



Journal of Geriatric Care Management

VOLUME 20
ISSUE 2
FALL
2010

*Published by the
National
Association of
Professional
Geriatric Care
Managers*

3275 West Ina Road
Suite 130

Tucson, Arizona
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Guest Editor's Message

By Emily B. Saltz, LICSW, CMC

Imagine my surprise to turn on my television recently and find that there are suddenly a variety of shows devoted solely to hoarding: "Hoarders," "Confessions: Animal Hoarding," "Hoarding: Buried Alive," "Clean House: Messiest House," just to name a few. Reality television has catapulted hoarding from an obscure problem to our nation's "trauma du jour." Suddenly everyone is fascinated by the dark side of our American love of acquiring and possessing, engaged by the secret misery of other people – who might even be our neighbors! – wading through mounds of junk as horrified family members look on.

My own interest in hoarding had much less visible beginnings, although no less dramatic. I was one of the first protective service workers hired in Massachusetts in 1982 under a new law advancing the broad mission of "protecting elders from abuse, neglect, and self-neglect." One

of my first cases involved two elderly brothers, Jimmy and Harry, who lived like hermits in an apartment building in an urban community. They were rarely seen out of their apartment during the day, making their only forays to the outside world under cover of darkness. The neighbors complained that there was a bad smell emanating from the apartment, that there was junk piled up all over the place, and that the apartment was a fire hazard. To make matters worse, the downstairs neighbors had been flooded several times when Jimmy and Harry forgot to turn off the bathroom faucet. The health department became involved in response to the neighbors' complaints, and soon the landlord started talking about eviction.

I was charged with the formidable task of "doing something" to get these brothers to accept services, clean up their apartment,

and make the environment safer. After my initial visit and immediate panic, I reminded myself why I had gone to social work school, and I began the process of developing a relationship with the two brothers and figuring out both short-term and long-term solutions to the unfolding crisis. Instinctively I knew that I had to get the external players – the neighbors, the landlord, and the health department – to back off, slow down, and give me time to make some progress with my clients. But where amid their world of bags and "stuff" was I to begin???

After a lot of unanswered knocks on the door (naturally, the brothers did not have a phone!) I managed to enter their apartment and their lives, we talked amid piles of filled garbage bags, and Jimmy and Harry soon became real people to me. Harry, I

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Journal of Geriatric Care Management

Published by the:
National Association of Professional Geriatric Care Managers

3275 West Ina Road, Suite 130, Tucson, Arizona 85741 • www.caremanager.org

Published two times a year for members of NAPGCM
Non-member subscriptions: \$95.00 per year

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learned, had been a classical pianist who had played on the great stages of Europe. Jimmy had been an amateur baseball player. They never failed to make me laugh, they told great stories, and, all these years later, they remain among my favorite clients. Of course, they had no idea what the fuss was about, and they saw no problem with their living situation. Everything they owned made perfect sense to them. I never did get them to totally clean up their place, but I did convince them to accept home-delivered meals and some amount of “cleaning” services to reduce the unpleasant odor and create pathways through their clutter. Together we made enough progress to satisfy the landlord and neighbors, and the public health authorities backed off. Thus began my interest and attraction to the eccentric and bizarre and often surprising life of hoarders.

I am honored to be the guest editor of this edition of the Journal of Geriatric Care Management, devoted solely to the topic of “Hoarding.” Even the most experienced GCM experiences feelings of helplessness and uncertainty when dealing with an elderly client who hoards. How and when to intervene, overcoming resistance to intervention, evaluating whether the hoarding behavior is a “choice” or a result of diminished capacity – these are just some of the many dilemmas we face. I am sure you will gain new and practical insights into this complex problem by reading the articles that follow.

Hoarding and Elders: Current Trends, Dilemmas and Solutions, by Emily B. Saltz, LICSW, CMC, presents an overview of hoarding and discusses the practical and ethical dilemmas that GCMs face when dealing with elderly hoarders. She uses research studies and case examples to illustrate the complexity of the problem, along with intervention guidelines to assist GCMs working with this vulnerable population.

There are two articles devoted exclusively to treatment interventions for hoarding. *Evaluating and Selecting Interventions for Older Adults with Hoarding and Cluttering Behaviors*, by Monika B. Eckfield, RN, MSN, PhD Candidate, describes exciting new treatment methods for hoarders including cognitive behavioral therapy, harm reduction, and motivational interviewing. She discusses each treatment method in detail, providing case examples to illustrate the utility of these approaches.

Home Based Intervention for Elderly Hoarders: What Really Works? by Christiana Bratotiis, PhD, MSW, describes a university-community project partnership through which elder hoarding clients receive home-based intervention. Project outcomes are presented and opportunities for future research are discussed.

Rooms of Shame: Senior Move Manager’s Perspective on Hoarding, by Margit Novack, MCP, cSMM, presents techniques that have been successful in reducing or eliminating hoarding. Her article is written from the unique vantage point of the move manager professional who is most often at the front lines of the hoarding problem.

Finally, *Nice Children Stolen From Car*, by Barbara Allen, is a poignant series of autobiographical vignettes written from the perspective of a fourteen year old growing up in a hoarding household. These vignettes provide a compelling portrait of the anguish and turmoil a young child experiences growing up in this chaotic environment.

I do have one final thought to share – when you are done reading the Journal, I encourage you to save it for further professional use – as long as you recycle everything else you acquired today!

Hoarding and Elders: Current Trends, Dilemmas, and Solutions

By Emily B. Saltz, LICSW, CMC

Summary

Compulsive hoarding stands at the crossroads of the mental health and public health systems. GCMs who work with hoarders struggle to balance the rights and autonomy of the individual while effectively responding to public health and safety imperatives. This article describes the ethical and practical dilemmas that geriatric care managers face in working with elderly hoarders. The author uses research studies and case examples to illustrate the complexity of the problem, along with intervention guidelines to assist professionals in working with this vulnerable population.

Hoarding and Elders: Current Trends, Dilemmas, and Solutions

Jackie D is a 70-year-old single woman living alone in her own apartment. She has a long history of mental illness and compulsive hoarding behavior. Her hoarding is so extreme that her apartment has become uninhabitable, and Jackie has been sleeping in her car or spending the night in local shelters. The city has initiated condemnation proceedings, and a guardian has been appointed by the court. The guardian retained a geriatric care manager (“GCM”) to assess the situation and give recommendations regarding the feasibility of cleaning out the apartment so that Jackie can resume living there.

When the GCM and the guardian arrived at Jackie’s apartment to conduct an initial assessment, they found out why she was sleeping in her car: they were literally unable to enter the premises. With the assistance of a building superintendent, they

were able to push open the front door, which was blocked by piles of plastic bags, bottles, and furniture. It took only a moment’s glance to assess why Jackie was no longer able to live in her own apartment.



Jackie D’s living room



Jackie D’s bedroom



Jackie D’s bathroom

The apartment was completely filled with large garbage bags that overflowed with clothing, papers, bottles, and other loose objects. The clutter was at least three feet high,

covering not only every inch of floor but burying the household furniture in each room. The GCM and guardian could move from room to room only by stepping over and on top of mounds of filled plastic bags in each room. In the kitchen, the filled bags were as high as the countertops, and the countertops themselves were covered with unbagged, unrelated items. The same obstructions existed in the bedroom, which was uninhabitable. In the bathroom, the toilet, sink and floor were rendered unusable by the same detritus.

In general, there was no apparent organization to the clutter, with bags and belongings mixed chaotically throughout the apartment. Perhaps because the apartment was quite cold, it did not have a strong odor. The rooms were all darkened by make-shift paper coverings that had been taped over the windows. The superintendent indicated that for the past several months Jackie tried to store her overflow belongings in shopping carts in the lobby, but other residents complained and the management prohibited her from continuing this practice.

Introduction

The case of Jackie D presents a vivid picture of the complex issues that a GCM faces in working with a hoarder. Since Jackie refused all offers of assistance, the guardian and the GCM were left with a long list of questions and dilemmas. Should the guardian initiate a total cleanout of the apartment and remove all of Jackie’s belongings so that she could move back in? Should the guardian involve Jackie in the cleanout process? Even if Jackie agreed to the cleanout, was there any chance of lasting success given Jackie’s lifelong history of hoarding?

Jackie D fits the classic profile of a hoarder: female, unmarried, and living alone. She is socially isolated and refuses offers of assistance. She has poor insight into her problem and employs significant degrees of denial in viewing her own circumstances. In trying to assist Jackie, her guardian and the GCM must confront difficult ethical issues. How can we protect Jackie's autonomy and ensure her fundamental right to live her life as she chooses at the same time that we address the public health and safety issues caused by her hoarding? How do we address her mental health issues, which have gone untreated for so long, when she refuses treatment? When is a hoarder legally competent to choose a hoarding lifestyle? On the other hand, when is a "forced clean-out" – an approach that has proven to be traumatic for many hoarders – a necessary act?

Compulsive hoarding stands at the crossroads of the mental health and public health systems. The two systems often collide because public health and safety professionals are primarily concerned about broader public safety and have a mandate to seek an immediate resolution to the safety risks that hoarding often poses to self and community. In contrast, mental health professionals often resist immediate intervention in order to reach a better understanding of the underlying mental health issues and establish a trusting relationship with the individual. GCMs who work with hoarders must learn to walk a fine line between protecting the rights and autonomy of the individual while effectively responding to public health and safety imperatives. This requires skillful navigation through related though often conflicting perspectives of our public safety and mental health systems.

Definition and Demographics

Hoarding is most commonly defined as the acquisition and inability to discard a large number of possessions that are of useless or limited value. Hoarding behavior inevitably leads to a situation where

the space, furniture, and items in the home cannot be used for "normal" living purposes. Clinically significant hoarding is associated with distress and functional impairment in daily life (Frost and Hartl, 1996; Steketee and Frost, 2007). Hoarding is almost always accompanied by excessive buying or acquisition of possessions, although it is not always limited to possessions – animal hoarding is a particularly complex form of the disease that involves the accumulation of and inability to care for a large number of animals or pets (<http://www.tufts.edu/vet/hoarding/harc.htm>). Hoarding is distinguished from "collecting" by the fact that collectors generally acquire and discard, while hoarders acquire and retain. Collecting is a pleasurable pastime; hoarding is an obsession.

Hoarding is distinguished from "collecting" by the fact that collectors generally acquire and discard, while hoarders acquire and retain. Collecting is a pleasurable pastime; hoarding is an obsession.

Current estimates are that approximately 3 – 5% of the U.S. population suffers from a hoarding problem (Samuels et al., 2008). The presence of hoarding behavior among elders with dementia is estimated at approximately 20% (Hwang et al., 1998). These numbers are little more than estimates for the simple reason that hoarding is a "hidden problem" that is vastly underreported and often misdiagnosed.

The typical age of onset for hoarders is during childhood or adolescence. Hoarding is a "slow growing" problem and it often takes years or decades for the problem to fully manifest itself as an obstacle to safe or healthy living. Hoarding tends to run in families. According to several studies, 80% of hoarders grew up in a household with a family member who hoards (Samuels, et al., 2002).

