Multidisciplinary Team Perspectives on Older Adult Hoarding and Mental Illness

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This qualitative study examined multidisciplinary team members’ perspectives of their involvement in older adult hoarding cases. Fifteen informants, as representatives of four hoarding teams, described cases in which teams did or did not work well together. Specifically, informants described their (a) team characteristics, (b) awareness of hoarding as a mental health illness, (c) barriers to providing mental health services for older adults who hoard, and (d) components of successful teamwork within the team and with the older adult as hoarder. Implications include research to better guide interventions, team training to develop common perspectives, and policy development that supports mental health representation on teams and in-home mental health treatment.

KEYWORDS hoarding, mental health services, multidisciplinary team, older adult
INTRODUCTION

Hoarding, characterized as animal and/or inanimate object hoarding, can have debilitating consequences for older adults who hoard, as well as for their families and communities. Social services and other agencies often expend considerable efforts in addressing the public health and safety problems that result from hoarding. Furthermore, many professionals are increasingly recognizing the need for a multifaceted response to address the diverse, social, environmental, familial, and personal components of hoarding. Because of the complex nature of hoarding and the diverse agencies needed to address a single hoarding case, many believe that a multidisciplinary approach (e.g., using task forces or teams) is needed and may be the only successful response to hoarding (Abramson, 2005; Franks, Lund, & Poulton, 2004; Frost, Steketee, & Williams, 2000; Patronek, Loar, & Nathanson, 2006; Steketee, Frost, & Kim, 2001).

A multidisciplinary approach to hoarding requires the involvement of a variety of public and private agencies (e.g., adult protective services [APS]; public housing authorities; area agencies on aging [AAA]; mental health professionals; law enforcement officers; fire, public health and code enforcement departments; home health agencies; animal control agencies; veterinarians; health care providers; public guardians; city utility companies and community leaders) representing human, animal, health, legal, and environmental concerns (Abramson, 2005; Anetzberger et al., 2000; Dyer & Prati, 2006; Patronek et al., 2006; Poythress, Burnett, Naik, Pickens, & Dyer, 2006; Teaster, Nerenberg, & Stansbury, 2003). In particular, mental health professionals are described as important members of a multidisciplinary approach and can contribute to the successful eradication of hoarding behavior, which if not addressed, will likely reoccur. Unfortunately, it appears difficult if not impossible to provide linkages between mental health providers and older adults as hoarders. For example, in spite of increasing professional awareness that those who hoard could benefit from mental health treatment, mental health services are not readily available due to funding limitations and a concomitant lack of mental health providers who have been specifically trained to address hoarding issues. The purpose of this qualitative study was to examine multidisciplinary team perspectives on their involvement in older adult hoarding cases. Fifteen informants, as members of four hoarding teams and representing multiple agencies (e.g., APS, mental health services, and animal control), were specifically asked to describe cases in which their team did or did not work well together to resolve a case. In doing so, all informants described (a) their team’s characteristics (e.g., team composition, and processes for working together); (b) the need for team members’ increased awareness of hoarding as a mental illness; and (c) barriers to and components of successful teamwork to address hoarding cases.
LITERATURE REVIEW

The Relationship Between Hoarding and Mental Illness: The Problem of Diagnosis

This literature review addresses the relationship between hoarding and mental illness, hoarding interventions, and barriers to obtaining mental health services for older adults as hoarders. Because multidisciplinary teams are engaged with older adults who hoard possessions as well as animals, this literature review will define both components of hoarding. Hoarding of possessions has been defined as a debilitating disorder characterized “by a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose” (Frost et al., 2000, p. 176). Patronek and Nathanson define animal hoarding as “failure to provide minimal standards of care for animals; lack of insight about that failure; denial of the consequences of that failure; coupled with obsessive attempts to maintain and even increase the number of animals in the face of these failures and deteriorating conditions” (2009, pp. 274–275).

Professional writers continue to debate whether or not hoarding is a symptom of obsessive compulsive disorder (OCD) or if hoarding is its own diagnosis (Abramowitz, Wheaton, & Storch, 2008; Pertusa et al., 2008). In the midst this debate, and often cited by its interlocutors, researchers from many fields have published studies that investigate the relationship between hoarding and various etiologies, such as brain function and impairment (Anderson, Damasio, & Damasio, 2005; Grisham, Brown, Savage, Steketee, & Barlow, 2007), genetics (Alonso et al., 2008; Mathews et al., 2007; Samuels et al., 2007), gender differences (Patronek & Nathanson, 2009; Samuels et al., 2007), and traumatic life events (Cromer, Schmidt, & Murphy, 2007). Clearly, our collective knowledge of hoarding phenomenology and etiology is expanding rapidly, and new conclusions are being made continuously; however, this also leaves the field as of yet without definitive statements on what hoarding is, what exactly causes it and, as is discussed below, how to treat it.

