Lennard was a 72-year-old man who was admitted to hospital for treatment of deep vein thrombosis. On discharge, a visiting nurse was referred to teach Mr. Lennard how to self-inject his medication. When Jackie, the nurse, arrived at his home, she discovered rooms piled high with furniture, books, disused electronics, and papers. Mr. Lennard had lived in this house with his mother (who he described as a “pack rat” herself), but had not had anyone over since the death of his mother 7 years ago. Mr. Lennard acknowledged that his living situation was “messy” but felt that once he got his “pep back,” he would get around to reorganizing things.

Jackie was concerned about the clutter and Mr. Lennard’s safety, particularly because he lived alone and osteoarthritis of his hips and knees made walking difficult for him. Jackie’s service with Mr. Lennard was only short term, so she completed a quick checklist from the Hoarding Toolkit to identify key safety concerns in the home to focus her intervention efforts: (a) the risk of falls due to clutter in the main walkways; (b) the fire hazard in the kitchen caused by the volume of papers and other flammables in that room. She documented these and included the checklist in her chart notes.

Jackie and Mr. Lennard discussed the specific safety concerns Jackie had noted. Although Mr. Lennard was ambivalent about reducing the clutter, he did agree that these two risks were important to address. Jackie and Mr. Lennard talked about how the risks could be reduced, starting with the things Mr. Lennard could do that did not involve discarding possessions.

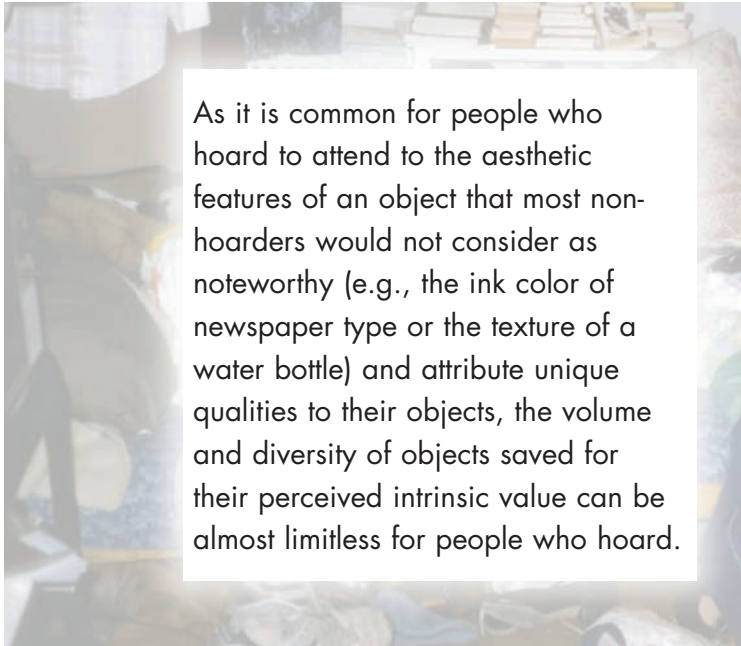
- Walkways/falls: Move piles to create space for clear paths between frequently used areas of the home; install better lighting in the front hallway, secure the edges of carpets that had frayed, and install a personal emergency medical alarm system.
- Kitchen fire hazards: move flammables away from stove, locate/use the automatic shut-off kettle for making tea (not the stove top), clear out the microwave so it can be used again to heat meals/cooking, fix the broken electrical outlet in the kitchen, and reduce the overall volume of possessions in the kitchen by 25%.

Mr. Lennard needed assistance to implement these plans and Jackie helped him to identify people he knew who could help. A local community

organization had been assisting Mr. Lennard with snow shovelling and lawn care for years. Mr. Lennard agreed to allow them in to fix the lighting and carpets. Mr. Lennard also had a niece who had been offering to help out since his mother died. She was able to provide hands-on help in the home (moving belongings, organizing the medical alarm, etc.)

Jackie met with Mr. Lennard and his niece, Sarah. Jackie helped them both to understand more about hoarding by using one of the psychoeducation handouts from the toolkit. They also jointly established rules about handling Mr. Lennard’s possessions, including that she would only touch things with his permission and that he would make the final decisions to keep or discard items. To reduce the clutter volume in the kitchen, Jackie had Mr. Lennard estimate how much would need to be cleared out to make it safer (25%). Jackie knew that discarding one in every four belongings from the kitchen was going to be difficult for Mr. Lennard and she reviewed with him a list of questions she found in the toolkit to help sort. Mr. Lennard selected a few that worked for him and Sarah agreed to remind him of these when they sorted the kitchen clutter together. During these sorting sessions, it was also agreed that Sarah was also going to help Mr. Lennard to stay focused and apply the “setup, sort, store” organization technique that Jackie had reviewed with them both. Sarah and Mr. Lennard also decided they would sort only what would fit into one large cardboard box in a day so as to not be overwhelmed by the task.

After a few weeks, Jackie met again with Mr. Lennard. The home was still very cluttered, but the walkways were clearer and volume of clutter in the kitchen had been noticeably reduced. Mr. Lennard was enjoying the company of Sarah and they planned to continue their meetings. Jackie suggested referring Mr. Lennard to a therapist so he could talk more about the impact of his mother’s death and his difficulties with hoarding. Mr. Lennard said he was not ready for this right now, but would think about it “down the road.” He did agree for Jackie to inform his family doctor of the hoarding issues so he could be followed more routinely over time. Jackie discharged her service knowing that some of the safety concerns in the home had been reduced and Mr. Lennard was open to continue working on managing the clutter, even if his home would never be clutter-free.



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and Hoarding Toolkit” was disseminated within the organization, and eventually shared with other community agencies to promote a coordinated, interdisciplinary response among human services workers including health professionals, case managers, first responders, legal aid workers, landlords, senior services, mental health specialists, professional organizers, and others.

The toolkit and accompanying training workshops have served as a vehicle to build capacity within the community health services system, maximizing available funding, and existing human resources for what can often be a lengthy and costly situation to address (Frost, Steketee, & Williams 2000; Frost, Steketee, Williams, & Warren, 2000; Yosef et al., 2009).

The hoarding toolkit is a compilation of worksheets and educational materials designed for use by clients, professionals, and lay persons alike to provide practical, research-based psychoeducation and skill-building resources. It is assembled so that service providers can select the most appropriate worksheets for the specific situations they encounter, offering the flexibility and breadth of resource required to adequately address the range and needs arising in situations of extreme clutter. Box 4 provides a case illustration of how the tools within the kit can be applied within a time-limited, harm reduction framework.

Conclusion

Hoarding can be a challenging disorder for those who experience its characteristic difficulty with discarding possessions, as well as those who are seeking to assist in situations of excess clutter and unsafe conditions. Acquiring tools specific to hoarding is essential for client and clinician alike when developing effective care plans. The Community Clutter and Hoarding Toolkit has been one organization’s response to support the skill sets of community healthcare providers, and has led to the application of a harm reduction focus when working the frontlines of hoarding interventions. ■

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