Diagnostic Criteria

Long deemed to be a subset of obsessive compulsive disorder ("OCD"), hoarding behaviors have been identified in 20 – 30% of OCD patients (Frost and Steketee, 1998). In the DSM-IV, hoarding has been listed only as a symptom of OCD. More recent research, however, suggests that hoarding is a distinct diagnosis with a unique profile of core symptoms and genetic markers that are different from OCD. At this time, there is a movement among researchers and clinicians to list hoarding as a separate and distinct diagnosis in the upcoming DSM-5 (Saxena, 2008).

Many hoarders experience significant depression, social phobia, and isolation. In addition to OCD, hoarding behaviors have been associated with other clinical disorders such as depression, anxiety, ADHD, schizophrenia, substance abuse, personality disorders, and dementia (Steketee and Frost, 2003).

Cognitive, Social, and Emotional Deficits Associated with Hoarding

Hoarding is a multifaceted problem associated with a number of deficits that define its central behaviors (Frost and Hartl, 1996).

Acquiring and Discarding

A central feature of hoarding is the act of continuously bringing physical items into one's environment through excessive buying or acquisition. The traditional methods for acquiring include retail shopping, buying at yard sales, ordering through mail order catalogues, and even, in

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some instances, searching the trash of others (or “dumpster diving”). Since hoarders acquire and save everything, random items like newspapers, flyers, ads, handouts, and free samples are often the focus of the hoarding mentality. With easy access to the Internet, hoarders no longer have to rely on retail shopping trips or mail-order catalogues to stock up on new possessions. Hoarders now have limitless opportunities to grow their collections with the simple click of the mouse at websites such as e-bay and amazon.com. For hoarders who prefer television, ample opportunities for shopping on the Home Shopping Network and QVC remain.

Acquiring by itself is not the problem. The problem is the hoarder’s failure or inability to discard acquired objects that normally would be considered of limited value or worthless. Hoarders perceive a very special relationship with their “stuff” and view their belongings as an extension of themselves. They may feel violated if their belongings are removed or touched without their permission.

Information Processing

For hoarders, all objects have a unique use or reason for keeping. The hoarder, however, has great difficulty in categorizing and organizing belongings and will instead become indecisive, ambivalent, and disabled by a concern that discarding the item would be a serious mistake. Impelled to consider all the attributes of a possession, and overwhelmed by the task of categorizing, the hoarder comes to regard each possession as “unique” and worth saving.

Memory

Researchers are exploring the role of subtle memory deficits in creating the hoarding instinct (Frost and Hartl, 1996). With less confidence in his or her own memory for retaining past experiences, the hoarder will gather and keep objects that become

proxies for memory. The importance of the remembered item can become exaggerated and a hoarder may be unable, for example, to throw out a 10-year old newspaper for fear of forgetting the “important” information contained in a particular article. Impairments in short-term memory can also affect hoarding behavior, since the individual may worry that putting things out of sight will cause them to become lost or discarded.

***They [hoarders]
derive emotional
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Throwing things
away means losing
security and safety
and possibly a part
of oneself.***

Emotional attachment and distorted beliefs about possessions

Hoarders develop extreme attachments to possessions and see their belongings as extensions of themselves. They derive emotional comfort from acquiring and being amidst their possessions. Throwing things away means losing security and safety and possibly a part of oneself.

Additionally, hoarders entertain distorted beliefs about the nature and importance of their possessions. They have an exaggerated need for control over and responsibility toward possessions, and they will often experience a sense of violation if others touch or, even worse, remove the objects. Hoarders are driven by a compulsion for perfection in managing their belongings, and they worry that failing to be perfect will have

catastrophic results. They may feel – and indeed be oppressed by – a sense of responsibility toward their own future needs or the needs of the world. They are odd “environmentalists,” staunchly believing that saving prevents waste. Moreover, since every object has many possible purposes, discarding an item, even if its use is highly unlikely, is abhorred and leads to feelings of guilt and regret.

Hoarding and Elders

For the GCM, encountering elderly clients with profound hoarding problems is not uncommon, and these cases are often the most difficult to manage. Unfortunately, the research on aging, dementia, and hoarding is extremely limited. Randy Frost, Gail Steketee, and Hyo-Jin Kim pioneered one of the first research studies on hoarding and elders in a study published in 2001, “Hoarding by Elderly People.” The study described the lack of empirical literature regarding hoarding and elders, but acknowledged that the link surely exists, noting that 40% of hoarding complaints to local health departments involved elder service agencies (Steketee and Frost, 2001). This study was also the first to conclude that forced clean-out of a hoarder’s home was traumatic and in most cases, not an appropriate intervention.

There are many reasons why elders develop or continue hoarding behavior late in life. Elderly hoarders suffering from chronic illness and physical or mental decline are at particular risk. Using an example from the author’s own caseload, Mr. C was 86 years old and a life-long hoarder suffering from diabetes, high blood pressure, and arthritis. He walked with a walker and was unsteady on his feet. His wife kept Mr. C’s hoarding behaviors in check by quietly monitoring and controlling their possessions. After she died, Mr. C’s piles of acquired objects began to take over his living space. Pathways for getting around the house disappeared, and he was left with limited access only to the kitchen, bedroom, and bathroom. Not surprisingly, Mr. C eventually fell in his home and was

not discovered until twelve hours later when a concerned neighbor alerted the police about his disappearance. He was hospitalized with a fractured hip and later admitted to a nursing home.

In Mr. C's case, although his hoarding began early in his life, the death of his wife and the decline in his physical functioning led to a hoarding-related crisis. His grief reaction over the loss of his wife may well have stimulated an intensification of his hoarding behaviors, and the absence of his wife, along with his own physical decline, caused his home environment to become unsafe. There are many other causes that spur elders like Mr. C into greater and more treacherous hoarding behaviors.

Compensation for Loss

Hoarding may be linked to an unresolved grief or loss experience (Frost & Hartl, 1996). All elders inevitably must cope with an accumulation of losses and late-life stressors, such as loss of family and friends, retirement or sale of a business, and reduced physical and/or cognitive skills. As another example, Mr. P was an 81-year-old man living alone in an apartment piled floor to ceiling with books, videotapes, canned goods, and papers. He explained that he began his "collecting" after his mother's death. He acknowledged feeling "empty" and depressed after she died. Mr. P expressed the link most poignantly between his hoarding problem and his personal grief over the loss of his mother: "Maybe I was trying to fill the house up after she was gone."

Previous Trauma

Generations are defined by the major historical events and cultural values of their time. The current generation of elders lived through epic historical events, including world war, the Great Depression of the 1930s, and the Holocaust. Economic travails like the Great Depression invariably teach the value of scrupulously saving, preparing for an unforeseeable future, and eliminating wasteful behaviors. Holocaust survivors (and survivors of other atrocities) learned extreme

lessons in the value of storing small items of food or clothing. While "hoarding" might be considered adaptive behavior under extreme circumstances, the same behaviors can only be regarded as maladaptive later in life when the immediate crisis that originally necessitated the behavior is in the past.

In the absence of the connectedness that comes with family and community, hoarding objects becomes a way for the lonely elder to provide him or herself with a measure of familiarity, comfort, and security.

Social Isolation

Elderly hoarders tend to live alone and in social isolation (Steketee, Frost et al, 2001). Their formal and informal support systems are inadequate or non-existent. In the absence of the connectedness that comes with family and community, hoarding objects becomes a way for the lonely elder to provide him or herself with a measure of familiarity, comfort, and security.

Memory Impairment and Dementia

The empirical research on the connection between hoarding and dementia is extremely limited (Hwang et al, 1998). Nevertheless, the anecdotal experience of many in the GCM community suggests that, as a practical matter, the link exists. We also know that in dementia patients, the hoarding instinct is a formidable obstacle to the elder's safety and health.

Dementia occurs as a result of

changes in the brain and can affect memory, mood, and behavior. Elders with memory loss may be unable to discriminate between items of relative importance, and as a result, save everything. They may be attempting to "regain control" by gathering familiar objects around them and refusing to let things go. Elders with dementia may "forget" what should really be classified as trash and may wind up saving dirty items, rotten food, and other inappropriate objects.

Hiding behaviors are common among elders with dementia. They may hide objects in order to keep them safe but frequently forget where these items are stored. A related symptom of dementia that can exacerbate hoarding tendencies is paranoia and mistrust. Elders suffering from dementia often become suspicious and accuse others of stealing, leading them to hoard their belongings in order to prevent anyone from taking them away. For example, Ms. D was a 76-year-old woman with dementia. Each day, she would wear at least ten layers of clothing at once because, as she explained, people were "trying to steal from me." In her view, keeping her clothing on all the time made her feel safe and protected.

Treatment Options

There is no easy solution to the hoarding problem, no magic bullet with guaranteed success. Different treatment options exist, some of which are in development now and offer an exciting potential for future treatment. The three major forms of intervention for hoarders that have emerged over the past several years include cognitive behavioral therapy, harm reduction model, and motivational interviewing. The cognitive behavioral therapy model, developed by Steketee and Frost, involves skill-building in the areas of decision-making, categorizing and de-cluttering. The harm reduction approach emphasizes helping the hoarder to live more safely rather than stop hoarding completely. Motivational interviewing combines the cognitive-behavioral model with motivational strategies used to promote readiness for change

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in clients. Each of these techniques is described in more detail in other articles in this Journal.

We do know, however, that traditional methods have not proven to be effective. There is little evidence that medication or psychotherapy, the two modalities most utilized in the past, have been effective in treating individual hoarders. Since hoarding has been traditionally treated as a subset of OCD, the psychotropic medications typically used in the treatment of that disease have not had lasting success in treating hoarding. If hoarding is reclassified in the future DSM-5 as an independent diagnosis, this will undoubtedly spur new research into more effective medications. Likewise, there is no evidence that psychotherapy – the “talking cure” – works as an effective tool. Indeed, psychotherapy can be lengthy, often several years in duration, making it less than optimal for the emerging crises the hoarder faces.

No matter which treatment option is chosen, it is crucial to recognize that denial is the hallmark of the disease and presents a substantial barrier to effective treatment. Hoarders frequently deny the seriousness of their behavior, often expressing a preference to live in cluttered space rather than give up their valuable possessions. This is particularly true of elderly hoarders who may keep the problem “hidden” and rarely seek treatment from professionals.

Intervention Guidelines

The diverse professional communities that work with the elderly – GCMs, researchers, elder care professionals, and mental health professionals – must recognize that hoarding simultaneously presents both mental health issues and public health and safety issues and that these dual problems must be addressed concertedly. Intervention with hoarders is a multi-step process that

recognizes the link between the two systems and involves:

- 1) Thorough mental and physical health assessment, including mental capacity.
- 2) Development of a positive and trusting relationship with hoarder.
- 3) Providing treatment for underlying diagnoses (e.g., depression, psychosis, OCD) even if the treatment does not improve the hoarding.
- 4) Reducing risk by emphasizing increasing safety rather than eliminating hoarding behavior and using treatment options such as cognitive behavioral therapy, harm reduction, and motivational interviewing.
- 5) Working with appropriate community agencies including protective services, fire and police, housing department, and elder service agencies to improve communication and develop a coordinated response to a hoarding situation.

