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Hoarding Behavior in the Elderly

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Case Study

Hoarding Behavior in the Elderly

by Henriette Kellum, LCSW

Educational Objectives

1. Identify the medical and mental health factors that contribute to hoarding behavior.
2. Describe the unique aspects of hoarding in the elderly.
3. Examine intervention and treatment strategies.

Background

As the older population in the United States increases, so, too, do the numbers of older adults who hoard. The impact of hoarding behavior on the health and safety of older individuals and the community can be significant, so are we prepared? Hoarding is defined as the acquisition of and failure to discard a large number of possessions, living spaces so cluttered that they can no longer be used for their intended purpose, and significant distress. When these three elements exist, hoarding is considered to be a “disorder” (Frost & Hartl, 1996).

Research on hoarding behavior began in the early 1990s and has led to widespread public awareness on the topic. Consensus is that approximately two to five percent of the general population in the United States has a hoarding condition. A recent study found that the onset of hoarding behavior is most common in adolescence, but that the severity increases with each decade of life (Ayers et al., 2010). Results from a Johns Hopkins study show that hoarding behavior is more prevalent among older adults (Samuels et al., 2008), and a study of hoarding complaints to a Massachusetts Health Department found that 40% of individuals referred were elderly (Steketee, Frost, & Kim, 2001). As our aging population rapidly increases, so will the number of older adults for whom hoarding is a problem.

Medical and Mental Health Factors of Hoarding

Too often persons who hoard are thought to be lazy, choosing to live in squalor. They are often blamed for the behavior, as if they have complete control over it. However, hoarding behavior is neither a

lifestyle choice nor the result of unwillingness to keep a tidy environment. Instead, it appears to be the result of complex medical and mental health factors. Hoarding was previously thought to be a behavior related to Obsessive Compulsive Disorder (OCD) and Obsessive Compulsive Personality Disorder (OCPD). Experts now believe it to be unique and separate from other neurological and psychiatric disorders, yet often co-existing with another mental illness. Genetic and neurobiological studies have found that hoarding behavior may be a result of genetic differences or brain injury (Saxena, 2007). Approximately 80% of persons who hoard grew up with a family member who hoards, and gene research has shown a positive correlation between hoarding behavior and a unique pattern on chromosome 14 (Samuels et al., 2008). One study of nine patients who experienced brain damage found a correlation between the location of the damage and hoarding behavior (Anderson, Damasio & Damasio, 2005). Mental illnesses that often co-exist with hoarding behavior include psychotic disorders such as schizophrenia, degenerative brain

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disorders such as dementia, obsessive compulsive disorder, traumatic brain injury, bipolar disorder, intellectual disabilities, Asperger's syndrome, and attention deficit disorder. A common characteristic of hoarding is impaired executive function. Executive function is the brain's ability to process information, which includes the ability to organize thoughts and activities, prioritize and concentrate on tasks, use time efficiently, categorize items, and make decisions. In addition to seeing executive function impairment in people who hoard, it is also often seen in the neurobiological conditions listed above. The connections among these various neurobiological conditions, hoarding behavior, and executive function impairment are as yet unclear.

Special Aspects of Hoarding in Older Adults

As the severity of hoarding increases with each decade of life, a particular concern is the increased vulnerability of older persons who hoard. Years of hoarding can result in overwhelming amounts of "stuff" that increase risk of falls. Fearing discovery by authorities who might condemn their homes, older hoarders may not allow workers into their house to make repairs. Consequently, there are often broken toilets, stopped up sinks, and structural damages that produce conditions that are hazardous and unsanitary. When downsizing after retirement, some may be unable to part with belongings or to envision the more limited space they are moving into, thereby overfilling their new environment. Some older persons develop hoarding behavior as a secondary symptom to dementia and

can no longer keep up with the organization necessary to maintain order. The Alzheimer's Association (2012) estimates that 13% of people over the age of 65 develop dementia; of these, approximately 20% exhibit hoarding behavior (Hwang et al., 1998). The death of a spouse who helped attenuate a hoarding problem can cause the problem to surface and place the hoarder at risk for the first time. There is a higher prevalence of hoarding behavior among those who are single and socially isolated. Families often have made numerous attempts over the years to offer assistance only to have their clean-up efforts return to previous conditions, and so, they give up.

Treatment and Intervention

There is no cure for hoarding behavior, but a number of treatment and intervention strategies have demonstrated some success. The first factor is the great variability of characteristics among those who hoard. If placed on a continuum, those who exhibit good interpersonal skills, cognitive ability, absence of psychosis, awareness of their hoarding, and motivation to change their situation would be at one end, while those who exhibit psychosis, dementia, physical frailty, social isolation, denial about their hoarding, and an unwillingness to accept help would be placed at the other. Similarly, some environments are livable and mildly cluttered, while others are hazardous and uninhabitable. To tailor services to clients who have such varied characteristics, a variety of strategies and resources must be available. What is helpful with one client may be completely ineffective with another.

The challenge for the service provider is to determine which strategies will be most helpful in any given case.