Hoarding Interventions

Although cognitive behavioral treatment (CBT) and pharmacological interventions have been used to treat hoarding behaviors, these treatments have demonstrated limited success, are intensive, and may be cost prohibitive (e.g., 26 sessions over 7 to 12 months; Tolin, Frost, & Steketee, 2007). Furthermore, even less is known about hoarding behaviors among older adults. For example, in a study on older adult hoarders receiving various interventions, 43% of cases did not improve, 15% worsened, 8% improved incrementally only to relapse, and overall only 15% sustained gains, leading the authors to conclude that with the older adult population,
“most intervention efforts appeared ineffective” (Steketee et al., 2001, p. 182). Frost and others concluded that what is truly known about treating hoarding is that no intervention has proven consistently effective, with successful treatment being a rarity (Frost, Steketee, & Greene, 2003).

One promising intervention strategy that communities have gradually adopted is a hoarding task force approach. Hoarding is multifaceted in the problems it can cause for an older adult hoarder—which can range from personal health concerns to destruction of property—and thus diverse agencies are needed to address a single hoarding case. As noted earlier, many professionals believe that a multidisciplinary approach (e.g., using task forces or teams consisting of representatives from various agencies such as mental health, AAA, law enforcement, APS, and animal control) is needed and may be the only successful response to hoarding (Abramson, 2005; Dyer & Prati, 2006; Franks et al., 2004; Patronek et al., 2006; Poythress et al., 2006; Steketee et al., 2001; Teaster et al., 2003). However, in spite of the fact that multidisciplinary hoarding teams are being organized in local communities, virtually no systematic research has examined a multidisciplinary approach to hoarding, let alone the types of hoarding cases addressed by these task forces or teams. Nearly all professional writings on multidisciplinary hoarding teams are conceptual in nature (e.g., explaining how to successfully develop a multidisciplinary hoarding team within a community).

Barriers to Service

The treatment of older adult hoarders is subject to similar barriers and challenges that older adults with mental health needs in general face. Factors such as too few geriatric mental health providers (Bartels, 2004), difficulties in Medicare and Medicaid reimbursement for mental health treatment (President’s New Freedom Commission on Mental Health, 2002), lack of accessibility (USDHHS, 1999), and older adults’ stigma about obtaining mental health services (Sirey, 2001) have all been cited as barriers and challenges for older adults with mental health needs. Despite these barriers, Robb, Haley, Becker, Polivka, and Chwa (2003) found that older adults generally have better attitudes toward receiving mental health services than younger adults. Furthermore, Bartels and others (2003) found empirical support for the effectiveness of multidisciplinary geriatric mental health intervention teams in overcoming the traditional barriers to mental health treatment, a finding supportive of the use of hoarding task forces or teams to intervene with older adult hoarders.

In summary, professional writings put forth differing views of hoarding and its relationship to mental illness. Research studies designed to intervene in hoarding behaviors have been minimally successful, and almost no research studies have examined the use of multidisciplinary teams in addressing hoarding behavior. Finally, multiple barriers (e.g., agency constraints,
older adults’ attitudes) exist for older adults as hoarders in obtaining mental health services. Consequently, this study examined the use of hoarding teams in working with older adults as hoarders. Every team member interviewed discussed the mental health needs and barriers to providing mental health services for older adults as hoarders. Research questions included the following:

1. How do hoarding teams view the phenomenon of hoarding?
2. How do hoarding teams work together to address hoarding cases?
3. How do hoarding teams address the mental health needs of hoarders?

METHODS

This qualitative research study, approved by the Human Subjects Committee, University of Kansas, examined multidisciplinary team members’ collaborative work on older adult hoarding cases. Study informants included team members from four geographic regions in Kansas (i.e., three urban, one rural) who represented various agencies. Because minimal systematic research has been conducted on multidisciplinary teams’ involvement in addressing older adult hoarding cases, a qualitative design, based in naturalistic inquiry, lent itself well to the development of ideas, major themes, conclusions, and grounded theory that emerged from an analysis of the interview data.

Two key concepts are delineated for the purpose of this study. A hoarding multidisciplinary team member is defined as any agency-based worker (e.g., mental health provider, animal control officer, public health nurse, APS social worker, AAA case manager, and law enforcement officer) who provides services (e.g., screening, assessment and/or treatment) to older adults who exhibit hoarding behaviors. Team members function as a member of an organized or informally based hoarding task force or team. An older adult with hoarding behavior is a person age 60 or older who has been identified by a team member as hoarding inanimate objects and/or animals.