GCMs face some of their most difficult challenges when working with frail elderly hoarders with diminished or intermittent mental capacity. Like most hoarders, these clients are often resistant to intervention and express a strong preference to remain at home, even if the environment is unsafe. However, when the GCM is not sure that the client has the capacity to “choose” their living situation, options for intervention become more complicated. The GCM often feels pressure to “do something” and may end up feeling frustrated and inadequate when the client resists their efforts. In order to determine whether to “intervene now” or “wait for a crisis,” the GCM needs to do a thorough assessment of the client’s capacity balanced with an understanding of the risk factors presented.

In this regard, Barbara Soniat, MSW, has developed a capacity/risk model of intervention for frail elders that is useful (Soniat & Micklos, 2010). This model looks at three areas of functioning: physical (activities of daily living); psychological; and social (availability of informal and formal supports, finances). Soniat defines an individual’s capacity as the ability to understand the consequences of one’s actions. Risk is defined as the probability of harm, injury, or loss. Once a thorough assessment of these variables is complete, intervention is based on evaluating competency vs. risk in the following manner:

If the client has:	Goal of intervention:
High risk/high capacity	Accept client’s right to self-determination
High risk/low capacity	Intervention required up to and including legal (guardianship, conservatorship, etc.)
High risk/moderate capacity	Reduce resistance; reduce risk; increase capacity

The elders with high capacity or low capacity do not present us, as GCMs, with a dilemma, since the course of action is likely to be much clearer with these elders. It is the clients in the third category, high risk/moderate capacity, that present us with gray areas of ethics and practice, because the balance between the client’s right to autonomy and the risk of harm can be difficult to strike.

Conclusion

Working with elderly hoarders unquestionably presents some of the most significant challenges we face as GCMs. Based on years of working with this population, the author has developed the following guidelines for appropriate intervention.

- 1) **Quick fix:** There is none! Resist pressure to intervene too quickly, and do not expect miracles overnight. Remind yourself (and other professionals) that hoarding is a problem that generally occurs over a long period of time and that your client’s problem will not be resolved easily or quickly.
- 2) **Positive relationship:** Success depends on building a positive relationship with your clients. You must gain their trust, assure them that you are there to help and not to “take away their stuff,” and remain extremely patient.

- 3) **Empathize:** Remember to see the problem from the client's point of view. Hoarders are especially sensitive to feeling judged or criticized. Respect the meaning and attachment to possessions that they have.
- 4) **Set goals:** Provide your client with choices that will enable him or her to reach specific goals while maintaining a sense of personal control. The immediate goals may involve addressing a crisis (e.g., an angry landlord, a fire department directive). Longer-range goals may address the deeper issues.
- 5) **Negative feelings:** It is not unusual, or even wrong, for a professional to have an aversion to the sights and smells associated with a hoarding disorder. If this is the case, do not take on the work. Your own negative response will make you ineffective.
- 6) **Removing belongings:** Never remove belongings without the client present (unless they agree to be absent). Forced or surprise clean-outs are almost always ineffective and can be very traumatic.
- 7) **Collaboration:** Hoarding is both a mental health and a public health crisis. In combating hoarding, it is critical to develop collaborative relationships between and among various agencies and professionals — mental health, adult protective services, animal control, building and safety, criminal justice, fire prevention, and home care agencies. Each has a role to play in addressing the intractable problem that your client may present.

As GCMs, we are working on the front line of a social problem that presents challenging practical and ethical issues that may well be growing as the population ages, and yet remains unclear both in its causes and in its scope. Future research will surely illuminate best practices in dealing with elderly hoarders, and the emerging new treatment methodologies are a welcome development. A deeper understanding of the connection between hoarding

and dementia will surely assist us in our work. Ultimately, broader solutions will require us to integrate approaches that involve mental health and public health concerns. As GCMs, we will provide the bridge not only between these professional disciplines but between what we presently know and what we have yet to learn.

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Evaluating and Selecting Interventions for Older Adults with Hoarding and Cluttering Behaviors

By Monika B. Eckfield, RN, MSN, PhD Candidate

Summary

Research on effective interventions for hoarding and cluttering behaviors in older adults is limited. However three approaches, harm reduction, motivational interviewing, and cognitive behavioral therapy, are commonly discussed as appropriate interventions to try when working with older adults. The purpose of this paper is to discuss these three approaches, factors to consider when evaluating whether an intervention is appropriate for your client, and their advantages and disadvantages. A case example is provided to illustrate the utility of these approaches. Additional interventions are sure to be developed and evaluated over the next several years, building our repertoire of “best practices.”

Introduction

All of us who work with older adults know that individuals come from a range of backgrounds and have had a unique set of experiences that have shaped their lives and their identities. Older adults with hoarding and cluttering behaviors are no different in this regard. As a Geriatric Care Manager, you may be in the position of spearheading an intervention to address a problematic living environment created by hoarding and cluttering behaviors. By considering your client’s individual characteristics, you can make the best decision on what interventions to try first and how to promote their readiness for change.

Hoarding and cluttering behaviors have been defined as the acquisition of and inability to discard items that appear to others to be useless or of limited value to the extent that they

cause distress or impairment to those who are living in the environment (Frost and Hartl, 1996; Steketee and Frost, 2007). These behaviors can lead to serious personal and public health problems by increasing the risks of morbidity and mortality, fires, and pest infestations (Frost, Steketee and Williams, 2000; Patronek, 1999). There is some evidence that hoarding and cluttering behaviors are more prevalent in older adults and that symptoms may worsen with advancing age (Ayers, Saxena, Golshan, and Wetherell, 2009; Samuels, Bienvenu, Grados, et al., 2008). In addition, older adults also appear to be at greater risk for poor outcomes from living in severely cluttered environments due to co-occurring physical impairments, social isolation, and cognitive changes (Kim, Steketee, and Frost, 2001). Therefore, it is critically important to know how to evaluate and select interventions to help older adults live safe, healthy lives in their homes.

The purpose of this paper is to review the current behavioral interventions for hoarding and cluttering behaviors and discuss reasons why they may or may not be appropriate for older adults. Three specific approaches will be discussed: Harm Reduction, Motivational Interviewing, and Cognitive Behavioral Therapy. These three interventions are not mutually exclusive and may be used in combination. For the three approaches presented here, suggestions for evaluating whether an intervention is appropriate for your client, as well as the advantages and disadvantages of each strategy, will be discussed. A case example will be used to illustrate the utility and limitations of each intervention.

Pharmacological treatments for hoarding and cluttering behaviors will not be discussed, because research has not yet demonstrated that currently available medications are effective in treating these behaviors. That is not to say that some individuals with hoarding and cluttering behaviors would not benefit from taking anti-anxiety or antidepressant medications. Hoarding and cluttering behaviors frequently co-occur with anxiety disorders and depression (Grisham, Steketee, and Frost, 2007; Samuels, Bienvenu, Pinto, et al., 2007). If your client suffers from anxiety or depression, treatment for these underlying disorders, including taking medication, may help resolve some of the symptoms that are intertwined with hoarding behaviors. For example, anxiety or depression may make it hard for individuals to make decisions, organize their thoughts and materials, develop plans, and carry them through. If you suspect an underlying anxiety or depressive disorder, encourage your client to have a medical evaluation. Addressing these issues first can pave the way toward more effective behavioral interventions.

Case Example, Mrs. B.W.

Mrs. B.W. is a 79-year-old woman who lives by herself in a one-bedroom apartment in a subsidized senior housing facility. She has been divorced for thirty years and has three adult children, one of whom lives nearby. Mrs. B.W. moved to this apartment eight years ago, and her bedroom is filled with boxes that have never been unpacked from the move. Because the bedroom is so cluttered and used primarily for storage, her bed and nightstand are located in her

living room. The remainder of the living room is filled with belongings: a sofa covered with stacks of folded clothes, two bookshelves placed back to back filled with books, papers, and smaller storage boxes, and stacks of storage crates or boxes from mail order purchases that are topped with loose items that she needs to “keep handy.” A path about 18 inches wide winds through the apartment from the front door to the kitchen and living room and into the storage room and bathroom. Medically, Mrs. B.W. has arthritis in both knees, high blood pressure, and is a breast cancer survivor. She takes five medications at three different times each day. The arthritis in her knees makes it painful for her to walk, bend, or lift heavy items. She keeps a walker by the front door which she uses when she goes out of the apartment.

Her apartment is inspected yearly to ensure safety codes are being met and to check for needed repairs; recently Mrs. B.W.’s landlord informed her that she is violating several safety codes. The landlord told her that she needs to clear items from behind the front door so that it can open fully, provide better access to the windows in both the living room and the storage room, and remove the cardboard box that is being stored in the oven; otherwise she may be at risk for eviction.

Mrs. B.W. feels physically unable to do the work and is very reluctant to let other people get rid of her belongings. She explains that her income is limited and if she gets rid of items that she later needs, she won’t have the resources to replace them. As her geriatric care manager, you have been hired by Mrs. B.W.’s adult children to help her maintain her residence. What will you do? Keeping Mrs. B.W.’s case in mind, let us consider some of the intervention options.

Harm Reduction

Mrs. B.W. does not want to part with her belongings, but she also does not want to be evicted. As a first step, you discuss with Mrs. B.W. the benefits of a harm reduction approach to her dilemma.

Harm Reduction is defined as a set of practical strategies that reduce the negative consequences of a particular health issue (Harm Reduction Coalition, 2010). The goal of harm reduction is not to eliminate the behavior itself, but to minimize the unwanted, negative consequences that often accompany the behavior. The most widely identified example of a harm reduction approach is needle exchange programs established for individuals with intravenous drug addictions. In this context, public health departments provide clean needles to drug abusers in order to prevent the spread of Human Immunodeficiency Virus and Hepatitis C. Clean needles are provided to individuals even if they do not begin treatment to change their addictive behaviors. In much the same way, a harm reduction approach to hoarding and cluttering behaviors seeks to minimize the risks posed by the behaviors rather than eliminating the behavior itself. The goal is to help the individual, and by extension their families and neighbors, live more safely.

Harm reduction approaches are appropriate for a wide range of older adults. This intervention can be introduced in any living situation where there are concerns about the safety, health, or comfort of the resident. A harm reduction approach does not require the individual to have “insight” into the reasons why they have kept so many things. It only requires individuals to recognize the potential for harm to them, others living in the home, or their neighbors, and to agree to minimize these risks. For this reason, a harm reduction approach may be an appropriate intervention when the older adult has some degree of cognitive impairment. It is also a good place to start with those individuals who are unwilling to seek treatment for their behaviors.

Harm reduction goals for individuals with hoarding and cluttering behaviors generally fall into one of three categories: safety, health, and comfort (Tompkins and Hartl, 2009). Goals that address safety issues should be addressed first

and include such things as moving flammable materials away from heat sources, clearing walkways of potential trip hazards, and clearing enough room around doors and windows so that they can be used as entrances or exits in an emergency. Examples of health goals include clearing access to the bathroom and washing facilities, ensuring proper food storage, addressing appropriate trash and waste disposal, and eliminating pest infestations. Goals that target items related to comfort include addressing heating and cooling problems in the home, designating and clearing appropriate places to eat, sleep, and sit within the home, and making space to conduct other daily tasks including hobbies or other personal interests.

