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Inside the World of the Compulsive Hoarder-By Matthew Robb, MSW, LCSW-C-Social Work Today-Vol. 6 No. 3 P. 27

It's not just a matter of excessive collecting—compulsive hoarding can be a life-threatening behavior.

Shortly after midnight on January 5, a nervous husband contacted the City of Shelton Police Department in Washington to report his wife missing. His call set into motion a chain of events that soon found bloodhounds sniffing out the neighborhood and police officers sifting through the Washington State couple's home. Finding no signs of the woman inside or out, suspicious detectives brought the man downtown for questioning.

Only after 10 hours of searching did they locate his wife, entombed in her own home. At 59, the woman—a compulsive hoarder—had died of “asphyxiation and suffocation” beneath a crushing, smothering avalanche of second-hand clothing, laundry baskets, and dozens of cases of Vick's mentholated rub. Her sad, strange death left behind a devastated husband and many questions about a condition that perplexes even seasoned clinicians.

Recalling his team's first response on January 5, Shelton Police Detective Harry Heldreth says the home's front porch tipped them off that this wouldn't be a routine missing person report.

“She had tarps covering cases and cases of toilet paper,” he recalls. “She had several hundred cases of Diet Pepsi. There were at least 100 full bottles of [fabric refresher] Febreze, still in the shopping bags.”

But this satellite stockpile paled next to what awaited inside.

“I had never seen anything like it,” recalls the 13-year police veteran. “The house was thoroughly packed—stuffed—with clothing items in every room, from floor almost to ceiling. We could only open the front door far enough to squeeze in. There was just one narrow trail that led from the front door to the back. At some points, we actually had to turn sideways, just to squeeze through. We couldn’t even enter one bedroom because clothing items were piled up so high behind the door.”

The officers quickly noticed something else: The home was ice-cold. As the woman’s hoarding ran amok, she had begun piling clothing items in front of the floor heaters, rendering them useless. When she needed more space, she turned to the fireplace—this in a region where the average temperature in January is a bone-rattling 32° F.

“It was so cold [that] the husband slept in his clothes and jackets,” Heldreth says. “He finally told her that her hoarding was out of control. He said they needed to make room, they needed to heat their house. But she kept on hoarding.”

As stunned investigators squeezed their way into the kitchen, they stumbled across pots and pans numbering “well into the thousands,” Heldreth says. Paradoxically, the refrigerator held just one food item: perhaps 100 containers of lemon-flavored yogurt. The deceased woman had recently undergone stomach surgery and successfully slimmed from 300 to 145 pounds, hence the appeal of yogurt.

Chaos reigned everywhere. “The bathroom—including the shower—was stuffed,” Heldreth recalls. “You had to crawl over about 3 feet of clothing items just to get to the toilet.”

After consulting with crime scene investigator specialists, the Shelton investigators finally determined that the woman had died trying to repair a broken telephone. Aiming for the wall jack, she began burrowing through the cotton and polyester mountain but made the mistake of backfilling the hole as she clawed her way forward. “Everything just collapsed in on top of her,” Heldreth says. “She was trapped underneath and couldn’t get out.”

The detective sighs. “I asked the husband why he would stay in that situation. He said he loved his wife and had his own faults. He said he felt sorry for what she was going through.”

Pausing to reflect, he says, “This was a tragedy. It’s one of those things that you look

at and say, ‘What happened?’”

Riddles, Mysteries, Enigmas—Unraveling such mysteries is the passion of social work professor Gail Steketee, MSS, PhD.

The Boston University researcher began studying hoarding shortly after pioneer Randy Frost, PhD—a Smith College professor of psychology—published his seminal work in 1996. Their subsequent collaboration helped amass a respectable knowledge base and has recently sparked national interest among research scientists, clinicians, and social service professionals. Today, clinical workshops and national conferences on hoarding abound.

Callously satirized and long dismissed as a statistical aberration, hoarding is actually quite prevalent, Steketee says. An estimated 1% to 2% of the adult U.S. population hoards, translating into 2 to 4 million individuals. The median age is approximately 50, but hoarding is found among Millennium Generation undergrads and retired baby boomers, the unemployed and upwardly mobile, and in blighted urbanscapes and manicured suburbia.

