

# Preparing for Patients with Hoarding Disorder

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*It's a typical warm May evening, and you and your partner are trying to figure out where you can grab dinner when the dispatcher's voice comes over the radio: "EMS 62, respond to 24 Prescott Ave. for a cardiac."*

*You and your partner arrive to find an average two-story single-family home with a well-manicured lawn and newly planted tulips arranged in window boxes. But when you get closer to the residence, an ominous stench reminiscent of rotting trash and ammonia hovers. You ring the doorbell and knock with no answer. Your partner peeks through an opening in the decorative front door and can clearly see an older white female prone on the floor, partially covered with and surrounded by debris, including clothing, trash and regular household items. This trash is piled to approximately shoulder height in the living room and extends into the rear of the house, parted only by little trails. Your partner also notices at least seven cats lounging about in the visible area, as well as flies on the walls and windows.*

*The woman is not responding, and you are unsure if she is breathing. While you and your partner are deciding what to do and whom to call for extra resources, the neighbors notice the ambulance lights and begin peeking through their curtains, the bolder ones taking to their porches. A middle-aged woman pulls up in a car with a screech and jumps out yelling about her mother and demanding, "Why are you just standing there?!" What do you do?*

As first responders to incidents involving hoarding, we are often thrust into situations that are high-stress not only for patients and their families but also for us. These are difficult responses due not only to the charged emotional atmosphere typical of medical emergencies but also to the need for possible

extrication of the patient, health and physical hazards to patients and responders, coordination of mutual aid and additional response agencies, and the possible need for follow-up with social services or hoarding task forces.

Understanding hoarding disorder, its characteristics and its comorbid diseases will help EMS providers empathize and build a rapport with these patients and their families. Providers also need knowledge of potential conditions during these responses for their safety, the possible strain on response structures, to assess mutual aid needs and to plan for response before an incident occurs.

### **A Psychological Illness**

Hoarding disorder is defined as a persistent difficulty discarding or parting with possessions because of a perceived need to save them.<sup>1</sup> It's estimated between 2%–5% the U.S. population has the disorder—up to 16 million people.<sup>2</sup> Chances are at some point you will encounter a patient living in a “heavy contents” environment, if you haven't already.<sup>3</sup> Hoarding disorder typically begins midlife but increases as affected individuals age; with the number of Americans older than 65 doubling to 72.1 million by 2030, it is likely the number with hoarding disorder will grow as well.<sup>4</sup>

There are many reasons an individual can have difficulty parting with possessions; most are spurred by emotional trauma in the individual's past. While a single event can trigger hoarding, the behavior is often chronic and increases slowly over many years. Some sufferers cite a history of poverty and not having basic living needs at some point in their life and feeling the need to save items for possible future use. Others save items to retain personal memories associated with them. Eighty-five percent of hoarding individuals grew up in a household with another hoarder;<sup>5</sup> researchers are still investigating whether there is a genetic connection.

Hoarding disorder has several features.<sup>6</sup> Its victims have excessive attachment to possessions and often will argue with family and friends about discarding items to the degree that relationships are strained or destroyed. The individual treasures the items even if they have no apparent use to others, and thinking of parting with the items causes anxiety. These individuals have trouble making decisions, which adds to the apprehension and frustration of choosing which possessions to keep or discard, stalling the cleaning process. Living spaces in the home become blocked by clutter and debris, leaving necessary functional spaces—kitchens, bathrooms, stairways—unusable. Often refuse and trash accumulates and attracts insects and vermin or other wild animals, and routine repairs to the home are not made due to embarrassment or distress.

Shame and embarrassment are heavily integrated into hoarding disorder and can lead to feeling overwhelmed and avoiding dealing with the growing hoard. Individuals with hoarding disorder tend to avoid having friends and family in their home, increasing their isolation and limiting social interaction with others. Many times the individual may not know how to ask for help. Family and friends are met outside the home or at another location, first responders included—these might be the moderately or extremely sick patients who meet you on the front steps or sidewalk. This isolation might be a subconscious protection related to previous interpersonal traumas, and accumulation of things, or even pets, may function as a replacement for these relationships.

Hoarding disorder can have various comorbidities: anxiety, depression, obesity, exacerbation of chronic medical conditions and association with dementia.<sup>7–9</sup> Researchers have only been studying hoarding disorder for approximately 20 years and are just learning what areas of the brain are affected in individuals who practice the behavior, leaving some of the links between hoarding disorder and psychiatric and neurological conditions incomplete.

### **Therapy for Hoarding Disorder**

Individuals who have hoarding disorder rarely seek help, and as with those battling addictions, treatment only works if the individual wants to seek help. Removing the contents of the hoard (animals in the case of animal hoarding) without their participation can shut down the avenue for treatment and increase the likelihood the hoarding behavior will surge. Cognitive behavioral therapy (CBT) is typically recommended and works by helping the individual become aware of inaccurate or negative thinking. CBT is also helpful for anxiety and depression.

Working with a therapist or coach at the patient's home is advised for using techniques learned via CBT to sort through items in the residence. Therapy can be conducted in one-on-one or group sessions; the best outcome is when family or loved ones participate as well, so all parties are acting in unison regarding treatment and cleanup.

### **Responder Safety**

The most important part of any EMS response is provider safety. Continuous situational awareness is especially necessary during hoarding responses due to high emotions among the patient and family, the instability of hoarded items and possible damage to building structures, exposure to pathogens or vermin, and hazardous materials hidden in hoarded items, to name just a few potential dangers. Responders can be exposed to human and animal excrement, animal carcasses, residual medical waste such as insulin needles, and possibly communicable infestations like bed bugs and scabies.<sup>3</sup> Respiratory antagonists are also a concern and include mold, ammonia from excess urine, and carbon monoxide from poor ventilation and improper use of alternative heat and power sources. Even common dust or dirt can be overwhelming in a hoarded environment.