A harm reduction plan consists of several key components: assembling a harm reduction “team” that always includes the individual with hoarding and cluttering behaviors and may also include interested family members, case managers, nurses, social workers, in-home care providers, trusted friends or neighbors, landlords, or others who are concerned about the individual and their situation; developing realistic harm reduction goals; deciding on ways to monitor progress toward these goals; brainstorming a list of strategies for team members to use to help the plan stay on track; and a written contract that clearly outlines the goals, strategies and agreements made by the harm reduction team members (Tompkins and Hartl, 2009). The plan requires ongoing monitoring, assistance, and encouragement to reach and maintain goals, and may be used with other interventions as well.

There are several advantages of a harm reduction plan. A wide range of individuals including friends, family members, personal care assistants, health and safety officials, and others can participate in the harm reduction plan with some basic training in the tenants of harm reduction. Because the overarching goal is to help individuals continue to live safely

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at home, all members of the harm reduction team start from a common place of care and concern for the individual. Since the individual is not being asked to discard their belongings or make drastic changes to their behaviors, the intervention tends to be easier for individuals to accept and is seen as the least threatening or invasive option.

However, there are disadvantages to a harm reduction approach to consider. Because it does not address the fundamental hoarding and cluttering behaviors, a harm reduction plan generally does not decrease the overall number of items in the home and it does not prevent additional items from being brought into the home.

Let's return to our case example and see how it might play out for Mrs. B.W. Let's assume that you have met with the client, her daughter, and her landlord and they have all agreed to be a part of the harm reduction team. In a team meeting, a specific list of what needs to be done and a reasonable time frame to complete each task is developed. Solutions include temporarily moving a few unpacked boxes from the storage room to the daughter's garage, replacing the cardboard box in the oven with non-flammable objects such as cake pans and ceramic bowls, and finding a new location in the apartment for the items that were behind the front door. These initial goals are met in a month's time and the team reconvenes to determine if the safety requirements have been met. Everyone on the team, including Mrs. B.W., discusses whether there are new goals that they would like to address.

Motivational Interviewing

For Mrs. B.W., the act of removing some boxes from her storage room as part of the harm reduction plan started her thinking about how much she would enjoy having part of her sofa cleared in

her living room so that she could sit there to watch TV, instead of always having to sit on her bed. At this point, motivational interviewing techniques would be useful to encourage Mrs. B.W.'s interest in making some small but meaningful changes in her living environment.

Motivational interviewing is defined as "an approach designed to help clients build commitment and reach a decision to change" (Miller and Rollnick, 1991). This strategy recognizes that individuals are often ambivalent about altering long-standing behaviors. Therefore, it is important that they define their own reasons for and motivation to change. As health and care management professionals, we can assess our clients' readiness and help them prepare for meaningful changes by using motivational interviewing strategies.

The theoretical foundation of motivational interviewing is Prochaska and DiClemente's (1986) transtheoretical model of behavior change that outlines six stages through which individuals may progress and regress: 1) not thinking about the change, or pre-contemplation; 2) contemplation; 3) preparation; 4) action; 5) maintenance; 6) and relapse. When lasting behavior changes have been achieved, the individual remains in the "maintenance" phase, reflecting a stable, improved lifestyle. Research studies involving over 50 different types of behaviors, ranging from addictions like smoking, gambling and substance abuse, to lifestyle behaviors such as dietary habits, exercise adherence, and medication compliance have used this model as a framework for promoting behavior change (Prochaska, 2008). While there have been no studies to date evaluating the effectiveness of motivational interviewing in *reducing* hoarding and cluttering behaviors, there is little to suggest these strategies would not support such efforts.

Miller and Rollnick's *Motivational Interviewing* outlines several strategies one can use to promote readiness for change in clients. For example, one of set of strategies is called the "eight building

blocks" to motivational interviewing. The authors use an alphabetical mnemonic device to help us remember these strategies, and they can be used in any order with clients. The building blocks are: giving well-timed advice; identifying and removing barriers; providing choices; decreasing the perceived desirability of the behavior; practicing empathy; providing feedback; clarifying and setting clear goals; and taking a proactive, helping attitude (pp. 20-29).

The types of clients for whom a motivational interviewing approach are most appropriate are those who are ambivalent and conflicted about the costs and benefits of changing their behavior, those who are actively considering change, those who have attempted to make changes in the past but have had relapses and have become frustrated or disheartened, or those who have made some progress modifying their behavior and need additional encouragement and support. Further, because behavior changes are so difficult to make and to maintain, this approach can be beneficial to use in combination with other interventions or treatment modalities.

There are advantages and disadvantages to a motivational interviewing approach when addressing hoarding and cluttering behaviors. Its advantage lies in how the approach is driven by the individual and meets each person where they currently are on their path to change. From this individualized starting point, motivational interviewing focuses on helping someone determine what will motivate them and what is holding them back from making changes. By identifying the sources of ambivalence and developing their own sense of motivation, this approach lays the groundwork to help individuals prepare for and initiate meaningful changes in their behaviors.

The disadvantage or limitation of this approach is that motivation can fluctuate from day to day and week to week, which is often discouraging to both the individuals with hoarding and cluttering behaviors and those working with them. Additionally,

motivational interviewing strategies are best employed by a knowledgeable counselor. How to engage in a dialogue that will effectively promote an individual's motivation to change is a learned skill, and while one does not need a specific professional degree to conduct motivational interviewing techniques, some education and training in this area is needed. In addition, although a harm reduction approach can be used with clients with some degree of cognitive impairment, they need to be able to engage in decision-making and problem-solving for motivational interviewing to be effective.

Returning again to the example of Mrs. B.W., the geriatric care manager using motivational interviewing techniques starts by asking Mrs. B.W. how she might go about making more space, what barriers keep her from clearing the sofa, and the various benefits she sees from having that space uncluttered. After discussing some different options with you, she decides to move some of the clothes stacked on the sofa elsewhere. She will need your ongoing support as she evaluates whether the change worked for her or whether other options need to be tried.

Cognitive Behavioral Therapy

After working with Mrs. B.W. for some time, you bring up the topic of meeting with a therapist to address her hoarding and cluttering behaviors. You share with her that cognitive behavioral therapy (CBT) has been helpful to others who, like her, are working toward changing their behaviors and that you would be willing to help her find a good therapist.

Cognitive behavioral therapy is not a single type of therapy, but a classification of therapeutic techniques based on a set of philosophical ideas. These include: that our thoughts cause our feelings and behaviors, that we can alter our behaviors by changing the way we think, and that since most of our reactions are learned we can re-learn

new ways of reacting to feelings and situations, thereby changing our behaviors (National Association of Cognitive-Behavioral Therapists, 2010). CBT is a highly structured and directive form of therapy that is conducted by a certified and trained therapist, either in private or group sessions. This therapeutic intervention typically takes place over a specified time period that varies from 10 to 26 weeks, with an average of 16 weeks. For CBT to be effective, it requires the individual in therapy to be motivated, actively involved, and frequently involves "homework" for the individual to complete between therapy sessions.

CBT is the intervention for hoarding and cluttering behaviors that has been studied and reported most frequently, however the outcomes have been disappointing (Rufer, Fricke, Moritz, et al., 2006; Abramowitz, Franklin, Schwartz, & Furr, 2003). Recently, a modified, multi-component cognitive behavioral treatment specifically designed to address hoarding and cluttering behaviors has been developed and tested (Steketee and Frost, 2007; Murdoff, Steketee, Rasmussen, et al., 2009). One feature of this new intervention that distinguishes it from previous CBT interventions is that it incorporates motivational interviewing techniques to combat the ambivalence commonly associated with these behaviors. In a report evaluating the effectiveness of a 26-week intervention based on this modified approach, 80% of individuals rated themselves as "improved" on subjective measures of hoarding and cluttering behaviors at the completion of the program, and therapists working with the study participants rated 70% of the individuals as "improved." On objective measures of hoarding and cluttering behaviors, 40% of study participants had improved at the conclusion of the intervention (Steketee, Frost, Tolin, et al., 2010). These results represent greater improvements in subjective and objective measures of these behaviors compared to previous CBT

approaches. While encouraging, additional studies evaluating this intervention are needed to support these initial findings. It is currently unknown how well individuals who improved during the treatment period maintain these behavioral changes over longer periods of time. With further study, it may become clear what features of the multi-component model are the most essential to promoting lasting behavioral changes for hoarding and cluttering.

As with all interventions, there are advantages and disadvantages to be considered with CBT. The advantage of CBT-based interventions is that there are studies documenting the effectiveness of the approach for treating hoarding and cluttering behaviors, even if limited in some cases. The disadvantage or limitation of CBT is that the individual must be ready and motivated to participate in the therapy. In addition, the intervention must be conducted by a skilled, trained therapist, unlike a harm reduction approach, which can be conducted by anyone who has received some basic skills training, or motivational interviewing, which involves strategies that can be learned by a range of professionals or other interested parties.

Whether CBT is an appropriate intervention for your client will depend on several factors. Consider whether your client is highly motivated, is ready to work toward significant change in their behavior and living environment, has access to a skilled therapist and a good support team, and has the cognitive capacity to engage in this intensive therapeutic approach. If these elements are in place, then the modified, multi-component CBT model for treating hoarding and cluttering behaviors may be the best option for your client.

In the example of Mrs. B.W., she has said she does not feel comfortable talking about her belongings with a therapist at this time, but might in the future. In the meantime, she has made some progress clearing space in her living room and continues to brainstorm with you about ways to

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make finding things in her apartment easier. With the help of her daughter, she has unpacked some of her boxes and decided she no longer needs the business clothes she used to wear for work. At your suggestion, Mrs. B.W. agreed to donate these items to a local women's shelter where they will be used and appreciated by others.

Conclusion

There is no single intervention or treatment that will work best for all of the challenging situations created by hoarding and cluttering behaviors. The three approaches presented here, Harm Reduction, Motivational Interviewing, and Cognitive Behavioral Therapy are certainly not the only strategies that could be employed in these situations, but they are the ones most commonly discussed among clinicians and researchers working with older adults with these behaviors. Because older adults may be at greater risk for poor outcomes compared to younger adults, a harm reduction approach should be considered first in most cases in order to minimize the risks to their health and safety. Then depending on the situation and the individual's characteristics, other interventions such as motivational interviewing and CBT should be considered.

In my work with older adults with hoarding behaviors, they have shared with me additional interventions that have been helpful to them. These include joining support groups, reading books or watching documentaries on these behaviors, or developing a trusted friend or "clutter buddy" who is willing to provide occasional and ongoing support to them in a variety of ways. While it can be frustrating not to have clear guidelines for how to best approach clients with hoarding and cluttering behaviors, it is also a very exciting time where creative new interventions are being tried and successes are being shared. Research into new interventions for these behaviors in general, as well as

those targeted for older adults, is a new and growing area, and additional approaches are sure to be added over the next several years to our repertoire of "best practices."

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Home-Based Intervention for Elderly Hoarders: What Really Works?

By Christiana Bratiotis, PhD, MSW and Kimberlie J. Flowers, MSW

Summary

Hoarding in elders may cause threats to health, safety, and housing stability. There are significant challenges to engaging elders in treatment focused on reducing clutter by discarding possessions and limiting acquisitions. The current project describes a university-community partnership through which elder hoarding clients received home-based intervention. Project outcomes are presented and opportunities for future research are discussed.