Recruitment involved identifying members of organized and informal hoarding multidisciplinary teams. A consultant panel, organized by the researcher, and consisting of one graduate social welfare student specializing in gerontology, one social work faculty member with expertise in ethics, and one gerontological program manager, assisted in recruitment. For example, one consultant panel member provided a list of members on two existing hoarding task forces and one informally organized hoarding team. Another panel member provided information about a newly formed fourth hoarding task force, and its members also were included for recruitment. Consequently, study participants were recruited from these four teams (i.e.,
two previously existing task forces located in urban environments, one informally organized team located in a rural environment, and a team located in an urban environment that was formed at the beginning of the study). The consultant panel also provided guidance throughout the design process (e.g., pilot-tested the tentative interview guide, assisted in the development of the initial coding guide, and provided feedback on a preliminary report of findings).

An introductory phone call was initiated with all potential research participants to explain the study’s purpose and procedures and to obtain an agreement to schedule an interview. Fifteen team members, representing the four hoarding teams, were contacted by this researcher, and all agreed to participate in the study. Audio-taped consent for phone interviews was obtained from all research participants. An initial in-depth, semistructured phone interview lasting between 40 and 90 min was conducted with all interviewees and addressed these topics: (a) team composition and characteristics; (b) interventions, referrals and follow-up on hoarding cases; (c) service barriers, and (d) components of successful teamwork for addressing hoarding cases. Additionally, the use of semistructured interviews with open-ended questions enabled interviewees to describe a broad range of factors that impacted their involvement in hoarding cases (e.g., team members’ awareness of hoarding as a mental health issue and barriers to obtaining mental health services to address hoarding behavior).

The constant comparative method of qualitative data analysis as described by Lincoln and Guba (1985) was used to analyze interviews; the qualitative software program, Atlas.ti, was used for data management. Data were analyzed using an iterative process of moving back and forth between the raw data and tentative codes until final coding categories were developed. Several strategies were used to establish trustworthiness in the study’s findings (e.g., the consultant panel and member checking). Consultant panel members gave feedback on introductory themes as a way of refining and confirming findings. The researcher also conducted member checks in the initial interview with all research participants and completed a second phone interview lasting between 15 and 30 min with three participants of varying years of experience in working on hoarding cases to further confirm the accuracy of findings. Through the use of these strategies, interview participants helped refine and add credibility to the findings.

All participants described concerns about the mental health needs of older adults who hoard as well as the barriers to obtaining mental health services to address hoarding. Consequently, this article reports on (a) team characteristics (e.g., team composition and processes for working together) as well as their perspectives on (b) awareness of hoarding as a mental health illness, (c) barriers to providing mental health services for older adults who hoard, and (d) components of successful teamwork within the team and with the older adult as hoarder.
RESULTS

Team Characteristics and Composition

Demographic and other characteristics were collected on each research participant as a member of a hoarding team including age, gender, level of education and degree, professional position, years of experience in working on hoarding cases, and hoarding training. Twelve research participants were women; three were men. Team members ranged in age from 26 to 66 years old with an average of 47 years of age, (see Table 1 for participant’s education, position, years of hoarding experience and team designation). Eight research participants recently (i.e., within the last four years) attended hoarding workshops spanning in length from 1 to 6 hr. Five participants described work experience with hoarding cases, but had no formal hoarding training.

What follows is a description of the composition of each hoarding team. Team One is an organized hoarding task force in an urban environment. Four members were interviewed from Team One and included one representative from APS, one from law enforcement, and two from AAA. Team composition included AAA (social worker and chair), APS, law enforcement, and mental health. This team developed from a Minor Home Repairs program in which AAA case managers were exposed to hoarding situations.

Team Two is an organized task force in an urban environment. One member from animal control was interviewed. Team composition included public health (social worker/nurse and chair), animal control, home health, mental health, and sometimes law enforcement. Some agencies are brought in to address specific needs of a hoarding case (e.g., child protective