Treatment research has focused on Cognitive Behavior Therapy (CBT) techniques and medication. Some positive results have been noted with these treatments, but clients must be willing participants and be able to be motivated to work on their problem. CBT is an evidence-based psychotherapy developed by Aaron T. Beck, M.D. in the 1960s for the treatment of depression. Since then, its use has expanded to treat a myriad of other psychiatric conditions. Rather than focus on the influence of early life experiences, as is the case with psychoanalytic therapies, CBT focuses on the present with the goal of alleviating symptoms, including changing behaviors. CBT takes the approach that behaviors, thoughts, and emotions affect one another, and that a change in one can positively influence another. In an effort to help people who hoard, researchers Frost & Steketee adapted CBT for hoarding clients. In 2007, they published a guide and workbook for therapists and clients titled "Compulsive Hoarding and Acquiring" (Steketee & Frost, 2007). Unique to CBT adapted for hoarding is the aspect of home visiting. Because many hoarding clients minimize or deny the extent of their hoarding behavior, this adapted treatment emphasizes education about hoarding and includes motivational interviewing strategies to help engage the client and motivate him/her toward change. Sometimes the educational aspect is handled in groups, which has the added benefit of clients' feelings being supported by others

with similar problems. The therapist and client approach the task of sorting and de-cluttering together, so that the client can experience exposure to personal items and receive helpful strategies to make decisions about them. Items that are less meaningful to clients and, therefore, easier to discard are the first to be sorted, as this helps the client become sensitized to the process, making it easier to approach more challenging items later on. Thoughts and perceptions about items are challenged, so that clients can let items go that they formerly could not. Reducing acquiring behavior is another important focus of treatment. Exposure to venues and items where clients routinely acquire and helping clients experience and “survive” not acquiring those items is another useful CBT strategy.

To participate in CBT, a person must have the cognitive ability to learn new information and the stamina to follow through with homework assignments. Homework might include writing down goals, making lists of the importance of items, sorting items in the home and bringing items to sessions. Treatment may take months and by itself may not be sufficient to tackle very severe hoarding environments and behavior in a timely way. Cognitive Behavior Therapy strategies, however, can be effective and should be considered for clients at different points during the intervention process. There is some indication that medication can be helpful, and a careful mental health evaluation is always needed in order to assess for treatable mental health conditions that occur along with the hoarding behavior. Other interven-

tions that have been effective in some cases are those offered by professional organizers and private care managers. These service providers frequently work in collaboration with mental health professionals to assure that the client’s mental health needs are not overlooked while there is such intensive focus on cleaning up their environment. Additionally, “Hoarding Task Forces” involving a multitude of agencies have formed in many jurisdictions and have been helpful. These are particularly prevalent in public agencies when a property may have code and fire violations or a client’s level of self-neglect meets criteria for involvement from a county’s Adult Protective Services program. With multiple agencies engaged in these task forces, the focus can be on having property clean-up for the safety of the individual and community, as well as planning and caring for the needs of the individual. Whatever the combination of services that is put together, in all cases it is imperative that there be a constant and supportive person who can develop a trusting relationship with the client, gauge the client’s readiness for an intervention, and anticipate the client’s response to it. Too often an intervention may involve a major clean-up, but, this completed, services discontinue. The focus in those cases is on the property rather than both the person and the property. These clients need a long term relationship with a trained professional who can help them through the cleanup phase and help develop a maintenance plan, which may include motivating, monitoring, organizing, and regular housekeeping services.

It should not be forgotten that persons who hoard have the legal right to refuse intervention and treatment. Based on existing property violations, fire and code enforcement authorities may take action against a client’s wishes by condemning the property or ordering clean up. When property conditions do not warrant such action and the client refuses services, no further intervention is possible. The only exception is when a client is incapacitated and a court appointed guardian or conservator can make decisions on a client’s behalf, including decisions regarding clean-up. Most often a guardian and conservator are appointed only in those cases where there is another condition present beyond hoarding, such as dementia, intellectual disability or a psychotic disorder and impairment. These are often the clients who are referred to Adult Protective Services for self-neglect. Respecting the individual’s right and desire to be independent and self-sufficient, while protecting him or her from self-neglect and harm, together create an ethical challenge for those called upon to intervene.

Case Study #1

Mr. R. first came to the attention of his local Fire Department when a neighbor complained about the mounds of trash she had glimpsed through his doorway as Mr. R. entered his home. Besides the neighbor’s concern, no-one suspected that Mr. R. had a problem. He was a bright, articulate 69 year old gentleman who had retired from his federal government job four years earlier and was volunteering in the community for a local charity that provided meals to shut-ins. A staff