Introduction

Hoarding is a mental health disorder that may become a risk to the physical health and safety of the person who hoards and their family, neighbors, and community. Many people are savers or collectors, but in the extreme, saving becomes a compulsion rather than a choice. According to Frost and Hartl (1996), "Compulsive hoarding is defined as: (1) the acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value; (2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and (3) significant distress or impairment in functioning caused by the hoarding" (p. 341). Hoarding may present a threat to personal health and safety by increasing risk of falls and prohibiting safe access to living spaces. Clutter may harbor and breed mold, bacteria, and dust, creating risk for infection and respiratory problems. Papers and other clutter on stoves and heaters present a fire risk. Many of these same issues can impact the community, especially fires and

insect and rodent infestation. An infestation of mice and cockroaches which begins in one apartment may quickly spread to neighbors and adjacent floors. Community health officials and public housing managers must balance the rights of the individual with their obligation to safeguard the public; circumstances may require eviction from housing or condemnation of a homeowner's property. This action often results in homelessness of the hoarder and extensive costs to the community to clear the apartment or property.

The prevalence of hoarding is estimated to be approximately 3-5% of the U.S. population (Samuels et al., 2008), and this rate seems to be greater among the elderly. A survey of 10 Manhattan social service agencies conducted by Weill Cornell Medical College in New York found that 10% of elderly social service clients exhibited hoarding behavior (Weill Cornell Medical College, n.d.). In Massachusetts, examination of reports to local Boards of Health indicated elders were the subject of 40% of all hoarding complaints (Frost, Steketee, & Williams, 2000). The issue of elder hoarding becomes more complicated when the living space is uninhabitable and the decision to remove or evict the elder is troubling to the housing manager, building inspector, or fire chief. Authorities are often reluctant to enforce eviction since this may result in sending the elder to a homeless shelter that is ill-equipped to deal with geriatric mental health issues.

Literature Review

Empirical study of hoarding among elders is limited and focuses

primarily on describing the behavior and incidence of hoarding in self-neglecting elders. Self-neglect, also referred to by some as Diogenes Syndrome, is described as a disorder which can include neglect of personal hygiene and personal care needs, domestic squalor, and hoarding of trash. The characteristic behavior of hoarding trash has been found to occur in over 70% of the self-neglect cases reported to public health authorities or adult protective services (MacMillan & Shaw, 1966; Frost, Steketee & Williams, 2000). Cases of hoarding among the elderly may go unacknowledged and unaddressed for years, until a health or safety crisis requires the need for emergency responders to enter the home. This emergency action often brings a dangerous clutter (and/or squalor situation) to light, initiating needed intervention. Community and legal pressure is sometimes a useful incentive to intervention. Many elders do not recognize a problem with their clutter and although family or neighbors are aware of the problem, they resist involvement because they do not know how to assist the elder hoarder (Franks, Lund, Poulton & Caserta, 2004; Greenberg, 1987). Community responses commonly do not address the underlying reasons for acquiring and saving. In some cases the home is condemned and the elder evicted, in other cases cleaning crews are hired to clear out the home. Discarding is done indiscriminately without the elder's input and without regard for the elder's feelings. More effective treatments protect the elder's right to self-determination and include more person-focused intervention to assist with understanding the reasons

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for hoarding as well as developing organizational and decision-making skills (Kim, Steketee & Frost, 2001; Lustbader, 1996).

Several case studies describe the behaviors and effects of hoarding (Franks, Lund, Poulton & Caserta, 2004; Greenberg, 1987). These studies are informative in describing: 1) behaviors such as lack of insight by the person who hoards, 2) excessive clutter and squalor that result in crisis intervention, and 3) limited effectiveness of non-therapeutic resolutions. For example, one person with hoarding was moved into a new condo when her home was uninhabitable. This elder boxed up trash from her home and moved it into her new condo and also acquired additional trash and decomposing food from dumpsters. This resulted in another clean out. Subsequent to that intervention, the elder was monitored by Adult Protective Services and her severe hoarding abated (Franks, Lund, Poulton & Caserta, 2004). The case studies highlight the effect of hoarding on both the individual and the community (Jackson, 1997; Lustbader, 1996; Pavlou & Lachs, 2006). Kim, Steketee and Frost (2001) found that more than 80% of elderly hoarders in their study (N=62) had a level of clutter that put them at serious risk for fire, falling, unsafe health conditions, and physical injury. For these elders, clutter significantly impacted their ability to move around their home and put them at-risk for inability to safely exit the home in case of emergency.

Many older adults who hoard exhibit the behavior in midlife or earlier. For some it may be related to a traumatic event or experience of loss. Although few studies have documented the relationship between traumatic events and hoarding behavior (Frost & Hartl, 1996), many people with hoarding cite life experiences that they relate to triggers for acquiring. Life events such as a difficult divorce, family estrangement,

and loss of a parent or spouse are cited as precursors to hoarding. In other studies, hoarding is associated with a psychiatric disorder like schizophrenia (Greenberg, Witzum & Levy, 1990) or obsessive compulsive disorder (Christensen and Greist, 2001). For still others hoarding is identified as a component of self-neglect or Diogenes Syndrome (Halliday, Banerjee, Philpot & MacDonald, 2000; Jackson, 1997; Pavlou & Lachs, 2006; Poythress, Burnett, Naik, Pickens & Dyer, 2006).

Many older adults who hoard exhibit the behavior in midlife or earlier. For some it may be related to a traumatic event or experience of loss. Life events such as a difficult divorce, family estrangement, and loss of a parent or spouse are cited as precursors to hoarding.

A small but growing number of studies address clinical interventions for hoarding. Steketee and Frost (2007) developed a specialized cognitive behavioral therapy (CBT) for hoarding. The CBT intervention focuses on building skills in the areas of decision-making, categorizing and de-cluttering. This treatment protocol relies on some level of internal motivation and client insight. Many elders however do not see the clutter as a problem and encouraging them to participate in CBT treatment can be difficult. Many of these elders

have been self-sufficient and isolated for years and are distrusting of any outsiders who approach them with offers to help resolve the problem. Therefore, a preliminary step of establishing a trusting therapeutic relationship is important to the success of elderly hoarding intervention (Cermele, Melendez-Pallitto & Pandina, 2001).

Harm reduction, an approach that emphasizes the reduction of negative consequences of high-risk behavior can be applied to hoarding (Thompkins and Hartl, 2009). Harm reduction interventions have historically been used to lower the risks associated with addictive behaviors such as drug and alcohol use and gambling (Marlatt, 1998). Using harm reduction with an elder who is unwilling to stop acquiring altogether or discard large number of possessions may help focus the intervention on a few immediate risks to harm and safety as the first step of a tiered intervention. Through use of motivation enhancement strategies and problem-solving, the elder is empowered to identify solutions that resolve the health and safety problems in a systematic way and at a pace that is tolerable (Bigler, 2005). The harm reduction approach, executed in a non-judgmental collaborative manner, serves as a foundation on which a trusting therapeutic relationship is established and specialized CBT for hoarding intervention is built.

Background

Elder Services of the Merrimack Valley, Inc., (ESMV) based in Lawrence Massachusetts, is a private non-profit agency. The ESMV mission is to provide programs and services to meet the diverse needs of older adults through home-based care, community services, and supportive living programs which maintain the dignity of human life by promoting self-determination and encouraging independence. Most of the programs and services are geared toward elders in the greatest economic and social need. The agency is a federally designated Area Agency on Aging and a state designated Aging Service

Access Point (ASAP), providing in home services to about 5,000 clients, of which 40% are minorities. Thirty-five years of experience have resulted in development of specialized programs geared to assist frail, indigent, and “hard-to-serve” elders, including those with mental health challenges. One troubling issue for ESMV was elders living in cluttered and often unsafe environments, at risk of losing their housing due to lease or public health violations.

Researchers at Boston University School of Social Work (BUSSW), Smith College, and Hartford Hospital Institute of Living developed and tested a 26-week specialized CBT for hoarding. This intervention includes assessment of the disorder and learning new skills for sorting, organizing, and discarding. The treatment addresses the psychological barriers to discarding, with the goal of enabling a person who hoards to understand the reasons that they compulsively acquire and have difficulty discarding (Steketee and Frost, 2007).

ESMV partnered with the BUSSW Hoarding Research Project to bring specialized CBT for hoarding intervention into the elder community. The large-scale clean-outs that ESMV once used as an intervention strategy did not work and often resulted in worse conditions in the home, coupled with angry, distrusting elders who refused all further social services. Using the specialized CBT intervention offered a solution that protects the rights and dignity of the hoarder while also facilitating clearing and organizing the home. A BUSSW clinician-researcher trained three clinicians at ESMV in the specialized therapeutic protocol. BUSSW also trained several non-clinical case managers and a resident service coordinator to assess the elder and the living space to determine if a home met intervention criteria. Once screened, the elder was provided the opportunity to voluntarily participate in the intervention.

ESMV utilized the Steketee and Frost (2007) CBT hoarding treatment and the training from BUSSW to

develop a modified intervention that specifically addressed some of the unique needs of the elder community served by ESMV. Hoarding referrals to ESMV are usually initiated by housing managers, health inspectors, or other public officials. Working with these authorities, the ESMV clinician developed a treatment plan to address the most immediate concerns and conditions in order to preserve tenancy. ESMV used a harm reduction approach to de-cluttering, engaging the elder to resolve the immediate problems as identified by the housing authority. This situation provided the motivation for the elder to engage with the clinician to address the imminent risk, and provided time to establish a therapeutic alliance that would facilitate longer term CBT intervention when the presenting problem was resolved.

Many of the elders seen by ESMV suffer from persistent mental illness, memory loss, physical illness, or disabilities that make it difficult to engage in de-cluttering. Regardless of the contributing factor, an intervention was usually necessary to discard possessions, sort and organize, and repair and decontaminate homes to make them habitable. All ESMV hoarding interventions were carried out working in partnership with the hoarder in their home.

Method

The following is a description of year one of the implementation of a specialized home-based hoarding intervention, combining a harm reduction approach with longer-term cognitive-behavioral therapy (Steketee & Frost, 2007). Participants included elders living in public housing and owner-occupied homes in the Merrimack Valley of Massachusetts.

Recruitment

Public housing managers inspect housing units annually and were therefore in a position to identify at-risk elders and refer them to ESMV. Managers were encouraged to refer all elders at risk of eviction or lease non-compliance due to excessive clutter. Elders living in privately

owned homes were referred by local boards of health, fire personnel, and councils on aging. The community referrals were originally made to ESMV Protective Services as elder at-risk reports. In total, 44 referrals were made to the program in the first year; 29 of these elders lived in subsidized housing and 15 lived in their own homes. All referred elders were contacted by the ESMV program and offered an opportunity to voluntarily participate in the program.