<table>
<thead>
<tr>
<th>Team member's professional position</th>
<th>Years of education or degree</th>
<th>Hoarding case experience (years)</th>
<th>Hoarding team</th>
</tr>
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<tbody>
<tr>
<td>APS Director</td>
<td>Bachelor of Social Work</td>
<td>7.0</td>
<td>1</td>
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<tr>
<td>Law Enforcement Officer</td>
<td>BS in Administrative Justice</td>
<td>8.0</td>
<td>1</td>
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<tr>
<td>AAA Minor Home Repair Manager</td>
<td>Bachelor of Arts</td>
<td>6.5</td>
<td>1</td>
</tr>
<tr>
<td>AAA Director</td>
<td>Master of Social Work</td>
<td>25.0</td>
<td>1</td>
</tr>
<tr>
<td>Animal Control Officer</td>
<td>2.5 years of college</td>
<td>24.0</td>
<td>2</td>
</tr>
<tr>
<td>Public Health Nurse</td>
<td>BS in Nursing</td>
<td>17.0</td>
<td>3</td>
</tr>
<tr>
<td>AAA Case Manager</td>
<td>Master of Social Work</td>
<td>6.0</td>
<td>3</td>
</tr>
<tr>
<td>AAA MSW Student Intern</td>
<td>BS in English &amp; Religion</td>
<td>0.5</td>
<td>3</td>
</tr>
<tr>
<td>APS Social Worker</td>
<td>Bachelor of Social Work</td>
<td>8.0</td>
<td>4</td>
</tr>
<tr>
<td>Mental Health Provider</td>
<td>Behavioral Science, Business</td>
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<td>4</td>
</tr>
<tr>
<td>AAA Case Manager</td>
<td>Bachelor of Social Work</td>
<td>10.0</td>
<td>4</td>
</tr>
<tr>
<td>AAA Case Manager</td>
<td>Master of Social Work</td>
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<td>AAA Case Manager</td>
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<tr>
<td>AAA Case Manager</td>
<td>BS in Nursing</td>
<td>5.0</td>
<td>4</td>
</tr>
</tbody>
</table>
services). This team developed four years ago through the “buy-in” of many agencies.

Team Three is a newly organized task force from an urban environment. Three members were interviewed from Team Three and included one representative from public health nursing and two from AAA. Team composition included AAA, APS (social worker and chair), animal control, public health, and mental health. The team has asked the fire department to participate, but it does not participate consistently. Within one month of beginning of data collection, this hoarding team developed as an offshoot of a larger elder abuse coalition.

Team Four represents members from an elder abuse coalition that operates in a rural area, and one purpose of the coalition is to address hoarding cases. Seven members were interviewed from Team Four and included five representatives from AAA, one representative from APS, and another representative who operates within a grant funded position as an in-home mental health provider. Elder abuse coalition representatives who also address hoarding cases are from APS, AAA, the legal profession, home health, law enforcement, and banking.

Hoarding Team Processes and Procedures

Processes and procedures each task force follows to intervene in hoarding cases involved three major factors: (a) determining if the hoarding is severe enough to warrant task force participation, (b) case-by-case assumption of leadership within the task force, and (c) multiagency participation and cooperation. First, team members discussed if the hoarding case was severe enough to warrant task force involvement. Teams One and Three had a formal evaluation for hoarding severity that played a role in determining if the case was appropriate for the task force, but more commonly, as it was commented on by members from all the teams, what most necessitated task force involvement was if multiple services were needed that one agency alone could not provide for the hoarder. For example, a public health nurse from Team Three worked with hoarders who had more hoarding related needs than she, in her role as a nurse, could provide, such as utility assistance, mental health concerns, and structural problems in the home. She stated, “Each of us know what we can and we can’t do, then, we decide who else we need to call in.” In these situations, a diverse task force with members from many different agencies, each providing unduplicated services, can meet the multifaceted needs of the hoarder.

Second, leadership on a specific hoarding case depends on the most immediate issues the hoarder presents. For example, if the case involves animal hoarding, then animal control will take the lead. In other situations, the leading role could be provided by an APS social worker or an AAA case manager, depending on which agency comes into contact with the client.
first and if the agency’s services best address the client’s hoarding problem. Leadership can change from agency to agency on the same case, depending upon which need becomes most pressing for the hoarder. Issues of time also affect which task force members take the lead. As an AAA social worker on Team One stated, “Every agency around the table on our hoarding task force has the position of regulatory requirements as far as their time frame for initiation. . . . Whoever has the highest or quickest response rate will be the one who takes the lead role.”

Third, no matter which agency assumes the lead on a particular case, the entire task force is expected to work together to provide services to the hoarder. Task force members stated that because of each agency’s limits such as funding, services provided, legal authority, and expertise, it is vital that agencies cooperate to provide services that fill in each other’s gaps. An AAA case manager on Team Three commented, “Everybody has to be involved. It can’t just be a kind of hands-off approach. I mean we might hand it to [another agency on the task force] because that would be more in their area to deal with if it were a crisis and because that’s not our [the AAA’s] area.”

Outside of these three major factors, task force members from all teams commented on the procedures for intervention in a hoarding case as being integrated into routine agency processes and procedures used for work with all clients. Examples included performing intakes and evaluations, making referrals, and providing services/taking actions within the agency’s regulations and abilities. In other words, for example, a case manager working with a hoarder still is going to do the work of a case manager (and the same is true for mental health professionals, APS workers, law enforcement officers, animal control agents, etc.), but it is the multiagency work across the hoarding task force that provides a unique context for the individual task force member’s processes and procedures on a hoarding case.

Team Members’ Perspectives on the Relationship Between Hoarding and Mental Illness

What follows are team members’ perspectives of (a) hoarding as a mental illness, (b) agency constraints for providing mental health services, and (c) the older adult’s right to refuse these mental health services.