Responders assess for scene safety on every call, and hoarding incidents are no different. If the scene is not safe, call for extra resources to access the patient. These resources may vary depending on conditions.

- Fire department—The fire department can assist with a multitude of conditions, including ventilation, shoring for structural damage, patient extrication when SCBA or other specialized equipment is required, and in some instances as extra manpower. They can also assist with securing the patient residence, especially if it requires more than just locking a door after patient extraction.
- Animal control—Some hoards include multiple animals, whether pets of the resident or wild animals that have gained access to the home. Animal control is also needed when there is

animal hoarding to secure the animals and ensure their safety, including extracting sick or injured animals if needed.

- Law enforcement—Depending on department capabilities, law enforcement can be helpful with violent patients or family, in crisis-intervention situations and as extra manpower.
- Hazmat team—If not aligned with the fire department in your area, the hazmat team is a great tool for patients who need decontamination, extrication on scenes with respiratory compromise or mitigation of household hazmat within the hoard.
- Psychiatric services—If there are psychiatric screeners available in the area, they may be able to assist EMS with reluctant patients with psychiatric comorbidities.
- Public works—In extensive hoarding environments it may be necessary to use heavy machinery not normally utilized in rescue scenarios. Public works typically has this type of equipment, but it should be used in conjunction with a larger response that includes the fire department for structural stability of the building and contents.
- Specialized private companies—Your ambulance may need to be decontaminated professionally prior to returning to service, particularly with exposure to bedbugs or other infestations secondary to the hoard. Having prior connections or an agreement can expedite service. If yours is a small department, you may also want to plan for mutual aid assistance until your apparatus is available for service.

With the challenges to safety listed above, you must ask yourself what should be used for PPE in a hoarding incident. All incidents will not be identical; choosing necessary PPE will depend on the severity of the hoard, what challenges are posed on scene, and the provider's level of training and role at the incident. At the very least cover as much of the body as possible, secure the sleeves and hood of any jacket, wear gloves and tuck pants into work boots. Recent EMS preparation for Ebola responses placed increased PPE options into most providers' hands: Tyvek suit, gloves, eye shield and an appropriate mask, depending on the exposure and training level of the provider (medical, N95, APR, SCBA) for the environment. If the responder may be exposed to structural damage or falling objects, consider a helmet and turnout gear, if provided. Be aware the patient, crew and ambulance may need to be decontaminated after transport to the hospital. Also keep in mind that the receiving hospital will need to prepare for the patient and should be notified in advance if isolation is required to both ready staff and ensure an appropriate room is available.

### **Dealing with Patients and Families**

Many people with hoarding disorder don't get help or allow others in their homes for fear of being belittled and judged. Family members may not know about the condition of their loved one's living environment and be shocked at the discovery. Others may know but also fear judgement and shame or be frustrated if they've tried to get the person with hoarding disorder to ask for help or not known how to assist. These emotions and high-stress family interactions may have been going on for many years; as a result relationships and interactions can be difficult. Add to this the normal stress included in an emergent illness in a hoarded environment, and the result is an emotional powderkeg.

How can EMS providers interact with the patient and family for the best patient outcome and provider safety?

- Communicate that items have to be moved and briefly explain the plan for patient movement.
- Treat hoard contents with respect, even if you perceive them to be refuse.
- Don't use derogatory terms. Hoarder is often negatively perceived due to recent media coverage.
- Be aware of radio communications as well as conversation near the patient. Turn down your radio if possible and necessary.
- If you perceive continued or increasing agitation, request law enforcement.
- As with all patients and family members, treat them with respect.
- Preplanning and Task Forces

Preplanning responses to hoarding incidents and organizing the large variety of agencies and resources needed to help patients with hoarding disorder is best done well before an incident occurs. After the necessary training for responders, the next best tool gained from preplanning is the communication among all the responding and followup agencies. Some will be familiar to EMS response and patient care, such as police, fire, hazmat, OEM and specialized psychiatric screeners. Others may not know much about EMS and how it operates; these could include social services, public health, public works and civilian vendors for specialized situations. Many regions have hoarding task forces that include these agencies and more. These are dedicated to assisting individuals with hoarding disorder, responders and neighbors, and following up with the appropriate help so these patients don't fall through the cracks.

Although there are many hoarding task forces in the United States, some notable ones include the Philadelphia Hoarding Task Force; Buried in Treasures Workshop (Easthampton, MA, and Atlantic and Union Counties, NJ); Fairfax County Hoarding Task Force (VA); and Orange County Task Force on Hoarding (CA).

## **Conclusion**

Responses to hoarded residences are a reality EMS providers must contend with and are likely to increase as the population ages, requiring all of us to be familiar with hoarding disorder, associated comorbid conditions and the potential hazards on scene. EMS has the opportunity to be the first contact these patients have with organizations that can offer help for both their medical and psychological complaints. Preplanning with other response agencies and interacting with local hoarding task forces are the first and most important tools in our arsenal to assist patients with hoarding disorder and mitigate emergent events and the ongoing hoarded environment, benefiting providers, patients, families and society at large.

After providing appropriate clinical care, one of the most important actions of EMS providers is to treat patients with hoarding disorder with respect and understanding. This enhances trust of public service and the medical system and hopefully leads to ongoing treatment and care.

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