Description of Elder Clients

Elder clients who participated in the ESMV hoarding treatment ranged in age from 60 to 90 years old. Of the 26 total participants, 52% were female, 48% male. Fifty-two percent of the elder clients were never married. Forty-four percent of the elders reported a high school education; 32% college education. Greater than half of the participants (64%) reported one or more significant life losses. Forty-four percent of elder clients recognized that they saved more items than most other people and recognized that people in their lives were concerned about their clutter and acquiring. Paper and clothing were the most commonly saved items (72% of elder clients). Other items saved included: food, tools, and craft supplies. Many participants reported that they passively acquired object such as junk mail and food containers. The ESMV clinician noted that 64% of clients had difficulty making decisions about discarding items. Seventy-six percent of clients indicated a need to control their items, captured in statements such as, “She [housing manager] has no right to tell me what to do with my stuff—it’s mine.” Sixty-eight percent of clients self-reported experiencing symptoms of depressed and/or anxious mood.

Treatment Intervention

Upon agreement by the client, a home visit was conducted by a screener to assess whether a hoarding situation existed and to determine the capacity of the elder to engage in cognitive-behavioral treatment.

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Initial screening was performed by the resident service coordinator of the building or by ESMV interns trained in the screening tool. If the elder was deemed appropriate, the treatment protocol was explained and consent for participation was obtained. The elder was informed that the program was not related to the housing office or board of health and participation did not guarantee that no further action would be taken by authorities to elicit code compliance. If an elder was reluctant to participate but met criteria for inclusion in the program, a clinician did a follow-up home visit to explain the program further. During this second visit the clinician was often successful in gaining agreement of the individual to participate in the program.

After initial screening, 11 elders in subsidized housing were determined appropriate for the program and agreed to treatment. Of the remaining housing referrals, eight did not meet clinical criteria for hoarding and seven refused to be screened for the program. Two elders were eliminated from the study based on exclusionary criteria of untreated mental illness, and a third elder was determined to be too cognitively impaired to participate. All 15 elders living in privately owned homes were screened and accepted into the program; all agreed to participate.

After screening, additional hoarding-specific assessments were administered, including the Clutter Image Rating (Frost, Steketee, Tolin, & Renaud, 2006), Hoarding Rating Scale (Tolin, Frost & Steketee, 2010), and Saving Inventory- Revised (Frost, Steketee, & Grisham, 2004). These formal assessments supplemented information obtained by the clinician who conducted a hoarding interview (Steketee and Frost, 2007). The hoarding interview provided information about the elder client's family and personal history, information processing problems,

and thoughts and beliefs about their belongings. The clinician developed a hoarding model (Steketee & Frost, 2007) for each client based on the accumulated information. This model was the basis for each elder client's individualized treatment plan.

The ESMV clinician conducted weekly visits to the elder's home to provide hoarding treatment: each visit lasted approximately two hours. Tools and techniques that were most effective in the de-clutter process

Nearly half of the elder clients were able to develop discarding and organizational skills within four to six months and did not require on-going treatment. The remaining elders required on-going clinical intervention and, while they discarded items with clinician assistance, they were unable to discard on their own.

were interpersonal therapy through which the elder was able to discuss when their "collecting" started and the events that triggered it, development of rules for discarding, and organizational skills. The length of treatment was client specific. Nearly half of the elder clients (N=12) were able to develop discarding and organizational skills within four to six months and did not require on-going treatment. These participants received monthly check-ins by the clinician

for four months after the treatment ended. The remaining elders (N=14) required on-going clinical intervention and, while they discarded items with clinician assistance, they were unable to discard on their own. Most elders cited difficulty making decisions without the clinician's approval and inability to focus on sorting and organizing as two primary obstacles to progress in treatment. The ESMV clinician recorded client progress on a spreadsheet, charting changes in level of engagement and insight as well as progress in sorting and discarding.

Findings

The ESMV hoarding program continues to present. After the first year, the project was evaluated and interesting and important outcomes observed. Three components of initial engagement emerged as salient: 1) the importance of a trusting and caring therapeutic alliance between the clinician and elder, 2) clinician mirroring the language used by elder to describe their clutter, and 3) developing an understanding of how the elder relates to their clutter and views their hoarding problem. Most of the elders were initially isolated, withdrawn and untrusting. Many previously experienced large clean-outs ordered by housing managers and described these experiences as traumatizing. In most cases, two to three initial clinician visits were necessary to establish a rapport with the elder before broaching the hoarding program. A key aspect of the rapport-building was to assure the elder that the clinician was not there to throw away their objects and the elder was always in charge of the treatment process. Affording the elder this control and respect was necessary before proceeding with assessments or the hoarding interview. Adding the component of addressing the immediate health and safety risks as defined by the housing official facilitated cooperation.

When starting the treatment intervention, approximately half (52%) of the elder clients had the presence of squalor, in addition to hoarding. Squalid conditions included

the trash and rotting food. Because most participants were not willing to agree to discard large amounts of clutter, the ESMV clinician determined that the elder may be more willing to participate when provided with an opportunity to directly control their response to the issues charged by the authorities. When the issue of health and safety was discussed, elders were willing to consider making several significant changes.

As described earlier, the ESMV clinician applied a harm reduction approach to ameliorate health and safety issues. In several cases, the risks of living in clutter and squalor were sufficient to be considered life-threatening and even small incremental improvements were preferable to no change in the elder's living situation. Most elders agreed to work with the clinician to eliminate imminent risks identified by the housing manager or other authority. These changes included sorting through and discarding trash, identifying food items that were unfit for consumption, clearing pathways to allow adequate access to egress, moving clutter away from heating sources, and clearing access to bathrooms. Each of these steps was prioritized with the client and approached in turn, according to a plan approved by the housing authority. In some cases items were actually discarded. In other cases, clients worked on organizing items and storing them in less cluttered areas of the home. With all elder clients, treatment progress met with approval of housing/public health authorities, and no eviction proceedings were initiated against elders participating in the program.

Case Example:

When Joanne filed a tax abatement request at the town hall, local officials did not expect the public health issue they were about to uncover. A routine home tax assessment revealed a home filled with trash, newspapers, magazines, clothes, and many other items. Only a single narrow pathway led from the front door to the kitchen. The elder

homeowner admitted she had trouble throwing things away and things really got worse when her husband died ten years ago. Joanne was resentful that the authorities were requiring her to de-clutter. She was anxious and very reluctant to allow anyone to help.

With a harm-reduction strategy in mind, the Elder Services clinician met with Joanne twice at the Senior Center to establish a relationship and explain the assistance available. The clinician helped Joanne understand that town authorities were concerned about fire risk and health hazards, due to unrefrigerated food. The clinician explained that she could work with the elder to identify and clear out expired, old food items and organize and store other possessions to the satisfaction of the authorities. The clinician made sure to emphasize that the goal was to make the home safe and not to just get rid of her stuff.

Joanne agreed to allow the clinician into her home to resolve the safety risks. Through this immediate intervention, the elder and clinician reached an agreement with the Board of Health that allowed Joanne to live in her home while working on the hoarding problem. As the immediate health and safety concerns resolved, Joanne and the Elder Service clinician developed a trusting relationship. Joanne agreed to ongoing work with the clinician, using CBT techniques to eliminate more clutter and resist acquiring.

Joanne and the clinician eliminated most of the clutter in the kitchen and bathroom and engaged professionals to repair long-standing plumbing and structural problems. Joanne successfully maintains the cleared space. Work continues on the other rooms of the home during weekly visits.

Discussion and Future Directions

A majority of the elder clients lacked consistent awareness of their hoarding problem and the resulting problems and interference in activities of daily living. This fluctuation in awareness is a common characteristic of hoarding and can be a major

roadblock to intervention. The harm reduction approach was introduced in the early stages of the ESMV program when it became evident that many elders were not likely to make changes without incentive. Most of the elders were referred by housing or inspectional services and were facing eviction or other legal consequences if they did not improve the condition of their home. With specific code and legal violations outlined by the referral source, clinicians were able to address the issues of safety with the elder, explaining the need to make the home risk-free. The findings of this project suggest that while elderly hoarders may not agree to clear out large amounts of clutter, they are able to adhere to housing and public health codes. With an approach that clearly articulates specific violations and needed improvements, engaging the elder in developing and executing a prioritized action plan is achievable. Using the therapeutic alliance, the ESMV clinician was able to address the immediate health and safety risks and establish a relationship that facilitated continued intervention using cognitive-behavioral techniques to maintain the living area.

It is hoped that the findings of the present project promote future research regarding engagement of elder clients in hoarding treatment. Establishment of a strong therapeutic alliance, use of both a harm reduction model and specialized CBT for hoarding in home-based hoarding treatment for elders shows strong promise.

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Rooms of Shame: Senior Move Manager's Perspective on Hoarding

By Margit Novack, MCP, cSMM

Introduction

Senior Move Managers is a new industry of professionals who assist older adults and their families with the physical and emotional aspects of downsizing, relocating, or modifying their homes. Senior Move Management is represented by the National Association of Senior Move Managers (NASMM). The core values and principles of behavior for this new industry, as expressed in NASMM's Code of Ethics, include advocacy, confidentiality, and maximizing client's dignity and autonomy (www.nasmm.org).

In the context of their work with older adults, Senior Move Managers frequently encounter hoarding situations. Often, the interaction begins with a call, "You've probably never seen anything as bad as this." These "rooms of shame" are typically hidden behind closed doors and the move manager may be the first professional to encounter the problem.

This article describes typical scenarios for Senior Move Management involvement with hoarders and techniques that have been successful in reducing or eliminating hoarding. The purpose of this article is to familiarize Geriatric Care Managers with Senior Move Manager capabilities so they will understand how best to partner with these professionals in hoarding situations.

Working with Elderly Hoarders

Since most Senior Move Managers work primarily or exclusively with seniors, their typical hoarding client is an elderly individual who has accumulated possessions for decades. Although circumstances vary with each client, hoarding behavior presents a common set of risk factors for elders, including:

1. Increased risk of falls

As the individual's balance and mobility decrease, floors covered with debris and lack of adequate pathways around furniture creates significant risk factors for falls.

2. Chronic conditions exacerbated

Medication compliance is hampered by the mounds of clutter; pulmonary conditions are made worse by the dust and mold; and home-based services cannot be delivered due to unsafe conditions.

3. Increased social isolation

Due to embarrassment or fear of discovery, many hoarders are reluctant to allow people into their home. This reluctance, combined with decreased mobility (lack of transportation, difficulty walking, and inability to drive) reduces social opportunities and increases the hoarder's isolation.

Using "things" to fill needs or to compensate for losses is a common theme in hoarding. For example, after his retirement, a physician begins donating to over a thousand charities. Having lost the prestige of his profession, the physician's donations make him feel important, but over time, the mail fills his home and becomes overwhelming. Eventually, he stops opening the mail and the papers take over his space.

For the isolated older adult, the human interaction involved in the purchasing process can fulfill deep emotional needs. In the words of one hoarder, "I never learned to drive and I can't get around much anymore. I order lots of things over the phone, and they get delivered by UPS. The UPS man is my friend, and I look forward to seeing him every day. If I stopped ordering things, I would be lonely."

Ironically, the need for human interaction can be a motivating factor

for decluttering as well. An isolated hoarder who enjoys the company of the Senior Move Manager may agree to dispose of items in order to keep the Senior Move Manager coming back. The Senior Move Manager or the GCM can use the development of a trusting relationship as a means to promote change in the hoarder's life.

Types of Hoarders

Hoarding situations encountered by Senior Move Managers in the general community are diverse. Initial contact is typically by a family member or by the hoarding individual himself. Additional sources of referrals include attorneys, trust officers, Geriatric Care Managers, home-based service providers and social service agencies. Sometimes the project involves clearing out a home where the hoarding individual is no longer present. More often Senior Move Managers are called in to work directly with the hoarding individual.