HOARDING AS A MENTAL ILLNESS

All four teams discussed the relationship of hoarding to mental illness, including (a) the confusion surrounding hoarding as a mental illness, (b) the necessity for addressing the mental health problems (e.g., depression and anxiety) of those who hoard, and (c) the importance of mental health interventions as part of a team approach.
First, Teams One, Two, and Four described confusion within themselves and among team members regarding their understanding of the mental health component of hoarding. For example, the mental health provider from Team Four remarked, “I’m trying to figure out hoarding myself. What does hoarding really look like besides just all the piles of stuff you see? Going over to the psychology part of it, what is their mind thinking of?” Team members’ awareness of hoarding as a mental health problem or illness may be reflective of the limited training team members cited as preparing them to work with hoarders. Interviewees described a range of training from participation in a few all-day workshops on hoarding to virtually no training, with an exclusive reliance on field experience. For example, an AAA case manager from Team Four described no training, but relied on “almost ten years” of field experience.

Second, Teams Two, Three, and Four indicated that mental health interventions designed for hoarders needed to address co-occurring mental health problems. As noted by an AAA case manager from Team Four, it is co-occurring mental health problems “that add . . . another reason of why it is difficult for them to overcome that hoarding illness.” Comorbid symptoms and/or diagnoses included depression (Teams Three and Four), paranoia (Team Three), anxiety (Team Three), schizophrenia (Team Four), delusions (Teams Two and Four), mania (Team Four), and suicide (Team Two). An animal control officer from Team Two described an older woman whose mental health problems needed to be the primary target of the hoarding task force’s intervention. This team member remarked that the older adult hoarder had collected over fifteen cats and her “house was . . . literally . . . falling down.” The older woman believed that

She was breeding special cats for the government, and that she walked around with a special press pass and she could write articles . . . it just got crazier and crazier. . . . The task force’s problem . . . was getting this woman the mental health help that she needed; I kind of feel that everyone was frustrated with that.

Team members also differentiated hoarding from other symptoms and diagnoses. An AAA case manager from Team Three stated, “Hoarding is a behavior, and it is not necessarily depression or anxiety that causes it, but those might be in there somewhere.” Overall, team members described hoarding as a mental health problem and discussed the significance of comorbid mental health conditions in providing any interventions.

Third, all teams discussed the need for mental health services as part of a multifaceted approach to treat hoarding behaviors. Interviewees discussed how ineffective a task force intervention is when the mental health component is missing. For example, an AAA case manager from Team Four described the following hoarding case:
When I visited with the lady, I could tell how depressed she was, and I felt like that was a lot of the hoarding issue, so I tried to talk to her about mental health services, but she wouldn’t have any part of it. That’s why I don’t feel successful with hoarding situations. I’ve never felt like I’ve changed their hoarding behavior; all that’s happened is that their condition has declined, or . . . some kind of incident has forced them out of the situation.

However, when mental health treatment is part of a multidisciplinary task force or team approach, interviewees viewed this as contributing to the effectiveness of the team’s intervention. An animal control officer from Team Two discussed a situation with a city code inspector who encountered a hoarder with immediate mental health concerns and how, because of the hoarding task force, the crisis was dealt with positively. The inspector had arrived at the hoarder’s home to remove “trunk loads full of stuff,” but the hoarder, being distraught and overwhelmed by the situation, threatened to commit suicide if anything was removed from his home. This caught the inspector off guard and so he called the police and said, “I’m standing on their front lawn saying we have to haul this stuff away now, and [he’s] telling me . . . ‘I’m going to kill myself’ . . . I need to know how to call somebody that can help with that because I can’t.” The police handled the immediate situation and then referred the case to the task force, made up of case managers, public health nurses, police officers, and mental health professionals. They were able to connect the hoarder to the appropriate services and address his mental health needs. The multidisciplinary approach not only connects the hoarder to an array of services, but also connects mental health professionals to other disciplines, allowing for more agile and effective work by each member of the team. For example, a public health nurse from Team Three described the advantage of her county’s task force:

If I had to spend most of the time being the social worker, I couldn’t address medical needs. You just can’t be everything for everybody and get it done well. It’s spreading too thin and nothing gets done as well as it should. . . . I’m out in the field, and I’m seeing these things, and I know the need, and I know my limitations: I’m not a mental health expert, and I know that I can’t get my job done without this [mental health services] help.