“Onset typically occurs in the teenage years,” Steketee notes, “but takes a long, long time to develop into a syndrome that impairs functioning. It’s a runaway train. It’s insidious. It starts with a small problem that gets bigger and bigger.” Historical precedents abound. Florentine poet Dante included hoarding in his Circle IV of Hell some 700 years ago. More recently, the list of notable “wealthy, intelligent, and educated” hoarders includes Honore de Balzac, Mary Todd Lincoln, and Andy Warhol.

Despite its scope and impact, hoarding merits only footnote status in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR), where it defies neat categorization and is associated with dementia, anorexia nervosa, pica, and some psychotic disorders. While DSM-IV-TR lists hoarding as one of many possible manifestations of obsessive-compulsive disorder (OCD), “extreme” cases tip the scales toward OCD. Steketee says creating a stand-alone diagnosis of compulsive hoarding for DSM-V may be warranted, but more information about hoarding behavior is needed and healthy debate will continue.

Hoarders are prone to depression and lesser degrees of social anxiety and generally exhibit perfectionism, indecisiveness, procrastination, and avoidance. The net negative effect on family members raised amid wholesale chaos—and sometimes abject squalor—is widely believed significant, but the data are still thin.

What items do hoarders typically hoard? Steketee lists paper items (old newspapers and magazines) at the top, followed by a hodgepodge of junk mail and other paper clutter. “The next biggest chunk is probably clothing,” she says, “then kitchen containers and utensils.” As the occasional news report or headline confirms, some people hoard animals—dozens or hundreds. Neglect is common.

New York City entrepreneur Ron Alford founded Disaster Masters, Inc. in 1980 to help Gotham’s “extreme disposophobics” escape “the guns of eviction.” Since then, the self-described “mental hygienist” and certified hypnotherapist has been profiled in more than 400 radio programs, TV shows, and newspaper articles. In 2004, he produced the documentary *Packrat: The Movie*.

Alford long ago coined the term disposophobia to describe the “malady suffered by extreme collectors.” His biggest case—at a Kentucky farmhouse in 2005—found him “stacking and packing solid” three tractor-trailer-sized construction dumpsters with junk.

“I’ve seen some disposophobics with thousands of chewing gum wrappers. One former schoolteacher in Yonkers [NY] was so obsessed with coupons that she started a coupon-clipping club in her apartment building. She had coupons stacked 4 feet high off the floor in two of her bedrooms.”

Alford describes some “acute disposophobics” as neat and others surrounded by a mountain of garbage. “The latter have so much stuff that vacuuming, sweeping, and cleaning are not an option.”

Chronic disorganization specialist Heidi Schulz, CPO-CD, offers another view. “Some of the really stuffed homes are very clean because there’s no air movement. There is a cleanliness one would not ordinarily expect.”

Pausing for effect, Alford quips, “Comedian Jay Leno is known for collecting dozens of automobiles. Does that make him a hoarder?”

Short answer: no. Hoarding and collecting are not the same. The Chicago audiophile whose kitschy apartment is gridlocked with 18,000 vinyl LPs or the Berkeley sophomore whose 60-gigabyte iPod contains some 15,000 downloaded songs or 8,000 digital images, are collectors, not hoarders.

“If there’s some kind of organizational scheme and the collecting does not appear to hinder functioning, it isn’t hoarding,” Steketee says. Confusion between the two is

easy, as visual disarray is the telltale of both the hoarder and “functional clutterer.” But when activities of daily living are impaired, the self-described packrat is pushed into the diagnostic domain of the hoarder.

The severity of hoarding runs the gamut, from moderate to extreme. Schulz ranks her clients on a five-level “clutter hoarding scale” endorsed by the National Study Group on Chronic Disorganization.