Senior Move Managers are typically contacted for help in implementing a move from one home to another, but when hoarding is a factor, the situation becomes much more complex.

Based on our experience in the field, Senior Move Managers see three distinct types of hoarders:

The Proud Hoarder

The proud hoarder sees no problem with her living situation, does not want help decluttering, and limits the move manager's intervention strictly to moving belongings from one place to another. The proud hoarder is often in denial about the seriousness of the cluttering situation. In the words of one client, "I need help moving. In the hallway there are about 90 cartons. There are 60 bins in the living room,

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and 40 more in my bedroom. I'll get rid of some, but most of my things are going with me. Last year I rented a storage unit and put my sofa and chairs in it to make space for my stuff. That's why there is no where to sit. I am moving to a smaller apartment so I can afford a second storage unit...."

The Embarrassed Hoarder

The embarrassed hoarder knows that her living situation is not normal and is humiliated by her inability to change her living situation. She lived a more "normal" lifestyle at some point in the past, and desperately wants to do so now, if only she could only get control over her cluttering. Usually a trigger – perhaps the death of a spouse, retirement, or depression – created emotional needs that are filled by hoarding behavior. Although decluttering is a struggle, the embarrassed hoarder is often receptive to help from professionals. While ongoing intervention to maintain the decluttered environment may be necessary, the embarrassed hoarder has real potential for significant improvement in her living environment. In the words of one client, "I heard about you from someone in my depression support group. My knees are bad and I live in a third story walk-up. If I could clean-up my apartment, I could move to a first floor apartment and life would be easier."

The Accidental Hoarder

The accidental hoarder is someone without a long history of hoarding, but circumstances such as changes in physical and/or mental status, or care giving responsibilities that are all-consuming, have made her less able to deal with the piles that are slowly building at home. The more clutter that accumulates, the more overwhelmed the hoarder becomes. Like the embarrassed hoarder, the accidental hoarder is often receptive to help from professionals. However, the same barriers that contributed to the clutter in the first place make it

harder for the accidental hoarder to make lasting changes. The accidental hoarder will often need to accept ongoing support to maintain any lasting gains.

Hoarding situations in Senior Living Residences

Increasingly, Senior Move Managers are contacted by staff at senior living residences regarding difficult hoarding situations. In these scenarios, the intervention is typically initiated by the community, not the resident. Sometimes an apartment is cluttered because the resident was unable or refused to downsize from a much larger home. The more cluttered the apartment is, the more overwhelmed the resident becomes, and the clutter grows. Clutter also occurs when the elder's physical and mental status deteriorates and she is no longer able to maintain the upkeep of her apartment.

Regardless of the cause, the community's interest is usually in protecting both public and personal safety. When the apartment is pest-infested, the Senior Move Manager's goal is typically to clean out enough debris so the residence can be treated for pests. When the intervention is to improve resident safety, the Senior Move Manager's goal usually corresponds to specific requirements set by the facility. For example, an administrator at an assisted living facility tells a resident who hoards, "The home health agency will not provide services in your apartment unless there are twenty-four inch paths for circulation" or "When you return home, you will be using a walker, so there need to be thirty-inch aisles for you to safely navigate." By accepting assistance to eliminate or even reduce clutter, the resident can avoid possible eviction and remain in her apartment independently and safely for a considerable period of time.

Senior Move Managers and Ethical Issues in Hoarding

In their work with elderly hoarders, Senior Move Managers

encounter many of the same ethical issues as Geriatric Care Managers, especially regarding when and how much to intervene. Issues such as evaluating the competency of a hoarder, balancing autonomy with safety, and defining success in working with elderly hoarders, are just some of the challenges that we face in working with these clients.

Case example:

A Senior Move Manager receives a call from Dr. M, an elderly dentist who said he was considering a move to a retirement community. On the first home visit, the Senior Move Manager observes that every room in the five-bedroom house is piled shoulder high, with only narrow aisles for circulation. The kitchen sink, stove, and refrigerator cannot be seen behind the debris. There is no furniture that is free of clutter. Dr. M sleeps on a cot in the basement and his food is delivered from Meals on Wheels. He appears well-groomed and content with his situation, although he admits that his friends no longer visit him at home and that possessions have taken the place of human connections in his life. He talks about the Collyer brothers, famous hoarders who died in 1947 when they were buried by piles of debris, and wonders if his home is as bad as theirs. He acknowledges that his environment poses a risk, and that he may fall or be unable to call for help. While he hopes this won't happen, Dr. M tells the Senior Move Manager that it's a risk he is willing to assume and he ultimately rejects assistance with decluttering. As an incentive to Dr. M, the Senior Move Manager offers to provide initial services for free. Despite this generous offer, Dr. M still refuses to accept help.

While Dr. M is clearly placing himself at risk, his mental and financial capacity is high. He is independent in all activities of daily living, has adequate finances to support his lifestyle, and he understands the risks his hoarding poses. Using the Risk/Capacity paradigm (Soniati, B., & Malady-Micklos, M. (2010). *Empowering Social Workers for Practice with Vulnerable Older Adults*. Washington

D.C.:NASW Press.), the Senior Move Manager concludes it is inappropriate to intervene at this time. Unable to convince Dr. M to accept help, the Senior Move Manager notifies a local social service agency so he can be monitored, should the situation change.

Another ethical issue in working with hoarders is how to define success and how far to push the hoarder into “clearing out” the space. In theory, success implies reducing or eliminating all clutter and preventing recluttering of the space. However, even if only modest gains can be made through reorganizing and relocating items, this can be considered success as well. For example, if a living room and bedroom can be made usable, even though a second bedroom continues to be unusable, the goal of increased safety will have been achieved.

Helpful techniques for working with hoarders

Hoarding situations are complex and there is no silver bullet for resolving the behaviors associated with hoarding. Based on our experience in Senior Move Management, we have found certain techniques that are helpful to remember when working with hoarders.

1. **Be non-judgmental:** Although this may sound obvious, not all helping professionals are cut out to work with hoarders. Hoarders are highly sensitive to nonverbal cues. If the hoarder feels judged or disapproved of, the ability to achieve change is dramatically reduced. As a professional, if you find your client’s environment disturbing, it is likely you will communicate this to the client. It is important to recognize your limitations in working with these clients.
2. **Listen closely to the client:** While there may be many agencies and/or family members who want immediate changes made in the hoarder’s living situation, resist the temptation to act too quickly. Be sure to ask the hoarding client

what changes *they* want to see happen, what *their* goals and priorities are, and what bothers *them* the most about their current living environment. For example, you may feel that decluttering an unusable kitchen is the most important place to start, but the client may tell you that the clutter in the second floor bedroom bothers them the most. By listening closely and “starting where the client is at,” the professional increases the likelihood of a successful intervention.

3. **Acknowledge the difficulty:** Most people don’t understand the stress involved when hoarders are asked to part with belongings. The professional needs to listen closely and empathize with the hoarder’s struggles. Don’t offer false hope that change will be quick or easy to achieve.
4. **Opt for low-hanging fruit:** When evaluating where to begin working with the hoarder, start with areas of the home that are less complex so the client can experience accomplishment as quickly as possible. This may help the client feel hopeful and more optimistic.
5. **Praise frequently:** Provide positive reinforcement. Hoarders have felt unsuccessful at handling their environment for years. Positive feedback builds self-esteem. The praise should be honest and not exaggerated.
6. **Group similar items together:** Many hoarders have similar items scattered throughout their home but are unaware of these patterns due to the sheer volume of clutter. Gathering together similar items enables the hoarder see what they actually have and to begin the process of categorizing and organizing their belongings. The hoarder may not agree to part with the items, but pointing out these patterns may decrease the likelihood of continuing to hoard that type of item.
7. **Provide creative disposal options:** Hoarders are major recyclers. Most hoarders believe that virtually every item has a use, and that “somewhere out there” is a person who needs or can use the particular item saved by the hoarder. One hoarder collected children’s toys and would spend each weekend giving toys away to children in poor neighborhoods. Unfortunately, the hoarder was collecting far more toys than she could ever hope to give away. Maintaining a list of charitable agencies and providing donation options that correspond with the client’s values may encourage them to part with items.
8. **Remove items agreed upon immediately:** Hoarders are known to have “removal remorse.” Once the client agrees to part with something, get it out of the house as quickly as possible.
9. **Provide voluntary homework:** Offer clients focused tasks that they can do between sessions. For example, if you have gathered together all the client’s purses and sorted them by color, ask the client to select two purses from each color to keep. Reinforce that the assignment is optional, so clients feel proud if they achieve it, and do not feel guilty if they can’t complete the task.
10. **Contact between sessions:** Use occasional phone calls between sessions to reinforce accomplishments, acknowledge the client’s feelings and communicate that you care.

Conclusion

Senior Move Managers encounter a significant number of hoarding situations, and as a result, many have developed expertise in working with elderly hoarders. To increase competency with hoarders, many Senior Move Managers pursue a variety of educational opportunities, such as sessions offered at the NASMM annual conference, teleclasses courses offered by the National Study Group on Chronic Disorganization (NSGCD – www.nsgcd.org) and online courses offered through eSMMART (www.esmmart.com).

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Rooms of Shame: Senior Move Manager's Perspective on Hoarding

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com). Hoarding is a frequent topic on NASMM discussion threads. To promote a common reference point for communicating about hoarders, NASMM has posted the NSGCD Hoarding Clutter Scale on their blog (<http://nasmm.wordpress.com/>).

Senior Move Managers represent a knowledgeable, professional resource with whom Geriatric Care Managers can partner in working with elderly hoarders. They are well-equipped to handle the labor intensive, sometimes time-critical requirements of working with hoarders. Since they specialize in late life transitions where downsizing is the norm, Senior Move Managers have a variety of proven resources for disposal or

donation of belongings. Since the hourly rate of most Senior Move Managers is considerably less than the rate charged by Geriatric Care Managers, collaborating with Senior Move Managers in hoarding situations minimizes costs to the client.

To locate qualified Senior Move Managers in your area, visit NASMM at www.nasmm.org and select **Find a Senior Move Manager**. Be certain to ask what kind of experience the Senior Move Manager has with hoarders, since some Move Managers prefer not to work with this population. All NASMM members are insured and agree to abide by the NASMM Code of Ethics.

Margit Novack, MCP, is President and CEO of Moving Solutions® and eSM MART™ (www.movingsolutions.com). Since 1996 Moving Solutions has helped thousands of people in the Delaware Valley with the physical and emotional aspects of downsizing and moving. Margit is a pioneer in the Senior Move Management industry and is Founding President of the National Association of Senior Move Manager (NASMM). In 2007 Margit founded eSM MART, a web-based training platform to professionalize the Senior Move Management industry that awards a Certificate in Senior Move Management (eSMM). Margit is a sought-after speaker on hoarding and on late-life transition issues. She has graduate and undergraduate degrees from the University of Pennsylvania.

Meet Clark

I buried my wife yesterday. She was a hoarder. I loved her and I took care of her, especially the past few years when she was bedridden. After fifty years of marriage, her dying words to me were not "I love you." They were "Don't touch my stuff."