AGENCY CONSTRAINTS FOR PROVIDING MENTAL HEALTH SERVICES

All teams described agency constraints that made it difficult to provide mental health services for older adults as hoarders. These constraints consisted of
(a) funding limitations, (b) the time consuming nature of providing mental health services, and (c) a lack of mental health providers able or willing to provide in-home services. First, funding limitations make it difficult to involve mental health team members in working on hoarding cases. A law enforcement officer from Team One stated:

I think the biggest problem ... we've come across as a task force is the availability for money for the mental health side of things ... Our mental health service through the county, [is required to] work ... a lot of billable hours. So their involvement with the task force has been limited because obviously when they send someone to a meeting, we can't pay them to do that.

This team member further remarked that due to funding limitations, mental health team members “haven’t been involved in the formation of or the ongoing efforts of the task force.” A public health nurse from Team Three described how her hoarding team creatively strategized about how to obtain mental health services in spite of funding limitations. This team member stated that one of her team members (an AAA case manager and a licensed masters level social worker) “is going to get [specialized training] so she will be able, perhaps, to respond to some of the mental health issues without actually creating another new job somewhere, or costing more money for the county.” This team member further reflected, “You ... have to be creative. In today’s economy we knew that the more creative we were—was the only way it was going to get done right now.”

Second, team members described mental health services as time consuming, thereby creating treatment barriers. For example, an AAA case manager from Team Three stated,

It’s a very slow process ... I mean, it’s financial ... I went to see Randy Frost talk about the hoarding. He was saying it takes about six months to see progress sometimes. What agency is going to send their worker out there to do therapy for six months if they can’t be reimbursed?

A mental health provider from Team Four discussed the challenges of devoting enough time to older adults who exhibited hoarding behaviors. This team member viewed the time consuming nature of treatment as a barrier to providing these mental health services:

My struggle is—I have so many I have to help; I don’t have the time. Somebody else is missing out when I’m trying to help someone else with high needs. Trying to get them to let me come in is one thing, then being able to spend two or three hours to build that trust is sometimes a challenge.
Third, agencies are often constrained, due to limited resources, in providing in-home mental health services. An AAA case manager from Team Three reported on the importance of being in the home to directly address the hoarding behavior. She stated, “You need to be in the home to work through that [hoarding behavior]. I mean really. . . . [Going to the home] seems to be where you need to go.” As further noted by an AAA case manager from Team Four, without in-home services, older adults are much less likely to access treatment for hoarding behaviors. This team member stated, “For a time we had a mental health professional that would go out to the home. That was something that I think would be very beneficial to our people who have hoarding issues.” Describing the problems with team members’ expectations that older adults would willingly seek treatment at a mental health center, this team member stated, “I haven’t found it very beneficial to try and utilize our county mental health services. These customers [with hoarding behaviors], plus other older adults with other mental health issues, don’t do well going to the mental health center. They really do well when you can get someone in their home.” In summary, older adult hoarders’ mental health needs challenge existing mental health service delivery systems that are not set up to provide potentially long-term, in-home, and cost-intensive services. Furthermore, and as addressed in the following section, an older adult’s refusal of mental health services to address hoarding behaviors also presents a substantial barrier.

THE OLDER ADULT’S RIGHT TO REFUSE MENTAL HEALTH SERVICES

The older adult’s right to refuse mental health services was described by Teams One, Three, and Four as a barrier to successfully addressing the mental health needs of those who hoard. For example, an APS director from Team One remarked that older adults typically refuse mental health services and often lack insight into their hoarding behavior. This team member questioned if it was “a good use of funds to continually go in and clean.” Instead, other options need to be explored such as “getting involved with the mental health center, moving them to a place that they weren’t going to be able to [hoard] . . . trying to be creative.” Unfortunately, according to this team member, older adults are “not usually willing” to work with mental health providers because they don’t “see it as a problem and they’ve been like that all their lives.”

Even though those who hoard may appear to have a mental health diagnosis, if they are viewed by team members as mentally competent to make their own decisions, then they are understood as having the right to refuse these services. For example, an AAA case manager from Team Four described an older woman who engaged in extreme clutter hoarding, “It is still her
choice [she is still her own guardian] to have all the material around her that she keeps collecting.” A social worker at APS from Team One described a hoarding case involving an older adult, formerly a college professor:

[He] has the “path”. . . . I felt like I was in a gerbil cage. There [were] literally shreds of paper like you might put down for your gerbil in a cage. The [paper] was covering the pathways at least a foot deep . . . because mice had gotten in and shredded it.

This team member also remarked that the elder “sat on a couch, and he had a little police scanner there, and a thirteen-inch color TV and that’s where he lived at. He defecated and urinated in a five gallon bucket.” As noted by the team member, “I do believe he had an [undiagnosed] mental illness,” but that he also “had [mental] capacity to a degree.” Consequently, when the elder said he was “definitely not interested in any other services” (e.g., mental health treatment), this team member did not think he could insist on the older adult’s participation in this treatment.