person from the Fire Department visited him but was unable to investigate the complaint due to Mr. R. not allowing him entry into his home. The Fire official was able to persuade Mr. R. to meet with a social worker from Adult Protective Services who evaluated Mr. R. and found him to be competent and able to refuse services. Over the next 10 years a complaint about Mr. R.'s hoarding behavior was made approximately once every two years. Complaints included references to a car that was so stuffed full of things that it was unsafe to drive, and rodents on the property. With each complaint services were offered to him, and each time he refused. CBT was not an approach used with Mr. R. for a number of reasons. He saw attempts to help him as unwelcome interventions which he did not want. He exhibited no motivation to change his behavior, a necessary component of CBT treatment. He continued to present as cognitively intact and competent to refuse services. When Mr. R. was not seen at his volunteer job for several days, a request was made of police to check on his welfare. Police found him unconscious in a corner of his bedroom where he had landed after sliding down a pile of papers. Mr. R. was hospitalized, received treatment for an infection of both legs, and had his home condemned by the fire marshal. While in the hospital, he was diagnosed with bi-polar disorder and placed on medication. Social workers helped Mr. R. find temporary housing and engage the services of a professional organizer to help him clean out and organize his belongings. After some house repairs, the Fire Marshall allowed him to move back in. Once the crisis passed, Mr.

R. refused ongoing mental health or case management services, as he felt they were too expensive and he stopped taking his medication. Some years later a repeat intervention took place. This time, in addition to his hoarding behavior, there was evidence that Mr. R. had early stage dementia. At that point he was evaluated by a psychiatrist who found him lacking the capacity to manage and safeguard his finances. It was discovered that Mr. R. had lost approximately \$25,000 after falling for a scam. The court appointed a conservator. There was now a mechanism in place to pay for private care management which Mr. R. accepted. With this ongoing help, his situation stabilized. Mr. R.'s environment, though still cluttered, remained safe and functional.

Case Study #2

Mrs. S. was 73 years of age when her husband brought her to a mental health therapist who suggested CBT treatment. Mr. S. had been unable to persuade his wife to dispose of her large collection of craft supplies so that they could sell their home. The couple had made a mutual decision to move into a home in a retirement community that was one fifth the size of the home they were leaving. Mrs. S. had made no progress during the six month period set aside to get the house ready for sale. Deadlines for the sale of their current home and move to their new home were fast approaching. Mrs. S. acknowledged that she had a problem with excessive buying and difficulty getting rid of things; however, she could not make a plan to reduce her belongings. She agreed to engage the services of a professional orga-

nizer and to continue work with the therapist on a twice a week basis. With Mrs. S. present, the professional organizer and Mr. S. removed all but 50 boxes of her craft supplies. A storage unit was filled with some, but many needed to be given to charity or otherwise disposed of. The process caused Mrs. S. to become severely depressed and angry; she talked about having thoughts of suicide. The completion of the process and her therapist's help caused her depressive symptoms to lift and she began expressing feelings of excitement about the upcoming move. To help prevent a recurrent hoarding situation, Mrs. S. continued treatment after her move. Emptying the temporary storage facility was her first goal. Her task was to bring a box of items to her session during which all items in the box were sorted into categories. With her therapist's help, she established four categories in which to sort items: trash, recycling, donating, and items to keep. Although the items were forgotten when packed up, she experienced anxiety when seeing them again and had difficulty placing items in any of the categories that were not "items to keep." Using a CBT strategy to change her thinking about items, however, she managed to dispose of more and more things as treatment progressed. One item that was particularly difficult for her was a bottle of bubble bath that she had purchased when her daughter was a toddler 30 years earlier. When the therapist asked how keeping the bottle would help her reach her goal of emptying the storage container (it would not) or if she would use it during the next five years (she would not) or if she could imagine a child in a shel-

ter enjoying it (she would like that), she was able to let go of it. Repeating this process with items over and over again sensitized her to the process and allowed her to make decisions much more quickly as time went on. Mrs. S. also agreed to take medications prescribed for depression and Attention Deficit Disorder, which had the effect of making her more focused during treatment sessions. She was able to allow a housekeeper to come once a week to help with keeping things organized and uncluttered. She agreed to these services on a long term basis to prevent a recurrence of the prior over-filled and disorganized state of her home.

Conclusion

Hoarding behavior can have significant impacts on the health and safety of older hoarders. To address hoarding behaviors, individuals, families, mental health professionals, elder service agencies, and residences for older adults will need the knowledge, skills, and support of a variety of resources. Long term involvement by a dedicated professional, such as a care manager, is necessary to maintain stability, monitor needs, assist with obtaining appropriate services, and coordinate care among service providers. Many older hoarders will need ongoing and regular mental health services, as well as in-home organizing and housekeeping to compensate for lack of executive functioning skills. Maintaining the elder's stability will require collaboration and partnerships between providers and agencies, ideally under the coordination of a care manager. Providing these services is time consuming, expensive, and

requires availability of professionals who are trained in dealing with hoarding behavior. Creative ways to help those without sufficient funds need to be found.

Study Questions

1. What medical and mental health factors contribute to hoarding behavior?
2. If executive functioning is impaired, why might that cause hoarding behavior?
3. What challenges are more likely for older persons who hoard, as compared to a younger population?
4. What principles of Cognitive Behavior Therapy (CBT) help to address hoarding behavior?

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