I was surrounded by her stuff for years. I want to get rid of it and reclaim my life.

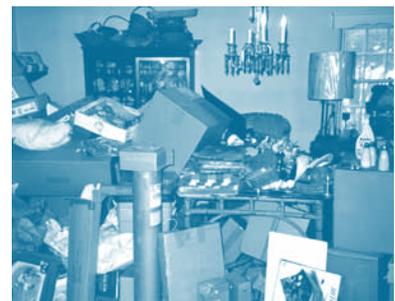
This is Clark's bedroom; it is neat and orderly.

This is the living room and dining room in the home Clark shared with his wife.

This is the bedroom of Clark's wife.

It wasn't always this bad. It grew gradually, and kept on growing, like an addiction. When did it start? When we were younger, we had company, we did things... then her stuff took over our lives. How did I let this happen? What could I have done that might have made things different?

Clark cleared out much of his wife's clutter from his home. Three years later, like a number of elderly, lonely widowers, Clark took his own life.



Nice Children Stolen From Car

By Barbara Allen

The Vignettes:

About Nice Children Stolen from Car: When my sister Cindy and I were little girls, we couldn't imagine that we could have actually been born into such chaos. There had to be another explanation! We came up with a number of different theories for our erroneous placement in this family, which we mentally envisioned as headlines in a newspaper: Adopted Children Find Real Parents, Wrong Babies Brought Home from Hospital, and Nice Children Stolen from Car while Parents Inside Store Buying Milk. The following vignettes are excerpted from Barbara Allen's memoir and are written from the perspective of a 14-year old.

The Collector:

Many hoarders refer to themselves as "collectors," my father included.

Our father calls himself "a collector." He makes this claim with considerable pride, as if our house were filled with prehistoric pottery and American Indian artifacts, instead of dented coffee cans and years-old newspapers.

While there is nothing museum-worthy about the contents of our house, it is nevertheless a sight to behold. Our father may call himself a collector, but he doesn't really collect things: he hoards them. Precarious piles, many nearly shoulder-high, representing years of accumulation, crowd each room; to make our way through the house we must use narrow paths that are barely discernible between the stacks of stuff.

Our father does not throw anything away. No matter if it is a Sears catalog from which he will never order or a used pizza box; once it has entered our house, it can never leave.

No one else is allowed to throw anything away either. My sister Cindy and I try one day. We gather together a useless jumble of toys: headless dolls, trucks without wheels, broken pieces of plastic that once belonged to something, but no one remembers what, and bundle them into a cardboard box. We cart the box outside to leave for the garbage men; our father carts it back in.

Mounds of clutter press up against the baseboard heaters in our bedroom; Cindy shows me a tattered piece of newspaper, the edges charred and brown. She doesn't sleep well anymore, she tells me. She's afraid we will die in a fire that starts next to our bed.

"It's all good stuff," he says.

There is so much "good stuff" that some of the piles topple over, blocking the hallway, clogging the stairs, destroying the paths we use to get from room to room. Mounds of clutter press up against the baseboard heaters in our bedroom; Cindy shows me a tattered piece of newspaper, the edges charred and brown. She doesn't sleep well anymore, she tells me. She's afraid we will die in a fire that starts next to our bed.

There is so much "good stuff" that we can't have friends visit. They might not understand the value of the rancid grease which lines the top of the stove in open baby food jars, or in the paper towers of unopened mail that arrived months ago. Our father fears visitors might blab our personal business to the neighborhood and beyond, and that, he tells us, is wrong.

"No one should know anything about what goes on inside our house. What happens inside," he says, "stays inside."

Along with the rest of the garbage.

Friend for Life

Like many children of compulsive hoarders, we were not allowed to have friends visit. Our house was kept a big, dark secret from all but closest family. My friend Rose changed that. In this vignette, you'll see why I still consider her my Friend for Life.

No one is allowed inside our house; that's our father's rule. Some exceptions are made, of course, for grandparents and a few close family members, but anyone else who shows up at the door is out of luck. They have to wait on the front walk until whomever they are visiting comes outside to greet them.

There are a lot of rules at our house that we kids would like to break, but this isn't one of them. We are desperately afraid that if the few friends we have find out how we really live, if they see the towering piles of clutter and dirt, it won't be long before we have no friends at all. Our father's ban on visitors prevents this from happening, so we are more than happy to go along with it.

My best friend Rose, however, is not a fan of the front walk waiting

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Nice Children Stolen From Car

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policy. She is also not the type of girl to put up with anything she doesn't like for very long. So one day, when she comes to our house, she not only doesn't wait on the walk, she doesn't even ring the doorbell; she simply opens the front door and walks right in.

My mother and I are in the disaster we call a living room when Rose makes her unexpected entrance. No one has ever just come into our house before, and we are so surprised by her presence that, for a few seconds, we stand paralyzed and speechless. I glance nervously at my mother, wondering what she will do, but she seems uncertain and confused by this turn of events.

"Hello," Rose says cheerfully. She is looking with great interest at the mountains of debris all around her. I want to run up and cover her eyes before she can see anything else.

"Hello," my mother answers, and then, something weird happens. It's as if a spell has been broken or some kind of barrier has been crossed. Rose is inside our house and there is nothing we can do about it. My mother shrugs. "Would you like some coffee?"

"Sure," Rose says, and my mother turns to lead the way into the kitchen.

The kitchen! Oh, God, not the kitchen! I feel a surge of panic; of all the rooms in our house, the kitchen is the worst. That's where our three unhousebroken dogs live; a large piece of plywood propped in front of the kitchen entrance keeps them from escaping and possibly messing up my father's junk piles. My mother now casually slides this board aside, as if it is perfectly normal, something everyone has blocking their kitchen, so that we can enter.

I turn to Rose. "Don't we have to be somewhere? Like right away?"

"No," she says, carefully sidestepping a puddle of dog urine as she follows my mother into the kitchen. She sits down at the table, pushing aside several dirty dishes and

empty cereal boxes to make room for the coffee cup my mother is filling for her. A dog nuzzles her ankle.

My mother reaches across me to hand Rose her coffee. To my dismay, I notice a small island of grease floating on the surface of the liquid; I see Rose hesitate briefly before she puts the cup to her lips. She looks at me, then smiles and takes a brave sip.

I watch in disbelief as Rose finishes her coffee. My mother offers her another cup, but she declines politely, saying that she and I have to get going. We say our good byes and, to my great relief, we leave.

It's hard living the way we do. That's why, no matter how bad each day is I try to find at least one good thing about it. I call this "pulling the happy out." Other people might think of it as "looking on the bright side," but our life doesn't often seem to have much of a bright side.

"Whew," says Rose, looking back at the house once we are outside. "That was really something."

But I don't want to talk about the house.

"You drank it," I say, admiringly. She probably doesn't realize it, but this simple act has made her my friend for life. "You drank the coffee."

"Well," she admits, "I had a little problem when I saw that floating scum. But then I reminded myself that you drink stuff like that everyday."

She smiles at me. "And you aren't dead yet."

Pull the Happy Out

Some hoarders are "clean" hoarders. They have an overabundance of stuff, but it is (more or less) organized. My father was a "dirty" hoarder. Not only did he have too much clutter, but our house was filthy. No one was allowed to clean, for fear they might disturb something in his piles which filled each room. He also put strict limitations on our bathing and hair washing under the pretense of "saving water." In addition, he was a borderline animal hoarder; our house was filled with unhousebroken dogs, cats, sometimes birds... and almost always, fleas. Living with my hoarder father (and enabler mother) required having a strategy to just make it through the day. Sometimes it worked better than others.

It's hard living the way we do. That's why, no matter how bad each day is I try to find at least one good thing about it. I call this "pulling the happy out." Other people might think of it as "looking on the bright side," but our life doesn't often seem to have much of a bright side. Sometimes the happy might be a meal that our mother finally doesn't burn or a morning when our father doesn't yell too much. There are other times when the only happy the day holds is the way the sun is shining. But whatever the happy is, I find it, pull it out, and hold onto it for dear life, trying to make it through just one more day until I am finally old enough to move out and leave this place forever.

As the days go by, it gets harder and harder to pull the happy out. I worry that maybe I won't make it, maybe before I turn eighteen I will die in that fire that Cindy always talks about, the one she fears will start in all this clutter. Or perhaps I will develop a serious illness and the symptoms will go unobserved by our mother, too absorbed in her soap operas to notice. Or our father will pound my head against the wall next time, instead of the cat's.

The hardest time to pull the happy out is during one of our regular flea infestations. We have dogs and cats

and dirt, so of course, we have fleas, sometimes worse than others. I hate a lot about the way we live, but the fleas are what I hate most. I can't stand the way they cluster on my socks and cling to the hems of my pants. Even though I carefully brush off my clothes before I leave the house, sometimes I even see a flea on myself at school, hopping cheerfully onto my bare arm during class. I pluck it off quickly, before anyone else notices, and ruthlessly pinch it to death between my fingernails.

The fleas seem to be everywhere. I find them floating in my milk and in my weekly bath water. I even hear them at night, snapping and popping as they leap with abandon through the piles scattered everywhere in our house.

Despite the fleas, I still struggle to pull the happy out: I get a good grade on a paper at school, Cindy and I share a funny joke at the bus stop, we have spaghetti instead of shepherd's pie one week.

Then, one morning, I can't do it. It is the day of our school spring concert and students are supposed to wear their nicest clothes for the performance. Most of my clothes

aren't very nice, but I find a dress that will probably be okay and a pair of pantyhose without any runs; it's a midweek concert, so I am hoping my hair doesn't look too bad yet. I am about to leave the house for the bus stop, when I happen to glance down at my legs. They are completely covered with fleas. That's when it happens. I flip out. I start hitting my legs, slapping the fleas, shrieking in a voice I don't even recognize as my own:

"They're all over me! They're all over me!"

I can't stop. My slapping gets faster and crazier, my voice gets higher and louder. For the first time in my life, I realize that I have been holding on, holding on by just a thread, and now I am in danger, real danger, of letting go. I am not going to die in a fire, or be killed by my father; I am going to lose my mind instead. I am going to go crazy before I can ever leave this stupid house.

"Stop it!" My mother's voice cuts through my flailing and screeching. "Stop it!" she says again. "What's wrong with you?"

What's wrong with me? Her words work like the slap that cures hysterical

people in the movies. I am standing here, covered with fleas, and *she* wants to know what's wrong with *me*?

My agitation subsides as a righteous anger flares up in its place. I stop hitting my legs, stop shrieking, and with a shaky breath, pull myself together. I pick up my books, which have been flung aside during my assault on the fleas, and leave the house, slamming the door behind me.

There is *nothing* wrong with *me*.

Barbara Allen has been a freelance writer for the past 20 years. About two years ago, she decided to turn her attention to the chronicling of her childhood with a parent who was a compulsive hoarder. The result is her memoir, *Nice Children Stolen from Car*, a series of autobiographical vignettes written from the perspective of a fourteen year old. She shares some of these stories at her blog, www.nicechildrenstolenfromcar.blogspot.com.

Barbara currently works as a Nurse Liaison for Marist Hill Nursing and Rehabilitation Center in Waltham, MA, and lives with her husband and teenage son in Framingham.



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