The older adults’ right to refuse mental health services functions as a critical barrier to addressing hoarding behavior. Team members cannot force older adults’ use of mental health services when they are considered mentally competent to make their own decisions. Furthermore, and as we will now examine, successful teamwork involves multiple components, including the development of trust between team members and older adults.

Successful Hoarding Team Work

Successful team work is dependent on several key components: (a) how well team members work together to address multiple issues such as role conflict, their knowledge of hoarding, and team roles and lack of agency representation (e.g., no mental health providers) on the team; (2) agency policies (e.g., ethical considerations such as client competency) that define the scope or extent of a team members’ involvement in a hoarding case; (3) external support (e.g., funding for mental health services and media publicity) for the hoarding team, and (4) team members’ capacities to develop trust with older adults as hoarders to address barriers to mental health services.

First, all four teams discussed the importance of working together to provide more comprehensive services to the older adult as hoarder. As noted by the AAA Minor Homes Repair Manager on Team One, “We’ve actually had since the beginning several agencies totally committed to regular attendance, participation in different subcommittees and our [educational] conference committee.” This “representation from the organizations at each and every meeting” makes it possible for Team One to develop a comprehensive plan of action that involves several agencies in addressing a hoarding case. When team members do not have knowledge about each others’ roles, they may
duplicate services, engage in conflict over hoarding case responsibilities, and/or provide an incomplete response to the hoarding case (e.g., only cleaning the house, but not addressing the older adult’s mental health needs). Further, team members who lack knowledge about team roles do not know who to call for help even when it is clear others need to be brought in to provide a more comprehensive team response. The animal control officer in Team Two noted the importance of team members with varying expertise. She stated, “I’m not equipped to handle someone who obviously has these mental problems and needs some help. . . . I need to know who to call.”

Finally, all teams discussed the lack of mental health participation on their team as a major barrier in working successfully together. Only Team Four had a mental health team member who was able to participate due to time-limited grant funding.

Second, agency policies defined the scope or extent of a team members’ involvement in a hoarding case, thereby affecting the team’s success in working together. All teams described agency policies that govern their involvement with elders. For example, the AAA case manager from Team Four stated that if the older adult as hoarder is “still competent and shows that she is of sound mind, she’s entitled to make bad decisions. That is totally her choice to have that home environment. Really, they [hoarding team members] have no authority . . . to do anything else.” However, as noted by the APS social worker from Team Four, if elders are assessed as incompetent, then they “can be placed into protective custody because of the danger [e.g., of fire from hoarding newspapers near a heater]” and removed from the home. Agency policies also govern the type of services provided to address hoarding cases. For example, the MSW student interning at the AAA from Team Three noted that his agency provides homemaking services, but has “certain regulations. The home can’t be a complete disaster.” Consequently, hoarding team members’ agency policies may limit or support the team’s success in working together.

Third, external support (e.g., local, state, and/or federal agencies) for hoarding teams can enhance or function as a barrier in the team’s successful work together. Teams One and Three discussed the importance of local, state, and/or federal funding for mental health representation on their hoarding team. For Team One, funding was not available to pay mental health providers to participate on the hoarding team, and they viewed their teamwork as incomplete and unsuccessful due to a lack of these services. For example, a law enforcement officer from Team One stated, “I think the biggest problem we see . . . is the availability for money for the mental health side of things. Mental health . . . involvement with the taskforce has been limited because obviously . . . we can’t pay them to [participate].” In contrast, Team Three was able to include a mental health representative on their team due to state grant funding for in-home mental health services. Finally, Teams Three and Four discussed the role of local publicity in motivating or
preventing external agencies from supporting the hoarding team’s work. For example, because neighbors of the older adult as hoarder threatened media coverage, Team Three was successfully able to work together to address this case. A public health nurse from Team Three stated that the older adult “began feeding rats in her driveway . . . and this municipality did not want that in the newspaper. So they were very, ‘Can you help? What can you do to help? We’ll do whatever.’” In a contrasting example, community representatives (e.g., city council members) refused to take action on a hoarding case due to potential negative publicity, thereby thwarting Team Four’s efforts.

Fourth, all teams viewed the development of trust with the hoarder as critical to the team’s success. A mental health provider from Team Four described their team’s efforts: “We’re trying to get [the older adults’] trust, because if we have their trust then they are willing . . . to let mental health and others work with them.” Developing trust with the older adult paves the way for other members to work with those who hoard. Describing how much time and effort it takes to develop trusting relationships, this team member depicted an older adult as hoarder whose home had recently been flooded:

[The older adult] had resisted numerous individuals that tried to assist her, so I went out to see if we could at least build some trust, to at least, hopefully, get somewhere with this person . . . [After eight weeks of attempts] I was able to get a [FEMA] inspector to go into the house with me . . . to check the house out . . . It was hard to walk through, not only with her belongings, but the fact that she let the house deteriorate. At one point . . . I was spending two to three days, maybe two to four hours at a time working with her . . . just trying to build rapport.