While a level 2 home may evoke the eyesore of Oscar Madison of “Odd Couple” fame, a level 5 dwelling is a virtual no-man’s land of major structural damage; absence of electrical power, water, sewer, or septic connections; standing water in rooms; infestation with rodents, mosquitoes, or local “critters”; unusable kitchen and bathrooms; human defecation; and spoiled food.

Since 1990, Schulz—who collaborates with psychologist Roland Rotz, PhD, in the Santa Barbara area—has seen an estimated “20 level 5 hoarders, 30 level 4s, and hundreds of level 3s.” The 15-year professional finds working with level 2 clients almost a breeze compared with the formidable challenges of level 4 or 5 clients.

Understanding the Hoarder □ Why do hoarders hoard? The pop culture explanation holds that hoarders are first-rate gatherers but fifth-rate disposers. In reality, hoarding is driven by many factors. Some regard their Himalayan hoard as a treasure trove too valuable to toss. Others may derive security, love, or validation from their objects. One person may hoard because he or she is too busy or too infirm to declutter. Another’s all-or-nothing perfectionism may make decluttering seem impossible. And simplistic or not, some hoarders simply lack good organizational skills.

Leading clinical researcher and New York University professor Fugen Neziroglu, PhD, notes that some hoarders are compulsive shoppers—commonly dubbed “shop and droppers”—who cannot slow the incoming tide of merchandise. This “compulsive acquisition” may explain some cases of shoplifting seen among hoarders, she says.

One man’s trash may indeed be another’s treasure, thus explaining why concerned friends see 20 tons of musty newspapers while the hoarder sees thousands of must-read articles containing potentially priceless pearls of wisdom. Similarly, the thinking goes, a broken table can be repaired, ill-fitting clothing hemmed, soft drink cans traded in for cash, broken glasses glued, toilet paper transformed into art, and 50,000 plastic grocery bags used for some indefinite something some day in the distant future.

Hoarders, generally speaking, are not oblivious to the wretched excess that engulfs them, Schulz says. “They are actually very, very ashamed of their homes. They pull the shades down. They lock their doors. It’s very cave like inside—dark, dead air.” Says Steketee, “They may think it’s perfectly reasonable to have the [items], but still wouldn’t invite people over because they fear disapproval.”

Rotz cites both “neurobiological underpinnings and behavioral imprinting” to explain hoarding, which he says often “runs” in families. In the case of the Shelton woman, both her mother and brother were hoarders. After his wife’s death, her husband said her hoarding began approximately 20 years ago as a mere molehill, with no apparent precipitating event.

Rotz says hoarded items often carry powerful representational meaning that leads to overattachment. Suggesting that a hoarder dispose of tens of thousands of valued possessions will likely churn up paralyzing what-ifs and anxiety. “The items often carry a big emotional charge for them,” Rotz says. “Frequently these items are explained by what I call traumatized attachment. They represent items that protect us from our fears.”

Reaching for an example, he says, “If I’m collecting tens of thousands of pennies in bottles, it’s because, ‘Man, that Great Depression isn’t going to get me again. This is the way I’m going to protect myself.’”

The hoarder may realize his or her rationalizations don’t hold up to rigorous scrutiny, but the persistence of his or her hoarding behavior nevertheless underscores “the tragedy of obsessive-compulsive disorders,” Rotz says. Recalling hundreds of clients, Schulz agrees. “They couldn’t separate their identity out from their stuff. They were that stuff.”

Psychodynamically oriented clinicians may or may not find fertile ground in exploring trauma, Steketee says. Underscoring Rotz’s behavioral imprinting theme, she says some people learn hoarding behavior from parents or siblings. Others, she says, “grow up in perfectly okay homes but have attention-deficit problems. As a result, they have real trouble sticking to a task, are very attached to things, and can’t get rid of them.”

Steketee notes that some instances of hoarding involve victims of sexual assault who are trying to “barricade” their home. “The stuff starts to accumulate and it feels safe,” she says. “People call it their bunker, their safe house.” Some observers may see a similarity with a panic room.

Rotz nods in agreement. “We frequently see a nestlike environment. Amid this massive enclosure of items, there is this sliver of a spot on the bed, perhaps. It’s almost as if they’re curling up into this little womb. It’s a sense of safety.”