An animal control worker from Team Two also reflected on the time and effort involved in establishing trust with hoarders. “You work at things piecemeal . . . and believe me, animal control has been working on cases for a long time and has created a bond with that person to keep working with them.” Finally, a law enforcement officer from Team One stated that the hoarding team “brings in organizations specifically designed to assist, whether it’s with the psychological side of it, the stuff that they have . . . or animals . . . it builds trust in us.” This trust is essential in working with the older adult as hoarder to obtain mental health services.

What follows is a case example of the hoarding team’s development of trust as a means of obtaining mental health services. An AAA case manager from Team Three depicted an older woman struggling with anxiety and depression who exhibited hoarding behaviors of extreme clutter. This team member saw the older adult for years and described a “really slow pace” in developing trust to work on this client’s hoarding behaviors, which had “taken over her kitchen counters and cabinets.” The older adult was
“involved with mental health to help her try and cope with that feeling of being overwhelmed and prioritize what she needs to do . . . [and the provider] . . . recently changed her medications. The last time I saw her she was a lot calmer, she said she wasn’t as overwhelmed. Next time I see her maybe we’ll see some kind of difference. The medication seems to be helping.” Building trust with older adults as hoarders is necessary to fully address their mental health and other needs. In summary, hoarding teams are successful when they learn to work well together, take into account team members’ agency policies, garner external support for the hoarding team, and develop trust with the older adult as hoarder.

DISCUSSION

The findings from this study suggest some important implications for research, practice, and policy with elders who come to our attention because of their hoarding behaviors. First, we need to continue to develop research studies that examine the etiology, contributing factors, and other contextual characteristics that can help us better understand this phenomenon called hoarding. Current literature indicates that there is little agreement about whether hoarding is an outgrowth of mental illness (e.g., obsessive compulsive disorder), a separate mental health diagnosis, or a cognitive impairment. This lack of clarity about hoarding leaves practitioners with little guidance about how to choose strategies to help elders who exhibit these behaviors. The studies noted earlier (e.g., Frost et al., 2003) illustrate the lack of potency of current interventions, which, in part, can be attributed to conflicting views of the nature of the problem.

Second, the lack of clarity has practice implications for the training of workers who are charged with providing services. A multidisciplinary team approach to working with this population rests on the capacity to arrive at a common understanding of hoarding. This seems especially important because of the broad range of service providers necessary for a comprehensive approach to treating elders. Given that hoarding teams include everyone from animal control to psychiatry, there are likely to be conflicting understandings of the problem, which is further complicated by their very different responsibilities in the larger community. More specifically, law enforcement and building inspectors’ responsibilities are quite different from mental health and animal control, and each discipline has its purpose, which can conflict with the functions and purposes of other team members. In order for multidisciplinary teams to make their diverse perspectives an asset in treating this population, it becomes essential that they are brought together to create a common perspective that informs their participation and allows them to both respect their differences and arrive at a unified approach to treatment. They also need time to work together to develop trust-based
relationships that can facilitate joint efforts to create useful service plans for individuals. In addition, these findings suggest that trust is central to develop between the team and the older adults as hoarders. Hoarding interventions rest on trust between the elders and team members; however, in order to build that trust, team members often are required to go out to the home for extended periods of time.

Third, trust among team members and between team members and elders is dependent upon opportunities to interact in ways that develop a sense of trust. Because building trust is a process that takes time, we need to address the policy barriers that often impede efforts for team members to come together on a regular basis. Current policies in mental health centers provide a useful example of what needs to change. As noted by our research participants, mental health professionals play an important role on hoarding teams; however, the focus on “billable hours” for most mental health centers restricts the amount of time staff can be allowed to work with teams in the community or to make home visits with elders. Without resources, crucial components of a “team” response are unlikely to occur, and consequently team members will be unable to bring their skills to bear on this problem.

The fourth implication involves managing ethical dilemmas embedded in tensions among self-determination, autonomy, and protection of life. This study suggests that practitioners lean toward honoring self-determination even when they see dangers presented by hoarding behaviors. Establishing criteria for workers to manage ethical decision making needs to become part of the training provided to teams (Koenig, Chapin, & Spano 2010).

In conclusion, hoarding is a complex behavior that represents a coping mechanism that we do not fully understand. Its complexity requires responses that involve collaboration among many different professionals and systems that do not normally work in close proximity. This qualitative study highlights some of the important structural barriers that currently exist and impede effective service delivery. Multidisciplinary team approaches suggest some potential to bridge current service gaps. However, we need to continue to pursue careful exploration of these teams’ experiences to produce more reliable approaches to address problems facing both individuals and communities when hoarding is the presenting problem.

REFERENCES