Recalling a former client, Schulz says, “She used a ladder to get into bed because her floor was covered with junk. It was like she was crawling into her cave of protection and needed 30 feet of stuff surrounding and protecting her from the world.”

Hoarders may or may not have similar clutter issues at work, Steketee notes. “Some people keep their office manageable, but their home is a disaster. But we also have the reverse, in which a spouse or partner keeps the house tidy, but the office is a disaster.” Steketee occasionally sees a classic folie à deux, finding one spouse hoarding hardware items while his or her partner packrats paper.

Hoarding is more than a visual (and olfactory) affront. Overloaded floors can collapse. Vermin can infest entire neighborhoods. Homes can become so tightly packed that fire, police, or medical crews cannot respond to emergencies.

“The elderly sometimes lose their medications within the piles,” Steketee says, “or their asthma starts to kick in because there’s too much dust, or their gait is unsteady and they fall on the stuff lying around them.” Local officials are sometimes hesitant to step in, cognizant that a full-blown professional abatement can cost a government agency upward of \$50,000.

Treatment Issues □ Living with or knowing a hoarder can be exasperating, but Steketee and Rotz caution family members against rolling up their sleeves and decluttering on their own. Confrontational tactics can spectacularly fail to resolve underlying pathology while instigating family conflict. Besides, such efforts are usually futile, Rotz says. A few months later, the decluttered home will be “at least half filled again.”

Rotz and Schulz employ an innovative collaborative approach geared to halt eviction proceedings while getting key players—the hoarder, family, friends, landlord, key city officials, and other notables—to buy into the treatment plan. Rotz and Schulz make sure the client participates in outlining and carrying forth the outlined provisions.

Approaching the hoarder with respect, sensitivity, and goodwill lowers defenses. Creating a sense of safety is key, “but it doesn’t happen overnight,” says Rotz. “The key element is their knowing we are not going to pull the rug out from underneath them. I also think there’s a way to go in and create such inviting space that [the hoarder] says, ‘Oh, that’s nice.’”

Standard cognitive-behavioral treatment (CBT) “isn’t very effective with OCD hoarders,” Rotz declares. “Give them a how-to book and they won’t declutter by themselves. Put them in a group learning environment and they will like the ideas but won’t follow through later at home.” Success, he says, must go beyond reshaping underlying assumptions and focus on helping the client understand how his or her rigid attachment and isolation only compound his or her trauma, depression, and anxiety.

Steketee calls CBT “the empirically effective treatment for hoarding,” but says therapy must strengthen skills in organizing, problem solving, impulse control, and more. Anecdotal reports tentatively suggest psychotropic meds “are not that helpful” for this population. Steketee is currently cowriting a manual for clinicians and a self-help book for hoarders.

One of Steketee’s former clients, Serene, reports “dramatic change” after recently completing a six-month clinical research project led by Steketee. “About 50% of my house is now absolutely presentable,” she notes.

The Boston University team’s nonjudgmental, accepting approach, Serene says, “opened up all these repressed feelings of vulnerability from past trauma and fears I had about a stranger coming into my home and seeing how I was living.” Therapy, she says, was instrumental in helping “understand myself, put things together, unpack my emotions, and understand the complex issue of hoarding.

“Before I used to look at all my stuff and think, ‘Oh God, how do I even start?’ Now I look at it and say, ‘Oh man, look at all that junk! Those books go on the shelf. I can toss all those bags. Someone else can use my old “fat” clothes.’”

“One thing we hoarders need is absolute acceptance and nonjudgment,” Serene says. “Throughout this whole process, I felt absolutely honored by the therapist who visited my home, even when I didn’t know how to honor my own emotions and perceptions. You don’t even realize how bad the hoarding is because it comes on so gradually. I almost can’t believe how CBT and home visits have changed my life. When I look at the ‘before’ therapy pictures of my home, I think, ‘Oh, that poor woman.’”

“Allowing a caring professional ‘in’ has taught me how to save my own life. Today, things are so much better. I can’t begin to tell you how grateful I am.”

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